

Ministry of Health & Family Welfare
National Health Authority

Letter

New Delhi
24th Sept 2020

To,
The Editor,
Thomson Reuters Foundation

Subject:- Response to the report titled “ANALYSIS-Privacy concerns as India pushes digital health plan, ID” published on 22nd Sept 2020 in Reuters which can be accessed at <https://www.reuters.com/article/india-health-tech/analysis-privacy-concerns-as-india-pushes-digital-health-plan-id-idUKL8N2G536U>.

Sir/Ma’am,

Despite detailed responses from the NHA to queries of Thomson Reuters, the story presents a selective and partial view of the facts. It quotes concerns from some individuals to which responses were already provided by the NHA but seem to have been omitted from the article. The article provides only brief excerpts at best, which leave the concerns largely unaddressed. The article does not endeavour to provide a balanced view of facts as is expected from an establishment of such repute. Further, the said story has been carried by other media/publications as well. Some points in the article that particularly merit further consideration and fair reporting, are as follows: -

1. “But without a data protection law or an independent data protection authority, there are few safeguards and no recourse if rights are violated, said Raman Jit Singh Chima, Asia policy director at Access Now, a digital rights non-profit.”

While quoting the concerns on the legal safeguards raised, the NHA’s response that was provided on the existing and proposed legal safeguards to ensure the privacy and protection of an individual’s rights was omitted, with only partial excerpts included later.

NHA Response (17th Sept 2020): “Adequate safeguards have been provided by way of the draft Health Data Management Policy. Feedback is still being received through the public consultation process, and the concerns highlighted shall be adequately addressed before finalization of the Policy. There is a pre-existing legal framework including laws, rules, and judgements of the Hon’ble Supreme Court for

the protection of privacy and prevention of abuse. Further, the draft Policy also draws from the provisions of the Personal Data Protection Bill and will be kept compliant with any future legislations and rulings as applicable. NDHM will follow the principle of “privacy by design” and ensure that privacy of data receives the highest degree of attention in how the data is collected, stored, shared, and used.”

2. “It will possibly be the largest centralised health ID and data storage system in the world, and it is being done in the absence of a data protection law and data protection authority,” he told the Thomson Reuters Foundation.”

It is also reiterated, no central data storage system of health records is being created under NDHM, as NDHM employs a federated architecture. This was also not clarified in the article as factually incorrect despite being clarified by the NHA in advance.

NHA Response (17th Sept 2020): “The NDHM follows a federated architecture. The information pertaining to the health condition of the patient shall lie in the repository of the concerned hospital or healthcare facility. There shall not be any central database for this purpose. NDHM seeks to provide a platform which will enable the data to be accessed by various healthcare providers (like doctors) with the consent of the patient. This will enable the healthcare professional to provide a better quality of healthcare.”

3. “Health is a state subject, but the central government is rushing this policy in the middle of a public health emergency, and forcing states to play ball. It’s very problematic.”

No attempt was made to clarify the unsubstantiated claims in the quote above, despite a detailed response from the NHA. The NHA understands that health is a State subject. States are and shall always remain critical partners in the formation and implementation of the NDHM. It has been ensured that States have been consulted in each step of the design. The National Digital Health Mission is essentially an implementation of the National Digital Health Blueprint released by the Government of India in 2019. There has been extensive dialogue with States before releasing the National Digital Health Blueprint (NDHB). There have been further consultations with States on the implementation of NDHM in July. States have also been requested to kindly provide their thoughts and feedback on the draft Health Data Management Policy and the Mission as well.

NHA Response (17th Sept 2020): “The policy does not deal with the policies and governance of Health by States. The objective of this policy is to delineate the “minimum standard for data and its privacy protection that should be followed across the board in order to ensure compliance with relevant and applicable laws, rules and regulations”. Hence, it does not seek to change the existing rights, duties, or obligations of any of the stakeholders, including individuals, States, Medical Councils, healthcare providers, and others. The policy only seeks to define the requirements and protections afforded to all participants in the National Digital Health Ecosystem, in addition to existing legal framework including laws, rules, and judgements of the Hon’ble Supreme Court.

This is required because even though Public Health is managed by State Governments, there is a need for uniformity in processes of healthcare and public health. This is also necessary so that the data and information can be portable for the benefit of the person seeking healthcare or for framing policies for the improvement of health indicators.”

4. “The new Health ID has the potential to be made mandatory and deny services to those who opt out, while also posing the risk of data abuse, human rights campaigners say.”

The NHA has consistently reiterated that the generation of Health ID is a purely voluntary exercise i.e. consent-based arrangement. The provision of such benefits shall be as per laws and judgements of the Hon’ble Supreme Court. Therefore, it is assured that the benefits of publicly financed healthcare shall continue in accordance with the law.

NHA Response (17th Sept 2020): It has been clearly stated that participation in the National Digital Health Mission is voluntary. An opt-out option will be available in case anyone who registered in the intervening period wishes to withdraw their participation from NDHM.

5. “The policy also allows the sharing of anonymised data with third parties - “a matter of grave concern”, particularly for sexual minorities and those with disabilities, he said.

The privacy implications of such data sharing requires in-depth examination because anonymised data can be identified if combined with other data sets such as voter records,” he said.”

In addition to the provisions in the Health Data Management Policy, anonymized data will fall under the purview of Non-Personal Data. NDHM will be compliant with the recommendations of the Expert Committee on Non-Personal Data Governance Framework, and any resulting policies. There are several globally accepted techniques for data anonymization. The Government would evaluate these methods before deployment.

NHA Response (17th Sept 2020): “NDHM will follow the principle of “privacy by design” and ensure that privacy of data receives the highest degree of attention in how the data is collected, stored, shared, and used.”

6. “More than 100,000 Health IDs have already been created in six federal territories, and made mandatory for doctors in government hospitals in at least one city, according to local media reports.”

The NHA’s response to this issue has also been omitted from the article, the absence of which portrays a skewed and distinctly different picture of the issue.

NHA Response (17th Sept 2020): “It has been clearly stated that participation in the National Digital Health Mission is voluntary. The authorities in this regard have been advised not to issue any such orders and withdraw/amend any such orders if already issued. It may be noted that PGIMER Chandigarh and others have

consequently modified the circular and it has been clarified that the registration for generating Health IDs is purely a voluntary exercise. An opt-out option will be available in case anyone who registered in the intervening period wishes to withdraw their participation from NDHM.”

It may be noted that the queries from Thomson Reuters dated 16th September 2020 were responded to by email dated 17th September 2020 by the NHA. The complete transcript of the same is enclosed in Annexure-A.

It is requested that the said clarification may be published in the interest of fair, balanced, and accurate reporting. It is also requested that the same may be communicated to other media/publications which carried the above story.

Sincerely,

National Health Authority,

Govt of India, New Delhi

Annexure-A

Response (by emails dated 17th Sept 2020) from the NHA to queries by Thomson Reuters (received by emails dated 16th and 17th Sept 2020)

1. Health has always been a matter for states to govern. Why is a central policy needed?

The policy does not deal with the policies and governance of Health by States. The objective of this policy is to delineate the “minimum standard for data and its privacy protection that should be followed across the board in order to ensure compliance with relevant and applicable laws, rules and regulations”. Hence, it does not seek to change the existing rights, duties, or obligations of any of the stakeholders, including individuals, States, Medical Councils, healthcare providers, and others. The policy only seeks to define the requirements and protections afforded to all participants in the National Digital Health Ecosystem, in addition to existing legal framework including laws, rules, and judgements of the Hon’ble Supreme Court.

This is required because even though Public Health is managed by State Governments, there is a need for uniformity in processes of healthcare and public health. This is also necessary so that the data and information can be portable for the benefit of the person seeking healthcare or for framing policies for the improvement of health indicators.

2. Why is the NDHM needed at this time, when the country is still battling a pandemic?

It may be noted that the COVID-19 pandemic has further demonstrated the need for the Government to move swiftly to improve access to medical facilities as well as improve medical infrastructure-both digital and non-digital. NDHM has been years in the making and has undergone multiple rounds of consultation in the development of the National Health Policy 2017, National Health Stack 2018, and finally the National Digital Health Blueprint 2019. Hence, it is incorrect to assume that this has been a rushed undertaking and has instead undergone careful deliberation for years. Indeed, given the COVID pandemic situation and changes in the ways of life and governance brought about due to this pandemic, it is all the more important to have digital systems in place to augment and improve healthcare.

3. There are concerns that the policy does not adequately protect data or privacy – particularly as the data protection law has not yet been passed. How will privacy be protected, and how will you ensure data is not abused? Why cannot the policy wait till the data protection bill is passed?

Adequate safeguards have been provided by way of the draft Health Data Management Policy. Feedback is still being received through the public consultation process, and the concerns highlighted shall be adequately addressed before finalization of the Policy. There is a pre-existing legal framework including laws, rules, and judgements of the Hon’ble Supreme Court for the protection of privacy and prevention of abuse. Further, the draft Policy also draws from the provisions of the Personal Data Protection Bill and will be kept compliant with any future legislations and rulings as applicable. NDHM will follow the principle of

“privacy by design” and ensure that privacy of data receives the highest degree of attention in how the data is collected, stored, shared, and used.

4. A pilot for the NDHM is already in place at some union territories, with doctors being made to compulsorily register for DigiDoctor. Why is this the case when the programme is said to be entirely voluntary?

It has been clearly stated that participation in the National Digital Health Mission is voluntary. The authorities in this regard have been advised not to issue any such orders and withdraw/amend any such orders if already issued. It may be noted that PGIMER Chandigarh and others have consequently modified the circular and it has been clarified that the registration for generating Health IDs is purely a voluntary exercise. An opt-out option will be available in case anyone who registered in the intervening period wishes to withdraw their participation from NDHM.

5. Anything else you would like to add.

The NDHM follows a federated architecture. The information pertaining to the health condition of the patient shall lie in the repository of the concerned hospital or healthcare facility. There shall not be any central database for this purpose. NDHM seeks to provide a platform which will enable the data to be accessed by various healthcare providers (like doctors) with the consent of the patient. This will enable the healthcare professional to provide a better quality of healthcare.

NHA may be reached out to, in case there are additional queries or doubts.

6. What is the need for a separate Health ID when most citizens already have Aadhaar?

The legal framework of the Aadhaar Act including judgments of Hon’ble Supreme Court of India do not allow the Aadhaar ID to be used for such purpose. This necessitates the creation of a separate Health ID. It may however be noted that, the option of generating Health ID using Aadhaar ID is also provided to users. Therefore, users need not remember all such numbers. It shall be possible to use the system using any number or ID like Health ID, Aadhaar ID (if used during generating Health ID), mobile number, etc.