**WHO Expert Advisory Committee on Developing Global Standards for Governance and Oversight of Human Genome Editing**

# Report of the first online consultation

**15 January–7 February 2020**

WHO Expert Advisory Committee on Developing Global Standards for Governance and Oversight of Human Genome Editing: report of the first online consultation, 15 January–7 February 2020

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**Contents**

Abstract ..... iv
Background ..... 1
First online consultation ..... 1
Summary of submissions ..... 2
Section 1. Questions on who was providing a response ..... 2
Section 2. Questions on the general approach taken by the Committee ..... 4
Section 3. Questions on the draft governance framework ..... 8
Section 4. Final comments ..... 15

## Abstract

The World Health Organization (WHO) held its first online global consultation on genome editing governance and public engagement. Major themes appearing in the responses included concern over appropriate outreach to a wide audience to ensure consideration of social implications beyond technical or medical considerations; suggestions about integrating the views of industry, bioethicists and governments; recognition of cross-border challenges to harmonization or coordination of policies; and the importance of ongoing consultation and transparency. Feedback was provided on a draft of the governance framework being developed by the WHO Expert Advisory Committee on Developing Global Standards for Governance and Oversight of Human Genome Editing. Very few respondents identified elements in the framework they found to be unacceptable. Many comments included suggestions for improving the framework, such as additions or alterations to the proposed framework. Some comments from different respondents were contradictory: for example, some wanted to ban certain types of research, while other objected to restrictions on scientific freedom. There were also conflicting suggestions as to the scope of the framework, with calls to both include and exclude basic research. There were several proposals to exclude specific groups from the framework, such as industry, citizen scientists and social media activists. The Committee carefully reviewed and considered the comments provided to revise and further develop the governance framework and to conduct a second online consultation during mid-2020.

## Background

In December 2018, the World Health Organization (WHO) established a global, multidisciplinary expert advisory committee to examine the scientific, ethical, social and legal challenges associated with human genome editing (both somatic and germline).[1] The Expert Advisory Committee on Developing Global Standards for Governance and Oversight of Human Genome Editing includes members from Africa, the Americas, South-East Asia, Europe, the Eastern Mediterranean and the Western Pacific.[2]

The Committee has been tasked with advising and making recommendations on appropriate institutional, national, regional and global governance mechanisms for human genome editing. During the course of its work, the Committee will review literature on current human genome editing research and its applications, consider existing proposals for governance and relevant ongoing initiatives, and solicit information about societal attitudes towards the different uses of this technology. The Committee will explore how best to promote transparent and trustworthy practices and how to ensure appropriate assessments are performed prior to any relevant work being undertaken.

## First online consultation

At its second meeting held in Geneva, Switzerland, between 26 and 28 August 2019:

> … in accordance with the principle of inclusivity, the Committee agreed to two rounds of consultation in the autumn/winter of 2019 and in the spring of 2020. The consultation will expand the views that feed into its work on the governance of human genome editing. The first round will seek input for the development of a governance framework, and the second round will help test a draft of the framework before it is provided to the Director-General. The education, engagement and empowerment working group will continue to develop plans and tools for the online consultation. The Committee requested WHO to make use of its regional and country offices, and their social media presences as well as other channels, to promote the consultation as widely as possible. WHO should consider targeted efforts to engage groups whose views are: (a) of particular relevance to its work; or (b) often under-represented in international science policy consultations. The Committee will be briefed on the consultation at its next meeting.[3]

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[1] Expert Advisory Committee on Developing Global Standards for Governance and Oversight of Human Genome Editing: https://www.who.int/groups/expert-advisory-committee-on-developing-global-standards-for-governance-and-oversight-of-human-genome-editing/about.

[2] https://www.who.int/groups/expert-advisory-committee-on-developing-global-standards-for-governance-and-oversight-of-human-genome-editing/about.

[3] https://apps.who.int/iris/bitstream/handle/10665/341018/WHO-SCI-RFH-2019.02-eng.pdf.

The Committee subsequently developed an online survey. WHO administered the survey and collected and analysed the responses.

At its third meeting held in Cape Town, South Africa, between 25 and 26 February 2020, the Committee was briefed on submissions made during the consultation. WHO provided members of the Committee with all of the submissions made during the consultation, as well as summaries of key issues identified. The Committee subsequently reviewed and considered these materials. WHO prepared a draft report of the consultation, which was reviewed and revised by the Committee. The Committee would use the insights derived from the first online consultation to revise and further develop the governance framework and to conduct a second online consultation during mid-2020.

## Summary of submissions

WHO hosted the online survey on its website and the link was circulated to WHO regional offices and through the networks of the Committee members. The survey was made available to all interested respondents between 15 January and 7 February 2020. The spread of COVID-19 increased significantly during that time, making the dissemination of the survey challenging. The Committee anticipated wider circulation than proved possible at the time.

The survey included 12 questions divided into four parts: (a) questions on who was providing a response; (b) questions on the general approach taken by the Committee; (c) questions on the draft governance framework being developed by the Committee; and (d) final comments – an open question for respondents to provide additional input for the Committee.

The majority of respondents did not respond to all questions. In general, only around a third of respondents answered any specific question. This could be because most respondents were only interested in a subset of questions or wanted to provide open-ended input into the work of the Committee, which question 12 allowed for. The Committee considered all responses in this report.

### Section 1. Questions on who was providing a response

In total, 325 unique responses were received, where:

Of the 325 respondents:

- 126 (39%) identified as individuals;
- 45 (14%) identified as responding on behalf of an organization;
- 154 (47%) did not specify whether responding as individuals or on behalf of an organization.

Responses came from individuals and organizations in 32 countries.[4]

[4] Argentina, Australia, Austria, Belgium, Brazil, Canada, Chile, Colombia, Costa Rica, Finland, France, Germany, India, Ireland, Japan, Mexico, Netherlands, New Zealand, Paraguay, Peru, Poland, Romania, Russian

The 126 responses from individuals came from 28 countries. Countries with the highest response rates included the United States of America (29), Canada (9), Japan (9), Germany (5) and South Africa (5). In terms of WHO regions, there was a particularly high level of response from Pan American Health Organization (PAHO) countries, with 11 member countries submitting responses.[5]

The 45 responses from organizations came predominantly from the United States of America (15), the United Kingdom of Great Britain and Northern Ireland (5) and Mexico (3). These organizations included biotechnology associations, professional scientific bodies, patient groups, and bioethics committees.

In terms of the roles played by respondents, most indicated playing a role in considering the ethical, religious, social, legal or value-driven implications of human genome editing, or having a personal interest in the topic (Table 1).

Federation, Serbia, Singapore, South Africa, Spain, Sweden, Switzerland, United Kingdom, United States of America, and Venezuela (Bolivarian Republic of).

[5] Argentina, Brazil, Canada, Chile, Colombia, Costa Rica, Mexico, Paraguay, Peru, United States of America, and Venezuela (Bolivarian Republic of).

**Table 1. Roles played by respondents in the first online consultation**

| Role | No. of responses |
|---|---|
| Conduct research which is, or might be, related to human genome editing | 5 |
| Have a role in influencing what research is undertaken or disseminated (e.g. through setting research agendas, taking funding decisions, or in publication of findings) | 6 |
| Help translate research into commercial opportunities (e.g. commercial organizations conducting clinical trials or delivering clinical services) | 6 |
| Have a role in a body considering the ethical, religious, social, legal, or value-driven implications of human genome editing | 52 |
| Have a role in a patient group or other body that represents, or might represent, those that may be affected by human genome editing | 12 |
| Have a role in a civil society group or other body that addresses, or might address, issues connected to human genome editing | 31 |
| Have a role in an international, regional or national organization or group that is, or might be, involved in the oversight of human genome editing | 24 |
| Have a personal interest in human genome editing | 50 |

## Section 2. Questions on the general approach taken by the Committee

### Engagement

*Question 4. The Committee is interested in promoting useful public education, engagement and empowerment on human genome editing. Do you know of any public engagement activities on emerging technologies (including human genome editing)? Do you have any suggestions for effective public engagement on human genome editing?*

Of those respondents who answered the question on engagement, just over half provided examples of useful engagement activities. The platforms identified in the responses included: