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Subject: Questionnaire on bioethics and disability

Please find below the answers to your questions, presenting legislation and practice in the Republic of Slovenia.

Unfortunately, we have been able to provide only limited responses to many of your questions, despite our best efforts to search for available resources. **We would therefore prefer for this document to not be posted on the OHCHR website.** We hope our contribution will nevertheless be of value for your research. Please feel free to contact us for any additional clarifications.

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

**a. Prenatal diagnosis**

Pursuant to the **Health Care and Health Insurance Act**,[[1]](#footnote-1) Article 23,prenatal medical examinations are included among the healthcare services covered by the mandatory health insurance; the exact types and timeline of examinations available are specified in the **Rules on carrying out preventive health care at the primary level**, Section 1.2.2.[[2]](#footnote-2)

**b. Disability-related abortion**

The provisions regulating abortion are found in the **Health Measures in Exercising Freedom of Choice in Childbearing Act**,[[3]](#footnote-3) Articles 17–30.

Induced abortion can be performed upon the request of the pregnant woman up to week 10 of pregnancy (Article 17).

After the conclusion of week 10 induced abortion may be performed upon the request of the pregnant woman only **if the intervention-related risk to the life and health of the pregnant woman and her future maternity is less than the risk that would be imposed on the pregnant woman or the child due to continuation of pregnancy and childbirth** (Article 18). The decision is made by one of the first instance commissions for artificial termination of pregnancy, composed of a social worker and two doctors; if the request for induced abortion is rejected, an appeal can be made to the second instance commission, composed of a social worker and three doctors (Articles 19 and 20).

In the case of a mentally incompetent pregnant woman, the request for induced abortion on her behalf can be made by her parents or a guardian (Article 22).

**c. Informed consent to medical treatment and scientific research**

Article 18 of the **Constitution of the Republic of Slovenia**[[4]](#footnote-4) provides that the conducting of medical or other scientific experiments on any person without his free consent is prohibited. Article 51 provides that no one may be compelled to undergo medical treatment except in cases provided by law.

The consent to medical treatment and research is further defined in the **Patients’ Rights Act**,[[5]](#footnote-5) Articles 26 to 38. Consent can be expressed in any manner, however a written consent is required for procedures involving higher risk or burden (Article 26, Paragraph 5). Urgent medical assistance is allowed without consent if the patient is incapable of providing it (Article 28).

Article 37 sets out the rules regarding approval in the case of patients incapable of providing consent due to mental health problems or other reasons. Approval to medical treatment in such cases is provided by a legal guardian; before one is appointed, consent can be provided by the patient’s relatives, listed in the article (Paragraph 4). The legal guardian or relatives cannot prevent the provision of urgent medical assistance (Paragraph 8).

Slovenia has signed and ratified the **Additional Protocol to the Convention on Human Rights and Biomedicine, concerning Biomedical Research** without reservations.

**d. Protection of persons with disabilities undergoing research**

Pursuant to Article 11 of the **Mental Health Act**,[[6]](#footnote-6) research on persons with mental disability can only be conducted if their written informed consent is provided. In addition, the research needs to be approved by the advisory body of the psychiatric hospital and the National Medical Ethics Committee. Article 11 further stipulates that such research is only allowed if it cannot be substituted by another similarly successful research and the dangers the patient is potentially exposed to are not disproportionate in comparison to the possible benefits of the research. The patient can revoke their consent at any time in any manner.

**e. Euthanasia and assisted suicide**

Euthanasia and assisted suicide are not permitted in Slovenia. Article 17 of the Constitution stipulates that human life is inviolable.

**2. Please provide any information and statistical data (including surveys, censuses, administrative data, literature, reports, and studies) in relation to:**

**a. The availability, accessibility and use of prenatal diagnosis**

As described under 1.a. above, prenatal diagnosis is available and fully covered for every person with mandatory health insurance in Slovenia. According to official data only 650 persons in Slovenia were without mandatory health insurance at the end of 2018, however the actual number may be higher according to some experts.[[7]](#footnote-7)

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

To our knowledge no studies or reports on the decision making of the first and second instance commissions are available. Furthermore, other published information on disability-related abortion also appears to be scarce, possibly indicating that decision making of the commissions is not restrictive and therefore not often brought into contention.[[8]](#footnote-8)

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

One contentious practice detected by the Ombudsman concerns non-consensual medical treatment of patients involuntarily committed to a psychiatric hospital.

Involuntary commitment can be ordered by the court through a procedure and on the grounds defined in the Mental Health Act. This, however, should not preclude the general requirements for consent for any medical treatment, as described under 1.c. above. Nevertheless, it appears that in practice involuntarily committed patients are often not able to refuse psychiatric treatment.

The issue has also been addressed by the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) in their most recent report for Slovenia,[[9]](#footnote-9) published on 20 September 2017 (Paragraph 125). A further analysis of the problem can be found in the English abbreviated version of the Ombudsman’s annual report for 2017[[10]](#footnote-10) (page 131).

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

The Slovenian association for Intensive Care Medicine and the National Medical Ethics Committee have jointly published **Ethical Recommendations on Medical Treatment and Palliative Care in Intensive Care Medicine of Patients at the End of their Lives**.[[11]](#footnote-11) The recommendations are intended to protect patients from medical treatment that would be too intense or not intense enough and to guarantee appropriate palliative care at the end of life. They emphasize an individualized approach, centered around the principles of autonomy, beneficence, and justice.

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

Problems related to experimental, controversial or irreversible treatments for disabled persons have not been detected.

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

Euthanasia and assisted suicide are not practiced in Slovenia.

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

Discrimination against persons with disabilities related to research involving humans has not been detected. Persons with mental disability are guaranteed additional protection by law, as described under 1.d. above.

**4. 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.**

The National Medical Ethics Committee[[12]](#footnote-12) has not published any documents specifically addressing the rights of persons with disabilities.

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

The composition and work of the National Medical Ethics Committee is set out in the **Rules on the membership, duties, responsibilities and working methods of the National Medical Ethics Committee.**[[13]](#footnote-13)The committee is composed of 16 experts representing various fields. Participation of persons with disabilities, or participation of the public in general, is not foreseen in the rules.

**6. 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.**

We are not aware of any such initiatives.

With compliments,

Miha Nabergoj

Adviser – analyst

Centre for Human Rights

1. Official Gazette of the Republic of Slovenia, No. 72/06, with further amendments: <http://pisrs.si/Pis.web/pregledPredpisa?id=ZAKO213>. [↑](#footnote-ref-1)
2. Official Gazette of the Republic of Slovenia, No. 19/98, with further amendments: <http://www.pisrs.si/Pis.web/pregledPredpisa?id=NAVO59>. [↑](#footnote-ref-2)
3. Official Gazette of the Socialist Republic of Slovenia, No. 11/77, with further amendments: <http://pisrs.si/Pis.web/pregledPredpisa?id=ZAKO408>. [↑](#footnote-ref-3)
4. Official Gazette of the Republic of Slovenia, No. 33/91-I, with further amendments: <http://pisrs.si/Pis.web/pregledPredpisa?id=USTA1>. [↑](#footnote-ref-4)
5. Official Gazette of the Republic of Slovenia, No. 15/08, with further amendments: <http://pisrs.si/Pis.web/pregledPredpisa?id=ZAKO4281>. [↑](#footnote-ref-5)
6. Official Gazette of the Republic of Slovenia, No. 77/08, with further amendments: <http://pisrs.si/Pis.web/pregledPredpisa?id=ZAKO2157>. [↑](#footnote-ref-6)
7. The issue is discussed in the following news article (in Slovenian): <https://siol.net/novice/slovenija/slovenci-brez-zavarovanja-izgovarjajo-se-da-so-zdravi-484916>. [↑](#footnote-ref-7)
8. Please note that further research is needed to make any definite conclusions in that regard. [↑](#footnote-ref-8)
9. Available at: <https://rm.coe.int/pdf/168074adf9>. [↑](#footnote-ref-9)
10. Available at: <http://www.varuh-rs.si/fileadmin/user_upload/pdf/lp/LP2017_VARUH_ENG.pdf>. [↑](#footnote-ref-10)
11. Available in Slovenian language at: <http://www.kme-nmec.si/files/2018/03/Eticna-priporocila-paliativa-v-intenzivni-medicini.pdf>. [↑](#footnote-ref-11)
12. Webpage of the institution (in Slovenian) available at: <http://www.kme-nmec.si/>. [↑](#footnote-ref-12)
13. Official Gazette of the Republic of Slovenia, No. 21/18, with further amendments: <http://www.pisrs.si/Pis.web/pregledPredpisa?id=PRAV13345>. [↑](#footnote-ref-13)