Jan Swasthya Abhiyan

(Peoples Health Movement – India)

Health for All - Now! ***Health is a Basic Human Right!***

Comments by Jan Swasthya Abhiyan on the Health Data Management Policy (HDMP) under the National Digital Health Mission (NDHM)

1. **Governance Structure:** The HDMP document states that "the governance structure for the NDHE shall be as specified by the NHA, which shall lead the implementation of the NDHM." The National Health Authority (NHA) was created as the National Health Agency in 2017 for the purpose of managing PM-JAY, and later placed under Niti Aayog. Since Niti Aayog is under the prime minister, the HDMP, which is a subset of the NDHM, can any time be subjected to arbitrary executive changes. The National Health Authority and its mandate to manage the NDHM, and the HDMP should be secured through legislations and not merely executive orders.

2. **Any entity can collect, process and distribute personal health data:** HDMP defines three crucial terms – 'data fiduciary', 'health information provider (HIP)' and 'health information user (HIU)'. Closely looking at the definition of these terms, it is seen that data fiduciary can be any person or any private company, who can determine the purpose and means of processing personal data. Data fiduciary can be HIP or HIU. HIP-s are any private hospital or diagnostic centers or service providers who register under NDHM. HIU-s can be absolutely anybody who can request access to such data based on consent. All this with a subtle provision that NHA will define and change terms and conditions of HIP and HIU from time to time. **This is absolutely unacceptable.**

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Secondly, the time limit of validity of a consent for collection or processing of personal health data must be defined and should not exceed a maximum limit of a few days, typically as needed by the patient to get treatment, surgery, medicines, diagnostics and other healthcare services for the duration of an illness. For chronic illnesses, the consent has to be newly obtained after expiration of the maximum limit of validity of consent.

3. **Personal Health Information or aggregated data cannot be monetised:** A program like NDHM and its associated policies should serve the purpose of access to affordable and quality healthcare for all citizens. Any data or analytics that flow out of NDHM should be used by Government or by state regulated entities to improve public health outcomes and should be used for that purpose only. It must be clearly stated in HDMP that no data, personal or aggregated, can be monetised by any party, including the Government.

4. **Inconsistencies between NDHM strategy and HDMP on Health ID:** In the HDMP document, Chapter IV talks about the principle of non-exclusion for Health ID and categorically mentions that no one would be forced to have a health ID and no one can be denied access to any service for not opting to have a Health ID. But in the NDHM strategy overview document, it states that all government health programmes are mandated to integrate with the service and issue Health IDs as part of their programs. This essentially means that someone, for example, who is receiving service under the Revised National TB program (RNTCP), will be required to create a Health ID. The principle of non-exclusion of anyone from any facility or service for not having Health ID should be final and cannot be overridden by any strategy/order/policy of NDHM or NDHE.

5. **Health ID mandatory? The deceiving game has already started even before HDMP has been officially finalised.** Recently the Joint Principal Medical Officer of Govt Multi-speciality Hospital, Chandigarh issued an order, dated 19.08.2020, where it was clearly mentioned that registration and generating Health ID under NDHM is mandatory for all the citizens of the country and directed all its employees, their family members and its allied dispensaries to register and create Health ID-s! This is an utter disregard to people's health rights and a shocking example of deceit with citizens.

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6. **Citizens will be forced to have yet another id:** Though, at this point in time, an assurance is being given that a unique Health ID will not be made mandatory, or that services will not be denied for not having a Health ID, once national programs, insurance providers, healthcare providers move to the NDHE platform, having a unique Health ID will become automatically compulsory for patients who are dependent on publicly financed health care provisions. With the experience of Aadhaar card where poor citizens have been left out of various social safety net programs for not being able to produce Aadhaar cards, such an assurance by HDMP will be proved a false one.

7. **Concept of Health Locker is ambiguous and misleading**: HDMP defines health lockers as a service of information exchange of electronic health records where presumably personal health information will be stored. It is not clear who maintains these lockers? NDHM Strategy document states that health lockers are cloud stores and several health lockers will exist to give patients choice. This indicates that multiple private service providers will be allowed to store personal data in health lockers, raising serious concerns on who will be held accountable for any breach of security of these lockers?

8. **Ownership and Power of Data Principals is unfounded**: Data principals are persons whose personal health data is collected. Chapter III (Consent Framework) of HDMP makes sweeping promises on how data principals will be given complete control and decision making power over collection and processing of their personal data. But given the huge disparities that exist today in our country in terms of level of education, socio-economic status and other social dynamics, actual real-life data principals will never be in a position to exercise such control, especially when a person seeking healthcare is already in a vulnerable state.

   The same HDMP document, in a later part of the document (in paragraph 14- Rights of data principals) makes erasure of own data heavily conditional, essentially curbing rights of data principals on their own personal data.

9. **Concept of Consent Manager is unclear:** HDMP mentions a concept of 'consent manager' in paragraph 11 (Method of obtaining consent) and states that consent can be obtained either from data principal or through a consent manager. Further clauses specify that consent manager can collect and process personal information. HDMP defines consent manager as an entity or individual who interacts with data principals and obtains consent of data principals. However, when a media article was published in Indian Express on 14.09.2020 that questioned whether the role of consent manager will be played by private players, NHA issued a rebuttal saying consent manager is 'an electronic system' which manages the consent! This is unfortunate that citizens are being misled by contradictory and unreliable information on something as crucial as method of consent to their personal health data.

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10. **Grievance redressal mechanism shifts the burden on data fiduciaries which are a sure shot formula of endless public suffering:** The grievance redressal mechanism described in HDMP is extremely weak to the point of non-existing as far as citizens are concerned. The policy states that the data principals will have to approach a 'data protection officer' who is an appointee of the data fiduciary, which can be any private healthcare entity. The system will obviously have many data fiduciaries, each with a data protection officer. This essentially means that citizens will have to go about in loops among many data protection officers of many data fiduciaries to resolve their grievances till they finally reach MOHFW or the Court. A strong and accountable grievance redressal system should be put in place with appropriate penalties and compensation, as the case may be, in the event of any breach of the patient's rights.

11. **Research use not to be conflated with data management of personal information:** HDMP states that anonymised and aggregated data can be made available by data fiduciaries for research. But for this purposes, separate channels and mechanisms and authorities must be created. Research use need not and must not be conflated with use of PHIs in individual patient care. This is important to demarcate because much of the so called research could be data mining for market research for a wide range of users far removed from the purposes for which individual trusted providers with the data.

12. **NDHM should be a program that States can optionally sign up to**: The Health Data Management Policy (HDMP) is the first step to implement National Digital Health Mission (NDHM). No national mission should be started for the subjects which are in the State list or in the list of subjects covered under the 73rd and 74th amendment. So, NDHM should just be a programme and not a national mission.

13. **Setting the right priorities to provide health for all:** The government has failed time and again to meet its commitments to increase public heath expenditure in order to increase health workforce, infrastructure, quality of services and manufacture of essentials like medicines, diagnostics, equipment etc. India's total healthcare spending (out-of-pocket and public), at 3.6% of GDP, is way lower than that of other developing countries like Brazil, South Africa, Russia and China. Thus it's a pertinent question that at a time when the country is reeling under the COVID-19 pandemic due to its weak public health system, why is NDHM being prioritised over other basic healthcare needs of the common citizens?

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