

From Surviving to Thriving:

Evaluation of the International Diabetes Federation – Life for a Child Program

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Disclaimer

This report contains the collective views of the evaluation team. We have aimed to describe as best as possible the various health systems in the countries visited as they presented to us in relation to the treatment and care of children and young people with Type 1 Diabetes. The information in the report has not been specifically verified. No photographs may be reproduced without permission of the authors.

Executive Summary

Introduction

The International Diabetes Federation's Life for a Child Program (IDF-LFAC) was established in 2001 with support from the Australian Diabetes Council and HOPE worldwide. Its purpose is to increase access to life-saving insulin and diagnostic tools for children and young people with type 1 diabetes (T1D) under the age of 25 in low and middle-income countries, many of whom die within one year of diagnosis. The program uses a simple formula whereby monetary and in-kind donations are given to established diabetes centers and associations, enabling them to provide the ongoing clinical care and diabetes education children need to stay alive. The recipients in turn provide comprehensive clinical and financial feedback to the IDAF-LFAC management team in Sydney, Australia.

IDF-LFAC aims to provide: (1) insulin and syringes; (2) blood glucose monitoring (BGM) equipment; (3) appropriate clinical care; (4) HbA1c testing; (5) diabetes education; and (6) technical support and training for health professionals, as well as 7) facilitating relevant clinical research, and where possible 8) assisting with capacity building. IDF-LFAC receives financial and in-kind support from private foundations, individuals, and corporations. Insulin and blood glucose monitoring equipment distribution is made possible by donations of insulin and the purchase of blood glucose monitors and strips at a reduced price from large pharmaceutical companies.

Evaluation Goals

The goal of this evaluation is to assess IDF-LFAC's organizational structure, strategic framework, processes, program impact, and potential to catalyze long-term sustainable improvements to T1D care delivery systems in its partner countries. LSHTM were commissioned to undertake the evaluation in 2014 when IDF-LFAC had active programs in 45 countries.

Methods

In order to carry out this evaluation, a multi-faceted approach was adopted. This consisted of:

- a) In depth interviews with key informants from IDF-LFAC and others with knowledge of its work
- b) Review of documentation on the operation of IDF-LFAC
- c) Field visits to five countries, to assess the IDF-LFAC operation on the ground. The countries were identified in consultation with IDF-LFAC and chosen on the basis of geography (at least three continents), length of IDF-LFAC presence in a country, number of children served by IDF-LFAC programs, overall state of T1D care in the country, strength of the country's health system and size of health budget, economic development (low and middle income countries), and ability to coordinate travel with IDF-LFAC staff, volunteers, and evaluation team members.
The countries visited were Rwanda, Jamaica, Mexico, the Philippines and India (Nagpur).
- d) An electronic survey of all recipient countries receiving IDF-LFAC support, designed to provide sufficient information to capture the

diabetes environment in each country and to situate the work of IDF-LFAC within it.

Findings

The review covers five themes:

- IDF-LFAC structure and organization
- Optimal strategic framework for high impact sustainable results
- Changes to policies that could improve quality, quantity, efficiency and effectiveness
- Impacts on countries, systems and children
- Impact on long term sustainability in T1D care delivery systems

This review overall shows that it is a strong program that is delivered well and is highly valued by the countries and the children young people and their families who are supported by the program. It is clear that the program enables children and young people with T1D to survive and as the program and country policies strengthen enables them also to thrive.

The IDF-LFAC program already does many things right and the team, albeit small, are extremely dedicated and enthusiastic and deliver the program well. Many aspects are to be applauded and continued.

The review identifies IDF-LFAC's strengths and challenges. It focuses particularly on their engagement in-country and on how they develop a strategic direction for care and treatment of T1D. It identifies a need for developing country leadership and building local capacity, implementing approaches that catalyze systemic improvements in T1D care delivery systems.

The ultimate goal must be for people with T1D to be able to get good treatment and care within their country's health system. Unfortunately this does not appear to be a realistic goal in the short term in most countries. Nevertheless, there is a need for a higher priority to be given to the medium and long term sustainability of the support provided for children with T1D, making full use of the experiences gathered by IDF-LFAC and the information that it has gathered on burden of disease, health needs, and barriers to be overcome in obtaining effective care by people with T1D.

The five themes are explored in depth and recommendations made in relation to each and in relation to the specific countries visited.

Recommendations

The main recommendations identify a number of key issues:

- Strengthening the initial process when deciding to start an IDF-LFAC program in a country, both in terms of needs assessment, so that the program is focused on children in most need, and with a clear strategy to embed IDF-LFAC within the health system of the country and to gain 'buy in', for the longer term from the Ministry of Health, ideally with a MOU and an exit strategy. This will require leadership from IDF. Mechanisms to strengthen leadership within country are also recommended, which again will require leadership from IDF but also specific external expertise for leadership skill development.

- Further enabling countries to be self-sufficient, by encouraging peer to peer development, enhancing expert input, utilizing the IDF-LFAC website for supportive resources and developing a newsletter. Whilst these may require initial focus and resource they should in time streamline the work of the LFC team.
- Education and training has been identified as a recurring theme and all the countries surveyed recognize the need both for further training of health care personnel and of children and families and awareness raising in the general population. Many of the existing educational materials developed by IDF-LFAC are excellent and welcomed but some require translation in terms of both language and culture.
- Education, vocational training and support to children and young people to enable them to be self-sufficient when they reach adulthood has been developed in a number of countries and needs further focus to expand to other countries.
- Enhancing the robustness of data collection from the program, both in terms of systems and in terms of requiring feedback from countries, to build into a powerful database across 45 countries and use the data to demonstrate the burden of disease. This should include outcome measures both throughout the program and when young people 'age out'.
- Finally we identified that there is much experience and a wealth of knowledge held in the heads of the IDF-LFAC team and suggest this should be captured by commissioning an oral historian.

This report seeks to enable the IDF-LFAC program to take stock of its activities, enhance the elements that are already working well, and refocus on the areas that have been identified that, we believe, will enhance its effectiveness and sustainability. However, it is recognized that this will require specific funding for 'start-up' of some elements and will also require some specific external expertise and for IDF to take a greater leadership role.

Introduction

The International Diabetes Federation's Life for a Child Program (IDF-LFAC) was established in 2001 with support from the Australian Diabetes Council and HOPE Worldwide. Its purpose is to increase access to life-saving insulin and diagnostic tools for children and young people with type 1 diabetes (T1D) under the age of 25 in low and middle-income countries, many of whom die within one year of diagnosis. The program has adopted a simple formula whereby monetary and in-kind donations are given to established diabetes centers and associations, enabling them to provide the ongoing clinical care and diabetes education children need to stay alive. The recipients in turn provide comprehensive clinical and financial feedback to the IDAF-LFAC management team in Sydney, Australia.

IDF-LFAC aims to provide: (1) insulin and syringes; (2) blood glucose monitoring (BGM) equipment; (3) appropriate clinical care; (4) HbA1c testing; (5) diabetes education; and (6) technical support and training for health professionals, as well as 7) facilitating relevant clinical research, and where possible 8) assisting with capacity building. IDF-LFAC receives financial and in-kind support from private foundations, individuals, and corporations. Distribution of insulin and blood glucose monitoring equipment is made possible by donations of insulin and the purchase of blood glucose monitors and strips at a reduced price from large pharmaceutical companies. These are then shipped to recipient countries. According to its website, IDF-LFAC currently has a presence in 48 countries, reaching 15,000 children and has plans for further expansion.

From 2011-2014, the Leona M. and Harry B. Helmsley Charitable Trust's Type 1 Diabetes Program provided approximately US\$700,000 annually to IDF-LFAC, representing half to three quarters of IDF-LFAC's total annual revenue during that time. The Helmsley Charitable Trust commissioned the London School of Hygiene and Tropical Medicine (LSHTM) to undertake an independent assessment of the impact and organizational capacity of IDF-LFAC. The results of this evaluation are intended to guide any future funding to IDF-LFAC and inform the Helmsley Charitable Trust's Type 1 Diabetes Program strategy development overall.

Evaluation Goals

The goal of this evaluation is to assess IDF-LFAC's organizational structure, strategic framework, processes, program impact, and potential to catalyze long-term sustainable improvements to T1D care delivery systems in its partner countries. In carrying out this evaluation program, materials have been reviewed and a wide array of stakeholders have been consulted to identify IDF-LFAC's strengths and challenges, with a particular focus on discerning the extent to which IDF-LFAC's engagement in-country is developing, or could develop country leadership and catalyze systemic improvements and local capacity building of T1D care delivery systems.

Terms of reference

Before work began on the evaluation, the Helmsley Charitable Trust met with the LSHTM evaluators and agreed on a series of questions with which to frame the structure of the report. The findings and recommendations have been fed back and discussed with staff of the Helmsley Charitable Trust and with the IDF-LFAC

team as well as with senior IDF staff. Based on these discussions, proposals are made for taking the findings forward in the work of all the parties involved.

This report describes the evaluation, including the methodologies used and findings and makes recommendations in relation to the evaluation goals.

Methods

In order to carry out this evaluation, a multi-faceted approach was adopted. This consisted of:

- a) In depth interviews with key informants from IDF-LFAC and others with knowledge of its work
- b) Review of documentation on the operation of IDF-LFAC
- c) Field visits to five countries to assess the IDF-LFAC operations on the ground. The countries were identified in consultation with IDF-LFAC and chosen on the basis of geography (at least three continents), sufficient duration of IDF-LFAC presence in a country, number of children served by IDF-LFAC programs, overall state of T1D care in the country, strength of the country's health system and size of health budget, economic development (low and middle income countries), and ability to coordinate travel with IDF-LFAC staff, volunteers, and evaluation team members.
- d) An electronic survey of all recipient countries receiving IDF-LFAC support, designed to provide sufficient information to capture the diabetes environment in each country and to situate the work of IDF-LFAC within it.

The evaluation was undertaken by a team comprising Dr Sue Atkinson (SA), Ms Miranda Eeles (ME), Ms Zoe Atkinson (ZA), and Dr Louise Sigfrid (LS), under the overall direction of Professor Martin McKee (MM), Professor of European Public Health, LSHTM. PHAST (Public Health Action Support Team), a not for profit, Community Interest Company, supported the work by identifying some team members and translation support.



Visiting May Pen Hospital in Jamaica

Interviews with key informants:

Interviews were conducted with members of staff from IDF-LFAC, IDF head office, and others who have knowledge of the program. Interviews were conducted with an array of stakeholders, including beneficiaries of the IDF-LFAC program and their families during the country visits. A full list of interviewees is in appendix 1

Review of documentation: A comprehensive portfolio documenting its operation was provided by IDF-LFAC and reviewed with staff during a meeting with MM in Sydney in September 2014.

Field visits: Field visits, each lasting between five and ten days, were conducted to the following countries:

- Rwanda (8th – 14th May 2014)
- Jamaica (21st – 26th July 2014)
- Mexico (25th October – 3rd November 2014)
- Philippines (10th -17th December 2014)
- India (3rd - 11th January 2015)

The field visits were arranged through IDF-LFAC and the relevant national diabetes association. The team consisted of SA, (all 5 countries) ME (Rwanda and Jamaica), ZA (Jamaica, Philippines and India) and Dr John Shanks (Mexico) with support from London by LS and MM. The team, with support from LS and together with the local diabetes association/lead coordinator in each country visited, and with advice from IDF-LFAC, arranged to meet a series of people involved with the delivery of IDF-LFAC and with health services delivery within the country.



Rwanda's welcome for the visiting team

As well as the 'country' questionnaire, which was completed during the visit, a series of interview schedules (appendix 8b) were developed for discussion with various categories of people within the country—including health workers in clinics and health centers treating children and young people with diabetes; Ministry of Health personnel; WHO country staff; partner organizations including NGOs such as Oxfam and commercial entities; children, young people and their families; experts and mentors. The full list of people interviewed is in appendix 1. Most of the visits and interviews were undertaken face to face, while most of the children and families were interviewed in their own homes, which provided a picture of their local circumstances. In many countries the staff of the diabetic association described the areas where the beneficiaries lived as 'slums'. A few interviews were undertaken via Skype or telephone, depending on availability of interviewee and geography. Consent was given by all interviewees in the field visits (consent form appendix 9). Most interviews were conducted in English, but some required interpretation into French (Rwanda), Spanish (Mexico) and some local languages (e.g. India, Philippines). The visit team themselves provided French and Spanish interpreting, but for local languages the local diabetic association staff acted as interpreters.



IDF-LFAC is delivered by the Dream Trust in Nagpur, India

The first visit undertaken was to Rwanda. This was arranged to 'piggy back' on an already arranged visit including key IDF-LFAC personnel (Graham Ogle (GO)), partner organizations (Marjorie's Fund and Team Type One), together with external experts and researchers who are undertaking work and support in

Rwanda. The Ministry of Health arranged a meeting with partners to discuss their ongoing involvement and strategy and facilitated a meeting with the Minister of Health. This provided an excellent overall introduction to IDF-LFAC and related health service issues for the visit team, who added further meetings to the visit, for example with WHO and Oxfam.

Summaries of the country visits and recommendations in relation to specific countries are at Appendices 3 to 7.

Survey: Following discussions with the Helmsley Charitable Trust and IDF-LFAC, an electronic survey (appendix 8) was designed, piloted, and translated from English into French and Spanish (for use as appropriate) before being sent to 38 recipients of IDF-LFAC support not receiving a field visit. Responses were obtained from 35. The non-responders were Burkina Faso, Iraq and Uganda. In addition there were the five surveys from the country visits, so a total of 43 countries were surveyed with 40 responses (response rate of 93%). The survey was not sent to two countries with established programs. In Morocco the program was on hold because of illness of a key individual and in Papua New Guinea the IDF-LFAC program supports only 1 child.



Visiting the Diabetic Federation in Mexico

In passing, it should be noted that several respondents welcomed the survey, noting how, as one said, completing it had been an 'eye-opener', making them consider how they might influence government and support sustainable health services in a way that they had not previously considered

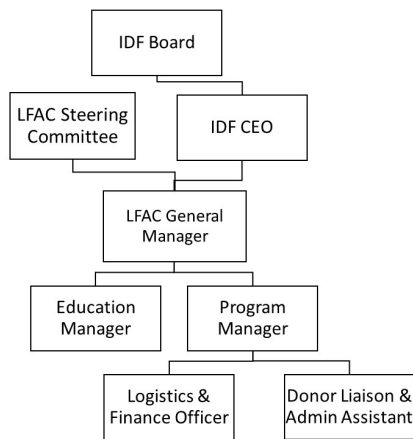
Findings

We begin by describing the IDF-LFAC's structure and mode of operation, where appropriate commenting on issues that arise that are relevant to its ongoing operations.

IDF-LFAC's organizational structure; strengths, weaknesses, and implications

The IDF-LFAC Program was established in 2000 with support from the then Australian Diabetes Council (now Diabetes NSW) and HOPE *worldwide*. It is managed by Diabetes NSW, on behalf of the IDF. Day to day management is undertaken by the general manager, Dr Graham Ogle, who is accountable to a Steering Committee and also, via the IDF Chief Executive Officer (supported by the Director of Policies and Programmes, Director of Partnerships and Director of Communications and Advocacy) to the IDF Board. Figure 1 shows the organizational structure and lines of formal accountability.

Figure 1 IDF-LFAC organizational structure



The IDF and IDF-LFAC program are geographically separate, with the former based in Brussels and the latter in Sydney. However, despite the distance and time zones that separate them, relationships between the IDF-LFAC staff and the IDF headquarters are good, and appear to have been so for some time, although we came to understand that, in the past, while IDF was pleased to be associated with IDF-LFAC, it was largely left to its own devices. Over the past two years the links between the two bodies seem to have become closer, following extensive changes in management at IDF headquarters, so that IDF is now taking a much greater interest in the work of IDF-LFAC than was the case in the past. Inevitably, however, the geographical distance involved between IDF and IDF-LFAC is a barrier to closer engagement, although key staff typically meet several times a year at various diabetes-related meetings.

We understand that these arrangements may change in the near future. On 10th March 2015 the IDF General Assembly adopted new Articles of Association that provide a legal basis for creating subsidiaries. The IDF Board will now decide on the next steps, which may include creating a subsidiary in Australia for IDF-LFAC as well as a 501(c) (3) 'friends of' in the USA that would manage donations from the USA in support of IDF-LFAC. This would be a so-called "Friends of" organization but would be governed by a separate board, with three out of five

members being US citizens, and would be organizationally independent of both IDF-LFAC and IDF. If these changes take place, it has been suggested that IDF-LFAC staff transfer to that subsidiary, but their work would be supplemented, by additional staff in IDF, who could develop future work on strengthening health systems.

The model adopted by IDF-LFAC since its inception has been one of rapid growth, extending coverage to approximately 5 new countries per year and exiting from very few. As a consequence, it is now supporting partners in 48 countries, with five started in 2014 and several new candidates under consideration, including some that are among the most difficult countries in the world to work in, such as North Korea, Syria, and the Central African Republic. IDF-LFAC staff are strongly supportive of this approach, citing the many achievements that it has delivered and the openness of the program to any country wishing to participate.

The core staff number fewer than five full time equivalents. IDF-LFAC justifies this as it is, in effect, operating a franchise, IDF-LFAC is managed in each country by a diabetes association, or similar, and with considerable outsourcing of practical arrangements. Thus, most insulin is shipped by UTI, a pharmaceutical distribution company based in Johannesburg (which has the advantage that, as the insulin is sourced in South Africa, it is labeled in English and Afrikaans, so if it did appear on the market in countries it is being supplied to, it would be instantly recognizable). Strips are distributed by Fedex. The national diabetes associations are responsible for making arrangements with customs authorities to import insulin and other materials, where necessary arranging for duty to be paid (see later). In some countries, such as the Philippines, insulin and other supplies are sourced locally but funded by IDF-LFAC.

IDF-LFAC selects countries in an *ad hoc* way, based mostly on requests from local diabetes associations or medical professionals (Table 1), although some requests come from other organizations working in the field of diabetes or child health, such as Insulin for Life and Operation Mercy. IDF-LFAC has established informal criteria for accepting new partner countries. Most, but not all, are members of the IDF. There have been some proactive attempts to identify local partners where IDF-LFAC had not previously operated, such as in Malawi. On several occasions, those seeking support have been declined, primarily because of concerns about their organizational capacity and, in particular, the absence of an identifiable local champion.

Table 1 Organizations initiating discussions about receiving IDF-LFAC support

Organization/representative	Percentage (number) of respondents
National Diabetes Organization	30.6 % (n=11)
Senior Medical Professionals	19.4 % (n=7)
Ministry of Health	2.8% (n=1)
Patient(s) with Type 1 Diabetes	8.3% (n=3)
Other (please specify)	38.9% (n=14)

IDF-LFAC staff confirm that they do undertake an initial questionnaire/ needs assessment in each country they work in, often conducted by an external 'expert', but only 50% of respondents to the survey reported that the IDF-LFAC support was informed by a formal needs assessment, while 22% reported that it was not and 28% did not know. The 'needs assessment' comprises a questionnaire concerning such issues as the number of children with T1D and numbers that do not have access to insulin etc. Other mechanisms for 'needs assessment' in relation to diabetes have been developed, notably the RAPIA (Rapid Assessment Protocol for Insulin Access)(Beran, Yudkin et al. 2006). A modified RAPIA was undertaken in the Philippines in 2008 but it does not appear to have been used by IDF-LFAC, nor by local endocrinologists, who, somewhat surprisingly, seemed unaware of the RAPIA research. Overall, the survey showed low awareness of number of children with T1D in the country; only one respondent seemed aware of the IDF Atlas (Patterson, Guariguata et al. 2014), an invaluable resource that has synthesized data on numbers of children and young people with T1D worldwide, with a major input from IDF-LFAC. Where the RAPIA has been undertaken, it afforded useful links between NGOs and IDF-LFAC. Consideration needs to be given as to how to develop a more robust 'needs assessment' approach, which could ensure that the children most in need, are being supported by IDF-LFAC and local diabetes associations. For example, in Mexico the IDF-LFAC program is delivered through state-based diabetes associations, involving those who already have the capacity to manage the IDF-LFAC program effectively. However these are not in the poorest states and IDF-LFAC is aware that they are not therefore reaching the children most in need.

Certain issues arise from this overview of IDF-LFAC's structure and processes, all raising important questions about its resilience to unexpected events.

First, its funding base is highly concentrated. At present about 50% comes from the Helmsley Charitable Trust, and 25% from a BNP Paribas foundation, Fondation de l'Orangerie. The program would be very vulnerable if it lost either. IDF and IDF-LFAC recognize the importance of diversifying its sources of funding (appendix 10).

Second, its operations are highly dependent on one individual, GO. Although he has seemingly boundless zeal and energy, there are inevitable questions about the ability of IDF-LFAC to cope should circumstances lead to his absence from the program. Given the number of children whose lives depend on its continuity, this must be a matter of great concern. We were advised that IDF-LFAC has discussed such a situation but there are no clearly articulated contingency plans. We were told that, at least in the short term, Martin Silink (chair of the Steering Committee) would assume some day to day responsibility, with support from the program manager (once someone is appointed to replace Robyn Short-Hobbs, who has recently departed), with some ad hoc support from a community of local pediatric endocrinologists. While not doubting the commitment of these individuals, we are not fully convinced that this could be more than a very temporary solution. A longer term, but related issue is the leadership of IDF-LFAC following the retirement of GO. GO plans to continue for another 10 years and anticipates the successor will be appointed during this period. However,

there would be clear advantages to allowing a potential successor to grow into the post, becoming familiar with its activities and progressively taking over responsibility. Though nothing would need to be done in this respect for a few years yet, we recommend that IDF-LFAC take time now to develop an explicit plan that can address both contingencies related to GO's work and, in the longer term, succession planning.

We have been impressed by the wealth of knowledge about IDF-LFAC and its recipients that GO has accumulated. We believe that it is important that this knowledge be institutionalized within IDF-LFAC, as well as ensuring that the lessons that have been learned are available to other organizations involved in similar activities. For this reason, we recommend that IDF commission an oral historian to document the experience with IDF-LFAC. We also explored the related issue of security and resilience of managerial information necessary for the sustainability of operations. We were reassured that there are robust arrangements for remote backup of documentary material and data.

A third concern relates to the very small core staff. As the organogram (Figure 1) shows, it has fewer than 5 FTE staff. Although the staff are all highly motivated, and they can draw on other volunteers for visits to countries, this does seem a remarkably small complement, given the workload. IDF-LFAC staff concede that the staff are spread extremely thin. Given the immediate needs of getting insulin and supplies to partners, it was reported that it was fundraising activities that tended to be displaced (although this raises questions about the balance of activity with respect to fundraising between IDF and IDF-LFAC). We recommend that the core staff be strengthened by the appointment of an additional administrator in Sydney. We believe that this should be considered a higher priority for available funding than expansion to additional countries.

Fourth, while the franchising model has many advantages, it places responsibilities on the recipients that they are not always able to accomplish. Thus, IDF-LFAC distributes diabetes education materials in different languages. It was apparent from the country visits that these materials are very well liked and seem to be effective both with children and young people and their families and with professionals. However, they do need to be translated into local languages and be produced in ways that are culturally appropriate. For example, in Jamaica families would have liked more 'visual' materials such as comic books, cartoons as they regard themselves as not a 'reading' nation. Some educational materials have been translated into various languages and some are available via the IDF-LFAC website. Consequently, we recommend that national associations be required to take more responsibility, building upon the work of IDF-LFAC in their countries but going beyond it, including adapting educational materials by means of 'in country' translations and adaptations.

Finally, IDF-LFAC has expanded rapidly into a large number of countries. However, in some the number of children being supported was extremely small (1 in Papua New Guinea) and although we were advised that type 1 diabetes is extremely rare in Melanesian populations, it seems implausible that there were not many more that were being missed. There is clearly a question of whether support on such a small scale is viable. Although we were reassured that the additional workload was extremely small, clearly it is finite. A different issue

arises in some countries where the need for IDF-LFAC support is clearly very large, but where they were only able to reach a very small proportion of the population, such as India, Pakistan, and Mexico. We recommend that IDF-LFAC review their criteria for working in countries where either they can support only a very small number of children or where the contribution is minimal in relation to the total disease burden, thereby giving them limited leverage in advocating for the structural reforms that will be needed to create a sustainable model of care.

How can IDF-LFAC achieve high-impact, sustainable results in partner countries?

Measuring success

We explored the question of how IDF-LFAC defines and measure the success of its work in each country. IDF-LFAC was able to articulate a clearly defined and appropriate vision, “that no child should die from diabetes” and a mission statement (Box 1). However, it was less clear that these words, which do not appear on their website, have been clearly communicated to their partners.

Box 1 IDF-LFAC Mission Statement

To support provision of the best possible health care, given local circumstances, to all children and youth (under 26 years of age) with diabetes in developing countries, through strengthening the services in these countries.

Conduct clinical research and international advocacy so as to improve diabetes care for children and youth, and where possible help both adults and also recipient countries with achieving sustainability.

Success is, first and foremost, defined by IDF-LFAC as evidence that care is improving. IDF-LFAC has operationalized this under three headings: stop deaths from occurring; provide “standard care” for all eligible children (adequate insulin, self-monitoring with at least 2 strips per day, regular HbA1c tests, and diabetes education); and reduce and prevent complications.

This can, in theory, be monitored using data supplied to IDF-LFAC on a range of process measures (e.g. increased diagnosis, children treated, spread throughout the country, improved data collection systems) and outcome measures (survival, fewer admissions with diabetic ketoacidosis, HbA1c levels). However, although IDF-LFAC has developed a web interface to support data collection, in English, French, Spanish and Russian (<http://database.lifeforachild.org/lifeforachild/>) only a few countries are using it and there is limited capacity to analyze the results of what is actually a major data monitoring exercise. The issues of data and monitoring are discussed further below. Two practical obstacles were noted. One is that the University of Sydney, consistent with common practice in high-income countries, requires evidence of approval by a local ethics committee before it will permit analysis of data on individual children. This is a very complex and expensive procedure in some countries. The second is that the database is internet based and some countries have difficulty with consistent connectivity and are not therefore able to input data successfully. This is being addressed by IDF-LFAC, which is exploring various alternative options.

The survey of national associations provided mixed evidence of progress in changing the management of diabetes in the countries (Table 2). Although 83% believed that the management and control of those children known to have diabetes had improved, only 42.5% believed that there had been an increase in the numbers of children correctly diagnosed. 48% believed that services now covered a wider geographical area than before IDF-LFAC partnered with them and 38% believed that staff training had improved. Less than half thought there was greater awareness of diabetes among the population. Of course, it is clearly not possible to attribute these changes specifically or with certainty to the work of IDF-LFAC but it is noteworthy that the respondents did believe that IDF-LFAC had played some role. From the country visits there was a strong view that IDF-LFAC had made a profound difference to children and young people with T1D in those countries. Most identified increases in diagnoses, better management, fewer hospitalizations (especially for diabetic ketoacidosis (DKA)) and gradually improving HbA1c levels.

Table 2 Positive impacts of the IDF-LFAC program, as identified by survey respondents

	Yes	No	Missing/ don't know
Numbers being correctly diagnosed	17 (42.5%)	7 (17.5%)	16 (40%)
Diabetes management and control	33 (83%)	1 (3%)	6 (15%)
Wider geographical coverage in diagnosis, treatment and care	19 (48%)	10 (25%)	11 (27%)
Staff training	15 (38%)	17 (42%)	8 (20%)
General awareness in the wider population about Type 1 diabetes	17 (42%)	14 (35%)	9 (23%)

Some specific examples were cited, such as how *“We have also engaged with the media and patients have explained the symptoms they had at the beginning on national TV”* (Kenya) and how *“LFAC has built hope. We lost one child but the other 6 would have surely died. Thanks to IDF-LFAC we have been operating for 4 years and the children are relatively well, coming to the ‘clinic’ every two weeks from far away distances. They are glad to come”* (Liberia). There were also broader benefits for children and their families: *“Parents economy has improved - when they don’t have to buy strips, so they can buy better food instead”* (Mexico). Other impacts mentioned included: *“Progress is real but very slow; in former years children and youth died, now they survive longer”* (Democratic Republic of Congo), *“Training during camps from IDF-LFAC staff help families and local staff update knowledge, and share information”* (Fiji), and *“None of our children has presented with severe ketoacidosis nor needed hospitalization for several years”* (Bolivia).

Respondents provided many positive examples of differences to the health and wellbeing of the children receiving support that partners attributed to the work of IDF-LFAC (Table 3).

Table 3 Examples of ways that IDF-LFAC has impacted on the lives of children

Bangladesh	<i>LFAC is reducing the huge burden of Social welfare department of BIRDEM by providing care to these children.</i>
Bolivia	<i>We have now the satisfaction of providing insulin and supplies to ALL children or young person diagnosed with Diabetes, the IDF-LFAC program makes a big difference Before it was very difficult for many families to buy Insulin and they often reduced the doses needed to make the insulin bottle last longer or let the kids get worse and die. Most children and youth diagnosed in recent years have not reached the point of ketoacidosis, as parents or paediatricians have directly identified diabetes as a cause of the symptoms presented and have taken proper and effective measures securing them endocrinologist specialist or paediatric endocrinologist care.</i>
Burundi	<i>Currently, children with diabetes are well followed up as they benefit from receiving insulin, glucometers and syringes, whereas previously they were almost abandoned.</i>
Cambodia	<i>The cost of testing regularly is about \$30 per month which is far beyond the means of most people in Cambodia, so the provision of glucometers and test strips is a huge benefit for our patients.</i>
Congo	<i>The positive difference in terms of glycaemic self-monitoring. Before the program the majority of children did not have glucometer and controlled blood glucose once a month, now they are 2 per day or 60 day blood glucose.</i>
Democratic Republic of Congo	<i>We started in 2000 and got support from IDF-LFAC in 2003. So improvement was from nothing to something. Progresses are slow. Before, most of the patients died after a few months of diagnosis: usually lack of insulin and DKA. Now they survive, some of them for more than 10 or 15 years. I am working in diabetes since 40 years and this program is the best and most respectful I ever worked with. They accept our failures and shortcomings with patience. Other programs are more demanding and refuse assistance if we cannot comply with their requirements. Now at least in Kinshasa most people or doctors know where to go for treatment when a young patient has diabetes</i>
Dominican Republic	<i>Helping us with as little as the supply of an A1C Machine has been a good help to provide something we don't have.</i>
Ecuador	<i>The difference is positive, because the children that receive the insulin from IDF-LFAC would not have the chance to survive without it; it has brought them the possibility to improve their quality of life. If we wouldn't have the IDF-LFAC support we could not attend the children with type 1, because we opened the "programa de apadrinamiento" since we receive their insulin support.</i>
Ethiopia	<i>Lack of insulin was our major concern and through IDF-LFAC children are able to stay alive but a lot has to be done since this is a big country with focus on communicable diseases, hence we still need to work hard to put diabetes on the front. Through the program we were able to do posters and distribute educational materials and the diagnosis rate has improved as the number of children reported from each centre increases.</i>
Fiji	<i>Establishment of local guidelines to manage DKA, other situations such as sick days, surgery etc.</i>
Guatemala	<i>We already have 105 children and youth that are likely to be self-</i>

	<i>monitoring and for 42 of them access to free insulin is thus helping to better manage their diabetes.</i>
Guyana	<i>The training that was done in March I was personally able to work with a private physician on a newly diagnosed 7 year old boy. Once this program is properly implemented it can make a big change and work wonders for Type 1.</i>
Haiti	<i>The most important thing is that children and young adults stay alive. Before, as the parent cannot afford the insulin, they had to leave the child die With the availability of the insulin and materials, children and young adults can stay alive and try to avoid complications. Children and young adults living outside of the capital of Port-au-Prince can receive the materials and insulin at the affiliated center of FHADIMAC where they are followed for their diabetes</i>
India	<i>LFAC is saving many lives in resource poor communities in India. Where no child had survived prior to IDF-LFAC we now have 56 children leading a normal life. However due to limited resources has not been able to provide long acting insulin, training of health care professionals and partner with local organizations to start a dialog for national policy for children with type one diabetes.</i>
Kenya	<i>The negative is the children have to check blood sugars, which they couldn't afford and now they think it is a lot of work. The positive is we are able to manage them with blood sugar controls. The HbA1c has gone down because now they understand.</i>
Liberia	<i>It may not be perfect, but we are going to buy time until the technology on IDM gets better. We know this way of blood sugars averaging 200 is not good enough but it is a step in the right direction. LFAC has built hope. We lost one child but the other 6 would have surely died. Thanks to IDF-LFAC we have been operating for 4 years and the children are relatively well, coming to the "clinic" every two weeks from far away distances. They are glad to come. They come with their coolers and pack of ice for check-up and insulin</i>
Mali	<i>It's just an amazing impact on Mali from 14 children with type 1 diabetes few years ago with life expectancy less than 1 year after diagnosis to 300 children with type 1 managed in six regions of Mali with diabetes clinics equipped for this and health professionals trained</i>
Nigeria	<i>With the availability of insulin fewer are dying, the insulin is distributed to all over the country</i>
Pakistan	<i>My patients cannot afford insulin or the strips. Now they know how to control their sugars. It is an amazing difference in their lives. One of my patients has had leg cramps for the past 3 years. In the book they recommend Amitriptyline. When we started that she immediately improved. She is grateful not to have the leg cramps any more.</i>
Tajikistan	<i>Insulin shortages have been a major problem in the past, particularly as the type 2 population has grown and taken precedence. IDF-LFAC provision of insulin has reduced the stress felt by families who wonder whether there will be insulin for their children. Glucometers have allowed some endocrinologists to train their patients in daily blood glucose testing, which has assisted with the adjustment of insulin and improvement in blood glucose control The glucometers have the potential to really improve the blood glucose control of children, but need to be accompanied by education for both the families and</i>

	<i>endocrinologists. The provision of supplies is at this point keeping the children alive - but because of low education the insulin and glucometers are not being used to their full potential. Since distributing IDF-LFAC insulin and glucometers, the wider endocrinology community has seemed to be more aware and interested in type 1 diabetes.</i>
Uzbekistan	<i>Provision with self-control tools, constant monitoring improved "team work" of "patient-parents-doctor" team (within Life for a child program) resulting in more tight control of glycaemia and, as a result, in decrease of acute and chronic complications and mortality among children and teenagers with type 1 diabetes</i>
Vietnam	<i>Helping patients monitor their complications better</i>

Source: respondents to the survey of country organizations (verbatim comments)

While these examples provide evidence that the program is very well received at country level, it is widely accepted that, ultimately, countries should become self-sufficient with regard to the management of children with diabetes. Thus, a key measure of success is the ability of IDF-LFAC to exit from a country, leaving a sustainable model of care in place. Progress in this regard has been much less. So far, IDF-LFAC has only succeeded in exiting from two countries (Romania, Montenegro), where the government took over responsibility. In a few other cases, governments have expanded their role but gaps remain (e.g. Azerbaijan, an oil rich country now supplies each diabetic with a far from adequate 50 strips per year) and IDF-LFAC remains engaged. In discussions during the course of the evaluation, some other countries were identified where, it was agreed, exit should be possible in the short term such as the Cayman Islands and Fiji. In fact, exit from Fiji took place during the evaluation, offering lessons that can be used to develop a generic policy for exit strategy, which should be codified for use elsewhere. There is also a strong argument for having, however tentative, a plan for 'exit' at the commencement of the IDF-LFAC program in each country. Such an exit strategy needs to be part of the overall model of care showing the 'evolution' of progress of IDF-LFAC.

Exit strategies can benefit from the momentum provided by the almost certain inclusion of universal health care in the post 2015 development agenda. We explored IDF-LFAC's goals at the international and the national level. Staff accepted completely the need for much stronger advocacy in the international arena, linking access to insulin with wider movements for access to essential medicines and universal health care, while taking advantage of the post-2015 development agenda. However, while the evidence that IDF-LFAC collects could be used to support such an advocacy strategy, including stories from those children being supported, it was recognized that there was insufficient capacity to engage meaningfully in this process at present. This is, however, an area where IDF could play a much greater role in association with the NCD Alliance and its members, where IDF already plays an active role, as well as organizations such as Health Action International, with their focus on access to essential medicines.

Making a difference

We explored IDF-LFAC's theory of change that they use to achieve their goals. This has several components:

- Working through existing organizations, already recognized as centers of excellence in provision of care;
- Working with and supporting local champions;
- Incremental improvements in care, progressively introducing new elements and not overwhelming local implementation capacity;
- Transfer of expertise through advice and mentoring;
- Flexibility and complementarity in working with partner organizations

Additional elements, undertaken where feasible, include support for clinical research, vocational training and related measures to support youth transitioning off the program (see later), and working towards sustainability of the program in each country. Different elements of the program may be appropriate to different countries, both depending on the health status and services in the country and on the evolution of the IDF-LFAC program.

From a health systems perspective, there is a potential danger that IDF-LFAC, with its model of care based largely on doctors working from hospitals, could replicate the worst of both vertical disease control programs traditionally adopted in low income countries to address challenges such as malaria and over reliance on hospitals as settings for care. There is now a widespread consensus that, other than in a very few situations, such a model is inappropriate and, instead, services should be integrated horizontally with mainstream health services (Oliveira-Cruz, Kurowski et al. 2003). Of 31 respondents to a question on this issue in the survey, 61% (n=19) thought that the IDF-LFAC program could be better integrated into the national health system but 39% (n=12) thought that this would not be possible. However, those that thought IDF-LFAC could be better integrated recognized that this would require better financing and strengthening of health systems, more stability, and prioritization by politicians.

This issue was explored with IDF-LFAC staff who, while accepting the desirability of a horizontal model, with services embedded in primary care, expressed concern about the virtual absence, in many countries of pediatric endocrinologists and the extremely low skills level of many doctors and other health workers in primary care settings. Moreover, they noted how, even in many high income countries, pediatric diabetes is rarely managed in primary care. The possibility of enhancing the skills of general pediatricians was also explored but, again, in many countries, they tend to be inexperienced. Indeed, this was part of a wider problem, well recognized in the international literature, of the severe shortage of skilled health workers in many countries. The only exception, in the experience of the IDF-LFAC staff, was the availability of nurse educators in most countries. It seems, therefore, that while far from ideal, the current model is probably the only viable one in most countries at present.

Experience from the country visits supports this. Even in some of the more developed countries there may be none, only one or a few pediatric endocrinologists in the country. Care of T1D children is provided by general

pediatricians and sometimes by adult endocrinologists, and the expertise of 'local' primary care doctors is not adequate to treat T1D children properly. Repeatedly, children were referred on to 'hospital' or 'diabetologists'. Whilst the direction of travel in many countries is to more horizontal programs and primary care based delivery, this was not a likely possibility in the near future.

In all the countries visited there is a NCD (non-communicable diseases) or similar national strategy covering diabetes, hypertension, cardiovascular disease, stroke but the focus is on obesity and Type 2 diabetes (T2D) and related issues. It rarely addresses T1D and often does not address the needs of children and young people at all. Likewise whilst there may be specific programs and strategies for child health, many of these are still focused on infectious disease and immunization and have not yet made the shift to chronic diseases such as T1D. Hence children and young people with T1D was not an owned responsibility or a priority in either strategy. As one Ministry of Health interviewee noted, "*type one diabetes is not a priority*" and another commented "*no one speaks up for type 1 diabetes*"

In discussions about the 'context' of the country, as described by WHO representatives, it was seen that there may be more appropriate 'linkages' that can be made, such as with maternal and child health programs. Finding the right place and level to integrate activities supported by IDF-LFAC into mainstream health programs is not without difficulty and will vary from country to country. However, explicit consideration of what approach should be undertaken at an early stage of IDF-LFAC engagement, as part of the development of a plan for integration with health services and eventual exit. This approach needs to be agreed with the local diabetic association and local champions and leaders, while recognizing that their existing networks may not extend to all possible collaborators in the different parts of the health system.

IDF-LFAC works very closely with pharmaceutical companies and is substantially dependent on donations in kind, from Lilly for insulin, Nipro Diagnostics for test strips, and Lifescan for meters and strips, along with some financial support from Sanofi. However, if countries are to become self-sufficient, they will have to develop effective procurement systems that can deliver these products at low costs, including, potentially, preferential pricing. In some of the more developed countries visited, the model is already based on local procurement and it was reported that this was at 'preferential pricing'. For example, in the Philippines the senior doctor procures insulin and other supplies locally and IDF-LFAC provides funding. Given a range of factors, including parallel trade, it is likely that the manufacturers may prefer to maintain tightly controlled donations and small scale preferential pricing rather than preferential pricing on a large, and potentially national, scale, given the risk of leakage back to high income countries. This is an obvious target for advocacy but we recognise that IDF, as a major recipient of funding from the pharmaceutical industry, may find this difficult to do. We note that IDF-LFAC staff report never having experienced any inappropriate pressure from industry, although this may reflect an unwillingness to confront the interests of some of its industrial sponsors. A further concern is the drive by manufacturers to increase market share of more profitable analogue modifications of insulin. However, we noted with approval that IDF-LFAC only accepts donations of non-analogue human insulin.

A further benefit of local procurement was seen in Nagpur in India, where this model enabled the local diabetologist to purchase a range of different insulins, including some pens, to ensure children were able to give themselves their afternoon dosage in schools. It was noted that there have been problems in schools when children tried to use syringes. (India country visit, Appendix 7)

The IDF-LFAC program contrasts with a competing program, run by Novo Nordisk, in seven countries (India, Ethiopia, Bangladesh, Tanzania, Kenya, Uganda, Guinea Conakry, Cameroon, and DRC). It supplies insulin, 2 test strips/day, and some education and there is some overlap with IDF-LFAC. We heard that it has faced problems in Kenya and Uganda. The Novo program involves a separate vertical system and prioritizes links with government (which has the obvious benefit to Novo of obtaining preferential access to policy makers) whereas IDF-LFAC emphasizes work within the existing health system. We were, however, told by the Ministry of Health in the Philippines, that while they were willing to accept donations from the pharmaceutical industry, they did not allow them to exert any influence on policies. We were not, however, in a position to evaluate this independently. A further limitation of the Novo program is that it only enrolls people up to age 18.

The type of agreements that are reached between IDF-LFAC before entering into a partnership with the Diabetes Association in a country, were explored, and particularly whether there is any expectation of or conversation with the government about taking on responsibility for caring for its own T1D patients, perhaps with IDF-LFAC technical assistance. IDF-LFAC staff report that they do not insist upon governmental approval to work in a country but they welcome it where this can be arranged. In practice, they rarely sign memoranda of understanding with governments and their formal agreements are with diabetes associations, other similar organizations (e.g. Hope Worldwide in the Philippines) or major teaching hospitals. This was borne out by the visits and respondents to the survey. 73% reported that there was no formal, written agreement with their government on the provision of T1D care and management in children and young people, while 24% did have one and (3%) did not know.

The visit team enquired whether the presence of IDF-LFAC and the implication that the country needed 'charity' to provide services was either an actual or potential source of leverage to persuade or 'shame' the country into providing insulin and better services for children and young people with T1D. Most diabetic associations had not considered this and nor had they developed strong relationships with the Ministry of Health to influence decisions. Some recognized that IDF-LFAC's presence could be influential but they had not used it in such a way. Some thought that their government was content to receive 'charity' and that pressure on governments came from more 'political' influences, such as in Mexico where one senior doctor considered that the fact that Columbia had recently taken the decision to provide treatment for people with T1D was more likely to influence their own government. However, as noted above, the government of Azerbaijan has been influenced by IDF-LFAC and is now providing 50 strips per year free to each diabetic. This demonstrates that IDF-LFAC may be able to exert influence on government policies but also that it does so relatively infrequently.

Supplies and importation

In many countries arduous and complex customs procedures and high import duties are critical obstacles to progress (Box 2 and Table 4). In a third of countries responding, they reported that taxes and duties are charged on imported insulin and other supplies (although a further third did not know or did not respond to this question). A third had experienced delays and over one in five had experienced insulin expiring while held in customs.

Box 2 Customs and import duties: a major challenge

Partners in both Nigeria and Kenya face seemingly intractable customs issues. The problems in Nigeria are well-recognised, with many far from transparent rules and widespread corruption. As a consequence, it has not been possible to import insulin which is, instead, bought locally at much higher prices. It is also impossible to import the cheap Nipro strips but instead it is necessary to purchase more expensive ACON strips because the manufacturer has developed a means to clear customs. The local champion and the Diabetes Association of Nigeria have tried very hard to overcome these problems but without success. An additional problem is the ongoing conflict in the north of the country, which makes it almost impossible to work there. Similar problems arise in Kenya, where the partner at the Kenyatta National Hospital has been unable to negotiate customs clearance, so that one insulin shipment expired, having languished in customs for over 15 months. A subsequent one cleared customs easily but the next one, despite using exactly the same procedure and engaging support from the CEO of the hospital and a government minister, also expired before it could be cleared. This means that it has been impossible to extend the program beyond Nairobi.

Table 4 Number and percentage of countries who identified problems with customs and importation processes.

	Yes	No	Missing/ don't know
Taxes and duties have to be paid	13 (32.5%)	14 (35%)	13 (32.5%)
Delays in delivery of medicines and supplies	15 (37.5%)	10 (25%)	15 (37.5%)
Medicines and supplies going out of date	9 (22.5%)	14 (35%)	17 (42.5%)

We asked the national associations for details of other specific problems that they faced (Table 5). The situation was extremely variable, but frequently difficult. Thus, they simply replied “*We don't know what to do*” (Ecuador) but others had no problems, as in the Maldives “*Supplies are coming through WHO/MOH without any obstacles*”.

Table 5 Specific challenges related to importing insulin and supplies

Ethiopia	<i>Although we try to get the items out as soon as possible, we need items that have long shelf life.</i>
Zimbabwe	<i>Negotiating with government authorities to waive these charges. This time we are going to engage the parliament portfolio committee on health.</i>
Haiti	<i>The administration paperwork is very heavy in Haiti. Even if we start working on it way before we receive them, to avoid the delay, we should take the merchandise (par anticipation: French) and therefore give a check upfront; money that FHADIMAC does have sometimes.</i>
Tanzania	<i>Clearance of goods from the customs can sometimes take long time due to many procedural steps that have to be fulfilled which in the end cause a lot of delays and inconvenience. These can be avoided in the future when the documentation is sent earlier before the goods arrive so that clearance procedures could be initiated in advance.</i>
Bolivia	<i>For the current government regulations, we cannot improve or change these procedures, but we pay much lower costs by demonstrating that they are donated products, but we can't stop paying the formalities and they are not as slow as before.</i>
Guatemala	<i>For us in the Association it would be a great help if we could persuade Congress to exempt us from taxes and duties but, not only is this a highly complex and lengthy procedure, it would require the mediation of a member of Congress. For this reason we have opted instead to request that the receipts and documentation for donations which we are sent should display the lowest possible sums, trying (also) to get advance clearance on all the necessary licences before the donation reaches Customs.</i>
Congo	<i>Since its beginning, the program is now known and benefited from support by the customs service with a fixed price of 25 USD for receipt of package.</i>
Tajikistan	<i>We have to submit all shipping paperwork (translated) to the government 2 weeks prior to receiving shipments. If the paperwork comes in on time and can be translated, the process is usually fine.</i>
Nigeria	<i>If funds are made available to pay or other NGO in the country could be involved or appeal made to government for waiver.</i>

We were able to confirm how, in the countries visited, the processes for importing insulin and supplies were complex and time consuming. In Jamaica, for example, the Director of the Diabetes Association considered it a major part of her participation in the IDF-LFAC program to ensure that importation was undertaken correctly and in a timely fashion, in order to ensure delivery. However, as noted above, in some countries, such as the Philippines and in Nagpur in India, they had moved to 'local procurement' using funding from IDF-LFAC. This model should be considered where possible, to overcome 'import' problems, but of course is only feasible in more developed countries where insulin is regularly available and where there are adequate safeguards to avoid diversion of supplies, a risk that is, to some extent, mitigated where insulin is supplied by IDF-LFAC because of the ease of identification of vials labelled in both English and Afrikaans, as noted earlier. Also there must be a consideration about the costs of locally procured materials. We do however recommend that IDF-LFAC include discussions on ways in which health ministries and other parts

of government can facilitate the import of supplies when negotiating IDF-LFAC's entry to a country or renewing agreements to operate there.

Other organizations providing support for Type 1 Diabetes

In each country there may be a number of organizations that either take, or could be encouraged to take an interest in children with diabetes. We asked respondents to the survey about other organizations that are engaged with this issue and how they relate to IDF-LFAC. 51% of respondents reported that there are other organizations besides IDF-LFAC that provide support to children and young people with T1D in their country. 34% reported that they were the only organization active in this field. Other organizations mentioned included: Novo Nordisk (n=6), Insulin for Life (n=2), the WDF, ISPAD, AYUDA, FUVIDA, CLAN, ISDFI, insurance schemes, other diabetes organizations and sponsorship of children by prominent business persons. Thus, in Tajikistan it was reported that *“Operation Mercy has created educational materials in Tajik and distributed these with the IDF-LFAC aid materials. Their main role is to support the NREC (Ministry of Health) in its efforts to improve the care of children with diabetes.”*

37% of respondents reported that IDF-LFAC partnered with other organizations to deliver support in their country, including Novo Nordisk, Insulin for Life, Operation Mercy, Eli Lilly, Nipro diagnostics, universities and other diabetes organizations. In the countries visited, it was a demonstrable strength of IDF-LFAC that they were flexible and collaborative in working with other such organizations. They were willing to adapt their 'model' to accommodate other partners. One partner in Rwanda commented that IDF-LFAC had a 'generosity of spirit' in their working with partners.

Building capacity

The day to day operations of IDF-LFAC focus on the distribution of insulin, strips and related material and of educational materials. However, IDF-LFAC cannot hope to take the place of a strengthened national health system and nor should it. Moreover, it cannot provide support indefinitely and, as noted above, should be exploring opportunities to exit countries, leaving an effective program to support children with diabetes. There are other examples of where this has been done, and local capacity has been developed, such as the World Heart Federation's Emerging Leaders program. This recruits young cardiologists displaying qualities of leadership and brings them together into a learning network in which they can acquire skills not only in cardiology but also in health systems, policy analysis, and advocacy.

IDF-LFAC does, however, provide support for training, on request and subject to availability of staff. In the survey, 35% (n=14) of countries reported that IDF-LFAC had provided training for health professionals, 30% (n=12) reported that IDF-LFAC delivered training to children/young people and 17.5% (11/33) that IDF-LFAC delivered training to families.

Table 6 Positive improvement of the training provided by IDF-LFAC on service delivery, control, management, training and awareness

Has the training had positive impact on any of these issues:	Yes	No	No response/ don't know
Clinical Services	13 (32.5%)	1 (2.5%)	26 (65%)
Changes to insulin regimes	13 (32.5%)	2 (5%)	25 (62.5%)
Patient outcomes	12 (30%)	1 (2.5%)	27 (67.5%)
HbA1c testing	11 (27.5%)	4 (10%)	25 (62.5%)
Patients' self-help/management of their own conditions	15 (37.5%)	0	25 (62.5%)
Patients' better glucose control	14 (35%)	0	26 (65%)
Reduction in severe episodes such as DKA requiring hospitalization	13 (32.5%)	1 (2.5%)	26 (65%)
Reduced mortality from diabetes in children and young people	10 (25%)	1 (2.5%)	29 (72.5%)
Increase in regular reviews to prevent complications e.g. eye examinations, foot examinations	11 (27.5%)	0	29 (72.5%)
A reduction in complications	9 (22.5%)	1 (2.5%)	30 (75%)
Delays in onset of complications	10 (25%)	0	30 (75%)
Wider awareness of diabetes	12 (30%)	1 (2.5%)	27 (67.5%)
Yours or other partners (e.g. health professionals) skills in advocacy lobbying to support from the government	8 (20%)	5 (12.5%)	27 (67.5%)

Additional training

All respondents expressed a need for more training of health care professionals, families and young people. The priorities identified were as follows:

- Seminars for general health care professionals
- Training of professional diabetes educators
- Training for families with diabetic children on how to manage their children
- Continued training for young adults with T1D
- General T1D education for the general public and media
- Diabetes education camps for children and families
- Training in how to give information to TV, medical journals and newspapers

Specific examples of needs identified in selected countries are shown in Table 7.

Table 7 Expressed needs for training in selected countries

Bangladesh	<i>Training of Health Care professionals by ISPAD experts</i>
Bolivia	<i>We urgently need to train all members of our team in the management of people with type 1 diabetes</i>
Kenya	<i>Most health care professionals think Type 1 Diabetes is the same as Type 2 DKA management. Training in insulin therapy and social skills in handling diabetic children</i>
Liberia	<i>Management of blood sugar in children whose food options are inconsistent; carbohydrate counting of local foods</i>
Dominican Republic	<i>Train new people to serve as Diabetes Coaches will be a great program in DR</i>
Ethiopia	<i>Robust training of health care professionals at all levels, empowering those living with diabetes and their families as well through the right education and information</i>
Guatemala	<i>Physicians in our country are unaware of the management of diabetes and give erroneous treatments and zero education in diabetes. Family education needs to be strengthen too</i>
India	<i>We urgently need training for professional Diabetes Educators who can empower patients in diabetes self- management education. Education of physicians in early diagnosis and management. Community awareness</i>
Tajikistan	<i>Endocrinologists require training on correct diagnosis and treatment of type 1 diabetes. Rural doctors (general practitioners) require training on the signs of diabetes in children. Families require basic diabetes education - most do not receive any training except the instruction of how much and when to inject insulin.</i>
Tanzania	<i>Additional training is required for the following: - parents and families for them to understand the condition and how to cope with it and support their affected child - microfinance skills and vocational training to ensure long term sustainability - training of school teachers to make them aware of the condition and how to cope with students having type 1 diabetes - peer educators for better control of blood glucose</i>

Much of this continued need for training is focused on clinical treatment of T1D, which may require more input from IDF and ISPAD, supported by additional experts and mentors. However, there is also a need for education of children and families and for greater awareness raising and advocacy development. Some of these aspects could be addressed by peer to peer country support and by increased use of the IDF-LFAC website and the development of a newsletter, which could provide support to countries through examples from elsewhere and sharing of templates and documents. The Mexican diabetes association in particular noted that country to country support would be helpful *“especially at the beginning – practical support from other countries who have an LFAC program up and running on ‘how to do it’ “*

Into adulthood

As noted above, the support offered by IDF-LFAC only continues until the individual is 25. In the survey we asked about the challenges that those with diabetes face at this time of transition. The responses were largely what might be expected. Thus, having diabetes places a major financial burden on individuals and families, for several reasons. These include limited employment opportunities, the cost of insulin and strips, the often very high cost of specialist

care, with few physicians having adequate experience in the management of the often small numbers of children with Type 1 diabetes who survive to adulthood, and the ability to maintain appropriate lifestyle modifications. There are also many 'social' issues for the 'graduates' of the IDF-LFAC program which impact on their lifestyle. For example, in India young women with T1D were very unlikely to marry as their condition was still highly stigmatized, although this did not seem to be the case for young men with T1D. In effect the young women with T1D therefore need to be self-sufficient. One married woman (aged 40) in India (Nagpur) told us that she had kept her diabetes a secret from her husband, for 16 years. She thought he would divorce her if he knew. Another young woman was about to marry but her and her fiancé had not told the fiancé's parents that she has diabetes as they would have opposed the marriage. While it is beyond the mandate of IDF-LFAC to support such individuals indefinitely, respondents from 31 countries (77.5%) reported that they did not have the ability to support affected individuals through this transition. IDF-LFAC should consider how they can best prepare countries to support young people as they transition off the IDF-LFAC program when 'aged out'.

In some countries, such individuals can benefit from the Insulin for Life program but we also identified some innovative ideas that might be emulated elsewhere. These included the development of a micro-credit program in Tanzania, designed to help people with diabetes establish their own businesses, offering them startup capital and training, as well as links with local business people. India (Nagpur) had developed a series of special support mechanisms, some simple, such as bicycles to support girls accessing and staying in schools in rural areas, some more complex such as educational grants to encourage the young people to stay in education so that they could develop skills to get jobs and support themselves, and a 'rehabilitation' program to provide support for them to set up their own businesses. These ranged from a water buffalo, developing into a yoghurt and cheese business, to sewing machines for seamstresses, as well as support with startup capital, business mentoring and advice and training to set up businesses such as selling Saris. (Country visit report Appendix 7)



Young woman in her sari shop in Nagpur, India

In Rwanda, IDF-LFAC supported the education center where the young people learned new skills equipping them for employment as barbers, tailors, beauticians, and chefs in order to become self-sufficient (country visit reports, Appendix 3 - 7).

IDF-LFAC has supported these initiatives and, with relatively little funding, these approaches are life-changing for the young people. Drawing lessons from these examples and sharing them more widely can offer a road to self-sufficiency for the young people and should be considered an important aspect of developing sustainable health programs for young people with T1D.

In some countries the IDF-LFAC program does not continue until age 25. For example, in Mexico and the Philippines it effectively finished at age 18. By that time the diabetes associations expected the children to either be in full time education or jobs. In Jamaica the transition from ‘children’s health services’ to ‘adult services’ was at age 12, although some pediatricians continued to offer informal support until about age 16. Some of the children and families were unaware that the IDF-LFAC support finished at age 25, reinforcing our perception that many diabetes associations were ill equipped to manage the transition. Crucially, we found no evidence that information was being collected on the fate of those who age out of the program.

Whilst many young people and families seemed unaware that support from IDF-LFAC would cease at age 25 or had not considered it, some ‘hoped’ that there would be other support available and some knew that they were likely to have to pay for insulin and care. The mother of one 14 year old we interviewed said *“he has started saving from his allowance so that he can buy insulin when there are no support services”*. Others were more innovative or fanciful, one 15 year old in Mexico hoped for ‘a cure’, another for ‘sniffable’ insulin to become available and a 16 year old in the Philippines was optimistic that a ‘pancreas transplant’ would be available at some stage in the future. Some were more pragmatic, one young woman in India said that her future husband would support her.



Young men in Rwanda trained as a chef and as a barber

The survey (table 8) showed that in less than half the countries, young people would get some support, insulin and medical care, 50% would have to pay for insulin and over 50% would have to pay for glucose testing, medical care and diabetes check-ups. This reinforces the importance of finding means to enable young people to become self-sufficient.

Table 8 Support received when people ‘age out’ of the IDF-LFAC program (> 26 years old), and any associated costs

Support received > 26 years old			
	Yes	No	No response/ don't know
Insulin	15 (37.5%)	12 (30%)	13 (32.5%)
Glucose testing	6 (15%)	18 (45%)	16 (40%)
Medical care	14 (35%)	12 (30%)	14 (35%)
Diabetes check-ups	15 (37.5%)	11 (27.5%)	14 (35%)
Does the young person have to pay?			
	Yes	No	
Insulin	20 (50%)	8 (20%)	12 (30%)
Glucose testing	22 (55%)	4 (10%)	14 (35%)
Medical care	20 (50%)	5 (12.5%)	15 (37.5%)
Diabetes check-ups	22 (55%)	4 (10%)	14 (35%)

Achieving Success

We asked IDF-LFAC staff where they felt they had achieved the greatest and least success. The most successful countries were named as Rwanda, Tanzania, Mali, Mauritania, and Azerbaijan. In each of these countries activities began in the capital city but rapidly expanded to other parts of the country, initially to regional centres and subsequently beyond. The least successful were Nigeria, Kenya, Guyana and Guatemala. The reasons are revealing, although not entirely surprising. As noted previously, one of the main issues in those countries that are less successful is the inability to bring insulin and related products through customs. The main determinant of success is seen as the commitment, organizational ability, and connectedness with the authorities of the local partner country. Importantly, it seems less important what type of partner is involved. Thus, in Rwanda, Tanzania and Mauritania the partner is the national diabetes association, in Mali it is a French-Malian diabetes NGO, and in Azerbaijan a senior doctor.

What could improve the quality, quantity, efficiency, or effectiveness of the work of IDF-LFAC?

Many of the issues covered in the previous sections relate to improving quality, efficiency and effectiveness. One issue not covered so far is the role of volunteer experts, on which IDF-LFAC relies extensively, to conduct site visits, conduct training and serve as mentors. We explored how they train and prepare volunteers to represent the program and ensure consistency in appropriate clinical standards and other issues given the challenging circumstances after the volunteer leaves. IDF-LFAC staff concurred that it can be a challenge to find skilled and motivated volunteers for site visits, especially now that they are promoting a South-South model, now widely used by many civil society organizations. They recognize the importance of the volunteer having adequate

experience and appropriate people skills. Shared language and culture are not a guarantee of success; an Azerbaijan - Tajikistan link was successful whereas a Sri Lanka - Maldives one was not. IDF-LFAC takes considerable care when screening potential expert volunteers to assess whether they are appropriate for participation, including review of their CV and, especially, references from trusted sources. They have turned people down.

Working relationship with IDF-LFAC

Only 32 countries rated their working relationship with IDF-LFAC but of those that did, 78% rated it as excellent and 22% as good. When asked how it could be improved some suggested by more regular communication and visits, more training and/or additional resources.

What impacts are IDF-LFAC's programs having on the countries, systems, and children with whom it works?

Coverage of diagnosis and support for children and young people with T1D

IDF-LFAC reports that it reaches 12,000 children a year. 37.5% of country respondents (n=15) believed that most children and young people with T1D in their country were being correctly diagnosed while 16 (40%) did not believe all were being diagnosed but 9 (22.5%) did not know or did not respond to this question.

55% of respondents (n=22) stated that children not supported through the IDF-LFAC program, were not adequately supported by other organizations, 30% that some of them were adequately supported through others and 15% thought that all children with T1D in their country were adequately supported by IDF-LFAC or through some other organization. This picture was reinforced by the country visits; it seemed unlikely, in any of the countries visited, that children across the whole country were being diagnosed and adequately supported. Even in Rwanda, which has an IDF-LFAC program that reaches across the whole country, through its district hospitals, it still recognized that capacity of local health care workers was inadequate to treat children with T1D. In other countries, e.g. Mexico, the IDF-LFAC program is well aware that it does not address the poorest areas and in the Philippines the main IDF-LFAC program has only operated in Manila and is just now being extended to a few children on one of the other 7,000 islands.

Support provided by IDF-LFAC

The support provided by IDF-LFAC varies among countries. This, in part, reflects their ability to obtain materials from other sources. Thus, there are a number of other sources of insulin, including the government and other donors, so that IDF-LFAC only supplies it to three-quarters of countries. On the other hand, there are few alternative sources of glucometers and test strips, so these are provided to almost all countries. A few countries only receive educational materials and three (Azerbaijan, Tanzania, and Zimbabwe) reported receiving the entire package of possible support (table 9). "Other support" listed by individual countries included; financing for a diabetes camp; glycosylated hemoglobin reagents; fridges for storing of insulin; one-off economic support for HbA1c tests;

translation of information for children; a Diabetes Education Centre (Rwanda); and research (Sudan, Tanzania).

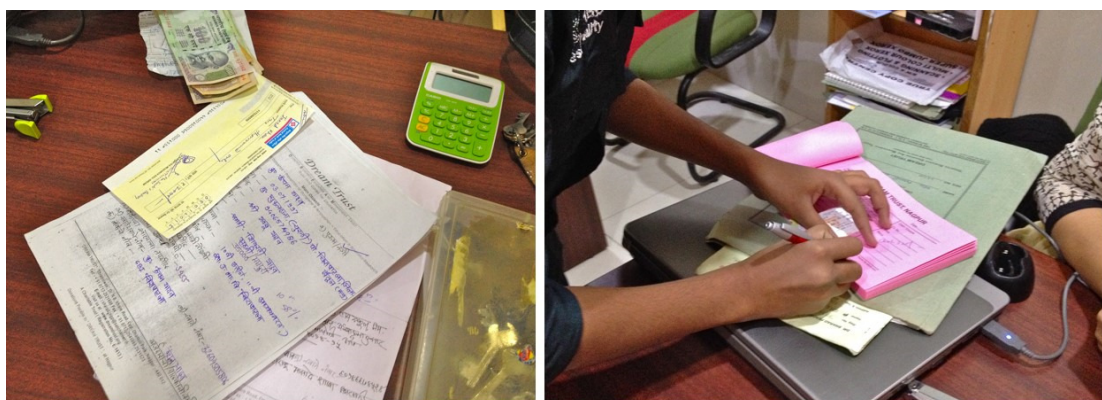
Table 9 Support provided by IDF-LFAC: Number (%) of countries receiving specific support from IDF-LFAC

Insulin	29 (76.3%)
Glucometers & strips	36 (94.7%)
Syringes	23 (60.5%)
HbA1c testing equipment	21 (55.2%)
Educational materials	26 (68.4%)
Training of health professionals	8 (21.1%)
Support from experts from abroad	9 (23.7%)
Other	12 (31.6%)
Total (countries responding to this question)	n=38

Clearly, despite its considerable reach, there are many children who could benefit from access to insulin but are unable to do so. The survey and the visits explored the barriers that exist to extending the reach of the program.

The following issues were commonly identified.

- **Access:** A majority of respondents reported that access in reaching children in rural areas and cost of transportation for children/families from rural areas to access support as a major barrier. This was also raised as a major difficulty in the countries visited. In Rwanda, some children had to walk anything from 2 to 6 hours to attend clinic and this was despite the IDF-LFAC program operating across the country in ‘district’ hospitals. These sort of distances were not unusual elsewhere. In India (Nagpur) the geographical coverage required up to 6 – 8 hours travel for some children, often by several buses and on foot. Recognizing this, and to encourage attendance, the local champion offers travel payments and has established an excellent robust system of repaying on production of tickets/receipts.



Repayment system for travel in Nagpur, India

In the Philippines they were trying to expand the IDF-LFAC program beyond Manila, at the request of the IDF-LFAC team, and had recently started clinics on one of the islands, but were finding it difficult to coordinate reliable insulin supplies. In Mexico, the delivery of IDF-LFAC programs is through those state based diabetes associations where there is capacity to manage the

program. However there is recognition by IDF-LFAC that this does not reach the most 'needy' children in rural areas, where there is the greatest poverty but no diabetes associations. Mechanisms to develop capacity to deliver IDF-LFAC programs to the most needy should be considered and stimulated. This issue was particularly pertinent in Mexico, where the diabetic associations in the most impoverished states lacked adequate capacity to work with IDF-LFAC. (See country visit report Appendix 5)

- **Awareness and education:** Many countries reported a lack of general awareness and understanding of diabetes in the population and amongst health care staff as barriers, e.g. awareness of early symptoms, management and treatment and knowledge about the disease in general. From the interviews with children and families in country visits there often appeared to be a difficulty with some families and schools and teachers not 'understanding' how to deal with children with T1D. Schools may 'overprotect' (such as not allowing them to participate in physical education), or not allow syringes into school, as they were associated with HIV and drugs, hence preventing children with T1D from giving themselves 'afternoon' doses of insulin. In India (Nagpur) the clinic had decided to provide insulin 'pens' for some of these children in order to overcome this problem.
- From other children and families it was apparent that the majority were unaware of T1D before diagnosis or that diabetes can affect children and there remain many 'misunderstandings' and 'myths' about T1D. Some children and young people had virtually stopped attending school once they were diagnosed. The diabetic associations usually worked hard to demonstrate that this was an inappropriate response and to encourage children to remain in education as long as possible.
- **Poverty:** Those with T1D face many cost pressures, which are often beyond the means of those living in poverty. Costs of medicines and of transport to access medicines are high and there are additional costs of parents having to take time off work to travel to diabetes centers or sit all day in clinics waiting to be seen and to get medication. This was a very common theme in all the country visits. Even in countries which, in theory, made insulin available, in practice it was often not available or there were major barriers to its delivery to poor children and families. (country reports in appendices 3-7)
- **Parent support and stigma:** Stigma was reported as a major barrier by many of the countries to providing effective support, especially with regard to diabetes management and in continuing education or gaining employment. Stigma also led to parents not accepting the diagnosis in their child and not providing adequate support. In Rwanda, one of the young people interviewed was a young woman in her late teens who was working as a cook in a private house. She said of her biological family that they "think of me as already a dead person".
- **Adherence:** This is often a consequence of limited access to care, but also reflects lack of education and acceptance of the diagnosis.
- **Access to affordable syringes, blood glucose monitoring and strips:** This is reported as a barrier by countries in most regions.

- Insulin storage:** Some countries in Africa and Western Pacific and elsewhere identified the lack of fridges or electricity to power them as a barrier to storing insulin. Many of the children and families interviewed on country visits reported that they stored their insulin in relatives', neighbors' or friends' fridges. The doctor in Nagpur had invented a double-layered terracotta pot for storage of insulin. Water is added to one compartment and it cools by the principle of 'cooling by evaporation'. This is provided to children and families who have no access to fridges. Such innovations could be shared with other countries, via IDF-LFAC's website or through a newsletter.



Terracotta pot for insulin storage

- Customs delays and/or charges:** Customs was reported as a barrier by four countries in different regions (Uzbekistan, Nigeria, Haiti and Ecuador). Some reported custom delays as the main issue and two reported customs charges as a major barrier.
- Transition to adult services:** One country also mentioned the transition from children to adult services as a barrier. The visit to Jamaica revealed that the transition age there is 12. For many of the pediatricians treating children with T1D this appeared very young, and several revealed that they informally continued to treat children beyond this age as they were not confident of the treatment they would get otherwise. This seemed to be less of a problem in rural areas where there may be a smaller number and 'closer' community of doctors and the pediatricians knew the 'adult' doctor who would take over the child's care. However such a young transition age meant that the IDF-LFAC program did not usually continue to age 25 and that these children and young people were 'lost' to follow-up, long before age 25.

The comments received elaborated on these issues. Thus, in Cambodia, it was noted that *"Awareness of symptoms of type 1 diabetes is extremely poor in Cambodia. As around 80% of the population live in rural areas, their first point of contact when they are sick is the local health centre which is usually staffed by a midwife and one or two nurses. They have no knowledge of type 1 symptoms and children usually present when almost in a coma. Children are often misdiagnosed as having dengue or similar diseases. When the child's condition doesn't change and if parents have enough money to pay for transport, they will take them to the district hospital where, again, staff have little or no knowledge about type 1 symptoms. In Siem Reap there are two free children's hospitals so if the child is lucky it may be diagnosed in one of these hospitals. CDA is working in collaboration with one of these hospitals and when the child is discharged we do follow-up care and support. The situation is better in the capital, Phnom Penh where there are more doctors with higher training."*

The Ethiopian respondent noted how *"The lack of human power at the association made it difficult to do monitoring and evaluation, hence we rely on hospitals for the*

report and for confirming that the supplies reach children. In rural areas it is difficult to work since most of the hospitals are found in urban areas, hence children from rural areas have to walk long distances to reach hospitals and get their supplies.”

The Nigerian respondent emphasized the problems with customs, discussed above, but also certain other problems *“Custom charges and duty clearance, No money for clearance. Children do not have money to come to clinic to collect insulin. Lack of proper storage facility for insulin at home.”* (Nigeria)

The complexity of the challenges was apparent in the Democratic Republic of Congo where the mix of problems differed in urban and rural areas, thus *“Rural: distances, lack of communication, poverty, illiteracy, lack of cold storage of insulin and HbA1c reagent, lack of proper training or capacity building of healthcare providers. Urban: (in a city of 10 million people) Poverty, illiteracy (50% cannot read or write properly) poor transportation, general health system deficient, health workers badly paid”* DRC. These same rural/ urban differences were also seen in the country visits.

Even in the more prosperous countries, such as Fiji, there are many problems even if on a smaller scale than elsewhere *“a) sourcing cheap supply of syringes and needles is a challenge. We buy our supplies from government bulk purchasing scheme. Retail is too expensive. b) Adherence to treatment is difficult. Most families struggle to cope with their child’s diabetes c) Lack of awareness on Type 1 DM in both public and among health workers who tend to approach type 1 DM as type 2. d) Transition of care to adult team. Young person can easily get lost in the system.”*

Support provided by the government

Ultimately, if IDF-LFAC is to exit countries, it will be necessary for governments to assume responsibility for the support that IDF-LFAC now provides. Yet, as the survey revealed, there is still some way to go (Table 10). Only 6 countries reported that the government supplied glucometers and strips, and of these, only two reported that they were offered to everyone under 26 years old.

Table 10 Numbers (percentage of total, including don't knows and no responses) of countries where specific support from the government is available, or not, and whether it is free to children and young people, or not

Support	Is it provided?		Is it available to all < 26 years old?		Is it free to all < 26years old?	
	Yes	No	Yes	No	Yes	No
Insulin	15 (37.5%)	4 (10%)	7 (17.5%)	11 (27.5%)	9 (22.5%)	9 (22.5%)
Blood glucose monitoring (meters and strips)	6 (15%)	14 (35%)	1 (2.5%)	16 (40%)	2 (5%)	13 (32.5%)
Syringes	10 (25%)	8 (20%)	2 (5%)	13 (32.5%)	4 (10%)	10 (25%)
HbA1c testing equipment	6 (15%)	13 (32.5%)	3 (7.5%)	15 (37.5%)	4 (10%)	11 (27.5%)
Educational material for children and families	3 (7.5%)	16 (40%)	2 (5%)	13 (32.5%)	2 (5%)	11 (27.5%)
Training for children and families	5 (12.5%)	14 (35%)	1 (2.5%)	15 (37.5%)	1 (2.5%)	13 (32.5%)
Specialist diabetes training for health professionals	8 (20%)	11 (27.5%)	1 (2.5%)	12 (30%)	1 (2.5%)	11 (27.5%)

Given the extremely weak health systems in many of the countries receiving support from IDF-LFAC, as well as the interational development context that prioritises infectious disease (Geneau, Stuckler et al. 2010), it is not entirely unexpected that there is little support for children and young people with diabetes. In these circumstances, it may be as important to consider the direction of travel. Yet, unfortunately, 62.5% (n=25) of respondents reported that government support for children with T1D had not improved since IDF-LFAC had begun to operate in the country. Where positive changes had occurred, they primarily involved a greater awareness of the burden of disease associated with Type 1 diabetes. Thus, the respondent from Azerbaijan noted that there was *“More attention to children”* while, in Tanzania, *“The MoHSW is now aware of the burden of the disease, the challenges faced in managing these children and its responsibility to ensure long term sustainability of the program after donors have left”*. In Rwanda the program had helped forge links with the government *“There is a close collaboration between the government institution NCD’s (RBC) and Association Rwandaise des Diabetiques in the actions of the national policy and activities on diabetes”*. There was also some evidence of greater awareness among other donors, as in Burundi *“Other donors are aware, beginning integration of the management of diabetes in primary health care in two pilot provinces, but with no age distinction”*.

In several of the countries visited there was a difference between the 'theoretical' availability of insulin and other support and what appeared to be available in practice.

In Jamaica, Philippines, Mexico and India, discussions with the Ministry of Health indicated that Insulin was either on an 'essential medicines' list (hence available from the government), or available through either insurance, public health systems or special 'poorest of the poor' mechanisms. In most cases, glucometers, strips and syringes etc. were not included in these packages or were available intermittently. In many cases insulin supplies are only available following an appointment at a public hospital, which might entail long queues and repeated visits, through an insurance scheme which required registration, that was often difficult or impossible for the very poor as they often did not have the right paperwork. In Jamaica, for example, the family had to register for the "National Health Fund", which required various paperwork and a tax number. Many of the poorest families were single parents and either not working or scraping a living in the black economy, so unable to produce tax numbers and the like. In India, insulin was said to be available through the public health system, provided by each state. In practice it was only available if the child was hospitalized. Some years previously, insulin had been available at outpatient clinics but a supply of only 15 days was given, after which the child and family would have to return to the hospital for another appointment, which usually took all day. It appeared that now, even this short supply of insulin was not available at outpatient clinics. Thus, in some of the more prosperous countries surveyed (e.g. Mexico, India) there is an intention by the government to supply insulin to those who cannot afford it, but the practice does not meet the theory. (country visit reports appendices 3 – 7)

Most countries do not supply glucometers and test strips, even though these are necessary for the child to monitor and manage their T1D, and in most countries the test strips are the single most expensive item to the family, more expensive than insulin. In Mexico, we were told by the ministry of health that there was a 'safety net' where glucometers were 'available' to the poorest 10% of the population. This appeared to be news to the local diabetic association and when quizzed as to how they could be accessed, the somewhat oblique reply indicated that they may have got lost in the community clinics and would have to be found. Even where glucometers are available there are multiple different makes and the test strips are unique to each make and not interchangeable. Families are often not able to access the right strips, or can only afford to buy a few strips to test blood glucose maybe once or twice a week or month. Hence it is often in these scenarios where in practice the family has to 'pay' for insulin and supplies that IDF-LFAC is providing support.

In some of the more prosperous countries, such as Mexico, the focus of the diabetic associations is on the education of children and their families and on good management of their T1D and reducing Hba1c. Hence, IDF-LFAC is supporting by providing (in conjunction with NIPRO) glucometers and enough strips for children to test up to seven times a day. The diabetic association has a 'co-responsibility' approach, requiring the child and family to 'sign up' to attend educational sessions every month to learn how to manage their T1D, and they expect to see results in reducing Hba1c levels. If the child and family default then their IDF-LFAC support may be transferred to another child. However, we pointed out that this could potentially disadvantage the most vulnerable children, maybe with dysfunctional or unsupportive families. The diabetic association appreciated this point and probably in practice their staff recognized and continued to support such children. In several cases we witnessed personal financial support, for example for travel money, being given to needy children by clinic or diabetic association staff. In one case in Mexico we made a two hour car journey detour and walked up mountain tracks to visit a teenage boy who lived with his grandmother in very poor circumstances. He had not attended the last clinic or educational session. The diabetic association coordinator wanted to deliver his insulin supplies and encourage him to attend the next clinic session. On leaving she slipped him some 'bus money', from her own pocket, to ensure he could afford to attend. Unfortunately he did not attend the session the following day, but the coordinator was confident he would return. We repeatedly saw this level of personal care, concern and support from the diabetic association and clinic staff in all the countries visited (country reports appendices 3 -7).



Education session at the Diabetes Association in Merida, Mexico

The diabetic association coordinator wanted to deliver his insulin supplies and encourage him to attend the next clinic session. On leaving she slipped him some 'bus money', from her own pocket, to ensure he could afford to attend. Unfortunately he did not attend the session the following day, but the coordinator was confident he would return. We repeatedly saw this level of personal care, concern and support from the diabetic association and clinic staff in all the countries visited (country reports appendices 3 -7).

Accountability

Given the volume of goods provided by IDF-LFAC, it is essential that there is accountability for their use. 33 (82.5%) countries reported confidence that all IDF-LFAC supplies reached the intended beneficiaries. In two countries (Burundi, Kenya) it was believed that there was a problem and two respondents (Guyana, Solomon Islands) explicitly said they did not know (others failed to respond to this question). The explanations were the same as those identified as barriers to greater uptake. Thus in Kenya they believed that insulin had purposefully been destroyed at least twice. Most countries work hard to make sure the supplies get to the intended beneficiaries. *"We do our very best and amount stolen or lost is really minimal. Control is really strict."* DRC. In India (Nagpur) they ask the children to return the used vials, to ensure they are not being sold on.

82.5% (n=33) stated that children and young people received their IDF-LFAC provided support free of charge, 8% that they did not (Sudan, Guyana, Cambodia). This was due, in Sudan, to patients having to pay for strips and lab tests while in Cambodia the strips were free but they have to pay for the insulin to cover shipping costs from Insulin for Life and Guyana stated that they did not know how to answer the question. Tajikistan noted that: *“they only have control of distributing the insulin to the endocrinologists, based on the number of clinical data sheets completed. But the endocrinologists themselves are in charge of distributing the insulin to their patients, and so we can never be 100% sure that it is free of charge. Of course the NREC instructs that it must be given for free; we believe that most endocrinologists follow this instruction, but we have never audited”*.

80% (n=32) stated that medicines and equipment were stored appropriately so they would not go off or expire before reaching the children/young people, 7.5% (3/37) stated that they were not all stored appropriately (Burundi, Solomon Islands and Tajikistan) and 5% (n=2) that they did not know if they were.

In all the counties visited, the main insulin supplies were kept in fridges, usually dedicated to IDF-LFAC supplies, but some in hospital pharmacy fridges. Some fridges had been provided by IDF-LFAC.

In the survey the following are examples of reasons for not all medicines being stored appropriately or reaching people before expiry date:

- *“There is a problem with recurring electricity cuts in the pilot center. We moved the main stock to the vaccination program site for safe keeping as it has a powerful generator. In addition the expiration dates are often short” Burundi*
- *“In Kinshasa no problem (cold storage is correct), in rural areas: power supply is absent or erratic. Solar equipment is very expensive and not easy to maintain and not available everywhere. Also transport to different provinces is complicated” DRC*
- *“There are problems with electricity, access to fridges” Jamaica*
- *“But we need insulin fridges specifically for the donated insulin” Kenya*



The IDF-LFAC fridge in Rwanda

- *“Refrigerator space in the capital city is limited, and the NREC does not have its own cold storage space. They attempt to keep it properly stored until distribution, but occasionally other medicines come in (i.e. vaccines) and the insulin is de-prioritized. Also, due to this lack of storage space (in the capital and also in each endocrinologists’ office throughout the country), the insulin is distributed annually to the children. And since many children do not have refrigerators in their homes (or no electricity) in rural areas, it may become too warm. This is an ongoing problem. Most children know to try and keep it in a cool place” Tajikistan*



Young man with his storage for insulin

Keeping insulin cool is difficult in many countries

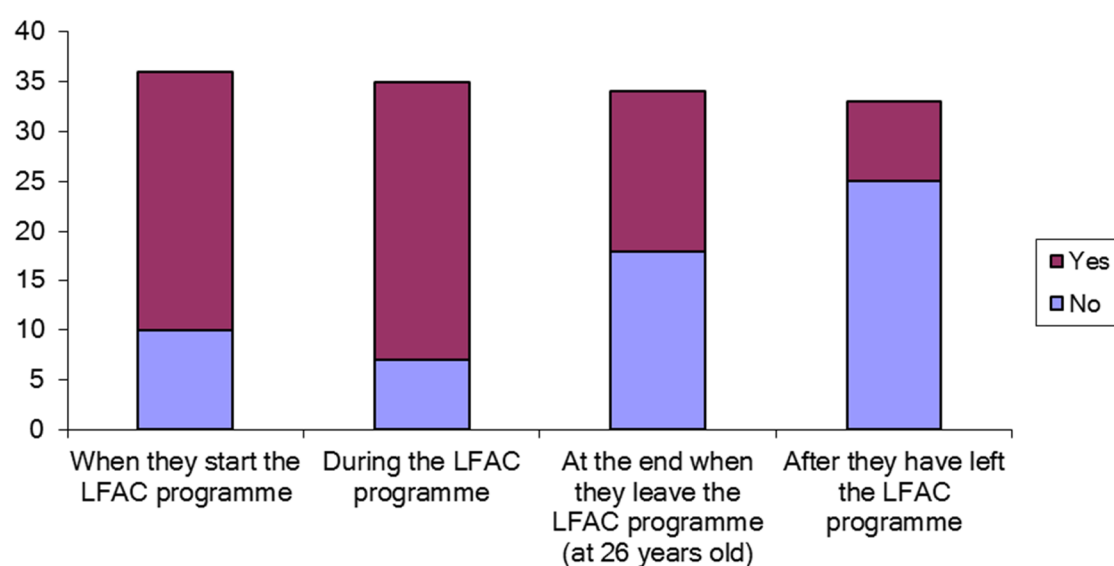
Collecting and sharing data

The IDF-LFAC program requests that each program (country) maintains at least annual records on each child and shares these with IDF-LFAC (submitting an annual IDF-LFAC data sheet). This and other data collection methods were explored in the survey and during the county visits. Ideally data are provided when the child is diagnosed/ recruited to the IDF-LFAC program, annually whilst they are being supported by IDF-LFAC and when they cease to be supported by IDF-LFAC at maximum age 26. (Fig 2) Unfortunately very few countries have systems to collect ‘outcome’ data after the young person has left the IDF-LFAC program, which is a major weakness.



Systematic filing of IDF-LFAC records in Rwanda

Figure 2 Countries collecting data at different time-frames



The potential value of the dataset is great, for both ‘in country’, as it provides an indicator of ‘burden of disease’ and the scale of support being provided, and this could be used in advocacy with Ministers of Health and others to increase support for people with T1D, but also as a global public good, as a dataset covering 45 (or more) countries can provide an extremely valuable resource to examine progress in managing T1D, relating this information to the performance of the health system and the economic development of the countries. Unfortunately this ambition is not yet realized.

Not all countries replied to this question in the survey, but of those that did, over 90% reported having data sets on all the children and young people supported through the IDF-LFAC program. About 50 – 75% reported collecting more detailed data about management, control and complications. 8% reported that they did not have data about all the children.

Table 11 Numbers (percentages) of countries collecting or not collecting different types of data on the children supported by the IDF-LFAC program

	Yes	No	Missing/ don't know
Age	35 (88%)	1 (3%)	4 (10%)
Sex	36 (90%)	1 (3%)	3 (8%)
Address/ village	32 (80%)	2 (5%)	6 (15%)
Education	29 (73%)	6 (15%)	5 (13%)
Diabetes management and control	31 (78%)	5 (13%)	4 (10%)
Diabetes complications	29 (73%)	6 (15%)	5 (13%)
Other medical complications	22 (55%)	8 (20%)	10 (25%)

Other data collected by individual countries included: lipids/cholesterol, family history of diabetes, history of smoking, BP; eye exam, blood test, creatinine, 3 daily blood glucose, glycosylated hemoglobin every 3 months, complete laboratory analysis once a year, ophthalmological control, annual foot review, weight and height, BMI, number of educational diabetes sessions attended, education, school grades. In India (Nagpur), as part of their initial assessment of a child being considered for the IDF-LFAC program they also collected some economic and related data about the family's circumstances, e.g. whether parents were working and average daily wage, home circumstances and room numbers etc., whether and how they had previously paid for insulin. This information helped the clinic to decide whether the patient was suitable for IDF-LFAC support.

70% (n=28) reported sharing the data collected with IDF-LFAC. 62.5% (n=25) reported that the IDF-LFAC program had improved data collection in their country. Yet while some countries clearly recognize the importance of data collection and using information, and the importance of monitoring in relation to the IDF-LFAC program, many do not. In the survey only 24 countries reported that they completed an IDF-LFAC data sheet every year on each child. This is not an onerous task but is only completed by 60% of countries.

In the countries visited there were excellent and very poor examples. Rwanda has developed an excellent data capture and information system, but this has been heavily supported by the 'research' support that they have from external experts. Lessons can be learned from this data set and system for other countries, and even if it is not immediately transferable then the principles involved should be shared.

At the other extreme, Jamaica was extremely poor at collecting data from the clinics. It was apparent that although the diabetic association has a responsibility to collect the annual datasheets for return to IDF-LFAC it does not do so. The doctors themselves in the clinics visited were, when reminded, aware of the annual datasheets but had not completed them as they had not been 'chased' for them. A suggestion that the diabetic association should use some 'leverage' as a *quid pro quo* for providing insulin and supplies, was not well received. However a more forceful way of IDF-LFAC ensuring they are collecting this data needs to be found.

In the Philippines the PSEDM (Philippines Society of Endocrinology and Diabetes Metabolism), one of the clinic bases for the IDF-LFAC program have just developed a database for their own delivery. This could possibly have benefitted from Rwanda experience and/or could be shared with others especially in the Philippines. The Philippines originally decided that the doctors in the three main clinics could be responsible for data collection and annual returns to IDF-LFAC but this has not worked out well and they have just appointed someone to collate the data, from the whole IDF-LFAC program. They have a backlog of data from 2013.

IDF-LFAC has set up an internet based database which countries can use to supply data back to IDF-LFAC and also to monitor children in their own programs. Whilst this seems a good solution, it requires ethical approval in each country,

which in some countries is both cumbersome and expensive, and it also requires robust internet connectivity, something that is not always available in all countries. IDF-LFAC is exploring options to make this system more readily available and useful, as only nine countries are using it.

It is clear that, in many countries (62.5%), IDF-LFAC has been instrumental in improving the data that are collected. However, some countries already had good clinical systems so there was little scope for IDF-LFAC to bring further benefits. It is, however, clear that the real benefits of this potentially huge data set have not yet been realized, given its scope to provide unique data on impact and outcomes of the program, suggesting the potential value that would accrue if IDF-LFAC could forge links with health service researchers, for example, engaging with academic networks such as Health Systems Global. The resulting outputs could be extremely valuable in advocacy.

Impact on diabetes management

The survey enquired what impact the IDF-LFAC program had on diagnostics, management and control, coverage, training and awareness

Whilst only about 74% of the survey recipients responded overall, the vast majority (83%) identified improved management and control of T1D as the major impact of IDF-LFAC and this was reinforced in the visits where all the countries identified the fact that children were surviving and there were fewer hospital episodes and fewer complications. Table 12 shows the impact of the IDF-LFAC program on diagnosis, treatment, care, training and awareness of T1D. Nearly 50% also identified that there was extended geographical coverage since IDF-LFAC and increased general awareness.

Staff training was another area identified but only 33% thought IDF-LFAC had impacted here. This accords with the 100% response that there is a need for more training of health care professionals.

Table 12 Number and percentage of countries reporting a positive impact of the IDF-LFAC program on a range of T1D services, including diagnosis, management, geographical reach, training and awareness.

	Yes	No	Missing/ don't know
Numbers being correctly diagnosed	17 (43%)	7 (18%)	16 (40%)
Diabetes management and control	33 (83%)	1 (3%)	6 (15%)
Wider geographical coverage in diagnosis, treatment and care	19 (48%)	10 (25%)	11 (28%)
Staff training	13 (33%)	17 (43%)	10 (25%)
General awareness in the wider population	17 (43%)	14 (35%)	9 (23%)

A number of other IDF-LFAC impacts were also identified, which exemplify the range of support that IDF-LFAC gives and how they are having impact in different countries.

- *“Parents economy has improved - when they don’t have to buy strips, so they can buy better food instead”* Mexico
- *“Training of primary care health care professional on how to care for these children. We have also engaged with the media and patients have explained the symptoms they had at the beginning on national TV”* Kenya
- *“LFAC has built hope. We lost one child but the other 6 would have surely died. Thanks to IDF-LFAC we have been operating for 4 years and the children are relatively well, coming to the “clinic” every two weeks from far away distances. They are glad to come. They come with their coolers and pack of ice for check-up and insulin”* Liberia
- *“The book from IDF-LFAC on caring for diabetics in a resource poor setting is very helpful”* Pakistan

From the country visits, there was repeated reference to how children would surely have died without the support of IDF-LFAC. In Rwanda there were apparently only 25 children diagnosed with T1D when the IDF-LFAC program started there in 2004, whereas by 2014 there were over 1000 children and young people who had been supported. Prior to IDF-LFAC they were either not diagnosed, or misdiagnosed possibly as AIDS or Malaria and consequently died. Similarly in India (Nagpur) the Dream Trust (through which IDF-LFAC is delivered) was set up in 1995 as a result of two girls, who had been recently diagnosed with T1D, dying. They died due to lack of insulin as it proved too expensive for their families. In many of these poor countries, some families, with several children, have had to make the heartbreaking decision that the other children have to take precedence over the child with T1D in their impoverished economic circumstances. The IDF-LFAC program ameliorates these problems.

Support for advocacy

LFAC have provided some advocacy training and support to some countries, with awareness raising being the most common, but even this was only in just under a third of countries. Table 13 shows various types of support received from IDF-LFAC.

Table 13 Support received from IDF-LFAC related to advocacy and sustainability

Activity	Yes		No		No response/ don't know	
	%	n	%	n	%	n
Awareness raising in the community / Information campaigns	30.0%	n=12	37.5%	n = 15	32.5%	n =13
T1D advocacy with government	15.0%	n=6	57.5%	n = 23	27.5%	n =11
T1D advocacy with civil society, professional organizations or others	12.5%	n =5	57.5%	n =23	30.0%	n =12
Encouraging government to take on the responsibility of care for its own Type 1 Diabetes patients	10.0%	n =4	55.0%	n =22	35.0%	n =14
Vocational training for children and young people to be able to be self-sufficient in managing their diabetes after leaving the program	12.5%	n =5	60.0%	n =24	27.5%	n =11
Work with pharmaceutical companies to provide medicines and supplies for Type 1 Diabetes at reduced costs	17.5%	n =7	47.5%	n =19	35.0%	n =14

There does seem to be considerable scope for countries to learn from each other, consistent with the South-South approach supported by IDF-LFAC.

Partnership working and peer to peer with other countries

15 countries (37.5%) reported that they worked in partnership with other countries and 17 (42.5%) that they don't. These partnerships included or were described as: "NACR"; providing training in another country; cooperating with neighboring countries; one received support from physicians/nurses in Belgium; co-operation via Insulin for Life; occasional visits from different countries; partnership work through ASPED and ESPED or through PenPal United's network and one through the pediatric endocrinology training center in Kenya.

Of 31 respondents to the question about whether peer to peer country support would be useful, the majority of countries, 90% (n=28) would welcome a support program or would like to work with other countries, 10% (n=3) were not interested. The country visits identified enthusiastic support for this approach.

How has the support from IDF-LFAC impacted on national policies?

Many specific examples of the positive impact of IDF-LFAC have been described in previous sections. The main themes that emerged from the survey included:

- Better training provision
- Expansion of free care
- More children surviving, improved quality of life and fewer complications
- Strengthening of health systems involved in T1D care

There were no negative themes that emerged, but a few individual comments, including one respondent saying that now, when the children could test blood sugars, which they could not afford in the past, the children found it a lot of work and another respondent pointing out that it was a good program but there were need for more training for health professionals. A third respondent commented that there was also need for more resources for long acting insulin, and

partnerships with local organizations to start a dialog for national policy for children with type one diabetes. As one Indian interviewee noted: *“LFAC is saving many lives in resource poor communities in India. However due to limited resources has not been able to provide long acting insulin, training of health care professionals and partner with local organizations to start a dialog for national policy for children with type one diabetes”*. (India- Haridwar)

Sustainability

The ultimate goal must be for people with T1D to be able to get good treatment and care routinely through their country’s health system. This does not appear to be a realistic goal in the short term in most countries. Even in the more prosperous countries visited, such as Mexico, there were still difficulties with meeting such a goal. The survey asked about the integration of the IDF-LFAC program into the national health services and the expected timeframe that IDF-LFAC would need to continue in that country.

Of 31 respondents to the question about integration, 61% (n=19) thought that the IDF-LFAC program could be better integrated into the National Health Service. Most recognized that a change in public health policy would be needed for T1D to become a health priority. In practice the model IDF-LFAC adopts of entry to each country through a ‘local champion’, utilizing the



LFAC delivery is through the Diabetic Association as a local champion

health service arrangements that exist in the country to deliver care, is designed to ensure that the IDF-LFAC program is well placed to become better integrated.

This approach by IDF-LFAC should be applauded and supported. It differs from some other NGOs who ‘arrive’ with a ‘model’ which they impose. Some of the experts interviewed recognized the importance of this integrated model that had been adopted by IDF-LFAC, but also the importance of ensuring the government/ ministry of health was engaged, suggesting that IDF-LFAC should *“not take another step without the Ministry saying what part they are going to take”* and the importance of *“expanding the engagement of the government”* and for *“a developing country to do things itself”* but that it did depend on what sort of infrastructure and framework there is to integrate with. Respondents to the questionnaire suggested that the IDF-LFAC activities could only be integrated with those of the Ministry of Health if there were certain structural or organizational changes in the government system, such as greater commitment by the government (Ethiopia, Guyana, Kenya); greater decentralization - *“We will develop general diabetes management protocols and specific protocols for type 1 diabetes. Decentralization of care to other provinces is recommended to reduce the distance of the associations for the provision of supplies. Capacity building is urgently needed”*(Burundi); access to low cost insulin through a government program - *“If the government finds partners who can provide low-cost insulin and it*

has a team of management of a specific program of diabetes and other NCD” (Republic of Congo); higher prioritization of T1D; and improved guidelines. Other changes included better infrastructure, higher health care expenditure, a health system with a social conscience, and freedom from inter-communal violence.

When asked what was the expected time-frame that IDF-LFAC would need to continue, over 80% of countries thought it would take 10 years or more before their government would take over the responsibility for treatment and care of children and young people with T1D.

These issues highlight the importance both of early engagement with the Ministry of Health when an IDF-LFAC program is starting in a country, and also the necessity for a ‘strategy’ for that country specifying how the program should evolve over time and what might be the exit strategy. Regular reviews, perhaps after 4 or 5 years in a country, should be undertaken to ‘take stock’ and ensure that the IDF-LFAC program is delivering support most efficiently and effectively. This is also an opportunity to reengage with the Ministry. Appropriate skills are needed for this sort of strategic dialogue and IDF and IDF-LFAC need to consider how best this can be taken forward. Similarly this approach needs to engage both with the ‘local champion’ individual or organization (often the local diabetic association) through which the IDF-LFAC program is organized, and with senior clinicians and endocrinologists who should be advocates for their patients and services. Leadership, advocacy and influencing skills are needed and IDF, working with suitable experts, should consider how these skills can be developed and enhanced in each country.

A further group of advocates may be the children and young people themselves, who, with appropriate support and skills development could become very powerful advocates. One young man, a ‘graduate’ from the IDF-LFAC program was already representing a group of people with T1D in Rwanda. Review of the ‘young leaders’ program and the need for a range of skill development, needs consideration and may need specific funding streams. Without this direction then there is a risk that IDF-LFAC continues to deliver insulin and care management ad infinitum.

The longer term

IDF-LFAC does not appear to have a strong advocacy role at a national level but several countries recognized that its activities had been instrumental in increasing the prominence of T1D within their Ministry of Health. During the Rwanda visit, it was apparent that IDF-LFAC played an advocacy role, alongside other partners, at an important meeting with the Ministry of Health, about the way forward within the framework of the NCD strategy and the continuing involvement of NGOs in strategy development and implementation. The Minister of Health herself clearly recognized the important role IDF-LFAC was playing.

The Tanzanian respondent reported how IDF-LFAC contributed to advocacy with civil society and professional organizations in collaboration with other stakeholders, and the Azerbaijani respondent reported that IDF-LFAC had supported their advocacy with a speech on television, newspaper articles, and frequent meetings with representatives of the Ministry of Health. This seems to have achieved results as the Azerbaijan government has now decided to provide

50 free strips per year to people with diabetes (as noted previously). Ethiopia and Mauritania both reported that training received by IDF-LFAC had helped with advocacy with the Ministry of Health and media programs

However, as was noted, *“The Tanzanian Government is lacking resources to support most of IDF-LFAC activities however some steps have been taken within the Ministry of Health and Social Welfare NCD unit where now there is sufficient manpower and recently hired a pediatrician which in itself is a step in the right direction. For long term sustainability there arise a need for an extended advocacy campaign that will constantly remind the Government into setting aside funds in order to efficiently run IDF-LFAC program.”* but *“LFAC could support the budget for mounting advocacy campaign with the Government”*.

In terms of international advocacy, IDF-LFAC has negotiated with some of the main insulin and other goods (glucometers and syringes etc.) suppliers to donate their products to the IDF-LFAC program. This is an important part of the program delivery but also has some negative effects. For example, there is restricted variety of goods available and, as noted previously, there still seems to be some problems in some countries with importation and customs. We reiterate the importance of IDF-LFAC negotiating, when it initially engages with a government or periodically renews its agreements, assistance from the government to reduce the costs (both in terms of taxes and duties and in labor) of complying with regulations, in regard to customs and importation of these ‘donated medical’ goods. Whilst this is not usually the province of the Ministry of Health, it would be symbolic of ‘government’ support.

In some countries, India (Nagpur) and the Philippines, the local IDF-LFAC program procured insulin and other goods locally, having negotiated a reduced price. This had the advantage that there were no importation and customs issues and also the local procurer (clinic/ doctor) could purchase a range of insulin types.

A key issue is the supply of test strips. It is apparent that manufacturers have adopted a business model, similar to that with printer cartridges and razor blades, where the initial equipment is inexpensive but the disposable goods are very expensive. This situation is maintained by designing for incompatibility with existing products and use of intellectual property laws to prevent emergence of competitors. We note that IDF-LFAC has initiated discussions with an inventor and manufacturer exploring a printer-based model, to create strips, albeit this is still in early stages of development. However, we believe that there is an extremely strong case for production of a generic glucometer along with facilities, such as adapted ink jet printers, that could produce low cost strips. While we recognize that the IDF may find it difficult to campaign on this issue given its considerable support from strip manufacturers, we recommend that the Helmsley Charitable Trust explore other mechanisms by which this might be achieved.

34 countries responded to the question about national diabetes care guidelines, and only 9 countries reported that they have national guidelines available to primary care physicians. One country noted that they have national guidelines but they are not readily available and not implemented. Guidelines can be an extra resource for health care workers, physicians, nurses, especially in

countries with limited diabetes training. Resources such as the IDF/ISPAD Pocketbook for the “Management of Diabetes in Childhood and Adolescence in Under-Resourced Settings” could be promoted to the countries and through the LFAC website and newsletters.

Impact on priorities of governments

When asked whether there had been any difference to the government’s prioritization of providing care to people with Type 1 Diabetes due to IDF-LFAC, only a minority of responders (21%) thought IDF-LFAC had made a difference and only 9% reported that IDF-LFAC had participated in conversations about diabetes-related policy and health budgeting with relevant health decision-makers in their country. In at least one country, Azerbaijan there has been a clear impact, with the government now providing strips, although as noted previously, this seems rather modest given the resources available to the Azerbaijani government. However, respondents to the survey described many ways in which IDF-LFAC had been seen to have a positive impact, as is exemplified by quotes such as “...LFAC has been a life saver..” (India), “...with the availability of insulin fewer are dying..” (Nigeria), “..LFAC has built hope” (Liberia), and “The government began to take an active part in providing diabetes supplies,.. improved diagnosis of diabetes, decreased acute and chronic complications of diabetes in patients” (Azerbaijan). From the visits a similar picture emerged. In Rwanda, IDF-LFAC was clearly an important player, alongside other partners in the overall development/ implementation of policy, but in the other countries visited this was not apparent. In Rwanda, one of the external experts commented that the presence of IDF-LFAC had stimulated the diabetes association to also become more of an advocate.

Respondents made some practical suggestions (below) on what IDF-LFAC could do to help the government take over responsibility for treating the children/young people. Many point to the importance and necessity of ‘official conversations’ and advocacy with policy and decision makers whilst some recognize the futility of this given the current state of their government and health system.

- *Start official conversation through the association and directly with the Ministry of health. (Ethiopia)*
- *It is difficult. Maybe train people high up in government on diabetes care first. (Kenya)*
- *For the moment the government is still involved in programs from the World Bank: e.g. malaria, TBC Aids, trypanosomiasis vaccinations (Ebola??). Diabetes should be added to those programs (DRC)*
- *LFAC could support the budget for mounting advocacy campaign with the Government. (Tanzania)*
- *Re-engage with Fiji government through meetings with policy makers to assess its readiness to take over full funding for all medical related cost for children and young people with type 1 diabetes. (Fiji)*
- *Leave sufficient funds and necessary equipment for the monitoring of diabetic children. (Burundi)*
- *Start on coordinating talks with decision makers at Government level. (Dominican Republic)*

- *More meetings with authorities.* (Sudan)
- *Partner with public health foundation, ministry of health and similar organization to have policies towards the needs of children with type one diabetes. Patients. They are the forgotten ones. Having policies is one thing and enforcing them another thing. Corruption is a big barrier for governance in India.* (India)
- *Yes they can encourage government for support of free insulin to type 1 diabetic patients at least after 25 years of age.* (Nepal)
- *Better education of endocrinologists would show the impact of proper care and treatment. They may advocate their own government once they see the difference that proper care makes.* (Tajikistan)
- *By engaging government in discussion at the highest level and through international agencies.* (Nigeria)

On the other hand, there was some cynicism that anything would help, as this quote from Bolivia indicates: *“At present I think is not appropriate or desirable to help this government as we believe that any help would not reach the beneficiaries.”*

Overall Impact of IDF-LFAC

Overall there were positive responses to the IDF-LFAC program through all aspects of the evaluation. Many of the children and families recognized the importance of what they were receiving both in terms of insulin, but also in terms of education about T1D and support to manage it. All were appreciative and expressed their gratitude spontaneously. In Nagpur, the mother of a 9 year old girl, who was also deaf, said *“she now talks again”* following her starting to receive support from IDF-LFAC, through the Dream Trust. Many had stories of how devastated they were when the child was diagnosed with T1D but also how the support from IDF-LFAC had changed their lives. From the survey, countries also indicated the positive impacts (Table 14)

Table 14 Descriptions of the positive impact of IDF-LFACs support:

Azerbaijan	<i>The government began to take an active part in providing diabetes supplies, improved diagnosis of diabetes, decreased acute and chronic complications of diabetes in patients</i>
Ethiopia	<i>Through the program we were able to do posters and distribute educational materials and the diagnosis rate has improved as the number of children reported from each centre increases.</i>
Haiti	<i>With the availability of the insulin and materials, children and young adults can stay alive and try to avoid complications. Children and young adults living outside of the capital of Port-au-Prince can receive the materials and insulin at the affiliated center of FHADIMAC where they are followed for their diabetes</i>
Democratic Republic of Congo	<i>Now at least in Kinshasa most people or doctors know where to go for treatment when a young patient has diabetes</i>
Fiji	<i>Establishment of local guidelines to manage DKA, other situations such as sick days, surgery etc.</i>
Bolivia	<i>Most children and youth diagnosed in recent years have not reached the point of ketoacidosis as parents or paediatricians have directly identified diabetes as a cause of the symptoms presented and have taken proper and effective measures securing them endocrinologist specialist or paediatric endocrinologist care.</i>
Ecuador	<i>If we wouldn't have the IDF-LFAC support we could not attend the children with type 1, because we opened the "programa de apadrinamiento" since we receive their insulin support.</i>
Uzbekistan	<i>Intensive insulin treatment regimen is implemented at all regions of the Republic.</i>
India	<i>In the resource poor communities IDF-LFAC has been a life saver. Where no child had survived prior to IDF-LFAC we now have 56 children leading a normal life. We also have about the same numbers following MDI from resource sufficient communities.</i>
Pakistan	<i>One of my patients has had leg cramps for the past 3 years. In the book they recommend Amitriptyline. When we started that she immediately improved. She is grateful not to have the leg cramps any more.</i>
Vietnam	<i>Helping patients monitor their complications better</i>
Tajikistan	<i>Glucometers have allowed some endocrinologists to train their patients in daily blood glucose testing, which has assisted with the adjustment of insulin and improvement in blood glucose control. Since distributing IDF-LFAC insulin and glucometers, the wider endocrinology community has seemed to be more aware and interested in type 1 diabetes.</i>
Nigeria	<i>With the availability of insulin fewer are dying, the insulin is distributed to all over the country</i>
Liberia	<i>LFAC has built hope. We lost one child but the other 6 would have surely died. Thanks to IDF-LFAC we have been operating for 4 years and the children are relatively well, coming to the "clinic" every two weeks from far away distances. They are glad to come. They come with their coolers and pack of ice for check-up and insulin</i>

A final question in the survey asked for any further comments about IDF-LFAC. Many expressed again their gratitude and that they were now able to treat disadvantaged children and young people with T1D through the program:

- *“the actual team of LFAC is very dynamic and very supportive” (Haiti)*
- *“Our patients need the LFAC support, please support LFAC that way you support our needy diabetic patients. No doubt: it is one of the best program I ever experienced (I have seen many in 40 years) (Kenya)*
- *“...with limited resources they have made a difference in the lives of children with diabetes. More needs to be done” (Ecuador)*
- *“I think that many children would not be alive if there was not this program that demonstrates the real existence of solidarity between individuals, institutions and charitable organizations.....proud and honored to work with this program.” (Bolivia)*
- *“thank you so much. Please come visit us. See what you are doing for our children” (Liberia)*

IDF-LFAC is clearly doing good things for children and young people

Recommendations

1. LFAC organizational structure and delivery

- i. IDF-LFAC should maintain its current **flexibility** of approaches so that it can provide what is needed in each country to best effect and most efficiently. The 'context' in the country in which IDF-LFAC programs are delivered is crucially important, with widely varying health system infrastructures and potential for sustainability.
- ii. It is essential that there is a clear **strategy to embed IDF-LFAC within the health system in each country**. This is a task that will require specialist expertise beyond what can be provided by IDF-LFAC. We recommend that IDF identify how best this could be achieved, with one option being the creation of a small team based at IDF headquarters but with strong links to other academic and civil society organizations involved in health systems research and development, such as the Helmsley Charitable Trust Type 1 Diabetes Program's grant to Health Action International. We would expect that IDF could raise the necessary funds for such activities.
- iii. Review the **approach to the initial 'needs assessment'**, which uses a questionnaire framework and is often undertaken by an external expert. In some countries the children that do receive support from IDF-LFAC may not be the most disadvantaged in that country. IDF-LFAC recognizes this problem, and probably those most in need in any particular center are covered. However further consideration needs to be given as to how those most in need (across a country) can be supported. Review of existing RAPIAs, as in the Philippines, may be useful. Combining both information from RAPIA, where this is available, and from the IDF-LFAC initial 'needs assessment' could be useful in that these can be used in combination and can assist making connections with relevant NGOs (e.g. as in Mali). Efforts should be made to focus on the children in most need. This may entail IDF-LFAC supporting the development of capacity in their 'local champion' to be able to deliver to the poorest parts of the country, as was seen to be a necessity in Mexico. Consideration needs to be given as to how this can be achieved and whether it requires specific additional funding.
- iv. Consider greater use of **expert volunteers** to offer support and mentoring to countries particularly at 'start up'. Also consider 'peer to peer' support and research. (see later).
- v. Develop a formal mechanism/system for **'review' of the IDF-LFAC input** after (say) 4 or 5 years, to ensure ongoing support continues to match needs and modify the IDF-LFAC program support as appropriate.
- vi. It is clear that Graham Ogle has accumulated a **wealth of knowledge** about the IDF-LFAC partners. There is a centralized 'Dropbox' repository of information shared by the IDF-LFAC team but consideration should be given as to whether there should be more 'summaries' provided to each country each year. There is also much information held in 'heads'. This is important for two reasons: a) succession planning, something that we believe will require attention in its own right, not least because many of the partners envisage

- engagement with IDF-LFAC for more than 10 years in the future and b) because it will be important to ensure that IDF/LFAC has an institutional memory that goes beyond one individual. We recommend that IDF **commission an oral historian** to work with Graham Ogle to document the rich experiences of IDF-LFAC.
- vii. Applaud and capitalize on the excellent work that individuals in IDF-LFAC bring to the program. **Clarify roles and responsibilities** between IDF-LFAC and IDF, and between IDF-LFAC and IDF and the Australian Diabetes Council/ Diabetes New South Wales (same organization but recent name change). Consider IDF holding more strategic and advocacy roles whilst IDF-LFAC focuses more on delivery of the program.
 - viii. IDF-LFAC should take time now to develop an explicit plan that can address both contingencies related to the Director's (GO) and the IDF team's work and, in the longer term, **succession planning** for key IDF-LFAC personnel.
 - ix. We recommend that the core staff be strengthened by the appointment of **an additional administrator** in Sydney. We believe that this should be considered a higher priority for available funding than expansion to additional countries.

2. Optimal strategic framework for high impact sustainable results

- i. **Continue to use the Diabetic Associations in the country** as the 'route' in and for them to use the 'health system' in that country for delivery. This ensures that the IDF-LFAC support is well 'grounded' and leads to more sustainable opportunities in the future. In some countries there is direct delivery through government (e.g. Burundi). The principle should be to use a 'local champion' who can make it happen.
- ii. Learn from the countries where **data collection and collation** is robust and 'require' this of all countries. IDF-LFAC should 'demand' the annual information returns and use the leverage of IDF-LFAC support and supplies by potentially 'threatening' to remove support unless robust information is delivered. IDF-LFAC should consider requiring each partner to use standardized data entry software, such as that already developed in the IDF-LFAC database (see below) or in Rwanda. This would ensure that the data were provided in a consistent format.
- iii. We recommend that **information be collected on the fate of those who 'age out' of the program**. This would provide powerful outcome data both specifically for the IDF-LFAC program but also on the burden of disease.
- iv. LFAC have set up an **electronic database** which is available to all countries to input their data. It is currently only used by a small number of countries (currently 9 and another has just gained ethical approval). There may be difficulties in some countries with internet access and with applying for/ obtaining ethical approval. IDF-LFAC are exploring 'standalone' or other formats including delimited Excel sheet or paper. We recommend that IDF-LFAC consider how to transfer data most efficiently and whether using **electronic data systems**, as have been set up in some countries e.g. Rwanda, Philippines, could be

- ‘transferred’ to other countries**, or at least to adopt similar principles, or to use ‘shared data management’ systems. (This may need further exploration, possibly with specific funding)
- v. We recommend that IDF-LFAC and countries recognize **the importance of data/ information to inform the ‘burden of disease’** (including diabetic sequelae and complications). This is a powerful tool, as a byproduct of the IDF-LFAC program, and can/ should be used to greater effect with ministries of health. This contributes towards the sustainability of the program. Linkage to the databases (above) needs exploration. Special funding may be needed to initiate this.
 - vi. LFAC should continue to work in **partnership** with other organizations/ NGOs. The flexible approach adopted by IDF-LFAC, working with any reputable sensible group, should remain, including at times acting as ‘peacemaker’ between groups. Similarly the approach adopted to ensure compatibility with the health system/ context of the country should remain, rather than a defined model that is imposed. **Pilot mechanisms for joint working/ shared funding** e.g. by using opportunities such as those with Marjorie’s Fund and with Team Type 1 in Rwanda. And then apply elsewhere.
 - vii. **IDF-LFAC should capitalize where possible on ‘research’** both to document benefits and to learn lessons for IDF-LFAC and other NGO delivery, as well as for clinical management. (link to 1.iv) re expert/ volunteers. However note that research support may be of limited duration and consideration has to be given to ‘handling’ when funding ceases. Learn from stellar experience in Rwanda, in Nagpur re care-giver research, the ‘epi’ study and elsewhere. Also explore if there are opportunities for working with public health groups. This may require specific funding e.g. to cover expert researchers’ air fares/ subsistence for visits etc.

3. Changes to policies that could improve quality, quantity, efficiency or effectiveness

- i. IDF_LFAC continues to balance ‘width and depth’ when deciding who to support and both approaches have pros and cons. However on balance it appears the current ‘wide’ approach may be appropriate, with varying depth of ‘packages’ as appropriate. However, this should include agreement on a set of minimum criteria that a country should meet for support to be viable, expressed in terms of numbers of children and existence of supportive infrastructure. Thus, it is unlikely that it will be appropriate to support countries with only a very small number of children or where the contribution is minimal in relation to the total disease burden, or to initiate support in the midst of ongoing conflict, as this should, more appropriately, be a responsibility of other organizations with experience in such areas, such as MSF. Caution needs to apply even if IDF-LFAC support is only delivered to a relatively stable part of a strife torn country (e.g. parts of Syria). More robust mechanisms for these criteria and on initial needs assessment and then review (see 1iii and 1v), should ensure the right ‘package’ is delivered in each country. This provides for a **tiered approach**, which looks at

- each country in terms of **leaving a sustainable legacy** both for the children and for the country as a whole.
- ii. In some countries there are children on 'partial' support (e.g. just glucometers and strips) and others on full package (i.e. including insulin and syringes etc.). The local clinicians making these decisions against a background of overall economic criteria remains sound. Some countries did not recognize that they were **applying sound criteria**, such as household space and income, a history of difficulties in access to or paying for insulin etc., but they were. These **criteria could be more formalized** but a view has to be taken as to whether this would be advantageous. Maybe at '**start up**' some **principles** including such issues could be shared with newly engaged countries, as part of set up guidelines, and for IDF-LFAC to encourage them in this approach. However local application is important for realism and for 'ownership'.
 - iii. We see more **capacity building and education and training** amongst health professionals within countries as critical to the delivery of quality and effective care for T1D. Nurse capacity, educators as well as professional training is needed. 100% of respondents to the questionnaire thought there was a need for more training of health care professionals. Relationships to ISPAD 'training' and IDF capacity building needs to be taken into account. Mentoring /expert relationships can also help here. More can be done with more resources. This may need a specific focus and funding stream.
 - iv. We recommend that IDF-LFAC should maintain the current age limits, but emphasize methods to support the diabetic associations to **prepare children (and families) to be self-sufficient by age 25**. So far, discussions seem to have been dominated by the issue of obtaining supplies of free access to those over 25. In part this is because many individuals with diabetes are excluded from the labor force. An alternative is to provide them with the skills and, where necessary capital or equipment to earn money. We have identified several promising models of support for 'self-sufficiency' in four countries, all supported by IDF-LFAC, i.e. in Rwanda (educational center); India (Nagpur) educational grants/ rehabilitation/ vocational training; microcredit in Tanzania; and mobile phone repair in Bangladesh. Another possibility, described in Haiti, is to employ young people with diabetes as diabetes educators. We see all these as holding great promise and consider that they could be a **legitimate area for extended support** by IDF-LFAC. Draw out lessons and principles and apply/support/ fund in other countries. Ethical issues of 'aged out' are thus diminished. IDF-LFAC may choose to adopt a role of '**start-up**' **funding to precipitate such action** but encourage the local diabetic association to look for local support or funding e.g. from Rotary, Lions or from partnership with NGOs focusing on vocational training and economic independency (e.g. Oxfam in Rwanda). This may need a specific focus and funding.
 - v. As well as such support to the young people themselves, the countries **(diabetic associations/ clinicians) also need to be prepared by IDF-LFAC as to how to support children through the transition** off the

IDF-LFAC program. This needs consideration as it was clearly an issue 'not addressed' in many countries.

- vi. IDF-LFAC should consider how it could 'match' up countries for '**peer to peer**' support (with suitable agreements from countries to adopt this approach). The vast majority of countries (93% of respondents to the survey) would welcome this approach. It would likely help with quality of care, and could also link to the suggestion of a newsletter and enhanced website. An initial peer to peer program could be set up and evaluated, building on the success of Mali and Burkina Faso and the less successful partnership between Sri Lanka and the Maldives. There may also be possibilities within countries e.g. between centers within India. This may need specific focus and funding.
- vii. "**Co-responsibility**" model is being used in Mexico to engage children and families in order for them to learn how to control and manage their T1D. It uses IDF-LFAC support as 'leverage'. This model of 'tied in' engagement should be explored elsewhere. Similarly in the Philippines a '**conditionality**' model is being used. There may be other similar models elsewhere. In Nagpur a '**nominal contribution**' from the patient for specific care (e.g. cataract removal) is required.. There needs to be caution that the most vulnerable children (maybe with less supportive or dysfunctional families) are not excluded, although in practice it appears that the diabetic association staff usually recognize the children who need particular support.. Develop a set of principles or guidelines which may be useful for other countries to adopt such an approach. These guidelines could be developed by the countries who use these approaches (e.g. Mexico), with support from IDF-LFAC and building on evidence from 'conditionality research'. Special focus and funding may be needed.

4. Impacts on countries, systems and children

- i. Many countries need help with '**awareness raising**' about T1D. IDF-LFAC should identify where this has been undertaken successfully and **develop guidelines/ principles** that could be shared with other countries. IDF-LFAC has already developed posters on preventing deaths from DKA, but this is focused mainly on health care workers. They are available in various languages. Currently there are many 'barriers' to children e.g. in schools where there are misunderstandings and fear of children using syringes. Zimbabwe has undertaken a 'schools program' which could inform other countries. AM (for IDF-LFAC/IDF) has developed a schools pack and **resources in various languages**. There are a number of examples of interventions to reduce stigma in diabetes, from countries such as Iran (Irani, Abdoli et al. 2014). A key message is that they must be **culturally appropriate**. Exploration of new mechanisms, including the use of social media approaches, may be worthwhile. This may need a specific piece of funded work.
- ii. IDF-LFAC should consider whether it should produce a (say) 2 monthly **bulletin or newsletter** to be circulated to all its partner countries. This could provide a good vehicle for sharing 'good practice' on such

activities as ‘awareness raising’, running diabetic camps etc. Countries themselves could contribute articles, debate and dialogue. IDF-LFAC could use it as a vehicle to develop/ disseminate ‘guidelines’ etc. and for countries learning from each other. They should also explore the use of social media, such as Twitter, as a means to communicate within the network and beyond it.

- iii. The IDF-LFAC support has to ‘start’ at the right point for each country. (This should be achieved by the initial needs assessment process). Some countries (lower income, less developed) need to start with ‘basics’ i.e. just ensuring children are diagnosed and have access to insulin. This will evolve over time to a model where there is less focus on ‘survival’ and more on ‘thriving’, which entails better control and management of T1D (utilizing glucometers, strips, HbA1c etc.). Initially IDF-LFAC and the diabetic associations need to support education of health professionals who are not experts in T1D in order that children can be diagnosed and given the right support. Developing a more formalized ‘**model of care**’ to demonstrate this ‘evolution’ through care packages and how this relates to benefit for the patient may be helpful to the delivery of the IDF-LFAC program. This should build on the table of development IDF-LFAC already has and also potentially relate to the IDF-LFAC ‘Index’ when this is finalized. The model needs to show the development and flow into the exit strategy. The model could also be used for liaison and advocacy with the country’s Ministry of Health. This may need specific funding and to complete the index work.
- iv. IDF-LFAC’s **Training and educational resources** are recognized as excellent. There needs to be capacity to ‘translate’ these into **appropriate languages and make them culturally appropriate**. National diabetic associations could be required to take more responsibility, building upon the work of IDF-LFAC in their countries, in adapting educational materials by means of ‘in country’ translations and adaptations. IDF-LFAC could also help by designing visual templates that appeal to children globally but in a few different designs, so that each country can download the design they prefer and add the text locally. Additional funding may be necessary.
- v. ‘**Camps**’ are recognized by children and families and by professionals as hugely beneficial to the children with T1D both in terms of ‘learning’ to manage their T1D and in making contact/ friends with other children and YP with T1D. (It is often the first time they have met other children with T1D). Funding to continue to support these and to enable the IDF-LFAC educator to contribute to these camps and provide educational materials would be beneficial (see iv) above). Other key staff, such as psychologists are also recognized as important. Again ‘**guidelines**’ are being drawn up by AM building on countries’ and IDF-LFAC experience of ‘camps’. Some children and YP suggested ‘international diabetes camps’, which is an interesting idea to explore. Whilst local funding may be more appropriate for camps themselves, specific IDF-LFAC funding may be needed to catalyze action, develop and disseminate guidelines, educate at camps etc.

- vi. Mechanisms for, and to encourage, **children and YP with T1D to be ‘in touch’ with each other** should be explored, potentially both within country and between countries. This should build on experience from countries where this approach is accelerating e.g. Rwanda, Bolivia and Tanzania and social media should be explored. The newsletter/ bulletin could be a vehicle for dissemination. Specific focus and startup funding may be needed.
- vii. There has to be a degree of ‘realism’ as to whether T1D is likely to be a ‘priority’ within each country for the Ministry of Health. Whilst the aim may be to provide health care for all, this may not be a realistic goal for all countries and they will have other priorities both economic and within health services. The burden of disease is an important tool (see 2 v). Access to insulin as an ‘essential medicine’ (WHO list) may be an important step. Steps should be taken by IDF early in the ‘start up’ of IDF-LFAC support to explore possibilities with Ministry of Health (see below). IDF-LFAC’s **‘exit strategy’ should be part of the startup** key agreement and the 4/5 year review program (see 1 v) (See also re sustainability, leadership and advocacy below)
- viii. Additional materials could be made available to countries by **additions to the IDF-LFAC website**. Whilst some guidelines and linkages are already available, further materials could be added and regularly updated, such as the IDF/ISPAD guidelines on managing T1D in food resource poor settings, advocacy tools such as examples of press releases, poster templates, videos, instructions for holding camps, setting up registers, stories from children supported by LFAC etc, and other materials added as they are developed.

5. Impact on long term sustainability in T1D care delivery systems

This section relates to action by IDF as well as IDF-LFAC

- i. IDF as the ‘parent body’ of IDF-LFAC and/or IDF through its respective Regional Offices, in concert with the national diabetic association should **instigate discussions with Minister/ Ministry of Health at startup of IDF-LFAC support**. Ascertainment of where T1D and insulin availability are placed in health priorities is important early on. Utilizing T1D ‘leaders’, including local diabetologists/ professionals/ IDF Regional Offices and diabetic association, to hold robust conversations with Ministry of Health and aim to **draw up an MOU**, with suggested time frame for IDF-LFAC support and for government ‘pick up’. This should include specific **support to exempt “donated goods” from import duties** or, if this is not possible, to reduce the costs of payment and complying with regulations. (Although this is not usually the province of the Ministry of Health, it would be symbolic of government support). Whilst this and the MOU may not be realized, it is a baseline for discussion and can be looked at in the 4/5 year review program. Thus, the **exit strategy should be explored at the time of entry** into a country, even though T1D may not be high on the country’s agenda at this time. It needs to be recognized that there will be a large backlog of countries already participating. The burden of disease

- information developed/collated in the country from the IDF-LFAC program is a useful tool for later discussions. (See 2 v).
- ii. The recent development of the **exit strategy** from Fiji, with its definition of achievement and standard of care should be formalized /**codified** and applied elsewhere.
 - iii. Whilst in theory in some countries there is access to insulin and T1D care, through the government systems, this may not be the case in practice. Diplomatic handling is necessary in these circumstances. There is a possibility of gradual **wean down of the amount of insulin** provided by IDF-LFAC in some countries.
 - iv. IDF/ISPAD/LFAC should at 'start up', '**mobilize' leaders within the country to act as advocates** within the country with politicians/MoH. These will typically be drawn from mid-career health professionals who are recognized as future leaders. There is much to learn from the World Heart Federation Emerging Leaders program. **Support to identify key players, develop advocacy and leadership and influencing skills** etc. should be provided by IDF. Leadership, advocacy and influencing skills are needed and IDF, with suitable experts, should consider how these skills can be developed. This role needs exploring in more detail and may need specific funding stream for IDF and suitable 'leaders' and experts in leadership to take it forward.
 - v. IDF to consider the inclusion of a specific **stream on health systems within the World Diabetes Congress (WDC)**, as is being done in the World Cardiology Congress, encompassing awareness raising and skills building, drawing extensively on presenters with expertise in these fields who may not so far be engaged with diabetes. This is different to a stream on global challenges in health, which already exists.
 - vi. The IDF-LFAC **presentations at the WDC could focus on specific common aspects** of the IDF-LFAC program, for example on stigma or on awareness raising and thus make 'linkages' both between countries and to diabetologists with particular interests/ research experience in some of the IDF-LFAC key issues. Potential links to new research support may be a possibility.
 - vii. **Key individuals** should also be identified and given suitable support to **develop advocacy, leadership and influencing skills** to promote T1D and its treatment and care. They should actively identify **champions**, such as politicians with an interest in T1D (or who may have T1D themselves or in a close family member) who could also, with support, **act as advocates**. While this is quite different from the role played by the existing IDF Young Leaders Program, it may be that some participants in it could play an enhanced role as advocates in the future.
 - viii. **Seeking 'opportunities'** where IDF-LFAC can demonstrate its contribution and 'worth' may be important in influencing the Ministry of Health e.g. their contribution/experience to developing diabetic registers, and/or from research findings. Identifying current examples may be worthwhile. Again specific funding may be needed or experts identified to contribute.

- ix. **The knowledge held by the IDF-LFAC team** is vast but not accessible. Mechanisms need to be found to capture and utilize this knowledge and to share experiences between countries. (See 1vi).
- x. There is a need for much stronger **advocacy in the international arena**, linking access to insulin with wider movements for access to essential medicines and universal health care, while taking advantage of the post-2015 development agenda. However, while the evidence that IDF-LFAC collects could be used to support such an advocacy strategy, including stories from those children being supported, it was recognized that there was insufficient capacity to engage meaningfully in this process at present. This is, however, an area where IDF could play a much greater role in association with the NCD Alliance and its members, where IDF already plays an active role, also organizations such as Health Action International, with their focus on access to essential medicines.

Conclusions

This review of the IDF-LFAC program has shown that it is a strong program that is delivered well and is extremely valued by the countries and the children, young people and their families who are the beneficiaries of the program. It is clear that the program enables children and young people with T1D to survive and as the program and country policies strengthen enables them also to thrive.

The IDF-LFAC program already does many things right and the team, albeit small, are extremely dedicated and enthusiastic and deliver the program well. Many aspects are to be applauded and continued.

The evaluation was undertaken using review of documentation, interviews with key stakeholders, and a survey to 43 countries where the program is active including visits to five countries. The country visits were especially powerful for examining the IDF-LFAC program *in situ* and in detail. A summary of each country visit – Rwanda, Jamaica, Mexico, the Philippines and India (Nagpur) - and specific recommendations in relation to each country are at Appendices 3 to 7.

The review covers five themes:

- IDF-LFAC structure and organization
- Optimal strategic framework for high impact sustainable results
- Changes to polices that could improve quality, quantity, efficiency and effectiveness
- Impacts on countries, systems and children
- Impact on long term sustainability in T1D care delivery systems

From this review it is clear that the aim must be to enable and encourage the country itself to provide the support necessary for children and young people with T1D, but recognizing that this may not be possible immediately in some of the poorest countries and hence IDF-LFAC can provide temporary support and development to a more sustainable state. From the evaluation we are able to make recommendations that would improve the program and may act as a focus for the next steps and further funding applications. The full list of recommendations, in relation to the five themes, are listed in the previous section, and a brief summary of key issues from the recommendations below.

The main recommendations identify a number of key issues:

- Strengthening the initial process when deciding to start an IDF-LFAC program in a country, both in terms of needs assessment, so that the program is focused on children in most need, and with a clear strategy to embed IDF-LFAC within the health system of the country and to gain 'buy in', for the longer term from the Ministry of Health, ideally with a MOU and an exit strategy. This will require leadership from IDF. Mechanisms to strengthen leadership within country are also recommended, which again will require leadership from IDF but also specific external expertise for leadership skill development.
- Further enabling countries to be self-sufficient, by encouraging peer to peer development, enhancing expert input, utilizing the IDF-LFAC website for

supportive resources and developing a newsletter. Whilst these may require initial focus and resources they should in time streamline the work of the IDF-LFAC team.

- Education and training has been identified as a recurring theme and all the countries surveyed recognize the need both for further training of health care personnel and of children and families and for awareness raising in the general population. Many of the existing educational materials developed by IDF-LFAC are excellent and welcomed but some require translation in terms of both language and culture.
- Education, vocational training and support to children and young people to enable them to be self-sufficient when they reach adulthood has been developed in a number of countries and needs further focus to expand to other countries.
- Enhance the robustness of data collection from the program, both in terms of systems and in terms of requiring feedback from countries, to build into a powerful database across 45 (or more) countries and use the data to demonstrate the burden of disease. This should include outcome measures both throughout the program and when and after young people 'age out'.
- Finally we identified that there is much experience and a wealth of knowledge held in the heads of the IDF-LFAC team and suggest this should be captured by commissioning an oral historian.

The aim of this report is to enable the IDF-LFAC program to take stock of the program and enhance the elements that are already working well and refocus on the areas which have been identified to enhance the program. It is recognized that this will require specific funding for 'start-up' of some elements and will also require some specific external expertise and for IDF to take a greater leadership role.

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Appendix 1 List of interviewees

IDF-LFAC (Sydney):

Dr Graham Ogle, General Manager

Robyn Short-Hobbs, Program Manager

Angie Middlehurst, Education manager

Diabetes NSW:

Stuart Eastwood (CEO)

IDF (Brussels):

Dr Petra Wilson (CEO)

Sir Michael Hirst (President)

Dr David Cavan (Director of Policies and Programs)

ACADEMICS/EXPERTS:

Professor David Beran, University of Geneva (RAPIA)

Professor John Yudkin, Institute Research Information Service, University College London

Dr Michiyo Higuchi, Chairperson & Senior researcher, Bridges in Public Health (Incorporated Association), Mizuho, Nagoya, Japan. (RAPIA in Philippines)

Professor Trevor Orchard, Professor of Epidemiology, Paediatrics and Medicine, University of Pittsburgh, (expert/research in Rwanda)

Dr Deborah Edidin, Asst Professor Paediatrics, Feinberg School of Medicine, North Western University, USA (expert/research in Rwanda)

Prof Nikhil Tandon, Dept. of Endocrinology and Metabolism All India Institute of Medical Sciences (AIIMS) Ansari Nagar, New Delhi (National Diabetes Register ICMR)

RWANDA

Diabetic Association:

Crispin Gishoma, Interim Director, Rwanda Diabetes Association

Ministry of Health, PAHO and Partners:

Dr Agnes Binagwaho, Minister of Health, Rwanda (joint meeting)

Dr Aimee Muhimpund, NCD Focal Point at Rwanda Bio-Medical Centre, MoH
Chantelle Geru, Country Representative, WHO

Patrick Wajero, Country Director, Rwanda, OXFAM

Thur de Kuyjer, Associate Country Director, Uganda/Rwanda, OXFAM

Jason Baker, Director, Marjorie's Fund

Christian Strong, Team Type One

Dr Gene Bukhman, Senior Health and Policy Adviser NCDs, Partners in Health, Director of Global Programs in NCD and Social Change, Harvard Medical School, Senior Technical Adviser for NCD to Rwandan Ministry of Health.

Clinicians treating children and young people with T1D:

Etienne Uwingabire, Senior Nurse, Rwanda Diabetes Association

Senior Doctor, Nyanza Regional Hospital, (also met with over 30 children and young people)

Children, Young People and families

6 young people, 2 female and 4 male between the ages of 18 and 27 years.

Also visited and met for group discussions:

Rwandan Diabetic Association (including 30+ children and young people)

2x District Hospitals (including 30+ children and young people)

Education Centre (including 25 young people)

JAMAICA

Diabetes Association:

Mrs Lurline Less, Director, Diabetes Association of Jamaica (DAJ)

Dr Errol Morrison, President, DAJ, President, University of Technology of Jamaica.

Sharlene Keens-Nembhard, Manager, DAJ

Ministry of Health, PAHO and Partners:

Dr Tamu Davidson Sadler, Acting Director, Chronic Diseases. MoH

Dr Kam Mung – Disease Prevention and Control Advisor, Jamaica, Bermuda and Cayman Islands, PAHO

Dr Malcolm, Sustainable development, PAHO

Miss Estee, Disease Prevention and Control, PAHO

Clinicians treating children and young people with T1D

Dr Michelle-Ann Richards Dawson, Senior Medical Officer, Bustamante Hospital for Children, Kingston

Professor Marshall Tulloch-Reid, Professor of Epidemiology and Endocrinology, Epidemiology Research Unit, University of the West Indies

Dr Bovette Butler, Senior Registrar Paediatrics, Spanish Town Hospital

Dr Anona Griffiths, Senior Resident Paediatrics, May Pen Hospital

Channer Samuels, Dietician, May Pen Hospital

Dr Ann-Marie Woodham, Paediatrician, St Ann's Bay Regional Public Hospital

Patricia Murray, Dietician (Nutritionist), North East Regional Health Authority and St Ann's Bay Regional Public Hospital

Elisabeth Christie, Pharmacist, St Ann's Bay Regional Public Hospital

Michelle Artcher, Laboratory Technician, Kingston General Hospital

Children, Young People and families:

4 young people, one male and three female between the ages 14 and 17years

MEXICO

Diabetes Associations:

Federacion Mexicana de Diabetes (FMD) (Mexico City)(Coordinates state diabetes associations)

Gisela Ayala, Director, FMD

Marcela Vega, President

Marie Elena Mota, Coordinator, LFAC program

AMD (Mexican Diabetes Association) Nuevo Leon, Monterrey:

Alejandra Clariond, President

Laura Quintanilla, Chair

Nelly Rodriguez, Director General, Coordinator of LFAC program

Jessica Salazar Morales, Diabetes Educator, Nutritionist

Maria Levy, Founder of first diabetes association in Mexico, (Monterrey 1972) and first lay President of IDF.

AMD Sureste, Merida:

Claudia Duran, President

Veronica Canul, Director and LFAC Coordinator

AMD Cancun:

Dra Lilian Chagoyan, Paediatrician, Cancun Hospital, Founder of AMD Cancun

Sarai, coordinator of AMD Cancun (see below)

Note: LFAC support to Cancun was agreed following the visit

Ministry of Health, PAHO and Partners:

Dra Gabriela Ortez Solis, Director, Subsection Prevention and Promotion of Health, National Centre for prevention and Control of Diseases, Ministry of Health

Dra Diana Carrasco Alcantara, Sub Director Chronic Diseases, Ministry of Health

Dr Enrique Gil Bellorin, Advisor in Chronic Diseases and Mental health, Country Contact, PAHO (OPS/OMS)

Xochitl Benitez Cordova, Coordinator of Diabetes Education, BD Medical (Manufacturer of syringes/needles)

Eduardo Becherell Castorena, National Commercial Manager, NIPRO Medical de Mexico (Manufacturers of glucometers and strips)

Alia Huerta Marquez, Manager of Diabetes Division, NIPRO Medical de Mexico

Sara Valencia, NIPRO

Jorge Franchini Gomez, Director of Projects, Farmacias del Ahorro (Fahorro)

Ximena Suinaga Romero de Terreros, Commercial SubDirector, Farmacias del Ahorro (chain of pharmacies with doctors in attendance- funder and partners with FMD)

Clinicians treating children and young people with T1D:

Dra Anna Lilia Rodriguez, Perinatologist, Institute of Perinatology, (INPER)

Dr Carlos Robles Valdes, President, Sociedad Mexicana de Endocrinologia Pediatrica, Institute National de Pediatria (INP)

Also nurses, nutritionists etc at the AMDs

Dra Lilian Chagoyan, Paediatrician, Cancun Hospital, Founder of AMD Cancun

Sarai, coordinator of AMD Cancun

Children, Young People and families:

Monterrey:

5 children. Three male and two female between the ages of 4 to 14 years

Merida:

4 children. One male and three female between the ages of 5 to 15 years

Cancun:

2 children. One male and one female between the ages of 7 to 11 years

PHILIPPINES

Hope WorldWide (coordinates the LFAC program):

Bervina (Vina) Casabar de Nuevo, LFAC coordinator

Carol C Arcilla, LFAC nurse and data coordinator (recently appointed)

Dr Rosa Sy, LFAC instigator and coordinator for Philippines, Paediatrician, past president PSEDM (Philippine Society for Endocrinology, Diabetes and Metabolism)

Ministry of Health, WHO, OXFAM and Partners:

Dr Carmela Granada. Program Director for Diabetes Prevention and Control, MOH

Dr Julie Hall. Country Representative, WHO

Dr Justin Morgan, Country Director, OXFAM

Clinicians treating children and young people with T1D:

ISDFI - (Institute for Studies on Diabetes Foundation Inc)

Dr Catindig-Fernando, Director and her team - Dr Francis Pasaporte, Dr Leyden Florido, Nerissa C Llanza, Dr Ronaldo Toledo, Mercedita Marcelino

PSEDM – (Philippines Society for Endocrinology, Diabetes and Metabolism)

Dr Jemino – Endocrinologist, President, PSEDM

Dr Jeremy Robles – Endocrinologist, Director, PSEDM

PGH – (Philippines General Hospital)

Dr Sioksoan Cua, Section on Paediatric Endocrinology, University of the Philippines and Philippines General Hospital

Dr Jackie Lou Soriana, Clinical Fellow, PGH

Children, Young People and families:

ISDFI

5 children. Two male and three female between the ages of 9 to 16 years

PSEDM

3 children and young people. Two male and one female between the ages of 10 to 20 years

PGH

3 children. Two male and one female between the ages of 12 to 14 years

INDIA

Dream Trust (Coordinator of LFAC program in Nagpur)

Seema Chalkhore, Manager of Dream Trust and LFAC coordinator

Also met with Nutritionist, Nurse, Administrator for Insulin and LFAC, Social Worker, Manager

Ministry of Health, WHO, OXFAM Partners etc:

Dr Sadhana Tayade, Joint Director Health Services, Ministry of Health, Mumbai, Maharashtra,

Dr R.L. Sathe, State Program Manager, NCD, Ministry of Health, Mumbai

Dr Pankaj Wagh, State program Coordinator, Ministry of Health, Mumbai

Dr Rupesh Mahajan, Consultant, Ministry of Health, Mumbai

Dr Atreyi Ganguli, National Professional Officer, Non Communicable Diseases Team, WHO Country Office for India

Dr Fikyu Tesfaye Tullu, Team Leader, Non Communicable Diseases Team, WHO Country Office for India.

Clinicians treating children and young people with T1D:

Dr Sharad Pendsey, Diabetologist and Founder of Dream Trust

Dr Sanket Pendsey, Diabetologist, Dream Trust

Children, Young People and families:

Met with group of 12+ children and young people supported by LFAC and Dream Trust, for collective discussion

Individual interviews:

6 young people. One male and five female between the ages of 19 to 40 years

Appendix 2 Coverage by IDF-LFAC

Country	IDF atlas estimated children < 29 years old with T1D*	Country respondents estimated children < 26 y with T1D	No. of children reportedly supported through the IDF-LFAC program	Total health expenditure per capita. PPP Int. \$ (WHO 2011)	Total health expenditure % of GDP (WHO 2011)
Azerbaijan	400	900	153	520	5.3
Bangladesh	17,400	5,000	2,030	61	3.7
Bolivia	200	250	160	264	5.5
Burundi	600	350	250	54	9.1
Cambodia	400	-	4	132	6
Cayman Islands	0	15			
Dominican Republic	200	10,000	350	509	5.5
DRC	3,000	-	391	26	7.5
Ecuador	800	3,000	50	635	7.9
Eritrea	200	2,500	1,050	17	2.9
Ethiopia	1,200	10,000	2,600	50	4.8
Fiji	20	45	30	194	4.2
Ghana	3,600	700	620	85	5.2
Guatemala	4,800	250	105	327	6.9
Guyana	0		35	194	5.6
Haiti	200	25,000	150	76	6.9
India	135,400	140,000	56	126	3.7
Jamaica	200	300	278	397	5.2
Kenya	2,000	1,000	250	72	4.4
Liberia	600	600	250	88	16.4
Maldives	40	76	76	510	6.2
Mali	2,600	300	300	69	6.5
Mauritania	600	-	50	138	6.1
Mexico	26,800	-	200	962	6.3
Nepal	800	1,000	150	61	5.1
Nigeria	27,600	200	200	128	5.4
Pakistan	3,200	2,000,000	17	28	10
Philippines	15,800	-	35	164	4.1
Republic of Congo	200	100	64	97	3.3
Rwanda	600	1,023	1,023	120	10.4
Saint Lucia	20	35		703	7.7
Solomon Islands	0	< 10	2	200	7.4
Sri Lanka	2,000	-	-	175	3.5
Sudan	19,600	6,000	2,000	162	7.2
Tajikistan	400	600	400	129	6
Tanzania	1,400	1,426	661	100	7.2
Togo	1,000	120	67	74	7.5
Uzbekistan	1,200	2,327	400	177	5.6
Vietnam	1,600	400	100	216	6.8
Zimbabwe	600	-	396	-	-

*The IDF atlas presents estimated prevalence of T1D for children < 14 years old. This number was multiplied to estimate numbers with T1D up to 28 years old.

Appendix 3 Rwanda country visit

8 – 14th May 2014

Introduction

Rwanda was the first country to host the evaluation team. The trip coincided with a visit by a number of other diabetes organizations and experts, some of whom worked as partners with IDF-LFAC both in Rwanda and elsewhere. These included Trevor Orchard from Pittsburgh University and Deborah Edidin from Feinberg School of Medicine, North Western University, who support IDF-LFAC with data collection and research; Jason Baker (JB) from Marjorie's Fund (MF) a US based charity that partners with IDF-LFAC in supporting the Diabetes Education Centre in Mwulire, south of the capital Kigali; and Christian Strong (CS) from Team Type One (TT1), another US charity that raises awareness and funds for people living with diabetes. Part of the purpose of their visit was to explore new partnerships and to see how their work can be better integrated into the national health system.

The visit was organized by the Rwanda Diabetes Association (RDA), an NGO that was founded in 1997 by Francis Gishoma and that is now being led by his son Crispin Gishoma.

Background

Rwanda is a small, landlocked country in the Great Lakes Region in central Africa. Around two thirds of the population live below the poverty line and the country is heavily dependent on foreign aid. The country's President, Paul Kagame, is a powerful leader who is striving to turn a land of mainly subsistence farmers into a middle-income country by 2020. The country has experienced decades of tension between the Tutsis and the Hutus, the two ethnic groups that make up the population.

20 years ago (1994) saw the genocide of around 800,000 Tutsis by the majority Hutus. This led to many children becoming orphans and traumatized the population that remained. The health effects of the genocide were substantial: facilities were destroyed, doctors and nurses were either killed or fled and supply chains for drugs collapsed. Some of the young people being supported by IDF-LFAC were small children at the time of the atrocities and are still living with the memories of what happened to them and their families. There remains a 'silence' in relation to this period of history among most of the population, and distrust and fear still exist. However, since that time, the country has made considerable progress both economically and in terms of development indicators – it is one of a few African countries on track to achieve seven of the eight Millennium Development Goals.

Many children and young people living with T1D face fear and discrimination. Traditional healers are still popular and there are some unfounded beliefs regarding potential 'cures' for T1D. General population awareness and acceptance is a long way off.

Some of the families we spoke to found the burden of a child with T1D too much to bear, so entrenched were they in their own state of poverty. One young woman we met through the IDF-LFAC program had been diagnosed with T1D five years previously. She was working as a cook for a family who provided her

with accommodation and food (albeit not necessarily the best food for her diabetes). She said of her own family that they “think of me as already a dead person”.

Another problem faced by many Rwandans is food insecurity. When you combine this with living with T1D, managing the disease becomes even more of a challenge, even if you are fortunate enough to have family support.

We visited a 26 year old woman who was living in a remote village in a rural area with her older brother and extended family. She complained of vision complications and had had a toe amputated. She explained that she did not take her insulin on a daily basis as she often had no food. Although she knew what vegetables she should eat for her diabetes, she said her brother was unwilling to give her a small plot of land on which to grow them as he needed it for his own vegetables.

Health

Rwanda is one of the few countries in Africa that has met the Abuja target of allocating at least 15% of its annual budget to health. It has a comprehensive health system that focuses on equity, decentralization and the integration of services. A community based health insurance scheme known as ‘Mutuelle de Santé’ is almost universal and is implemented on a sliding scale with the poorest of the poor getting health care for free.

In terms of health spending, Rwanda’s main priorities are disease prevention and control, maternal health, and nutrition. Much more is needed to address chronic diseases.

The Ministry of Health is in the process of developing a NCD/ chronic disease strategy, which includes diabetes, but will not include ‘vertical’ programs on specific diseases. Its main focus in respect of diabetes will be on T2D as this has the greater burden of disease. They want to include inter-sectoral approaches which will cover the range of prevention, diagnosis, treatment and care.

The MoH recognizes the contributions that various partner / NGO organizations have made to health. The Minister of Health, Dr Agnes Binagwaho, was very interested and supportive of IDF-LFAC and recognized the benefit that was being delivered to children in Rwanda, many of whom would otherwise have died. (Prior to IDF-LFAC only a handful of children were diagnosed with T1D, many died without diagnosis. Over 1000 children are currently living with T1D as a result of IDF-LFAC interventions.)

While we were there, a meeting was organized by the Ministry to better understand the activities of different organizations working on T1D. At the end of the meeting, the Ministry agreed to set up a coordinating group that would meet regularly to share information on overall diabetes care and management and data collection.

The public health service in Rwanda consists of 39 district hospitals and related community services.

The geography of the country means that many of these are remote and isolated and cover large areas, with poor transport links. Services in urban areas and Kigali are generally better developed and with more and better trained and equipped doctors available. There is only one pediatric endocrinologist in the country who is based in Kigali. The local district doctors and nurses have to cover the whole range of all disease entities and hence do not have expertise in T1D. The plan is to



Meeting with LFAC beneficiaries and their families at one of the district hospitals

train nurses to have expertise in chronic diseases in each district/locality so that they can deal with all chronic diseases. T1D would be included in this. Health services are not completely free at the point of delivery - payments need to be made for consultations at hospital clinics and for medications although this is subsidized by the Mutuelle scheme and is waived for the poorest of the poor.

LFAC Delivery

LFAC has been active in Rwanda since 2004 through its partnership with the Rwandan Diabetes Association (RDA). It provides both supplies, including insulin and syringes, some glucometers and strips and HbA1c machines. It also funds staff at the RDA to coordinate and run the service.



The Director of the RDA showing the geographical spread of hospitals in Rwanda

There have been and continue to be challenges with deliveries, Customs and storage, for example there has been a shortage of syringes over the past two years and children and young people have had to buy their own and then reuse. Payments have to be made for supplies to clear Customs (5% of value), which RDA manages and IDF-LFAC funds.

The RDA delivers the IDF-LFAC program through 34 of the 39 district hospitals and soon they hope to work with all of them. Education on T1D diagnosis, treatment and management has been provided to doctors and nurses in these hospitals. Visits are carried out every three months, by two RDA/LFAC nurses, to all the district hospitals, to follow up on the IDF-LFAC children and YP. These visits are becoming more of a challenge now that the number of district hospitals has increased. Similarly RDA expressed a need for additional staff such as nutritionists, psychologists and nurse educators.

In ten years, IDF-LFAC has helped around 1000 children. Eight hundred are currently in the program and 157 have 'aged out' i.e. they are over the age of 25, and no longer receive support from IDF-LFAC.

The model of delivery adopted by IDF-LFAC in Rwanda – partnering with the RDA as a 'route' into the system and using the existing health service systems for delivery is a good one. Some NGOs have their own model and 'impose' it on the country. This is likely to be less successful in the long run.

The RDA, with support from IDF-LFAC and Marjorie's Fund has established a **Diabetes Education Centre (DEC) in Mwulire**, around 2 hours drive south of Kigali. This provides a temporary home for some of the more vulnerable older children and young people and helps them learn how to manage living with diabetes and to acquire a vocational skill. 130 children and YP have been through the center since it started in 2010, and have attended beauty salon workshops and acquired skills in farming techniques, hairdressing and tailoring. The aim is to ensure that the YP are self-sufficient and hence able to support themselves in terms of their insulin and other supplies for T1D which they will need to purchase after they have left the IDF-LFAC program.

We met some YP who had benefited from this educational program, including one young man who was now a successful chef; another was working as a barber. The approach of ensuring that YP are self-sufficient by the time they are 25 is critical to the sustainability of the IDF-LFAC program.

Several countries have differing models for developing YP to be self-sufficient. Rwanda has the Diabetes Education Centre, India (Nagpur) has a rehabilitation program and educational scholarships, Bangladesh has a focus on developing skills to repair mobile phones, and Tanzania has a microcredit approach. These four models (and any others available) should be evaluated and lessons learned for other countries.

Partnership working

Two partner organizations were included on this visit. This was useful to see how different diabetes charities could work together and with IDF-LFAC.

The first was Team Type 1 who, following one of their cycling races in Rwanda, had made an offer to the government to provide 900 'testing kits' (glucometers) and a million strips. An MOU had been drawn up between TT1 and the Ministry of Health to this effect. Distribution was to be handled by RDA. Although IDF-LFAC had supported and provided some glucometers and strips in the past (from a different company) they showed generosity of spirit to welcome this offer, agree to divert their own strips and glucometers to another country and embrace the partnership. IDF-LFAC demonstrated a degree of pragmatism and flexibility to work with others to make the best things happen for the children and YP with T1D.

The second was Marjorie's Fund who partnered with IDF-LFAC in supporting vocational training and diabetes education of children and young people at the DEC, to ensure they were able to get employment and be self-sufficient by the age of 25. MF recognized the importance of 'generosity of spirit' as well as available funding in partnership working, and that IDF-LFAC demonstrated these

qualities. These opportunities for multiple partnership working provide an opportunity to 'pilot' and evaluate such joint venture approaches.

Both partners – MF and TT1 - recognized the amazing work that IDF-LFAC had already undertaken and that more than a thousand lives had been saved due to the IDF-LFAC program.

In effect IDF-LFAC will continue to fund staff and supplies (insulin, syringes), Marjorie's Fund will support educational programs and TT1 will provide glucometers and strips to enable children and young people to manage their T1D. This aims to ensure that the children and young people are not just 'surviving but are thriving'.

Some other NGO organizations are active in Rwanda and are adopting different approaches to improving health outcomes in infectious and non-communicable diseases. Rather than fund disease specific programs, Partners in Health, for example are supporting a 'whole health system' approach in three districts of Rwanda. This works out at around \$15 per capita over a catchment area of roughly one million people and means services can be designed to cut across diseases and thus be more integrated into the national health system. Preliminary discussions around partnership between IDF-LFAC and PIH began while we were there, focusing on how the work already done by IDF-LFAC at district level can provide a basis for seeding a more integrated team. Thus, the focal points that have been trained in T1D care and management could be trained in other tasks to do with complex, chronic care and would be employed full time. It would be interesting to see how this partnership develops.

One of the other advantages of working in partnership with other NGOs is that they can come together to 'lobby' for better services and support from the government. This only works if the partners agree to support each other and not 'compete'. This approach was successfully seen in practice in Rwanda with the Minister of Health, Dr Agnes Binagwaho, where she recognized the importance of IDF-LFAC in supporting the RDA in raising awareness of T1D, training health care workers and producing culturally appropriate educational materials.

Data and Register

LFAC has also had a considerable impact on the RDA's ability to do record keeping and data management. This support has been provided by Dr Trevor Orchard, Professor of Epidemiology at Pittsburgh University and Deborah Edidin, from Feinberg School of Medicine, North Western University. Students linked to Trevor's program have come out every year to assist in setting up a register and do research on T1D, thus enabling the RDA to maintain an up to date register of all patients seen in the IDF-LFAC program. An electronic data system has been developed. Most other countries are still using paper based systems and some of these are variable in quality. Consideration needs to be given as to whether the Rwanda developed system is transferable, or if not whether the principles could be transferable to other countries to develop their own data systems. For example an electronic system was being developed in the Philippines that might benefit from learning from Rwanda's experiences.

Thanks to IDF-LFAC's support, the RDA has been able to act as an advocate for children and young people with T1D, particularly with the Ministry of Health, as

they have the evidence of the burden of disease from the data capture and information gathering and research (albeit small in comparison to other chronic disease). This is a powerful tool.

The Minister of Health seemed interested and supportive of the IDF-LFAC partnership model and recognized the benefit that was being delivered to children in Rwanda, many of whom would otherwise have died. However, she was also keen to see how the IDF-LFAC program could be better integrated into the national health system.

Recommendations

- e) LFAC adopts a more flexible model of support and aims to provide what is needed in the country. IDF-LFAC undertakes a basic needs assessment with a number of key individuals to find what is needed in each country to improve diabetes care and management for children and YP.
- f) The model of delivery adopted by IDF-LFAC in Rwanda, using the Diabetic Association as a 'route' into the system and using the existing health service systems for delivery is a good one. Continued/further integration within the existing health system is recommended.
- g) Building on the work already done at the district level, in training HCW about T1D, but exploring whether the district 'focal points' can be trained in wider chronic disease management, as is intended by the MoH, may be worth considering in order to 'mainstream' the IDF-LFAC program and T1D care into the local health services.
- h) LFAC needs to consider whether they need to 'review' the needs of the country on a regular basis, say every 4 or 5 years, and to develop an approach to carry this out.
- i) Further population awareness raising about T1D is still needed. The RDA have been active in radio and newspaper interviews etc. Many 'misunderstandings' / beliefs and stigmatization still remain in the population and more needs to be done to tackle discrimination. RDA and IDF-LFAC should consider what mechanism of awareness raising could be put into effect, possibly using new social media approaches, or more conventional methods such as churches, radio and TV, volunteers etc. IDF-LFAC could do more on advocacy training, identifying young leaders who could go on to become champions, raising awareness both amongst the general population and with MoH. Utilizing potential political champions (e.g. MPs with T1D) or local celebrities to speak out about living with T1D could be explored.
- j) With the expansion of the IDF-LFAC program to all the district hospitals there may need to be additional nurse support to ensure the 3 monthly visits and clinic checks can be carried out. Funding for additional staff such as psychologists, nutritionists, educators also need to be considered.
- k) Several countries have differing models for developing YP to be self-sufficient. Rwanda has the Diabetes Education Centre, India (Nagpur) has a 'rehabilitation' program and educational scholarships, Bangladesh has a program focusing on developing skills to repair mobile phones, and Tanzania has a microcredit approach. These four models should be evaluated and lessons learned for other countries.

- l) The approach of ensuring that YP are self-sufficient by the time they are 25 is critical to the sustainability of the IDF-LFAC program. Mechanisms for achieving this need to be supported and propagated.
- m) IDF-LFAC is willing and able to work in partnership with other NGOs etc. in a flexible and pragmatic way. They are generous in spirit and use their (combined) resources to best effect. This is a strength of IDF-LFAC and its approach and should be continued. In addition, multiple partnership working provides an opportunity to 'pilot' and evaluate such joint venture approaches.
- n) Similarly partnerships with other capacity building organizations or 'self-sufficiency' mechanism such as vocational training should be explored (e.g. Oxfam in Rwanda has programs in supporting capacity building in young people and in micro financing models, which could link to the Diabetes Education Centre.
- o) Consideration needs to be given as to whether the data and register system developed in Rwanda is transferable, or if not whether the principles could be implemented in other countries to develop their data systems. For example an electronic system was being developed in Philippines that might benefit from learning about Rwanda's experiences.
- p) The approach to data system development, i.e. using external academic 'experts' and their teams also needs to be considered for replication. There are considerable win wins possible.
- q) The RDA, with IDF-LFAC's support, has been able to act as an advocate for children and young people with T1D, particularly with the Minister of Health, as they have gathered the evidence of the burden of disease from the data capture and conducted research. This is a powerful tool. This should be considered as an approach elsewhere to ensure sustainability.

Appendix 4 Jamaica country visit

21st – 26th July 2014

Context and health services

Health services in Jamaica are a mix of private and public provision. In the public sector, health services are delivered through a network of primary/secondary/tertiary care facilities, comprising of 24 hospitals and more than 340 health centers. The facilities are managed by four regional health authorities and located across the island's 14 parishes.

Some institutions provide both private and public services, for example the University of the West Indies (UWI) provides both, and often supports those who cannot afford more expensive care packages in an informal way.

NCD is now the leading cause of mortality and morbidity in Jamaica. To help address this issue, an NCD Committee was formed in 2012, bringing together representatives from relevant line ministries, NGOs and civil society. An NCD program is 'work in progress' but is focused on adults.

The government is facing huge challenges in terms of health financing which currently stands at between 2-3% of GDP. Two years ago, Jamaica was re-classified as a lower middle-income country. This reduced the country's eligibility for highly concessional loans and grant assistance. To make matters worse, the government has to pay roughly 50% of its income on repaying an IMF loan, as well as having to adhere to strict conditions re the hiring of new staff. One hospital we visited had been asked to make substantial 'cuts', including for emergency services.

In 2003, the Government set up the National Health Fund (NHF) to help individuals living with chronic disease access essential medicines. The NHF covers 15 chronic diseases, including T1D; with an NHF card, patients living with T1D are entitled to get insulin, a glucometer and the first batch of strips, as well as HbA1c 4 times a year, provided they use public hospitals and pharmacies. If accessed elsewhere there is a co-payment.

In reality there are many problems in making this happen. Patients have to 'register' in order to have access to the NHF, there appears to be a reluctance by some to do so and for others they do not have the necessary documentation, for example a 'tax number' is needed to register but many families are single parents and are surviving in the 'black' economy. The public health system also appears to be overwhelmed with long queues and waiting times, limited stock and intermittent supplies, with insulin sometimes not available. Families end up being forced to use the private system and paying for their medication and strips. In addition, the patient will often see different clinicians each time and some may be not very experienced in T1D. Owing to a shortage of health personnel in some of the public hospitals, medical students are sometimes servicing the clinics. Hence the 'government system' is unpredictable, understaffed and often overwhelmed and there is little continuity. In effect it is often 'inaccessible'.

In Jamaica, pediatric services only deal with children up to age 12. They are then transferred to adult services. Some pediatricians, notably in the private sector,

'hold on' to their patients until they are in their late teens, in order to provide the continuity and appropriateness of care needed. In general, however, this means children are transferred over with no relationship history with a particular doctor and as the system is paper-based, leads to patients getting 'lost to follow up'. In more rural areas, by contrast, with smaller services and a limited number of clinicians, there are often better 'connections' between pediatric and adult doctors and so there is less concern about handing the patient over at age 12.

Due to this early hand over age, there was little focus within the IDF-LFAC program on children and young people in late adolescence or early 20s and the 'age out' issues at age 25 did not seem a significant issue. However, there was concern that the poorest and most vulnerable families would not be able to afford medication. One doctor we met - endocrinologist Dr Marshall Tulloch Reid, from the University of the West Indies (UWI), said he paid for medication and testing for a number of patients who could not afford them. He is also setting up a special adolescent clinic at UWI to help address the particular challenges faced by this age group.

Everyone we spoke to was extremely positive about the IDF-LFAC program. Clinicians spoke of improved home testing and monitoring by patients, improved consistency both in terms of supplies and in HbA1c testing in health settings and better access to medication for resource poor families. The Senior Medical Officer at Bustamante Hospital for Children said "LFAC has made us more structured - in documenting cases and monitoring - children have their own glucometers and they come to the clinic with their log book. Both the dietician and the pharmacist have records of the patients so it has improved our own data collection of diabetes patients." The Ministry of Health recognized that the presence of IDF-LFAC had raised awareness of T1D and, together with other partners, had helped with starting to develop a patient register.

Thus, IDF-LFAC fills a necessary gap and was generally welcomed and thought to be necessary for the next 5 - 10 years at least. There appeared to be little prospect of the government system providing more reliable and comprehensive services within that timeframe.

LFAC Delivery

The 'context' and how health services are provided in each country is important and the IDF-LFAC team is flexible to accommodate this, whilst remaining focused on what it does best i.e. ensure children and young people have access to treatment and management of their T1D.

As elsewhere, IDF-LFAC is delivered/ coordinated/ managed through a national body - in this instance the Diabetes Association of Jamaica (DAJ). The DAJ implements the IDF-LFAC program through the two main pediatric hospitals in Kingston (Bustamante Hospital and UWI) and through public hospitals and clinics in a number of different parishes geographically spread across the island, i.e. through existing health service delivery mechanisms. Most of the ten centers have between 15 and 20 children covered by the IDF-LFAC program but in a few places there are more, e.g. Spanish Town has between 35 and 40. Overall Kingston seems fairly well provided with health services but it's a different story in the more isolated rural parishes.

Even though access to T1D treatment is possible for those who cannot afford to pay privately (through the NHF), this does not appear to work well in practice. In theory under the NHF, patients living with T1D can get insulin and syringes for free, plus one glucometer and a few strips (with co-payments). The patient then has to buy more strips. IDF-LFAC fills the gap for children and young people by providing both insulin and glucometers and strips etc. However the glucometers that IDF-LFAC provided are a different brand to the government ones and use different strips. This has created the potential for confusion.



Visiting an LFAC beneficiary and her family in Jamaica

As IDF-LFAC's implementing partner in Jamaica, the DAJ is responsible for dealing with the mechanics and custom transactions of the delivery of supplies and their distribution to the ten centers supported by IDF-LFAC. The quantities delivered are based on a simple 'list' of children provided by the pharmacist from the relevant hospital/clinic. Some of the 'systems' for maintaining such records seem somewhat ad hoc. Both the delivery driver and the nurse coordinator at DAJ have good relationships with the clinics but overall coordination and record keeping of the program needs to be improved. Clinicians spoke of limited communication, feedback and follow up about the IDF-LFAC program from DAJ staff and little information sharing. "We need an administrator who comes and checks on things," said the Senior Medical Officer at Bustamente Hospital.

More capacity building/training is needed. Some nurses have been educated in T1D (funded by the NHF and coordinated by Professor Tulloch Reid at UWI) but they have only attended short courses (1 and ½ days) so their depth of knowledge is minimal. Also, there appears to be little rationale as to who is selected to attend these courses. Often when they return to their hospital base they are working in A&E or theatres or on other wards but not on the pediatric wards so they are not available to 'educate' the children and YP and their families. Some agree to do so but this is ad hoc and not organized in any formal way.

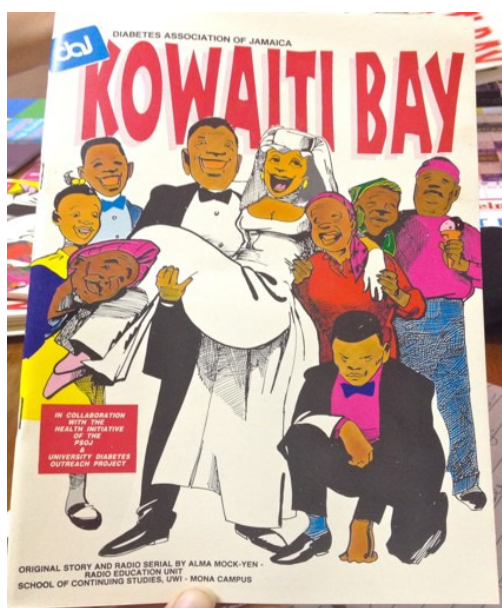
Whilst children and YP living with T1D are seen by a clinician and by the nurse manager/coordinator at DAJ, additional psychological support is needed for the more vulnerable children. This is especially noticeable as there aren't enough nurse educators who have the right training.

More education and training is needed both for children, YP and their families and for professionals. There is a need for more appropriate teaching/educational materials. Jamaica is not, apparently, a 'reading' nation and hence videos, cartoons, comics, or picture books would be more suitable. The 'Bumblebee' video was enjoyed and welcomed, but as some children do not have access to DVD players, computers or the internet it would be good to diversify the materials into formats that can be easily accessed. These can be adapted from IDF-LFAC's educational materials and made relevant and appropriate to a Jamaican audience.

One popular activity run by the DAJ is an annual 'Diabetes Camp'. The main aim is to educate children and YP about their diabetes and its management. It also provides an opportunity for those living with T1D to meet each other and share experiences. The camps last a week and are run by a psychologist and are not cheap. However, children who can't afford to pay for the fees are helped financially either by staff at the DAJ, or by sponsorship from elsewhere.

There is also another diabetes camp "Yellowbird" (PHOTO) which used to be run by the DAJ but is now run separately, some children had attended both, some children had not attended either.

Many of the children and young people and their families were unaware that the IDF-LFAC support will end at age 25. This could be for a number of reasons. When children and YP are transferred to 'adult' services at age 12, many disappear into the system and are lost to follow up after that time. Some of the doctors involved in the IDF-LFAC program did not know that the support ends after the age of 25 and recognized that much more advocacy and awareness raising both about the IDF-LFAC program and about T1D was needed amongst the senior management in health services (e.g. district and regional medical officers) across the island.



Culturally appropriate educational resources

Data and Register

There was a paucity of information about the children receiving support from IDF-LFAC. The amount of insulin and supplies was based on a somewhat ad hoc set of 'lists' from the 10 health centers/clinics.

DAJ did not seem to recognize their role in data collection and tracking supplies and in 'requiring' this from the delivery clinics. Indeed some of the clinicians were either unaware of the need for annual returns on each child or had not been asked for them. This is not much to ask in return for IDF-LFAC support. Where data is collected, it is recognized by clinicians as helpful in stimulating 'better' record keeping, and it provides useful information on the pattern of the disease over time and on the burden of disease. DAJ and IDF-LFAC should

consider how they can achieve better records and use the 'leverage' of the support from IDF-LFAC to achieve this.

A national (paper based) diabetes register was started with initial support from various partners, which was acknowledged by the Ministry of Health. However it appears the project ran out of funds in December 2013 and is not being progressed. It would seem worth considering whether further support to this venture would be beneficial.

Recommendations

- r) The overall management, coordination and record keeping of the IDF-LFAC program in Jamaica needs to be improved. DAJ and IDF-LFAC should consider how they can achieve better data collection and record keeping and use 'leverage' of the support from IDF-LFAC to achieve this as quid pro quo. An external 'expert' (Dr Larry Deeb) is been identified to visit Jamaica and identify how to address this issue.
- s) More capacity building/training is needed, particularly for nurse educators, many of whom only have very limited training. Those who have been trained should be enabled to give support to children and their families, rather than, as at present, when the trained 'educators' are working in other fields in the hospital and are not available to pediatric wards. Appropriate psychological support is also needed for some children.
- t) Educational materials need to be adapted for Jamaica in order to be culturally appropriate e.g. as pictures/ comics/ cartoons etc.
- u) Diabetes camps are well received and valuable to the children. However consideration should be given as to whether something more systematic/ substantial could be done for all the children and YP with T1D.
- v) Further support from IDF-LFAC for the national register to be developed should be considered. This could be generated from expert volunteers (similar to what has happened in Rwanda) who could work on improving data collection and establishing a proper register.
- w) LFAC to undertake a review of what support is needed in the country. Is it really insulin or would the educational aspects be more important? It may be that different support is needed in Kingston than in more rural areas/parishes.

Appendix 5 Mexico Country Visit

October 26th – November 3rd 2014.

Context and Health services:

Mexico is an upper middle-income country with a reasonably robust yet fragmented health service. It has the second largest economy in Latin America and has a population of around 116 million. Despite this, prosperity remains a dream for many Mexicans and the socio-economic gap between the rich and poor remains wide.

In terms of health financing, the majority of the population is covered by one of several insurance schemes with the private sector playing a significant role in the supply and financing of health-care services.

The main insurance schemes include:

- ISSSTE (for government and public sector workers)
- IMSS (for most of the working population)
- Seguro Popular (for those in low paid jobs or not covered by the other insurance schemes)
- Private (small sector)
- 5. Others (covering the military and oil industry workers)

Decisions about what is available through these various insurance schemes appear to be made both at 'federal' and at 'state' level.

In respect of Type 1 diabetes (T1D), access to insulin is routinely covered by the various insurance schemes, but the type of insulin may vary from scheme to scheme and place to place. Glucometers and strips to test blood glucose levels and other equipment (e.g. syringes/ lancets) are usually not available through the public insurance schemes, and patients often have to buy them.

However, concern was repeatedly expressed about the unreliability of government-supplied insulin both in terms of quantity (intermittently unavailable), variety (specialist types prescribed to children were not provided) and quality. There was a perception that the 'Chinese' manufactured cheap insulin that was provided made control of T1D more difficult to maintain.

A national strategy on diabetes and obesity was developed in 2013, with strong political support from the President, but this focuses mainly on Type 2 diabetes (T2D) in adults, and there is little or no attention to T1D in children and young people. Children's health services remain more focused on infectious diseases than on chronic conditions.

The country is relatively rich and some people (but not all) said that there was no reason why the government (through the public insurance schemes etc.) shouldn't provide all that was necessary (i.e. including glucometers and strips) within a few years' time. However many thought this was unlikely in the 'near future'.

LFAC has not been seen as providing any 'leverage' or influence to encourage the government to better support children with T1D. However, several people we spoke to understood the 'potential' to influence the political agenda and that this could be achieved through some of the leading clinicians.

Federacion Mexicana de Diabetes:

The Federacion Mexicana de Diabetes (FMD) was set up in 1988 and acts as an umbrella body for diabetic associations in the country. They acted as our 'host' and their coordinator travelled with us on all the visits. Diabetic associations have been set up either in individual states and municipalities and function independently. Some are affiliated to the Federacion and some are not. The first diabetic association was set up in 1972, in Monterrey, by Maria Levy. She has been active in diabetes care for many years and is a past president of the IDF (she was the first woman and first 'patient' president). She was diagnosed with T1D at the age of eight. She was instrumental in recognizing the need for insulin for children with T1D, in developing countries and the instigation of what became the IDF-LFAC program.

Local/ State Diabetic Associations:

Visits were made to diabetic associations and related services in each of following places:

- Mexico City
- Monterrey
- Merida
- Cancun

Diabetes associations provide education and support to children with diabetes (mainly type 1) and their families and they also support the general population with type 2 diabetes. Most associations have nutritionists, educators and podiatrists, many of whom work on a voluntary basis.

The state and municipality diabetes associations are run by passionate lay individuals, often parents/mothers of a child with T1D. They fund raise locally to support their work, and often rely on 'benefactors' (e.g. 'donations' of premises or transport). They are often able to 'tap into' the local affluent population.

Not all states have diabetic associations and it is often the poorer states, potentially with more 'need', who do not have them, or have very small associations with little capacity.

The associations providing IDF-LFAC support (four at present and hopefully two more - Cancun and Acapulco - soon) are those that have 'capacity' to manage the IDF-LFAC program rather than where the greatest 'need' (poverty) is in the country. In the poorest regions there are not viable diabetic associations. There is recognition that IDF-LFAC support is not based on a comprehensive 'needs assessment'. It does, however,



Sugar free mini Obleas with FMD logo

support the most underprivileged children in the states/centers where its programs are running. We suggested to the FMD should consider whether they could 'stimulate' diabetes associations or increase capacity in poorer states/areas.

The FMD has been innovative in developing fund raising mechanisms. One such scheme involved companies paying for certain 'diabetic' foods to be 'approved' by the FMD e.g. "Sugar free mini Obleas"

Discussions were also held with clinicians, partners and beneficiaries of IDF-LFAC including:

- specialist hospitals/endocrinologists who provide the clinical services to children and young people with T1D
- BD – a company that manufactures needles and syringes and provides some information and training to diabetes 'educators'
- NIPRO – the company that provides glucometers and strips for children, via IDF-LFAC
- Farmacias del Ahorro – a pharmacy chain that provides financial support to FMD and medical consultation services in their pharmacies.
- Children and young people and their families

LFAC delivery

LFAC has been providing support to Mexico since 2012, so it is one of their newest country programs. Support consists of providing NIPRO glucometers and strips (to test blood glucose) and educational materials for children and their families via the diabetic associations.

FMD felt that they had an upper limit of 200 children that could be supported by IDF-LFAC. Whilst IDF-LFAC claim that there is no upper limit, there may be a 'de facto' limit to the support IDF-LFAC can offer depending on resources available. The support here is not for basic insulin etc. provision but for more sophisticated management of T1D.

The number of IDF-LFAC supported children is divided between the diabetic associations involved:

- Monterrey – 65
- Guadalajara – 50
- Merida – 25
- Guadajuanto – 50
- Total = 190

When we visited, Cancun did not have IDF-LFAC support but were hoping to get it once the required paperwork had been put together for approval. Since then, IDF-LFAC has confirmed that both Cancun and Acapulco are now on the program.

The main aim of the diabetic associations is to provide children and families with the knowledge and ability to be able to manage their diabetes and live 'normal' lives. This revolves around frequent blood glucose testing and modifying diet and insulin to achieve 'control'. The children have HbA1c tests regularly (every three months, usually at the diabetic association) and the aim is to get the results below eight.

LFAC provides support for ‘managing’ T1D (glucometers and strips) that would not otherwise be available unless the families paid for them themselves (basic care including insulin is provided by the government). Therefore, IDF-LFAC’s support means the system can provide ‘better ‘ service and improved management and control of T1D rather than attending to basic needs.

There is a strong focus on educating the child and family to manage their diabetes and on ‘**co responsibility**’. This means the child and family need to ‘sign up’ to fortnightly educational sessions (and cooking classes etc.) at the diabetes association, and in return they receive a



Visiting an LFAC beneficiary and her family

glucometer and strips. If they fail to attend they are ‘struck off’ the program. Whilst this has its value we questioned whether there is a risk that the most ‘vulnerable’ children (e.g. from dysfunctional families or without family support etc.) may be abandoned. They recognized the point we were making. In practice there is evidence that informally they do support children in these circumstances, including diabetic association staff personally supporting children with travel money to encourage them to attend the diabetic association clinics.

It is worth considering whether the co-responsibility model (that uses IDF-LFAC support as a ‘leverage’ mechanism) could be transferred to another country program.

Each diabetes association has a ‘waiting list’ of children who could be on the IDF-LFAC program. Clarification is therefore needed re the maximum number of children that IDF-LFAC can support.



Visiting specialist hospital INP in Mexico City

In some more rural areas where health services are ‘thin on the ground’ there are some government run mobile services “Caravan”). This might provide a mechanism for children from more deprived backgrounds to be reached. These services often support the rural deprived populations of Mayan origin.

Summer camps have been run for some time and are clearly appreciated by the children and young people. These are sponsored by local businesses or individuals so children and families do not have to pay, or may make a small contribution. As in other countries, these provide an excellent opportunity for children to learn about diabetes and its management, but also to meet other children and YP with T1D, often for the first time.

As IDF-LFAC has only recently been active in Mexico, none of the young people are close to 26 years old so issues relating to 'graduating' from the IDF-LFAC program have not arisen. Most children and YP are in education, training or jobs by their late teens so this may not be an issue. In at least one of the diabetes associations the children are only expected to be supported until the age of 18.

Data and Register:

There is consistently good record keeping and data feedback to IDF-LFAC. The Ministry of Health aims to produce a national 'diabetes register'. This would cover adults at first and eventually will also include children. Currently incidence and prevalence figures are unknown.

Recommendations:

1. The Federacion (FMD) and IDF-LFAC should consider whether they could 'stimulate' diabetes associations to be developed or increase capacity in poorer states and more deprived areas, where underprivileged children with T1D are not currently receiving IDF-LFAC support and where services may be poor. Support from either Lilley Mexico or from rich entrepreneurs (e.g. Telecom millionaires) should also be considered by FMD.
2. The 'co-responsibility' model that uses IDF-LFAC support as a 'leverage' mechanism to ensure engagement of children with T1D and their families appears to be effective. Consideration should be given as to whether this approach is transferrable elsewhere.
3. There needs to be clarification about the 'upper limit' number of children and potentially whether more children may be able to be supported within the current IDF-LFAC 'envelope' of support.
4. FMD and Diabetes Associations should consider whether they can 'piggyback' on the rural 'caravan' that provides health services to reach more deprived children.
5. Given Mexico's economic position, the 'government' should be able to provide better support to children and young people with T1D. Consideration should be given as to how IDF-LFAC, or IDF regional office can work with other local leaders and the FMD to encourage the government to do so, using information from IDF-LFAC delivery on the burden of disease.
6. The lack of a country wide 'needs assessment' prior to the start of the IDF-LFAC program is demonstrable. Both FMD and IDF-LFAC recognize that they are not meeting the needs of the poorest. Consideration needs to be given to the 'needs assessment' process and how IDF-LFAC can better base its program support where most needed.

Appendix 6 Philippines Country Visit

10th-17th December 2014

Context and government health system:

The Philippines is a low-middle income country in the South East Asian region, comprising over 7100 islands and a population of 94 million.

Given its geographic location in the Western Pacific, the country experiences typhoons, earthquakes and volcanic eruptions on a regular basis, making it one of the most disaster-prone areas in the world. Much of the country is mountainous and the population, made up of more than 180 ethnic groups is dispersed over a wide area. In the south, conflict breaks out intermittently.

In terms of health, the Philippines faces what is termed the 'double burden of disease' where both infectious diseases and non-communicable diseases are leading causes of mortality and morbidity. Despite these challenging conditions, over the last 40 years, indicators of health status have improved dramatically with infant mortality dropping by two thirds and life expectancy increasing to over 70 years. However, considerable inequities in health care access and outcomes remain. Life expectancy in richer provinces is more than 10 years longer than in poorer ones.

The country has a complicated, heavily decentralized and fragmented health system. Over time a dual system of public and private provision has evolved with both operating on a fee for service basis (the latter is subsidized through the national health insurance agency PhilHealth). Public services are used by the poor and the not so poor; the private sector is used by around 30% of the population who can afford fee for service payments. In terms of health financing, around one third of health services are paid for by the government, more than 50% from out of pocket payments and the rest is a combination of private sources and social insurance.

In the private sector, individuals are covered either by private health insurance (paid for by employers) or having to pay themselves. PhilHealth, which previously only covered the working population, is open to all (without contribution) and is free to the poor and, since 2014, the elderly (60+). However it covers only a proportion of hospital costs (around 20%) and does not cover outpatient fees. The 'poorest of the poor' (i.e. approximately the bottom 10%) are 'enrolled' by local government, but this is variable from place to place. Some underprivileged patients in this category have been given local 'grants' (often just one off funding) but it appears that decisions are made more by 'who you know' than any strict criteria. Conflicts of interest in all levels of government are common.

Only some hospitals are 'accredited' to deliver PhilHealth. From 2015, insulin is supposed to be available in outpatient clinics as well as 'in' hospital. (NB there are elections in 2016 so there may be other changes to the health system as a result). The Pediatric General Hospital in Manila is open to everyone. Some 'private' hospitals offer charitable support to the poor.

The main urban areas are better supplied with doctors and health services. This is especially true of subspecialties such as endocrinologists, diabetologists and pediatric endocrinologists. There is considerable migration of Philippine health

care workers to other countries, including UK. It was reported that some Philippine trained doctors are currently migrating to UK and elsewhere to work as nurses. This is an added drain on staffing in the Philippines.

Nationally and through Ministry of Health discussions, the sort of 'support' provided by IDF-LFAC and others is seen as acceptable as long as they do not try to dictate or influence policy and there is no conflict of interest. There is a recognition that the government is not able to provide all health services needed although universal coverage is a desired end stage.

LFAC support:

LFAC currently supports 35 children (p.a.) in three centers in the capital Manila:

1. PSEDM (Philippines Society for Endocrinology, Diabetes and Metabolism)
2. ISDFI (Institute for Studies on Diabetes Foundation Inc)
3. PGH (Philippines General Hospital)

Some of the children receive partial support (e.g. only insulin) and some full support (e.g. insulin, meters, strips +/- syringes). One hundred and ten children in total have been supported by IDF-LFAC since 2001. The centers apply criteria such as the economic situation of children and their families, to identify who should receive assistance.



Department of Health, Philippines

HOPE WorldWide (Hope WW) coordinates the overall IDF-LFAC program. Dr Rosa Sy initiated the support from IDF-LFAC (2001) when she was President of the PSEDM, following discussions with Graham Ogle. IDF-LFAC provides funding for local purchase of insulin and supplies. Dr RS has negotiated a good price for insulin etc. from the manufacturers.

Originally the three centers took the decision that the doctors would maintain records/ provide data to IDF-LFAC etc., and in this way the available IDF-LFAC funding could be used to buy insulin to support more children. However this approach did not work very well and so now they have appointed a nutritionist to coordinate and collate the data.

'Conditionality' is a strongly held theme. In all three centers they expect the children to learn how to manage their T1D, to attend clinics and to show improvement in their HbA1c results. If not, then children are removed from the IDF-LFAC program and the 'place' goes to someone else.

Additional support for needy children is provided by a number of other charities e.g. 'Adopt a Diabetic Child' and from PHARMA (pharmaceutical industries) and

also from local government but it is patchy, so the doctors 'box and cox' as to who gets what from which program. This flexible system seems to work reasonably well.

There are 20 pediatric endocrinologists across the Philippines, mainly based in urban areas (Manila) and 200 – 300 adult endocrinologists. Each of the IDF-LFAC- supported centers provides education to their alumni. In general, diabetologists have good contacts with other diabetologists etc. so they do not see the need for any 'peer' support from other countries via IDF-LFAC.



Interviewing LFAC beneficiaries and their families, Philippines

PSEDM is a 'professional association' for endocrinologists/ diabetologists. They recognize that their role includes building relationships with and 'lobbying' government for more resources for diabetes. They do not expect IDF-LFAC to do this. IDF-LFAC has not tried to influence Ministry of Health policies.

Internal 'leadership' support is seen as important. For example ISDFI has a program to support rural and family doctors to be able to take local leadership over diabetes.

PGEDM is starting, at the request of IDF-LFAC, to provide support for a few children outside Manila e.g. in Cebu (one of the central islands) through their trained alumni. But there are challenges in providing the insulin and to organize transport etc. It remains much easier to concentrate in Manila, but these are not necessarily the most needy children.

Camps for children that teach them how to manage their T1D are popular among children and their families. Each center runs their own camps, usually supported by volunteers and sponsors etc. However there is no follow up with the children afterwards and no mechanism for them to stay in touch with each other.

Where there is contact between families and children with T1D, (e.g. by chance in clinics and through 'camps') this is taken up with enthusiasm. Parents also expressed a wish to be 'in touch' with other parents of children with T1D.

Social context

Diabetes associations or clubs do not appear to exist. Patient empowerment and peer support for any disease is not common and may not be within the Filipino culture.

It was suggested that diabetic clubs/associations may be able to be stimulated via HopeWW or via the church which has a strong influence in the country.

Data and information

The incidence and prevalence of T1D in children and young people is unknown. Surveys that have been carried out have been for adults. It is generally

considered likely that most children with T1D across the Philippines are diagnosed and treated even if they have to pay. However, given that there are few skilled staff and limited supplies in the rural and more remote island areas, if there are children diagnosed with T1D, they are unlikely to do well.

HOPE WW provides IDF-LFAC with data annually (with the exception of 2013). With the new appointment, HopeWW were about to collate the 2014 data following our visit. PSEDM has recently set up a database for children with T1D, which includes all the relevant clinical and other data. This could potentially be used for overall data collation, but at present is only starting to function within PSEDM. Consideration should be given by HOPE WW and PSEDM together with IDF-LFAC as to the most cost effective way to maintain data collection.

In 2008, a modified version of the RAPIA needs assessment was undertaken by Michiyo Higuchi (Higuchi 2010) and David Beran (Beran and Higuchi 2013). Unfortunately, those we met were unaware of this initiative/research and did not recollect being part of the process, although the methodology might imply that they should have been. The RAPIA approach provides a comprehensive needs assessment on both T1D and T2D but does not focus on children and YP. However, where it is available, it would provide extremely useful data on the status of provision and care for people living with T1D info and could be used to inform the needs assessment undertaken by IDF-LFAC.

Recommendations:

1. Having 'conditions' attached to IDF-LFAC care and support appears to function well as it develops a culture of reciprocity where children and young people 'agree' to learn how to manage their T1D and show improvement. This approach should be considered in other countries.
2. There are clear benefits when children and YP living with T1D are put in touch with each other. Similarly parents would welcome peer support. More could be done to build these relationships beyond the camp setting. This could be facilitated by HOPE WW or possibly through the churches. Lessons learned from other countries could help inform this development.
3. PSEDM may benefit from hearing about other countries who have set up their own databases before setting up their own. The database could potentially be used for the whole IDF-LFAC program in the Philippines and not only the PSEDM part. This also needs to be reviewed in relation to the IDF-LFAC database. HOPE WW and PSEDM together with IDF-LFAC need to consider the most cost effective way to maintain data collection, and ensure there is not duplication of effort.
4. Further investigation into the modified RAPIA need assessment that was carried out in the Philippines may be beneficial in identifying 'need' more robustly and thus ensure support is given to the most vulnerable.

Appendix 7 India (Nagpur) Country Visit

3-11 January 2015.

Context:

Nagpur is a large city in the state of Maharashtra right in the center of India. India is the world's largest democracy, the second most populous country after China and a multi-lingual federal state. It has a national Non Communicable Disease (NCD) strategy which includes diabetes, (mostly T2D), obesity, cardio vascular disease (CVD) and stroke. Whilst this is a national program it is the responsibility of the individual states to decide on priority areas, how resources are spent and then to implement. States hold the health and health care responsibility. There are effectively no health insurance schemes. Everybody pays to see a doctor and for hospital visits. A tiny proportion - 1 – 2 % of the population, have private health insurance.

Government health system:

A government health system exists but it is intended for those who cannot afford private payments, and is mainly focused on hospital care. The structure of this government system includes local community 'district' services and cascades up through to district/area hospitals. Children with T1D may be diagnosed through this system but are usually referred to the local district hospital, as the community level is unlikely to have the expertise. The state (Maharashtra) Ministry of Health said that insulin is available through this system. However this was not the experience of many of the children and families we spoke to.

In the past, insulin was available both in hospitals but also in outpatient clinics, but patients would only be given enough for 15 days (sometimes one month) and the patient would then have to return and re attend the outpatient clinic. There were long waiting times and often insulin was not available, as it had run out.

In general, although the state government is supposed to provide insulin for people with T1D, patients either have to pay for their own or, if they can't afford it, rely on charities and NGOs to provide assistance. This is done on an ad hoc basis, with no mechanism to organize this in any coordinated way. It is likely that there are similar arrangements in other parts of India, but no systematic information is available. These charitable arrangements are often dependent on the local doctors' attitude/philanthropy etc.

LFAC supports nine centers across India covering approximately 1500 children and young people.

LFAC delivery in Nagpur:

The LFAC program is integrated into the work of Dream Trust (DT), a charity that was set up in 1995 by Dr Sharad Pendsey, a diabetologist, and his wife, following the deaths of two girls diagnosed with T1D. DT's work focused on primarily girls who were underprivileged and had no access to or could not afford to pay for insulin. (Dr SP and Dr GO met at a conference where SP presented a paper on DT and the support provided to underprivileged children.)

DT provides a package of treatment and care, similar to that provided to private patients, (although private patients may be able to afford more modern technology such as insulin pumps etc.)

The LFAC and DT clinics take place two days a week, the rest of the time is for private patients. The clinic team is made up of nurses, educators, administrators, and social workers and all are available to all patients. Patients who need care are given it, and either supported by LFAC or by DT / sponsorship etc. There is also a further trust set up - the Pendsey Trust, which similarly raises funds for diabetes treatment.

Children and young people (YP) are usually 'referred' to DT, either by another physician/ diabetologist (often soon after first diagnosis) who knows of DT support to poorer patients or by word of mouth. DT also advertises its activities in local newspapers and these are a source of self-referral.

DT raises funds in various ways including support from the UK, Austria and elsewhere and sponsorship. (www.dreamtrust.org)

LFAC has supported DT since 2002. They started off by helping 15 children, now 45 children and YP are supported by LFAC each year. LFAC does not provide actual supplies, but gives funding and DT orders insulin and other supplies locally. Funding provides for a full package of support including insulin, glucometers and strips and syringes. The children and YP are seen every three months at the DT clinic and



Meeting a group of LFAC beneficiaries at the Dream Trust

given supplies for 3 months (more frequently as necessary, during initial stabilization period etc.). Children and YP are asked to bring back empty vials and syringes (to ensure they are not 'selling' insulin or syringes).

The clinic has good systems in place to record who receives what insulin etc. Insulin is ordered weekly from a local distributor and arrives the day prior to the LFAC and DT clinic. The clinics are well organized and a backup supply of insulin is also kept at the clinic in case they need more on any particular day.

Whilst the majority of supplies is standard insulin, some insulin pens are provided for children to use in school. This is because many schools are reluctant to let children bring in syringes and so children were missing their afternoon insulin dose.

Previously the US charity 'Insulin for Life' provided insulin to DT, but there were problems with customs and so LFAC stepped in and provided funding for the local purchase of supplies. DT also uses the LFAC educational materials and some are being translated into local languages.

Dr SP is well known as a diabetic 'educator' and is an expert on diabetic foot. He has published papers and books, and delivers educational workshops for other clinicians throughout India. His son, Dr Sanket Pendsey, also a diabetologist, works in the same practice.

Dr SP has devised a terracotta 'pot' with a 'cooling' chamber (using the mechanism of water evaporation as a cooling effect) and lid, which can act as a 'cool box' for insulin if the patient has no access to a fridge.

Social context:

Girls and women with T1D face considerable prejudice in Nagpur. Although illegal, female infanticide and feticide is still practiced in some states, such that the women to men ratio may be 750:1000. It is also illegal to ascertain the sex of the fetus (to try to prevent abortions of female fetuses). Marriage for women is the norm, possibly in late teens or early twenties. 70% marriages are still arranged and the preference is to stay within the same caste.

Many women with T1D are rejected for marriage, although there appears to be no such prejudice against men. T1D in women is therefore often kept secret.

This leads to the need for women to be self-sufficient.

Extended support:

A number of innovative ways to extend support to children and YP with T1D have been set up including paying for travel expenses, educational scholarships, vocational training, bicycles, sewing machines, and 'rehabilitation' to enable young people to set up their own businesses and attain self-sufficiency.

LFAC provided special grant funding in 2013 and 2014 for these endeavors, most of it going to LFAC patients but some to those of DT (with agreement from GO), particularly for some 'graduates' of LFAC aged over 26.

The grants work in the following ways:

Travel: Money is given to support the child/ YP (and one parent if a child) to travel to the DT /LFAC clinic. Bus/travel receipt/ticket is required and the money signed for. (Photo) DT covers quite a large geography and travel may take up to 6 hours from distant rural areas. Most children have to travel between two to three hours.

Education: Grants are given to children and YP to continue their schooling as education is seen by DT as the key to eradicating poverty and being self-sufficient. Receipts for books, educational expenses and uniforms need to be produced and signed for and support from the principal or head teacher is required. The grants are usually between 1000 – 3000 rupees (£10 - £30).

Bicycles are also provided for some children in order to reduce the school drop-out rate, especially for girls in rural areas who may need to travel long distances to get to school.

'Rehabilitation': This focuses on older YP, some of whom may be 'graduates' of LFAC and over the age of 25. The idea is to support the YP to start a business so that they can be self-sufficient. DT has provided sewing machines, bicycles to enable the selling of goods in a particular area, a buffalo to make cheese, yoghurt or ghee to sell, help in setting up a stationery and general store in a rural village,

or a sari and jewelry shop. Funding may be provided for initial stock and set up costs etc. The individual has to make a proposal to the “rehabilitation advisory group”, an external group of business people, who will help with support and ensure a viable business plan.

Since some rehabilitation did not work very well, they have now introduced ‘**vocational training**’ including workshops on how to set up a business and mentoring from the advisory group members to ensure successful projects are supported.

Treatment of other medical conditions:

Some YP have developed complications or other medical conditions. These may be treated through support from DT/LFAC. One example is of a young woman (aged 19) who developed cataracts. These were removed using support from DT, and from a supportive ophthalmologist friend of Dr S.P. The girl had to pay a small amount and DT funded the rest. DT believe that a contribution from the patient is important for them to recognize the costs and appreciate the support they are being given.

Data and Register:

The DT and LFAC clinic keep good records and make annual returns to LFAC. It is a paper system and they would welcome any opportunity to develop an electronic database.

They are flexible as to how children move in and out of LFAC and DT support, and this seems to work well.

A National register (ICMR) of children and YP (less than 25 years of age) is being set up by the All India Institute of Medical Sciences (led by Professor Nikhil Tandon). It covers children diagnosed since 2006 and backdated to 2000. The first report is due to be published soon and covers 5540 children from 5 centers across India. It looks at treatment and follow up/ complications etc. It will be ‘representative’ but not provide overall incidence/ prevalence. This register will contribute to the global mapping study that LFAC and ISPAD are setting up.

Recommendations:

1. Lessons can be learned from a ‘can do’ attitude that identifies when children and young people (especially girls) are in need of support for their T1D and provides that support, covering costs flexibly from LFAC, DT, Pendsey Trust and sponsorship. LFAC is a substantial part of the overall DT funding.



Young man who received LFAC support to set up a general store

2. Good 'systems' are in place for record keeping and monitoring spend and ensuring any expenditure is valid with receipts etc. required. Models could be transferred elsewhere e.g. for travel and educational grants.
3. The extended support systems for education, vocational training, and rehabilitation act as a stepping stone to self-sufficiency and are worth modeling elsewhere. DT recognizes this and has put systems in place that help ensure their success. The fact that those benefitting from the grant have to contribute in some way and account for expenditure prevents a culture of dependency and encourages self-reliance. Relatively small amounts of funding from LFAC have achieved major success
4. The model of a 'nominal financial contribution' from patient/family for some special treatments (e.g. Cataract removal) should be considered elsewhere as a mechanism of engagement and ownership.
5. Learning from other electronic database systems such as the one developed in Rwanda or the one being implemented in the Philippines could be used to help DT build their own.

Appendix 8 Survey questionnaire to diabetes associations

(This questionnaire was used for the e-mail survey and during country visits)

This is a questionnaire to find out more about the International Diabetes Federation's 'Life for a Child' (LFAC) programme and their work in support of children and young people who have Type 1 Diabetes in partner countries. It is part of an evaluation conducted by the London School of Hygiene and Tropical Medicine for the Helmsley Charitable Trust, one of LFAC's major donors. The aim of the evaluation is to assess LFAC's organizational structure, programme impact and potential to catalyse long term sustainable improvements to Type 1 Diabetes delivery systems in its partner countries.

This questionnaire will be sent to all countries that LFAC supports. We would appreciate if someone from your organization can answer the questions, giving as much detail as possible. If possible, please fill out the questionnaire online at the link

<https://www.surveymonkey.com/s/29B3YYX>

It should take around 45 minutes to complete.

Where we state children and young people we refer to people less than (<) 26 years old.

Taking part in the evaluation is entirely voluntary. Your comments will be confidential and will not be attributed to you in the final report or presentations, but we may want to use quotes anonymously and we plan to list all the people surveyed, unless you tell us not to include your name/organization.

If it is not possible to do it online, please answer the questions below and then send the completed form to LFACsurvey@lshtm.ac.uk

Please feel free to add any additional comments about the impact of the programme at the end. Your contributions are much appreciated and can help inform improvements for the future.

To answer the questions below, click on the grey square and start writing, boxes will expand to fit text. For questions with a 'yes/no/don't know' answer, check the relevant box by clicking on the grey square.

NAME:

DATE:

COUNTRY:

ORGANIZATION:

Your role in the organization:

What year did you start working with LFAC?

LFAC Type 1 Diabetes Programme - Country Questionnaire

1. Children and young people reached

- a.** To the best of your knowledge, how many children and young people (under 26 years old) in your country are currently living with Type 1 Diabetes? (Please give an estimate/approximate number if you do not have a precise number)

- b.** How many children and young people with Type 1 Diabetes are supported through the LFAC programme?

- c.** Briefly describe how the LFAC programme works in your country.

- d.** Briefly describe any barriers experienced in reaching and supporting children with Type 1 Diabetes? Please consider both urban and rural areas.

- e.** Are there other organizations besides LFAC providing support to children and young people living with Type 1 Diabetes in your country?

YES NO DON'T KNOW

If yes, please state which organizations and briefly describe what support they

provide?

- f. Does LFAC partner with other organizations to deliver support for children and young people with Type 1 Diabetes in your country?

YES NO

If yes, please name the organizations involved and briefly describe the partnership.

- g. For the children not supported by the LFAC programme - Are they adequately supported by other organization(s)?

YES – Some of them YES – All of them NO

If YES (All or Some of them), by whom? (e.g.. government/other NGO/ paying themselves)

- h. Do you believe most children and young people with Type 1 Diabetes in your country are being diagnosed and given support today?

YES NO DON'T KNOW

- i. In the list below, please tick the support provided by LFAC:

	Check if YES
Insulin	<input type="checkbox"/>
Blood glucose monitoring (meters and strips)	<input type="checkbox"/>
Syringes	<input type="checkbox"/>
HbA1c testing equipment	<input type="checkbox"/>
Educational materials for children/families in relevant language(s)	<input type="checkbox"/>
Training of health professionals	<input type="checkbox"/>
Support from Diabetes experts from other countries	<input type="checkbox"/>
Other (please specify)	<input type="checkbox"/>

j. What are the three main difficulties in ensuring all children and young people with Type 1 Diabetes (under 26 years old) receive the care and treatment they need?

- 1.
- 2.
- 3.

2. Procurement and supply of Type 1 Diabetes medicines and supplies

a. Does your government provide any Type 1 Diabetes medicines, supplies or training to support children and young people (under 26 years old)?

YES NO

If yes, please fill out of the table below:

	Yes	No	Is it available to all children and young people?		Is it free for all children and young people?		Additional comments (such as co-payments or population coverage)
			Yes	No	Yes	No	
Insulin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Blood glucose monitoring (meters and strips)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Syringes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
HbA1c testing equipment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Educational materials for children/families	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Training for children and families	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Specialist diabetes training for health professionals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

b. Since LFAC started its programme in your country, has any aspect of government provision of Type 1 diabetes support to children and young people changed?

YES NO DON'T KNOW

If yes, how has it changed?

- c. Do all medicines and supplies provided by LFAC **reach** the intended beneficiaries (children and young people)?

YES NO DON'T KNOW

If no, please explain why not?

- d. Do children and young people in the LFAC programme get their medicines and supplies free of charge?

YES NO

If no, please explain why not:

- e. Are medicine and supplies **stored** appropriately so they do not go off or expire before they reach the intended beneficiaries?

YES NO DON'T KNOW

If no, please explain why not?

3. Data collection

- a. Do you have data on the children and young people supported through the LFAC programme?

YES NO

b. Does this data include:

	Yes	No
Age	<input type="checkbox"/>	<input type="checkbox"/>
Sex (male/female)	<input type="checkbox"/>	<input type="checkbox"/>
Address/Village	<input type="checkbox"/>	<input type="checkbox"/>
Education	<input type="checkbox"/>	<input type="checkbox"/>
Diabetes Management and Control	<input type="checkbox"/>	<input type="checkbox"/>
Diabetes Complications	<input type="checkbox"/>	<input type="checkbox"/>
Other medical conditions	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify)...		

c. Do you fill in an LFAC data sheet for each child each year?

YES NO

d. Do you have data that can be used to understand the diabetes-related health status, including morbidity and mortality of participants:

	Yes	No
When they start the LFAC programme	<input type="checkbox"/>	<input type="checkbox"/>
During the LFAC programme	<input type="checkbox"/>	<input type="checkbox"/>
At the end when they leave the LFAC programme (at 26 years old)	<input type="checkbox"/>	<input type="checkbox"/>
After they have left the LFAC programme	<input type="checkbox"/>	<input type="checkbox"/>

e. Is this data shared with LFAC?

YES NO

f. Has the LFAC programme in your country had an impact on data collection on Type 1 Diabetes in children and young people?

YES NO

4. Training

a. Has LFAC provided training for any of the following:

	Yes	No	Don't know
Health Professional	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Children/Young People	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Families	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Others (please specify)			

b. If yes, has the training improved any of the following:

	Yes	No	Don't know
Clinical services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Changes to insulin regimes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patient outcomes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Improved HbA1c	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patients' self-help/management of their own conditions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patients' better glucose control	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Reduction in severe episodes such as DKA requiring hospitalization	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Reduced mortality from diabetes in children and young people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Increase in regular reviews to prevent complications e.g. eye examinations, foot examinations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A reduction in complications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Delays in onset of complications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Wider awareness of diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Yours or other partners (e.g. health professionals) skills in advocacy ¹ /lobbying for support from the government	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Others: (please specify)			

Please give examples:

¹ Advocacy includes speaking out publicly in support of people living with Type 1 Diabetes to promote or support change (for example in government policy).

c. Do you think there is a need for more training for any of the below?

	Yes	No
Health Professionals	<input type="checkbox"/>	<input type="checkbox"/>
Patients	<input type="checkbox"/>	<input type="checkbox"/>
Families	<input type="checkbox"/>	<input type="checkbox"/>
Others	<input type="checkbox"/>	<input type="checkbox"/>

Please briefly describe what type of additional training is needed:

d. Does your country have National diabetes care guidelines accessible to all primary care clinicians?

YES NO DON'T KNOW

5. Impact of LFAC

a. Has the LFAC programme improved any of the following for children and young people with Type 1 Diabetes:

	Yes	No	Don't know
Numbers being correctly diagnosed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Diabetes management and control	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Wider geographical coverage in diagnosis, treatment and care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Staff training	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
General awareness in the wider population about Type 1 Diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify)			

If yes to any above, please give brief examples of how it has improved?:

- b.** In your opinion, please describe what difference (negative and positive) LFAC has made in your country towards the care and treatment of children and young people living with Type 1 Diabetes?

6. Strategy and Operations

- a.** Who initiated discussions about receiving LFAC support in your country?
(Please check one box)

National Diabetes Organization	<input type="checkbox"/>
Senior Medical Professionals	<input type="checkbox"/>
Ministry of Health	<input type="checkbox"/>
Patient(s) with Type 1 Diabetes	

	<input type="checkbox"/>
Other (please specify)	

- b.** Who was involved in establishing the LFAC programme in your country (please check all appropriate boxes)

National Diabetes Organization	<input type="checkbox"/>
Senior Medical Professionals	<input type="checkbox"/>
Ministry of Health	<input type="checkbox"/>
Patient(s) with Type 1 Diabetes or their families	<input type="checkbox"/>
Other (please specify)	

- c.** Was the LFAC programme design based on a formal assessment of need?

YES NO DON'T KNOW

If yes, please explain briefly how it was done.

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- d.** Does your organization have a formal written agreement with your government on the provision of Type 1 Diabetes care and management in children and young people?

YES NO DON'T KNOW

If yes, please send a copy to LFACsurvey@lshtm.ac.uk

- e. What impact do import taxes and customs duties and procedures have on LFAC programmes in your country?

	Yes	No	Don't know
Taxes and duties have to be paid	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Delays in delivery of medicines and supplies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medicines and supplies going out of date	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify)			

- f. If yes to any of the above, how can this be improved? Please describe briefly.

- g. How do you rate your working relationship with LFAC?

	Please check box
Excellent	<input type="checkbox"/>
Good	<input type="checkbox"/>
Average	<input type="checkbox"/>
Poor	<input type="checkbox"/>

h. How could this be improved? Please describe briefly.

i. Could the care and treatment of children and young people with diabetes provided by LFAC programme be better integrated into national health services in your country?

YES NO

If yes, please describe in what way?

7. Sustainability/long term impact/advocacy

a. How long do you expect LFAC to continue to support treatment and care for children and young people with Type 1 Diabetes in your country?
(Please click and choose from the drop-down menu)

One year

b. When do you expect your government to take over this responsibility?
(Please click and choose from the drop-down menu)

One year

If more than 10 years what is needed for the government to take over

sooner?

c. Which of the following has LFAC supported in your country?
Awareness raising in the community / Information campaigns on Type 1 Diabetes

YES NO DON'T KNOW

If yes,

how?

Advocacy with government to raise diabetes higher on the policy agenda in the country

YES NO DON'T KNOW

how?

If yes,

Advocacy with civil society, professional organizations or others to raise diabetes higher on the policy agenda in the country

YES NO DON'T KNOW

If yes,
how?

Encouraging government to take on the responsibility of care for its own Type 1 Diabetes patients

YES NO DON'T KNOW

If yes,
how?

Vocational training for children and young people to be able to be self-sufficient in managing their diabetes after leaving the programme

YES NO DON'T KNOW

If yes,
how?

Work with pharmaceutical companies to provide medicines and supplies for Type 1 Diabetes at reduced costs

YES NO DON'T KNOW

If yes,
how?

Research on Type 1 Diabetes in your country

YES NO DON'T KNOW

If yes,
how?

Other, please specify:

d. Has LFAC made a difference to the government's prioritization of providing care to people with Type 1 Diabetes?

YES NO DON'T KNOW

e. Has LFAC ever participated in conversations about diabetes-related policy and health budgeting with relevant health decision-makers in your country?

YES NO DON'T KNOW

f. What do you think LFAC could do to help the government take over responsibility for treating these children?

g. Do you work in partnership with other countries, providing or exchanging support or training?

YES NO

If yes, please describe:

h. Would you welcome a country to country peer support programme / like to work with other countries?

YES NO

8. After LFAC

- a. When young people leave the LFAC programme at 26 years old, what support do they receive in terms of insulin, glucose testing, medical care and diabetes check-ups and from whom?

	Support?		From whom?	Does young person have to pay?	
	Yes	No		Yes	No
Insulin	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>
Glucose testing	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>
Medical care	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>
Diabetes check -ups	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>

- b. Please briefly describe the main issues facing people more than (>) 26 years old when they leave the LFAC programme.

- c. Has LFAC prepared you to support people with Type 1 Diabetes after the age of 26?

YES NO

If yes, how?

Do you have any other comments on the LFAC programme in your country?

Appendix 8b Survey questions/frameworks (5) used on country visits for particular groups of interviewees.

1. Questions for Ministry of Health staff

Date:

Name:

Position:

Interviewers:

1. What are the overall funding mechanisms for health care in your country?

2 What are your priorities in terms of health spending?

3 Funding for diabetes

- a. Does the Ministry of Health have funds for the treatment and care of Type 1 Diabetes? If so, how much? If not, why not?
- b. Does the Ministry of Health receive funds from donors for Type 1 Diabetes? If so how much and from whom?
- c. How are these funds used?
- d. Do you get diabetes care/ support from other national or international organizations? If yes, please list names and briefly describe what and how they get support

4 Prevalence of Diabetes type 1 in your country

- a. Do you know how many people have Type 1 Diabetes in your country? If yes, how many?
- b. Do you know how many children and young people (YP) have Type 1 Diabetes?
- c. Do you have national guidelines for Type 1 Diabetes? If yes, could we see them? If not, why not?
- d. In what ways do you support people with Type 1 Diabetes?

5 Knowledge and opinion of the LFAC programme

- a. What do you know about the Life For A Child programme?
- b. What is your **opinion of the presence** of LFAC's support for children and YP in your country? (positive and negative)

6 Impact of LFAC programme

- a. What impact has the LFAC support had on the **geographical coverage of children and young people's diabetes care** in your country?
- b. What impact has LFAC had on the number of children being correctly diagnosed?
- c. What impact has LFAC had on the numbers of children getting the medical support they need compared to before?
- d. What impact has LFAC had on the numbers of staff being trained in diabetes care?

- e. Is the LFAC support and equipment enough to reach all children and youth with Type 1 Diabetes? If no, please describe what there is additional need for?
- f. How would children and young people access treatment and care for Type 1 Diabetes if LFAC was not there?

7 Sustainability

- a. Has LFAC helped the development of long-term sustainable improvements to T1D care delivery systems in your country?
 - i. Yes
 - ii. No
 - iii. Partly
 - iv. Not sure

If yes, how? If no, why not?

- b. How do you think sustainability of Type 1 diabetes care can be improved?

8 Influence on health budgeting, policy and advocacy

Has LFAC engaged with you in policy and advocacy discussions at the national level? If so, please describe what the discussions were about and if there was any result.

9 What are the main challenges facing children and young people < 26 years old with diabetes in your country today and in the future?

10 When participants leave the LFAC programme at 26 years old, do they get any support from the government?

- i. If yes, sometimes or partly please explain how this works:
- ii. If no, please briefly describe any main issues facing young people when they leave the programme.

11 What additional support do you think would best help you improve the care and treatment of children and young people with Type 1 diabetes in your country?

12 Do you have any other comments on the LFAC Type 1 Diabetes support programme in your country?

2. Questions for Experts/Volunteers

Name:
Title/Position:
Organization:
Date:
Interviewer:

INTRODUCTION

1. What do you know about the LFAC programme?
2. What have you done for LFAC?
3. How did you come to partner with LFAC? (*where relevant*)
4. Where have you volunteered with LFAC? (*where relevant*)

A: LFAC ORGANIZATIONAL STRUCTURE

5. What do you think about the LFAC programme? (service delivery, partnering with local diabetes associations, use of volunteers etc.)
6. What are LFAC's strengths and weaknesses?

B: OPTIMAL STRATEGIC FRAMEWORK

7. Currently LFAC's approach is wide and shallow (many countries, limited engagement) rather than narrow and deep. Is this the right strategy to take?
8. Do you think the delivery of LFAC programmes is adequately integrated into national health systems? How could this be improved?
9. Are there other models that you know of that provide support, care and treatment for people with Type 1 Diabetes that are more effective? If so, what and have they been evaluated?
10. What do you think about LFAC's close relationship with pharmaceutical companies? What impact do you think that has on their programmes?

C: CHANGES TO POLICIES THAT COULD IMPROVE QUALITY, QUANTITY, EFFECTIVENESS OR EFFICIENCY

11. LFAC relies on volunteer experts to conduct site visits and trainings and serve as mentors. How effective and sustainable is this? Is this enough?
12. How does LFAC train/prepare volunteers to ensure consistency in appropriate clinical standards?

D: IMPACTS ON COUNTRIES, SYSTEMS AND CHILDREN

13. Has LFAC's presence in partner countries led to the ability to collect more accurate incidence/prevalence data for T1D in these countries? If so, where and how?
14. What impact has LFAC had on the organization of youth diabetes care and the geographical extent of care in the countries supported?

E: LONG TERM SUSTAINABILITY

15. How does LFAC catalyse long term sustainable improvements in T1D care delivery systems? How can LFAC make its programmes more sustainable?
16. Has LFAC made a difference in governments' prioritization of providing care to people with T1D? If yes, please give examples.
17. How does LFAC engage in policy and advocacy discussion at national level? Could this be improved? How?
18. How effective is LFAC in influencing national decisions and or policies on care and treatment for children and young people with Type 1 diabetes? If yes how? If no, how could this be improved?
19. Do you think LFAC should move towards integrating more into national health systems and priorities (e.g. NCD or complex, chronic care programmes)? If so, why? If not, why not?

3. Questions for Partner Organizations

Name:

Title:

Organization:

Date:

Interviewer:

A. Programmes in country

1. What does your organization do here re T1 Diabetes care?
2. How long have you worked here?
3. Who do you work with? (government, National NGO, regional networks, other countries etc.)

B. LFAC

1. Have you heard of Life for a Child?
If yes, what do you know about it?
2. Do you partner with Life for a Child? If yes, how?
3. What are the pros and cons of Life for a Child?
4. How can Life for a Child be improved?
5. How do you coordinate your activities with those of Life for a Child and other organizations providing care and treatment for patients with Type 1 Diabetes?
6. How could this be improved?
7. How sustainable is the Life for a Child model?
8. How effective is LFAC in influencing national decisions and or policies on care and treatment for children and young people with Type 1 diabetes? If yes how? If no, how could this be improved?
9. How soon do you think the government can take over the responsibility of providing care and treatment for children and young people with T1D?
10. What steps could be taken to improve long-term sustainability of diabetes care and treatment?

4. Questions for Children and Families

Date:

Name:

Male/female: (delete as appropriate)

Age:

Name of village/town/city:

Interviewer:

1. How old were you/was your child when first diagnosed?
2. Had you heard about diabetes before you/your child was diagnosed?
3. Have you/your child had any complications from your diabetes? If so, what?
4. What is the hardest thing about living with diabetes?
5. How does diabetes affect your everyday life?
(e.g. schooling, family, work, visit friends, others)
6. What support do you currently receive?
From whom? (e.g. LFAC)
7. Do you have to pay for any Diabetes medicines or treatment?
If yes, how much? (indicate cost next to relevant item on list)

	Free of charge? (Yes or No)	Cost
Insulin		
blood glucose monitor		
blood glucose test strips		
Syringes		
education sessions		
health checks		

8. How often do you/your child go to the clinic?
9. Is anything stopping you/your child going to the clinic? If yes, what? (Use prompts below as guide)
 - travel distance/time
 - travel cost
 - cost of attending clinic
 - o fee
 - o loss of earnings
 - other?
10. When did you have your last medical visit to check your diabetes?
11. What did they check?
e.g. HbA1c, weight, height, feet, vision, urine, blood, blood pressure
12. Where do you get your insulin?

- 13. Do you ever have difficulties in getting insulin? If yes, what?**
- 14. Where do you store your insulin?**
- 15. Do you/your child always take your insulin when you need to? If no why not?**
- 16. Do you test your /your child's glucose levels? If yes, how many times a day? If not, why not?**
- 17. Do you have enough syringes and glucose test strips to manage your diabetes?**
- 18. Where and how have you found out more about Diabetes?**
- 19. Are you in contact with other young people who have Diabetes? If yes, is this helpful? If not, would you like to be?**
- 20. If there were three things that could help you manage your diabetes better, what would they be?**
- a. _____
- b. _____
- c. _____
- 21. Have you had any help on how you will look after yourself and manage your diabetes when you turn 26? If yes, what?**
- 22. Do you have any other comments on your diabetes care and support**

5. Questions for health centers/clinics

Name: _____
Clinic/Health Centre: _____
Location: _____
Interviewer: _____
Date: _____

1. Children and young people reached

- a. How many children and young people (YP) with Type 1 Diabetes are registered with your centre/clinic? _____
- b. How many of these have you seen/supported in the past year? _____
- c. Please briefly describe what type of care and support you provide?
- d. How many of the children and YP that you see live in the city, and how many live in more remote, rural areas? City: _____ Remote/rural areas: _____
- e. How do you reach and provide support to children in more remote areas / rural areas?
- f. What kind of support do you receive from the LFAC programme? Please tick the relevant option and say what percentage this is of the total:
 - i. Insulin _____%
 - ii. Blood glucose monitoring (meters and strips) _____%
 - iii. Syringes _____%
 - iv. HbA1C testing equipment _____%
 - v. Educational materials for children/families _____%
 - vi. Training of health professionals _____%
 - vii. Other: _____%
- g. Is this support enough? Yes No
- h. If no, please describe what else you need (*use list below as prompts*)
 - i. Insulin
 - ii. Blood glucose monitoring equipment (meters and strips)
 - iii. Syringes
 - iv. HbA1C testing equipment
 - v. Educational materials for children/families
 - vi. Training for children and families
 - vii. Other: _____
- i. Do you get support from any other national or international organizations re diabetes care and treatment? If yes, please state which organizations and briefly describe what support they provide.

- j. Please describe any difficulties experienced in reaching and supporting children and young people with Type 1 Diabetes (<26 years old)? Please consider both urban and rural areas.

2. Procurement and supply

- a. Do any children or YP with Type 1 diabetes have to pay for their own treatment?
Yes No Don't know
- b. If yes, please describe (For what? How much?):
- c. Does the government provide any medical supplies or other support to children and YP with Type 1 Diabetes?
Yes No Don't know
- d. If yes, please list what:
- e. How is your health centre/clinic supplied with (who from and how?):
- i. Insulin
 - ii. Syringes
 - iii. Bloody glucose monitoring (meters and strips)
 - iv. HbA1C testing equipment
 - v. Educational materials
 - vi. Training for children and families
 - vii. Specialist diabetes training for health professionals
- f. Since LFAC started its programme, has any aspect of government provision of Type 1 diabetes support to children and young people changed?
Yes No Don't know
- g. If yes, how has it changed?

3. Data collection

- a. Do you collect data on the children and young people (<26 years old) supported through the LFAC programme? *Yes No Don't know*
- b. Does this data include basic data such as;
- | | | |
|------------------------------------|------------|-----------|
| i. Age | <i>Yes</i> | <i>No</i> |
| ii. Sex (Male/Female) | <i>Yes</i> | <i>No</i> |
| iii. Address/village | <i>Yes</i> | <i>No</i> |
| iv. Education | <i>Yes</i> | <i>No</i> |
| v. Diabetes management and control | <i>Yes</i> | <i>No</i> |
| vi. Diabetes complications | <i>Yes</i> | <i>No</i> |
| vii. Other medical conditions | <i>Yes</i> | <i>No</i> |
- c. Is the data used to monitor progress and risk of complications in:
- i. Individual children? *Yes No*

- ii. Groups? Yes No

- d. Is this data shared with LFAC? *Yes No*

- e. Has the LFAC programme in your country had an impact on data collection on Type 1 Diabetes in children and young people? *Yes No Don't know*

- f. Do you continue to see the same patients once they are over 26 years old and no longer supported by LFAC? *Yes No Don't know*

- g. If yes, do you continue to record data on morbidity and mortality on all diabetes patients? *Yes No Don't know*

4. Training

- a. Have you received any training from LFAC? *Yes No Don't know*
 If yes, please describe type of training received and who it was for?
 What has been the impact of the training? (Use prompts below as a guide)
 - i. clinical services
 - ii. changes to insulin regimes
 - iii. patient outcomes
 - iv. improved HbA1c
 - v. patients self-help/management of their own conditions
 - vi. better glucose control
 - vii. reduction in severe episodes such as DKA requiring hospitalization
 - viii. reduced mortality from diabetes in children and young people
 - ix. increase in regular reviews to prevent complications e.g. eye examinations, foot examinations
 - x. a reduction in complications

- b. Is there a need for more training? *Yes No Don't know*
 If yes, briefly describe what type of training is needed and for whom?

5. Impact of LFAC

- a. Has the LFAC programme improved any of the following for children and young people with Type 1 Diabetes? Prompt:
 - i. Numbers correctly diagnosed:
 - ii. Diabetes management and control:
 - iii. Wider geographical coverage in diagnosis, treatment and care:
 - iv. Staff training:
 - v. General awareness of diabetes in the wider populations about Type 1 Diabetes:
 - vi. Other?

If yes, please give brief examples of how it has improved?

- b. In your opinion, what difference (positive and negative) LFAC has made towards the care and treatment of children and young people living with Type 1 Diabetes?

6. Sustainability/ long term impact

- a. Has LFAC helped the development of long-term sustainable improvements to Type 1 Diabetes care for children and young people? *Yes* *No*
Don't know
- b. If yes, please describe briefly how?
- c. How long do you expect LFAC to continue to support treatment and care for children and young people with Type 1 Diabetes in your country?
One year/Three years/Fives years/Ten years or more
- d. When do you expect the government to take over this responsibility?
One year/Three years/Fives years/Ten years/Not in the foreseeable future

7. After LFAC

- a. When young people leave the LFAC programme at 26 years old, what support do they receive in terms of insulin, glucose testing, medical care and diabetes check-ups and from whom?
- b. If yes, is this free of charge or is there a cost to the individual?
- c. Please briefly describe the main issues facing young people >26 years old when they leave the LFAC programme:
- d. Do you have any other comments on the LFAC programme in your country?

Appendix 9 Consent form

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(University of London)**



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**Professor Martin McKee
FMedSci**

CBE MB BCh MD MSc DSc FRCP FRCPI FRCPE FFPH

E-mail: martin.mckee@lshtm.ac.uk

Dear colleague,

This is a questionnaire survey aimed at evaluating the Life for a Child's (LFAC) support for children and young people with Type 1 Diabetes Mellitus. This includes its impact on health systems and policies as well as the children and young people supported through the programme. This survey is being undertaken by the London School of Hygiene and Tropical Medicine, at the request of the Leona M. and Harry B. Helmsley Charitable Trust, one of the main supporters of LFAC. The survey will be sent to all countries that LFAC support. The goal of the evaluation is to support LFAC as it goes forward, ensuring that it is sustainable in the long term and is able to respond to changing needs. Taking part in the evaluation is entirely voluntary. Your comments will be confidential and will not be attributed to you in the final report or presentations unless you agree to being quoted. We might include the name of your organizations in a list in the final report. If you don't want the name of your organization to appear in the final list, please let us know. Your contributions are much appreciated and can help inform improvements for the future.

Please contact Dr. Louise Sigfrid on e-mail: louise.sigfrid@lshtm.ac.uk if you have any further questions.

Yours sincerely,

Professor Martin McKee



Evaluation of Life for a Child Programme

1. I confirm that I have read and understand the information about this evaluation given to me in writing or in person. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to not answer all the questions or withdraw at any time without giving any reason.
3. I understand that the information given by me, may be used in future reports, articles or presentations. This information will be anonymous unless I have agreed to being quoted.
4. I understand that my name or the name of my organization will be included as a general list of people interviewed in reports, articles or presentations.
5. If you do not want your name to appear in the general list please tick this box:
6. I give permission for photographs taken of me and my family to be used for reports, presentations, publications and on the London School of Hygiene and Tropical Medicine website for the purpose of presenting the results from this evaluation:
7. I agree to take part in the above evaluation.

Name of Participant

Date

Organization _____

Signature _____

Interviewer

Date

Signature

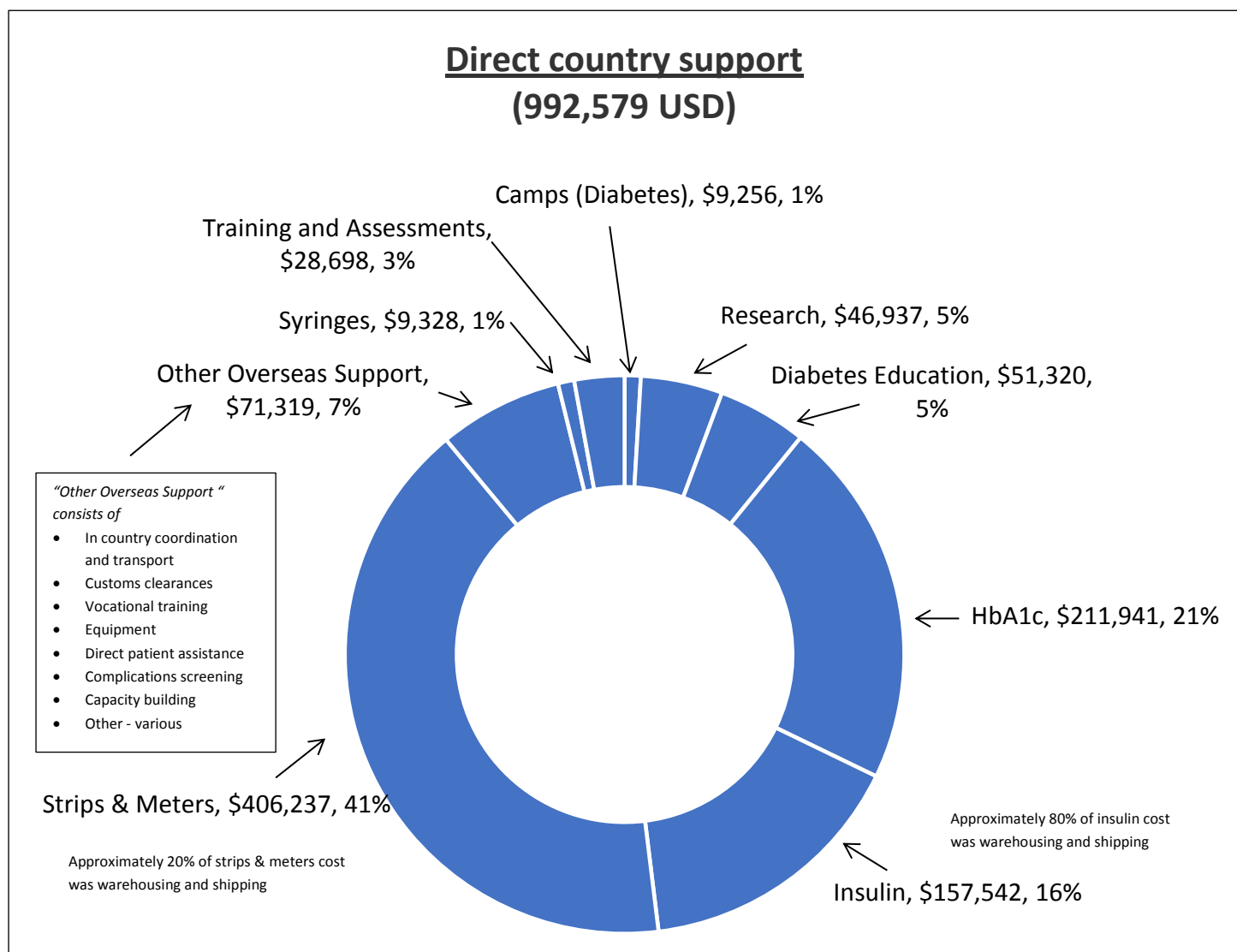
Appendix 10

EXPENDITURE AND IN-KIND SUPPORT IN 2014 (in USD)

Total Cash Expenditure \$1,412,134

Made up of:

- Direct country support \$992,579 (70.3%)
- Program Development, Monitoring and Administration \$419,555 (29.7%)



In-Kind support

Insulin	\$3,156,230
Blood glucose meters and strips	\$2,986,566
Syringes	\$236,600
Other	\$7,500
Total	<u>\$6,386,896</u>

Leverage of funds expended to total (including in-kind) \$7,779,030 to \$1,412,134 = 5.5 : 1.