

Action4Diabetes: A UK charity revolutionising type 1 diabetes healthcare across South-East Asia

Action4Diabetes (A4D) is a small, focused UK diabetes charity that is making sustainable and scalable progress in the battle to provide quality type 1 diabetes healthcare in emerging countries across South-East Asia (SEA). A4D's mission is to save and empower children and young people with type 1 diabetes in deprived communities across SEA by providing them with access to essential healthcare and education.

Access to care, medication and education in SEA countries

There is little representation of prevalence, outcomes and indicators of disease burden of type 1 diabetes in SEA countries, where government funding of insulin and blood glucose monitoring kits is either absent or is limited to the most basic forms of human/animal insulin. Care gaps exist between developed countries and resource-limited countries within SEA. In the *Lancet* Commission 2020, it was estimated that approximately 15 000 young individuals with type 1 diabetes died in 2017 globally, out of a total diabetes prevalence of 1.61 million people (Chan et al, 2021). However, data from SEA countries were very limited.

In many of these resource-limited countries, poverty, insufficient infrastructure and lack of professional knowledge often lead to scarce insulin availability and poor access to diabetes education. As a result, children with type 1 diabetes in these settings often have an extremely poor outcome and are frequently misdiagnosed, develop complications and die prematurely. Current tariffs on insulin analogues and glucose self-monitoring supplies are totally unaffordable and beyond the means of the vast majority of people. Many clinics in SEA continue to use human or animal insulin with twice-daily regimens due to lack of affordability. However, these regimens are often associated with high HbA_{1c} and frequent hypoglycaemia, especially when there is limited ability to self-monitor blood

glucose (Ogle et al, 2016). Culturally sensitive educational material written in individuals' native languages and appropriate to their cultural diets are often not available.

In SEA, factors such as limited insulin, food insecurity, unavailability of blood glucose monitoring supplies and lack of transport contribute to poor glycaemic control and complications that adversely affect quality of life (Ogle et al, 2019). These are exacerbated by poverty, varying government health policies, lack of price transparency, complexity in supply chains and insufficient competition among industries that make insulin and blood glucose monitoring supplies (Cefalu et al, 2018).

While in some resource-limited countries programmes such as [Life for a Child](#), [Insulin for Life](#) and [Changing Diabetes in Children](#) have substantially improved type 1 diabetes outcomes, many of these programmes tend to be *ad hoc* and are not yet sustainable over the long term, where resource utilisation and outcomes are monitored and tracked down to individual clinics and people with type 1 diabetes. A4D is the only UK-based charity providing comprehensive partnership programmes with defined local diabetes clinics, which guarantees ongoing supplies of free insulin, blood glucose meters and hospital emergency funds, and which actively tracks HbA_{1c} outcomes across the majority of supported countries in SEA.

Pasil's story

In Laos, prior to 2016, no one had been diagnosed or treated for type 1 diabetes. Healthcare professionals in regional hospitals across the country did not have the resources to deal with the condition, and even if they did the patient would not have been able to afford the care.

Pasil ("Little Fish") arrived at Mahosot Hospital in Vientiane, Laos, on a stretcher in early February 2016. Aged nine, she had severe diabetic



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Pasil



Borey

ketoacidosis, and the hospital did not have the resources to look after her. Fortunately, A4D Co-Founder Charles Toomey was in Vientiane at the time, and the day before he had met with healthcare professionals to discuss starting A4D in Laos. On Pasil's arrival, clinicians at Mahosot Hospital contacted Charles and asked for help.

Today, Pasil is a healthy and happy 14-year-old living in a small village a two-hour drive away from the capital, and there are now 42 young Laotians living with type 1 diabetes who are cared for by A4D. Just like Pasil, they can now test their blood glucose levels every day and manage their condition. Without the diligent, programmed and systematic care offered by A4D, many children across SEA would simply not be alive.

Borey's story

Borey, a 24-year-old Cambodian living with type 1 diabetes, is another example of a young person who has been helped by A4D. Growing up in Siam Reap, in northern Cambodia, Borey struggled to control his blood glucose levels. During his adolescent years, and prior to any A4D support, he had been given oral tablets in combination with an underdosing of insulin, owing to an incorrect diagnosis.

Borey, like most people in the region, lives on a diet predominantly made up of sticky rice. This glutenous carbohydrate has a very high glycaemic load and plays havoc with blood glucose levels. However, Borey, like most young Cambodians,

has little other food options and his knowledge of nutrition was poor. Sticky rice, along with a low level of numeracy for self-monitoring, can lead to poor control and, ultimately, the severe health consequences that result from unchecked blood glucose levels.

In 2019, the Siam Reap hospital that has partnered with A4D told the charity about Borey's case. His vision had become blurry and both he and his family were fearful that he would lose his sight. A4D was able to sponsor him through an eye clinic in Phnom Penh, Cambodia's capital. There he was diagnosed with secondary cataract disease and diabetic retinopathy in both eyes. A4D raised the necessary funds that allowed Borey to undergo the complex retinal surgery that saved both his sight and his hope to live a normal and fulfilled life.

Five A4D programmes

A key part of A4D's strategy is to partner directly with government clinics, and this is critical to its ability to ensure effective execution and monitoring of its programmes. Since starting out in 2015, A4D has grown to include a team of three full-time staff, and it now operates in seven different countries in the SEA region. Keeping costs to a minimum, A4D is able to provide a disadvantaged young person with essential type 1 diabetes care for just £35 per month. A4D supports 491 people across the SEA region in a sustainable and responsible way. A4D has the programmes and the business culture to offer far more support, but involvement from outside the region is now necessary to tackle the huge need that SEA presents.

Currently, A4D has five key programmes (detailed below and in *Figure 1*). These work together to support a young person with type 1 diabetes from diagnosis to adulthood, ensuring that they can live a full and active life.

Clinic Support Programme

The aim of the Clinic Support Programme (CSP) is to improve diabetes outcomes and patients' quality of life. A4D provides free life-saving medical supplies, including insulin, blood glucose monitoring kits and HbA_{1c} tests. As part of the programme, A4D also supports other medical needs like hospitalisation cover and clinic transportation,

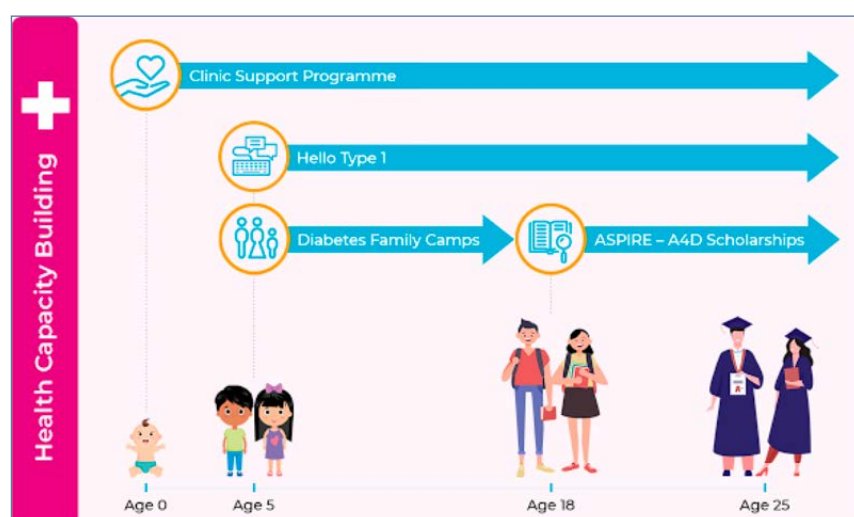


Figure 1. The five programmes operated by Action4Diabetes.

where needed. A4D has developed a robust system that allows it to track and monitor the progress of each individual with type 1 diabetes and the distribution of medical supplies that it provides. Currently, A4D partners with 22 local public hospitals to implement this programme to support people with type 1 diabetes aged 0–25 years. The total number of patients actively receiving medical support under the CSP in Spring 2021 was 491 (Figure 2). A4D programmes are based on clinical evidence and reinforced by patient feedback. Initiatives include the following:

- **Watch list:** High-risk individuals (e.g. those with poor glycaemic control and those not attending clinic appointments) are selected for close monitoring, coupled with an individual action plan.
- **Protein food basket:** A4D provides high-protein foods for children with malnutrition or growth problems.
- **Jerry's Mini Zoom programme:** Monthly digital communication with all A4D's patients, their carers (as appropriate) and healthcare professionals via clinic-based live digital meetings.

HelloType1

[HelloType1](#) is an online platform of type 1 diabetes resources developed in the local language and is currently live in Cambodia. It is aimed to empower people with type 1 diabetes and their families to provide diabetes self-care, for improved outcomes and better quality of life. This ground-breaking online platform is also an educational resource for healthcare professionals. HelloType1 aims to provide online type 1 diabetes education and support in regional languages for over 5000 people living with type 1 diabetes by the year 2023.

Diabetes family camps

Living with type 1 diabetes can be difficult, especially in countries where awareness of the condition is low. Since 2016, A4D diabetes family camps have fostered a community among young people with type 1 diabetes and their families. The camps include children as young as four years old through to young adults in their early twenties, together with their family support members. A typical diabetes family camp is a 2–3-day



Figure 2. Breakdown of young people with type 1 diabetes who have been supported by Action4Diabetes.

programme organised by A4D in collaboration with the local hospital paediatric unit and its medical professionals. The camps provide an inspirational, educational and fun experience for young people with type 1 diabetes and their families. To date, A4D has organised 16 diabetes family camps in Myanmar, Thailand, Cambodia, Laos, and Malaysia, engaging more than 1200 participants.

ASPIRE scholarships

The ASPIRE programme provides scholarships for further education and training to young people with type 1 diabetes from low-income households. Too often in SEA, type 1 diabetes leads to children dropping out of school and losing their ambitions and expectations in life. ASPIRE gives young people aspirations. A4D currently has five students enrolled in this programme.

Health capacity building

Medical knowledge of type 1 diabetes in SEA often falls short. In order to create sustainable systems of healthcare, A4D funds doctors in under-resourced hospitals and facilitates training in up-to-date type 1 diabetes management. Since 2016, A4D has supported three doctors at diabetes clinics in our partner hospitals in Cambodia and Myanmar. Besides working at the clinic, these doctors also complete patient home visits, sometimes hundreds of miles from the clinic in remote areas where home refrigeration does not exist. To provide the healthcare training, A4D partners with established institutions and type 1 diabetes experts from around the region. Through workshops and

Table 1. Expenditure of Action4Diabetes in 2020.

Expenditure (2020)	Amount (USD)	%
Management cost	14 729.81	7.7%
Clinic Support Programme	138 404.60	72.0%
HelloType1	9626.67	5.0%
Diabetes family camps	5196.04	2.7%
ASPIRE scholarships	5737.22	3.0%
Health capacity building	15 536.10	8.1%
Other	2957.77	1.5%
Total	192 188.20	100%

mentor programmes, A4D has helped educate over 150 healthcare staff in best practice of type 1 diabetes management.

Expenditure

A4D's expenditure in 2020 is detailed in *Table 1*.

How you can help

If you are interested to donate to the charity or hear more about the work it does, and how you could become part of its mission, we would love to hear from you. For further information, please use any of the following contact points:

- Email: admin@action4diabetes.org
- Website: <https://www.action4diabetes.org>
- Facebook: www.facebook.com/Action4Diabetes
- Twitter: <https://twitter.com/Action4Diabetes>

About the authors

Charles Toomey and Jerry Gore set up the UK registered charity Action4Diabetes (A4D) to save and empower young people with type 1 diabetes in deprived communities across South-East Asia (SEA) by providing them with access to essential healthcare and education. The long-term aim is that these children will survive and thrive through their childhood and into adolescence so that they become full, productive and contributing members of society.

Charles has lived and worked in healthcare in SEA since the mid-1990s. His experiences have

provided him with a deep understanding of the healthcare systems across SEA and the ability to design and execute programmes that ensure the cost-effective sourcing and delivery of medical supplies, and other interventions that upgrade the delivery of healthcare and improved outcomes that are essential for people living with type 1 diabetes.

Jerry was diagnosed with type 1 diabetes in 2001. One of the UK's leading expedition mountaineers, Jerry has interacted with local people in countries such as Pakistan, Nepal and India during his climbing exploits, allowing him to survey the tattered patchwork cloth of humanity in such countries, and realising that a child newly diagnosed with type 1 diabetes in economically depressed environments would have almost zero chance of survival. Jerry started his work supporting impoverished children with type 1 diabetes by raising money in 2009 through his JICs (Jerry's Insulin Challenges), a series of extreme mountain and road bike challenges.

Fiona Ooi is based in Malaysia and has over 15 years' experience of the delivery of diabetes-related programmes across SEA. She has overseen the growth of A4D's operations in SEA and the successful development and delivery of multiple programmes since 2016.

Associate Professor May Ng, A4D's voluntary Chief Medical Advisor, grew up in Malaysia. She is responsible for providing advice, training and educational support for healthcare professionals in SEA. She also leads on clinical, research and educational projects with other healthcare professionals in SEA. She receives no compensation, financial or otherwise, for the personal contribution of her work, either from A4D or from any of its partners or sponsors. ■

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To learn more, visit:
<https://www.action4diabetes.org>