Advisory Committee on developing global standards for governance and oversight of human genome editing: call for contributions

The WHO Expert Advisory Committee on Developing Global Standards for Governance and Oversight of Human Genome Editing (the Committee) was set up by the Director General of the WHO in December 2018 to examine the scientific, ethical, social and legal challenges associated with human genome editing (both somatic and germ cell). As well as evidence gathering, the panel was asked to review the current literature on the state of the research and its applications, and societal attitudes towards the different uses of this technology. Following this, WHO will receive advice from the Committee on appropriate oversight and governance mechanisms, at the international, regional, national and local levels.

In order to fulfil this remit, the Committee is in the process of developing a governance framework. In an effort to understand and include a wider set of views, the Committee has provided a draft of its governance framework for public comment. The Committee are interested in views on the approach they have taken to the governance framework, its content, as well as insights on good governance of human genome editing.

We are collecting some personal information to help the Committee to understand who has responded to this consultation. Please note that we will securely store this data per WHO rules and policies, we will not use this information except for the propose for which it was provided, and we will not share the information with third parties.

If you have any queries in relation to this survey, please contact Anne-line Imbsen imbsena@who.int.

Deadline for responses is: Wednesday 19 August 2020

There are 12 questions in this survey.

About you

1. What is your name?

Please write your answer here:

2. What is your affiliation?

Please write your answer here:

3. What is your country of residence?

Please write your answer here:

Your contribution

4. Have you read the DRAFT Governance Framework (https://www.who.int/docs/default-source/ethics/governance-framework-for-human-genome-editing-2ndonlineconsult.pdf)? *

Please choose **all** that apply:

☐ Yes
☐ No

5. Please comment on the approach taken by the Committee in developing its DRAFT Governance Framework?

*

Please write your answer here:

6. Please provide your opinions on the specific proposals relating to governance of human genome editing specific considerations for good governance in the DRAFT Governance Framework (Part 3)? *

Please write your answer here:

7. Please comment on the tools, institutions, and processes for human genome editing governance in the DRAFT Governance Framework (Part 4)?
*

Please write your answer here:

8. Please provide your opinions on the scenarios in the DRAFT Governance Framework (Part 6), including whether we have missed any important details?
*

Please write your answer here:

9. Please comment on the questions to be considered when developing governance measures (Annex)?

Please write your answer here:

10.What would you want to see in a decision tree to assist those taking governance decisions? (We are currently consider creating a decision tree based on the questions to be considered when developing governance measures (Annex))?

Please write your answer here:

11. Are there additional measures we could include to deter or avoid bad practice around applications of human genome editing (such as rogue clinics or other 'bad actors', inappropriate uses of the technology, etc.)?

Please write your answer here:

12.What else do you want to tell us about good governance of human genome editing?

Please write your answer here:

Thank you for your contribution.

Submit your survey.

Thank you for completing this survey.