



# INTRODUCTION TO ETHICS

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# AIM OF THE PRESENTATION

To inform change agents and help them understand the concept of Ethics and how the ethics rules are applied in HIV/AIDS activists' work



# ETHICS AND MORALITY

**ETHICS** – Greek **Ethikos** – custom or habit

**MORALITY** – Latin **Moralitas** – custom or habit

**ETHICS is a set of moral principles - rules of behavior based on ideas about what is morally good and bad**

The basic concepts and fundamental principles of decent human conduct. It includes study of universal values such as the essential equality of all men and women, human or natural rights, obedience to the law of land, concern for health and safety and, increasingly, also for the natural environment

# What we stand for as activists in HIV/AIDS

- The **motivation** for and **commitment** to responding to HIV/AIDS.
- **Professionalism** in work and **respect for diversity**
- The meaningful **involvement of PLHIV** and affected communities in all aspects of the HIV/AIDS response (GIPA Principles)
- A **human rights** approach to HIV/AIDS
- **Public health principles** in our work
- Addressing **the causes of vulnerability** to HIV infection and the impacts of HIV/AIDS
- Our programmes are informed by **evidence** in order to respond to the needs of those most vulnerable to HIV/AIDS and its consequences



# Core values

- Valuing human life
- Respecting the dignity of all people
- Respecting diversity and promoting the equality of all people without distinction of any kind, such as sex, race, colour, age, language, religion, political or other opinion, national or social origin, property, birth, physical or mental disability, health status (including HIV/AIDS), sexual orientation or civil, political, social or other status
- Preventing and eliminating human suffering
- Supporting community values that encourage respect for others and a willingness to work together to find solutions, in the spirit of compassion and mutual support
- Addressing social and economic inequities and fostering social justice



# The CSO workplace

- CSOs are usually committed to creating and maintaining a harmonious environment where all staff can work together and people are treated with dignity and respect
- We should contribute to this effort by treating our colleagues, clients and others with fairness, tolerance, courtesy, and by showing respect for differences



# Personal conduct

- Your behavior and attitudes on and off work reflects to your community and the organization you are part of
- Your personal relationships with family and friends should not affect the impartial performance of your official functions
- How you manage your time, apply yourself to your duties, and work with others will greatly contribute to the achievements and effectiveness of your organization



# Conflict of interest

- A conflict of interest occurs when your private interests interfere—or appear to interfere—with the interests of the funders or decision makers (e.g. pharma industry or government)
- We should strive to avoid situations where we can be seen to benefit personally, directly or indirectly, or allow another to benefit, from the decisions we make
- To avoid possible conflicts of interest, try to anticipate and avoid situations where you could be faced with competing interests that may impact your impartiality
- Always assess and declare possible conflict of interest!





# Conflict of interest II

- Accepting an honor, decoration, favor, gift or remuneration in connection with official duties may give rise to a real or potential conflict of interest, as it may be seen to create an obligation
- We should not use our office or knowledge gained from our work to favor family members or friends. Nor should we prejudice the position of those colleagues or our clients whom we may dislike



# Use of privileged information

- Not all information available to us through our position can be made public, even when it is not specifically protected as ‘confidential’
- Confidential information must never be disclosed or used improperly for personal or other private gain
- The work that you produce as a staff member is the property of the organization
- Do not tolerate the unauthorized copying or disclosure of another’s intellectual property
- You may use other people’s information only if you have received their consent or if it is publicly available without restriction

# Use of CSO property and assets

- Vehicles, telephones, computers, e-mail, Internet, and other technologies should be used only for official business purposes
- You are responsible for using these assets wisely and in the best interests of your organization or community



# Working in communities

- It is our obligation to respect different peoples, languages, cultures, customs and traditions. We must also be respectful of people whose lives we impact upon, and be sensitive to the local cultures in which we operate. We should not add to the great stigma that is already in place
- Zero tolerance for harassment, sexual exploitation and sexual abuse
- Further protection for the most vulnerable sectors of populations, especially women and children



# Setting an example

- Remember that you represent or you may be seen as a representative of your community or organization
- When speaking to the media or using social media platforms, it is important to keep in mind some basic facts to protect your own interests and those communities that you represent
- Try to be a good role model for the next generation

# Raising concerns

- Speaking up can clarify misunderstandings, and prevent ethical lapses
- It is always best to prevent or correct problems in their early stages
- Some organizations have internal structure to deal with disputes or ethical concerns (e.g. EATG's Ombudsperson)



# Ethics committees in research

- A body responsible for oversight of medical or human research studies.
- Research Ethics Committee (REC) in the United Kingdom
- Medical Research Ethics Committee (MREC) in the Netherlands
- Comités de Protection des Personnes (CPP) in France
  
- Independent ethics committees - A group formally designated to protect the rights, safety and well-being of humans involved in a clinical trial by reviewing all aspects of the trial and approving its startup
- An IEC reviews the appropriateness of the clinical trial protocol as well as the risks and benefits to study participants. It ensures that clinical trial participants are exposed to minimal risks in relation to any benefits that might result from the research
- While participation of at least one lay person in ethics committees is longstanding practice and of undisputed value, the type and extent of patient involvement varies widely between - and even within - European member states

# Healthcare ethics

## Generally four principles

- principle of respect for autonomy
- principle of non-maleficence
- principle of beneficence
- principle of justice



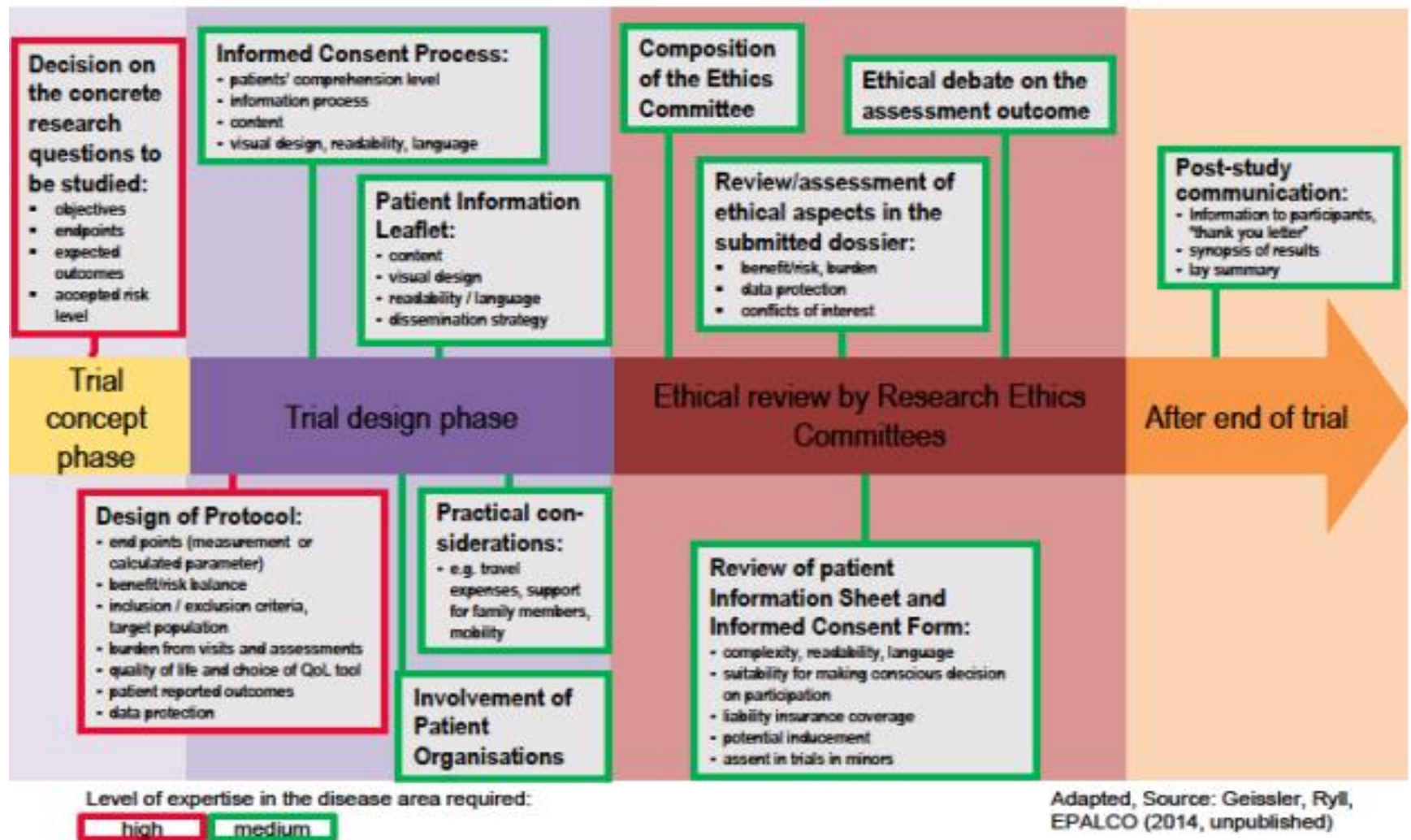


# Patient involvement in ethical review of clinical trials

- Patients can be involved in the ethical review of clinical trials at different time points



# Involvement of patients in ethical review along the clinical trial process



# Trial Concept Phase

- Research questions, e.g. for specific indications, patient populations, etc.
- Defining the objectives of the trial to ensure its relevance for patients
- Acceptable/relevant endpoints
- The suitability of measurements and assessments, e.g. quality of life questionnaires
- Comparators (placebo or active comparator) and their acceptability for patients
- Acceptable risk levels: patients might have a specific opinion on the level of risk they are prepared to accept



# Trial Design Phase

- a suitable number of patients can be recruited in an acceptable time frame
- the benefits of trial participation outweigh the risks
- the burden to patients is acceptable
- administration of the trial medication is as easy and reliable as possible
- measurements and assessments are practicable, acceptable to patients and reliable
- informed consent process including the preparation of the patient information sheet and informed consent form

# Ethical Review Phase

- Suitability of patient liability coverage (insurance)
- Data protection measures
- Potential conflicts of interest
- Avoidance of inducement, for example ensuring that patient fees or travel expenses are appropriate
- How patient organizations can contribute to the patient information and recruitment processes

Sponsors sometimes involve patients in communication with participating patients after the end of the trial.



**Thank you for your  
attention!**

**WE CONTINUE WITH THE  
DISCUSSION**