



HIGH-LEVEL POLITICAL FORUM ON SUSTAINABLE DEVELOPMENT

United Nations High Level Political Forum 2022

*Building back better from the COVID-19 Pandemic
while advancing the full implementation of the
2030 agenda for sustainable development*

Clan
Caring & Living As Neighbours

HIGH-LEVEL POLITICAL FORUM
ON SUSTAINABLE DEVELOPMENT

@MATES4KIDS

**Maximizing Access to Essential Supplies for Kids (MATES4Kids):
Global Multi-Stakeholder Collaboration and Partnership
to #LeaveNoChildBehind**

**VIDEO
Hyperlink**

OFFICIAL EVENT REPORT

6 July 2022

Acknowledgements

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Public Health Matters
Society of Pediatric Endocrinology & Diabetes (SPED), Pakistan

A video of the event is available on [CLAN's You Tube account](#).

Table of Contents

Acknowledgements	2
Table of Contents	3
Table of Figures	4
List of Abbreviations	4
Executive Summary	5
Background	6
Summary of consultation meeting	7
Meeting objectives	7
What is @MATES4Kids?.....	7
Meeting structure	8
Setting the scene for consultation.....	11
Principles to guide future actions of MATES4Kids	19
Consultation outcomes	20
Next Steps.....	20
References	21

Table of Figures

Figure 1: A visual metaphor of adrenal hormone production in a person who has CAH.	6
Figure 2: Summary of meeting, and key points of speaker’s presentations.	10
Figure 3: CLAN framework for action, and five pillars	11
Figure 4: MATES4Kids proposed project timetable, with key events for recruitment opportunities	12
Figure 5: MATES4Kids projected participating countries, by phases	12
Figure 6: Geographical distribution and commute visualisation for CAH children to receive essential medication.	13
Figure 7: Distribution of Indonesian Paediatrics (having Indonesian Paediatric society membership; Ikatan Dokter Anak Indonesia; IDAI), translation by Google translate.(2).....	15
Figure 8: PrimaKu dashboard and functionality.(3)	16
Figure 9: Type I Diabetes essential items supply chain to Ukraine.	18

List of Abbreviations

Abbreviation	Full text
CAH	Congenital adrenal hyperplasia
CLAN	Caring and Living as Neighbours
CoP	Continuity of practice
IFL	Insulin for Life
IPA	International Paediatrics Association
LMICs	Low- and middle-income countries
MATES4Kids	Maximising access to essential supplies for kids
NCD	Non-communicable diseases
SDG	Sustainable Development Goal

Executive Summary

CLAN (Caring and Living as Neighbours) was proud to partner with key stakeholders from around the world to deliver a side event at the 2022 United Nations High Level Political Forum (UN HLPF) on the 6 July 2022 to discuss Maximising Access To Essential Supplies for Kids (MATES4Kids).

The theme of 2022 UN HLPF was *"Building back better from the coronavirus disease (COVID-19) while advancing the full implementation of the 2030 Agenda for Sustainable Development"*. The forum aimed to focus on five SDGs in particular:

- SDG 4 - quality education
- SDG 5 - gender equality
- SDG 14 - life below water
- SDG 15 - life on land, and
- SDG 17 - partnerships for the Goals.

The title of CLAN's event was *"Maximizing Access to Essential Supplies for Kids (MATES4Kids): Global Multi-Stakeholder Collaboration and Partnership to #LeaveNoChildBehind"*. The overall goal of the meeting was to showcase and strengthen partnerships that are implementing innovative and sustainable solutions to equitable access to essential medicines for children living with CAH in LMICs and identify key opportunities for future action.(1) Keynote speakers came from Australia, Ecuador, Indonesia, Pakistan, Uganda, the United States and Zimbabwe, and represented a range of non-government organisations (NGOs), academic and other professional organisations.

The event focused on priorities for action to redress inequities facing children living with Congenital Adrenal Hyperplasia (CAH) in low- and middle-income countries (LMICs), with view to identifying solutions that could be expanded to other non-communicable diseases (NCDs) of childhood.

Meeting objectives were to:

- Raise awareness of the challenges facing children and young people living with NCDs in the context of the COVID-19 Pandemic
- Showcase innovative solutions that have already been achieved to redress inequities experienced by children living with CAH and
- Consider how achievements to date and other recommendations might help inform efforts to build back better for the international NCD Community after the COVID-19 pandemic.

Some key solutions and recommendations to help increase equitable access to CAH essential medications emerging from this consultation include:

- Improve local production of essential medications in LMICs, to decrease costs of medications
- Strengthen partnerships between local communities in LMICs and the MATES4Kids network to enable, mediate and advocate for adequate funding, resources, and information needed to effectively meet the needs of children living with NCDs
- Leverage new and existing technologies (such as mobile phone apps and newborn screening) to bypass population-based barriers and enable more equitable access to essential medicines and equipment and
- Establish the infrastructure (such as patient registers and policy changes) and innovative supply chains needed to strengthen access to essential medications despite difficult scenarios.

Background

Congenital Adrenal Hyperplasia (CAH) is a genetic disorder that affects the adrenal glands. The classic form of CAH restricts adrenal production of two hormones (cortisol and aldosterone), with a consequent increase in androgen production (see Figure 1, for visual depiction) as the body works hard to overcome the blockage. This lack of cortisol and salt-retaining hormone means that children with CAH need to take medicines several times a day: not just to prevent life-threatening adrenal crisis in the short-term; but also to avoid the destructive longer term impact of virilisation on developing bodies caused by excess male hormone levels.

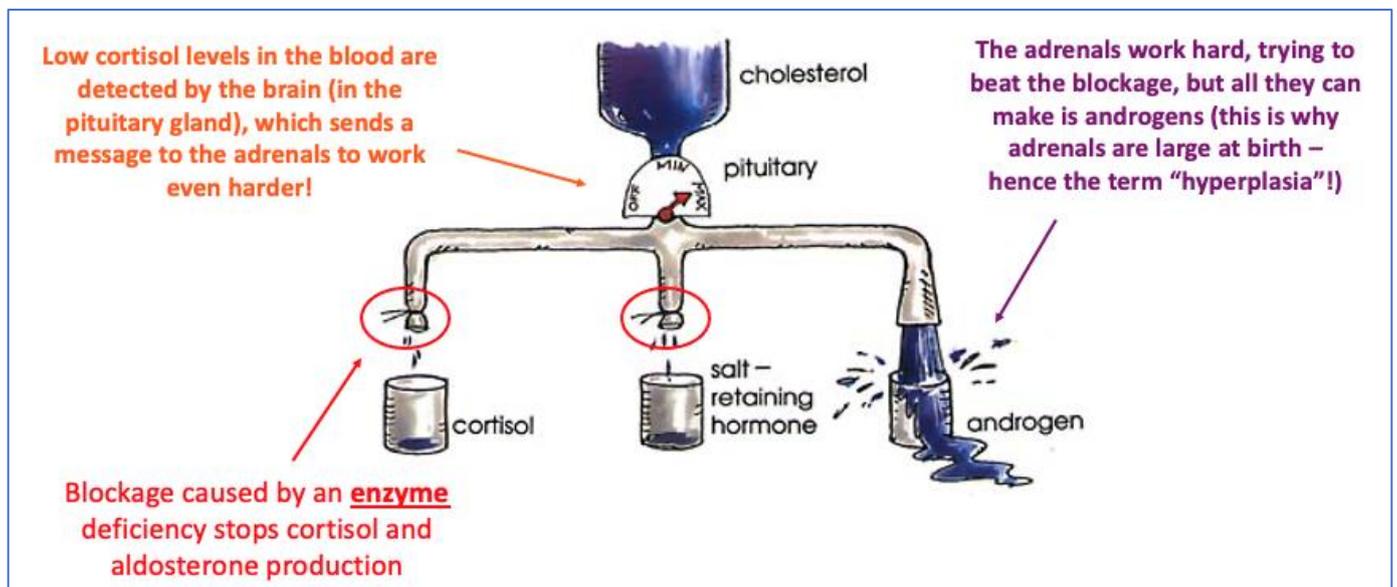


Figure 1: A visual metaphor of adrenal hormone production in a person who has CAH.

The main method to supplement the lost hormones in CAH is two essential medications: hydrocortisone, and fludrocortisone. Hydrocortisone is the drug that replaces cortisol hormones in the body (needed by the cells in the body to use glucose for energy). Fludrocortisone replaces aldosterone, the salt-retaining hormone which helps control the amount of sodium in the body. Notably, these medications must be taken multiple times a day, and for life.

There are significant inequities in CAH management between children in LMICs and children in high income countries (HICs). While children living with CAH in HICs can generally enjoy a relatively normal quantity and quality of life thanks to affordable access to effective treatment, children in LMICs routinely experience higher rates of preventable mortality and morbidity and lower quality of life. For this reason, multiple organisations have attempted to improve access to these essential medications in LMICs. The MATES4Kids network is aiming to bring together individuals and organisations who are committed to improving access to essential medicines for children living with CAH and other NCDs in LMICs.

Summary of consultation meeting

Meeting objectives

This event at the 2022 UN HLPF sought to bring together representatives of organisations that CLAN has worked with to address inequitable access to health for children with CAH in LMICs, as well as other key players involved in efforts to improve access to essential medications and equipment for other childhood NCDs – such as insulin, syringes, needles and strips needed for the management of type 1 diabetes. In doing so, the event emphasises how successful partnerships are helping to redress inequitable access to essential medicines for children in low resource settings.(1)

The meeting objectives were to:

- Raise awareness of the challenges facing children and young people living with NCDs in the context of the COVID-19 Pandemic
- Showcase innovative solutions that have already been achieved to redress inequities experienced by children living with CAH and
- Consider how achievements to date and other recommendations might help inform efforts to build back better for the international NCD Community after the COVID-19 pandemic.

What is @MATES4Kids?

MATES4Kids is a coalition of like-minded organisation and individuals committed to collaborative action. By sharing stories and strengthening networks and connections, the movement seeks to support collaborative efforts to identify, implement, and monitor practical solutions to improve access to essential medicines and equipment for global CAH and other NCD communities.

MATES4Kids is committed to collaborative action that helps the world achieve Sustainable Development Goal (SDG) 3.4 by 2030 (ie to reduce by 30% the premature mortality associated with NCDs). In particular, MATES4Kids aims to reduce the preventable mortality currently associated with CAH by 30% by 2030 and has outlined a strategic pathway to achieving this ambitious goal.

Meeting structure

The consultation consisted of a ninety minute online meeting held as a side event on Zoom during the 2022 UN HLPF. The speakers joined from a diverse range of countries and organisation working in the field of child health, with representation of all six WHO regions a highlight.

The meeting was divided into three main sections (as seen in Figure 2). The meeting started with an introduction to CLAN and MATES4Kids and introduction to the strategic goals of the MATES4Kids movement. Next, presenters shared a series of four 15-minute presentations, each highlighting local experiences and successes, as well as potential solutions to the inequities facing CAH communities in LMICs. Finally, a small, facilitated discussion occurred, to explore questions and queries regarding MATES4Kids and the information shared.

Topic/Title	Speaker	Content overview
Part 1 - Introduction to CLAN and MATES4Kids		
Welcome	Annie Sanchez (Ecuador)	<ul style="list-style-type: none"> Acknowledgement of Country Introductory remarks House-Keeping
Introduction to CLAN	Emma Santini (USA)	<ul style="list-style-type: none"> Highlights the aim and mission for CLAN. Discusses CLAN's framework for action to improve quality of life for children living with NCDs in LMICs.
What is @MATES4Kids	Dr. Kate Armstrong (Australia)	<ul style="list-style-type: none"> Highlights the purpose of MATES4Kids. Highlights the aim of MATES4Kids (to reduce preventable mortality currently associated with CAH by 30% by 2030). The current inequities to health that children with CAH in LMICs face compared to their counterparts in high income countries. Proposed timeline of MATES4Kids (including key opportunities for recruiting more countries) Importance of taking an equity approach to improving quality of life for children with NCDs in LMICs.

Part 2 - Experiences and successes in challenging inequity of CAH management in LMICs.

<p>Essential medicines for CAH patients in Pakistan: Challenges with and without COVID</p>	<p>Prof. Jamal Raza (Pakistan)</p>	<ul style="list-style-type: none"> • Highlights the challenges that CAH children face in developing countries, including Pakistan. • Emphasises the unavailability of essential medications as a key concern and challenge. • Discusses his efforts to improve accessibility (and decrease cost) of essential medications for CAH with Dr Shaikh, and Tabros Pharma by establishing local production of hydrocortisone and fludrocortisone. • Discusses his work with CLAN and the National Institute of Child Health (NICH) in establishing the Door Step delivery project (delivery service for essential CAH medications in Pakistan), to decrease travel costs for acquiring medication. • Discusses how local production enabled Pakistan to export supplies over to Zimbabwe, at low prices.
<p>CLAN Africa and partnerships amidst COVID-19</p>	<p>Dr. Andrew Twineamatsiko (Uganda) Trudy Nyankabagwe (Zimbabwe)</p>	<ul style="list-style-type: none"> • Highlights the work CLAN Africa has done to ensure health equity for children in Africa (specifically Uganda, Zimbabwe, and Burundi) in addressing NCDs (such as CAH, Type-1 diabetes, epilepsy, and Nodding syndrome). • Emphasises the importance of a partnership-based approach, in enabling local partner organisations to help improve the quality of life for CAH children in their area. • Specifies how partnerships can help local partner organisations through: <ul style="list-style-type: none"> ○ Helping develop and implement programs; ○ Sharing resources; ○ Providing advice, knowledge, and frameworks; ○ Learning from successes and mistakes; and ○ Accessing constituents and funding. • Emphasises the role of raising awareness of CAH in the community to enabling further CAH efforts.
<p>Partnerships preventing infant and child mortality in Indonesia – improving access to essential medicines; expanding newborn screening to protect the most vulnerable.</p>	<p>Prof. Aman Pulungan (Indonesia) Dr Agustini Utari (Indonesia)</p>	<ul style="list-style-type: none"> • Highlights the 10 recommendations on transforming access to diagnosis published by the Lancet Commission, as part of a framework for improving equity to health for CAH children. • Emphasises the burden of both communicable and non-communicable diseases in Indonesia. • Highlights some challenges Indonesia faced in managing NCDs and their progress in addressing these challenges.

		<ul style="list-style-type: none"> ○ Emphasises that one specific challenge Indonesia faces is the potential gap of Indonesians who are not being detected for CAH and therefore receive CAH treatment. • Emphasises partnerships that IPA has made with local partner groups to facilitate equitable access to health in Indonesia. • Discusses the effectiveness of their technological solution (PrimaKu) in addressing health inequities in Indonesia, through two features: <ul style="list-style-type: none"> ○ Self-measured health tools, to encourage monitoring of health at home. ○ Telemedicine access, to enable doctors to reach wider audiences, especially in less accessible regions.
Partnerships shaping humanitarian responses	Dr Alica Jenkins (Australia) Oleg Novikov (Ukraine)	<ul style="list-style-type: none"> • Emphasises inequities of diabetes management in LMICs, with focus on essential diabetes equipment cost being too high for some families with low income in LMICs. • Emphasises the goal of Insulin for Life (IFL), being to ease and save the lives of people with low income and diabetes in disadvantaged regions, by providing key diabetes resources at no cost. • Emphasise the impact of emergencies in disrupting insulin supplies for weeks on end, and how IFL enables quick access to insulin after a disaster, • Emphasises the role of collaboration in IFL, from partnerships that enable cheap access to insulin to having a large community with different skillsets. • Discusses their work of IFL in providing type-1 diabetes aid to Ukraine, and emphasising the role of local partner groups in Ukraine in distributing supplies, using their local knowledge and resources.

Part 3 - Next steps and facilitated discussion		
Facilitated discussion	Carmen Auste (Philippines) Kate Armstrong (Australia)	<ul style="list-style-type: none"> • Limited time, so only one query was answered. • Supplies of vital medicines during COVID 19 pandemic, and challenges regarding this (answered by Prof. Raza) <ul style="list-style-type: none"> ○ Low cost of medicine in Pakistan (and free in public sector) helped sustainability (can purchase it out of pocket). <ul style="list-style-type: none"> ▪ Conversely, insulin is not as sustainable, due to low availability ○ Door Step Program requires funding and financial evaluation to see if it is sustainable in the a large scale.

Figure 2: Summary of meeting, and key points of speaker's presentations.

Setting the scene for consultation

Introduction to CLAN: Emma Santini, Project Support Officer for MATES4Kids opened by describing the vision and mission for CLAN. Specifically, CLAN aims to help all children living with chronic health conditions in low resource settings achieve a quality of life on par with that of their neighbours' children in wealthier countries.

The CLAN framework for action (Figure 3) underpins CLAN's approach to improving the quality of life of children with chronic health conditions. The framework takes a rights-based community development model to enable the highest quality of life for children with chronic conditions in LMICs. Importantly, local involvement is key to the model, which helps with creating long-term sustainable change.

The framework rests on five main pillars as methods to improve the quality of living for children with chronic diseases in LMICs. These pillars are:

1. Affordable access to essential medicines and equipment
2. Education, research, and advocacy
3. Optimisation of medical management
4. Encouragement of family support networks and
5. Reducing financial burdens on families that result in poverty, helping people to become financially independent so that they can provide necessary health care for their children in the long term.

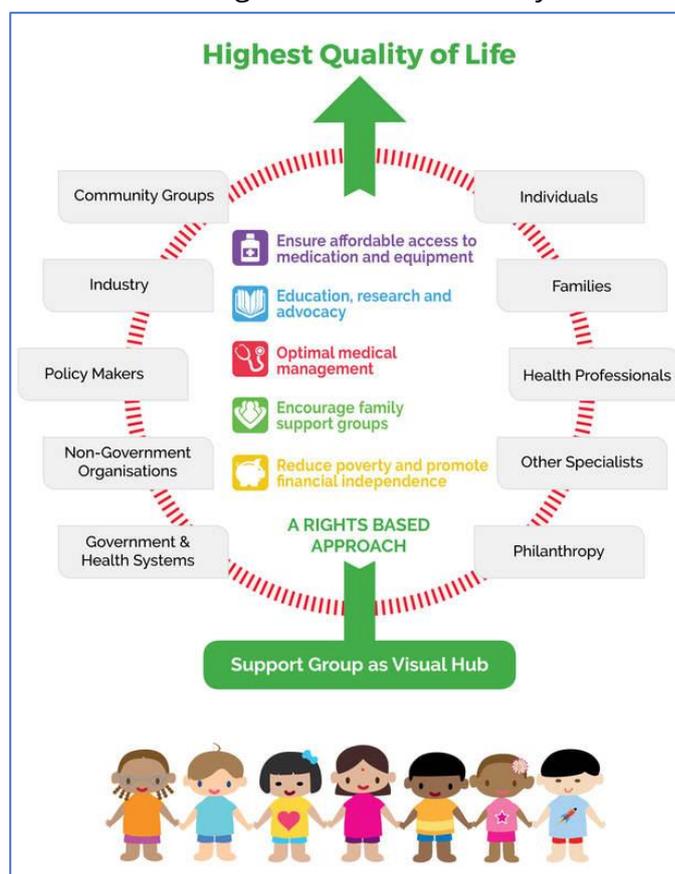


Figure 3: CLAN framework for action, and five pillars

Introduction to @MATES4Kids: Dr Kate Armstrong, President of CLAN and Co-Chair for @MATES4Kids

@MATES4Kids outlined the purpose of @MATES4Kids, an international movement that aims to improve access to essential medicines for the global CAH community through collaborative partnerships. As part of this effort, @MATES4Kids aims to help share data, stories, successes, and insights, to help identify practical solutions and initiatives, and a briefing note to WHO in 2022 (see Figure 4) was a key deliverable in this regard.

@MATES4Kids is keen to learn from and leverage the achievements of other childhood NCD communities and opportunities for collaboration will be actively sought. Upcoming meetings of note are the UN High Level Meetings relating to Universal Health Care (2023) and NCDs (2025). These meetings may be beneficial, as they could provide platforms for @MATES4Kids to share their work, network and identify new opportunities for improvement.

The end goal for @MATES4Kids is to reduce preventable mortality currently associated with CAH by 30% by 2030 (in line with SDG 3.4) and Dr Armstrong highlighted the vital importance of an equity approach to achieving this. Equity is about having targeted and specific action for some peoples and communities. This approach was chosen as communities will require tailored approaches and solutions to effect change. Communities must lead all actions, identify priorities and share their stories.

To achieve its goal, @MATES4Kids will focus on partnering with communities in 40 low and middle income countries by 2030. @MATES4Kids will take a 4 phased approach to recruiting partners across the world (Figure 5, below), with specific focus on WHO regions with the greatest inequities. Each country will be invited to join a community of practice as part of a 3-year commitment, with acknowledgement of the need for countries and communities to transition to independence over time.



Figure 4: @MATES4Kids proposed project timetable, with key events for recruitment opportunities

WHO region	Phase 1 (Sep 2023)	Phase 2 (Sep 2025)	Phase 3 (Sep 2027)	Phase 4 (Sep 2030)
Africa	2	3	6	Transition
Americas	2	2	2	Transition
Eastern Mediterranean	2	2	1	Transition
Europe	2	1	1	Transition
South East Asia	2	3	3	Transition
Western Pacific	2	2	2	Transition
Total	12	13	15	+ Other NCDs

Figure 5: @MATES4Kids projected participating countries, by phases

Pakistan's experiences and successes to address CAH treatment equity: Professor Jamal Raza, Executive Director at Sindh Institute of Child Health and Neonatology opened by highlighting the key challenges that CAH children face in developing countries, including Pakistan. Prof. Raza emphasised that the lack of availability for essential CAH medicines is a key challenge. He described how, despite key medications for CAH (hydrocortisone, and fludrocortisone) being placed on the WHO Essential Medicine List, the medications were still not readily available in all countries. Furthermore, Pakistan had difficulty producing hydrocortisone and fludrocortisone locally, as local pharmaceutical industries determined there was low profit margins in creating the medication. As such, the medication was not freely available, with the main source being through smuggling.

The creation of a local supply of CAH essential medication markedly reduced prices for the medication. Due to the efforts of Prof. Jamal Raza, Dr Latif Shaikh, and Tabros Pharma over the course of a few years, it was possible to create a local production plant for hydrocortisone and fludrocortisone. This local production substantially reduced prices, with hydrocortisone being 0.02 times its previous price (from \$1 USD per tablet to \$0.02 USD), and fludrocortisone being 0.03 times its previous price (from \$1.40 USD per tablet to \$0.04 USD). In addition, this supply chain has since been used to export medications to other countries. A collaboration with Muzzamil Barry and CLAN allowed Pakistan to send packets of hydrocortisone and fludrocortisones to Zimbabwe at low prices (hydrocortisone: \$0.04 USD per tablet; fludrocortisone: \$0.06 USD per tablet; includes shipping costs).

Another success for Pakistan in improving equitable access to medications was introducing a delivery program for essential medications. This reduced the substantial cost of travel to hospital associated with accessing medication for families. These costs were previously estimated to be at \$12 to \$15 USD per visit. Figure 6 highlights the large distribution and commute times that contribute to the high travel cost. The COVID-19 pandemic exacerbated these travel barriers, with patients being unable to travel due to travel restrictions that were designed to prevent COVID spread.

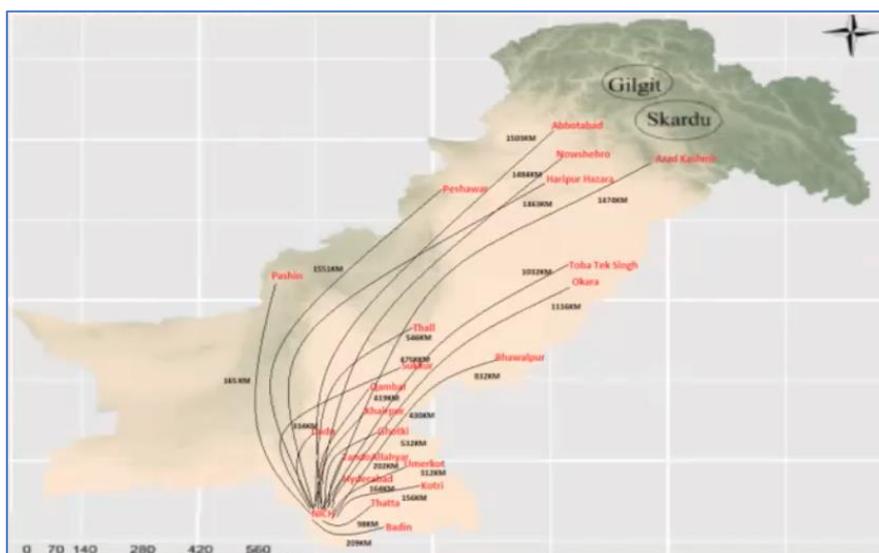


Figure 6: Geographical distribution and commute visualisation for CAH children to receive essential medication.

To address this cost, the Door Step Delivery Project was implemented from March to August 2020, and aimed to decrease costs of medication by having them directly delivered to people's homes instead. The project sent medications via couriers, with each charge being \$1 to \$3 USD per shipment (a 5-to-15-fold decrease in cost). This low cost was achievable as the cost were subsidised by CLAN. The program also had unseen benefits during COVID, where the delivery system was able to bypass people trapped in villages, due to COVID restrictions.

CLAN Africa's efforts to address CAH treatment equity: Dr Andrew Twineamatsiko, Community Development Officer for CLAN Africa, began by highlighting the work that CLAN Africa has achieved for ensuring health equity for all children in Africa. In particular, he emphasised how the organisation works in Uganda, Burundi, and Zimbabwe, in supporting conditions affecting children including CAH, type-1 diabetes, epilepsy, and Nodding syndrome.

Zimbabwe's experiences and successes to address CAH treatment equity: Trudy Nyankambagwe, Founder of Child and Youth Care in Zimbabwe continued discussing health equity work in Africa, by highlighting the successes Child and Youth Care had in the time they have operated. They particularly focus on the importance of collaboration in enabling local partner programs in LMICs. In particular, they highlight two ways in which collaboration can help local partner programs, being financial support and resources, and sharing of knowledge.

One of the key forms of collaboration is financial support, as that allows local partner groups to have the funding necessary to address the needs of their patients. For example, Child and Youth Care Zimbabwe emphasises how partnerships have decreased costs for access to medications. Financial partnerships with CLAN and Pakistan enabled for reduced costs and speedier access in accessing essential medications. Child and Youth Care Zimbabwe also emphasises how financial partnerships, through funding, enables their ability to run health equity programs. Key programs that are enabled by funding include support group meetings, and delivery of medications.

Another important aspect of partnerships that enables health equity is the sharing of knowledge for tackling chronic diseases. Specifically, sharing knowledge allows for various perspectives for problem solving and innovation, which can enhance actions that local partner groups are doing to enable health equity. For example, Child and Youth Care Zimbabwe points to how the CLAN's strategic pillars in their action framework for action has allowed them to provide structure and more focus to their efforts. Furthermore, Ms Nyankambagwe emphasised the sharing of previous successes and mistakes from more experienced organisations is helpful, as it allows for new partner groups to make faster progress and use programs that have demonstrated to be effective.

Ms Nyankambagwe also emphasised the importance of awareness campaigns for increased community awareness, and therefore action. She highlights the successes of the CAH month in June, and how that was effective in raising awareness in CAH in Zimbabwe. A notable success of the program is how it raised awareness of CAH in potential players that can contribute to the equitable access of CAH, such as medical professionals. This increased awareness allowed CAH to further inform health care lecturers on CAH. Ms Nyankambagwe emphasised the usefulness of social media in raising awareness of CAH and promoting CAH equity. Social media campaigns are effective at disseminating information about the condition, the CAH social circles that exist, and the needs and their challenges, as well as their progress and what still needs to be achieved.



Figure 7 - The inaugural CAH Club meeting in Zimbabwe, 28 June 2022

Indonesia's experiences and successes to address CAH treatment equity: Professor Aman B Pulungan, Executive Director of the International Paediatric Association (IPA), and Dr. Agustini Utari, Member of the IPA began by discussing the 10 recommendations on transforming access to diagnostics from the Lancet commission, that the IPA pushes for the next assembly. Prof. Pulungan then discussed the burden of communicable and non-communicable diseases in Indonesia, with 6% of under-five deaths in 2015 being due to NCDs.

Like other nations, Indonesia faces challenges in managing NCDs in children, but has made some progress to addressing these challenges. Prof. Pulungan noted local production of CAH medicines had been established in 2018, but fludrocortisone is still unavailable currently. The state of newborn screening in Indonesia was discussed, with a current lack of CAH screening and low rates of screening for congenital hypothyroidism a major challenge. Prof. Pulungan shared data relating to CAH screening in Indonesia and compared expected prevalence figures to the small number of registered patients with CAH in Indonesia, emphasising the high rates of preventable mortality at play.

Prof. Pulungan showcased the partnerships and collaborations that IPA has developed to promote equitable access to health in Indonesia. A prominent number of collaborations are with local support groups, such as KAHAKI (Communities for Families with CAH – Indonesia), Turner Syndrome Society of Indonesia, FOSTEO (Forum Osteogenesis Imperfecta Indonesia), and IKADAR (Society for children and teenagers with diabetes). He also highlighted grants and international collaborations to help with equitable access, such as “Collaborating with Changing Diabetes in Children”, and a Grant for the PEDIA project (type I diabetes education program, in collaboration with CLAN-APPES) which won the inaugural WHO NCD Lab.

Indonesia faces barriers to equitable access to CAH treatment that can be difficult to overcome. In Indonesia, there are an estimated 4.4 million babies born every year. There is also a high need for more paediatricians, with low numbers of paediatricians by population ratio (5.7 per 100,000, which is below the recommended of 49.2 per 100,000), and uneven distributions of paediatricians (mostly located in urban areas, seen in Figure 8). There are also large physical barriers to access, with Indonesia being comprised of 17,000 islands. It is difficult to address these discrepancies quickly and efficiently, and specific and innovative efforts are required to overcome such barriers.

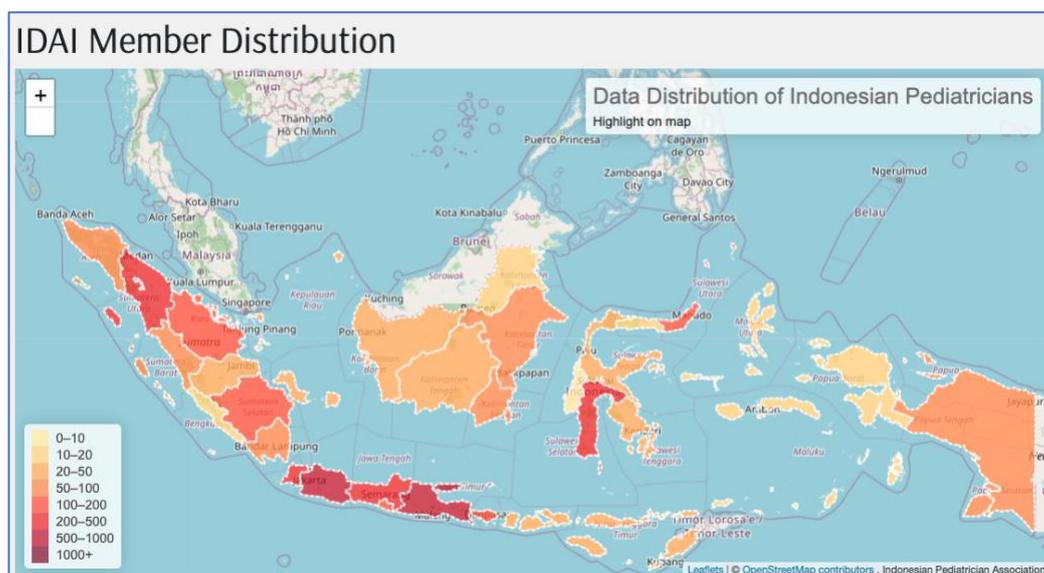


Figure 8: Distribution of Indonesian Paediatrics (having Indonesian Paediatric society membership; Ikatan Dokter Anak Indonesia; IDAI), translation by Google translate.(2)

On this note, Prof. Pulungan shared some specific strategies Indonesia has used to increase identification of CAH and improve equitable access to child health services. Indonesia's technological solution was through PrimaKu (application dashboard shown in Figure 9), which addressed two specific needs. First, it improved surveillance of child health conditions, and second, it facilitated teleconsultation for app users. Use of the application started from 2017. It was developed by leading experts, with input from public figures in Indonesia.

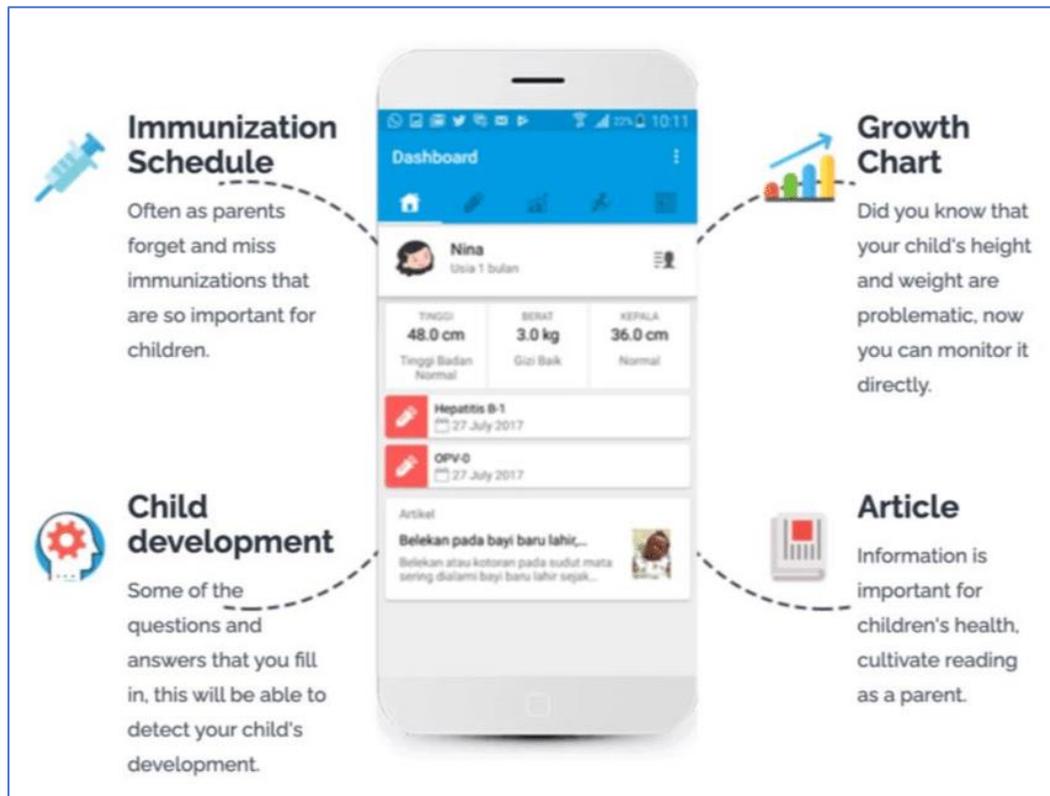


Figure 9: PrimaKu dashboard and functionality.(3)

PrimaKu's self-measured health tools drive health improvements in Indonesia. PrimaKu is suggested to have reduced the incidence of malnutrition in Indonesia, as children whose parents use PrimaKu had lower incidence rates for low weight-for-average, compared to the Indonesian government data (around 50% decrease, for every province). The technology was deemed successful, and this was attributed to three factors. Firstly, PrimaKu encourages home monitoring, which improves community awareness of health conditions. Secondly, PrimaKu allows for easier follow-up and recall of children, allowing for more continuity of care. Finally, PrimaKu also allows for a large amount of data to be used to inform policy efforts.

The other technological solution impacting child health in Indonesian has been PrimaKu's telemedicine, which aimed to address the difficult access to health care services, particularly in less accessible regions. This app allows users to have teleconsultations via their smartphone, which eliminates the need to physically travel to nearby paediatricians, which may otherwise be high in demand.

Improving access to essential type-1 diabetes resources in Ukraine during the Ukraine war: Dr Alica Jenkins, Insulin for Life (IFL) Global and IFL Australia President, and Oleg Novikov, IFL volunteer (not present), began with an overview of the inequities associated with diabetes treatment and life in LMICs. While people with diabetes in HICs can live their life to the fullest extent, people in LMICs too often struggle to obtain essential type I diabetes supplies. This is especially concerning as 80% of people with diabetes live in disadvantaged regions.

To address this inequity, IFL aims to ease and save the lives of people with diabetes in disadvantaged regions. IFL achieves this through three actions. The first action is collecting or purchasing type 1 diabetes supplies, and donating it to disadvantaged regions on an ongoing basis, as well as regions in a crisis (e.g. disaster). The second action is to support diabetes camps, HbA1c testing, complication screening and community screening/education days. And finally, IFL aims to improve access to diabetes care through partnerships and research.

Dr Jenkins discussed how emergencies (e.g. humanitarian disasters) can create extreme burden on individuals with Type I diabetes. Emergencies can disrupt insulin supply in many ways, including losing supplies, or communications, or having hospital facilities diverted to other priorities. Furthermore, when receiving supplies, diabetes supplies are often not in the 1st responder shipments, and instead can take weeks to re-establish a supply chain. However, people with type I diabetes cannot last weeks without insulin. Therefore, IFL aims to address this gap, by establishing insulin supply chains and information in emergencies early.

Dr Jenkins highlighted the importance of a global village approach (acknowledging varied perspectives and collaboration), in operating IFL. For example, she emphasised how industry collaborations and partnerships can allow for easier access to insulin, with suppliers able to donate, or sell at discounted costs. In addition, their collaboration with the Global diabetes community “Spare a rose” provides funding for IFL’s work in Ukraine.

Dr Jenkins discussed IFL’s work in Ukraine in some detail, describing how collaborations with other organisations allowed them to establish supply chains in areas for crisis. Specifically, they have been able to send supplies of insulin into Ukraine and enable timely delivery of insulin which would otherwise not be delivered in the first shipment of other responders. To ensure Ukrainians are able to obtain their supply of Insulin during the conflict, Insulin for Life organisations (initially European organisations, such as the United Kingdom, Austria, and Germany, before expanding further, see Figure 10), partnered with local networks in Ukraine, to help distribute insulin supplies across Ukraine. The Ukraine local expertise was helpful as local champions were knowledgeable about routes in and distribution sites in Ukraine, as well as had the personnel to ensure safe delivery during war time.

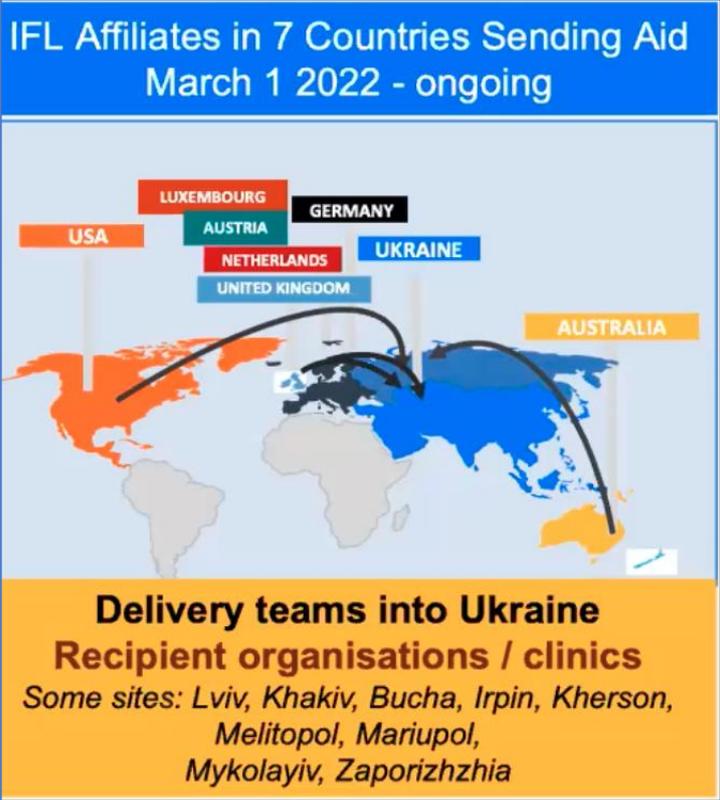


Figure 10: Type I Diabetes essential items supply chain to Ukraine.

As at the time of this event, the program had delivered 91 shipments and 310 parcels of type I diabetes supplies to Ukraine. Notable successes include 140,000 mLs of insulin, 470 insulin delivery systems, and 313,000 monitoring tools. In addition, IFL has provided advice for insulin management given harsh conditions of war (e.g., insulin without a refrigerator, or reusing shafts).

Principles to guide future actions of MATES4Kids

Several themes were consistently repeated throughout the discussion on the factors most effective in redressing inequities experienced by CAH Communities. Key lessons from the consultation include:

- **Improve local productions of essential medications in LMICs, to decrease the cost of obtaining medications.** A key goal for @MATES4Kids in achieving equitable access to CAH treatment in LMICs is establishing a local supply of essential medications. To achieve this, partner groups should partner with existing pharmaceutical experts and companies where possible, but also explore new opportunities for local manufacturing and supply.
- **Strengthen partnerships between local communities in LMICs and the @MATES4Kids Network, to enable, mediate and advocate for adequate funding, resources, and information needed to effectively meet the needs of children living with NCDs.** Working with communities and their local partners in LMICs is essential for sustainability. Financial support that facilitates the start-up of community development initiatives, such as support groups or innovative access schemes (such as programs to help deliver essential medications) can save lives in the short-term, whilst longer term solutions are identified. Members of the @MATES4Kids network can also support local partner groups by sharing their own experiences and problem-solving skills with local partner groups who can then adapt to local conditions. Strategic frameworks (such as CLAN's Strategic Framework for Action) can provide valuable structure and guidance to complex equity efforts for CAH children in a region.
- **Leverage new and existing technologies (such as mobile phone apps and newborn screening) to bypass population-based barriers and enable more equitable access to essential medicines and equipment.** @MATES4Kids will advocate for support to fund, pilot, and implement technologies that can help save lives and connect CAH and other NCD community members to necessary treatment and consultations. Newborn screening is a proven public health initiative that must be urgently scaled in LMICs. Likewise, mobile apps and teleconsultations are a promising avenue for improving equity, especially in areas where travel is difficult, or where key services are unequally distributed. However, it should be noted that these technologies must be tailored to the existing technology availability of the region. Supporting people living in particularly vulnerable circumstances to access technology can be extremely empowering.
- **Establish the infrastructure (such as patient registers and policy changes) and innovative supply chains needed to strengthen access to essential medications despite difficult scenarios.** Policy changes are often needed to enable longer term, sustainable access. Likewise, practical platforms (such as patient registers and community pharmacies) can have a role to play. Where local production of drugs is not an option, the @MATES4Kids network could help establish connections between local partner organisations and powerful distribution groups and suppliers and leverage strengths to facilitate cost effective deals. @MATES4Kids can also supplement distribution between countries and develop or subsidise innovative courier solutions to deliver CAH medication to isolated communities at cost-effective prices.

Consultation outcomes

Next Steps

MATES4Kids highlights the following steps to enable progress on the proposed action log:

No	Action description	Owner	Date due	Status
1	Connect with countries and identify regional champions within Community of Practice (CoP).	@MATES4Kids		
2	Identify need through snapshot surveys of the population.	@MATES4Kids		
3	Encourage a call to action, through a report from the UN high level political forum 2022, as well as regular @MATES4Kids working group meetings.	@MATES4Kids		
4	Establish communities of practice.	@MATES4Kids		
5	Participate in global meetings to share successes and maintain momentum.	@MATES4Kids		
6	Share experiences and social innovations in briefing papers for WHO, Ministers of Health and other key stakeholders.	@MATES4Kids		
7	Diplomatic involvement and deeper engagement through embassy teams.	@MATES4Kids		
8	Acquire funding from diplomats interested in involvement (Potential countries such as US, UK, Canada, New Zealand, Germany, Japan, Australia, and France).	@MATES4Kids		

References

1. United Nations. Maximizing Access to Essential Supplies for Kids (MATES4Kids): Global Multi-Stakeholder Collaboration and Partnership to #LeaveNoChildBehind [Internet]. New York: United Nations; 2022. Available from: <https://hlpf.un.org/2022/programme/maximizing-access-to-essential-supplies-for-kids-mates4kids-global-multi-stakeholder>.
2. Ikatan Dokter Anak Indonesia. Sebaran Anggota IDAI [Internet]. Jakarta Pusat: Ikatan Dokter Anak Indonesia; 2019. Available from: <https://www.idai.or.id/tentang-idai/sebaran-anggota-idai>.
3. Nurhaeni N, Chodidjah S, Adawiyah R, Astuti A. Using a mobile application ("PrimaKu") to promote childhood immunization in Indonesia: A cross-sectional study. *Belitung Nursing Journal*. 2021;7(4):329-35.