

COUNCIL OF EUROPE



CONSEIL DE L'EUROPE

Strasbourg, 12 June 2018

DH-BIO/abr RAP 13

COMMITTEE ON BIOETHICS

(DH-BIO)

13th MEETING

Strasbourg, 23-25 May 2018

ABRIDGED REPORT

I. Adoption of the agenda

1. The Committee on Bioethics (DH-BIO) held its 13th meeting in Strasbourg from 23 to 25 May 2018. The agenda of the meeting and the list of participants appear in Appendix I and Appendix II to this report.

II. Developments in the field of bioethics

2. The DH-BIO took note of the developments in the field of bioethics within the member states, including with a view to a ratification of the Oviedo Convention.
3. Furthermore, information was provided on a recent seminar organized by the OECD on neurotechnologies in which Dr Mark Bale presented the relevant work of the DH-BIO. He informed the DH-BIO about a major workshop on this topic to be organized in Shanghai in September 2018. He referred to the preparation of guiding principles for responsible research and innovation in neuroscience by the Working Party responsible for this topic, which might consider asking the formal opinion of the DH-BIO on these guiding principles.
4. The DH-BIO also took note of developments in the (case-law of the) European Court of Human Rights and relations with international organisations. With regard to other Council of Europe bodies, the DH-BIO was informed about the adoption by the Committee of Ministers, on 18 May 2018, of the Protocol (CETS No. 223) amending the Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data (ETS No. 108) (modernisation of the Convention). The Protocol will be open for signature on 25 June 2018 in Strasbourg during the 3rd part-session of the Parliamentary Assembly.
5. The DH-BIO was also updated on developments in the reports of the Parliamentary Assembly of the Council of Europe on artificial intelligence and public debate.

III. 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

6. The DH-BIO took note of the following:
 - Additional Protocol on the prohibition of cloning human beings (ECTS n°168), ratified by Turkey on 1 November 2017
 - Additional Protocol on genetic testing for health purposes (ECTS n°203) ratified by Portugal on 26 March 2018
 - Additional Protocol concerning biomedical research (ECTS n°195) signed by the Czech Republic on 11 May 2018

IV. Gene editing

7. DH-BIO agreed with the proposal made by the Bureau for the examination of the ethical and legal issues raised by new genome editing technologies, and, in particular, on the scope and organisation of the work envisaged.
8. In view of ensuring common knowledge about these developments among delegations, the DH-BIO agreed to entrust the Bureau, in consultation with the Rapporteur on genetics and genomics, and in cooperation with the Secretariat, to select and commission an expert with drafting a technical study describing the state of

the art of gene editing technologies in human somatic and germ line cells in the health field.

9. The DH-BIO also entrusted the Secretariat, in consultation with the Rapporteur on genetics and genomics and in coordination with the Bureau, with the preparation of an overview document listing ethical issues and other perspectives already identified/expressed in relevant opinion/statements/reports published by ethics bodies, professional organisations, patient organisations, and other relevant actors both at national and international level. To that end, delegations are invited to send to the Secretariat links to such documents published at national and international level, either in English or in French.
10. The two documents would be made available to all DH-BIO members by the end of 2018, with a view to provide a basis for the discussion on ethical and legal issues raised by new gene editing technologies.
11. It was also agreed to invite delegations to provide information on the legal interpretation of Article 13 and Article 18(2) of the Oviedo Convention as reflected in national legislation.

V. Public Debate

12. The DH-BIO congratulated the Drafting Group on the work achieved and supported the approach proposed or the further development of the guide.
13. There was a constructive exchange of views on key aspects of public debate during which certain members of the DH-BIO called for guidance on:
 - understanding the challenges of public debate,
 - transparency of the process and vested interests therein
 - how to ensure that information is balanced and of the requisite quality to allow for fully informed public debate,
 - the roles and responsibilities of national ethics committees and/or equivalent bodies.
14. The DH-BIO stressed the importance of providing concrete examples of public debate initiatives (or elements/steps of the process) and lessons learned from the experience, including from countries and regions of Europe where public debate is less developed. To this end, delegations were invited to provide to the Secretariat any concrete examples of public debate or elements/steps in public debate processes, as well as contact information of any national bodies concerned or experts in this field.
15. The DH-BIO agreed to declassify the draft guide.
16. The DH-BIO also agreed with the Bureau proposal to organise a seminar on public debate on the first day of the 15th meeting of the DH-BIO in June 2019.

VI. Cooperation with other committees

T-PD: draft Recommendation on the protection of health-related data

17. The DH-BIO was informed that the adoption of the draft Recommendation on the protection of health related data was foreseen at the next plenary meeting of the T-PD (19-20 June 2018). As soon as the revised draft Recommendation will be available it will be sent to DH-BIO delegations who were invited to liaise with their colleagues in the T-PD to raise awareness, where relevant, on possible problems of compatibility

between certain provisions of the draft Recommendation and provisions of Rec(2016)6 on research on biological materials of human origin.

Ad Hoc Committee for the Rights of the Child (CAHENF)

18. The Secretary of the CAHENF thanked DH-BIO members for their contribution to the on-going work on the development of guidelines for age assessment of migrant children. In view of further guidance to be sought from the DH-BIO on multidisciplinary age assessment, delegations were invited to propose by 2 July 2018, experts in this field to help addressing related ethical issues. One of the key question would be in particular if medical examination should be last or first resort.
19. The Secretary of the CAHENF underlined the importance of the work of the DH-BIO on the implications for the rights of the child of developments in the biomedical field. This should usefully be taken into consideration as part of the mid-term evaluation of the strategy of the rights of the child in June next year and to consider possible further action beyond 2021.

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

20. The DH-BIO was informed about the adoption by the CD-P-TO of its position statement on global kidney exchange concept, which the DH-BIO had supported.

VII. Working methods and future activities of the DH-BIO

21. The DH-BIO held an exchange of views with Mr Christos Giakoumopoulos, Director General of General Directorate I – Human Rights and Rule of Law, on the current priorities as identified in the last report of the Council of Europe Secretary General on the State of Democracy, Human Rights and the Rule of Law and the role of the DH-BIO “to address ethical and legal challenges related to bioethics [...] that will require particular attention in the future”. He underlined the relevance of principles of the Oviedo Convention as well as the methodological experience of the DH-BIO to address the challenges raised
22. Mr Mikhail Lobov, Head of the Department on Human Rights Policy and Cooperation, underlined the importance of cooperation activities to assist member states in their own capacity building on bioethics to render Council of Europe standards practical and effective. In this connection, he stressed the value of mainstreaming bioethics into education and research for example by means of an academic network. In this context he underlined the importance of the new HELP course on key human rights principles in biomedicine.

VIII. Additional Protocol on the protection of the human rights and dignity of persons with mental disorder with regard to involuntary placement and involuntary treatment

23. The DH-BIO examined the draft Additional Protocol with change proposals resulting from the consultation meeting (Paris, 12-13 February 2018), and agreed to a number of changes. The Secretariat agreed to revise the Draft Explanatory Report to bring it in line with the changes agreed upon in the draft Protocol.
24. The DH-BIO, with the exception of one delegation which will confirm its vote by 11 June 2018, decided:

- a. to send the draft Additional Protocol for opinion by 5 November 2018 to the following Council of Europe bodies/Committees:
 - i. to the Steering Committee on Human Rights (CDDH), the European Committee for the Prevention of Torture (CPT), the Parliamentary Assembly, the Commissioner for Human Rights and the Conference of INGOs;
 - ii. to the European Committee on Crime Problems (CDPC), regarding the applicability to persons subjected to an involuntary measure, to address a mental health condition 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). The DH-BIO agreed to put the same question also to the CPT;
- b. to declassify the draft Additional Protocol as revised during the 13th DH-BIO together with its revised draft Explanatory Report.

IX. Follow up to the Conference for the 20th anniversary of the Oviedo Convention: Strategic Action Plan

25. The Chair of the Drafting Group presented the first elements for strategic action plan based on three thematic areas, namely “governance”, “vulnerability”, and “privacy/data”, with emphasis on the human rights challenges both within and beyond the framework of the Oviedo Convention.
26. The DH-BIO held an exchange of views in which delegations appreciated this initial approach and highlighted the strategic nature of the further work. Emphasis was also placed on developing possible cooperation with other Council of Europe organs as well as other intergovernmental organisations.
27. Support was expressed for the steps considered by the Drafting group for what was referred to as a “roadmap” for the work of the DH-BIO for the next five years.

X. Cooperation activities

Belarus

28. The DH-BIO was informed about the activities carried out and foreseen in the framework of the Action Plan of the Council of Europe for Belarus in 2018, including:
 - a conference on informed consent (December 2017)
 - a conference on organ donation (April 2018),
 - a student competition on bioethics (to end in July 2018)
 - a legal assessment of the transplantation law and (second part of 2018).

Russian Federation

29. Reference was also made to cooperation activities carried out in the Russian Federation in particular:
 - as part of the International Legal Forum held in Saint Petersburg (15-18 May 2018) a session on “At the Edge Between Law and Ethics: Modern Challenges in the Field of Latest Biomedical Technologies”, in which Dr Siobhán O’Sullivan, rapporteur general for the conference organised on the occasion of the 20th anniversary of the Oviedo Convention participated,
 - a session on bioethics, with a particular focus on prohibition of financial gain, during in-service training for civil servants organized at MGIMO on 26 April 2017.

XI. Bureau Elections

30. The DH-BIO re-elected by acclamation Professor Constantinos Phellas as Bureau member for a new two year term.

XII. Dates of next meetings

31. The DH-BIO agreed on the following dates for its next meetings to be held in Strasbourg:
- 14th meeting of the DH-BIO: 20 – 22 November 2018
 - 15th meeting of the DH-BIO: 4 – 7 June 2019

XIII. Other business

HELP course on essential human rights principles in biomedicine (Bioethics)

32. The DH-BIO was given a presentation on the progress achieved on the course on essential human rights principles in biomedicine for legal and health professionals, which has been developed by a group of international experts with the support of the HELP Unit and the Secretariat of DH-BIO. The first articulate version of the course (in English) would be freely accessible online after registration on the HELP website (<http://help.elearning.ext.coe.int/>) by the end of June 2018. In the course of national implementation, the course would be translated into other languages and adapted to the legal order of the countries concerned, subject to available funding.
33. Delegations interested in the implementation of the course in co-operation with their national training institutions were invited to contact the DH-BIO Secretariat in view of exploring possible options.

APPENDIX I
Agenda of the 13th meeting of the DH-BIO

1. Adoption of the agenda
-  2. Developments in the field of bioethics (to be dealt with in writing)
-  3. 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 (to be dealt with in writing)
4. Gene editing
5. Public debate
-  6. Cooperation with other committees
7. Working methods and future activities of the DH-BIO
8. Additional Protocol on the protection of the human rights and dignity of persons with mental disorders with regard to involuntary placement and involuntary treatment
9. Follow up to the Conference for the 20th anniversary of the Oviedo Convention: Strategic Action Plan
-  10. Cooperation activities
11. Bureau election
12. Dates of the next meetings
13. Decisions taken by the DH-BIO at its 13th meeting
14. Other business

Wednesday 23 May 2018 (9.30-13.00)

9.30	1. Adoption of the draft agenda
 To be dealt with in writing	<p>2. Developments in the field of bioethics</p> <p>Delegations, including observers, are invited to send information in writing.</p> <ol style="list-style-type: none"> a. Developments in member states and other states b. Developments in the field of bioethics in international organisations c. Relations with other international organisations: list of meetings d. Developments in other Council of Europe bodies e. Developments at the European Court of Human Rights
 To be dealt with in writing	<p>3. 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</p>
	<p>4. Gene editing</p> <ul style="list-style-type: none"> - Presentation of the replies by delegations to the questionnaire - On that basis, discussion on the organisation of the examination of the ethical and legal issues in accordance with the December 2015 DH-BIO Statement on gene editing

Wednesday 23 May 2018 (14.00-18.00)

14.00-14.30 	<p>14. Other business</p> <ul style="list-style-type: none"> - Help course: update <p>Presentation of the newly developed HELP course on bioethics</p>
	<p>5. Public debate</p> <ul style="list-style-type: none"> - Presentation of the outline prepared by the Drafting Group - Discussion with a view to providing guidance for the Drafting Group and agreement on the approach for the further development of the draft guide
	<p>6. Cooperation with other committees</p> <ol style="list-style-type: none"> 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) d. Ad Hoc Committee For the Rights of the Child (CAHENF)

Thursday 24 May 2018 (9.00-13.00)

	<p>7. Working methods and future activities of the DH-BIO</p> <ul style="list-style-type: none"> - Exchange of views with Mr Giakoumopoulos, Director General of DGI on the future activities and priority setting for the Council of Europe
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10.30	<p>8. Additional Protocol on the protection of the human rights and dignity of persons with mental disorders with regard to involuntary placement and involuntary treatment</p> <ul style="list-style-type: none"> - Presentation of the proposals for the revision of the draft Additional Protocol and Explanatory Report resulting from the consultation meeting held on 12-13 February 2018, in the light of the comments received from delegations - Discussion on the draft Protocol <u>with a view to a decision</u> to send it for opinion: <ul style="list-style-type: none"> a. to other Council of Europe bodies/committees Steering Committee on Human Rights (CDDH) and the European Committee for the Prevention of Torture (CPT) as well as, subject to the DH-BIO agreement, to the Ad Hoc Committee for the Rights of Persons with Disability (CAHPDH), the CoE Commissioner for Human Rights and the CoE Parliamentary Assembly; b. to the European Committee on Crime Problems (CDPC), regarding the applicability to persons subjected to an involuntary measure to address a mental health condition 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), in agreement with the decision taken by the DH-BIO at its 4th meeting (26-28 November 2013). The same question could be put also to the CPT, if DH-BIO agrees. <p>Subject to DH-BIO decisions, the deadline for such opinions could be set by 26 October 2018.</p>
Thursday 24 May 2018 (14.30-18.00)	
	<p>8. Additional Protocol on the protection of the human rights and dignity of persons with mental disorders with regard to involuntary placement and involuntary treatment <i>(To continue)</i></p>
	<p>9. Follow up to the Conference for the 20th anniversary of the Oviedo Convention: Strategic Action Plan</p> <ul style="list-style-type: none"> - Presentation of and discussion on the approach and preliminary outline prepared by the Drafting Group with a view to provide possible guidance and agreement on the approach to be followed
Friday 25 May 2018 (9.00- 13.00)	
	<p>9. Follow up to the Conference for the 20th anniversary of the Oviedo Convention: Strategic Action Plan <i>(To continue where necessary)</i></p>
	<p>10. Cooperation activities</p> <ul style="list-style-type: none"> - Cooperation activities within the framework of the Council of Europe Action plan for Belarus 2017-2018 - Cooperation activities in the Russian Federation (International Legal Forum, MGIMO)
	<p>11. Bureau election</p> <p>Delegations are invited to proceed to the election of one Bureau member for a two year term.</p> <p>Submission for nominations should be sent in writing to the Secretariat by <u>14.00 on Thursday 24 May 2018.</u></p>

	12. Dates of the next meetings Dates proposed: <ul style="list-style-type: none">- 14th meeting of the DH-BIO: 20-23 November 2018- 15th meeting of the DH-BIO: 4-7 June 2019 (alternative 18-21 June 2019)
	13. Decisions taken by the DH-BIO at its 13th meeting <ul style="list-style-type: none">- Approval of the list of decisions
	14. Other business <ul style="list-style-type: none">- Update on gender equality

APPENDIX II
List of participants

MEMBER STATES / ETATS MEMBRES

Albania/Albanie -

apologised/excusé

Andorra/Andorre – Mme Imma RODRIGUEZ, BATLLIA D'ANDORRA, Av. Tarragona, Ed. Les Columnes 62, Andorra, la Vella, AD 500 PRINCIPAUTÉ D'ANDORRE

apologised/excusée

Mme Sònia TUMÍ SÀNCHEZ, BATLLIA D'ANDORRA, Av. Tarragona, Ed. Les Columnes 62, Andorra, la Vella, AD 500 PRINCIPAUTÉ D'ANDORRE

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 – Mag. Martina ERLEBACH, juge, référendaire de la section civile, droit national de la famille, département I 1, 1070 Vienne, Museumstraße 7

Dr. Isabelle HASSLER, Federal Chancellery of Austria / Co-ordination Science, Research, Technology, Education, Social issues, Health, Secretariat of the Austrian Bioethics Commission, Ballhausplatz 2, 1010 Vienna

apologised/excuse

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

apologised/excusée

Azerbaijan/Azerbaïdjan – Dr. Gulnara BALAKISHIYEVA, Ph.D. in molecular biology, Senior Researcher at Department of Fundamental Problems of Biological Productivity, Institute of Molecular Biology and Biotechnology, Azerbaijan National Academy of Sciences, 2a Matbuat avenue, Az-1073, Baku

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

Bosnia and Herzegovina/Bosnie-Herzégovine – Dalibor PEJOVIC, Head of Unit for Statistics and Analytical Affairs and Reporting in Health, Department for Health

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

apologised/excusée

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

Cyprus/Chypre – Prof. Constantinos N. PHELLAS, Chair of the Cyprus National Bioethics Committee, University of Nicosia, 46, Makedonitissas Ave. P.O. Box 24005, 1700 Nicosia

Czech Republic/République Tchèque – (Ms) doc. PhDr. Ing. Hana KONEČNÁ, Ph.D. , Jihočeská univerzita v Českých Budějovicích, Zdravotně sociální fakulta, Katedra klinických a preklinických oborů, J. Boreckého 167/27, 370 11 České Budějovice

Denmark/Danemark – Emilie SORENSEN, The Ministry of Health, Holbergsgade 6, Copenhagen

Estonia/Estonie – Prof Hele EVERAUS, Head of the Clinic, Haematology and Oncology Clinic, Tartu University, Tartu University Hospital, Puusepa 8, 51014 Tartu

Finland/Finlande – Ms Ritva HALILA, M.D., Ph.D., docent, Senior Medical Officer, General Secretary, National Advisory Board on Social Welfare and Health Care Ethics (ETENE), Ministry of Social Affairs and Health, P.O. Box 33 (Meritullinkatu 10), FI-00023 Government

Ms Katja FOKIN, Legal Officer, Unit for Human Rights Courts and Conventions, Legal Service, Ministry of Foreign Affairs

Ms. Krista OINONEN, Government Agent before the ECtHR, Director, Unit for Human Rights Courts and Conventions, Ministry for Foreign Affairs **apologised/excusée**

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Germany/Allemagne – Prof. Dr. Elmar DOPPELFELD (Honorary chair of the "Permanent Working Party of Research Ethics Committees in Germany Inc."), Lenaustraße 15, D-50858 Köln

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Dr. Ingo HÄRTEL, Federal Ministry of Health, Division 317, Friedrichstraße 108, D-10117 Berlin

Dr. Stefan OSSEGE, Federal Ministry of Education and Research, Division 612, Friedrichstraße 130 B, D-10117 Berlin **apologised/excusé**

Dr. Dietmar WALTER, MPH, Federal Ministry of Education and Research, Division 612, Kapelle-Ufer 1, D-10117 Berlin

Mr. Volker SCHÖFISCH, Ministerialrat, Bundesministerium der Justiz und für Verbraucherschutz, Mohrenstraß 37, D-10117 Berlin **apologised/excusé**

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

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apologised/excusé

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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Mr Rögnvaldur Gunnar GUNNARSSON, legal adviser at The National Bioethics Committee

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Luxembourg – Delphine STOFFEL, Ministère de la Santé, Division des Affaires Juridiques, Villa Louvigny, Allée Marconi L-2120, Luxembourg

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Republic of Moldova/République de Moldova – Ms Rodica GRAMMA, Associate Professor, State University of Medicine and Pharmacy (USMF) "Nicolae Testemitanu"

Monaco - **apologised/excusé**

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Romania/Roumanie – Mrs Beatrice Gabriela IOAN, Associate Professor, President of the Bioethics Commission of the Romanian College of Physicians, Institutul de Medicina Legală, str. Bunavestire nr. 4, IASI

Mr. Gheorghe BORCEAN, President de L'Ordre des Medecins et Prof. Ass.a L'Universite de Medecine et Pharmacie " Victor Babes" de Timisoara, Vice-President of the Romanian College of Physicians, Spitalul Municipal Caransebes, str. Gradinilor nr. 36^a, CARANSEBES, jud. CARAS-SEVERIN 325400

Russian Federation/Fédération de Russie – Ms Irina NEKHAeva, attachée, Department for the common European cooperation, Ministry of Foreign Affairs

San Marino/Saint-Marin - Dr Luisa BORGIA, Vice-President of the National Ethics Committee, Contrada Le Grazie, n.3, 62029 Tolentino (MC), Italia

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 National Committee for bioethics of UNESCO Commission of Serbia, Serbian Academy of Sciences and Arts, 11000 Belgrade

Slovakia/Slovaquie – Assoc. Prof. Jozef GLASA, MD, PhD, PhD; Institute of Pharmacology and Clinical Pharmacology, Slovak Medical University; National Reference Centre for Management of Chronic Hepatitis; Institute of Medical Ethics and Bioethics n.f.*; Ethics Committee, Ministry of Health SR; Limbová 12, 83303 Bratislava

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Spain/Espagne – M^a Concepción MARTIN ARRIBAS, Subdirección General de Investigación en Terapia Celular y Medicina Regenerativa – Instituto de Salud Carlos III – ISCIII, Avda. Monforte de Lemos 5, 28029 Madrid

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