Module
G07

Generic Foundational Course

Introduction to Public Health Research and Pathogen Surveillance Ethics and Policies

NGS Academy for the Africa CDC

Module
G07

Module last updated:
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Introduction to Public Health Research and Pathogen Surveillance Ethics and Policies

Number of sessions	3–4
Total learning time	12–15 hours
Target audience	All personas - wet laboratory personnel (i.e., scientists, laboratory technicians, etc.), dry laboratory personnel (epidemiologists, bioinformatics scientists, and bioinformaticians), and managerial personnel (i.e., HODs, laboratory managers, policymakers, etc.).
Format	Lectures, videos
Level of the module	Introductory

👤 Contributors

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📖 Module description

This module provides a basic introduction to the ethical, legal, and social considerations and implications of pathogen genome sequencing and surveillance. The key ethical concepts, principles, and policies guiding pathogen genome surveillance strategies and research are also explored. These policies and frameworks play a pivotal role in guiding ethical practice during public health surveillance and responses. In this module, participants are introduced to the following topics and/or concepts:

- The origin of health principles in healthcare ethics
- The protection of the rights and welfare of all participants in human research activities
- The regulatory and ethical codes governing human research activities
  - The US CDC's "Human Research Protections" Policy
  - The International Ethical Guidelines for Health-Related Research Involving Humans
  - Declaration of Helsinki – Ethical Principles for Medical Research Involving Human Subjects
  - The Nuremberg Code
- The standards and operational guidance that govern the ethics review of health-related research with human participants

- The principles and values that guide public health ethics
  - The Public Health Code of Ethics by The American Public Health Association
  - The Principles of the Ethical Practice of Public Health by the American Public Health Leadership Society
- Benchmarking ethics oversight of health-related research involving human participants
  - A tool by the WHO
- The emerging role of pathogen genomics in public health
- The ethical, legal, and social implications of genomic sequencing
- Ethical guidance for public health emergency preparedness and response
  - Ethical goals and decision making in public health emergencies
  - Bridging the gap between ethics and decision-making in pandemics
  - Proposals for strengthening the global architecture for health emergency preparedness, response, and resilience
  - The WHO Surveillance System of Attacks on Healthcare (SSA)
- The ethics of pathogen genomic surveillance and public health
  - Guidelines on ethical issues in public health surveillance by the WHO
- Active vaccine safety surveillance
  - A guide by the CIOMS
- The ethics of public health data management and sharing
  - US CDC/ATSDR policy on releasing and sharing data
  - NIH Data Management and Sharing Policy
  - NIH Genomic Data Sharing Policy
- Facilitating data sharing and use of surveillance data for public health action
  - Standards by the US CDC
- Strengthening global public health surveillance through data and benefit sharing
- Considerations related to data privacy, consent, and potential misuse
- The Nagoya Protocol and pathogen sharing

⚙️ Module learning outcomes

On completion of this module, the participants will have a basic knowledge of, or will be able to:
- Describe the rights of participants in human research activities
- Define the various regulatory and ethical codes that govern human research activities, and protect research participants
- Analyse standards and operational guidance that govern ethics review processes that involve health-related human research activities
- Explain the principles and values that guide public health ethics
- Identify tool(s) that benchmark ethics oversight of health-related human research activities
- Identify the emerging role of pathogen genomics in public health
- Describe the ethics that guide public health emergency preparedness and response
- Describe the principles and methods that guide active vaccine safety surveillance
- Explain the ethical principles and standards used to facilitate public health data management and sharing
- Explain how surveillance data is used for public health action

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- Identify how global public health surveillance is strengthened through data and benefit-sharing
- Discuss various considerations related to data privacy, consent, and potential misuse
- Explain what the Nagoya Protocol is and how it impacts the sharing of pathogen genomic data

Module assessments

Module practical: Not applicable

Module quiz: Assessment questions available on the ASLM platform

Module resources

- NIH | NLM Article - Principles of Clinical Ethics and Their Application to Practice
- US CDC | Human Participant Protection in US CDC Research
- US CDC Policy - Procedures for protection of human research participants
- WHO | Global Health Ethics
- WMA Declaration of Helsinki – Ethical Principles for Medical Research Involving Human Subjects – WMA – The World Medical Association
- NIH | NLM: The Nuremberg Code
- US HHS | The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research
- CIOMS | International ethical guidelines for health-related research involving humans (2016)
- WHO | Standards and operational guidance for ethics review of health-related research with human participants
- US CDC | Public Health Ethics
- APHA | Public Health Code of Ethics
- PHLS | Principles of the Ethical Practice of Public Health
- NIH | NLM Article - A Code of Ethics for Public Health
- US CDC | Ethics and Public Health: Model Curriculum
- WHO tool for benchmarking ethics oversight of health-related research involving human participants
- US CDC Video - The Emerging Role of Pathogen Genomics in Public Health
- US CDC Article - Ethical Guidance for Public Health Emergency Preparedness and Response: Highlighting Ethics and Values in a Vital Public Health Service
- WHO report (2021) - Bridging the gap between ethics and decision-making in pandemics: report of the WHO Pandemic Ethics and Policy Summit
- US CDC Resources - Introduction to Public Health Surveillance
- WHO Video - The Ethics of Public Health Surveillance
- WHO Q&A: Ethics in Public Health Surveillance
- WHO Guidelines on Ethical Issues in Public Health Surveillance
- WHO | Surveillance in Emergencies
- WHO | 10 proposals to build a safer world together – Strengthening the Global Architecture for Health Emergency Preparedness, Response and Resilience: draft for consultation
- WHO | Surveillance System for Attacks on Health Care (SSA)

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- [CIOMS | Guide to Active Vaccine Safety Surveillance](#)
- [US CDC | Surveillance Resource Center](#)
- [US CDC | Standards to Facilitate Data Sharing and Use of Surveillance Data for Public Health Action](#)
- [US CDC Article - Strengthening Global Public Health Surveillance through Data and Benefit Sharing](#)
- [NIH | Scientific Data Sharing](#)
- [NIH | Final Policy for Data Management and Sharing](#)
- [NIH | Genomic Data Sharing Policy](#)
- [US CDC-ATSDR data release guidelines and procedures for re-release of state-provided data: US CDC-CSTE Intergovernmental Data Release Guidelines Working Group (DRGWG) report](#)
- [WHO Expert Group on Ethics & Governance of Infectious Disease Outbreaks and other Emergencies](#)
- [Frontiers in Bioengineering and Biotechnology Article - Cyberbiosecurity Challenges of Pathogen Genome Databases](#)
- [ScienceDirect Article - Ethics and governance challenges related to genomic data sharing in southern Africa: the case of SARS-CoV-2](#)
- [NIH | NLM Article - Disease surveillance data sharing for public health: the next ethical frontiers](#)

📃 References

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