This report details the findings from a largely qualitative, online survey based on the wider public’s understanding of genome editing and its potential uses within human reproduction. This survey differs from those which have preceded it by engaging with the wider public and adopting a voluntary, weighted-sample strategy so that its findings are relatively representative of the United Kingdom’s population.

The survey was designed using Qualtrics\(^1\) software and was live between 1\(^{st}\) March 2018-31\(^{st}\) May 2018 for voluntary participation. The data was analysed using SPSS\(^2\) and NVivo\(^3\) software. The reported findings are drawn from a final dataset of 521 participants. These findings will primarily be used to inform the next stages of my PhD research at the University of Cambridge in the Department of Sociology.

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1 Qualtrics is online software through which surveys can be created and analysed.

2 SPSS is software largely used to analyse numerical (quantitative) and statistical data (IBM, 2018).

3 NVivo is software used to find common themes and reasons/meanings from non-numerical (qualitative) data (QSR International, 2018).
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Introduction

This report is based on an online survey which forms the first of three phases of research for my PhD. The sequential phases of my research consist of semi-structured interviews and focus groups to investigate the findings in this report further.

The survey was primarily designed and created to connect with the wider public on the topic of human germline genome editing in relation to disease and disability. The aim was to bridge a gap within research conducted to date, which has largely been conducted with participants with a vested or professional interest in the landscape of genome editing technology, or with incentivised participants.

Respondents to the survey upon which this report is based were given no external motivation, such as money or rewards, to complete the survey, and had to meet the following three criteria to participate:

- be aged 16 years or over
- be living in the United Kingdom (UK)
- be voluntarily participating

The above criteria were set on the basis that 16 years is the minimum age in the UK from which citizens can legally reproduce. Respondents living in the UK form the wider public, and voluntary participation provides an ethical, non-incentivised perspective.

The survey was designed over a period of three months, following extensive deliberation and pilot research. The word ‘genetic’ was chosen over the industry preferred term ‘genome’ for the title of the survey due to the familiarity that the wider public has with the term. Within this report, I will use both terms interchangeably.

This report details some of the findings from the survey with discussions, and suggestions for further lines of inquiry. A summary of the methodology used for this survey is provided in Appendix 1 and a copy of the full survey in Appendix 2.

Any questions or comments about the survey or this report are welcome, and can be addressed to Amarpreet Kaur ak997@cam.ac.uk.

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4 Germline Genome Editing is when the DNA in sperm/eggs and/or embryos is altered, i.e. when edits that are heritable are made to DNA.

Objectives

The survey was devised to meet several objectives, which are listed below:
- to ascertain the wider public’s understanding(s) and knowledge of genome editing, and to establish how understandings of genome editing (where they exist) have been formed/reached
- to determine if different types of genetic conditions, i.e. diseases and disabilities, elicit different attitudes towards genome editing on human embryos as a reproductive choice/option
- to establish how the wider public are likely to view the legal status of, access to, and uses of genetic editing in the UK in the future

Each objective had a corresponding set of questions in a section of the survey which are detailed in the following survey overview.
Survey Overview

The survey opened with introductory information and a respondent validity check to manage expectations, and to highlight considerations of anonymity and respondents’ rights to withdraw their data. The survey ended with questions collating demographic information, so that I could ensure the desired weighted sample was being obtained.

The first section of the survey, ‘Understanding/Knowledge of Genetic Editing’ questioned respondents’ knowledge of genetic editing and asked respondents to define genetic editing before providing a basic definition as a baseline for understanding the rest of the survey. In the first section, respondents were also asked where they have heard/learnt about genetic editing, or what comes to mind when they think of genetic editing.

The second section of the survey, ‘Hypothetical Practical Applications’, comprised of five scenarios and formed the bulk of the survey. The scenarios were designed to question various factors of disease and disabilities, such as possible differences in attitudes towards conditions which affect cognitive, physical, and/or physiological abilities. Painful conditions, late onset conditions, degenerative conditions, and fatal conditions were also factors which featured in the scenarios. Additionally, the risk of transmission, treatment available for a given condition, quality of life, and life expectancy were questioned in the second section of the survey.

The third section of the survey, ‘Legislation and Ethics’, clarified that germline genome editing via human embryos is currently prohibited in the UK and sought respondents’ opinions on legalising it. In the third section, the possibility of travelling to other countries to access genome editing technology if it remains illegal, restrictions on the potential uses of the technology, and possible risks/’misuses’ of the technology were also questioned.

The three sections were sequenced to progressively introduce respondents to various considerations surrounding human germline genome editing so that an overall, relatively informed opinion could be sought at the end of the survey.

Respondents could only navigate forward through the survey to ensure that responses would not be changed, and no question in the survey could be skipped. All questions in the survey have a valid response rate of 100% as there are no missing answers (values).

The survey took an average of 15-20 minutes for respondents to complete, with the fastest respondent taking just under 10 minutes, and the longest respondent taking 2 hours and 27 minutes.

See page 4 of this report for explanation of weighted sample.
Respondents’ Overview

My weighted sample was primarily based on reaching 500 respondents, however, I am fortunate that my final data set is comprised of 521 respondents. I sought this number of respondents in order to reach a confidence level of 95% with a 4-5% margin of error. This confidence level means that I can be certain that ± 5% of the approximated population of 48,043,809 would respond the same way as respondents to my survey. Selecting a lower margin of error (which would have required a greater number of respondents) would have been unfeasible within the pragmatic constraints of my research because of the amount of primary qualitative data I anticipated generating.

To obtain a somewhat representative sample of the wider UK population relative to the survey, I selected several demographics which I considered to be pertinent. These demographics were gender, age, religion and whether the respondent is affected by a genetic condition. The latter two demographics were deemed significant as religious people and those affected by genetic conditions are often anticipated to have strong views on genome editing (MacGillivray and Livesey, 2018: 36). Quotas for gender and age were calculated using data from the UK’s Office for National Statistics’ 2011 census available online. These quotas were overtly met and are evidenced in the following pages with graphs created from the survey data using SPSS software.

Respondents were also asked to state their occupation; to an extent, this data could indicate socioeconomic status and/or level of education, but was collated to ensure that the wider public was being reached. Finally, respondents were asked to disclose their nationality; I collated this information primarily for contextual purposes. Representation of these two demographics are displayed in word clouds after the summaries of the weighted demographics.

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7 A participation sample of 385-601 was required to achieve a 4-5% margin of error.

8 This estimated population size is based on UK census data from 2011.

9 I recognise that other demographical information, such as geographical location and/or race could have increased how representative the sample is. However, collating and weighting such information would have made the survey longer for respondents to complete, and could have acted as a disincentive to completion.
The word ‘gender’ was chosen over ‘sex’ for this question, so that respondents could write what they personally choose to identify as the most. Answers to this question were originally open text and were later grouped (recoded) to either female or male, i.e. respondents who wrote ‘f’ or ‘trans-female’ etc. were recoded to female, so that the above graph could be created.

Rounding the numbers, 52% (271/521) of respondents to the survey are female and the remaining 48% (250/521) are male, which is representative of the UK population according to UK census data from 2011.
What age are you?

The age ranges displayed in this graph have been generated from grouping (recoding) the original data. Respondents answered this question with a single age. The youngest respondent was aged 16 years and the oldest respondent was aged 82 years. Documenting respective ages enables a more contextualised understanding of respondents’ answers, particularly for younger respondents where the age range could encompass high school students, college students and undergraduate students.

In comparison to other reported surveys/research to date\(^\text{10}\), this survey is unique as it includes a representative number of responses from younger respondents, i.e. individuals aged 16-18 years. Capturing the views of younger respondents is of importance when considering the scope of germline genome editing technologies, as younger generations are most likely to have reproductive choices which include the consideration of such technologies. For this reason, the attitude towards the developing scope of germline genome editing in the UK of younger generations is perhaps of greater significance than the attitudes of older generations.

However, the attitudes towards human germline genome editing of older generations are more likely to include a wider perspective and be justified by lived experience than younger generations, hence the views of older respondents are also invaluable, particularly in relation to disease and disability.

\(^{10}\) See Appendix 3 for a list of published reports on genome editing to date.
Are you religious?

The overall minimum quota for respondents to self-identify their religious status was set at 30% (also based on UK census data from 2011). However, I was keen to capture views from at least the six main religions\textsuperscript{11} represented in the UK population, and thus divided this quota between the six religions for equal representation. Rounding the numbers, 37\% (191/521) of respondents to the survey self-identified as being religious whilst the remaining 63\% (330/521) did not. Respondents who self-identified as being religious were questioned further.

\textsuperscript{11} The six main religions are considered to be Buddhism, Christianity, Hinduism, Islam, Judaism and Sikhism (Garner, 2004).
Have your religious beliefs influenced your answers in this survey?

Due to the limitations of this survey I cannot evidence that the individual quotas per religion were met, as many respondents who identified as religious felt that their religious beliefs did not influence their answers. Thus, data disclosing respective religions for such respondents is not available.

Nonetheless, respondents who feel that their religious beliefs influenced their answers in the survey to some extent (definitively or potentially), and are therefore explicitly represented within my survey data, distinguish themselves as one or more of the following:

- Buddhist
- Christian
- Discordian
- Hindu
- Humanitarian
- Jewish
- Muslim
- Noachide
- Quaker
- Sikh
- Sufi
- Zen

Respondents from various denominations of Christianity, or who are either Jewish or Sikh, particularly feel that their religious beliefs influenced their answers. As such, many of the responses shared in the findings sections of this report can be attributed to these religious influences, which may seem overrepresented. However, the overall number of respondents per the six main religions is roughly equal.
Finally, due to the relationship of the survey to disease, a minimum quota of 25% of respondents identifying as being affected by a genetic condition was set. This quota was chosen based on a desire to ensure that individuals with primary experience of living with a wide range of genetic diseases and/or disabilities would be represented in my findings to a greater extent than in findings from other surveys/research on genome editing\textsuperscript{12}.

Have you ever been affected by a genetic condition?

\begin{center}
\begin{tikzpicture}
\begin{axis}[
    ybar, bar width=25pt, ymajorgrids, grid style=dashed, ymin=0, ymax=85, width=\textwidth, height=6cm,
    ylabel=Percent, xlabel=Yes/No,
    symbolic x coords={Yes, No},
    xtick=data,
]
\addplot[ybar, fill=green!50!white] coordinates {
(Yes, 29.17)
(No, 70.83)
};
\end{axis}
\end{tikzpicture}
\end{center}

Rounding the number of respondents, 29\% (152/521) self-identified as having been affected by a genetic condition, while the remaining 71\% (369/521) of respondents are of the opinion that they have never been affected by a genetic condition.

The 29\% of respondents who identified as being affected by a genetic condition shared how they have been affected:

- Family members/children have a condition
- Friends’ friend’s children with condition
- Mental health issues
- Mobility issues
- Pain
- Personally has condition
- Physical/physiological/visual/audio impairment
- Reduced social life
- Risk of passing condition to child

The range of responses to this question is indicative of how respondents interpreted it\textsuperscript{13}, and is thought to be a revealing aspect of the survey, not a limitation.

\textsuperscript{12} See Appendix 3 for a list of published reports on surveys/research on genome editing to date.

\textsuperscript{13} How have you been affected by a genetic condition?
The condition(s) that respondents are affected by are listed as follows:

- Achromatopsia
- Attention Deficit Disorder
- Attention Deficit Hyperactivity Disorder
- Agammaglobulinemia
- Ankylosing Spondylitis
- Attenuated Familial Adenomatous Polyposis
- Antiphospholipid Syndrome
- Asperger's Syndrome
- Asthma
- Auditory Processing Disorder
- Autism
- BRCA Gene
- Cardiac Disease
- Cataracts
- Charcot Marie Tooth Disease
- Chronic Granulomatous Disorder
- Chronic Mucocutaneous Candidiasis
- Chronic Kidney Disease
- Common Variable Immune Deficiency
- Continental Glaucoma
- Crohn's Disease
- Cystic Fibrosis
- Deafness
- Duane Syndrome with Radial Ray Anomaly
- Dyslexia
- Eczema
- Ehlers Danlos Syndrome
- Epilepsy
- Fragile X
- G6PD Deficiency
- Gilbert's Syndrome
- Good's Syndrome
- High Cholesterol
- Huntingdon's Disease
- Hydrocephalus
- Hypertension
- Hypertrophic Cardiomyopathy
- Ichthyosis Vulgaris
- Idiopathic Spinocerebellar Ataxia
- Keratosis Pilaris
- Klippel Feil Syndrome
- Lipoedema
- Lupus
- Lynch Syndrome
- Maple Syrup Urine Disease
- Marfan Syndrome
- Mannose-binding Lectin Deficiency
- Myalgic Encephalomyelitis
- Multiple Epiphyseal Dysplasia
- Multiple Sclerosis
- Muscular Dystrophy
- Myhre Syndrome
- Myopia
- Neurofibromatosis Type 1
- Osteoarthrits
- Osteopenia
- Primary Ciliary Dyskinesia
- Polycystic Ovarian Syndrome
- Pernicious Anaemia
- Primary Addison's Disease
- Psoriasis
- Renal Agenesia
- Retinal Dystrophy
- Retinitis Pigmentosa
- Reynaud's Phenomenon
- Scoliosis
- Severe Combined Immunodeficiency IL7RA
- Short sightedness
- Sjogren's Syndrome
- Sotos Syndrome
- Spina Bifida
- Stargardt Disease
- Type 1 Diabetes
- Waardenburg Syndrome
- Xeroderma Pigmentosum
- Zellweger's Syndrome

Some of these listed conditions have an association with a disorder in a single gene whilst others may have associations with multiple genes and/or environmental factors. Conditions associated with a single gene, in theory, would be more likely to benefit from germline genome editing to avoid genetic disease in the nearer future than conditions that are not (Nuffield Council on Bioethics (NCOB), 2016: 45-47).
The majority of respondents to the survey were students. However, this includes high school students, college students, undergraduate students, and postgraduate students either studying for a master’s degree or undertaking a PhD.

Other respondents are from a very wide variety of occupations, including professional and skilled occupations, as well as some who are currently unemployed or retired.

The word cloud below visualises all the occupations detailed by respondents:

As is evident from the word cloud, the vast majority of respondents to the survey have no direct expertise or professional interest in human germline genome editing technologies. For this reason, I am confident that this survey has reached the wider public sufficiently.
Respondents to the survey had to be either British Nationals or citizens living within the United Kingdom. These restrictions were chosen to ensure that respondents have first-hand familiarity with British culture, customs, and laws.

Nationalities of respondents to the survey are displayed in the following word cloud:

![Word Cloud]

Rounding the numbers, 87% (452/521) of respondents are British, and a further four respondents have a dual nationality which includes being British. The remaining 65 respondents are citizens from other countries who are resident within the United Kingdom.

Nationalities were documented so that respondents’ answers can be contextualised accordingly if/where appropriate.
Findings

The findings in this report were reached by mixed-method analysis, i.e. by analysing quantitative (numbers) and qualitative (words) data from the survey. First, all data from the survey was checked and analysed in SPSS, question by question. Qualitative answers were then imported in NVivo where word frequency searches were conducted for the top 45 words. The frequency searches enabled the most prominent themes across respondents’ answers to be easily identified\textsuperscript{14}. Themes were then analysed further and a selection of quotes from each was chosen to support the identified themes conveyed in this report.

Respondents are quoted in this report. The number at the beginning of each quote indicates the position of the respondent within the complete data set, i.e. ‘27.’ is respondent 27 out of the 521. The respondents’ numbers have also been coloured according to the multiple-choice answer that they selected for the accompanying question to provide context for their quote; i.e. green for ‘Yes’, red for ‘No’, and orange for ‘Other’. Additionally, respondents’ demographics have been shared beneath their quotes to provide more context to their views.

Demographics are reported in the following sequence: gender, age, occupation, whether a respondent is a parent, religion, and if/how a respondent is affected by a genetic condition. A respondent’s nationality has only been reported if they are not British, solely for contextual purposes.

\textsuperscript{14} Every answer to each question was also read separately to ensure that themes which may not have been identified by word frequency searches due to their wording were not missed. See Appendix 1 for more information on methodology.
Section 1: Knowledge and Understanding

Q1. Do you know what genetic editing is?

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>163</td>
<td>31.3</td>
</tr>
<tr>
<td>No</td>
<td>116</td>
<td>22.3</td>
</tr>
<tr>
<td>I think so</td>
<td>242</td>
<td>46.4</td>
</tr>
<tr>
<td>Total</td>
<td>521</td>
<td>100.0</td>
</tr>
</tbody>
</table>

N.B. ‘Frequency’ is the number of respondents, whilst ‘Percent’ is the percentage of respondents out of the total 521.

Respondents who answered ‘yes’ to Q1. were asked to detail what genetic editing is. 14/163 of these responses were considered either partially (7/163) or completely incorrect (7/163). The remaining responses were descriptive of modifying DNA in some form, with some being more scientific than others, and several mentioning CRISPR-Cas9.15

The following word cloud is of the top 45 words derived from respondents detailing what genetic editing is. As is evident in the word cloud, respondents associate genetic editing with DNA and genes, and mentioned various synonyms of editing, such as changing, modifying and adding/removing.

Respondents who answered ‘I think so’ to Q1. were asked to detail what they think genetic editing is. 46.69% (113/242) of these responses were considered to be correct, with a further 35.12% (85/242) being partially correct, and the remaining 16.94% (41/242) being incorrect. Responses which were considered to be partially correct were deemed so because they were often too specific, i.e. they thought that genome editing is isolated to embryos or disease etc.

15 CRISPR-Cas9 is one of several genome editing techniques.
A further question, ‘How did you hear/learn about genetic editing?’ was asked to respondents who answered ‘yes’ or ‘I think so’ to Q1. (405/521 respondents). The following word cloud reveals the top 45 responses to the question:

The word cloud indicates that the leading source for hearing/learning about genetic/ genome editing in the UK is the news and other forms of media. This finding is quite significant when such sources have often led to long-term misrepresentations of reproductive technologies, such as preimplantation genetic diagnosis (PGD)\(^\text{16}\) being associated with ‘designer-babies’ (Franklin and Roberts, 2006).

In this light, professionals and experts involved with germline genome editing in the UK should perhaps consider taking a more proactive role in working with journalists and related bodies. By working with journalists and media producers, professionals and experts could ensure that correct representations and reliable information about germline genome editing are relayed to the wider public.

The second leading source from which respondents have heard/learnt about genetic/ genome editing is through formal, compulsory education, i.e. in GCSE Biology or through other education providers. Fortunately, this source is likely to be more reliable and factual, however, access to such sources is often limited.

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\(^{16}\) PGD is a two-stage process in which embryos created via in vitro fertilisation (IVF) can be tested for specific genetic disease(s) before they are transferred to a woman’s uterus (HGC, 2004).
Respondents who selected ‘no’ to Q1. (105/521) were asked ‘What comes to mind when you think of genetic editing?’. As evidenced in the following word cloud of the top 50 words used in response, these respondents are also thinking along the lines of genome editing:

For Q2. a very basic description of genome editing was provided within the survey. The description read ‘Genetic editing (also known as genome editing) is a technique through which specific parts of DNA can be added, removed or altered’, and was followed by the closed question ‘How different was your answer to the description provided?’. Two options were available:

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very different</td>
<td>42</td>
<td>8.1</td>
</tr>
<tr>
<td>Similar</td>
<td>479</td>
<td>91.9</td>
</tr>
<tr>
<td>Total</td>
<td>521</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Respondents who selected ‘very different’ for Q2. were asked ‘Why do you think there was a difference?’. This was due to: a lack of knowledge; not enough detail in the answer; not using the correct terminology/’scientific’ wording.

Using the supporting qualitative answers to Q1. and taking Q2. into account, I can summarise that 82.53% (430/521) of respondents to my survey have knowledge/understanding of what genetic editing is to some extent. Only 17.46% (91/521) of respondents did not know what genetic editing is.
Section 2: Hypothetical Practical Applications

Questions in section 2 were based on five scenarios. Each scenario was constructed to assess different factors of disease. Names were chosen to reflect the multi-cultural diversity within the UK population. Details provided in the scenarios were deliberately vague to keep them open to interpretation. I designed this deliberately as a number of genetic conditions could apply to the factors of disease in question, and I did not want respondents to focus on specific conditions.

Each multiple-choice question in this section had a selection of three answers to choose from, ‘Yes’, ‘No’, or ‘Other’. If a respondent selected ‘Other’, they were required to share what their specific view is in order to progress to the next question. For this reason, the descriptive responses which accompany the selection of ‘Other’ are reported with the findings to the multiple-choice questions.

Scenario 1

This scenario was primarily designed to act as a baseline and control to the proceeding scenarios.

Alecia and Bernardo have a genetic condition which is treatable but has no cure. If their child inherits the condition it may experience some pain during its life as a result of the condition and will have to receive regular treatment throughout its life to manage the condition. The condition is not known to impair cognitive or physical abilities. On average, people with the condition have a slightly reduced life expectancy.

Q3. Should genetic editing be allowed in this scenario?

As indicated by the graph, 66.22% (345/521 respondents) feel that genetic editing should be allowed in this scenario. This reveals that a significant proportion of respondents are in favour of genome editing, while 28.98% (151/521) are against genome editing.
In this scenario, ‘Other’ included respondents who are unsure/wanted more information before making a decision, and/or needing to take other factors into consideration in order to make a decision on a case-by-case basis.

12. Depends on the condition and individual circumstances.  
(Female, 27, Nurse, not a parent, Sikh, not affected)

147. Not sure I have sufficient info to make a decision, is the pain mild or severe, constant or intermittent, will the gene therapy definitely not cause any other impacts?  
(Female, 53, Housewife, parent, religious but no influence, son affected)

Respondents were then asked what considerations influenced their answer to Q3. The most prominent considerations which respondents cited pertain to the quality of life, reduced life expectancy, and how life threatening a condition is. Avoiding/reducing/alleviating pain, in addition to being able manage pain were the second most prominent considerations reported, followed by financial implications.

Quality of life

23. I think if someone's quality of life can be improved through science then we should do it.  
(Male, 35, Chef, not a parent, not religious, not affected)

213. Child's ongoing quality of life might be enhanced by the technique, including a reduction in pain.  
(Female, 62, CEO, parent, not religious, she and children have condition)

258. Quality of life. Even though it won't impact ability over time it will impact the person.  
(Male, 26, Counsellor, Irish, not a parent, not religious, not affected)

450. Quality of life for the child primarily. However, there is also a second moral dimension based off increased pressure put on national health service throughout the child's life due to not treating it which could be avoided. Prevention is better than a cure.  
(Male, 24, Freight Forwarder, not a parent, not religious, affected via family members)

Life expectancy

43. Shortened life expectancy. Social factors the child would face.  
(Female, 40, Carer, religious but no influence, affected – son)

299. The life expectancy wasn’t severely affected, and neither was the cognitive or physical abilities.  
(Female, 17, College Student, not a parent, not religious, not affected)

368. People have a right to the maximum life expectancy and best standard of living reasonably possible.  
(Male, 47, Police Officer, parent, not religious, not affected)

403. Life expectancy is reduced by a number of equally manageable factors for all humans. The condition does not sound exceptionally debilitating and parents would have prior knowledge of living with the complications.  
(Male, 26, Student/Barista, not a parent, not religious, not affected)
Pain

49. If there is a possibility to avoid bringing pain to the world I think that's a decent use of science.
   (Female, 28, Mobile Advertiser, Italian, not a parent, Catholic/Sikh, not affected)

81. A child should not have to go through pain/procedures throughout their whole life. If it can be prevented, it should. It’s unfair.
   (Female, 28, Software Tester, parent, Sikh, not affected)

118. Pain can be managed.
   (Female, 73, Retired Careers Advisor, parent, not religious, not affected)

192. I have chronic pain and would not wish a child to suffer in a similar way.
   (Female, 44, Engineer, not a parent, not religious, has condition)

Cost

21. The fact that the child will experience pain and require treatment which has a cost to the state so if the problem can be edited out why not do it?
   (Female, 36, NGO, not a parent, not religious, not affected)

148. The possibility of a) improved quality of life for the child and b) reduction in costs/labour for the medical system.
   (Female, 28, German, not a parent, not religious, not affected)

187. The fact that the child will experience pain. The fact that treatment over the course of the child’s life may amount to more than the cost of genetic editing.
   (Male, 16, High School Student, not a parent, not religious, not affected)

203. Taking regular medications can be a bother for both parents and the child. Medications may not be without side effects. If the conditions can be treated by the suggested method in the long run it would not be such a drain on NHS.
   (Female, 62, Retired Teacher, parent, not religious, not affected)

Additional reasons why some respondents answered ‘no’ to Q3. are as follows:

   (Female, 23, FT work, not a parent, not religious, not affected)

28. The fact the condition is treatable and that won't cause too many issues for the child.
   (Female, 24, Charity Worker, not a parent, not religious, has condition)

31. It is not life threatening and can be treated. Does not impede cognitive or physical function.
   (Female, 57, Lecturer and Nurse, parent, Christian, not affected)

379. The child could still live a full life with treatment. Not worth it.
   (Male, 24, Mechanical Engineer, not a parent, not religious, not affected)

In summary, if science can reduce or avoid the possibility of pain, increase life expectancy, and/or reduce costs to the NHS, respondents are in favour of genome editing. However, the need/availability of treatment divided respondents’ views on whether genome editing should be permissible or not. This factor of treatment is addressed further in scenario 3, for Q8.
To assess if the transmission of a condition influences attitudes towards genome editing, this factor was made definitive for Q4. The findings reveal a 7.89% increase in respondents (41 more) holding the opinion that access to genome editing should be allowed in such cases.

Q4. If Alecia and Bernardo’s child will definitely inherit their condition, should they be allowed to access genetic editing?

The accompanying qualitative analysis to the 2.11% rise in participants selecting ‘Other’, clarifies that this rise is due to the majority of the respondents feeling that genetic editing should only be accessible in such cases where the parent(s) fund the process themselves. Only one participant holds the opposite view that germline genome editing should only be allowed if the option is free and accessible to all.

281. If this is not publicly funded then yes.  
(Male, 32, Driving Instructor, parent, not religious, has condition)

498. If it is free and universal yes.  
(Female, 22, Undergraduate Student, French, not a parent, not religious, has condition)

When asked what considerations influenced their answers, the prospect of a child being born into a life of pain/suffering, or experiencing preventable pain is of the greatest concern to respondents. Preventing transmission and therefore conditions which would cause pain, reduce quality of life or result in a lifetime of care – especially if this care involved greater suffering, were also prominent considerations cited by respondents. Additionally, some respondents commented on the certainty of transmission.

Life of pain/suffering

36. The inevitably of the disease and further pain and reduced life expectancy of the child.  
(Female, 22, Undergraduate Student, not a parent, not religious, has condition)
110. The impact of lifelong treatment on the individual’s wellbeing and the financial implications for society generally.
(Female, 30, Homeless Officer, not a parent, religious but no influence, no condition)

123. The condition is treatable and does not sound severe enough to warrant this type of intervention, however parental choice and experiences are important.
(Female, 34, Genetic Counsellor, not a parent, not religious, has condition)

512. Pain and long-term treatment have influenced my decision as it would directly impact their life and put extra strain on the NHS/Medical Facilities – only if it will DEFINITELY affect their day to day lives and put strain on the NHS/Medical Facilities.
(Male, 34, Unemployed – illness, not a parent, religious but no influence, has condition)

Prevention

52. If the child doesn’t have to go through the implications of the condition, then I think every attempt to remove it should be done. It’s not fair to bring a child up with the condition if you know there was a chance it could be removed.
(Female, 20, Civil Servant, not a parent, not religious, not affected)

278. If science can alleviate suffering, it should. Could depend on cost though.
(Male, 24, PhD Student, not a parent, not religious, not affected)

348. I can see no reason for people to suffer if there is a way to prevent it.
(Female, 81, Retired, parent, Christian, has condition)

367. To prevent their condition being passed on to their children, preventing suffering, pain and shortened life span, not to mention the cost of care.
(Female, 47, Telecoms Engineer, English, not a parent, not religious, has condition)

Certainty of transmission

47. Even if the child would definitely inherit the condition, it would only impact their life slightly - so not worth the risk of the consequences of DNA editing.
(Female, 22, Pilot, not a parent, not religious, not affected)

105. Certainty of inheritance and genetic change may improve quality of life.
(Female, 46, General Practitioner, parent, religious but no influence, has condition)

342. The certainty that it would be passed on and that if they could access treatment a child would not have that pain specifically related to that condition.
(Female, 44, Writer, parent, not religious, has condition)

456. Just the fact that it’s certain the child will inherit the condition.
(Male, 25, Software Engineer, not a parent, not religious, not affected)

Respondents who feel that genetic editing should not be allowed in the described circumstances, shared that they hold this view primarily for the following reasons:

221. There is no point in doing it in this scenario as it will be a waste of resources and money attempting to treat the child.
(Male, 17, College Student, not a parent, not religious, has condition)

223. little reduction to quality of life not severe enough to warrant editing.
(Female, 23, Undergraduate Student, American-Cypriot, not a parent, not religious, not affected)
340. This condition will not change the daily life of the person and the possibility is there to only make this worse. (Male, 27, Civil Servant, not a parent, not religious, not affected)

379. The risks outweigh the benefits. I don’t think it is worth it. (Male, 24, Mechanical Engineer, not a parent, not religious, not affected)

As evident in the presented findings, the risk of inheriting a genetic disease, even one which only involves the possibility of pain and is treatable, has a considerable influence on attitudes towards genome editing. This suggests the majority of respondents to this survey have a predisposition to be in favour of allowing the eradication of any disease from society regardless of the severity, if the disease will be inherited. However, this suggestion does not imply that there is an intolerance towards people with disease, but that a greater preference to prevent disease exists.

The reason why this predisposition to eradicate all heritable disease from society exists, requires further research. Nonetheless, using the findings from the remaining scenarios I hope to illuminate which types of genetic disease and factors of disease are of greater concern to respondents and why. Considerations to quality of life, pain and suffering, as well as financial implications to the NHS, are discussed later in this report.
Scenario 2

This scenario was primarily designed to assess how cognitive impairments are perceived by the wider public in relation to physical and physiological impairments.

Daniella and Carl are both carriers of a genetic condition which is known to impair cognitive ability. The condition is not known to affect physiological abilities or cause any pain. People with the condition have a normal life expectancy and are reliant on others to care for them throughout their life.

Q5. Should genetic editing be allowed in this scenario?

With the introduction of impaired cognitive ability and dependency on others, despite the factors of pain and reduced life expectancy being removed from this scenario, a further 8.83% (46 more) of respondents feel that genetic editing should be allowed. This increase suggests that cognitive ability and dependency are more influential than pain and life expectancy as factors of disease. However, the supporting qualitative responses to this question shared below, challenge these assumptions and provide greater clarity and insight.

Respondents who selected ‘Other’ for this question, predominantly cited the risk of transmission, the level of care which would be needed, and safeguarding measures in terms of regulation, in their answers. Additionally, several respondents wrote that in the given scenario, people should not have (genetically related) children/they should adopt children.

200. Shouldn’t have children.
(Male, 56, Reprographics Studio Operator, not a parent, not religious, not affected)

505. They should adopt a child who has already been born, but if they insist on having their genetically own child then genetic editing is permissible.
(Female, 20, Undergraduate Student, American, not a parent, not religious, has condition)

17 8.83% more respondents in relation to Q3. - scenario 1.
To understand respondents’ views to a greater extent, they were asked what considerations influenced their answer. The prospect of not having an independent life and being reliant on receiving care from others is a greater consideration than cognitive impairment for respondents. This distinction is an important factor to consider, particularly because this finding reflects a significant shift in attitudes towards cognitive impairments.

A carer’s wellbeing (whether family or otherwise) was given more prominence than the wellbeing of individuals with such genetic conditions, as impaired cognitive function was cited as not impeding the individual’s personal happiness. However, cognitive impairment is associated, by respondents, with potentially reducing quality of life. Conditions without pain, which respondents associated with suffering, are discernibly considered more palatable. This is a contributing factor in the decision of many respondents who are of the opinion that genetic editing should not be allowed in this scenario.

Lack of independent life

26. To give a child the best chance at living a normal life where they might be able to grow to become independent.
   (Female, 30, Project Manager, not a parent, not religious, not affected)

39. Having a cognitive impairment that requires lifelong care is a huge risk to that child’s quality of life. So, to be able to improve their chance of not experiencing that is positive but not enough is known about what happens to the DNA in future children.
   (Female, 44, Health Visitor, parent, not religious, has condition)

58. The child will not be able to live an independent life.
   (Female, 33, Midwife, not a parent, not religious, not affected)

219. Cognitive skills are essentials to live an independent life. In this scenario the quality of life and basic independence is potentially quite reduced. If something can be done to help, then one should be able to consider it.
   (Female, 44, Conference Producer, French, parent, not religious, not affected)

Carer’s wellbeing

121. The condition would affect not just them but others as they would require help and assistance throughout their lifetime.
   (Female, 23, not a parent, not religious, not affected)

151. Needing lifelong care is also very serious and I can see why parents would want to avoid it for their child (especially since they’ll be the lifelong carer - with all the required emotional, physical, economic costs, plus concerns re. what happens once they’re gone).
   (Female, 28, Editor, not a parent, not religious, not affected)

161. Impact of condition on patients and on those who care for them.
   (Male, 57, Freelance Copywriter, not a parent, not religious, has condition)

216. Because the strain on having a child that will become an adult and needs constant care is detrimental to others in the family - parents are not always going to be there to look after them.
   (Female, 52, Cardiographer, parent, not religious, daughter has condition)
Happiness

111. Not causing any physiological issues or pain or impacting life expectancy would perhaps suggest that they could still pursue life happily without the need for treatment anyway.

(Male, 19, Teacher, not a parent, not religious, not affected)

156. Cognitive impairment could be a major factor of distress in someone's life, given social stigma or the need for costly care, etc., and so if the condition can be safely prevented then why not. but again, if the potential risks of genetic editing are worse than the gains of not living with the condition, then that should be considered.

(Female, 32, Academic, not a parent, not religious, has condition)

369. Everybody deserves a healthy happy life. If that child/person has the opportunity to live a better life, then surely, they have the rights to this life.

(Female, 26, Student Nurse, parent, not religious, not affected)

485. If we are talking quality of life, then plenty of people with limited cognitive function live happy lives.

(Male, 21, Journalist, not a parent, Jewish, has condition)

No pain

5. Because it's solely cognitive ability rather than a condition that causes pain. Even though there is a long way to go in providing services to assist those with various cognitive abilities that are seen outside of the norm, they still exist.

(Female, 26, Postgraduate Student, not a parent, religious but no influence, not affected)

234. If the condition doesn't cause any pain why would it be used? We are all reliant on other people at some point in our life.

(Female, 23, Graphic Designer, Scottish, not a parent, Sikh, not affected)

363. Just because someone is slightly different doesn't mean they're worse. I see physical disabilities and pain are worse.

(Female, 31, Veterinary Nurse, not a parent, Christian, has condition)

364. The condition is cognitive and will require support, but it does not affect physical function or cause pain.

(Female, 50, Medical Secretary, not a parent, not religious, has condition)

The majority of respondents to Q5. were keen to express that impaired cognitive ability and/or learning disabilities alone do not warrant the use of genome editing. As evident from the quotes shared above, physical impairments, pain and dependency are of far greater concern to respondents; this is because these factors are seemingly strongly associated with quality of life and happiness.
For Q6. physical and physiological abilities were brought into consideration.

Q6. If Daniella and Carl’s condition was found to also affect physical and/or physiological abilities, should they be allowed to access genetic editing?

The additional 5.37% (28/521) respondents in favour of allowing genome editing if physical and/or physiological abilities are affected by a genetic condition, concurs with my findings from Q5., with these factors being far more influential than cognitive impairments.

The severity of abilities affected was the most common reason for selecting ‘Other’ in this scenario.

3. It depends what other conditions and what impact they would have on the child and their carers.  
   (Male, 23, Masters Student, Irish, not a parent, not religious, not affected)

416. whether the child’s condition would be a deficiency or whether it would be a burden - neither is clear.  
   (Male, 32, Lecturer, parent, Christian, not affected)

In this scenario, physical abilities are closely associated with quality of life by respondents, more so than physiological or cognitive abilities. Preventing conditions which would reduce an individual’s physical ability, a factor also associated with independence, was the most prominent consideration in this scenario.

Quality of life

222. Physical disabilities make life so much more difficult for the everyday person. I believe that if this can be potentially treated, it should be allowed.  
   (Male, 19, Undergraduate Student, Canadian, not a parent, religious but no influence, not affected)

421. It would improve the overall quality of life by not requiring special needs to accommodate physical disabilities.  
   (Male, 29, Engineer, not a parent, religious but no influence, not affected)
474. Quality of life would be severely affected with psychological and physical effects.  
(Female, 18, College Student, not a parent, not religious, not affected)

500. The fact that the child may be physically and cognitively disabled would mean it would likely have a low quality of life and be burdensome to others. In this case even if the gene editing failed, the child would likely be profoundly disabled anyway, so it may as well go ahead.  
(Female, 20, Undergraduate Student, not a parent, not religious, has condition)

### Dependency

172. As I understand this would mean some ill health for the child (or not? I know, it depends on how we understand cognitive impairment...) - but somehow, I feel even stronger for this case here, as the child would be dependent on others, which may be an extra challenge for the parents (and the child too?). So, if there is a chance of editing it out, why not? And probably even more in this case - but it also depends on HOW this condition would affect the child, that is if the child would SUFFER due to it. If it suffered, editing should definitely be not only allowed but even recommended. If it didn't suffer but was just different physically/physiologically, it may of course be a burden to the child in the normative society, so editing should be allowed - but as a free choice. Perhaps it just should be allowed depending on if the condition is understood as a disease or not? If it is understood as a disease, editing should be allowed.  
(Male, 38, Research Associate, Polish, not a parent, religious but no influence, not affected)

311. Reduce dependency on society and NHS / social services where possible. Also, who wouldn't prefer to have independence?  
(Female, 57, Nurse, parent, Catholic, not affected)

324. If we have a chance to allow people to live a life independent of the care of others they should have that opportunity, but even more so. People deserve an opportunity to flourish.  
(Male, 28, Teacher, not a parent, not religious, not affected)

468. The thought of someone relying on others their whole life is sad. If this can be avoided, why not!  
(Male, 37, TV Producer, parent, not religious, not affected)

### Cognitive impairments

96. Impaired cognition means more expense on state. Why not help reduce this and allow the individual to benefit from normal intelligence and be able to contribute to mankind instead of being a burden?  
(Male, 32, Doctor, parent, religious but no influence, not affected)

233. I am sure any child with the condition would be loved and supported, but the fact is in a normative society, their quality of life is likely to be better if they do not have cognitive impairment.  
(Female, 54, Lecturer, parent, not religious, family members affected)

336. Learning difficulties are not life-limiting, but the ongoing cost of care is a serious issue.  
(Male, 57, Charity Chief Executive, not a parent, not religious, not affected)

401. Lack of cognitive ability will affect his/her ability to live a fulfilled life.  
(Male, 25, Research Associate, not a parent, not religious, not affected)
In summary of scenario 2, taking physical and physiological impairments into account, these factors hinge on notions of fulfilment, cost, and burdens. Some respondents’ answers to Q6. indicate that they feel that physical impairments would prevent an individual from reaching their full potential. Furthermore, physical impairments are seemingly considered to create burdens in normative society, especially when combined with cognitive impairments. The recurrence of considerations towards the cost of disease on the NHS will be discussed on page 59 of this report.
Scenario 3

The primary factor being questioned in scenario 3 is late-onset /adult-onset conditions, i.e. conditions that are not symptomatic at birth or during childhood.

Ekam and Fauja have a genetic condition which usually does not start presenting symptoms until a person is at least 20 years of age. Until a person starts experiencing symptoms they are otherwise healthy and well. Once a person starts experiencing symptoms they are usually affected by lots of pain and have periods where they are reliant on other people to care for them to some extent. There is no cure for the condition and the only available treatment is medication to manage pain. People with this condition usually meet the average life expectancy.

Q7. Should genetic editing be allowed in this scenario?

![Bar Chart]

In relation to previous scenarios, whilst an increase of 8.06% (42 more) of respondents from scenario 1 feel that genome editing should be allowed in this case, this increase is less than scenario 2. This finding suggests that pain is more influential than life expectancy, and/or that late-onset conditions are less influential as a factor of disease to warrant prevention through genome editing. The following qualitative responses corresponding to this question clarify respondents’ opinions.

The majority of respondents who selected ‘Other’ for this question, were mostly undecided / unsure whether genome editing should be allowed in this scenario. However, of the respondents who gave more descriptive answers, the risk of transmission, and the certainty of pain were cited as the main considerations. Again, the opinion that adoption should be considered in light of such conditions was also prevalent amongst responses.

180. If child was guaranteed to inherit the condition then it could be considered. (Female, 42, Teacher, parent, not religious, not affected)

470. I think they should seriously consider adopting rather than bringing suffering upon their child by proceeding with the birth. (Male, 32, Community Support Worker, not a parent, Buddhist, not affected)
As per previous questions, respondents were asked what considerations influenced their answer to Q7. The late-onset factor in this scenario was given significantly less consideration than the factor of pain. Considerations towards pain are largely grouped into three clusters:

1. Pain should be avoided as this causes suffering and possibly dependency
2. Pain is subjective and can be managed, thus it is not reason enough to warrant genetic editing
3. Pain is debilitating and reduces quality of life; it should therefore be prevented

Cluster three is notably derived from individuals who have experience of living with pain, whether past or present, and/or know the impact that pain can have. On the other hand, cluster one takes moral and ethical stances instead of using personal/lived experience.

Avoid pain

14. If you can avoid pain in later life with genetic engineering it seems a kindness. (Female, 28, Lecturer, not a parent, Christian, not affected)
41. It would be best to try and get rid of any issues first of all as this would be helpful for both the child and the parents, so they don’t have to worry about it appearing when the child grows up. (Female, 16, High School Student, not a parent, religious but no influence, not affected)
217. Even though no symptoms are present until after 20 years of age, no one should have to go through managing pain if this is preventable. (Female, 45, Mother, parent, not religious, daughter has condition)
304. Pain relief through preventing the condition from being present would make the person’s life a lot better. (Male, 17, College Student, not a parent, religious but no influence, not affected)

Management of pain

34. Pain is subjective. The parents would be able to identify whether it is liveable or excruciating enough to risk potential side effects. (Male, 20, Undergraduate Student, not a parent, not religious, has condition)
124. Symptoms can be managed and do not affect independence or life expectancy. (Female, 38, Self-Employed Disability Assessor, not a parent, religious but no influence, has condition)
264. The condition as described has no cognitive or physical effects, nor a detrimental effect on life expectancy. Pain can be managed with medication, such that the risk of this alone does not outweigh the possible risks of the gene editing procedure. (Male, 29, PhD Student, not a parent, not religious, not affected)
349. The condition is not guaranteed and can be managed. 20 years is a long time in research maybe a cure could be found before then. (Female, 43, Teacher, Irish, parent, not religious, not affected)
Pain is debilitating

89. It’s very difficult to have to rely on medication for your lifetime as there will always be side effects.  
(Female, 45, Accountant, parent, Sikh, has condition)

131. Pain is an awful and debilitating thing to have to live with and the current benefits system makes it hard to access appropriate care with these 'invisible' disabilities.  
(Female, 22, Student Support Worker, not a parent, Christian, not affected)

132. Having to manage pain that can’t really be treated, only masked by medication.  
(Female, 38, Legal Secretary, parent, not religious, has condition)

225. Pain is debilitating, and pain medications are likely to shorten your life somewhat.  
(Female, 33, Nurse, not a parent, not religious, not affected)

Age at onset of condition

155. The age at which the condition manifests itself.  
(Female, 21, Undergraduate Student, Indian, not a parent, religious but no influence, not affected)

158. Regardless of what age a condition presents itself, or whether it is guaranteed to present itself, if it is directly harmful or would require parents to provide extra care which may be beyond their means then parents should have access to editing.  
(Male, 28, Administrator, not a parent, not religious, has condition)

291. The fact that the severity of the condition once the symptoms manifest themselves are so stark in contrast to how they would’ve been before in regard to their health is quite shocking. To suddenly be healthy and then suddenly be almost bedridden is tough physically, mentally and emotionally therefore any treatment which can be done to help make this condition less intolerable is definitely needed. Therefore, in relation to this scenario, genetic editing ought to be allowed.  
(Male, 19, Apprentice, not a parent, Christian, not affected)

362. This condition sounds similar to that of MS. In this case yes, they should be allowed, regardless of the age of beginning the quality of life may be poor.  
(Female, 20, Undergraduate Student, not a parent, not religious, has condition)

From the respondents’ quotes above, pain is an obvious multi-faceted factor of disease. Respondents have different attitudes towards pain depending on their own experiences. However, whilst pain may be a more influential factor of disease over life expectancy and late-onset conditions overall, if pain can be managed, then cognitive impairments and life expectancy become more influential considerations. This change with manageability is because respondents feel that reducing pain can improve quality of life. Respondents who took the late-onset factor into consideration largely feel that genome editing should be allowed for conditions which include this factor. Most respondents feel this way because not only would individuals with such conditions have an awareness of how life was before the symptoms of the condition, they would still potentially end up suffering; the avoidance of pain is what respondents are most concerned with.
A cure or effective treatment was the primary consideration for Q8., emphasising the factor of disease management.

Q8. If a cure or effective treatment for Ekam and Fauja’s condition becomes available, should they be allowed to access genetic editing?

As visible in the graph above, the availability of a cure or effective treatment for a condition evoked a sharp drop in the number of respondents being in favour of genome editing. The decrease falls below the number of respondents who were in favour of genome editing in scenario 1 by 14.97% (78 respondents) and generates an increase in respondents who feel that genome editing should not be allowed in such scenarios by 8.26% (43 respondents). The supporting qualitative responses to this question assist our understanding of why this factor elicits this response.

‘Other’ factors for this scenario include the cost, how effective the cure or treatment is, whether genetic editing would have more or fewer side-effects than the treatment or cure, and the risks involved.

78. If the treatment is widely offered and available and isn’t going to cost more than the genetic editing process then it should be up to the parents to decide whether they would like genetic editing or rather treat it later on in their child’s life.  
(Female, 28, Consultancy, South African, not a parent, not religious, has condition)

478. depends which is more cost effective and has fewer negative effects.  
(Male, 21, Undergraduate Student, not a parent, Jewish, not affected)

According to respondents, among influential considerations to Q8. Is that a cure, rather than effective treatment, is available for genetic conditions. This serves as a strong deterrent to genetic editing. This consideration extends as far as some respondents feeling that if an effective treatment/cure is available, then genetic editing is somewhat redundant. However, of respondents still considering genome editing as a possible treatment, some feel that it may be the more expensive option and are therefore cautious about this expense. Similarly, other respondents
expressed that finding an effective cure could be costlier than genome editing. Additionally, some respondents feel that ‘prevention is better than the cure’ and that editing out a condition would ensure adverse symptoms are never encountered, and that future generations will not require a cure. Other respondents were mindful of the age at which a cure can be introduced, and how effective a cure could be.

Genetic editing is redundant if treatment / cure is available

37. If their child develops the condition and they have a cure, then why not use the cure (which by the time the child is affected could be further developed) as opposed to the stress of an IVF procedure for genetic modifications to a child.
   (Female, 20, Underwriter, not a parent, not religious, not affected)

76. There would be no need if a cure was available.
   (Female, 46, Retail Assistant, parent, not religious, not affected)

189. If the condition is easily treatable then genetic modifications seems unnecessary.
   (Female, 16, High School Student, Polish, not a parent, not religious, not affected)

447. If they can remove the cause of the disease, there would be no need for a cure.
   (Male, 22, Software Engineer, not a parent, not religious, not affected)

Cost of treatment vs. genetic editing

137. Cost to the NHS.
   (Female, 47, Mother, parent, not religious, daughter has condition)

193. Why should someone have to grow up with that uncertainty... or have to face adulthood with medication when you can get rid of the diseases... I wonder if it's more cost effective as well to get rid of the diseases before people are born rather than relying later on cures and treatments.
   (Male, 35, Communications Worker, not a parent, not religious, not affected)

330. Long-term health costs to the NHS - potential for better quality of life for the child.
   (Male, 35, NHS Worker – Management, not a parent, religious but no influence, not affected)

484. Cost, they should have the right to choose genetic editing if they so wish. But which will cost more would be the primary factor for me in this case (medication vs. genetic editing).
   (Male, 24, Unemployed, British-Polish, not a parent, religious but no influence, not affected)

Implications for future generations

140. It would have the added effect of nullifying the question in future generations because the problematic gene would be gone.
   (Male, 23, Postgraduate Student, Irish, not a parent, not religious, not affected)

210. Sounds harsh, but hard cases do not make a good 'law'. I think the risks of unintended consequences for future generations are too high.
   (Male, 45, Chartered Accountant, parent, not religious, not affected)

315. This was a harder question, but if a genetic modification could prevent the need for treatment/cure measures in the future (or future generations - here is where my knowledge gets fuzzy) then it should be used.
   (Male, 41, Lecturer, parent, not religious, not affected)
Having a sick child almost die, suffer pain etc. is still the reality for some prior to the cure being available or operation (whatever it might be) scheduled. Future children wouldn’t need a cure the condition wouldn’t be present in the first instance.

(Female, 30, Company Director, parent, religious but no influence, daughter has condition)

Effectiveness of treatment

66. Depends on how effective the cure if found to be. In the end it’s all a weighing of probabilities.

(Female, 27, PhD Student, German, not a parent, not religious, not affected)

211. If effective treatments, or a cure, are available then genetic editing is unnecessary.

(Male, 33, Environmental Consultant, parent, not religious, not affected)

412. If there is an effective treatment, then I believe then it could be treated. However, it depends what ‘effective treatment’ entails.

(Male, 19, Undergraduate Student and Entrepreneur, not a parent, not religious, not affected)

499. If the treatment is effective, then there is less incentive for the mother to go through the IVF process and introduce the associated risks.

(Female, 21, Undergraduate Student, not a parent, not religious, has condition)

In this scenario, considerations to the risk-benefit ratio of utilising genome editing, whether rooted in health and wellbeing or economics, became more prevalent. On one side prevention is felt to be better, but on the other an effective cure/treatment is thought to negate that consideration. Whether genome editing should be allowed for conditions where an effective cure or treatment exists/is on the horizon would require far greater deliberation than is required for other factors of disease.

Once again, the late-onset factor remained relatively neglected in qualitative responses.
Scenario 4

This scenario was predominately concentrated on the factors often encompassed by degenerative conditions.

Holly and George are affected by a painful genetic condition which is degenerative. People with the genetic condition do not know how they will be affected by the condition and require a regular range of medical tests (e.g. blood tests, scans etc.) to check their ongoing health. Eventually, people with this condition start losing their physical abilities but have a normal life expectancy.

Q9. Should genetic editing be allowed in this scenario?

In light of findings from previous scenarios, the 14.01% increase (43 more) from Q3. in respondents feeling genome editing should be allowed in such scenarios is unsurprising, because pain was a certainty in this scenario. However, the supporting qualitative data reveals that respondents’ choice in the multiple-choice aspect of this question was (also) influenced by the factor of degeneration and/or the loss of physical abilities.

‘Other’ factors in this scenario centred on how the individual would be affected/the nature of the condition / how extreme the symptoms of the condition would be. However, in this scenario, most respondents who selected ‘other’ were unsure/undecided/feel they need more information before they can decide.

77. It depends at what age they start experiencing degenerative problems. If they experience it at old age, then genetic editing should not be allowed. But if these painful conditions are experienced at a young age then it should be allowed.
(Male, 16, High School Student, not a parent, Sikh, not affected)

384. This would depend on the nature of the condition.
(Male, 51, University Administrator, not a parent, not religious, has condition)
'Quality of life' is the most prominent factor in the considerations which influenced answers to Q9., insofar as respondents feel that the conditions encompassed in the proposed scenario would diminish an individual’s quality of life and should therefore be prevented. The notion of reducing/preventing pain, whether physical or emotional, is also a significant factor in this scenario, with pain being closely associated with quality of life and being thought to increase with the factor of degeneration. Views on physical ability shared in Q6. are developed further in responses to this scenario.

Preventing pain/suffering

48. The more cruel the suffering, the more cruel it is not to prevent it if possible.  
   (Female, 30, PhD Student, American, not a parent, not religious, not affected)

96. If genetic editing was deemed completely safe, it could be a better option than letting the person go through the pain of developing the condition then having it cured.  
   (Female, 21, Unemployed, not a parent, not religious, has condition)

177. Possible benefits (avoiding pain and disability, need for care and medical treatment associated with the condition). Implications of some/all people being able to prevent their children being born with the conditions. Other background factors e.g. prior testing, availability of treatment (for all or only very rich people?), possibility of full informed consent without coercion.  
   (Male, 25, Unemployed, not a parent, not religious, has condition)

228. The genetic editing could prevent them from experiencing increasing amounts of pain throughout their lives.  
   (Male, 16, High School Student, not a parent, not religious, not affected)

Reducing Pain

9. If we have the capacity to remove/reduce pain and incapacity why should we not?  
   (Female, 57, Educator, parent, not religious, not affected)

114. Allowing the unborn child to escape the pain and increased strain on NHS.  
   (Female, 25, Trainee Solicitor, not a parent, not religious, not affected)

212. The person will be in constant pain and it will get worse. Why should they have to suffer if there is adequate treatment that can prevent it?  
   (Male, 17, College Student, not a parent, Muslim, not affected)

383. A balance must be struck between respecting the rights of disabled people as functioning human-beings, and the relief of pain. There is no need to suffer unnecessary pain.  
   (Male, 50, Academic, British-Chinese, parent, not religious, has condition)

Degeneration

10. If the condition is degenerative, painful and there is no way to know the outcome, even if the life expectancy is normal, the quality of life can be very low.  
   (Female, 27, PhD Student, Spanish, not a parent, religious but not influence, not affected)

18. If they lose their ability to do things on their own - they will need to adjust to a new life style which can have negative impacts - their quality of life can be reduced and therefore they should have access.  
   (Female, 31, Lecturer, not a parent, not religious, not affected)
120. They require medical testing etc before the condition is even diagnosed and this itself may cause pain and suffering before they even begin to experience symptoms. As it is degenerative, their quality of life is likely to decline, which could also cause them mental stress.

(Female, 20, Undergraduate Student, not a parent, Catholic not affected)

175. Degenerative illnesses are debilitating and costly to the NHS. If people can be spared watching the life they have built being destroyed and they can continue to be productive and healthy members of society this should be strived for.

(Female, 37, Medical Administrator, parent, not religious, has condition)

Physical ability

64. Any condition that limits one’s physical ability should be given a chance to correct their genetics.

(Female, 26, Teacher, not a parent, religious but no influence, not affected)

97. Life expectancy is not an indication of quality of life. If they lose their physical mobility not only will that affect them physically it will likely affect their mental health & that of the people around them.

(Female, 28, Studio Manager, not a parent, not religious, family members have condition)

201. Being severely physically disabled, I say that no one should experience a physical constraint. It is a physical prison and a constant physical and psychological battle.

(Female, 35, Civil Engineer, Greek, not a parent, not religious, has condition)

286. Without physical ability life is simply harder even in a society that values accessibility. It is desirable to treat this as it will reduce strain on carers and increase quality of life, again it is also more cost effective.

(Male, 22, Undergraduate Student, not a parent, not religious, not affected)

Degeneration and loss of physical ability in this scenario shares similarities with responses from Q7. which extended consideration to the late-onset factor, insofar as respondents acknowledge an awareness of loss. Knowing that abilities are being lost is considered to have adverse effects on mental health, and thus reduce quality of life further. However, unlike responses to Q7., responses to this question greatly expand on the process of adaptation as loss is incurred, and the affects this loss could have on perceptions of quality of life.

Quality of life, in essence, encompasses an individual’s general well-being, including their emotional state and their life satisfaction – which can derive from the opportunities that are accessible to an individual, as well as their own perception.
Cognitive ability is questioned again in Q10., however, in this scenario a cognitive impairment is not present from birth.

Q10. If people with Holly and George's condition could also lose their cognitive abilities, should they be allowed to access genetic editing?

As is evident from the graph above, in comparison to the previous question, there is very little change in opinion with the factor of degenerative cognitive ability. Only 1.34% more of respondents (7/521) feel that genome editing should be allowed in such scenarios, which could suggest that this factor is not very influential. The accompanying qualitative responses to this question clarify the data.

Respondents who selected 'Other' to this question were largely unsure. However, the risk of cognitive abilities being lost was cited, as was the severity of lost cognitive abilities.

319. It depends on the chances of this happening. (Male, 53, Retired, parent, not religious, not affected)

372. Depends on how severe the loss of cognitive abilities would be. (Female, 21, Undergraduate Student, not a parent, Christian, has condition)

There are several influential considerations to respondents’ answers to Q10. In addition to quality of life, having the best start in life, and notions of living a ‘healthy’ or ‘normal’ life are among the most prominent considerations in this scenario. Respondents shared that they feel genetic editing in such contexts would improve a person’s / family’s quality of life or prevent further reduction in a person’s quality of life. Respondents extended consideration to these factors with the beliefs that cognitive ability is important, and that loss of cognitive ability would lead to dependency. Additionally, some respondents feel that losing cognitive ability is an unpleasant experience that is best avoided, particularly when in addition to loss of physical abilities. Overall, losing cognitive ability/the degeneration of cognitive of ability is considered more undesirable than being born with a cognitive impairment due to the individual’s awareness in the matter.
Chance for a healthy/normal life

45. Everyone should be given the chance at a happy healthy life.
   (Female, 34, MRP Controller, parent, not religious, not affected)

54. They should be allowed to live a normal life.
   (Female, 22, Customer Advisor, not a parent, not religious, not affected)

115. We all should have the right to live a normal healthy long life.
    (Female, 53, Administrator, parent, religious but not influence, not affected)

245. A person has a right to lead a normal independent painless life.
    (Male, 82, Retired Civil Engineer, parent, Sikh, not affected)

Genetic editing could improve quality of life

47. Quality of life reduced greatly with loss of cognitive abilities too, the risks of genetic editing would be worth the try.
    (Female, 22, Pilot, not a parent, not religious, not affected)

322. The child will be better off for not having the condition.
     (Male, 28, PhD Student, not a parent, not religious, not affected)

479. We should not keep scientific breakthroughs that can improve quality of life away from people.
     (Male, 22, President of a Union, not a parent, Jewish, not affected)

504. Having epilepsy and experiencing mild cognitive difficulties from medication is not a great experience. If it could be avoided life outcomes and educational experience would be enhanced.
     (Female, 22, Undergraduate Student, not a parent, not religious, not affected)

Dependency with loss of cognitive function

98. I feel this may be a case that could be considered. As stated before if both physical and cognitive abilities are impacted you will not be able to live life and would be heavily reliant on those around you.
    (Female, 34, Social Worker, parent, not religious, not affected)

109. Apart from other problems they may have or are dealing with, if they lose out on their cognitive development they will surely need one to one support and become reliant on others.
    (Female, 40, Carer, parent, religious but no influence, not affected)

117. The resultant loss of cognitive abilities means their constant dependence upon full time care and hence loss of full engagement with life and living.
    (Male, 72, Retired, parent, Christian, not affected)

241. They would likely need full-time carers if this happened which is something they may not be able to afford.
    (Female, 18, Undergraduate Student, not a parent, Agnostic, not affected)

Awareness of losing abilities

28. If that person is going to have to be looked after for the rest of their lives as they get worse and they're aware of their worsening condition, I don't think anyone should be put through that.
    (Female, 24, Charity Worker, not a parent, not religious, not affected)
102. Because the child can lead a life that is aware and cognitive until it dies.  
(Female, 46, Production Operative, parent, religious but no influence, not affected)

174. Having cognitive abilities and then losing them.  
(Male, 43, Artist, not a parent, not religious, has condition)

464. Losing something you have already had would be harder than not understanding in the first place, but still needs to be treated with caution.  
(Female, 20, Undergraduate Student, British-Israeli, not a parent, Jewish, not affected)

Among the above quotes from respondents is an implication that impairments and dependency render individuals abnormal; this implication may not be considered entirely true. Additionally, the introduction of degenerative cognitive ability evokes a greater sense of dependency on others which is not present with degenerative physical ability as an isolated factor.

Dependency, whether on others or the state, is considered highly undesirable by respondents. Dependency is felt not only to reduce personal freedom, but to perhaps also create burdens. Awareness of loss and becoming dependent remain highly influential among respondents’ considerations in this question and could be explored further.
Scenario 5.

This scenario was mainly focused on life expectancy. Notions of suffering or pain were not implied in this scenario but were nonetheless interpreted to be present due to the description of receiving ‘intrusive medical treatments’.

Javeria and Imran are carriers of a fatal genetic condition. People who inherit the condition have a reduced life expectancy and have to receive very intrusive medical treatments from birth until they die. Cognitive ability is not affected by this condition, but physical abilities may be impaired as physiological abilities deteriorate.

Q11. Should genetic editing be allowed in this scenario?

86.56% (451/521) of respondents are in favour of allowing genome editing in this scenario, the peak number of respondents across all scenarios. Respondents who selected ‘Other’ for this question, mainly wrote that they are undecided or require more information.

Many notions surrounding life were considered to be influential for respondents in this scenario. Quality of life was regraded most prominently, with explanations including needing a lifetime of care or being confined to a hospital for treatment. Other notions included a consideration to the scenario presenting a life-threatening disease and to a reduced life expectancy; both were deemed quite undesirable. Considerations towards fatality and intrusive medical treatments were cited more than the deterioration of abilities.

Lifetime of care

59. To rely on medication one’s whole lifetime, it is a hard life style to go with.
(Male, 33, Interpreter and Teaching Assistant, Kurdish, not a parent, not religious, not affected)

190. They have a reduced quality of life. They have to take extreme medication all their life. Like not just a tablet. Affecting them physically does a lot of harm throughout their life. Having psychological problems.
(Female, 16, High School Student, Iraqi, not a parent, Muslim, has condition)
256. If the treatments they need are regular and intrusive then this would affect quality of life and seems like the cost and time spent on managing the condition is too high.

(Female, 25, Postgraduate Student, not a parent, Sikh, not affected)

350. Self-evident; a chance an individual does not have to endure and face a lifetime of pain and the likelihood that life will be shorter.

(Male, 59, Probation Officer, parent, not religious, not affected)

Life expectancy

8. The fact the disease is fatal, associated with intrusive medical procedures. It sounds like affected persons will have a life mostly spent in the hospital, probably in pain, and debilitated. That's a life not worth living. In addition, health care costs will be high.

(Female, 31, PhD Student, Dutch, not a parent, not religious, not affected)

17. The fatal nature of the condition and the need for lifelong interventions.

(Male, 41, PhD Student, not a parent, not religious, not affected)

32. The condition causes early death, a lot of medical intervention and has financial implications for the NHS. It causes stress for the family. It affects the person's and parents' quality of life. They should be given genetic editing.

(Female, 27, Optometrist, Irish, not a parent, religious but no influence, not affected)

240. It's a fatal condition that can possibly be treated by changing genetic information, so I think it should be attempted.

(Female, 16, High School Student, not a parent, Muslim, not affected)

Awareness of fatal nature of condition

48. I personally don't think it's ethical to carry a child to term if it's known they have a condition like this; their quality of life is so poor that it would be unethical to knowingly bring them into this world. If such a condition could be prevented through genetic editing then it should be; otherwise, termination should be strongly considered.

(Female, 30, PhD Student, American, not a parent, not religious, not affected)

151. It's fatal, requires intrusive management, and you have full cognitive functionality so will be aware of what's happening (provided you live that long) - very sad illness.

(Female, 28, Editor, not a parent, not religious, not affected)

160. The fatal nature of the condition, the intrusive medical treatments from birth. Even if cognitive ability isn't affected, it's tough to be aware of what is going on around you without being able to take part in it.

(Female, 31, Administrator, not a parent, not religious, not affected)

291. The fact that the condition is fatal is a major determining factor as it shortens the life expectancy of those affected. The fact that there is awareness to the reality that the affected will have a significantly reduced life expectancy it's best to make that life, regardless of how short, as bearable as is possible.

(Male, 19, Apprentice, not a parent, Christian, not affected)
The factor of fatality, despite no mention of how long life expectancy would be in this scenario, seemed to negate most considerations towards pain and all other factors of disease due to the quality of life in this scenario. This finding suggests that most respondents are welcoming towards the possibility of preventing premature death from disease. Quality of life in this scenario extends beyond the individual with the condition to encompass the affect that the individual’s condition will have on others. Once again, in the same manner as all preceding scenarios, consideration towards the cost of treatment for the NHS is prevalent in responses to this question.
The final question in section 2 of the survey concerned euthanasia.

Q12. If euthanasia was legal in the United Kingdom, should people with Javeria and Imran’s condition be allowed to access genetic editing?

On the whole, respondents originally in favour of genome editing for people with Javeria and Imran’s condition, changed their multiple-choice answer to ‘Other’ with the introduction of euthanasia. In comparison, only one respondent who was originally against genome editing being allowed changed to ‘Other’. The number of respondents who feel that genome editing should not be allowed was the smallest in this scenario, at 8.64% (45/521).

Predominately, respondents who selected ‘Other’ in this scenario could not see / did not understand the link with euthanasia.

266. I cannot see the connection between euthanasia and gene editing  
(Female, 60, Support Group Founder, parent, not religious, son has condition)

428. Not sure what the relevance of euthanasia is?  
(Male, 51, IT Analyst, parent, Sikh, not affected)

497. Euthanasia should be irrelevant to genetic editing debate.  
(Male, 27, Engineer, not a parent, Christian, not affected)

The introduction of euthanasia in this scenario was intended to question whether the risk of transmitting a genetic condition would be more or less acceptable if an option to end pain/suffering was available, in lieu of going through genetic editing. Both genetic editing and euthanasia have the potential to stop pain, however, how the technologies are interpreted by the wider public varies considerably.

Euthanasia was regarded in several different contexts in responses to this scenario and greatly influenced respondents’ answers to Q12. Some respondents are against euthanasia; many respondents who hold this opinion wrote that ‘euthanasia is not the answer’ and that this treatment should not be legalised; religious beliefs were also cited, as was potential misuse. Other respondents suggested that euthanasia should be a last resort, that euthanasia enabled freedom of choice, and that this
treatment should be a legal option. Nonetheless, many respondents considered genetic editing and euthanasia to be separate topics. More elaborate responses reveal that such opinions largely originate from the stance that pain and suffering would not be prevented through euthanasia. However, a large proportion of respondents wrote that introducing euthanasia to the scenario did not influence their previous response.

Against euthanasia

27. Euthanasia is killing and should be avoided at all costs - preventative medicine over an escape to insufferable pain.  
   (Female, 18, Classical Musician, not a parent, Catholic, not affected)

30. Euthanasia is wrong.  
   (Male, 64, Retired, parent, Christian, not affected)

408. Euthanasia should not be used to get rid of individuals who do not enjoy perfect health.  
   (Female, 69, Retired Scientist, parent, not religious, has condition)

495. I oppose the legalisation of euthanasia, and I would campaign to have any such a law repealed (as indeed I have already campaigned against such laws being passed, albeit in my capacity as a private citizen rather than a representative of the charity where I work). I think legal and ethical considerations relating to the beginning of life are very different from legal and ethical considerations relating to the end of life, and I find it frustrating that people assume one's moral views on the former lead ineluctably to certain moral views on the latter.  
   (Male, 38, Communications Manager, not a parent, not religious, has condition)

Religious influence towards euthanasia

1. From a religious aspect, I do not believe in euthanasia.  
   (Female, 26, Investigations Officer, Pakistani, not a parent, Muslim, has condition)

162. We are not God, only he has the right to give life and take it away.  
   (Female, 44, Carer, parent, Sikh, not affected)

301. Euthanasia is against my religion as it is ending life.  
   (Male, 16, High School Student, not a parent, Muslim, not affected)

472. It’s against my religious beliefs.  
   (Female, 42, Nurse, Indian, parent, Catholic, has condition)

Euthanasia should be a last resort

7. Euthanasia should be the last resort.  
   (Female, 28, Unemployed, not a parent, not religious, not affected)

207. I don't really see how it makes any difference. I also favour (cautiously) the provision of euthanasia, but very much as a last resort option. Far better to weed out the problem before the person is born, clearly.  
   (Male, 47, Book Editor, not a parent, not religious, not affected)

264. Euthanasia should be a last resort offered only after all other treatment options have been exhausted. The existence of euthanasia as an option therefore does not affect the morality of any particular treatment.  
   (Male, 29, PhD Student, not a parent, not religious, not affected)
Euthanasia is not, in my eyes, an alternative to genetic editing. If anything, having euthanasia as an option should put greater pressure to develop genetic editing. I support euthanasia if there is no other option, but in this scenario, there is.

(Female, 30, Administrative Assistant, not a parent, not affected)

Euthanasia should be legalised

53. Euthanasia should be legal in the UK.
   (Male, 23, Postgraduate Student, not a parent, religious but no influence, not affected)

171. I think euthanasia should be legal.
   (Female, 52, Writer, parent, not religious, sibling affected)

197. Euthanasia should be made legal in the UK, and it would be the decision of individuals as to whether they chose that option. It wouldn't be reasonable to refuse genetic editing on the basis that euthanasia was legal, as there will always be some people who wouldn't choose that route.
   (Male, 45, Public Sector, not a parent, not religious, not affected)

410. The decision should still be with them, but I think euthanasia should be legal regardless.
   (Male, 21, Undergraduate Student, not a parent, not religious, not affected)

Euthanasia does not prevent pain/suffering

57. Euthanasia would allow someone to end a life of pain and suffering but would do nothing to actively attempt to improve the person's life. Gene editing would be an active attempt to help the person. Whether or not they can choose to die at a later stage is irrelevant.
   (Female, 24, Masters Student, South African, not a parent, not religious, not affected)

60. The person with the condition would still suffer massively until they did/didn't decide to euthanise and then the family would have to deal with the backlash from this too.
   (Female, 24, Teacher, not a parent, not religious, has condition)

150. Euthanasia does not prevent people from having the illness, and it is not a cure for a fatal illness, i.e. their child's quality of life will still be impacted.
   (Female, 30, Project Manager, not a parent, not religious, not affected)

186. Euthanasia is not a better option than preventing the suffering in the first place.
   (Female, 17, College Student, not a parent, not religious, has condition)

Genetic editing and euthanasia are different issues

106. Not everyone will choose the path of ending their life even I think. Obviously genetic editing will be the better option.
   (Female, 47, Manager, parent, Sikh, not affected)

199. Euthanasia is a completely different subject with a separate set of ethical considerations and is off topic.
   (Male, 58, Company Director, not a parent, not religious, not affected)

242. Euthanasia seems a totally different thing to genetic editing.
   (Female, 65, Charity Worker, American, parent, not religious, has condition)
Euthanasia and gene editing aren't comparable for me. One is intended to prevent suffering, the other to end it when it has become unbearable - the suffering has already happened. For context, I do think euthanasia should be legal.

(Female, 27, PhD Student, not a parent, not religious, not affected)

Pro-euthanasia

202. Just because they have the option to kill themselves with dignity doesn't mean they may not want children at some point and not want to pass on the condition.

(Female, 19, Undergraduate Student, not a parent, not religious, not affected)

240. Euthanasia is definitely a complicated topic. But I think it should be acceptable as long as the patient absolutely cannot handle the pain and if the doctors know that they won't make it past a certain age. Also, the patient should ask for it themselves and not feel forced. The condition is said to be fatal and those who have it seem to suffer excruciating pain.

(Female, 16, High School Student, not a parent, Muslim, not affected)

313. Why would that matter? Euthanasia is amazing done ethically.

(Male, 39, Bus Driver, not a parent, Latter Day Saint, has condition)

355. Euthanasia should be considered for degenerative conditions that have reached their conclusion...not at the start of a condition...life is unpredictable and who knows what may happen...!

(Male, 56, Medically Retired, parent, religious but no influence, has condition)

As a means to prevent pain and suffering, genome editing is clearly a more popular option than euthanasia. Euthanasia is associated with ending life only after pain and suffering has been encountered, which may not always be the case. Several respondents mentioned that euthanasia may not be a feasible option for many, however, the same could be true of genome editing. This was the only question in which cost to the NHS was not mentioned by any respondents.
The findings reported in this section have determined that different types of genetic conditions, i.e., conditions which affect cognitive/physical/physiological and/or painful/late-onset/degenerative/fatal conditions, elicit different attitudes towards genome editing as a reproductive choice/option. Furthermore, other factors of disease such as risk of transmission, treatment available for a condition, quality of life and life expectancy elicit different attitudes towards genome editing.

The different attitudes elicited from respondents through the various factors of disease and disability have been systematically discussed as they have arisen from each of the five scenarios. However, thus far, overarching themes which were prevalent across responses to questions in section 2 of the survey have largely been ignored. Such themes include the cost of genome editing for the NHS, the notion of free choice, i.e., individuals being able/allowed to make whatever decision they feel is right for themselves, and germline genome editing furthering inequalities within society. Respondents also repeatedly mentioned the need for human germline genome editing to be proven as a ‘safe’ technique for preventing disease and for the legal applications of the technology to be robustly regulated, before being made available as a reproductive choice/option. Several respondents mentioned that preventing disease would be against God’s will, or that the choice to alleviate or cause pain and suffering is up to God. Finally, some respondents feel that instead of developing technologies which are likely to always present with risk, people wanting to avoid transmitting a disease to their child should adopt. This final attitude overlooks the fact that some parents value a biological/genetic link to their child(ren) and adoption would not fulfil this desire (Franklin, 2013). These overarching themes are evidenced in the reported findings for section 3 of the survey, where they become more prevalent due to the ethical considerations stemming from them.

The overarching views in this section suggest that the majority of respondents are in favour of few restrictions being placed on genome editing for the purposes of preventing genetic disease. However, what is considered a disease constantly evolves, has historically been problematic, and could be abused. Whilst respondents to my survey are currently in agreement that genome editing should not be used for non-medical purposes, i.e., aesthetic characteristics such as eye colour, this could change in the future if such characteristics are reframed as a ‘disease’. For this reason, factors of disease may prove to be more useful in deciding what diseases should not be prevented, should germline genome editing be legalised. Considering the favourability for genetic disease to be edited out, further research with individuals affected by genetic disease may help untangle which factors of disease should be taken into prime consideration and why. This suggested research could also help determine how individuals living with genetic disease and disability feel towards genome editing technologies potentially preventing future generations sharing similar life experiences to themselves, and whether this is felt to be necessary.
Section 3: Legislation and Ethics

This section was intended to elicit views on the legal context of genetic editing in the United Kingdom, and to gauge if/how respondents could foresee the technology being misused.

The first question in this section established a baseline for the proceeding questions.

Q13. Should genetic editing be legalised in the United Kingdom?

The responses to this question indicate that there is very little direct opposition to legalising germline genome editing in the United Kingdom, as only 4.80% (25/521) of respondents feel that genetic editing should not be legalised. However, as the qualitative responses below demonstrate, there are several considerations which need to be addressed before the wider public would largely be in favour of genetic editing being legalised in the United Kingdom.

There are several significant factors which influenced respondents’ answers to Q13., listed below:

Robust regulation to prevent misuse, when misuse is defined as any intervention not intended to prevent serious genetic disease (any use that is not medical)

56. Needs to be very careful control of the process. Once it is tried and tested for preventing disease and illness where is the line drawn? Could make arguments for all sorts of ‘improvements’ and move towards some dystopian future.
   (Male, 22, Undergraduate Student, not a parent, not religious, not affected)

63. It has the potential to make a huge difference to the quality of life of so many people. However, it would need legislating really really carefully in order that it not be misused.
   (Female, 31, Midwife, parent, not religious, not affected)
The proven, transparent, safety and success of the technology – this includes risk of negative side effects

50. If it is safe, affordable and the level of success is high.
(Male, 41, PhD Student, Iraqi, not a parent, not religious, not affected)

323. If genetic editing works efficiently and safely, it should be available to all people who can benefit. If there are risks, these should be well understood and explained so that an informed choice can be made.
(Male, 56, Computer Programmer, not a parent, religious but no influence, not affected)

Fair access to the technology in order to avoid increasing inequalities

402. It should be legalised only if it is available on the NHS. Genetic editing which is only available to the very wealthy sets a dangerous precedent whereby class distinction could eventually be accompanied by a distinction of genetic superiority/inferiority.
(Male, 20, Undergraduate Student, not a parent, not religious, not affected)

460. Depends how much it costs and whether it will be regulated. It wouldn’t be particularly fair for wealthier people to be able to disease-proof their children whereas the poorer families could not. It ought to be fairly distributed based on need, not wealth. If it was so cheap that anyone could have it done, then there would need to be criteria put in place, to ensure it was only used in cases where it would alleviate pain, inconvenience and dependence, and not pure cosmetics.
(Male, 24, Research Assistant, not a parent, not religious, not affected)

If the cost of utilising the technology outweighs the cost of other treatment

361. How the condition impacts the affected person & their family. Costs of treating & caring for the affected person during their life time.
(Female, 48, Charity CEO, parent, not religious, not affected)

430. The availability of it, the cost of it and the effectiveness of it.
(Male, 19, Undergraduate Student, not a parent, not religious, has condition)

Judgement on a case-by-case basis

46. It should be considered on a case by case basis
(Female, 20, Undergraduate Student, not a parent, not religious, has condition)

473. Needs to be considered on a case by case basis
(Female, 46, Secretary, Polish, parent, Catholic, not affected)

These factors support findings and/or recommendations from other research on human genome editing. Discussions surrounding the regulation and legislation of germline genome editing are ongoing and research is constantly being collated to assist deliberations. The findings within this report are likely to be added to such discussions.

See Appendix 3 for a list of other published research and/or recommendations involving human genome editing.
The second question in section 3 of the survey was based on the concept of ReproTravel\(^\text{19}\) and was posed to determine how British citizens feel about other British citizens utilising the option.

Q14. If genetic editing remains illegal in the United Kingdom but is legal in other countries, should people living the United Kingdom be allowed to travel abroad to access genetic editing?

The majority of respondents, 65.64% (342/521), are in favour of allowing people living in the UK to travel abroad to access genetic editing. Only 7.49% (39/521) of respondents are against allowing people living in the UK to travel abroad to access genetic editing. The remaining, 26.87% (140/521) of respondents feel that allowing people living in the UK to travel abroad to access genetic editing depends on various factors, which are detailed as follows:

The intent of genetic editing – genetic editing for ‘designer babies’, i.e. aesthetic reasons are deemed unacceptable. Respondents are only in favour of travel for medical reasons.

\textbf{308.} only to cure illness not to create designer babies.  
(Male, 16, High School Student, not a parent, not religious, not affected)

The reason why genetic editing is not legal in the UK

\textbf{320.} It will depend on the reasons for why it is illegal. Would legislators have a reason to think that this would interfere with domestic welfare, health, or security?  
(Male, 28, Researcher, Danish, not a parent, not religious, not affected)

\footnote{ReproTravel is shorthand for Reproductive Travel and is defined by Professor Marcia Inhorn (2015), who is a medical anthropologist at Yale University, as transnational healthcare in the field of assisted reproduction. ReproTravel is essentially when citizens of one country travel to another specifically to access assistive reproductive services.}
The safety of genetic editing outside of the UK

173. Safety. We have an NHS which puts the welfare of the patient first. Some other countries operate healthcare on who can afford it, which creates a culture of huge disparity in access to quality healthcare options. If it is available, it should be available to all who need it not just those with money.

(Female, 44, Professional, not a parent, not religious, has condition)

How follow-up care will be navigated through transnational borders

327. Availability of trained professionals to be able to deal with any follow up care/intervention back in the UK. Cost would also be a bit of an issue if the person could not self-fund the treatment.

(Male, 34, Cancer Research Nurse, not a parent, not religious, not affected)

Acknowledging that not everyone would be able to afford to travel abroad to access treatment not available through the NHS

144. Should be depending on the reason for wanting genetic editing. Travel and being able to travel abroad is usually only available to those who are wealthy. Becomes a rich man's game.

(Female, 34, Manager, not a parent, religious but no influence, not affected)

Whether travel was being funded privately or through the NHS (the latter not being deemed unacceptable)

365. Privately only, all future care private, i.e. no cost to NHS ever.

(Male, 53, Surveyor, parent, religious but no influence, has condition)

The difficulty of preventing people from ReproTravelling

281. Impossible to police

(Male, 32, Driving Instructor, parent, not religious, has condition)

These factors invite further discussion and research which extend beyond the capacity of this report and my current area of research. However, whilst these factors are shared by respondents holding a minority view which questions ReproTravel, they are substantial considerations which should be addressed by related researchers, policy makers and legislators moving forward. The greater issue presented by these factors, is to the reasoning, management, and implications of seeking/utilising treatment options in other countries, especially with regard to (personal) safety and the values of the NHS. As such, being aware of developments in germline genome editing across the globe is important to the future of germline genome editing in the UK.
The third question in section 3 was developed to elaborate on the intricacies of the second question.

Q15. If genetic editing remains illegal in the United Kingdom, but is legal in other countries and people living in the United Kingdom travel abroad to access genetic editing, should they be prosecuted?

The vast majority of respondents to Q15., 76.39% (398/521), feel that people who live in the UK should not be prosecuted if they travel abroad to access genetic editing if it remains illegal in the UK. This suggests that, to an extent, over ¾ of respondents are in favour of ReproTravel. Respondents who feel their answer to this question depends on various factors, wrote that the following concerns influenced their response:

The reason for travelling abroad to access genetic editing; medical reasons are acceptable depending on the genetic disease, but ‘designer babies’ are not okay

141. If they did it for appropriate medical reasons (something that affects quality of life) then they shouldn’t be prosecuted, but if they did it for a designer baby then they should.

(Female, 42, Early Years Practitioner, parent, Christian, not affected)

Only desperate people are likely to use genetic editing, thus only those seeking genetic editing for the ‘right’ reasons are likely to go abroad

20. Making it illegal makes it difficult for people to access and, much like with euthanasia, means that really probably only very desperate people will do it, which that would probably mean that only people wanting to use this technology for the 'right' reasons would break the law. Would people break the law to get a blue-eyed baby? I doubt it. Thus, I think keeping it illegal acts as a big disincentive and therefore I also think that people that then go on to break that law probably shouldn’t be prosecuted.

(Female, 33, PhD Student, not a parent, not religious, not affected)
Too difficult to police

119. Not keen on increasing prison populations for things that are difficult to police. The police would have little resource to prosecute this either - how would it be proved? There would end up being a black market in people going abroad to afford this and poorer people being further stigmatised as poor and having more disabled children.

(Female, 43, Administrator, not a parent, not religious, has condition)

483. It depends on whether the UK legal system has jurisdiction to prosecute for acts that are legal where they are performed.

(Male, 35, Research Fellow, Israeli, not a parent, not religious, not affected)

Individual's choice / free-choice to access healthcare and treatment

126. Patients choice about their body over local laws.

(Female, 21, Undergraduate Student, not a parent, not religious, not affected)

341. I don't see it as 'crime'. It's an individual's choice. If they are well informed & seek it out, then perhaps they cannot be stopped.

(Male, 35, Freelance Motion Designer, parent, not religious, not affected)

The reason why it is illegal in the UK

347. Why it remains illegal.

(Female, 33, Academic, parent, not religious, not affected)

The likelihood that it will cause harm

310. If there could be harm to the child.

(Female, 39, Nanny, parent, religious but no influence, not affected)

Several of the factors detailed above are not dissimilar to those cited in Q14. However, the ability of, and the strain on the punitive system is of concern to some respondents and in conjunction with Q14., invites further discussion. ReproTravel is a related area of research distinct from the main focus of my current research but is an area waiting to be explored to a greater extent. ReproTravel by its very nature involves consideration to policy, laws, and ethics in more than one country and therefore invites a more globalised discussion on how this should be navigated safely for the greatest benefit to all.
Respondents who selected ‘Yes’ to Q15. were asked how people living in the United Kingdom who travel abroad to access genetic editing should be prosecuted. Four prominent suggestions were evident:

Fine

202. Reasonably hefty fines.
(Female, 19, Undergraduate Student, not a parent, not religious, not affected)

Imprisonment

257. Jail sentence.
(Male, 30, Recruiter, Belgian, parent, Muslim, not affected)

Refused re-entry to the UK/deported

74. They shouldn’t be allowed to come back to UK. Deported.
(Female, 34, Osteopath, French, not a parent, Sikh, not affected)

Banned from accessing NHS care

291. They should be made to pay for all future health care and be banned from benefiting from free health care from the NHS.
(Male, 19, Apprentice, not a parent, Christian, not affected)

These suggestions are all plausible options and could be of assistance in future discussions. These suggestions are perhaps indicative of respecting the laws, values, and services in the UK, and of patriotism.
The fourth question in section 3 of the survey was based on access to genome editing.

Q16. Should genetic editing be available through the National Health Service (NHS)?

14.59% (76/521) of respondents feel that genetic editing should not be available through the NHS, whilst 39.54% (206/521) feel that it should be. The majority of respondents, 45.87% (239/521), feel that their answer depends on various factors. Factors which influenced respondents’ choice to Q16. are listed below:

Depends if NHS can afford to fund genetic editing

262. The NHS cannot currently afford to pay for the current cost of desired or required medical procedures - should we really be looking to escalate the costs further by adding even more expensive techniques to the repertoire? It’s a discussion that isn’t being had but needs to happen.
(Male, 46, Game Designer and Author, parent, Hindu-Christian, has condition)

520. NHS may just be too oversubscribed/ under water right now to have to deal with what I guess is an expensive process.
(Female, 21, Graduate Student, French, not a parent, not religious, not affected)

Due to privatisation, corporate stakeholders could gain access to patients’ details

5. The NHS is being increasingly privatised and it's not entirely certain if big corporate stakeholders also have access to details of the patients concerned.
(Female, 26, Postgraduate Student, not a parent, religious but no influence, not affected)

Only for serious/fatal genetic diseases

354. For serious conditions affecting life-long quality - then yes. More minor conditions then no - if someone wants to 'invest' in treatment for their descendants that's up to them.
(Male, 50, IT Technician, not a parent, not religious, has condition)
256. If it’s a very serious disease where the patient would be potentially brain
dead or physically disabled.
(Female, 25, Postgraduate Student, not a parent, Sikh, not affected)

Only for diseases with 100% certainty of transmission

64. It should not be available for everyone but definitely should be available for
people whose child will suffer and be disabled from birth till they die. So only in
such situations.
(Female, 26, Teacher, not a parent, religious but no influence, not affected)

220. It would depend on the condition that the parents had. Ultimately, NHS has
a limited budget and they have to cut their cloth accordingly. It you are just trying
to prevent a possible condition that may cause discomfort as per scenario one,
then no the NHS shouldn’t pay. But if we are talking about a condition that would
definitely be passed on and would cause considerable pain and distress for the
child then yes.
(Female, 33, Police Officer, not a parent, not religious, not affected)

Safety and success of genetic editing

323. If genetic editing works efficiently and safely and the NICE\(^\text{20}\) considers it
appropriate and affordable, it should be available to all people who can benefit.
(Male, 56, Computer Programmer, not a parent, religious but no influence, not affected)

508. If the editing is safe and effective, then yes it should.
(Female, 21, Postgraduate Student, not a parent, not religious, not affected)

If not available through NHS, could create greater inequalities within society

14. This is a complex issue. The NHS is already in a very precarious and
unstable position and presumably genetic editing doesn’t come cheap. If anyone
with a claim that genetic editing might improve their unborn children’s lifestyle
were granted genetic editing, then the cost of that would obviously be significant.
On the other hand privately funded genetic editing creates stronger divisions
between the wealthy and the poor and sends the message that only those with
money should be granted a pain free life, which is obviously extremely damaging.
(Female, 28, Lecturer, not a parent, Christian, not affected)

The cost-benefit ratio to the NHS with genetic editing and lifetime care

479. There should be a cost benefit analysis done for the condition, the cost of
genetic editing and the cost of caring for a person born with the condition in
question. If the condition is severe or the cost difference for care is notable, that
which is more beneficial to society, the person and the parents should be
considered.
(Male, 22, President of a Union, not a parent, Jewish, not affected)

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\(^{20}\) NICE is the abbreviation for the former National Institute for Clinical Excellence, which has now been renamed
the National Institute for Health and Care Excellence (still abbreviated as NICE).
493. Depends on how cost-effective it is. And would have to be limited to certain conditions e.g. the degenerative conditions or untreatable conditions discussed in this survey, rather than for cosmetic changes or for conditions which can be easily treated.

(Male, 24, Postgraduate Student, not a parent, not religious, not affected)

Would assist regulation, practically and ethically

20. I think that its availability through NHS would be a good mechanism for regulating it, practically and ethically, and making sure it was only used where it really was going to address life limiting illnesses.

(Female, 33, PhD Student, not a parent, not religious, not affected)

123. Provided it is regulated and provided solely for significant medical conditions with careful counselling then it would be best for the NHS to lead the way.

(Female, 34, Genetic Counsellor, not a parent, not religious, has condition)

Only with the right regulation

21. With the right regulations yes it should be available.

(Female, 36, NGO, not a parent, not religious, not affected)

71. As long as the research has been done and regulations are in place, the alleviation of symptoms that improves quality of life and improves life expectancy is a positive thing.

(Male, 21, Undergraduate Student, not a parent, not religious, not affected)

Long-term effects

173. It has to be based on particular factors e.g. quality of life, impact on the individual, society/ community and long-term implications. It should only be available for those who absolutely need it.

(Female, 44, Professional, not a parent, not religious, has condition)

Charities should fund genetic editing as NHS is struggling

106. NHS funding already in trouble. Charities should be involved along with personal funding from clients if possible.

(Female, 47, Manager, parent, Sikh, not affected)

Not if people from abroad will be able to come and access it

109. This could be a reverse factor. People from other countries may access this if not allowed in their own country.

(Female, 40, Carer, parent, religious but no influence, not affected)
A private health service would avoid abuse of tax payer’s money

128. I believe in a private health service to avoid the abuse of tax payers’ money to serve foreigner. Note I am an economic migrant myself.
(Male, 47, Factory Worker, Indian, parent, Sikh, not affected)

Many of the factors mentioned for Q16. express concern about the cost to the NHS. This concern also ran quite dominantly, throughout qualitative responses to the scenarios in section 2 of the survey.

The time at which the survey was live and inviting responses from the wider public was fraught with news, details and statistics on the NHS’ struggles, particularly in relation to funding. The NHS’ economic strains is an ongoing concern thus the repeated consideration of the costs to the NHS in survey responses is not unfounded.

To date however, the NHS has heavily invested in genetic medicine, and is presently in the midst of a project titled ‘The 100,000 Genomes Project’21. The data from the project could be monumental in assisting genetic diagnoses and determining the future capabilities of genome editing.

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21 For further information about the project, see https://www.genomicsengland.co.uk/about-genomics-england/the-100000-genomes-project/.
The fifth question in section 3 was devised to determine whether people with genetic disease(s) may face social pressure to seeking genome editing should the option become available.

Q17. Should people with a genetic condition seek genetic editing?

The responses to this question are strongly aligned to the qualitative responses to the scenarios in section 2 of the survey. Throughout the responses in section 2 is a common theme of free will and liberty, a notion that people should have the choice to do as they wish (within reason). The majority of respondents to this question, 78.89% (411/521), feel that people with a genetic condition should only seek genetic editing if they want to. This suggests that no explicit societal judgement/pressure would be placed on people with a genetic condition who may opt not to seek genome editing.

Respondents who selected ‘Depends on various factors’ for Q17. explained that the following factors influenced their choice:

Life expectancy

364. I think the severity of the condition - some conditions can be treated do not affect life expectancy, cognitive function, etc whereas others have very very significant impact on multiple functions (physical, psychological, life expectancy, cognition, etc) and the person has no quality of life whatsoever.

(Female, 50, Medical Secretary, not a parent, not religious, has condition)

Medical treatment

98. The NHS should make it only available for the very serious conditions that would mean life-long care and treatment. If it could be life changing, then
ultimately the NHS would benefit from preventative genetic editing in comparison to future treatment and management.

(Female, 34, Social Worker, parent, not religious, not affected)

Quality of life for parents/carers

10. Medical treatment, quality of life with the condition for both the parents or carers and life expectancy.

(Female, 27, PhD Student, Spanish, not a parent, religious but not influence, not affected)

Severity of condition

70. Depending on the severity of their condition.

(Male, 65, Retired, parent, not religious, not affected)

Age

94. Age, and nature of genetic problem.

(Male, 30, Teacher, Indian, not a parent, religious but no influence, not affected)

Pain

505. If they can spare a potential child pain or decrease the burden it will place on society they should. However, they should also consider the weight and risk of the procedure and consider whether they really need a child that is genetically their own or whether they could adopt/foster a child.

(Female, 20, Undergraduate Student, American, not a parent, not religious, has condition)

Cost

330. Patients' personal preferences. Cost v quality agenda (i.e. what are the costs involved vs. long-term health outcomes - quality adjusted life years (QALY)

(Male, 35, NHS Worker – Management, not a parent, religious but no influence, not affected)

Benefits and risks of utilising genetic editing

142. The mental state of the individual, cost, objective benefits and risks.

(Female, 32, Clinical Researcher, not a parent, Christian, not affected)
The nature of the condition(s) is the most prevalent theme across the factors listed for this question. These considerations reflect the various factors of disease questioned within the scenarios in section 2.

The sixth question in section 3 was designed to encourage respondents to think about how genome editing could be misused.

Q18. Should there be restrictions on what genetic editing can be used for?

Only 4.41% (23/521) of respondents feel that there should be no restrictions on what genetic editing can be used for. The majority of respondents, 78.50% (409/521), feel that there should be restrictions, and the remaining 17.08% (89/521) selected ‘Depends on various factors’ as their answer. Influential factors in respondents’ answers to Q18. included:

Aesthetic characteristics / cosmetics

129. This has a danger of pursuing perfection rather than eradicating illness or disability.

(Male, 50, Social Worker, parent, Sikh, not affected)

If there is an alternative treatment/a cure available

239. If there is a cure.

(Female, 18, Unemployed, not a parent, not religious, not affected)

Eugenic misuse

433. If it doesn't lead to eugenics, or misuse.

(Male, 25, Psychologist, Italian-Colombian, not a parent, not religious, has condition)
Potential misuse for financial gain

89. People could abuse the service for financial or cosmetic benefits.
   (Female, 45, Accountant, parent, Sikh, has condition)

Risks

210. In general I am anti due to unforeseen risks, negative impact on society and diversion of funds from more worthwhile research areas.
   (Male, 45, Chartered Accountant, parent, not religious, not affected)

Potential use for enhancement instead of treatment

273. Genetic editing should be a treatment not enhancement.
   (Female, 33, Research Scientist, not a parent, Catholic, not affected)

Ethics

459. Moral and ethical issues as well as financial.
   (Male, 49, Warehouse Manager, parent, not religious, not affected)

Freedom of choice

350. Freedom of choice. This is tricky, though, because the choice does not belong to the person who will face the consequences.
   (Male, 59, Probation Officer, parent, not religious, not affected)

Cost

222. How harmful the procedure will be to them, as well as how costly it will be for the NHS.
   (Male, 19, Undergraduate Student, Canadian, not a parent, religious but no influence, not affected)

The factors listed for this question reiterate qualitative responses to the scenarios in section 2 of the survey, and serve as a useful summary of the common/overarching themes which stemmed from the responses.
Respondents were next asked ‘What do you think could be the consequences of not limiting what genetic editing can legally be used for?’. This question was primarily asked to encourage respondents to think about the potential ‘misuses’ of genome editing technologies, and to encourage a more critical consideration of the capacity of such technologies. Issues raised are as follows:

Used for aesthetic/cosmetic characteristics – ‘designer babies’ / Nazi style eugenics

348. It could be used to make some form of ‘master race’ similar to what I understand was intended by Nazism. Which would be seriously wrong. On a lighter note it could be used to produce a child with certain characteristics such as blue eyes.

(Female, 47, Telecoms Engineer, English, not a parent, not religious, has condition)

Increased inequality/greater rich-poor divide

460. The potential for unknown effects on the future gene pool. Wealthier people paying for private gene editing, to ensure their children are tall, attractive, disease-free, intelligent, muscular, etc. etc. Greater rich-poor divide.

(Male, 24, Research Assistant, not a parent, not religious, not affected)

Marginalisation/devaluation of disabled people

3. Increased inequality, designing 'perfect' babies, marginalisation of disabled people, loss of the experiences and mindsets of people with physical or cognitive disabilities.

(Male, 23, Masters Student, Irish, not a parent, not religious, not affected)

Reduced biodiversity

187. A decrease in genetic diversity (if trends in genetic editing arise) or a new ‘species’ of humans that have a different genome.

(Male, 16, High School Student, not a parent, not religious, not affected)

People could be forced to utilise the technology

25. Could be forced upon people against their will.

(Male, 23, Financial Advisor, not a parent, not religious, not affected)

Could be used for enhancements

77. Improving the cognitive and physical abilities to a level that they would not otherwise be. Enhancing these factors could lead to an unfairer society where people who undergo genetic editing are more favourable for things such as job opportunities, sport etc.

(Male, 16, High School Student, not a parent, Sikh, not affected)
(Female, 53, Careers and Employability Advisor, not a parent, not religious, has condition)

Population growth

60. None, apart from the population growth that would be linked to more people surviving.  
(Female, 24, Teacher, not a parent, not religious, has condition)

Value judgements

63. MASSIVE!!! Value judgements made against people based on health. Discrimination of those in poorer health/not had genetic editing in the work place, health insurance, etc. etc. Ultimately a boring completely homogenous society...? It sends a chill down my spine just thinking about it.  
(Female, 31, Midwife, parent, not religious, not affected)

Could be weaponised

307. People could abuse it to harm others or as a biological weapon.  
(Male, 17, College Student, German, not a parent, not religious, not affected)

Growing intolerance of disabled people

(Male, 41, PhD Student, not a parent, not religious, not affected)

177. Increased prejudice and discrimination against people with disabilities or other characteristics considered "undesirable" if not everyone able to access genetic editing to same extent. Increased division and inequality between those who can afford to use genetic editing for whatever they want and those who cannot. Certain conditions ceasing to exist (as someone with multiple neurodevelopmental conditions I'm familiar with the debate in the autism community around the possibility of a genetic test for autism and how this might be used - the abortion rate for foetuses with Down's syndrome is often cited), either due to stigma or people being coerced or made to undergo genetic editing treatments in order to eliminate conditions seen as a burden to society.  
(Male, 25, Unemployed, not a parent, not religious, has condition)

Could be made free for all

393. free for all.  
(Male, 44, Director, parent, not religious, has condition)
Greater strain on the NHS

475. Resources will always be a strain on the NHS. Thus, tough decisions will be required on how best to allocate resources.
(Male, 75, HR Business Partner, parent, not religious, not affected)

Irreversible change to the gene pool

491. Irreversible change to human gene pool.
(Male, 43, CEO, parent, not religious, not affected)

The responses to this question offer foundational considerations on what policy and legislation for germline genome editing should aim to prevent.
The penultimate question in the survey aimed to gather a sense of respondents’ opinions towards genome editing, having considered some potential applications of the technology.

Q19. Overall, what do you think of genetic editing having considered how the technology could be used?

![Graph showing percentage of responses]

69.29% (361/521) of respondents feel that overall, genome editing technology is good, whilst 5.37% (28/521) feel that the technology is bad. The remaining 25.34% (132/521) of respondents gave the following explanations to why they selected ‘Other’ in answer to the question.

The technology could be helpful

1. Helpful for some.
   (Female, 26, Investigations Officer, Pakistani, not a parent, Muslim, has condition)
   440. I would need to be convinced that the practice could not be abused but I am all for helping people with genetic conditions.
   (Male, 36, Contractor, parent, not religious, not affected)

Hard to judge

4. I find it hard to judge.
   (Male, 24, Postgraduate Student, Irish, not a parent, religious but no influence, not affected)
   83. I don’t think I really understand it well enough to make an overview judgement of whether it’s good or bad. It’s a complicated thing!!!
   (Female, 34, Charity Worker, not a parent, not religious, not affected)

Further research still needs to be done

277. Its therapeutic potential needs to be carefully researched and a suitable ethical and legal framework established around what it can and cannot be used for before a definitive answer can be given.
349. With strict legislation and clear research data over a long period of time it is a valid and useful medical break-through.

People should adopt instead

8. It's great if the technology is around. However, how/if it should be implemented is another question. I think people with serious genetic conditions should accept the risk of getting a sick child and thus should perhaps not have one. There are plenty of children in homes that are waiting for adoption.

470. I think it could be used for good or bad, but overall, I think people should choose the simplest option i.e. adopt a child rather than proceed with genetic manipulation.

All technology comes with moral implications

17. No technology is good or bad itself; it is the use to which it is put which has moral implications and consequences.

169. I think it can eventually be a force for good (particularly in reducing disease and inherited conditions) but we need a greater understanding of how genes fully affect the organisms they inhabit, and a better moral framework (generally in society) before proceeding.

Depends on reasons for use/application

39. It depends on the ethics of those using it. Say there are bad intentioned people in every walk of life.

157. Depends entirely on its use and prospects for future.

Could be dangerous/misused

70. Like nuclear technologies... in the right hands they can be hugely beneficial to the human race. In the wrong hands they are decidedly dangerous.

221. It depends on how we use the technology but if used correctly it could be ground-breaking in curing genetic diseases.

Both good and bad

23. Like most new technology, it could be used for good or bad reasons.
474. It can be both good and bad depending on how it is used and the reasons for it.

(Female, 18, College Student, not a parent, not religious, not affected)

Several explanations to this question reference ethical and moral considerations, both of which were also prevalent throughout the qualitative responses to the scenarios in section 2. Such considerations are plentiful and remain at the centre of many discussions on genome editing. The number of participants who feel that germline genome editing is ‘good’ is perhaps unprecedented, especially considering the undetermined risks which could unfold. This finding suggests a greater trust in new (reproductive) technologies than has been historically present, which is perhaps refreshing considering that the potential misuse of genome editing technologies was also questioned in this survey.
As a concluding question (following the questions collating demographic information), respondents were asked one of the following questions depending on whether they were already a parent:

Q20. If you have a genetic condition or were to be diagnosed with a genetic condition, would you seek genetic editing if you wanted to have a child?

![Graph showing responses to Q20 question](image)

This graph displays the responses of the 311/521 respondents who answered this version of the question.

Respondents who chose ‘Other’ for this question, cited the following:

- Depends on (severity of) condition
- Do not want to have (further) children
- If it impacts quality of life
- Not sure/potentially
- Would need to consider further research
If you have a genetic condition or were to be diagnosed with a genetic condition, would you seek genetic editing if you wanted to have another child?

![Graph showing responses](image)

This graph displays the responses for the remaining 210/521 respondents.

Respondents who selected ‘other’ for this question, cited the following:

- Depends on prognosis/severity of condition
- Depends on support/counselling available
- If there was a high risk of transmission
- Not applicable
- Not sure/maybe
- Past childbearing age

Combining the responses from both versions of the question, overall, 68.71% (358/521) of respondents answered that they would seek genetic editing if they have /were to be diagnosed with a genetic condition. 13.62% (71/521) of respondents answered that they would not seek genetic editing if they have/were to be diagnosed with a genetic condition. These findings imply that germline genome editing could be a popular line of enquiry for those exploring their reproductive options in light of possessing a genetic disease, and that genome editing could be a technology in high demand if it is proven to be feasible.

The overarching themes in this report call for questions to be asked on how germline genome editing will be proven to be a safe/reliable/feasible technology, what legislation will have to change to enable this to happen, and who should/is best placed to determine the overall safety/feasibility of the technology. Hopefully, the forthcoming phases of my research will address these questions with suitable experts and professionals to obtain answers.
Key Conclusions

- Research/discussions/debates on human germline genome editing need to consistently obtain input from younger generations as these generations are more likely to face the consequences of the technology.

- The news and related media are the leading sources through which the wider public hear/learn about genome editing. Thus, experts on genome editing should be more proactive in working with journalists and media producers to ensure that correct representations and reliable information are relayed to the wider public.

- 83% of respondents to the survey had preliminary knowledge/understanding of what genetic editing is to some extent.

- Findings from the survey revealed that a predisposition to eradicate all disease from society exists, almost regardless of the severity of a condition.

- Of all the factors of disease and disability which were questioned in the survey, pain and suffering, dependency on others/the state, and physical impairments were of the greatest concern to respondents; these factors are strongly associated with quality of life and happiness.

- Respondents keenly expressed that impaired cognitive ability and/or learning disabilities in themselves do not warrant acceptability for germline genome editing. This finding is particularly interesting because it reflects a significant shift in attitudes and societal acceptance towards cognitive impairments than that which has been historically present.

- The availability of a cure for a genetic condition would serve as a strong deterrent to genome editing as some respondents feel that this availability would make genome editing somewhat redundant.

- Further research and discussion is required on people living in the United Kingdom being allowed to travel abroad to access germline genome editing should it remain illegal in the UK. However, depending on the reason for doing so, 76% of respondents feel that people who do travel abroad to access germline genome editing should not be prosecuted.

- Over 69% of respondents feel that genome editing technologies are ‘good’, whilst only 5% of respondents feel that such technologies are ‘bad’.

- Nearly 69% of respondents answered that they would seek genetic editing if they have/were to be diagnosed with a genetic condition. This finding suggests that genome editing would be a popular enquiry for those with a genetic condition when exploring their reproductive options.
Appendices

Appendix 1

Methodology

Ethical approval to conduct the survey was granted by the University of Cambridge’s Department of Sociology.

Once I had designed a complete draft of the survey on Qualtrics, I sent a link, in stages, to a predetermined group of ten trusted acquaintances to pilot the survey. The first three pilots helped me ascertain what wording needed to be changed, information which needed to be edited, and parts of the survey which were not working as intended. The next three pilots ensured that validations to questions were working correctly, questions were being answered as intended, and all formatting was aligned. The last four pilots offered me greater reassurance that the survey was almost ready to be activated and guided me on final changes, such as the inclusion/exclusion of definitions and navigation options.

After I activated the survey, I posted the link on social media to inform ‘friends’, followers, and contacts that the survey was ready for responses. I waited until the first ten complete responses had been recorded as a precaution to any teething issues before initiating my participation strategy. As a tactical measure, convenience sampling\textsuperscript{22} was adopted to cue snowball sampling\textsuperscript{23}.

The link to my survey was sent to a preselected list of people and organisations to circulate on their social media and/or in their newsletters with the intention of reaching a diverse range of respondents. Selection was based on age, occupation, religion, ability, and potential outreach. On the list, my ex-colleagues who work in chaplaincy care/religious organisations, and people I know with genetic conditions and/or disabilities were specifically targeted as these bodies are identified as being likely to have strong opinions about germline genome editing (MacGillivray and Livesey, 2018: 36).

The number of responses and demographics were regularly monitored whilst trying to achieve the desired sample of 500 respondents. Although the desired sample of 500 respondents was reached on 26\textsuperscript{th} April 2018, the survey remained live until 31\textsuperscript{st} May 2018 as respondents had the right to withdraw their data until then.

Once the survey was deactivated, all the data was exported to SPSS and ‘cleaned’. ‘Cleaning’ involved removing any incomplete surveys which had bypassed my validation measures on Qualtrics. Some people had entered a single letter or dots to move forward in the survey, instead of writing an actual answer; such responses

\textsuperscript{22}Convenience sampling is a non-probability sampling technique in which participants are generated because of a connection to the researcher. Such participants are generally easily accessible and in close proximity to the researcher (Fink, 2003).

\textsuperscript{23}Snowball sampling involves asking well-situated people to suggest others who can provide information or lead the researcher to different sources (Emmel, 2013: 40).
were removed from the final data set. As such, in the final data set 521 responses remained.

Next, responses in the final data set were systematically checked to ensure responses which contained instructions such as 'see previous', 'see above' or 'I meant to select 'No' for this question' were all adhered to before I began analysing the data. Furthermore, some demographical data, i.e. gender and age, were formatted so I could analyse these data numerically in order to produce the graphs shared in this report.

The final data set was analysed question by question. The multiple-choice questions were analysed solely in SPSS, and graphs were made of each of these questions for the report. Questions with qualitative answers were first copied and pasted into Microsoft Word to be numbered and formatted, before being uploaded to NVivo. Qualitative analysis began with word frequency searches for initial coding and then the reading of every single response to ensure all themes had been identified. Quotes were selected for each identified theme and other opinions which I felt invited further discussion. Quotes can be matched back to respondents in the full data set via their respective numbering as explained on page 13 of this report.
Appendix 2

Survey

N.B. The survey consisted of 67 blocks in total, some of which did not display depending on the respondents’ answers. Please note, the block numbers do not correlate with the question numbers in the report, as no question numbers appeared in the survey itself.

Understandings of Genetic Editing and its Potential Uses within Human Reproduction

Start of Block: Participant Information

Q1
Understandings of Genetic Editing and its Potential Uses within Human Reproduction

This survey has been designed by Amarpreet Kaur (http://www.amarpreetkaur.co.uk/current-research.html) as part of her PhD research to establish understandings and opinions of genetic editing on human embryos in the United Kingdom specifically in relation to disease and disability. No prior knowledge of genetic editing is expected or required to answer the questions in this survey.

The survey consists of four sections; Understanding / Knowledge of Genetic Editing, Hypothetical Practical Applications, Legislation and Ethics, and Demographics. The survey takes around 15 minutes to complete depending on your answers. Once you have answered a question you will not be able to return to it so please answer all questions fully before moving on to the next one.

All of your answers shared in this survey are completely anonymous; this means that your individual answers cannot be personally linked to you. As answers are anonymous they cannot be withdrawn without you identifying yourself to Amarpreet via email (ak997@cam.ac.uk). You can withdraw your answers until 31st May 2018, 23:59.

If you have any questions or comments about this survey or research please do not hesitate to get in touch.
Q2 The following statements will validate your ability to participate in this survey. If all three statements are not confirmed you will be directed to the end of the survey.

- I am 16 years of age or older (1)
- I am currently living in the United Kingdom (2)
- I am voluntarily participating in this survey (3)

End of Block: Participant Information

Start of Block: Section 1: Understanding / Knowledge

Section 1

Understanding / Knowledge of Genetic Editing
Q4 Do you know what genetic editing is?

- Yes (1)
- No (2)
- I think so (3)

Display This Question:
If Do you know what genetic editing is? = Yes

Q5 Please detail what genetic editing is.

Display This Question:
If Do you know what genetic editing is? = I think so

Q6 Please detail what you think genetic editing is.

Display This Question:
If Do you know what genetic editing is? = Yes
Or Do you know what genetic editing is? = I think so

Q7 How did you hear/learn about genetic editing?

Display This Question:
If Do you know what genetic editing is? = No

Q8 What comes to mind when you think of genetic editing?
Q9 Genetic editing (also known as genome editing) is a technique through which specific parts of DNA can be added, removed or altered. How different was your answer to the description provided?

- Very different (1)
- Similar (2)

Q10 Why do you think there was a difference between your answer and the description of genetic editing?

End of Block: Section 1: Understanding / Knowledge

Start of Block: Section 2: Hypothetical Practical Applications

Q11

Section 2
Hypothetical Practical Applications

Q12 The couples in the following scenarios are all affected by various genetic conditions. A new procedure, genetic editing, could alter the DNA that causes their conditions so that their children do not inherit their conditions. None of the couples are affected by infertility but would have to use in vitro fertilisation (IVF) to create their embryos. The procedure would be performed on the couples’ embryos in a laboratory before being transferred into the mother to hopefully establish a
pregnancy. The procedure is considered to be safe but has not yet been tested or proven to work, and as with all complex procedures there will be risks. Any of the couples’ children could still be born with any other genetic condition that has not been edited out, and there is no guarantee the procedure will be a success.

*Please read each scenario carefully before progressing to the next question as you will not be able to return to it*

Q13 Scenario 1

Alecia and Bernardo have a genetic condition which is treatable but has no cure. If their child inherits the condition it may experience some pain during its life as a result of the condition and will have to receive regular treatment throughout its life to manage the condition. The condition is not known to impair cognitive or physical abilities. On average, people with the condition have a slightly reduced life expectancy.

Should genetic editing be allowed in this scenario?

- Yes (1)
- No (2)
- Other (3) ________________________________________________

Q14 What considerations influenced your answer?

________________________________________________________________

Q15 Scenario 1

If Alecia and Bernardo’s child will definitely inherit their condition, should they be allowed to access genetic editing?

- Yes (1)
- No (2)
- Other (3) ________________________________________________
Q16 What considerations influenced your answer?  
________________________________________________________________

Q17 Scenario 2

Daniella and Carl are both carriers of a genetic condition which is known to impair cognitive ability. The condition is not known to affect physiological abilities or cause any pain. People with the condition have a normal life expectancy and are reliant on others to care for them throughout their life.

Should genetic editing be allowed in this scenario?

- Yes (1)
- No (2)
- Other (3) ________________________________________________

Q18 What considerations influenced your answer?  
________________________________________________________________

Q19 Scenario 2

If Daniella and Carl's condition was found to also affect physical and/or physiological abilities, should they be allowed to access genetic editing?

- Yes (1)
- No (2)
- Other (3) ________________________________________________
Q20 What considerations influenced your answer?

________________________________________________________________________

Q21 Scenario 3

Ekam and Fauja have a genetic condition which usually does not start presenting symptoms until a person is at least 20 years of age. Until a person starts experiencing symptoms they are otherwise healthy and well. Once a person starts experiencing symptoms they are usually affected by lots of pain and have periods where they are reliant on other people to care for them to some extent. There is no cure for the condition and the only available treatment is medication to manage pain. People with this condition usually meet the average life expectancy.

Should genetic editing be allowed in this scenario?

☐ Yes (1)

☐ No (2)

☐ Other (3) ________________________________________________________________

Q22 What considerations influenced your answer?

________________________________________________________________________

Q23 Scenario 3

If a cure or effective treatment for Ekam and Fauja's condition becomes available, should they be allowed to access genetic editing?

☐ Yes (1)

☐ No (2)

☐ Other (3) ________________________________________________________________
Q24 What considerations influenced your answer?
________________________________________________________________

Q25 Scenario 4

Holly and George are affected by a painful genetic condition which is degenerative. People with the genetic condition do not know how they will be affected by the condition and require a regular range of medical tests (e.g. blood tests, scans etc.) to check their ongoing health. Eventually, people with this condition start losing their physical abilities but have a normal life expectancy.

Should genetic editing be allowed in this scenario?

☐ Yes (1)
☐ No (2)
☐ Other (3) ________________________________________________

Q26 What considerations influenced your answer?
________________________________________________________________

Q27 Scenario 4

If people with Holly and George’s condition could also lose their cognitive abilities, should they be allowed to access genetic editing?

☐ Yes (1)
☐ No (2)
☐ Other (3) ________________________________________________

Q28 What considerations influenced your answer?
________________________________________________________________
Q29 Scenario 5

Javeria and Imran are carriers of a fatal genetic condition. People who inherit the condition have a reduced life expectancy and have to receive very intrusive medical treatments from birth until they die. Cognitive ability is not affected by this condition but physical abilities may be impaired as physiological abilities deteriorate.

Should genetic editing be allowed in this scenario?

- Yes  (1)
- No  (2)
- Other  (3) ________________________________________________

Q30 What considerations influenced your answer?

________________________________________________________________

Q31 Scenario 5

If euthanasia was legal in the United Kingdom, should people with Javeria and Imran's condition be allowed to access genetic editing?

- Yes  (1)
- No  (2)
- Other  (3) ________________________________________________

Q32 What considerations influenced your answer?

________________________________________________________________

End of Block: Section 2: Hypothetical Practical Applications
Q34 Should genetic editing be legalised in the United Kingdom?

- Yes (1)
- No (2)
- Depends on various factors (3)

Display This Question:
If Should genetic editing be legalised in the United Kingdom? = Depends on various factors

Q35 What factors influenced your answer?

__________________________________________________________________________________________
Q36 If genetic editing remains illegal in the United Kingdom but is legal in other countries, should people living in the United Kingdom be allowed to travel abroad to access genetic editing?

- Yes (1)
- No (2)
- Depends on various factors (3)

Q37 What factors influenced your answer?

________________________________________________________________

Q38 If genetic editing remains illegal in the United Kingdom, but is legal in other countries and people living in the United Kingdom travel abroad to access genetic editing, should they be prosecuted?

- Yes (1)
- No (2)
- Depends on various factors (3)

Q39 How should people living in the United Kingdom who travel abroad to access genetic editing be prosecuted?

________________________________________________________________

Q40 What factors influenced your answer?

________________________________________________________________
Q41 Should genetic editing be available through the National Health Service (NHS)?

- Yes  (1)
- No  (2)
- Depends on various factors  (3)

Display This Question:
If Should genetic editing be available through the National Health Service (NHS)? = Depends on various factors

Q42 What factors influenced your answer?
.................................................................................................................................

Q43 Should people with a genetic condition seek genetic editing?

- Yes  (1)
- No  (2)
- Only if they want to  (3)
- Depends on various factors  (4)

Display This Question:
If Should people with a genetic condition seek genetic editing? = Depends on various factors

Q44 What factors influenced your answer?
.................................................................................................................................
Q45 Should there be restrictions on what genetic editing can be used for?

- Yes (1)
- No (2)
- Depends on various factors (3)

Display This Question:
If Should there be restrictions on what genetic editing can be used for? = Depends on various factors

Q46 What factors influenced your answer?

Q47 What do you think could be the consequences of not limiting what genetic editing can legally be used for?

Q48 Overall, what do you think of genetic editing having considered how the technology could be used?

- Good (1)
- Bad (2)
- Other (3)

Display This Question:
If Overall, what do you think of genetic editing having considered how the technology could be used? = Other

Q49 Please explain your answer

End of Block: Section 3: Legislation and Ethics
Start of Block: Section 4: Demographics
Q51 Your answers to the following questions will be used to help understand your answers to the previous questions in this survey and to check the diversity in people answering this survey. This survey will not give a complete picture of what everyone living in the United Kingdom thinks, but knowing whether there are particular groups of people that have not answered this survey will help take into account perspectives that may be missing.

Q66 How did you come across this survey?

________________________________________________________________

Q67 Why did you choose to participate in this survey?

________________________________________________________________

Q52 What gender are you?

________________________________________________________________
Q53 What age are you?

____________________________________________________________________

Q54 What is your occupation?

____________________________________________________________________

Q55 What nationality are you?

____________________________________________________________________

Q56 Are you single?

○ Yes (1)

○ No (2)

Q57 Are you a parent?

○ Yes (1)

○ No (2)

Q58 Are you religious?

○ Yes (1)

○ No (2)

Display This Question:
If Are you religious? = Yes
Q59 Have your religious beliefs influenced your answers in this survey?

- Yes (1)
- No (2)
- Possibly (3)

Display This Question:
If Have your religious beliefs influenced your answers in this survey? = Yes
Or Have your religious beliefs influenced your answers in this survey? = Possibly

Q60 What religion are you?

__________________________________________________________________________

Q61 Have you ever been affected by a genetic condition?

- Yes (1)
- No (2)

Display This Question:
If Have you ever been affected by a genetic condition? = Yes

Q62 How have you been affected by a genetic condition?

__________________________________________________________________________

Display This Question:
If Have you ever been affected by a genetic condition? = Yes

Q63 What genetic condition(s) were you affected by?

__________________________________________________________________________

Display This Question:
If Are you a parent? = No
Q64 If you have a genetic condition or were to be diagnosed with a genetic condition, would you seek genetic editing if you wanted to have a child?

- Yes, and I would use it if I could (1)
- Yes, but I don’t know if I would use it (2)
- No (3)
- Other (4) ________________________________________________

Display This Question:
If Are you a parent? = Yes

* Q65 If you have a genetic condition or were to be diagnosed with a genetic condition, would you seek genetic editing if you wanted to have another child?

- Yes, and I would use it if I could (1)
- Yes, but I don’t know if I would use it (2)
- No (3)
- Other (4) ________________________________________________

End of Block: Section 4: Demographics
Appendix 3

List of Published Reports ((to date) on genome editing)

- *Genomics and Genome-Editing: Future Lines of Inquiry*, House of Commons Science and Technology Committee, April 2017
- *Basic Understanding of Genome Editing*, Progress Educational Trust, September 2017
- *Potential Uses for Genetic Technologies: Dialogue and Engagement*, The Royal Society, December 2017
- *Genome Editing and Human Reproduction*, Nuffield Council on Bioethics, July 2018
References


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