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HELP course on key principles for the protection of human rights in the biomedical field

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HELP Network Conference 2015

Interactions between *legal* and *other* professionals in human rights training

- Need to provide legal professionals with general training in Human Rights in Biomedicine

- Providing inter-professional trainings for a mixed audience of legal and health professionals, where appropriate

« *I wish to underline the need, for legal professionals, to be familiar not only with the European Convention on Human Rights…. I am thinking namely to the Oviedo Convention [Convention on Human rights and Biomedecine]* »

Dean Spielmann, President of the ECHR, HELP network Conference 2015

HELP Course: Key human rights principles in Biomedicine

- Increasing number of relevant cases before the **ECtHR**

  → High level seminar on « *International case law in bioethics:Insight and foresight* », December 2016

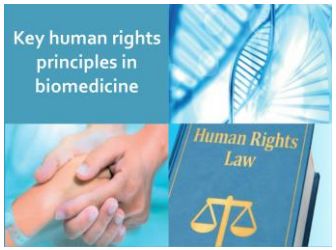
- Responsibility of both legal and health professionals for the implementation of human rights in biomedecine

  → **Two target audiences**

- Promoting interdisciplinary exchange

- Core principles to be further developed at a later stage

HELP Course: Key human rights principles in Biomedicine



- Finalised in June 2018

- Working group

  - **Prof. Jean-René Binet**, Rennes Faculty of Law, Director of Ecole doctorale SHOS
  - **Prof; Fabio Macioce**, Università di Roma LUMSA
  - **Ivana Roagna**, attorney at law, senior training specialist
  - **Dr Ronals Rozkalns**, attorney at law and medical doctor

  With the support of **Ian Culkin**, e-learning designer

  - Secretariat support: **HELP** Unit and **Bioethics** Unit

HELP Course: Key human rights principles in Biomedicine

Legal framework covered:

- CoE (Oviedo + Protocols; ECtHR)
- UN
- EU

- 8 substantive modules
- Knowledge checks after each module
- Additional materials available in the links
- **Glossary** – accessible throughout the entire course

Substantive modules

- Introduction: Definitions, international legal sources, principles
- Free and informed consent
- Medical Confidentiality

- Transplantation of Human Organs and Tissues
- Genetic Testing
- Biomedical Research
- Protection of the Embryo and Procreation
- End of Life

Introduction

1.

Introduction

Learning objectives

Welcome to the first substantive module of this Course on Bioethics! By the end of this session you will be able to:

- recognise the multiple ethical issues that arise in medicine, health and biotechnology;
- define the notions of human rights, bioethics and biomedicine and of the main concepts needed to explore the Course further;
- describe the relevance to bioethics of the European Convention on Human Rights (ECHR) and of other international human rights instruments;
- appraise the judicial interpretation of human rights applied to bioethical issues;
- illustrate the scope of application of the Oviedo Convention and recall the main rights and principles it enshrines.

Free and informed consent

2.

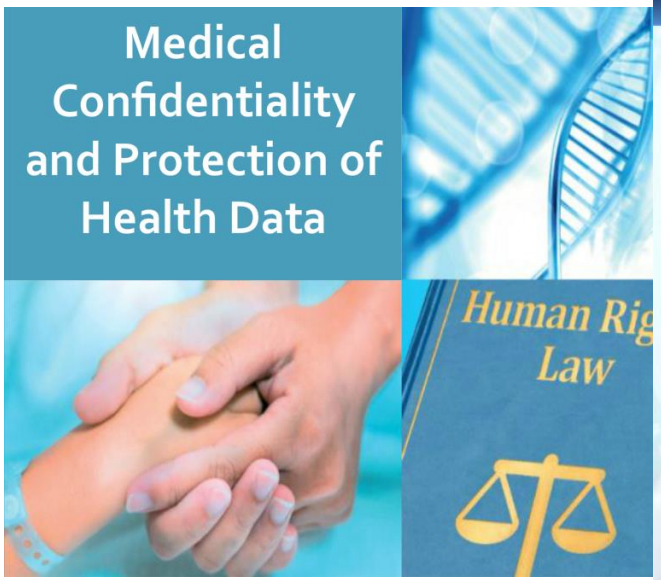
What is free and informed consent

Learning objectives

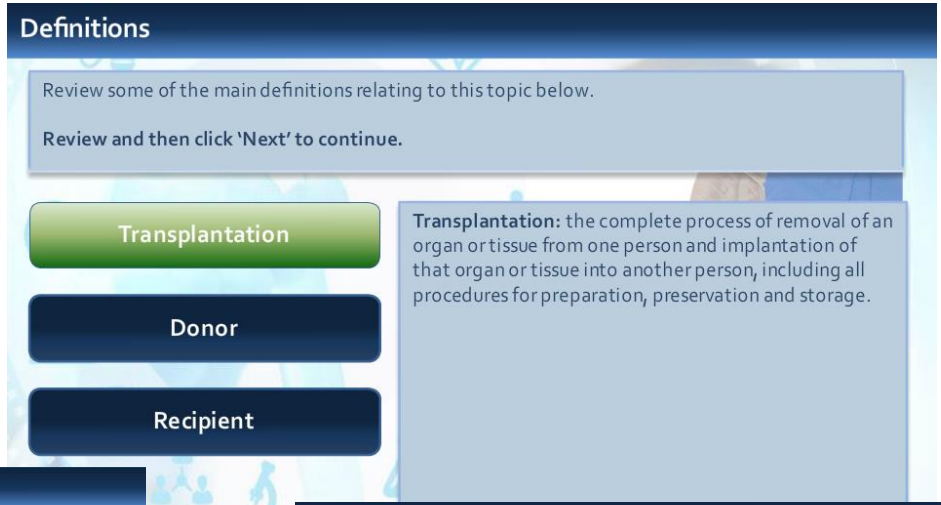
Welcome to the second substantive module of this Course on Bioethics! By the end of this session you will be able to:

- define free and informed consent and identify its components
- Internalise the legal and human rights principles applicable to it;
- Discuss the application of the process of informed consent to persons not able to consent and in emergency situations;
- Assess the responsibilities of health professionals in the process of informed consent.;

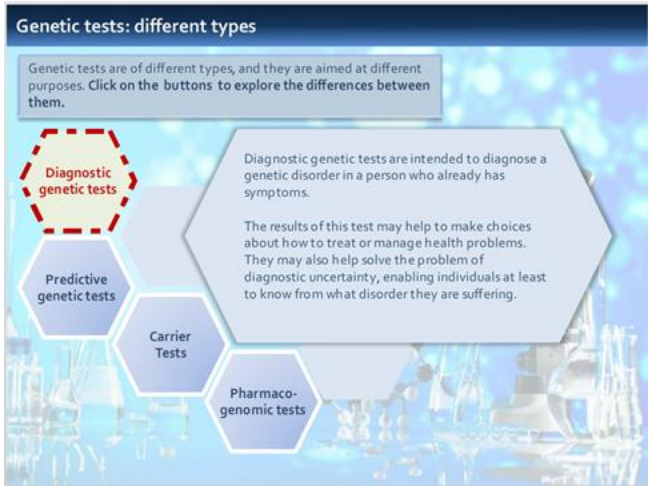
Medical confidentiality and protection of health data



Transplantation of human organs and tissues



Genetic testing



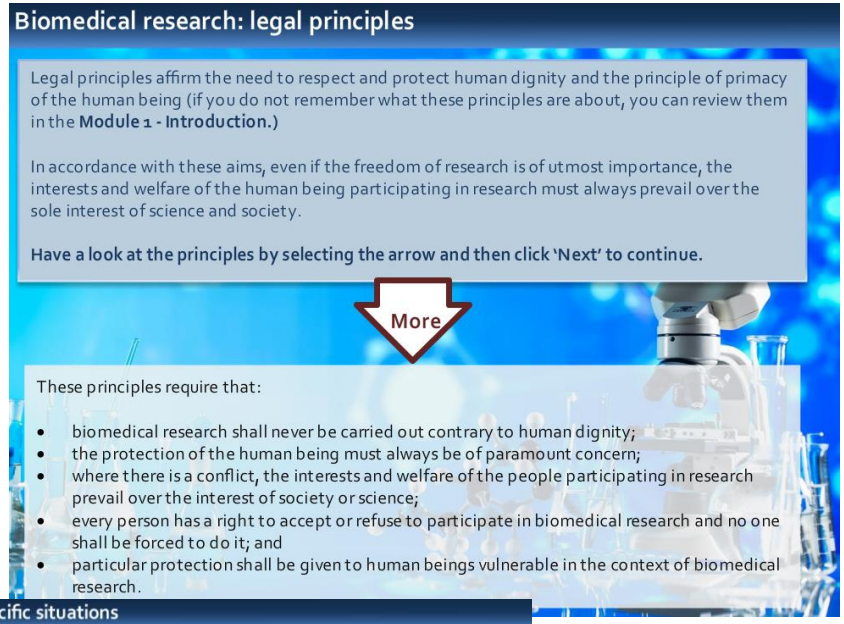
Learning Objectives

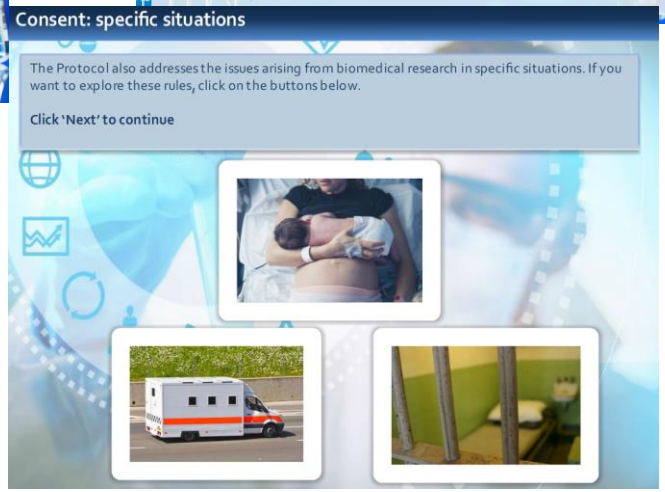
Welcome to the third substantive module of this course on Bioethics! By the end of this session you will be able to:

- list the different types of genetic tests;
- identify the general principles and human rights obligations applicable to genetic testing;
- appraise the judicial interpretation of such obligations by the ECtHR;
- apply the rules connected to the detention and processing of genetic samples and data, including for insurance purposes, in your daily work.

Click next to continue

Biomedical research





Protection of the Embryo and Procreation

Beginning of life and beginning of rights

In the case of Vo v. France mentioned above, the ECtHR considered that it was "neither desirable, nor even possible as matters stand, to answer in the abstract the question wheth
the purposes of Article 2 of the Cor
text)."

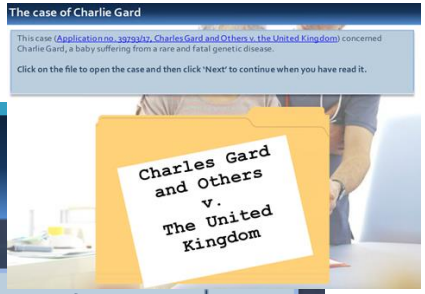
In its subsequent case-law, the Cou
ECtHR does not determine whethe
the right to life, the ECtHR affirms
certain degree of respect which wo

Thus in a judgment of 2015, in whic
prohibition to donate her embryos
property protected by Article 1 of P
ECtHR stated that "human embryo
"possessions" within the meaning o

In the same case, the ECtHR acknowledged that "the "protection of the embryo's potential for life" may be linked to the aim of protecting morals and the rights and freedoms of others" and can thus justify a prohibition on donating human embryos for research.

Click 'Next' to continue.

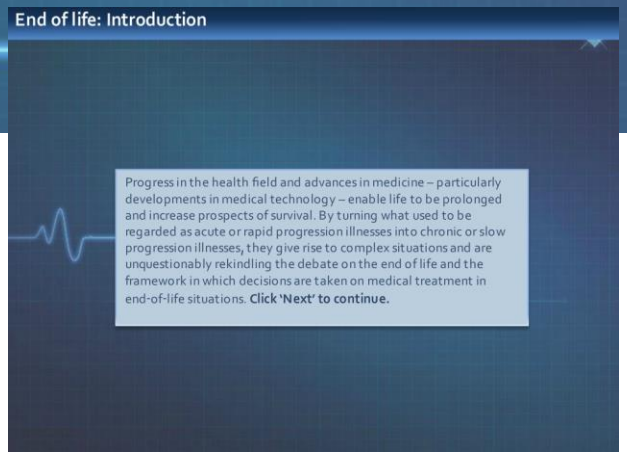
End of life



Legal instruments

Even if end-of-life situations are not expressly regulated in international legal instruments, a number of principles and norms are relevant in those cases

Binding Instruments		Non-binding Instruments
European Convention on Human Rights	Oviedo Convention	Recommendations of the Committee of Ministers of the Council of Europe



Next steps

- 2018 :
  - Free availability as an online-learning tool on the HELP platform http://help.elearning.ext.coe.int/
  - Launching in Belarus (Belarus Action Plan)

- Expression of interest by national institutions: Russian authorities, Armenia, Moldova, Romania, Italy,…
  - Budget: voluntary contribution, including in kind

- Contact with training institutions in the health field

- Future: Development of course on specific topics

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www.coe.int/bioethics

https://www.coe.int/en/web/help/