

Digital health and the AI economy

Some considerations for equity and the right to health for all

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IT for Change

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EXAMINATION OF THE ACTOR-INFRASTRUCTURE ECOSYSTEM

- Undertaken by **IT for Change** and the **University of Western Australia** in **India** and **Australia**.
- A two-year research study considering the critical nature of digital public infrastructures (DPIs) and the urgent need for examining the ethical frameworks underpinning their development and deployment.
- Explores **three domains** — **Healthcare, Agriculture** and **Urban Development/Smart Mobility** — that are anticipated to be widely transformed by **DPIs, big data, AI**, and **immersive technologies, among others**.
- Investigates and explores how the State — as an enabler, regulator and deployer of emerging advancements and capabilities — ensures ethical practice and responsible innovation in cyber and critical technologies.

Digitisation in Public Health: India's Approach

- Universal healthcare is the primary driver for digitisation of India's health sector. (G20 Declaration)
- The Ayushman Bharat Digital Mission (ABDM) is designed to allow for rapid digitisation, scaling and adoption.
- It focuses on individual relationship in patient care.
- The result – there's little information on how data that is collected is used and by whom; largely unregulated data transfers.
- Centralizing inherently decentralized structures has a direct impact on trust.
- The context of datafication changes the architecture - the infrastructures and ethics - of public health delivery.

“Distrust is as important as trust. With blind trust, systems fail and there are no alternatives”

- Digital rights activist

“The state's role, with regards to technology, is two-fold: to provide incentives to digitisation, particularly in rural areas; and secondly, to monitor the digitisation efforts.”

- Government stakeholder

The regulatory gap

- Health data is regulated under the Data Protection Act, in addition to sector specific policies and guidelines. The latter are unenforceable in courts of law.
- India's data protection regulation does not provide for specific provisions on health data. (Variations in data retention policies)
- Compliance obligations for private entities are limited (notice requirements are lax), and the government is granted wide ranging exemptions (from *all* sections of the data protection law).
- Regulation limited to notice and consent mechanisms - does not look at bodily autonomy, economic and exclusionary harms or group risks to privacy.
- The rights of communities to their data not supported through any complementary policies on data stewardship or data commons.

“You cant dematerialize healthcare. The Unified Payments Interface had a single regulator in place i.e. the RBI. In the absence of such a regulator, the health sector will be dominated by private entities.”

– Independent researcher

E-Trade and the Global South - following the flows

- A shift to the quantified self and platform-enabled data generation implicates the collection of non-clinical, self-reported data, such as data from wearable devices and behavioural data, as well as IoT devices (environmental data, socio-economic data) etc.
- All data is health data!!
- The non-clinical nature of the data allows non-clinical stakeholders to derive value for themselves from this data. (For example, Google has a number of interests in health: it owns FitBit, is working with health insurance companies, has developed AI-powered skin-care tools and previously acquired patient data from the UK National Health Service.)
- Traditionally, most patents are filed in the field of pharma, however, patents related to medical and bio technology, and database management systems are on the rise - preventing data pools from being accessible for public health research, legitimising monopolies
- Platform-enabled datasets draw attention away from research methodologies for contextual research - with real-time data from individuals seen to fill in for inadequacies of traditional statistical systems

E-Trade and the Global South - harms and risks

- Statistic: In 2019, the global digital health market was worth an estimated 175 billion U.S. dollars. With an expected CAGR of almost 25 percent from 2019 to 2025, the digital health market should reach nearly 660 billion dollars by 2025. (Statista, 2023)
Dominant players include China, United States, India, Japan, Germany (Statista, 2023); The Medical Device Industry alone is expected to be worth US\$ 50 billion by 2025 in India. (Patenting Trends in Global Healthcare Start-ups, 2021)
- Weak bargaining power of developing countries reduces countries to mere data exporters, leading to:
 - risk of misuse of health data (targeted ads—this has been prohibited by the EU Digital Services Act, but there is no global rules regime);
 - exodus of the social commons of data for AI models (from sophisticated models for AI-generated ‘cures’ to dubious fitness advisories)
 - privacy violation and unethical market practices - aggregate data may identify that X is likely to get Y disease and therefore cannot be granted insurance
 - innovation-washing - predatory data models in fintech or insurance that target the poorest in the name of digital innovation

How Public Health Data is at Risk

Case Study: Google DeepMind x Royal Free London NHS Trust

- Google acquired DeepMind in 2014
 - DeepMind signed deal with RFL NHS Trust in 2015, gaining access to 1.6 million patient records
 - Included information such as HIV status, abortion history, depression diagnosis, etc.
 - DeepMind used data to develop ‘Streams’, an app that can track when patients are at risk of acute kidney injury, which was tested on patients between 2015 and 2016
 - Year-long investigation by Information Commissioner’s Office found that DeepMind failed to comply with the Data Protection Act
 - Patients were not adequately informed of how their data would be used
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- *Case highlights how public health data can easily be accessed by technology corporations even with data protections in place.*
 - *FTAs could pave the way for MNCs gaining access to sensitive public health data in the Global South - where data protection and liability regimes for corporations are lax.*

E-Trade and the Global South - a consideration for MC 13

- WTO Moratorium on Customs Duties on Electronic Transmissions means eservices in health - outside of the ambit of tariffs.
 - The moratorium has already led to a loss of tariff revenues of at least \$56 billion between 2017-2020 for LDCs. Extending the moratorium on customs duties for electronic transmissions hinders developing countries' digital development.
 - India and other developing countries have stated in the WTO that the Councils for Trade in Goods and Services, Council for TRIPS (Trade Related Aspects of Intellectual Property Rights) and the Committee for Trade and Development should take up discussions on e-commerce as per their respective mandates originally set.

The Way Forward

- From digitalisation as Hobson's Choice to a rights-based national policy articulation - where the right to health is protected throughout the data lifecycle
- Structural interventions in the form of regulation – built around principles of accountability, including enforcement and monitoring mechanisms, redressal etc.
- Understanding of health data as a resource to be governed as a semi-commons - with a public good layer, health data commons governance and access and use regimes that prioritise public health innovation.
- International health data regimes to look at rules for global equity in public health research, collective benefit sharing, and guardrails for freeriding.