

REPORT

Bioethics and Law Observatory (OBD)

UNESCO Chair in Bioethics

University of Barcelona

www.bioeticayderecho.ub.edu



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
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1. Introduction

The techno-scientific breakthroughs have an impact on the dignity and on the rights which has resulted in a bioethical issue at a global level. In order to study this contemporary conflicts, the Bioethics and Law Observatory (OBD, initials in the original language) offers a flexible project framed in the respect for the recognized human rights.

The OBD is a research centre of the University of Barcelona which carries out its activity through interdisciplinary and secularist viewpoints. Its members understand that bioethics is a field of knowledge that requires plural approaches and solid scientific bases to discuss the ethical, legal and social implications of biotechnology and biomedicine. The aim is to provide arguments and proposals to encourage autonomy and responsibility in bioethical decisions that result in the construction of a more transparent and democratic society.

2. Composition

2.1. Directory

Director

María Casado

UNESCO Chair in Bioethics of the University of Barcelona holder. Professor of Philosophy of Law. Director of the Consolidate Research Group “Bioethics, Law and Society” of the Government of Catalonia. Director of the Bioethics and Law Journal of the University of Barcelona. Founder and Director of the Master in Bioethics and Law of the University of Barcelona. Member of the Bioethics Commission of the University of Barcelona.

Deputy Director

Itziar de Lecuona

PhD in Law and Master in Bioethics and Law of the University of Barcelona. Professor, Public Health Department, University of Barcelona. Member of the Consolidate Research Group “Bioethics, Law and Society” of the Government of Catalonia. Co-coordinator of the Master in Bioethics and Law and co-director of the Master in Food Ethics and Law of the University of Barcelona. Member of the Bioethics Commission of the University of Barcelona; of the

Ethics in Research Commission of the Hospital Clinic of Barcelona and the Bioethics Commission of Catalonia.

Board of Directors

Lluís Cabré

Head of the Unit of Intensive Care and Emergencies of the Hospital of Barcelona. Member of the Deontological Commission of the Official College of Physicians of Barcelona, of the Consolidate Research Group "Bioethics, Law and Society" and President of the Bioethics and Law Association of the University of Barcelona. Teacher of the Master in Bioethics and Law of the University of Barcelona.

Mirentxu Corcoy

Professor of Criminal Law; Director of the Criminal Law and Criminal Science Department; and teacher of the Master in Bioethics and Law of the University of Barcelona.

Fabiola Leyton

PhD in Philosophy and Master in Bioethics and Law of the University of Barcelona. Postdoctoral researcher of the Bioethics and Law Observatory and Associate Professor of Philosophy of Law of the University of Barcelona. Member of the Consolidate Research Group "Bioethics, Law and Society" of the Government of Catalonia. Editor of the Bioethics and Law Journal of the University of Barcelona. Teacher of the Master in Bioethics and Law of the University of Barcelona.

Gemma Marfany

PhD in Biology from the University of Barcelona. Full Professor of Genetics of the University of Barcelona. Director of the Research Group "Human Molecular Genetics" of the University of Barcelona. Teacher of the Master in Bioethics and Law of the University of Barcelona.

Joaquim Martínez-Montauti

Coordinator of the Internal Medicine Department of the Hospital of Barcelona. Member of the Consolidate Research Group "Bioethics, Law and Society" of the Government of Catalonia. Teacher of the Master in Bioethics and Law of the University of Barcelona.

Josep Santaló

Professor of Cellular Biology from the Autonomous University of Barcelona and specialized in reproduction. Teacher on the Master in Bioethics and Law of the University of Barcelona. President of the Biosecurity Commission and former President of the Commission of Ethics in Animal and Human Testing of the Autonomous University of Barcelona. Member of the

Working Group on the studies and ethical reflection of Biomedical Research of the Bioethics Commission of Catalonia of the Ministry of Health of the Government of Catalonia and the Hinxton Group: An International Consortium on Stem Cells, Ethics and Law. Co-editor and Head of the Reproductive Medicine and Clinical Embryology.

Yasmina Soto

Graduated in Humanities from Autonomous University of Barcelona; Master in Bioethics and Law and Master in Digital Content Management of the University of Barcelona. Support technician of research of the University of Barcelona and member of the Consolidate Research Group “Bioethics, Law and Society” of the Government of Catalonia.

More information in: www.bioethicsandlaw.es/directory

2.2. Consolidate Research Group “Bioethics, law and society” of Generalitat de Catalunya (SGR-558)

The Consolidate Research Group “Bioethics, Law and Society”, of the Generalitat de Catalunya, which constitutes the core of the OBD, has as its principal objective the interdisciplinary study of the ethical, juridical and social implications of the development and application of the biotechnology and biomedicine.

Considering that the normative framework based on agreement and rationalization, with a relevant binding character, is particularly important in the Law and Social state, the group analyzes the legal system constituted by the convergence of moral rules, legal ones and ethics, placing the focus on public policies and their impact on citizens.

More information in: www.bioethicsandlaw.es/grc

2.3. UNESCO’s Chair

The UNESCO Chair in Bioethics at the University of Barcelona, founded in 2007, frames its work on the respect and promotion of human rights and advocates a conception of multidisciplinary, flexible and secular bioethics. It is based on the experience gained by the OBD in the fields of research and training, while promotes the knowledge transfer to other countries through networking.

It is part of the group of nine UNESCO Chairs in Bioethics established around the world, being the only one in the Spanish state in this field. It is also part of the [UNITWIN Network of UNESCO Chairs](#) world and the [Catalan Group of UNESCO Chairs](#).

Its objectives:

- To contribute to a global, plural and multidisciplinary discussion on the principles and fields of study of the Bioethics, in the framework of the recognized Human Rights.
- To promote an integrated activities system of research, formation and dissemination in Bioethics, and facilitate collaboration among researchers and professors of the universities and institutions of higher education in Spain, Europe and Latin America.
- To boost the transfer of the experience acquired in the OBD to developing countries in the fields of research, education and knowledge transfer, while sharing its methodology and formation actions.

More information in: www.bioethicsandlaw.es/unesco

3. Research

OBD analyses the bioethical issues in the framework of respect and promotion of the recognised Human Rights and, through the elaboration of research projects funded by public calls, generates a body of knowledge and publications available to the society.

3.1. Projects

Over two decades of the existence of the OBD, the research lines developed are varied as a result of an ability to detect at an early stage the most advanced implications of biotechnology applications. Topics of interest have evolved over time to accompany the evolution of bioethics. Starting with the analysis of new genetic technologies applied to the aging, followed biomedical issues of assisted human reproduction or nanotechnology, among many others, or the use of big data on health and the nowadays objectification of the human body traffic.

More information in: www.bioethicsandlaw.es/research

3.2. Publications

The multidisciplinary nature of the work at the Bioethics and Law Observatory is reflected in the variety of publications, in the diversity of approaches and contents, as well as in the way to divulge individual or joint work.

3.2.1. Articles and books

Research carried out by OBD members is published in the form of books, book chapters, monographs and scientific articles. The varied disciplinary perspectives involved in the bioethical analysis converge in the study and treatment of each issue in collective books and articles in specialised scientific journals.

More information in: www.bioethicsandlaw.es/publications

3.2.2. Documents

The OBD responds to techno-scientific issues that are of public debate by publishing and disclosing reports and documents contrasting views of the group and of invited specialists. The resulting status of the issue and specific proposals are published in a brief format to be disseminated and be useful to the media and public policy development. Subsequent to the publication of each "Document", a wide distribution is made to the scientific and professional community and the parliamentary groups. Likewise, public appearances and press conferences are held.

All documents are available in Open Access in PDF format in Catalan, Spanish and English languages, through Publicacions UB.

More information in: www.bioethicsandlaw.es/documents

3.2.3. Bioethics and Law Journal

The Bioethics and Law Journal (*Revista de Bioètica y Derecho*) (ISSN:1886-5887), whose quarterly electronic publication in Open Access (DOAJ) started in 2004, it is a scientific journal indexed in the main repositories of quality and is, alongside OBD, promoting the understanding of plural, interdisciplinary and secular Bioethics framed on the respect of the recognized Human Rights.

More information in: www.bioethicsandlaw.es/journal

3.3. Permanent interuniversity Seminar in Bioethics

The Permanent interuniversity Seminar in Bioethics is performed by a combined face-to-face meetings and online exchanges that allow the generation of knowledge in research projects of universities that are integrated into the networks of the Bioethics and Law Observatory and the UNESCO's Chair.

3.4. Visiting Professors' Program

A program of research visits to the headquarters of the UNESCO Chair of Bioethics and Law Observatory and to the universities that are part of the network allows the reception of high-level researchers.

4. Training

The Observatory members perform their teaching duties in the various degree and postgraduate courses, Masters and PhDs taught at the UB itself and also at other Spanish and foreign universities.

At the same time, the OBD organizes Courses and Conferences of a varied thematic and geographical scope, and provides customized training for those agencies and entities that require it.

4.1. Master in Bioethics and Law

The Master in Bioethics and Law is a degree from the University of Barcelona adapted to 120 ECTS credits which lasts two academic years. The program started in 1995 and has been developing steadily since then.

The teachers of the Master has a professional and academic prestige, led by Dra. María Casado –head of the UNESCO Chair in Bioethics at the University of Barcelona.

Co-organized by the UNESCO Chair in Bioethics and the Bioethics and Law Observatory, the Master in Bioethics and Law is a postgraduate training program of the UB adhered to

the Integrated Base Program for the Study of Bioethics from the UNESCO's educational Program.

The Master is aimed at the training in bioethics of health professionals, ethics committee members, legal professionals, journalists and, in general, to those interested in obtaining a comprehensive, flexible and integrated vision of bioethics. Its content is framed by the respect of the internationally recognized human rights, while providing an interdisciplinary training to enable rational decision making to bioethics problems and issues.

The methodology is adapted to the needs of each student, from different professional and geographical areas, so the Master can be entirely coursed at distance, through the virtual campus, or in blended format.

More information about the Master in: www.bioethicsandlaw.es/master

4.2. PhD Programs

4.2.1. Bioethics and Law line

The PhD line in Bioethics and Law has as its main objective the advanced training of researchers in different areas of bioethics and its relationship to human rights, from an interdisciplinary point of view. It is an interdisciplinary line that is attached to the Program in Law and Political Science, taught at the Faculty of Law, which is part of the offer of the Doctoral School of the UB

More information in: www.bioethicsandlaw.es/phd

4.2.2. LAST-JD. Erasmus Mundus

The OBD is part of the LAST-JD program (Erasmus Mundus) coordinated by the University of Bologna and created by the European Union to train doctors. This is an innovative program that allows candidates to conduct research on topics such as bioethics, computer science and law that require an interdisciplinary and international approach.

More information in: www.last-jd.eu

4.3. Customized training

The OBD offers customized training to organizations and institutions that require it. Particular groups often require specific tuition channeled towards solving particular interests and needs. On these cases, courses, whether theoretical or practical, are personally tailored to fulfil the needs of the group.

More information in: www.bioethicsandlaw.es/training

5. Dissemination and knowledge transfer

The Bioethics and Law Observatory - UNESCO Chair in Bioethics, is aware of the need for interaction between society and the university, which is even more glaring in the case of public entities, such as the University of Barcelona. Consequently, the OBD is involved in the process of knowledge transfer through teaching and scientific disclosure.

5.1. Direct actions of knowledge transfer:

- Normative impact and influence on the development of public policies: The Spanish, national and regional legislation, widely picked up the recommendations made in the group's work. To have an impact on regulatory changes is one of the main aims of the OBD; therefore, its achievement is a maximum recognition of the research work carried out in the OBD.
- Ethics Committees: Most OBD members are part of ethics and bioethics committees, either national or regional, research or health-care oriented, or created ad hoc in several specific requests. Especially stands out the Bioethics Committee of the University of Barcelona, created in 1995, recognized as a national model, which has given rise to an entire national network of bioethics commissions from other universities and public research centers. <http://www.ub.edu/comissioibioetica/en>.
- Scientific and health research institutions and communities: They have incorporate the conclusions and recommendations made by the OBD as part of their criteria of good

practice and have included them in their guidelines and protocols, disseminating them through its various communication channels.

5.2. Scientific dissemination actions

In order to promote informed social debate to encourage transparency and strengthen the capacity of autonomy and responsibility of citizens in a democratic society, the OBD performs actions of science disclosure.

In close cooperation with various actors of civil society –such as scientific communication associations, councils, professional associations, institutes, cultural centres, libraries and varied cultural institutions–, debates, roundtables and conferences are held. The OBD also maintains a sustained presence and a fluid relationship with the media, understanding the importance of their collaboration raising public awareness on scientific and bioethical issues.

In the OBD's website, which has the consideration of Certified Medical Web (CMW), multimedia content that provides stakeholders the necessary information to participate in an informed discussion is offered.

Several initiatives can be highlighted as actions that promote public participation: the initiative "[Libertad para decidir](#)" (Freedom to choose) and the dissemination platforms [Nanoyou](#) and [Xplorehealth](#), which emerged from European projects. Also exhibitions have been made related to the content of OBD's research projects such as embryo research "¿Tú qué piensas?" (What do you think?), [BIONET](#) and "Exponano, més petit que petit" (Exponano, smaller than smaller).

6. Research and teaching networks

The Bioethics and Law Observatory (OBD) is part of several networks that dedicate their work to the Bioethics from plural and multidisciplinary options.

In some cases, these networks are coordinated by the OBD itself: these are the "[Red sobre Bioética y Derechos Humanos](#)" (Bioethics and Human Rights Network) –backed by the Generalitat de Catalunya–, the [Network for the Teaching of Bioethics](#), which was originated

in one [Alfa Project](#) of the European Union, the "[Red de Comités de Ética de las Universidades Españolas y otros Organismos Públicos de Investigación](#)" (Network of Ethics Committees of Spanish Universities and other public research organizations) or co-coordinated, as in the [Ibero-American Network International Association of Bioethics](#) (IAB). In other cases, the OBD is a member of other national and international networks of prestige, such as the [UNITWIN Network of UNESCO Chairs](#), the [Unesco.cat](#) network, the network of the [International Institute of Research in Ethics and Biomedicine](#) (IIREB) and the [European Association of Global Bioethics](#).

Because of its work in the networks the OBD has become a reference for the creation of other centres of teaching and research in bioethics in the academic world in various countries where there is a close and ongoing collaboration.

This is the case in the Latin American region with the creation of the Argentine Observatory on Bioethics at the Latin American Faculty of Social Sciences in Buenos Aires; with various training initiatives at the University of Cuyo and Mendoza; the Institute of Bioethics PUCRGS, in Porto Alegre; the University of the Republic in Uruguay; and the Seminary of Bioethics at the University of Mexico. By means of various agreements the OBD also works closely with institutions such as the Library of Congress of Chile –which provides advice to parliamentarians of that country–, with the Federal Council of Medicine of Brazil –which brings together Brazilians doctors–, or the College of Bioethics of Mexico, which tries to influence lawmakers in their country with its proposals.

In Europe, the OBD has strong relationships with institutions and researchers from various countries through different networks. It is specially noteworthy, the role of the members of the OBD as an active part of the [League of European Research Universities](#) (LERU) linking 21 European research leaders universities to share their views and promote high quality research and a values-oriented research integrity.

The OBD also participates in social networks to encourage participation in the bioethical debate. Its presence includes [Twitter](#), [Facebook](#), [Linkedin](#), [Youtube](#) and [Google+](#).

More information in: www.bioethicsandlaw.es/networks



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