REGULATION OF HEALTH DATA FOR ARTIFICIAL INTELLIGENCE IN UGANDA

By

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Context

Assessing Uganda's regulation of health data in reference to the World Health Organization (WHO)'s recommendations for health data protection in the development and application of Artificial Intelligence (AI).

COMMENTARY

- AI holds great promise in health to improve;
  - Care, research, systems management, Public health and surveillance

- However, to fully reap these benefits ethical challenges to its development and application must be addressed, including;
  - Autonomy, data control and use, Accountability and algorithmic biases (2).

- This calls for the need to prioritize the ethical principles and human rights obligations.

- The existing biases encoded in data used to train algorithms, must be overcome in order to effectively use AI for health.

Health data

- Development of a successful AI system for health relies on high-quality data
  - to train and validate the algorithmic model.
- However, these systems can suffer with uneven management of such sensitive health data (3).
  - Data quality and use (eg repurposing)
  - Violation of consent, privacy or autonomy (Data colonialism)
    - Undermines the agency, dignity and human rights of those individuals

- Need for regulation of data in the research and implementation of AI-based health technologies,
  - for compliance purposes and to build public trust in these solutions (4).

Regulation of Health data for AI

- Currently, no well-defined regulations in place to address the legal and ethical issues that may arise due to the use of AI in health settings (2).

- In Uganda -scant well-defined regulations for research and use of AI in health (2).

Regulatory way-forward

- **Human rights standards, data protection laws and ethical principles** are all necessary;
  - to guide, regulate and manage the use of AI for health by involved stakeholders.

- Data protection regulations are enforced by data protection authorities which;

  - develop and administer regulations
  - provide guidance and technical advice and
  - conduct investigations.

- A WHO expert group responsible for the regulation of AI for health has discussed areas to be considered in examining new AI technologies.

WHO's regulation recommendations

- WHO in its report "**Ethics and governance of AI for health**" considered issuing model legislation and recommendations as reference for governments to;
  - develop their own laws to ensure appropriate protection, regulations, rules, and safeguards

- The development and use of AI for health will be guided by appropriate ethical norms and standards.

- This would build the trust of stakeholders involved in the use of AI in health-care systems (1).

- This paper describes how Uganda is positioned to conform to those recommendations in the regulation of health data for AI, as explained herein.

*Recommendation 1. Governments should have **clear data protection laws and regulations** for the use of health data and protecting individual rights, including the **right to meaningful informed consent**.*

- [Data Protection and Privacy Act, 2019](#) ('the Act') in 2019 and
- [Data Protection and Privacy Regulations, 2021](#)('the Regulations') in May 2021.

- The Act and Regulations support the protection of privacy of personal data through regulation of its collection, processing and storage.

- This Act mirrors the a number of international conventions
  - The UK [Data Protection Act, 1998](#)
  - the Universal Declaration of Human Rights to which Uganda is a signatory.
  - the European Union General Data Protection Regulation (GDPR).

Recommendation 2. *Governments should establish* **independent data protection authorities** *with adequate power and resources* **to** *monitor and* **enforce** *the rules and* **regulations in data protection laws**.

- Uganda has the Personal Data Protection Office (the Office)
  - The national data protection authority
  - Oversees the implementation of and enforcement of the Act
  - Is independent in operation

- Section 6 of the Regulation: the Office shall cooperate with other government authorities like ministries, departments and agencies.

For example;
  - with Uganda National Drug Authority
  - with the Uganda National Council for Science and Technology (UNCST).
  - UNCST is responsible for ethical oversight of research involving human participants (5).

Recommendation 3. *Governments should require entities that seek to use health data to be transparent about the scope of the intended use of the data.*

The Act states that;

- Section 12: Data be collected for a lawful purpose that is;
  - specific, explicitly and related to the functions of the data collector, or data controller.

- Section 17 (1) allows further processing of data but this should be;

  - Specific
  - Public benefit eg forensic, historical, statistical or research purposes.

- This requirement for data transparency would reduce the possibility repurposing data thus avoiding ethical, legal and human rights concerns

*Recommendation 4. Mechanisms for **community oversight of data** should be supported. These include data collectives and the establishment of data sovereignty by indigenous communities and other marginalized groups.*

- The Act doesn't stipulate community oversight of data.

- However, in the absence of specific regulation, data handlers are expected to act with integrity and respect human rights

Recommendation 5. Data hubs should meet the highest standards of informed consent if their data might be used by the private or public sector, should be transparent in their agreements with companies, and should ensure that the outcomes of data collaboration provide the widest possible public benefit

- Neither the Act nor the Regulation stipulates data handling by the data hubs.

However,

- Stipulations in section 34 of the Regulation could prevail:

- Section 34 (1) consent to data collection, control and processing

- Section 34 (2): Use without consent is and offense (1)".

Recommendation 6. *Governments should enact laws and policies that require government agencies and companies to conduct **impact assessments of AI technologies**, which should address ethics, human rights, **safety and data protection**, throughout the life-cycle of an AI system.*

- **Section 12 of the Regulation** stipulates assessment of data

- Subsection (2): Every data protection impact assessment shall include;

  - (a) predicted processing and the purposes of the processing;

  - (b) the risks to personal data and the measures to address the risks; and

  - (c) any other matter the Office may require.

- Subsection (3): The Office shall make public a list of the processing operations subject to the requirement for a data protection impact assessment

Recommendation 7: *Governments should consider **adopting models of co-regulation with the private sector** to understand an AI technology, without limiting independent regulatory oversight. Governments should also consider building their internal capacity to effectively regulate companies that deploy AI technologies and improve the transparency of a company's relevant operations.*

- Section 6 of the Regulation stipulates the power of the Office to cooperate with other authorities.

- ministries, departments and agencies in the implementation of the Act and regulations.

- Subsection (2): All ministries, departments and agencies shall accord to the Office such assistance as may be necessary to ensure proper discharge of the functions.

Conclusion and recommendation

- Principally, the rules and principles of the Act and the Regulation;

    - contain important rights for those who give data
    - Stipulate obligations of data collectors and processors

- These could shape the way AI should be developed.

- However, there is need for more specific safeguards to informational privacy and other fundamental rights typical of AI.

    - Big data management presents a challenge for the application of traditional data processing laws and principles

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