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CONSEIL DE L'EUROPE

Strasbourg, 17 November 2023

CDBIO / RAP 4

**STEERING COMMITTEE FOR HUMAN RIGHTS
IN THE FIELDS OF BIOMEDICINE AND HEALTH (CDBIO)**

4th meeting

14-17 November 2023

Riga, Latvia

Report

Conference “Promoting autonomy in mental healthcare” [Conference - Promoting autonomy in mental healthcare - Human Rights and Biomedicine \(coe.int\)](https://www.coe.int/t/e/human_rights/mental_healthcare/Pages/Conference_Promoting_Autonomy_in_Mental_Healthcare.aspx)

1. Delegations were invited to exchange on the Conference on “Promoting autonomy in mental healthcare” held on 14 November 2023, and organised in cooperation with the Ombudsman of the republic of Latvia and the University of Latvia, in the framework of the Latvian Presidency of the Committee of Ministers of the Council of Europe.
2. Delegations praised the opportunity to share experience in other countries through concrete examples, and the new synergies that could be created on that basis.
3. One observer noted the progress made over the years in the work of the CDBIO and appreciated the willingness for change in mental healthcare.
4. The importance of multidisciplinary team and the need for partnership showed by the examples were pointed out. The importance of the voice of patients and the need for a real partnership with people seeking care as expert for themselves were underlined. The need for resources and support for persons with lived experience was underlined by one observer.
5. It was noted that those examples illustrated the cultural shift needed to go from hospital to diversified modalities of care. The need for capacity building of professionals was also underlined.
6. One delegation stressed the interest also to look at cost efficiency to support the changes. Research already carried out proved that, contrary to what was often believed, these practices promoting autonomy actually saved money by enabling a person to go back to work for example.
7. The CDBIO thanked the Office of the Ombudsman of the Republic of Latvia and the University of Latvia for the excellent organisation, their support and the way they welcome the Committee.

I. Adoption of the agenda

8. Siobhan O’Sullivan (Ireland), CDBIO Chair, opened the meeting and welcomed the new members of the Committee. The list of participants appears in Appendix I to this report.
9. The agenda was adopted. It appears in Appendix II to this report.

II. Draft Recommendation on respect for autonomy in mental healthcare

10. The CDBIO examined the draft Recommendation on respect for autonomy in mental healthcare revised in the light of comments received from delegations.
11. In respect of Article 2, one delegation suggested that the future explanatory memorandum (EM) specify that “mental healthcare” also includes care provided by related social services.
12. In respect of Article 3, sub-section 2, one delegation suggested that it would be useful to explicitly specify that “legal safeguards” (which may change over time) should respect human dignity. It was agreed that the phrase “respecting human dignity” be added at the end of the provision.
13. In respect of Article 6, one observer suggested that the wording “persons with lived experience of mental health care should be involved” should be changed to “persons with lived experience should be involved via their representative organizations”, in order to be more compliant with the wording of the CRPD (general comment 7). A discussion ensued and delegations underlined the risk of having individuals speak on behalf of others, and the need for a structured and

organized approach to consulting persons with disabilities on general. It was also acknowledged that in a number of Member States, such organizations did not exist. An agreement was reached regarding the phrase “Persons with lived experience, individually or via representative organizations” and it was agreed that the EM will elaborate on the need to encourage the development of organizations in countries where these did not exist and to refer to regional European organizations.

14. One participant expressed concern over the possible confusion, in Article 8, between “advance care planning” and “advance directives” that could encompass end-of-life issues and suggested to reformulate using language similar to that of article 9 of the Oviedo Convention. In the discussion that ensued, the Committee agreed that in this recommendation and provision, “advance care planning” referred to a person’s treatment plan or care relevant to the mental health issue at hand and not to other situations (such as end of life situations). It also enabled to clarify that the scope of the provision extended to circumstances of future crisis without being limited to such circumstances. A consensus was found with the wording: “Persons receiving mental healthcare should be encouraged to express their preferences and wishes for their future care” and it was agreed that a reference to crisis situations would be made in the EM.
15. In respect of Article 9, one observer expressed the view that its object (improving the environment of mental healthcare facilities) may divert from the need to prioritize community-based care; in other words, it should not be assumed that adapting existing facilities would be sufficient. It was agreed that the EM will elaborate on the fact that the provision did not only apply to institutions and that, generally, a move towards community-based care was needed. One delegation further suggested that the environment should respect the privacy of persons and it was agreed that the EM will also include a reference in that regard.
16. In respect of Article 10, several delegations suggested that the footnote also refer to “other (important) healthcare services and other assisted decision-making services”.
17. In respect of Article 11, one observer expressed the view that the wording could be changed to reflect the fact that family members (of a person receiving mental health care) may never be consulted without the agreement of the person concerned. It was agreed that this will be mentioned in the EM, while recognizing that different rules may apply in the case of children receiving care.
18. In respect of Article 12, one delegation suggested to specify that responses to complaints should be “appropriate and timely”. Moreover, it was suggested and agreed that the EM will elaborate on the fact that persons wishing to lodge a complaint should be supported (in various manners), in order for the complaints mechanism to be “effective”.
19. In respect of Article 13, it was suggested and agreed that a reference to “recovery” be added to the actual text and that the EM will expand on this notion.
20. In respect of Article 14, one delegation suggested to add, at the end of the sentence: “and to promote their acceptance in society”. It was also suggested and agreed to change the title of the article to “Addressing stigma and discrimination”, based on the agreement that the provision needed to cover the need to prevent any future stigma and discrimination and combat existing stigma and discrimination.
21. In respect of Article 15, it was suggested and agreed to replace “sufficient training” (which could be interpreted as “minimal”) with “appropriate training”. The EM will expand on the nature of the training.
22. In respect of Article 16, it was suggested and agreed to replace “increase” with “promote” and “promoted” with “encouraged”.

23. In respect of Article 18, one delegation suggested to specify in that monitoring needed to be “regular”. In the discussion that entailed, other delegations expressed the view that regularity was implied in the term “monitoring”. It was agreed not to amend the text of the provision but that the EM would underline the fact that monitoring was to be understood as an ongoing process. Further, it was suggested and agreed to replace “standards” with “principles set out in this recommendation”.
24. In respect of Article 19, one delegation asked the Committee whether the text could usefully be developed by adding a reference to “record keeping”. The discussion that entailed pointed to the difficulty for the recommendation to set out or to list which information would need to be recorded. It was agreed that “local reviews” could include audits, and that this could be mentioned in the EM.
25. In respect of Article 20, it was suggested and agreed to replace “increase” with “promote” (as in Article 16).
26. The CDBIO agreed to submit the draft, as a working document, for a targeted consultation (from 4 December 2023 to 16 February 2024) with a view to finalising and approving the draft Recommendation by the end of 2024. The text will be submitted to a list of relevant stakeholders, including all respondents of previous CDBIO consultations on the subject of mental health as well as all speakers of the conference held on 14 November. It was decided that the current footnotes will be kept in the submitted draft, as a preview of the content of the future EM.

III. Artificial intelligence and biomedicine

27. Joni Komulainen, Chair of the Drafting Group on AI, presented the report on the impact of AI on the ‘patient-doctor’ relationship, revised in the light of comments from CDBIO delegations, and from participants to the pilot youth forum on AI in healthcare, held on 6 June 2023.
28. CDBIO delegations welcomed the revised draft, underlining its quality, utility and well-structured approach to issues raised by AI. The potential for AI to transform and/or otherwise support health systems was highlighted, suggesting the need to accentuate the opportunities and tone of the report.
29. Certain delegations sought clarity on wording, others asserted that issues of bias and liability (responsibility and ethics therein) of AI systems could be further developed. The Chair underlined the need to further explore the therapeutic relationship in seeing how it will and/or should evolve – in other words, what future AI-enabled ‘patient-doctor’ relationship could be envisaged and how do we ensure that it is one which safeguards the human dignity and fundamental rights and freedoms of the individual.
30. There was an exchange of views on the need for a targeted consultation on the report, to efficiently integrate the views of different stakeholders, including those of patients’ and healthcare professionals. This resulted in the agreement of the CDBIO to organise a targeted consultation on the report (from approx. 1 December 2023 to 31 January 2024) - targeting patients’ associations and bodies of healthcare professionals – and to entrust the Drafting Group with the task of revising it in the light of the comments to be received thereafter so that it may be finalised and adopted at its next plenary, in June 2024.

IV. Overview of legislation and practices on patients' rights

31. The Chair reminded delegations about the request from the Committee of Ministers for an overview of the national legislation on the protection and promotion of patient's rights.
32. Dr Rumi Yotova (UK) presented the early findings of her analysis of the replies to the questionnaire addressed to delegations with a view to get this overview (her PowerPoint presentation appears in Appendix III to this report). She pointed out four areas where great diversity can be noted among member states: regulation on genetics, on reproductive health, mental healthcare and biomedical research. She also indicated that only 5 member states (among the 18 that replied) have specific legislation to address access to healthcare for marginalised groups. Furthermore, only two member states indicated requiring patients' rights training for healthcare professionals. She also pointed out the absence of regulation on public consultation in 9 member states.
33. In reply to a question on public health aspects and prevention in relation to patients' rights, Dr Yotova specified that the replies did not make it possible to identify these aspects; the same was true for the rights of future generations.
34. The delegations thanked Dr Yotova for the work carried out so far. It acknowledged its relevance also in the context of the horizon scanning exercise.
35. The CDBIO agreed to publish the replies to the questionnaire on patients' rights centred health care systems, and to publish the analysis of the replies carried out by Rumiana Yotova (UK), as a separate document, once finalised.

V. Equitable access to appropriate innovative treatments and technologies in healthcare

36. The Chair recalled that at its 3rd plenary meeting, the CDBIO agreed not to prepare a new draft Recommendation to ensure equitable access to innovative treatments and technologies but to entrust a Drafting Group with drafting a discussion paper on the issue. The Discussion paper should examine how the general and procedural principles of Recommendation CM/Rec(2023)1 also apply to the decision-making processes of innovative treatments and technologies.
37. The Chair invited Tomáš Doležal, Chair of the Drafting Group, to present the preliminary draft discussion paper, the methodology adopted, the outcomes, and the conclusions. Then, the Chair invited delegations to express their view on how to go further with the process, the form of the written instrument to be developed, and the substantial additional elements that could be addressed.
38. Delegations welcomed the draft discussion paper, the analysis carried out, and the summary of the work done by other international organizations. Delegations agreed on entrusting the Drafting group to continue the work by elaborating a white paper including further information, analysis, and examples.
39. Delegations agreed that the scope of the work should be extended beyond innovative treatments and technologies intended for severe or life-threatening health patient conditions; the scope should consider a broader range of patients' health conditions as long as the safety and efficacy of the innovative treatments and technologies concerned are supported by scientific evidence.
40. The European Court of Human Rights jurisprudence should be considered, particularly for cases regarding experimental treatment cases. The white paper could include considerations of the possible tensions created by innovative treatments and technologies between individual rights and public health needs and the long-term perspective of decision-makers choices. The draft white paper will be presented to the 5th CDBIO plenary meeting.

VI. Guide on children participation in decision making process on matters relevant to their health

41. Ritva Halila, Co-Chair of the Drafting Group of the Guide introduced the final version of the Guide. The Secretariat indicated that the text had been amended in light of the comments received from CDENF and CDBIO delegations, most of which had concerned references to national legislations. The text had also been enriched thanks to additional examples provided.
42. Two delegations indicated some difficulties regarding the content of General comment 12 (2009) of the UNCRC regarding the right of the child to be heard, that is quoted in the Guide, and referring specifically to the following paragraph: “*States parties need to introduce legislation or regulations to ensure that children have access to confidential medical counselling and advice without parental consent, irrespective of the child’s age, where this is needed for the child’s safety or well-being. Children may need such access, for example, where they are experiencing violence or abuse at home, or in need of reproductive health education or services, or in case of conflicts between parents and the child over access to health services. The right to counselling and advice is distinct from the right to give medical consent and should not be subject to any age limit*”. Another delegation indicated a similar issue with age limits for children to decide without parental authorisation.
43. However, none of these delegations have any other difficulty with the content of the Guide. Two of these delegations made statements in that respect which appear in Appendix IV to this report.
44. The CDBIO adopted, by unanimity of the votes cast, with three abstentions, the Guide on child participation in decisions about their health, jointly developed with the CDENF, and agreed to present it to the Committee of Ministers for it to take note.
45. The CDBIO welcomed the online version of the Guide on child participation in decisions about their health and exchanged on the possible follow-up to be given to the Guide; notably through the translation of the guide into non-official languages, other dissemination activities and possible development of related child-friendly materials.

VII. Preparation of a new strategic action plan (SAP II)

46. The CDBIO Chair reminded about the decision of the Committee at its last plenary meeting, to develop a new strategic action plan by the end of 2025 and to organise a horizon scanning exercise to that end in 2024. A drafting group was set up to propose a methodology for this exercise.
47. The Drafting Group prepared a questionnaire intended to delegations, national ethics committee and national human rights institutions. In agreement with Bureau, this questionnaire was already sent for replies by 31 January 2024 so as to benefit from the replies to prepare the horizon scanning event foreseen on 3 April 2024 in Paris.
48. Delegations underlined the importance of benefiting from youth perspectives for the horizon scanning exercise. The Secretariat suggestion to reach out to CoE relevant youth committee(s) as well as, where possible, relevant bodies set up by other intergovernmental organisations such as YouthWise at the OECD, was supported.
49. The need to also to increase link with the EU was also pointed out by one delegation. The UN Interagency Committee on Bioethics could also provide a good opportunity for an exchange of information.
50. The Chair presented the proposal from the Group for the horizon scanning event to which high calibre speakers would be invited, targeting namely academics and thought leaders. The meeting

will take place back to back with the Bureau meeting, extend to the members of the Drafting Group for the horizon scanning. She invited delegations to identify particular topics that they consider particularly relevant so as to be able to identify relevant speakers. These topics could be linked to technological developments, evolution of practices or societal attitude.

51. The following topics were mentioned by delegations:

- Impact of climate change on health
- Shortage of healthcare professionals
- Discrimination with regard to LGBTI+
- Representation of minorities in clinical trials
- Embedding bioethical consideration in future policy
- Children born out of gametes donation
- Mistrust in science
- Euthanasia and assisted suicide
- Social determinant of health to be included in the care
- Genomics and child autonomy
- AI and informed consent process
- Robotics and older persons
- All perceptions of age in the society
- Synthetic embryo

52. The CDBIO agreed with the proposal made by the drafting group in charge for the organisation of the horizon scanning exercise with a view to developing a new strategic action plan (2026 - 2029).

53. **Delegations were invited to reply to the questionnaire designed to this end by 31 January 2024 and to send names of possible high level speakers for the horizon scanning event to be held on 3 April 2024, in Paris.**

VIII. Bureau elections

54. The terms of the Chair and Vice-Chair, elected in November 2022 were coming to an end. Furthermore, the terms of Mark Bale (UK) in the Bureau were also ending and he was not re-eligible.

55. The CDBIO, by acclamation:

- re-elected Siobhan O'Sullivan (Ireland), as its Chair, for a new one-year term, not renewable
- re-elected Tomas Dolezal (Czech Republic), as its Vice-Chair, for a new one-year term, not renewable;
- elected Sanne Van Weezel (The Netherlands), in the Bureau for a two-years term, renewable once.

IX. Other business

a. Youth Forum

56. The rapporteur of the pilot youth forum, Tesi Aschan, presented her report which summarised key learnings from the event, exploring its strengths and opportunities as well as its unique features (e.g. shared culture and language of the youth participants).

57. There was an exchange of views on how to organise a larger-scale diverse youth forum, in 2025. Discussion ensued on the practicalities and achievability of such a forum (noting the need to establish clear objective(s), decide of the scale of event, secure the financing of the forum(s), and determine how best to designate youth representatives).

58. On the proposal of the Chair, the CDBIO agreed to set-up a drafting group to examine the feasibility of a larger-scale youth forum in 2025, with a view to reporting back on the group's findings at its next plenary in June 2024.

b. Launch of the Guide to health literacy

59. The CDBIO welcomed the programme for the Conference "Health literacy and human rights – trust building and equitable access to healthcare", to be held in Rome (Italy), on 12 December 2023. The event is organised by the Council of Europe, in cooperation with the National Office Against Racial Discrimination of Italy, with the support of the Ministry of Family, Natality and Equal Opportunities and of the Ministry of Health of Italy.

c. Action Plan Armenia

60. The Secretariat presented briefly the latest developments in the cooperation project on "Human Rights and Biomedicine II" carried out in the framework of the Armenia Action Plan. She referred to the HELP course on human rights in mental healthcare being developed in this context, as well as the different training activities carried out for health care professionals, but also members of the national ethics committee and research ethics committee. She indicated that specific activities were also planned to the training of health care professionals coming from Nagorno Karabakh.

d. Replies to questionnaire on PMA

61. The Secretariat presented the online version of the replies to the questionnaire on medically assisted procreation.

62. The CDBIO welcome the online publication of the replies to the questionnaire providing an overview of the legal framework and practices in the member states relevant to medically assisted procreation.

e. Gender equality

63. The Gender Equality Rapporteur, Iuliia Davydova, made a presentation on the gender dimensions of the CDBIO's work (in Appendix V to this report), based on her participation in Council of Europe trainings. Delegations underlined the importance of gender in their work, noting the opportunity this presented for the Committee's work in preparing its new strategic action plan. The CDBIO took note of the proposals by the Gender Equality Rapporteur to be considered in the development of its work programme.

f. PACE Recommendation 2263 (2023) – "Mental health and well-being of children and young adults"

64. The representative of the PACE presented briefly the content of the recommendation.

65. The delegations were reminded about the invitation of the Committee of Ministers to make possible comments on the PACE rec 2263 (2023) by 12 January 2024. **They were invited to send their comments by 25 November 2023.**

66. Considering the deadline set for the sending the comments to the Committee of Ministers, the CDBIO agreed to entrust its Bureau with the task of finalising the comments on the basis of the remarks to be sent from delegations and in the light of the relevant work carried out by the Committee.

X. Dates of the next meetings

67. The CDBIO agreed to hold the next meetings on:

- 5th plenary meeting: 11-14 June 2024, in Strasbourg
- 6th plenary meeting: 26-29 November 2024 (tbc), in Strasbourg

XI. Adoption of decisions taken at the 4th plenary meeting

67. The Delegations agreed to adopt by written procedure the abridged report presented to delegations on Friday 17 November 2023. In the absence of opposition by Monday 20 November 2023, the abridged report was adopted.

Appendix I
List of participants

MEMBERS / MEMBRES

ALBANIA / ALBANIE	Awaiting nomination / <i>Nomination en attente</i>	
ANDORRA / ANDORRE	Awaiting nomination / <i>Nomination en attente</i>	
ARMENIA / ARMENIE	Izabel ABGARYAN Chair of the Medical Ethics Committee	Apologised/Excusée
AUSTRIA / AUTRICHE	Sabine FASCHING Federal Chancellery Secretariat of the Bioethics Commission	Apologised/Excusée
	Ulrich PESENDORFER Ministry of Justice and jurisdiction	Apologised/Excusé
	Andreas VALENTIN Member of the Bioethics Commission	
AZERBAIJAN / AZERBAÏDJAN	Ismayil S ZULFUGAROV Head of Proteomics Lab Institute of Molecular Biology and Biotechnologies of the Azerbaijan National Academy of Sciences	Apologised/Excusé
BELGIUM / BELGIQUE	Katrien VAN WOUWE Attachée au service Relations internationales du SPF Santé publique, Sécurité de la chaîne alimentaire et Environnement	Apologised/Excusée
BOSNIA AND HERZEGOVINA / BOSNIE-HERZÉGOVINE	Dunja PEJOVIC Coordinator of the Regional Health Development Center for Mental Health in SEE Ministry of Civil Affairs	Apologised/Excusée
BULGARIA / BULGARIE	Vihra MILANOVA Head of Psychiatric Clinic Alexandrovska University Hospital	Apologised/Excusée
CROATIA / CROATIE	Vanja NIKOLAC Head of Service, Service for blood, tissues and cells inspection Ministry of Health	Apologised/Excusée
CYPRUS / CHYPRE	Zoe KYRIAKIDOU Member of the Cyprus National Bioethics Committee	
	Constantinos N. PHELLAS Chair of the Cyprus National Bioethics Committee University of Nicosia	Apologised/Excusé

CZECH REPUBLIC / REPUBLIQUE TCHEQUE	<p>Tomáš DOLEŽAL Ph.D., LL.M., Head of the Department of Private Law and Head of the Research Unit for Medical Law and Bioethics Czech Academy of Science, Institute of State and Law</p> <p>Hana KONEČNÁ Ph.D., University of South Bohemia in České Budějovice</p>
DENMARK / DANEMARK	<p>Berit Dea HVOLBY Apologised/Excusée Head of Section, Personalized Medicine, Research and Privacy Ministry of Health</p>
ESTONIA / ESTONIE	<p>Aime KEIS Vicechair of the National Committee on Bioethics and Human Research University of Tartu</p>
FINLAND / FINLANDE	<p>Maija MIETTINEN Ministerial Advisor Ministry of Social Affairs and Health General Secretary, National Advisory Board on Social Welfare and Health Care Ethics (ETENE)</p> <p>Tinja SCHRÖDER Unit for Human Rights Courts and Conventions Legal Service Ministry for Foreign Affairs</p>
FRANCE	<p>Kamyar ASSARI Apologised/Excusé Consultant juridique Sous-direction des droits de l'Homme Direction des affaires juridiques Ministère de l'Europe et des Affaires étrangères</p> <p>Lucie BOZEC Apologised/Excusée Chargée de mission greffe Bureau bioéthique, éléments et produits du corps humain (PP4) Direction générale de la Santé (DGS) Ministère de la Santé et de la Prévention</p> <p>Fadia DIB Médecin chargée de la procréation, embryologie et génétique humaine Bureau bioéthique, éléments et produits du corps humain (PP4) Direction générale de la Santé (DGS) Ministère de la Santé et de la Prévention</p> <p>Estelle FAUCHARD Apologised/Excusée Rédactrice Bureau du droit des personnes et de la famille Sous-direction du droit civil Direction des affaires civiles et du sceau (DACs) Ministère de la Justice</p> <p>Jacques MONTAGUT Apologised/Excusé Ancien membre du CCNE</p> <p>Diane RICHARD Apologised/Excusée Bureau du droit des personnes et de la famille Sous-direction du droit civil Direction des affaires civiles et du sceau (DACs) Ministère de la Justice</p>

GEORGIA / GÉORGIE	<p>Givi JAVASHVILI Head of Family Medicine Department Tbilisi State Medical University Chairman of the National Council on Bioethics</p>
GERMANY / ALLEMAGNE	<p>Elmar DOPPELFELD Honorary Chair of the "Permanent Working Party of Research Ethics Committees in Germany Inc."</p> <p>Carlo GRIMM Division 611 Federal Ministry of Education and Research</p> <p>Ingo HÄRTEL Apologised/Excusé Division 316 Federal Ministry of Health</p> <p>Thomas HEINEMANN Philosophical-Theological University of Vallendar (PTHV)</p> <p>Judith MENTGEN Apologised/Excusée Head of Division III A 6 – Insurance law; IOPC-Funds; UNCITRAL; bioethics; genetic diagnostics Federal Ministry of Justice</p> <p>Vincent WÄCHTER III A 6 – Insurance law; IOPC-Funds; UNCITRAL; bioethics; genetic diagnostics Federal Ministry of Justice</p>
GREECE / GRECE	<p>Andreas KARABINIS Apologised/Excusé Intensivist, Professor of Emergency Medicine Athens Medical School National and Kapodistrian University of Athens</p> <p>Foteini TZAVELLA Apologised/Excusée Associate Professor University of Peloponnese</p>
HUNGARY / HONGRIE	<p>Tamás KARDON Associate professor, Secretary of the Scientific and Research Ethics Committee of Medical Research Council</p>
ICELAND / ISLANDE	<p>Rögvaldur G. GUNNARSSON Apologised/Excusé Legal Advisor Ministry of Welfare</p> <p>Kristín Ninja GUDMUNDSÓTTIR Apologised/Excusée Legal Advisor Ministry of Health</p>
IRELAND / IRLANDE	<p>Siobhán O’SULLIVAN Royal College of Surgeons</p>
ITALY / ITALIE	<p>Assunta MORRESI Prof. Associato di Chimica Fisica, Dipartimento di Chimica, Biologia e Biotecnologi Università degli Studi di Perugia</p>

	Laura PALAZZANI Lumsa, Facoltà di giurisprudenza Roma	Apologised/Excusée
LATVIA / LETTONIE	Signe MEŽINSKA Associate Professor, Faculty of Medicine Senior Researcher, Institute of Clinical and Preventive Medicine University of Latvia	
LIECHTENSTEIN	Awaiting nomination / <i>Nomination en attente</i>	
LITHUANIA / LITUANIE	Asta ČEKANAUSKAITĖ Director of Lithuanian Bioethics Committee	
LUXEMBOURG	Awaiting nomination / <i>Nomination en attente</i>	
MALTA / MALTE	Pierre MALLIA Professor of Family Medicine, Bioethics & Patients' Rights, Chairperson, National Health Ethics Committee, Dept. of Health, Chairperson, Bioethics Consultative Committee Ministry of Health Coordinator, Bioethics Research Programme, Univ. of Malta, President, Malta College of Family Doctors	Apologised/Excusé
REPUBLIC OF MOLDOVA / RÉPUBLIQUE DE MOLDOVA	Vadim AFTENE Head General Department of Policies in the Field of Integrated Medical Services Ministry of Health	
MONACO	Thomas ALTHAUS Médecin de Santé Publique Direction de l'Action Sanitaire	Apologised/Excusé
MONTENEGRO / MONTÉNÉGRO	Olivera MILJANOVIĆ MD, PhD, Head of Centre for Medical Genetics and Immunology – Clinical Centre of Montenegro, Chief lecturer of biomedicine, bioethics, clinical genetics and pediatrics at the Faculty of Medicine University of Montenegro	
NETHERLANDS / PAYS-BAS	Harrie STORMS Ministry of Health, Welfare and Sports Sanne VAN WEEZEL Ministry of Health, Welfare and Sports	
NORTH MACEDONIA / MACÉDOINE DU NORD	Awaiting nomination / <i>Nomination en attente</i>	
NORWAY / NORVEGE	Anne FORUS Senior Adviser, ph.d, Biotechnology and health legislation department Division of specialised health care services Norwegian Directorate of Health	
POLAND / POLOGNE	Mariola GROCHULSKA Département des droits de l'homme Ministère de la Justice	

PORTUGAL	Awaiting nomination / <i>Nomination en attente</i>
ROMANIA / ROUMANIE	<p>Gheorghe BORCEAN Président de l'Ordre des Médecins et Prof. Ass. à l'Université de Médecine et Pharmacie " Victor Babes" de Timisoara Vice-President of the Romanian College of Physicians Spitalul Municipal Caransebes</p> <p>Beatrice Gabriela IOAN Associate Professor President of the Bioethics Commission of the Romanian College of Physicians Institutul de Medicina Legala</p>
SAN MARINO / SAINT-MARIN	<p>Luisa BORGIA Professor of Bioethics, Polytechnic University of Marche President of National Bioethics Committee</p>
SERBIA / SERBIE	<p>Zvonko MAGIC Head of the Institute for Medical Research in the MMA (Military Medical Academy), professor of the human genetics at the Medical Faculty and Cochairmen of the National Committee for bioethics of UNESCO Commission of Serbia Serbian Academy of Sciences and Arts</p>
SLOVAK REPUBLIC / REPUBLIQUE DE SLOVAQUIE	<p>Jozef GLASA Institute of Pharmacology and Clinical Pharmacology, Institute of Health Care Ethics, Slovak Medical University in Bratislava; Institute of Medical Ethics and Bioethics n.f.; Ethics Committee (NEC) Ministry of Health</p>
SLOVENIA / SLOVÉNIE	<p>Marjeta TERČELJ ZORMAN Apologised 15-17/Excusée 15-17 Vice President of the National Ethics Commission</p>
SPAIN / ESPAGNE	<p>Carlos M. ROMEO-CASABONA Apologised/Excusé Professor of Penal Law, Head Inter-University Chair in Law and the Human Genome</p>
SWEDEN / SUÈDE	<p>Tesi ASCHAN Legal Adviser The National Board of Health and Welfare, Socialstyrelsen</p>
SWITZERLAND / SUISSE	<p>Damaris CARNAL Deputy Head of Section International Affairs Division</p>
TÜRKIYE / TÜRKIYE	<p>Tuna İLBARS Unit Coordinator Department of Blood and Blood Products Directorate General of Health Services Ministry of Health</p>
UKRAINE	<p>Iuliia DAVYDOVA Professor, Head of High-Risk Pregnancy Department Institute of Pediatrics, Obstetrics and Gynecology, member of Local Bioethics Committee</p>
UNITED KINGDOM / ROYAUME-UNI	<p>Mark BALE Advisor to the Science Research and Evidence Directorate Department of Health and Social Care</p>

PARTICIPANTS / PARTICIPANTS

CDCJ	Rodrigo RODRIGUEZ Apologised/Excusé Département fédéral de justice et police DF Office fédéral de la Justice OFJ Domaine de direction Droit privé
UNITED NATIONS OFFICE OF THE HIGH COMMISSIONER FOR HUMAN RIGHTS / HAUT-COMMISSARIAT DES NATIONS UNIES AUX DROITS DE L'HOMME	Awaiting nomination / <i>Nomination en attente</i>

OTHER PARTICIPANTS / AUTRES PARTICIPANTS

EUROPEAN UNION / UNION EUROPEENNE	Awaiting nomination / <i>Nomination en attente</i>
EUROPEAN COMMISSION / COMMISSION EUROPEENNE	Jim DRATWA Apologised/Excusé Head of Ethics and Head of the EGE Secretariat Member of the Bureau of European Policy Advisers (BEPA) European Commission
CONFERENCE OF INGOS / CONFERENCE DES OINGS	Frank Ulrich MONTGOMERY Apologised/Excusé Standing Committee of European Doctors (CPME) Ruth ALLEN Apologised/Excusée International Federation of Social Workers (IFSW)
CANADA	Peter MONETTE Apologised/Excusé Health Canada
HOLY SEE / SAINT- SIEGE	Leonardo NEPI
JAPAN / JAPON	Tetsushi HIRANO Apologised/Excusé Chargé de mission
MEXICO / MEXIQUE	Patricio J. SANTILLAN DOHERTY Apologised/Excusé National Commissioner of Bioethics Gustavo Fernando OLAIZ BARRAGAN Apologised/Excusé Deputy Director on Public Policy and Bioethics National Commission of Bioethics
USA / ETATS-UNIS D'AMERIQUE	Awaiting nomination / <i>Nomination en attente</i>
UNESCO	Dafna FEINHOLZ Apologised/Excusée Chief of the Bioethics Section
OECD / OCDE	David WINICKOFF Apologised/Excusé STI/STP

WHO / OMS	Andreas REIS Co-Unit Head, Health Ethics & Governance Research for Health Department Science Division
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OBSERVERS / OBSERVATEURS

CONFERENCE OF EUROPEAN CHURCHES (CEC) / CONFERENCE DES EGLISES EUROPEENNES (CEC)	Elizabeta KITANOVIC Membre du Groupe de travail	Apologised/Excusée
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INGOS / OINGS

REHABILITATION INTERNATIONAL (RI)	Regina ERNST RI National Secretary for Germany	Apologised/Excusée
	Carolyn KÖNIG (14-15/11) International affairs and relations German Social Accident Insurance (DGUV)	
EUROPEAN ASSOCIATION OF SERVICE PROVIDERS FOR PERSONS WITH DISABILITIES (EASPD)	Ferran BLANCO ROS (14-15/11) Responsable de l'Àrea de Projectes i Desenvolupament	
EUROPEAN DISABILITY FORUM (EDF)	John Patrick CLARKE , EDF Vice-President Gunta ANCA , Chair of the Latvian Disability Council Olga KALINA , Chair of the European Network of (Ex)Users and Survivors of Psychiatry	

CONSULTANTS / CONSULTANTES

UNITED KINGDOM / ROYAUME-UNI	Elaine GADD (online 14/11) Consultant for the Draft Recommendation for the promotion of voluntary measures
	Rumiana YOTOVA (online 16/11) Consultant for the Overview of legislation and practices on patients' rights

INVITED GUESTS / INVITES

FINLAND / FINLANDE	Joni KOMULAINEN (15/11) Chair of the Drafting group on AI in healthcare
	Ritva HALLIA (online 16/11) Co-Chair of the 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

SECRETARIAT / SECRETARIAT

<p>PARLIAMENTARY ASSEMBLY / ASSEMBLÉE PARLEMENTAIRE</p>	<p>Tanja KLEINSORGE Apologised/Excusée Head of Secretariat Committee on Social Affairs, Health and Sustainable Development</p> <p>Anita GHOLAMI Committee on Social Affairs, Health and Sustainable Development</p> <p>Yulia PERERVA Apologised/Excusée Committee on Social Affairs, Health and Sustainable Development</p>
<p>OFFICE OF THE COMMISSIONER FOR HUMAN RIGHTS / BUREAU DU COMMISSAIRE AUX DROITS DE L'HOMME</p>	<p>Patricia OTVOS Apologised/Excusée Adviser</p>
<p>OFFICE OF THE SPECIAL REPRESENTATIVE OF THE SECRETARY GENERAL ON MIGRATION AND REFUGEES / BUREAU DE LA REPRESENTANTE SPECIALE AUPRES DE LA SECRETAIRE GENERALE SUR LES MIGRATIONS ET LES REFUGIES</p>	<p>Anne KAYSER Apologised/Excusée Administrator</p>
<p>COMMITTEE ON ARTIFICIAL INTELLIGENCE / COMITE SUR L'INTELLIGENCE ARTIFICIELLE (CAI)</p>	<p>Kristian BARTHOLIN Apologised/Excusé Secretary</p>
<p>STEERING COMMITTEE ON ANTI DISCRIMINATION, DIVERSITY AND INCLUSION / COMITE DIRECTEUR SUR L'ANTI-DISCRIMINATION, LA DIVERSITE ET L'INCLUSION (CDADI)</p>	<p>Wolfram BECHTEL Apologised/Excusé Secretary</p>
<p>SEXUAL ORIENTATION AND GENDER IDENTITY UNIT / UNITE ORIENTATION SEXUELLE ET IDENTITE DE GENRE (SOGI)</p>	<p>Eleni TSETSEKOU Apologised/Excusée Head of Unit</p>
<p>EUROPEAN COMMITTEE FOR THE PREVENTION OF TORTURE AND INHUMAN OR DEGRADING TREATMENT OR</p>	<p>Hugh CHETWYND Apologised/Excusé Head of Division</p>

PUNISHMENT : COMITE EUROPEEN POUR LA PREVENTION DE LA TORTURE ET DES PEINES OU TRAITEMENTS INHUMAINS OU DEGRADANTS (CPT)		
COMMITTEE OF THE CONVENTION FOR THE PROTECTION OF INDIVIDUALS WITH REGARD TO AUTOMATIC PROCESSING OF PERSONAL DATA / COMITÉ CONSULTATIF DE LA CONVENTION POUR LA PROTECTION DES PERSONNES À L'ÉGARD DU TRAITEMENT AUTOMATISÉ DES DONNÉES A CARACTÈRE PERSONNEL (T-PD)	Isabelle SERVOZ-GALLUCCI Secretary	Apologised/Excusée
STEERING COMMITTEE FOR THE RIGHTS OF THE CHILD / COMITE DIRECTEUR POUR LES DROITS DE L'ENFANT (CDEF)	Katrin UERPMANN Secretary	Apologised/Excusée
EUROPEAN COMMITTEE ON BLOOD TRANSFUSION / COMITE EUROPEEN (ACCORD PARTIEL) SUR LA TRANSFUSION SANGUINE (CD-P-TS)	Richard FORDE Secretary	Apologised/Excusé
EUROPEAN COMMITTEE ON ORGAN TRANSPLANTATION / COMITE EUROPEEN SUR LA TRANSPLANTATION D'ORGANES (CD-P-TO)	Marta LOPEZ-FRAGA Secretary	Apologised/Excusée
DIRECTORATE GENERAL OF DEMOCRACY AND HUMAN DIGNITY - YOUTH POLICY DIVISION / DIRECTION GENERALE POUR LA DEMOCRATIE ET LA DIGNITE HUMAINE – DIVISION DE LA POLITIQUE POUR LA JEUNESSE	Lana COP Secretary	Apologised/Excusée

<p>HUMAN RIGHTS, JUSTICE AND LEGAL COOPERATION, STANDARD SETTING ACTIVITIES DEPARTMENT - HUMAN RIGHTS AND BIOMEDICINE DIVISION / SERVICE DES ACTIVITES NORMATIVES EN MATIERE DE DROITS DE L'HOMME, JUSTICE ET COOPERATION JURIDIQUE - DIVISION DES DROITS DE L'HOMME ET DE LA BIOMEDECINE</p>	<p>Laurence LWOFF Secretary of the CDBIO / <i>Secrétaire du CDBIO</i> Tel: +33 (0) 388 41 22 68, Email: laurence.lwoff@coe.int</p> <p>Lee HIBBARD Administrator / <i>Administrateur</i> Tel: +33 (0) 388 41 31 04, Email: lee.hibbard@coe.int</p> <p>Lorenzo MONTRASIO (online) Scientific Administrator / <i>Administrateur scientifique</i> Tel: +33 (0) 390 21 61 87, Email: Lorenzo.montrasio@coe.int</p> <p>Aurélie PASQUIER Administrator / <i>Administratrice</i> Tel: +33 (0) 390 21 52 75, Email: aurelie.pasquier@coe.int</p> <p>Catherine FORNE Assistant / <i>Assistante</i> Tel: +33 (0) 388 41 22 20, Email: catherine.forne@coe.int</p> <p>Laura HENNINGER (online) Assistant / <i>Assistante</i> Tel: +33 (0) 388 41 30 05, Email: laura.henninger@coe.int</p> <p>Tatiana WINTER (online) Assistant / <i>Assistante</i> Tel: +33 (0) 388 41 33 67, Email: tatiana.winter@coe.int</p>
<p>INTERPRETING, TRAVEL, EVENTS AND MULTIMEDIA DEPARTMENT (ITEM) / SERVICE DE L'INTERPRETATION, DES VOYAGES, DES EVENEMENTS ET DU MULTIMEDIA (ITEM)</p>	<p>Corinne McGEORGE (14-17/11)</p> <p>Claudine PIERSON (14-17/11)</p> <p>Lucie DE BURLET-SUTER (14-15/11)</p>

Appendix II
Agenda

Tuesday 14 November 2023 (09.00-17.30)	
	<u>Conference “Promoting autonomy in mental healthcare”</u>
Wednesday 15 November 2023 (09.00-12.30 / 14.00-17.30)	
	<p>1. Adoption of the draft agenda</p> <ul style="list-style-type: none"> ○ New CDBIO members invited to introduce themselves ○ Reminder about the main decisions to be taken during the meeting
	<p>2. Draft Recommendation on respect for autonomy in mental healthcare</p> <p><i>Objective: Agreement on the launching of a consultation on the draft Recommendation</i></p> <ul style="list-style-type: none"> - Examination of the draft Recommendation revised by the Bureau - Agreement to launch a consultation on the draft Recommendation
	<p>3. Artificial intelligence and biomedicine</p> <p><i>Objective: Guidance to the Drafting Group for the further development of the report</i></p> <ul style="list-style-type: none"> - Examination of a revised draft report - Consideration of possible targeted consultation of the draft report
	<p>9.a Youth Forum <i>(Where necessary to continue on Friday)</i></p> <p><i>Objective: Presentation of the rapporteur report on the Pilot Youth Forum – Key elements for the preparation of the 2025 Youth Forum</i></p> <ul style="list-style-type: none"> - Presentation of her report by Tesi Aschan, rapporteur: <ul style="list-style-type: none"> First part on the discussion on AI in healthcare Second part on the planning and organisation process - Discussion on key elements for the preparation of the 2025 Youth Forum

Thursday 16 November 2023 (09.00-12.30 / 14.00-17.30)

4. Overview of legislation and practices on patients' rights

Objectives: Examination of the replies to the questionnaire and their analysis, with a view to its publication

- Presentation of the analysis by Dr Rumiana Yotova and discussion on the document
- Decision on the next steps:
 - presentation to CM and publication
 - consideration under the Horizon scanning exercise

5. Equitable access to appropriate innovative treatments and technologies in healthcare

Objective: Guidance for the further development of the draft discussion paper

- Presentation of the discussion paper and the note of the Bureau
- Decisions on next steps

6. Guide on children participation in decision-making process on matters relevant to their health

*Objective: **Adoption** of the guide (adoption by the CDENF is also on the agenda its plenary meeting the same week)*

- Presentation of the final draft revised in the light of the comments received from CDENF and CDBIO delegations
- Subject to the adoption of the guide, launching of the guide, possible translation(s) in non-official languages and development of related materials

Friday 17 November 2023 (09.00-12.30)

7. Preparation of a new strategic action plan (SAP II)

Objective: agreement on the methodology for the horizon scanning

- Examination of the proposal made by the Group for the preparation of the horizon scanning event with a view to its approval


8. Bureau election

*Objective: Election of the Chair and Vice Chair
Election of a new Bureau member for a two-years term renewable once*

- Submission for nominations should be sent in writing to the Secretariat by Wednesday 15 November 2023 at 2.00 pm.

	<p>9. Other business</p> <p>a. Youth Forum (<i>to continue where necessary</i>)</p> <p>b. CDBIO Guide to health literacy <i>Objective: Information on the launch of the guide - organised with the support and cooperation of the Ministry for Family, Natality & Equal Opportunities and the Ministry of Health of Italy – to be held in Rome, on 12 December 2023</i></p> <p>c. Armenia Action Plan II <i>Objective: Information on the cooperation project Human Rights and Biomedicine II</i></p> <p>d. Replies to questionnaire on PMA <i>Objective: presentation of the online version of the replies</i></p> <p>e. Gender equality <i>Objective: brief presentation of proposals by the CDBIO Gender Equality rapporteur</i></p> <p>f. PACE Recommendation 2263 (2023) – “Mental health and well-being of children and young adults” <i>Objective: Entrusting the Bureau with the preparation of the comments on the Recommendation in the light of the relevant work of the CDBIO and the remarks made by CDBIO delegations</i></p>
	<p>10. Dates of the next meetings</p> <ul style="list-style-type: none"> ○ <i>5th meeting of the CDBIO: 11-14 June 2024, Strasbourg</i> ○ <i>6th meeting of the CDBIO: [26-29 November] 2024, Strasbourg</i>
	<p>11. Adoption of decisions taken by the CDBIO at its 4th meeting</p> <p><i>Objective: Approval of the abridged meeting report</i></p>

POINTS TO BE DEALT WITH IN WRITING

	<p>12. Developments in the field of bioethics</p> <p>Delegations, including observers, are invited to send information in writing.</p> <ul style="list-style-type: none"> a. Developments in member states and other states b. Developments in the field of bioethics in international organisations c. Developments in other Council of Europe bodies d. Developments at the European Court of Human Rights



13. Chart of signatures and ratifications of the Convention on Human Rights and Biomedicine, the Protocol on the Prohibition of Cloning Human Beings, the Protocol concerning Transplantation of Organs and Tissues of Human Origin, the Protocol concerning Biomedical Research and the Protocol concerning Genetic Testing for Health Purpose



14. Cooperation with other committees

- a. Steering Committee for Human rights (CDDH)
- b. European Committee on Organ Transplantation (CD-P-TO)
- c. European Committee on Blood Transfusion (CD-P-TS)
- d. Consultative Committee of the Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data (T-PD)
- e. Steering Committee for the Rights of the Child (CDENF)
- f. Steering Committee for Legal Cooperation (CDCJ)

Appendix III

PowerPoint presentation of Rumiana Yotova



Report on the
Replies to the Quest

Appendix IV

Statement of the MoH of the Slovak Republic on the Guide to Children's Participation in Decisions about their Health



Declaration of the
Slovak Delegation a

Revised commentary of MoH of Türkiye on the Guide To Children's Participation in Decisions about their Health



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Appendix V

Presentation by Iuliia Davydova, Gender Equality Rapporteur



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