



Gene editing as responsible research and innovation

Anna Olsson

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Olsson@i3s.up.pt



Background

- I'm an animal welfare scientist with a farm animal background and >20 years of working with animal welfare and ethics of animal use in research and biotechnology, mainly lab animals
- This presentation is largely based on research and experience from the MSCA Doctoral network IMGENE (Improving Genome Editing Efficiency)
- PhD project Pedro Ramos, co-supervised by Maria Strecht and Cord Brakebusch



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Safe and purposeful genome editing under harmonized regulation for responsible use: views of researchers

Pedro Dias Ramos ^{ab*}, Maria Strecht Almeida ^b and I. Anna S. Olsson ^{ab}

^a*I3S – Instituto de Investigação e Inovação em Saúde, Universidade do Porto, Porto, Portugal;* ^b*ICBAS – Instituto de Ciências Biomédicas Abel Salazar, Universidade do Porto, Porto, Portugal*

Interviews with 22 researchers working with gene editing in a biomedical and/or animal science context

Frontiers in **Genome Editing**

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EDITED BY
José Carlos Segovia Sanz,
Centro de Investigaciones Energéticas,
Medioambientales y Tecnológicas, Spain

REVIEWED BY
Francisco Javier Molina-Estevez,
Fundación para la Investigación
Biosanitaria de Andalucía Oriental
(FIBAO), Spain
Jinxue Ruan,
Huazhong Agricultural University, China

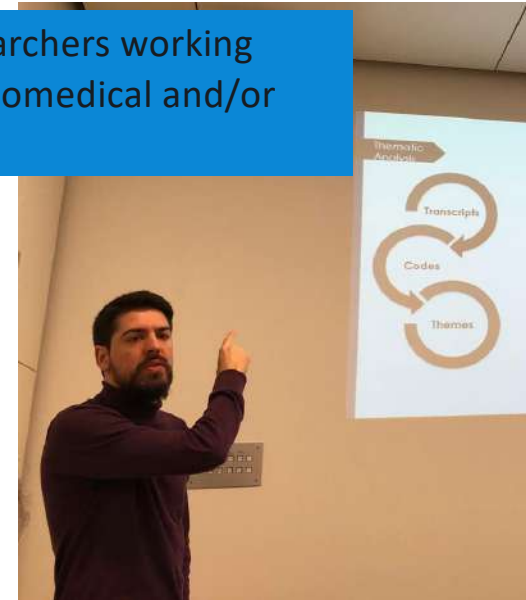
*CORRESPONDENCE
Pedro Dias Ramos,
pedro.ramos@ibmc.up.pt
Maria Strecht Almeida,
mstalmeida@icbas.up.pt
Ingrid Anna Sofia Olsson,
olsson@i3s.up.pt

What do people think about genetic engineering? A systematic review of questionnaire surveys before and after the introduction of CRISPR

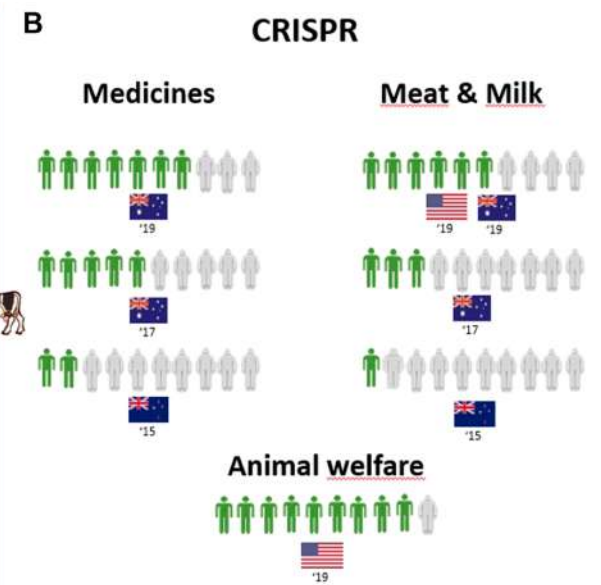
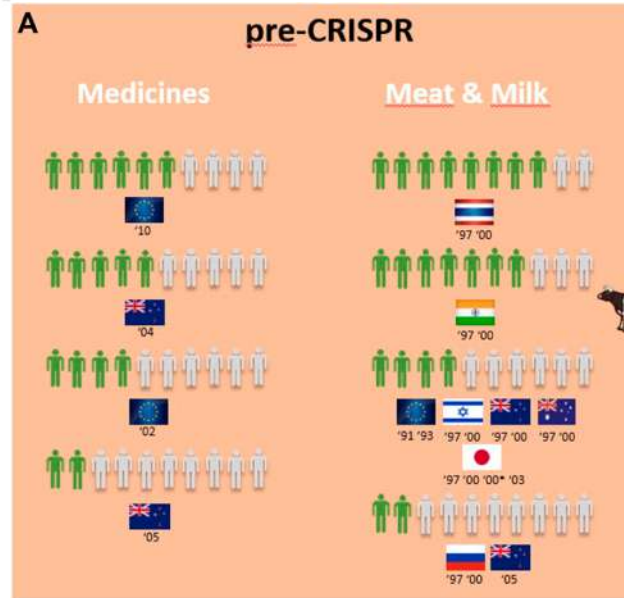
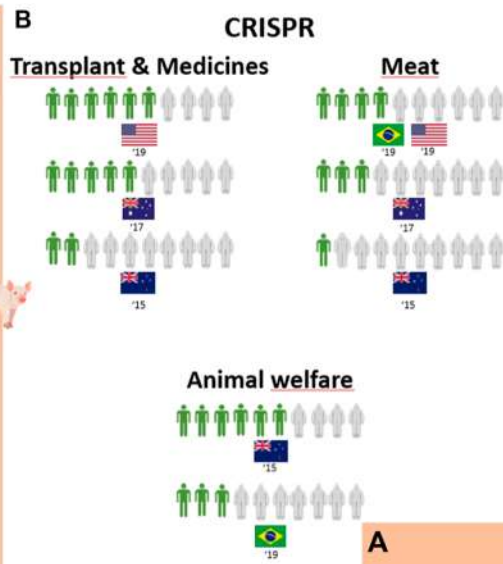
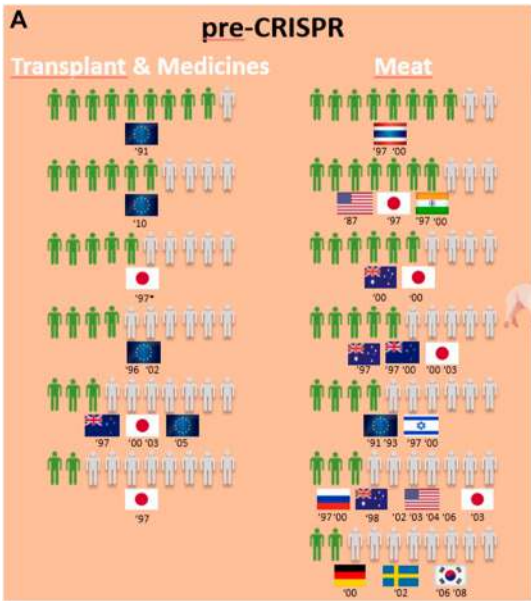
Pedro Dias Ramos ^{1,2*}, Maria Strecht Almeida ^{2*} and Ingrid Anna Sofia Olsson ^{1,2*}

¹*I3S – Instituto de Investigação e Inovação em Saúde, Universidade do Porto, Porto, Portugal;* ²*ICBAS – Instituto de Ciências Biomédicas Abel Salazar, Universidade do Porto, Porto, Portugal*

53 questionnaire studies with a representative sample of the general population, addressing applications in humans and non-human animals

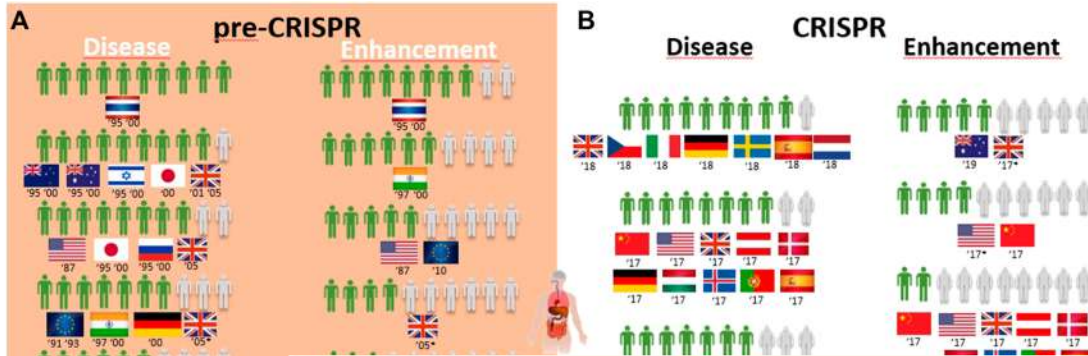


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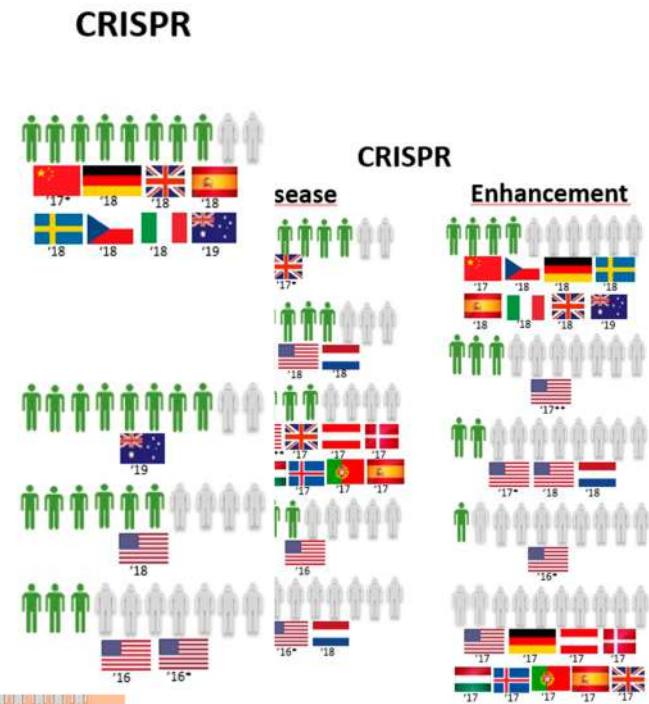
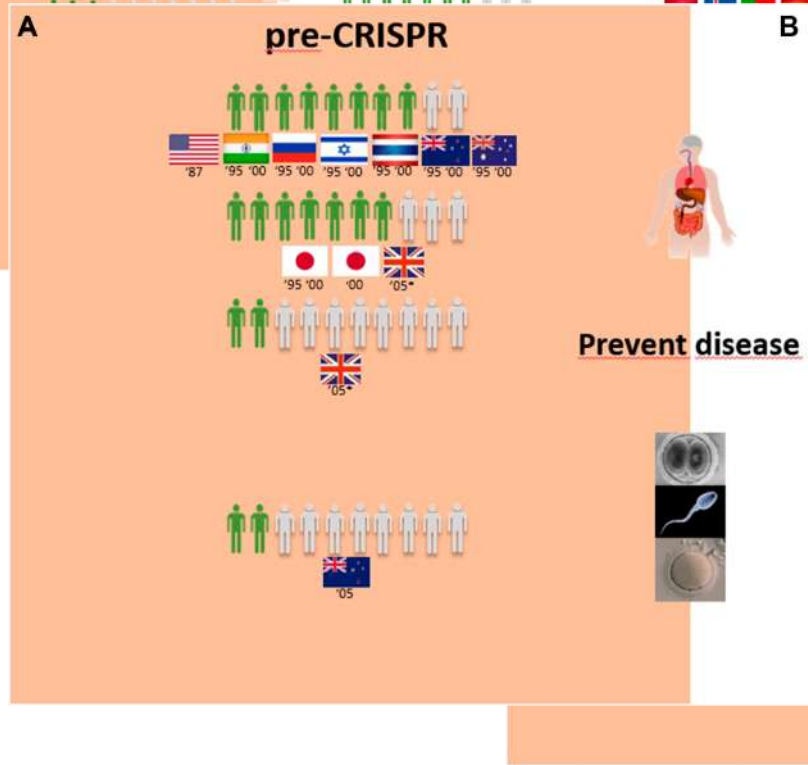


Animals





Humans





A very simplified synthesis of the results

Humans

- Disease prevention / treatment generally acceptable, enhancement is not
- Somatic applications generally acceptable, more ambivalence regarding germline

Animals

- Biomedical applications generally acceptable, food production much less so



Important reflection on methods

- Overall, low-medium methodological reporting standard
 - Information often missing on key aspects such as validity, reliability, risk of bias, sampling
- Huge variation in methods between studies
 - Consistency over time and across countries is very rare



There's more to understanding public perception

- The surveys don't reflect the full range of issues raised in ethical analysis of gene editing technology
- In particular issues of wider social relevance are missing: eugenics, social justice, access to technology and funding for technology development
- Room for more comprehensive approaches with public engagement, e.g. citizen policy approaches => participatory governance

Scientist perspective



- More research needed to improve the technology and increase knowledge of the genome function
- Critical of applications that are perceived as unsafe / unpredictable (based on current knowledge)
- Critical of applications that are perceived as irrelevant
- Large international / cultural differences in regulation seen as problematic
- Scientists have an important role to play in the science-society dialogue



Scientists are also citizens and share some of the same concerns about the use of gene editing

- “[...] if one can prevent a life-threatening disease, perhaps I could give it a thought. But if it’s just to increase the person’s skills or something like that, then I’m against it by all means”
- “Are there people that will be genetically modified? Is there a status that people will acknowledge? Is something that is supposed to be private? [...]Will there be any discrimination in favor of people that underwent germline genetic modification?”

Scientists highlight the need for science-society dialogue and regulation



- “[...] I don’t say that we should use or take advantage of the extreme situation of a given technology, but we should know the limitations and then the society such [as] politicians and ethical people should draw the limits of where we should use the technology”
- “The more important thing is that you educate people, because the [official issue] must not only come from experts because obviously experts tend to have “bigger limits”, so [probably] experts take the technology to an extreme [somehow]. We should educate people to know about it and to understand [and to] also [have] judgment about it. Judgment based on knowledge, not judgment based on belief. So I think it’s important that you can educate people because at the end not all the laws are made by the [scientists].”



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ARRIGE

Association for Responsible Research and Innovation in Genome Editing

ETHICS OF CRISPR GENE THERAPY

WHITE PAPER

APRIL 2024



“Without some fairly dramatic efforts, the current crop of gene therapies will not result in global public health benefits, and to the extent that they become available at all, they will entrench existing inequities with respect to access to the best care.”

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