

The UNESCO DECLARATION ON BIOETHICS AND HUMAN RIGHTS

Principles to Practice

Joseph E Thornton MD

University of Florida

UF-VA Bioethics Unit, International Chair Bioethics

A Cooperating Center with the World Medical Association

Disclosures

Finance:

- Retired Faculty of the University of Florida

Associations:

- Catholic Medical Association
- American Psychiatric Association

Other

- 2026 Political Candidate for Florida State Senate District 06
- Opinions are my own and do not represent a group

Learning Objectives

Be	At the end of this session the participant will be able to
Describe	Describe the UNESCO Declaration On Bioethics and Human Rights
Demonstrate	Demonstrate how principles are applied in clinical situations
Demonstrate	Demonstrate interactions of policies and practice
Help	Help disseminate global awareness of the Declaration

UNESCO

1993

The United Nations Educational, Scientific and Culture Organization (UNESCO) recognizing the challenge of global medical care and newly emerging technologies established a bioethics program in 1993.

UNESCO Declaration



2005



The UNESCO Universal Declaration on Bioethics and Human (Declaration) was formalized on October 19, 2005.



This presentation details the Declaration and then promotes awareness through a global survey developed by the UF-VA UNESCO Bioethics Unit.

UNESCO Declaration

28 articles covering

5 domains

The strength of the Declaration is its systematic and comprehensive coverage of the bioethics field.

General provisions – 2 articles

Principles -15 articles

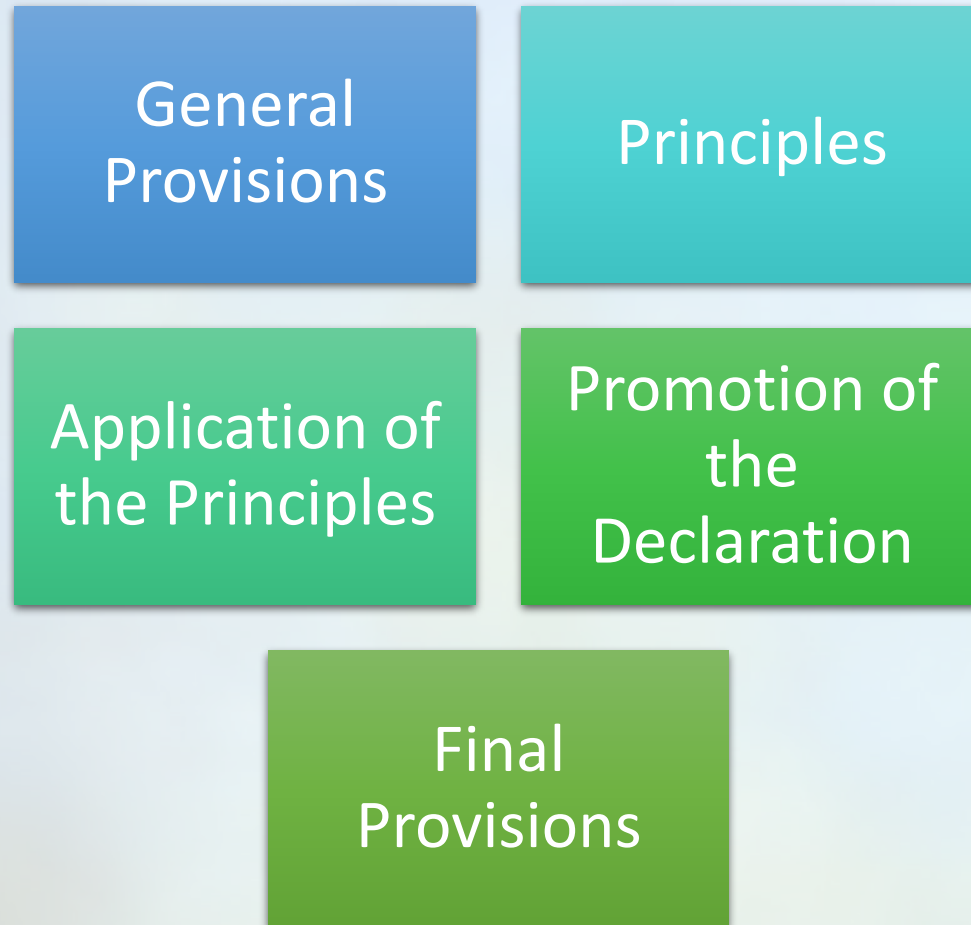
Applications – 4 articles

Promotion - 4 articles

Final provisions – 3 articles

UNESCO

Universal Bioethical Declaration



General Provisions

Scope

- Ethical issues related to medicine, life sciences and associated technologies as applied to human beings
- Addressed to States
- Provides guidance to public and private institutions, organizations, groups and individuals

Aims

- Provide a universal framework for ethical deliberations
- Promote respect for human dignity and rights
- Promote interests of present and future generations
- Promote concerns for biodiversity

UNESCO 15 Bioethical Principles

Article 3 – Human dignity and human rights

Article 4 – Benefit and harm

Article 5 – Autonomy and individual responsibility

Article 6 – Consent

Article 7 – Persons without the capacity to consent

Article 8 – Respect for human vulnerability and personal integrity

Article 9 – Privacy and confidentiality

Article 10 – Equality, justice and equity

UNESCO Bioethical Principles

Article 11 – Non-discrimination and non-stigmatization

Article 12 – Respect for cultural diversity and pluralism

Article 13 – Solidarity and cooperation

Article 14 – Social responsibility and health

Article 15 – Sharing of benefits

Article 16 – Protecting future generations

**Article 17 – Protection of the environment, the
biosphere and biodiversity**

UNESCO'S 15 BIOETHICAL PRINCIPLES

	Human Dignity and Human Rights	Autonomy and individual responsibility	Benefit and Harm	Privacy and Confidentiality	Consent
	Equality Justice and Equity	Persons without Capacity to Consent	Human vulnerability and personal integrity	Non-discrimination	Respect for Cultural diversity
	Solidarity and Cooperation	Social Responsibility and Health	Sharing of Benefits	Protecting Future Generations	Protecting Biodiversity, Biosphere and Environment

Article 3 – Human dignity and human rights

Full respect to

- human dignity,
- human rights

and fundamental freedoms

The individual should have

priority over the sole

interest of science or society.

Case 1

- 63 yo tobacco smoking obese patient lives in household with persons known to be ill with respiratory illness (Disease X)
- The clinician should (choose 1)
 - Be forced to participate in a placebo controlled trial of a vaccine to protect people from infection with Disease X (society benefits from knowledge of vaccine)
 - be educated on methods he can do to reduce risk of infection and spread of Disease X (eg self quarantine, self monitor symptoms, report to clinicians if sick) (mixes patient autonomy with good medical advice)
 - Be told he has been lucky that he is not sick and to return to clinic if he gets sick (full autonomy for patient but without benefit of care)

-

Article 4 – Benefit and harm

Maximize direct and
indirect benefits

- to patients, research participants
- and other affected individuals

Minimize

- Harm to such individuals should be minimized

Article 5

Autonomy and individual responsibility

Respect Autonomy

- of persons to make decisions,
- Also respecting the autonomy of others

Protect persons

- who are not capable of exercising autonomy,
- special measures are to be taken
- to protect their rights and interests.

Case 1b

- 63 yo tobacco smoking obese patient lives in household with persons known to be ill with Disease X
- Patient works as a school teacher for developmental disabled children. He refuses quarantine mask and vaccination stating it is his right to stay free
- Clinician should recommend to policy makers
 - Yes it is the individual right to be free
 - No, the individual does not have the right to expose others to risk

Article 6 Consent

Consent requires

- Capacity
- Adequate information
- Voluntary and free
- May be withdrawn without disadvantage

Scientific research requires consent

Capacity

Informed

Free

Withdrawn without disadvantage

Exceptions

- to this principle should be made only in accordance with ethical and legal standards adopted by States, consistent with the principles and provisions set out in this Declaration, in particular in Article 27, and international human rights law.
- In appropriate cases of research carried out on a group of persons or a community
- additional agreement of the legal representatives of the group or community concerned may be sought.
- In no case should a collective community agreement or the consent of a community leader or other authority substitute for an individual's informed consent.

UNESCO'S 15 BIOETHICAL PRINCIPLES

	Human Dignity and Human Rights	Autonomy and individual responsibility	Benefit and Harm	Privacy and Confidentiality	Consent
	Equality Justice and Equity	Persons without Capacity to Consent	Human vulnerability and personal integrity	Non-discrimination	Respect for Cultural diversity
	Solidarity and Cooperation	Social Responsibility and Health	Sharing of Benefits	Protecting Future Generations	Protecting Biodiversity, Biosphere and Environment

Article 7

Persons without the capacity to consent

Special protection is to be given to persons who do not have the capacity to consent:

- the person concerned should be involved to the greatest extent possible in the decision-making process of consent, as well as that of withdrawing consent;

Direct benefit

- research should only be carried out for his or her direct health benefit,

Exception

- Research which does not have potential direct health benefit should only be undertaken by way of exception, with the utmost restraint, exposing the person only to a minimal risk and minimal burden and if the research is expected to contribute to the health benefit of other persons in the same category

Refusal of such persons to take part in research should be respected.

Article 8

Respect for human vulnerability and personal integrity

- In applying and advancing scientific knowledge, medical practice and associated technologies,
- Human vulnerability should be taken into account.
- Individuals and groups of vulnerability should be protected
- Personal integrity of such individuals respected.

Article 9 – Privacy and confidentiality

- Respect
 - The privacy of the persons concerned and the confidentiality of their personal information should be respected.
- No Disclosure
 - Information should not be used or disclosed for purposes other than those for which it was collected or consented to,

Article 10

Equality, justice and equity

- The fundamental equality of all human beings
 - In dignity and rights
 - is to be respected
 - so that they are treated justly and equitably.

UNESCO 15 Bioethical Principles

Article 3 – Human dignity and human rights

Article 4 – Benefit and harm

Article 5 – Autonomy and individual responsibility

Article 6 – Consent

Article 7 – Persons without the capacity to consent

Article 8 – Respect for human vulnerability and personal integrity

Article 9 – Privacy and confidentiality

Article 10 – Equality, justice and equity

UNESCO Bioethical Principles

Article 11 – Non-discrimination and non-stigmatization

Article 12 – Respect for cultural diversity and pluralism

Article 13 – Solidarity and cooperation

Article 14 – Social responsibility and health

Article 15 – Sharing of benefits

Article 16 – Protecting future generations

**Article 17 – Protection of the environment, the biosphere
and biodiversity**

Article 11 – Non- discrimination and non- stigmatization

No discrimination

Against any individual or group

No exceptions

on any grounds,

violation of human dignity, human rights and fundamental freedoms.

Case 2

63 yo depressed male with suicidal ideation test positive for Disease X and has a cough. He smokes tobacco and has hypertension. He is to be admitted involuntarily to a psychiatric hospital. The psychiatric hospital asks for the Emergency Department to first treat him with monoclonal antibodies to prevent the worsening of Disease X (as recommended by the USA CDC)

As the Hospital Infectious Disease Director you advise

- No, the treatment is not proven for “psych “ patients
- No, “psych” patients cannot give informed consent
- No, the families of psych patients always sue doctors
- Yes, the CDC recommendations apply to this patient for treatment

Article 12 – Respect for cultural diversity and pluralism

Important

cultural diversity and pluralism should be given due regard.

Limited

However, such considerations are not to be invoked to infringe upon human dignity,
human rights and
fundamental freedoms,
nor upon the principles set out in this Declaration,
nor to limit their scope

UNESCO'S 15 BIOETHICAL PRINCIPLES

	Human Dignity and Human Rights	Autonomy and individual responsibility	Benefit and Harm	Privacy and Confidentiality	Consent
	Equality Justice and Equity	Persons without Capacity to Consent	Human vulnerability and personal integrity	Non-discrimination	Respect for Cultural diversity
	Solidarity and Cooperation	Social Responsibility and Health	Sharing of Benefits	Protecting Future Generations	Protecting Biodiversity, Biosphere and Environment

Article 13 – Solidarity and cooperation

Encourage

Solidarity among human beings

International cooperation towards that end

Social policy scenario

You are the State Department Health Advisor to the President of the United States. The USA currently has 100 million “extra” doses of vaccine and could pay for 500 million more

You advise the President

- Give the extra dose only to all USA citizens first and then sell remaining doses to the highest bidder
- Donate the 600 million doses to the UN for global distribution to best dampen the Disease X spread worldwide
- Vaccinate all Americans first with a 3rd dose (hold in reserve another 100 million just in case the refuses accept vaccine) then allow the UN to distribute the extra doses

Solidarity – Personal Practice

- Your state government has recommended mask wearing for individuals whenever in public, including outdoors and in state parks.
- Your reading and medical knowledge convinces you that the measures are excessive, and masks are not required unless near many other people even outdoors.
- Do you
 - Ignore the mask rule at the park because with your special knowledge you know the rule does not apply to you
 - Or
 - Wear the mask, even though it may not benefit you, but to help others appreciate the importance of doing everything we can to prevent the spread of disease.

Article 14 – Social responsibility and health

Purpose of governments (States)

- The promotion of health and social development for their people is a central purpose of governments that all sectors of society share.

Progress in science and technology should advance:

- access to quality health
- access to adequate nutrition and water;
- improvement of living conditions and the environment;
- elimination of the marginalization and the exclusion of persons on the basis of any grounds;
- reduction of poverty and illiteracy.

Social Responsibility Case

As an attending physician you are aware that patients sick with Disease X but who do not require hospital level of care are discharged, even if they are homeless and discharged to the street.

You decide your role is

- Hospital doctor only so it is not your problem
- Community member so you think the “homeless” should be locked away from others
- Advocate that healthcare is basic care and includes housing. Therefore, you advocate for supported housing, food and transportation for all discharged patients

Article 15 – Sharing of benefits

Benefits should be shared

- with society as a whole and within the international community,
- particular with developing countries.

Benefits may take any of the following forms:

- special and sustainable assistance to participants in research,
- access to quality health care;
- provision of new interventions stemming from research;
- support for health services;
- access to scientific and technological knowledge;
- capacity-building facilities for research purposes;
- other forms of benefit

Benefits should not constitute improper inducements to participate in research.

Sharing of Benefits

Some testing of Disease X vaccines occurred in Country A

Now that the vaccines are developed how should the benefit of the vaccine be shared?

- The leaders of A Country get a personal check for \$1 millions for giving permission
- The leaders of A Country get \$10 million dollars to share with the people they select
- The people of A Country are provided 20 million doses of vaccine
- The person who participated in the vaccine trial were paid several hundred dollars and so no further sharing of benefits is required

Article 16 – Protecting future generations

- Future generations
- The impact of life sciences on future generations, including on their genetic constitution, should be given due regard.

Disease X and future generations

There are reports that Disease X vaccine is causing sterility in male vaccines

As a health care leader you should

- Dismiss the reports because vaccines have never done that before
- Set up a registry to study the question
- Take the media reports as a medical emergency and stop the distribution of the vaccine

Article 17 – Protection of the environment, the biosphere and biodiversity

Due regard to

Interconnection between human beings and other forms of life,

Importance of appropriate access and utilization of biological and genetic resources,

Respect for traditional knowledge and

Role of human beings in the protection

- of the environment,
- the biosphere
- and biodiversity.

Application of the Principles

Article

Article 18 Decision making

Article

Article 19 Ethics Committees

Article

Article 20 Risk assessment and
management

Article

Article 21 Transnational practices

Article 18

Decision making

Promote

- Professionalism, honesty, integrity and transparency in decision-making

Use

- Best available scientific knowledge and methodology

Engage in regular dialogue

- Persons and professionals concerned and society as a whole

Promote

- Opportunities for informed pluralistic public debate, seeking the expression of all relevant opinions, should be promoted.

Article 19 Ethics Committees

Establish Ethics Committees

Independent, multidisciplinary and pluralist ethics committees

Role

- (a) assess the relevant ethical, legal, scientific and social issues related to research projects involving human beings;
- (b) provide advice on ethical problems in clinical settings;
- (c) assess scientific and technological developments, formulate commendations and contribute to the preparation of guidelines on issues within the scope of this Declaration;
- (d) foster debate, education and public awareness of, and engagement in bioethics.

Article 20 Risk assessment and management

- Appropriate assessment and adequate management of risk related to medicine, life sciences and associated technologies should be promoted



Article 21 Transnational practices

States involved in transnational research should adhere to the principles in this Declaration.

Transnational research should be reviewed by all the involved states

Transnational health research should be responsive to the needs of host

Article 21

The importance of research contributing to the alleviation of urgent global health problems should be recognized.

When negotiating a research agreement, terms for collaboration and agreement on the benefits of research should be established with equal participation by those party to the negotiation.

States should take appropriate measures, both at the national and international levels, to combat bioterrorism and illicit traffic in organs, tissues, samples, genetic resources and genetic-related materials.

Promotion of the Declaration

1

Article 22 Role of
the States

2

Article 23 Bioethics,
education, training
and information

3

Article 24
International
cooperation

4

Article 25 Follow-up
action by UNESCO

Article 22

Role of the States

States should take all appropriate measures or other character, to give effect to the principles set out in this Declaration supported by action in the spheres of education, training and public information.

States should encourage the establishment of independent, multidisciplinary and pluralist ethics committees, as set out in Article 19.

Article 23

Bioethics, education, training and information

- States should endeavour to foster bioethics education and training at all levels
- States should encourage the participation of international and regional intergovernmental organizations and international, regional and national non-governmental organizations in this endeavour.

Article 24 International Cooperation

States should foster international dissemination of scientific information and

encourage the free flow and sharing of scientific and technological knowledge.

States should

- Promote cultural and scientific cooperation
- Enter into bilateral and multilateral agreements
 - enabling developing countries to build up their capacity to participate in generating
 - and sharing scientific knowledge, the related know-how and the benefits thereof.

States should respect and promote solidarity between and among

- States, as well as individuals, families, groups and communities, with special regard for those rendered vulnerable by disease or disability or other personal, societal or environmental conditions and those with the most limited resources.

Article 25

Follow-up action by UNESCO

UNESCO shall promote and disseminate the principles set out in this Declaration.

In doing so, UNESCO should seek the help and assistance of the Intergovernmental Bioethics Committee (IGBC)

and the International Bioethics Committee (IBC).



UNESCO shall reaffirm its commitment to dealing with bioethics and to promoting collaboration between IGBC and IBC.

Final Provisions

Article

Article 26 Interrelation and complementarity of the principles

Article

Article 27 Limitations on the application of the principles

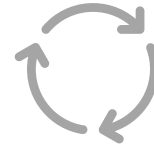
Article

Article 28 Denial of acts contrary to human rights fundamental freedoms and human dignity

Article 26 Interrelation and Complementarity of the Principles



This Declaration is to be understood as a whole and the principles are to be



understood as complementary and interrelated. Each principle is to be considered in



the context of the other principles, as appropriate and relevant in the circumstances.

Article 27

Limitations on the application of the principles

- If the application of the principles of this Declaration is to be limited, it should be by law,
 - including laws in the interests of public safety, for the investigation, detection and prosecution of criminal offences, for the protection of public health or for the protection of the rights and freedoms of others.
- Any such law needs to be consistent with international human rights law.

Article 28 Denial of acts contrary to human rights fundamental freedoms and human dignity

- Nothing in this Declaration may be interpreted as implying for any State, group
- or person any claim to engage in any activity or to perform any act contrary
- to human rights, fundamental freedoms and human dignity.
-
-



UF-VA ICB UNIT
FLORIDA- USA

UF-VA Bioethics Unit

Mission

to promote the teaching of ethics into
everyday clinical practice

Objectives of the UF-VA Bioethics Unit

Integrate
principles of
bioethics into
daily clinical
practice.

Moral distress and burnout

Increase the
visibility of
teaching
bioethics in the
clinical setting

World Bioethics Day

Promote
awareness of
the UNESCO
Declaration on
Bioethics

UNESCO Bioethics Survey

Support the
curriculum of
the UNESCO
Bioethics
Program

Ethics Benchmark Tool

World Bioethics Day October 19



UF-VA UNESCO Bioethics Unit World Bioethics Day Committee

Joseph Thornton, MD	Unit Head
Rajiv Tandon, MD	Chair, Steering Committee
Regina Bussing, MD	Steering Committee
Yaelis Guzman, MD	Resident Committee
Tian Sui, MD	Resident Committee
Caroline Nickerson	Committee

International World Bioethics Day Committee

Honorable Chair: Prof. Amnon Carmi
Head of Committee: Dr. Praveen Arora

Regional Coordinators:

1. Unit & Sub-Units of Italy: Dr. Miroslava Vasinova
2. Units in Asia & Pacific: Prof. Russell D'Souza
3. Units in India: Dr. Mary Mathew assisted by Col Dr. Derek D'Souza & Prof. Bipin Batra
 - a. India East subdivision: Dr. Mingma Sherpa
 - b. India West subdivision: Dr. Amol Hartalkar
 - c. India North subdivision: Dr. Manoj Goyal
 - d. India South subdivision: Dr. Mini Jacob & Dr. Peter Prasanth
4. Units in South Asia: Dr. Princy Louis Palatty(India) & Dr. Harischandra Gambheera(Srilanka)
5. Units in South East & East Asia: Prof. Toshiko Sawaguchi(Japan)
6. Units in Australia: Prof. Rodger Fernandes & Dr. Theong Ho Low
7. Units in Pacific: Dr. Sharon Biribo (Fiji)
8. Units in America: Prof. Moty Benyaker & Prof. Mira Kochsnousky
9. Units in China: Prof. Wu Chongqi
10. Units in Europe: Dr. Gerhard Fortwengel
11. Units in Africa: Prof. EFA Pierre

Members:

1. Dr. Rui Nunes
2. Dr. Altin Stafa
3. Dr. Tsai Fu Chang Daniel
4. Dr. Sabina Semiz
5. Prof. Suncana Roksandic
6. Dr. Alexander Lachapelle (IFMSA)

The Common Program of Events for World Bioethics Day 2017

12:00 pm - Part 1

Greetings by Unit Head: Joseph E. Thornton, M.D.
Presentation of the International Forum of Teachers Certificate

12:15 pm - Part 2

Mindfulness Relaxation Minutes

We will join the UF Psychiatry weekly Mindful Relaxation Minutes
for an opportunity to rejuvenate and reduce stress

12:45 pm - Part 3

Presentation

Case report and panel discussion on Disparity in Health Care Options for
Post Hurricane Maria Puerto Rico compared to Post Hurricane
Katrina in New Orleans

1:15 pm - Part 4

Panel Discussion

Operation Maria Rescue – A grass roots action plan to aid the people of
Puerto Rico - a guided participatory discussion
<https://sites.google.com/view/operationmariarescue/home>

2:30 pm - Break

3:00 pm - Part 5

Panel Discussion

Combating Hate and Racism using the Principles from the
UNESCO Declaration on Bioethics and Human Rights

4:30 pm - Part 6

Rolling presentations of Posters, Projects, Events and Photography including:

- The Christensen Project
- Arts in Bioethics
- 12th World Conference: Bioethics, Medical Ethics & Health Law Cyprus, March 22, 2017
- 2nd UF-VA UNESCO Bioethics International Seminar, Orlando September 2017

5:30 pm - Part 7

Dismissal and assignments

Ethics Curricula Benchmark Tool

UNESCO Declaration as a benchmark for curricula

- Assess for systematic comprehensive ethics,
- Facilitate discussion on ethical topics between different systems
- Enhance comprehensive integrated ethics training for clinical trainees at any stage of their career

Contact e-mail: joethornton@ufl.edu

Email: joethornton@ufl.edu



UF-VA

BIOETHICS UNIT

GLOBAL SURVEY

Global Survey

- In recognition of the First World Bioethics Day 2016, The University of Florida - Veterans Administration UNESCO Bioethics Unit developed a participatory introduction to the UNESCO Declaration on Bioethics and Human Rights.
-
- At the end of this survey, the participant is asked to identify their national (and state) location for purposes of showing the global distribution of the survey.
-
- Learn about the UNESCO Declaration on Bioethics
- <https://www.surveymonkey.com/r/UNESCO-BIOETHICS>
-
- <https://www.surveymonkey.com/r/UNESCO-BIOETHICS>