

COUNCIL OF EUROPE



CONSEIL DE L'EUROPE

Strasbourg, 13 October 2022

BIO/ENF-CP RAP(2022)3

**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**

3rd meeting (22-23 September 2022, Paris)

MEETING REPORT

I. Opening

1. Ms Ritva Halila (CD-BIO, Finland) and Mr Joost Van Haelst (CDENF, Belgium), 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 Ms Ritva Halila, as previously agreed. The Chair reminded the Drafting Group about the objectives of the meeting, namely 1) to discuss the draft guide, which the consultant had revised in the light of the comments and examples received by the CD-BIO and CDENF delegations, and 2) plan the stakeholders' and children's consultations.

II. Adoption of the Agenda

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

III. Discussion on the revised draft of the Guide to good practice concerning the participation of children in the decision-making process on matters regarding their health

3. The consultant presented the revised version of the draft Guide (BIO-INF/CP (2022) 1REV) and put forward a number of pending questions. The members of the drafting group commented on the text and proposals as the presentation progressed.
4. Regarding terminology, it was decided that "children" was the preferable term. "Minor" will therefore only appear when quoted in specific legislation. The glossary at the end of the document will be kept but with slight amendments.
5. Regarding the visual aspect of the draft, it was noted that the colour code used in the document (yellow for examples, red for special focus) was temporary and the final version should be easily readable when printed in black and white. As previously agreed, a diagram (Hart's ladder of participation) illustrating the different levels and stages of child participation will be included.
6. With regard to the relevance of examples, it was recalled that the group had previously agreed that the scope of the Guide focuses on individual decision-making processes. Selected examples should therefore reflect this. Examples of relevant collective initiatives can remain/be included in the text, in so far as these contribute to improving the conditions of individual decision-making. When the link between collective and individual levels is not self-evident, it should be more clearly explained in the presentation of examples.
7. Members of the drafting group reflected on a comment from a delegation which questioned the relevance and/or applicability of the guide's principles/guidelines in times of emergency. The members of the Group agreed that the Guide needs to clearly affirm the necessity to apply child participation principles in times of emergencies, to the extent feasible.
8. The members acknowledged the need for a conclusion to the Guide but decided that it would be drafted after the consultation process.
9. It was recalled that when the draft is finalized, some sections will be highlighted to "stand out", especially for the web version of the Guide. Until then, the "Remember"

sections will be removed or placed elsewhere in the text (when the information is not, in fact, a repetition).

10. A reference will be included regarding the additional challenges posed by emerging technologies, but these will not be developed in detail in the text.
11. The annexe to the Guide will be removed, on the basis that the focus is placed on practice, not legislation. Some of the elements present in the current annexes could be made available as additional information via the webpage.
12. Some limited editorial work will be carried out before the consultation process (English language check and inclusion of hyperlinks) but should not delay the launch.

IV. Consultation process

13. The draft Guide will be submitted to relevant stakeholders and to children (children's groups), to gather additional suggestions to improve the Guide.
14. Both consultations will take place between 10 October and 18 November 2022.
15. The consultation of stakeholders will be launched on 10 October.
16. Feedback will be collected via an online questionnaire (7 questions, including: does the guide reach its objective(s)? Is the language appropriate? Anything to add or delete? Appropriate diversity of examples? Further examples to provide? Any other comment?)
17. The Secretariat will send out the draft Guide to a list of identified stakeholders. To this end, the drafting group agreed on the content of an introductory letter.
18. Delegations will be invited to disseminate the draft guide to relevant national stakeholders (a list of possible national stakeholders to consult will be provided to them).
19. In parallel, the draft Guide will be submitted to children's groups. The objective is to gather their opinion regarding the relevance of the topics dealt with in the Guide. Given the time constraints, the consultation will target children who are already part of existing advisory bodies. To this end, the consultant will disseminate the draft Guide within the TEDDY network, while other members of the drafting group may share with other groups whom they know well. The methodology used for this specific consultation was discussed, including the tools which will be required (existing video, leaflet and short questionnaire to be developed). It was agreed that the consultant will take the lead in this process.

V. Closing the meeting – Next steps

20. The BIO/ENF-CP Drafting Group agreed to hold a meeting shortly after the end of the consultation meeting, **on 7 December 2022 (online)** and then on **26-27 January 2023 (online)** to work on a revised version of the draft Guide.
21. The updated timeline for the development of the Guide appears in Appendix III.

Appendix I
List of participants

Drafting group members

Finland

Ritva HALILA, MD, Ph.D,
Chair of CDBIO
Senior Medical Officer, Ministry of Social Affairs and Health

Chair

Belgium

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

Chair

France

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

Apologised

Sweden

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

Apologised

Independent Expert

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

Consultant

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

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Directorate General II – Directorate General of Democracy

Children's Rights Division

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Appendix II

	THURSDAY 22 SEPTEMBER 2022
09.30 – 09.50 CET	Opening of the meeting 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 Ana Guerreiro , Administrator, Children Rights Division
09.50 – 10.00	Adoption of the agenda BIO-ENF/CP (2022)OJ2
10.00 – 10.20	Presentation of the draft Guide to good practice concerning the participation of children in the decision-making process on matters regarding their health, revised in the light of the comments received from delegations in CDBIO and CDENF Ms Annagrazia Altavilla , consultant to the Secretariat
10.40 – 12.00	Discussion on the revised Guide <ul style="list-style-type: none">- Revised draft- Examples included
12.00 – 13.30	Lunch break
13.30 – 15.00	Discussion on the revised Guide (to continue where necessary) <ul style="list-style-type: none">- Revised draft- Examples included
15.20 – 17.00	Organisation of the consultations Doc. BIO-ENF/CP (2022)2 Rev4 Stakeholders consultation <ul style="list-style-type: none">• Selected stakeholders• Consultation process• Timeline

FRIDAY 23 SEPTEMBER 2022

09.30 – 12.30 CET

Organisation of the consultations (to continue)

Doc. BIO-ENF/CP (2022)2 Rev4

Stakeholders' consultation

- Selected stakeholders
- Consultation process
- Timeline

Children's consultation

- Consultation process
- Timeline

12.30 – 13.00

Concluding remarks:

- Main conclusions of the meeting of the drafting group
- Next steps to be taken
- Date of the fourth meeting of the drafting group

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	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
<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	06 April 2022
BIO/ENF-CP	Comments by the Drafting Group before sending the draft to the Committees	20 April 2022
5th Plenary meeting of the CDENF (online)	Update on the state of play of the work	18 -19 May 2022
1st Plenary meeting of the CDBIO	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"> - guidance from CDBIO and CDENF - examples received 	End of August 2022

3rd meeting of BIO/ENF-CP (2 days)	Examination and agreement on the revised draft	22-23 September 2022
<i>Consultant/Secretariat revise the draft</i>	Revision in the light of comments received from BIO/ENF-CP	01 October 2022
Stakeholders Consultation Process	Written consultation of selected stakeholder representatives	10 October – 18 November 2022
Children Consultation Process	Consultation of a representative group of children	10 October – 18 November 2022
2 nd plenary meeting of the CDBIO	Update on the draft Guide	2-4 November 2022
6 th plenary meeting of the CDENF	Update on the draft Guide	15-17 November 2022
4th meeting of BIO/ENF-CP (0.5 day)	Preliminary discussion on the outcomes of the consultation process. Organisation of the revision process	7 December 2022
<i>Consultant/Secretariat revise the draft</i>	Revision of the draft, in light of the comments received from the consultation with stakeholders/children	End of December 2022
5th meeting of BIO/ENF-CP (1.5 days)	Examination of, and agreement on the revised draft	26-27 January 2023
Joint Bureau meeting CDBIO/CDENF	Examination of the draft in view of its presentation to the parent Committees	February 2023 (TBC)
3 ^d plenary meeting of the CDBIO 7 th plenary meeting of the CDENF	Examination of the final version of the draft Guide by CDBIO and CDENF plenaries with a view to its adoption.	CDENF: 28 – 30 March 2023 CD-BIO: 4-6 June 2023
4 th plenary meeting of the CDBIO 8 th plenary meeting of the CDENF	Final examination and adoption of the Guide by CDBIO and CDENF plenaries	Autumn 2023