

Key Takeaways of Australia Workshops

27th, 28th and 31st May

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 Australia on 27th, 28th and 31st May 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 15 – 25 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

The Australian government has put in place an official National Immunisation Program (NIP) Schedule which details a series of immunisations to be administered at specific times in a person's life, from birth to adulthood¹. All vaccines listed in the NIP schedule are free, and details which vaccines should be taken and when. While there is a policy framework put in place by the government, more can be done to further increase and sustain the uptake of vaccinations by the general population across all ages.

Our workshop participants identified **low awareness and limited vaccine confidence** as the top delivery challenge for life-course immunisation. They shared two key reasons for this. First, the heightened hygiene measures as a result of covid-19 has led to an overall drop in flu cases, resulting in a sense of complacency around the population who perceive themselves at lower risk of catching the flu. Second, there are still widespread misconceptions around the understanding of vaccine effectiveness, and sentiments of vaccine hesitancy being perpetuated by the media.



Besides this, the second highest-ranked delivery challenge for life-course immunisation is around the **lack of surveillance and data collection**. While Australia has a national register, i.e., the Australian Immunisation Register (AIR) that records all vaccines given in Australia, it is important to look at ways to further enhance the current data collection methods. As of 1 March 2021, registration of COVID-19 and Influenza vaccinations were made mandatory into AIR, and all other vaccinations as of 1 July 2021. In a 2018 study by the National Centre for Immunisation Research and Surveillance (NCIRS), it was found that there was an overall 14% error rate in the AIR, mostly attributed to incorrect transfer of information from the practice management software to AIR, as well as duplicate record-keeping practices.

How can we raise the awareness and confidence of vaccines?

1. Affirmations on the safety and efficacy of vaccines from KOLs

The government and health ministries are largely responsible for driving the nation-wide advocacy and promotional communications around this. The relevant media agencies that have been engaged by the government stakeholders should be cognisant of the ongoing feelings of vaccine hesitancy among the

¹ <https://www.health.gov.au/health-topics/immunisation/immunisation-throughout-life/national-immunisation-program-schedule>

people and drive the messaging around capturing the empathy of individuals. For example, seeing KOLs (including celebrities, athletes) sharing their narratives on their personal vaccination journeys – that they are doing this not only to protect themselves, but to keep their families safe. This can help to encourage people to think more seriously about vaccinations. It is to note that the challenge in Australia at this moment stems from the distrust with the government, along with the frequently changing advice given to the population.

2. Addressing stimulus and engagement based on two sector variables, i.e. vaccines by population groups

	Childhood	Seasonal	Travel	Specific (HPV)	Other
Parents					
Aged					
Female / Male	<div style="background-color: #4a7ebb; color: white; padding: 5px; border: 1px solid black;"> Table for illustrative purposes only </div>			<i>For e.g. Need to convey the benefits of the HPV vaccine to young women; and ease their worries about potential side effects that may arise.</i>	
Travelers			<i>Local travel agents/national airlines (e.g. Qantas) can send a gentle reminder to all travelers on the recommended vaccines that they need to take based on their destination</i>		
Business					
Vulnerable Populations (i.e. those with pre-existing conditions)					

Table 1: A sample table of vaccines by cohort to analyse and thereafter determine the required stimulus and engagement plans

The nature of how the required stimulus and engagement is addressed will vary for each cohort and vaccine type. As such, the following nuances should be considered:

- Risk
- Access
- Cost
- Negative messaging to counter

- Emotional factors at hand

Australia currently fares very well in encouraging childhood vaccinations, but more can be done to increase the rate of vaccination uptake especially in adults. Our workshop participants noted that having a common communication channel may not fare so effectively in driving the appropriate messaging to the right audiences, given the nuances described above. As such, targeting each cohort group with the relevant vaccinations and thereby engaging them appropriately could help to encourage and increase the average vaccination uptake.

3. Encouraging and incentivising General Practitioners (GPs) to promote vaccinations

The GP vertical only became a formally recognised speciality 20 years ago in Australia. As it is a relatively young speciality, best practices are continuously being identified to serve as guidelines for GPs. It would be beneficial for GPs to start actively advocating suitable vaccinations for their patients, as part of their best practice guidelines. This would naturally help to increase awareness of vaccinations on the patients' part, and GPs could receive incentives for their efforts around this. This would likely be a highly effective way to ease patients' concerns around vaccines, as studies have shown that doctor-patient communication plays a crucial role in positively impacting vaccination attitudes among patients².

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

1. Capturing vaccination information in a "digital passport"

Australia has in place its Australian Immunisation Register (AIR) that records all vaccines given to all people in Australia, be in under the National Immunisation Program, through school programs, or privately (for flu or travel). The data from this record could be populated towards an individual "digital vaccine passport" which outlines the vaccination record for each individual. The "digital vaccine passport" could be built as a bolt-on feature to the MyGov app or could be a standalone app on its own (similar to the HealthHub app created for use by the Ministry of Health in Singapore).

In fact, Air New Zealand has already started to trial digital vaccine passports for flights on routes to Australia, which enables authorities to quickly and easily check whether the prospective traveller has been vaccinated. The infrastructure for this system is based on the International Air Transport Association (IATA)'s digital Travel Pass app. Perhaps it may be beneficial for an individual's vaccination data captured from the AIR to be integrated across the Australian digital vaccine passport app (either a standalone app or within MyGov) to IATA's app for easy and convenient data transfer. That said, it is important to ensure compliance with national data regulations, and a robust data security framework should be put in place to prevent misuse of data.

2. Leveraging blockchain technology for storage of immunisation documents

Blockchain, or open source distributed ledger technologies present a secure solution to storing vaccination records. The key functional of blockchain in this use case is that a decentralised ledger would be anonymous, immutable and transparent, where anonymity is protected (with access rights recognised through either a private key or authorised biometrics)³, and it makes it easier to manage data sharing across different entities. A McKinsey research study recommends that pilot programs can be first put in place with blockchain specialist teams, so that governments can then devise a national roadmap to provide guidance and best practices for building the necessary capabilities for these blockchain applications to be implemented⁴.

² <https://www.tandfonline.com/doi/abs/10.1080/10410236.2021.1895426?journalCode=hth20>

³ <https://www.nature.com/articles/d41586-021-00411-6>

⁴ <https://www.mckinsey.com/business-functions/mckinsey-digital/our-insights/using-blockchain-to-improve-data-management-in-the-public-sector>

How can we ensure adequate funding capacity for life-course immunisation?

1. Opening up some of the restrictions around commercialisation by commoditising vaccines

Allow consumers to shop for vaccines online, as they would approach regular online shopping. Online shopping of vaccinations however should be linked with health advice. Regulatory clearance may need to be put in place for vaccines to be purchased by consumers. Potentially allow for a bit of profit margin to be created in the private sector sales and then redeploy this surplus towards creating funding capacity in the government.

This might be more suitable for oral vaccines, but tricky to administer given quite several people may have needle anxieties and fears.

2. Sharing the burden of cost across stakeholders

It may be worthwhile to explore how the burden of cost could be shared across different stakeholders – that is, between the users (consumers), private sector stakeholders (such as travel insurers, health insurers) and the government. For example, for initiatives that require partnerships and collaborations between the government and private sector, the cost burden could be split between these two entities. A guiding principle that could be useful to keep in mind is that whoever has the most vested interest in the solution could be the majority cost bearer.

Diabetes Management Workshop

As the most populous region in the world, the Asia-Pacific (APAC) represents a disproportionately large share of the Diabetes burden. As of 2021, around 1.8m Australians have diabetes, including all types of diagnosed diabetes and undiagnosed type 2 diabetes patients (an estimated 500,000 individuals)⁵. With the total cost impact of diabetes in Australia at an estimated AUD 14.6bn⁶, urgent attention is needed to ensure that our current and future diabetes treatment and delivery models are supported with sustainable financing mechanisms.

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

The top ranked challenge cited by our workshop participants was the **need to evolve the delivery model** for diabetes. One critical area of focus is the need to improve the current mechanisms around the annual cycle of care (ACC) for patients with diabetes. The ACC is a checklist used by GPs to review the diabetes management and general health of those with diagnosed diabetes. In a 2018 study, it was found that the ACC completion rates sat between 0.9% in an Indigenous population, to 37% over a 12 to 18-month period in non-Indigenous people. There exists a highly variable rate of diabetes ACC completion, which is critical because the ACC helps to screen for diabetes complications such as kidney disease or retinopathy. If these complications are detected late, it may delay and affect the efficiency of the course of treatment.



The second ranked challenge cited by our workshop participants was the **complexity and inaccessibility of self-management** of diabetes. In Australia, the National Diabetes Services Scheme is a channel that provides resources on helping patients manage their diabetes. However, it may be useful for more targeted support to be rendered to patients, to provide them with clearer guidance based on their unique health profiles and lifestyle backgrounds. Furthermore, it is important to advocate for a more patient-centric approach that would better align with patient preferences. In fact, up to 1 in four Australian type 2 diabetes patients believe that insulin is indicative of their condition getting worse⁷. More needs to be done to address the reluctance and concerns around injecting insulin for treatment.

⁵ <https://www.diabetesaustralia.com.au/about-diabetes/diabetes-in-australia/>

⁶ <https://www.ncbi.nlm.nih.gov/pubmed/23298663>

⁷ <https://www.ndss.com.au/news/one-in-four-australians-with-type-2-diabetes-avoid-insulin-because-of-psychological-factors/>

How can we evolve the delivery model for diabetes management?

1. Creating a Patient Centred Primary Care Collaborative (PCPCC)

Strengthening links across the patient – healthcare provider (HCP) value chain

It is worthwhile to explore broader ways where healthcare providers (HCPs) can look at how to better manage the course of treatment for diabetes in their patients. This means that they could start to more actively engage in referring their patients to other HCPs for more specific aspects of treatment. For example, General Practitioners (GPs) could first carry out the diagnostics and then route the patients to other specialist doctors such as a nutritionist to provide the patient with advice on any dietary concerns that they may have. The nutritionist would have deeper expertise in the topics of food and diet plans, and thus be able to offer the patient with more appropriate and detailed advice on the topic than what a GP can offer.

Exploring digital health solutions to create easier access to healthcare for diabetic patients

To bring greater convenience to patients by reducing travel time needed to visit a clinic, digital and tele-health solutions will be helpful. Currently, *Healthdirect Australia*, a government association that provides virtual health services⁸ offers a video call service designed for clinician to patient consultation. That said, it is important to note that not all patients may be digitally-savvy and so, some initial training and support may be needed to onboard them smoothly onto these platforms. This initial training could be performed by the HCP during the patients' medical appointment at a clinic.

Taking this a step forward, a specialised Diabetes telemedicine system could be devised and built into this service, which would ideally offer a user friendly interface that tells a patient of their required dosage of medications, as well as recommended diet and lifestyle advice (either from their GP or from their nutritionist/dietician). The objective of this system is to further simplify the treatment approach for diabetes patients and make it more convenient for them to access important information that they may need.

Providing mental health support to ensure holistic healthcare

Some of our workshop participants shared their personal experiences living with diabetes, and a common thread identified was the importance of a support system. Typically, this is derived from the patient's family members. As studies have shown how changes in blood sugar may affect a patient's mental health and anxiety levels⁹, it is important for HCPs to check in on their patients' mental well-being as well as their physical well-being, to ensure that they are supported from a holistic healthcare perspective. As needed, the HCP may refer the patient to seek additional support from patient support groups, or therapists.

2. Improving the process around check-ups and testing

Currently, patients with diabetes may face practical inefficiencies around a long waiting time (approximately 4 to 5 working days) for their test results to be ready, and on top of this they would also need to travel personally to the clinic to retrieve their test results. It may be worthwhile to simplify this process by allowing for the results to be released online through a secure system so that patients can conveniently access their test results.

⁸ <https://about.healthdirect.gov.au/video-call>

⁹ <https://www.mhanational.org/diabetes-and-mental-health#:~:text=Changes%20in%20blood%20sugar%20can,of%20stress%2C%20depression%20and%20anxiety.>

health#:~:text=Changes%20in%20blood%20sugar%20can,of%20stress%2C%20depression%20and%20anxiety.

How can we reduce the complexity and inaccessibility of self-management for diabetes?**1. Implementing data collection mechanisms that provide useful data points to the right target audience**

It will be worthwhile to explore ways to connect key data points from stakeholders that orbit across the patient's healthcare value chain to derive purposeful analytics for the end-user.

For example, a patient's blood test results may be fed into the system by their primary HCP, and this data can be received by the patient's nutritionist who can then advise the patient on suitable dietary and lifestyle recommendations based on their latest health profile. In addition, the dosage information for any medication or supplements that have been provided by these HCPs may also be inputted in the system. At the end of a cycle, the patient gets a clear view on their health progress and can better keep track of the types of diets and treatment approaches that may work best for them. Additionally, patients may choose to use health wearables which automatically collect data around a patient's sleep cycle and daily activity intensity, for example. These data points may be equally useful for their HCPs to understand and be aware of as well.

The analytics that can be derived from this data collection mechanism will only be useful if all involved stakeholders agree to regularly update the system with the relevant data points when manual data entry is needed. That said, a level of automation can be built into this data collection process to make the process easier for all stakeholders.

2. Streamline the sources of information around diabetes care and management

There are numerous sources of information for diabetes treatment guidance. However, this runs the risk of potentially confusing them especially if the information is contradictory or misleading. It may be worthwhile to either:

- (a) Encourage patients to look toward a single source of information; or
- (b) Allow for multiple information providers to navigate the dialogue

If the former is selected, there may be a need for the government health agencies to intervene and shed light on the situation. While people should be given the freedom to read and research on the topic as they prefer, it can be argued that it is the government's duty of care to ensure that people are being guided towards the right information sources that are in their best interests.

3. Creating a unified, integrated CRM containing key data points of registered patients with diabetes

Australia's National Diabetes Services Scheme (NDSS) hosts a centralised customer relationship management (CRM) database that contains all details of registered diabetes patients. *MyDesmond*, a support program within the NDSS, is dedicated for those with type 2 diabetes and carries various features such as activity tracking options (linking functions with wearable technologies) as well as health tracker functions where users can self-report their latest data on weight, HbA1c and track their progress.

It would be beneficial to use *MyDesmond* as a starting point and look towards integrating this with the national health system (i.e. connection with HCP medical records or hospital medical records). Proper data integration in place has been shown to help improve patient care (as HCPs are more well-versed with trends around their patients' conditions) and thereby improve clinical outcomes¹⁰.

¹⁰ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6178202/>

How can we ensure adequate funding capacity for diabetes management?

1. Exploring the use of employer-led incentives

It is important for employers to play a part in helping their employees who are diagnosed with the condition to keep healthy and feel well-supported, through providing employee perks that are beneficial to these individuals.

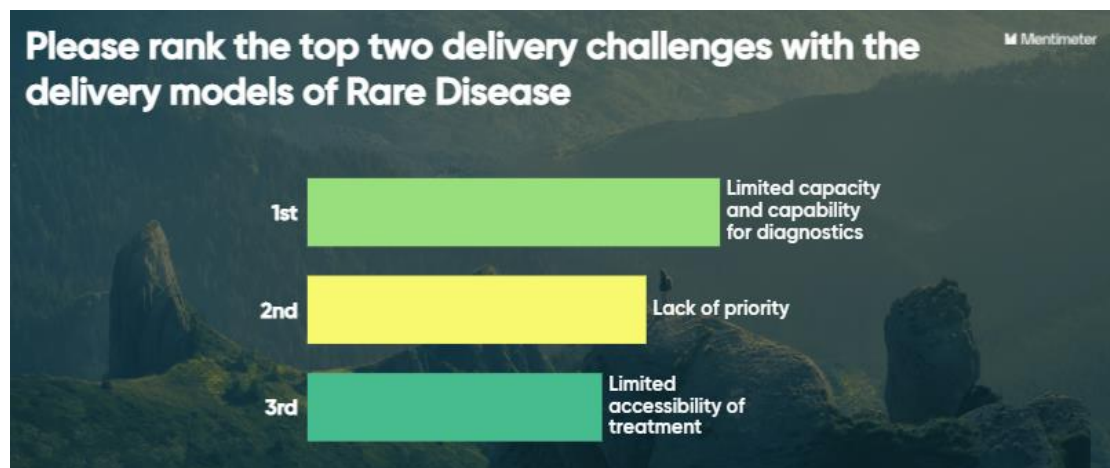
In IBM in the US, all employees with diabetes were given a USD 100 payment bonus if they maintained their weight over a 12-month period, to look after their health. In a similar vein, employers in Australia may wish to incentivise their employees either with cash or gifts in the category of health and wellness. By drawing emphasis to the importance of healthcare in the workplace, more individuals would be reminded and encouraged to look after their health. As a result, a healthier workforce translates to reduced susceptibility of illness and thus less burden on the national healthcare system.

Rare Diseases Workshop

In Australia, a rare disease is classified as such if it affects fewer than 5 in 10,000 people. Approximately 8% of Australians (c. 2 million people) live with a rare disease. Some examples of rare diseases include cystic fibrosis and Huntington's disease. About 80% of rare diseases are genetic and getting diagnosed for these diseases take time because each patient presents a complex case that is often something not commonly seen by most doctors.

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

The **limited capacity and capability for diagnostics** was the top ranked delivery challenge for Rare Diseases. There is a need for better access to early diagnosis and care coordination for people with Rare Diseases. For example, the lack of screening tests and limited knowledge on the part of HCPs for diagnosing Rare Diseases could cause diagnostic delays of at least 5 years among Australian adults. Overall, the lack of clinical guidelines, lack of treatment options and inability to access drugs that are available overseas but not licensed in Australia posed challenges when embarking on course of treatments.



The second ranked delivery challenge is the **lack of priority** placed on Rare Diseases in Australia. At the moment, there is a fragmented network of Rare Disease registries in Australia, making it challenging to efficiently research and track Rare Diseases. Furthermore, there is a lack of definition around rare Diseases – this makes it difficult for people to prioritise when fundamentally, they are unable to clearly define it. It would also be beneficial to start improving the awareness of physicians on Rare Diseases – a 2017 survey found that only 40% of Australian paediatricians had Rare Diseases adequately covered in their respective curriculum.

How can we improve the capacity and capability for diagnostics in Rare Diseases?

1. Implement early diagnosis testing measures

Recognising the importance of early and timely diagnosis and genetic counselling

As shared by a number of our workshop participants, the impact of not knowing that one has a disease is far worse than knowing that they do have the disease. Delayed diagnosis typically entails a later start to treatment, and for some of these diseases there is benefit in starting treatment as soon as it is possible (particularly for the well-being of the patient themselves).

Equally, it is also important to establish steps for genetic counselling with the patient and their family once a positive diagnosis is confirmed. Genetic counselling aims to help individuals

understand and adapt to the medical, psychological, familial, and reproductive implications of their genetic contribution to specific health conditions¹¹.

Highlighting the benefits of new-born screening

In Australia, new-born bloodspot screening is offered to all babies across all hospitals in Australia. This is to essentially test for certain rare genetic conditions and metabolic disorders. Screening is beneficial because it helps to identify a new-born's risk of developing a serious condition, and thereby allow for early intervention which would lead to better health outcomes for both the baby and the patient's family. As of now, Australia still lags in testing for conditions that currently do have a treatment pathway. HCPs and midwives can do their part in their capacity to encourage parents to have their new-borns tested for these potential diseases, as some parents may not be aware of these tests or the value in early screening.

Cost-efficiencies of early and accurate diagnosis

Costs is measured not just in monetary terms, but also in the length of time that the patient would have had to change the value and quality of life with an earlier diagnosis. It is recognised that early and accurate diagnosis will provide valuable time savings, enabling the patient to have earlier access to treatment to improve their quality of life.

2. Recognising the importance of offering mental health support to diagnosed patients and their families

As our workshop participants pointed out, there is more to diagnosis than just a name. Following the diagnosis of a rare disease, many patients would benefit from having peer support and access to support services (often through patient advocacy groups). In essence, attending to the patient's mental health is equally important as their physical health, largely because of the physiological and psychological impacts that come with living with some of these rare diseases.

A large challenge in Australia is the lack of integrated care for Rare Diseases, where there is a need for holistic and coordinated care and support (such as collaborations between specialist and allied parties). Integrated HCPs could also play a more active role here in advocating the importance of holistic healthcare, i.e. both mental and physical health, and thus offer to provide the patient with the support and resources that they may benefit from (be it referral to a therapist or family counsellor, for example).

3. Using data to acquire more knowledge on Rare Diseases

While there is arguably a plentiful amount of data available, there needs to be a better use of existing data. Leveraging analytic tools such as AI and blockchain can help to aggregate data and is sitting in disparate systems, enabling data science experts to perform analytics and derive useful insights from the data. AI and advanced analytic tools may help important insights to surface that may have not been picked up by humans and could be useful knowledge in understanding more about rare diseases.

Aggregation of data is useful, because research has found that the very nature of Rare Diseases calls for quantity, breadth, and depth of data to support research towards improvements in this

¹¹ <https://www.singhealthdukenus.com.sg/research/prism/about-genetic-counselling#:~:text=Genetic%20counselling%20is%20a%20communication,contribution%20to%20specific%20health%20conditions.>

space¹². In fact, targeted analytics could help to improve patient identification, medical decision making and clinical research for rare diseases¹³.

How can we raise the priority placed around Rare Diseases?

1. Improving the mechanism for care coordination around patients with Rare Diseases

Presently, the Rare Voices Australia (RVA) is working on coordinating a National Rare Disease Plan with the support of the Health Department to form a single source of end-to-end guidance or support for patients with Rare Diseases. The lack of this could create a confusing situation for patients with Rare Diseases, because for one, there is no clear visibility for the patient in terms of how to navigate their next steps. Without a consolidated e-record in place, patients often must visit various specialists for their conditions, and the information on their condition is not automatically passed across specialists (if from different hospitals). Data integration methods mentioned above could be useful to ease the efficiency in this process.

Furthermore, patients may need advice in terms of finding the right financial, employment and education support for themselves. Much of their time is spent trying to find the right platforms or being re-routed to the right stakeholder. As such, it would be beneficial for each patient with Rare Disease (if they are open to it), to have a dedicated nurse or care-co-ordinator who can provide them with a bird's eye view of support that they may need.

2. Build up Centres of Expertise (COEs) for patients with Rare Diseases

COEs are expert structures that combine and coordinate a wide range of services to provide multidisciplinary expertise and perspective, as well as specialised care for patients suffering from a specific Rare Disease, or a group of Rare Diseases¹⁴. Usually, COEs help to bring resources such as disease experts, researchers, genetic counsellors, and patient advocates together, all with the aim of providing the best specialised care from a holistic perspective to the patient.

New South Wales currently has in place efforts to offer more coordinated care services in this light, but more can be done across other states for the benefit of other Rare Disease patients as well. Work is also been done in Western Australia (which is currently more advanced than NSW in this space) to support COEs.

Furthermore, telehealth or virtual consultation could be actively considered as a part of a patient's healthcare support medium, to bring them greater convenience in not having to visit the clinic physically.

3. Launching an international registry for each Rare Disease

As there tends to be a lack of specialists around the world for each Rare Disease, it may make sense to consolidate resources and create an international registry to benefit Rare Disease patient communities across the globe. This would also enable information to be shared more easily, perhaps around clinical trials where people may have the interest to enrol in but are unsure how to proceed in terms of next steps.

Currently, registries exist for people who have been diagnosed and undergone treatment, but not for those who have been diagnosed but have yet to undergo treatment. It may be beneficial for these data points to also be fed in, to create a more comprehensive data source.

¹² <https://rarediseases.org/innovative-data-and-analytics-platform-to-accelerate-drug-development-for-rare-diseases/>

¹³ <https://graticule.life/2020/08/17/thoughts-on-advanced-real-world-data-and-rare-diseases/#:~:text=Real%2Dworld%20data%20and%20targeted,data%20to%20support%20these%20improvements.>

¹⁴ <https://bluematterconsulting.com/rare-disease-centers-of-excellence/>

4. Skills training for GPs and creation of a virtual symptom checker

As there are not too many Rare Disease cases that GPs tend to see on a regular basis, it may be beneficial to train GPs in providing them with some guidance on diagnosis and next steps for managing patients with Rare Diseases. GPs can attend training courses to be more aware of the more common types of Rare Diseases seen in Australia and receive guidance on best practice protocols that they should bear in mind.

To further support GPs, a virtual symptom checker could be created so that GPs can input symptoms that they recognise from a patient, and the system would then reveal some clarity on the diagnosis to guide the GP in the right direction (for example, the next point-of-contact specialist to refer the patient to for further testing as needed). Once this is in place, the GP can then be able to do a proper referral for the patient to secondary care.

To create a useful virtual symptom checker, it should contain comprehensive data points that would be able to accurately match symptoms to a potential diagnosis. Disease experts could support in the research and development of this tool, by providing a list of symptoms to identify people with Rare Diseases. Then, the system would carry out an AI analysis to derive insights on the diagnosis. A similar concept had been piloted in France, by the Institute of Genomics (*France Genomique*), and so could be worthwhile to explore for use in Australia as well.

How can we ensure adequate funding capacity for Rare Disease management?

1. Organise a fundraising campaign with the support of patient advocacy groups

It may be worthwhile for various patient advocacy groups from the same Rare Disease to collectively organise a fundraising campaign. With social distancing measures in place, these campaigns could be broadcasted on national TV to also raise awareness for the Rare Disease itself at the same time. A successful example is carried out in France by The French Muscular Dystrophy Association (AFM-Téléthon), which managed to raise 77,298,024 Euros from their TV broadcast¹⁵.

2. Put in place a self-funded instalment plan

A self-funded instalment plan could be created to help alleviate the cost burden of treatment costs on patients with Rare Diseases. This is currently being carried out in Hong Kong by the Hong Kong Alliance for Rare Diseases, which has partnered with a non-profit pharmacy to introduce the easy payment mechanism¹⁶.

3. Government funding programs

The Australian government currently funds many healthcare programs through the Pharmaceutical Benefits Scheme (PBS)¹⁷, with very strict criteria around it. However, it is to note that the bucket of funded programs can be bottomless, where a new drug being introduced and added to the PBS would lead to the expenditure of PBS increasing. With this said, the Australian government is worried about the expenditure of PBS and considering putting a limit on the bucket of funded programs, to control how much is spent.

¹⁵ <http://www.afm-telethon.com/news/77-298-024-raised-for-the-2020-telethon.html>

¹⁶ <https://www.thestandard.com.hk/breaking-news/section/4/156144/Easy-payments-offered-for-rare-diseases-drugs>

¹⁷ <https://www.pbs.gov.au/pbs/home>

Hence, Rare Diseases, being a part of the bucket, is facing a limit in the funds available. The Australian government is only willing to set aside a certain amount of funds on Rare Diseases in the bucket, resulting in competition between Rare Diseases, as to how much is spent on each disease. It then poses a question on should there be more funds in the bucket for Rare Diseases? Or how should the funds available then be equitably used?