Challenges and Recommendations
in Data Governance
FOR THE DEVELOPMENT OF ARTIFICIAL INTELLIGENCE IN HEALTH IN LATIN AMERICA AND THE CARIBBEAN

POLICY BRIEF

Transform Health | IECS INSTITUTO DE EFECTIVIDAD CLÍNICA Y SANITARIA | CiPS IMPLEMENTACIÓN E INNOVACIÓN EN POLÍTICAS DE SALUD | CLIAS

What is Data Governance?

o   Data Governance is the set of principles, policies, and practices aimed at ensuring the efficient management of data to make decisions about them throughout their life cycle to optimize the capacity of individuals, organizations, or governments for political, strategic, and operational management.

o   Specifically in health, it refers to the process of managing and decision-making to guide the eneration, collection, storage, and management of health data through policies, practices, standards, benchmarks, and normative regulations that are actionable and cross-cutting.

Why is proper data governance important for developing Artificial Intelligence (AI) solutions in healthcare?

o   Ensures data quality, providing high-quality inputs for algorithm development.

o   Facilitates broad and ethical access to datasets, enabling developers and researchers to advance innovative AI solutions

o   Guarantees privacy and confidentiality of data, building the necessary trust for individuals to share their data.

o   Promotes transparency in the use of health data, crucial for gaining public acceptance and trust.

o   Fosters data interoperability among health systems, enabling AI models to leverage a broader range of information.

o   Provides incentives and structures for collaboration among institutions, researchers, and companies, encouraging joint innovation in AI in healthcare.

o   Facilitates data standardization, allowing AI models to be applied consistently across different contexts and locations.

o   Addresses bias management in data, promoting equity, justice, and representativeness in the results of AI models applied to healthcare.

o   Safeguards individual and collective rights in the use of health data to train AI models, ensuring privacy and autonomy protection.

What are the main challenges faced by the Latin America and the Caribbean (LAC) region in these aspects?
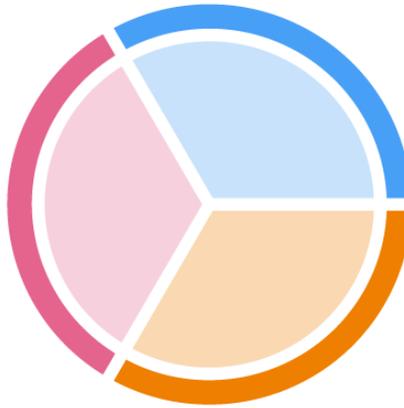
o   **REGULATORY:** The countries in the region have inadequate regulatory frameworks for the protection of people's data and communities.

o   **DATA QUALITY:** Repositories available in the region are scarce, and data often exhibits low quality and various biases, posing risks of deepening existing inequalities.

o   **INFRASTRUCTURE:** LAC countries face deficiencies in infrastructure for the development of responsible AI solutions, such as inequitable access to the internet or insecure information systems.

o   **STATES CAPACITIES:** The lack of specialized agencies in data usage and the inability of states to efficiently ensure the protection and security of people's data are challenges for many countries in the region.

o   **COORDINATION AMONG STAKEHOLDERS:** LAC countries have the opportunity to move towards common strategies not only among states but also with companies, universities, and other actors to define common parameters for the use and exchange of data

How to respond to these challenges and build a better governance of health data?

The Health Data Governance Principles, developed by Transform Health, aim to contribute to the creation of a global framework for the governance of health data that can support the use of technologies and digital data for collective well-being. The objective is to provide a human rights and equity perspective to the use of this data and contribute to the construction of resilient and sustainable health systems that advance towards Universal Health Coverage (UHC). They are a public good, available for incorporation into political work, policy design, and advocacy for health data, and can serve as a guide to address the challenges in the region.

PROTECT PEOPLE
- Protect individuals and communities
- Built trust in data systems
- Ensure data security

PRIORITIZE EQUITY
- Promote equitable benefits from health data
- Establish data rights and ownership

PROMOTE HEALTH VALUE
- Enhance health systems and services
- Promote data sharing and interoperability
- Facilitate innovation using health data

¿What do we propose from CIIPS? Some recommendations:

REGULATORY

o Generate broad, clear, updated, and reliable regulatory frameworks on data governance that ensure both data protection and the promotion of innovation. These frameworks should include specific provisions for addressing the safe and secure use of health data.

o Regulations should anticipate data protection measures against the aggregation of data for the creation of population profiles.

o Incorporate health data governance at different levels of the healthcare system: from government to hospitals, care centers, universities, and any affiliated institution.

DATA QUALITY

o Promote the collection and use of local data that align with the context, the demographic and the epidemiological profiles of the countries in the region to generate higher-quality solutions that are more representative of local populations.

o   Strive for the reduction and control of biases throughout the development of AI projects.

o   Encourage the generation of updated public databases with complete and high-quality data.

o   Train individuals responsible for working with data in all phases of the data cycle to ensure the preservation of data quality.

o   Integrate elements of data usage and management into the educational curricula of healthcare professionals in training.

ETHICAL

o   Address ethical issues from the initial stages of project design to implementation and follow-up.

o   Involve ethics experts and experts from other disciplines from the beginning of projects to mitigate biases.

o   Aim for the anonymization of health data, hosting data in secure locations, as well as temporary and compartmentalized archiving.

o   Collect data to answer a research question, meaning, for a specific purpose.

INFRASTRUCTURE

o   Promote domestic and foreign investment in digital infrastructure.

o   Design comprehensive cybersecurity plans that include experts from different disciplines to achieve an integrated perspective, including the healthcare sector.

STATES CAPACITIES

o   Promote the existence of specialized agencies in data use and protection, privacy, and access to information, and ensure that these agencies have experts in health data.

o   Encourage the formation of a specialized state bureaucracy in data use and health data.

o   Develop manuals, guidelines, and best practices for developers of AI applications in health to understand the governance path they should follow to develop an AI solution in health.

- Promote the design and implementation of National Digital Health Strategies to foster innovation and articulate data governance with clear objectives.

- In federal or highly decentralized countries, consider adapting data governance to sub-national levels.

COLLABORATION AMONG STAKEHOLDERS

- Promote coordination between national states and regional and international organizations to advance common goals.

- Encourage the participation of different actors: developers, start-ups, academia, citizens, and others, to support governments in creating ecosystems.

- Stimulate citizen participation and digital education to raise awareness of their rights, obligations, and responsibilities regarding the use of their data.