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NATIONAL DIGITISATION OF HEALTH DATA:
EXPLORING POSSIBILITIES AND CHALLENGES

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NATIONAL DIGITISATION OF HEALTH DATA: EXPLORING POSSIBILITIES AND CHALLENGES

ABOUT CIDS

CIDS (Conversations in Development Studies) is a peer-reviewed, quarterly research journal publication produced by the research team of Centre for New Economics Studies, Jindal School of Liberal Arts and Humanities, O.P. Jindal Global University. This student-led editorial journal features solicited research commentaries (between 2500-3000 words) from scholars currently working in the cross-sectional aspects of development studies. Each published CIDS Issue seeks to offer a comprehensive analysis on a specific theme identified within development scholarship.

The editorial team’s vision is to let CIDS organically evolve as a space for cultivating creative ideas for research scholars (within and outside the University) to broaden the development discourse through conceptual engagement and methodological experimentation on contemporary issues. Any research commentary submission features: a) brief review of the literature on a research problem; b) the argument made by the author with details on the method used; c) documenting the findings and relevance of them in the larger scope of the literature; and (in some instances) d) present a brief policy action plan for agencies of the state (to address the issue highlighted in the commentary). There are no pre-identified limitations or restrictions to methodological frameworks used by solicited scholars (i.e., those writing the commentary). However, the research method incorporated in any accepted submission must be explained along with its relevance in context to the study undertaken.
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About this Issue

NATIONAL DIGITISATION OF HEALTH DATA: EXPLORING POSSIBILITIES AND CHALLENGES

On 23 September 2019, the Government of India announced its commitment to accelerating progress towards achieving Universal Health Coverage by 2030, which entails ensuring that all people have access to quality health services. The Ministry of Health and Family Welfare (MoHFW) acknowledged that to achieve these aims, India needs to digitise healthcare. According to the World Health Organisation’s ‘Global strategy on Digital Health 2020-2025’, Digital Health is the practice of developing and using digital technologies to improve healthcare. This includes everything from eHealth to cutting-edge innovations in artificial intelligence and robotics. In India, a part of this initiative has been to develop a ‘National Digital Health Ecosystem’ — a centralised repository of health data that enables the seamless exchange of information, and processing of data from all verified hospitals, clinics, doctors, physicians, nurses, and pharmacies. However, this centralisation of data has required the policy to consider and account for multiple stakeholders — each with their own objectives and strategies.

This issue of CIDS aims to capture the stances of four key stakeholders in the health data digitisation process - a) the government/policy makers, b) the private sector, especially private hospitals and hospital chains, c) community healthcare workers, and d) engineers and technology innovators. The issue will analyse the key concerns of each stakeholder, their position on the digitisation of health data, steps taken by them towards either incorporating or rejecting possible digitisation, and the effect that digitisation of data has had or will have on them and their functioning. By contrasting the various perspectives, the issue will study the differences or similarities between the policy’s vision and the experiences of those who work in private hospitals and community healthcare. This will contribute to a better understanding of whether the impediments and incentives recognized by policymakers correspond to the experiences of individuals for whom the policy is being created.

Centralized digitization of health data will only be efficient if it’s adopted on a large scale. Without the entirety of the ecosystem operating on the same standards and the digital documents being made easily transferable, the benefits are not completely available. India is a laissez-faire leaning healthcare system, resulting in individual doctors and institutions needing to be persuaded to adopt

2 R. Sarwal & A. Kumar, ‘The long road to Universal Health Coverage’ (NITI Aayog, 2020) <https://www.niti.gov.in/long-road-universal-health-coverage#:~:text=India%20is%20committed%20to%20achieving,per%20cent%20of%20the%20population>
the larger protocols and digitisation resources.\textsuperscript{6} Policy guiding the implementation of health data
digitisation will have to account for the competing concerns and holdups of both private hospitals
and community healthcare workers.

The fragmented nature of healthcare delivery in India slows down and reduces the benefits of
digitisation of the services. The largest hospital chain, Apollo, operates less than 1% of all hospital
beds in India and there isn’t an integrated digital records system even among community health
workers working with the same region on overlapping concerns. The government needs to create
policy that overcomes these hurdles, works efficiently across multiple contexts and providers, and
offers incentives to convince said providers to adopt these systems.

Over the last decade there is a growing consensus, especially amongst state authorities, that there
is a need for a targeted digital health scheme in India. In 2017, the National Health Policy
envisioned the creation and development of a digital health information system that promised
integration across the board, efficiency, and transparency.\textsuperscript{7} After multiple levels of deliberations
and a devastating public health crisis, in late 2021 the Prime Minister announced the National
Digital Health Mission (NDHM) that aims to achieve universal health coverage and portability by
generating a unique Health ID for every citizen.\textsuperscript{8} This would be done by utilising a National Health
Stack (NHS). According to consultation documents circulated by Niti Aayog, the NHS is a
nationally shared digital infrastructure that is “built with a deep understanding of the incentive structures
prevalent in the Indian healthcare ecosystem”.\textsuperscript{9} In fact, there is a 16% increase in the budget allocated for
health this year. Priorities are clear, as there is an increase in funding especially for infrastructure
development of health systems.\textsuperscript{10}

However, there are several concerns with the project. To begin with, the NHS would ultimately
be one of the largest health databases in the world. And while on one hand a universal integrated
system would have notable benefits and help deliver better healthcare, there are serious concerns
around security, anonymity, privacy, and misuse of sensitive health data by private entities.\textsuperscript{11}
Aadhaar, with a similar goal of centralising welfare, had several issues with data theft and leaks,
and is often severely criticised for creating a barrier between people and access to basic services.

\textsuperscript{6} World Health Organisation (n 5)
\textsuperscript{7} Prabha Raghavan & Pranav Mukul, ‘Explained: What is the National Health ID, announced by PM Narendra Modi?’
\textit{(The Indian Express, 27 September 2021)} <https://indianexpress.com/article/explained/explained-what-is-the-national-health-id-announced-by-pm-modi-6556155/>
\textsuperscript{11} Mithun MK, ‘The risks of storing health records of 1.3 billion Indians on the National Health Stack’ \textit{(The News Minute, 20 October 2021)} <https://www.thenewsminute.com/article/risks-storing-health-records-13-billion-indians-national-health-stack-156707#text=The%20National%20Health%20Stack%20databases%20in%20the%20world%20will%20contain%20from%20prescriptions%20to%20diagnostic%20reports>
With the Personal Data Protection Bill\(^{12}\) (“PDP Bill” \textit{hereinafter}), still in its early stages, there is also no robust and fully functional legal framework in place for data protection and privacy.\(^{13}\) Moreover, expenditure on health still makes up only a meagre 0.35% of the total GDP, which brings into focus serious questions about implementation. Lastly, there seems to be a wide gap between central initiatives and state implementations for many reasons.\(^{14}\) CIDS Team interviewed Dr. Indranil Mukhopadhyay, Associate Professor of Developmental Economics and Public Health, O.P. Jindal Global University for this sub-theme to examine the vision and ambition for the project. How does it compare with previous initiatives and more decentralised efforts?

Simultaneously, India has experienced a rapid growth in the healthcare sector and a parallely high growth in privatisation of healthcare.\(^{15}\) According to the National Sample Survey (NSS) on health conducted in 2017-18, less than one-third of Indians go to public hospitals.\(^{16}\) Thus, any valid digitisation of health data would need to onboard private hospitals and hospital chains. Post the launch of the Ayushman Bharat Digital Health Mission (ABDHM), experts asserted that the major challenge to the mission’s success would be convincing private healthcare providers to come on board.\(^{17}\) This is especially true because, as earlier stated, India’s healthcare system is \textit{laissez faire} leaning, meaning that the government needs to incentivise individual hospitals to undertake the process.\(^{18}\) Private hospitals, however, have expressed a number of concerns and faced varied challenges relating to the digitisation of their health records. The CIDS Team interviewed Dr. Abhijit Hazarika, CEO, Ayursundra Hospitals, Guwahati, Assam for this sub-theme to examine the position of private hospitals on adopting centralised digitisation of their data. What are the challenges the hospitals will face?

At the level of healthcare community work, ASHA (accredited social health activist), AWW (Anganwadi Worker) and ANM (Auxiliary Nurse Midwife), have seen a shift in how they collect and record data, with a number of them using digital devices. Manually recording the data is a tedious process that often results in inaccuracies or redundancies.\(^{19}\) The digital devices allow the workers to operate more efficiently, logging and sharing information with the interface, and getting care information and diagnoses faster. Community workers have, however, faced a number of challenges with this digitisation of data at the ground level. Even among community workers, there

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\(^{12}\) The Personal Data Protection Bill 2019, Bill No. 373 of 2019 \(<\text{164.100.47.4/BillTexts/LSBillTexts/Asintroduced/373_2019_LS_Eng.pdf}>\)

\(^{13}\) Ibid


\(^{15}\) Ayona Bhattacharjee & Deepanshu Mohan, ‘India’s Healthcare System Is Becoming More and More Unequal’ (the Wire, 12 June 2017) \(<\text{https://thewire.in/health/india-healthcare-system-inequality/>}\)


\(^{17}\) Rhythma Kaul, ‘Centre starts work to digitise records’ (Hindustan Times, 11 November 2021) \(<\text{https://www.hindustantimes.com/india-news/centre-starts-work-to-digitise-records-101636587658038.html/>}\)

\(^{18}\) Swami Subramaniam (n 6)

\(^{19}\) Saumya Kalia, ‘Anganwadi Workers Return 80,000 Faulty Smartphones Given for Data Collection’ (The Swaddle, 1 September 2021) \(<\text{https://theswaddle.com/anganwadi-workers-return-80000-faulty-phones-given-for-data-collection/>}\)
exists fragmentation within the data collected. The three kinds of workers mentioned earlier — ASHA, ANM, and AWW — do not have an integrated system within most states despite working with the same community and kinds of data.\textsuperscript{20} The devices and training provided to them are often not sufficient to log and track large amounts of data. The devices have technical glitches and outdated systems, with limited storage and functioning bandwidth, which restricts them from logging data.\textsuperscript{21} The CIDS Team interviewed \textbf{Sambha Patel, Auxiliary Nurse Midwife (ANM)} for this sub-theme, to examine the legwork involved in digitising data at a community level and to document the opinions of community workers on digitisation.

Lastly, what lies at the very core of a digital health scheme is the development of the technology itself. In this case, it is primarily the creation of the National Health Stack (NHS). As the technological backbone of the entire project, it is supposed to enable a seamless flow of information, and is meant to serve the needs of the various stakeholders in the wider healthcare ecosystem — it allows for easy access to affordable healthcare, better service delivery, for some it offers improved cost efficiency, and for others a better way to do research, predict and analyse diseases, or make effective policies. However, there are several concerns that arise. For instance, in the final two months of 2020 alone there were well over seven million cyber-attacks on the Indian healthcare sector, and there exist several concerns about the misuse of sensitive health data by private entities.\textsuperscript{22} CIDS Team interviewed \textbf{Shweta Mohandas, Policy Officer, Centre for Internet and Society India}, and also held a panel discussion with \textbf{Ava Mumtaz Haidar, Research Analyst, Aapti Institute} \& \textbf{Aishani Rai, Research Consultant, Aapti Institute} to look at the several considerations, difficulties, and roadblocks to achieving the utopic seamless integrated healthcare system.

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\textsuperscript{20} Ashok Alexander, ‘Real-time data sharing among rural health workers can save lives’ (\textit{Live Mint}, 15 February 2018)  

\textsuperscript{21} Saumya Kalia (n 19)

\textsuperscript{22} Suprita Anupam, ‘National Health Stack: iSPIRT’s Attempt To Replicate India Stack (Deja Vu Anyone?)’ (\textit{Inc 42}, 18 July 2020) <https://inc42.com/features/national-health-stack-ispirts-attempt-to-replicate-india-stack-deja-vu/>
The Ambition of Governments

The National Health Stack (NHS) would ultimately be one of the largest health databases in the world — and while on one hand a universal integrated system would have notable benefits and help deliver better healthcare, there are serious concerns around security, anonymity, privacy, and misuse of sensitive health data by private entities. Moreover, expenditure on health still makes up only a meagre 0.35% of the total GDP, which brings into focus serious questions about implementation. Prioritising digital healthcare services over primary physical healthcare services also raises important concerns relating to accessibility. Lastly, there seems to be a wide gap between central initiatives and state implementations for many reasons.

At one level, this sub-theme examines the vision and ambition for the project. How does it compare with previous initiatives and more decentralised efforts? How would centralise data records help, and how would universal access be ensured? Do we have enough tools and facilities, and how would effective regulation and implementation be ensured? In other words, what are the key opportunities and challenges? This sub-theme also progresses to explore how would policy efficiently balance private commercial interests and the need for strict regulation? The sub-theme also examines the relationship between the Centre, State, and District governments, assessing the need for protocol governing data transfer and access between the three levels. Therefore, at another level, the sub-theme will survey the relationship between Central-State-Local government, when it comes to questions of digital health and its effective implementation.

CIDS Team interviewed Dr. Indranil Mukhopadhyay, Associate Professor of Developmental Economics and Public Health, O.P. Jindal Global University for this sub-theme.

Could you describe the National Digital Health Mission and what its main ambitions are?

Dr. Indranil Mukhopadhyay: Let me first start with a disclaimer, I am not an expert on digital health. I wrote a piece for the India Forum out of my interest. Some of my arguments are relatively better structured there, I prefer that you refer to that article for some of the arguments if I’m missing something. Nevertheless, I’ll give you a broad overview and my concerns. At the same time, there are people that are experts who are working on this subject more systematically, and I consider their views much more critical here. My take on the digital mission and digital health comes from a pure health system perspective. Also, because I am essentially an economist, I prefer to look at the economics behind digital heads. So, these are the entry points I have on this subject. So, what is the broad idea? The stated objective is that this will provide a better choice to patients. That patient can now choose between various providers while seeking health care. That’s one of the critical objectives of this mission and that needs to be carefully looked at. This will also expand access to health care for people at the margin. The other argument is that this will improve health system decision making, by bringing information about people’s health in one place, in a format that is digitally accessible.

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23 Mithun MK (n 12)  
24 Suprita Anupam (n 14)  
In order for there to be centralized digitization of health data and for it to be efficient, it must be implemented on a large scale. This would include bringing on members from the private sector, like private hospitals and hospital chains. What are the possible challenges that might come in the way of these stakeholders adopting data digitization?

**Dr. Indranil Mukhopadhyay:** The private sector is a very critical element of this vision because you are essentially saying that patients should be able to choose between various providers. Additionally, the health system should be able to decide where to divert care, and how to coordinate different healthcare providers. The private sector, given the way it is structured in India, plays a critical role. But you know, there is this caveat that we need to put in here. The private sector, as we commonly perceive it, is not only about the big hospitals. In India, there are around 1,000,000 private entities working on health. A majority of them are unorganized, individual private providers. There are multiple pharmacies and individual doctors. Some are trained in the Indian system of medicine, while some are trained in allopatherpy or other Western systems. Some are not even trained. They’re semi-qualified, unskilled providers. It’s a huge complex mix. The thing is, they’re connected to each other in various ways: kinds of payments, incentives, referrals. It’s a very, very complex system that we are talking about. The aim is also to register all the individual practitioners, nurses, and doctors. First of all, it’s a hugely challenging task, but it’s important to do this. This should be a priority — that we try to bring all of these providers into one network of information. This is Centralization.

I’ll give you an example to situate why I’m saying this. Say, when banking services, financial services, were digitized. First, there were core banking facilities introduced in banks. The providers were brought into a network, and then you gradually open it to the individuals, the consumers, all of us. Any effort towards digitization should be a step-by-step approach. Unless you do the first step, you should not get into trying to take private information and health information into account. That’s my take on this. That should be the priority. Another point is, in this effort to digitize or register all the private practitioners and professionals, there are huge challenges. One major challenge is that there are private providers, doctors who are engaged in private practice, or were in nursing homes, who are essentially public sector workers who are moonlighting in the private sector. There are huge conflicts of interest here. There would be significant resistance from the private sector of various kinds to be part of this. There could be maybe some corporate hospitals saying that they would take part but then the large-scale private sector would not take part. Even the corporate sector is not willing to share most of the data that would be required to make informed decisions of the kind that is being envisioned. I think this is the biggest challenge. We don’t have any regulatory system that forces the private sector or public sector to be part of a network, share data, or share information. So, this kind of regulatory framework is a must before getting into any kind of further digitization.

That’s interesting — there is some kind of an imbalance, as you said, the ambition for the project is to increase autonomy amongst users. However, the private hospitals don’t really see any benefit or they feel like it might be a question of their own autonomy in terms of their decision-making as private entities so they don’t really see a benefit. That actually leads us to our next question, which is, what possible incentives can the policy or
policymakers implement or give to everyone in this private network that you just described?

Dr. Indranil Mukhopadhyay: There are various ways to implement policies where there are conflicts of interest, and offering incentives is one of the ways which is often thought of as a good way. However, I feel more than incentives, it is the regulatory framework that is crucial, so you need to compel certain actors to work in a certain direction that is not suitable for collective action. You need to bring them under some kind of regulations first. Then I would also qualify that there are incentives already in place. Under the Prime Minister's Jan Arogya Yojana, which is the employees’ state insurance scheme, they are the major public sector procurers. Government-funded procurement of private health services is taking place in the country and that’s where the private sector is benefiting, and it's going to benefit more as these schemes expand.

The thing is that incentives are there, but there is no regulation. At least this should be a situation where if you are taking benefits from the public procurement systems, public-private partnerships of any kind if you're engaging with the government in any way and the people’s money is being used in your service, you should be part of this regulatory architecture. That’s my reaction.

Another important component of the policy is community health workers, who record data for large sections of the population — especially those that are marginalized and with limited access — that would otherwise not be included in the system. Are there systems that community workers already use, which might be integrated into the larger network?

Dr. Indranil Mukhopadhyay: There are — there is a system of maternal and child health tracking for various vertical disease control programmes like Tuberculosis. Data being collected very regularly. In fact, there are multiple channels through which data is being collected. The key challenge is centralizing and having one health record. The experience has not been very encouraging globally. If you look at the United Kingdom or United States, it has brought in numerous challenges. Immunization, maternal child health tracking for malnutrition, Tuberculosis, for HIV – various systems of data collection are already in place and most of it is now gradually getting digitized.

In what ways will the digitization of healthcare affect the ability of individuals to access healthcare services? Certain sections of society were left out of the Aadhaar platform, which will be linked to the Health ID. Are there any provisions within the policy to increase the penetration and accessibility of healthcare services? What additional measures are necessary? It might also be helpful if you could tell us what we can learn from the attempts to centralize data in the United Kingdom and the United States.

Dr. Indranil Mukhopadhyay: In regards to whether it’s going to facilitate access, there is a notion currently being promoted by the Government, both Center and State – this digital platform will replace physical healthcare services, or at least compliment them. For instance, for mental health, in the budget, there is a tele-mental health programme being launched. Challenges to access are quite known. Only 16% of the population has access to the Internet or a quality mobile device where they can avail of these services. These are well-documented challenges vis-a-vis access.
People do not have the skills or information to seek care when it is available only digitally. That being said, I am not saying that there is no place for digital health data. I want to make it very clear that there are places where digital health can supplement well-functioning, primary health care.

Comprehensive, integrated primary care can make use of digital health data selectively. It can improve access. However, you need physical health care available close to people. There are three dimensions of access — availability, accessibility, and affordability. All of these need to be taken into account and then you can supplement that service with some bit of digital health care. For instance, for mental health, we do not have a single mental health specialist in many districts of the country. We don't have a cadre of social workers in mental health who would have played a very important role in community-based interventions. For non-communicable diseases, we need a similar cadre. This would benefit disproportionately the better-off sections of society.

At the same time, I would like to bring in another point here. The first point I made about digital healthcare services giving people more agency over their choice, it’s a false notion regarding health care. As individuals, we do not choose what health care we need. We depend on the provider, the doctor, the nurse, and the frontline health worker to guide us to the correct health services. If you have the health providers integrated into a network and that network is available to your frontline health worker, he or she would be able to tell you where to go, and how to get access. Rather than centralizing this digital system, it should be decentralized. It should be managed at a village level, at the district level. Rather than focusing on trying to digitize our health information, it should be an aide to the frontline worker who can guide the patients. It can be a doctor, it can be a nurse, an ANM, or an ASHA worker. That approach is completely being bypassed and undermined. I'll come to the underlying economic motives behind that.

For the second question you asked, about what we can learn from the United Kingdom and United States examples, I request you to go back to the India Forum article I have written, it's called Deep Dive into Big Money26. I have argued and provided a detailed explanation. The basic points here are one, for the United Kingdom, this entire exercise has been very costly. Then there was huge resistance from the primary care General Practitioners (GP) in the United Kingdom and they had to modify it. They had to initially stall it, but then it was pushed from the background. For a country, like India - that spends one of the lowest amounts of public resources on health, in terms of per capita or in terms of percentage of GDP, this is a huge task and it would need massive investment.

The other point is that digital data is collected for one purpose and it is used for ten other purposes, and that’s how the economy works. There are huge big data giants around the world operating in this and they have huge interest. That’s why it is being centralized. There are dangerous, very deeply concerning tendencies here. The examples are there in the piece I have written. There were issues where the companies that were given some of these rights to collect and store digital data were also companies who are working with, say, defence establishments. They were handling both. They were also working to identify criminals or say, not in the same bracket, but they were also using the data to identify illegal immigrants of a country. If you bring the two aspects of work

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26 Indranil (n 25)
together, you can see the implications. It can create huge discrimination against people. This can be used by the police state. So, there are deep-rooted concerns and there are huge economic interests.

Could you also comment on the similarities or differences between this policy and the Aadhaar policy enacted earlier?

Dr. Indranil Mukhopadhyay: I am not an expert on Aadhaar. Having our financial data linked to Aadhaar, having all our records linked to Aadhaar, has huge implications. But now the attempt is to include how we behave, what our health condition is, and what we are thinking. The danger is multi-fold. As a result, the kind of regulation checks required should also be increased. One of the ways to prevent misuse of this data is to decentralize. Ideally, where should the health care decisions be taking place? To the maximum, it should be at the district level. Ideally, much of it should be at the village level, at the bottom-most level. Beyond that, this data should not be accessible to others. Even if you are making this anonymous, the danger doesn’t get reduced. They are also trying to link the Health ID with Aadhaar. Those who are working specifically on the scheme, they would be able to tell you of the specificity of the two regulations and the bills. Again, I’m not an expert on this, but I believe we need to be much, much, much more cautious here.

The technological infrastructure necessary to ensure the efficiency of data digitization is considerable. Currently, the technology is primarily the creation of the National Health Stack. Do we have all the infrastructure necessary to carry out the digitization mission at the level it is planned?

Dr. Indranil Mukhopadhyay: There is no resource constraint as such. If the country wants to invest in this, it could do that. We have the technological know-how, that is not my major concern. The concern is, whether we should invest in this or not? Whether we should invest in collecting information from people before setting the health system house in order. It is about priorities. It’s going to be hugely costly but we can find resources if needed, it just needs to be done appropriately.

Do you think a decentralized policy would be more efficient to implement as opposed to something like this, something that is planned?

Dr. Indranil Mukhopadhyay: If it has to work, it has to work in a decentralized way. This is a system that is created for a different set of incentives, not to provide better care. Essentially this design is not about providing better access to people, giving people the choice. The notion of choice is a misnomer. But better access? No. This is designed to serve the commercial interests. If it has to work, it needs to be decentralized.

Concerns regarding security, anonymity, privacy, and misuse of sensitive health data by private entities have been brought up in relation to the policy. How does the policy tackle these concerns?

Dr. Indranil Mukhopadhyay: There is a lot of literature on this. People are writing, who are experts, and I think their concerns are very much valid. The kind of regulatory architecture we
need to safeguard people’s rights to privacy and prevent misuse of this kind of very sensitive information, we don’t have in place. This has already started with vaccination. All our health data have already been taken. How they are going to use it is a separate thing. It is deeply concerning. You can digitize but it is much more difficult to regulate. We do not have the regulatory architecture in place, the kind of training and complementary systems that are needed to regulate, are not there in place. It still needs much more caution. We need to take a staggered approach. So that it is not only about creating policies, you have to implement regulations. We don’t have any expertise in regulating health services in the country. Our Clinical Establishment Act just wanted to register all clinical establishments and some broad regulation of what you can do, what you cannot do. Very simple, broad regulation, that is not in place for this. Forget about the functioning and regulation, if there are information leakages if the sensitive data is being used for other malfeasance. This is far, far more complicated and we haven’t taken the first step at regulation so I feel that this is very deeply concerning.

**Given the topics we have discussed, what are the key considerations policymakers must keep in mind relating to the policy?**

**Dr. Indranil Mukhopadhyay:** Conversations on how the policy can be improved are connected to the current architecture and the incentives of the policy. The incentive for the entire drive is geared towards commercialized healthcare. A system that runs on insurance schemes. A system where this centralized data can be used for multiple purposes, often commercial purposes. A system that will also be used by the insurance companies to deny care to people. There are some regulations, but they are vastly inadequate. So how to do this better?

First of all, we need to put that regulatory architecture in place. Regulation of private sector entities, regulation of insurance providers. We do not have a separate regulatory mechanism for health insurance providers. Private health insurance is known for denying care to patients and we are aiding that business of exclusion. The second level of regulation is regulation of the misuse of this kind of data and the safety of health information. We are far, far away from this one. Another goal is to prioritize providing access to physical healthcare, particularly for primary care people. The Health and Wellness Center, which was an important element or vehicle to improve access to primary care, is not expanding at a desirable pace. It needs to be stepped up and we need to think about a different approach toward digitalization.

We should first focus on bringing all the service providers into an information system. For personal information, they should be beyond the level of frontline health workers. They should be anonymized. You have to link individuals to a set of frontline health workers who would help them. That is the National Health system in the United Kingdom where you go to a GP, that GP helps you choose healthcare, that GP becomes your guide. That person’s commercial interests should be separated from the interest of the patient. Their sole intention or incentive should be to provide the best care to the patient and not aligned with commercial incentives. So, this is what

27 Clinical Establishments (Registration and Regulation) Act 2010, No. 23 of 2010
<https://www.indiacode.nic.in/bitstream/123456789/7798/1/201023_clinical_establishments_%28registration_and_regulation%29_act%2C_2010.pdf>
needs to be done before you collect digital health information. Provide comprehensive primary care and then think of collecting their digital health information. If you are collecting this data, use it for decentralized decision-making, not beyond. No personal information should reach beyond a district level.

Everything can be managed at the district level. Whatever care is necessary, it can be provided at the district level. If there is some gap in information, you send it to the state level and tertiary institutions. But the data should be there, not at the state level or national level, but at the district level. That is enough to make a rational decision, and provide appropriate and rationalized care.

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Private Hospitals: The Key to Digitization?

Post the launch of the Ayushman Bharat Digital Mission (ABDM), experts asserted that the major challenge to the mission’s success would be convincing private healthcare providers to come on board.28 This is especially true because, as earlier stated, India’s healthcare system is laissez-faire leaning, meaning that the government needs to incentivise individual hospitals to undertake the process.29 Private hospitals, however, have expressed a number of concerns and faced varied challenges relating to the digitisation of their health records. They have experienced resistance from their physicians and a lack of inter-operable IT systems in the marketplace. Doctors are hesitant to adopt these methods as digitizing records requires them to put in extra time to complete EMR’s and enable a level of transparency they are not used to. Additionally, they had concerns over the costs of implementing the systems and the required security and consent protocols.30 Security is necessary since healthcare data has proved to be a particularly popular target in other countries, especially the U.S., for ransomware attacks.31 The hurdle of incentives for private companies could be overcome through the possibility of private partnerships. For example, one of the drivers of digitization in the U.S has been changes in payment arrangements between hospitals and insurers.32 However, this brings up additional challenges relating to privacy, security and safeguards against exploitation of the data.

This sub-theme examines the position of private hospitals on adopting centralized digitisation of their data. What are the challenges the hospitals will face? What are the reservations held by the individual stakeholders such as the managers and the doctors? How can these challenges or reservations be addressed? What incentives are the hospitals and its stakeholders most interested in? How would they like these incentives to be carried out? And have the policymakers accurately analysed and pinpointed these incentives and challenges?

CIDS Team interviewed Dr. Abhijit Hazarika, CEO, Ayursundra Hospitals, Guwahati, Assam for this sub-theme.

In late 2021 the Prime Minister announced the National Digital Health Mission (NDHM). Has your organization discussed or considered adopting the processes described in the Policy?

Dr. Abhijit Hazarika: Let me take a few steps back. We started Ayursundra, basically as a healthcare service provider. We had diagnostic centres and now we have a hospital, expanding to two more hospitals in Assam, with plans to move into more parts in the Northeast. There were a lot of things in our minds when we came into this business. Digitization of healthcare and medical data was one of them. I appreciate this initiative of the government to digitize health data. It will help in the seamless transmission of data between hospitals, better accessibility for people, and higher chances of innovations resulting from the availability of data. From my personal experience

28 Rhythma Kaul (n 17)
29 Swami Subramaniam (n 6)
32 Adam C. Powell (n 32)
in private healthcare in the Northeast of India, I would welcome the process of digitization, but attention is needed at two levels. One, making the system of digitization watertight, ultimately it will be a data archive and you cannot play around with it. Therefore, developing a pan-Indian policy regarding this will be a big challenge. Second, is the predicament that comes in when we start to implement it. The two biggest challenges therefore would be to first get it up and then to keep it running.

Another challenge would be relating to data entry. What to put in and how to put in. If you put in faulty data, you would botch the entire process of how the patient is being treated. It is important as it helps in keeping prescription records so that the patient can be evaluated on follow-ups, a proper MRD (Medical Records Department) can be made so that the prescription records could seamlessly be shared among public-private medical institutions — wherever the patient goes. I am not even coming to the part of privacy, security of data. The first step, putting in the data, would itself be a major challenge.

Policymakers have stated that there are numerous administrative and/or diagnostic benefits those hospitals can expect to receive from this digitization of the data. What are your opinions on this assertion?

Dr. Abhijit Hazarika: Security and consent protocols should be the same in both public and private medical institutions. There must not be any difference. When you look at the entire country, 15 States out of the total 35 States and Union Territories have private healthcare providers doing the bulk of the work. About 70% of the medical services are met by private players. However, interestingly, only 35% of the healthcare requirement is met by the private players in the northeast, where we are based. The rest is met by the public health institutions.

People have understood the importance of data, especially after COVID-19. There will however always be a threat to data security. Hackers and anyone with the intent to do so may indulge in such malicious activities. The danger is there when you keep the data so close to your chest. For this, we need high-end firewalls, alarms for security breaches, and the like. However, my worry here is the predicament resulting from putting in the wrong data for the wrong person. Considering the fact that we live in a massively populated country; one percent of human error could change the lives of lakhs of people. Therefore, there has to be some central authority that might help in editing the wrong data. It cannot be fixed in stone, there have to be some checks and balances involved. Audits, by some neutral party. For the money part, yes, it would incur some costs. Considering a separate set of people to put in data, to review data, some may be in tertiary care, some in the rural areas, there will be expenses incurred in terms of the logistics.

According to the National Sample Survey (NSS) on health conducted in 2017-18, less than one-third of Indians go to public hospitals. This means most health data is stored by private hospitals. As the CEO of one such hospital, have you personally, or your colleagues’ raised concerns related to the ownership of the data?

Dr. Abhijit Hazarika: We started doing EMR (Electronic Medical Records) way back in 2010 when we started. The idea was to figure out whether the doctors in our centres were writing the
medicines correctly, and whether our pharmacies were using the medicines. People were not readily interested in the data collection but we, in the back of our minds, knew it would be wonderful in ten years’ time. We had a much smaller footfall of about 200-250 a day. So, we had the system of EMR up and running. However, people were not very keen on writing electronically. We too had a professional to scan and input the data at the end of the day. However, usually, people are sceptical to put in their own data since it is personal. The big chains of hospitals have very high standards of monitoring of data. However, that kind of monitoring will not exist in smaller hospitals. You cannot make mistakes here. I am not talking about data mining, pharmaceutical companies using the data to create products, etc. I am talking about the very basic things.

At the end of the day, you are going to be putting in the data and saying a percentage of that is faulty. Upon this faulty data policies would be made which would affect millions. But, for a start, if we are given the know-how and Standard Operating Procedures regarding the process, we can begin.

Big hospitals are not that keen on government policies and initiatives. When they have to pay for the doctor, infrastructure, consumer goods, and electricity, they would not be able to provide the quality service at an affordable rate mandated by the government. For the digitization part, hospitals will find a way of doing it, and it is currently being done. Some hospitals continue doing so by charging for the services of digitization from the patients themselves. Therefore, there should be some central controlling authority. It happened in the COVID-19 pandemic where some people made a lot of money while some did not. However, with competent people at the helm, this process can be credibly carried out.

The issue is with smaller hospitals. They do not have the deep pockets like the bigger ones, which can afford them to not be paid for months. Costs of digitization, especially for smaller hospitals are, therefore, a concern.

**Policy-makers have stated that there are numerous administrative and/or diagnostic benefits those hospitals can expect to receive from this digitization of the data. What are your opinions on this assertion?**

**Dr. Abhijit Hazarika:** Yes, sharing data will help. Sharing the trends of a particular disease, the presence of some disease in society, and the prognosis for a particular disease, would certainly help. There will be a lot of data and therefore there could be a variety of interpretations. Would there be some sort of department that would interpret this for the sake of uniformity? Handout a particular readout annually regarding the trends in the data?

Another important point is anonymity. The anonymity of the hospital or exact place or location from where the data is going is important as a competitor could take advantage of that. A bigger shark could eat up the smaller businesses resulting from the access to that kind of data.

For patients, the process sounds simplistic. You will have a health card, and a health address that you could out into any hospital you go to. For them, since their health data is digitized and
accessible, there is no scope for hiding that data. But the question would be are we mature enough to use this transparency of data correctly? Or will it be used to harm others?

**What incentives could the government offer private institutions to make sure that policy implementation is uniform across government and private entities?**

**Dr. Abhijit Hazarika:** My take on incentives is that if you give something, they will want more of it. Big or small, hospitals would manage that tiny little amount of money. This is because, in the case of small hospitals, the footfall is not so great that a lot of money will be spent on keeping the records. They don’t have to be paid anything in incentives to keep records. They will charge 50 rupees extra to get this done. If they explain this clearly to the patient, they will understand. On one hand, you have to be disciplined to carry out this process, and on the other hand design a system that is fool-proof. It should be a simple process so that even people with medium skill levels can easily work through it. This should be mandatory for all hospitals. Ultimately, you are doing it for your own country, for the people. This should outweigh the need for any incentives.

**Regarding accessibility in rural areas, has your hospital worked towards that end?**

**Different hospitals would store information differently and in different regions. How would that work in accordance with centralized policy?**

**Dr. Abhijit Hazarika:** Our hospital worked on something which we called the last-mile. It was basically centred upon the concept of accessibility to healthcare — not really a lot of data involved — but primarily to connect the last mile, because that was the biggest problem in our state. A lot of money had been siphoned off by tricksters, the middlemen who actually get people from the hospital and take them to strange places. So, we wanted to get access to the different districts. Couple of villages will begin with that. We tried to create a network of these districts and last-mile programmes, but the plans were halted due to COVID-19.

Now, however, as things are turning out to be much clearer, maybe in the next six months or a year, perhaps we would still go back to our last-mile programmes and implement them to completion. Regarding different hospitals storing data differently and their relation to centralized policy, a proper policy needs to be first made, and as I mentioned earlier, if it falls in the wrong hands, a lot of things would be very unpleasant. Then somebody would make a lot of money on that. So before delving into something like that, it is important that a committee is set forward, and competent people are there to figure out something. That has to be done in the regularity of about firstly, say, for instance, three months and then probably later on go back to about twice a year, for audits.

**Both Aadhaar and CoWIN left out certain groups of people. What do you think led to this and what could be done to fix this policy wise?**

**Dr. Abhijit Hazarika:** First of all, we should credit the government. For a country this big, CoWIN was a great platform. We are not a very disciplined country but it helped people get vaccinated in a relatively small amount of time. Your personal health was an issue here. Your family was an issue here. So, people were scared. I mean, fear actually makes people do a lot of things in
a very disciplined manner. Obviously, there were a huge group of people who did not have access to the digital know-how and equipment, which would have given them direct access rather than going to a particular centre and getting registered.

Regarding Aadhaar, people are worried about their privacy, which is probably a wrong notion here. This is the effect of these huge social media platforms, where people get the false courage to write things about, and opine on everything outside their line of expertise. So, a proper policy in which people are aware of the good things which Aadhaar can do should be constructed. FAQs about what actually is Aadhaar should be circulated. When you are talking about health, we have to compensate and do our bit, otherwise, it doesn’t make sense. Everything is not commercial for us. Yes, of course, you have to sustain yourself to make a profit and it is a business of medicine, but certain things can be sacrificed.

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Healthcare Workers: Warriors on Ground

Community workers have faced a number of challenges with digitisation of health data at the ground level. Even among community workers, there exists fragmentation within the data collected. The three kinds of workers earlier mentioned — ASHA, ANM, and AWW — do not have an integrated system within most states despite working with the same community and kinds of data. Some workers have not been provided with smartphones, meaning they have to use their personal devices — denying access to other members of their family and allowing their device to be surveilled forgoing their privacy. They have also brought up concerns about the devices tracking their daily movements and whereabouts. Additionally, the community workers have received limited training and information on the digitisation processes and have to juggle these tasks with a number of other responsibilities. Policy addressing digitisation of health data at the ground level must also include incentives for the workers to take up and integrate digitisation into their existing routines.

This sub-theme examines the legwork involved in digitising data at a community level and the opinions of community workers on digitisation. What is the perspective of the Community Health Workers (CHW) on the possible benefits and drawbacks of data digitisation? What are the obstacles they have faced in the process? What are their concerns in relation to the process? What are their demands and how have they articulated them? And have the policy makers been able to accurately pinpoint these hurdles, the best ways to overcome them and the necessary incentives required?

CIDS Team interviewed Sambha Patel, Auxiliary Nurse Midwife (ANM) for this sub-theme.

Can you describe your work with recording health data?

Sambha Patel: We do fieldwork. We have to do all the work ourselves, such as surveying, vaccinating, giving polio shots, etc. We work on all the initiatives set by the government.

What type of data do you record?

Sambha Patel: We ask who the head of the family is, the number of family members, their age, whether they have phone numbers and if they do then we record everyone’s numbers.

What platforms or methods do you use to record the data?

Sambha Patel: We have a register where we take down all the points and data collected during the survey. When we conduct the survey, we ask how many members are there in the family, how many children live there, whether they are below or above the age of five years, etc. We then

33 Ashok Alexander (n 20)
compile the data and give it to our superiors. We use our phones to record the data. For example, if they told us we have to record five patients, we would then go and conduct the survey and record it on our phones.

Have you been provided with all the materials you need to carry out this work?

Sambha Patel: No, we don’t get the things we need. We need medicines in the field. For children that come in for the first time, with fever or other infections, we need to give them vaccines, which we are not given. The government doesn’t give us these essential products.

Are the things you’ve been provided of good quality?

Sambha Patel: The things are not of good quality. If we do by chance get the medicines such as paracetamol, usually it so happens that we don’t have the medicine logged in the books. We have to then manage. If expecting mothers come by to get injections, we then somehow have to manage it. All that the government does is give orders and directives to problems, but never provides the materials we need to implement the solution. They tell us what to do and when it needs to be done, but they do not give us any tools to carry out the instructions.

Have you been provided the training you need to record data digitally?

Sambha Patel: No, we didn’t get the proper training. We had to leave our families and children and go to survey during the pandemic, the government never heard our pleas or requests. They only gave us directives on how many houses we had to survey and which localities we had to cover.

Have you had difficulties with the community when recording the data? What kinds of difficulties?

Sambha Patel: We had to face a lot of difficulties when we went on the field. We had to hear taunts and sarcasm from the community, such as why we have to always conduct surveys or why we come again and again to ask the questions. However, it is what we have to do, we need to conduct these surveys.

We used to go not once, but four times to collect data, and along the way we had several cases of abuse as well. The locals used to taunt us by saying that all the government knew was to collect data, but they are not doing anything with the data. They do not use the data to provide solutions to the problems we are facing. We needed their ID when we gave them vaccines. They wouldn’t even provide their Aadhaar Cards for vaccination.

What support do you think the government can provide you?

Sambha Patel: First and foremost, we would like our salaries on time. We live outside and we have to pay rent. We get our salaries sometimes 2-3 months late. Our wage has not increased in several years. It is difficult to manage a household with only Rs. 10,000 per month. They want all the work done in time, but there is no sight of payment.
Have you heard of anyone who has tried to protest or request for support?

Sambha Patel: We discuss and share all our grievances and problems with our supervisor.

Were they able to get any aid?

Sambha Patel: No, they haven’t been given any help or solution yet.

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Technology: Enabling the Seamless Implementation

The creation of the National Health Stack (NHS) — the technological backbone of the entire project — is supposed to enable a seamless flow of information, and is meant to serve the needs of the various stakeholders in the wider healthcare ecosystem. It allows for easy access to affordable healthcare, better service delivery, for some it offers improved cost efficiency, and for others a better way to do research, predict and analyse diseases, or make effective policies. In this sub-theme, the objective is to understand not just the vision, but the everyday intimate uses and benefits for all stakeholders. There are important questions about privacy and security, but equally important are questions of interface, usability, and accessibility. The CIDS Team in this sub-theme is looking at the several considerations, difficulties, and roadblocks to achieving the utopic seamless integrated healthcare system?

CIDS Team interviewed Shweta Mohandas, Policy Officer, Centre for Internet and Society India for this sub-theme.

What is the technological vision for the National Digital Health Mission (NDHM) and the National Health Stack?

Shweta Mohandas: The idea is to have an integrated Health ID that goes through seamlessly and you have a Health Digi-Locker where you can have one ID with all your health details by all different health services providers. There is a uniformity and the word used in all the documents is “seamless”; what they hope to achieve is a seamless way of getting health data or having health records maintained. Additionally, the documents also state that they want to make it easier for both the patient and the other person at the health institution to access the data. The other idea is to have this data for statistics and to have all this data in one place and use it to figure out ways it can be made non-personal to help the government in disease prevention as well as research.

What are the resources necessary to carry out the digitization mission at the level it is planned?

Shweta Mohandas: We can look at two types of needs — infrastructure and personal. In terms of infrastructure, we definitely would need medical facilities and health care facilities under health management systems to have the capacity to digitize and store and maintain records. The second idea is that of application. It needs to be robust, especially in the case of health. The application would have to be error-proof, and be fast enough, especially if it’s going to be used during emergencies. The third one is the personal element. People who are filling out these forms, or people who are working in hospitals or other clinics who are filling up the details, need to know the systems and not make any errors as once the system receives the details and it goes into a patient’s file, it will be difficult to modify issues. There are also the questions of technological literacy. People might not know about the issues or pick up the small errors on the app like their name being spelled incorrectly or the application not working. I think there is also a need to have a look at the infrastructure from the ground up and install infrastructure on the personal level before having plans to go through full digitalization.
The policy aims to digitize data across a diverse range of regions with varying accessibility and different stakeholders. How does the technology accommodate their individual concerns and needs?

**Shweta Mohandas:** There are instances through which we can understand the nuances of accessibility. In the health sector, it is the medical personnel and hospital staff, who are filling in the forms owing to the knowledge of medical terminology while the patient does not. Other issues come in terms of languages. If it is only in English then it makes it difficult to create a Health ID for all. All here would include a lot of people who don’t speak English. Third, for persons with disabilities, there is also the issue around how accessible the website or the application is. When Arogya Setu was launched there were accessibility issues in which persons with disabilities faced difficulties in registration as traveling to places for the same was not accessible to them. The same issue must not happen again with the Health ID.

What are the separate needs that could arise for both private hospitals and community health workers?

**Shweta Mohandas:** I think for private hospitals the process will be much easier. From my own experience in Bangalore in getting our vaccination in a private hospital, we had to register, and it generated our Health ID, and we had a number. So, for private hospitals, if they have a chain, it will be easier for them to store the data and one can easily access their vaccination or other medical details using that Health ID. But if they’ve already decided on the system of recording and maintaining files it will be difficult to use that Health ID in a different hospital. Therefore, there should be uniformity or a standard of how the form should be filled or how the data should be entered so that it is continuous throughout. There should be scope for editing and going back to the data as well. For issues related to faulty or incorrect data, there should be someone of the designation similar to that of a ‘grievance officer’ who would look over such concerns.

In the final two months of 2020 alone, there were well over seven million cyber-attacks on the Indian healthcare sector. What practices could be adopted to protect private health data?

**Shweta Mohandas:** The PDP Bill37 is not yet out. Yet the National Health Stack is trying to implement these services even before there are avenues for data protection. It is not clear what the rights of the person are or the data responsibilities that the private players and the health management systems need to adhere to. The National Health stack defines Health ID but does not define what this health is or what constitutes health data. Would it only include data collected by hospitals and clinics, or would it also include the number of fitness apps or other places where you are actually giving your health data now? Is the airport collecting health data in terms of your temperature and the oxygen levels and your vaccination status also part of that Health ID? Does it become one just because it’s collecting this data?

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37 The Personal Data Protection Bill 2019 (n 13)
While reading through the PDP Bill, we found out that there is no clear indication that a Health ID is part of health data because it says it is rather detailed data about a person. Whether the Health ID is data about a person, or it is an ID that gives all the data about the person, is not very clear. Second, there is ambiguity about whether a Health ID would go under sensitive personal data or not. The National Health Stack and the Health ID that comes through it were not passed as an act of parliament but as a policy. So, as an official identifier, it does not qualify as sensitive personal data. In that case, questions arise on what would happen to the privacy of that health data and what responsibilities organizations have while collecting this data.

Essentially keeping the data secure in such a way that there aren’t any breaches, but if they’re having breaches, also to let people know today – again the PDP Bill does not require that even if it does come into force. But in terms of an act of faith, I think private organizations, they should tell that “OK”, this data has been breached. We are figuring out what to do – but let the people know that their data has been breached. Definitely, they have to look at having secure systems, having encryption, having cyber security protocols at the highest level – and figuring out how to keep the data safe, how to keep the recordings of the health data safe, I think we can definitely look at best practices that are happening in other parts of the world and also figure it out, and comply with those. Definitely does not apply to India – but keep it to those standards or see what are the organizations around the world where there is compliance helped data to be kept very secure, to see what they are doing, and then apply that here.

How is the NHS different from the Aadhaar backbone and how could this prevent people from being left out from the system?

**Shweta Mohandas:** A lot of things are being linked with Aadhaar, but I think we need to look at how the implementation will work out. Once again, there needs to be cyber security in place. Linking is already implemented and it is now much more seamless — for instance, we have OTPs and other things. While there is definitely a backbone that has been functioning, we need to look at the issues that Aadhaar had. There have been major issues of breachers or glitches that they’ve had to work towards. But if we were to just look at having the system, what is needed is not just having organizations, but people responsible. This is so that if there is an issue, it is resolved at the earliest because no system is perfect indefinitely. If it is built at such a large scale, there will definitely be issues or glitches. So, there should be someone to figure this out and say that there might be issues and there will be problems. This is what happened with Aadhaar – but there should be ways through which data is kept safe.

Given the topics we have discussed, what are the key considerations policy makers must keep in mind relating to the technology aspect of the policy?

**Shweta Mohandas:** Looking at the technology aspect, there should be some standards in terms of either looking at international standards or adopting best practices in making standards for maintaining data, standards for training people, standards for data collection, standards for privacy, and so on. So, that is one, definitely just to look at standards and best practices of other countries and see how it has worked. Second, training of personnel and training of the people who are dealing with the data and dealing with these institutions is essential. Third, we need to look at how
it is in line with the PDP Bill. There is time to wait till the personal data is out, to see what form it takes, to assess its capabilities, and the compliances that need to be done in accordance with it. So, I think it’s better to definitely just wait for the PDP Bill to be released and then implement this. But we can’t be sure since there has already been some former implementation through the CoWIN platform. That already seems to be done. So, I think one key consideration is definitely establishing and maintaining standards for training and looking at the PDP Bill. Looking at ways in which transparency can be maintained, privacy by design, and accessibility.

You have mentioned the PDP Bill a lot, so how crucial it is for this program, the implementation of this program and like protecting the data of the citizens of India?

Shweta Mohandas: The PDP Bill is in the draft and we still don’t know what the final version will be? However, I still believe that even in the 2019 draft, which hasn’t changed significantly from the 2018-2019 version — in terms of the definitional limits of sensitive personal data, or more specifically personal health data. So having the rights is one thing, but we also have to look at responsibilities. We must think about not just having our privacy policy that is comprehensive but having it in different languages. We don’t get this if we were to just follow the sensitive personal data rules in the Information Technology Act. We also need to look at compliance, the responsibilities that come with having this sensitive personal data, and the handling of this data.

The PDP Bill also talks about the cross-border transfer of sensitive personal data and the requirements and compliances that are needed for transferring data. These are necessary and must be exerted at a greater level because this is also data collected by the State. While there are exemptions to the processing of data by the State, there must be a sense of responsibility too. Responsibility is the central question. There must be more responsibility for private organizations that are collecting health data to work with the health management policy and their own data processor as a data fiduciary. Once the data protection authority is established, there will be a ‘central authority’ where one can go for issues that are particularly related to data. So that is also another aspect that will come through, and be beneficial. The PDP Bill will definitely clear up a lot of confusion, but these policies and policy drafters need to talk to each other and see how they can make it better. There must be a seamless implementation of data protection policies and principles related to health data.

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38 The Information Technology Act 2000, No. 21 of 2000
<https://www.indiacode.nic.in/bitstream/123456789/13116/1/it_act_2000_updated.pdf>
Big Data vis-à-vis Security Concerns

What lies at the very core of a digital health scheme is the development of the technology itself. In this case it is primarily the creation of the National Health Stack (NHS) — which is the backbone of the entire project, it is supposed to enable a seamless flow of information. However, there are several concerns that arise. For instance, in the final two months of 2020 alone there were well over seven million cyber-attacks on the Indian healthcare sector, and there exist several concerns about the misuse of sensitive health data by private entities.

In this sub-theme, the everyday intimate uses and benefits for all stakeholders is explored. For instance, the ways in which the same technology is used by a doctor, a university researcher, and an individual patient, would be vastly different — how is the data presented to each? How exactly is the technology designed to be beneficial for each type of user? What are the several considerations, difficulties, and roadblocks to achieving the utopic seamless integrated healthcare system?

CIDS Team interviewed Ava Mumtaz Haidar, Research Analyst, Aapti Institute & Aishani Rai, Research Consultant, Aapti Institute for this sub-theme.

What is the technological vision for the National Digital Health Mission (NDHM) and the National Health Stack (NHS)?

Ava Mumtaz Haidar: I have been researching the NDHM & NHS now and supporting Aapti Institute over the last few months. This digital project has been in the works for over about 3-4 years. The NDHM which I think they’re now calling the ABDM and the NHS are infrastructures that seek to have what they call open standards of creation, open-source codes, open APIs to a certain extent, and interoperability of design.

If I’m a programmer and I write, or a developer and I write a code for a certain kind of technology. What I write is the human-readable code and what the machine reads and translates is a machine-readable code. But essentially, in open-source software and what open-source code essentially does is that it frees up the sort of ability to replicate the code and maybe mould it for other specific purposes. This is being practiced with digital infrastructures around the world, where they’re trying to have large scale, population-scale projects, and transformations of state infrastructure, to ensure that as many people possible who can develop upon a common software base can do so for the specific needs in their location, who they are fiduciaries of, who they can benefit through their development of the code. But essentially these things are usually proprietary. That’s why tech companies have for long been in the private space, the restrictions and rights around them are privately held. But open-sourcing codes for instance would change that.

This is not to say that technology would be free in a certain sense, but you would be free to use it and free to replicate and innovate on top of it. Where distinct solutions can be found for different states Maybe in India, depending on different means of what the technology can do in that particular state. So that’s when we say open-source code - with open APIs, they are application

39 Suprita Anupam (n 22)
programming interfaces. Essentially what an API is, is the conduit or the translation ability between two software and being able to talk to each other.

This is unrelated to health, but I will use an example just to maybe illustrate that point a little. Say I’m Big Basket and I make a list, I make a category of all the goods that come up on my interface that I want my consumers to be able to see, and I have a tie-up maybe with the delivery app and just a very sort of neutral delivery app that deals with all kinds of deliveries, and I want to make sure my catalogue is on this delivery app. What I want to make sure of is that my digital catalogue can be easily read by the delivery apps’ readability, a machine they use to pull or translate the information, right? So essentially, I make the conversation between my API and the API of the other technological application seamless. I make sure that the machines can talk to each other.

In the context of health, it is to make sure that data itself between different health apps and different health digital services can talk to each other and can also be interoperable. We cut out the need for making two-three different technologies for maybe the same kind of purpose or even if we do, we can make sure that there’s seamless conversation and integration between the two. That is why, I think that with the NDHM, what they emphasize a lot in their documents is that it’s an ecosystem and not a system. Which is to say that there should, at the end of the day, be a circularity between all the technological advancements and developments within that larger ecosystem. As opposed to many different small things. Anyway, this is just one part of it. It is just one part of the technology. But things like open-source, open API and interoperability just refer to the ease and manoeuvrability of technology.

I’ve spoken about APIs, how they may apply to other parts of the technologies, basically the seamlessness of it, the openness of the technology to integrate with existing technologies like Aadhaar or UPI, this is something the NDHM seeks to be able to have. This is one part of the NDHM’s technological vision.

What the State, I think envisions with the creation of something like a National Digital Health Mission is that it is able to set a baseline of data architectures. It can say here’s—a big bank of information, here are registries. This is the base information we have in terms of health care in India who are stakeholders, whether you are a patient or provider or research or a physician, the hospital, private or government, and so on. And after having these based registries of who belongs to this ecosystem, the government and the private sector are expected to build health services on top of that. So, we look at the data as the start of the building blocks, the foundation, and then all the digital services on top of that to be partnered and built by the government and by the private sector and private individuals as well. So that is also part of the technological vision, that it is collaborative. You don’t just rest on the government to be able to provide all steps to the technology. It’s also about what the private sector has already demonstrated in terms of its talent and what it can do further. So based on sort of a sandbox approach, this is what the NHS seeks to have in terms of its approach to building technologies — to make sure that there’s enough space for collaboration, to make sure that they’re making the best of all worlds, the private sector is able to chip in and provide solutions. The government is able to do that at its own pace as well.
Finally, I think that there are some technical considerations, such as that the NDHM should subscribe to the Indian Enterprise Architecture framework. So that it is equalized across all screens and platforms and portals. Make sure it’s democratic in its usage and, then it’s buffered by all these smaller principles of think big, start small, scale fast. It’s got these visions for its technology, but that’s sort of the long and short of it I would say.

You mentioned that the technology will be open-sourced. Does that make it more vulnerable?

**Ava Mumtaz Haidar:** Well, I think it might be sort of the intuitive answer. If the technology can be innovated upon by nearly any actor, can’t there be sort of harmful additions or innovations within that? But whether that has to do with cyber security risks, I think that’s a separate question. The point is that, when the tech is proprietary, the risks to it of course have to do with the data privacy within that technology, but how vulnerable, how many flaws might this piece of technology have? How many gaps does it have that they didn’t think about? Then the proprietary in the United States is kind of lost because then it opens itself up to other commercial capturing. With open-source, there’s not as much potential for what they say is commercial capturing, right? So, the risks to data privacy of course exist. I think whether it’s proprietary or open-source.

**Could you describe the components of what the National Health stack is and how it particularly tackles the NDHM’s policy goals?**

**Ava Mumtaz Haidar:** So, there are chiefly five components to the National Health Stack. I'll just, say what the component is and then maybe address side by side how it is tackling the policy goal, The first of these, is a set of E-registries — it is a master data bank, as they’ve made plans for health care professionals registry, healthcare facilities registry, and so on and so forth — just to make sure that there is sort of data bags to know who is a stakeholder and who isn’t. This would comprise the foundation. Like I said earlier, the digital health services that could eventually be the service that we’re looking for, where I think it may address the sort of policy goal is if the NDHM seeks to create a digital health highway or ecosystem, then this is the first step of the course to identify who is part of the ecosystem. Looking in terms of criminal record, you may see someone’s a victim versus a plaintiff. But in this, in this scope of healthcare, you say someone’s a patient versus some other medical researcher versus private health care providers. Someone you know is a traditional health care provider — somebody who may not have medical training in that official sense, but is a legitimate, trusted, health care professional. The point is that you understand who is in the ecosystem. That’s how the E-registry I think addresses that.

The second is a set of coverage and claims platforms and portals. I mean if we think about it, when we have our dealings with insurance — when we have that kind of burden that we look at a lot of people work and then getting that process started, then getting that back with signatures and so on and so forth. I think a lot of the people would like this part of NHS where they can skip the queue system, making sure that most of these things that require a lot of reading are digitized.

The third is a personal health records framework. Which is a digital solution to sorting between what part of data would patients’ can access, how many levels of privacy will be there. Further,
there will data from that we could actually have overall benefit — the digital ecosystems, knowledge of health care, and of the people that belong to the health care system. So, this is the difference between what would be the data I own and should not need to give out versus the data that it would be in my best interest to maybe parcel this out depending on you know who is sort of asking for the data — and what this represents is then a conceptual framework for ethical health data usage and where I would say subscribes best to what the NDA was trying to do is. Implement best practices, do not harm this layer of security for the data principle and it is, in that same breadth, a greater good goal where you can improve the quality of your health care if you have the access that you convince the patient to trust you.

Fourth is — a National Health Analytics platform, which is for some of the same functions as what I had mentioned earlier about the Personal Health Records Framework. The National Health Analytics platform combines the information that you would garner from these different portals and platforms and services that are built on top of the base architecture, and what it is at the end there is more data. It’s whatever super data or whatever it is on top of what is the base data and you know whether that’s the number of patients who have a certain complication with a certain disease or a certain state that has a higher prevalence of a certain disease or you know, certain problem to the accessing health care. Certain gendered or social differences might come up in the treatment of someone in their healthcare sort of provision. All these things contribute to the data on top.

But what we can do with this is then you can give it to policymakers. We can give it to long-term research. As we can say – hey – this is what’s going on now. What can we do to restructure and reproduce better outcomes in health in general? So, what this does therefore very directly is also addressed. The idea is that digital health can provide better health care in the long run. That, I suppose, is the policy goal being met in its greatest way possible — and finally, I think this is sort of the part of the more auxiliary digital services of the stack. There are a few and the most dominant of them. I think the digital Health ID which was rolled out earlier last year — would speak to a level of inclusion that you might want from a National Digital Health Ecosystem. If you have a Health ID, then you kind of make a projection for you know you want to make sure that everyone is tagged with certain identification. We want the digitization of every citizen into a patient and so on and so forth. So that our auxiliary services with the stack. But in any case, that’s what constitutes the National Health stack as of now.

What resources do you think are necessary to carry out this healthcare mission at the scale that they want to? Because the aim is to have a nationwide health care system and to also have it seamlessly integrated. So, what are the resources that we need?

Aishani Rai: What we are looking at and based on the prior research that we have done at Aapti in any form where we look at digitizing and the enabling tech and looking at digitization of any mission at the national level which is going to be the ultimate goal. We feel that there are two primary barriers and now when we look at these two primary barriers, what are we talking about? We’re talking about the barrier of accessibility, we’re talking about the barrier of trust – and now when we break it down, when we try to make this applicable to the healthcare sector, what exactly are we looking at like, where do the breakdowns actually exist? Apart from patients you also have
other users, like healthcare service providers, who were also users of platforms and of this digitized data, right? So, if we were to look at overcoming the barriers of accessibility and trust, where do we see intervention now? As an organization, we fundamentally believe and propose the concept of offline architectures and offline intermediaries. What exactly do we mean when we talk about offline intermediaries? Who are these offline architectures and what exactly do we mean by offline intermediaries? It basically refers to any mechanism, be it human or non-human. But definitely not technological mechanisms.

We’re looking at these mechanisms or what makes tech more accessible to last-mile communities and who are these last-mile communities that we are talking about, say, rural people, women, the elderly. So basically, anyone who faces a barrier in accessing technology. These offline intermediaries and architectures seem like they are aimed at bridging the gap between tech and the actual user. Now if we were to look specifically into the healthcare sector it would be ASHA workers. I feel that ASHA workers play a very important role and they are the ones who can be considered digital health agents. There has been a substantial amount of research, wherein interviews have been conducted with ASHA workers, about whether they would be willing to navigate and understand tech and make it more accessible to their target audiences – and they have definitely expressed their willingness to do that. I feel it’s very important for us to look at the power and the potential that these offline intermediaries have and, in that way, you are able to overcome the barrier of accessibility or the first part.

Secondly, it also acts as it also helps in overcoming the barrier of trust because if you think about it: what is a digital interface at the end of the day – it is saved for someone who lives in an extremely remote or rural community, right? There’s no face to the other end of the communication. They do not know that the data that they’re providing, does it go into safe hands or like, where exactly does it go?

So, there’s a complete shield. It’s completely anonymous, and there’s no human intervention that they can see for themselves, which is the primary carrier of trust, so therefore in some way or the other, when we introduce these offline intermediaries into the picture, then they act as that level of trust or they are the face of the trust and it kind of help to overcome the psychological barrier of trust. I feel offline architectures have a double role in overcoming trust and also enabling accessibility. So, when we’re looking at enabling accessibility, what exactly is the role that we’re looking at for these offline architectures?

It’s very important for the State to support them in terms of making them understand how to use the tech, but at the same time, it’s more like percolated, like a populated effect or like a trickle-down effect, wherein these people will then, you know, tell rural communities how to use the phones that they already have.

If you actually look at the stats, we can clearly see those rural communities that have access to mobile phones. So, internet penetration or having access to the device over here is not the primary. The primary problem is not being able to use it in the manner that the State wants them to use it, say to avail healthcare facilities to avail financial facilities. So that’s where the problem is and I feel this is where offline intermediation is the primary resource that we should be looking at.
Could you explain offline architects once again?

Aishani Rai: Yes, basically when we look at offline architecture, it refers to any mechanism which is non-technological. In this case, we’re looking at human intervention. At the end of the day, I may have a mobile device, and I have accessibility to the internet, but I really don’t know how to use it. I need someone to help me use the technology. Currently, when we look at tech, we might say give them the phone and they will be able to use their mobile in the way they want it. Basically, making tech accessible is your primary solution. But does it actually happen? The problem we are witnessing is that there’s a huge gap wherein people have access to devices, but they’re not able to use them for the purposes that the state wants them to use — or you know, something like making them actually part of the digital financial sector, the digital healthcare sector. That’s not happening. The translation is not happening. There’s clearly a breakdown, right? So, if this is the breakdown that’s happening, then what intervention do we see? At the end of the day, your tech in itself cannot solve your problems. You need some other intervention, non-tech intervention to actually ensure that people have access to this tech. So having access to tech is not merely having access to a mobile phone. There’s a lot more that goes beyond that. Then you need intervention for that. So that is what we look at, that is what we mean when we look at offline architecture.

Does the NDHM policy mention this kind of approach at all?

Aishani Rai: No, that’s the thing. The NDHM doesn’t, which is why we believe that this is a resource that the NDHM should tap into and formalize. So that’s what we’re looking at Aapti.

The policy aims to essentially digitize data across a diverse range of regions with varying accessibility and different stakeholders. How does the technology accommodate for these different stakeholders and their needs, and specifically their concerns?

Ava Mumtaz Haidar: Before going into the detail of what is available in the NDHM’s knowledge bank with respect to how they deal with the differential recipients of technology, I would like to say that these are at the end of the day aspirational moles of technology. This is to say – this is the feature attached to the technology which seeks to have a proper impact on those who need it beyond the proper consideration. It’s too early to sort of qualify to what extent these measures may actually have an impact. But as far as what they have noted, I think that they seek to leverage the partnerships I was telling you about earlier, making sure that they have appropriate incentivization for private hospitals, private providers to set up in areas that have lower levels of literacy, have lower levels of access - and when I say literacy, I really don’t just mean literacy. I mean digital literacy.

So remote areas, places where there’s a very little sort of like technological pervasion. What they have also detailed in some parts of the stack are ways to make the public believe that there is a greater benefit and in the very real sense of making sure that they emphasized the decreased costs of having to use technological infrastructures. They’ve said that there would be faster redressal through online platforms, which I think is an easily demonstratable thing that being online can kind of decrease your wait time in queues, it can decrease your hassle of paperwork. We all believe
that. I think it has more to do with whether the state is able to provide that assurance, right? Can it actually prove that it is more convenient for you to approach the online architecture versus the physical one? That’s the second thing.

The third I would say is perhaps – the consent frameworks. If the State and private entities are fully able to convince populations of how well they can protect their data, from other parts of the ecosystem, whether or not it’s warranted or not. Consent frameworks make sure that when your data is being shared and you participate in data sharing, you know it’s for your good or that it might be for the greater health care. A clear, transparent consent framework seems to be the aim of the NDHM. I would also say that, very specifically, within their strategy document, they’ve talked about how telemedicine, which also comprises a building block - there are 34-35 building blocks within the NDHM – telemedicine would focus very closely on areas that have less access, have less digital perversion, and do the work private entities would do. They would just make sure that there’s greater reach. But this seems to be one of the few ways in which the technology itself could be designed to have some kind of positive effect across, as you said, different populations in the same country.

What the government wants to do through this platform – is provide incentives for those private hospitals that set up in rural areas. Could you just elaborate on how that would be?

Ava Mumtaz Haidar: The wording is private providers. So, whether it is private individuals or private tech, clinicians, or private physicians in large or individual capacities – and this deck and document I would say are very speculative and that it’s aspirational. It seeks to do a lot of this – and we have yet to see the effects of something like this. But what I remember reading is that there is a scorecard method. Essentially there are ways in which to either subsidized or incentivize the ability of private providers to exist in locations like this. To be able to provide the service to people who need it more, or not more essentially, who have historically not had it. The State has its own innovative measures.

If I could reference maybe a different digital infrastructure to just provide an example of what that could look like. With UPI, the RBI has set up a fund called the Rural Infrastructure Fund, which is a fund dedicated just to the connection of populations in rural parts of India, and specifically the northeast with the UPI infrastructure. So those funds are for greater integration with the UPI, but they are for private entities, private banks, or shops, whoever can create measures that enhance the capacity of the infrastructure. So, these are ways in which the government has tried and tested making sure that digital infrastructure is a little bit more pervasive. But again, this is speculative as mentioned.

Aishani Rai: I feel it’s something that we can’t really look at in isolation. There’s a lot that goes behind the tech, and there are a lot of layers that actually need to be embedded. What I’m trying to say is that at the end of the day they can solve problems, but it’s to a certain extent and at the end of the day, taken by itself it is not really the solution that we’re looking at. Why I say this is because at the end of the day you have a lot of layers of State governments and you also have a lot of company practices that need to be embedded into this step to ensure that it works the way we intended for it to work. So, a lot of these principles, when we look at tech in itself, can’t really
solve the problem, but at the end of the day, if you as a company have a particular value or a particular principle that you are standing for, then that value or principle is something that will be reflected or embedded into the design of your technology, and then actually your tech can solve for the problem. So, I feel that’s very subjective.

For instance, we have the whole concept of notice and consent in the digital health system wherein you have so many apps and consumer apps around you constantly collecting data from normal consumers like us. So now the basic policy that we have, the State will stipulate is that you have to take consent. So legally speaking, these consumer apps are taking consent. They are doing their basic legal requirement through the notice and consent mechanism. But the problem, is it actually solving your problem?

Right now, it isn’t because technically these notice and consent mechanisms have time and again proven to be absolutely exploitative, wherein if I were to compare two companies then, on one hand, you’re basically saying that the first company policy would be to collect as much data as possible because their company probably doesn’t adhere to the principle of minimum data collection. But at the same time, you have another company that does actually have a company policy of adhering to the minimum data collection policy. So, by paper, by law, if you look at it, both of them are not liable, but if you look at whether someone is actually solving the problem, it's only the latter company that is actually solving the problem. Their company practice is embedded into the technology and that’s where technology is actually solving your individual needs and concerns. So that’s something that I would want to add to this question.

What are the separate needs that maybe could arise for both private providers and community health workers with this technology?

Aishani Rai: We have done a little bit of work on this and what we seem to have noticed – is that when we look at private sector hospitals the transition costs are very high, especially in rural communities and rural areas where even though they are very well aware of the benefits offered by digitized health data systems, they are not ready to venture into such a system merely because of the financial and infrastructural incapacity to do so. A possible suggestion would be to just increase the amount of research into the cost-benefit analysis, which highlights to these rural communities the benefits of actually transitioning to a digital healthcare system vis-à-vis the status quo that they are at present. I just feel there’s a huge dearth of evidence and I think it’s very important for us to create that system of incentivizing and that will come only if the government has enough evidence to show to these people. What are the benefits of actually transforming? Because until and unless you show them the benefits, I don’t think they will be ready to transform. So, this is the first concern.

The second concern would be from a legal perspective when we’re looking at the liability and accountability frameworks. There’s a huge cyber security and privacy concern wherein we are looking at risks of data collection, digitization, and storage. And now that we’re moving into private hospitals, not just at the rural but serving at the urban level, there’s a huge risk of data transfer which that is something that they will have to account for, especially given that there’s a lot of data transfer happening between hospitals and insurance companies. Now whether it’s ethical, whether
it's legal, that is something which is very questionable because when you are transferring data to an insurance company then there is a very high possibility of the insurance company denying me insurance coverage. So, I feel there’s a huge risk of data transfer and that's also a concern that private hospitals should take seriously. It’s very important for them, and also to know what exactly the legal framework is around their liability and their accountability. For instance, if one private hospital were to transfer healthcare data of a patient to an insurance company and tomorrow if the insurance company uses it to deny coverage, then can the liability be traced back to the private hospital? So, these are among the several concerns that private hospitals face with respect to in general digitization of data.

The second part of the question is regarding community health workers, and I think the best example that I could think of is the ASHA workers. We feel that there are two main problems when we look at ASHA workers as community health workers. One is the lack of formalization. So currently, if we were to look at ASHA workers as digital health agents, they are not formalized by law, and when we look at what do you mean by formalized? What do we mean when we say formalization? Basically, they have no state support and their status on paper is voluntary. This is a huge concern for them because, with this whole voluntary structure, they don’t get the benefits that an employee of the State would get. They also have additional issues of poor working conditions and the technological incapability of navigating and a lot of logistical infrastructures.

Though we see that they have that willingness and an urge to help their target audience, there is no State support to enable this. If you introduce a formalization of these community healthcare workers will go a long way in overcoming their problems, and in this way, we make offline intermediation a very structured and a more stable career option, for people who are interested in becoming an ASHA worker. So that’s the first issue, which is a lack of formalization.

The second issue is something that has already been widely covered. During the pandemic, they used a device to conduct door-to-door collection of data, and those very devices were used to track them down. Basically, these devices were used as surveillance tools. This is something that was raised by several of them, wherein they stated that they were definitely not comfortable using such devices, and it did have an impact on them wherein they did not want to really experiment with technology because obviously, no one would want to be tracked. So, it’s very important for the State to keep a check on such measures and avoid them because these are definitely trusted deteriorating measures and it’s a simple fact that if ASHA workers themselves are not able to trust tech, then we definitely can’t expect their target audience is to trust technology. So, it ultimately defeats the whole purpose. These are two issues that we know are faced by community healthcare workers in the digitization of health data.

In two months in 2020, there were seven million cyber-attacks on the healthcare sector. This was, of course, during the pandemic period. So, what practices should be adopted to protect private health data, and how does this ecosystem also incorporate those measures?

Aishani Rai: Primarily, I feel that the first way to actually look into cyber-attacks is that you really need to have a very strong stance on encryption. We feel that end-to-end encryption is something
that is very vaguely worded in your Information Technology Act\textsuperscript{40} wherein they mention that it’s the duty of the State to promote encryption and that people should incorporate best practices. But I feel it is something that must be strongly put forth wherein intervention occurs at both levels. So, we need to have the State policy on encryption and on cyber security practices broadly, particularly given that encryption has a huge potential in terms of ensuring the safety of sensitive personal healthcare data. Next, we would also require intervention at the business level. There are a lot of additional measures that need to be taken up. We’re looking at institutional capacity. For instance, encryption in itself is a tech solution, but is there enough institutional capacity? Something that we have come across a lot throughout our research is that at the end of the day the weakest link in an organization is “between the chair and the computer”. This is a very common dialogue that we’ve all heard of. But what exactly does it mean? It basically means that at the end of the day, even if you have measures in place or you have the best cyber security practices, there’s still no institutional capacity to actually ensure that it’s being enforced in the manner that we intended it to be enforced.

So how does it translate, say for a private hospital, at the end of the day – you do have encryption, but finally there is still a gap wherein the person or the cyber security expert, the human intervention can himself or herself fail in implementing the tech. So, it’s very important for us to have adequate training for employees at every level where data is being collected and digitized. The best example is that you can have encryption everywhere throughout your whole private hospital, but the person sitting at the receptionist, might not actually be trained. For instance, there’s a mail that pops up and they actually end up clicking on it and it leads to the compromise of your whole data. You know it’s very counterproductive when it makes your whole cyber security system very redundant. At the end of the day, the human capacity in every organization must be trained, or at least they must be well versed with how cyber security threats actually happened. So, it’s not just tech, but it’s also your institutional capacity at every private hospital that needs to move towards cyber security measures.

Secondly, we need to look into businesses in general – and when I say business, I mean hospitals and other private sector entities that are actually using healthcare data and collecting healthcare data. It is very important for them to incorporate principles of minimum data collection. Now, this may seem like something which is very easy to suggest, it is very idealistic that businesses should incorporate minimum data collection. However, if you look at the ground reality, that does not happen. Now, this is where I would like to say that at the end of the day, whether a business does it or not is something which is completely up to them. Only a business can decide whether it will actually adhere to principles of minimum data collection or not. But you can’t just leave it to the businesses.

It’s very important for us to recognize the power of other actors like the State and Civil Society to push for things and incentivize or nudge businesses towards adhering to minimum data collection principles. For example, there is a digital financial industry association – this particular association is basically a group of private money lending apps, and one of the main principles that this association stands for is minimum data collection. So, it’s very important that these industries or

\textsuperscript{40} Information Technology Act 2000 (n 40)
associations, in whichever sector they are, promote, incentivize, and produce research on how sticking to privacy does in fact have a link to profitability. That’s the biggest business incentive for any enterprise to actually move towards minimum data collection. I feel that it’s very important at both levels. At the state level, through regulation, pushing them and nudging them to adopt minimum data collection principles – and simultaneously, industry associations have a much stronger role given that it’s coming from within the business ecosystem wherein they are linking privacy and profitability. At the end of the day, businesses do care about profitability and this is a very big way to incentivize them. These are practices that the digital healthcare ecosystem can also learn from and move towards a similar pathway.

Ava Mumtaz Haidar: You asked what the NDHM does and specifically their involvement in this. Again, the idea is that there should be a strong sense of data being shared and collected at every stage with consent. The NHS is very specific about that, where it states that not only will consent be taken at every stage, it will also make sure that it centers the data principle in every stage of data collection and processing, and there is transparency around it.

So, what they’ve done is – say that consent will be foundational and these are the ways in which that consent will be affected. My point is that what you’ll find is that the NDHM has a document called the health data management policy. The NHS and NDHM all give you their versions of what constitutes privacy. But when it comes to the legally actionable part that works around the data, we should look at that document for sure. The health data management policy will lay down how that data will be treated, the role of data fiduciaries, what kind of redressal do you have against privacy and security concerns, and so on. It is what they call privacy by design. So internationally, across infrastructures around the world, that is seen as the standard for a digital public good or digital public infrastructure form. It’s a very commonly accepted technological standard now, and it is not just something that has been invented out of thin air. It is something that people around the world are being more and more conscious of.

In 2017, when the NHS was starting to gather steam, there was a Bloomberg Quint article\(^{41}\) that debated whether man-made health data is doomed to be a crisis. Because the way in which you collect data has as much of an effect on how that data is used for the public good. What the article does is, it starts with this anecdote of someone trying to approach the hospital for delivering their baby and they’re an HIV positive patient, and because that information is already in the hands of someone who has their Aadhaar and so on and so forth, it’s data that’s just used against them and they denied entry into the hospital, and they lose their children.

So, it’s really the very collection of data where you have to start looking for issues of privacy and security. It cannot start at the point of data exchange. It has to start at the very base. Are you making sure you’re asking for data in a way that best preserves the do no harm principle through best practices and security measures?

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Taking about data privacy, could you elaborate on the concerns of privacy and confidentiality and misuse of sensitive health data by private entities.

**Aishani Rai:** My earlier part covered how the State should have a policy and where we can look at business intervention. But the Civil Society and the intersection of all three stakeholders is something that we advocate for, which is health data stewardship. At the end of the day, the interventions that I spoke of previously are something that could be taken by external parties. But when we look at health data stewardship as a concept, it’s a solution wherein each community member — people like us, the users of the data subjects, the data principles — have more control over the data that we basically own. So, the concept of health data stewardship more or less runs on community participation for increasing user agency. This is mainly what we mean by health data stewardship.

But, what exactly would this mean if we were to translate this concept into practice? In simple words, we would look into increasing transparency in health sharing agreements, we’re looking at conducting regular audits by citizen groups, and mobilization creating frameworks where users and data cooperatives can negotiate and create clear consent mechanisms. So, I feel that is a very important solution and a very new-age solution that we should be looking at, especially in the concept of health data digitization. This is basically a very user-centric model of stewardship. There are examples of data cooperatives, they review medical research proposals and consent, and share their data for specific projects. So, we’re basically looking at more organizations like this that create frameworks of consent-based or community participation in health care data.

**If we can have an example or two about what misuse of a sensitive data looks like, that might be useful. What does misuse entail?**

**Aishani Rai:** I would like to give you an example that lies at the intersection of your AI-based healthcare, consumer apps, which are constantly collecting healthcare data. One of the best examples of misuse would be behavioural monitoring. Given that you have these consumer apps that we use say day in and day out, or even your wearable devices that are constantly tracking data, there is absolutely nothing stopping them from tracking the data. At the end of the day, when we’re looking at the collection of sensitive data, are we as users aware of exactly what the wearable device company does with this data? For example, if they were to sell it to an insurance company, the insurance company would have complete access to the primary data itself. But not just the raw data, which these variable device companies have collected, but also the aggregated forms of the data. If you run a couple of algorithms on it, you will be able to make so many conclusions about whether I’m a healthy person or not?

Right now, that is your fundamental and primary misuse wherein I might have signed up for my data to be shared with an insurance company, but I am still being denied insurance. So, we look at data sharing and collection of sensitive healthcare data by one party and then being transferred to another party like an insurance company and then that insurance company ultimately denies me the benefit of actually availing an insurance based on some predictions which they have made at the back end, which is the knowledge that I do not even have access to. That’s why it’s very important to have frameworks of consent, the user must understand where exactly what data is
being collected and how it's being collected. And most importantly where and with whom is it being shared. Another misuse would be that collecting data can have severe behavioural effects. For instance, it could lead to a chilling effect on my behaviour. So, if I know that I am constantly being tracked by this particular healthcare device. This would nudge you to act in a certain way or not act in a certain way. We might realize where these predictions are coming from and we also change our behaviour but it’s not always necessary that we change it for the better. Ultimately it does affect your autonomy.

**How is the National Health Stack different from the Aadhaar backbone?** And we specifically raise the question about Aadhaar here because it was a state centralization of Social Security and the NHS is trying to do something similar. With Aadhaar we saw different people being left out of the system and not being able to avail Social Security measures simply because they fell through the cracks of the formalized systems. So how does the National Health stack and the NDHM compare in relation to Aadhaar?

**Ava Mumtaz Haidar:** I think it’s really good you bring this point in about interoperability. I think that’s key to the difference. This is to say that, the NHS at its core is something that infrastructurally wants to bring together a lot of health data, whether it’s fragmented or new data. Look at where the gaps are, fill those in, and put that data into actionable use. Either make sure that everyone who needs access to it in a positive social way can have access to it, or that services on top of it can be built with an equalized data bank and all values are accounted for in an equal way. So, in that way, the NHS is this larger infrastructural conduit. Whereas Aadhaar, on the other hand, is an enabler. It’s a five-way ticket, but ultimately it is one ticket – and it’s a traveller within many different infrastructures, one of which is actually healthy. Anecdotally, if you’ve got your vaccine right, could I ask what ID you used? If you say I don’t have my Aadhaar, but I have my Health ID, will you accept that? How willingly do you think that the person on the other end would say yes? Okay, fair enough. It might work, but you don’t know that it will work.

Over the last two years, the budget has been dedicated to building the Health ID. Over the last two years, we’ve had COVID and if there was ever a time to make sure that this was happening, it was now right. Given that the Aadhaar is a more legitimised, and a more official trusted symbol, not necessarily within the State, but also within local health care providers, larger private healthcare providers. You could have gone to any kind of health care provider, and I assure you that they would have asked Aadhaar before anything else. So, I think that given that Aadhaar has had its faults in terms of potentially not accounting for everyone or leaving people out, it has a stronghold that the NHS is seeking to build. Given that one is infrastructure, the other is a five-way ticket, there’s a difference in legitimacy for sure. This is because Aadhaar has had a much longer legacy in the last few years in India.

The second thing I am going to say is that given that it’s a unit as opposed to the infrastructure, Aadhaar is actually to be enveloped within the healthcare system, and as you said, if the goal is interoperability, then it only makes sense that many digital infrastructures are connected with each other. Aadhar is supposed to be roped into the NDHE (National Digital Health Ecosystem) or ABDM (Ayushman Bharat Digital Mission), whichever you use, would also speak to the ease of integration that the government is seeking to have from a health care system.
Finally, just in terms of the health identification aspect, if you were to go to a website right now, it would ask you if you would like to create a Health ID, you’d say yes, and they would ask if you have your Aadhaar or your driver’s license and you actually have the option of saying no, and then they’ll say that – if you don’t want to use either if you don’t have either, then you can use your phone number. Which is just as easy to produce. In any case, if you are in the position to avail Health ID, the assumption is then that you have at least a mobile phone, and at least one screen to do it off of. I’m not sure if this even partially answers your question on whether it can combat what the Aadhaar was not able to – but, I do think that the digital health ecosystem does want to make use of what’s in the digital architecture already, make sure that whoever can we connected fast enough is connected fast enough. This is one way of doing that — making sure that it’s a phone number that you link as opposed to something as private as another card.

To wrap up, given everything we’ve discussed so far, what are the key that considerations that policymakers must generally keep in mind when they’re thinking about a healthcare technology and policy?

Ava Mumtaz Haidar: First off, I think we’d say that a lot more clarity is required in terms of the plans that the State might have in providing certain upliftment to people who are disadvantaged, to people who don’t have access, to people who need more resources availability. How these things will be addressed, are the million-dollar questions around most digital architectures and infrastructures in India. We should have more clarity.

The second thing is just a fundamental difference between literacy and digital literacy. I could be extremely well-read and have a knowledge of the language but not be capable enough to work on devices or vice versa – and this means making tactical decisions in the way in which technology looks. So, you look at the design, you look at iconography, you look at what is appealing, what works on the screen, what is easier to navigate, and you have to make sure there’s diversity in the language presentation as well. Small things like this minimize the gap between those who are extremely tech-savvy versus those who are extremely not. That would be a second consideration.

The third I suppose, as we mentioned earlier, with certain partnerships, with the involvement of industries, of private businesses, of the private sector, and the non-profit private sector, civil private sector, philanthropies as well, all these different entities outside of the State can play a huge role in most developmental sectors and they can do it in their own way, and they have been doing it for a very long time. But where there might be greater strides is if their role is clearly defined by the state. If the state is spearheading this is a project, it may not be enough to say that this is where this contribution might be valuable, but rather this is who we can contribute to in this way, because this is where they have demonstrated great talent and this is the space where it’s going to go really well if they partner up. So, all I’m saying is that a clearer depiction of the roles that different part of parts of the ecosystem can play might actually bring us closer to questions of accountability, actionability, and funding.

Aishani Rai: Ava has summarised it, but one key takes away from both our ends would be that at the end of the day, it’s very important for the State to realize that tech is definitely not the
solution to the problem, and it’s very important that we think beyond tech. When we look at thinking beyond tech, we are trying to incorporate many of the principles into your tech, and we’re looking at layers of governance from the state side, and we’re looking at company practices and policies from the business side of things. So, it’s very important to integrate all three and then develop your tech accordingly. So that’s when your tech can actually solve for the majority of the issues.

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