

COUNCIL OF EUROPE



CONSEIL DE L'EUROPE

Strasbourg, 6 December 2013

DH-BIO/ abr RAP 4

COMMITTEE ON BIOETHICS

(DH-BIO)

4th MEETING

Strasbourg, 26-28 November 2013

ABRIDGED REPORT

Adoption of the agenda

1. The Committee on Bioethics (DH-BIO) held its 4th meeting in Strasbourg from 26 to 28 November 2013. The agenda of the meeting and the list of participants appear in Appendix I and Appendix II to this abridged report.

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 Purposes

2. The DH-BIO was informed that on 7 August 2013, Moldova ratified the Additional Protocol to the Convention on Human Rights and Biomedicine, regarding Biomedical Research.

Developments in the field of bioethics

3. The DH-BIO took note of the developments in the field of bioethics within the member states, as well as in international organisations. It was also informed of the relevant developments in other Council of Europe bodies.

Decision-making process regarding medical treatment in end-of-life situations

4. The DH-BIO examined the draft Guide revised by the Drafting Group in the light of the comments received in the framework of the public consultation organised from February to April 2013.
5. Following one modification to a paragraph concerning the principle of autonomy, and subject to editorial and linguistic revision, the DH-BIO approved the Guide on the decision-making process regarding medical treatment in end-of-life situations.
6. The DH-BIO agreed:
 - to send the Guide as approved to the Steering Committee for Human Rights (CDDH);
 - to invite the CDDH to take note of the Guide and to submit it to the Committee of Ministers for taking note.
7. The DH-BIO agreed to launch the Guide at a Conference to be organised under the Austrian Chairmanship of the Committee of Ministers on 5 May 2014.

Predictivity, genetic testing and insurance

8. The DH-BIO examined a preliminary draft text for a possible legal instrument prepared by the Secretariat in consultation with experts having participated in the previous Working Group, which had been revised in the light of comments made by delegations.
9. Following this examination and in response to the terms of reference given by the Committee of Ministers¹, the DH-BIO agreed:
 - to prepare a non-legally binding instrument in the form of a Recommendation on the use for insurance purposes of personal health-related information, in particular information of a genetic and predictive nature;
 - to make public the preliminary draft Recommendation prepared by the Secretariat in consultation with experts having participated in the previous Working Group, in order to

¹ Terms of reference of the DH-BIO:

Expected results for 2013:

“(ii) b. a feasibility study is conducted and, if appropriate, a draft legal instrument prepared on the use of predictive health related data for insurance purposes;”

facilitate consultation of the text by delegations at national and international level, after having introduced a few changes, in particular in the Preamble and the Purpose.

10. Delegations were invited, after having carried out their consultation, to send their comments on the preliminary draft Recommendation no later than 30 March 2014, with a view to their discussion at the 5th plenary meeting (5-7 May 2014).
11. The DH-BIO also agreed to invite, in this context, the Consultative Committee of the Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data (T-PD), to comment on the preliminary draft Recommendation.

Genetic testing for health purposes: information document on genetic testing, in particular its nature and possible implications of its results

12. The DH-BIO was informed that the information document on genetic testing had now been translated into 27 non-official languages thanks mainly to the help and support of the European Society of Human Genetics (ESHG) and EuroGentest.
13. Delegations were invited to:
 - indicate the names of organisations/institutions to which the information document could be sent directly for dissemination;
 - send information on the dissemination and use of this information document at national level.

Re-examination of Recommendation (2006) 4 on research on biological materials of human origin

14. At its last plenary meeting, the DH-BIO agreed to consult the Consultative Committee of the Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data (T-PD) on the issues identified by the Drafting Group, in particular those relating to the concepts of identifiable or non-identifiable biological materials, and transborder flows. The Secretary of the T-PD presented the opinion prepared in response to this request. The DH-BIO thanked the T-PD for the elements of answers provided.
15. The DH-BIO examined the revised draft Recommendation prepared by the Drafting Group in the light of the comments made by delegations. It discussed in particular the articles concerning the removal of biological materials, from persons not able to consent, for storage for future research and concerning storage for future research of residual biological materials.
16. The DH-BIO agreed, in principle, to keep the provisions concerning the removal of biological materials, from persons not able to consent, for storage for future research. The formulation of these provisions may, however, be revised.
17. With regard to residual biological materials, the DH-BIO agreed to keep in the text the reference to the provisions concerning prior information foreseen in the case of removal for storage for future research.
18. The DH-BIO entrusted the Drafting Group with preparing, and subsequently submitting to the Bureau, a revised version of the draft Recommendation based on the following instructions:
 - review all provisions in order to, where necessary, insert a reference to associated data;
 - review the relevant provisions in order to address the case where biological materials have been anonymised.
19. The DH-BIO agreed, subject to approval by the Bureau, to make public for consultation the draft Recommendation, revised in this way, as a working document.
20. The DH-BIO entrusted the Secretariat with sending this text to experts/organisations/institutions that had been invited to attend the symposium organised in June 2012 and to invite them to send their comments on the text no later than 15 August 2014.

21. The DH-BIO entrusted the Drafting Group to prepare after this a revised version of the text in the light of the comments which will be received during the consultation.

Additional Protocol on the protection of the dignity and fundamental rights of persons with mental disorders with regard to involuntary treatment and involuntary placement

22. The Committee considered the question of the scope of the future additional protocol, with the participation of all the members of the Drafting Group entrusted with the preparation of this protocol.
23. It was agreed to keep the scope originally foreseen by the Steering Committee on Bioethics (CDBI), excluding “measures taken in relation to criminal offences”.
24. Regarding the applicability of the future protocol to persons subjected to an involuntary measure on the ground of a mental disorder while serving a prison sentence or in detention, but without any link between the measure and a criminal offence (whether the offence at the origin of the prison sentence or detention or a different one), it agreed to ask the opinion of the European Committee on Crime Problems (CDPC), when work on the preparation of the protocol has progressed further.
25. The DH-BIO supported the proposal made by the Drafting Group to organise a hearing with the INGOs representing the different sectors concerned. This hearing would be held on 10 or 11 March 2014 (date to be confirmed), during a meeting of the Bureau and would be co-chaired by the Chairperson of the DH-BIO and the Chair of the Drafting Group.
26. Delegations that have not yet done so were invited to send their comments on the issues raised by the Drafting Group no later than 10 December 2013 so as to allow the Group to examine them at its meeting to be held on 12-13 December 2013.
27. In the light of the comments received from the delegations and the remarks which will be made at the hearing, the Drafting Group would prepare a preliminary draft Protocol to be submitted to the DH -BIO at its 5th meeting (5-7 May 2014).
28. The DH-BIO agreed to submit in due course the text of this draft for comments to the Office of the High Commissioner for Human Rights of the United Nations (OHCHR).

Prenatal sex selection

29. The DH-BIO considered the proposals for action(s) made by the delegations to address the issue of prenatal sex selection.
30. The DH-BIO agreed to entrust the Bureau with the task of reflecting further on this question, in the light of the proposal presented by the Secretariat on the basis of the suggestions sent by delegations, and taking into account the cultural dimension of the issue.

Cooperation programme (DEBRA)

31. The Secretariat informed the DH-BIO that, at the request of the Slovak Delegation, a conference would be organised in Bratislava, at the end of May 2014, on genetic testing for health purposes in Central and Eastern Europe. The aim of this conference would be to contribute to promoting the principles laid down in the Additional Protocol to the Convention on Human Rights and Biomedicine, concerning Genetic Testing for Health Purposes.

Election of the Chair and the Vice-Chair

32. By acclamation and for a new term of office of one year, the DH-BIO re-elected as its Chairperson Dr Anne Forus (Norway) and, as its Vice-Chair, Dr Mark Bale (United Kingdom).

Future activities and working methods of the DH-BIO

Expert study on emerging technologies

33. The draft study on scientific developments in the field of emerging technologies was presented to the DH-BIO by the Rathenau Institute (NL) which had been commissioned to prepare it. The study would be finalised at the end of December 2013 and then made public.
34. The DH-BIO agreed to entrust the Bureau with the task of selecting the drafter(s) of the second study on emerging technologies which would focus on ethical questions raised by these technologies. The selection would be based on suggestions to be sent by delegations no later than 10 January 2014.

2014-2015 biennium

35. The DH-BIO was informed of the adoption by the Committee of Ministers of its terms of reference for the period 2014-2015. These include all the activity proposals made by the DH-BIO for this next biennium.

Trafficking in human organs

36. The Committee was informed that the Parliamentary Assembly had adopted an Opinion on the draft Convention against Trafficking in Human Organs, which had been transmitted to the Committee of Ministers. The draft Convention would be examined by the Committee of Ministers' Rapporteur Group on Legal Co-operation (GR-J) on 12 December 2013.

Dates of the next meetings

37. The DH-BIO agreed to hold:
 - its 5th plenary meeting from 5-7 May in Strasbourg. The Conference to launch the Guide on the decision-making process regarding medical treatment in end-of-life situations would be held on 5 May under the Austrian Chairmanship of the Committee of Ministers;
 - its 6th plenary meeting from 12-14 November 2014 in Strasbourg.

Equality between women and men

38. Dr Béatrice Ioan (Romania), Gender Equality Rapporteur within the DH-BIO, informed the Committee about the discussions that took place during the training day for Gender Equality Rapporteurs and the exchange of views with the Gender Equality Commission (GEC), organised on 12-13 November 2013.

Other business

Male circumcision and Article 6 of the Convention on Human Rights and Biomedicine

39. Following a request made by the General Secretariat, delegations had been invited, at the last plenary meeting (May 2013), to send information on the legal situation in their respective countries on the issue of male circumcision. All the delegations having sent such information had agreed to it being made public
40. The DH-BIO noted that, in the information sent, many countries pay attention to the conditions under which the intervention is carried out so as to minimise the risks for the health and well-being of the child.
41. The DH-BIO took note that the Secretariat would send a comment to inform the Secretariat of the Committee of Ministers about this aspect, which the latter might wish to take into consideration when preparing the draft reply to PACE Recommendation 2023 (2013) on children's right to physical integrity.

Cooperation with National Ethics Committees

42. The DH-BIO took note of the suggestions made by delegations concerning the possibilities for closer cooperation with National Ethics Committees.
43. The Bureau would consider this question and, if appropriate, make (a) proposal(s) to the DH-BIO at its next plenary meeting.

Co-operation with other committees

Consultative Committee of the Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data (T-PD)

44. The DH-BIO was informed of the work in progress by the T-PD, as well as the wish of this committee to cooperate more closely with the DH-BIO on issues concerning health-related data.
45. The DH-BIO planned to hold a joint meeting of its Bureau and that of the Consultative Committee of the Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data (T-PD) in order to examine how to strengthen cooperation between the two committees, in particular for the purpose of the re-examination of Rec(97)5 on the protection of medical data.

European Committee on Organ Transplantation (CD-P-TO)

46. In response to the request by the CD-P-TO, the DH-BIO expressed its interest to be associated with the reflection engaged by the CD-P-TO on the issue of donation in the framework of end-of-life care, including the hearing foreseen on this topic.

Drafting Group on the Human Rights of Older Persons (CDDH-AGE)

47. The DH-BIO was informed that the Steering Committee for Human Rights (CDDH) had approved the same week the draft Recommendation on the human rights of older persons which would be transmitted to the Committee of Ministers for adoption.

APPENDIX I

Agenda

Items for information, without decision required by the DH-BIO, are indicated by the following symbol:



1. Adoption of the agenda



2. 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 Purposes



3. Developments in the field of bioethics

4. Decision-making process regarding medical treatment in end-of-life situations

- Presentation of the revised draft Guide concerning the decision-making process regarding medical treatment in end-of-life situations
- Discussion with a view to its **approval and subsequent submission to the Committee of Ministers.**

The Guide could be launched during the Austrian Chairmanship of the Committee of Ministers (on the occasion of the 5th meeting of the DH-BIO May 2014)

5. Predictivity, genetic testing and insurance

- Presentation of the revised draft of a possible legal instrument on predictivity, genetic testing and insurance as prepared by the Secretariat in consultation with experts having participated in the previous working party
- Discussion with a view to a **formal decision on:**
 - **the possible preparation of a legal instrument;**
 - **if appropriate, the type of instrument (binding or non-binding).**



6. Genetic testing for health purposes: information document on genetic testing in particular their nature and possible implications of their results

Information on progress made in the preparation of the leaflet in non-official languages and in the dissemination of the leaflet in member states

7. Re-examination of Recommendation (2006) 4 on research on biological materials of human origin

- Presentation of the revised draft
- Discussion, in particular on the provisions concerning:
 - materials from person not able to consent;
 - storage of residual material,

with a view to a **decision to make it public for a consultation** to be organised in the first semester 2014

8. Additional Protocol on the protection of the dignity and fundamental rights of persons with mental disorders with regard to involuntary treatment and involuntary placement

- Information on the progress made by the Drafting Group
- **Discussion** in the light of the comments made by delegations, **on** the questions identified by the Drafting Group, in particular with regard to the **scope of the Additional Protocol** on the Protection of Human Rights and Dignity of Persons with Mental Disorders with regard to Involuntary Placement and Involuntary Treatment

9. Prenatal Sex Selection

Examination of proposals made by delegations on possible actions that could be undertaken by the DH-BIO, including the preparation of possible guidelines and good practices, with a view to a **decision on (a) possible activity(ies)**



10. Cooperation programme (DEBRA)

Delegations wishing to organise DEBRA activities in 2014 are invited to send their written request by 10 November 2013 at the latest.

11. Election of the Chair, Vice-Chair

The DH-BIO is invited to elect its Chair and Vice-Chair, whose terms of office will start on 1 January 2014.

Deadline for submission of nominations: Wednesday 27 November, 2.30pm

12. Future activities and working methods of the DH-BIO

a. Expert study(ies) on emerging technologies

Presentation by the Rathenau Institute of the draft study on scientific developments in the field of emerging technologies and exchange with a view to finalization of the study

- Exchange of views
- Work plan for the preparation of the second study on ethical issues



b. 2014-2015 biennium. Information on the CoE programme of activities



13. Trafficking in Human Organs



14. Relations with other international bodies

15. Dates of the next meeting

Dates proposed:

5th meeting of the DH-BIO: 13-15 May 2014 (alternative 20-22 May 2014)

16. Other business



a. Male circumcision and Article 6 of the Convention on Human Right and Biomedicine

Information on the elements provided by the delegations

b. Cooperation with National Ethics Committees

Discussion on the proposals made by the delegations



c. Cooperation with other Committees

i) Consultative Committee of the Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data (T-PD)

ii) Ad hoc Committee on Data Protection (CAHDATA)

iii) European Committee on Organ Transplantation (CD-P-TO)

iv) European Committee on Blood Transfusion (CD-P-TS)

v) Drafting Group on the Human Rights of Older Persons (CDDH-Age)

APPENDIX II

List of participants

MEMBER STATES / ETATS MEMBRES

Albania/Albanie -

apologised/excusé

Andorra/Andorre – Mr Pere PASTOR VILANOVA, Juge, Cour Suprême de Justice, Avda de Tarragona, AD 500 Andorra la Vella, Andorra

Armenia/Arménie – Mr Igor MADOYAN, Phd, President of National Center of Bioethics, n.24, ave Sayat-Nova, apt. 14, entrance 1, 0001 YEREVAN

Austria/Autriche – Dr. Doris WOLFSLEHNER, Head of the division “Bioethics” at the Federal Chancellery of the Republic of Austria, Ballhausplatz 2, 1014 Wien

Dr Renate FALLY-KAUSEK, Medical Officer, Federal Ministry of Health, Department III/8– „health of children and young people, gender aspects, nutrition“, Radetzkystasse 2, A-1030 WIEN

Dr. Peter BARTH, Oberstaatsanwalt, Abteilungsleiter-Stellvertreter in der Zivilrechtssektion, 1070 Wien, Museumstraße 7

Azerbaijan/Azerbaïdjan –

apologised/excusé

Belgium/Belgique – Mme Régine WILMOTTE, Juriste au sein de la direction générale des Etablissements de Soins du Service public fédéral « Santé publique », Place Victor Horta 40, boîte 10, 1060 Bruxelles, Belgique

Bosnia and Herzegovina/Bosnie-Herzégovine – Dr.Serifa GODINJAK, Head of Department for European Integration and International Cooperation, Sector for Health, Ministry of Civil Affairs, Trg BiH 1, 71000 Sarajevo, Bosnia and Herzegovina

Bulgaria/Bulgarie – Ms Sylvia TOMOVA, Ministry of Health, Legal Directorate, Chief Legal Advisor, Place St Nedelia 5, Sofia 1000

Croatia/Croatie - Dr. Vanja NIKOLAC, Head of Service, Service for blood, tissues and cells inspection, Ministry of Health, Ksaver 200a, 10 000 Zagreb, Croatia

Cyprus/Chypre – Mrs Rena PETRIDOU-VRAHIMI, Attorney of the Republic of Cyprus, Office of the Attorney General of the Republic of Cyprus, Appeli Street n° 1, 1403 NICOSIA **apologised/excusée**

Czech Republic/République Tchèque – Pr. Pavel MARTASEK, Professor of Medicine, Expert on Genetics, Dept. of Pediatrics, Center for Applied Genomics, 1st School of Medicine, Charles University, Ke Karlovu 2, Building D /2nd floor, 128 08 PRAGUE 2

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Finland/Finlande – Jaakko HALTTUNEN, Counsellor, Ministry for Foreign Affairs, Legal Service, Unit for Human Rights Courts and Conventions, PO Box 441, FI-00023 Government, Finland

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Mme Sandrine BOURDIN, Magistrate au sein du bureau du droit des personnes et de la famille à la direction des affaires civiles et du Sceau

Mme Caroline AZAR, Ministère de la Justice, Direction des Affaires Civiles et du Sceau, 13, Place Vendôme, F-75001 PARIS **apologised/excusée**

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Greece/Grèce – Dr Stamatia GARANIS-PAPADATOS, Lecturer, National School of Public Health, 196 Alexandras Avenue, 11521 Athens

Hungary/Hongrie - Ms Eszter MAROSI, Head of Secretariat, Medical Research Council, H-1051 Budapest, Arany János utca 6-8. 3/334

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Ireland/Irlande – Ms Angela O'FLOINN, Dept of Health, Hawking House, Dublin 2, Ireland

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Italy/Italie - Prof. Francesco d'AGOSTINO, Honorary President of the National Committee for Bioethics, Comitato Nazionale per la Bioetica, Via della Mercede 96, 00187, Roma **apologised/excuse**

Latvia/Lettonie – Dr.Vents SĪLIS, Assistant Professor at Riga Stradins University, Department of Humanities, Dzirciema street 16, Riga, LV- 1007

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Lithuania/Lituanie – Dr Eugenijus GEFENAS, Chairman of Lithuanian Bioethics Committee, Associate Professor at Vilnius University, Lithuanian Bioethics Committee, Vilnius str.33, LT-2001 VILNIUS

Ms Jurate SEREPKAITE, Chief specialist, Lithuanian Bioethics Committee, Vilnius str. 33, LT-2001, Vilnius
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M. Petru MOSCALIUC, Consultant, Law Department, Ministry of Health
apologised/excusé

Monaco -
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Serbia/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

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Rahel MÜLLER, avocate, Collaboratrice scientifique, Département fédéral de justice et police DFJP, Office fédéral de la justice OFJ, Domaine de direction de Droit privé, Gestion, état-major, Bundesrain 20, 3003 Berne

"The Former Yugoslav Republic of Macedonia"/"l'ex-République yougoslave de Macédoine" – **apologised/excusé**

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United Kingdom/Royaume-Uni - Dr Mark BALE, Principal administrator, Head of Genetics Branch; Scientific Development & Bioethics Division, Department of Health, Wellington House, Waterloo Road, London Road, London SE1 6LH

INVITED EXPERTS / EXPERTS INVITES

Prof. Bernard DUBUISSON, Faculté de droit et de criminologie, Collège Thomas More, Place Montesquieu, 2, 1348 Louvain-la-Neuve, Belgium

Prof. Elaine GADD, Honorary Professor, School of Law, Queen Mary University of London, Fox Court, 14 Gray's Inn Road, London, WC1X 8HN

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