Public Views of Genome Editing in Humans

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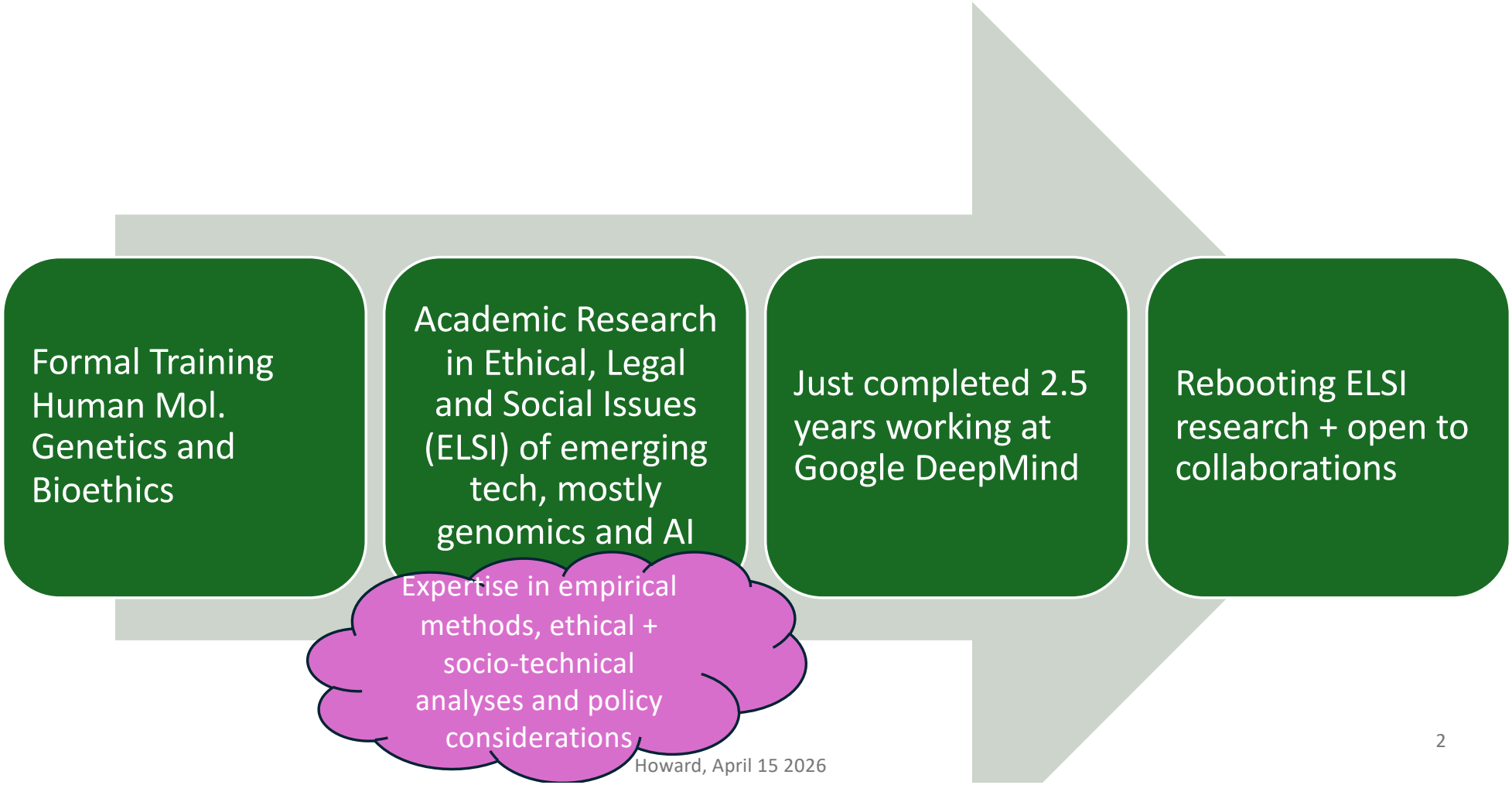
Thanks & a bit about me



3 Topics to Cover

01 Public Views on GE in Humans

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02 Challenges in obtaining publics' views

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03 How views on GE in Humans and GE in non-human animals may influence each other

1- Public Views of Heritable Genome Editing in Humans: Generally

CAVEAT:

- Surveys use different **questions and framing** so difficult to compare properly between them AND
- not always clear if questions are asking about Heritable or Somatic gene editing or if people understand the difference between testing, screening and DNA manipulation

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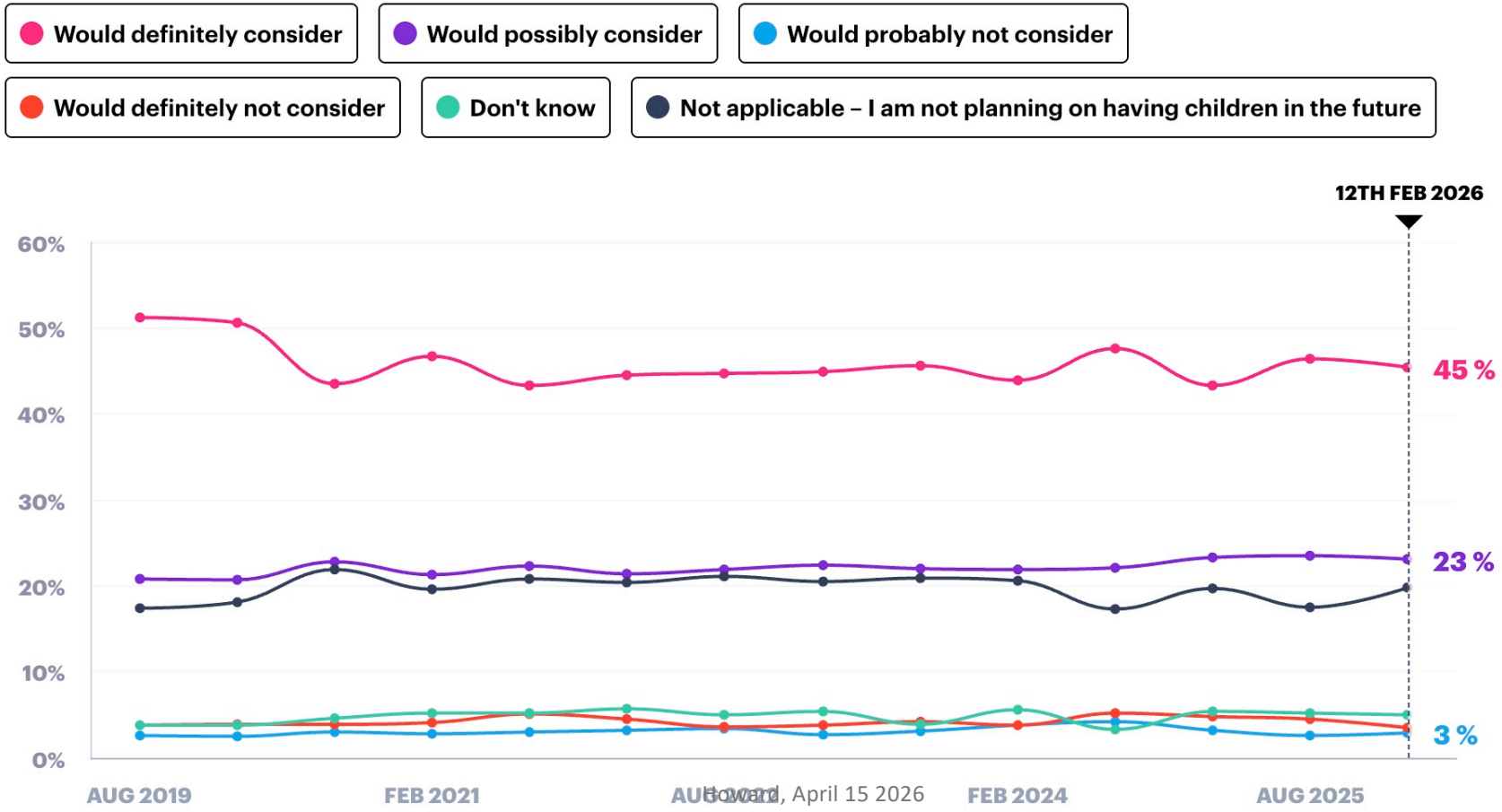
That said, the trend in genetics in general

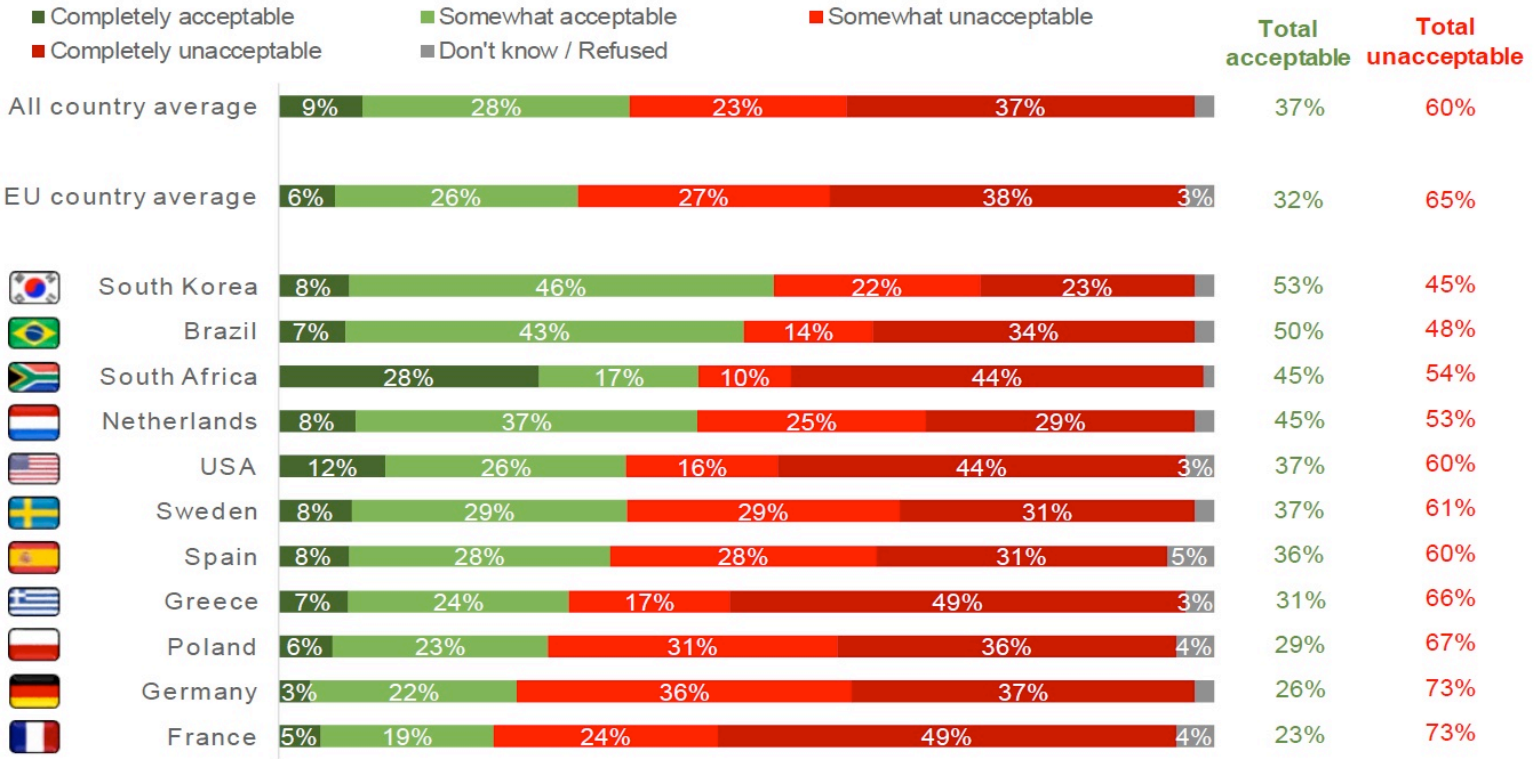
- Fair acceptance/majority for some type of genetic manipulation **to help understand or cure serious health conditions**
- **Disagreement with genetic manipulation (or testing) for "enhancement" (***intelligence)**

If the technology was available, would you personally consider using gene editing if...you were carrying genes for a genetic disorder and ran the risk of passing them onto future children, YouGov, n=2000



SIENNA EU project 2017-2021, n=11 000

Figure 8: Acceptability of conducting laboratory experiments on human embryos for any purpose



Q071: GEN_Q14 How acceptable do you consider each of the following to be? 'Using human embryos in laboratory experiments for any purpose'
Base: all respondents.

So what?

The difference between somatic and heritable genome editing in humans is very important, yet not made clear in many surveys

How can we interpret results given the weaknesses of survey tools/methodologies and difficulties in comparing between surveys?

- Despite this, some-what "valid" type of trends seem to form over time
- Careful and honest

How can these be used for next steps?

- Empirical results are not a normative arguments per se

- Surveys/Focus group approaches do not usually provide policy alternatives and consequences so while we might use results to "inform" action in a general way, we cannot use the answers to a "views" survey to answer policy actions directly

2- Challenges of obtaining views on high tech

So tell me, how much would you say you agree with me?

A lot?

Very much?

Extremely very much?

Or just a little very much?

2- Challenges of obtaining views on high tech

Low literacy in tech and consequences of tech
PLUS biased/bad questions means that respondents' answers don't always mean what we might think. Over-interpretation is a real problem.

- We should be extra careful about this and honest about the quality of the instruments we use

Only getting half the picture: Majority of studies focus on what the experts want to know, not what publics' want to discuss.

- Experts should be explicit about this

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Little time for surveys and focus groups means that nuance and details are often lost, the details of how the question is posed matters.

- including "I don't know" as an option is important

Interviews or deliberative approaches may offer more depth but they still need to be done well and should not be over-interpreted.

- Qualitative work is not quantitative
- Hiring "experts" from companies like Kantar may not be the answer either

So what?

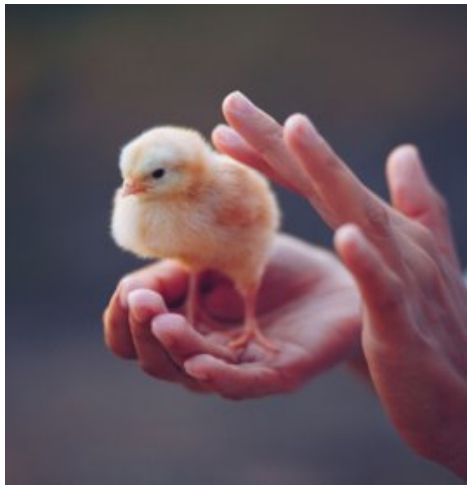
- **Get Radically honesty** about why you are asking publics and what you will do with the results.
  - If you want to increase acceptance, focus and be honest about that
  - Maybe what you want is a marketing campaign or a type of activity that is not necessarily academic research?

- **Get Radically honesty** about methodological limitations

- **Be descriptive and humble** in interpreting results, resist over-interpretation

3- (Non-experts) Publics' Views

- People care about the "why" in tech use
- Being direct and showing trade-offs in more in-depth discussions could be useful
- What would increased literacy mean?
- Emotions will not be overcome in the time of a survey, or a focus group
- What will happen once AI solves "animal language"...



3- Views on GE in humans and non-human animals

Genetically Engineered Animals in biomedical research

- Drosophila, mice, rabits,
- More agreement for serious diseases

Genetically Engineered Farm animals

- Salmon (AquAdvantage)
- Pigs (GalSafe)
- Cattle (Heat-tolerant)
- chickens: Research, such as at The Roslin Institute, has produced chickens with gene modifications designed to interrupt the transmission of avian flu

Thanks!
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Check out this survey and article if you have time!

https://surveys.genomethics.org/survey/yourdnayoursay?_=1

Public Understanding of Science
Volume 34, Issue 7, October 2025, Pages 901-915

https://doi.org/10.1177/09636625251326490

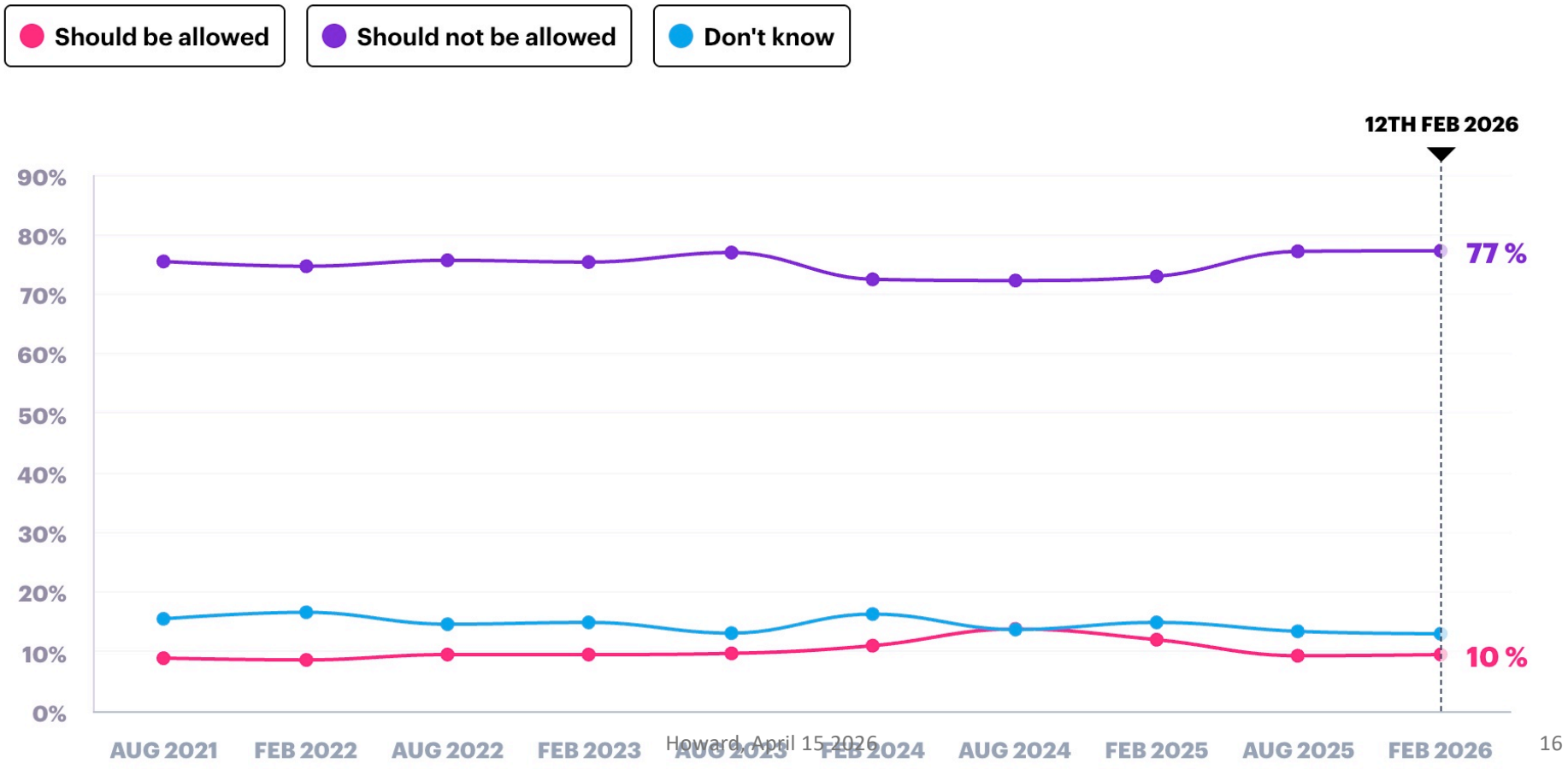
Sage Journals

Article

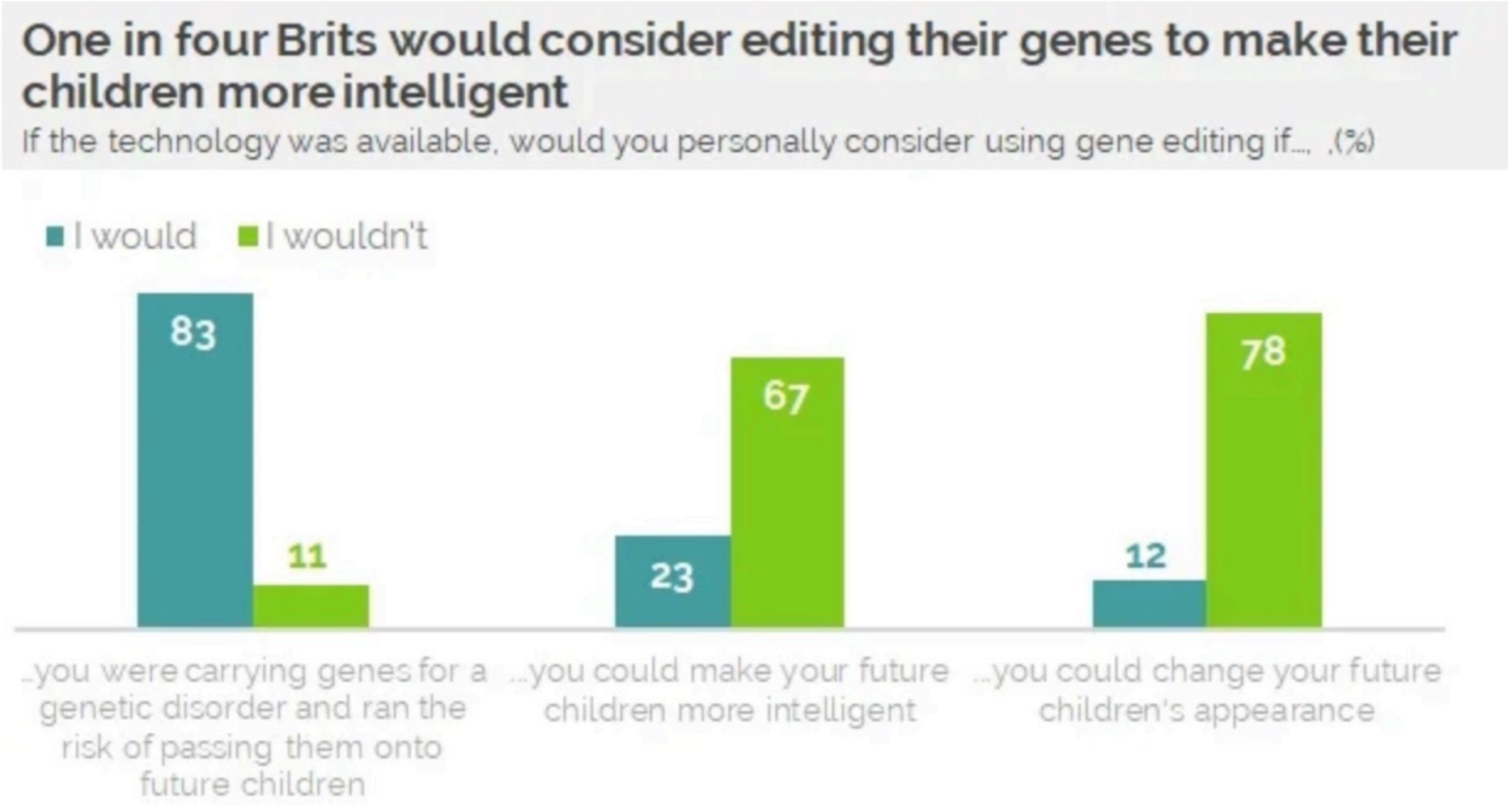
A citizen-centred approach to public engagement on the ethical, legal and societal issues of health technologies

Chloé Mayeur [1], Heidi Carmen Howard [2], and Wannes Van Hoof[3]

If the technology was available, do you think gene editing should or should not be allowed in order to...Change people's appearance, YouGov, UK, n=2000

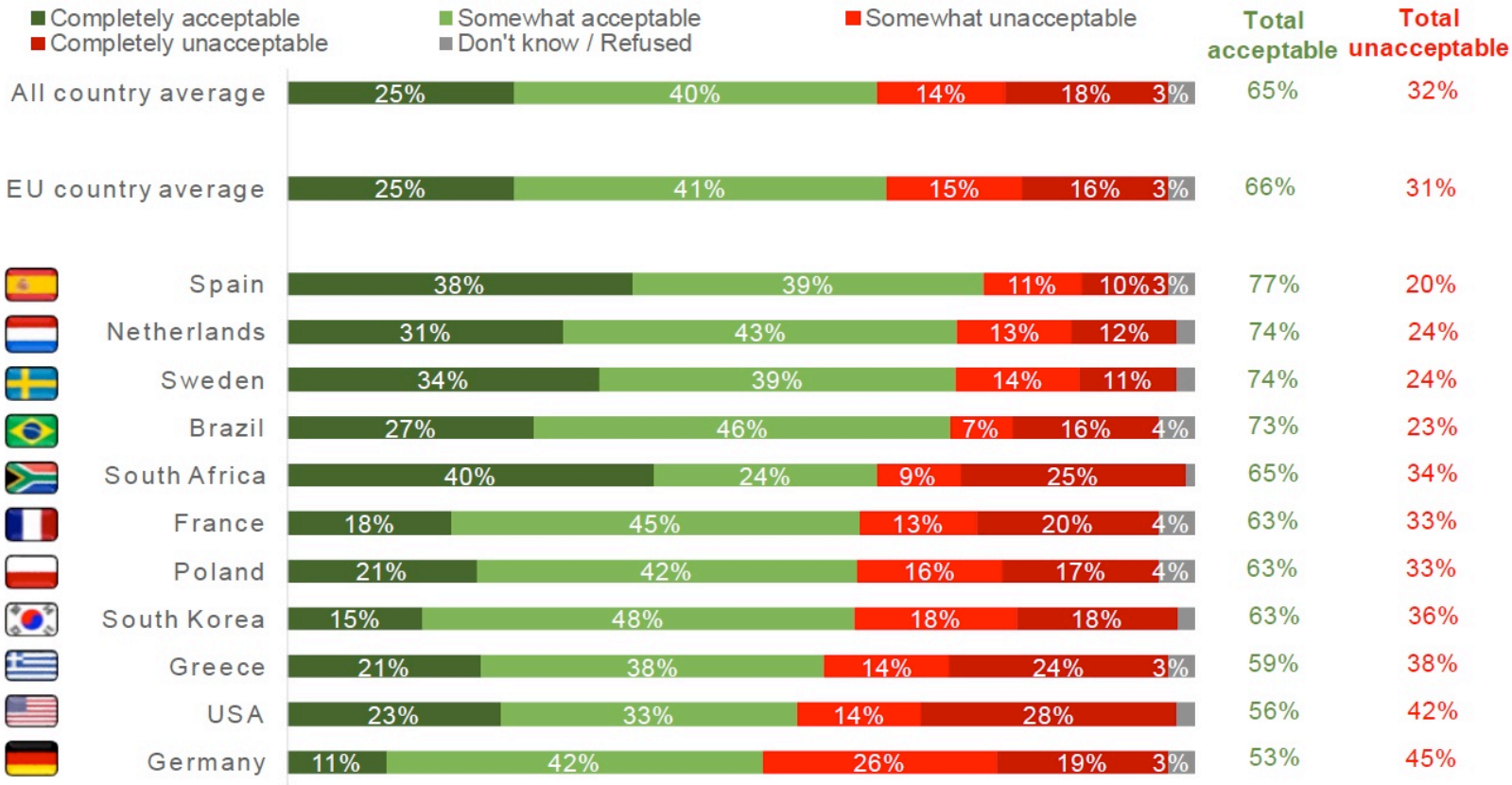


YouGov, n=5000, https://d3nkl3psvxxpe9.cloudfront.net/documents/YG-Archive-GeneEditingInternal-3108218.pdf



SIENNA EU project 2017-2021, n=11 000

Figure 10: Acceptability of conducting laboratory experiments on human embryos to better understand how to treat or cure health conditions



Q071: GEN_Q14 How acceptable do you consider each of the following to be? 'Conducting laboratory experiments on human embryos to better understand how to treat or cure serious health conditions'
Base: all respondents.

Public Views of Genome Editing in Humans: Specifically

- **Self-reported awareness of gene editing**
- Based on an all country average, 80% of respondents reported having heard or read at least something about gene editing in humans. Overall, 6% said they had heard or read ‘a lot’, 18% ‘a fair amount’, 31% ‘a little’, and 25% ‘hardly anything’.
- Looking at those saying they had heard or read a lot or a fair amount about gene editing in humans, self-reported awareness was highest in Germany (40%) and South Korea (39%) and lowest in Poland (9%), Spain (13%) and Sweden (14%).
- As with self-reported awareness of genetics, those with university degrees were more likely to have heard or read a lot or a fair amount about gene editing in all countries apart from Spain and Germany.

Example 1, Phone Survey

Sienna EU SWAFS-18, 4 mil, 42 months

11 country phone survey, performed by Kantar Public	n= 11 000,	Fr. Nl. De. Gr. Es. Se. Brazil, China, S.Africa, Pl. USA)
AIM: Obtain awareness & societal acceptance techs	15 minutes total (so 5 mins per tech)	3 tech areas: genomics, Ai and enhancement

Example 2, Focus Groups

Sienna EU SWAFS-18, 4 mil, 42 months Methodology

5 countries Fr. De. Es. Pl. Gr.

40 participants/panel

Explore and understand views of ethical issues

To i.d. policies wanted by citizens

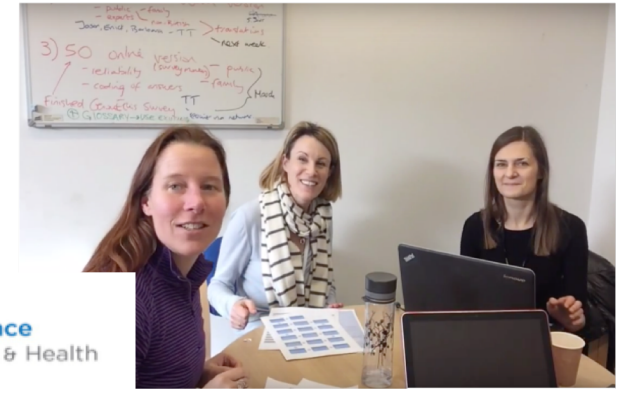
Deliberative approach

Performed by Kantar Public

1 day, 3 tech areas: genomics, AI and enhancement

Example 2 : Your DNA Your Say multilingual online survey

- Headed by Anna Middleton at Sanger Inst. Wellcome Campus, UK
- 25 questions + 9 films re: biobank, registries, data, medical, genetic data
- **Public's attitudes on sharing medical and genetic info**
  - for different purposes: clinical, research
  - with different types of "users": researchers, clinicians, industry
  - levels of protections
  - perceived risks
  - what would help you decide to donate
  - trust in different users and organisations



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