



Key Takeaways of India Workshops

20th, 22nd and 23rd April 2021

*The quest to achieving sustainable healthcare in Asia Pacific cannot be achieved alone. It requires multi-stakeholder collaboration to make a difference. In that spirit, Sanofi and KPMG, with the support of the World Economic Forum (WEF), are producing a position paper surrounding the theme of “**Sustainable Healthcare in APAC: Financing & Delivery Models**”, with the objective of identifying and unlocking financing and delivery models in APAC to achieve better health outcomes with a more efficient use of resources.*

This report will inform programming and high-level dialogue on global health system resiliency at relevant World Economic Forum-hosted events and other country/regional platforms. To ensure the report offers insightful and actionable solutions, three co-creation workshops were organised in India on 20th, 22nd and 23rd April 2021 to collaborate with stakeholders across the public and private sectors.

The workshops covered three different thematic areas: Life-course Immunisation, Diabetes Management and Rare Disease. Each workshop was attended by approximately 25 - 30 participants, consisting of government associated institutes, public and private health practitioners, NGOs and multilateral organisations, patient advocacy groups, banks, private insurers, pharmaceutical companies and others.

Chatham House rule was observed during the workshops. The insights and solutions gathered during the workshops have been summarised in this report, with no direct attribution to any participants. However, contributing participants and organisations would be credited as a contributor to the position paper.

We thank all workshop participants for their valuable contributions.

Life-course Immunisation Workshop

Immunisation prevents 2-3 million deaths per year and is widely recognised as one of the most cost-effective public health interventions. However, life-course immunisation uptake rate remains generally low in India. The country has achieved high vaccination coverage for children but not for adults.

Despite the benefits, why are people not getting vaccinated?

Our workshop participants ranked **low awareness and limited vaccine confidence** as the top delivery challenge for life-course immunisation. For one, the National Vaccine Policy focuses on children rather than adults resulting in over two-thirds of Indian adults being unaware of adult vaccination itself. In addition, very few (< 5%) of healthcare workers have been vaccinated from influenza due to their own vaccine hesitancy.

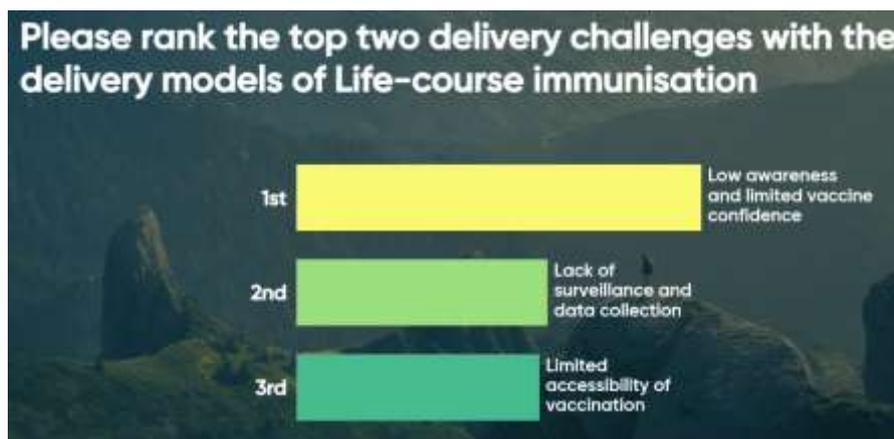


Fig 1: Participants' respond over a virtual poll

Some of the reasons for this, as highlighted by our participants include:

- **Cultural resistance**

Participants shared how people in India tend to adopt a mindset that generally takes on an attitude of 'corrective care' rather than 'preventive care'. They recognise that immunisation is permanent and instead opt towards the idea of 'building one's immunity naturally' by taking medicines as and when needed.

- **Weak policy framework**

The Indian government has made relatively less effort towards driving the cause for life-course immunisation. In fact, it was only during the urgency brought forth by Covid-19 that pushed the government towards providing vaccinations for healthcare workers and members of the public. Presently, healthcare providers (HCPs) do not typically seek to recommend life-course immunisations to their patients. As life-course immunisation appears to be largely absent from treatment protocols, uptake has been low from patients.

Collectively, these reasons create a compound effect around a lack of understanding around vaccinations and its potential benefits.

Besides this, the second highest-ranked delivery challenge for life-course immunisation is around the **lack of surveillance and data collection**. This means there is a lack of quality data on disease burden and limited epidemiological studies available which serves to hinder the assessment of vaccine importance and impact. Additionally, the key decision makers in India lack evidence around the effectiveness of vaccines in the local population. At present, India does not have a regulatory framework around electronic health records (EHR) resulting in varied adoption across hospitals – some may be aware of the guidelines but may not be following them closely [1] which create lapses in potentially useful patient data collection.

How can we raise the awareness & confidence of vaccines?

1. Providing incentives for vaccinations

Historically, the success rate of initiatives geared toward reducing vaccine hesitancy have been variable. Hence it may be worthwhile exploring the idea of providing incentives for vaccinations.

- ***Direct benefit transfer***

Direct benefit transfer refers to cash incentives given directly to the beneficiary.

For example, the Indian government has been encouraging women to opt for institutional birth deliveries and implemented a scheme known as Janani Suraksha Yojna (JSY), which translates from Hindi to 'Pregnant Women Safety Scheme' [2]. As part of this, a cash incentive of Rs 2,000 is provided to the mother and to the Accredited Social Health Activist (ASHA) (in an approximate 70% - 30% split ratio).

Though cash incentives arguably work well, it is instructive to note that these will add to cost of vaccinations, and it will be imperative to keep in mind the broader frame of financials around such policies of this nature.

- ***Insurance-linked incentives***

We can look towards exploring the prospect of collaborating with insurers to link benefits/subsidies on earmarked insurance premiums as tied to an individual's vaccination status.

To ease concerns around potential side effects from vaccinations, insurers may also provide free coverage for unexpected complications that may arise from vaccines. For example, DBS in Singapore partnered with Chubb Insurance to provide their customers with free coverage for any unexpected hospitalisation after receiving their Covid-19 vaccines [3].

2. Enhancing the ecosystem of vaccinators

Expanding the healthcare point-of-contact network

The Indian retail pharmacy market is expected to expand at a compound annual growth rate of 10.96% from 2020 – 2025 [4]. Leveraging on this channel expansion, it is possible that selected major pharmacy chains, such as Fortis Healthworld and Apollo Pharmacy, could be adapted to incorporate the structural and medical facilities needed for vaccinations to take place. Given the widespread network of pharmacies in India, this could be one way to increase accessibility to vaccines by creating more points-of-contact for the public.

That said, it is important to also consider the characteristics of the vaccine and delivery requirements. For example, thermostable vaccines and oral vaccines can be extended to more points-of-care centres. However, more specialised vaccines such as the Covid-19 vaccine may require a specially trained HCP.

Set-up adult immunisation centres

Setting up dedicated adult immunisation centres would improve public accessibility to vaccines, as well as raise awareness on the availability of immunisation options. These centres can also be open for HCPs to receive their vaccinations (including Covid-19 and influenza vaccines). Currently, there are no national adult immunisation guidelines in India. That said, national multidisciplinary coordination in this aspect would work well together with the opening of more access points to improve vaccine coverage for adults [5].

How can we improve the surveillance and data collection for life-course immunisation?

It is important to keep in mind that a proper legal framework for data protection would ideally need to be put in place across all recommendations related to surveillance and data collection.

1. Creating vaccine registries

Currently, the health records situation in India is highly fragmented, where there is an inadequate record-keeping of patient medical history especially in public facilities [6]. To address concerns around the lack of patient records and data in the Indian health system, the Indian government launched the National Digital Health Mission (NDHM) in 2020. As part of this, unique health IDs will be created for individuals to store their digital health records [7].

This can be taken one step further, where a patients' birth data and immunisation data could be reflected in the same digital health record. This way, a physician would have a more comprehensive view around a patient's medical history and at the same time, be in the loop of their vaccination status. Such a topic is particularly relevant during the "digital vaccine passport" dialogue happening as a result of the COVID-19 situation.

2. Tracking data by potential use cases

The data collected can be useful to different groups of stakeholders and provide insights that may be helpful for more effective policy decision-making. It would be useful to understand the potential policy utilisation outcomes of the data, and work backwards to understand what type of data needs to be collected and how can this be done.

- ***Understanding the value of prevention***

By weighing the cost of treatment against the cost of prevention, we can potentially seek to create a case that encourages the outpatient market to look towards prevention mechanisms rather than solely treatment.

Cost-related data points can be collected around two groups of people: ones that have received vaccination for a disease, and ones that have not been vaccinated and subsequently contracted the disease.

- ***Cost of insurance premiums***

Tracking pay-out ratios across vaccinated vs unvaccinated population could create important information that can be useful to employers and individuals themselves. For example, the unvaccinated population would lend towards paying higher premiums than the non-vaccinated population.

How can we ensure adequate funding capacity for Life-course Immunisation?

1. Consolidation of corporate social responsibility (CSR) funds

In India, corporates are required to allocate a percentage of their revenues towards CSR. These CSR funds can then be pooled together and earmarked for building and supporting the necessary infrastructure and capabilities required to facilitate adult vaccinations. For example, the training of medical personnel to administer the vaccine, the procurement and storage of vaccines and promotional activities to encourage adult vaccination.

Gavi, the Vaccine Alliance collaborates with numerous global donors who contribute towards Gavi's health programs. Donors include members of the private sector (such as TikTok, Mastercard, Unilever), foundations (such as The Bill & Melinda Gates Foundation, Red Nose Day Fund) as well as various countries including Finland, Denmark and Australia [8]. However, reliance on Gavi funding is not sustainable, and it would be ideal to encourage self-reliance at a national level by countries establishing their own local mechanisms for fund pooling.

2. Encouraging partnerships between insurers and employers

An employer-led healthcare initiative carried out in partnership with insurers could help employees cover the cost of vaccinations. For a vaccination program at company-level, insurers could offer discount vouchers to their partner company's employees so that they would be able to obtain vaccinations. For example, corporate flu vaccination has shown to be a popular and convenient option in the UK where employees of partner companies can visit some of their local pharmacy chains and receive their flu vaccination at their own time. There is sound reason for employers to provide this to their employees, as flu vaccinations are known to be a simple and cost-effective way to keep employees healthy and productive at work.

Diabetes Management Workshop

As the most populous region in the world, the Asia-Pacific (APAC) represents a disproportionately large share of the Diabetes burden. In India, 77mn people live with diabetes, placing the country as second highest in the world for people with the disease [9]. Growth projections from the IDF Diabetes Atlas predicts that in the next 25 years from 2019, circa 134mn Indians will be diabetics [10] [11]. Keeping these (likely underreported) statistics in mind, it is especially crucial for more people to understand how to reduce their diabetes-associated risks. For those living with diabetes, it is important to understand how to care and manage their condition well to prevent complications [12].

What are the greatest challenges with the delivery models of Diabetes Management?

The top ranked challenge cited by our workshop participants was the **complexity and inaccessibility of self-management** of diabetes. Our research found that a large majority of diabetic patients may spend their time incorrectly self-managing their condition due to confusion about the injection method and tools, and face challenges with controlling their plasma glucose. As highlighted by our participants, there exists a significant lapse in patient knowledge around diabetes self-management, resulting in diabetic patients being unaware of how to properly treat and look after themselves. In addition, patients also face limited access in obtaining diabetes medicines in India. For example, only 44% of pharmacies in New Delhi carry insulin, much lower than the World Health Organisation (WHO) recommended availability target of 80%.



Fig 2: Participants' respond over a virtual poll

The second ranked challenge was the **need to evolve the delivery model**. Patients in India must often travel long distances to district, provincial or national level hospitals for treatment, which becomes a deterrent for them to seek treatment due to the cost of transport and travel time incurred. Furthermore, the quality of diabetes support varies considerably depending on the awareness levels and expertise of the care providers. This means that the care providers themselves may not be sufficiently capable to dispense information on diagnosis and guide patients on everyday self-care, with most patients having to depend on specialists such as doctors and endocrinologists.

How can we reduce the complexity and inaccessibility of self-management for diabetes?

Digital literacy is steadily increasing in India, with concrete steps being taken by the government to boost such skills among citizens [13]. While the internet penetration rate in India stands at 45% which may seem relatively low [14], it translates to over 616mn people having access to the internet, which presents a sizable addressable market to tap on these recommendations.

1. Creating a more robust digital infrastructure for diabetes self-management

Leveraging digital platforms for information sharing and teleconsultation

India has a lively health-tech start-up space, with several players now utilising artificial intelligence and cloud to bring better diabetes care towards patients [15]. This could present a promising opportunity to explore a potential bolt-on around their tech capabilities and create a patient-centric digital interface geared towards key information sharing from HCPs to diabetic patients.

Our workshop participants highlighted the following key features to include such as:

- teleconsultation capabilities (a nascent, but growing market considering the Covid-19 situation) [16];
- a function to remind patients on regular self-care steps (such as for blood glucose and insulin tracking);
- a FAQ feature for patients to clarify their doubts;
- circulars from medical bodies regarding tips on diabetic self-management.

It would also be useful for a patient to be able to access their electronic health records at a glance, as this would keep them clearly informed of their condition status.

Government-led promotion of an open innovation concept

Another idea is for government health bodies to advocate for an open innovation concept, where the outcome leans towards an integrated point-of-care system to provide a holistic patient system across the whole customer journey, from pre-visit, in-clinic and post-visit. A strong patient journey mapping structure helps to ensure better communication between patients and HCPs, and that patients have an overall improved experience and greater clarity on the next steps of their health-care regimen [17].

This could potentially work in line with India's National Health Stack (NHS), a digital framework that is aiming towards digitalising health records for all citizens by 2022. At the heart of the NHS design is a strong IT spine that seamlessly links across national health electronic registries, a coverage and claims platform, as well as other horizontal components [18].

Key Considerations

That said, it is important to keep in mind the data privacy element that comes with all tech-based solutions underpinned on information sharing models.

Furthermore, the implementation of these systems can only be successful with widespread adoption. As such, proper training should be administered to patients to onboard them onto the digital platforms. This means that it is likely that initial support needs to be carried out physically, with the inclusion of accessibility features such as multi-language functions and ease of usage. Through this, it is hoped that such systems would help simplify and improve the accessibility for patients seeking support for diabetes management. With enough evidence, governments can even consider reimbursement as part of their inclusiveness in UHC new models of care.

How can we evolve the delivery model for diabetes management?

1. Creating a more organised treatment protocol

Mobilising greater collaborative effort to reinforce treatment protocols

To ensure that diabetic patients receive the support that they need, government and patient advocacy or community groups can collaborate with medical professions to help with the implementation of treatment protocols.

Currently, there exists a patient support program which was launched by the pharmaceutical industry. The team has collaborated with HCPs to organise health camps that allow for simple diagnostic testing and supports its current base of 50,000 diabetic patients through providing disease management support over online monitoring tools and online medication dispensary [19]. Ideally, a similar model can be replicated to reach out towards more members of the population and achieve a broader coverage across states.

In addition, our workshop participants shared how it can be difficult for patients to seek support systems for their mental health and holistic health management in India, especially for those living in rural areas. This is because living with diabetes entails several responsibilities, such as tracking blood glucose and insulin, as well as remembering to schedule doctors' appointments. Research by the Royal Australian College of General Practitioners found that collaborative care by inter-professional teams can help suppress and ease any symptoms of diabetes distress and anxiety in affected patients [20]. As these lifestyle engagements can be emotionally consuming, it is essential that patients stay healthy in both their mind and body to be able to look after themselves properly [21] by being able to reach out to a support group in their community.

How can we ensure adequate funding for diabetes management?

1. Creating multi-sectoral funding pools

Conceptualising dedicated programs for specific causes by consolidating relevant stakeholder groups

Besides the government, it is also important to keep in mind the other relevant stakeholder groups as they would be the ones most likely to sponsor a cause that is aligned with their raison d'être. For example, for a program that supports children with diabetes, we can expect funding streams from children charity organisations, and corporates who pledge towards this cause.

Developing a shared value-model that intersects corporate purpose and societal impact

As defined by Harvard Business Review, shared value is a result of policies and practices that contribute to competitive advantage whilst simultaneously strengthening the communities in which a company operates [22].

With the adoption of such a model, the private sector (namely pharmaceutical corporates and medical device suppliers) can collaborate with patient beneficiary organisations or hospitals to donate or subsidise their products (such as insulin, blood glucose monitors), especially for the lower-income patients.

This has been successfully orchestrated previously, where Nestle sent a team of researchers to India to study the state of malnutrition and anaemia across 1,500 poor households. They then launched a special, low-priced micronutrient-rich spice product, called *Maggi Masala-ae-Magic* using non-profit distribution channels to reach the most remote and affected communities [23].

On this note, there exist ample opportunities to create innovative shared value outcomes that could present tangible benefits to the communities affected by diabetes in India.

2. Developing more inclusive insurance policies

Exploring the prospect of composite social insurance

Many workshop participants cited the high costs of medical accessories needed for diabetes care (such as blood glucose meters and insulin pumps). In fact, these out-of-pocket treatment costs add up to a sizable sum as these costs are incurred on a regular basis for diabetic patient self-care. As such, it would be beneficial for the government to build a financially sustainable model that confers benefits directly to the patient.

Further, as diabetes is a lifestyle-related disease, it is not only medicines but also proper nutrition that will help patients better manage their condition. For example, this could be done through the provision of insurance coverage around medical accessories for diabetes care, as well as providing patients with support on nutrition (for example, those with Type 2 diabetes may benefit from complimentary or subsidised access to organic and low glycaemic-index products such as quinoa and millet [24]).

Linking insurance as an extension of telemedicine and e-pharmacy

With the rising adoption of telemedicine and e-pharmacy and tying back to our points around novel delivery models, it may be worthwhile to explore the prospects of extending insurance coverage in the space of telemedicine. This would alleviate the financial burden of a patients' out-of-pocket expenses and provide convenience to them in obtaining the medicine that they require.

3. Introducing government-led economic intervention

Imposing sin tax

'Sin tax' is an excise tax can be specifically levied on products that are known to elevate the risk of diabetes, particularly sugar-sweetened drinks. An example of a use case is Mexico, which saw an average decline in the purchase of taxed beverages, by 8.2% over two years [25]. While helping to lower patients' risk of diabetes and obesity, sin tax can work to increase revenue available to the government to support public health measures dedicated to diabetes management.

Rare Diseases Workshop

In India, a disease or disorder is considered rare when it affects fewer than 1 in 2,500 individuals [26]. Rare diseases, also referred to as orphan diseases, are often chronically debilitating and severely life threatening. In India, late diagnosis of rare diseases is a pressing problem and, in most cases, delays in treatment can significantly reduce the chances of recovery for patients [27].

What are the greatest challenges with the delivery models of Rare Diseases?

Expectedly, the lack of priority was ranked as the top delivery challenge. Despite India being home to one-third of the world's rare disease population, the country has yet to efficiently fund a National Health Policy dedicated to this population subset [28]. At a public health level, there are conflicting priorities due to larger addressable populations diagnosed with other diseases, and a lack of availability of information around rare diseases. Our workshop participants shared that at the heart of this, there is an apparent lack of education and awareness around rare diseases in India.



Fig 3: Participants' respond over a virtual poll

Limited accessibility of treatment was ranked as the second top delivery challenge. Less than 5% of rare diseases have approved treatments globally and in India, only 15 – 20 rare diseases have Drugs Controller General of India (DCGI)- approved treatments. Furthermore, the inclusion/exclusion criteria for patient identification and treatment support remains unclear. As most treatment options are highly expensive, and insurance policies do not cover these life-long treatment expenses, many patients face a lack of access [29].

How can we increase the priority assigned to Rare Diseases?

1. Raising awareness: Encouraging multi-stakeholder collaboration and supporting patient advocacy groups

There is a lack of awareness around rare diseases, which is a pressing problem because this often leads to a late diagnosis and thus causing a delay in treatment [30]. To support this, we can look towards better supporting and enabling patient advocacy groups. Two of the main patient advocacy groups in India in this space are the Organization for Rare Diseases India (ORDI) which collaborates with tertiary care government hospitals or multi-speciality hospitals to support patients in diagnosis, treatment and supportive care, and LSD Support Society, India (LSDSS, India).

A more concerted effort from both public and private hospitals (driven by the Health Ministry) would be useful in helping these patient advocacy groups receive the support and resources that they need.

Furthermore, multi-stakeholder collaboration must be encouraged to support this cause. In Europe, Eurordis (a non-governmental patient-driven alliance of patient organisations across the region)

organised their third Multi-Stakeholder Symposium on Improving Patients' Access to Rare Disease Therapies in 2019 [31]. Such events aim to discuss actionable and practical solutions that can be implemented to promote access to rare disease therapies.

2. Better diagnostics: Supporting healthcare practitioners with actionable solutions

Tertiary care Hospitals, across various states/ regions, that have been identified as Centres of Excellence (CoE's) by the Ministry of Health (MoH), with the support of HCP led organizations like SIAMG (Society of Indian Academy of Medical Genetics) / ISIEM (Indian Society of Inborn Errors of Metabolism), can help to provide short-term training programs to educate doctors about rare diseases. A public-private-partnership may be especially useful, because the private sector (pharmaceutical companies and diagnostics companies) can help to provide the knowledge based on their research findings, provide support on a diagnostics front, as well as funding to run their courses. At the same time, the planning and execution of programs can be led by the government [32]. This way, doctors and healthcare providers will be better informed on the various rare diseases and can send patients suspected of rare diseases for diagnostic testing at an early stage.

To ensure that the new and incoming doctors are also well versed on the state of rare diseases in India, medical schools can look towards including the study of rare diseases in their curriculum. The Medical Council of India (MCI) has added genetics courses into their Bachelor of Medicine and Bachelor of Surgery (MBBS) curriculum, but it would also be important to incorporate the broader scope of rare diseases too, as well as for the Doctorate of Medicine (MD) courses [33].

Furthermore, it would be critical to have a proper protocol in place to guide doctors. Our workshop participants shared how rare diseases are currently perceived by the Health Ministry as too difficult a problem, making it challenging to even start solutioning. As such, we must look to re-write the narrative for rare diseases towards a serious yet manageable issue that we can work to tackle with concrete and clear steps.

Some of the key points raised by our workshop participants to drive the above include:

- Creating an official definition for rare diseases in India and categorizing based on treatment potential.
- The current estimates there are over 70m patients with rare diseases in India, is based on estimated prevalence, and such numbers, given the high cost of treatment for some of the disorders, make the problem seem unmanageable while the reality is that the actual number of patients diagnosed with rare diseases is significantly smaller. This is also borne out from the experience of managing patients with rare diseases in other parts of the world.
- Prioritising treatable conditions within the Group 1, Group 2 and Group 3 [34] list of rare diseases and establishing a clear and encompassing treatment definition for these diseases.
 - That is, to start from diseases which already have a treatment plan and then understand how to educate healthcare practitioners (HCPs) on how to properly carry out the diagnosis.
 - From there, HCPs can be in a better position to identify patients which have the symptoms so that diagnosis can be done efficiently.
 - Adopting this “vertical pyramid” approach to diagnosis is a way of spreading awareness and creating actionable change by working within a “disease-centric” policy.
 - Once the approach to treatment and diagnosis for a specific rare disease has been approved by the government, HCPs can then continue to build on that framework and subsequently look at the next set of rare diseases of concern.

- It would be useful to track outcomes in terms of diagnostics and treatments at regular check points (for example, every 6 months or one year) to help HCPs keep informed of their progress and change the course of treatment as necessary.

Our workshop participants are confident that proposing a manageable and clear solution-driven approach to the government would help prioritise rare diseases in their public health agenda. It is especially critical to communicate the severity of rare diseases with a solution-driven messaging, to raise awareness and drive for actionable change.

How can we improve the accessibility of treatment for patients with Rare Diseases?

1. Improving the usability of The Indian Rare Disease Registry

Currently, the Indian Rare Disease Registry is still not functional. However, it would be beneficial to create a simple registry where healthcare practitioners could input the relevant data points involved. As a starting point, it would be ideal to collect basic information such as around the patients' family health history, then moving on to more specific data points such as genetic screening results, or disease-specific information.

Alternatively, we could make use of already available international registries as per their availability, to not reinvent the wheel altogether.

Research conducted by Harvard Business School recommends that it would be ideal to incorporate best practices around patient-focused registries in two ways: ensuring that information is dynamically collected over the long term to create longitudinal data, and also to keep the end goal in mind of aggregating the information in a Registry to identify disease causality and developing cures [35].

To ensure that the Registry contains relevant and updated information, there needs to be push from top-down and patient-advocacy groups to motivate healthcare practitioners to actively collect and share the data, for the benefit of all. Our workshop participants highlighted a possible barrier, in that some clinics may have their own vested interest to collect data for their proprietary research and publications. As such, this makes it even more important for the Ministry to advocate on the importance of contributing towards maintenance of an updated National Registry.

2. Drafting a Common Compendium Document

At a grassroots level, more people need to be educated and aware of their options should they have reason to believe that themselves or their loved ones may have a rare disease. With the information collected from the Registry, HCPs can collaborate with research institutes to create a Common Compendium Document and distribute it to health clinics so that patients can be better informed on the conditions that they may have.

The Health Ministry has recently approved the National Policy for Rare Diseases in 2021 which aims to lower the high cost of treatment for rare diseases, through a provision for financial support up to Rs 20 lakhs (USD 29,962) for rare diseases that require a one-time treatment. However, it offers no support for patients with rare disease who require lifelong treatment support, such as those suffering from Pompe Disease and Gaucher Disease [34].

How can we ensure adequate funding for Rare Diseases?

1. Ensuring better use of the existing government budget with earmarking, supplemented with private sector contributions

There is a government budget allocated for the National Policy for Rare Diseases, but it is grossly insufficient considering the high cost of treatment for rare diseases [36]. Rare diseases, given their chronic nature, entail long term treatments. Currently the government funding provision is only for one-time treatments, and does not cover Group 3 disorders, that entail long term, recurring treatment expenses. That said, we could look towards evolving the existing policy towards state-level financing through the following approaches:

- Setting KPIs to use funds at a state level
- Carrying out a “horizon scan” across the pipeline at a governmental level, in order to allocate funds towards specific rare disease budgets
- Mandating for clearer visibility on spending

As part of this, it would also be helpful to supplement the existing government budget with “top-ups” from the private sector. There can be the inclusion of three additional sources of funds and subsidies, as follows:

- Crowdfunding. The underpinning concept is that multiple people provide a small or variable sum of money to finance the costs of a large project [37]. This has successfully been carried out by several life-science start-ups in Europe through online crowdfunding campaigns that provide the capital for R&D in drug development and regenerative medicine [38].
- Mandatory CSR contributions from major corporations, more of which could be channelled towards rare diseases [39]. Currently, much of the spend is being put to building hospitals or facilitates management.
- Private insurance mechanisms. A use case is carried out in South Africa, where an insurer had launched a product giving insureds subsidised access to genetic testing after the policy has been issued [40], and this may especially be useful for families where one sibling or more has been diagnosed with a rare disease (given that many rare diseases are genetic in nature).

2. Encouraging the private sector to contribute funds towards screening for research benefits

The private sector could play an instrumental role in driving the first step of this journey, i.e. at the diagnostics stage. By funding the screening stages of rare diseases, the private sector players could gain critical insights and data points from these screening results. They can then benefit from this data by using it for research and development towards potential future innovations.

From a Corporate Social Responsibility (CSR) perspective, healthcare institutions can work with these private sector players by encouraging the them to “adopt” a disease, as part of their mandatory CSR funding contributions that already exist in India. Examples of such companies could not just be limited to pharmaceutical companies or traditional screening companies, but major corporates like Tata and Reliance.

As part of this, there needs to be stronger national legal infrastructure in place around patent laws for orphan drug research so that the private sector players who are investing in the screening stage for rare diseases are protected from an intellectual property perspective.

3. Creating opportunities for private insurers to support funding in the screening phase

It often takes a long time for a rare disease patient to effectively be diagnosed, as there tends to be a lot of wastage and unnecessary claims that may take place during that time period. As such, private insurers could play a useful role by investing in the screening phase to derive better analytics around the claims process. In doing so, insurers can help to improve efficiency in the existing system and improve affordability for patients.

4. Implementing risk pooling mechanisms to improve affordability of treatment for new and innovative therapeutics

High cost drugs can be made more affordable through a concerted effort by health insurance providers. For example, in Canada, the Canadian Drug Insurance Pooling Corporation (CDIPC) which comprises 23-member health insurance companies, effectively helped over 45,500 Canadians to afford high cost specialty drugs which can run up to \$10,000 per year per individual [41]. A similar model can be adopted in India, where multi-stakeholder collaboration in this aspect can be crucial to help patients with rare disease afford the expensive cost of their treatment.

5. Improve the coverage of Ayushman Bharat to support patients with rare diseases, from a holistic healthcare perspective

Currently Ayushman Bharat does not cover rare diseases, but if someone with a rare disease were to contract an illness, they would not receive coverage because they are associated with being part of a “high risk” group. As such, it would be ideal that the policy underpinning Ayushman Bharat could be modified to one that is more inclusive and does not limit access to treatment for patients diagnosed with rare diseases.

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