

Session Outcome Document

Sovereign Health Systems and the Collective Privacy Gap: What the World's First Indigenous-Sovereign AI Health Initiative Reveals About the Limits of Current Governance

Innovation Network Global and Innovation Network Canada, with the Dynamic Coalition on Emerging Technologies, UN Internet Governance Forum

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<https://www.itu.int/net4/wsisis/forum/2026/Agenda/Session/488>

Key Issues Discussed:

- The session examined what Pam Dixon (World Privacy Forum) described as the collective privacy gap. While privacy law and human-rights instruments are constructed around the individual, artificial intelligence increasingly operates on collective data, and much of the intelligence embedded in today's health AI is drawn from datasets that underrepresent the communities carrying the greatest burden of disease. Drawing on more than a decade of work on collective governance, including with the UN Statistical Commission and on New Zealand's algorithmic-governance work where the Māori conception of privacy is collective rather than individual, Dixon characterised the gap as at once legal, socio-cultural, and technical.
- Against the backdrop of more than 4.6 billion people without access to essential healthcare, Healthcare Without Borders was presented as a working implementation case for how community-governed digital infrastructure can allow communities to contribute to future health intelligence while retaining control over their data, governance, and decisions.
- Representatives of the Tsleil-Waututh Nation described sovereignty in healthcare as the community acting as its own voice in every decision. Non-consensual testing during the residential-school era continues to deter members from seeking care, and holding health information within the community, then co-designing and owning the infrastructure rather than adopting it, was presented as essential to rebuilding trust. The Nation participates as co-developer of both the governance model and the technology, not as a recipient.
- Dr. Luigi Serio (CERN, in personal capacity) described federated learning, in which models are trained where data is generated and only model parameters are exchanged, so records never leave the source. Developed for particle-physics data, the approach is already implemented in three European healthcare projects, producing high-performing prediction, diagnosis, and prevention models while data remains local.
- Sovereign clinical intelligence running on low-power devices without connectivity was presented alongside federated learning as the combination that allows a community to retain full control of its data while contributing to and benefiting from shared models. Dino Dell'Accio (UN Joint Staff Pension Fund) described the Fund's blockchain-based digital identity system, used to confirm proof of life for beneficiaries across many countries and reframed as digital dignity, in which zero-knowledge proofs preserve individual privacy within collective infrastructure.
- Dr. Raghwa Gopal set out five measures against which health leaders will judge the first implementation: health outcomes, trust in data governance, operational performance, economic sustainability, and scalability across jurisdictions. Broad transformation depends on an innovation

becoming repeatable, which requires common standards, interoperable technologies, supportive policy, committed leadership, and genuine partnership with communities.

- Dr. Nalini Saligram (Arogya World) reported reaching 29.5 million people in India over fifteen years, including the mDiabetes programme of 62 messages over six months, now augmented with AI, noting that 80 percent of type 2 diabetes is preventable through diet, activity, and avoiding tobacco. Adapting validated prevention content within the initiative was proposed on three conditions: cultural relevance, recruitment through a trusted local partner, and lower cost.
- Panelists examined adaptation across dispersed and under-served systems. Councillor Juliana Haimbodi described Namibia's population of about 2.1 million across a vast area with care concentrated in urban centres, setting three conditions: digital health must complement rather than replace clinicians, data must remain in-country with strong cybersecurity, and connectivity and digital literacy require investment. Nurain Janah (Kandūfā Foundation) described the Maldives as 1,200 dispersed islands on the front line of climate-related health impacts, where specialised care requires travel abroad, raising community ownership of traditional knowledge and its intellectual property. Dr. Amit Rana, a clinician, identified care providers as the system's most constrained resource and described how connected, co-designed care can reduce fragmentation, cognitive load, and burnout.

Key Outcomes of the Session

- Healthcare Without Borders was presented with the Tsleil-Waututh Nation as founding implementation partner and first reference implementation, now in preparation and co-designed with the Nation across both governance and technology, intended to inform later implementations elsewhere.
- Federated learning was reported as already delivering high-performing clinical models in three European healthcare projects with data kept local, evidence that collective intelligence and data sovereignty are compatible rather than opposed.
- The collective privacy gap was defined as both a legal and a technical gap, positioning collective and community rights, alongside individual rights, as the governance question that sovereign AI-enabled health infrastructure must answer, and underscoring that equitable AI-enabled healthcare depends as much on governance and trust as on technology.
- Arogya World expressed interest in adapting its validated diabetes-prevention content within a modular ecosystem alongside clinical intelligence, wellness applications, and interoperable infrastructure. Namibia and the Maldives reaffirmed interest in adaptation, the latter referencing its recently launched Maldives Health Digital Blueprint. The Council of Europe Convention 108+ was identified as an accessible instrument for states without data-protection law (Pam Dixon).

Key Recommendations and Forward-Looking Actions

- Develop community-governed digital health infrastructure as a replicable reference model for the WSIS e-health agenda toward 2035, documenting, evaluating, and publishing lessons from the first implementation so that other Indigenous Nations, governments, and jurisdictions can adapt them while respecting local governance, culture, and priorities.
- Advance data-governance frameworks that recognise community-level rights alongside individual rights. For states without data-protection legislation, Convention 108+ offers an accessible instrument with enforcement effect against external data extraction.
- Hold health data under community or national control, in-country rather than in foreign cloud jurisdictions, adopting on-device inference and federated learning as the reference architecture for sovereign participation in shared models, and invest in the connectivity, cybersecurity, and digital literacy that make such systems usable.
- Pursue a phased international pathway that builds on the Tsleil-Waututh reference model, with context-specific implementations in interested jurisdictions including the Maldives, Namibia, India,

and Australia, each strengthening the next while communities retain sovereignty over data and decisions.

- Use the convening of 56 Commonwealth Heads of Government in Antigua and Barbuda in November 2026 to establish a multi-stakeholder mechanism for scaling community-governed digital health, including sustainable financing and capacity building that address the resource and power asymmetry small states face in negotiating interoperable, non-extractive systems.