



Digital Health: Access, Equity and Surveillance

11th Krishna Raj Memorial Lecture

Organised by Anusandhan Trust - SATHI,
Indian Law Society(ILS), Centre for Health, Law and Policy (C-HELP)



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**Digital health:
Access, Equity and Surveillance**

Organised by

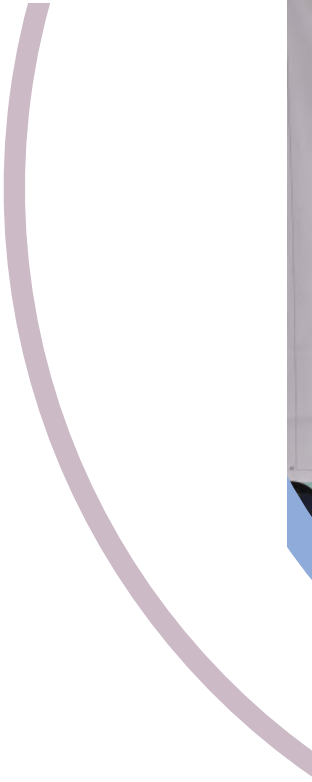
Anusandhan Trust – SATHI,
Indian Law Society (ILS),
Centre for Health Equity, Law and Policy (C-HELP)

23rd April 2022



C-HELP
CENTRE FOR HEALTH
EQUITY, LAW & POLICY





Anusandhan Trust has instituted the Krishna Raj Memorial Lecture Annual Series on Contemporary Issues in Health and Social Sciences in his memory and to honour the intellectual and academic traditions that Krishna Raj set in place as the visionary editor of the Economic and Political Weekly (EPW) for over 35 years (1969- 2004).



A mixed audience of around 50 people attended the lecture, held at the Principal Pandit Auditorium in ILS Law College, Pune on 23rd April 2022 from 4 pm to 6.30 pm, with another 100 people watching it online.

The Principal of ILS Law College, Professor Dr Sanjay Jain warmly welcomed the dignitaries and attendees and briefed the gathering about the centenary year celebrations of ILS Law College.

Anusandhan Trust SATHI research head Shweta Marathe then offered a brief overview of SATHI – Support for Advocacy and Training to Health initiatives, which is the action head of Anusandhan Trust and talked about the history of the Krishna Raj Memorial Lecture Series.

Head of Institute, Anusandhan Trust- SATHI, Dr Dhananjay Kakade who moderated the session introduced the dignitaries on the stage.

The keynote Speaker

Apar Gupta is the Co-Founder and Executive Director of the Internet Freedom Foundation, a digital rights advocacy organization in India for which he has been awarded the Ashoka Fellowship in 2019. Apar is a practicing lawyer, along with being an activist and a writer on the intersection of technology and democratic rights in India.

Anita Gurumurthy is a founding member and executive director of IT for Change, where she leads research on the platform economy, data and AI governance and feminist frameworks on digital justice. She actively engages in national and international advocacy on digital rights and contributes regularly to academic and media spaces.

Vivek Divan is the Head of C-HELP (ILS), Pune. His expertise is at the intersection of law, health and sexuality with particular focus on HIV, TB and LGBTQIA+ concerns.



Context setting

While setting the context for the theme of Digital health: Access, Equity and Surveillance, Dr. Dhananjay Kakade recalled the first wave of the COVID 19 pandemic in India, when the Indian government prioritized the mandatory installation of a smartphone application, rather than augmenting healthcare services for an unprecedented public health crisis and enabling millions of migrant workers to find their way back home.

The government dismissed concerns of IT experts who pointed out serious security flaws in the AarogyaSetu App. Like the AarogyaSetu, contact tracing apps without any sunset clause are merely an illustrative example of the dilemma of privacy and surveillance related issues in the digital health domain that need to be addressed. The role of the state, privacy laws, corporate interests, and safeguarding citizen rights and interests in the data industry is a complex landscape and relatively a new but growing field of academic enquiry and scrutiny.

There is also the need to delve into the implications of digital technology in health on women and examine if it does reduce barriers to access and provide healthcare as claimed. He observed that before and during the COVID-19 pandemic, digital health applications have rarely been designed from a gender equity perspective, focusing on fairness in distribution and the different needs of genders. In the light of substantial evidence that women have lower access to and exclusion from app design, tackling gender inequities in digital health is more crucial than ever.

Other key questions that contributed to this theme were –

1. Are there examples from other countries where mechanisms for data protection and the need for public health data are managed well?
2. What needs to change in India's Digital Health Landscape from citizens' and patients' perspectives?
3. What could be a potential pathway to accommodate contending interests in India's digital health landscape?
4. Digital health access and use should be viewed through an intersectional lens because they both depend not only on gender but also on factors like socioeconomic status, caste, and geographical location. What could be an outline of inclusive digital health technology?

Keynote Summary: A Brave New India

Apar Gupta opened the keynote session by presenting a critical perspective on the COVID-19 pandemic of the past two years that disrupted lives on an unprecedented scale and challenged public health systems leading to a surfeit of public policy responses using digital technologies which were coercive, inequitable and illegal. Questioning if government responses during these times were to care for citizen health or to profit from this moment of social frailty and individual fear, Apar traced the rapid evolution of digitisation in practices and policies concerning public health over the past two years and the implications of this trend.

The first case of Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2), the virus that caused COVID-19 was officially detected in India on January 30, 2020 on the very same day the World Health Organisation (WHO) declared it a public health emergency of international concern. Six weeks later, the Prime Minister announced a janta curfew on March 19, 2020, followed by a national curfew for the next three weeks on March 24, 2022. The curfews were periodically interspersed by the prime minister's calls for making noise by clapping as a mark of appreciation for health care professionals and lighting candles to boost public morale to which people responded enthusiastically.

In contrast to these displays of social solidarity were the actions of people as individuals and family units. It caused little surprise when lists of those who contracted COVID-19 and were quarantined were rapidly shared through instant messaging platforms such as WhatsApp, with such actions even approved by the state, as reported by the media.

This public health intervention, seemingly without thought and exposing the personal details of Indians, ignored decades of research and findings by public health experts on HIV or Tuberculosis. People with COVID-19 were unlucky, but if their name and status became known to their neighbors, they were truly cursed. In many cases it caused denial of basic services, deliveries, rations and timely access to health care. This age-old bond of physician-patient confidentiality, as reflected in Regulation 2.2 of the Indian Medical Council Regulations, was repeatedly ignored by State Governments and could be considered a breach of the fundamental right to privacy.

Any invasion of privacy required a valid law that was proportional to its intended democratic purpose and contained safeguards. But little was done by way of the exercise of any powers under the National Disaster Management Act or the issuance of Advisories by the Union Ministry for Health and Family Welfare.

While the disclosure of personal information by 'COVID lists' was the first, somewhat crude wave of technology implementation, digitization became more ubiquitous and severe over time. As the State struggled with the availability of physical and human





resources, greater faith was placed in technology than the public healthcare system to prevent transmission.

He highlighted the use of this trend as demonstrated by the use of invasive and inaccurate surveillance technologies for 'super spreade' or 'hotspot' events such as the Tablighi Jamaat religious congregation that took place in Delhi's Nizamuddin Markaz Bangelwali Mosque from March 13th to 15th, 2020, where thousands traveled from several Southeast Asian countries to Delhi to attend the event, some of whom then

traveled further to several Indian states. On the detection of COVID cases in those states, the media fueled a social panic targeting their religious identity, and used phrases such as '*Corona Jihad*', '*Tablighi Virus*' and the '*Markazmayhem*', to conclude a 'epidemic of Islamophobic' fake news and hate speech.

The Delhi Chief Minister, on April 1, 2020, leaned on technology to announce the use of cellphone tracking through GPS coordinates by Delhi police. The legal basis for this surveillance and data sharing was never disclosed. The harvest of personal data including call logs and approximate movements has till date not been put to tests of proportionality, or even faced a technical audit. Other examples of the use of surveillance technologies by the Delhi Police included reported use of drones fitted with HD cameras and loudspeakers to monitor public movement. Again, there was no clear legal basis and no way to confirm if public authorities have any limitations in terms of access and use of people's personal data. Such data was also shared with other state governments who prosecuted members of the jamaat under provisions of the Indian Penal Code, 1860, the Epidemic Diseases Act, 1897, Foreigners Act, 1946, and the Disaster Management Act, 2005; these were subsequently withdrawn, the digital evidence being of little to no use with the High Courts of Bombay, Karnataka and Madras.

Apar cited examples of other states such as Kerala, Tamil Nadu and Karnataka in India which also deployed a combination of location surveillance, geofencing, drone, and facial recognition technologies to ensure people comply with quarantine/isolation requirements. For example the Karnataka Government developed an android app called Quarantine Watch in which people were required to download the application and share hourly photos between 7:00 AM and 10:00 PM with GPS location coordinates. Failure to do so would mean the risk of being transferred to a mass quarantine centre.

The circulation of 'covid lists', the criminalisation of the Tablighi Jamaat - the clockwork coercion of selfie uploads, and use of facial recognition showed the dominant and evolving use of modern technology in COVID response.

Apar opined that *'contact tracing applications that continue to operate without any legal framework, technical audits, or enforceable safeguards have become the new normal in the brave new India.'*

Highlighting the ubiquity of mobile devices (including smartphones), that collect vast troves of personal information, he mentioned that governments across the world have sought to harness mobile technology for rapid contact tracing and identification of hotspots to contain the transmission of the COVID-19 virus and slow down the epidemic.

The principal deployment of contact tracing in India is through the 'AarogyaSetu' app whose intended purpose was *'for the health and well-being of every Indian. It will enable people to assess themselves the risk of their catching the Corona Virus infection. It will calculate this based on their interaction with others, using cutting edge Bluetooth technology, algorithms and artificial intelligence.'*

Apar pointed out that it was illogical to assume that the App would cater to the, *'health and well-being of every Indian'*, given levels of teledensity, internet connectivity, and smartphone ownership as per data released by the Telecom Regulatory Authority of India & Department of Telecom. With even the developers of AarogyaSetu acknowledging that at least 50 percent of the population had to download the app for it to work effectively, would it mean that the app was set up to fail, or only work in urban pockets or cities? If it did, then it would provide discriminatory protections to Indians in villages which would have low, if any, smartphone ownership.

He stressed that it was a matter of concern that there was no way to test the in-app algorithms for its accuracy to determine 'at-risk' assessment or the training data, and there is no public information till date if anyone has ever audited this algorithm.

The Prime Minister in his address on April 14, 2020, extended the lockdown to May 2, 2020 and exhorted the public to, *'download the Arogya Setu Mobile App to help prevent the spread of corona infection.'* This resulted in a surge of downloads, with over 50 million users in just 13 days. However, did the App really deliver on its promises to help prevent the spread of the Corona infection?

Apar quoted the IT expert Subhasis Banerjee, who assessed the app on two parameters of utility and privacy for the High Court of Kerala and concluded that the Aarogya Setu App was wholly unreliable in India's fight against Covid -19, while the low penetration of smartphones in India, on which the app can run, rendered it virtually useless. He contrasted the the impressive containment achieved in Kerala and Dharavi in Mumbai using methods of local community based manual contact tracing, concluding that the app's success was not proportionate. Such





critique is consistent with a global review as on date of the efficacy of digital contact tracing with meta studies including India concluding '*Almost no data quantified an association between (digital contact tracing) adoption rate and infection transmission at the community level.*'

Elaborating further, Apar stressed that the Aarogya Setu provides real-time data to the government and can be used to restrain citizens' physical movement, save or even put them in peril of infection. The terms of service of the App contain a disclaimer stating that the Government cannot be held legally responsible should the Aarogya Setu App and accompanying services lead to errors in accurately identifying people who have tested positive for COVID-19.

These consequences expose the intent and design of Aarogya Setu that eschews a legal and accountability framework -- such as an act of parliament. Instead, a much criticized privacy policy was modified into a 'protocol', which was marketed as an effective privacy protection mechanism. The Sunset Clause in such a natural setting mean the destruction of the personal data, but this 'sunset clause' applied to this 'protocol' itself. It requires reviews of the Protocol in six months or earlier. However, response to requests filed under the Right to Information Act have not revealed much except what seem like mechanical 12 month extensions to the protocol. The practical consequence is that Aarogya Setu and personal data on it is likely to be perpetually stored, freely shared, generously enriched, and coercively used without user consent.

Though initially declared as a voluntary action, installation of the Aarogya Setu app was soon being made mandatory for all Government Offices, airports, apartment complexes and housing societies. An order issued on Labor Day under the National Disaster Management Act, 2005 mandated the mandatory installation and operation of Aarogya Setu for employees, with violators liable for criminal sanction and jail time. Apar observed that such orders impacted the movement of daily wage laborers; the owners of factories and shops in the small and unorganized sector who would be prone to harassment. For many such vulnerable citizens, the 'bridge to health' became a path to jail.

With cyber security researchers having highlighted risks and breaches in May 2020, there were initially denials, then promises of, 'open sourcing' Aarogya Setu. However, the server side code has never been uploaded. All these fundamental problems have core implications on user trust. India-specific research has shown that the primary barrier to the use of Aarogya Setu is a lack of trust, with respondents citing invasion of their privacy and fears of government surveillance behind uninstalling it.

Vaccination and Health IDs

Given the nature of COVID-19, vaccination was the primary way to safeguard public health and resume economic and public participation. Vaccination started on January 16, 2021, amidst controversy with a staggered rollout that was rationed first for the most at-risk groups - starting with 30 million healthcare workers, then those with co-morbidities and the old. From the start, vaccination depended on access to technology as it was facilitated by the Covid Vaccine Intelligence Network website popularly called as Co-WIN. Walk-in registrations were only permitted at a later date, thereby at certain times making access to broadband internet and a smart phone essential to safeguard against infection. Co-WIN, on May 1, 2022 opened for registration of individuals ranging from 18-44 years of age group as the only way to get vaccinated, 'to avoid over crowding'. With the second wave peaking in India, Apar shared his stressful experience of booking a paid 'slot', highlighting his privilege and the many efforts he and his friends made to book one of the prized and sought after vaccination slots. Exclusion was furthered as the platform was available only in English.

In the absence of the internet and without knowledge of how the portal functions, the majority of India's rural population is being discriminated against, and a form of technical rationing is being implemented by CoWIN based on broadband connectivity and digital literacy. As a deadly second wave raged on, data showed that as of June 4, 2021, the same number of vaccines were administered in 114 of the least developed districts as were administered in 9 urban which combined had half the population of the former. Co-WIN's issues were not limited to inequity. It also demonstrated a complete lack of respect for data protection. For instance, it did not even contain a privacy policy till the High Court of Delhi issued directions. For those people who provided registration details through Aadhar, a Digital Health ID was automatically created without their consent or any meaningful choice being offered.

The datafication of personal health data today continues without any legal protection and is largely governed by a labyrinth of policy frameworks holding confusingly similar acronyms administered by the National Health Authority. For example, the *Aayushman Bharat-Pradhan Mantri Jan Arogya Yojana (AB-PMJAY)* is essentially a public insurance scheme aimed towards universal healthcare coverage. Digitization was an inherent element of the scheme which relied on cashless and paperless delivery. At the time of its launch in September 2018, it was announced that 'Fraud detection and Data privacy' policies were being formed, 'in compliance with all laws and regulations applicable'. The only issue was India did not have any meaningful data protection law.

The National Health Blueprint, released by the Ministry of Health and Family welfare, gives the impression that the policy has been carefully designed to protect data, peppered with words like 'privacy by design', 'consent manager', 'anonymizer', 'citizen to be in control'. However, upon looking closer, these words lose meaning by relying purely on unauditable technical frameworks and the absence of any legislative framework or independent, regulatory oversight.

While announcing the launch of the National Digital Health Mission on Independence Day in 2020, the prime minister announced that every Indian would be given a unique Health ID, which would work like a Health Account, recording medical history and relevant information in one place, enabling people to access healthcare more efficiently.

A subsequent strategy overview acknowledged that, *'The National Digital Health Mission will implement the core and common digital building blocks required for healthcare and*



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make them accessible as digital public goods to both the public and private ecosystem.'

The private sector has not only been a stakeholder, but a beneficiary and a partner in digital health for the Government of India. It serves as a contractor to build such platforms, create policies through joint working groups and is able to integrate its services on government platforms as well as with the personal data of patients. While debates centered over conflict of interest, Apar perceived the larger dangers to be for shrinking public health systems that are overpowered by 'market-oriented visions'. He questioned if the State would then be reduced to an aggregator or intermediary passively connecting the sick and infirm with private hospitals, testing labs, insurance companies and pharmacies.

He highlighted the ongoing datafication and the stack based technical architecture happening not only in health, but in each area of human activity that shapes the lives of crores of Indians. For farmers there is an AgriStack, for laborers there is the e-SHRAM portal and for schoolchildren and teachers there is a NDEAR (National Digital Education Architecture). These digital databases are without an anchoring legislation but have developed frameworks within publicly available policy documents. They advocate for greater data processing and storage for satisfying public and private purposes. In addition to database specific frameworks, there exist data unification policies such as Data Empowerment and Protection Architecture (DEPA) that advocate 'breaking data silos', encouraging combination of personal data across databases.

Apar argued that we should not be opposed to technology, but advocate for it to be applied with humanistic and constitutional values. In the absence of a data protection law or meaningful surveillance reforms, there is a promotion of commercial imperatives of processing and licensing it to the private sector. For example, revenue generation prompted licensing of citizens' data to the private sector through the Bulk Data Sharing Policy of the Ministry of Road Transport and Highways in March, 2019. Subsequently, vehicular data in the VAHAN and SARATHI databases was licensed for Rs. 3 crore annually. The policy was withdrawn after the data was used in a communal riot to identify persons by religion, based on vehicles parked at their houses.

In conclusion, Apar hoped he was able to demonstrate that Indian society, primarily the Union Government despite using modern technology for public health, was chained to tribalism refusing freedom through constitutional values. Fear and uncertainty enabled the expansion of surveillance and policing powers and offered broken promises of a digital utopia, delivering instead coercion, distraction and exclusion. This applied most acutely to large sections of the population which lacked economic and social power -- the weak and the poor.

He concluded his speech by quoting former Chief Justice, Mr. M.C. Chagla who wrote to Morarji Desai stating, '*You say you are apprehensive about the future. So am I. I love my country with the same intensity and fervor as anyone else. And I am seeing tendencies which if not checked will lead us to unbridled dictatorship. You and I don't count. Our vanity, our amour-propre, our sensitivity, is nothing compared to the future destiny of our people.*'

Discussant Response

In her comments, Anita Gurumurthy said she wanted to offer some additional reflections that would interpret the question of health data governance from a Right to Health For all perspective, building on the issues opened up in the keynote address. The universal right to health requires that we think of an appropriate, adequate and rights enabling data infrastructure that recognizes our social embeddedness. The effectiveness of health delivery has always been contingent on data systems for a variety of purposes over several centuries, epidemiological data for disease management, for experimental research, data about health systems, healthcare infrastructure, community health seeking behavior and much more. Feminists have pointed to how data science as an app that reproduces reality as a device that structures and reinterprets society as a venerated rationality, which reorders ranks and categorizes human beings, must be seen as a core ingredient shaping social power.

She observed that datafication of healthcare does not merely deal only with the question of how best to evolve individual controls over the terms on which bodies are being datafied. Acknowledging that data is an inherently social artifact, she pointed out that bodily data cannot tell any story without this embeddedness. Thus even if people were able to opt out of apps like Aarogya Setu on an individual level, such autonomous attempts to manage privacy will go nowhere in resisting the invasion of our data privacy.

Big data science could thus be described as a process that not only teases out the relationship between individuals, things and phenomena, but also as one that actively reconstructs individuals in their social embeddedness. Ideas of data rights and freedoms must therefore recognize data as a catalyst of social relationality and the quest for data justice and equity must put the spotlight here, going beyond the limited, even if vital preoccupation with individuals and their rights

Her second submission was that the social analysis of the invasion of our bodies in the crisis of statist governmentality and the rapacious exploitation of data for capitalist greed needs to start with an a priori assumption of data as the knowledge commons.

She explained that to challenge the inequity and injustice of datafication is to restructure the rules that create and produce the material relations of data, social knowledge, how data is elected, classified and used. People need to ask and need policies to answer how the health data paradigm can be engineered as a commons of social knowledge, rooted in the values of solidarity and justice and how it can be managed through an idea of sovereignty, that is rooted in a feminist relational ontology and ethics of collective control.

Health equity considerations exhort that public reasoning and mechanisms draw the lines for health data as a public good, managing these lines through accountable institutional processes. There is no option to democracy when health data is conceptualized as a public good, benefits or the Who gains question





will be cast not to yield to only individual benefits, but population level public health benefits. This should not be misunderstood to imply that individual agency or consent does not count.

Rather it should be inferred as underlining the case for public reasoning to arrive at data pursuits, data collection, sharing, storage, use, reuse, et cetera, privileging some truths over other truths.

Public health professionals, who have been dealing with questions of public health, know this better than anyone else, because it denotes a shift of gear to democratic public reasoning as the basis of data governance that may, and as necessary legitimize the wider unconsented reuse of data, overseen by processes in which all citizens can participate.

Today, there is much hype about privacy and consent but there is a need to delve into the meaning of consent and its nature. If society decides in a parliamentary process to consent to something in which individuals are implicated, privacy is protected in such a case through a broad consent framework for data rooted in a social license. The expectation is that reasonable reuse of data will bring the public good of universal and quality healthcare with safeguards against individual and collective harms.

The principle of health data commons as a public good is well established. The EU statement on the processing of personal data and the context of the COVID 19 outbreak issued in March, 2020 elaborates how exceptions to personal data protection may be permitted in fighting health emergencies. South Africa's Personal Information Act 2013 allows for a public interest exemption for health data processing for research purposes, without data subject consent when the research purpose serves a public interest and the processing is necessary for the purpose concerned.

She stressed that the social license that she was talking about is not a *Fait Accompli* for abuse of data and it comes with certain inbuilt principles. One - broad consent for health data collection and processing is not blanket consent. Genuine dialogue and engagement that might result in a broad license must be distinguished from more narrowly focused public relations exercises that seek to capture or persuade the public of the legitimacy of decisions already taken by the powerful, and from simple awareness raising information exercises. While legitimate disagreement is inevitable, if a social license is to be maintained, both the final result and process used to achieve that result must be one, which reasonable citizens can at least recognize as defensible on the grounds that it reflects common social values and goals.

Two - the duty of data processes and users to safeguard privacy persists even when the public good rationale is invoked. Health data is considered a special category of personal data under

the EU GDPR article 92. Legitimate public interest exemptions to its processing on grounds other than consent include protecting against credible threats to health, such as a pandemic or ensuring high standards of quality and safety of healthcare, medicines, products and devices. However, even when such exemptions are invoked, processing is only possible on the basis of national or union law which provides suitable and specific measures to safeguard rights and freedoms of the data subjects.

Three - irrational commodification through the data stacks in different segments - in health, in education, in agriculture, in all social and economic sectors cannot be allowed in the guise of building a data commons. Closer home in the context of the Ayushman Bharat digital mission, it is important that anonymization of the retained data is not just used as a justification for indiscriminate and or otherwise inappropriate data sharing and expropriation, particularly involving commercial actors.

Fourth - a duty to share needs to be imposed on private sector actors. For example, the PCPNDT Act mandates that every ultrasound machine in the country should be registered. So in some ways, the public health system, can for legitimate purposes, draw upon private and public sector health data. She cited the example of Germany, where public health insurance providers will soon begin to transfer anonymized health data of millions of people to public institutions for research under the 2020 Data Protection Act. This means that data should be made accessible for legitimate purposes that involve health equity.

Fifth - Citizen Science development through health data cooperatives needs encouragement. This is now popular in developed countries, allowing citizens to pull information and mobilize communities of solidarity and to link up with public or private scientific researchers to promote discovery and innovation. Initiatives of data stewardship communities such as Open Humans, My Data are explicitly concerned with facilitating data sharing for social benefit, exploring issues that are otherwise quite marginalized within conventional academic and research discourse and not part of big pharma's interest.

Commenting on the adage that all data is health data, Anita stressed that as big data science, especially new pathways in artificial intelligence, particularly machine learning, deploys radical possibilities to mix, match, and meddle with social reality, health implications of data and AI can come from anywhere. They can arise in how junk food use is tracked and promoted among low income populations through data of low literacy phone users or how menstrual data and fem tech apps is used to promote dubious ideas of female empowerment and wellbeing.

The question about data for health equity thus is a deeper social question of how the data paradigm itself connects to all questions that shape individual ontology, power, greed, opportunism, control, authority. The WHO has issued a set of principles for ethics in health, AI, artificial intelligence, and health in 2021. But the world needs a better debated global constitutionalism that outlines the very purpose of data epistemologies. Ethics





and principles may bear no meaning if companies can use the data of female subjects in developing countries for market based priorities, simply because no GDPR (general data protection law) protects them against the avarice of private profit. So female citizens in the EU are protected, but female citizens in India are not.

Another burning question that was not dealt with is about the relationship between materialities of data and the materialities of health delivery infrastructure. The fact that social sector spending on health and education is an important agenda cannot be overemphasized, especially as the world deals with a socioeconomic and public health emergency of unprecedented proportions. Ironically, in an age when data science can potentially mitigate the suffering of the majority, posing the question about investments in health data and investments in healthcare delivery as a binary is unhelpful. Our politics as data rights and health rights activists needs to be imaginative.

Anita concluded her comments by stating the need to show why and how the infrastructures of health as a public good and of data as a knowledge commons need to be bound through a social contract of care. Our agenda in this regard will need to grapple with many questions, most of which are in the realm of further research and action, defining the relationship between a universal right to help and human rights in data. Assembling health data within frameworks of the social knowledge commons will mean new policies to rethink consent from a social perspective, carefully craft exceptions to consent, check the runaway power of big pharma and big finance through mandatory data access and privilege people's access to their data and knowledge. A health data social contract rooted in solidarity and care will then preserve a thriving society, not only free from harm, but full of vibrant agency.

In his comments, Vivek Diwan reiterated that from a legal point of view, there was a landmark ruling from the Supreme Court (Puttaswamy) which requires that if there is a need to breach the right to privacy, it must be sanctioned by a law and pursues a legitimate aim. It must have a proportional action and a rational connection to the aim. It must be the least restrictive option, and it must have safeguards from abuse. It was noteworthy that even after two years of the pandemic, the state has not complied with the judgment and there is still no law which actually legitimizes almost any action that has taken place in terms of collection of data in the context of COVID. While there are policy frameworks, India does not yet have a data protection act. He stressed that lawyers need to engage with this issue to address the lacunae, considering the value of fundamental rights like the right to privacy, right to health and several others which have been impinged in the context of challenges like COVID.

Focusing on a previous generation of work on issues of confidentiality, privacy, and health, he referred to the crisis of the HIV/AIDS epidemic from the eighties to the early 2000's, which

continues to be a significant public health issue in parts of Sub-Saharan Africa, Russia, the Caribbean and in pockets of India where it festers in communities which lack a voice. HIV came with huge stigma and taboo as it was a sexually transmitted disease and little understood, let alone discussed and had cataclysmic consequences for those affected. Public health experts realized early on that instead of punishing, isolating or clamping down on people who tested positive, it was important to empower them that they have the right to accessing a health system and avail of healthcare for themselves and their families. In the context of empowering people living with HIV/AIDS, there was significant dialogue and enquiry to articulate their rights as patients and citizens. This process is relevant now as there has emerged a similar need to articulate rights and the meaning of empowerment in the context of health data and digital technology and its deployment in public health crises like COVID-19.

Commenting on privacy of health status, Vivek questioned if there should be a guarantee of privacy and confidentiality of a person's health status, considering that 'outing' sensitive information such as HIV positivity could result in everyone shunning or excluding that person.

Harking back to experiences of the HIV movement, he hoped that different communities would become involved in the dialogues, exchanging their own experiences of how COVID-19 impacted them and sit with policy makers to create policy, programs and interventions in society, which are actually helpful to the people at the receiving end of healthcare in such a crisis. He quoted the example of health workers who were at the absolute forefront of the epidemic, but that the new occupational safety code in India today has no mention of healthcare workers and their needs regarding protection and safety in the workplace.

He also expressed concern about the methods of health data collection in the context of COVID-19, saying he was unaware that a unique health ID was allotted to him when he had his first vaccination dose and the implication of sensitive electronic health records such as HIV status being recorded on that ID without his knowledge. Lack of clarity regarding how that data is going to be used might mean that it might be shared from one healthcare worker to another, to possibly a private enterprise, which collects data and mines it for all kinds of information to make profit. So he emphasized that the discussion about privacy and confidentiality is not to protect private interests, it's a public interest that is being served. He pointed out that the knowledge that healthcare facilities could be obliged to inform the patient's sexual partner, workplace, government health record system about the patient's HIV status, might actually dissuade people from going to clinics to get tested, and lead to the epidemic going underground, as people would fear to check their HIV status.



He referred to the HIV Act which was passed in India five years ago, which has very strict standards concerning disclosure of HIV status and informed consent and said a similar precision would be required in a law regarding breach of privacy and sharing of information in the digital health domain.

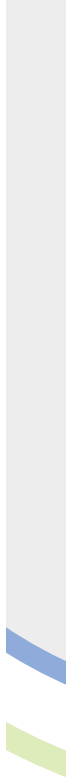
He concluded by flagging the issue of the Aarogya Setu app and the need to delve into its efficacy to curb the spread of the Delta variant of COVID-19 that swept across India some 9 months after the initial outbreak of COVID-19.

Dhananjay thanked all the speakers for their thought provoking and insightful speeches. He then moderated a question and answer session, which saw the speakers taking questions and comments from the present and online audience.





Annexures



Annexure

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'Brave New India'

11th K. R. Memorial Lecture
ILS Law College, Pune

Apar Gupta, Advocate¹ | April 23, 2022

A warm welcome to the brave new normal. We have all faced personal tragedies with resilience, surviving a pandemic that disrupted our lives on an unprecedented scale. Amid these challenging times, frontline public health workers acted as superheroes, even warriors for the preservation of human life.

Let us pause for thought -- maybe, even our language.

Many of these buzzwords, "*the new normal*", "*challenging*", "*resilient*", "*unprecedented*", have been used by us to numb the tragedy of the past two years. Each one of us, some more than others, have faced personal loss and a period of social isolation -- a lingering sense of captivity. We have needed these words as common identifiers with colleagues, friends and family. To express grief, care for their burden without adding our own. Here, none of us are alone, and we all share the bonds of survival and lingering anxiety from COVID-19 that does not seem to end. In this, "the new normal", even our public health systems, were "challenged" on an "unprecedented" scale, leading to a surfeit of public policy responses using digital technologies which were coercive, inequitable and illegal. This leads me to ask. Have government responses been to care for our health and comfort our grief, or to profit from this moment of social frailty and individual fear? I hope to provide some thought, if not answers, to this question, by examining the rapid digitisation in practices and policies concerning public health.

1 The lecture is based on the collective work of academics, activists, epidemiologists, journalists, lawyers, technologists, public health experts who have been cited to the best of my ability. I would like to thank all those individuals, collectives and organisations who collaborated with me to inform, share knowledge and increase the power interventions in public interest. Most of all, I am grateful to my colleagues -- past and present at the Internet Freedom Foundation -- I am in debt to them. All errors are entirely mine.

First, some basic facts. The first case of Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2), the virus that caused COVID-19 was officially detected in India on January 30, 2020.² That very day the World Health Organisation (WHO) declared it a public health emergency of international concern.³ After six weeks, on March 19, 2020, the Prime Minister announced a janta curfew.⁴ Alongside this, he urged people across the country to “*clap our hands, beat our plates, ring our bells to boost [their] morale...*”. Media depictions showed enthusiastic compliance from people banging household utensils and shouting into the air, “*go corona go!*”.

Shortly after, on March 24, 2022, the Prime Minister announced a national curfew for the next twenty one days⁵, exercising powers under the National Disaster Management Act, 2005, which also appoints him the Chairperson of the authority.⁶ Our Prime Minister again reached out to us through a video message on April 3, the ninth day of the lockdown, asking us to switch off our lights, light candles, diyas and even mobile flashlights, stating, “*there is no bigger force than our spirits. Let's fight coronavirus together!*”.⁷ People responded enthusiastically. In Delhi, I remember hearing the bursts of fireworks with dread.

The lives of others

Putting a large question mark to these displays of social solidarity were our practices as individuals and family units. We were scared, lacked full understanding about COVID-19 and searched for safety. It caused little surprise when lists of those who contracted COVID-19 were rapidly shared through instant messaging platforms such as WhatsApp. This was fairly common in groups of building societies and Resident Welfare Associations. Such actions

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- 2 M.A. Andrews, Binu Areekal, K.R. Rajesh, Jijith Krishnan, R. Suryakala, Biju Krishnan, C.P. Muraly, and P.V. Santhosh, 'First confirmed case of COVID-19 infection in India: A case report' (2020) 151(5) IJMR <<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7530459/>> accessed 21 April 2022
 - 3 'Statement on the second meeting of the International Health Regulations (2005) Emergency Committee regarding the outbreak of novel coronavirus (2019-nCoV)' (World Health Organisation, 30 January 2020) <[https://www.who.int/news/item/30-01-2020-statement-on-the-second-meeting-of-the-international-health-regulations-\(2005\)-emergency-committee-regarding-the-outbreak-of-novel-coronavirus-\(2019-ncov\)](https://www.who.int/news/item/30-01-2020-statement-on-the-second-meeting-of-the-international-health-regulations-(2005)-emergency-committee-regarding-the-outbreak-of-novel-coronavirus-(2019-ncov))> accessed 21 April 2022
 - 4 Prime Minister's Office, 'Text of Prime Minister's address to the nation on combating COVID-19' (PIB, 19 March 2020) <<https://pib.gov.in/PressReleasePage.aspx?PRID=1607254>> accessed 21 April 2022
 - 5 Prime Minister Office, 'Text of PM's address to the nation on Vital aspects relating to the menace of COVID-19' (PIB, 24 March 2020) <<https://pib.gov.in/PressReleaseDetail.aspx?PRID=1607995>> accessed 21 April 2022
 - 6 The Disaster Management Act, 2005, s 3(2)(a) <https://ndma.gov.in/sites/default/files/PDF/DM_act2005.pdf> accessed 21 April 2022
 - 7 Prime Minister Office, 'Text of PM's address to the nation' (PIB, 03 April 2020) <https://www.youtube.com/watch?v=t3nCfGh75-A&ab_channel=NarendraModi> accessed 21 April 2022

even had state approval.⁸ As per a Reuters report, “*authorities in the southern state of Karnataka posted lists of quarantined people across several districts online, which were shared on local WhatsApp groups. The lists, complete with addresses, [were] used to create at least one website where users can fill in their zip code to check if anyone is quarantined nearby.*”⁹ This public health intervention, seemingly without thought and exposing the personal details of Indians, ignored decades of research and findings by public health experts on HIV or Tuberculosis. If caught COVID-19 you were unlucky, but if your name was known to your neighbours, you were truly cursed. In many cases it has caused a denial of basic services, deliveries, rations and timely access to health care. This age-old bond of physician-patient confidentiality, as reflected in Regulation 2.2 of the Indian Medical Council Regulations, was repeatedly ignored, even ruptured by State Governments. It was a breach of law, as the Supreme Court in the *K.S. Puttaswamy v. Union of India* case held that, “*...An unauthorized parting of the medical records of an individual which have been furnished to a hospital will amount to an invasion of privacy.*”¹⁰ In 2017, the apex court in this case had pronounced a rights doctrine on the fundamental right to privacy. Any invasion of privacy required a valid law, that was proportional to its intended democratic purpose and contained safeguards. But little was done by way of the exercise of any powers under the National Disaster Management Act or the issuance of Advisories by the Union Ministry for Health and Family Welfare.

As pointed out in a letter by the Jan Swasthya Abhiyan to the Union Minister for Health, “[t]hese... arbitrary and reactionary measures... cause fear, isolation and stigmatisation. Such measures will drive the disease underground, as people will not come forward for testing, and will likely worsen the situation and hence, should not be undertaken at all. Trust is the bedrock of the doctor-patient relationship that has serious implications for access to information and health care and should not get affected due to the arbitrary decision of the State to reveal names of patients in the public domain.”¹¹

I remember being put in contact with a family from Jaipur who was recently discharged from a Hospital in Delhi. The daughter-in-law over-call fighting fatigue expressed her helplessness as she asked questions. Her family, which had recently recovered from COVID-19, was being threatened by residents of the locality against going back to Jaipur to conduct the last rites of

8 Naveen Menezes and Bellie Thomas, ‘Government Publishes Details of 19,240 home quarantined people to keep a check’ (Bangalore Mirror, 25 March 2020) <<https://bangaloremirror.indiatimes.com/bangalore/others/government-publishes-details-of-19240-home-quarantined-people-to-keep-a-check/articleshow/74807807.cms>> accessed 21 April 2022

9 Devjyot Ghoshal and Subrata Nagchoudhury, ‘Vitriol and violence: A coronavirus death exposes paranoia in India’ (Reuters, 29 March 2020) <<https://www.reuters.com/article/uk-health-coronavirus-india-paranoia-ins-idUKKBN21G06W>> accessed 21 April 2022

10 [(2017) 10 SCC 1]

11 ‘Concern over breach of confidentiality of persons suspected of or diagnosed with Coronavirus (COVID-19)’ (Peoples Health Movement-India, 23 March 2020) <<http://phmindia.org/wp-content/uploads/2020/03/jsa-breach-confidentiality.pdf>> accessed 21 April 2022

her maternal grandmother who had passed away in Delhi. They had forbidden her body from being brought back for its last rites, or the family from returning. I had little to offer for help or answers as society had turned on each other. India had stumbled into a hobbesian trap that ignored law, that ignored reason. While the disclosure of personal information by “COVID lists” was the first, somewhat crude wave of technology implementation, digitisation became more ubiquitous and severe over time. As we struggled with the availability of physical and human resources, greater faith was placed in technology than the public healthcare system to prevent transmission.

Track, trace and jail

This is amply demonstrated by use of invasive and inaccurate surveillance technologies for congregations that were termed as “super spreader” or “hotspot” events. This was prominently visible in the prosecution of attendees of the Tablighi Jamaat religious congregation that took place in Delhi's Nizamuddin Markaz Bangelwali Mosque from March 13th to 15th, 2020. In retrospect, this ill-advised and negligent congregation saw thousands travel from several Southeast Asian countries to India.

The attendees visited Delhi and then travelled to several Indian states. On the detection of a COVID cases, the media fueled a social panic targeting their religious identity. Researchers analysed 11,074 stories published from 271 media sources around this incident that used phrases such as “*Corona Jihad*”, “*Tablighi Virus*” and the “*Markaz mayhem*”, to conclude a “epidemic of Islamophobic fake news and hate speech.”¹²

In response to the media maelstrom, the Delhi Chief Minister, on April 1, 2020, leaned on technology to announce the use of cellphone tracking through GPS coordinates by the Delhi Police. The legal basis for this surveillance and data sharing was never disclosed. The harvest of personal data which would include call logs and approximate movements has till date not been put to tests of proportionality, or even faced a technical audit. This is not the only example of the use of surveillance technologies in Delhi. The Delhi Police reportedly used drones fitted with HD cameras and loudspeakers as per a news report to, “*disinfect the basti and monitor movements*”.¹³ Again, there was no clear legal basis and no way to confirm if public authorities have any limitations in terms of access and use of people's personal data.

12 Soundarya Iyer and Shoibal Chakravarty, ‘Tablighi Jamaat: Impact of media narratives’ (The Hindu BusinessLine, 7 August 2020) <<https://www.thehindubusinessline.com/opinion/tablighi-jamaat-impact-of-media-narratives/article32297022.ece#>> accessed 21 April 2022; Aniruddha Jena, Ram Awtar Yadav and Raviteja Rambarki, ‘Demonizing the others: vendetta coverage of Tablighi Jamaat and Kumbh Mela during the COVID-19 pandemic in India’ (2021) 48(4) Media Asia <<https://www.tandfonline.com/doi/abs/10.1080/01296612.2021.1946282>> accessed 21 April 2022.

13 Vasudha Venugopal, ‘Aarogya Setu, drone data to play part in lockdown exit strategy’ (The Economic Times, 8 April 2020) <<https://economictimes.indiatimes.com/industry/healthcare/biotech/healthcare/aarogya-setu-drone-data-to-play-part-in-lockdown-exit-strategy/articleshow/75040648.cms?from=mdr>> accessed 21 April 2022

By using technology for policing rather than a medical action the State Government of Delhi and the Union Ministry for Home Affairs prioritised criminality over health. Such data was also shared with other state governments¹⁴ who prosecuted members of the jamaat under provisions of the Indian Penal Code, 1860, the Epidemic Diseases Act, 1897, Foreigners Act, 1946, and the Disaster Management Act, 2005. Most of these prosecutions were subsequently withdrawn, the digital evidence being of little to no use with the High Courts of Bombay,¹⁵ Karnataka¹⁶ and Madras¹⁷. More recently, the High Court of Delhi questioned the Delhi Police for registering criminal cases against those who provided shelter in their homes and mosques to the attendees asking, “*what is the offence? what is the violation?*”¹⁸. It is with good reason the Indian Scientists’ Response to CoViD-19 (ISRC), a collective of over 500 stated, “*Over the past few days, several prominent media personalities and politicians have suggested that the primary blame for the continued growth of the COVID-19 epidemic in India lies with a Tablighi Jamaat event that was held in Delhi on March 13. The available data does not support such a speculation.*”¹⁹

Other states in India were also deploying a combination of location surveillance, drone, and facial recognition technologies to ensure people comply with quarantine/isolation requirements. In Kerala authorities used a combination of call records, phone location data, and surveillance camera footage to check if people have been in contact with infected persons.²⁰ In Tamil Nadu, police in the Tiruvallur district were using an Android application called CoBuddy which deploys facial recognition along with geofencing to keep track of people under quarantine. To ensure they do not leave their phone, the app requests people to share a photo of their face 2-3 times at random with the app. The Karnataka Government developed an android app called Quarantine Watch in which people were required to download the application and share hourly photos (between 7:00 AM and 10:00 PM) with GPS location coordinates. Should people fail to abide by the hourly requirement they run the risk of

14 Writ Petition (PIL) No. 42 Of 2020 (Gujarat High Court) para 6 <<https://indiankanoon.org/doc/29569536/>>

15 Konan Kodio Ganstone And Others vs The State Of Maharashtra Cri.W.P. 548/20 & Ors at para 51 <https://www.livelaw.in/pdf_upload/pdf_upload-380282.pdf> accessed 22 April 2022

16 Farhan Hussain vs State By Thilak Park P S CW N. 2376/2020 <https://www.livelaw.in/pdf_upload/pdf_upload-379660.pdf> accessed 21 April 2022

17 Md Kameul Islam & Ors. v State & Another 2020 Cri LJ 3692 at para 9 and 27

18 Sofi Ahsan, “What is the offence committed?”: Delhi HC asks police on those who provided shelter to Tablighis’ (The Indian Express, 12 November 2021) <<https://indianexpress.com/article/cities/delhi/what-is-offence-committed-delhi-hc-police-on-those-who-provided-shelter-to-tablighis-7619633/>> accessed 21 April 2022

19 ‘On Tablighi Jamaat event’ (ISRC, 8 April 2020) <<https://indscicov.in/2020/04/08/on-tablighi-jamaat-event-dated-08-april-2020/>> accessed 21 April 2022

20 Arjun Kharpal, ‘Use of surveillance to fight coronavirus raises concerns about government power after pandemic ends’ (CNBC, 30 March 2020) <<https://www.cnbc.com/2020/03/27/coronavirus-surveillance-used-by-governments-to-fight-pandemic-privacy-concerns.html>> accessed 21 April 2022

being transferred to a mass quarantine centre.²¹ Now, imagine being infected with COVID, suffering from fever, and recovering from exhaustion, and then being asked to follow a stringent timetable of data extraction.

The circulation of “covid lists”, the criminalisation of the Tablighi Jamaat - the clockwork coercion of selfie uploads, and use of facial recognition shows the dominant use of modern technology in COVID response. The first responders was not the nurse or doctor, but a beat constable or havildar. Despite the use of modern tools, we remained feudal, illegal and unscientific. This becomes more evident through contact tracing applications that continue to operate without any legal framework, technical audits, or enforceable safeguards. This is the new normal in the brave new India.

Digital contact tracing became vapourware

According to the WHO, contact tracing occurs in three steps namely, contact identification, listing and follow up. In particular, contact tracing is a pillar which helps public health officials in containing and slowing the pace of further transmission of the virus.²² This pace of transmission is measured by the unit R0 (R naught) which essentially connotes the number of people an infected person can spread the disease onto.²³ Contact tracing is viewed as a strategy whereby timely interventions can break up new infection chains and slow down or buffer a “COVID wave”. Traditionally, contact tracing has been administered by health care workers and volunteers. However, with the ubiquity of mobile devices (including smartphones), that collect vast troves of personal information, governments across the world have sought to harness it for rapid contact tracing and identification of hotspots.

The principal deployment of contact tracing in India is through “Aarogya Setu”. This application has a contested paternity between the NITI Aayog and the Ministry of Electronics and IT. Both were proceeding with parallel projects until it was settled through the Cabinet Secretariat. As per its notification titled, “Constitution of a Committee for developing and implementing a Citizen app technology platform for combating COVID-19” dated April 3, 2020, seven persons with four drawn from government, two who are chairpersons of India’s storied corporate groups and an IIT Academic were tasked with the development of a contact tracing application in a public-private partnership.²⁴ Curiously, this committee did not contain

21 ‘COVID-19| People in home quarantine told to send selfies every hour to govt’ (The Hindu, 30 March 2020) <<https://www.thehindu.com/news/national/karnataka/covid-19-people-in-home-quarantine-told-to-send-selfies-every-hour-to-govt/arti cle31208001.ece>> accessed 21 April 2022

22 ‘Infection prevention and control: Contact tracing’ (WHO, 9 May 2017) <<https://www.who.int/news-room/questions-and-answers/item/contact-tracing>> accessed 21 April 2022

23 Joseph Eisenberg, ‘R0: How scientists quantify the intensity of an outbreak like coronavirus and predict the pandemic’s spread’ (The Conversation, 27 March 2020) <<https://theconversation.com/r0-how-scientists-quantify-the-intensity-of-an-outbreak-like-coronavirus-and-predict-the-pandemics-spread-130777>> accessed 21 April 2022

24 F. No. 101/2/1/2020-CA.IV, Cabinet Secretariat, Government of India, April 03 2020

any representative from the Ministry of Health and Family Welfare, a medical health expert, or epidemiologist. Worse, despite the constitution of this committee, mystery surrounded the origin of the Aarogya Setu App with the Government even apologising before the Chief Information Commission after being issued a show cause on the failure to provide complete information on the origins of Aarogya Setu.²⁵

More curiously, a day before the committee was constituted, on April 2, 2020 Aarogya Setu was launched. As per the press release, Aarogya Setu's intended purpose was *"for the health and well-being of every Indian. It will enable people to assess themselves the risk of their catching the Corona Virus infection. It will calculate this based on their interaction with others, using cutting edge Bluetooth technology, algorithms and artificial intelligence."* The application was designed in a manner where a user's risk level of exposure to COVID-19 is represented according to a colour-coded warning system.

Now, please note the words, *"health and well-being of every Indian"*. It defies fact and reason that it will cater to "every Indian", given levels of teledensity, internet connectivity, and smartphone ownership as per data released either by the Telecom Regulatory Authority of India in its Monthly Connectivity Reports or by the Department of Telecom in its Annual Report. It would be fair to say that many Indians cannot afford mobile internet, and if they can they will have difficulty purchasing a smartphone. What is more interesting is that even the developers of Aarogya Setu acknowledged that at least 50 percent of the population must download the app for it to be an effective solution.²⁶ Considering India does not have that many smartphones, would it mean the app was set up to fail? Or, if it could only work in urban pockets or cities? If it did, it would provide discriminatory protections to Indians in villages which would have low, if any, smartphone ownership.

Now, further note the use of the words, *"cutting edge Bluetooth technology, algorithms and artificial intelligence"*. To me these are no better than the spell of a shaman when there is no way to test the algorithm for its accuracy or the training data. These concerns are heightened when people involved with the app's development disclosed that, without human supervision, algorithms determine the "at-risk" assessment.²⁷ Has anyone audited this algorithm, or has it been made public? No.

Undeterred, the Prime Minister in an address on April 14, 2020 congratulated the country for maintaining resolve and extending the lockdown to May 2, 2020. Importantly, he prescribed 7

25 Gaurav Vivek Bhatnagar, 'Centre Apologises for 'Irresponsible Submissions' Regarding Aarogya Setu Before CIC' (The Wire, 8 December 2020) <<https://thewire.in/government/centre-irresponsible-submissions-aarogya-setu-rti-response>> accessed 21 April 2022

26 Karishma Mehrotra 'Behind Aarogya Setu app push: 'At least 50% people must download for impact' (The Indian Express, 11 April 2020) <<https://indianexpress.com/article/coronavirus/behind-aarogya-setu-app-push-at-least-50-people-must-download-for-impact-635712> 1/.> accessed 21 April 2022

27 Ibid.

tasks, out of which task number 4 was to, “Download the Arogya Setu Mobile App to help prevent the spread of corona infection.”²⁸ This resulted in a surge of downloads, with its creators jubilant at the numbers of user installations. The Chairperson of the NITI Aayog tweeted, “Telephone took 75 years to reach 50 million users...Pokemon Go 19 days. #AarogyaSetu, India’s app to fight COVID-19 has reached 50 mn users in just 13 days-fastest ever globally for an App.” Installation numbers have been repeatedly used by public officials to signal success. The Ministry of Electronics and IT still publishes user download numbers in its record of monthly achievements.²⁹ These numbers should not distract us from the core objectives of Aarogya Setu, as in the Prime Minister’s words to, “help prevent the spread of corona infection”. So did Aarogya Setu deliver on its promises?

As per Subhasis Banerjee, a professor then at IIT Delhi, who provided an expert affidavit to the High Court of Kerala, the assessment of Aarogya Setu rested on two parameters. Its utility and privacy. He stated, “That possible high noise-to-signal ratio for infection risk assessment, lack of an associated error model without any estimate of the rates of the false positives and false negatives, etc. make Aarogya Setu wholly unreliable in our fight against Covid19. In addition, the low penetration of smartphones in India [while 61% of the population in India have mobile phones, only 17% of these are smartphones on which the application can run is likely to render it virtually useless. In contrast, we have the examples of Kerala and Dharavi in Mumbai where methods of local community based manual contact tracing have led to impressive containments. Coupled with the inadequate privacy protection, Aarogya Setu does not appear to be proportionate.” Such critique is consistent with a global review as on date of the efficacy of digital contact tracing with meta studies including India concluding, “Almost no data quantified an association between [digital contact tracing] adoption rate and infection transmission at the community level.”³⁰ This year in February, researchers published a study in the Lancet on the effectiveness of the CovidSafe App used in New South Wales stating that it, “generated a substantial additional perceived workload for public health staff and was not considered useful.”³¹ Till date there have been no independent audits for Aarogya Setu’s efficacy, and all we have to go with are press statements in which aggregate figures of

28 Prime Minister’s Office, ‘Text of PM’s address to the Nation’ (PIB, 14 April 2020) <<https://pib.gov.in/PressReleaseDetail.aspx?PRID=1614215>> accessed 21 April 2022

29 Ministry of Electronics and Information Technology, Government of India, ‘Major achievements Month of February, 2022’ (Report) s 3 <<https://www.meity.gov.in/writereaddata/files/Monthly%20achievements%20month%20of%20February%202022.pdf>> accessed 22 April 2022

30 Clara Mazza, Daniela Girardi, Leandro Gentile, Maddalena Gaeta, Carlo Signorelli and Anna Odone, ‘Public health effectiveness of digital contact tracing in the COVID-19 pandemic: A systematic review of available data’ (2021) 92(6) Acta Biomedica <<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8851023/>> accessed 21 April 2022

31 Florian Vogt, Bridget Haire, Linda Selvey, Anthea L Katelaris and John Kaldor, ‘Effectiveness evaluation of digital contact tracing for COVID-19 in New South Wales, Australia’ (2022) 7(3) Lancet Public Health <<https://pubmed.ncbi.nlm.nih.gov/35131045/>> accessed 22 April 2022

detection of hotspots have been provided.³² These are advertorial rather than scientific claims not being open to peer review or scrutiny.

Even if Aarogya Setu is junk, many may wonder what is the harm in installing it on your smartphone. After all, it is just one more application to install and use, “*just in case*”. But Aarogya Setu is not any other application: it provides real-time data to the government and can be used to restrain your physical movement, save or put you in peril of infection. Take, for instance, interior designer Jitendra Machhar from Ghatkopar, Mumbai who had tested positive for COVID-19 in May 2020. Till February, 2021 when MidDay reported the story, Aarogya Setu continued to show him as positive, because of which he has not been able to enter offices for work. Machhar submitted online complaints but the problem has not been resolved so far.³³ This was only to be expected as the terms of service contained a disclaimer stating that the Government cannot be held legally responsible should the Aarogya Setu app and accompanying services lead to errors in accurately identifying people who have tested positive for COVID-19.³⁴

These consequences expose the intent and design of Aarogya Setu that eschews a legal and accountability framework -- such as an act of parliament. Instead, we first got a privacy policy that was criticised, then a “protocol”,³⁵ which was marketed as an effective privacy protection mechanism, notably because of a “sunset clause”.³⁶ A “sunset clause” would in such a natural setting mean the destruction of the personal data, but this “sunset clause” applied to this “protocol” itself. It requires reviews of the Protocol in six months or earlier. Have such reviews taken place? It seems unlikely. Response to requests filed under the Right to Information Act³⁷ have not revealed much except what seem like mechanical 12 month extensions to the

32 Aparna Banerjee, 'Aarogya Setu identified over 3,000 Covid-19 hotspots in 3-17 days ahead of time: Kant' (Mint, 26 May 2020) <<https://www.livemint.com/technology/tech-news/coronavirus-update-aarogya-setu-identified-over-3-000-covid-19-hotspots-in-3-17-days-ahead-of-time-kant-11590503060663.html>> accessed 21 April 2022

33 Rohit Parikh, 'Mumbai: Glitch in Aarogya Setu app brings Ghatkopar man's life to halt' (Mid-Day, 09 February, 2021) <<https://www.mid-day.com/mumbai/mumbai-news/article/mumbai-glitch-in-aarogya-setu-app-brings-ghatkopar-man-life-to-halt-23158991>> accessed 21 April 2022

34 'Terms & Conditions' (Aarogya Setu) <<https://www.aarogyasetu.gov.in/terms-conditions/#:~:text=While%20the%20Services%20are%20intended,all%20or%20a%20certain%20class>> accessed 22 April 2022

35 Ministry of Electronics and Information Technology, Government of India, 'Notification of the Aarogya Setu Data Access and Knowledge Sharing Protocol, 2020 in light of the COVID-19 pandemic' (Order No: 2(10)/2020-CLeS) <https://www.meity.gov.in/writereaddata/files/Aarogya_Setu_data_access_knowledge_protocol.pdf> accessed 21 April 2022

36 'We Studied the Protocol: And No This Doesn't Sufficiently Protect Your Privacy' (Internet Freedom Foundation, 13 May 2020) <<https://internetfreedom.in/we-studied-the-protocol-and-no-this-doesnt-sufficiently-protect-your-privacy/>> accessed 21 April 2022

37 'A look at Aarogya Setu through the Right to Information lens #SaveOurPrivacy' (Internet Freedom Foundation, 27 May 2020) <<https://internetfreedom.in/aarogya-setu-through-the-right-to-information-lens/>> accessed 21 April 2022

protocol.³⁸ The practical consequence is that Aarogya Setu and our personal data on it is likely to be perpetually stored, freely shared,³⁹ generously enriched, and coercively used without our consent. For Aarogya Setu, the sun never sets.

The Prime Minister addressed us next on May 12, 2020 calling for an, “Atma Nirbhar Bharat” by stating five pillars to achieve it. He stated that the “*Third Pillar is Our System*. A system that is driven by technology which can fulfil the dreams of the 21st century; a system not based on the policy of the past century.”⁴⁰ This faith in technology within government systems was already being executed with Aarogya Setu being made mandatory for all Government Offices.⁴¹ It soon spread to airports, apartment complexes, and the tyranny of housing societies and resident welfare colonies. To be demanded as a digital toll for the poor and labour classes. However, even then for large sections of the Indian population for some time Aarogya Setu formally remained voluntary, even as it could be demanded every now and then. Many participated in this charade showing a screenshot on their smartphone. Who were we fooling, except ourselves?

This voluntary-mandatory kabuki dance ended on labour day when an order was issued under the National Disaster Management Act, 2005 mandating the mandatory installation and operation of Aarogya Setu for employees. Further any violation would invite criminal sanction for offences that could lead to a jail time upto 2 years.⁴² It is to my regret and I say this with a sense of shame, this was only done in India -- unlike any other democracy.⁴³ Imagine the impact on daily wage labourers, or the owners of factories and shops in the small and unorganised sector who would be prone to harassment. Not to be outdone, the Noida Police in Uttar Pradesh exercised curfew powers requiring Aarogya Setu for any resident or anyone

38 'Notification of the Aarogya Setu Data Access and Knowledge Sharing Protocol, 2020 in light of the COVID-19 pandemic' (Ministry of Electronics and Information Technology) <<https://www.meity.gov.in/content/notification-aarogya-setu-data-access-and-knowledge-sharing-protocol-2020-light-covid-19-0>> accessed 21 April 2022

39 Gaurav Vivek Bhatnagar, 'Aarogya Setu Data Was Made Available to J&K Police in Kulgam, Reveals RTI' (The Wire, 1 April 2021) <<https://thewire.in/government/aarogya-setu-data-was-made-available-to-jk-police-in-kulgam-reveals-rti>> accessed 22 April 2022

40 Prime Minister's Office, 'English Rendering of Prime Minister Shri Narendra Modi's Address to the Nation on 12.5.2020' (PIB, 12 May 2022) <<https://www.pib.gov.in/PressReleasePage.aspx?PRID=1623418>> accessed 22 April 2022

41 Express Web Desk, 'Aarogya Setu app now mandatory for central govt employees' (The Indian Express, 29 April 2020) <<https://indianexpress.com/article/india/aarogya-setu-app-now-mandatory-for-central-govt-employees-6384664/>> accessed 22 April 2022

42 '45 organizations and more than 100 prominent individuals push back against the coercion of Aarogya Setu' (Internet Freedom Foundation, 02 May 2020) <<https://internetfreedom.in/45-organizations-and-105-prominent-individuals-push-back-against-the-coercion-of-aarogya-setu/>> accessed 22 April 2022

43 Patrick Howell O'Neill, 'India is forcing people to use its covid app, unlike any other democracy' (MIT Technology Review, 07 May 2020) <<https://www.technologyreview.com/2020/05/07/1001360/india-aarogya-setu-covid-app-mandatory/>> accessed 22 April 2022

entering the Gautam Buddha Nagar District.⁴⁴ Quite simply, the “bridge to health” became a path to jail.

This is not all, later in May 2020, cyber security researchers highlighted risks and breaches. This first led to denials⁴⁵ then promises of, “open sourcing” Aarogya Setu.⁴⁶ Even a bug bounty programme was announced. However, the server side code has never been uploaded.⁴⁷ Further, a visit on Github, as on date, shows even the current code of Aarogya Setu has not been uploaded, with the last update dated 2 years ago. All these fundamental problems have core implications on user trust. India-specific research has shown that the primary barrier to the use of Aarogya Setu is a lack of trust. In the survey respondents cited invasion of their privacy and fears of government surveillance behind uninstalling it.⁴⁸ Unsurprisingly, Aarogya Setu was rated as one star on five by the MIT Tech Review⁴⁹ scoring even lower than the movies of its brand ambassador Ajay Devgn⁵⁰ or privacy assessments of Pokemon Go.

What remains of Aarogya Setu? Over time it has lost its value as a digital contact tracing app. This disinterest is visible when you click on the weblink mentioned beside the Aarogya Setu Twitter handle which shows a 403 error code reading, “Forbidden”. If you do manage to go to the official application, you will notice no updates have been made this year. Government attention has shifted to grander visions for building, “digital health ecosystems”. But Aarogya

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- 44 'We legally contest the Noida authorities order of criminally prosecuting people who do not have Aarogya Setu #SaveOurPrivacy' (Internet Freedom Foundation, 06 May 2020) <<https://internetfreedom.in/we-contest-the-noida-authorities-direction-that-may-make-aarogya-setu-a-path-to-jail/>> accessed 22 April 2022
 - 45 (Aarogya Setu, 06 May 2020) <<https://www.aarogyasetu.gov.in/wp-content/uploads/2020/11/mygov-1000000001256856957.jpg>> accessed 22 April 2022
 - 46 Ministry of Electronics and IT, Government of India, 'Aarogya Setu is now open source' (PIB Delhi, 26 May 2020) <<https://www.aarogyasetu.gov.in/wp-content/uploads/2020/11/mygov-100000000762834133.pdf>> accessed 22 April 2022
 - 47 'Four months on, Aarogya Setu is still not open-source. WHY and WHEN is what the nation really wants to know! #SaveOurPrivacy' (Internet Freedom Foundation, 19 August 2020) <<https://internetfreedom.in/aarogya-setu-should-be-open-source-now/>> accessed 22 April 2022
 - 48 Ashish Viswanath and Saini Das, 'Explaining citizens' resistance to use digital contact tracing apps: A mixed-methods study' (April 2022) vol. 63(1) International Journal of Information Management <https://www.researchgate.net/publication/357314149_Explaining_citizens'_resistance_to_use_digital_contact_tracing_apps_A_mixed-methods_study> accessed 21 April 2022; Chithira Vijayakumar & Tanisha Ranjit, 'Virus detected: A profile of India's emergent ecosystem of networked technologies to tackle Covid-19' (Internet Democracy Project, 31 May 2021) <<https://internetdemocracy.in/reports/virus-detected#conclusion>> accessed 22 April 2022
 - 49 Aditya Chunduru, 'After MIT tech review downgrades Aarogya Setu rating, source code for app made public' (Deccan Chronicle, 27 May 2020) <<https://www.deccanchronicle.com/technology/in-other-news/270520/after-mit-tech-review-downgrades-aarogya-setu-rating-source-code-for.html>> accessed 22 April 2022
 - 50 Aarogya Setu App, (MyGov India, 22 April 2020) <<https://www.youtube.com/watch?v=vFaFmJt9xKo>> accessed 22 April 2022

Setu will continue to linger, collect, and share our sensitive personal data like a zombie.⁵¹ Today, Aarogya Setu due to its massive installation base is used for onboarding users for vaccine registration or the generation of the digital health ID.

Vaccination and Health IDs

Almost at the same time, a parallel effort at vaccination and the creation of digital systems for health were proceeding. The first is fairly well documented, and the second is still in a process of policy and technical iteration. Let us first start with vaccination. In his address to the nation on October 20, 2020 the Prime Minister urged for hope stating, “work is underway on several corona vaccines currently in India. The situation seems to be reassuring”.⁵² Curiously, there was no mention of Aarogya Setu or the first wave which had crossed its maximum active caseload sometime around September 17, 2020.

Vaccination has a long history in India with a comprehensive overview of past efforts stating, “the operational challenges keep the coverage inequitable in the country”.⁵³ Equity is the primary value to be served in the words of the Director General of the World Health Organisation to, “to ending this pandemic”.⁵⁴ Given the nature of COVID-19, vaccination was the primary way to safeguard public health and resume economic and public participation. The vaccines did come, belatedly on January 16, 2021,⁵⁵ with controversy⁵⁶ and a staggered rollout that was rationed first for the most at risk groups -- starting with 30 million healthcare workers, then those with co-morbidities and the old. From the start, vaccination depended on access to technology as it was facilitated by the Covid Vaccine Intelligence Network website popularly called or as Co-WIN.⁵⁷ Walk-in registrations were only permitted at a later date, thereby at certain times making access to broadband internet and a smartphone essential to safeguard ourselves against infection.

51 Multi-domain orgs and individuals raise concerns about Aarogya Setu #SaveOurPrivacy' (Internet Freedom Foundation, 18 September 2020) <<https://internetfreedom.in/aarogya-setu-multi-domain-joint-statement/>> accessed 22 April 2021

52 'Till there's a vaccine, we cannot weaken our fight against Coronavirus: PM Modi' (Narendra Modi, 20 October, 2020) <<https://www.narendramodi.in/prime-minister-narendra-modis-address-to-the-nation-551959>> accessed 22 April 2021

53 Chandrakant Lahariya, 'A brief history of vaccines & vaccination in India' (April 2014) vol. 139(4) The Indian Journal of Medical Research <<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4078488/>> accessed 22 April 2021

54 'Vaccine inequity undermining global economic recovery' (World Health Organisation, 22 July 2021) <<https://www.who.int/news/item/22-07-2021-vaccine-inequity-undermining-global-economic-recovery>> accessed 22 April 2021

55 Krishna N. Das and Neha Arora, 'India to multiply vaccinations amid coverage concerns' (Reuters, 16 February, 2021) <<https://www.reuters.com/article/us-health-coronavirus-india-vaccine-idUSKBN2AG1IZ>> accessed 22 April 2021

56 Kamala Thiagarajan, 'Covid-19: India is at centre of global vaccine manufacturing, but opacity threatens public trust' (The BMJ, 28 January 2021) <<https://www.bmj.com/content/bmj/372/bmj.n196.full.pdf>> accessed 22 April 2021

57 Ministry of Health and Family Welfare, Government of India, 'CoWIN' <<https://www.cowin.gov.in/>> accessed 22 April 2022

Co-WIN, on May 1, 2022 opened for registration of individuals ranging from 18-44 years of age group as the only way to get vaccinated, “to avoid overcrowding”.⁵⁸ As the second wave was rising that would peak nationally around May 6, 2021, I was anxious. Taking a paid slot, I got vaccinated that very day. How? Through privilege, checking at odd hours, friends messaging me on a group we made to coordinate information on vaccination slots, I was able to Co-WIN at fastest finger first and avail this prized slot. My house help only got her appointment for May 18, 2022. This was after repeated attempts at coordinating a OTP on her feature cell phone and using my laptop at the same time. Exclusion was furthered as the platform was available only in English rather than all languages listed in the Eighth Schedule of the Constitution of India.

In the absence of the internet and without knowledge of how the portal functions, the majority of India’s rural population is being discriminated against, and a form of technical rationing is being implemented by CoWIN based on broadband connectivity and digital literacy. According to the Indian Telecom Services Performance Indicator Report for October-December, 2020, released on April 27, 2021, the percentage of the rural population that subscribes to the internet is 34.60 per cent. It even conflicts with the early-stage learnings from CoWIN’s own dashboard. On April 28, the dashboard showed that for the 45-plus age group, out of a total 14,42,10,652 vaccination registrations, only 2,52,96,511 were through CoWIN. This is anecdotally reinforced even in high connectivity areas. For instance, while Delhi has one of the highest teledensity in India, it was reported from the Shakurbasti slum by its pradhan Virendra Kohli, “As far as I know, no one in the 18-44 category has booked a slot yet because they don’t understand how to. Some have come to me for help but I haven’t been able to understand it either.” The harvest of such technocratic solutionism is evident in results.

As a deadly second wave, one in which I heard ambulance sirens all day and night, the Prime Minister expressed sorrow and addressed the nation on May 21, 2021 urging mass vaccination, saying, “This protective shield will reach everyone in the near future.”⁵⁹ However, as of June 4, 2021, the same number of vaccines have been administered in 114 of the least developed districts as were administered in 9 urban cities, which combined have half the population of the former.^{60,61} As per the Co-WIN dashboard as on April 22, 2022, about 93% of

58 Ministry of Health and Family Welfare, Government of India, ‘Liberalised Pricing and Accelerated National Covid-19 Vaccination Strategy’ (21 April 2021) <<https://www.mohfw.gov.in/pdf/LiberalisedPricingandAcceleratedNationalCovid19VaccinationStrategy2042021.pdf>> accessed 22 April 2022

59 Prime Minister’s Office, ‘English rendering of PM’s interaction with doctors, paramedical staff and frontline workers of Varanasi’ (PIB, 21 May 2021) <<https://pib.gov.in/PressReleaseDetail.aspx?PRID=1720586>> accessed 22 April 2022

60 Krishna N. Das, Abhirup Roy and Rajendra Jadhav, ‘Analysis: India’s vaccine inequity worsens as countryside languishes’ (Reuters, 7 June 2021) <<https://www.reuters.com/world/india/indias-vaccine-inequity-worsens-countryside-languishes-2021-06-04/>> accessed 22 April 2022

61 Tanvi Karandikar, Avinash Prabhu, Mehul Mathur, Megha Arora, Hemank Lamba and Ponnuragum Kumaraguru, ‘Co-WIN: Really Winning? Analysing Inequity in India’s Vaccination Response’ (Cornell University, 9 February 2022) <<https://arxiv.org/abs/2202.04433>> accessed 22 April 2022

the eligible population or 73.33% of citizens have received their first dose.⁶² This is undoubtedly a victory, but it leaves us to question who have been the victors.

Co-WIN's issues were not limited to inequity. It also demonstrated a complete lack of respect for data protection. For instance, it did not even contain a privacy policy till the High Court of Delhi issued directions.⁶³ There seemed to be a data tax. To get vaccinated you people were posed with experimental facial recognition technologies or the provision of Aadhaar.⁶⁴ For those, who provided registration details through Aadhaar, a Digital Health ID was automatically created without their consent or any meaningful choice being offered.⁶⁵ It is important to note that the modern theory and practice of informed consent emerges from the context of decisions between a patient and a physician.⁶⁶

The datafication of personal health data today continues without any legal protection and is largely governed by a labyrinth of policy frameworks holding confusingly similar acronyms administered by the National Health Authority. It owes its origins to the pre-pandemic Aayushman Bharat-Pradhan Mantri Jan Arogya Yojana (AB-PMJAY) launched by the Prime Minister on September 23, 2018 in Ranchi.⁶⁷ It is essentially a public insurance scheme aimed towards universal healthcare coverage. Digitisation was an inherent element of the scheme which relied on cashless and paperless delivery. At the time of announcement a separate section, "Fraud detection and Data privacy" announced policies were being formed, "in compliance with all laws and regulations applicable". The only issue was India did not have any meaningful data protection law. The implementation authority was first set up as the National Health Agency, then reconstituted as the Ayushman National Health Authority⁶⁸ and it soon began issuing e-cards even though, "no scheme specific card is required to avail the

62 'Dashboard' (Vaccinate India) <<https://vaccinate-india.in/dashboard>> accessed 22 April 2022

63 'Delhi High Court issues directions on suggestions to improve the CoWIN platform #VaccinesForAll' (Internet Freedom Foundation, 7 June 2021) <<https://internetfreedom.in/delhi-high-court-issues-directions-on-suggestions-to-improve-the-cowin-platform/>> accessed 22 April 2022

64 'Joint Statement: Say no to Aadhaar based Facial Recognition for Vaccination!' (Internet Freedom Foundation, 14 April 2021) <<https://internetfreedom.in/sign-on-and-support-close-to-10-organisations-and-158-individuals-who-are-warning-against-aadhaar-based-facial-recognition-for-vaccination/>> accessed 22 April 2022

65 Abantika Ghosh, 'Used Aadhaar for Covid vaccine? Modi govt created your digital health ID without asking you' (The Print, 1 October 2021) <<https://theprint.in/health/used-aadhaar-for-covid-vaccine-modi-govt-created-your-digital-health-id-without-asking-you/742958/>> accessed 22 April 2022

66 V Mallardi, 'The origin of informed consent' (2005) 25(5) Acta Otorhinolaryngol Ital <<https://pubmed.ncbi.nlm.nih.gov/16602332/>> accessed 22 April 2022

67 Ministry of Health and Family Welfare, 'Ayushman Bharat –Pradhan Mantri Jan Arogya Yojana (AB-PMJAY) to be launched by Prime Minister Shri Narendra Modi in Ranchi, Jharkhand on September 23, 2018' (PIB, 22 September 2018) <<https://pib.gov.in/Pressreleaseshare.aspx?PRID=1546948>> accessed 22 April 2022

68 Government of India, 'National Health Authority' < <https://nha.gov.in/NHA.html>> accessed on 22 April 2022

benefits... to create awareness and facilitate availing of benefits”.⁶⁹ Later this card would become a formal and central method of authentication for beneficiaries.⁷⁰

Almost at the same time, the Ministry of Health and Family welfare released the National Health Blueprint with its Chairperson stating in the preface, “[t]he policy lays significant emphasis on leveraging digital technologies for enhancing the efficiency and effectiveness of delivery of all the healthcare services.”⁷¹ To him, it was a continuation of his role as the former Chairperson of a Committee that proposed a, “National Health Stack”.⁷² A facial reading of the document gives the impression that the policy is a model for privacy protection. After all, it has all the right words, “privacy by design”, “consent manager”, “anonymizer”, “citizen to be in control”. However, upon looking closer, these words lose meaning by relying purely on unauditable technical frameworks and the absence of any legislative framework or independent, regulatory oversight.

These elements were combined into the National Digital Health Mission in 2020 that was launched on independence day from the ramparts of the Red Fort by the Prime Minister stating, “The National Digital Health Mission is also being launched from today. It will bring a new revolution in India's Health Sector. Technology will be used prudently to reduce the challenges in treatment. Every Indian will be given a Health ID. This Health ID will work like a Health Account of every Indian. This account will contain your details of every test, every disease, the doctors you visited, the medicines you took and the diagnosis. When and what was the report, all such information will be incorporated in the Health ID.”⁷³ The Prime Minister has promised that such massive collection of sensitive personal data is being gathered to, “eliminate all these difficulties related to appointment with a doctor, depositing money, making a slip in the hospital, etc.”⁷⁴ A subsequent strategy overview acknowledged that, “The National Digital Health Mission will implement the core and common digital building blocks required for healthcare and make them accessible as digital public goods to both the public and private ecosystem.”⁷⁵

69 Ministry of Health and Family Welfare, ‘Ayushman Bhart-PMJAY Cards’ (PIB, 29 November 2019) <<https://pib.gov.in/Pressreleaseshare.aspx?PRID=1594168>> accessed 22 April 2022

70 Ministry of Health and Family Welfare, ‘Ayushman Bharat Pradhan Mantri Jan Arogya Yojana (AB-PMJAY)’ (PIB, 23 July 2021) <<https://www.pib.gov.in/PressReleasePage.aspx?PRID=1738169>> accessed 22 April 2022

71 Ministry of Health and Family Welfare, National Digital Health Blueprint (Report) Preface by J Satyanarayana <https://main.mohfw.gov.in/sites/default/files/Final%20NDHB%20report_0.pdf> accessed 22 April 2022

72 Ministry of Health and Family Welfare, National Digital Health Blueprint (Report p. 6) Preface by J Satyanarayana <https://main.mohfw.gov.in/sites/default/files/Final%20NDHB%20report_0.pdf> accessed 22 April 2022

73 Prime Minister's Office, ‘The Prime Minister Shri Narendra Modi addressed the Nation from the ramparts of the Red Fort on the 74th Independence Day’ (PIB, 15 August 2020) <<https://pib.gov.in/PressReleseDetail.aspx?PRID=1720586>>

74 Ibid

75 ‘National Digital Health Mission - Strategy Overview’ (National Health Authority, July 2020) <https://abdm.gov.in/publications/ndhm_strategy_overview> accessed 22 April 2022

The private sector has not only been a stakeholder, but a beneficiary and a partner in digital health for the Government of India. It serves as a contractor to build such platforms, create policies through joint working groups and is able to integrate its services on government platforms as well as with the personal data of patients.⁷⁶ While some commentators may focus on issues of conflict of interest, to me the larger dangers are for shrinking public health systems that are overpowered by “market-oriented visions”.⁷⁷ Here, I may be permitted to hypothesise, but will the State be reduced to an aggregator or intermediary passively connecting the sick and infirm with private hospitals, testing labs, insurance companies and pharmacies?

Several developments have happened subsequently which merit finer analysis but follow the same broad template. Briefly, a health data management policy is finalised on December 14, 2020.⁷⁸ Unique Health Identifier Rules, 2021 are notified under the Aadhaar Act that enabled the, “voluntary” creation of Unique Health ID from Aadhaar Act, 2016 which is the skimpy, legal basis on which they were created during the vaccination programme.⁷⁹ The Prime Minister on September 27, 2021, launched the Ayushman Bharat Digital Mission which began the national rollout of the Unique Health ID.⁸⁰ More recently on February 26, 2022 the Union Cabinet has approved a specific allocation of Rs. 1,600 cr of allocation towards Ayushman Bharat Digital Mission.⁸¹ Things seem to be moving briskly with the National Health Authority at present inviting an expression of interest for, “creating a digital health ecosystem in India.”⁸²

There is much more to say about datafication and the stack based technical architecture not only in health, but in each area of human activity that shapes the lives of crores of Indians. For

76 Saritha Rai, 'Swasth, the alliance of billionaires & start-ups that hopes to fix India's healthcare system' (The Print, 23 June 2020) <<https://theprint.in/india/swasth-the-alliance-of-billionaires-start-ups-that-hopes-to-fix-indias-healthcare-system/446848/>> accessed 22 April 2022

77 'Digital health technologies and health-care privatisation' (The Lancet, August 2019) <<https://www.thelancet.com/action/showPdf?pii=S2589-7500%2819%2930091-3>> accessed 22 April 2022

78 'National Digital Health Mission: Health Data Management Policy' (Ministry of Health and Family Welfare, Government of India) <https://abdm.gov.in/health_management_policy> accessed 22 April 2022

79 'Ministry of Health and Family Welfare (E-Health Section) e-Gazette Notification' <<https://egazette.nic.in/WriteReadData/2021/224099.pdf>> accessed 22 April 2022

80 'Prime Minister of India launches countrywide Ayushman Bharat Digital Mission' (PIB, 27 September 2021) <<https://pib.gov.in/PressReleaselframePage.aspx?PRID=1758511>> accessed 22 April 2022

81 'Cabinet approves implementation of Ayushman Bharat Digital Mission with a budget of Rs.1,600 crore for five years' (PIB, 26 February 2022) <<https://pib.gov.in/PressReleasePage.aspx?PRID=1801322>> accessed 22 April 2022

82 'Open Call for Expression of Interest (Eoi) for creating digital health ecosystem for India' (National Health Authority) <[https://abdm.gov.in/assets/uploads/eoi_docs/Open_Call_for_Expression_of_Interest_\(Eoi\)_vF.pdf](https://abdm.gov.in/assets/uploads/eoi_docs/Open_Call_for_Expression_of_Interest_(Eoi)_vF.pdf)> accessed 22 April 2022

farmers there is an AgriStack⁸³, for labourers we have the e-SHRAM portal⁸⁴ and for schoolchildren and teachers there is a NDEAR (National Digital Education Architecture).⁸⁵ These digital databases are without an anchoring legislation but have developed frameworks within publicly available policy documents. They advocate for greater data processing and storage for satisfying public and private purposes. In addition to database specific frameworks, there exist data unification policies such as Data Empowerment and Protection Architecture (DEPA) that advocate “breaking data silos”.⁸⁶ DEPA is supported by policies encouraging combination of personal data across databases. It includes India Digital Ecosystem Architecture (InDEA)⁸⁷, which is being updated and the Draft India Open Data Access Policy⁸⁸ for the free sharing of data within government and its enrichment, valuation, and licensing to the private sector. A noticeable feature within the unification frameworks is their emphasis on innovation and growth that will be spurred by greater data capture through individual digital platforms which then will need to be combined to provide a complete profile of an individual. Further data unification exists under digital security programmes such as Crime and Criminal Tracking Network System (CCTNS) that leads to 360 degree profiling.⁸⁹

To be clear, we should not be against technology, but for it to be applied with humanistic and constitutional values. In the absence of a data protection law or meaningful surveillance reforms there is a promotion of commercial imperatives of purposeless processing and licensing it to the private sector. Even finding recognition within the National Economic Survey 2019, which serves as a guide to India's yearly, national federal budget, it states, “Governments already hold a rich repository of... data about citizens.. Merging these distinct datasets would generate multiple benefits with the applications being limitless ... The private sector may be granted access to select databases for commercial use... Given that the private sector has the potential to reap massive dividends from this data, it is only fair to charge them

83 'Consultation Paper on IDEA' (Department of Agriculture, Cooperation & Farmer Welfare, Government of India, 1 June 2021)
<https://agricoop.nic.in/sites/default/files/IDEA%20Concept%20Paper_mod31052021_2.pdf> accessed on 22 April 2022

84 Ministry of Labour and Employment, Government of India, 'e-SHRAM portal' <<https://eshram.gov.in/>> accessed on 22 April 2022

85 'National Digital Education Architecture' (Department of School Education and Literacy, Ministry of Education, Government of India)
<https://www.ndear.gov.in/files/NDEAR%20Main%20Report_July%2026_210728_194926.pdf> accessed 22 April 2022

86 'Data Empowerment And Protection Architecture - Draft for Discussion' (NITI Aayog, August 2020)
<<https://www.niti.gov.in/sites/default/files/2020-09/DEPA-Book.pdf>> accessed 22 April 2022

87 'InDEA 2.0 Framework' (Ministry of Electronics & Information Technology, January 2022)
<https://www.meity.gov.in/writereaddata/files/InDEA%202_0%20Report%20Draft%20V6%2024%20Jan%2022_Rev.pdf> accessed 22 April 2022

88 'Draft India Data Accessibility And Use Policy' (Ministry Of Electronics and Information Technology, Government Of India, 21 February 2022)
<https://www.meity.gov.in/writereaddata/files/Draft%20India%20Data%20Accessibility%20and%20Use%20Policy_0.pdf> accessed 22 April 2022

89 National Crime Records Bureau, Ministry of Home Affairs, Government of India, 'Crime and Criminal Tracking Network & Systems (CCTNS)' <<https://ncrb.gov.in/en/crime-and-criminal-tracking-network-systems-cctns>> accessed 22 April 2022

for its use.⁹⁰ Revenue generation prompted licensing of citizens' data to the private sector has been through the Bulk Data Sharing Policy of the Ministry of Road Transport and Highways in March, 2019.⁹¹ Subsequently, vehicular data in the VAHAN⁹² and SARATHI⁹³ databases was licensed for Rs. 3 crore annually. The policy was withdrawn after the data was used in a communal riot to identify persons by religion, based on vehicles parked at their houses. Each of these policies have profound implications for the future of our country. Each one deserves greater scrutiny and debate. The promise of both technology and constitutionalism offers great hope to improve the lives of ordinary Indians to be squandered to greed for power or profit.

If you consider this lecture polemical, or one-sided, I urge you to examine two relevant considerations. First, the prepotent social narrative is one of victory over COVID. As per recent CSDS data less than one third from three of four recent poll bound states blame the central government for Covid deaths, and it remains immensely popular.⁹⁴ Here, I only want to offer a moment of pause, for thought. Second, the issue itself is literally of life and death. As per a recent New York Times article the estimates of deaths in India have been severely underreported in a WHO global study that is being resisted by the Union Government. It states, "The W.H.O. will show the country's toll is at least four million, according to people familiar with the numbers who were not authorised to disclose them, which would give India the highest tally in the world,".⁹⁵

I hope through this lecture, I have been able to demonstrate that Indian society, primarily the Union Government despite using modern technology for public health, was chained to tribalism refusing freedom through constitutional values. Here, fear and uncertainty enabled the expansion of surveillance and policing powers and offered broken promises of a digital utopia, delivering coercion, distraction and exclusion. This applied most acutely to large

90 'Data "Of the People, By the People, 04 For the People" - National Economic Survey 2018-2019' (Ministry of Finance, Government of India, July 2019) p. 94 <https://www.indiabudget.gov.in/budget2019-20/economicsurvey/doc/vol1chapter/echap04_vol1.pdf> accessed 22 April 2022

91 Bulk Data Sharing Policy & Procedure' (Ministry of Road Transport and Highways, Government of India, March 2019) <<https://parivahan.gov.in/parivahan/sites/default/files/NOTIFICATION%26ADVISORY/8March%202019.pdf>> accessed 22 April 2022

92 Ministry of Road Transport & Highways, Government of India, 'Vahan' <<https://vahan.nic.in/nrservices/#>> accessed 22 April 2022

93 Ministry of Road Transport & Highways, Government of India, 'SARATHI' <<https://sarathi.parivahan.gov.in/SarathiReport/sarathiHomePublic.do>> accessed 22 April 2022

94 The Hindu Bureau, 'The Hindu-CSDS-Lokniti post-poll survey 2022: Welfare, regional factors provided ballast to BJP in Uttar Pradesh' (The Hindu, 12 March 2022) <<https://www.thehindu.com/news/national/the-hindu-csds-lokniti-post-poll-survey-2022/article65215064.ece>> accessed 22 April 2022

95 Stephanie Nolen and Karan Deep Singh 'India Is Stalling the W.H.O.'s Efforts to Make Global Covid Death Toll Public' (The New York Times, 18 April 2022) <<https://www.nytimes.com/2022/04/16/health/global-covid-deaths-who-india.html>> accessed 22 April 2022

sections of our population which lacked economic and social power -- the weak and the poor. Our own personal tragedies pale, almost seem petty in comparison.

If you have heard this lecture fully some of you may feel anger. Likely, towards the government, maybe even towards me. I urge you to forsake anger, cynicism, defensiveness or the rhetoric of civilisational pride. We must choose a scientific temper for the pandemic is far from over and lives continue to be at risk. To conclude, I will invoke the words of one of the most famous alumni of the Indian Law School, Pune, our former Chief Justice, Mr. M.C. Chagla who wrote to Morarji Desai stating, *"You say you are apprehensive about the future. So am I. I love my country with the same intensity and fervour as anyone else. And I am seeing tendencies which if not checked will lead us to unbridled dictatorship. You and I don't count. Our vanity, our amour-propre, our sensitivity, are nothing compared to the future destiny of our people."*⁹⁶

Thank you for your patience. I look forward to the remarks of the discussants and wish you and your family good health in this brave new India.



96 M.C. Chagla, 'Roses in December: An Autobiography' (Bharatiya Vidya Bhavan 2000) p 481.

Annexure

II

List of previous lectures and speakers in the KR Memorial Lecture series

-
- Tenth : ‘Hospitals as factories of medical garbage?’ by Sarah Hodges
-
- Ninth : Contemporary Issues in Health and Social Sciences by Dr Sunil Pandya
-
- Eighth : The golden Rule: A Remedy for Decadence in Global Health by Eric Suba
-
- Seventh : Rethinking Population Education: Challenging the Gender and Structural Violence of Prevailing Norms by Dr Betsy Hartmann
-
- Sixth : Ethics of Public Health interventions: A view from the frontline by Dr Yogesh Jain, JSS
-
- Fifth : Universal Access to Health care. The speakers were Dr K. Srinath Reddy by Dr Armando de Negri Filho
-
- Fourth : Equity and health by Dr Gita Sen
-
- Third : Clinical Trials and HealthCare regulation in India a day long workshop on the subject.
-
- Second : Dominant Development and Peoples’ Alternatives Play and Interplay in Chhattisgarh by Ilina Sen
-
- First : Making and Un-making Poverty: Social science, Social Programmes, and Poverty Reduction in India and Elsewhere by Anirudh Krishna
-



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