Why a guide?
- Medical progress: – Enables life to be prolonged and increases prospects of survival
  – Acute or rapid progression illnesses turned into chronic or slow progression illnesses
- Place of the patient - Protection of her/his autonomy and dignity
- Convention on Human Rights and Biomedicine (Oviedo Convention) (CETS No 164, 1997)
- European patient rights Treaty
- Committee on Biomedicine (DH-BIO) to facilitate the implementation of principles laid down in the Oviedo Convention:
  - Article 2 - Priority of the human being
  - Article 3 - Right to access to health care
  - Article 4 - Professional obligations
  - Article 5 - Free and informed consent
  - Article 6 - Protection of persons not able to consent
- To address these complex and sensitive questions taking into account societal, cultural, legal, organisational differences as well as the diversity of the medical end-of-life situations

Steps
- Symposium on decision making process: 30 November – 1 December 2010
- Draft Guide made public for consultation Spring 2013
- Adoption by the DH-BIO November 2013
- Launching conference: 5 May 2014, under the auspices of the Austrian chairmanship of the Council of Europe Committee of Ministers

Object
- To propose reference points for the implementation of the decision-making:
  - Actors – Stages of the process – Factual elements influencing decisions
- To bring together normative, as well as ethical reference works, and elements relating to good medical practice
- To contribute, through clarifications provided, to the overall discussion on decision-making process in end-of-life situations in particular complex ones (debated issues outlined)
- Does not aim at taking position on the relevance or legitimacy of one decision or another in a given clinical situation
- Does not address the issue of euthanasia or assisted suicide

Scope
- Decision-making process
- Regarding medical treatment
- In end-of-life situations

Definition of end-of-life for the purpose of the guide:
« For the purpose of this guide, end-of-life situations are understood as those in which a severe deterioration in health, due to the evolution of disease or another cause, threatens the life of a person irreversibly in the near future. »

➢ Applicable in whatever the place and the conditions in which end-of-life situation is being dealt with

Target audiences
- Health professionals concerned (primarily)
- Patients, their relatives and family or other support providers, for them to better understand the implications of the situations and thus, participate in the process
- The public, offering a tool for the discussion and public debate on the decision making process in end-of-life situations.
Introduction

Ethical and legal frames of reference for the decision making process

A. The principle of autonomy
   1. The obligation to deliver only appropriate treatment
   2. The concept of needless or disproportionate treatment
B. The principles of beneficence and non-maleficence
   1. The obligation to deliver only appropriate treatment
   2. The concept of needless or disproportionate treatment
C. The principle of justice – Equitable access to health care

The decision making process

A. The parties involved and their role
   1. The patient, his/her representative, family members, attorney, persons of trust and other support providers
   2. Carers (doctor, care team, other bodies)
B. The deliberative process and decision making
   1. Preliminary remarks
   2. Different phases of the decision-making process: description and analysis

Conclusions

The Guide

• Contributes to promoting respect for patient rights
• Anchored into the reality of the actors in the field
• Takes into account the diversity of
  - legal, societal, cultural... contexts
  - the clinical situations and care conditions
• Useful tool for training professionals and informing the public
• Proposes benchmarks relating both to the practices and the principles that can be applied in the situations concerned
  - a source of material for discussion within our societies on the issue
• Used as a reference by the Conseil d’Etat (France) and the European Court of Human Rights: Lambert and others v. France (no. 40040/14, § 30, judgment of 5 June 2015 )
• Available in 22 European languages

Highlights

Focus on:

• Assessment of the patient’s ability to take decision (criteria)
• Arrangements for previously expressed wishes
• Arrangements for the application of advance directives

Disputed issues:

• Limiting, withdrawing or withholding artificial hydration and nutrition
• Advance directives: content and legal status
• Sedation for distress in terminal phase