

[G. Gaskell](#), I. Bard, A. Allansdottir, J. Hampel, E. Hildt, N. Kronberger, S. Laursen, S. Nordal, A. Quintanilha, G. Revuelta, J. Sándor, I. Singh, H. Somsen, H. Torgersen, V. Torre, H. Zwart, N. Saladié, R. Vieira da Cunha, A. Meijknecht, C. Hofmaier, M. Varju, S. Seyringer, P. Eduard, W. Toonders, J. Borlido Santos

Public views on gene editing and its uses

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On gene editing and its uses: the views of the public

George Gaskell¹, Imre Bard¹, Agnes Allansdottir², Juergen Hampel³, Elisabeth Hildt⁴, Nicole Kronberger⁵, Sheena Laursen⁶, Salvör Nordal⁷, Alexandre Quintanilha⁸, Gema Revuelta⁹, Judit Sándor¹⁰, Ilina Singh¹¹, Han Somsen¹², Helge Torgersen¹³, Vincent Torre¹⁴, Hub Zwart¹⁵, Núria Saladié⁹, Rui Vieira da Cunha⁸, Anna Meijknecht¹², Christian Hofmaier³, Márton Varju¹⁰, Simone Seyringer⁵, Peter Eduard⁶, Winnie Toonders¹⁵, Júlio Borlido Santos⁸

¹Department of Methodology, London School of Economics, London, UK.

²Toscana Life Sciences Foundation, Siena, Italy.

³Center for Interdisciplinary Risk and Innovation Studies, Stuttgart University, Germany.

⁴Center for the Study of Ethics in the Professions, Illinois Institute of Technology, Chicago USA

⁵Department of Social and Economic Psychology Johannes Kepler University, Linz, Austria.

⁶Experimentarium, Science Communication Centre, Copenhagen, Denmark.

⁷Centre for Ethics University of Iceland, Reykjavik, Iceland.

⁸Institute of Molecular and Cellular Biology, Porto, Portugal.

⁹Centre on Science, Communication and Society Universitat Pompeu Fabra, Spain.

¹⁰The Center for Ethics and Law in Biomedicine Central European University, Budapest, Hungary.

¹¹Department of Psychiatry and Oxford Uehiro Centre University of Oxford, UK

¹²Tilburg Institute for Law, Technology, and Society, Tilburg University, Tilburg, The Netherlands.

¹³Institute of Technology Assessment Austrian Academy of Sciences, Vienna, Austria.

¹⁴Centre for Neurobiology, International School for Advanced Studies, Trieste, Italy.

¹⁵Institute for Science, Innovation and Society Radboud University of Nijmegen, The Netherlands.

Correspondence should be to G.G. e-mail: g.gaskell@lse.ac.uk

Abstract

This paper reports on an online contrastive vignette study investigating the public's views of gene editing for therapy and enhancement in adult and prenatal contexts. The study, comprising quota samples of 1000 respondents per country, involved 10 European countries and the United States. Vignettes featuring gene editing for therapy compared to enhancement are seen as more morally acceptable and gain more support. Adult therapy attracts majority support, while prenatal enhancement elicits almost complete rejection. The assessment of adult enhancement and prenatal therapy are more ambivalent. These results and the respondents' accounts of the reasons behind the decision point to a focus on the uses of gene editing, rather than the technology itself. The study is a contribution to understanding the practical dimensions of the ethical question: how can gene editing contribute to human flourishing?

Public views on gene editing and its uses

Rapid advances in genome editing, including CRISPR-Cas9 endonucleases, and their potential application in medicine and enhancement have been hotly debated by scientists and ethicists. Although a veto on germ line gene editing has been proposed¹, the use of gene editing on human cells in the clinical context remains controversial, particularly for interventions aimed at enhancement². In a report on human genome editing the US National Academy of Sciences (NAS) note that "important questions raised with respect to genome editing include how to incorporate societal values into salient clinical and policy consideration"³. We report here our research that opens a window onto what the public think.

We conducted on-line quota sample surveys of 1000+ respondents in Austria, Denmark, Germany, Hungary, Iceland, Italy, the Netherlands, Portugal, Spain, UK and the USA (see the Supplementary Note, Section 1) to elicit judgments about gene editing using the contrastive vignette method^{4,5}. In our study, four vignettes in an experimental design combined two contexts and two recipient categories (see the Supplementary Note, Section 2). The contexts were therapy (curing a disease) and enhancement (improving memory and learning capacity). The recipient categories were adult and prenatal. The vignettes presented brief accounts of situations leading to a decision to use gene editing. Each respondent read one of the four vignettes assigned at random and was then asked, "Do you think he/they made a morally acceptable decision?" and "In his/their shoes would you make the same choice?" Responses were recorded on an 11 point scale (from -5 = 'No, definitely' not to +5 'Yes, definitely'). Comparing the responses across vignettes reveals the effect of the experimental manipulations.

A multiple regression analysis (see Table 1) shows that the ‘therapy’ vignettes compared with ‘enhancement’ vignettes have on average higher scores on moral acceptability and on agreement that the respondent would make the same choice (to use gene editing) by over 4 points in the 11 point scale. The ‘prenatal’ compared with the ‘adult’ recipient elicits a lower assessment of both moral acceptability, and whether the respondent would make the same choice. Adding age, gender and education level of the respondents to the regression showed only that female respondents are more cautious about gene editing in general.

Table 1: Regression coefficients for the target and purpose of gene editing.

See Supplementary Note, Table 1 for country level results

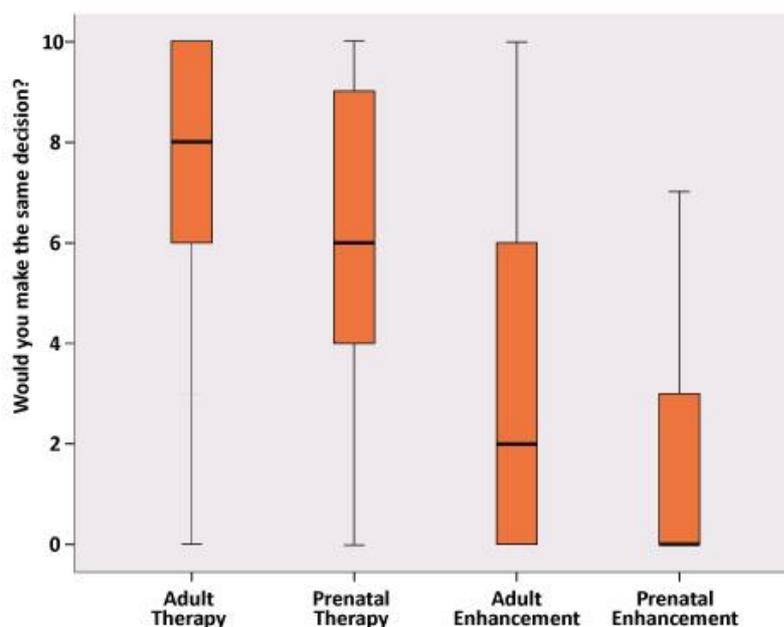
| Response variable | Adult compared with prenatal | Enhancement compared with therapy | (R ²) % of variance in ‘would you make the same choice’ accounted for by the model. |
|---------------------------------|------------------------------|-----------------------------------|-------------------------------------------------------------------------------------------------|
| Is it morally acceptable? | 1.89** | -3.68** | 0.36 |
| Would you make the same choice? | 1.47** | -4.34** | 0.37 |

** p<0.001

Across the eleven countries in the study support is consistently greater for treatment than enhancement (between 3.3 and 5.2 scale points). Similarly, across all countries there is greater support for intervention on adults than prenatals, but the magnitude effect of the target recipient is smaller (between 1.0 and 2.1 scale points). This is in agreement with the NAS report that there are “indications of public discomfort with using genome editing for what is deemed to be enhancement”.

A notable feature of the responses to the vignettes is how the range of opinion varies across the targets and purposes of the intervention (see Fig. 1).

Figure 1: Would you make the same decision? Box plots of responses to each gene editing vignette



For both ‘adult therapy’ and ‘prenatal enhancement’ the responses show a broad agreement. The former is accepted with a median response of eight, whereas the latter is rejected with a median response just above zero. In contrast, ‘adult enhancement’ and ‘prenatal therapy’ appear to be morally ambiguous, reflected in very diverse opinions. 50% of the responses range over about half of the 11 point scale.

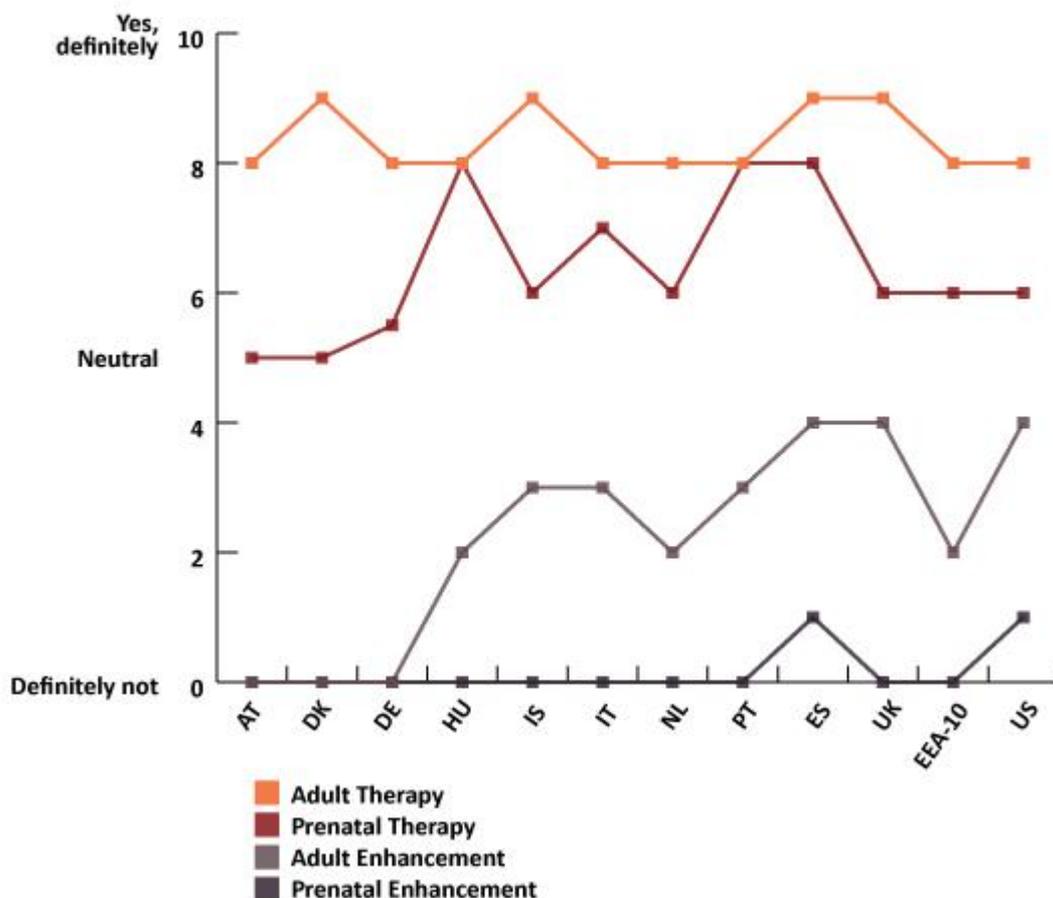
To explore the respondents’ thinking we asked: “In a few words, can you tell us why you agree or disagree with the decision”. Almost three out of four people added comments, suggesting that the topic is of importance. A systematic content analysis identified 21 broad themes. (See the Supplementary Note, Section 3). For ‘adult therapy’, 75% of the comments are positive evaluations of gene editing technology; in order of frequency: *improvements to quality of life*; *curing dementia*; and the *benefits outweighing the risks*. For ‘prenatal therapy’ the proportion of support for gene editing declines to 60%. The positive content is the same as for ‘adult therapy,’ with the additional comment: *it is natural for parents to want the best for their children*. Gene editing for ‘Adult enhancement’ achieves only 26% positive comments. On the negative side people mention there is *no need*; *being normal or average is OK*, and that there might be *risks and*

unknown consequences. ‘Pre-natal enhancement’ elicits only 11% positive comments. In order of frequency the negative remarks say gene editing is: *unnatural and messing with nature*; *there is no need*; *there are risks of unknown consequences*; and *it is just wrong*.

Might previous debates around modern biotech carry over into people’s thinking about gene editing? For example, do respondents view gene editing through a critical lens of genetically modified organisms (GMOs)? The answer is no; fewer than 3% mentioned GMOs. Other issues that did not feature beyond 1% or 2% included *designer babies* and some of the ethical questions around human enhancement—*increasing social disparities*, *obtaining an unfair advantage* and *undermining character*.

Turning to differences between countries, Figure 2 shows the median scores for the four experimental vignettes.

Figure 2: National differences on ‘Would you make the same decision?’



'EEA_10' is the aggregate over the 10 European countries. We show the median rather than the mean because in some countries at least half of the respondents gave a zero for the enhancement vignettes. The differing assessments of 'therapy' (between 5 and 9) versus 'enhancement' (between 0 and 4) highlight the fact that it is the application, rather than the technology itself, that is the critical issue for the public. Gene editing as applied to 'adult therapy' receives consistent support across all countries. And although there are differences between countries over the use of gene editing for 'prenatal therapy', it is supported in the majority of countries. More than half of the sample in Austria, Denmark, Germany, Hungary, Iceland, Italy the Netherland, Portugal and the UK say they would not use gene editing for pre-natal enhancement. This pattern is also seen in Austria, Denmark and Germany for 'adult enhancement'.

Across the countries, a stronger precautionary judgment is evident for gene editing for therapy and enhancement in the prenatal compared with the adult scenario. This is somewhat counter-intuitive. For example, assuming successful use in the therapeutic context, gene editing at the prenatal stage will have greater positive impact on the future outcomes of the recipient, simply because the recipient will live fewer years with a medical disability, compared with intervention in adulthood. In the enhancement context, prenatal intervention will arguably cause less distress than in the adult context. In adults, concerns about the violation of the sense of self, or of personal authenticity, are often presented as reasons to avoid enhancement^{6,7}. Concerns about authenticity violations in the prenatal context are likely to be less compelling to many people, although there may be other ethical considerations that again tip the balance. Such issues will need to be critically interrogated in the deliberation over the uses of gene-editing technology. Although the US public joins people in the UK and Spain in being a little less negative than other EEA10 countries about adult enhancement, differences between the US the EEA10 countries are notable by their absence.

As with many other technologies, the public's attention is on the applications or uses; these drive moral judgments. Yet scientific experts tend to focus on the technology as such. This harks back to the old struggle between regulating the process (the technology) or the applications (uses of the technology) that has caused so many problems for agricultural biotech in Europe⁸. Focusing on the technology will lead to inconsistent regulation, always lagging behind scientific progress. Focusing on uses will also present challenges: if countries opt for different regulations on the uses and target recipients of gene editing, some people may take to medical tourism. Should policy

prioritize national interests or be transnational to reduce the risks associated with diverging policies? Perhaps it is time to set up a multinational institutional structure to guide innovative technological applications that are societally contentious.

A final word on the value of surveys in this controversial territory. Public opinion cannot and should not tell us what is right to do. However, as the NAS report notes “Public participation should be incorporated into the policy-making process for human genome editing and should include ongoing monitoring of public attitudes, informational deficits, and emerging concerns about issues surrounding enhancement.” This survey is a contribution to understanding the practical and contextual dimensions of the ethical question; how can gene-editing technology contribute to human flourishing?

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Notes

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Supplementary notes

Section 1: The survey design and procedures

Respondi coordinates double opt-in access panels of respondents for online surveys. The sample size for this study was specified at circa 1000 and selected to reflect the gender, age and education profile of those 18 years and older in each country. The number of invitations sent out to achieve 1000 completed and quality interviews took account of the expected response rate; on average 25 per cent.

Section 2: Genome Editing Experimental Vignettes

(Adult therapy)

Please read this story carefully.

John has dementia. Among other symptoms, his short-term memory and learning capacities are slowly getting worse. John learns about a new gene-editing technology that has been developed. It would rewrite the gene sequence in some affected cells, and could delay or prevent his memory and learning decline. He decides to undergo the therapeutic genetic modification.

(Prenatal therapy)

Please read this story carefully.

John and Sarah are expecting a baby. The couple is informed that their child will inherit a tendency to develop dementia. Later in the child's life, this will result in slowly worsening cognitive abilities, including short term memory and learning capacities. They also learn about a new gene-editing technology that would re-write some relevant genetic sequences before the baby is born. As a result, the later risk of memory and learning decline is significantly lower. They decide to use the therapeutic genetic modification.

(Adult enhancement)

Please read this story carefully.

John is a healthy adult with average short-term memory and learning capacities. John learns about a new gene-editing technology that has been developed. It would rewrite some relevant genetic sequences, and could improve his memory and learning capacities. He decides to undergo the enhancing genetic modification.

(Prenatal enhancement)

Please read this story carefully.

John and Sarah are expecting a baby. The couple is informed that their child will be healthy with normal cognitive abilities. They also learn about a new gene-editing technology that would re-write some relevant genetic sequences before the baby is born. As a result, the child's memory and learning capacities could be enhanced. They decide to use the enhancing genetic modification.

Instructions and response alternatives

Please read the following questions and drag the slider to indicate your answer. If your answer to a question leans towards 'yes', then you drag to the right side of the scale, from 1 to 5. The stronger your agreement, the closer you would be to 5. Conversely, if you lean towards 'no', then you drag the slider to the left side of the scale, and the more strongly you feel about this, the closer you would be to -5.

Do you think John/the couple made a morally acceptable decision?

In John's/ the couple's shoes, would you make the same choice?

In a few words, can you tell us why you agree or disagree with John's/ the couple's decision?

The vignettes and the accompanying questionnaire were designed by the research group. Translation from English into the national languages was undertaken by members of the research group, all of whom speak English as a first or second language. Assiduous attention was paid to ensuring comparability of meaning of words and phrases.

Section 3: Coding frame for content analysis of open ended question "in a few words. Can you tell us why you agree or disagree with the decision?"

- 1 Support – unqualified statement
- 2 Support mentioning therapy, improving quality of life
- 3 Support mentioning safety/ benefits outweigh risks
Support mentioning natural for self/parents to want
- 4 best
- 5 Support mentioning autonomy/ individual choice
- 6 Uncertain, can't decide
- 7 Wrong - unqualified
- 8 Immoral, unethical
- 9 No need – normal or average OK
- 10 Only used for diseases
- 11 Unlikely to work – low efficacy
Playing god, unnatural, messing with nature, accept
- 12 fate
- 13 GM wrong, non-reversible, against evolution
- 14 Risks, unknown unintended consequences
- 15 Designer babies, master race, Nazis, Frankenstein
- 16 Obtaining an unfair advantage
- 17 Parents have no right to impose on child
- 18 Increase social disparities
- 19 Would be abused/doping
Undermines character, improvement from effort not
- 20 drugs
- 21 Other

Supplementary Table 1. Gene Editing Vignettes – Regression coefficients by country

| Country | Response variable | Adult vs. prenatal | Enhancement vs. therapy | R ² |
|-----------------|---------------------------------|--------------------|-------------------------|----------------|
| Austria | Is it morally acceptable? | 1.974** | -3.595** | 0.33 |
| | Would you make the same choice? | 1.482** | -3.847** | 0.30 |
| Denmark | Is it morally acceptable? | 2.094** | -4.216** | 0.44 |
| | Would you make the same choice? | 1.399** | -5.168** | 0.49 |
| Germany | Is it morally acceptable? | 1.995** | -3.981** | 0.38 |
| | Would you make the same choice? | 1.240** | -4.509** | 0.37 |
| Hungary | Is it morally acceptable? | 2.193** | -3.994** | 0.38 |
| | Would you make the same choice? | 1.435** | -4.853** | 0.40 |
| Iceland | Is it morally acceptable? | 2.102** | -3.654** | 0.39 |
| | Would you make the same choice? | 1.733** | -4.526** | 0.42 |
| Italy | Is it morally acceptable? | 1.344** | -3.907** | 0.36 |
| | Would you make the same choice? | 1.003** | -4.441** | 0.37 |
| The Netherlands | Is it morally acceptable? | 1.581** | -3.613** | 0.37 |
| | Would you make the same choice? | 1.364** | -3.976** | 0.35 |
| Portugal | Is it morally acceptable? | 1.648** | -3.473** | 0.35 |
| | Would you make the same choice? | 1.415** | -4.557** | 0.39 |
| Spain | Is it morally acceptable? | 1.689** | -3.603** | 0.37 |
| | Would you make the same choice? | 1.309** | -4.607** | 0.42 |
| United Kingdom | Is it morally acceptable? | 2.458** | -3.438** | 0.39 |
| | Would you make the same choice? | 2.299** | -3.953** | 0.37 |
| United | Is it morally acceptable? | 1.752** | -2.978** | 0.26 |

| | | | | |
|--------|---------------------------------|---------|----------|------|
| States | Would you make the same choice? | 1.452** | -3.305** | 0.25 |
|--------|---------------------------------|---------|----------|------|

* p<0.05

** p<0.001