

## Original Article

# The IDF Life for a Child Program Index of diabetes care for children and youth<sup>†</sup>

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**Background and Objectives:** Care for children and youth with diabetes varies markedly around the world. We developed a standardized, reproducible measure that can be used to document and compare critical factors influencing treatment outcomes.

**Methods:** A questionnaire consisting of 36 multiple-choice questions covering major components of care (such as insulin therapy, blood glucose monitoring, etc.) was sent to 75 countries: 43 under-resourced countries where the International Diabetes Federation's Life for a Child Program operates, and 32 others (mainly developed nations). Results for each country were scaled to a score with a range of 0–100.

**Results:** Responses were received from 71 countries. Scores varied widely and were highly correlated to per capita gross domestic product ( $R^2 = 0.72$ ,  $P < 0.001$ ) and health expenditure ( $R^2 = 0.77$ ,  $P < 0.001$ ). For the 37 low- and lower-middle income countries, only two had complete government provision of human insulin and none of blood glucose test strips. Marked differences according to income were also found for access to home refrigeration; usage of insulin pens, multiple daily injections, pumps, glucagon and ketone strips; hemoglobin A1c (HbA1c) testing; and complications screening.

**Conclusions:** The index is a comprehensive, easily administered survey instrument. It demonstrated stark differences in access to numerous components of care necessary in achieving good outcomes for children and youth with diabetes.

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**Key words:** blood glucose monitoring – childhood diabetes – developing countries – index – insulin

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It is estimated that there are almost 500 000 children <15 yr of age with diabetes (1, 2), with a similar or even higher number of persons aged 15–25 yr having this disease. Unfortunately, the care for children and youth with diabetes varies widely around the world. In many developed nations children and youth have complete access to all components of care. In some other countries, quality care is inaccessible or unaffordable. Sadly, many children and youth with type 1 diabetes die

soon after diagnosis (or even before diagnosis, often misdiagnosed as another illness). Others often have poor diabetes control and frequently develop early and devastating complications.

Multiple publications exist regarding the care in individual developed countries, with some studies (3, 4) comparing care provided by centers in various developed nations. For less-resourced countries, clinical assessments have been published for a few

countries such as Tanzania (5, 6) and Rwanda (7). The International Diabetes Federation (IDF) survey on insulin and diabetes supplies (8), and detailed diabetes health systems assessments conducted by the International Insulin Foundation in six countries (9–12). However, these studies focus mainly on access, availability, and cost of supplies of diabetes care overall, and do not cover a number of specific components related to childhood and youth diabetes care.

Therefore we have developed an index which covers essential components of diabetes care that influence outcomes for children and youth with diabetes, including insulin (13), monitoring of glycemic control (14), diabetes education (15), and complications screening (16). The aim of the IDF Life for a Child (LFAC) Index of Diabetes Care for Children and Youth is to document the current global status of such components of care, and provide a standardized, reproducible measure that can be used to assess the availability of critical components of diabetes care which in turn influence outcomes. The index highlights areas that deserve attention within countries and across regions, will assist with local and international advocacy, and can be used to monitor improvements in provision of care.

## **Methods**

### Development of survey instrument

A questionnaire with 36 multiple-choice questions was developed by the investigators – two pediatric endocrinologists and one diabetes nurse educator, all with wide experience in diabetes care at all resource levels. The questions covered components of diabetes care that were grouped into five broad areas: insulin, other supplies, health professionals, organization of care, and other components of care. See Appendix 1 for details.

The questionnaire was reviewed by experts involved in multinational diabetes initiatives in Europe, Africa, and Asia. It was then piloted in two African and two Asian countries, refined according to the comments received, and finalized. Translations into French and Spanish were conducted by diabetes experts who were fluent in the respective languages.

### Administration of survey

The questionnaire was sent to 75 countries – all 43 countries supported by or about to commence support from the IDF LFAC, along with 32 other countries to provide a global picture.

The survey was emailed to the key person(s) known to be completely aware of the standard of childhood

and youth diabetes care in each country surveyed. The questionnaire was completed and returned by email.

Two versions of the questionnaire were used – ‘Country’ and ‘Clinic’. The two versions only differed on the replacement of ‘country’ with ‘state/province’ in the wording of the 23 questions, otherwise the content for all question did not alter.

The ‘Country’ questionnaire was used when it was thought that the respondent would be able to answer for the situation in the entire country. This version was sent to 66 countries. In 43 of these it was sent to the person known by LFAC to be involved in coordinating childhood and youth diabetes care within the main clinic in the country – generally the senior physician at the clinic, or otherwise the head of the local diabetes association (when the latter was directly involved in coordination of care).

For 23 high- and upper-middle income countries with many leading clinics, the ‘Country’ questionnaire was also used as there was generally homogenous provision of government services. The questionnaire was sent to a representative clinic coordinated by a recognized expert, known to LFAC, who was familiar with care across the respective country.

The ‘Clinic’ questionnaire was used in nine countries as it was known by the investigators that there was no specific leading clinic and furthermore, unlike in higher-income countries with more homogenous care, it was known that care varied markedly between the clinics. These countries were: Democratic Republic of Congo, Ecuador, Ghana, Liberia, Nigeria, Pakistan (each with two questionnaires sent and returned), Thailand (3), India (4) and Mexico (6). For each of these countries a mean score of each question was used in the overall analysis.

### Developing the scale

The minimum score for each question was 0, and the maximum score varied from 2 to 8 depending on the number of options. The minimum possible total raw score was 0 and the maximum 131. Raw scores for each question (from 0–2 to 0–8 depending on the number of options) were scaled to a score of 0–10. This provided a total score of 0–360. This total was then divided by 3.6 so as to be expressed as a score with a minimum of 0 and a maximum of 100.

### Relationship to income levels and health expenditure

Health expenditure (HE) per capita, and gross domestic product (GDP) per capita based on purchasing power parity (PPP) in current international dollars was acquired for each country from the World Bank website (17) (generally 2012 data). The same source

was accessed to classify all countries as low income, lower-middle income, upper-middle income, or high income. If World Bank data was not available, the CIA Factbook was used (18).

Statistical analysis

Trend analysis across income levels was performed in SAS using the Cochran–Armitage test, adjusted using the Benjamini–Hochberg False Discovery Rate to control for multiple comparisons. Correlation was calculated by Pearson’s test. A p value of <0.05 was considered significant.

Results

The LFAC Index questionnaire was sent to 75 countries, with 71 of these returning the questionnaire (see Table 1). No response was received from four countries – China, Indonesia, Israel, and South Africa. All 71 countries that returned the questionnaire completed all the questions.

Overall scores

Scaled scores (maximum 100) ranged from 17.6 to 97.6 (mean 53.4). Table 1 shows the scaled score quintile for each country.

Domain results

*Insulin.* Results for insulin provision in three age-groups – <15, 15–18, and 18–25 yr were averaged as there was no significant difference when evaluated across age groups. A total of 2.3% of countries had no government/non-government organization (NGO) provision with insulin available only through private pharmacies, in 8.5% there was some provision through NGOs in one or more major centers only, in 5.2% there was some provision through government sources (GS) in one or more major centers only, in 19.7% provision in major centers and some regional areas by NGOs, in 16.9% provision in major centers and some regional areas by GS, in 7.5% full provision of human insulin by NGOs (+/- some GS), in 7.0% full provision of human insulin by GS, in 9.4% full provision of human insulin and some provision of analog insulin by GS, and in 23.5% full provision of analog insulin by GS.

At the institution that filled out the questionnaire, the most common insulin regimen was twice-daily pre-mixed insulin in 16 countries; twice-daily regular and NPH insulin in 18; multiple daily injections (3–4/day) of human insulin in nine; multiple daily injections of analog +/- human insulin in 21; and pump therapy in 7.

Table 1. Scaled LFAC Index score (out of 100) for each country surveyed

Score	Numbers of countries	Countries (in alphabetical order)
0–19	6	Burkina Faso, Burundi, Haiti, Liberia, Mauritania, Solomon Islands
20–39	20	Cambodia, Dominican Republic, Democratic Republic of Congo, Ecuador, Ethiopia, Gambia, Ghana, Guatemala, Guyana, Iraq, Jamaica, Kenya, Nepal, Nigeria, Papua New Guinea, Republic of Congo, Tajikistan, Togo, Vietnam, Zimbabwe
40–59	20	Azerbaijan, Bangladesh, Bolivia, Egypt, Eritrea, Fiji, India, Maldives, Mali, Mexico, Morocco, Pakistan, Philippines, Rwanda, Sri Lanka, Sudan, Tanzania, Thailand, Uganda, Uzbekistan
60–79	7	Bermuda, Botswana, Cayman Islands, Cuba, Malaysia, Montenegro, Romania
80–100	18	Australia, Czech Republic, Denmark, France, Germany, Hungary, Ireland, Italy, Japan, Korea, Luxembourg, Netherlands, New Zealand, Norway, Singapore, Sweden, United Kingdom, United States

Country-wide, the most common insulin regimen was twice-daily pre-mixed insulin in 20 countries; twice-daily regular and NPH insulin in 20; multiple daily injections (3–4/day) of human insulin in 6; multiple daily injections of analog +/- human insulin in 21; and pump therapy in 4.

*Other supplies.* For children <15 yr, there was no government provision of blood glucose meters and strips with few children monitored in nine countries, some provision through non-government sources in 33, complete provision (two or more tests per day) by non-government sources in 6, and full provision by government in 23. Results were similar in the 15–18 yr age-group, with less government or non-government provision in some countries in the 18–25 yr age group.

In 12 countries there was no government support for syringes and limited access from other sources – families must buy syringes privately. There was some provision of syringes through non-government sources in 24, and full provision in 7. Five countries had full syringe provision by the government, 6 had full pen provision, 7 had some government assistance with pumps, and 10 full government assistance with pumps.

Clinics in four countries had no access to hemoglobin A1c (HbA1c) testing. Five countries had laboratory equipment only in the main clinic, 25 in the main

and also in regional clinics. Twenty had point-of-care testing in the main clinic alone and 17 also in regional clinics. In 12 countries families must pay all costs of medical care and laboratory testing. Twelve had some support from non-government sources and 17 had support from GS. Full support was available from non-government sources in 4, and from GS in 26.

More than 25% of families needed to travel long distances (>2h traveling time each way) for supplies and review in 29 countries. In 19 countries, 5–25% of families had long travel times, and in 23% of countries <5% of families had long travel times.

*Health professionals.* The highest level of pediatric diabetes nurse training was a general nurse in 12 countries. There was a nurse with interest in diabetes in 14, a trained diabetes nurse educator in the major clinic in 19, and a trained diabetes nurse educator also in regional clinics in 26.

Eighteen countries did not have any other health professionals in the diabetes care team. Fourteen had a dietician in the surveyed clinic, 16 had a dietician and social worker in the surveyed clinic, 4 also had dieticians in regional clinics, and 19 had dieticians and social workers in both the surveyed and also regional clinics.

*Organization of care.* There was no pediatric or adolescent clinic in 17 countries – children and youth were cared for within the adult clinic. Care was provided through pediatric clinic(s) in 34 countries, and a further 20 had a pediatric and also a transition clinic. The estimated proportion of children and youth receiving ‘standard care’ at the surveyed clinic was <10% in 11 countries, 10–33% in 6, 34–66% in 9, 67–95% in 13, and >95% in 32. The estimated proportion of children and youth receiving ‘standard care’ across the country was <10% in 19 countries, 10–33% in 10, 34–66% in 10, 67–95% in 11, and >95% in 21.

*Other components of care.* There was no active diabetes association in three countries. Nine had an association which was not an IDF member, 21 had an association that was an IDF member not actively involved in meeting the needs of children and youth with diabetes, and 38 had a member association that was active in this way. No diabetes camps or activity days had been held in nine countries. Sixteen had education half-days or days in the past, 18 had occasional camp(s), and 28 had annual camps.

There was no diabetes register or data collection in 13 countries. Thirty-five had a limited register and data collection, 8 had a comprehensive register and data collection in one region, and in 15 it was nationwide.

Seventeen countries had no data on incidence, prevalence, or types of diabetes. Seventeen others had

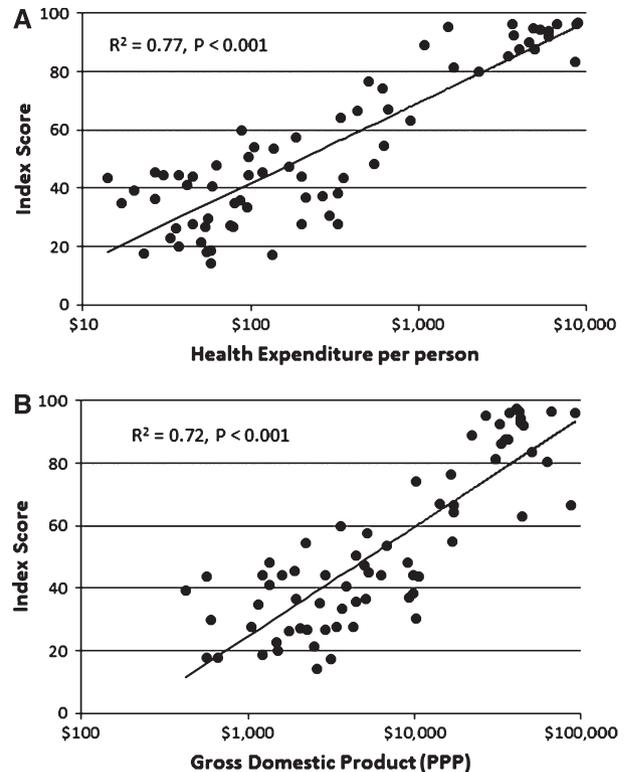


Fig. 1. Association between Life for a Child (LFAC) Index score and economic indicators (log plots). (A) Index score compared to per capita health expenditure. (B) Index score compared to per capita gross domestic product (purchasing power parity).

limited data that was not recent, 23 had limited recent data, and 14 had comprehensive data.

#### Relationship to income levels and HE

The scaled score was evaluated against the log-plot of 2011 per capita HE – see Fig. 1A, (data not available for Bermuda); and GDP (PPP) – see Fig. 1B. The  $R^2$  correlation to HE was 0.77 ( $P < 0.001$ ), and for GDP (PPP) 0.72 ( $P < 0.001$ ). Table 2 shows the mean scaled scores for each country income level.

The relationships of eight key indicators to country income level are shown in Fig. 2. All demonstrated a strong ( $p < 0.001$ ) relationship to income level. Data on refrigeration was comparable to published country electrification rates (19). The relationships of country income level to other selected indicators are shown in Table 2.

For insulin, the lowest GDP and HE for countries where government health services could completely provide insulin was Vietnam (\$3 265 and \$95, respectively). Only 4 of the 53 countries with  $GDP < \$10\,000$  could provide insulin (Vietnam, Fiji, Thailand, and Egypt). Three countries of the 28 with  $GDP > \$10\,000$  did not provide insulin. For HE, 12 of the 40 countries with  $HE > \$100$  did not provide insulin.

Table 2. Scaled LFAC Index scores, and selected indicators, according to country income levels

	Low income countries (n = 19)	Lower-middle income countries (n = 18)	Upper-middle income countries (n = 14)	High income countries (n = 20)	P
Score [mean (range)]					
Scaled score (0–100)	31.8 (17.6–48.0)	39.1 (14.4–59.7)	51.4 (27.7–76.6)	88.1 (63.0–97.6)	<0.0001
Insulin (number of countries/% of countries)					
Multiple daily injections or pump therapy country-wide	1 (5.3%)	2 (11.1%)	7 (50.0%)	19 (95.0%)	<0.0001
No duty on insulin	9 (47.3%)	7 (38.9%)	11 (78.6%)	15 (75.0%)	0.02
Other supplies					
Complete syringe provision by government	2 (10.5%)	3 (16.7%)	5 (35.7%)	18 (90.0%)	<0.0001
Use of insulin pens $\geq$ 10% (excluding pump therapy)	0 (0%)	1 (5.6%)	8 (57.1%)	20 (100%)	<0.0001
Point of care HbA1c testing in leading center	7 (36.8%)	9 (50.0%)	4 (28.6%)	17 (85.0%)	0.01
$\geq$ 5% children having urine or blood ketone strips at home	2 (10.5%)	2 (11.1%)	3 (21.4%)	20 (100%)	<0.0001
Full government support for medical care and laboratory testing	1 (5.3%)	2 (11.1%)	6 (42.9%)	17 (85.0%)	<0.0001
Health professionals					
Trained diabetes nurse educator in country	11 (57.9%)	12 (66.7%)	4 (28.6%)	18 (90.0%)	0.15
Organization of care					
Screening for eye complications regularly conducted in leading center	7 (36.8%)	12 (66.7%)	9 (64.3%)	20 (100.0%)	<0.0001
Screening for foot complications regularly conducted in leading center (where clinically indicated)	6 (31.6%)	9 (50.0%)	7 (50%)	20 (100.0%)	<0.0001
67% or more of children in leading center receiving standard care	4 (21.0%)	11 (61.1%)	10 (71.4%)	20 (100%)	<0.0001
67% or more of children in country receiving standard care	3 (15.8%)	8 (44.4%)	8 (57.1%)	20 (100%)	<0.0001
Presence of 24-h diabetes emergency call service	6 (31.6%)	7 (38.9%)	6 (42.9%)	19 (95.0%)	<0.0001
Other components of care					
Locally adapted education materials for children/youth	7 (36.8%)	8 (44.4%)	8 (57.1%)	19 (95.0%)	<0.0001
Some or substantial interaction between health professionals and teachers/schools	6 (31.6%)	4 (22.2%)	0 (0%)	19 (95.0%)	<0.001

HbA1c, hemoglobin A1c; LFC, Life for a Child.

P values refer to relationship of the respective indicator to country income group (assessed by trend analysis).

Conversely, all 10 countries where governments provided full assistance with pumps had GDP (PPP) > \$25 000 per annum).

For meters and strips, the lowest GDP and HE for countries where government health services could fully provide meters and strips was Fiji (\$4493 and \$168, respectively). Fiji was the only country of 53 with GDP < \$10 000 that could provide strips. Six of the 28 countries with GDP > \$10 000 did not provide strips. For HE, only 2 countries of the 46 with HE < \$500

could provide strips (Fiji and Botswana), with 21 of 24 nations with HE > \$500 providing strips.

## Discussion

### Key findings

The LFAC Index demonstrates stark global differences in the availability of all components of diabetes care for children and youth. The instrument was easy to

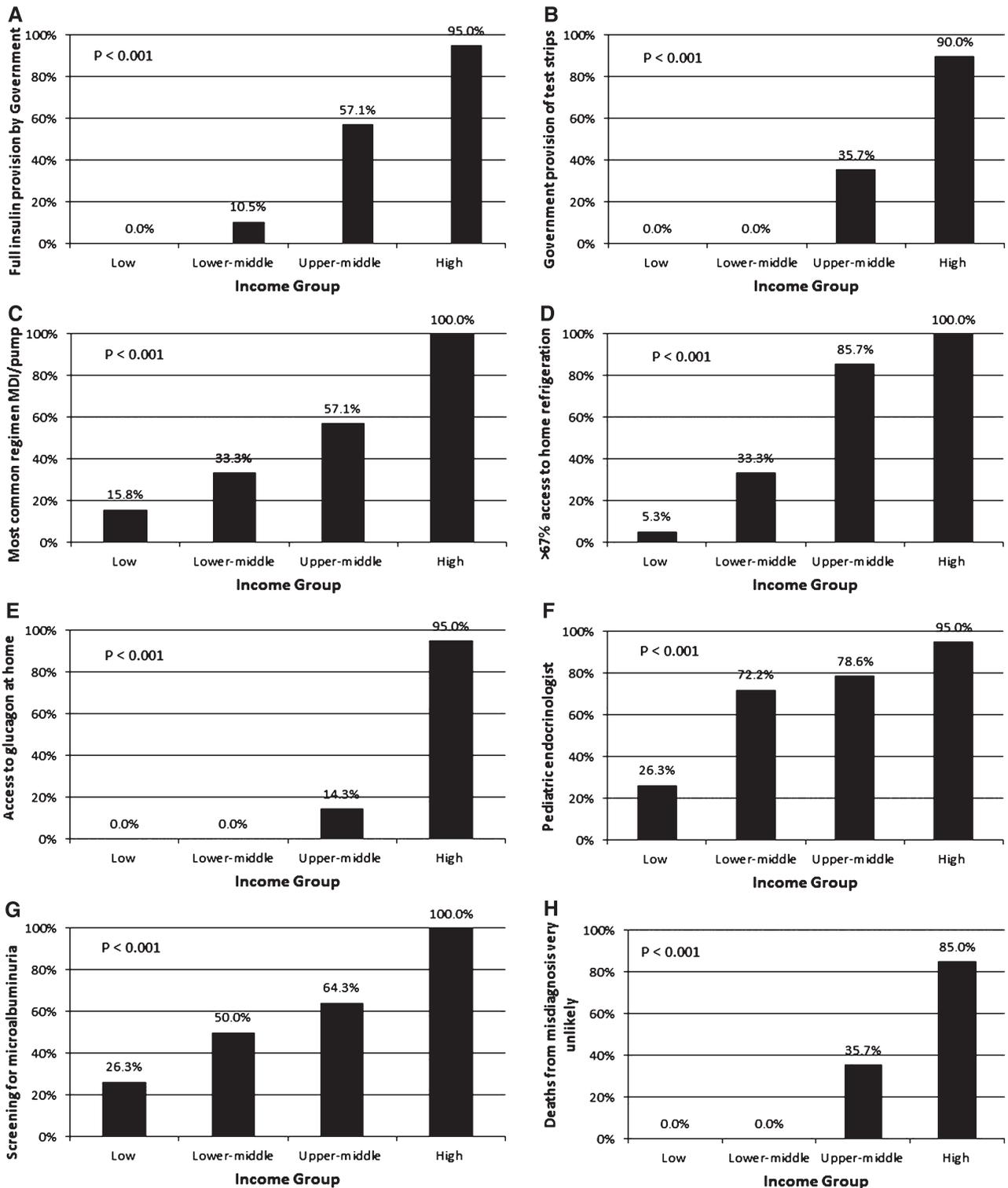


Fig. 2. Relationship of key indicators to country income level. (A) Complete provision by government of insulin for children <15 yr. (B) Complete provision by government of 2+ test strips per day for children <15 yr. (C) Most common insulin regimen at major center multiple daily injections or pump therapy. (D) About >67% of families having access to a home refrigerator. (E) About >5% of children having glucagon at home. (F) Pediatric endocrinologist in country. (G) Screening for microalbuminuria regularly conducted at leading center. (H) Good knowledge in country about symptoms of diabetes, with deaths from misdiagnosis thought to be very unlikely. For all graphs, the number of countries is: low income (19), lower-middle income (18), upper-middle (14), and high income (20). P values refer to relationship of the respective indicator to country income group (assessed by trend analysis).

use, as demonstrated by the high response rate and full completion of questions. It identifies strengths and weaknesses within countries, and indicates areas that need attention on an individual country and regional level. Key benchmarks for provision of care are defined – such as affordable provision of insulin by governments to all in need, and provision of at least ‘standard care’. The results also provide baseline data that can be used as a benchmark to monitor progress over time – for instance on a second-yearly assessment. The index will also be useful in lobbying and advocacy on both a national and global scale to strive for equity of care.

The index score, and almost all key indicators were highly correlated to a country’s per capita GDP, and even more highly correlated to HE. No government health service in any low-income country, and only a few in lower-middle income countries were able to provide human insulin [an essential medicine as defined by the World Health Organization (WHO) (20)] to all children in need, with fewer providing blood glucose test strips (at a very modest minimum level of two tests per day). Government provision of insulin syringes was often also poor. Access to glucagon and urine ketone strips was extremely low except for high-income countries [despite glucagon also being on the WHO essential medicines list (20)].

The study reveals further challenges with insulin therapy in that many families do not have access to home refrigeration, with insulin losing its potency much more quickly in hot environments (21).

Deaths from misdiagnosis of diabetic ketoacidosis (DKA) are thought to be likely or very likely in most surveyed countries.

The availability of other components of youth diabetes care – the complete multidisciplinary team with a dietician and social worker, 24-h telephone advice, diabetes camps, locally produced and relevant education materials, use of standardized international or national treatment guidelines, transition clinics from pediatric to adult care, professional associations, engagement of schools – varied markedly and generally only high income countries had most or all of these in place.

### Study limitations

The major limitation of the study is that only one respondent was used in most countries. Whilst this respondent was the leading expert in all less-resourced countries and a leading expert in more resourced countries, it is possible that they were not aware of some variations in care within their country that may have led to different answers in one or more questions.

### Key implications

Without government health system support, costs can be prohibitive for families. Health Action International conducted a snapshot survey of the price of a 10 mL vial of 100 IU/mL insulin in 60 countries in 2010 (22). The mean price varied from \$13 to \$24 depending on the manufacturer. For an adolescent with diabetes receiving 45–50 U/day, an annual supply would be about 18 vials. Even at the lower price of \$13 this would cost \$234 per year. This study shows that a number of nations still impose customs duty on insulin, needlessly elevating insulin prices.

Blood glucose monitoring is even more costly – the annual cost of two test strips per day is \$219–\$730 (based on LFAC internal data from country questionnaires).

Given the high cost of supplies, even after eliminating customs duty and maximizing the impact of advocacy within a country, it still may not be possible to achieve universal coverage for all key components of care until GDP rises substantially. Even in countries where GDP is growing at 8–10% per year, this may still take some years as in many countries the current per capita GDP is <\$2000 and HE <\$100 per capita. In the interim, external assistance will often be needed if insulin, blood glucose meters and strips, and other supplies are to be provided to all children and youth in a particular country (23). In countries where there was limited government provision, adequate human insulin and provision of two test strips per day were available in many nations for most or all children due to the dedicated actions of local diabetes associations and clinics, in partnership with international initiatives such as IDF LFAC, Changing Diabetes in Children, and Insulin for Life. Covering over 40 countries, these initiatives have the potential to make a substantial impact (23–25).

Syringes usually cost around \$0.20 so the total cost of single-use syringes is substantial. Even though this is ‘off-label’ use, syringes (and lancets) are often re-used a number of times in lower-resourced countries, apparently generally with no consequences. However, there are limits beyond which the injection becomes too painful, and risk of infection presumably increases with time.

Delivery systems and insulins that are the standard in most high-income countries are costly. Pen needles and insulin cartridges are more expensive than use of syringes and vials. Use of analog insulins and insulin pump therapy is more costly again. Such interventions have advantages, but quality outcomes can be achieved without these components, and governments should not divert limited funds to their use until all more basic components of diabetes care can be delivered.

Glucagon and ketone strips help prevent serious episodes of hypoglycaemia and hyperglycaemia, and

reports to LFAC indicate that fatalities from both of these conditions are not uncommon in such countries. The wider introduction of urine ketone strips should be promoted as this is a relatively inexpensive supply, with glucagon also to be encouraged for families that can afford it.

Further efforts in complications screening are strongly indicated as poorer blood glucose control and complications are more frequent in lower-resourced settings (5, 7).

A number of lower-income countries now have pediatric endocrinologists. This is partly due to the training schools in Nairobi and Lagos established by European Society of Pediatric Endocrinology (ESPE) and International Society for Pediatric and Adolescent Diabetes (ISPAD).

Only one key indicator was not correlated to GDP – the presence of at least one trained diabetes nurse educator in the country. Regional analysis indicated that nurse educators were less common in Central Asia, South America, and South-East Asia, which may reflect the more physician-centric nature of the health systems. This is in contrast to some African and Pacific nations where the number of doctors is often limited, and nurses make clinical assessments and have prescribing rights.

Misdiagnosis of DKA is known in many countries, with often fatal consequences. Diabetes in young people and even adults is frequently misdiagnosed as malaria, gastroenteritis, typhoid, pneumonia, malnutrition, or human immunodeficiency virus infection/acquired immune deficiency syndrome (HIV/AIDS) (26, 27). Such deaths can still occur in developed nations (28). The authors believe that misdiagnosis is likely to be the commonest cause of death for children with diabetes in less-resourced countries.

#### Future directions

The introduction of multiple daily dose regimens would be a useful intervention in many countries, as a number are still using twice-daily injections of pre-mixed or of individual mixtures of short- and long-acting insulin. We note that blood glucose monitoring, health professional training, and education of young patients and their families must be in place for this changeover to occur – otherwise harm could result from an increased risk of severe hypoglycaemia.

Some pharmaceutical companies do offer preferential insulin pricing to low income countries, and development of regional pooled procurement programs may result in lower prices (as occurred with inhaled corticosteroids for asthma through the asthma drug facility) (29, 30). An increase in the number of insulin

and blood glucose monitoring manufacturers may also lead to reduced prices.

Given the frequent lack of home refrigeration, studies on the efficacy of alternate methods of cooling (such as evaporative cooling using a clay pot) would be valuable, as would more detailed information on the stability of newer insulins at prolonged higher temperatures.

Education campaigns are needed to address deaths from misdiagnosis and late diagnosis of DKA. Such programs have been shown to reduce the incidence of DKA (31, 32), and IDF LFAC and ISPAD are promoting and facilitating use of a six-icon poster (showing the six commonest presenting features of type 1) in appropriate languages (33).

Registers, incidence and prevalence data, and epidemiology studies aid clinical management, teaching, resource allocation, and advocacy, and should be encouraged and fostered. Establishment of a mentoring/teaching relationship between a lower-resourced center and a developed country center with more advanced care can help with health professional training and establishment of diabetes camps.

In conclusion, the LFAC Index of Diabetes Care for Children and Youth provides a straightforward method of assessing critical components of diabetes care globally. The results highlight gaps on a country level, and reveal regional and global patterns, thus guiding local and international interventions, and assisting advocacy. The index could also be used to show rates of improvements over time, and assist in monitoring of interventions.

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#### Conflict of interest

No potential conflicts of interest relevant to this article were reported.

#### Author Contributions

G. O. designed the study, conducted the analysis and wrote the manuscript, and is the guarantor. A. M. implemented the study and contributed to the analysis and manuscript. M. S. was involved in the study concept and design, and reviewed and edited the manuscript. The authors thank the experts who answered the survey from all the countries involved, Rachel Miller and Trevor Orchard (University of Pittsburgh) for assistance with the statistical analysis, and Mark Atkinson (University of Florida) for helpful comments on the manuscript.

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**Appendix 1. Questions in survey instrument (multiple choice answer options depended on question)**

Section 1 – Insulin

Q1: What is the insulin situation for children <15 yr in your country?

Q2: What is the insulin situation for youth aged 15–18 yr in your country?

Q3: What is the insulin situation for youth aged 18–25 yr in your country?

Q4: What insulin regimen is used for the majority of children and adolescents with type 1 at your center?

Q5: What insulin regimen is most commonly used for children and adolescents with type 1 at other centers in the country?

Q6: What is the current situation regarding import duties and taxes on insulin in your country?

Q7: How many families in your country have a refrigerator in their own home to store the insulin?

Section 2 – Other supplies

Q8: In your country, where do children and youth obtain insulin delivery systems (syringes/pens/pumps) from?

Q9: In your country, what percentage of children, excluding any on pump therapy, use an insulin pen instead of syringes/needles?

Q10: In your country, where do children <15 obtain meters and strips from?

Q11: In your country, where do adolescents (15–18-yr-old) with diabetes obtain meters and strips from?

Q12: In your country, where do 18–25 yr olds with diabetes obtain meters and strips from?

Q13: What is the status of HbA1c testing in your country?

Q14: What percentage of children and youth in your country with type 1 has urine ketone strips at home?

Q15: What percentage of children and youth in your country with type 1 has glucagon at home?

Q16: Who is responsible for funding the cost of medical care and laboratory testing in your country, other than glucose and HbA1c, for children and youth with diabetes?

Q17: Overall, what percentage of families of children and youth in your country with diabetes must travel considerable distances for diabetes supplies and review?

Section 3 – Other health professionals

Q18: What is the highest level of pediatric diabetes training in the diabetes team in your country?

Q19: What is the highest level of pediatric nurse diabetes training in your country?

Q20: What other health professionals are included in the diabetes team in your country?

Q21: What professional endocrinology organizations exist in your country?

Section 4 – Organization of care

Q22: How is your center currently structured with regards to diabetes care?

Q23: What is the current situation regarding complications screening for microalbuminuria for children and youth in your center?

Q24: What is the current situation regarding eye complications screening for children and youth in your center?

Q25: What is the current situation regarding feet complications screening for children and youth in your center?

Q26: What is the estimated proportion of children and youth with diabetes in your center receiving ‘standard’ care (adequate insulin, self-blood glucose monitoring and HbA1c testing, and some diabetes education)?

Q27: What is the estimated proportion of children and youth with diabetes in your country receiving ‘standard’ care (adequate insulin, self-blood glucose monitoring and HbA1c testing, and some diabetes education)?

Q28: Availability and use of treatment guidelines for management of diabetic ketoacidosis (guidelines may be ISPAD, IDF/ISPAD, CDiC, or locally developed)

Q29: What emergency care – 24-h telephone on-call service – is available to children and youth with diabetes and their families?

Section 5 – Other factors

Q30: What diabetes education materials for type 1 diabetes in children and youth are available in your country?

Q31: Is there an active Diabetes Association in your country?

Q32: Concerning diabetes camps in your country . . .

Q33: What level of knowledge do health professionals in your country (outside your center) have regarding symptoms of diabetes and ketoacidosis in children and youth?

Q34: Is there a childhood and youth diabetes data collection system in your country?

Q35: What level of childhood and youth diabetes epidemiology data is available in your country?

Q36: In your country, what is the degree of engagement between diabetes health professionals and teachers at schools attended by the children and youth with diabetes?

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