

Implementation Guide for using the Model Law on Health Data Governance to Strengthen National Frameworks

SECTION 1: PURPOSE

The intention of this section is to articulate the foundational principles and objectives of the model law. These foundational principles and objectives, and implementation guidance below, can be considered and applied widely when strengthening the national legislative landscape dealing with the governance of health data, whether those entail updating current laws or developing new ones. These are foundational principles and objectives are therefore not limited to countries developing a whole new health data governance law.



RATIONALE

RECOGNITION OF THE SPECIAL NATURE OF HEALTH DATA

The distinct characteristics of health data are acknowledged, which have far-reaching implications for individual privacy, community identity, and the advancement of healthcare research and innovation. The law recognizes that health data is not just another category of personal data; it is deeply intertwined with individuals' personal and medical histories, cultural practices, and collective well-being.

Understanding the special nature of health data is essential for crafting a legal framework that adequately protects the rights of individuals and communities while promoting the beneficial use of health data for research and innovation. This recognition lays the groundwork for the specific protections and governance structures established by the model law.

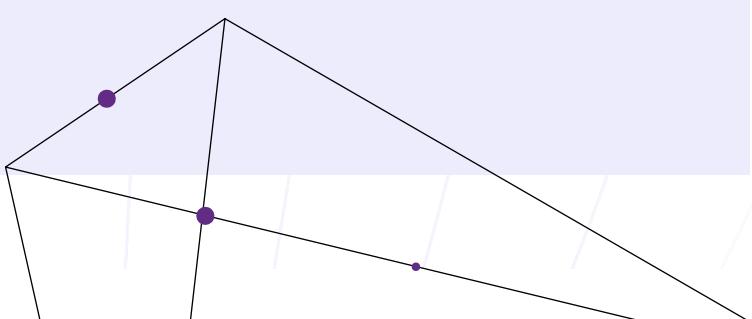
AUGMENTATION OF EXISTING DATA PROTECTION LAW

This provision emphasizes that the model law is designed to supplement existing data protection laws by addressing the unique aspects of health data. While general data protection laws provide a broad framework for safeguarding personal data, they may not fully capture the complexities and sensitivities associated with health data.

By augmenting existing data protection laws, the model law ensures that the specific needs and challenges of health data governance are addressed. This includes balancing the interests of individual data subjects, communities, and the health research community in a way that promotes both privacy and innovation.

SPECIFIC AIMS OF THE MODEL LAW

The specific aims of the model law are to establish effective governance structures for health data processing, safeguard individual privacy rights, protect community interests in health data, and foster a conducive environment for health research and innovation. Additionally, the law aims to manage non-identifying government-generated health data as a public good, facilitate health data sharing in the public interest, and provide a flexible legal framework that can adapt to future technological advancements in health data collection, analysis, and use. These aims collectively ensure that health data is governed in a manner that balances privacy, community rights, and the need for innovation in healthcare.





INTERNATIONAL CONSIDERATIONS

The purpose of this law is closely tied to several international regulations, guidelines, treaties, and agreements. These include pandemic preparedness frameworks (e.g., IHR, PIP Framework), data protection frameworks (e.g., GDPR, OECD Guidelines), human rights principles (e.g., UDHR, ICCPR), intellectual property treaties (e.g., TRIPS), and global health initiatives (e.g., WHO, GHSA). Aligning the foundational principles and objectives of the law with these international frameworks ensures that the law is globally relevant, supports public health and pandemic preparedness, and protects individual privacy and proprietary rights in health data.



IMPLEMENTATION TIPS

This section sets out the ideological position underlying the model law. Care should be taken that this approach is not contrary to the objectives of other laws or policies.



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Transform Health is a global coalition of organisations that work to harness the potential of digital technology and the use of data to achieve universal health coverage (UHC) by 2030. To learn more about Transform Health visit: www.transformhealthcoalition.org.

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