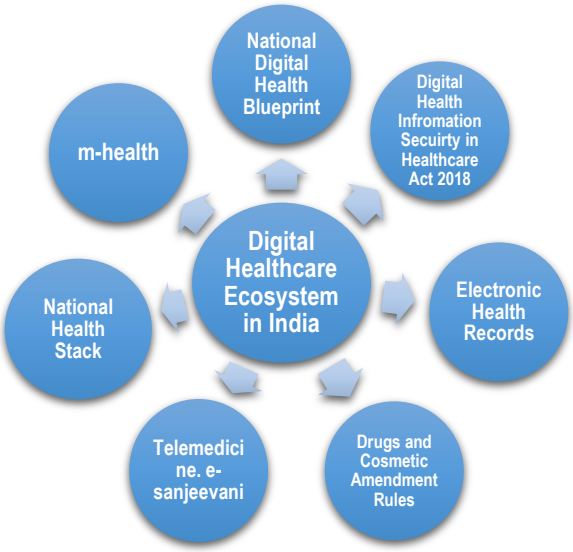
Digital Healthcare: A Way Forward

Background

In recent years, there has been a growing focus on technological solutions within the healthcare sector in India. The need and opportunity for the digital health care ecosystem are premised on the demand and supply gap in achieving the Sustainable Development Goal 'Good Healthcare and Well Being' (SDG Goal 3).[1]

In the assessment of India's achievement of SDG 3, it scores 58.8 out of 100 [2], pointing towards the lack of access to adequate health care services. This has specifically come to light in facing the current pandemic wherein we are increasingly realising shortages in medical and nursing staff (doctor-population ratio of 1:1404, WHO recommends 1:1000),[3] inadequate healthcare infrastructure (0.55 beds per 1000 population as per the national average, WHO recommends 5 beds per 1000 population)[4] and shortage of medical supplies.

In such a scenario, the role of technology in bridging this gap is being highlighted. To this end, the government has introduced new telemedicine guidelines,[5] has introduced the Arogya Setu app[6] for contact tracing, and called upon local manufactures to start production of ventilators and PPE kits. Apart from the above COVID-19 specific initiatives, the government had already been taking



initiatives on issues like telemedicine.[7] These include national teleconsultation service e-sanjeevani[8] developing National Health Stack,[9]draft Digital Information Security in Healthcare Act (DISHA) 2018,[10] Drugs and Cosmetics Amendment Rules 2019[11] and, most recently, the National Digital Health Blueprint (NDHB).[12] Along with this, there also has been growing interest of the private sector in digital health care and few of the private hospitals have also started using Artificial Intelligence in their operations.[13] It was also observed that, in between 2014-2018, health tech start-ups raised funding of US$504 mn.[14]

While the country is moving towards more integrated data systems and digital

healthcare solutions, there are also challenges related to adoption and trust, privacy and security concerns, and interoperability in digital healthcare solutions.

In this regard, some of the key assessments are highlighted below.

Key Assessments

1. **Access and Adoption:** There always have been major concerns regarding the reach of the public health care system in India. This is specifically true for rural areas, as these regions face a shortage of around 37 percent doctors in primary healthcare (including vacant positions and shortfalls) as of March 2019.[15] There are more shortages in specialised categories at the level of Community Health Centres (CHC)- physicians (85.7 percent) and pediatricians (82.6 percent)[16]. To mitigate these challenges, the government had envisioned several initiatives to reach remote areas with unequal access to healthcare. However, these have not grown in scale.

   The telemedicine initiative, which was started in 2001 by Indian Space Research Organisation (ISRO), has only connected to 45 rural hospitals and 15 super specialty hospitals as of 2019 [17]. While the government has now signed an MoU with ISRO to expand it to 100 telemedicine centres[18], but most of such services are currently operated by private health care units.[19] In this regard, a study by Consumer Unity & Trust Society (CUTS) on e-clinics (mode of telemedicine) services in Rajasthan revealed that the uptake of e-clinics has suffered on account of poor digital infrastructure, trust deficit due to negative publicity, lack of trained personnel and lack of supporting regulatory infrastructure regarding e-prescriptions.[20]

   In the wake of the pandemic and increasing demand for online consultations , the government has released new telemedicine guidelines addressing licensing, prescription, and consultation norms.[21] However, these guidelines still heavily rely on the capability of the patients to convey the right symptoms to the doctor and for doctors to be trained with digital technologies.[22] Additionally , challenges of digital divide persist with just 36 percent internet penetration in India as of 2019.[23]

Concerning data collection, there have been challenges such as - acceptance of Electronic Health Records (EHR) by the doctors as it consumes more time, burden of financial and administrative liabilities if something goes wrong, lack of awareness regarding rules of ethical data collection, lack of user-friendly interface for data collection, and internet connectivity limitations.[24] As a result, only 5 percent of health data is collected in India,[25] especially for hospitals in rural areas which lie on margins of data collection and are integrated within formalised system yet.[26] Hence, lack of access and adoption of existing digital healthcare solutions and data collection have failed to scale up to desired levels and attain acceptance in remote areas

2. **Privacy and Data Protection:** The government has taken several initiatives to integrate and create a centralised repository of health data through Electronic Health Records (EHR),[27] Strategy for National Health Stack and NDHB to use data for better tracking, efficiency and for developing Artificial Intelligence tools for diagnostics.

   Materialising these initiatives has become crucial now, considering the relevance of data in epidemiological surveillance and contact tracing to mitigate the effects of the pandemic. Simultaneously, privacy concerns regarding data of infected and quarantined people being made public by some of the state governments and risks of surveillance due to lack of apt privacy protocols of the Arogya Setu app launched by the government have increased.

The app collects self-assessment data (data on body temperature, symptoms of cough and cold, etc.), demographic data, and contact data to warn people about COVID-19 infected areas.[28] In this regard, litigation was also instituted in Karnataka High court, contesting the mandatory requirement for downloading the App as it can cause privacy breaches.[29] As a result of these growing concerns, the government published the privacy protocols followed by the application[30] and removed its mandatory status[31] and made the source code of the application public.[32]

However, these protocols do not highlight the transparency standards, clear data retention limits, and clear measurement of proportionality and necessity in the use of the health data. Moreover, these risks are not new as in an incident last year medical records of 35000 patients were leaked from a diagnostic laboratory.[33] With regard to open source code, there have been concerns raised that only a fragment of the entire code is made public.[34] Furthermore, the government has not issued justifications for the usage of centralised storage of data and entities which have access to such data.[35]

In the light of such concerns, data governance frameworks such as the draft Digital Information Security in Healthcare Act 2018, Personal Data Protection Bill (PDPB) 2019 and the NDHB need to be revisited, to address issues of de-harmonisation within these frameworks with respect to approaches to ownership of data[36] and right to be forgotten and deletion. Additionally, this crisis has brought to light the risks of government surveillance which could get elevated with no legal test of 'legitimacy, proportionality, and necessity' under PDPB 2019 to avoid exploitation of data in emergency situations.

3. **Interoperability and Integration:** One of the key elements for better deployment of digital healthcare solutions is ensuring interoperability between health care infrastructures, both online and offline. One such initiative is in the form of NDHB, which has proposed for a 'Federated Digital Information System', to form one unified database for health and medical records by linking both private and public sector healthcare infrastructure at primary, secondary and tertiary levels.[37]

   Although one of the key concerns is the siloed nature of health sector both at central and state level. To address this, there is a need to carve in the concept of substitutability within NDHB, to make systems more modular or felxible to accommodate already existing methods of data collection.[38] This is necessary as a standardised platform and a rigid mode of data collection might be difficult to

adopt for legacy systems which have been working in isolation and can create a trend of non-compliance.

Furthermore, NDHB has limited its reach to health data collection rather than extending and integrating it with other on-ground initiatives such as Anganwadi workers and digital payments through the Unified Payment Interface for health care services. Even within the private sector, there is a lack of integration with the existing mode of health care. This was revealed in a study which analysed 50 COVID-19 applications and found that only 8 percent of applications had a provision of booking teleconsultation. Also, while around 54 percent of the application collected clinically relevant data, there were no standards for integrating that data to the central repository.[39]

Recommendations

The pandemic has shown us the critical role that digital health care solutions can play, especially when access to hospitals has become limited and riskier for non-COVID care. In this regard, World Health Organisation (WHO) has released Global

Strategy on Digital Health, which proposes to build digital health strategies that are relevant for national contexts, is appropriately integrated, ensures ethical standards of data collection, and capacitating existing infrastructure and human resource for digital transformation.[40] Considering this, some of the key recommendations regarding the above-mentioned challenges are given below-

- The use of digital healthcare solutions should be seen as a facilitator for better delivery of existing healthcare services. There is a need for building awareness, capacity, and trust of consumers to understand the utility of these solutions as facilitators to get easy appointments with doctors, getting guidelines on general health care, getting guidance from experts, etc. Concerning telemedicine, there is a need to connect more hospitals to the network and giving appropriate training to doctors as well as health workers for optimal use of the consultation process.

  At the same time, government initiatives should also focus on capacitating frontline healthcare workers such as Accredited Social Health Activists (ASHA) and Anganwadi workers to utilise digital health solutions so that they can become technology 'liaisoners' for the patients and guide them through the process. For this, there is a need for investment in building better infrastructure and involving local panchayat bodies into the process.[41] Furthermore, to make these solutions better, proper channels for feedback and grievance redress should be set up.

- There is an urgent need for data protection legislation and sector level guidelines to come into place to address the growing privacy concerns surrounding medical and health data harmoniously. PDPB 2019 should adhere to a balanced approach by adopting the appropriate legal test of 'proportionality, legitimacy, and necessity' to ensure privacy while government's use of health data in emergencies.

  In this regard, we can be benefited from the approach taken by Canada, which has set up a body called 'Data Trust' for ensuring adherence to legal norms and best practices in utilising, sharing, and retention of health data in such situations.[42] Other useful practices include ensuring principals of privacy by design in such applications in a way that data goes through proper encryption and is only decrypted by trusted executables such as epidemiologists or healthcare policymakers; such applications must be designed through an open and consultative process.[43]

- Interoperability and integration of ongoing initiative will be key to optimising the use of health data and

health care service delivery. For this, the scope of NDHB must be expanded to indicate its harmonisation with other initiatives across ministries and departments which are involved in the healthcare ecosystem currently or can be seen as potential facilitators of the same.

To ensure interoperability, NDHB must aim to accommodate the micro-level health units to understand their process and systems of data collection. The government should support hospitals in building appropriate infrastructure for data collection, both at the state and central level. There should be an initiative to recognise the silos of clinical data to integrate them with centralised data collection infrastructure.

Additionally, a futuristic approach must be adopted by also including the data collected from wearables like fitness trackers or pacemakers in the interoperable health data ecosystem after proper anonymisation.

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