

# Draft National Health Data Management Policy

October 24, 2020

Prime Minister on the 74th Independence Day launched the National Digital Health Mission (NDHM) under which a digital health ID would be created for all Indians. The Draft National Health Data Management Policy is the maiden step in realizing NDHM's guiding principle of individual's security and privacy.

**In news:** Draft National Health Data Management Policy is released.

**Placing it in syllabus:** Society – health

**Dimensions**

1. In news
2. Provisions
3. Importance
4. Criticisms

## Content:

### In news:

- The **National Health Authority (NHA)** has released the **Draft Health Data Management Policy of the NDHM** in the public domain.
- NHA is the apex agency of the Government of India responsible for the design, roll-out, implementation and management of Ayushman Bharat-PM-JAY and NDHM across the country.
- The **objectives** of the draft Policy includes creation of a framework for secure processing of personal and sensitive personal data of individuals who are a part of the NDHM.
- It is in **compliance with** all applicable laws and

international standards such as **ISO/TS 17975:2015** that defines the set of frameworks of consent for the collection and processing of health data by healthcare practitioners and other entities

- It **encompasses various aspects** pertaining to health data like data privacy, consent management, data sharing & protection.

## **Provisions:**

- **All health records of an individual would be stacked at one place** thus not restricting the health records of a person to just the health facility where they undergo treatment.
- The policy permits hospitals, diagnostic centres and other entities, known as **data fiduciaries**, to collect personal or sensitive personal data as specified in the policy.
- **Sensitive personal data include** a person's physical, physiological, and mental health data, financial information, sex life, sexual orientation, medical records and history, biometric data, and genetic data.
- **Other information which can be collected** under this head include transgender status, intersex status, caste or tribe, and religious or political belief or affiliation.
- Those who opt to avail the health ID card, (referred to as **data principals** in the document) are given complete control and decision-making power over how their personal data is collected and processed.
- Any personal data or sensitive personal data can be collected only after the **consent of the individual**.
- Individuals also have the **right to revoke the consent or restrict** sharing of any personal data at any time.
- Any personal or sensitive data which is not essential for this purpose shall not be processed for creating the ID.
- **Privacy notes should be shared with individuals** not only

while enrolment, but also when it is modified and also before further processing for any previously unidentified purpose.

- Before engaging with any data processor, fiduciary must enter into a contract.
- The data fiduciary will also have confidentiality agreements and non-disclosure agreements.
- **Regular audits by independent auditors** approved by the Central Government should be carried out at least once every year to ensure compliance.
- **Any data processed under this policy should not be made public** – if it is being used for clinical or academic research, statistical analysis, policy formulation, etc., the data must be anonymized or de-identified in an aggregated form.
- Those institutions with access to the data under NDHM must have a designated **Data Protection Officer (DPO)** so that individuals who have queries must be able to approach the DPO.
- The data fiduciaries should formulate and implement a **'personal data breach management mechanism'** to make sure that any instances of violation or non-compliance get promptly reported to the NHA and other relevant entities.
- NHA should formulate and implement procedures to **'identify, track, review and investigate' such incidents** and maintain a record of these instances along with the action taken.
- In case of any incident of data breach, the person responsible for it will be liable in accordance with the provisions of applicable law.

### **Importance:**

- The confidential health data will be collected from individuals across the country and stored at multiple levels- Central, State/Union Territory, and at the

health facility level and hence **electronic health records of individuals can now be accessed from anywhere in the country digitally.**

- It increases **awareness of the importance of data privacy.**
- It instills a **privacy-oriented mindset among all the stakeholders** and participants of the ecosystem.
- It could be an important **step towards achieving the United Nations' SDG of Universal Health Coverage** by covering financial risk protection, increasing access to quality essential healthcare services, medicines and vaccines for all.

### **Criticisms:**

- It is criticized as its concern is more about data than about health.
- This could lead towards greater privatization of health care.
- The Internet Freedom Foundation has also filed a petition in the Delhi High Court on the draft policy.
- There are concerns about the implementation and data privacy aspects.
- The information might be vulnerable to attack and misuse.

### **Mould your thought:**

1. What are the salient features of draft Health Data Management Policy? What are the concerns regarding it?

### ***Approach to the answer:***

- State the policy objective
- Write down its provisions
- Write the criticisms
- Conclude by writing its importance