



Strasbourg, 7 June 2019

Decisions 15th DH-BIO

**COMMITTEE ON BIOETHICS
(DH-BIO)**

15th meeting

4-7 June 2019

Strasbourg

Decisions taken by the Committee on Bioethics at its 15th plenary meeting

Public Debate

High level Seminar on public debate as a tool for the governance of new technologies – 4 June, organised under the auspices of the French Presidency of the Committee of Ministers

The DH-BIO congratulated the French Presidency, the speakers, the Secretariat and everyone else who contributed to the success of the high-level seminar. The Committee praised the quality of the event and underlined a number of issues arising from it.

Draft Guide on Public Debate

The Committee decided to invite the drafting group to take note of the specific proposals made and the written comments received from the targeted consultations on the draft guide. This included the need to clarify certain wording and to develop and increase the number of geographically diverse country examples referred to. The Committee welcomed the offer by UNESCO to collaborate and thereby refer to examples of public debate from outside of Europe. **DH-BIO delegations were invited to send to the Secretariat additional examples of public debate at the latest by 23 August 2019.**

Genome editing

The DH-BIO took note of the replies to the questionnaire summarised by the Rapporteur, Ingo Haertel (Germany). It decided to await the findings of the studies by two experts respectively on ethical issues raised by genome editing technologies and the overview of the technological advances, and to continue observing relevant work undertaken namely by the WHO.

Strategic Action Plan

The Committee thanked the drafting group for their work in preparing the draft strategic action plan. It considered the draft, in particular the action proposals, and had wide ranging discussions on priorities. Children's participation in decision making processes, older person's access to innovative treatments, public debate, and the challenges of neurotechnology were all highlighted in conjunction with possibilities for cooperation, capacity building and exchanges with the OECD, WHO, and UNESCO.

Noting that, at that stage, there was no clear consensus on the choice of action proposals, the **Committee invited DH-BIO members to send comments and/or indicate their priorities among the actions proposed to the Secretariat, at the latest by 26 July 2019.**

Priorities for the 2020-2021 biennium

The Committee took note of possible priorities presented by the Secretariat in the light of the discussion at the Bureau meeting. It decided, following extensive discussion, on the following priority actions for the next biennium:

- (i) Finalisation of the draft Additional Protocol for the protection of human rights and dignity of persons with mental disorders with regard to involuntary placement and involuntary treatment.
- (ii) Carrying out and publication of the study on good practices in mental health care - How to promote voluntary measures (subject to funding).
- (iii) Launching of the Strategic Action Plan with particular focus on the human rights challenges raised by new technologies, such as neurotechnologies.
- (iv) Examination of ethical and legal issues raised by developments in genome editing technologies, in relation to Article 13 of the Oviedo Convention.

- (v) Mapping legislation and best practices with a view to developing a guide for health care professionals on children's participation in the decision making process.
- (vi) Launching of the Guide on Public Debate.
- (vii) Further translation and dissemination of the HELP course, keeping in mind the double target audience: legal but also health professionals

Additional Protocol on the protection of the human rights and dignity of persons with mental disorders with regard to involuntary placement and involuntary treatment

The DH-BIO took note of the replies, received from professional organisations, to the questionnaire on the draft additional protocol prepared by the Bureau. Following an exchange on the way forward, the DH-BIO **agreed to invite Delegations to submit, by 23 August 2019, concrete drafting proposals** in view of the comments received, keeping in mind the decision taken at its 14th plenary meeting to carefully review the draft, having particular regard to strengthening the aspect of alternative and preventive measures.

The DH-BIO further agreed to hold an extended Bureau meeting on 14 October 2019, in Paris, with the participation of delegations having submitted drafting proposals, with a view to presenting a revised draft Protocol at the 16th plenary meeting.

Draft study on good practices in mental healthcare – how to promote voluntary measures

The DH-BIO examined the concept note prepared by the Secretariat and agreed on the importance of the work proposed. Delegations expressed their support for the concept note and agreed on the need to further define the scope and the methodological approach of the study.

The representatives of INGO's and the PACE Rapporteur expressed their support for the project and agreed to contribute to its further development.

Delegations welcomed the support and the readiness of INGO's and of the PACE rapporteur to contribute to this project. They agreed that the work should be instigated without delay.

The DH BIO agreed that Delegations and INGO's, as well as the other relevant bodies of the Council of Europe, would be invited to send their suggestions on how to approach the scope and methodology of the study by 23 August 2019 with a view to refining the concept note.

The DH-BIO agreed to designate a Rapporteur for the study on good practices in mental health care and to entrust, subject to confirmation, the representative of Finland with this task.

The DH-BIO entrusted the Secretariat, in co-operation with the Rapporteur, to organise a Round Table meeting with relevant actors in the field (including representatives from the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT), the Council of Europe Commissioner for Human Rights, PACE, European Network of National Human Rights Institutions (ENNHRI) and relevant INGOs and professional organisations), in view of further refining the scope and methodology of the study, taking into account relevant work already undertaken in the field.

Delegations were invited to explore options of voluntary contributions towards the financing of this project.

Bureau Elections

The DH-BIO elected by acclamation, Ms Ritva Halila (Finland) as its new Vice-Chair for a six month term, renewable once for one year.

The DH-BIO elected by acclamation Mr Mark Bale (United Kingdom) as member of the DH-BIO Bureau for a term of two years, renewable once.

Other business

Committee of Ministers request for comments on PACE Recommendation Rec 2156 (2019) on anonymous donation of sperm and oocytes: balancing the rights of parents, donors and children

The DH-BIO held an exchange on the issues raised in PACE Rec 2156 (2019) and examined the draft comments prepared by the Secretariat in the light of the written comments sent by delegations. The DH-BIO considered that the wording of paragraph 8 of the draft comments, relating to information on the conception and information about the identity of the donor, should be reworded to reflect the opinions expressed, and agreed on the wording and content of the other paragraphs.

The DH-BIO entrusted the Secretariat to re-word paragraph 8 of the draft comments to reflect the opinions expressed and to send the draft to Delegations **for possible comments on the revised paragraph 8 by 14 June 2019**. It further entrusted the Bureau with finalising the comments in light of possible submissions and to forward it to the Committee of Ministers.

Proposal to prepare a request to the ECtHR under Article 29 of the Oviedo Convention (participation restricted to the Representatives of the Parties of the Oviedo Convention)

The representatives of the States Party to the Oviedo Convention agreed to entrust the Bureau, assisted by the Secretariat, with drafting a proposal for a request for an advisory opinion on legal questions concerning the interpretation of the Oviedo Convention that they will examine at the 16th Dh-BIO plenary meeting.

The representatives of the States Party to the Oviedo Convention were invited to send their proposals for possible questions to the Secretariat by 23 August 2019.

Dates of next meetings

The DH-BIO agreed on the following dates for its next meetings to be held in Strasbourg:

- 16th meeting of the DH-BIO: 19-21 November 2019
- 17th meeting of the DH-BIO: 2-5 June 2020