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| **Session:** PS 3.2 – Strengthening Health Data Governance**Date:** Saturday 1 February 2025; Time 15:00 - 17:00 hrs**Author(s)/ Speaker(s):** Nirmal Rijal and Mrinal Kanti Tripura**Background paper on the topic** |

**Health Data Governance**

***Data Governance for Indigenous Data Sovereignty in South Asia***

**Background and Context**

This paper draws from and is inspired by studies undertaken in Nepal by the first author along with co-researchers in Bangladesh, India and Sri Lanka (2021-2023) to explore, among other things, the participation of digital ecosystem stakeholders in the region’s digital development. Complemented by a comprehensive desk review, the authors argue for the participatory inclusion of Indigenous and tribal communities in the development and implementation of regional and national health data governance frameworks; for Indigenous data sovereignty through culturally sensitive policy and technological development; and for health policies to protect intellectual property and patent rights of these communities, in the wake of commercial and scientific interest in traditional medicinal systems associated with transformations in healthcare technology.

The unprecedented digital development behind this transformation in healthcare technology brings boundless opportunities, as it does associated challenges – two of which warrant mention in the context of this paper around how global development has perennially witnessed marginalization and exclusion. The first challenge lies around the potential for digital health technologies to exacerbate such exclusion; and the second challenge revolves around the equitable and ethical utilization of the humongous health data thus generated.

Approximately 30% of global data, today, comes from healthcare, with a growth rate higher than that in manufacturing, financial services and media/entertainment. However, awareness around how their health data is collected, stored, processed, analyzed, shared and ultimately used, is low, especially among the Indigenous people of South Asia. This necessitates the participatory development of robust frameworks for data governance to ensure that their health data is not vulnerable to breach, misrepresentation and exploitation.

This paper discusses three Indigenous communities of South Asia – the Adivasis of India, the Indigenous Peoples of the Chittagong Hill Tracts in Bangladesh, and the Indigenous Nationalities of Nepal. Known to possess unique health profiles influenced by their distinct lifestyles, environments, and genetic heritage, these communities often face significant health disparities, exacerbated by socioeconomic marginalization, limited access, and a lack of culturally appropriate health services. How their health data is collected and used can therefore have significant implications for addressing these disparities and ensuring equitable health outcomes.

That brings us to the important principle of data sovereignty – the right of individuals and communities to control the collection, ownership, and use of their data. For the Indigenous populations of South Asia, health data sovereignty is not only a matter of privacy and autonomy but also one of survival, identity, and self-determination. As such, the principle asserts that Indigenous communities should have control over who collects their data, how it is stored, and how it is shared and used. Such control is crucial for several reasons, as discussed below.

**Cultural Appropriateness**

Indigenous knowledge systems and practices are deeply rooted in their cultural context, and healthcare systems that ignore this reality often fail. With control over their health data, Indigenous communities can ensure that health policies and programs have respect for and align with their cultural values and knowledge systems.

For example, culturally relevant psycho-social group interventions used in India to address mental health issues among Indigenous communities focus on building trust, providing social support, and improving mental health outcomes. Such community-based approaches respect the cultural context and have been effective in improving mental health outcomes[[1]](#footnote-1).

**Likewise**, traditional medicine practices across South Asia – Ayurveda, Yoga, and Siddha, for example – deeply rooted in the cultural heritage of Indigenous communities are not only culturally appropriate but also effective in promoting health and well-being. Integrating these traditional practices into health interventions ensures that they align with the cultural values and knowledge systems of the communities[[2]](#footnote-2).

While these examples highlight the importance of culturally appropriate health interventions in South Asia, they also point to the importance of data ownership and custodianship in the design of effective health policies and programs for the communities they serve.

**Protection Against Misuse**

There is a long history of exploitation and abuse of Indigenous data, often collected without consent and used in ways that harm rather than help these communities. In 2014, a mass sterilization drive conducted in Bilaspur, India, without proper aseptic precautions led to the deaths of 12 women, many of whom were from tribal and Scheduled Caste communities[[3]](#footnote-3). The drive highlights how the misuse of health data and lack of informed consent can have fatal health consequences.

Historically, research related to Indigenous peoples has often been conducted without their input or control over the data leading to policies and research outcomes that do not meet the needs and priorities of Indigenous communities[[4]](#footnote-4). A systematic review revealed that the majority of the tribal population in India failed to access public healthcare services indicating a disparity in the use of health data to address the mental health needs of these communities[[5]](#footnote-5).

Ensuring Indigenous peoples’ control over their health data prevents such exploitation and supports the ethical use of data. For example, the Adivasi communities in India have been advocating for control over their health data to prevent misuse and exploitation. By establishing community-led health data repositories, they ensure that their health information is collected, stored, and used according to their cultural values and consent protocols. This prevents external entities from exploiting their data for commercial or research purposes without their permission.

The Indigenous communities of the Chittagong Hill Tracts have established community-based health information systems that they manage and control by themselves. This ensures the ethical use of their health data for community benefit, preventing unauthorized access and misuse.

Indigenous communities in Nepal have been working to establish their own health data governance frameworks to ensure that their health data is collected and used in ways that respect their cultural context and consent. This protects them from exploitation by external researchers or organizations that may seek to use their data without proper authorization or consent.

**Empowerment**

Access to accurate health data empowers communities to identify their health needs, track health outcomes, and advocate for appropriate resources and policies. It also enables their meaningful participation in national and international health initiatives, ensuring that their voices are heard, and their needs are addressed.

For example, the Adivasi communities in India utilized health data to identify their specific health needs and advocate for better healthcare services. By tracking and sharing data on health outcomes with policymakers, they secured more resources for culturally appropriate interventions[[6]](#footnote-6).

Through their community-based health information systems, the Indigenous Peoples of the Chittagong Hill Tracts are able to monitor health trends and outcomes, helping them better advocate for policies that address their unique health needs and ensure that their voices are heard in national health debates[[7]](#footnote-7).

Indigenous communities in Nepal have used health data to participate more meaningfully in national and international health discourses. With access to accurate health data, they have been able to influence health policies and programs to better meet their needs, ensuring that their cultural context is respected, and their health rights are protected[[8]](#footnote-8).

**Land Ownership, Biodiversity, Food and Health**

The health data of the Indigenous peoples of South Asia probably fails to take into account how their health situations have changed with changes in their food habits. This change in food habits results from changing patterns of land use, and the misappropriation of tribal and Indigenous lands and territories – regions that have traditionally remained bio-diversity hubs because of the strong bonds between Indigenous peoples and nature. Indigenous data governance frameworks need to take into account this correlation between biodiversity degradation and deterioration in Indigenous peoples’ health.

**Patent Rights**

South Asia is home to intergenerational Indigenous knowledge reflecting community traditions in prevention, diagnosis and treatment in health. With unprecedented advancement in technology, there is the danger that ‘big pharma’ could trial and patent traditional medicines, not only depleting Indigenous resources, but also creating barriers of access. Regional and national policy frameworks need to comply with WHO, WTO and World Intellectual Property Organization frameworks to safeguard the patent rights of Indigenous communities and vital resources[[9]](#footnote-9).

Ayurveda, a traditional system of medicine, has witnessed the patenting of turmeric and neem-based products by foreign companies, leading to legal battles. Concerned with the exploitation of traditional knowledge, the Indian government has had to intervene to revoke such patents and protect Indigenous knowledge[[10]](#footnote-10).

In Nepal, extensive research and patenting of traditional medicinal plants like Yarsagumba (Cordyceps sinensis) by foreign entities has led to the depletion of local resources. This has in turn restricted access for Indigenous communities who rely on these plants for their livelihoods and traditional healthcare. There is the need for national policies that ensure that traditional knowledge is protected and that benefits are shared equitably with Indigenous communities[[11]](#footnote-11).

In Bangladesh, traditional medicinal plants have attracted the interest of pharmaceutical companies and the lack of robust legal frameworks to protect traditional knowledge has resulted in the unauthorized use and patenting of these resources by external entities. This not only depletes scarce resources but also prohibits access for communities who have used these remedies for generations[[12]](#footnote-12).

**Challenges and Remedies**

The positive examples notwithstanding, achieving health data sovereignty for Indigenous peoples in South Asia is not without it challenges. These include the lack of robust legal frameworks supporting data sovereignty, limited capacity within Indigenous communities to manage health data, and non-cooperation of mainstream health institutions.

Legal recognition of health data sovereignty is a critical step at addressing these challenges. Governments in South Asia need to develop and implement policies that recognize the rights of Indigenous communities over their health data. This includes ensuring that data collection practices are aligned with the principles of free, prior, and informed consent (FPIC) and that data-sharing agreements respect Indigenous ownership and control.

Capacity-building initiatives should provide training and resources to enable Indigenous communities to collect, manage, and use their health data effectively. Partnerships with academic institutions, civil society organizations, and other stakeholders should be promoted.

Finally, fostering a collaborative relationship between Indigenous communities and mainstream health institutions could help with recognizing and valuing Indigenous knowledge systems and ensuring that health data initiatives are co-designed and co-implemented.

**Indigenous Data Sovereignty: Alliances and Instruments**

This section provides a short description of key alliances and instruments that exist to promote Indigenous data sovereignty. While this is not an exhaustive list, it can help to serve and support Indigenous data governance advocates and activists in South Asia, or globally.

The UNDRIP – a comprehensive international instrument adopted by the UN General Assembly in 2007 – lays out the rights of Indigenous peoples globally, establishing minimum standards for their survival, dignity, and well-being. These include the right to self-determination; cultural rights and identity; land and resources; participation in decision-making; free prior and informed consent; and non-discrimination – highlighting the rights of Indigenous communities to inclusion and participation, including in the development of data governance frameworks[[13]](#footnote-13)[[14]](#footnote-14).

The CARE Principles for Indigenous Data Governance – a set of guidelines designed to ensure that data ecosystems respect and uphold the rights and interests of Indigenous Peoples – advocates for Collective Benefit, Authority to Control, Responsibility, and Ethics[[15]](#footnote-15). They complement the FAIR principles (Findable, Accessible, Interoperable, Reusable) by emphasizing the importance of people and purpose in data governance[[16]](#footnote-16). They aim to empower Indigenous communities to manage their data in ways that support their self-determination and innovation.

While the Global Digital Compact – a framework aimed at improving digital cooperation and ensuring that digital advancements benefit all people, including Indigenous communities – does not specifically focus on Indigenous data sovereignty, it emphasizes principles such as data protection, human rights online, and digital inclusion[[17]](#footnote-17). These principles align with the goals of Indigenous data sovereignty, which seek to ensure that Indigenous communities have control over their data and that their rights are respected. Additionally, the Compact encourages the inclusion of Indigenous voices in digital policymaking and highlights the importance of respecting Indigenous values and collective interests[[18]](#footnote-18).

The Global Indigenous Data Alliance (GIDA) – an international network of Indigenous researchers, data practitioners, and policy activists who advocate for Indigenous Data Sovereignty and Governance – aim to ensure that Indigenous Peoples have control over their data and that their rights and interests are respected in data governance. GIDA promotes the CARE principles, which emphasize the importance of Indigenous values and collective interests in data management[[19]](#footnote-19).

The Asia Indigenous Peoples’ Pact (AIPP) has developed the Asian Framework on Indigenous Knowledge and Data Sovereignty, which emphasizes the importance of Indigenous Peoples' rights to control their knowledge and data, which is crucial for their self-determination and effective self-governance. Aligned with Indigenous values and collective interests, it outlines key values and principles necessary to uphold Indigenous ways of knowing and respects their rights[[20]](#footnote-20).

While it is important for legal and regulatory frameworks related to data across countries to remain in harmony, as recognized by the 2025 G20 Health Ministers’ declaration, it is crucial that such frameworks also take into account the needs and priorities of Indigenous peoples, ensuring alignment across borders. Again, the participation of Indigenous peoples across South Asian borders remains imperative. The authors appeal to coalitions like Transform Health and others to ensure that Indigenous peoples’ interest and participation are ensured in the development of the global (and regional) health data governance framework, including a model law, that they advocate for to be developed and endorsed by governments.

**Conclusion**

The arguments and examples discussed in this paper underscore the importance of robust data governance frameworks to protect the rights and interests of Indigenous peoples in South Asia. Only truly inclusive processes for the development of health data governance frameworks can ensure protection for such communities against data-related harm, discrimination and exploitation. While equitable frameworks can ensure reliable electronic health record systems vital for predictive analytics to help identify trends, patterns and potential health risks, skewed and/or underrepresented data can misrepresent their unique health needs. A recent surge in advocacy by champions from these communities has led to a more pronounced voice seeking equitable benefits from health data based on increased calls for data ownership and custodianship. That they now seek and secure a seat at regional, national and sub-national policy debates that relate to data governance frameworks is a positive result emanating from such advocacy. In conclusion, a significant step towards achieving health equity and justice for Indigenous peoples of South Asia can be achieved by prioritizing health data sovereignty within global, regional and national data governance frameworks.

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3. [The Health of Indigenous Populations in South Asia: A Critical Review in a Critical Time](https://journals.sagepub.com/doi/pdf/10.1177/0020731420946588) [↑](#footnote-ref-3)
4. [From exploitation to empowerment: how researchers can protect Indigenous peoples’ rights to own and control their data](https://www.nature.com/articles/d41586-024-03640-7) [↑](#footnote-ref-4)
5. [Tracing the Disparity Between Healthcare Policy–Based Infrastructure and Health Belief–Lead Practices: a Narrative Review on Indigenous Populations of India | Journal of Racial and Ethnic Health Disparities](https://link.springer.com/article/10.1007/s40615-023-01810-3) [↑](#footnote-ref-5)
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