

COUNCIL OF EUROPE



CONSEIL DE L'EUROPE

Strasbourg, 20 December 2021

Confidential
BIO/ENF-CP RAP (2021) 1

**BIO/ENF-CP Drafting Group
on Developing a Guide to good practice concerning
the participation of children in the decision-making process
on matters regarding their health**

First Meeting, 29 November 2021
Videoconference

MEETING REPORT
29 November 2021

I. Opening

1. Ms Ritva Halila (Finland) and Mr Joost Van Haelst (Belgium), co-Chairs of the BIO/ENF-CP Drafting Group, opened the meeting thanking members of the group for their interest and participation.
2. Ms Halila explained that the co-Chairs had decided to alternate the roles per each meeting of the group and that the first meeting would be chaired by herself.
3. Ms. Laurence Lwoff, Head of Bioethics Unit and Secretary of the Committee on Bioethics (DH-BIO) of the Council of Europe, highlighted the relevance of the work within the framework of the strategic action plan on Human Rights and new Technologies in Biomedicine and the upcoming work-program in the new Steering Committee (CDBIO).
4. Ms Katrin Uerpmann, Secretary of the Steering Committee for the Rights of the Child (CDEF), in her welcoming remarks, referred to the relevance of the task of the drafting group in the context of the COE's work on child participation and within the framework of the upcoming Strategy for the Rights of the Child (2022-2027, pending adoption by the CM).
5. The members of the drafting group briefly presented themselves. The list of participants of the meeting is presented in Appendix I to this report.

II. Adoption of the Agenda

6. The drafting group adopted the agenda for this meeting as it appears in Appendix II to this report.

III. Introduction by the Secretariat

7. The Secretariat introduced the scope of the work as was agreed by the two parent committees and outlined in the concept note, taking as a starting point Article 6 of the Oviedo Convention (individual consent process) and covering both medical practice and research.
8. The task of the drafting group would be to elaborate, under the joint authority of the two parent Committees (DH-BIO and CDEF), a draft guide, containing principles and good practices, to involving children in medical decision making.
9. This guide shall promote the protection of the rights and furthering of the best interests of the child, and include consideration on the rights and responsibilities of the child's legal representatives, as well as of other persons involved at the different stage of the consent process. It should also shed light on the child's interests interconnected with those of their family members.
10. The Guide should primarily be addressed to healthcare professionals but should also be accessible to the children's parents and/or legal representatives.

IV. Presentation of the first draft outline of the Guide to good practice concerning the participation of children in the decision-making process on matters regarding their health

11. Ms Annagrazia Altavilla, consultant to the Secretariat, introduced the first Draft Outline of the Guide (BIO/ENF-CP (2021)01), explaining the proposed structure of the Guide, its aim, its target group, the background, the legal context both at national and international level, and the geographical scope.
12. Separate attention was given to the informed consent process implying notions of information, consent, assent and decision-making capacity. The Consultant provided an

overview on principles governing children's participation as a process, challenges in implementing children's participation, as well as contexts raising specific ethical and legal issues.

13. The presentation was followed by an exchange with the members the BIO/ENF-CP group.

V. Discussion on the Outline of the Guide

14. During the discussion on the outline of the Guide, members of the BIO/ENF-ISE made the following proposals:

- to make a clear distinction in the Guide between terms of "consent", "assent" and "authorisation" and their accurate use;
- to consider the individual participation as the starting point of the Guide, as being a substance of the individual process of consent to a medical intervention or treatment (as it is stipulated in the Oviedo Convention);
- to add thematic categories for the examples provided;
- to add a section "Why does child participation matter?" addressed to health workers to explain in a very practical way the benefits of having child-participation;
- to take into account the link between the Decision Making Capacity (DMC) and the best interest of the child;
- to include a specific section on specific groups, notably children with disabilities and special needs;
- to add a section on actions within challenging social and family contexts (e.g. conflicting views of parents or of child and carer, others)
- to consider a possibility to produce, as a follow-up to the work on this Guide, a child-friendly version of the Guide (possibly including video materials);
- to reflect at a later stage of the preparation of the Draft Guide on the most suitable, practical and user-friendly form the Guide should be presented.

VI. Organisation of the work of the Drafting Group

15. The BIO/ENF-CP approved the revised time-line, as presented by the Secretariat. The Timeline is presented in Appendix III of the report.

16. The BIO/ENF-CP entrusted the Secretariat, in collaboration with two of its members (Ms Ritva Halila and Mr Andrew Clarke) to prepare a draft template the purpose of collecting additional examples on children participation among stakeholders to be send to all BIO/ENF-CP members **for possible comments by 7 January 2021.**

17. The BIO/ENF-CP agreed to send **their written comments and suggestions on the draft Outline of the Guide by 20 December 2021.**

18. Members of the drafting group further agreed to send relevant materials to the Secretariat to be shared with the drafting group.

VII. Date of the next meeting

19. The BIO/ENF-CP Drafting Group agreed **to hold its next meeting on 10-11 March 2022.** The format will be adapted according to the current travel restrictions and sanitary situation in general.

20. The BIO/ENF-CP Drafting Group agreed to adopt the report of the meeting in written procedure.

Appendix I
List of participants

Drafting group members / Membres du groupe de rédaction

Finland / Finlande

Prof. Ritva HALILA **Chair**
Chair of DH-BIO
Docent, Senior Medical Officer, Ministry of Social Affairs and Health

Belguim / Belgique

Mr Joost VAN HAELEST **Chair**
Member of the CDENF Bureau
Policy Officer Children's Rights, Department for Culture, Youth and Media
Flemish Government

France

Ms Stefania CHIRU
Policy Officer
European and International Affairs Office
Directorate-General for Social Cohesion
Ministry of Solidarity and Health / Delegate Ministry for Equality f/h

Ireland / Irlande

Ms Siobhan O'SULLIVAN **Apologised**
Professor, Chief Bioethics Officer, Department of Health

Russia / Russie

Ms Leyla NAMAZOVA-BARANOVA
Professor, MD, PhD, Academician of Russian Academy of Sciences

Sweden / Suede

Ms Tesi ASCHAN
Legal Adviser
The National Board of Health and Welfare, Socialstyrelsen

United Kingdom / Royaume Uni

Mr Andrew CLARKE
Independent expert, health advisor, health professional and researcher in acute care, primary care, public health, child rights and protection

Observers / Observateurs

Mexico

Ms Berenice CRUZ MAYA
Director of Institutional Development at the National Bioethics Commission

Consultant / Consultante

Ms Annagrazia Altavilla

SECRETARIAT
Directorate General I – Human Rights and Rule of Law

Bioethics Unit / Unité de bioéthique

Ms Laurence LWOFF, Secretary of the DH-BIO / Secrétaire du DH-BIO, +33 (0) 388 41 22 68, laurence.lwoff@coe.int

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Ms Laura HENNINGER, Secretariat, +33 (0) 388 41 30 05, laura.henninger@coe.int

Children's Rights Division / Division des droits de l'enfant

Ms Katrin UERPMANN, Secretary of the CDENF / Secrétaire du CDENF, +33 (0) 390 21 43 25, katrin.uerpmann@coe.int

Ms Audrey WINUM, Secretariat / Secrétariat, +33 (0) 390 21 46 50, audrey.winum@coe.int

Maren LAMBRECHT, Secretariat / Secrétariat, +33 (0) 390 21 47 78, maren.lambrecht@coe.int

Lanzarote Committee / Comité de Lanzarote

Ana Isabel GUERREIRO, Secretariat / Secrétariat, ana.guerreiro@coe.int

Interpreters / interprètes

Appendix II

Agenda / Ordre du jour

09.30 – 09.50 CET	Opening of the meeting: introduction to the work of the drafting group Ms Ritva Halila , DH-BIO Chair, Chair of BIO/ENF-CP, Mr Joost Van Haelst , CDENF Bureau member, Chair of BIO/ENF-CP Ms. Laurence Lwoff , Head of Bioethics Unit, Secretary of the Committee on Bioethics (DH-BIO) of the Council of Europe Ms Katrin Uerpmann , Secretary of the Steering Committee for the Rights of the Child (CDENF)
09.50 – 10.20	Tour de table: self – presentation by members of the drafting group
10.20 – 10.30	Introduction by the Secretariat
10.30 – 11.00	Presentation of the first draft outline of the Guide to good practice concerning the participation of children in the decision-making process on matters regarding their health Ms Annagrazia Altavilla , consultant to the Secretariat
11.00 – 12.00	Discussion on the Outline of the Guide Working Document: BIO-ENF/CP (2021)01 Draft Outline of the Guide on children participation in the decision-making process on matters regarding their health Reference Document DH-BIO (2021) 17 Summary of the results of the survey on children participation
12.00 – 13.30	Lunch break
13.30 – 15.30	Organisation of the work of the Drafting Group <ul style="list-style-type: none">• Methodology/Distribution of tasks• Timeline• Consultation process (children consultation process, other stakeholders) Reference document DH-BIO (2021)11 REV Concept note_Drafting Group_Guide _E
15.30 – 16.00	Concluding remarks: <ul style="list-style-type: none">• Main conclusions of the first meeting of the drafting group• Next steps to be taken• Date of the second meeting of the drafting group proposed dates: 02 March 2022 03 March 2022

04 March 2022
11 March 2022

Appendix III
Timeline

BIO/ENF -CP
CDBIO CDENF
Consultation
Consultant / Secretariat

Milestone		Content	Date
First meeting of BIO/ENF-CP		Exchange on the draft outline, agreement on the methodology, timeline and organisation of the work	29 November 2021
<i>Consultant/Secretariat prepare a first draft guide</i>		Based on guidance received from BIO/ENF-CP	21 February 2022
Second meeting of BIO/ENF-CP (1 [1.5] days)		Examination of the draft guide, identification of examples, agreement on the modalities for child- and stakeholder consultation	[10 (afternoon)]-11 March 2022 Strasbourg, online or hybrid (depending on the sanitary situation)
<i>Consultant/Secretariat revise the first draft</i>		Revision in the light of the discussion at the 2 nd meeting of the BIO/ENF CP	End of March 2022
Written comments requested from CDBIO and CDENF Delegations on the first draft and on concept notes of the consultation processes (children and stakeholders)			April 2022
<i>Consultant/Secretariat revise the draft</i>		Revision in the light of comments received from CDBIO and CDENF	May 2022
5 th Plenary meeting of the CDENF (online)		Update on the state of play of the work	18 -19 May 2022
1 st Plenary meeting of the CDBIO		Update on the state of play of the work	31 May - 3 June 2022
Consultation	Child	Consultation of a representative group of 8-12 children	June/mid - August 2022
	Stakeholder	Written consultation of selected stakeholder representatives	

<i>Consultant/Secretariat revises and complements the draft Guide</i>	Revision based on <ul style="list-style-type: none"> - guidance from CDBIO and CDENF - examples received - outcome of the child and stakeholder consultation 	August 2022
3rd meeting of BIO/ENF-CP (2 days)	Examination and agreement on the revised draft	End of September 2022 (TBC)
2nd plenary meeting of the CDBIO	Examination of the draft Guide in view of its finalisation	7 – 10 November 2022 tbc;
6th plenary meeting of the CDENF	Examination of the draft Guide in view of its finalisation	16-18 November 2022
<i>Consultant/Secretariat revise the draft</i>	Final revision in light of last comments received from CDBIO and CDENF	December 2022/January 2023
Joint Bureau meeting CDBIO/CDENF	Examination of the draft in view of its presentation to the parent Committees	February 2023 (TBC)
Examination of the final version of the draft Guide by CDBIO and CDENF plenaries with a view to its adoption.		Spring 2023