

COUNCIL OF EUROPE



CONSEIL DE L'EUROPE

Strasbourg, 10 May 2022

BIO/ENF-CP RAP (2022) 2

**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**

**Second meeting, 10-11 March 2022**  
*Videoconference*

**DRAFT MEETING REPORT**

## **I. Opening**

1. Mr Joost Van Haelst (CDENF, Belgium) and Ms Ritva Halila (CD-BIO, Finland), co-Chairs of the BIO/ENF-CP Drafting Group, opened the meeting thanking members of the group for their interest and participation, and specifying that this session would be chaired by Mr Van Haelst, as previously agreed. The Chair reminded the Drafting Group about the objectives of the meeting, notably to produce a preliminary draft guide for presentation to both parent committees at their upcoming meetings.
2. Ms Laurence Lwoff, Head of the Human Rights and Biomedicine Division, informed about the implications for the drafting group of the Committee of Minister's decision of 25 February 2022 to suspend the Russian Federation from its rights of representation in the Committee of Ministers.

## **II. Adoption of the Agenda**

3. The drafting group adopted the agenda for this meeting as it appears in Appendix II to this report, thereby agreeing to discuss point 3 (State of play of activities), in the context of point 5.2 (Exchange on next steps towards finalisation of the guide).

## **III. State of play of BIO/ENF-CP activities**

4. See below under 5.2.

## **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**

5. The Secretariat presented the preliminary draft Guide (BIO-ENF/CP (2022)1(confidential)), as prepared on the basis of a background paper provided by the consultant. The background paper would be shared with the group following last editorial revisions shortly after the meeting.
6. The members of the Drafting Group expressed their general satisfaction with the Draft, which they considered to be well-structured and a good starting point, and emphasised the importance of producing a guide which is tailored to the target audience, implying that it has to be easy to read, practical, meaningful and accessible.
7. The drafting group exchanged on the target group of the guide which would primarily be health professionals. The guide should also be accessible to other stakeholders, such as parents and other legal representatives and public health policy makers. The [Guide on the decision-making process regarding medical treatment in end-of-life situations](#) could serve as inspiration in this respect.

## **V. Discussion**

### **1. Continued revision of the draft Guide**

8. Regarding the scope of the Guide, the group agreed that the guide should acknowledge the collective level of child participation, but focus primarily on the individual decision-making process. Collective initiatives could notably be included as a way of improving the quality of conditions under which decisions are taken.
9. The group further agreed to limit the scope of the guide to "children" within the meaning of the UNCRC (under 18 years). The question was raised whether the scope should also encompass children having legal capacity to consent to medical interventions

under national law, while Art. 6 (2) of the Oviedo Convention, which formed the starting point for this guide, only applied “where, according to law, a minor does not have the capacity to consent to an intervention”. While acknowledging that the case of children having legal capacity did not strictly fall under the notion of “child participation”, some group members pointed out that the right to receive information, as enshrined in the UNCRC, applied regardless of capacity to consent, and the group agreed on the importance of appropriate and child-friendly information in both settings.

10. The group emphasised the importance of addressing common barriers faced by children when participating in decisions relating to their health, such as: socio-cultural differences, misinformation, lack of awareness of health care professionals, possible conflict of interests with or between parents or other carers, and barriers faced by specific groups of children, such as children with disabilities, and children belonging to marginalised and minority groups.
11. The drafting group continued the revision of the text, paying particular attention to clearly differentiate between the different elements of informed consent (information, consent, assent, dissent and decision-making capacity).
12. With regard to the examples from member States, it was agreed that, in case of doubt, these should be checked with national Delegations prior to inclusion in the text.
13. It was agreed to develop a visual part (a diagram or a picture, possibly inspired by Hart’s ladder of participation) showing different levels and stages of child participation. It was also proposed to use more graphics in the Guide in order to illustrate better the main concepts.

## 2. Exchange on next steps towards finalisation of the guide

14. The Secretariat introduced the new proposed timeline for the development of the Guide as it appears in Appendix III to this report, to allow for sufficient time for a meaningful children and stakeholder consultation process. The members of the Drafting Group agreed with this approach.
15. The BIO/ENF-CP agreed to send **their written comments and suggestions on the draft Guide by 18 March 2022** with a view to allow enough time for the Consultant to prepare the revised version by 7 April 2022.

## VI. Other tasks of the Drafting Group

16. General modalities of organisation of the children and stakeholder consultation process were discussed. It will be held in October-November 2022. The Secretariat is to prepare a concept note on its organisation and to present it to the Drafting Group for comments.
17. The Secretariat updated on the progress achieved with regard to collection of examples of practices of decision-making process, noting that only three examples were received. It was agreed to make another call for examples through target dissemination of the form by members of the Drafting Group.

## VII. Any other business

18. The Secretariat informed about a video clip produced by the TEDDY network with support of the CDBIO Secretariat on general concepts of informed consent of children and their right to receive information about their health. The clip will be finalised in April and will be presented to the Spring Plenaries of both Committees.

### VIII. Closing the meeting

19. The BIO/ENF-CP Drafting Group agreed **to hold its next meeting on 22-23 September 2022**. The format would be adapted according to the current travel restrictions and the general sanitary situation.

Appendix I  
List of participants

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**Drafting group members / Membres du groupe de rédaction**

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**Finland / Finlande**

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

**Belgium / Belgique**

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

**France**

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

**Sweden / Suede**

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

**Independent Expert/Expert indépendant**

Mr Andrew CLARKE  
Senior Health Advisor for Save the Children UK, United Kingdom

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**Observers / Observateurs**

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**Mexico**

Mr Gustavo Fernando OLAIZ BARRAGAN, Deputy Director of Public Policy and Bioethics at the National Bioethics Commission

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**Consultant / Consultante**

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Ms Annagrazia Altavilla, Chair of TEDDY, European Network of Excellence for Paediatric Research

**SECRETARIAT**  
**Directorate General I – Human Rights and Rule of Law**

**Human Rights and Biomedicine Division / Division Droits de l'Homme et Biomédecine**

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## Appendix II

### Agenda / Ordre du jour

Thursday, 10 March 2022 - 14:00 - 17:00 hrs

#### 1. Opening of the meeting

1. Opening by the Chairpersons

[BIO\\_ENF-CP\(2022\)OJ2](#)

#### 2. Adoption of the agenda and order of business

[BIO-ENF\\_CP RAP\(2021\)1](#)

Report of the first meeting of the drafting Group

#### State of play of BIO/ENF-CP activities

3. - Information by the Secretariat  
- Exchange on the timeline

BIO-ENF/CP (2021) 2 REV 2  
(confidential)

Timeline for the upcoming work of the BIO/ENF-CP

#### 4. Presentation of the preliminary draft Guide to good practice concerning the participation of children in the decision-making process on matters regarding their health.

4.1

Presentation by the Secretariat  
Further revision of the draft

Working documents:  
BIO-ENF/CP (2022)1(confidential)  
Draft Guide to good practice concerning the participation of children in the decision-making process on matters regarding their health

Reference documents:  
[DH-BIO \(2021\) 17](#)  
(confidential)  
Preliminary summary of the survey results on children participation

[BIO/ENF/CP \(2022\)2](#)  
Compilation of Relevant Standards and examples of Guides for professionals

Friday, 11 March 2022 – 9:30 – 16:00 hrs

#### 5. Discussion

- 5.1 Continued revision of the draft Guide
- 5.2 Exchange on next steps towards finalisation of the guide

Working documents:

See above

#### 6. Other tasks of the working group

Oral update by the Secretariat

[BIO-ENF/CP \(2021\) 3 REV 2](#)

<p><b>6.1</b> Child participation</p> <p><b>6.2</b> Stakeholder consultation</p> <p><b>6.3</b> Collection of Examples</p>	<p>Template for collection of examples for good practices          BIO-ENF/CP (2022)3          Compilation of examples of practices (confidential)</p>
<p><b>7. Any other business</b></p>	
<p><b>Closing the meeting</b></p>	
<p><b>8.1</b> Main conclusions</p> <p><b>8.2</b> Next steps to take</p> <p><b>8.3</b> Date of the third meeting of the drafting group</p>	<p><u>3<sup>rd</sup> meeting suggested for:</u>          September 2022 (date to be determined)</p>



Appendix III

Timeline

BIO/ENF -CP
CDBIO CDENF
Consultation
Consultant / Secretariat

<b>Milestone</b>	<b>Content</b>	<b>Date</b>
<b>First meeting of BIO/ENF-CP</b>	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	February 2022
<b>Second meeting of BIO/ENF-CP (1 [1.5] days)</b>	Examination of the draft guide, identification of examples, agreement on the modalities for child- and stakeholder consultation	[10 (afternoon)]-11 March 2022 Strasbourg, online
<i>Consultant/Secretariat revise the first draft</i>	Revision in the light of the discussion at the 2 <sup>nd</sup> meeting of the BIO/ENF CP	06 April 2022
<b>BIO/ENF-CP</b>	Comments by the Drafting Group before sending the draft to the Committees	20 April 2022
<b>5<sup>th</sup> Plenary meeting of the CDENF (online)</b>	Update on the state of play of the work	18 -19 May 2022
<b>1<sup>st</sup> Plenary meeting of the CDBIO</b>	Update on the state of play of the work	31 May - 3 June 2022
Written comments requested from CDBIO and CDENF Delegations on the first draft and on concept notes of the consultation processes (children and stakeholders)		20 June 2022
<i>Consultant/Secretariat revises and complements the draft Guide</i>	Revision based on <ul style="list-style-type: none"> <li>- guidance from CDBIO and CDENF</li> <li>- examples received</li> </ul>	End of August 2022

	- outcome of the child and stakeholder consultation	
<b>3<sup>rd</sup> meeting of BIO/ENF-CP (2 days)</b>	Examination and agreement on the revised draft	September 2022 (TBC)
<i>Consultant/Secretariat revise the draft</i>	Revision in the light of comments received from BIO/ENF-CP	01 October 2022
<b>Stakeholders Consultation Process</b>	Written consultation of selected stakeholder representatives	October - November 2022
<b>Children Consultation Process</b>	Consultation of a representative group of children	October - November 2022
2 <sup>nd</sup> plenary meeting of the <b>CDBIO</b>	Update on the draft Guide by the Secretariat	2-4 November 2022
6 <sup>th</sup> plenary meeting of the <b>CDENF</b>	Update on the draft Guide by the Secretariat	16-18 November 2022
<i>Consultant/Secretariat revise the draft</i>	Final revision in light of last comments received from the consultation with stakeholders, CDBIO and CDENF	20 December 2022
Joint <b>Bureau meeting CDBIO/CDENF</b>	Examination of the draft in view of its presentation to the parent Committees	February 2023 (TBC)
3 <sup>d</sup> plenary meeting of the <b>CDBIO</b> 7 <sup>th</sup> plenary meeting of the <b>CDENF</b>	Examination of the final version of the draft Guide by <b>CDBIO</b> and <b>CDENF</b> plenaries with a view to its adoption.	Spring 2023
4 <sup>th</sup> plenary meeting of the <b>CDBIO</b> 8 <sup>th</sup> plenary meeting of the <b>CDENF</b>	Final examination and adoption of the Guide by <b>CDBIO</b> and <b>CDENF</b> plenaries	Autumn 2023