

# Deployment of Digital Health Policies and Technologies: During Covid-19





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# Table of Contents

<b>Executive Summary</b>	<b>4</b>
<b>Methodology</b>	<b>6</b>
<b>Introduction</b>	<b>7</b>
<b>Part One</b>	<b>9</b>
MOBILE APPS LAUNCHED BY THE GOI & STATE GOVERNMENTS DURING THE PANDEMIC	10
THE NATIONAL DIGITAL HEALTH MISSION – HEALTH DATA MANAGEMENT POLICY	12
INTERPLAY OF THE COVID-19 VACCINATION PROCESS & DIGITAL HEALTH TECHNOLOGIES	23
<b>Part Two</b>	<b>25</b>
ON-GROUND IMPLEMENTATION OF DIGITAL HEALTH	26
OBSERVATIONS AND ANALYSIS FROM THE INTERVIEWS CONDUCTED	27
<b>Conclusion</b>	<b>32</b>

# Executive Summary

In the last twenty years or so, the Indian government has adopted several digital mechanisms to deliver services to its citizens. Digitisation of public services in India began with taxation, land record keeping, and passport details recording, but it was soon extended to cover most governmental services – with the latest being digital health. The digitisation of the healthcare system in India begun prior to the pandemic. However, given the push digital health has received in recent years especially with an increase in the intensity of activity during the pandemic, we thought it is important to undertake a comprehensive study of India’s digital health policies and implementation. The project report comprises a desk-based research review of the existing literature on digital health technologies in India and interviews with on-field healthcare professionals who are responsible for implementing technologies on the ground.

The onset of the pandemic saw several apps being launched by the government (at the central and state levels). the prominent one being Aarogya Setu, the central government’s contact-tracing app. At the same time, different state governments also launched their own contact-tracing apps. Apps were also launched to monitor the movement of quarantined patients. Though the use and downloading of the apps were officially voluntary, as with other voluntary digital services, they became de-facto mandatory in their implementation.

However, within the first six months of the pandemic, it became evident that tracing apps have limited efficacy and pose significant privacy and security challenges. Several apps launched by state governments are now defunct and have not been updated in the last 12 months. The government deployed the strategy of digital governance and digital public service delivery in the Covid-19 vaccination process as well, through the development and deployment of the CoWIN application.

A slew of digitisation policies were rolled out during the pandemic, the most notable being the National Digital Health Mission (re-designed as the Aayushman Bharat Digital Mission), which empowered the government to generate Health IDs for citizens and saw the government use the vaccination process to generate Health IDs for citizens, in several reported cases without their knowledge or consent. The entire digitisation process has been undertaken in the absence of any legislative mandate or judicial oversight.

It has primarily been undertaken through the issuance of executive notifications resulting in absent or inadequate grievance-redressal mechanisms.

Our field research confirmed to an extent what is already widely believed; that there is a disconnect between the digital health policies announced at the central level and the support received by frontline staff for their implementation at the ground level. This is especially true when it comes to the status and level of internet penetration and digital literacy across the different parts of the country. From our interviews, it became clear that frontline workers such as social health activist (ASHA) workers, who were primarily responsible for driving Covid-19 vaccinations, were provided with little or no training on the CoWIN portal or on how to digitally register vaccine beneficiaries. As frontline workers implementing a community-facing programme, ASHA workers were critical to the Covid-19 vaccination drive not only for its implementation but also in terms of educating people about the need for vaccination. However, one common refrain in our conversations with ASHA workers was that though they were given additional responsibilities during the pandemic, they were not adequately compensated for the same.

Another theme that emerged was that though the digitisation of the vaccination process per se did not create any problems, challenges arose due to inadequate skilled manpower, which meant that doctors and other healthcare professionals had to dedicate a considerable amount of their time in uploading the details of the beneficiaries on CoWIN – which at times led to considerable delays in generating vaccine certificates.

The techno-solutionist approach to health fails to appreciate the ground realities of India- inadequate internet services, lack of digital literacy, the gender divide when it comes to accessing the internet, and perhaps most importantly, the abysmal state of the public healthcare system in India.



# Methodology

Digitisation of the healthcare system in India began before the pandemic, but the pandemic has given it an additional push. Given the push digital health has received in recent years, especially during the pandemic, it is imperative to undertake a comprehensive study of India's digital health policy and implementation.

The project brief is based on

- i. an analysis of publicly available information in the form of government documents, notifications, and orders, including digital health policies such as the National Digital Health Mission and the Blueprint released by the central government and affiliated bodies such as the state-affiliated think tank, Niti Aayog;
- ii. in-depth interviews;
- iii. a review of secondary literature such as media articles and reports produced by civil society organisations in India on the subject of the nation's digital health policy;<sup>1</sup> and
- iv. a review of the privacy policies of the apps developed by the different state governments where possible; however, some apps were available to only users residing within the state or the municipal area, and we, therefore, could not access the privacy policy or the terms of use of those apps.

In-depth interviews were conducted with 13 respondents between August to November 2021, across the three selected states—Chhattisgarh, Madhya Pradesh, and Jharkhand. Respondents included primary healthcare workers, village officials, district-level officials, health rights activists, and doctors. Each interview lasted between 30 to 45 minutes.

Due to the ongoing pandemic, several interviews had to be conducted telephonically. Verbal informed consent was taken from all participants for the interviews as well as for audio recording and storage.

*Note: For the purposes of this report, the terms National Digital Health Mission (NDHM) and ABDM (Aayushman Bharat Digital Mission) have been used interchangeably.*

# Introduction

The Covid-19 pandemic has shown and highlighted the role that a well-functioning public healthcare system plays in healthcare management. This was also recognised by the Economic Survey of India, 2020–21, in the chapter titled “Healthcare Takes Center Stage, Finally!”<sup>2</sup> highlighting both the importance of healthcare and the lack of attention given to it previously.

The Economic Survey is an annual review of the Indian economy published by the Finance Ministry and tabled in Parliament before the presentation of the Union Budget. The Survey observed that India ranks 179th among 189 countries in terms of the share of the national budget allocated to healthcare (India ranks at the same level as countries with significantly lower GDPs such as Haiti and Sudan)<sup>3</sup> The Survey pointed out that the aggregate density of health workers is 23 per 10,000 population, which is close to half the density recommended by the World Health Organization (44.5 health workers per 10,000 population). Further, as of 2019, there was 1 doctor per 1,511 people and 1 nurse per 670 people, which is lower than the WHO standard of 1 doctor per 1,000 people and 1 nurse per 300 people.<sup>4</sup>

To make governance systems more efficient, in 2015, the Government of India (GoI) launched the Digital India Mission. The press release<sup>5</sup> by the central government announcing the Digital India programme speaks of a ‘cradle to grave’ digital identity as its vision areas.<sup>6</sup> Digitising the entire governance ecosystem has been a part of the government’s agenda since 2006<sup>7</sup>, when the National e-Governance Plan (NeGP) was developed. Initially, the mission focused on governance services such as banking, land records, and the issuance of pensions and passports. Over time, the ambit of digitisation has been expanded to include nearly all possible interactions between the state and its citizens such as healthcare, education, and transportation.<sup>8</sup>

At its core, two fundamental issues arise with expanding and including the entire governance infrastructure within the digitisation ambit. The first is that internet access in India is far from ubiquitous, with the latest estimate of internet penetration in the country standing at 61.06 percent<sup>9</sup> at the end of June 2021; the second is that the entire digitisation process has been undertaken in the absence of any legislative mandate or judicial oversight.

It has primarily been undertaken through the issuance of executive notifications issued by the Ministry Electronics and Information Technology, Government of India. Executive notifications issued in the absence of any legislation are not subject to any oversight in Parliament.

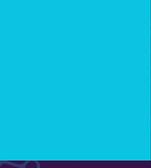
Digitisation of healthcare received a major push during the pandemic. The healthcare sector saw several digitisation policies being rolled out, with the most notable being the National Digital Health Mission (NDHM; re-designed as the Aayushman Bharat Digital Mission). Mobile phone apps and web portals launched by central and state governments during the pandemic are also examples of this—though as the following paragraphs will indicate, the several apps are now defunct and redundant.

The rollout of the NDHM also saw Health IDs being generated for citizens. In cases reported across states, this rollout happened during the Covid-19 vaccination process without the informed consent of the concerned person. It is important to note that India does not have a comprehensive data protection law. Currently, personal data and sensitive personal data are to a limited extent regulated by the Information Technology (Reasonable Security Practices and Procedures and Sensitive Personal Data or Information) Rules, 2011 (SPDI Rules).

However, government and government agencies are outside the purview of these rules and therefore, any measure such as the Health ID which is rolled out by the government does not come within the purview of the SPDI Rules. They also do not provide sufficient protection for the processing of personal data, raising concerns about citizens' privacy and the governance and oversight mechanisms of digital health initiatives.

Through this report, we highlight concerns arising from the rushed implementation of a gamut of digital health policies in the context of the pandemic. The report is divided into three parts. The first part provides a brief overview of the state of the mobile apps developed by the government, followed by an analysis of the concerns associated with the NDHM-HDMP.

The second part analyses the on-ground implementation of digital health policies. This is followed by a concluding section with key concerns and recommendations in the third part of the report.



# Part One



## MOBILE APPS LAUNCHED BY THE GOI AND STATE GOVERNMENTS DURING THE PANDEMIC

The pandemic saw the GoI, state governments, and local bodies such as municipal corporations launch several apps for the management of Covid-19 patients and movement tracking, among other uses. As per a report by the Internet Democracy Project,<sup>10</sup> 72 apps were launched by the end of November 2020, with some state governments launching multiple apps, thus demonstrating the country's technocratic approach to handling the pandemic. The prominent one being the GoI's digital contact-tracing app – Aarogya Setu- which was the first and sole contact tracing app launched by the GoI.

A report on contact-tracing apps by the Center for Internet and Society<sup>11</sup> observed that given the attention on Aarogya Setu, the other apps launched by state governments escaped scrutiny and public attention. Several apps either did not have a privacy policy or the policy was vague and often did not provide important details such as who was collecting personal data, the time for retaining the data, and whether the personal data could be shared with other departments, most notably law enforcement authorities.<sup>12</sup>

A prominent example of state level adoption of technology to control people's movements was the Karnataka government's Quarantine Watch. The Quarantine Watch app can only be used by home-quarantined people in Karnataka who have been registered in the state's official database. The app required users to answer a questionnaire about their symptoms and to upload mandatory hourly selfies to be taken through the app between 7 am and 9 pm to capture their GPS location, which was used to verify that they are quarantining. GPS and network-based location, along with the camera were part of the required permissions sought by the app.

It is unclear whether the people under home quarantine are currently still required to use the app, though the app is still available on the Google Play Store. The app has no dedicated privacy policy, the user is redirected to the privacy policy of the revenue department of the Karnataka government.

The Karnataka government also launched an app called Corona Watch to monitor the movement of Covid-19 positive patients over 14 days. As an analysis done by Software Freedom Law Center shows,

“The app opens up a Google Maps frame and marks the location of the infected patients and the spots they have visited. No personal details are explicitly provided by the application. However, the address, specific to the street, is given by the marker. And there is also a feature to open the coordinates within the app in Google Maps.”<sup>13</sup>

Most of the apps launched by state governments and municipal authorities have either not been updated since June 2020 or have been removed from the Play Store. This highlights the fact that most of these apps were launched and released as a knee-jerk reaction to the pandemic and as part of a similar global trend. Given the limited utility of contact tracing, the use of such apps was either discontinued or the purpose of the app was modified. The limited utility of the apps was noted not only in India. A report by Access Now<sup>14</sup> noted, several countries in the European Union that had jumped onto the contact-tracing apps bandwagon at the start of the pandemic in 2020 soon abandoned the project and, like in India never properly explained to the public what exactly was happening, and what went wrong.

As discussed earlier, either the apps are no longer available or the objectives of some apps appear to have changed, but there is little or no clarity regarding whether there has been any change in the privacy policy of the apps to reflect those changes or whether the users of the app were notified of the changes to the purpose of the app. The purpose of the Aarogya Setu app has been expanded to verifying and uploading vaccination certificates, beneficiaries can use the app to register on CoWIN and download their vaccine certificates. The vaccination dashboard, and information regarding the availability of vaccines in a particular vaccination centre, are now also available on Aarogya Setu.

The CoWIN website has also been linked with Aarogya Setu- beneficiaries can use the app to register on CoWIN and download their vaccine certificates. The vaccination dashboard and information regarding the availability of vaccines in a particular vaccination centre are now available on Aarogya Setu. The rationale for linking CoWIN with Aarogya Setu is unclear, considering that Aarogya Setu is primarily a contact tracing app. Interestingly, the GoI has also backtracked on its original stance. At a time when CoWIN website and the Aarogya Setu were not linked- when asked why the CoWIN application could not be integrated with Aarogya Setu and be used for registration of beneficiaries, government officials had stated that as Aarogya Setu is primarily a contact tracing app it would not be feasible to integrate the two applications.<sup>15</sup>



## THE NATIONAL DIGITAL HEALTH MISSION – HEALTH DATA MANAGEMENT POLICY

In 2017, the central government formulated the National Health Policy (NHP). A core component of the NHP was deploying technology to deliver healthcare services. The NHP recommended the creation of a National Digital Health Authority (NDHA) to regulate, develop, and deploy digital health across the continuum of care. In 2018, the first attempt to create and establish an NDHA was made through the enactment of the Digital Information Security in Healthcare Bill (DISHA Bill). However, the Bill has not yet been introduced in Parliament. Simultaneously, in 2019, the Niti Aayog, (which is the think tank body of the GoI) proposed the National Digital Health Blueprint (Blueprint). The Blueprint recommended the creation of the National Digital Health Mission.<sup>16</sup> It also stated that an institution such as the National Digital Health Mission (NDHM), which is undertaking significant reforms in health, should have legal backing.

The NDHM-HDMP was rolled out in a pilot phase in six union territories in August 2020. It was renamed Aayushman Bharat Digital Mission (ABDM) and rolled out across the country on 27 September 2021. It is important to highlight that the policy was launched before it was finalised- it was at the stage of receiving comments from the public. The form to obtain the consent of individuals and the privacy notice were also developed after the launch of the policy. The purported objective of the ABDM is 'to create a seamless online platform that will enable interoperability within the digital health ecosystem'. As per the statement issued by the Prime Minister, "every citizen will now get a Health ID and their records will be digitally protected."<sup>17</sup> The Health ID is to be generated as per the National Digital Health Mission: Health Data Management Policy (NDHM-HDMP) released in December 2020.

As per the NDHM-HDMP, the Health ID is a unique 14 digit number which identifies a person in the digital health ecosystem, authenticates them and links their health records with their consent across multiple systems and stakeholders. The Health ID is a separate document from Aadhaar-Aadhaar is one of the six ID documents that can be used to generate a Health ID. It is not mandatory for individuals to obtain a unique digital health identity for accessing health services in the country. The policy has also given the option to the individuals to withdraw their consent and opt out of the Digital Health Ecosystem- once an individual does that then the individual can also ask for the data and the Health ID to be deleted.

There is no publicly available evidence to suggest that any analysis of the successes and/or drawbacks NDHM-HDMP was undertaken, prior to expanding to the rest of the country. With the rollout of the ABDM, several state governments such as Uttarakhand,<sup>18</sup> Delhi,<sup>19</sup> Telangana,<sup>20</sup> Odisha,<sup>21</sup> Bihar,<sup>22</sup> and Tamil Nadu have also announced projects to issue Health IDs and digitise the health records of citizens.<sup>23</sup>

## **a. Absence Of Any Legislative Framework**

The entire digitisation process is operating in a legal vacuum. To date, there is no legislative backing for the ABDM. The Health Data Management Policy is not a substitute to a law enacted by Parliament. Policies are not justiciable, i.e., they are mostly not enforceable in courts, as courts step into the realm of policymaking only if the policy is in contravention of fundamental rights or manifests arbitrariness. Therefore, any grievance-redressal mechanism established under a policy will not have the same authority as a mechanism established under a law passed by Parliament. Policies themselves do not confer any legal right. In this regard, it would be pertinent to refer to other government IDs that allow access to government services.

For example, under the National Food Security Act (NFS), 2013, state governments issue an identity card known as a 'ration card' to targeted beneficiaries using which they can purchase essential commodities at a discounted price. Prior to the enactment of the NFS Act, ration cards were issued by state governments as per the provision of the Public Control Orders formulated by the Gol.

The NFS Act strengthened the legal remedies available under the Public Control Orders and the legal rights available to the beneficiaries to avail themselves of a ration card and procure the essential commodities at a fair price. It also established a grievance-redressal mechanism for beneficiaries to register their complaints with respect to denial of services. Like the rollout of Health IDs, between 2009 and 2016, the Aadhaar project in India was also governed through several executive notifications. Finally, in 2016, the Gol enacted the Aadhaar (Targeted Delivery of Financial and Other Subsidies, Benefits and Services) Act, 2016, giving legislative sanction to Aadhaar.

While the NDHM had initially recognised the need for Privacy and Security by Design<sup>24</sup>, it has also opted to go down the policy route rather than the legislative route.

As per the NDHM, a 'National Policy on Security of Health Systems and Privacy of Health Records' will be developed in accordance with the Personal Data Protection Bill, 2019.

In comparison, in countries such as Australia (My Health Records Act, 2012), Estonia (the Health Services Organisation Act), and the United Kingdom (Health and Social Care Act, 2012), digital health technologies and initiatives are premised on an existing health data legislative framework and an overarching data protection law.

The absence of any legislation underlying the NDHM and/or an overarching data protection law also raises concerns about the safety, security, and privacy of the data collected. As discussed earlier, a policy framework does not confer legal rights that can be enforced in courts. Rights and a grievance-redressal mechanism for addressing any infringement of safeguards and rights require legislative backing. Further, NDHM-HDMP does not also address privacy and security concerns and their relationship with any future data protection law.

The pandemic has seen several health data breaches. On 5 January 2021, it was reported that the results of the Covid-19 tests of several people were published on different government websites.<sup>25</sup> The leaked data included the name and age of the patient, the test result, and the name of the hospital where the test was conducted. A similar breach occurred at a large private hospital in Kerala.<sup>26</sup> Instances of such breaches are not limited to private hospitals; sensitive data was also leaked from government hospitals and have in certain instances been made publicly available for a substantial period. In comparison to many countries that spend close to 5% of the total hospital budget on IT, Indian private hospitals tend to spend only 2.5% of their total hospital budget on IT.<sup>27</sup>

As per the NDHM-HDMP, privacy by design<sup>28</sup> is the guiding principle of the NDHM, yet, many privacy issues exist within this ecosystem, which is concerning due to the nature of the sensitive health data involved. Though the HDMP specifies that Aadhaar is not mandatory for obtaining a Health ID, there are concerns (discussed in the following paragraphs) regarding how Aadhaar is being linked with the Health IDs surreptitiously through the vaccination process. Further, though the government has issued clarifications that Aadhaar is not mandatory for either testing or vaccinations, on the ground, officials insist on the submission of Aadhaar for both testing as well as vaccination.

Health data is accorded a higher degree of protection across several data protection laws.<sup>29</sup> There is also an increasing awareness about the sensitive nature

of health and health related data.<sup>30</sup>The Gol has also classified health data as sensitive personal data both under the existing SPDI Rules, 2011, and the proposed data protection law. Linking of the Health ID with Aadhaar in the absence of (a) adequate safety safeguards or (b) either a comprehensive data protection law or a specific law addressing the concerns associated with the digitisation of health raises privacy concerns (especially as Aadhaar is now linked with many critical public and private services being availed by citizens).

These concerns also emanate from the lack of clarity on whether the Health ID is meant to be a confidential number. As an article by the Center for Internet and Society<sup>31</sup> noted, there is no clarity on the protection afforded to the Health ID either under the NDHM-HDMP or the proposed data protection bill. Health IDs are now being shared with entities that fall outside the definition of health service providers as defined in Health ID documents.

The NHA has invited government entities and private tech companies to integrate with ABDM and provide the services to be offered through ABDM- Health ID being one of them.<sup>32</sup> As on May 26, 2022, 40 third party apps have been integrated with ABDM. These integrated apps are now authorised to create Health IDs; build services for Health Information Providers to be able to share health records through a personal health record app; and build services for doctors or Health Information Users to view the records<sup>33</sup>. These entities will be dealing with and have access to sensitive personal data, which could lead to patients not disclosing all the necessary information, fearing misuse of their sensitive data.

There is precedence to this concern. In 2015, the National AIDS Control Organisation started urging states to collect the Aadhaar numbers of people living with HIV. They were asked to submit their Aadhaar numbers to antiretroviral therapy centres so that they can be linked to their patient identity cards and they can more easily avail of social security entitlements. However, this resulted in several patients not taking the required medicines as they were uncomfortable with sharing their Aadhaar numbers due to the extensive linking of Aadhaar with other services/benefits. They feared unauthorised access to their Aadhaar details and consequently their identity being compromised.

A study conducted by Radhika Radhakrishnan<sup>34</sup> analysing the datafication of health in India observed that privacy concerns are also compounded by the low levels of digital literacy in the country.

For instance, the study noted that

“Health ID registration requires a password to be generated when the enrolment is being done through a phone number instead of Aadhaar. Since patients often find it difficult to generate their own passwords, the health workers doing their registration provide passwords for them.”

Such privacy and security concerns are compounded by a lack of legislative oversight both in terms of the absence of (a) any legislation regulating the NDHP-HDMP and (b) a comprehensive data protection law governing both private and government entities.

## **b. Inadequate Governance Structure and Potential Conflict Of Interest**

The lack of a legislative framework also means that there is no clarity regarding the regulatory oversight of such bodies that have either been established or are proposed to be established. The Blueprint had recommended that the NDHM include two separate arms – one for regulation and the other for operational maintenance – but, to date, there has been no delineation of responsibilities and obligations in the NDHM. It is a monolithic entity overseeing both the regulation as well as maintenance of the ecosystem. The NDHM-HDMP stated that the governance structure shall be specified by the NDHM and shall consist of such committees, authorities, and officers at the national, state, and health facility levels necessary to implement the NDHM. In effect, the governance structure of NDHM will be laid out by the NDHM itself.<sup>35</sup>

Further, there is no independent authority/entity responsible for overseeing the management of the NDHM. The National Health Authority (NHA) has been given the responsibility of implementing the NDHM. However, the NHA was established in 2019 to implement India’s health insurance – Ayaushman Bharat. The scheme consists of two components (i) Health and Wellness Centers; and (ii) Pradhan Mantri Jan Arogya Yojna (Health Insurance Scheme). This contrasts with provisions in other countries, wherein the governance structure of implementing authorities has been provided for in the parent act and not delegated to subsequent policies. In Australia, the My Health Records Act, (MHR), 2012, specifies that the ‘System Operator’ will be responsible for operating the health record system. The MHR Act also specifies the functions of the System Operator, which include establishing and maintaining an ‘access control mechanism’ to enable the healthcare recipient to set controls on the access of healthcare provider organisations and nominated

representatives to the recipient's health records. Further, the System Operator must specify default access controls that apply if a registered healthcare recipient has not set such controls. The Australian Digital Health Agency has been recognised as a Systems Operator under the MHR Act.

The Public Governance, Performance and Accountability (Establishment of the Australian Digital Health Agency) Rules, 2016, lay out the eligibility criteria for appointment to the Australian Digital Health Agency. The NHA was established in 2019 through an executive notification and has been entrusted with the responsibility of implementing the national health insurance scheme (known as Ayushman Bharat Pradhan Mantri Jan Arogya Yojana (PM-JAY)) and has also been envisaged as being the implementing, regulatory, and adjudicatory body under the NDHM. Under the PM-JAY scheme, the NHA is responsible, among other activities, for

**“Working closely with Insurance Regulatory and Development Authority on development and implementation of Health Insurance Regulations targeting insurance companies, Third Party Administrators, hospitals and other stakeholders.”**

As per the NDHM-HDMP, the NHA will be responsible for designing strategy, building technological infrastructure, and implementing the NDHM to create a National Digital Health Ecosystem. Under the current framework, the NHA would have too many roles and a conflict of interest in managing the NDHM. With the government being the largest collector of health data, it is concerning that an independent regulatory/agency has not been established to monitor the health ecosystem in the country.

### **c. Lack of Clarity on the Role of the Data Protection Authority Proposed to be Established Under the Personal Data Protection Bill and the NDHM**

The NDHM-HDMP states that the policy must be read in conjunction with, and not in contradiction with, any applicable law; however, it does not refer to the Personal Data Protection Bill, currently pending in Parliament. The Bill establishes a Data Protection Authority (DPA) and specifies the procedure to be followed by the authority either upon receipt of a complaint<sup>36</sup> or upon taking suo-motu cognisance.<sup>37</sup> The NDHM-HDMP is silent about the role of the DPA or the interaction of the grievance-redressal mechanism established under it with the DPA. Further, there is no appellate procedure specified in the NDHM-HDMP- it merely

states that in case the complaint filed by the data principal is not resolved by the grievance redressal officer appointed by data fiduciary, the data principal can approach the National Data Health Mission- Grievance Redressal Officer.

In contrast, Australia's MHR Act clearly outlines the interaction between it and Australia's Privacy Act, 1988.<sup>38</sup> This is an important issue to highlight as the NDHM-HDMP has already been rolled out in the country in the absence of any legally backed privacy protections.

The grievance-redressal mechanism established under the NDHM-HDMP also falls short of being robust. It provides data fiduciaries (entities that collect and store data) with significant discretion with respect to handling complaints. Data principals face the risk of arbitrary rejection of complaints without any appeal procedure. The harms of such arbitrariness are evident in the case of the health insurance industry, wherein one of the most common complaints against companies, who are free to lay down their own procedure for settling insurance claims, is the rejection of claims without any reasoning.<sup>39</sup>

#### **d. Health IDs going the Aadhaar way?**

It is worthwhile to note certain similarities between the rollout of Health IDs and Aadhaar. The Aadhaar (Unique Identification Authority of India) project was initially operated and sanctioned under a January 2009 notification issued by the Planning Commission (predecessor to the Niti Aayog).<sup>40</sup> The project operated in a legal vacuum for several years, until it was given a statutory status with the creation of the Unique Identification Authority of India (UIDAI) under the Aadhaar (Targeted Delivery of Financial and Other Subsidies, Benefits and Services) Act, 2016 (Aadhaar Act).

However, in between the operationalisation of the Aadhaar project in 2009 and the enactment of the law in 2016, executive notifications were enacted that made the 'voluntary' Aadhaar de-facto mandatory. Aadhaar was made mandatory by the central government and several state governments for accessing various services, such as the Public Distribution System (PDS)<sup>41</sup>, health services, and social security benefits. The executive notifications were challenged before the Supreme Court, which in its interim orders of 2013<sup>42</sup> and 2015,<sup>43</sup> held that the Aadhaar is not mandatory for citizens to avail the services and benefits due to them.

In 2018,<sup>44</sup> the Supreme Court upheld the constitutional validity of the Aadhaar Act, albeit with certain caveats and restrictions.

However, by then Aadhaar had become a ubiquitous identity document, sought by both private organisations as well as government agencies.

Similarly, the NDHM-HDMP clearly articulates that the

“participation of an individual in the NDHE will be on a voluntary basis and where an individual chooses to participate, he/she will be issued a Health ID (as defined in this Policy).”

As per the NDHM, Health IDs were initially rolled out on a pilot basis in the six union territories of India. The NHA also rolled out the NDHM Health Records App for citizens to self-enrol to create their Health ID.

However, as per newspaper reports<sup>45</sup>, several people who had registered for the Covid-19 vaccine on the CoWIN website using their Aadhaar numbers were issued a UHID number on their Covid-19 vaccine certificates. CoWIN is a platform deployed by the central government on which the vaccination beneficiaries have to mandatorily be registered. As per Clause 2a of CoWIN’s privacy policy, “If you choose to use Aadhaar for vaccination, you may also choose to get a Unique Health ID (UHID) created for yourself.” The privacy policy stresses the voluntary nature of this process by stating that “This feature is purely optional.”

Health IDs have been de-facto generated for beneficiaries who had registered using their Aadhaar<sup>46</sup> numbers across the country, without citizens having any choice in opting into the project. The beneficiaries who have had their Health IDs created through the vaccination process have not been informed about the creation of such an ID or their right to opt out of the digital health ecosystem. The beneficiaries are also not informed of their right to de-activate the UHID and reactivate it later if required. This is in contravention of consent procedures laid out by the NDHM. The consent form<sup>47</sup> displayed to citizens who are self-enrolling states,

“I hereby declare that I am voluntarily sharing my identity information with National Health Authority (NHA) for the sole purpose of creation of Health ID. I understand that my Health ID can be used and shared for purposes as may be notified by ABDM from time to time including provision of healthcare services. Further, I am aware that my personal identifiable information (Name, Address, Age, Date of Birth, Gender and Photograph) may be made available to the entities working in the National Digital Health Ecosystem

(NDHE) which inter alia includes stakeholders and entities such as healthcare professionals (e.g. doctors), facilities (e.g. hospitals, laboratories) and data fiduciaries (e.g. health programmes), which are registered with or linked to the Ayushman Bharat Digital Mission (ABDM), and various processes there under.

I am aware that my personal identifiable information can be used and shared for purposes as mentioned above. I reserve the right to revoke the given consent at any point of time.”

However, this consent form and the information contained in it are not shared with beneficiaries who register on CoWIN using their Aadhaar. As per newspaper reports,<sup>48</sup> people are also completely unaware of the purposes of a Health ID. On 30 November 2021<sup>49</sup>, the Ministry of Health and Family Welfare, in response to a question in the upper house of Parliament on the creation of Health IDs through the vaccination process stated that due consent is sought and recorded on CoWIN.

The response reproduces the terms of consent recorded for UHID creation;

“I, hereby declare that I am voluntarily sharing my Aadhaar Number / Virtual ID issued by UIDAI, with National Health Authority (NHA) for the sole purpose of creation of Health ID. I understand my Health ID can be used in any healthcare interaction across India. I authorize NHA to use my Aadhaar number / Virtual ID for performing Aadhaar based authentication with UIDAI and store my e-KYC (Name, Address, Age, Date of Birth, Gender and Photograph) information as per the provisions of Aadhaar Act, 2016 only for the stated purpose. I understand that UIDAI will share my e-KYC details with NHA on successful authentication.

I have been duly informed about the option of KYC without using my Aadhaar details and through use of other Govt. issued IDs and its associated details shall be stored by NHA for the purpose of creation of Health ID. I consciously choose to use Aadhaar number / Virtual ID for the purpose of availing benefits across National Digital Health Ecosystem (NDHE). I am aware that my e-KYC information (Name, Address, Age, Date of Birth, Gender and Photograph) excluding Aadhaar number / VID number will be made

available to the entities working in the NDHM framework for enabling the healthcare services to me across National Digital Health Ecosystem (NDHE). I reserve the right to revoke the given consent at any point of time from the National Health Authority (NHA) at my own discretion.”

This is only visible on the vaccinator module and not the user-facing beneficiary module of CoWIN. The user-facing side of CoWIN, which citizens use to book vaccination slots, does not provide such a consent form. A report by *Caravan Magazine*<sup>50</sup> noted that several people were issued Health IDs before their national rollout. All of them had provided Aadhaar as the identification proof for vaccination. A person had initially resisted but had finally relented and given his Aadhaar details for registration after being made to wait for hours. He was also provided with a Health ID.

The de-facto mandatory nature of Health IDs is concerning, as this is like the de-facto mandatory use of Aadhaar for accessing welfare services, which got legislative sanction after the enactment of the Aadhaar Act. However, several studies<sup>51</sup> have revealed that many Aadhaar holders face authentication problems while trying to access food grains through the PDS and other state entitlements. Another study conducted in Andhra Pradesh<sup>52</sup> revealed that in 2015, more than half of the eligible beneficiaries could not access the entitlements due to them under different social welfare programmes. Multiple reports have highlighted the effectively coercive nature of Aadhaar, in which citizens are forced to register for the provision of services.<sup>53</sup>

As highlighted by Usha Ramanathan, an advocate with expertise in privacy law,<sup>54</sup>

“the Supreme Court’s decision on Aadhaar, had given legal sanction to ‘coerced consent’ by stating that ‘Since we have held that enrolment is voluntary in nature, those who specifically refuse to give the consent, they would be allowed to exit from the Aadhaar scheme.’”

By the time the judgement was pronounced, Aadhaar had become the ubiquitous ID sought by government agencies as well as private companies for providing any service. Although the HDMP clearly articulates that the absence of a Health ID should not lead to denial of health services, the Aadhaar example shows how voluntary linkage becomes mandatory.

## e. Concerns with Sharing of Data

As per Clause 28.1 of the NDHM-HDMP,

“any personal data processed by a data fiduciary may be shared with an HIU in response to a request made by such HIU for personal data pertaining to the data principal, only where consent of the data principal is obtained in accordance with Chapter III of this Policy.”

Further, as per Clause 29.1, data fiduciaries can make use of anonymised and de-identified data available

“for the purpose of facilitating health and clinical research, policy formulation.....and any other purpose that may be specified by the NHA.”

This provision raises the following important issues to consider and highlight:

A Health Information User (HIU) has been defined as entities that requests access to personal data of the data principal and considering the expansive scope of the applicability of the NDHM-HDMP- it appears that the data fiduciary can share the data with entities ranging from healthcare facilities, pharmaceutical companies to research organisations. Further, it is also concerning to note that while sharing of personal data has been permitted with such a wide range of entities; it does not specify or provide for any mechanism wherein the benefits that accrue from the sharing of such personal data is shared back with the concerned data principal(s).

The concept of benefit sharing defined as the has not been addressed in the NDHM-HDMP and no reference has been made to any other policy document, legislation or guidelines addressing these concerns.

As per the NDHMP- HDMP, it appears that the data fiduciaries can and will share personal data with insurance companies. Under the DISHA Bill<sup>55</sup>, there was an explicit prohibition on sharing anonymised health data with insurance/ pharmaceutical companies. Insurance companies already have access to a significant amount of personal health information; and the use of such personal health information even in an anonymised condition leads to concerns about the harms from the usage of such data, especially to historically marginalised communities.



## INTERPLAY OF THE COVID-19 VACCINATION PROCESS & DIGITAL HEALTH TECHNOLOGIES

The Covid-19 vaccination process started in India on 16 January 2021, with the rollout of the first phase of vaccination for healthcare workers and other frontline workers. The second phase of the vaccination process started on 1 March 2021 and along with it, the government deployed the Covid Vaccine Intelligence Network (CoWIN) platform to streamline the Covid-19 vaccination process.

Initially, beneficiaries needed to pre-register on CoWIN to get a vaccination appointment. Walk-ins and other means to get an appointment were not permitted. However, the GoI subsequently modified this rule and walk-in appointments and on-spot registration on CoWIN were made permissible from June 2021. States also instituted localised policies that varied from the central guidelines. For instance, our interviews with healthcare workers in Chhattisgarh revealed that the state government had permitted walk-in registrations and appointments from the beginning (i.e., when vaccines were permitted for people 18–45 years of age).

The mandatory use of CoWIN for registration initially led to several glitches being reported, leading to challenges in accessing vaccines. These included user data being incorrectly registered and beneficiaries not receiving the one-time password required to schedule the appointment.<sup>56</sup> It also brought to the forefront the gap in digital access in the country, which stands at 61% as per estimates.<sup>57</sup>

On 22 April 2021, the Supreme Court took *suo motto* cognisance of the unprecedented health emergency in the country during the second wave of the Covid-19 pandemic. While examining the steps taken by the government, the Supreme Court also highlighted the digital divide in the country.

The court in its order dated 31 May 2021<sup>58</sup> noted that

“A vaccination policy exclusively relying on a digital portal for vaccinating a significant population of this country between the ages of 18-44 years would be unable to meet its target of universal immunization owing to such a digital divide. It is the marginalized sections of the society who would bear the brunt of this accessibility barrier.”

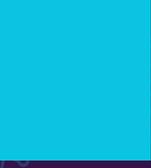
As mentioned earlier, walk-in registrations have now been permitted, and in some

states, health officials have also been asked to provide vaccination at home for beneficiaries who are unable to come to vaccination centres. Beyond the issue of accessibility, the deployment of CoWIN also raised privacy concerns, as until the order of the Delhi High Court on 2 June 2021, the website did not have a dedicated privacy policy; rather, its 'privacy policy' simply directed users to the Health Data Policy of the National Health Data Management Policy, 2020.

As an article by the Center for Internet and Society noted,<sup>59</sup> a health policy cannot and should not be a substitute for specific independent privacy policies of different apps that may be designed by the Government to collect and process the health data of users. Health Data is recognised as sensitive personal data under the proposed personal data protection bill and should be accorded the highest level of protection.

After the order of the Delhi High Court, CoWIN introduced a separate dedicated privacy policy on its website.





# Part Two



## ON-GROUND IMPLEMENTATION OF DIGITAL HEALTH

As discussed previously, the digitisation of the healthcare system in India began prior to the pandemic, but it has given a push to the rollout of digitisation tools by the government. To assess the rollout of digital health initiatives, we conducted field research in three states in eastern India – Chhattisgarh, Jharkhand, and Madhya Pradesh. We picked these states because they have low levels of digital penetration and infrastructure, with 29% of the population having access to the internet in Chhattisgarh and Jharkhand. This figure is marginally better when it comes to Madhya Pradesh, with 31% of the population having internet access.

We interviewed 2 Anganwadi workers (community-based frontline workers of the Integrated Child Development Services programme of the GoI); 6 ASHA workers; 1 Auxiliary Midwife Nurse, 1 data-entry operator in a civic hospital; 1 Senior Medical Officer and a member of the National Health Mission (NHM); 3 public health activists; and 2 sarpanches (head of the panchayat).

At the outset, our study, albeit limited in its sample- revealed what is widely known: a pan-India rollout of digitisation of the healthcare sector is not feasible considering the wide disparities in internet access across states. The problem gets accentuated when we look at the gender disparity in internet access in these states.

As per the National Health Family Survey (NFHS-5)<sup>60</sup> released by the GoI, in Madhya Pradesh and Chhattisgarh, only 26.9% of women (between the ages of 15–49 years) have used the internet at least once (both urban and rural areas). This figure is marginally better when it comes to Jharkhand, where 31.4% of women have used the internet at least once.

A very high differential is also seen among the female and male populations who have used the internet at least once. In every state, the percentage of male users exceeds that of female ones. In some states like Bihar, Tripura, Andhra Pradesh, and Telangana, there are almost double the number of male internet users than female ones.<sup>61</sup> This difference is more pronounced when it comes to internet usage by women in rural and urban regions.



## OBSERVATIONS AND ANALYSIS FROM THE INTERVIEWS CONDUCTED

### a. Uneven Rollout Of Digital Initiatives and Lack Of Proper Training

ASHA workers were introduced under the National Rural Health Mission (NRHM) in 2005. They are the first point of contact between the community and the healthcare system, and they have undertaken a range of community-based interventions related to the containment of Covid-19. These include community awareness through home visits on key aspects related to Covid-19 transmission and prevention, contact tracing, facilitating access to testing, etc. These duties are in addition to their 'regular' duties such as taking care of the maternal health of women, bringing children to clinics for immunisation, and improving village sanitation. As of 30, September 2021, there are a total of 71,983 ASHA workers in Chhattisgarh, 82,021 in Madhya Pradesh, and 42,670 in Jharkhand.<sup>62</sup>

As frontline workers with experience in implementing community-facing programmes, ASHA workers were seen as critical to implementing the Covid-19 vaccination drive. Further, ASHA and other healthcare workers were critical not only to the actual vaccination drive but also in educating people about the need to get vaccinated. However, one common refrain in our conversations with ASHA workers was that although they were given additional responsibilities during the pandemic, they were not adequately compensated for the same. As ASHA workers are not classified as workers and are rather seen as volunteers by the government, they do not receive a fixed remuneration but are provided with a 'monthly incentive' of INR 2,000 per month. In 2020, the GoI had advised state governments to provide an additional INR 1,000 per month to the ASHA workers who were also engaged in Covid-19 duty. Further, an insurance scheme was launched for all healthcare workers including ASHA workers engaged in Covid-19 duty. However, as per newspaper reports, several state governments are yet to credit this amount.<sup>63</sup> In June 2021, ASHA workers in Madhya Pradesh went on a strike demanding a fixed remuneration of INR 18,000 per month, this was preceded by a strike by ASHA workers in Maharashtra and Karnataka raising similar demands.<sup>64</sup>

A few ASHA workers also informed us that during the initial phase of the vaccination rollout, they had to bear the wrath of people who were initially hesitant to get vaccinated. The additional expenses for undertaking digitisation measures

had to also be borne by the healthcare workers- the expenses were both in terms of the cost of the tools (such as internet and data expenses, purchasing a new phone) and the increase in the additional physical responsibilities as they had to undertake all these measures in addition to the regular responsibilities. An auxiliary nurse midwife (AMN) worker<sup>65</sup> in Chhattisgarh, informed us that they were given a one-time training on how to register beneficiaries on the CoWIN platform, but they had to bear the expense of purchasing a smartphone, SIM card, and internet access. They were not provided with any additional funds for the same, and they also faced the risk of their salary getting deducted if the work did not go smoothly.

As per media reports, state governments such as Rajasthan, Himachal Pradesh, and Haryana had proposed giving ASHA workers smartphones to conduct digital health surveys and collect information about the health of the residents of their villages. Once the ASHA workers received the smartphones, they were asked to download the apps that the government had created for them. One such app was a tracking app known as 'MDM 360 Shield', and in cases where the ASHA workers were provided with smartphones, this app was pre-installed on them. The app allowed senior officials to track the location of ASHA workers and add/delete information on the handsets.<sup>66,67</sup> This use of such surveillance apps appears to be concentrated in a few states.

We asked the ASHA workers and the village heads in Chhattisgarh and Madhya Pradesh whether they were provided with smartphones by the administration and/or whether they had been asked to download any application on their phones. They informed us that they have not been asked to download any applications by the government or provided with a phone.

It also became clear that states such as Chhattisgarh and Jharkhand (which do not have adequate digital infrastructure and digital literacy) cannot solely rely upon digital infrastructure and did not do so during the pandemic, unlike other states. These states did not rely on mobile phones and digital registration as they were aware of the low digital penetration in their state. Though registration on CoWIN is permissible through common service centres (CSCs), through our interviews, we determined that beneficiaries were rarely using CSCs to register on CoWIN. Several ASHA workers informed us that their job was to inform beneficiaries about the vaccination process and take them to the concerned vaccination centre. They did not register the beneficiaries, which was the responsibility of either the AMN worker or other persons. The registration was done on the spot at the vaccination centre, and prior registration on CoWIN was not essential.

## b. Steep Curve from Policymaking to Implementation

Any digital policy announcement should take into consideration challenges such as a lack of digital literacy, lack of adequately trained personnel, unequal access to digital devices, high cost of internet and mobile phones and unequal access to the internet. From the interviews, we understood that the digital health policies announced by the central government often fail to take into consideration issues around adequately trained manpower. This was evident from the fact that though digitisation per se did not create any problems or impediments in the vaccination process, the problem/delay arose during the uploading of data on CoWIN. As most of the registrations were done using physical forms – i.e., details such as name, ID number, address, and age etc were manually recorded at the registration site – these details had to be then transferred to the on to CoWIN by data entry operators.

At times, there was a considerable delay in uploading the data on CoWIN, which meant that there was a delay in the vaccination certificate being generated. This also meant that at times there were errors in uploading the data on CoWIN, and therefore, an incorrect or invalid certificate was generated for the beneficiary.<sup>68</sup> An officer working at a sub-divisional public health centre in a village in Jharkhand, informed us that during the pandemic, they did not have a large enough workforce to undertake the digitisation activities. For the vaccination process, they appointed one data entry operator who was responsible for uploading the beneficiaries' details and resolving any technical issues. The inadequate internet connection in rural parts of the state meant that data-entry officers had to often go from the village to the sub-departmental office to upload the data, leading to a delay and/or at times incorrect data being recorded.

The delay in uploading the data or incorrect data being uploaded meant that at times vaccine beneficiaries did not receive their certificate and continued to be reflected as unvaccinated on CoWIN.

This steep curve from announcing digital health policies to effective implementation at the ground level is also evident from the experience of state governments with electronic health records (EHRs). During our interview with a doctor and a block-level officer in Chhattisgarh, we were informed that though he was aware of EHRs, local government hospitals do not maintain such records. This despite EHRs being announced as early as 2012 under the Clinical Establishments (Registration and Regulation) Act, 2010, and updated in 2016.

As health is a state subject under the Indian Constitution, state governments are required to adopt and enforce the Act by enacting the necessary legislation. As a report by the Center for Internet and Society <sup>69</sup>highlights, one of the reasons for the slow adoption of EHRs is a reluctance on the part of healthcare workers. A reason for the inertia is the fact that doctors are required to upload the patient's data themselves, and, as the report highlights, the average Indian doctor sees about 40–60 patients a day, leaving them with very little time. This shortage of doctors was also highlighted by a health rights activist working in Jharkhand. According to him, the digitisation of the vaccination process did not cause too many problems, instead, the problems mainly arose from an acute shortage of doctors and hospital beds.

Our findings underscore that in the absence of adequate healthcare facilities and properly trained healthcare professionals, the adoption of digital health technologies is not feasible, particularly in under-resourced states.

### **c. Defunct Technological Solutions**

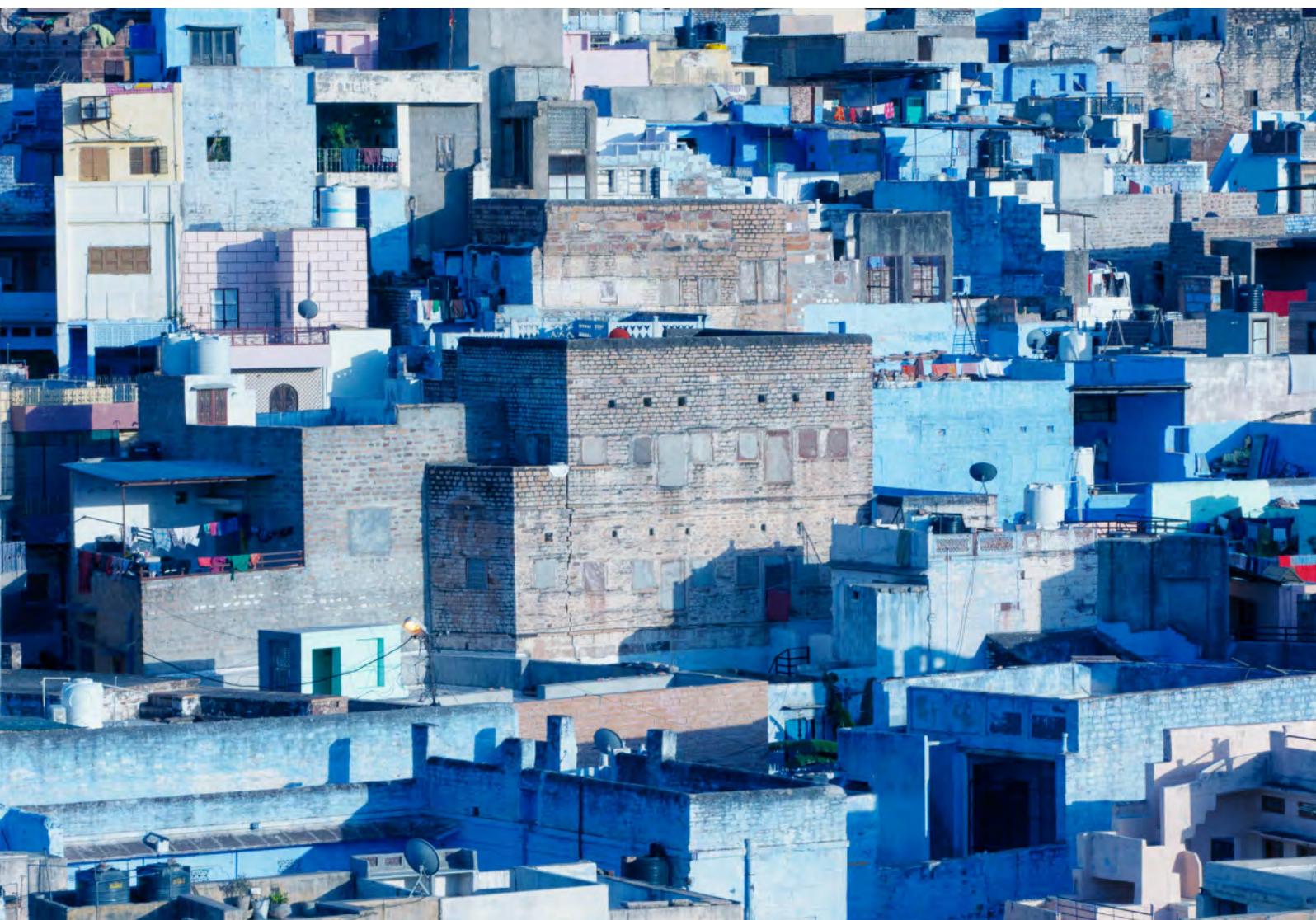
Chhattisgarh and Madhya Pradesh had developed apps during the pandemic; these apps, much like the apps developed by other governments soon became defunct, as they were not used and suffered from several technical glitches. The same was true of CG Teeka, a web portal developed by the Chhattisgarh government for registering vaccine beneficiaries. Unlike CoWIN, beneficiaries did not require a phone number to register on CG Teeka.

The state government announced that it had set up help desks at the municipal corporation and panchayat level to help in the registration process. However, the portal was in operation for only about a month before it merged with CoWIN. This merger was not seamless- A public health activist working in Chhattisgarh, told us that she took her first vaccine dose after booking her slot through CG Teeka, and that when her second dose was due, CG Teeka was no longer in operation. The data-entry officer re-entered her first dose details in CoWIN, and only then could she take the second dose. According to her, people who did not have any documentation or receipt of the first dose they took via CG Teeka faced a lot of issues as the vaccination teams at the other vaccination centres didn't have access to the CG Teeka database.

We also interviewed three civil society members working in the field of health rights, and they told us that they were not aware of any apps being used by ASHA workers either in Madhya Pradesh or Chhattisgarh.

According to a health rights activist in Jharkhand,<sup>70</sup> digitisation of the vaccination programme per se did not cause any problems; problems mainly arose due to vaccine shortages and fear and resistance among community members. He did indicate that there were some problems in booking slots online initially, but this was later streamlined. The district-level officials started mobilising community members and took them to vaccination centres for on-the-spot vaccinations. On-the-spot registration started in Jharkhand prior to the central government permitting such registration.

Similarly, a health rights activist in Madhya Pradesh informed us that registration for vaccines is now primarily being done on-site (especially in rural areas) – online registration is not mandatory. Registration is done physically by district officials (they note the mobile number and the identity document) and then upload this information to the CoWIN website. He informed us that, unlike in Jharkhand and Chhattisgarh, online registration in Madhya Pradesh was initially mandatory, but due to problems with online registration, the government permitted on-site registration from June onwards. According to him, the problem was the shortage of vaccines and not digitisation.



# Conclusion

The state of India's healthcare has been a subject of discussion and debate for a long time. However, recent efforts by the government (at the central as well as the state level) has shifted the focus to digitisation. While digitisation may be necessary and can help in addressing challenges such as transparency, maintenance of large and voluminous health records, and providing doctors easy access to patients' medical records, it should not be at the cost of addressing basic challenges that limit access to affordable and effective healthcare.

India also currently does not have any comprehensive law regulating health data. As discussed in the report, the current law which are the SPDI Rules, are only applicable to private companies, and the government is exempt from its purview. This report highlights the key concerns emanating from the Health Data Management Policy demonstrating how these concerns are further exacerbated due to the lack of a comprehensive data protection bill and the lack of an adequate grievance-redressal mechanism. Health IDs were generated through the Covid-19 vaccination process for citizens across the country even prior to the national launch of the NDHM-HDMP. The IDs were generated without the informed consent of the beneficiaries, in violation of their right to privacy.

The ABDM was initially piloted in five union territories but was soon rolled out across the country without any assessment of its success and failures. As the research and interviews highlight, periodic evaluation, and review of the ABDM need to be undertaken and more field-level research is required to understand the problems faced in terms of both digital access and digital literacy.

During our fieldwork, we found that there was a disconnect between the policies formulated at the central level and ground realities. Thus, states such as Jharkhand and Chhattisgarh that have low internet penetration permitted on-site registration (both offline and online) for the vaccination from the beginning. The respondents were unaware of Health IDs and/or the NDHM-HDMP, even the medical practitioners who were aware of Health IDs were unaware of its purpose and its linkage with electronic health records. Our fieldwork also re-confirmed what is known – a lack of adequate technological infrastructure and skilled manpower affects access to healthcare.

Further, the field work also highlights that several of the digitisation measures that were rolled out, either became defunct or were soon dismantled, leading to question as why were they approved in the first place, i.e. what problem was identified and reasons/evidence was used to justify them, and this reminds us to question how decisions are made as to not only what is needed but also if it will be effective, i.e. will it lead to better access and better care?

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