

Strasbourg, 4 June 2021

DH-BIO / Abr RAP18

COMMITTEE ON BIOETHICS (DH-BIO)

18th meeting

1-4 June 2021

Kudo

Abridged report

I. Adoption of the agenda

1. The Committee on Bioethics (DH-BIO) held its 18th meeting online from 1 to 4 June 2021. The list of participants and the agenda of the meeting appear in Appendices I and II to this report.

II. <u>Collection of examples of good practices aiming at promoting voluntary measures</u> in mental health care

- 2. The Secretariat recalled that the scope of this initiative is to identify practices carried out within Council of Europe member States which have contributed to reducing or ending recourse to involuntary measures in mental health care by either targeting the prevention of involuntary measures in mental health care or otherwise having such an impact. The objective of this work is to provide practical examples, to serve as an inspiration for policymakers and service-providers.
- 3. The draft Compendium including examples of good practices aiming at promoting voluntary measures in mental health care was presented by Dr Piers Gooding (Australia), consultant, who briefly described identified groups of practices and made general comments on the results achieved. Identified groups of examples included hospital-based practices, community-based practices, hybrid and other practices.
- 4. The web version of the draft Compendium was presented to the Committee for its comments.
- 5. Delegations, participants and observers exchanged views on the draft Compendium and on the way forward for this work to be finalised. Delegations expressed general support of the work carried out by Dr Gooding.
- 6. Delegations, participants and observers, in particular relevant INGOs were invited to contribute to the draft Compendium with other examples of practices aiming at promoting voluntary measures in mental health care, as well as to send other relevant comments on the draft to the Secretariat <u>by 30 June 2021</u>.

III. <u>Health literacy</u>

- 7. In the light of the pandemic and the human rights issues it raised, the Committee had agreed to extend the scope of the work on health literacy to other vulnerable groups than older persons foreseen under the Equity pillar of the Strategic Action Plan and its strategic objective "Combating health disparities created by social and demographic changes in Council of Europe member states", in particular the concern that healthcare is less accessible to certain populations because of their social circumstances. Further, the Committee noted the view of the Bureau that "persons in vulnerable situations" would allow for a broader scope of persons and potentially anybody.
- 8. The draft report "Advancing health literacy for equitable access to healthcare towards a guide to health literacy policy, strategy and service design" was presented by the consultant experts, Leena Paakkari (Finland) and Kristine Sørensen (Denmark). This included reference to five key challenges, namely access to digital spaces, access to valid health information, access to appropriate care, communication between individuals and health professionals, and shared decision-making regarding care and prevention. Reference to health literacy as an asset which saves time, costs and lives, and to health literacy responsiveness of decision makers to improve patient journeys, were also emphasised.

- 9. Delegations highlighted several issues to be considered in the finalisation of the experts' report and the development of the guide, notably the informed consent of persons in vulnerable situations, communication and patient safety, the articulation between health literacy and bioethical principles, misinformation, and the decisions regarding valid health information.
- 10. The DH-BIO agreed with the proposal of the Bureau to set-up a small drafting group of members, experts and other representatives. The Chair welcomed the expression of interest by the two delegations and invited other delegations to express their interest to the Secretariat, at the latest <u>by 30 June 2021</u>.

IV. Information update on ethical aspects of the Covid-19 pandemic

11. Delegations exchanged on new concerns raised by the pandemic. Welfare of children and families, isolation of older persons, public debate initiated, as well as special actions concerning specific groups of persons, were among the issues referred to.

V. <u>Additional Protocol concerning the protection of human rights and dignity of</u> persons with regard to involuntary placement and involuntary treatment within <u>mental health care services</u>

- 12. The Bureau has considered the excellent progress made in the complementary work to the draft Additional Protocol on the collection of good practices on the promotion of voluntary measures in mental healthcare and has recommended postponing the vote on the draft Additional Protocol to the 19th plenary meeting (November 2021) to present it together with the collection which will be finalised by then.
- 13. The Committee (by 23 votes in favour, 3 votes against and 1 abstention) agreed with the Bureau proposal and postponed the vote on the draft Additional Protocol to the 19th plenary meeting (November 2021).

VI. <u>Genome editing technologies</u>

- 14. The DH-BIO rapporteur presented the Bureau proposal on the way forward following the agreement reached at the 17th plenary meeting in relation to Article 13.and in the light of the comments sent by delegations.
- 15. Delegations welcome the proposal and underline the importance for the DH-BIO to continue working on these issues as this is an area where the scientific community and governments continues to work on.
- 16. The Committee agreed with the proposal from the Bureau to:
 - Set up a drafting group to provide clarifications on the terms "preventive, diagnostic and therapeutic" and to avoid misinterpretation of the applicability of this provision to "research"." Three delegations expressed their interest in joining the group. Other expressions of interest to become member of the drafting group should be sent to the Secretariat by 30 June 2021.
 - to publish the following communiqué:
 "In accordance with its statement on gene editing technology adopted in December 2015 and its Strategic Action Plan on Human Rights and Technologies in Biomedicine (2020-2025); the Committee on Bioethics (DH-BIO) examined

Article 13 of the Oviedo Convention in the light of developments in human genome editing.

Taking into account the technical and scientific aspects of these developments as well as the ethical issues they raise, it considered that the conditions were not met for a modification of the provisions of Article 13.

However, it agreed on the need to provide clarifications, in particular on the terms "preventive, diagnostic and therapeutic" and to avoid misinterpretation of the applicability of this provision to "research"."

17. The Bureau, in coordination with the Rapporteur on genetics and genomics and with the support of the Secretariat, will make proposals for a possible work on mitochondrial transfer to be discussed by the Committee at its 19th plenary meeting.

VII. <u>Children's participation in the decision-making process on matters regarding</u> their health

- 18. The Secretariat has informed the Committee about the progress done with regard to the development of the Guide on children's participation in the decision-making process on matters regarding their health as it is foreseen by the SAP. In particular, as the first step in the Guide's development, the Secretariat has conducted an online survey on children participation in decision-making process in matters regarding their health (the Survey) which has received 185 answers from 36 countries from Europe and beyond.
- 19. The summary on the Survey was presented by the consultant expert, Dr Annagrazia Altavilla (France). Along with thorough analyses of the Survey results, it was concluded that the high rate of negative answers on different topics points out a lack of awareness of issues related to participation of children in decision making regarding their health. This was followed by an exchange of views with delegations. The latter expressed general support for the continuation of work and further development of the Guide.
- 20. The Secretary of the Steering Committee for the Rights of the Child (CDENF) has conveyed a full support from the part of the CDENF in this initiative and has reiterated that "giving voice to every child" is among the priority actions proposed by the new draft Council of Europe Strategy for the Rights of the Child (2022-2027).
- 21. The DH-BIO agreed with the written Bureau proposal to set up a joint drafting group co-chaired by a member of the DH-BIO and a member of the CDENF. The Chair welcomed the expression of interest by one delegation. and confirmed her willingness to participate in the work of the drafting Group as DH-BIO Rapporteur on children. The other delegations are invited to express their interest in joining the drafting group to the Secretariat, at the latest by 30 June 2021.

VIII. Equity in access to treatment and equipment in a context of scarcity

- 22. The Chair reminded this is the continuation of the work supported by the DH BIO during the 17th plenary on equitable access to healthcare in the context of scarce resources. This work aims to support policymakers in framing priorities for allocating healthcare taking into consideration ethical principles.
- 23. The Committee welcomed the proposal from the Bureau on the way forward and the outline for an instrument prepared by Prof. Kristof Van Assche (Belgium).
- 24. The Committee agreed with the methodology and the setting up of a drafting group. The Committee suggested preparing a draft text with a mix of substantive and procedural

principles to ensure a practical contribution to the management of shortage situations taking into account ethical principles.

25. The Secretariat reminded the importance of focusing the scope on shortages and scarce resources, keeping a clear distinction with the subsequent work on equity of access to innovative treatments. The Secretariat also reminded delegations that this work on treatment and equipment was considered as a priority.

26. Delegations were invited to express their interest in becoming a member of the drafting group or suggesting experts from their national network to the Secretariat by 30 June 2021.

IX. <u>Neurotechnologies</u>

- 27. The draft report on common human rights issued raised by different application of neurotechnologies in the biomedical field was presented by Dr Marcello lenca (Switzerland), expert consultant. In particular, Dr lenca overviewed a history and taxonomy of neurotechnologies and pointed out its current progress and limits. He gave examples of ethical and human rights challenges raised by application of neurotechnologies. Finally, he informed the DH-BIO about ongoing policy developments related to "neurorights".
- 28. This was followed by an exchange of views with delegations who thanked Dr lenca for the quality of his work and expressed their full support for its continuation.
- 29. The representative of the OECD expressed the full support of the OECD for the work done by the Council of Europe with regard to the assessment of the human rights issues raised by the application of neurotechnologies and confirmed the OECD interest in the joint-organisation of the upcoming Round table.
- 30. The representative of UNESCO also expressed the interest and support of her organisation to this initiative.
- 31. The Committee agreed with the Bureau proposal for a joint organization with the OECD of the Round Table foreseen in the SAP in November 2021, with the participation of UNESCO. A preparatory group consisting of the representatives of the DH-BIO, OECD and Dr lenca will be set up to that end.
- 32. The Committee agreed on designation of Dr Siobhan O'Sullivan (Ireland), as the General Rapporteur for the Round Table.

X. <u>Election to the Bureau</u>

33. The Committee elected, by acclamation, Mark Bale (United Kingdom), for a second terms of two years in the Bureau.

XI. <u>Decisions taken by the DH-BIO at its 18th meeting</u>

34. In agreement with the delegations, the completed list of decisions taken during the meeting was sent to the Committee members and approved in the absence of comments by the deadline set.

XII. Dates of the next meetings

 The DH-BIO agreed on the following dates for the next plenary meetings: 19th plenary meeting: 2-5 November 2021 20th plenary meeting: 31 May-3 June 2022

XIII. <u>Other business</u>

Terms of reference

- 36. The Committee welcomed the proposal prepared by the Secretariat for its new terms of reference 2022-2025. It supported the suggestion to give to the Committee the status of steering committee, as Steering Committee on Human Rights in Biomedicine and Health (CDBIO).
- 37. Such change would mean that the CDBIO, starting in 2022, would be working directly under the authority of the Committee of Ministers. Delegations agreed however, on the importance and relevance of the links developed with the CDDH since 2012 and, even if the CDBIO would not anymore be subordinate to the CDDH, wished to maintain the important exchanges between the two committees.
- 38. The Committee also agreed that consideration should be given to the possibility of inviting the relevant intergovernmental committee for the setting up of a youth forum foreseen in the Strategic Action Plan.

Strategic Action Plan methodology and timeframe proposal for the priority actions planned

Genomics

- 39. The Committee took note of the presentation by Dr Ingo Härtel (Germany), Rapporteur on amongst the public, practitioners, and policy makers to ensure that patient and public interest is a key priority in the development and regulation of genomic medicine", to be held in Autumn 2022.
- 40. Delegations highlighted several issues, including the genetic testing and protection of future generations as well as genomics of pathogens with reference to SARS-CoV-2 virus.
- 41. The Committee noted the relevant reports, both adopted and under preparation, of the Parliamentary Assembly of the Council of Europe, and the work of the International Bioethics Committee.
- 42. The Committee agreed to set-up a small preparatory group, together with the Rapporteur, to develop the workshop. The Chair welcomed the expressions of interest and support by 6 delegations as well as the Parliamentary Assembly of the Council of Europe and the Conference of European Churches.

Artificial intelligence (AI)

43. The Committee took note of the information provided by the Secretariat on the framing and planning of the development of a report on the application of AI in healthcare and its impact on the doctor-patient relationship, including the role of healthcare professionals in respecting the autonomy, and right to information, of the patient, and in maintaining transparency and patient trust as critical components of the therapeutic relationship.

- 44. Delegations underlined the importance of AI for digital health having regard to its regulation, compliance with bioethical principles and values, progress in telemedicine especially during the COVID-19 pandemic, patient safety, and patient dialogue in the development of innovative products and procedures.
- 45. The Committee supported the proposal of the Secretariat to entrust Dr Brent Mittelstadt, Senior Research Fellow at the Oxford Internet Institute, University of Oxford, as consultant, with the preparation of an expert report and, where possible, to present its finding at its 19th plenary meeting.

Appendix I List of participants

MEMBERS / MEMBRES

ALBANIA / ALBANIE	Awaiting nomination / Nomination en attente
ANDORRA / ANDORRE	Mr David PÉREZ SURRIBAS President of the National Committee of bioethics
ARMENIA / ARMENIE	Ms Anna MKRTUMYAN Head of the Legal Department Ministry of Health
AUSTRIA / AUTRICHE	Dr Renate FALLY-KAUSEKapologised/excuséeMedical OfficerFederal Ministry of Health
	Dr Isabelle HASSLERapologised/excuséeFederal Chancellery of Austria / Co-ordination Science, Research, Technology, Education, Social issues, Health Secretariat of the Austrian Bioethics Commission
	Mr Stefan SCHWABapologised/excuséMinistry of Justice
AZERBAIJAN / AZERBAÏDJAN-	Dr Gulnara BALAKISHIYEVA Senior Researcher at Department of Fundamental Problems of Biological Productivity Institute of Molecular Biology and Biotechnology Azerbaijan National Academy of Sciences
BELGIUM / BELGIQUE	Mr Paul COSYNS Emeritus Professor Universiteit Antwerpen Dienst Psychiatrie van UZA
BOSNIA AND HERZEGOVINA / BOSNIE-HERZÉGOVINE	Mr Dalibor PEJOVICapologised/excuséHead of Unit for Statistics and Analytical Affairs and Reporting in HealthDepartment for HealthMs Dunja ŠMITRAN
	Ministry of Civil Affairs
BULGARIA I BULGARIE	Ms Sylvia TOMOVA Chief Legal Advisor Legal Directorate Ministry of Health
CROATIA / CROATIE -	Dr Vanja NIKOLAC Head of Service, Service for blood, tissues and cells inspection Ministry of Health
CYPRUS / CHYPRE	Prof. Constantinos N. PHELLAS Chair of the Cyprus National Bioethics Committee University of Nicosia

CZECH REPUBLIC /	Doc. JUDr. Tomáš DOLEŽAL
REPUBLIQUE TCHEQUE	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
	Ms doc. PhDr. Ing. Hana KONEČNÁ Ph.D., Jihočeská univerzita v Českých Budějovicích Zdravotně sociální fakulta, Katedra klinických a preklinických oborů
DENMARK / DANEMARK	Ms Sabine GODSVIG LAURSEN Head of Section Ministry of Health
	Ms Anne Cathrine BOLLERUP
ESTONIA I ESTONIE	Dr Aime KEIS Assistant, Chief lecturer of medical ethics Faculty of Medicine University of Tartu
FINLAND / FINLANDE	Prof. Ritva HALILA Docent, Senior Medical Officer Ministry of Social Affairs and Health
	Ms Maija MIETTINEN Ministry of Social Affairs and Health
	Ms Mia SPOLANDER Legal Officer
	Unit for Human Rights Courts and Conventions, Legal Service Ministry for Foreign Affairs
FRANCE	Dr Mélodie BERNAUX Bureau bioéthique, produits et éléments du corps humain, de la politique des produits de santé et de la qualité des pratiques et des soins Ministère des solidarités et de la santé
	Ms Lucie BOZEC Bureau bioéthique, produits et éléments du corps humain, de la politique des produits de santé et de la qualité des pratiques et des soins Ministère des solidarités et de la santé
	Ms Guilaine GANRY Bureau du droit des personnes et de la famille Sous-direction du droit civil Ministère de la Justice
	Ms Marion JABOT Bureau bioéthique, produits et éléments du corps humain de la politique des produits de santé et de la qualité des pratiques et des soins Ministère des solidarités et de la santé
	Ms Justine COURTECUISSE Ministère des solidarités et de la santé
	Dr Jacques MONTAGUT Ancien membre du CCNE

[
	Ms Anne FREUDENREICH Sous-direction des droits de l'Homme Ministère de l'Europe et des affaires étrangères Mme Romane MINEREAU Ministère de l'Europe et des affaires étrangères	
GEORGIA / GÉORGIE	Prof. Givi JAVASHVILI Head of Family Medicine Department Tbilisi State Medical University Chairman of the National Council on Bioethics	
GERMANY / ALLEMAGNE	Dr Thomas BAUERMANN Division III B 6 Federal Ministry of Justice and Consumer Protection Prof. Dr. Elmar DOPPELFELD	
	Honorary Chair of the "Permanent Working Party of Research Ethics Committees in Germany Inc." Mr Carlo GRIMM	
	Division 611 Federal Ministry of Education and Research	
	Dr Ingo HÄRTEL Division 316 Federal Ministry of Health	
	Prof. Dr. Thomas HEINEMANN Philosophical-Theological University of Vallendar (PTHV)	
	Ms Katharina LOHMANN Division 316 Federal Ministry of Health	
GREECE / GRECE	Prof. Andreas KARABINIS Intensivist, Professor of Emergency Medicine Athens Medical School National and Kapodistrian University of Athens	
	Dr Foteini TZAVELLA Sociologist, Assistant Professor in Sociology of Health Department of Nursing School of Health Sciences University of Peloponnese	
HUNGARY I HONGRIE	Prof. Ernö BÁCSY MD, PhD, DSc, Medical Research Council of Hungary	
ICELAND / ISLANDE	Mr Rögnvaldur G. GUNNARSSONapologised/excuséLegal AdvisorMinistry of Welfare	
	Ms Thorunn STEINSDOTTIR Legal Advisor Ministry of Welfare	

IRELAND / IRLANDE	Dr Siobhan O'SULLIVAN Chief Bioethics Officer An Roinn Sláinte Department of Health Teach Hawkins	
ITALY / ITALIE	Prof. Assunta MORRESI Prof. Associato di Chimica Fisica, Dipartimento di Chimica, Biologia e Biotecnologi Università degli Studi di Perugia	
	Prof. Laura PALAZZANI Lumsa, Facoltà di giurisprudenza Roma	
LATVIA / LETTONIE	Dr Vents SĪLIS Assistant Professor at Riga Stradins University Department of Humanities	
LIECHTENSTEIN	Awaiting nomination / Nomination en attente	
LITHUANIA / LITUANIE	Dr Asta ČEKANAUSKAITĖ Director of Lithuanian Bioethics Committee	
LUXEMBOURG	Ms Julie-Suzanne BAUSCHapologised/excuséePrésidente de la Commission nationale d'éthique	
MALTA / MALTE	Prof. 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	
REPUBLIC OF MOLDOVA / RÉPUBLIQUE DE	Ms Rodica GRAMMA Associate Professor State University of Medicine and Pharmacy (USMF)	
MOLDOVA	Mr Andrei SVETapologised/excuséHead of the Legal DepartmentMinistry of Health, Labour and Social Protection	
MONACO	Mr Xavier RAUSCHERapologised/excuséAdministrateur JuridiqueService du droit International, des droits de l'homme et des libertésfondamentales	
	Mr Gabriel REVEL Service du droit International, des droits de l'homme et des libertés fondamentales	
MONTENEGRO / MONTÉNÉGRO	Ms Olivera MILJANOVIC Prim. doc., Director Centre for Medical Genetics and Immunology Medical Centre of Montenegro	

Harrie STORMS nistry of Health, Welfare and Sports Sanne VAN WEEZEL nistry of Health, Welfare and Sports Olgica VASILEVSKA apologised/excusée nior Counselor, Directorate for Multilateral Relations and Security operation, Sector for Council of Europe, OSCE and other European ganizations nistry of Foreign Affairs	
Olgica VASILEVSKAapologised/excuséenior Counselor, Directorate for Multilateral Relations and Securityoperation, Sector for Council of Europe, OSCE and other European ganizations	
nior Counselor, Directorate for Multilateral Relations and Security operation, Sector for Council of Europe, OSCE and other European ganizations	
Ms Anne FORUSSenior Adviser, ph.d, Biotechnology and health legislation departmentDivision of specialised health care servicesNorwegian Directorate of HealthMs Vårin HELLEVIKDepartment of Specialized Mental health care and AddictionTreatment Norwegian Directorate of Health	
Mariola GROCHULSKA partement des droits de l'homme histère de la Justice	
of. Jorge SOARES esident du Conseil National d'Ethique pour les Sciences de la Vie	
Gheorghe BORCEAN esident de l'Ordre des Médecins et Prof. Ass. à l'Université de decine et Pharmacie " Victor Babes" de Timisoara e-President of the Romanian College of Physicians talul Municipal Caransebes s Beatrice Gabriela IOAN sociate Professor esident of the Bioethics Commission of the Romanian College of ysicians	
titutul de Medicina Legala Lyalya GABBASOVA	
Andrew GAIDEROV puty Director partment of International Affairs histry of Health Daria KHUKHREVA histry of Health Olga OPANASENKO unsellor partment of the Humanitarian Cooperation and Human Rights histry of Foreign Affairs	

	Ms Maria ORESHINA 1st secretary	
	Department of European cooperation	
	Ministry of Foreign Affairs	
	Mr Eduard RYZHKIN	
	Senior Counsellor	
	Department of European Cooperation Ministry of Foreign Affairs	
	Ministry of Foreign Analis	
SAN MARINO / SAINT- MARIN	Dr Luisa BORGIA President of the National Bioethics Committee	
SERBIA I SERBIE	Prof. Dr 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	
SLOVAKIA / SLOVAQUIE	Prof. 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	
SLOVENIA / SLOVÉNIE	Prof. Marjeta TERČELJ ZORMAN Dr.Med.	
SPAIN / ESPAGNE	Ms Concepción MARTIN ARRIBAS	
SPAIN / ESPAGNE	Subdirección General de Investigación en Terapia Celular y Medicina Regenerativa Instituto de Salud Carlos III – ISCIII	
	Prof. Carlos M. ROMEO – CASABONA	
	Professor of Penal Law, Head	
	Inter-University Chair in Law and the Human Genome	
SWEDEN / SUÈDE	Ms Tesi ASCHAN	
	Legal Adviser	
	The National Board of Health and Welfare, Socialstyrelsen	
SWITZERLAND / SUISSE	Prof. Dr. Rodrigo RODRIGUEZ	
	Département fédéral de justice et police DFJP Office fédéral de la Justice OFJ, Domaine de direction Droit privé	
	Ms Nina SCHERRER Wissenschaftliche Mitarbeiterin	
	Sektion Forschung am Menschen, Eidgenössisches Departement des	
	Innern EDI, Bundesamt für Gesundheit BAG, DB Öffentliche Gesundheit, Abteilung Biomediz	
	Mr Patrick GRÜTER	
TURKEY / TURQUIE	Ms Tuna İLBARS	
	Unit Coordinator	
	Department of Blood and Blood Products	
	Directorate General of Health Services Ministry of Health	

	Prof. Ergun ÖZSUNAYapologised/excuséProfessor of CivilComparative Law and EU Private lawIstanbul Culture University, Faculty of Law	
UKRAINE	Ms Iuliia DAVYDOVA Professor, Head of High-Risk Pregnancy Department Institute of Pediatrics, Obstetrics and Gynecology, member of Local Bioethics Committee Prof. Olesya HULCHIY Vice-Rector Shupyk National Medical Academy of Postgraduate Education	
UNITED KINGDOM / ROYAUME-UNI	Dr Mark BALE Deputy Director Health Science & Bioethics Division Department of Health Dr Pete MILLS Assistant Director Nuffield Council on Bioethics	

PARTICIPANTS / PARTICIPANTS

PARLIAMENTARY	Mr Benny BORGHEI apologised/excusé	
ASSEMBLY / ASSEMBLÉE	Committee on Social Affairs, Health and Sustainable Development	
PARLEMENTAIRE	Ms de BRUIJN WEZEMAN	
	Rapporteur on the deinstitutionalisation of people with disabilities	
	Ms Jennifer DE TEMMERMANapologised/excuséeRapporteur, Committee on Social Affairs, Health and SustainableDevelopment	
	Mr Olivier FRANÇAISapologised/excuséRapporteur Général pour sciences et technologueCommittee on Culture, Science, Education and Media	
	Ms Anita GHOLAMIapologised/excuséeCommittee on Social Affairs, Health and Sustainable Development	
	Ms Dana KARANJACapologised/excuséeCommittee on Culture, Science, Education and Media	
	Ms Tanja KLEINSORGE Head of Secretariat Committee on Social Affairs, Health and Sustainable Development	
	Committee on Coolar Analis, freakn and Custamable Development	
	Ms Aiste RAMANAUSKAITE Committee on Social Affairs, Health and Sustainable Development	
OFFICE OF THE COMMISSIONER FOR HUMAN RIGHTS / BUREAU DU	Mr Hasan BERMEK Adviser	
COMMISSAIRE AUX DROITS DE L'HOMME		

CDCJ	Prof. Dr. Rodrigo RODRIGUEZDépartement fédéral de justice et police DFOffice fédéral de la Justice OFJDomaine de direction Droit privéMs Ekaterina KUDELICH	
СРТ	Mr Michael NEURAUTER Head of Division of the Secretariat of C	apologised/excusé PT
T-PD	Ms Sophie KWASNY Head of Unit	apologised/excusée
CDENF	Ms Katrin UERPMANN Secretary of the Steering Committee for the Rights of the Child	
CD-P-TS	Mr Guy RAUTMANN Secretary to the European Committee of	apologised/excusé on Blood Transfusion
CD-P-TO	Ms Marta LOPEZ-FRAGA Secretary	apologised/excusée

OTHER PARTICIPANTS / AUTRES PARTICIPANTS

EUROPEAN UNION /	Awaiting nomination / Nomination en attente	
UNION EUROPEENNE	Awaiting nomination / Nomination en attente	
EUROPEAN	Dr Jim DRATWA	
COMMISSION /		
COMMISSION	Head of Ethics and Head of the EGE Secretariat	
EUROPEENNE	Member of the Bureau of European Policy Advisers (BEPA)	
EUROPEENNE	European Commission	
	Ms Barbara GIOVANELLI	
	Ms Mariann KARCZA	
CONFERENCE OF INGOS	Mr Miguel CABRAL	
I CONFERENCE DES		
OINGS		
CANADA	Awaiting nomination / Nomination en attente	
HOLY SEE / SAINT-SIEGE	Mgr Jacques SUAUDEAU	
JAPAN / JAPON	Awaiting nomination / Nomination en attente	
MEXICO / MEXIQUE	Ms Berenice CRUZ MAYA	
	Directrice du Développement Institutionnel à la Commission Nationale	
	de Bioéthique	
	Mr Gustavo Fernando OLAIZ BARRAGAN	
	Sous-directeur des Politiques Publiques et de Bioéthique à la	
	Commission Nationale de Bioéthique	
	Mr Eden GONZALEZ	
	Commission Nationale de Bioéthique	
	Ms Alejandra TOVAR	

USA I ETATS-UNIS D'AMERIQUE	Awaiting nomination / Nomination en attente	
UNESCO	Ms Dafna FEINHOLZ KLIP Section de la bioéthique Division de l'éthique des sciences Ms Orio IKEBE	apologised/excusée
OECD / OCDE	Mr David WINICKOFF STI/STP Ms Laura KREILING	
WHO / OMS	Dr Andreas REIS Technical Officer HIS/KER Cluster of Health Systems and Ir	apologised/excusé

OBSERVERS / OBSERVATEURS

BELARUS / BELARUS	 Mr Andrei BABCHANOK Head of Legal Department Ministry of Health Mr Siarhei LIASHCHUK Head of the National Transplant Registry Ms Valerya SOKOLCHIK Head of the Repablican Center of Bioethics Belarusian Medical Academy of Postgraduate Education
CONFERENCE OF EUROPEAN CHURCHES (CEC) / CONFERENCE DES EGLISES EUROPEENNES (CEC)	Rev. Sören LENZ Executive Secretary

INGOS / OINGS

REHABILITATION INTERNATIONAL (RI)	Dr Régine ERNST apologised/excusée Project Manager on Rehabilitation and Foreign Affairs
EUROPEAN ASSOCIATION OF SERVICE PROVIDERS FOR PERSONS WITH DISABILITIES (EASPD)	Mr Josep Maria SOLÉ CHAVERO Board member of EASPD
EUROPEAN DISABILITY FORUM (EDF)	Mr Pat CLARKE Ms Marine ULDRY Ms Kristijan GRDJAN (MHE) Mr Jonas BULL (MHE) Ms Helen PORTAL (Inclusion Europe) Ms Olga KALINA (ENUSP) Ms Stephanie WOOLEY (ENUSP) Ms Jolijn SANTEGOEDS (ENUSP)

CONSULTANTS / CONSULTANTS

BELGIUM / BELGIQUE	Prof. Kristof VAN ASSCHE
	Consultant in equity of access to treatment and equipment in a context
	of scarce resources
DENMARK / DANEMARK	Dr Kristine SØRENSEN
	Consultant in health literacy
FINLAND / FINLANDE	Dr Leena PAAKKARI
	Consultant in health literacy
FRANCE / FRANCE	Dr Annagrazia ALTAVILLA
	Consultant in children participation
SWITZERLAND / SUISSE	Dr Marcello IENCA
	Consultant in neurotechnologies
AUSTRALIA /	Dr Piers GOODING
AUSTRALIE	Consultant in good practices in mental healthcare

an KLEIJSSEN tor / Directeur nation Society - Action against crime Directorate / <i>Direction de la</i>
té de l'information et de la lutte contre la criminalité hristophe POIREL tor / Directeur an Rights Directorate / Direction des droits de l'Homme
aurence LWOFF etary of the DH-BIO / Secrétaire du DH-BIO -33 (0) 388 41 22 68, Email: laurence.lwoff@coe.int eta HIBBARD nistrator / Administrateur -33 (0) 388 41 31 04, Email: lee.hibbard@coe.int orenzo MONTRASIO nistrator / Administrateur -33 (0) 390 21 61 87, Email: Lorenzo.montrasio@coe.int atalia ZAYTSEVA nistrator / Administratrice -33 (0) 390 21 62 51, Email: Natalia.zaytseva@coe.int etatherine FORNE tant / Assistante -33 (0) 388 41 22 20, Email: catherine.forne@coe.int aura HENNINGER ttant / Assistante -33 (0) 388 41 30 05, Email: laura.henninger@coe.int atiana WINTER ttant / Assistante

	Mr Federico CONTI Trainee / Stagiaire Ms Emilie WILBERG Trainee / Stagiaire
THE INTERPRETING,	Ms Chloé CHENETIER
TRAVEL, EVENTS AND	Interpreter / Interprète
MULTIMEDIA	
DEPARTMENT (ITEM) /	Ms Lucie DE BURLET
LE SERVICE DE	Interpreter / Interprète
L'INTERPRETATION, DES	
VOYAGES, DES	Mr Jean-Jacques PEDUSSAUD
EVENEMENTS ET DU	Interpreter / Interprète
MULTIMEDIA (ITEM)	

Appendix II Agenda/order of business

 New DH-BIO members invited to introduce themselves Reminder about the main decisions to be taken during the meeting Decision on the Bureau proposal to postpone to the 19th plenary meeting the vote on the draft Additional Protocol Collection of examples of good practices aiming at promoting voluntary sures in mental health care Objectives: Presentation of the draft compendium by Dr Piers Gooding (Australia), Consultant and exchange with delegations Discussion on the further step towards the finalisation of the compendium to be finalised in November 2021) Health literacy Objectives:
 Sures in mental health care Objectives: Presentation of the draft compendium by Dr Piers Gooding (Australia), Consultant and exchange with delegations Discussion on the further step towards the finalisation of the compendium P timeline: Compendium to be finalised in November 2021)
 Sures in mental health care Objectives: Presentation of the draft compendium by Dr Piers Gooding (Australia), Consultant and exchange with delegations Discussion on the further step towards the finalisation of the compendium P timeline: Compendium to be finalised in November 2021)
 Presentation of the draft compendium by Dr Piers Gooding (Australia), Consultant and exchange with delegations Discussion on the further step towards the finalisation of the compendium timeline: Compendium to be finalised in November 2021) Health literacy Objectives:
Objectives:
Objectives:
 Presentation of the draft report by Dr Leena Paakkari (FI) and Dr Kristine Sørensen (DK), Consultants, and exchange with delegations Discussion on the further step towards the development of a Guide: methodology and timeline (SAP provisional timeline: Guide to be finalised in Spring 2022)
Wednesday 2 June 2021 (9.30-13.00)
Protocol concerning the protection of human rights and dignity of persons with regard to involuntary placement and involuntary treatment within mental health care services
Other business Terms of reference proposal (2022-2025) SAP: Methodology and time frame proposals for the priority actions planned

	4. Information update on ethical aspects of the Covid-19 pandemic
12.30- 13.00	If time allowed, brief exchange of updated information on ethical aspects of the pandemic
	Thursday 3 June 2021 (9.30-13.00)
	6. Genome editing technologies
09.30- 11.30	 Objectives: Discussion on the elements to be clarified with a view to an agreement Modalities of work and timeline
	7. Children's participation in the decision-making process on matters regarding their health
11.30- 13.00	 Objectives: Presentation of the summary of the survey by Ms Annagrazia Altavilla (F), Consultant Modalities of work and timeline for the development of a guide: joint drafting group (DH-BIO and CDENF) (NB: SAP timeline: Guide to be finalised in Autumn 2022)
	Friday 4 June 2021 (9.30-13.00)
	8. Equity in access to treatment and equipment in a context of scarcity
09.30- 10.45	 Objectives: Examination of the outline for draft guidelines on equity in access to treatment and equipment in a context of scarcity prepared by Prof. Kristof Van Assche (B), Consultant Discussion on the next step towards the development of guidelines: methodology and timeline
	9. Neurotechnologies
10.45- 12.00	 Examination of the study prepared by Dr Marcello lenca (CH), Consultant Preparation of the round table to be held in November 2021
10.00	10. Bureau elections
12.00- 12.10	 Mark Bale (UK): 1st term is coming to an end. He is re-eligible for a second term
12.10- 12.40	11. Decisions taken by the DH-BIO at its 18 th meeting
	 Approval of the list of decisions

	12. Dates of the next meetings
12.40-	Dates proposed:
12.50	 19th meeting of the DH-BIO: 2-5 November 2021 20th meeting of the DH-BIO: 31 May-3 June 2022

POINTS TO BE DEALT WITH IN WRITING

	14. Developments in the field of bioethics
	Delegations, including observers, are invited to send information in writing.
6	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
Ø	15. 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
	16. Cooperation with other committees
6	16. Cooperation with other committees
Ø	16. Cooperation with other committees a. European Committee on Organ Transplantation (CD-P-TO)
Ø	 16. Cooperation with other committees a. European Committee on Organ Transplantation (CD-P-TO) b. European Committee on Blood Transfusion (CD-P-TS) c. Consultative Committee of the Convention for the Protection of Individuals with
Ø	 16. Cooperation with other committees a. European Committee on Organ Transplantation (CD-P-TO) b. European Committee on Blood Transfusion (CD-P-TS) c. Consultative Committee of the Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data (T-PD)
()	 16. Cooperation with other committees a. European Committee on Organ Transplantation (CD-P-TO) b. European Committee on Blood Transfusion (CD-P-TS) c. Consultative Committee of the Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data (T-PD)