



Health Data Governance Principles

Guiding questions for global, national local consultation

Transform Health has launched a public consultation on a set of Health Data Governance Principles, which will be open from 27 October until 3 December. We are encouraging partners to carry out their own regional, national or local consultations during this period to gather further insights from diverse stakeholder groups and to share these as part of the Public Consultation. The following questions can be used to guide discussions during your own consultation on the Principles. While we encourage feedback on all questions, you are welcome to adapt and prioritise the questions based on your context. Please share feedback from your consultation through the online survey on the [Public Consultation page](#). If you have any questions, contact: Kirsten.Mathieson@transformhealthcoalition.org.

Guiding questions	Consultation feedback
<i>Introduction, framing, clusters</i>	
1. Title: “Health Data Governance Principles - Towards universalizing the benefits of health digitalization” <i>Do you have any feedback on the title or subtitle of the principles?</i>	
2. Framing: The Principles are grounded in UHC and bring in a human rights and	

<p>equity lens to digital health.</p> <p><i>Would you make any changes to the framing?</i></p>	
<p>3. Objectives: The principles are framed around three objectives: (1) protecting people (individuals and communities); (2) promoting health value (through data sharing and its innovative uses); and (3) prioritising equity (equitably distribute the benefits that arise from digitization and digitalization of health systems).</p> <p><i>Would you make any changes to the objectives?</i></p>	
<p>4. Audience: The principles are intended as a resource for a variety of stakeholders involved in the governance of health data, including governments, international organizations, the private sector, nonprofit organizations, research and academic institutions, foundations, civil society, and global coalitions. They target governments, developers and other stakeholders that collect and use health data and can eventually be used as a mechanism to hold them accountable to equity and human rights agendas.</p> <p><i>Do you have any feedback on the intended audience of the principles?</i></p>	

5. **Clusters:** The Principles are grouped around three clusters:
- **Protect people** – Protect individuals and communities, Build trust, Advance data security
 - **Promote health value** – Enhance health systems and services, Promote data sharing and interoperability, Facilitate innovation
 - **Prioritize equity** – Ensure equitable benefit, Establish data rights and ownership

Do you agree with how the principles are clustered? Would you make any changes?

Protect people: *Protect individuals and communities, Build trust, Advance data security*

6. **[Principle] Protect individuals and communities:** Health data governance must address the protection of individuals and communities at every stage of the data lifecycle. Data governance should also seek to balance the protection of individuals and communities with the societal value of data use for health.

Do you agree that this should be included as a principle? Are there any additional Core Tenets that should be included under this principle? Should any be removed? Any further feedback

<p><i>on this principle?</i></p>	
<p>7. [Principle] Build trust: Health data governance must reinforce trust in data collection and use, and in data systems. Trust requires safeguarding data, preserving privacy, and establishing transparent and inclusive processes of data collection, analysis, and use.</p> <p><i>Do you agree that this should be included as a principle? Are there any additional Core Tenets that should be included under this principle? Should any be removed? Any further feedback on this principle?</i></p>	
<p>8. [Principle] Advance data security: Data security encapsulates multiple dimensions including recommending good practices on collection, storage, use, dissemination, analysis and disposal of health data. These are reflected across these Health Data Governance Principles.</p> <p><i>Do you agree that this should be included as a principle? Are there any additional Core Tenets that should be included under this principle? Should any be removed? Any further feedback on this principle?</i></p>	

Promote health value: Enhance health systems and services, Promote data sharing and interoperability, Facilitate innovation

9. **[Principle] Enhance health systems and services:** Health data governance should enhance health system efficiency and resilience and the improvement and expansion of health services— contribution to ongoing efforts to advance health equity and Universal Health Coverage.

Do you agree that this should be included as a principle? Are there any additional Core Tenets that should be included under this principle? Should any be removed? Any further feedback on this principle?

10. **[Principle] Promote data sharing and interoperability:** Data sharing is basic to creating data-based health value. Undertaken at national, regional, and global levels, it allows for deeper and more significant insights related to health needs and challenges, including preventing and responding to health emergencies.

Do you agree that this should be included as a principle? Are there any additional Core Tenets that should be included under this principle? Should any be removed? Any further feedback on this principle?

11. **[Principle] Facilitate innovation:** Health data governance should be forward-looking and anticipate (wherever possible) the application of emerging technologies such as artificial intelligence. Leveraging the innovation possibilities during the ongoing 'digital age' is key to attaining the SDGs and UHC.

Do you agree that this should be included as a principle? Are there any additional Core Tenets that should be included under this principle? Should any be removed? Any further feedback on this principle?

Prioritize equity: Ensure equitable benefit, Establish data rights and ownership

12. **[Principle] Ensure equitable benefit:** Equity must be inherent to health data governance—ensuring (1) equitable representation in data of all individuals and communities regardless of social or economic characteristics, and (2) equitable access to data generated health value for all, especially the individuals and communities who originally contributed the data.

Do you agree that this should be included as a principle? Are there any additional Core Tenets that should be included under this principle? Should

<p><i>any be removed? Any further feedback on this principle?</i></p>	
<p>13. [Principle] Establish data rights and ownership: Health data governance should be rooted in strong and clear data related rights. Data ownership implies that individuals and communities have a right to know, control and determine how their data is used, and to benefit equitably from such data.</p> <p><i>Do you agree that this should be included as a principle? Are there any additional Core Tenets that should be included under this principle? Should any be removed? Any further feedback on this principle?</i></p>	
<p>Additional feedback</p>	
<p>14. <i>Are there any additional principles that should be included? If so, please provide a description, including suggested core tenets.</i></p>	
<p>15. <i>Do you have any further suggestions to improve the principles?</i></p>	