The Global Health Network Nigeria Advocacy Visit and Research Capacity Strengthening Workshop

The Federal Medical Centre, Abuja

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'Research Ethics, Registries & Strengthening Health Information Systems'

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Learning Objectives

By the end of this presentation, participants should be able to;

- Define key concepts related to research ethics, registries, and health information systems (HIS).

2. Explain the ethical principles that guide health research

- Identify the role and importance of clinical and public health registries

4. Describe how Research Ethics Committees (RECs) and registries enhance transparency and accountability.

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What is Research Ethics?

Research ethics refers to the principles guiding the planning, conduct, and reporting of research involving human participants to ensure that their dignity, rights, and safety are protected.

Registries

Research

- Systematic reviews
- Randomized controlled trials
- Clinical trials

Public Health, Social, and Clinical

- Immunization
- Births and deaths
- Illness specific registries (cancer, diabetes etc)

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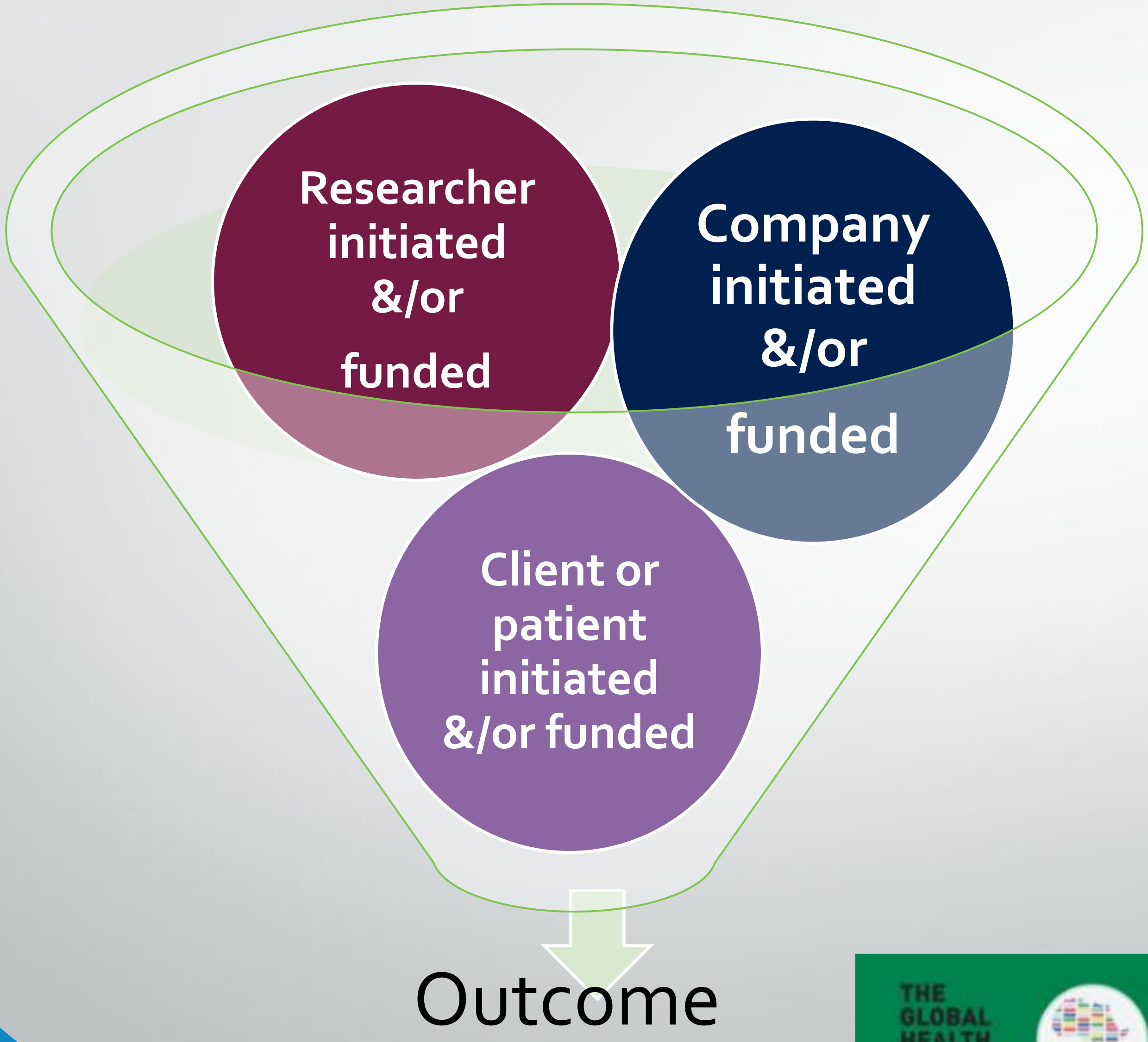
Clinical Trials



Researcher initiated &/or funded

Company initiated &/or funded

Client or patient initiated &/or funded

Outcome

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Health Information Systems (HIS)

HIS

- A system designed to manage healthcare data

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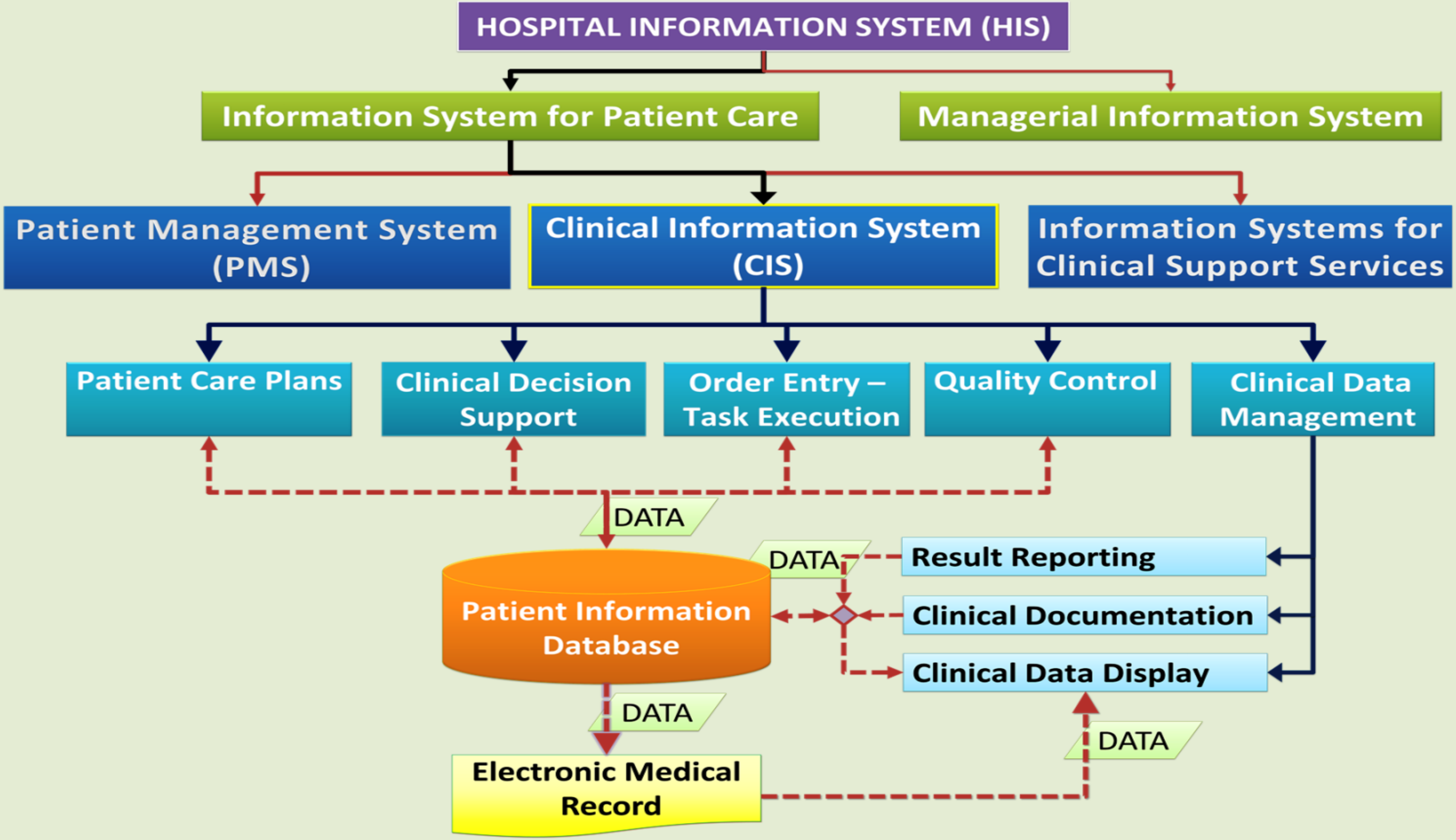

HOSPITAL INFORMATION SYSTEM (HIS)

Information System for Patient Care

Managerial Information System

Patient Management System (PMS)

Clinical Information System (CIS)

Information Systems for Clinical Support Services

Patient Care Plans

Clinical Decision Support

Order Entry – Task Execution

Quality Control

Clinical Data Management

DATA

DATA

Result Reporting

Patient Information Database

Clinical Documentation

Clinical Data Display

DATA

DATA

Electronic Medical Record

Why ethics matter in HIS

- Ethics govern how we collect, store, manage and share information!

Why does research ethics matter for healthcare professionals?

- Safeguards patients’ rights and safety
- Builds public trust in research
- Ensures scientific credibility
- Upholds professional and legal standards

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Core ethical principles

- Autonomy
- Beneficence & non-maleficence
- Justice

Autonomy

- Voluntary participation
- Informed consent
- Protection of vulnerable populations
- Confidentiality and privacy

Beneficence & non-maleficence

- Maximize benefits
- Minimize risks
- Avoid harmful interventions

Justice

- Fair participation
- Ensure balance
    - No group should bear an unfair or disproportionate risks or burdens
- do not exploit vulnerable populations

Vulnerable populations

Children

Pregnant women

Prisoners

Various forms of disability

Hospital patients

The elderly

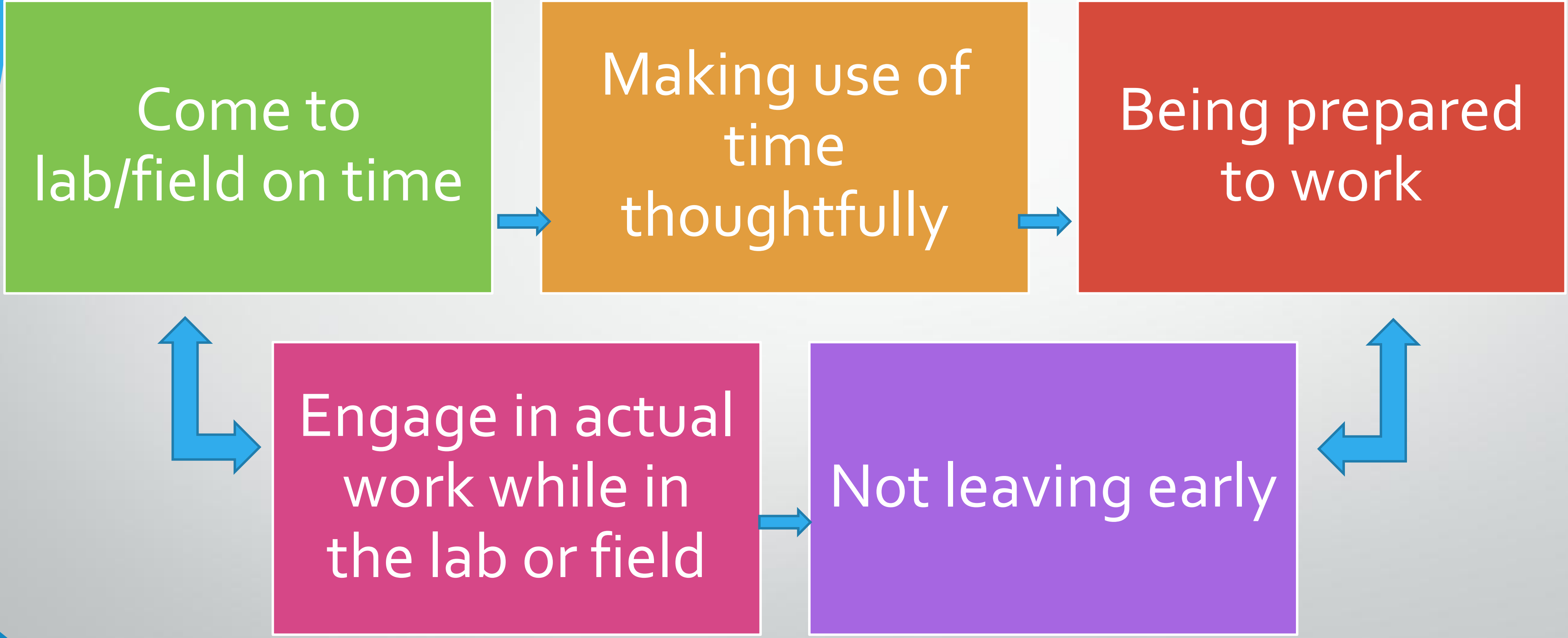
Refugees

Institutional Review Board

(Ethical Clearance Committees)

- Reviews all research efforts involving human subjects (some countries have boards for the use of animal subjects too)
- Develop policies for research with human subjects
- Provide education to investigators and departments regarding policies, procedures and related issues
- Maintain records in accordance with federal regulations (records are kept for a minimum of three (3) years after the termination of the project

Researcher integrity



Come to lab/field on time

Making use of time thoughtfully

Being prepared to work

Engage in actual work while in the lab or field

Not leaving early

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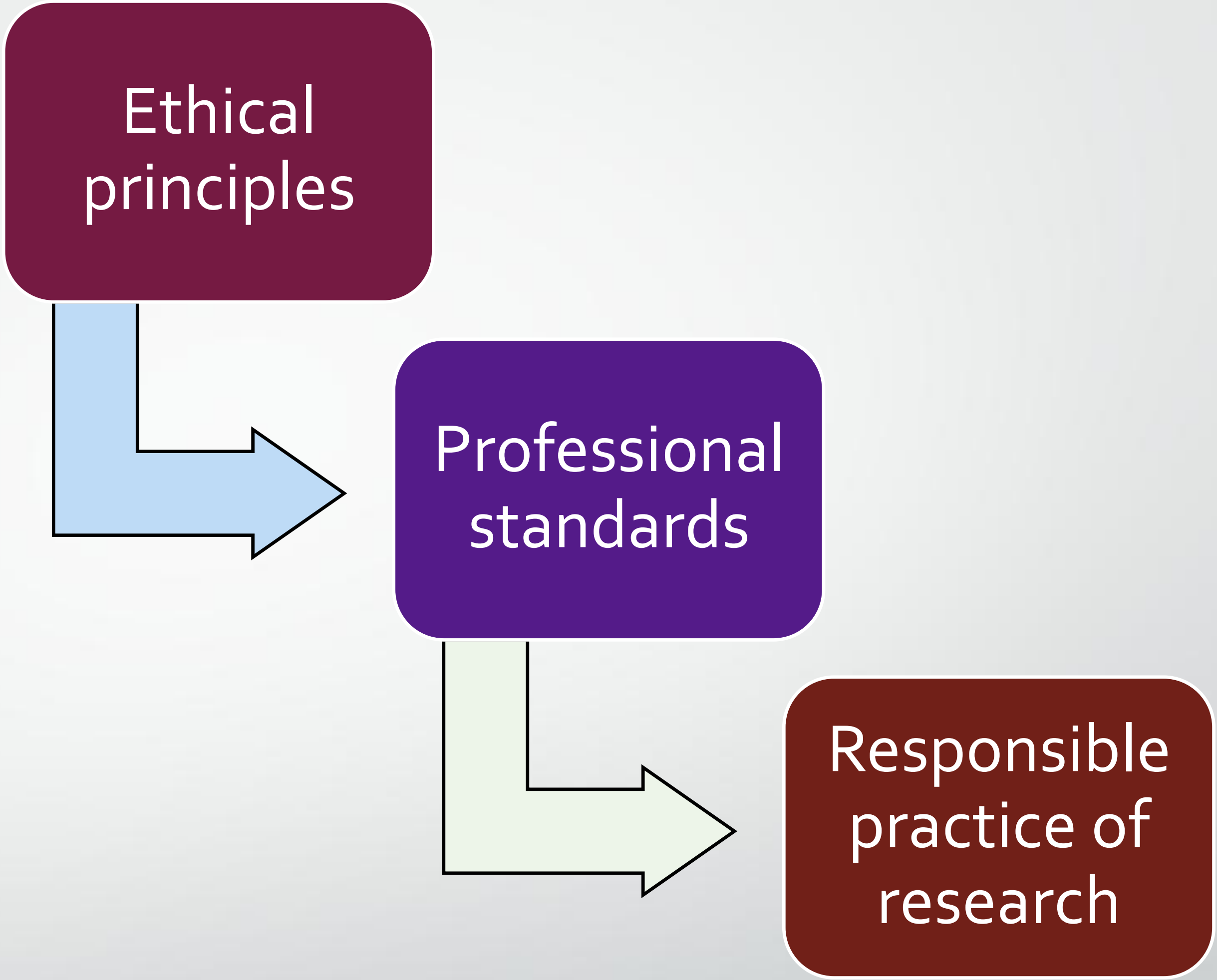
Research integrity

- Research integrity may be defined as active adherence to the <u>ethical principles</u> and <u>professional standards</u> essential for the responsible practice of research.

(National Academy of Science)



Ethical principles

Professional standards

Responsible practice of research

Conclusion

- Research ethics ensures safe, fair, and high-quality research.
  - The Ethical Review Committees ensure that researchers develop protocols that follow the standards.
- Healthcare providers play a critical role in protecting participants.
- Ethical research leads to better health outcomes and improves the public's trust.

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References

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