

Privacy, Policy and Preparedness and the Road Towards India's Digital Health Ecosystem

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INTRODUCTION

India has been in the process of implementing a digital health ecosystem over the last few years, and the government has set this in motion by launching health IDs, and publishing policies on health data management and insurance. While the ambition to have a health ID through the Ayushman Bharat Health Account number (ABHA number) and a digitally connected health ecosystem is well grounded, there are still some challenges that need to be addressed for this to benefit both providers and receivers of healthcare services. This article aims to shed light on three of the challenges that need to be taken into account.

While privacy was recognised as a fundamental right in 2017, the Digital Personal Data Protection Act was only passed in August 2023 after six years of deliberations. While this Act is a more succinct document compared to the earlier drafts, it is weaker in terms of the rights granted to the individual. For example, the Act does away with several protections that the earlier versions had granted to health data. In terms of policy, the National Health Authority has been publishing policies since 2017 that look at the framework and ecosystem and management of health data. However, these policies are scattered (some left as drafts) and often-times do not even refer to each other. The last requirement ties in with the capacity of both the healthcare industry as well as the government in terms of how prepared they are for undertaking and maintaining a digital health ecosystem. This paper will look at the three conditions of Privacy, Policy and Preparedness separately while looking at the key issues, and suggesting possible recommendations based on the identified issues.

PRIVACY

Background and Key Issues

One of the developments that stemmed from the Right to Privacy judgment¹ was the push towards creating data protection legislation. The first draft of the Personal Data Protection Bill was released in 2018, following which revised versions of the Bill were released in 2019, 2021, and 2022. On the ninth of August 2023, the Parliament passed the Digital Personal Data Protection (DPDP) Act 2023, the provisions of which will come into effect after the notification by the government.

It is pertinent to note that some of the most significant policy developments in healthcare, including the use of technological measures during the pandemic, happened in the absence of the DPDP Act. One example of this was the COVID Vaccination Intelligence Network (Co-WIN) created to facilitate booking of vaccination appointments. It was reported that many people had involuntarily created their ABHA number by linking their Aadhaar number (12 digit individual identification number) for vaccination.² While it is possible to delete the ABHA number there is very little information as to whether all the data related to it will also be deleted.³ The Co-WIN website also did not have a privacy policy until six months after its launch, when the Delhi High Court issued a direction for it to do so. Even then, the privacy policy directed users to the Health Data Policy of the National Health Data Management Policy, 2020.⁴

While the Act is still not operationalised, there is still a need to look at how it fares in protecting health data and ensuring individual autonomy and privacy. At the outset, the Act does not differentiate between sensitive personal data and personal data. The DPDP Act leaves the categorisation for certain data fiduciaries as significant data fiduciaries based on the sensitivity of the data to a government no-

1. Protection of personal data: A legal perspective. Supreme Court Cases. Accessed 12 September 2023. (<https://www.scconline.com/blog/post/2021/06/15/protection-of-personal-data/>).

2. Mehab Qureshi. 2021. Govt Created Health IDs Without Consent, Say Vaccinated Indians. The Quint, 9 June 2021. (<https://www.thequint.com/tech-and-auto/govt-created-uhid-without-consent-say-vaccinated-indians>).

3. ABHA (Ayushman Bharat Health Account) Fundamentals. Ayushman Bharat Digital Mission. Accessed 12 September 2023. (<https://healthid.ndhm.gov.in/>).

4. Aman Nair, Pallavi Bedi. 2021. Pandemic technology takes its toll on data privacy. Deccan Herald, 13 June 2021. (<https://www.deccanherald.com/specials/pandemic-technology-takes-its-toll-on-data-privacy-996870.html>).

tification.⁵ This differs from the 2018, 2019 and 2021 versions in which the definition of sensitive personal data included health data and genetic data.⁶ The earlier versions also prescribed greater responsibility to data fiduciaries⁷ processing sensitive personal data, including the requirement for explicit consent.⁸

Similarly, the earlier versions defined health data as “data related to the state of physical or mental health of the data principal and includes records regarding the past, present or future state of the health of such data principal, data collected in the course of registration for, or provision of health services, data associating the data principal to the provision of specific health services”. This definition, though unclear in certain aspects, especially in the question of whether the health ID would be included,⁹ was still a good guide to understanding what would be considered as health data. The inclusion of health data as a part of sensitive personal data also ensured that health data would have a greater level of protection right at the outset, compared to now, where there is a need for an executive notification for such inclusion.

A Separate Health Data Legislation?

With the definition of both sensitive personal data and health data removed from the DPDP Act, it might be time to explore the possibility of a separate legislation for health data. The idea of a separate legislation for health data is not new; in 2018 the government came out with the Digital Information Security in Healthcare Act (DISHA), which aimed to ensure data privacy, confidentiality, reliability and security of digital health data.¹⁰ Reports suggest that the DISHA was subsumed into the

5. Section 10, The Digital Data Protection Act 2023.

6. Shweta Mohandas and Pallavi Bedi. 2023. CoWIN Breach: What Makes India's Health Data an Easy Target for Bad Actors? The Quint, 19 June 2023. (<https://www.thequint.com/opinion/cowin-data-breach-health-sensitive-details-policies-solution>).

7. Section 9, Personal Data Protection Bill 2019.

8. Section 11, Personal Data Protection Bill 2019.

9. Shweta Mohandas and Pallavi Bedi. 2022. The Data Protection Bill 2021: A Missed Health Opportunity. Medianama, 22 February 2022. (<https://www.medianama.com/2022/02/223-data-protection-bill-health-data-unique-id/>).

10. Comments on Digital Information Security in Healthcare Act. Ministry of Health and Family Welfare. Accessed 15 August 2023. (<https://main.mohfw.gov.in/newshighlights/comments-draft-digital-information-security-health-care-actdisha>).

data protection legislation to avoid duplication of efforts; the DPDP Act has also left space for the possibility of a health data legislation.¹¹

The health data policies are not as binding as legislation and the only way to ensure privacy and data protection is through existing legislation (either the DPDP Rules or as a new sectoral legislation, the framework of which exists in DISHA). As the DPDP Act deals with personal data as a whole, a much better option would be to draw inspiration from other jurisdictions that have a separate legislation for regulation of health data, and to take from existing policies and draft legislations like DISHA.

POLICY

Background and Key Issues

In 2017 the National Health Authority (NHA) came out with the National Health Policy, with a goal to work towards improving the existing healthcare system through measures including deployment of digital tools to provide access to inexpensive healthcare without compromising on quality.¹² The goal was also to establish a federated health information ecosystem linking data from both private and public hospitals and enabling the creation of Electronic Health Records.¹³

In order to materialise these goals the government came out with two other policies: the National Health Stack and the National Digital Health Blueprint. The National Health Stack published by the NITI Aayog (the public policy think tank of the Government of India), had two components, the National Health Electronic Registries, which was a registry of the health data of a person, and a Coverage and Claims platform for facilitating insurance coverage and conducting fraud detection. The National Digital Health Blueprint published in 2019 by the Ministry of Health and Family Welfare aimed at maintaining the data infrastructure required to create a seamless flow and exchange of health data as well as an easily accessible electronic health records system.

Following the Blueprint, the Ministry of Health and Family Welfare has been publishing Health Data Management Policies, which was revised three times; the

11. Data Transfer of Digital Health Records. Press Information Bureau Government of India Ministry of Health and Family Welfare. Accessed 12 September 2023. (<https://pib.gov.in/Pressreleaseshare.aspx?PRID=1578929>).

12. National Health Policy, Ministry of Health and Family Welfare.

13. National Health Policy, Ministry of Health and Family Welfare.

latest version was released in April 2022. The Health Data Management Policy aims to act as a guidance document across the National Digital Health Ecosystem and sets out the minimum standard for data privacy protection that should be followed by all stakeholders to comply with existing regulations and legislations.¹⁴ In addition to this the Consultation Paper on the proposed Health Data Retention Policy released in April 2021 acted as a guidance for healthcare facilities to aid the implementation of record retention and compliance. Along with this, in 2022, the NHA released the NHA Data Sharing Guidelines for the Pradhan Mantri Jan Aarogya Yojana (PM-JAY), India's state health insurance policy. The PM-JAY aims to cover 100 million families that require financial assistance by providing coverage up to five hundred thousand Rupees per family each year for secondary and tertiary care. The most recent health policy that was released was the Consultation Paper on Unified Health Interface (UHI), released in March 2023. The UHI is envisioned as an interface that would connect health service providers and patients, by facilitating easy appointment booking, telehealth services and allied health services.¹⁵

Along with these policies the most rigorous implementation of the digital health system was the Co-WIN application to facilitate booking of vaccination appointments, which also became a way to register and assign a health ID to the people.

While we can see that there have been numerous documents that try and simplify the process of health data creation and management, these policies often do not refer to each other, creating issues of continuity and questions over which policy would take precedence over the others. At times policies create definitions and entities that clash with an existing policy. For example, the Health Data Management Policy in its section on the Governance structure consists of the Data Protection Officer ("Ayushman Bharat Digital Mission-Data Protection Officer or ABDM- DPO"), who functions as an intermediary between the regulator and different stakeholders, as well as a decision maker on matters concerning data; while the PM-JAY Data Sharing Guidelines in its governance structure includes a data protection committee along with the Data Protection Officer with similar responsibilities as the ABDM-DPO. The PM-JAY Data Sharing Guidelines also has a separate section on privacy and data management without referring to the existing health data management policy. To add to this, there are other government documents like the

14. Draft Health Data Management Policy April 2022, Version 02, National Health Authority, April 2022.

15. Consultation Paper on Operationalising Unified Health Interface (UHI) in India. National Health Authority India, 13 January 2023. (https://abdm.gov.in:8081/uploads/Consultation_Paper_on_Operationalising_Unified_Health_Interface_UHI_in_India_9b3a517a22.pdf).

Data Empowerment and Protection Architecture (DEPA), which tasks the National Digital Health Mission with piloting the DEPA for health data when the Health Data Management Policy was published.¹⁶ It is also surprising to note that neither the recent Health Data Management Policy of 2022, nor the UHI mention the Co-WIN application.

Need for Comprehensive Policies

One of the most important things to note is that the actual implementers of the policy are health service providers who need to keep up with and implement these policies in addition to their existing work. According to a reply by the health ministry in the Parliament, as of February 2023, there was a shortage of 3,000 doctors and 21,000 nurses and support staff in thirty one of India's government hospitals.¹⁷ This shortage, along with the added task of being in the loop about various health data policies, leads to a greater pressure on existing health service providers.

One way to address this issue could be to have a single document that encompasses all aspects of health data, taken from the existing documents to create an easily searchable compendium of India's health data ecosystem. Another possible way could be by having an accessible dashboard of policies which are in effect available to the general public in multiple Indian languages. The implementation and functioning of the policies could also be taught at medical colleges to equip the healthcare professionals with a better understanding of their roles and functions.

PREPAREDNESS

Background and Key Issues

While the government is concentrating its efforts on building digital health infrastructure, the investment in physical health infrastructure lags far behind. A recent World Health Organisation (WHO) Report stated that there are only 0.5 public hos-

16. The Centre for Internet and Society's comments and recommendations to the: Data Empowerment and Protection Architecture. The Centre for Internet and Society, 30 November 2020. (<https://cis-india.org/depacomments>).

17. Shivam Patel. 2023. India builds more hospitals as population surges but doctors in short supply. Reuters, 10 May 2023. (<https://www.reuters.com/world/india/india-builds-more-hospitals-population-surges-doctors-short-supply-2023-05-10/>).

pital beds for every 1000 people.¹⁸ India is also way below the threshold of 44.5 doctors, nurses, and midwives per 10,000 people suggested by the WHO, with just 6.1 doctors and 10.6 nurses and midwives per 10,000 people.¹⁹

Yet another issue is that of internet infrastructure. Although it is growing in India, it is still not enough for an online-only system. Finally, there has been an increase in incidents of cyberattacks targeting hospitals, creating uncertainty on their capacity to keep the health data of millions of people protected.

Infrastructure and Personnel

The numbers of healthcare centres in the form of hospitals and nursing homes are disproportionately spread across Indian states, where in some states the ratio is as low as 1.8 hospitals available per 100,000 people.²⁰ It is important to note that while the policies are being published at the central level, health remains a State subject. This means that each State has to take it upon itself to ensure the creation and implementation of a digital health ecosystem. However, the capacity and budget vary across different States. For example, it was reported that the health budget of the State of Madhya Pradesh was not enough to cover the urgent need for public health services.²¹ This is in addition to other factors such as existing infrastructure, geography and population. Hence it is unreasonable to expect that all the States would be able to budget for and implement health digitisation at the same pace. The public health sector, which is key in providing accessible and affordable healthcare, is severely underfunded, ranking sixth lowest worldwide in terms of the percentage of Gross Domestic Product (GDP) invested in health.²² Experts at-

18. Aravindan Srinivasan. 2023. Health Infrastructure, Capacity Building & Investments: The focal points to improve healthcare in India. *The Economic Times*, 20 July 2023. (<https://health.economictimes.indiatimes.com/news/industry/health-infrastructure-capacity-building-investments-the-focal-points-to-improve-healthcare-in-india/101970232>).

19. Karan, Anup, Himanshu Negandhi, Suhaib Hussain, Tomas Zapata, Dilip Mairembam, Hilde De Graeve, James Buchan, and Sanjay Zodpey. 2021. Size, composition and distribution of health workforce in India: why, and where to invest? *Human resources for health* 19, no. 1 (2021): 1-14.

20. Garima Sadwani. 2023. CAG Report On PMJAY: 7.5 Lakh Beneficiaries Linked to One Invalid Phone Number. *The Quint*, 9 August 2023. (<https://www.thequint.com/fit/ayushman-bharat-discrepancies-in-pmjay-scheme-cag-report>).

21. TNN Updates, Madhya Pradesh budget needs to allocate more funds for health. *The Times of India*, 3 March 2023. (<https://timesofindia.indiatimes.com/city/bhopal/state-budget-needs-to-allocate-more-funds-for-health/articleshow/98377955.cms?from=mdr>).

22. Walton-Roberts, M., Runnels, V., Rajan, S.I. et al. Causes, consequences, and policy responses to the migration of health workers: key findings from India, 1:18.

tribute the low spending on public health infrastructure to the fact that historically, healthcare was not seen as a viable economic expenditure for the country, along with a lack of political will to invest in strengthening public health.²³ This continued underfunding problem has led to a compounding effect: the Ministry of Health and Family Welfare estimated that the present amount to uplift the healthcare infrastructure was close to five trillion Rupees, the bulk of which was just for primary healthcare.²⁴ However, the private health sector is growing steadily. As of 2020, there were 43,486 private hospitals in India. In contrast, there were only 25,778 public hospitals, indicating that India has a health system that favours people who can afford expensive healthcare.²⁵

On the other hand, both public and private hospitals are already overburdened with patients, leaving very little time and energy to take on the administrative burden of digitisation. This is exasperated by the toll the pandemic took on both the Indian healthcare system and the medical professionals. India had some of the highest numbers of COVID cases worldwide, with multiple incidences of people not being able to secure hospital beds. The pandemic also led to the disruption of the treatment of non-communicable diseases, in which the health system, doctors and patients are trying to catch up on lost time.

In the context of the PM-JAY scheme, it was reported that there was a lack of initiative by medical teams, due to the paucity of human resources and staff already burdened by clinical work.²⁶ The time and resources needed to adapt to the new healthcare system added to their existing constraints.²⁷ In addition to this, cur-

23. Sumathi Bala. 2021. India's Covid crisis exposes deep-rooted problems in public health after years of neglect. CNBC, 19 May 2021. (<https://www.cnbc.com/2021/05/18/india-covid-crisis-shows-public-health-neglect-problems-underinvestment.html>).

24. Accumulation of Poor Health Infrastructure. *Economic and Political Weekly*, 01 May 2021. (<https://www.epw.in/journal/2021/18/editorials/accumulation-poor-health-infrastructure.html>).

25. Christophe Jaffrelot and Vihang Jumble. 2020. Private Healthcare in India: Boons and Banes. *Institut Montaigne*, 3 November 2020. (<https://www.institutmontaigne.org/en/expressions/private-healthcare-india-boons-and-banes>).

26. Mita Choudhury, Nitya Chutani, and Vismay Basu. 2023. Ayushman Bharat expose: How to nudge India's public health infrastructure. *The Indian Express*, 28 July 2023. (<https://indianexpress.com/article/opinion/columns/ayushman-bharat-expose-how-to-nudge-indias-public-health-infrastructure-8864104/>).

27. Rapid Adoption of Electronic Health Records Path and Pitfalls. *Centre for Policy Research*, 15 June 2022. (<https://cprindia.org/briefsreports/rapid-adoption-of-electronic-health-records-paths-and-pitfalls/>).

rently smaller healthcare centres had to buy online storage and equipment to store patient data.²⁸

The issues with personnel are not limited to doctors, but also the community health workers called Accredited Social Health Activists (ASHA) workers. While they are heralded as the backbone of India's public health system, ASHA workers, who are mostly women, are considered volunteers, which prevents them from exercising their labour rights, and from being covered by steady policies for payment, safety and social security.²⁹

Strengthening Infrastructure and Capacity

A fully functioning digital health ecosystem can only be built on top of an existing robust healthcare system. The above sections shed light on the issues of funding and staffing of public health centres, indicating that India may need to look at creative ways to build infrastructure. One way could be through public-private partnerships and engaging with grassroots organisations, private hospitals as well as philanthropic institutions.³⁰ More resources could also be spent on strengthening the physical infrastructure before investing more on the digital health ecosystem.

The long-term benefits of a digital health system can only manifest when there is correct data entry. Incorrect or incomplete data could do more harm in the long term and lead to misdiagnosis. It is essential to provide support to healthcare professionals for maintaining health records. This could be in the form of training, financial and technical support from the government, and the creation of a simple and standardised system of data management. Moreover, support and assistance to the ASHA workers through training and work formalisation can help them perform their duties more effectively and efficiently. In addition, government agencies must provide them with the required tools, such as data collection devices with pre-paid internet connection.

28. Tabassum Barnagarwala. 2022. How India is creating digital health accounts of its citizens without their knowledge. Scroll, 27 August 2022. (<https://scroll.in/article/1031157/how-india-is-creating-digital-health-accounts-of-its-citizens-without-their-knowledge>).

29. Namrata Sidwani. 2022. Data hurdle: ASHA workers lose perks. The New Indian Express, 15 August 2022. (<https://www.newindianexpress.com/cities/bengaluru/2022/aug/15/data-hurdle-asha-workers-lose-perks-2487643.html>).

30. Srinivasan. Health Infrastructure, Capacity. The Economic Times.

Connectivity

While mobile connectivity in India has been increasing, especially in the rural areas, challenges beyond mobile phones remain. According to recent reports, there are 759 million active internet users (a person who accesses the internet through any device at least once a month) in India in 2022, of which 399 million are from rural areas and 360 million are from urban areas.³¹ Nevertheless, this is still not enough to implement mobile-first measures in delivery of healthcare services. While almost-800 million internet users is a large number it is still just half of India's population, while the other half does not use or does not have access to the internet. In addition, at times a family shares one phone, which results in mixing of data based on the details of the family members.³² A single mobile connection could also make it difficult to have multiple health IDs linked to a number.

Two attempts at a smartphone-first approach had been made during the pandemic, which revealed how it affected a number of people. One was India's contact tracing app Aarogya Setu that initially only worked on smartphones, but which later was made compatible with feature phones when people were not able to travel without the app installed on a smartphone.³³ Second, booking for vaccination was first made possible only through the Co-WIN application, which required not only an internet connection but also a smartphone as well as the ability to navigate the website and book an appointment. This issue was also flagged by the Supreme Court, which shed light on the digital divide and the accessibility of the portal.³⁴

In addition, India has more internet shutdowns than any other country in the world. In 2022, India witnessed 84 cases of internet shutdowns. The blanket implementation of the shutdowns has consequences for healthcare facilities that rely on the internet to fill in and access health records. It was reported in 2020 that the

31. PTI. 2023. Over 50% Indians are active internet users now; base to reach 900 million by 2025: report. *The Hindu*, 24 May 2023. (<https://www.thehindu.com/news/national/over-50-indians-are-active-internet-users-now-base-to-reach-900-million-by-2025-report/article66809522.ece>).

32. Dr. Rajesh Tandon. 2020. One device households. *Times of India*, 17 July 2020. (<https://timesofindia.indiatimes.com/blogs/voices/one-device-households/>).

33. Shiv Nalapat. 2022. Aarogya Setu: Are India's non-smartphone users at risk of being left in the cold? *Times Now News*, 13 May 2022. (<https://www.timesnownews.com/technology-science/article/aarogya-setu-are-india-s-non-smartphone-users-at-risk-of-being-left-in-the-cold/591350>).

34. Radhika Roy. 2021. 'Digital Divide Will Have Serious Implications On Right To Equality & Health': Supreme Court On CoWIN Portal. *Live Law*, 2 June 2021. (<https://www.livelaw.in/top-stories/supreme-court-cowin-portal-digital-divide-covid-vaccine-175103>).

beneficiaries of the Ayushman Bharat, a health insurance scheme, were not able to access their records or avail the benefits of the scheme due to an internet blockade in Kashmir.³⁵

Not Just Mobile-First Approach

Hence, looking at the ground reality of internet access and internet shutdowns, there is a need to take a step back and look at other ways to enable a functioning health ecosystem. This could be through offline modes, features compatible with landline and feature phones, as well as keeping the older analogue system as an option until everyone has access to a working internet connection.

Security

While the various policies facilitate data collection and retention, we should look at measures taken to ensure the security of the data. There have been two major breaches in health data that have been reported in the past two years. First, in 2022, a major ransomware attack on India's premier medical institution All India Institute of Medical Sciences (AIIMS) left millions of people's personal data vulnerable.³⁶ More recently, in June 2023, it was reported that a breach in the Co-WIN application had led to personal data being available on a Telegram bot.³⁷ It was reported that the Telegram bot was able to retrieve the information of citizens registered with Co-WIN, including names, Aadhaar and passport numbers upon entry of phone numbers.³⁸ There was also a breach in the Ayurveda, Yoga and Naturopathy, Unani, Siddha and Homeopathy (AYUSH) portal as recently as September 2023,

35. Swagata Yadavar and Athar Parvaiz. 2019. In Jammu & Kashmir, the shutdown has brought Modi's pet health scheme to a grinding halt. Scroll, 7 September 2019. (<https://scroll.in/article/936465/in-jammu-kashmir-the-shutdown-has-brought-modis-pet-health-scheme-to-a-grinding-halt>).

36. Outlook Business Desk. 2022. Cyber Attack Derails AIIMS Delhi Services: How Data Of Patients Is In Danger. Outlook India, 29 November 2022. (<https://www.outlookindia.com/business/aiims-ransomware-attack-cyber-attack-derails-aiims-delhi-services-how-data-of-patients-is-in-danger-news-241071>).

37. John Xavier. 2023. Explained | What does the alleged CoWIN data leak reveal? The Hindu, 18 June 2023. (<https://www.thehindu.com/sci-tech/technology/explained-what-does-the-alleged-cowin-data-leak-reveal/article66980831.ece>).

38. Xavier. 2023. Explained | What does the alleged CoWIN data leak reveal? The Hindu.

which made the personal information of over three hundred thousand people vulnerable.³⁹

Security Before Data Collection

These two instances show that it is necessary to look at data security both at the hospital level and at the central level. The issue of data security was also a cause for concern for medical professionals, who highlighted the importance of protecting the sensitive information of patients, such as HIV or mental health status.⁴⁰ In addition, the federated nature of the health ecosystem puts the responsibility on the health service provider to set up servers and hence maintain the security. The NHA also clarified that there would not be a central database of medical records. Instead, data would be fetched from the servers of the health service providers.⁴¹ There should be more concerted efforts to ensure that the data that is being collected is stored securely, with appropriate cybersecurity measures, and personnel in place who are responsible for security. While health data leaks are not unique to India, India is in the position to establish a digital health ecosystem with a strengthened security practice. One of the approaches to ensure security would be to come up with data security protocols with respect to health data. The health service provider's staff would also need to be trained on the protocol as well as best practices for handling health data. This is important because the existing documents guiding data security, such as health data management policies and the DPDP Act, mention reasonable security safeguards but do not provide specific guidelines.

CONCLUSION

There is no doubt that it is necessary to bring forth a digital revolution in healthcare in India. The National Health Policy states that there is a need to ensure universal access to healthcare as well as a seamless way to share health data. A digitised healthcare system, including telehealth services and easy access to health data, will benefit most people in India.

39. Sarasvati NT. 2023. Jharkhand AYUSH Portal Reportedly Breached, Records Of 3.2 Lakh Patients Exposed. Medianama, 7 September 2023. (<https://www.medianama.com/2023/09/223-jharkhand-ayush-portal-breached/>).

40. Barnagarwala. How India is creating digital health accounts of its citizens without their knowledge. Scroll.

41. Barnagarwala. How India is creating digital health accounts of its citizens without their knowledge. Scroll.

Health data is a valuable data point for many companies. The law should ensure that this data is not misused/used to cause harm as well as ensure that the data does not go into the wrong hands through data breaches. A few changes in policy could ensure that the healthcare system is better adapted for a digital health ecosystem. At the outset, in order to protect health data, it needs to be defined clearly. This could be either through an addition in the existing DPDP Act or with a law governing health data. A law like DISHA would ideally be apt, as it would ensure a single place to look at the regulations governing health data. It could also bring about greater responsibility to the institutions collecting health data. While the legislation process takes time, the health data policies could be made clearer and more comprehensive with clear indication of which ones are currently in use in order to allow healthcare professionals and institutions to better adapt their practices and implement them. Finally, no policy can be fulfilled without on the ground implementation. For a completely functional digital health ecosystem, it is necessary to have a strong public health system, sufficient staff for both healthcare professionals and administrative departments, robust privacy regulations, as well as the strong online and physical infrastructure needed to support a digital system. These factors should be examined and addressed in order to create a system that provides not only easy access to health data, but also provides better and more inclusive healthcare services. While the road ahead for a digital healthcare ecosystem in India is difficult, one can hope that India will be on the right path to provide a good standard of healthcare to those that would benefit the most from universal healthcare.

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