Beyond Metrics: How Community-Led Data Governance and Indigenous Data Sovereignty Are Reimagining Health Justice

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Introduction

In an era of digital transformation and big data, data-driven decision-making in healthcare has become a gold standard. Governments, nonprofits, and private actors alike are increasingly turning to metrics, dashboards, and algorithms to inform policy and resource allocation. But amid this data deluge lies a dangerous blind spot: the persistent erasure and misrepresentation of indigenes and marginalized communities. Dominant data practices—often colonial, extractive, and opaque—frequently reduce individuals to variables and entire communities to risk scores, without their consent or control. In response, movements advocating for **community-led data governance** and **Indigenous Data Sovereignty (IDS)** are gaining momentum, challenging not only who holds data, but how it is collected, interpreted, and used.

The Legacy of Data Colonialism

For indigenous communities globally, data has historically been a tool of domination rather than empowerment. Colonial governments systematically collected data to dispossess land, criminalize cultural practices, and erase indigenous identities. In contemporary contexts, national statistical systems and health surveillance often perpetuate similar harm, labeling indigenous populations as "hard to reach" or "data poor" while continuing to extract data without consent.

This has tangible consequences. Many public health datasets aggregate indigenous populations into "other" categories, erasing cultural and geographic diversity. Health inequities—such as higher rates of diabetes, suicide, and maternal mortality—are obscured or misrepresented, limiting the effectiveness of health interventions. As data drives funding, policy, and research, invisibility in the data means invisibility in the solution.

What Is Indigenous Data Sovereignty?

Indigenous Data Sovereignty refers to the right of indigenes to govern the collection, ownership, and application of data about their people, lands, and resources. It stems from internationally recognized rights to self-determination, such as those enshrined in the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP).

IDS frameworks, like the **CARE Principles** (Collective Benefit, Authority to Control, Responsibility, Ethics), developed by the Global Indigenous Data Alliance, emphasize the relational, cultural, and ethical dimensions of data. Unlike the dominant **FAIR** principles (Findable, Accessible, Interoperable, Reusable), which are concerned with technical optimization, CARE centers power, equity, and accountability. It asks: Who benefits? Who decides? Whose knowledge is valued?

Community-Led Data Governance in Practice

Efforts to implement community-led data governance are emerging across continents. In Aotearoa New Zealand, the Māori Data Sovereignty Network (Te Mana Raraunga) has developed ethical frameworks to guide researchers and public institutions in engaging with Māori data. In the United States and Canada, tribal governments have established Tribal Epidemiology Centers and data sharing agreements to assert control over health data.

The Urban Indian Health Institute, for example, produces community-led health reports that combine quantitative data with cultural knowledge and storytelling. Their work challenges the "deficit narrative" often embedded in mainstream data and replaces it with strength-based, community-defined metrics of wellness.

Reimagining Health Justice Through Data Justice

True health justice requires more than equitable access to care—it demands equity in the very tools used to define health needs and outcomes. Community-led data governance is not just a procedural shift; it's a paradigm change that reframes data as a collective asset, embedded in cultural context and governed by those to whom it pertains.

By centering lived experience, traditional knowledge, and community priorities, these models move beyond extractive research and toward relational accountability. They enable communities to tell their own stories, define their own indicators of health, and guide resource allocation in ways that are culturally congruent and just.

Recommendations for Equity-Centered Institutions

To support this reimagining, health institutions and researchers must:

1. **Recognize and respect Indigenous data governance protocols**, including adherence to tribal Institutional Review Boards (IRBs) and community review boards.

2. **Implement CARE principles** in data stewardship policies, alongside FAIR principles.

3. **Ensure co-design and co-ownership** of research and health data projects with communities.

4. **Invest in capacity building** so Indigenous and marginalized communities can steward their own data infrastructures.

5. **Shift power** by funding long-term community-driven data initiatives rather than short-term extractive studies.

Conclusion

Data is not neutral. It is a reflection of the values, priorities, and power structures of those who create and control it. For too long, Indigenous and marginalized communities have been counted without being heard, measured without being seen. By embracing Indigenous Data Sovereignty and community-led data governance, we can move from surveillance to solidarity, from invisibility to empowerment, and from metrics to meaning. In doing so, we lay the groundwork for a more just, participatory, and accountable health system—one that serves everyone, not just those in power.

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