To:

National Health Authority, 9th Floor, Tower - 1 Jeevan Bharati Building, Connaught Place, New Delhi - 110001

23rd August 2021

We thank the National Health Authority for the opportunity to provide feedback on the Consultation Paper on Unified Health Interface. The process of consultation is a welcome one, and we hope that this spirit of transparency and due process is continued in the framing of future reports, policies by the Authority.

We appreciate the Authority for reflecting feedback on the NDHM policy into this Consultation Paper (hereinafter referred as "paper"). We have been particularly pleased to see the approach to governance and stakeholder consultation adopted by this paper. However, we believe that this draft is still quite far away from a meaningful, implementable policy document - many of the ideas posited in the document, including the identification of stakeholders, pricing formula and mechanisms for grievance redressal, lack clarity and will lead to confusion and incorrect implementation. This is not to say that the conversation on the UHI is not important but in India where a personal data protection framework still does not exist, and sector specific data related regulations are being contemplated - the move to implement a UHI requires more public discussion.

At Aapti Institute, we have been working on the idea of data stewardship and offline intermediaries, examining lived experiences at the intersection of technology and society. Our detailed submission below builds off our engagement on questions of agency, digital literacy and data rights, and draws from international best practices. We hope that this draft will go through several transparent iterations.

We look forward to engaging further on this issue,

Aapti Institute



### <u>Comment on the Consultation Paper on Unified Health Interface released by the</u> <u>National Health Authority</u>

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#### Chapter 1

**Question 1.7.1:** Please refer to section 1.6.3. The Telemedicine Guidelines were issued by The Board of Governors of the Medical Council of India (MCI) in March 2020. Stakeholders are requested to go through them and suggest changes to the policy, if any, to ensure adoption of telemedicine and e-pharmacy.

**Issue:** The low rate of adoption of telemedicine services stem from issues relating to the lack of access to telemedicine services, privacy and confidentiality of patients, lack of clarity in legal responsibility and liability, and inadequate governance structure.

**Response:** The adoption of Telemedicine Guidelines (Guidelines)<sup>1</sup> is foundational to the Unified Health Interface (UHI) ecosystem. Adoption of the Guidelines would lead to an increased uptake of digitized services by patients which is core to the idea of UHI. In 2018, only 17% of the respondents in a survey on telemedicine usage stated that they used it and are willing to use it again.<sup>2</sup> However, there is scope for growth as 41% revealed that they have not used it but are willing to try. <sup>3</sup> 2020 has been the year of telemedicine with a 502% rise in online consultations from people above the age of 50.<sup>4</sup>

We have identified lack of accessibility and trust as primary barriers to telemedicine adoption and have suggested changes accordingly.

#### Lack of Accessibility

Telemedicine platforms are inaccessible to Registered Medical Practitioners(RMPs) and patients alike. For patients to access telemedicine services, RMPs must be enrolled onto the platform. In this section, we have broken down what this lack of accessibility refers to both parties and have suggested changes to the Guidelines to increase its adoption.

**Registered Medical Practitioner accessibility:** RMPs in rural areas are well aware of the benefits of telemedicine such as increased access to diagnostic services or second opinions. These services are scarcely available in rural and remote areas affecting healthcare of rural and remote communities. Though aware of these benefits, there is a lack of evidence that the benefits outweigh the financial, human resource and infrastructural costs attached to provide

<sup>3</sup> Id.

<sup>&</sup>lt;sup>1</sup> The Telemedicine Guidelines, 2020. <u>https://www.mohfw.gov.in/pdf/Telemedicine.pdf</u>

<sup>&</sup>lt;sup>2</sup> Statistica Research Department (2021), "Opinion on the usage of telemedicine in India in 2018", <u>https://www.statista.com/statistics/917308/india-attitude-towards-using-telemedicine/</u>

<sup>&</sup>lt;sup>4</sup> Lifestyle Desk (2020), The Indian Express, "502% spike in online consultations from people above the age of 50 in India: Report",

https://indianexpress.com/article/lifestyle/health/covid19-pandemic-telemedicine-online-consultation-in dia-report-7114607/



these services.<sup>5</sup> An overarching solution of engaging civil society and researchers to conduct studies documenting cost-effectiveness of telemedicine and pilot projects in furtherance of building evidence, assessing the costs and benefits to RMPs, is suggested.

**Patient accessibility:** Patients also benefit by not traveling long distances to procure care. The trust in the quality of telemedicine services is not the core issue.<sup>6</sup> Their inability to navigate through these platforms due to lack of knowledge of digitized modicums deter their accessibility. We suggest that adoption of telemedicine can be increased by incorporating offline intermediaries. Offline intermediaries are persons who help intermediate between the platform and the healthcare provider/ patient. They enable accessibility to the platforms by breaking barriers related to lack of trust and knowledge in navigating through the platform. Their significance and role in accelerating the provision of digital health care service is outlined in Chapter 3.

#### Lack of Trust

Though patients seem to be satisfied with the quality of telemedicine services, they are skeptical of peripheral issues relating to privacy, legal responsibility and a lack of governance structure which determine the level of trust.

#### (a) Patient privacy and confidentiality; and liability framework

Clause 3.7.1.2 states that RMPs are required to abide by privacy and data protection legislations. However, the issue remains that India does not have a data protection law in place. For the adoption of Telemedicine Guidelines, the implementation of an overarching data protection law (Personal Data Protection Bill, 2019(PDP))<sup>7</sup> is critical.

The significance of a clear liability framework in the online space is heightened considering the nature of information collected. Information collected is not limited to medical records and case histories but includes personal images of patients shared for the purpose of diagnosis, which otherwise would not have been shared in the offline model. The Guidelines do prevent the wilful sharing of these pictures. However, it fails to stipulate provisions in case of negligence or breach. Assignment of liability must not be based solely on the intention and

<sup>&</sup>lt;sup>5</sup> World Health Organization (2010), "Telemedicine: Opportunities and Developments in Member States", <u>https://www.who.int/goe/publications/goe\_telemedicine\_2010.pdf</u>

<sup>&</sup>lt;sup>6</sup> Acharya & Rai (2017), J Family Med Prim Care, "Evaluation of patient and doctor perception toward the use of telemedicine in Apollo Tele Health Services",

https://www.jfmpc.com/article.asp?issn=2249-4863;year=2016;volume=5;issue=4;spage=798;epage=803;aulast=Acharya

<sup>&</sup>lt;sup>7</sup> The Personal Data Protection Bill, 2019,

https://iapp.org/media/pdf/resource\_center/India\_Draft\_Personal\_Data\_Protection\_Bill.pdf



knowledge of the RMP but on standards of 'reasonable duty of care', thereby covering negligent breach as well.

Clause 3.7.1.3 states that RMPs will not be held responsible for breach of confidentiality if there is a reasonable evidence to believe that patient's privacy and confidentiality has been compromised by a technology breach or by a person other than RMP. The RMPs should ensure that a reasonable degree of care is undertaken while availing such services.

The duty of confidentiality has been limited to only intentional breach. For cases of unintentional breach or negligence by the RMPs, the standard of due diligence is unspecified. There is no further clarification on what would amount to a 'reasonable duty of care' which should be observed by RMPs. It is suggested that instead of resorting to a blanket clause of diligence, specific measures should be enumerated. These measures can be mandatory (such as privacy policies) or determining factors of liability in the case of unintentional breach (such as deployment of cybersecurity measures). Privacy policy should be inclusive of essential elements of consent, purpose of information collected, disclosure of information, and security practices and other minimum requirements deemed appropriate. This policy should be in consonance with the PDP Bill framework. The adherence to minimum requirements stipulated in law shall be certified by a designated authority (similar to the structure stipulated in Clause 22 of the PDP Bill). Beyond the PDP Bill, health data and electronic health record governance have been discussed in the NDHM in its Health Data Management Policy<sup>8</sup> and formerly proposed DISHA.

#### The case of Norway's TeleECG initiative

Methods to structure liability are stipulated in several telehealth initiatives/ guidelines. We can learn from the teleECG initiative in Norway which is a telemedicine service used to facilitate early diagnosis and treatment of suspected myocardial infarction in patients not in hospital. The legal responsibility of each party in providing the service has to be clearly laid out. Each person in the process of providing care has a role and responsibility. These workflows can be documented for every service provided for legal and security reasons.<sup>9</sup>

A similar 2-step approach/procedure can be adopted:

(1) determining the responsibility of each party which should be informed to the patient prior to availing the service (The RMP will have to enlist the circumstances in which they will be liable. If there are multiple parties involved in giving care, then the division of responsibility must be stipulated indicating clearly which service was provided by which caregiver) and;

<sup>&</sup>lt;sup>8</sup> The National Digital Health Mission: Health Data Management Policy, <u>https://ndhm.gov.in/health\_management\_policy</u>

<sup>&</sup>lt;sup>9</sup> World Health Organization (2010), *supra* note 5.

(2) documentation of the care given which must be made transparent to the patients post service provision.

The Telemedicine Guidelines should lay down this 2-step procedure which is the minimum due diligence that every RMP adheres to. The purpose of this procedure is to *inform* the end user about the liability framework (who will be responsible and under what circumstances), facilitating information symmetry. However, the Guidelines should stipulate that knowledge and acceptance of the same does not bar the end user from raising a complaint. If there is any dispute with respect to ascertaining liability, which the end user wants to challenge, they must be allowed to do so in the appropriate grievance procedure.

#### (b) Governance framework

The guidelines do not stipulate a regulatory or enforcing authority. Clause 6 stipulates the special responsibilities of the Board of Governors (BoG) in supersession of the Medical Council of India (MCI). These responsibilities are limited to rule-making. However, for the determination of breach, enforcement of the liability framework and addressing patient grievances, constitution of an appropriate regulatory authority is necessary.

The Guidelines in clause 5.6 places the responsibility to set up a grievance redressal mechanism only on Technology Service Providers (TSP). The role of the BoG-MCI is not stipulated . The operation of the grievance redress mechanism has not been determined. For instance, the points of contact, the mode of communication and escalation mechanisms are not stipulated in the Guidelines.

It is suggested that first an authority should be identified. Institutionalization by way of an authority is crucial for the adoption, implementation and development of the services. Secondly, with specific reference to the grievance redressal mechanism- the role of the TSP in establishing effective grievance redress mechanisms should be elaborated. To supplement this clause, the role of the authority or already existing authority (BoG-MCI) should be stipulated as an appropriate point of contact if the issue is not resolved.



#### Chapter 2

**Question 2.4.1:** As a stakeholder in the health ecosystem, what benefits and risks do you see if an open network approach to digital health services is implemented? Please respond with details.

**Issue:** mapping the risks and benefits for end user communities who are the principal data subjects.

**Response:** As part of civil society, it is imperative that we represent the interests of the end user community who in the UHI ecosystem refer to the patient community, the principal data subjects who own the sensitive health data. The UHI ecosystem is built on the health data exchange layer, the primary source of which is sensitive health data belonging to each patient.

#### **Risks:**

#### The issue of multiple stakeholders and parties in the UHI ecosystem

The UHI ecosystem consists of multiple stakeholders and multiple technological layers which increase the complexity of the ecosystem for the end user to grasp. The number of participants are many and understanding their role in the ecosystem may deter patients from using the platform. In an offline space, there are only two parties- the HSP and the patient. Even in the closed digital network, the platform would be the intermediary third party. In this system, understanding the roles are relatively easier as the number of parties are limited.

The UHI ecosystem is based on the concept of interoperability of platforms, which is built on the interoperability of health data. This brings into the ecosystem a plethora of stakeholders other than the three primary stakeholders - consent managers, TSPs, registries, state. Apart from private parties, the UHI ecosystem is managed and operated by the state. The framework of accountability in case of a breach or lapse is myred from the perspective of the end user who is unable to understand the inter-connectivity amongst stakeholders.

The following concerns stem from the issue of multiple stakeholders:

- (a) Privacy and security: The issues of privacy and security are magnified due to the underlying framework of the UHI ecosystem, which is characterized by an inherent lack of trust stemming from anonymity of multiple parties. There is a perceived loss in agency and control over one's own data. Informed consent which forms the backbone of privacy frameworks need to be clarified to the end users.
- (b) Consent mechanism: The understanding of consent is easier in a closed platform network vis-a-vis an open platform where multiple parties exist. Thus the privacy policy explaining the consent mechanisms should clarify the existence of each party, the role of each party and whether the party will have access to the health data, to what

extent and their purpose of usage. The UHI envisages the state to have access to anonymized and aggregated data. This issue and its workaround is discussed in Chapter 3, but nevertheless it is identified as a risk to end users which deters them from participating.

(c) **Grievance redressal:** When multiple parties are involved, end users are more concerned about their options in the event of a breach.<sup>10</sup> In a closed network, the first point of contact is the platform; however in an open network like the UHI, the first point of contact can be multiple parties- the platform, the HSP, or the National Digital Health Mission (NDHM), which according to the UHI policy will manage the grievance redressal mechanism. Moving forward, the role, responsibility and liability of TSPs in the grievance redressal mechanism have to be clearly defined as they are the primary interface for end users. The inability to pinpoint a primary point of contact amidst multiple stakeholders can make the ecosystem perplexing to end users.

#### The way forward

All the risks can be mitigated by empowering communities to effectively manage their own data. The relationships between stakeholders over data must be grounded in democracy and inclusivity. User agency should be accelerated by giving communities more control over their own data. We strongly advocate for *health data stewardship* to be integrated in the UHI ecosystem accelerating equitable data governance which allows for the realization of societal value of data and parallely, respecting individual autonomy. <sup>11</sup> This concept has been discussed in more detail in Chapter 3.

#### **Benefits:**

In a closed platform network, the bargaining power leans in favour of the platform with no room for the consumer to manage his data. The UHI ecosystem seeks to bridge the information asymmetry between parties. Where the state partakes in the market, the aim is to establish market structures to equalize the bargaining power. The UHI ecosystem stands on mechanisms such as consent managers which precisely seek to bring in more transparency over the usage of health data and subsequent viewing/ sharing.

The presence of the state in itself assures users of a strong regulatory and safe environment for the end users to transact, reflecting pillars of accountability.

https://www.consumersinternational.org/media/1292/connection-and-protection-the-internet-of-things-and-challenges-for-consumer-protection.pdf

<sup>&</sup>lt;sup>10</sup> Consumers International (2016), "The Internet of Things and challenges for Consumer Protection",

<sup>&</sup>lt;sup>11</sup> The Data Economy Lab (2021), "Health data governance: Empowering communities to effectively manage their data",

https://thedataeconomylab.com/2021/05/25/health-data-governance-empowering-communities-to-effectively-manage-their-data/



The most obvious benefit of the UHI ecosystem is interoperability facilitating access. Inclusion is facilitated due to the increased benefits of access in comparison to closed networks. Where the costs (monetary) in using either networks are the same, the benefits (accessibility to enhanced healthcare services) are more in an open network.



#### Chapter 3

**Question 3.8.1:** The primary stakeholders in the UHI ecosystem are mentioned in section 3.3. While the list is more indicative than exhaustive, are there any other primary or secondary stakeholders that should be considered while building the interface? If yes, please outline their role in the UHI ecosystem.

Issue: Bridging the gap in access to platforms by HSPs and patients

**Response:** The UHI policy identifies 3 primary stakeholders- end users (patients), Technology Service Providers (TSPs) and Health Service Providers (HSPs). The very purpose of the UHI ecosystem is to connect end user patients to the HSPs, via End User Applications (EUAs)/ Health Service Provider Applications (HSPAs). Though these applications fulfil the purpose of connectivity by bringing closer HSPs and end users, a gap exists between the platform and the HSP/ end user. This relates to accessibility by HSPs and patients to these platforms/applications. We have identified offline intermediaries as the primary stakeholder in the UHI ecosystem who can fill this void.

Offline intermediaries, in the context of the UHI ecosystem, refer to those persons who facilitate the process of mediation between the platform on one hand, and the HSPs and patients, on the other hand. These intermediaries could be ASHA workers, NGO intermediaries, or local ward officials. Their role as an intermediary will vary depending on their professional capacity and expertise. Their limitations also vary which must be understood and dealt subjectively.

Interoperability of platforms is one of the key aims of the UHI ecosystem aiming at enabling more people to access a variety of health care services. However, this interoperability is secondary to the functioning of the UHI ecosystem. Where the primary goal is to facilitate access and inclusion of healthcare services to the masses, it is pertinent that the masses are effective participants in the UHI ecosystem, who are aware of their role, rights and possess adequate knowledge about the ecosystem. Participation is effective when these users are able to navigate through the platforms with ease and confidence. The UHI ecosystem will fulfil its goal of developing a robust healthcare system only when participants use the platforms.

Offline intermediaries bridge the gap between the platform and healthcare providers and platforms and patient community by breaking barriers that prevent HSPs and patients from using digital platforms to provide/access healthcare. The skills and knowledge required vary depending on whether they will work with HSPs or patient communities.

For instance, offline intermediaries that deal with HSPs enable them to overcome barriers of financial inability requiring them to possess knowledge of operational functions of HSPs to identify costs associated with provision of healthcare facilities. Offline intermediaries that

work with patient communities bridge the gap between communities that lack digital access, or awareness and ability to access, and providers.<sup>12</sup> They can assist in increasing awareness of digital solutions through information dissemination via citizen trusts and enhance ability through capacity building efforts.<sup>13</sup>

The policy proffers digitization of healthcare via UHI to increase access to healthcare services. However, given the existing digital divide that is present in our country, the policy, if implemented without bringing the masses into the UHI framework, will create a digital *healthcare* divide. The digital divide between the urban- rural sector in the utilization of digital services across the board is stark. Only 13 percent of people over five years of age in rural areas have the ability to use the internet against 37 percent in urban areas.<sup>14</sup> The gender divide stands at a male- female split of 65-35 split.<sup>15</sup> For instance, our study on CoWin elicited results that when tech-mediated health care services are implemented without the support of offline intermediaries, the digital healthcare divide deepens.<sup>16</sup> These tech mediated vaccine distribution services adversely affect marginalized sections, particularly women, who show lower rates of vaccination, and greater dissonance with navigating digital systems. The importance of offline intermediaries in the UHI ecosystem is magnified as they prevent the widening of the digital healthcare divide.

The primary function of offline intermediaries is to propel the network's effect. The barriers that prevent patients from using the platforms are costs, lack of internet connectivity and trust.<sup>17</sup> Infrastructural barriers such as the lack of internet connectivity require efforts by the state. However, offline intermediaries, to a certain extent, can help overcome the economic barriers of cost/affordability. Concepts of cost and affordability are relative and intermediaries can help communities ascertain the true value of these digital health services. They enable informed decision making by comparing costs of accessing physical health care vis-a-vis the

https://www.devex.com/news/why-india-s-digital-divide-is-hampering-vaccine-access-99943

<sup>&</sup>lt;sup>12</sup> Sharma, Natarajan & Udhayakumar (2021), "Last Mile Access Report",

https://uploads.strikinglycdn.com/files/294143ba-333f-4bcc-9379-6d4742d15509/Last%20Mile%20Re port-Digital-Aapti%20Institute.pdf <sup>13</sup> Id

<sup>&</sup>lt;sup>14</sup> NSS Report No.585(75/25.2/1) (2017-2018), "Household Social Consumption on Education in India: NSS 75th Round",

http://mospi.nic.in/sites/default/files/publication\_reports/Report\_585\_75th\_round\_Education\_final\_150 7\_0.pdf; Refer Pandey (2020), DownToEarth.org.in, "COVID-19 lockdown highlights India's great digital divide",

https://www.downtoearth.org.in/news/governance/covid-19-lockdown-highlights-india-s-great-digital-di vide-72514

<sup>&</sup>lt;sup>15</sup> IAMAI (2019), "Digital in India: Round 2 Report",

https://cms.iamai.in/Content/ResearchPapers/2286f4d7-424f-4bde-be88-6415fe5021d5.pdf , Centre for Catalyzing Change (2021), "Policy Brief: Bridging the Digital Divide for Girls in India",

https://www.c3india.org/uploads/news/Bridging the Digital Divide-Policy Brief 2021 (website)1.pdf <sup>16</sup> Aapti Institute (2021), CoWin Study (Forthcoming- copy available on request); Jain (2021), Devex.com, "Why India's digital divide is hampering vaccine access",

<sup>&</sup>lt;sup>17</sup> FICCI & BCG (2020), "Leapfrogging to a Digital Healthcare System Re-imagining Healthcare for Every Indian", <u>https://ficci.in/spdocument/23337/FICCI-BCG-HEAL-2020-Report.pdf</u>

costs of accessing digital healthcare (requiring a limited investment of a smartphone). Overcoming the psychological barrier of distrust in digital healthcare is the focal function of offline intermediaries. The layer of digitalization (platforms) is characterized by anonymity. Humans are the traditional faces of trust and these faces gain significance during the initial phases of transition from physical to digital healthcare.<sup>18</sup>

It is equally important for HSPs to participate in the UHI ecosystem. The primary barrier that disincentivizes smaller clinics, pharmacies and dispensaries is their financial inability to build and develop their own HSPAs, in comparison to larger corporate healthcare entities. This may give an unfair advantage to these large corporations facilitating their entry into the market. The cost of transition is lower for these corporate entities as they can own and maintain their own HSPAs, which is not the case for smaller and rural clinics. Thus, remote, rural and small HSPs should be informed of the incentives of partaking in the ecosystem such as increased discoverability by communities and ability to decide their own prices (refer 4.1.2) to offset the aforementioned disincentive. Where patients are not bound by geographical borders and distance, these small clinics and doctors will face the threat of a loss of consumers for their services, compelling them to be a part of the ecosystem.

#### Amplifying Network Effects for rural and remote areas, and marginalized communities:

*First*, participation of rural HSPs benefits rural communities. Though care services can initially be provided digitally, rural clinics are efficient gateways for follow up care. They are the first points of physical contact for these communities. However, locating the nearest physical care service is an equally cumbersome task for remote communities. When these clinics are enrolled on these platforms, they not only provide initial digital care, but also signal to communities about their very existence in the area. *Second*, competition in the ecosystem will compel healthcare providers in rural areas to upgrade their services, ultimately strengthening rural healthcare systems.

Offline intermediaries are the pillars of a digitized healthcare system by enabling access to the online platforms. Inability to include either of the key stakeholders- HSPs or patients defeats the broader purpose of access in the UHI ecosystem.

#### Model of working:

State support for offline intermediaries enables the realization of the right to health for citizens. A lack of state support results in exclusion of marginalized populations where players continue to target urban and wealthy populations. It is proposed that these offline intermediaries should be formalized by the state. Initially, they should be supported by the state for a given period of time considering that significant investment (financial and human)

<sup>&</sup>lt;sup>18</sup> Natarajan & Ravichander (2020), The Hindu, "Humans are still core to Digital India", <u>https://egov.org.in/wp-content/uploads/2021/01/Humans-are-still-core-to-Digital-india.pdf</u>

needs to be made in institutionalizing these offline intermediaries. Moving forward, offline intermediaries can be engaged by firms/ platforms that seek to penetrate into rural and remote markets.

Given the recommendation that offline intermediaries should be state supported, it is also possible for them to perform additional functions. For instance, they can serve as a point of contact between state agencies and HSPs/patients and strengthen feedback mechanisms. There are several processes in the UHI ecosystem that are managed by the state, which affects the usability of the services. For instance, offline intermediaries can collect collective community feedback from patient communities or HSPs in a particular geographical area. Feedback can be collected with respect to grievance redressal and ratings systems (example: whether the checks and balances system works). They can help communicate on-ground challenges faced by users as they navigate through the platforms. Using this feedback directed at platforms, the state can help standardize UHI protocols for them.

#### The case of ASHA healthcare workers

ASHA workers who currently are human agents of healthcare are classified as voluntary workers. This informal framework disincentivizes them from partaking in the healthcare sector. In the voluntary structure, benefits are limited as they grapple with concerns of poor working conditions and inadequate pay, technological knowledge and logistical infrastructure.<sup>19</sup> This indicates that the first step towards progress lies in formalization representing offline intermediation as a structured career.

ASHA workers, if trained from the fronts of tech and health, could be *digital* health agents. The pilot project in Bihar that sought to bring preventive digital healthcare to the state relied on ASHA workers to digitally collect and distribute healthcare data. <sup>20</sup>ASHA workers acknowledged the potential of technology to bridge the gaps in access to healthcare and reduced their burden as health care volunteers, and further expressed their willingness to learn how to navigate through devices. However, recent instances indicate that technology has been used as a tool to mass surveil ASHA and other low income workers.<sup>21</sup> When mass surveillance by the state is masked by welfare purposes, workers lose their trust in the state, deterring them to work for the cause they were employed. Additionally, they are citizens of the state who are constitutionally guaranteed the right to privacy as enshrined under Article 21 of the Indian Constitution.

<sup>&</sup>lt;sup>19</sup> Shaw (2021), New Indian Express, "Budget push can turn ASHA workers to digital health agents", <u>https://www.newindianexpress.com/thesundaystandard/2021/jan/31/budget-push-can-turn-asha-work</u> <u>ers-to-digital-health-agents-2257313.html</u>

<sup>&</sup>lt;sup>20</sup> NEC, Nec.com "India's Healthcare is Transforming, and New Challenges are Arising", <u>https://www.nec.com/en/global/insights/article/2020091502/index.html</u>

<sup>&</sup>lt;sup>21</sup> Bansal (2021), Codastory.com, "How healthcare workers in India fought a surveillance regime and won", <u>https://www.codastory.com/authoritarian-tech/indian-health-workers/</u>



**Question 3.8.2** The proposed objectives of UHI and UHI Network have been detailed in sector 3.4. Please share your comments on the comprehensiveness of these objectives, methods to ensure these objectives are adhered to. Please comment if there are other objectives which must be included in section 3.4.

Issues: Facilitating trust and privacy in the UHI ecosystem

**Response:** Para 3.5 states that all entities in the UHI network should feel secure that information about their services, patients and others are private and in their control.

#### **Privacy:**

Privacy means that data subjects should be afforded rights that allow them to exercise control over their own data. <sup>22</sup> The key privacy issues and solutions are traced below:

- (a) Need for Data Protection Legislation: The basis of data principal rights in India stem from the Personal Data Protection (PDP) Bill, 2019. Hence, for the successful implementation of the UHI, the implementation of the PDP Bill is vital. In the case of healthcare, the issue of privacy is exacerbated given that health data is sensitive data. In the absence of the PDP Bill, there is no legal basis for granting and realizing of user rights. The PDP Bill is an overarching umbrella privacy protecting legislation. Users should have complete visibility on data storage, collection, usage and sharing. Even if these user rights are granted in sector specific policies, its scope to cover all stakeholders is questionable. Moving forward, when the PDP Bill is passed , there could be potential conflicts between sector specific laws and the PDP Bill. For instance, there will be several authorities with overlapping functions established under the PDP Bill and the UHI policy.
- (b) **Community participation for increasing user agency or Health Data Stewardship:** the framework of consent should be made more inclusive of community interests as it is their data that is pivotal to data sharing. Increasing transparency in health sharing agreements, conducting regular audits by citizen groups and mobilization of negotiation between users and data cooperatives ensure that fair consent frameworks.<sup>23</sup>
- (c) **Consent to government access to anonymized data is not stipulated:** 3.5 reiterates that aggregated and anonymised data may be made available to the policy makers and programme managers to ensure more informed decision making by the Government. This means that the state will have unfettered access to aggregated and anonymised citizen health data. This policy stipulates that if the data is anonymized or aggregated then

 <sup>&</sup>lt;sup>22</sup> Bennan & Mulligan (1999), 23 NOVA L. REV, "Privacy in the Digital Age: Work in Progress".
<sup>23</sup> The Data Economy Lab (2021), "Health data governance: Empowering communities to effectively manage their data",

https://thedataeconomylab.com/2021/05/25/health-data-governance-empowering-communities-to-effectively-manage-their-data/



consent of the data subject is irrelevant. This runs counter to the consent framework in the NPD Report, which mandates that consent for the anonymization of data should be taken.<sup>24</sup> We suggest that the policy should follow consent driven anonymization and even sharing of such anonymized data. This has been envisaged in the PDP Bill and reference can be drawn from the European Union's General Data Protection Regulation<sup>25</sup>, and Digital Services Act<sup>26</sup>, that enable safe re-use of data for research purposes through consent-driven anonymization and sharing.<sup>27</sup>

#### Trust

Trust in the ecosystem can be enhanced by leveraging the proposed: i) grievance redressal mechanism and ii) rating and reputation systems as a part of Section 5.1.3.5 of this consultation paper.

#### (a) Grievance Redressal:

The Policy stipulates in 5.1.3.5, that the grievance redressal function will be managed by the NDHM. This is a general obligation with no insight into the mechanisms of how the function will be implemented. We suggest a two pronged approach of addressing grievance redressal. Grievance redressal is required at two instances: (1) breakdown of data sharing and governance, (2) breakdown of service delivery

With respect to breakdown of data sharing and governance, the NDHM policy envisages that the data fiduciaries appoint a DPO and a NDHM Grievance redressal officer for health in case grievances remain unresolved.<sup>28</sup> The roles of data fiduciaries has not been clarified and the NDHM framework of accountability is complex making it inaccessible to users. With respect to breakdown of service delivery, concerns related to identification of party responsible for breakdown in service and subsequent manner of redressing grievance has not been specified.

The policy should address these breakdowns separately by adopting a common approach. Pathways to access and then communicate the grievances must be established. First points of contact and escalation mechanisms (avenues to appeal decisions if the user is not satisfied) need to be established. Modes of communication and time frames should be specified.<sup>29</sup> The

https://static.mygov.in/rest/s3fs-public/mygov\_160922880751553221.pdf

<sup>&</sup>lt;sup>24</sup> Section 5.4 (iii) - Consent for Anonymised Data, Revised Report on Non-personal Data Governance Framework, 2020

<sup>&</sup>lt;sup>25</sup> (EU/201654) General Data Protection Regulation, 2016.

<sup>&</sup>lt;sup>26</sup> (EU/202055)The Digital Services Act.

<sup>&</sup>lt;sup>27</sup> Aapti Institute (2021), "India: Health Data Stewardship Landscape and Recommendations", (Forthcoming - copy available on request)

<sup>&</sup>lt;sup>28</sup> Grievance Redressal (Secs. 32(1), 32(2) and 32(4)), National Digital Health Mission: Health Data Management Policy, 2020, <u>https://ndhm.gov.in/health\_management\_policy</u>

<sup>&</sup>lt;sup>29</sup> Aapti Institute (2021), *supra* note 27.

role of the TSP should be clarified in the UHI ecosystem of grievance redressal. Further, systems of accountability and decision making should be transparent to prevent arbitrary rejection of complaints. The knowledge and navigation through these systems depends on digital literacy. Here, the role of offline intermediaries can be highlighted when dealing with last mile patient communities.

With specific reference to breakdown in data sharing and governance, we suggest that the UHI policy clarify whether it aligns with the NDHM policy or whether it chooses to adopt another mechanism, in addition to adopting the common approach aforementioned.

#### (b) Rating and reputation (R&R) system:

The policy envisages a citizens only rating system which will be managed by the state through the UHI portal. The inherent limitation to a citizens only rating system is that it captures extreme behaviours.<sup>30</sup> Ratings can either be made compulsory or voluntary. If they are made compulsory, then it would be able to capture responses by all users in the ecosystem, reflecting an almost accurate representation of the service. However, it would be unfeasible for frequent transactions that take place. For instance, purchasing medicines from a pharmacy is a transaction that occurs frequently and expecting the user to rate the service leads to '*ratings*' fatigue leading to a latency in delivery of services in what may be dire emergencies. If rating were voluntary, then it would fall short of accurately representing user responses.

First, we suggest independent quality audits which are necessarily a part of discoverability and assessment. Second, the system of R&R is based on citizen feedback thus it is important to integrate content moderation mechanisms ensuring the non-health reviews are not captured. Lastly, services can be classified based on the frequency of transaction- the frequency of visiting a doctor is far lesser than purchasing medicines. The former can adopt compulsory ratings and the latter, voluntary. A determination of which service would prefer a system of rating can be left to the collective decision of the service provider (by means of majority consensus-example: surveys at the time of onboarding).

The second issue to be addressed is whether R&R should be a determining factor in fair discoverability. If made compulsory, then it is fair for R&R to be one of the criteria to determine fair discoverability. If voluntary, then we suggest a system of checks and balances to be implemented as it is acknowledged that the R&R does not truly represent the quality of services. We suggest that the system can be one of the determining factors for fair discoverability; however, the system should divulge all the relevant statistics (no. of people who reviewed, averages etc).

<sup>&</sup>lt;sup>30</sup> Reshef (2017), Digital Commerce 360.com, "The Limitations of Online Ratings and Reviews", <u>https://www.digitalcommerce360.com/2017/04/07/the-limitations-of-online-ratings-and-reviews/</u>



The third issue to be addressed is whether the idea of compulsory disclosure of user names is privacy preserving, as per the provisions of the PDP Bill in the digital healthcare system. The concept of health is in itself private and compulsory disclosure of names should not disincentive patients from giving legitimate feedback. Reviews can be made anonymous, however a chance to rebut must be afforded to the HSP, as suggested in the policy.<sup>31</sup>

**Question 3.8.3:** UHI will support a range of digital health services and is expected to evolve with time. How should the digital health services be phased in the upcoming versions of UHI?

**Issue:** To assess the scope of coverage of digital health services that could be successfully supported by the UHI ecosystem and to formulate an approach enabling implementation and adoption of the UHI ecosystem which could be rolled out subseq in phases.

#### **Response:**

#### Phases of evolution of digital health services

The UHI ecosystem supports a range of digital health services, as mentioned in Para 3.2. The list being inclusive provides ample scope for its expansion.

#### (a) Emergency care services

The UHI could transform the emergency care services provided in India. India needs to upgrade emergency medical services which determine the quality of ambulance care.<sup>32</sup> As it stands today, emergency medical technicians lack adequate training in providing traumacare. The UHI ecosystem could act as a driving force creating a demand for such services thereby improving the quality of its supply.

#### (b) Supportive informational healthcare services

The list as it stands today relates to service provision between the end user and HSP entities such as discovery and provision of healthcare professionals. However there exist a host of services that support health care provision such as establishment of blood banks and organ donations. From a patient perspective, during emergencies where time is critical, searching for blood and organs can be cumbersome. The patients lack of awareness of the existence and location of these facilities and the need to approach multiple banks make it a tedious process.

<sup>&</sup>lt;sup>31</sup> Caveat: Only the HSP should be able to view the identity of the patient to respond appropriately but shall not disclose the identity of the patient.

<sup>&</sup>lt;sup>32</sup> Datar (2017), E-Health Network, "Why India needs trained Emergency Medical Technicians?", <u>https://ehealth.eletsonline.com/2017/11/why-india-needs-trained-emergency-medical-technicians/</u>



The UHI ecosystem can prove to be an effective platform that can streamline the provision of these services. On the other hand, it can also help potential donors connect to banks.

#### (c) Enabling connectivity between stakeholders

Digital health applications that reorient reporting based tools will focus on active community based models rather than reactive care models. They will reduce the burden of data collection from front line workers.<sup>33</sup> The UHI could be a platform for promoting people centred health care systems by increasing access to evidence based self-management tools.

The ecosystem could enhance connectivity between HSPs by providing services for each other to better entity management and patient care. For instance, the <u>Covid 19 Preparedness App</u> enhances front line interoperability by tending care that immediately becomes a part of the health record, which is available to all HSPs. The value of such platforms increases when made available in an open network vis-a-vis a closed platform.

#### (d) State function

The UHI can be a portal for information dissemination by the state. The significance of credible information was realized during the pandemic. Every application that is enlisted on the UHI ecosystem can display information released by state approved authorities disseminating public health information. This ensures consistency across all government bodies and easier accessibility to vital information by citizens. (one stop access to information). This information could cover a diverse range of topics- breakouts of public health emergencies according to geographical areas, precautionary measures, state emergency contact points etc. For instance, the National Health Portal which was established with the aim of improving health literacy of the masses could be integrated into the UHI ecosystem.<sup>34</sup>

The platform could help the state to track the use and deployment of necessary resources based on large scale reporting systems. These reporting systems include mandatory disease reporting, knowledge of community morbidity rates or antibiotic resistance.<sup>35</sup> These could be made available via the UHI ecosystem.

#### (e) Progressive Utilities

https://www.who.int/docs/default-source/documents/gs4dhdaa2a9f352b0445bafbc79ca799dce4d.pdf <sup>34</sup> HIMSS, Himss.org, "Interoperability in Healthcare",

<sup>&</sup>lt;sup>33</sup> World Health Organization (2021), "Global strategy on digital health 2020-2025",

https://www.himss.org/resources/interoperability-healthcare

<sup>&</sup>lt;sup>35</sup> Luna, Campos & Otero (2019), Inter-American Development Bank, "Interoperability in Digital Health: Reference Material",

https://publications.iadb.org/publications/english/document/Interoperability in Digital Health Referen ce\_Material\_en.pdf



The UHI ecosystem can be utilized for medical fundraising where people can donate to causes of their preference. It will give visibility to lesser known organizations that are involved in facilitating the fundraising.

Healthcare transcends borders. Moving forward, the ecosystem must consider whether it can accommodate global collaboration and to what extent. This invites legal jurisdictional challenges and other efforts related to coordination between entities. The purpose of collaboration would not only focus on connecting patients to HSPs but also HSPs to HSPs. for instance, the incentives of a global collaboration include transfer of knowledge of best practices,know-how of implementation of new methods and evidence-based learnings of digital health.<sup>36</sup>

#### Phases of adoption and implementation

Adoption and implementation of UHI can also be facilitated in phases. For instance, in the case of Kanta Services, a unique digital service concept operational in the healthcare sector of Finland, a national coordinating agency was established in Phase II of the implementation of the services. This step was part of their middle out design approach that was chosen instead of adopting a purely top-down or bottom-up approach. State funding has also been cited as one of the causes for successful adoption of the services.<sup>37</sup>

Similarly, we suggest that one coordinating agency must be identified for the implementation of the UHI ecosystem. This agency can also be made responsible for granting state subsidies.

<sup>&</sup>lt;sup>36</sup> World Health Organization (2021), *supra* note 33. *Refer* Cory & Stevens (2020), Information Technology and Innovation Foundation, "Building a Global Framework for Digital Health Services in the Era of COVID-19",

<sup>&</sup>quot;https://itif.org/publications/2020/05/26/building-global-framework-digital-health-services-era-covid-19 <sup>37</sup> Jormanainen (2018), 10 (4) Finnish Journal of eHealth and eWelfare, "Large-scale implementation and adoption of the Finnish national Kanta services in 2010–2017: a Prospective, Longitudinal, Indicator-based study",

https://www.researchgate.net/publication/329435092\_Large-scale\_implementation\_and\_adoption\_of\_ the Finnish\_national\_Kanta\_services\_in\_2010-2017\_a\_prospective\_longitudinal\_indicator-based\_stu dy



#### Chapter 4

**Question 4.3.1:** Have all incentives / disincentives for various stakeholders to participate been covered in chapter 4? If not, please provide the list and mention the role and description of the stakeholder.

Issue: Mapping the incentives for end users and health aggregators and disincentives for HSPs

#### **Response:**

#### Incentives for the primary stakeholders:

*End user/ patients*: The policy envisages that patients benefit from access to a diverse set of healthcare services due to interoperability of the platforms. These are the direct benefits of the UHI ecosystem.

There exists indirect benefits of competitive prices of healthcare services. The platform enables end users to compare prices and seek the most affordable healthcare. Availability of varied services enables faster requests for second opinions and transitioning between healthcare providers creating agile health service provision.<sup>38</sup> A 2017 study of Canada's interlinked health system reveals the economic benefits of integrated healthcare systems which reduce duplication of care afforded, thus decreasing the number of hours a patient spends in care environments, increasing economic productivity.<sup>39</sup> Further, UHI compels HSPs to upgrade their services and improve quality of healthcare. This healthcare provided is not limited to the digitized space but extends to offline healthcare architectures. For instance, UHI will expand the reach of local hospitals who will be pushed to invest in their digital care as well as physical care services. To undertake follow up care and consultation efficiently, these clinics will have to strengthen their physical infrastructures. The benefits outweigh the costs of being part of the UHI.

*HSP entities*: An interoperable network backed by a health information database allows entities to track patient information in real time facilitating better decision making as it helps them to avoid hospitalization of patients when not required. There is a direct economic benefit by reducing unnecessary admissions and readmissions, in terms of decreased provider hours and increased economic productivity, as has been traced in the 2017 study of Canada's interlinked health system.<sup>40</sup>

*Health Service Aggregators (one type of HSP entities):* The UHI is the foundation on which these applications can build the healthcare services. There are huge benefits associated with

<sup>&</sup>lt;sup>38</sup> Luna, Campos & Otero (2019), *supra* note 35.

<sup>&</sup>lt;sup>39</sup> Id.

<sup>&</sup>lt;sup>40</sup> *Id.* 



reduction in operational costs and burdens. For instance, UHI establishes standardization in certain processes such as the grievance redressal and rating mechanisms. These are managed by the NDHM which shares the responsibility of managing these operations.

In the Unified Payment Interface (UPI) ecosystem, the banks bear the burden of maintaining the UPI transactions. In a recent <u>IIT Bombay report</u>, it was proffered that the government and the RBI can share the costs of maintaining the UPI infrastructure, given benefits they derive from the ecosystem (example: efficiency towards tax compliance, reduction on cash expenditure, overall convenience for public good). <sup>41</sup> Similarly, in the UHI ecosystem, the state should bear the expenses for operation and management of the infrastructure in furtherance of the digital health care services.

#### Disincentives for primary stakeholders:

HSP entities: Rural, remote and small clinics incur unaffordable costs in the transition to digitized models of HSPs aggregator platforms. In comparison to large corporate entities that are financially capable of creating their own HSPAs, smaller clinics are unable to do so which prevents them from entering into the market.

**Question 4.3.2:** For the disincentives mentioned in chapter 4 and the ones provided as an answer to the question above, please provide details on possible mitigating measures that may be taken to minimize the impact of said disincentives.

**Issue:** With respect to HSPs, extension of the mechanism of dual services provided by medical practitioners independently and via hospitals to prevent any possible conflict of interest that may occur financially or administratively.

#### **Response:**

The question is whether the existing legal contractual relationship that exists between hospitals and doctors can be extended to the online space. We must first analyse the difference between the online space and offline space to understand how such a system of dual presence is allowed in the offline space.

In the offline space, consultants are incentivised to be a part of hospitals given the reputation of the hospital, enabling them to access more patients and sophisticated physical infrastructure. However, the online space permits certain specific healthcare services to be provided via digital media without any requirement of physical infrastructure. It provides equal

<sup>&</sup>lt;sup>41</sup> PTI (2020), Business Standard, "Govt, RBI need to share cost of maintaining UPI infrastructure: Report"

https://www.business-standard.com/article/pti-stories/govt-rbi-need-to-share-cost-of-maintaining-upi-in frastructure-report-120082401555\_1.html

visibility to medical practitioners that the hospital provides as the channel of discoverability is the same. In the UHI ecosystem, the same doctor will treat patients through a particular hospital and independently. In this case, patients can deduce that such a doctor will provide a certain quality of service that is tantamount to the perceived reputation of the hospital, however may choose to approach the doctor in the capacity of an independent practitioner due to lower pricing. Thus, the digital layer creates a level playing field for medical practitioners to practice independently. However, simultaneously, it creates a conflict of interest between hospitals and doctors, especially with respect to pricing.

First, with respect to price, from a policy or regulatory front, the state cannot interfere between the contractual terms between the hospital and independent practitioner. Legally restrictive clauses cannot be suggested for medical consultants of hospitals. This will run counter to the objective of the UHI which seeks to bring more HSPs into the ecosystem. Even digital healthcare services come at a minimum cost and hence the market should be allowed to determine prices which will inadvertently be competitive in nature, benefitting the end users.

The way forward is leveraging the constant of time. The medical practitioner can be made to represent the hospital for mutually agreed upon hours (or timings) where the hospital bears the responsibility to schedule online healthcare services or agree upon attending a minimum number of patients. Hospitals are benefited as they are guaranteed patients and doctors benefit by leveraging dual presence as being part of a reputed hospital, increases their independent practice as well.

**Issue:** With respect toTSPs, creation of a level playing field that ensures services of existing market players are not disrupted and there are no barriers to entry for new market players.

#### **Response:**

#### Continuity of services of existing players:

The UHI should not be perceived as a market disruptor for existing players. It should be promoted as a technological advancement which, if adopted, will simplify processes of diversification and expansion of healthcare services. Every health aggregator enters the market providing one kind of healthcare service, and eventually expanding into new avenues, targeting new consumer bases. This process fastens due to the UHI ecosystem.

Players diversify with the objective of targeting new consumer bases. Usually, players first diversify their services and then gain new consumers. Interoperability makes it possible for players to target these consumers prior to the provision of new services. A vast consumer base already exists due to UHI interoperability. UHI interoperability allows them to experiment with the kind of services they intend to provide. The existence of end users in the UHI ecosystem makes it easier for existing players to provide new services. It saves resources to bring new

consumers onto the platform. Their focus is now limited to providing a lucrative service that attracts end users to utilize their services.

Existing players must leverage UHI by aligning their services according to the UHI and integrating into the ecosystem. Instead of considering UHI as their competition, they can make their applications/ services UHI compatible, potentially increasing discoverability and attracting more consumers. This is similar to the strategies adopted by the then existing players of the UPI ecosystem. Paytm and other wallets rebranded themselves as UPI enabled, apart from providing the basic wallet facility.<sup>42</sup>

Risk mitigation strategy includes incentivizing even existing players to integrate UHI into their services by informing them of benefits of diversification. Second, the perception about UHI as a potential competitor should be changed and it should be viewed by the industry as an additional service or technological enhancement that, if provided, will increase their consumer base. Lastly, from a regulatory perspective, the state can mandate integration of players into the UHI ecosystem if they have a market share above a certain threshold. Mandatory integration into the ecosystem can also be based on whether the HSP qualifies as Significant Data Fiduciary, as according to the PDP Bill, or a Data Business according to the Non Personal Data Report, 2020<sup>43</sup>

#### Increasing new players in the market:

To ensure service providers are incentivized to enter into the market despite the existing competition and market share held by large players, the state must help these players overcome commercial and technological barriers. These commercial barriers relate to transaction costs and enhanced compliance burdens. State subsidies could cover costs of standardization enabling smoother and quicker transition into the UHI ecosystem.

To a certain extent, UHI in itself subsidizes infrastructural costs for digital healthcare service providers which would be drastically high if they were to operate in closed networks. A parallel can be drawn to the UPI network. UPI enabled easier entries for new market players. It provided the necessary technical architecture to build new use cases for payment applications allowing each platform to create its new space. <sup>44</sup> The already existing interoperability helped them focus only on innovation of services. In the UPI ecosystem, the state was a market enabler that allowed new players to thrive.<sup>45</sup>

<sup>&</sup>lt;sup>42</sup> Srivastava (2019), The Passage, "Payment firms look for new pastures after UPI levels the playing field", <u>https://thepassage.cc/article/1212</u>

<sup>&</sup>lt;sup>43</sup> The Report by the Committee of Experts on Non-Personal Data Governance Framework, 2020, https://static.mygov.in/rest/s3fs-public/mygov\_160922880751553221.pdf

<sup>&</sup>lt;sup>44</sup> Srivastava, *supra* note 42.

<sup>&</sup>lt;sup>45</sup> World Economic Forum (2020), "Innovation in Payments and Fintech: A comparison of the Chinese and Indian ecosystems",



Level playing field can be obtained where the policy actively prevents strategic impediments. Strategic impediments are barriers that are deliberately created by big market players to deny market entry. <sup>46</sup> The UHI framework is a mechanism that overcomes these barriers by establishing interoperability, access to infrastructures, and health data. The way forward is to inform these benefits to platforms and incentivise based on "innovation" promoting entry of new players. For instance, new players can be incentivised financially by subsidizing costs if they capture a certain share of the market post entry. Entry to the market shall not be based on competition limiting factors such as capital requirements.

Offline intermediaries play a vital role in enabling access by HSPs and patients to platforms. New players could engage with offline intermediaries harnessing the untapped potential of rural areas. These offline intermediaries could be trained in the working of the platforms who would then inform communities of the diverse use cases of a particular platform and help them navigate through the platform.

**Issue:** Mitigating the disincentive to rural, remote and small clinics who incur unaffordable costs in the transition to digitized models of HSPs aggregator platforms.

**Response:** We emphasize on the need of state support (financial and technical) to these small, remote and rural HSPs to cover the costs of transition. State support is necessary to improve uptake for digital health solutions given that these small entities are incapable of competing with corporates.

#### The Case of Kanta Services Finland:

Kanta service is a unique digital service concept operational in the healthcare sector of Finland. Its users include- citizens, pharmacies, healthcare services and social welfare services. Evidence suggests that for its successful adoption and implementation by healthcare service providers, provision of adequate state funding is the primary organizational requirement.<sup>47</sup>

Another mitigation strategy are offline intermediaries and civil society who inform the cost effectiveness of UHI ecosystems. They ensure distributed access to capacity building mechanisms around digital infrastructure. For these HSPs, especially private ones, serving in unprofitable/difficult to reach markets, 'market linkage' bridging mechanisms are necessary

https://www.cgap.org/sites/default/files/publications/2019\_11\_Working\_Paper\_FairPlay.pdf

http://www3.weforum.org/docs/WEF Innovation in Payments and Fintech China India ENG 2020 .pdf

<sup>&</sup>lt;sup>46</sup> Soursourian & Plaitakis (2019), CGAP/ World Bank, "Fair Play: Ensuring Competition in Digital Financial Services",

<sup>&</sup>lt;sup>47</sup> Jormanainen (2018), *supra* note 37.



#### Chapter 5

**Question 5.3.1:** The End User Application is expected to display all services returned by the UHI Gateway to users and allow them to choose an appropriate HSP. Are there any alternatives to this method?

**Issue:** Grant users agency to determine the parameters along which they can sort or filter the service requests returned by the UHI Gateway.

**Response:** In its current form, Service Discovery under Section 5.1.3.1 follows that service requests made by users through the UHI Gateway will be transmitted to HSPs that can respond to requests, depending on factors such as pricing, availability, etc. This service request transaction is expected to abide by a few "associated parameters" that are as yet unspecified in the paper. One way of ensuring that the EUAs are responsive to user preferences is to provide options that allow for customization of these requests. The "associated parameters" then can include considerations such proximity/distance, availability, option for tele-consultation, years of experience (in case of doctors, nurses, homecare providers), gender of physician, pricing, reviews and ratings, among others. The NDHM, tasked with managing the UHI Gateway, must hold broad-based public consultations with ecosystem stakeholders - patients and advocacy groups, caregivers, service providers (health and technical), offline intermediaries (ASHA - urban and rural and Anganwadi workers) - to identify the parameters for sorting and filtering that could be included within EUAs.

Moreover, the abundance of use cases of consumer-facing health applications hold interesting insights for what some of these parameters should like. For example, <u>Practo</u> is a digital health platform that connects patients/users with relevant providers for appointment bookings, consultations and check-ups. It provides both web-based and app-based services that allow users to filter their response requests along five parameters - video consultation, availability, gender and consultation fee. Additionally, users can sort the requests based on previous reviews/recommendations, years of experience, price and relevance. The twin options - filter and sort based on preferences - can ensure that users have the convenience to make informed decisions about the health services they wish to avail. Similar use cases include Lybrate; 1mg, and PharmEasy are other platforms that allow users to buy medication, schedule diagnostics (at home and labs) and receive preliminary consultations with physicians.

# **Question 5.3.2:** Are there any challenges to the proposed approach to pricing of services mentioned within Section 5.1.3.2?

**Issue:** The proposed formula for pricing entails a plausible UHI Gateway charge that could inflate the price of health services and contribute to hesitation among stakeholders for uptake of the UHI itself.



**Response:** According to the formula proposed in the paper, the final fee remitted to users includes three components - cost of the health service charged by the HSP, EUA service charges and UHI Gateway charges (if any). At the outset, the paper acknowledges that it is imperative to keep transaction costs low to encourage uptake for the UHI itself. Moreover, it adopts the view that transactions below a certain threshold should be kept free of gateway charges to encourage buy-in into the UHI. It cites the Unified Payments Interface (UPI) example wherein transactions below INR 1000 conducted via the interface are made available without any corresponding gateway charges.

However, it is crucial to note that the UPI pricing formula is significantly different from the proposed pricing formula for the UHI. For starters, the UPI consists of a set of APIs developed by the National Payments Corporation of India and per Government's 2019 notification, payment service providers are prohibited from charging a service fee for payments made via UPI and RuPay cards.<sup>48</sup> Moreover, the cost of maintaining the UPI is borne by the NPCI which is the primary payment network provider. Users make electronic money transfers through mobile applications provided by a technology company - examples include Amazon Pay, Google Pay, PhonePe, PayTM - and are able to do so without bearing corresponding service charges from these providers. These technology companies in turn have contracts with select banks designated as "payment service providers" and the banks pay a transaction fee to tech companies.

The consequent integration of financial services is made possible through an end-to-end interoperable framework such as the UPI that assures users maximum security through its two-factor authentication requirements. For users, there are no direct costs involved in using UPI for payments as both the consumer-facing mobile application (provided by tech companies) and payment service providers (i.e. banks) do not levy any charges for the aforementioned transactions. This attribute of the UPI ecosystem has encouraged wide uptake for the interface, with platforms like PhonePe clocking over 1 billion monthly transactions.

The UHI should aim to emulate this model of pricing that does not burden end-users with additional charges for using an interface. Firstly, the cost of developing and maintaining the UHI Gateway should be covered by the NDHM, the nodal agency concerned with the management of the UHI. Secondly, EUA service charges should be covered by the HSPs that use EUAs to reach users. This is because HSPs, particularly large corporatised networks of

<sup>&</sup>lt;sup>48</sup> Shetty (2021), Times News Service, "Payment gateways still charge for UPI, RuPay", <u>https://timesofindia.indiatimes.com/business/india-business/payment-gateways-still-charge-for-upi-rup</u> <u>ay/articleshow/80241228.cms</u>

<sup>&</sup>lt;sup>49</sup> Akolawala (2021), Gadgets360, "PhonePe on Adding Nearly 45 Million Monthly Active Users in COVID-Hit 2020",

https://gadgets.ndtv.com/apps/news/phonepe-online-payments-platform-co-founder-rahul-chari-indian -startups-101-2470274



private hospitals, can afford to pay for this service due to vast amounts of profits accumulated by them.<sup>50</sup>

Elsewhere around the world, the experience of Finland holds valuable insights for implementing the UHI. The <u>Kanta</u> facilitates interoperability in the healthcare and social sector by providing end-to-end digital services that benefit citizens, pharmacies, care providers (hospitals, clinics, doctors, dentists) and other social welfare players. Phased implementation between 2010 and 2018, backed by credible results of pilots conducted over 2 decades, have made the Kanta particularly reliable.<sup>51</sup> The ultimate success of Kanta services is attributed to generous state funding that encouraged stakeholders to adopt the framework.<sup>52</sup> In a similar vein, Estonia's X-road and accompanying <u>e-Health Record</u> services integrate health data across providers in the country such that it is available to patients/users in one platform. The emerging digital revolution was enabled by early state investments in IT and data-driven technologies, affording its citizens transparency, interconnectedness and decentralization of digital services.<sup>53</sup>

Therefore, it is incumbent upon the NDHM to fund, maintain and manage the UHI Gateway to encourage widespread adoption. Moreover, state support is critical for MSMEs, particularly SaaS start-ups, looking to innovate on digital health solutions. This would not only help leapfrog India's digital healthcare ecosystem but also provide much needed impetus for the Government's 'Make in India' initiative.

**Question 5.3.3:** Are there any other areas that should be supported for service fulfillment under section 5.1.3.3?

**Issue**: UHI Gateway does not participate in fulfilment, but provides logs of transactions necessary for dispute resolution.

**Response:** It is not necessary that the UHI Gateway participate directly in service fulfillment, following the role envisaged for UPI within the digital payments ecosystem. However, the transaction logs containing information about time of booking, service fulfillment and payment

<sup>51</sup> Tohola, et al., (n.d.), Recibus, "Fasttrack to deploying electronic prescriptions system", <u>https://www.recibus.com/wp-content/uploads/sites/2/dae-uploads/recibus\_fast-track-to-deploying-elect</u> <u>ronic-prescription-system.pdf</u>

<sup>53</sup> For more information, please visit

https://e-estonia.com/wp-content/uploads/e-estonia-guide-210820.pdf

<sup>&</sup>lt;sup>50</sup> Nathanael (2020), The Hindu, "Profiteering during the pandemic",

https://www.thehindu.com/opinion/op-ed/profiteering-during-a-pandemic/article32262912.ece

<sup>&</sup>lt;sup>52</sup> Jormainenem (2018), Finish Institute for Health and Welfare, "Large-scale implementation and adoption of the Finnish national Kanta services in 2010–2017: a prospective, longitudinal, indicator-based study",

https://www.researchgate.net/publication/329435092\_Large-scale\_implementation\_and\_adoption\_of\_ the Finnish\_national\_Kanta\_services\_in\_2010-2017\_a\_prospective\_longitudinal\_indicator-based\_stu dv



settlement will be useful in the context of dispute resolution only if the NDHM notifies meaningful mechanisms for grievance redressal. A critique of this function and alternatives for the same are explained as a part of the response to Question 5.3.4.

**Question 5.3.4:** Post-fulfilment, as described in section 5.1.3.5, covers ratings and grievances. Are there any other areas that must be supported by the Gateway for post service fulfilment in section 5.1.3.5?

**Issue:** Complete digitization of the process of grievance management ignores considerations of access and digital literacy that is necessary to ensure participation of users in the process.

**Response:** In its current form, the paper purports that the NDHM shall assume responsibility for addressing grievances related to digital open platforms only. This is acceptable given the scope of the NDHM as the primary network provider of the UHI. However, the proposal to wholly digitize the process of grievance management is premature in a country where smartphone penetration stands at a mere 54.23% in 2020.<sup>54</sup> Smartphones serve as crucial proxies to understand problems of access and affordability since they are the primary tools used to access digital services. On the other hand, internet penetration is steadily expanding, with over 749 mn. internet users across the country. <sup>55</sup> But, infrastructural bottlenecks persist in the nature of poor network connectivity which is particularly exacerbated for rural areas.<sup>56</sup> Solving these twin challenges - smartphone penetration and internet connectivity - is crucial to overcome the digital divide that could prevent users from accessing services via the UHI ecosystem.

Significantly, offline intermediaries - human faces that bridge the gap between technical platforms on one side and patients and healthcare providers on the other end - constitute a critical subset of stakeholders that remain amiss in the UHI Consultation Paper. Leveraging the role of ASHA and Anganwaadi workers in this regard, to fulfill the functions of offline intermediaries, can help users participate meaningfully in grievance redressal, the UHI network and avail the benefits of digital health solutions (refer response to Question 3.8.1 for more information about roles and functions of offline intermediaries).

Lastly, the grievance redressal process notified by the paper fails basic administrative law tenets: the structure and procedure for raising grievances, the points of contact, mode of communication, powers and constitution of the adjudicatory authority and avenues for appeal

 <sup>&</sup>lt;sup>54</sup> Statista (2021), "Smartphone penetration rate in India from 2010 to 2020, with estimates up to 2040", <u>https://www.statista.com/statistics/1229799/india-smartphone-penetration-rate/</u>
<sup>55</sup> Statista (2021), "Number of internet users in India from 2010 to 2020, with estimates up to 2040",

https://www.statista.com/statistics/255146/number-of-internet-users-in-india/ <sup>56</sup> PriceWaterhouse Cooper (n.d.), "How mHealth can revolutionise the Indian healthcare industry", https://www.pwc.in/assets/pdfs/publications/2017/how-mhealth-can-revolutionise-the-indian-healthcar e-industry.pdf

remain unspecified. It is important that the forthcoming UHI policy address this glaring omission in order to build a reliable and accessible dispute resolution mechanism.

Grievance redressal under the Mahatma Gandhi National Rural Employment Guarantee Scheme provides a lucid precedent for designing mechanisms in a manner that is responsive to its beneficiaries' concerns. It outlines 9 situations/concerns under which beneficiaires can raise grievances, ranging from payment-related issues to funds and material allocation. Additionally, it mandates the appointment of an Ombudsperson at the level of each district for receiving complaints, enquiring and processing awards.<sup>57</sup> However, MGNREGS' approach stands out for its integration of both online and offline process for dispute resolution, enabling beneficiaries to raise complaints through a centralised portal as well as through offices of the designated nodal agency in each state concerned with the implementation of the scheme. A similar approach for the UHI in which district-level and state-level health departments are roped in to facilitate to registration of grievances and their management is essential to address concerns of digital literacy and fair access to dispute resolution.

**Question 5.3.5:** The proposed approach for allowing users to share ratings for the HSPs as well as EUAs has been laid out in 5.1.3.5. Please comment on the same and share any other approach that might be adopted.

**Issue:** Reviews and ratings (RR) may be skewed to reflect extreme experiences, if the R&R process is made optional.

**Response:** The policy calls for a citizens-only rating system which will be managed by the NDHM as a part of the UHI. The inherent drawback to a citizen- only R&R system is that it captures <u>extreme behaviours</u>. Alternatively, adopting a middle path approach in which submission of ratings are made compulsory upon the fulfilment of each service while reviews/recommendations remain optional can encourage users to provide quick feedback. However, care must be taken to avoid complete gamification of the UHI such that ratings of HSPs become the sole determinant of visibility on EUAs. Incorporating user ratings as one the parameters of filter options under Section 5.3.1.1 will go a long way in maintaining the fair discoverability principles of the UHI. (For a detailed discussion on R&R system, please refer to the response under Question 3.8.2)

<sup>&</sup>lt;sup>57</sup> Ministry of Rural Development, MGNREGA Division (2017), "Revised Guidelines for Appointment of Ombudsperson - Reg.",

https://nrega.nic.in/netnrega/writereaddata/Circulars/2205Ombudsperson\_guidelines.pdf



#### <u>Chapter 6</u>

**Question 6.5.1:** What approaches, other than the ones mentioned in chapter 6, should be considered for managing and governing the UHI gateway? Please provide details.

**Issue:** Criteria for selection of Specification Committee as well as experts remain unspecified. Window and scope of public consultation unclear.

**Response:** At the outset, the paper envisages that the NDHM will develop UHI Open Protocols and related elements over four stages: design by specification committee, followed by consultation with experts and the public to make revisions to the UHI. The last stage is notification for adoption by the NDHM for all players in the UHI ecosystem.

First, the paper fails to stipulate eligibility criteria for organisations/technical service providers who qualify to be a part of the Specification Committee. It is imperative that the NDHM follow utmost considerations of transparency and fairness by clarifying the criteria for participation in the design process of the UHI Open Protocols. This will also help maintain fairness in the process of building the UHI, while allaying fears about unfair preferences and competition.<sup>58</sup>

Second, the paper purports the public consultation process as a cornerstone of developing UHI Open Protocols. However, the scope of such a consultation process, who can participate in it and the value of recommendations suggested by members of the public remain unclear. Further, it is paramount to ensure that the window for public consultation adheres to the Pre-legislative Consultation Policy requirements, providing a minimum period of 30 days for public responses.<sup>59</sup> This will help the National Health Authority (NHA) avoid their initial mistake of notifying a period of one week as the window for public consultation on the Draft Implementation Strategy of the NDHM.<sup>60</sup>

**Question 6.5.2:** What should the UHI Gateway charge in the initial few years of operation? How can this model evolve over time?

**Issue:** Additional fee levied in the nature of UHI Gateway charges can increase the cost of availing digital health services and serve as a disincentive to the adoption of the UHI itself.

 <sup>&</sup>lt;sup>58</sup> Singh and Porecha (2020), The Ken, "Behind the rush and hush of India's National Digital Health Mission", <u>https://the-ken.com/story/behind-the-rush-and-hush-of-indias-digital-health-mission/</u>
<sup>59</sup> Clause 2, Pre-legislative Consultation Policy, Legislative Department, Ministry of Law and Justice, <u>https://legislative.gov.in/documents/pre-legislative-consultation-policy</u>

<sup>&</sup>lt;sup>60</sup> Software Freedom Law Centre (2021), "NHA confirms that the consultation period for Draft Implementation Strategy of NDHM is in contravention of Pre-Legislative Consultation Policy", <u>https://sflc.in/nha-confirms-consultation-period-draft-implementation-strategy-ndhm-contravention-prel</u> <u>egislative</u>

**Response:** The current pricing formula proposed by the paper calls for the levying of UHI Gateway charges as a way to cover the cost of developing and maintaining the interface. However, the possibility that this can inflate the overall cost of services, in turn making digital health solutions more expensive to end-users may act as disincentives to the adoption of the interface and undermine the goal of making such solutions ultimately affordable. Alternatively, the pricing model adopted by UPI wherein the cost of developing and maintaining the protocol is borne by the National Payments Corporation of India can ensure that cost of conducting digital payments is absent or nearly negligible to end-users. This has gone a long way towards ensuring that the UPI remains an attractive solution to transition the Indian populace towards digitally-mediated payments. Therefore, it is incumbent upon the NDHM to bear the cost of developing, implementing and maintaining the UHI to ensure widespread adoption of the interface among relevant stakeholders. The experience of <u>Finland</u> and <u>Estonia</u> demonstrate that state support (financial primarily, technical as well) is essential to produce uptake for digital health solutions. For a more detailed discussion on the recommended pricing formula and mechanism, please refer to the response for Question 5.3.2.

**Question 6.5.3:** Please share your views on the duration for which NDHM should manage and govern the UHI gateway, and if NDHM should open the path to multiple gateways. Please provide details on the benefits and risks of the options.

**Issue:** Appointing non-state bodies to manage and govern the UHI can impinge on independence and accountability. Further, instituting multiple gateways will magnify the cost of developing and maintaining the UHI. It can lead to overlaps in functionality and scope, undermining the unified nature of the interface.

**Response:** In our view, the NDHM or any associated state-constituted body should be the sole and permanent entity to manage and govern the UHI Gateway. This will ensure that UHI is not susceptible to private interests and can be held accountable to the Indian polity, since the nodal agency notified to manage the same is a state entity. Consequently, it becomes possible for users to gain visibility into the design and approval process of the NDHM while making governance decisions regarding internal policies (ex: which platforms can be on-boarded or suspended from the UHI). This is imperative to ensure the UHI Gateway and its managing entity (here, NDHM or its affiliates) are retained within the purview of the Right to Information Act, 2005 - the foundation of accountable governance systems.

As for the creation of multiple gateways, the resultant cost of developing, implementing and and maintaining these gateways will create undue stress on the finances of the NDHM. Instead, it would be fiscally more prudent to create one unified gateway, as was the case with UPI, and make incremental additions to the interface. The UPI is a pioneer in encouraging transition to digital payments that is made possible on account of the developer-friendly APIs that underpin the interface. Further, additions to the UPI ecosystem such as the BHIM App ensure the long-term viability of the ecosystem. Adopting a similar approach with the UHI -



one which is founded in robust systems characterised by an interoperable interface with developer-friendly open protocols (APIs) - will make the interface indispensable to herald a digital health revolution in India.