**Questionnaire on bioethics and disability**

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

Prenatal diagnosis in Japan cannot be applied the health insurance, but is not prohibited by legislations. So, people can get it, when they meet some requirements and cover large payment amount.

* 1. Disability-related abortion

Abortion is generally subject to criminal penalty provided for in Article 212 to 216 of the Criminal Code in Japan. However, when an abortion is done in accordance with the proceedings on abortion provided for in the Maternal Protection Law, the abortion becomes acquittal. Abortions for reasons of mater’s health condition, financial situation, or pregnancy by rape etc. are acquittal. Abortion on the basis of disability is not clearly mentioned in the Law, but it is done by using financial reasons as hideout.

Japan had the Eugenic Protection Law, which provided forced sterilization and abortion based on disability by the administration, until 1996. When the Eugenic Protection Law was amended to the Maternal Protection Law in 1996, the provisions on forced sterilization were deleted, but customs of sterilization and abortion are still tenaciously remain until now. Problems of abortion based on disability include problems on both parents with disabilities and fetus with disabilities, and both become victim of abortion by using financial reasons as hideout.

* 1. Informed consent to medical treatment and scientific research

Japan does not have a code for rights of patients.

Article 1.4 of the Medical Law and the Medical Practitioner Law provide for that the informed consent is obligation of medical staffs.

Japanese laws require consent for medical invasive. However, in cases of fatal urgency, omission of the consent is exceptionally accepted. In these cases, when the patient become to have capacity to give a consent, his or her consent, including rejection of treatments, is required.

* 1. Protection of persons with disabilities undergoing research

Protection of persons with disabilities undergoing research is provided for in the Clinical Trials Act in Japan. But in fact, not a few researches launched with only external consent without free and informed consent. For example, participants with disabilities in the follow-up survey carried out in 2012 on people who finished treatments provided for in the Medical Treatment and Supervision Act, gave external consents of their participation, but they were not convinced.

* 1. Euthanasia and assisted suicide

Assisted suicide is subject to criminal penalty provided for in Article 202 of the Criminal Code in Japan as murder at the victim's request. In addition, regarding euthanasia, positive euthanasia such as use of poison etc. is also subject to criminal penalty provided for in Article 202 of the Criminal Code as the murder at the victim's request, but negative euthanasia such as discontinue of life-prolonging treatments in terminal stage is not included in the murder at the victim's request. However, difference between positive and negative euthanasia is not always clear. Therefore, the Ministry of Health, Labour and Welfare established “the Practice Guidelines for Process of Decision-Making Regarding Treatment in the End of Life Care” in March 2018 and provided for the proceedings of negative euthanasia in soft law.

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

Japanese government does not have statistical data of prenatal diagnosis.

The Ministry of Health, Labour and Welfare decided to start a fact-finding survey on the new type of prenatal diagnosis (the non-invasive prenatal genetic test: NIPT) on 29 July 2019, and will investigate the number of cases and states of counselling for pregnant woman etc.

A team with the National Center for Child Health and Development reported on 28 December 2018 that there were at least about 70,000 cases of prenatal diagnosis in 2016 and the number of cases was increased by 2.4 times during a decade, compared to 29,300 cases in 2006. The academic society could not grasp cases done in unauthorized institution. So, actual number seemed to be larger than the report.

(Reference: https://r.nikkei.com/article/DGXMZO39528020Y8A221C1CR8000?s=5)

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

Japanese government does not have statistical data of operation for disability-related artificial abortion. The number of artificial abortion was 168,015 in FY2016, and 168,015 in FY2017. Disability-related abortion seems to be included in them.

(Reference: https://www.mhlw.go.jp/toukei/saikin/hw/eisei\_houkoku/16/dl/kekka6.pdf)

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

Unable to figure out.

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

The Ministry of Health, Labour and Welfare established “the Practice Guidelines for Process of Decision-Making Regarding Treatment in the End of Life Care” in March 2018.

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

Unable to figure out.

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

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

A woman with kidney dysfunction hospitalized in the Tokyo Metropolitan Fussa Hospital dead in August 2018, because the doctor stopped dialysis against her will. The Japanese Society for Dialysis Therapy determined their direction to revise their guideline on stopping dialysis until December 2019 and will include stopping it before terminal stage in the subjects, though only stopping dialysis in terminal period is accepted in the existing guideline.

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.

Japan does not have an administrative organization which is correspond to the national ethics committees. Each ministries independently establish guidelines on ethics on research.

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

Organizations of persons with disabilities hardly participate in the process of ethics on research, independently provided for by each ministries.

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.

Issues on bioethics have been one of the most important issues in social movements of persons with disabilities in Japan. Regarding euthanasia, they have regarded themselves as persons who were in position of being killed by euthanasia and protested against it. In addition, they have regarded life in itself as the most fundamental human rights, and insisted that living and existences of persons with severe disabilities became power to change the society.

Decision of negative euthanasia based on disability is not based on real will of the person, because it is a result of adoptive preference based on discriminations against persons with disabilities. Therefore, euthanasia is denial of life on the basis of disability and violent Article 10 of the Convention on the Rights of Persons with Disabilities. Self-determination on life and death should not be regarded as rights of self-determination, because it includes self-denial of life based on disability. The rights will be made real by changing from society which is difficult to live for persons with disabilities and makes them painful enough to have desire to death, to inclusive society where people can live with disabilities.