**Questionnaire on bioethics and disability**

**The questionnaire below is directed at national governments; however, WHO will frame its response by describing the WHO’s normative guidance and the ways WHO works with respect to each topic described below.**

**Answers below are a result of consultation of the WHO Disability Programme with WHO units on Reproductive Health and Research, Global Health Ethics, and Service Delivery and Safety.**

1. Please provide information on the legislative and policy framework in place in your country in relation to:
   1. Prenatal diagnosis

**WHO advises that maternal and fetal screenings should be included in universal health coverage (UHC). As of yet WHO has no further guidance about which screenings to include or how they should be administered.**

* 1. Disability-related abortion

**WHO’s position is that women should not be denied prenatal diagnostic screenings due to concern they may use that information to have an abortion, i.e., the mother should have the right to do what she wishes with the information she is provided. As of yet WHO has no further guidance about any questions related to abortion due to suspected disability of the child.**

* 1. Informed consent to medical treatment and scientific research

**The International Ethical Guidelines for Health-related Research Involving Humans (ATTACHED) from the Council for International Organizations of Medical Sciences (CIOMS) were developed in collaboration with WHO and serve as the standard for the WHO Ethics Review Committee (ERC).**

**Various WHO disease-specific guidelines stress the importance of informed consent for medical treatment (e.g., guidelines on HIV, tuberculosis, Ebola, malaria, etc.)**

* 1. Protection of persons with disabilities undergoing research

**CIOMS guidelines address research with vulnerable populations in general, explicitly naming people with disabilities and people with “incurable or stigmatized conditions or diseases” as potentially vulnerable groups. The guidelines also include provisions related to compensation to individuals who acquire disability as a result of the research they are a part of.**

* 1. Euthanasia and assisted suicide

**WHO does not work on euthanasia or assisted suicide, however WHO has several publications and guidance documents on palliative care more generally (ATTACHED).**

1. Please provide any information and statistical data (including surveys, censuses, administrative data, literature, reports, and studies) in relation to:
   1. The availability, accessibility and use of prenatal diagnosis

**WHO has no data on this topic.**

* 1. The availability, accessibility and use of disability-related abortion

**WHO has no data on this topic.**

* 1. The practice of informed consent to medical treatment and scientific research

**WHO has no data on this topic.**

* 1. The existence of measurements of quality of life which affect both clinical decision-making and health policy

**WHO has developed various tools that assess quality of life, functioning, and/or disability which are used by countries in different settings. These tools include the** [**WHO Quality of Life assessment**](https://www.who.int/mental_health/publications/whoqol/en/) **(WHOQOL),** [**WHO Disability Assessment Schedule**](https://www.who.int/classifications/icf/whodasii/en/) **(WHODAS), and the** [**Model Disability Survey**](https://www.who.int/disabilities/data/en/) **(MDS). The WHODAS and the MDS are based on the** [**International Classification of Functioning, Disability and Health**](https://www.who.int/classifications/icf/en/) **(ICF), a framework for measuring health and disability. WHO states that the WHOQOL and the WHODAS could be used in a clinical setting, but the MDS is not designed to be used in a clinical setting.**

**WHO does not systematically capture how data from these tools is being used in countries to affect clinical decision-making and or health policy.**

* 1. The practice of experimental, controversial and/or irreversible treatments

**WHO set up an expert advisory panel on genome editing, which is currently examining gene therapies and related governance options, including all ethical considerations therein. WHO does not yet have data on the practice of gene therapies or other experimental, controversial and/or irreversible treatments.**

* 1. The practice of euthanasia and assisted suicide on persons with disabilities

**WHO has no data on this topic.**

1. Please provide information on discrimination against persons with disabilities on research involving humans.

**Anecdotal evidence suggests that people with disabilities are excluded from research, both by being *a priori* excluded from study populations or being excluded if a selected individual is deemed not able to give consent to participate. WHO has no official information in this regard.**

1. Please describe how national ethics committees address the rights of persons with disabilities. Please provide information on protocols, guidelines, decisions, investigations or publications in relation to persons with disabilities.

**WHO is the secretariat of the** [**Global Summit of National Bioethics Committees**](https://www.who.int/ethics/partnerships/globalsummit/en/)**. The next meeting for this summit is in Portugal in March 2020. This summit has not addressed extensively the rights of persons with disabilities yet.**

**Within WHO, the WHO Ethics Review Committee which reviews all WHO-supported research, follows the CIOMS guidelines and gives special consideration to all vulnerable groups, including people with disabilities.**

1. Please describe to what extent and how persons with disabilities are involved in the work of national ethics committees.

**See above response to question 4. WHO has no further information.**

1. Please refer to any innovative initiatives that have been taken at the local, regional or national level to promote and ensure the rights of persons with disabilities in bioethical discussions.

**WHO has convened an** [**expert advisory group on genome editing**](https://www.who.int/ethics/topics/human-genome-editing/en/)**, as described above, which will examine all ethical issues related to the subject. Similarly, WHO has also convened an** [**expert advisory group on ethics and governance of artificial intelligence**](https://www.who.int/ethics/topics/big-data-artificial-intelligence/en/)**.**

**Attachments:**

* **CIOMS and WHO International Ethical Guidelines for Health-related Research Involving Humans**
* **WPCA and WHO Global Atlas of Palliative Care at the End of Life**
* **WHO Guidelines for the Pharmacological and Radiotherapeutic Management of Cancer Pain in Adults and Adolescents**
* **Integrating palliative care and symptom relief into paediatrics: A WHO guide for health care planners, implementers and managers**
* **Integrating palliative care and symptom relief into primary health care: A WHO guide for planners, implementers and managers**
* **Integrating palliative care and symptom relief into the response to humanitarian emergencies and crises: A WHO guide**
* **Planning and implementing palliative care services: a guide for programme managers**