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A Deep Dive for Big Money

The Ayushman Bharat Digital Mission

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The big data analytics envisaged by Ayushman Bharat Digital Mission could promote private insurance and big tech firms at the cost of patient outcomes and privacy.

Amidst the Covid-19 pandemic, the union government and the National Health Authority are fast moving to implement the Ayushman Bharat Digital Mission (ABDM). They claim that ABDM will help individuals choose the healthcare they want and improve healthcare decision making and efficiency.

But the urgency of its implementation raises questions about the motive behind the initiative. There remain serious concerns about the safety and integrity of personal information.

The ABDM is ambitious. Its stated objective is to "develop the backbone necessary to support the integrated digital health infrastructure of the country". The ABDM aims to provide a unique health ID to all individuals, backed by electronic health records (EHR). It will create a registry of health facilities and health professionals across different systems of medicine.

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Collecting electronic health records of 1.4 billion citizens, integrating information on healthcare providers and professionals, and using this data for making healthcare decisions in real-time appears fascinating. Yet each of these steps is likely to be mammoth and expensive, with multiple challenges. The United Kingdom, for instance, in 2010 dismantled its electronic health record systems after spending more than 12 billion pounds over five years — one of the most expensive healthcare IT failures to date (Lays 2011).

As a country, with the dubious distinction of having one of the lowest levels of public spending on healthcare, and with poor health outcomes, can India afford such expensive mistakes?

A shot in arm for private insurance

The big data analytics envisaged by ABDM suits a particular type of health financing and delivery system: private voluntary insurance schemes. Indeed, ABDM becomes a prerequisite for the expansion of such schemes, as envisaged by plans for financial protection for the non-poor in the informal sector ("the missing middle").

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Voluntary insurance schemes operate on principles of risk rating. People who are judged to have a higher risk of falling ill have to pay higher premiums. Thus, information about the health status of enrolled people becomes crucial in deciding premium prices, co-payment rates, as well as denying claims. When governments purchase coverage on behalf of citizens, like under the Prime Minister Jan Arogya Yojana (PMJAY), health records of population groups become a crucial tool in negotiating premiums. When providers are to be paid, exhaustive information about their performance becomes essential in deciding package rates.

The profits of the insurance industry thus depend crucially on the availability of health records of individuals. But the Indian health system currently neither has exhaustive data on the health profiles of individuals nor rigorous information about healthcare providers, the kind of data required by insurance companies, the payers, or for PMJAY.

Both PMJAY and ABDM are thus part of a larger project towards the greater commercialisation of healthcare and to convert healthcare into a source of monopoly and oligopolistic profits — all of this using public resources.

Function creep

Programmes like ABDM could also help Big Tech get a grip over India's health system.

> Most health systems, particularly those in low- and middle-income countries, do not have the financial or technological capacity to develop algorithmic technologies.

The global health data economy is estimated to be worth $152 billion. It is dominated by the technology giants like Google, Facebook (now Meta), and Amazon. These firms extract the commercial value of health data by collaborating with healthcare providers to develop new algorithmic technologies (Dickens 2020). Their expertise is sought because most health systems, particularly those in low- and middle-income countries, do not have the financial or technological capacity to develop algorithmic technologies needed to operationalise digital systems. The public sector also lacks the necessary commercial expertise to strike up effective deals with the tech giants.

Google, Meta, and Amazon profit from advertising sales premised on their ability to collect, analyse, and draw inferences from personal data. A key source of revenue for the big data market is to use data collected for one purpose for other uses. Electronic health records handed over to tech giants have not been immune to this kind of function creep.

For instance, the UK's National Health Service gave Google's DeepMind free access to 1.6 million patient records in exchange for developing a new clinical application to detect acute kidney injury (Dickens 2019). The deal granted DeepMind exclusive property rights to technologies developed through this collaboration, allowing it to control access, set prices and earn profits, using public resources, all at the cost of severe compromises on the right to privacy and safety of patient data.

Palantir, a secretive tech giant, provides technology to the Immigration and Customs Enforcement agency in the United States for conducting immigration raids that have led to hundreds of arrests, deportations, and family separations. In April 2020, Palantir won a contract with the Department of Health and Human Services to build the Protect Now platform aggregating hundreds of different data sources from the government and private sector in the US (Davis 2020). This opens the possibility of electronic health records being used for the abuse of human rights.

Closer home, India's health ministry has handed Persistent Systems a contract to build a digital data hub to record, store, and process health information across 10 Indian states. According to an investigative report by *The Wire*, Persistent Systems is linked to operatives using Tek Fog, a highly sophisticated app to hijack major social media and encrypted messaging platforms and amplify right-wing propaganda to a domestic audience. (The company, in a statement, said it had no links to Tek Fog.)

Such practices around the use of technology within the context of public health pose serious concerns, especially for vulnerable sections of society. Privacy regulations to safeguard electronic health records from potential fraud, that have been put in place in the European Union or North America, are virtually absent in India.

Voluntary for whom?

Enrolment under the ABDM is voluntary. But the experience of Aadhar shows that what was voluntary to start with gradually became mandatory for many basic services. Even after a Supreme Court judgement to curb the executive excess, Aadhaar continues to be routinely demanded for basic rights such as Anganwadi services, school enrolment, or Covid-19 vaccination for adults. There is no reason to believe that ABDM would not be used similarly and would not end up being another source of exclusion of the needy.

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For individuals, enrolment should be voluntary. But if healthcare professionals and providers fail to enrol, it would defeat the whole purpose. After all, to choose between healthcare providers, we need comprehensive real-time data from *all* providers.

Given a history of non-compliance of the private sector with public programmes, particularly its reluctance to share data and information, and the myriad conflict of interests that prevail, ABDM is unlikely to succeed in creating a comprehensive database of healthcare providers and professionals. ABDM should make mandatory the sharing of health records by establishments empanelled under

publicly funded and organised programs like PMJAY, Employees' State Insurance Corporation, or Central Government Health Scheme.

The myth of choice

ABDM documents repeatedly invoke patient choice as a key goal. The argument is that information on the performance of providers would allow patients to choose the most efficient provider, enhance competition, bring down prices, and increase efficiency. But there are problems in trying to equate clinical decisions with business decisions. Healthcare sector experience multiple forms of market failures which makes establishing conditions of competition virtually impossible.

> Patients seldom act as rational consumers because they do not have adequate information about the need or timing of healthcare.

Most research show that consumers seldom apply choice for seeking healthcare (Glide and Smith 2013). The UK introduced a Choose and Book programme in 2004, to allow patients a choice of doctor appointments and hospitalisations. But very few patients and doctors used the system, a phenomenon termed as "clinical resistance" (Greenhalgh 2013).

Patients seldom act as rational consumers because they do not have adequate information about the need or timing of healthcare, or the possible outcome of the healthcare sought. They depend on the decision of the physician. The physician, guided by the Hippocratic Oath and aided by clinical information and skills, acts as an agent of the patient (the principal) to choose an appropriate mode of healthcare.

Trust in the physician's judgment becomes a crucial driver when the ability to choose is limited. The more complex healthcare gets, the more is the gap between the patient's knowledge and that of the physician. The physician enjoys a monopoly over clinical decisions.

So long as this principal-agent relationship is guided by trust and the physician's interest is aligned with that of the patient, healthcare provisioning works on a rational basis. The moment the physician is governed by commercial interests, patients are subjected to potential maleficence and unnecessary modes of treatment. Healthcare costs increase, resources get diverted to those who can afford care, and access is denied to the poor and needy.

> Consumer choice continues to remain a myth even as the cost of care shoots up to levels unsustainable even for the most affluent countries, not to mention developing ones.

Markets address this problem of information asymmetry between the patient and the physician through insurance. Here the physician and providers become agents of the insurance provider, who in turn is the agent of the patient. Yet, even as governments and insurance companies try to curb unnecessary use of services (induced demand), information asymmetry continues to prevail and induced demand deceives the eyes of most regulators. More resources are thrown in to heal the symptoms, without trying to address the fundamental problem.

Thus, to sustain the market for healthcare providers, insurance is brought in. To sustain the insurance system, Third Party Administrators (TPAs), who scrutinise claims on behalf of insurance companies, become essential. For TPAs to function effectively, a complex digital health architecture is invoked. Consumer choice continues to remain a myth even as the cost of care shoots up to levels unsustainable even for the most affluent countries, not to mention developing ones. In the United States, for instance, approximately a third of the total spending in healthcare goes into regulation and administrative costs. About $496 billion is paid for billing and insurance related costs (Gee 2019). This is more than the total public spending on health of 154 countries around the world.

Data, for what?

The experience of the pandemic has shown us how weak our data systems are. Even when public programmes collect enormous volumes of data, using significant resources — often at the cost of delivery of healthcare — the health system does not make appropriate use of data to make informed decisions. Policies often contradict or ignore evidence, and data is used selectively to further vested interests. The health system often does not collect the data we need, hides data that exposes faults, and seldom analyses the data it collects. We do not even know how many hospital beds we have in our country, how many health professionals are there, where they are located and what services they provide. Even basic data like death registration is far from complete, making it difficult to measure death estimates. Epidemiologists and mathematicians have pointed out that incomplete death registration has led to considerable

under-counting of Covid-19 deaths (Guilmoto 2021).

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However, these problems do not make a case for a programme like the ABDM. Do we need personal health records to make more informed healthcare decisions? Does having real-time information about healthcare providers and professionals increase patient choice? Is it at all possible to protect such data from commercial misuse or comprise of personal protection? Can a resource constraint economy like ours afford to have such an extensive architecture? Who benefits from the system most? Some of these questions remain unanswered in the current official discourse.

Using digital technology to make healthcare choices would benefit only a small affluent section of the society and systematically leave out the vulnerable sections, whom Prime Minister Narendra Modi frequently invokes. Only 15% of women and a fourth of men in India use the internet in India (Nikore 2021). This digital divide has created barriers to economic opportunity for a large part of the vulnerable section of society.

The experience with the COWIN app for booking Covid-19 vaccination slots is instructive. Large sections of the population found it difficult or even impossible to book their vaccination using the app — in particular, the elderly, people with poorer educational backgrounds, women, people working in the informal sector, and rural residents, found it difficult to access vaccines. This added to the chaos of the early phase of vaccination.

An alternative

Centralised collection, digitisation, and storage of health data could end up establishing unprecedented dominance by big capital and the state and curbing the rights of citizens. In centralised systems, where governments retain data gathered by private entities on a central server, it is harder to protect the data from being shared for commercial use or human rights abuses. Such attempts need to be resisted and an alternative health system needs to be created. Such a health system would necessarily be democratic, decentralised, people-centric, and non-commercialised.

> An alternate system would also need data, but such data would be locally managed and not centrally stored, and hence less vulnerable.

An alternative vision of healthcare should be based on the foundations of primary care, where an individual would develop a long-term relationship of trust with the health system. Any personal records collected would be stored at the local level. The choice of secondary and tertiary care would be mediated by the primary provider. She would possess the information about the appropriate provider and would also know the patient well, act as a source of support to the sick, and would be able to suggest the best course of action. Instead of commercial interest, she would be accountable to the people directly.

Such an alternate system would also need data, but such data would be locally managed and not centrally stored, and hence less vulnerable to breaches, threats and commercial misuse. Here the emphasis would be more to have robust and comprehensive health system data, rather than an expensive centralised system for electronic health records.

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