

ANNUAL REPORT OF ACTIVITIES 2016

Bioethics and Law Observatory (OBD)
UNESCO Chair in Bioethics
University of Barcelona



Organització
de les Nacions Unides
per a l'Educació,
la Ciència i la Cultura



Càtedra UNESCO de Bioètica
de la Universitat de Barcelona



Observatori de
Bioètica i Dret
Universitat de Barcelona

www.bioeticaidret.cat
www.bioeticayderecho.ub.edu
www.bioethicsandlaw.es

Activities carried out by the Bioethics and Law Observatory during 2016

In 2016 we've celebrated the 21th anniversary of the Bioethics and Law Observatory (OBD) of the University of Barcelona. In this context, OBD has been involved in a wide range of activities fostering autonomy, shared responsibility and decision-making in Bioethical issues with the aim of achieve a more transparent and democratic society.

14 researchers of the Observatory are involved in a research project called "**Transfers of biological material of human origin: social, legal and bioethical aspects**" (**BODYBIOLAW**), funded by the Ministry of Economy, Industry and Competitiveness (Ref. DER2014-57167-P). This research project has served to determine practices around the transfer of biological material of human origin and to investigate if a hidden market exists. In the project framework, two collective books have been published about this topic. Moreover, in February of 2016 took place the [X Seminar on the Universal Declaration on Bioethics and Human Rights \(UNESCO\): Article 21 "Transnational Practices: Human body against the global market"](#). Likewise, members of the OBD have participated in several national and international research projects and have published a large amount of papers in high impact journals.

The Opinion Group of the Bioethics and Law Observatory has published various documents that have been widely echoed. In June 2016 the [Declaration on research integrity in responsible research and innovation](#) was published. The document, which was drawn up jointly by the UNESCO Chair in Bioethics of the University of Barcelona (UB) and the Catholic University of Portugal (UCP), analyses research integrity within the framework of responsible research and innovation. On the 9th of November the public presentation of the [Document on ageing and vulnerability](#) was carried out. The Document includes a set of recommendations with the main goal of promote an improvement of quality of life in elderly population by fostering their autonomy. Finally, on the 15th of December took place the press conference of the [Document on bioethics and gene editing in humans](#). It showed the rigorous work carried out by the Opinion Group of the Bioethics and Law Observatory about the ethical issues regarding the gene-editing techniques; in particular, it focuses on the CRISPR technique that is able to effectively modify the genetic endowment of humans. Likewise, one year after the publication of the [o Document on bioethics and Big Data: exploitation and commercialisation of user](#)

[data in public health care](#) (February 2015), it has been possible to prove its impact through the modification of the project VISC+ that took into account the recommendations developed by the Group. All the documents are available in open access in the [website](#) of the Bioethics and Law Observatory of the University of Barcelona.

Two books have been published in the **Bioethics Collection**, edited by Edicions UB and directed by Dra. Casado: On one side, **“To die in freedom”**, collective book coordinated by Albert Royes, aims at fostering a debate about an issue that affects the democratic quality of our society and the exercise of individual freedom. On the other side, **“The origin of Bioethics as a problem”** arises from the doctoral thesis carried out by Manuel Jesús López Baroni presented in 2015 within the framework of the PhD Program of the University of Barcelona, line of research “Bioethics and Law” directed by Dra. Casado.

The volumes 36, 37 and 38 of the [Bioethics and Law Journal](#) (Revista de Bioètica y Derecho, ISSN 1886-5887) have been published in Open Access, as the previous volumes of the journal. This Journal was launched in 2004 as a channel of communication among the Bioethics and Law Observatory, the Master in Bioethics and Law and the UNESCO Chair in Bioethics of the University of Barcelona. The framework to address all the bioethics issues that the Journal talks about are respect to Human Rights and a plural, lay and interdisciplinary point of view. For the third consecutive year the Journal has received quality recognition by the University of Barcelona.

In 2016, members of the Bioethics and Law Observatory have taken part in more than 20 seminars, workshops and national and international congresses. These activities have fostered critical thinking and mutual learning. It must be highlighted the membership participation in the [XIII International Congress of the International Association of Bioethics](#), organized by the International Association of Bioethics (IAB) in Edinburgh. Likewise, OBD has generated the educational content in the **Program “Youth, Science and Ethics”**, organized by the Catalan Foundation of Research and Innovation that this year has focused on the ethical aspects of climate change, and has led the [results presentation](#) that took place on the 29th of November in Cosmocaixa. Thus, it was possible to create a space of mutual learning among the scientific community and Catalan students from different highschools.

On the other side, the **involvement in Ethics Commissions** is a common activity for the membership of the Bioethics and Law Observatory. Currently, the membership participate in the following Commission: Comisión Nacional Para el Uso Forense del ADN, Comité Ético

del Banco Nacional de ADN de Salamanca, Comité de Bioética de Catalunya, Comité de Ética de la Investigación Clínica del Hospital Clínico de Barcelona, Comisión de Bioética de la Universidad de Barcelona, Comité de Ética Asistencial del Hospital Clínico de Barcelona, Comité de Ética Asistencial del Hospital de Barcelona, Comisión sobre Reproducción Humana del Hospital de Barcelona, Comisión de Responsabilidad Social de la UB, Grupo de Trabajo de la League of European Research Universities (LERU) and Consejo Asesor sobre aspectos éticos, legales y sociales del Instituto Europeo de Tecnología e Innovación, área de Salud, Comunidades de Conocimiento e Innovación (KICs) de la Unión Europea (Spanish Hub). Moreover, María Casado, PhD, director of the Bioethics and Law Observatory and of the Master in Bioethics and Law of the University of Barcelona, is part of the UNESCO advisory council to train judges in Bioethics.

In parallel, the [Master in Bioethics and Law of the University of Barcelona](#) and the [Association of Bioethics and Law and Alumni & Friends](#) have carried out many meetings and discussion sessions. The uses of Big Data in situations of crisis or the anonymity in gamete donation are just some of the topics that the association has talked about. Likewise, in 2016 the Observatory of Bioethics and Law has launched the [Master in Food Ethics and Law](#).

Research Projects

Title: Transfers of biological material from human origin: social, legal and bioethical aspects

Lead Researcher: Dr. Ricardo García Manrique

Financing Entity: Ministry of Economy, Industry and Competitiveness

Duration: from 01/01/2015 to 31/12/2017

Members of the group that have been involved in this project: 14

Publications

Documents of the Scientific and Technical Opinion Group

Title: Declaration on Research Integrity in Responsible Research and Innovation

Coordinators: María Casado, Maria do Céu Patrão Neves, Itziar de Lecuona, Ana Sofia Carvalho and Joana Araújo

Description: This volume, which was drawn up jointly by the UNESCO Chair in Bioethics of the University of Barcelona (UB) and the Catholic University of Portugal (UCP), analyses research integrity within the framework of responsible research and innovation. In this context, key issues related to bioethics which have become key elements to develop European and international research policies are tackled.

Publisher: Editions of the University of Barcelona

The Document was presented on the 27th of October of 2016.

Title: Document on ageing and vulnerability

Coordinators: María Casado, Pilar Rodríguez and Antoni Vilà

Description: This Document presents a set of recommendations that aims at promoting an improvement of quality of life in elderly population by fostering their autonomy.

Publisher: Editions of the University of Barcelona

Title: Document on Bioethics and gene-editing in humans

Coordinators: Josep Santaló and María Casado

Description: This Document analyses the impact of gene-editing in humans. All with the aim of foster a social debate and build an adequate juridical, ethical and deontological framework.

Publisher: Editions of the University of Barcelona

The Document was presented on the 15th of December of 2016 by the Dean **Dr. Cardellach** in collaboration with the authors of the Document: Josep Santaló, María Casado, Montserrat Boada, Mirentxu Corcoy, Itziar de Lecuona, Manuel J. López Baroni, Gemma Marfany and Albert Royes.

Books

Title: To die in freedom

Author/s: Albert Royes (coord.)

Publisher: Edicions de la Universidad de Barcelona

Description: To die in freedom means to decide when and in which way does a person want to finish his or her life, helped by healthcare professionals, when the death does not seem to be the worst of the alternatives. The Bioethics and Law Observatory of the University of Barcelona has always argued in favour of the decriminalization of euthanasia and the assisted suicide in certain conditions as they are fundamental rights should be guaranteed by the State. The first part of the book contains all documents that the Observatory has published on this issue since 1994 until now. In the second part the texts of the EXIT-ADMD Suisse Romande are reproduced. The information that "To die in freedom" offers.

Title: The origin of Bioethics as a problem

Author/s: Manuel Jesús López Baroni

Publisher: Edicions de la Universitat de Barcelona

Description: ¿When and where Bioethics was born? Traditionally, the creation of the neologism "Bioethics" has been attributed to Potter, in 1970. However, the origin of bioethics overcomes widely the northamerican context because clinical ethics has centuries of history and, moreover, all cultures and religions have reflected about problems like health, life and death. "Bioethics" was the term used by some theologians in order to indoctrinate healthcare professionals according to the catholic dogma in issues related to reproduction or death. This caused a defensive reaction and the incorporation of feminist, laicist and multicultural thoughts to the discipline. Finally, the rapidly advance of biotechnology and the fear of the consequences of human gene-edition has contributed to the consolidation of Bioethics as a plural and interdisciplinary field.

**Bioethics and Law Journal (Revista de Bioètica y Derecho, ISSN 1886-5887) in
Open Access**

Edition and publication of number 36:

<http://revistes.ub.edu/index.php/RBD/issue/view/1317>

Authors: Florencia Luna, Ricardo García Manrique, María Graciela de Ortúzar, María Cimmino, Loreto María García Moyano, Begoña Pellicer García, Begoña Buil Tricas, Raúl Juárez Vela, Sandra Guerrero Portillo, Isabel Antón Solanas, Jorge Antonio Herrera Llamas, Rodrigo Hernán García Alarcón, Karen Herrera Aguilar, Anamaria Gonçalves dos Santos Feijó, Anelise Crippa, Jéssica Lauren Steffen, Esther Farnós Amorós, Juan Carlos Fernández Fernández, Anna Badia Martí.

Edition and publication of number 37:

<http://revistes.ub.edu/index.php/RBD/issue/view/1363>

Authors: Fabiola Leyton, Eleonora Lamm, Nieve Rubaja, Ricardo García Manrique, Lídia Buisan i Espeleta, María Florencia Santi, Marta Ortega Gómez, Salvador Quintana, Adriana Krasnow, Roberto Baptista Dias da Silva, Thamires Pandolfi Cappello, Sergio Martinez, Adaiana Lima, Michela Pettoriali, Mónica Navarro-Michel, Isabel Maceda Fernández.

Edition and publication of number 38:

<http://revistes.ub.edu/index.php/RBD/issue/view/1403>

Authors: Albert Royes i Qui, María José Plana, Ana Rubio, Leonardo Xavier Brito Alvarado, María Jose Miranda Lucas, Dolors Comas d'Argemir, Sonia Maria Marinho, Fermin Roland Schramm, Noelia Igareda González, Ricardo Oliveira Rotondano, Ana Virgínia Gabrich Fonseca Freire Ramos, Lorena Rodrigues Belo da Cunha, Mónica Ballesteros Polo.

Seminars, courses and congresses

Activity: Meeting among the UNESCO Chairs in Bioethics of the Iberian Peninsula

Organizer: UNESCO Chair in Bioethics of the University of Barcelona and UNESCO Chair of the Catholic University of Oporto

Date: 21th of January of 2016

Participants: María Casado and Itziar de Lecuona

Activity: 11th Conference of Experts "End-of-life care"

Organizer: Catalan Society of Critical and Intensive Medicine (SOCMIC)

Date: 4th of February of 2016

Participants: Lluís Cabré and Itziar de Lecuona

Activity: 10th Seminar on the Universal Declaration on Bioethics and Human Rights (UNESCO): Article 21: "Transnational practices: human body against global market"

Organizer: UNESCO Chair in Bioethics of the University of Barcelona – Bioethics and Law Observatory

Date: 18th of February of 2016

Participants: María Casado, Itziar de Lecuona, Ricardo García Manrique, Ana Rubio and Albert Royes

Activity: Seminar "Implications of VISC+ Project"

Organizer: Health and Social Consortium of Catalonia

Date: 25th of February of 2016

Participants: Lidia Buisán

Activity: Meeting "Ways to Foster Research Integrity and Good Research Practice"

Organizer: League of European Research Universities (LERU) and University of Lund

Date: 8th of March of 2016

Participants: Itziar de Lecuona and M^a José Plana

Activity: CPA Premanent Seminar: "legal treatment of mental illness"

Organizer: University of Girona.

Date: 15th of March of 2016

Participants: Maria Àngels Porxas Roig

Activity: "1st HEIRRI Conference Teaching Responsible Research and Innovation at University"

Organizer: "Higher Education Institutions and Responsible Research and Innovation"

Date: 18th of March of 2016

Participants: Itziar de Lecuona

Activity: International Congress “Legal challenges in the 21st century”

Organizer: University of Sevilla

Date: 29th of March of 2016

Participants: María Casado

Activity: 3rd Edition of the Youth Scientific Congress

Organizer: Catalan Foundation of Research and Innovation

Date: 6th of April of 2016

Participants: Itziar de Lecuona

Activity: Seminar “Bioethics and Law”

Organizer: University of Granada

Date: 7th of April of 2016

Participants: María Casado

Activity: "EIT Health CAMPUS - Ideation Strengthen our Education Agenda"

Organizer: IESE Business School

Date: 11th of April of 2016

Participants: Itziar de Lecuona

Activity: 23rd International Congress on Law and Human Genome

Organizer: Interuniversity Chair in Law and Human Genome of University of Deusto

Date: 11th of March of 2016

Participants: Itziar de Lecuona

Activity: Seminar "Corpografías VIII. La ley sobre la piel: retóricas entre derecho y cuerpo. Contagio, transmisión, infiltración"

Organizer: Diego Falconi

Date: 3rd of May of 2016

Participants: Ricardo García Manrique

Activity: Sharing ideas: "University goes to Highschool"

Organizer: Programa de Millora i Innovació Docent de la Universitat de Barcelona

Date: 4th of May of 2016

Participants: Itziar de Lecuona

Activity: Course "UBIC of Health and Medical Sciences"

Organizer: "International Summer School" of the University of Barcelona

Date: 23rd of May of 2016

Participants: Itziar de Lecuona

Activity: Seminar on Philosophy of Law 2015-16 "The role of the judge in a democratic society"

Organizer: School of Law (University of Barcelona)

Date: 31st of May of 2016

Participants: María Casado

Activity: SSIBE Workshop: "Dudas y reflexiones éticas en la asistencia sanitaria"

Organizer: Comité de Ética Asistencial de los Servicios de Salud Integrados Baix Empordà

Date: 2nd of June of 2016

Participants: Albert Royes

Activity: Seminar "Scientific fraud and other bad practices"

Organizer: University of Salamanca.

Date: 3rd of June of 2016

Participants: Eduardo L. Mariño Hernández

Activity: Seminar on Philosophy of Law 2015-16 "¿Cómo presentar una comunicación en un Congreso?"

Organizer: School of Law of the University of Barcelona

Date: 6th of June of 2016

Participants: Víctor Méndez

Activity: Seminar on Educational Research "Ethics and Research"

Organizer: School of Education of the University of Barcelona

Date: 13rd of June of 2016

Participants: María Casado

Activity: LERU Research vice-rectorship meeting

Organizer: "The League of European Research Universities" (LERU)

Date: 13rd of June of 2016

Participants: Itziar de Lecuona

Activity: 22nd Scientific Colloquium on "Epigenetics and Human and Animal diet"

Organizer: EFSA, Autoridad Europea de Seguridad Alimentaria en Valencia

Date: 14th of June of 2016

Participants: María José Plana

Actividad: Seminar "25 years of the Catalan Association of Bioethics"

Organizer: "Societat Catalana de Bioètica en Ciències de la Salut"

Date: 21st of June of 2016

Participants: María Casado

Activity: Seminar on Care Ethics. Vallès Oriental: Shared decisions in order to respect the values of individuals

Organizer: Hospital General de Granollers

Date: 21st June of 2016

Participants: Itziar de Lecuona

Activity: International Congress 'Biomedical Research. Scientific and legal challenges of the 21st century'.

Organizer: School of Law of the University of Sevilla and the Research Group SEJ-504 International Biolaw Network of Excellence RIECOMM (DER2015-71828-REDT) of the Ministry of Economy, Industry and Competitiveness.

Date: 25th of June of 2016

Participants: Carlos María Romeo Casabona

Activity: 13rd International Forum on Quality Evaluation of Research and Higher Education

Organizer: University of Granada and Spanish Association of Behavioral Psychology

Date: 30th of June and 2nd of July of 2016

Participants: Fabiola Leyton and Yasmina Soto

Activity: XIII International Congress of the International Association of Bioethics.

Organizer: International Association of Bioethics (IAB)

Date: from 14th to 17th of June of 2016

Participants: Dra. María Casado, Itziar de Lecuona, Ricardo García Manrique, María José Plana, Pol Cuadros, Yasmina Soto and Maria Àngels Porxes

Activity: Ibero-American Network International Association of Bioethics

Organizer: International Association of Bioethics (IAB)

Date: 15th and 16th of June of 2016

Participants: María Casado and Florencia Luna

Activity: 9th International Congress on University Teaching and Innovation (CIDUI)
"Impacts of innovation on teaching and learning"

Organizer: several Catalan universities, among which we can find University of Barcelona

Date: 5, 6 and 7 of July of 2016

Participants: Itziar de Lecuona

Activity: Discussion on the participatory and deliberative session of the Public Program of Data Analysis for research and innovation in health in Catalonia

Organizer: Agència de Qualitat i Avaluació Sanitàries de Catalunya (AQUAS)

Date: 5th of July of 2016

Participants: Lidia Buisán and Itziar de Lecuona

Activity: Informative Session of the Public Programme of Data Analysis for research and innovation in health in Catalonia

Organizer: “Agència de Qualitat i Avaluació Sanitàries de Catalunya” (AQUAS)

Date: 12nd of July of 2016

Participants: Lidia Buisán and Itziar de Lecuona

Activity: 9th DataBeers - Barcelona

Organizer: DataBeers

Date: 19th of July of 2016

Participants: Itziar de Lecuona

Activity: Discussion "Biomedical revolution: new challenges, new dilemmas"

Organizer: Social Council of Pompeu Fabra University (UPF)

Date: 12nd of September of 2016

Participants: María Casado

Activity: 9th Meeting Luso-Brasileiro of Bioethics / 3rd Portuguese-speaking countries Meeting of Bioethics "Protecção e desenvolvimento global"

Organizer: Centro de Estudios de Bioética y de Sociedad Brasileña de Bioética and Instituto de Bioética de la Universidad Católica Portuguesa

Date: From 15th to 17th of September of 2016

Participants: María Casado

Activity: Program “Youth, Science and Ethics” organized by the Catalan Foundation of Research and Innovation

Organizer: Coorganized by the Catalan Foundation of Research and Innovation and la Caixa Foundation, in collaboration with the Education Department of the Government of Catalonia. The Bioethics and Law Observatory of the University of Barcelona has led the presentation of results that took place on the 29th of November in Cosmocaixa

Date: From 28th of September to 29th of November.

Participants: Itziar de Lecuona, Fabiola Leyton, Catia Faria and Mar Escarrabill

Activity: Course "Ethical and Scientific implications of the human gene-editing technique CRISPR"

Organizer: University of Pablo de Olavide, coordinated by Dr. Manuel Jesús López Baroni.

Date: 30th of September of 2016

Participants: María Casado

Activity: 5th Session on Active Ageing "Active Ageing and ethical values from the perspective of bioethics and law"

Organizer: Palma Council, governing board of Mallorca and Centro Baleares Europa

Date: 3rd of October of 2016

Participants: Ignasi Coll Rolduà

Activity: Open Class "Sesgo algorítmico: de la discriminación hacia la minería de datos justa"

Organizer: Departament of Philosophy of Law of the University of Barcelona

Date: 3rd of October of 2016

Participants: Fabiola Leyton

Activity: Colloquium Juliana González

Organizer: Bioethics National Commission of Mexico

Date: 10th and 11th of October of 2016

Participants: María Casado

Activity: Third Season of Discussion at Àgora Lliure-UPF

Organizer: Teatre Lliure

Date: 15th of October of 2016

Participants: Itziar De Lecuona

Activity: 29th Congress of Sociedad Española de Farmacología Clínica

Organizer: Vall d'Hebron Research Institute

Date: 19th, 20th and 21st of October of 2016

Participants: Itziar de Lecuona and Esther Cucurull

Activity: Recognition to the Program of Bioethics of FLACSO Argentina

Organizer: Organización Panamericana de la Salud, Organización Mundial de la Salud y FLACSO

Date: 31st of October of 2016

Participants: Florencia Luna

Activity: Conference "Right to Health and Social Inequalities"

Organizer: Bioethics and Law Observatory

Date: 3rd of November of 2016

Participants: María Casado

Activity: Conference "Food Chain in the Digital Single Market".

Organizer: European Commission of cooperation with the Slovak Presidency of the European Union Council.

Date: 9th of November of 2016

Participants: María José Plana

Activity: Course of Continuous Training of Hospital de Granollers

Organizer: Hospital General de Granollers

Date: 15th of November of 2016

Participants: Itziar de Lecuona

Activity: Course "Control del Comercio Electrónico de Alimentos"

Organizer: Consume, Food Safety and Nutrition Agency (AECOSAN)

Date: 23rd of November of 2016

Participants: Maria José Plana

Activity: Third Shared General Lecture: "Right to Health within the international legal field".

Organizer: Research Group SEJ-504 International Biolaw Network of Excellence RIECOMM (DER2015-71828-REDT) of the Ministry of Economy, Industry and Competitiveness

Date: 1st of December of 2016

Participants: María Casado and Ana Badía Martí

Activity: Round Table "Palliative care, sedation in agony, dignified death and advance care directives"

Organizer: Master in Forensic Science of the University of Barcelona

Date: 1st of December of 2016

Participants: Ignasi Coll

Activity: 10th Conference of the European Food & Feed Law Review

Organizer: EFFL Journal

Date: 8th of December of 2016

Participants: María José Plana

Activities carried out by the Master in Bioethics and Law and the Bioethics and Law Association

Activity: Session of the Bioethics and Law Association "Anonymity in gamete donation"

Date: 28th of January of 2016

Description: Session carried out by Florencia Luna.

Activity: Face-to-face sessions of the Master in Bioethics and Law (UB), with the students of the 17th and 18th edition

Date: From 8th to 19th of February of 2016

Activity: II Meeting Alumni & Friends of the Master in Bioethics and Law (UB)

Date: 8th of February of 2016

Description: Initiative with and for ex-students and students of the Master in Bioethics and Law to foster discussion about bioethical issues.

Activity: Session of the Bioethics and Law Association "Book Review 'The domain fo life' by Ronald Dworkin"

Date: 15th of March of 2016



Description: Session carried out by Albert Royes

Activity: Session of the Bioethics and Law Association "Bioethics during Obama legislature"

Date: 2nd of June of 2016

Description: Session carried out by Manuel Jesús López Baroni

Activity: Opening of the 19th Edition of the Master in Bioethics and Law of the University of Barcelona (2016-2018)

Date: 27th of October of 2016

Description: Opening of the new course of the Master in Bioethics and Law in charge of Dras. María Casado and Itziar de Lecuona

Activity: Session carried out by the Bioethics and Law Association, in collaboration with Carlos Castillo, "The use of Big Data during crisis situations"

Date: 24th of November of 2016

Description: Session carried out by the Bioethics and Law Association in collaboration with Alumni & Friends of the Master in Bioethics and Law of the University of Barcelona. Dr. Carlos Castillo, researcher at EURECAT has given a talk called "The use of Big Data during crisis situations"



Activities carried out by the Master in Food, Ethics and Law

Activity: Session called "Food, Ethics and Law"

Fecha: 19th of May of 2016

Description: The event analyses the rol of ethics and law in food research and innovation throught an interdisciplinary view

Activity: Opening of the 1st Edition of the Master in Food, Ethics and Law of the University of Barcelona (2016-2017)

Date: 6th of October of 2016

Description: Opening of the new course carried out by Maria José Plana, codirector of the Master

Activity: Face-to-face sessions of the Master in Food, Ethics and Law (UB), 1st Edition

Date: From the 6th of October to the 15th of December of 2016



Organització
de les Nacions Unides
per a l'Educació,
la Ciència i la Cultura



Càtedra UNESCO de Bioètica
de la Universitat de Barcelona



Observatori de
Bioètica i Dret
Universitat de Barcelona

www.bioeticaidret.cat
www.bioeticayderecho.ub.edu
www.bioethicsandlaw.es