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Global Health Ethics

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What is Health Ethics?

- Ethics, derived from the Greek *ethos*, or “behavior”, is concerned with questions about right versus wrong conduct and what constitutes a good or bad life, as well as the justificatory basis for such questions, the situations in which values conflict (e.g. ethical dilemmas), and the systematic analysis and resolution of these conflicts.
- Health ethics is the interdisciplinary field of study and practice that seeks specifically to understand the values undergirding decisions and actions in health care, health research and health policy, and to provide guidance for action when these values conflict.
- It is distinguishable from the narrower medical ethics, which is concerned with ethical issues that arise in the clinical context related to the care of specific patients, as well as the broader bioethics, which refers to ethical issues arising from the creation and maintenance of the health of all living things.

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What is Health Ethics?

- Health ethics has a broad focus, taking in ethical issues faced by health professionals, health policy-makers and health researchers, as well as by patients, families, and communities in a range of contexts related to health, including clinical care, health services and systems, public health, epidemiology, information technology and the use of animals in research.
- Health ethics is increasingly on the curriculum in health professional and bioscience training, as well as programmes in health administration, health economics, public health, law, biotechnology (e.g. genomics) and environmental health. Though it is a comparatively young field, there is an extensive and growing international literature in the area, and many research efforts are devoted to understanding it.

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What is Health Ethics?

https://youtu.be/VJ_s51QGbg8

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What is the difference between ethical, social and personal values in health?

- Values describe what is important to an individual, a group, or a society. Values that are commonly invoked include autonomy, fairness, equity, compassion, honesty, freedom, solidarity, trust and respect. Some of these values might be specified as principles, e.g. “health inequities in a population ought to be minimized” or “patients should give free and informed consent to treatment”.
- Sometimes a situation may give rise to a conflict between different values, such as when achieving greater equity may involve some reduction in individual autonomy, or between values at the universal, group, or individual levels. Moreover, different societies may have different values and practices. Most people would agree that tolerance of such differences is important, and we must, generally, respect values that differ from our own.

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What is the relationship between health ethics and the law?

- Both ethics and law are normative frameworks, i.e. they define how people ought to act. Ethics and law are often complementary. However, something can be legal and yet conflict with ethical standards. For instance, there are no laws prohibiting countries from investing vast public resources in the development of medical interventions of minor public health significance, such as a cure for male-pattern baldness. Similarly, ethics is concerned with a broader set of relationships and behaviors than most forms of legal regulation. For example, speaking disrespectfully to one’s parents may be considered unethical, even though it is not against the law. It is also possible that individual laws may themselves violate important ethical principles, e.g. laws that discriminate against certain groups in a population. Ethical analysis of the law can stimulate important reform efforts or acts of civil disobedience.

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What is the relationship between health ethics and the law?

- Even when ethics and law are consistent, important differences between the fields remain. For example, laws sometimes provide general standards, the interpretation of which requires further ethical analysis. In addition, the violation of an ethical norm entails different sanctions than the breaking of a legal code. In the former case, the violator might suffer rejection and disapproval by society; in the latter, a concrete punishment, such as a fine or imprisonment, might be imposed.
- In sum, while ethics and law are different in certain ways, ethics remains a foundation for law, and often provides a justificatory basis for legal norms.

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Global Health Ethics: Overview

- Ethical questions related to health, health care, and public health cover topics as diverse as moral issues around reproduction, state obligations in the provision of health care services, and appropriate measures to control infectious disease. Scholars and health care professionals have debated ethical questions related to health and health care since the earliest days of medicine. Recent formal efforts to articulate international standards of ethics applicable to health and health care can be traced to the Nuremberg trials of 1947, during which the horrors of Nazi medical experiments came to light.

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Global Health Ethics: Overview

- The principles that emerged from those trials, known as the Nuremberg Code, are broadly applicable to many types of health-related research involving human participants, including clinical trials. The growing breadth and complexity of contemporary health challenges have produced a range of difficult questions that cannot always be adequately addressed by relying exclusively on existing policies, guidelines or codes of conduct. Debates over access to new and expensive pharmaceuticals and medical technologies, as well as increasing awareness of the gross health disparities that exist both within and between countries, have called attention to the need for an ethics of health policy and practice.

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What are key ethical issues in health research?

Research ethics govern the standards of conduct for scientific researchers. It is important to adhere to ethical principles in order to protect the dignity, rights and welfare of research participants.

The WHO Manual (Section XV.2) defines research with human subjects as 'any social science, biomedical, behavioural, or epidemiological activity that entails systematic collection or analysis of data with the intent to generate new knowledge, in which human beings:

- are exposed to manipulation, intervention, observation, or other interaction with investigators either directly or through alteration of their environment; or
- become individually identifiable through investigator's collection, preparation, or use of biological material or medical or other records.

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What are key ethical issues in health research?

The goal of biomedical research is the creation of knowledge to improve the health of populations. Ethical questions in research include:

- Does the research have social value for the communities that take part or from which the participants are drawn?
- Who benefits from the research?
- Are subgroups of the population treated fairly?
- Are the rights and well-being of individual research participants protected?

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Major concepts in health research

- **Human rights:** Fundamental freedoms and rights enshrined in a set of universal legal statements. Some of the most important characteristics of human rights are that: they are acknowledged in international declarations; states and state actors are obliged to respect them; they cannot be waived or taken away (although the enjoyment of particular human rights may be limited in exceptional circumstances); they are interdependent and inter-related; and they are universal.
- **Autonomy :** refer to the ability of an individual to be his or her own person, to make his/her own choices on the basis of his/her own motivations, without manipulation by external forces.
- **Beneficence:** Principle requiring that governments, health care providers, and researchers do good for, provide benefit to, or make a positive contribution to the welfare of populations, patients and study participants.
- **Non-maleficence:** A principle requiring that health care providers and researchers do not inflict undue harm, either intentionally or through negligence.

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Major concepts in health research

- **Confidentiality:** The obligation to keep information secret unless its disclosure has been appropriately authorized by the person concerned or, in extraordinary circumstances, by the appropriate authorities.
- **Equity (*Distributive Justice*):** focuses on equal outcomes and this may require an unequal distribution of some good to bring about the equal outcome. Health equity requires responding to “differences in health which are not only unnecessary and avoidable but, in addition, are considered unfair and unjust”.
- **Egalitarianism:** A belief in equality. However, egalitarians disagree about what it is that should be equal, for example whether people are entitled to equal opportunities, an equal share of resources, or whatever level of opportunities and resources are necessary to generate equal results.

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Major concepts in health research

- **Justice:** A highly contested concept that can, roughly, be thought of as giving people what they deserve.
- **Informed consent:** Agreement to a certain course of action, such as treatment or participation in research, on the basis of complete and relevant information by a competent individual without coercion.
- **Privacy:** Privacy seeks to protect a person from scrutiny by others. Respect for privacy implies that a person should not be expected to share personal information unless they so choose. Any violation of privacy requires ethical justification although it might be outweighed by other considerations in some cases.
- **Health maximization:** is the way that when resources is allocated the beneficial impact on health should be as large as possible.

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Should public health data be shared, and if so, who with?

In the context of emergency situations, rapid data sharing is imperative. It is also appropriate to share public health data for legitimate research purposes that have been approved by an ethics review committee. But data collected in the name of the public health should never be shared for the purpose of taking action against individuals or for uses unrelated to public health. Access to such personal information by agencies responsible for national security, law enforcement, or the allocation of social benefits should usually be allowed only after legal due process. To preserve trust in public health surveillance systems, there should be a compelling justification for sharing identifiable data for non-public health uses.

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Ethical issues regarding groups

1. Social and economic disparities at national, regional and global levels magnify concerns that efforts to improve the health of some populations might have the unintentional consequence of making things worse for others. When studies are carried out in disadvantaged societies, the members of those societies who take part are being put at risk, while – because of their economic or social disadvantages – they may not be able to benefit from the knowledge gained by the study. Unfairness can be reduced or eliminated by ensuring that study populations enjoy the benefits of the research. At the same time, great caution is required when the only chance for medical care is linked to participation in biomedical research studies. This is a problem in resource-poor countries, as well as for people of low socioeconomic status in wealthy nations.

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Ethical issues regarding groups

2. Ethical questions also emerge in the selection of topics for research. The health concerns of affluent populations often drive the research agenda, leading to the development of new drugs and devices for which there is a large (and profitable) market. The health problems of resource-poor populations offer fewer opportunities for commercial success and therefore tend to receive less attention from investigators, exacerbating disparities between rich and poor.

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Ethical issues regarding groups

3. Another ethical challenge arises when businesses or individuals patent new drugs or devices to help ensure that product sales recoup investments and generate profits. While laws that protect intellectual property can provide valuable incentives for research and development, they also increase the price of new drugs and devices, and can thereby severely restrict or prevent access to life-saving therapies for resource-limited populations. This issue has generated intense debate within the HIV/AIDS community, and in some cases has led to the development of proposals for or implementation of alternative financing mechanisms designed to reduce economic barriers to essential treatments.

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Ethical issues regarding groups

4. Another set of ethical issues in global health is related to cultural relativity. It is sometimes asked whether ethical standards are universal, given that different people in different countries may hold different values or place different weights on common values.

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Ethical issues regarding groups

5. Another challenge in global health ethics concerns international research, especially where investigators from wealthy countries conduct research in impoverished settings where participants are especially vulnerable or where language and cultural barriers make informed consent difficult. One of the most hotly debated issues regarding international research ethics during the past two decades has been about standards of care: what level of care should be provided to participants in the control arm of a clinical trial in settings where the usual standard of care is especially low? And what level of care or other benefits should be provided to participants or participating communities at the conclusion of a trial?

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Examples

- Some important issues come up as the research is done in low and middle country setting. In cases of new drug trial where one group of participants receive a new drug while the other group does not, or receive the established treatment or placebo that raises a lot of debate. In cases where patients do not receive any care after the trial ends, and there is chance that without the medication, the patient might deteriorate, that poses ethical dilemma. In most of the low and middle income countries the clinical trial may be the only source of medication for the poor. As for ancillary care, they are not the part of the original design of the trial however, researchers are faced with providing ancillary care for the patients other than what disease they are studying. This again happens in low and middle income countries where diseases like pneumonia, diarrhea, parasitic infections are very common.

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The Importance of Ethical and Human Rights Issues in Global Health

- Failure to respect human rights is often associated with harm to human health.
- Health research with human subjects puts people at risk for the sake of other people's health.
- Health investments must be made in fair ways since resources are limited.
- Universal Declaration of Human Rights and other legally binding multilateral treaties.
- Governments are obliged to *respect, protect, and fulfill* the rights they state.

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Future Challenges in Global Health Work

- Students of global health get insufficient exposure in their training to ethical issues.
- No mechanisms of enforcement of human rights.
- Shortage of trained personnel for reviewing research.
- Lack of reviews of how investments are made.
- There is no clear definition regarding the human rights in global research in particular in low and middle income countries.

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WHO Standards and Operational Guidance for Ethics Review of Health-Related Research with Human Participants

http://apps.who.int/iris/bitstream/handle/10665/44783/9789241502948_eng.pdf?sequence=1

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