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Dictionary of Global Bioethics



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Preface

The Dictionary of Global Bioethics seeks to clarify terms, concepts, arguments, perspectives, and theories used in the emerging field of global bioethics. Bioethics emerged in North America as a new discipline in the 1970s and quickly expanded to other continents. Many new ideas and original approaches were used as a result of this discipline becoming increasingly applied not only within various healthcare contexts, but also in policies, regulations, and legislations. Later and especially since 2000 it became clear that the scope of bioethics was genuinely global following the globalization of medical research, medical technologies, and healthcare practices and in the face of global challenges such as pandemics and climate change. Viewed in this light bioethics is increasingly redefined as "global bioethics." This book aims to assist those who want to understand the most commonly used concepts in this emerging field of global bioethics.

This dictionary is a reference work that follows and supplements two previous reference volumes. The Handbook of Global Bioethics (2014) elaborates the global ethics principles included in the Universal Declaration on Bioethics and Human Rights that was unanimously adopted by the member states of UNESCO in 2005. It also elaborates several relevant global problems. The Encyclopedia of Global Bioethics (2016) systematically discusses topics and themes that are relevant in the contemporary global bioethics debate. This dictionary is different in that it provides brief clarifications of relevant topics. The presentations are succinct much as is the case with regular dictionaries and aim to help the reader to get an initial feel for meaning, content, relevance, and associated issues. Although it does not always provide final definitions (which is sometimes difficult because the field is emerging and developing) the topics do provide dynamic conceptualizations and thematic problematizations that elucidate what is at stake and spell out the various perspectives and related challenges as briefly as possible.

The entries presented are arranged in four categories that can be broken down into four different parts: "organizations" (Part I), "documents" (Part II), "persons" (Part III), and "topics" (Part IV). The selection of entries has been based on just how frequently they occur in the relevant literature dealing with global bioethics. We have scanned the keywords and indexes of reference publications, books on global bioethical issues, and journal publications in this area. However, the selection is ours and therefore is open to criticism.

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Nonetheless, we are convinced that this dictionary covers the most relevant issues in today's global bioethics.

Part I deals with those organizations that actively work in the field of global bioethics. We have included those that have a global outreach and mission in addition to actively working within the field of global bioethics. Although some organizations are regional or based in a particular country, those included here have as part of their mission to make contributions to the global debate. We have not included organizations with a more limited scope or those that do not contribute to the global ethical debate. Some of the organizations selected have been around for some time and during the past few decades have increasingly focused on global challenges. Some have deliberately promoted ethical approaches and contributed to the growth of global bioethics. Others are relatively new and owe their establishment to the processes of globalization. All the organizations presented play active roles in global bioethics despite having different natures. They range from professional associations, international agencies, international ethics committees, and scientific and humanitarian bodies.

Part II discusses relevant documents. We have identified and listed those that play a significant role in global bioethics and can be used as reference points for global debate. Most of these documents have been produced by international organizations. Since many topics in Part IV of this book refer to these documents further explanation is warranted in Part II. We have not included documents that have been developed at the national level despite possibly having a global impact. Declarations and policy statements have been adopted over the years by international bodies in response to global challenges. The first documents were focused on medical research. Later documents dealt with other specific issues such as environmental concerns, international exchange and trade, and genetics and life sciences. A few documents pertain in particular to global bioethics since they formulate ethical frameworks and principles for the ethical application of medicine, healthcare, and medical research around the world.

Part III briefly introduces a small band of people who have played substantial roles in promoting global bioethics or have introduced concepts that have significantly contributed to amplifying the global bioethical debate. Some worked for organizations and institutes that promoted ethical reflection on global issues. Others promoted fundamental ideas that were constitutive of current global ethical discourse. We are aware of many people around the globe who have enriched bioethics with their intellectual and practical activities. Although many have been working in the field of bioethics, not all have explicitly argued that bioethics should be a global endeavor. To lessen any risk for biases we have chosen to present only those people who have made a recognizable contribution during their lifetime but are sadly no longer among us.

Part IV comprises the bulk of the dictionary. It presents brief descriptions of topics in alphabetical order. Choosing which topics to include was relatively easy, although it can never be complete since global bioethics is constantly changing with new issues and topics arising all the time. An example is the COVID-19 pandemic that was unknown when we started to

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work on this book. The selection of topics was based on the systematic perusal of current literature relating to global bioethics. Some topics are familiar to bioethical discourse and included in other dictionaries. However, the emphasis will be on their relevance to global bioethical discourse. Many other topics are new. The processes of globalization have generated a range of new challenges facing bioethics. Furthermore, medical innovation and new biotechnologies pose new moral questions that need to be addressed often in a global context.

The *Dictionary of Global Bioethics* has been designed to be a helpful resource, especially for students and young scholars. It offers a broad introduction to global bioethics and gives readers a quick feel for the main concepts and relevant knowledge. It should also be a helpful resource for different academic scholars and professionals (healthcare professionals, researchers, educators, and lawyers) who, armed with deep knowledge and vast experience in their own fields of expertise, can benefit from a fast and straightforward look at other associated fields. Anyone wanting to know more about global developments in bioethics will hopefully find this book a useful resource.

Since this is the first dictionary covering the rapidly evolving field of global bioethics we realize this edition will need constant improvement and continuous updating. Any feedback on the overall composition or on particular entries would therefore be appreciated. Suggestions for future entries would also be welcome.

We would like to thank Floor Oosting (Springer/Nature) for her encouragement and support in developing the dictionary. We hope the book will be of use to those interested in global bioethics and will inspire them to explore the new ethical panoramas that continuously present themselves across the globe.

Pittsburgh, USA Ponta Delgada, Portugal Henk ten Have Maria do Céu Patrão Neves

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Maria do Céu Patrão Neves studied philosophy at Lisbon University (Portugal) and Louvain-la-Neuve (Belgium) (Ph.D. 1991) and bioethics at The Kennedy Center, Georgetown University, Washington DC, where she was a visiting scholar. She is currently Full Professor of Ethics at the University of the Azores (Portugal). She has taught applied ethics and biomedical ethics in several Portuguese universities. She was consultant on Ethics of Life for the President of the Portuguese Republic, a member of the National Ethics Committee, and sat on the Board of Directors of the International Association of Bioethics. She is a member of several ethics committees and advisory boards, a member of UNESCO's Global Ethics Observatory (a system of databases relating to the ethics of science and technology), and an expert on ethics for the European Commission. Her latest book is TheBrave World of Bioethics: The Origin of Bioethics in Portugal through Its Pioneers (2016). She is editor of Applied Ethics (12 volumes, 2017–2018) and Ethics, Science, and Society: Challenges for BioPolitics (2019). She is coordinator of the project "Biomedical Ethics and Regulatory Capacity Building Partnership for Portuguese Speaking African Countries (BERC-Luso)" financed by the European Development Clinical Trials Partnership/European Commission (2018–2021).

Part I Organizations



ASBH

The American Society of Bioethics and Humanities (ASBH) was established in 1998 through a merger of three existing organizations in the United States: the Society for Health and Human Values (SHHV), the Society for Bioethics Consultation, and the American Association of Bioethics. The oldest organization in the field of what later became bioethics was the SHHV, which was founded in 1969 as a professional association of persons committed to human values in medicine. It undertook several initiatives, notably in the field of medical ethics education.

The goals of the ASBH are to promote the exchange of ideas, to foster multidisciplinary, interdisciplinary, and interprofessional scholarship, research, teaching, policy development, professional development, and collegiality among people engaged in clinical and academic bioethics and the medical humanities. Such people engage in the following activities: encouraging consideration of issues related to values with regard to health services; the education of healthcare professionals; conducting educational meetings relative to the issues in healthcare ethics; encouraging research related to the ethical issues

at hand; and contributing to public discussion of these endeavors and interests including how they relate to public policy (http://asbh.org/). The governing body of the ASBH is the Board of Directors. This board consists of a five-member executive committee, nine directors at large, and one student director. The ASHB meets annually in a different US city every October. The society also has several committees. Each of these consist of members with similar interests (e.g., on public health or rural bioethics) who meet and communicate with one another throughout the year. Another committee is the Clinical Ethics Consultation Affairs Committee. This committee supports the goals of healthcare ethics consultation (including the certification of consultants) and is currently developing standards of accreditation for clinical ethics programs. The ASBH consists of approximately 1,800 members who are affiliated with a range of disciplines such as medicine, nursing, social work, theology, philosophy, education, medical humanities, and research studies. Many of these members work in a variety of healthcare settings such as hospitals, government agencies, and universities.



CIOMS

The Council for International Organizations of Medical Science (CIOMS) was established in 1949 in Brussels by the WHO and UNESCO (https://cioms.ch). The two founding organizations were concerned with facilitating the exchange of views and scientific information in the medical sciences. They achieved this goal by securing continuity and coordination between international organizations of medical sciences and by furnishing them with material and other forms of aid to keep them fully updated about their mission. The exchange of information and the provision of substantial and financial assistance to conferences and their participants helped them to achieve this endeavor. CIOMS is an international, non-governmental, and non-profit organization that brings together member organizations from the biomedical scientific community such as medical research councils and academies of sciences. The mission of CIOMS is to advance public health through guidance on health research including ethics, medical product development, and safety. It is especially interested in promoting international activities and thus has taken a global perspective from its inception. Initially focused on coordinating international medical conferences **CIOMS** became more engaged with health policy, ethics, and human values, especially after the adoption

by the World Health Assembly in 1977 of the goal of health for all. An early area of interest was medical research and clinical trials. CIOMS has emerged as a leading agency in exploring and clarifying the ethical issues involved in the use of human subjects in drug and vaccine research, especially for developing countries. Under the leadership of its Secretary-General Zbigniew Bankowski it organized international dialogue and issued ethical guidelines. In 1989 CIOMS published the International Guiding Principles for Biomedical Research Involving Animals. In 1993 it published the International Ethical Guidelines for Biomedical Research Involving Human Subjects. These guidelines were widely used in developing countries. CIOMS was also one of the first to articulate the role of vulnerability in medical research. The guidelines were revised and updated in 2002 and 2016. CIOMS was also one of the first international organizations to draw attention to global bioethics. Following a conference in Mexico in 1994 it adopted the Declaration of Ixtapa that emphasized a global agenda for bioethics. The governing body of CIOMS is the General Assembly who represent its international and national membership. The Executive Committee has 16 members including a permanent secretariat located in Geneva and housed in offices made available by the WHO.



Council of Europe/CoE (See also Oviedo Convention)

The Council of Europe (CoE) is the oldest European organization still active and the continent's leading human rights organization (https://www. coe.int/en/web/portal). It was founded in the aftermath of the Second World War (1949) in Strasbourg (France) by 8 countries to promote human rights in Europe. Today it comprises 47 member states and 6 observer members. Before becoming members of the CoE all countries have to sign the European Convention on Human Rights, a treaty designed to protect human rights, democracy, and the rule of law. The CoE has two main bodies: the Committee of Ministers, composed of the Ministers for Foreign Affairs of the member states, is the council's decision-making body; and the Parliamentary Assembly, composed of members of the national parliaments of each member state, seeking to spread human rights and democratic ideals in its neighborhood. The European Court of Human Rights and the European Directorate for the Quality of Medicines are two other very important bodies both aiming to promote common standards, charters, and conventions streamlining cooperation among European countries. Regarding bioethics the CoE has long been concerned about important human rights issues raised by the application of biology and medicine. Its first recommendations on the issue date from 1976. In 1985 the Resolution "On human rights and scientific progress in the field of biology, medicine and biochemistry" recommended that council intensify its work in relation to these problems from the standpoint of human rights and consider practices and legislation from both

national and international contexts. The CoE was the first international institution to acknowledge the need for an international body to address bioethical issues. The Committee of **Experts** Bioethics/CAHBI, an ad hoc pluri-disciplinary body, was set up in 1985 under the direct authority of the Committee of Ministers to intensify work on the impact of the progress of biomedical sciences on human beings, later to be recognized as the fourth generation of human rights (i.e., biological rights) or rights related to the application of biology and medicine to human beings. In 1992 the CAHBI became permanent and its name changed to Steering Committee on Bioethics/CDBI. In 2012, following the reorganization of intergovernmental bodies the CoE, the Committee Bioethics/DH-BIO took over the responsibilities of the CDBI. The main concerns of the bioethics committee prevailed such as guaranteeing a person's integrity, respecting human dignity, and drawing up common guidelines for all member states so that they can deal with the new situations created by rapid development of the life sciences. The most prominent achievement of the CoE's Ethics Committee was the Convention on Human Rights and Biomedicine (1997) and its additional protocols. The CoE also developed important resolutions on different topics such as Xenotransplantation (2003), Protection of the Human Rights and Dignity of Persons with Mental Disorders (2004), and Research on Biological Materials of Human Origin (2006, revised 2016). In 2014 the major topic was the total ban on any form of trading

in human organs. In 2015 the DH-BIO adopted a Statement on Genome Editing Technologies. Some other works are in progress such as predictivity, genetic testing and insurance, medical treatment in end-of-life situations, and emerging technologies.

Although the CoE's influence is restricted to European member states, it has an impact world-wide because its documents and the rulings of the European Court establish soft law and powerful precedents.