

Appendices

1. Appendix A LFAC non-insulin supplies questionnaire

Access to HbA1c Testing and Insulin Syringes/Pens

As part of Life for a Child's health systems research into affordability and availability of care, we are studying access to HbA1c testing and insulin syringes/pens. By completing the following assessment, you will help us better understand this global issue. This work is supported by a grant from the Leona M and Harry B Helmsley Charitable Trust.

Centre Name:	
Name of Respondent:	
E-mail:	
Date:	

A. HbA1c Testing

1. HbA1c Testing at Your Centre

1.1. How is HbA1c measured in your centre (e.g., DCA, Clover or Bio-Rad, etc.)?

1.2. Do you have to buy cartridges for machines, and if so, how much do they cost in local currency?

1.3. If HbA1c testing is provided at your centre, what is the amount per test that young people <26 have to pay (or is it free)?

1.4. On average, how many HbA1c tests per year does each young person with diabetes have at your centre?

2. HbA1c Testing in Public and Private Health Systems

2.1. Please complete the table below:

	Levels of National Health System			
	Primary Health Care Facility or 'First Level of Care'	District Hospital	Regional Hospital	Tertiary Hospital
HbA1c Provided (Y/N)?				
Measurement method (e.g., DCA, Clover or Bio-Rad,				

etc.)				
If provided, what % of the time is it available? (100% always, 75% mostly, 50% sometimes, 25% rarely, 0% never)				
Cost to patient (in local currency)				

2.1 In local currency, how much do young people with diabetes pay per HbA1c test when it is accessed at a private health facility?

2.2 Is HbA1c testing covered under any public health insurance program in your country?

2.3 If HbA1c testing is provided in public health insurance programs, please list the names of the programs:

2.4 If HbA1c testing is provided in public health insurance programs, how much do young people with diabetes pay per test?

3. Monitoring and Feedback

3.1. When patients have their HbA1c tested, is their result discussed at that clinic visit, in a follow up phone call, or at the next clinic visit?

Timing of discussion	At Your Centre (Please tick one)	In the Public Health System (Please tick one)
At current clinic visit		
Follow up phone call		
At the next clinic visit		
Other, please specify below:		

3.2 What kind of education/support are patients given in helping them to interpret their HbA1c results?

At Your Centre	In the Public Health System

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3.3 Do you think this education/support is adequate and that patients are provided with the knowledge and strategies to help guide improvements in their glycaemic control?

At Your Centre	In the Public Health System

4. Challenges

4.1. What are the biggest challenges your centre faces in providing HbA1c testing supplies? Please provide details in the relevant boxes below:

Challenges	Description of Challenge
Maintenance of Testing Machine	

Stockouts	
Adequate Oversight of Supplies	
Adequate Supplies	
Refrigeration	
Trained Staff	
Cartridge Cost	
Machine Cost	
Other challenges	

4.2. If your centre has had an interruption in supply stock, or cannot provide HbA1c testing, what methods were/are used to assess patients' long-term glycaemic control?

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4.3. If your centre has ever experienced problems with stockouts, how long was your centre without HbA1c testing capabilities?

4.4. If your centre provides Point-of-Care HbA1c testing (e.g., DCA, Clover) have you ever had a problem where you required technical assistance from the manufacturer? If so, were you able to receive technical support or access the maintenance required?

4.5. Does the manufacturer have any offices in your country?

4.6. Do you know of any young people with diabetes who have forgone HbA1c testing due to cost or other barriers? Please provide details below:

4.7. Please provide any other challenges you have faced with respect to providing HbA1c testing:

B. Insulin Syringes and Pens

1. Syringe and Pen Usage in Your Centre

1.1. Could you estimate what percentage of young people with type 1 diabetes <26 years of age in your centre are injecting insulin with syringes?

1.2. Could you estimate what percentage of young people with type 1 diabetes <26 years of age in your centre are injecting insulin with pens?

1.3. Could you estimate what percentage of young people with type 1 diabetes <26 years of age in your centre are injecting insulin with insulin pumps?

1.4. If the situation is different outside of your centre (i.e., in other parts of the country) for the questions above, please provide estimations below:

2. Provision at Your Centre

2.1. Does your centre provide syringes to people with diabetes?

2.2. If your centre provides syringes, where do they come from?

2.3. If your centre provides syringes, what is the cost per syringe to your centre?

2.4. If your centre provides syringes, what is the cost per syringe to a young person <26 years old?

3. Provision in Public and Private Health Systems

3.1 Outside of your centre, where do young people go to access insulin syringes?

Institution	Insulin Syringes Provided? (Yes/No)	Cost (in local currency)
<i>Public Health System</i>		
<i>Private Retail Pharmacy</i>		

Public Health Insurance Program		
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3.2 Do patients receiving private treatment mostly use syringes or pens in your country?

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4. Life for a Child Support

If Life for a Child provides syringes to your centre, please answer Section 4. If Life for a Child does not provide syringes skip to Section 5.

4.1. If LFAC provides syringes to your centre, how many syringes are young people given per week?

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4.2. Are you happy with this amount, or do you think the quantity should increase, or decrease? Provide details below:

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5. Usage Details

5.1. For syringes, what needle length is commonly used in young people with diabetes in your country (e.g., 1/8" (4mm), 5/16" (8mm), or 3/16" (5mm)?)

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5.2. For syringes, what size syringes are commonly used by young people with diabetes in your country (e.g., 3/10 cc/mL, 1/2 cc/mL, or 1 cc/mL)?)

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5.3. For syringes, what needle gauge are commonly used by young people with diabetes in your country (e.g., 28 gauge)?)

5.4. Aside from any syringes provided to your centre by LFAC, which syringe brand is most commonly used in your country?

5.5. Which insulin pen brand is most commonly used in your country?

5.6. For those who use insulin pens in your country, do they mainly use refillable pens, or disposable ones?

5.7. In your opinion, do young people with diabetes prefer pens or syringes? Please provide details below:

5.8. On average, how many times do young people with diabetes at your centre re-use their syringe or needle before disposing of them?

5.9. How many injections do you encourage young people per week to perform if you do not use syringes provided by LFAC?

6. Safe Disposal of Needles

6.1. Is there national guidance on the safe disposal of needles? Please provide a copy if you have one:

6.2. If there is national guidance on needle disposal, what do the guidelines recommend?

6.3. If there is no national guidance on needle disposal, how does your centre advise people with diabetes to dispose of needles? *Please send us a copy of your recommendations if you have them:*

6.4. Is improper disposal of insulin syringes and/or pen needles a problem in your country?

7. Patient Education

7.1. Please tick where you encourage young people to give injections below:

Injection Site	Recommended? (Please tick)
Stomach	
Thighs	
Buttocks	
Front of arm	
Back of arm	

Other, please specify	
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7.2 At what age do you start encouraging children to do injections by themselves?

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8. Challenges

8.1. Are infection issues a common problem due to syringe/needle reuse in young people at your centre? Please tick the corresponding number in the scale below to indicate your response:

1	2	3	4	5
Never	1-2 isolated cases	Not uncommon	Common	Very common

8.3 Have you encountered any problems with needle reuse, and/or disposal? Please share details below.

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8.4 Is lipohypertrophy (development of fatty lumps at insulin injection sites) a common problem in young people at your centre?

Please tick the corresponding number in the scale below to indicate your response:

1	2	3	4	5
Never	1-2 isolated cases	Not uncommon	Common	Very common

8.5 Do young people express feeling stigmatized when injecting their insulin with syringes in public? Please provide details below:

8.6 If young people express experiencing stigma with injecting their insulin, how do they feel this could be lessened? Please provide details below:

8.7 Please share any other challenges young people express about injecting insulin below:

9 Other

9.3 What percentage of young people with type 1 diabetes <26 years of age in your country use a continuous, or flash glucose monitoring device (e.g., Dexcom or Libre) to measure their glucose levels?

2. Appendix B: Barriers faced by diabetes centres in providing HbA1c testing

<p><i>Cartridge cost</i></p>	<p>Without the support of LFAC it would be very difficult to afford the cost of HbA1c test</p> <p>Cartridges not available locally</p> <p>The cost is very high, in addition to paying taxes</p> <p>Shortage of budget to procure</p> <p>We lack financial resources to support at least two HbA1c tests per year per child</p> <p>The main challenge is to find sponsors who can pay for the cartridges</p> <p>Due to the fluctuation of dollars, sometimes the price at the local suppliers rises</p> <p>Reagents are expensive</p>
<p><i>Stockouts</i></p>	<p>Lack and price of reagents</p> <p>Sometimes due to issues of importing the reagents, there is a lack of cartridges to perform the tests</p> <p>Lack of resources to maintain the stock</p> <p>Delay on the supply delivery</p> <p>Customs clearance</p> <p>If our stocks run out we have no source of supply except the stock replenished by LFAC</p> <p>For the donated device we use, there is no sale of reagents locally</p>

	<p>Sometimes availability of stock becomes limited especially when the new budget is announced</p> <p>Sometimes the cartridges are slow to arrive, and we have spent almost a year without supplies</p> <p>Stockouts are due to a breakdown in the import process by the main distributor</p> <p>Health facility procurement system is not efficient</p>
<i>Maintenance of testing machine</i>	<p>Little knowledge of how to maintain the machine</p> <p>Lack/unavailability of experts for maintenance</p> <p>The cost of maintaining and repairing the machine is very expensive</p> <p>Maintenance of temperature and the solution levels</p> <p>Preparing quality control</p> <p>Regular preventive maintenance contracts are not in place at most of the facilities due to the costs involved</p> <p>Protection of the device against moisture and dust</p> <p>Interruption in power supply as electricity cut off is frequent and leads to damage of machines</p>
<i>Adequate oversight of</i>	<p>Limited training on utilization and maintenance</p> <p>Dependent on the cash flow and availability of funds to order the supplies</p>

<i>supplies</i>	Lack of staff
<i>Adequate supplies</i>	<p>Adequate supplies are very expensive, and we have to order them from overseas</p> <p>Mostly the supply is adequate but occasionally we have problems where patients need to pay for the test</p> <p>The price of A1c reagents of high quality is unaffordable for Public Health Clinics (patients cannot afford this) and at the same time tests provided in private clinics for the higher price are biochemical (not of the highest quality)</p>
<i>Refrigeration</i>	<p>Insufficient number of refrigerators, only one center has one</p> <p>Maintaining temperature between 2-8 °C</p> <p>Reagents not refrigerated in transit, limited inhouse storage capacity</p> <p>The cold chain maintenance is facing frequent power cuts</p>
<i>Trained staff</i>	<p>Insufficiently trained staff</p> <p>Due to staff attrition, training and retraining is regularly required</p> <p>Staff retiring, or staff transferred to other projects</p>
<i>Machine cost</i>	<p>The device is too expensive and not available</p> <p>We can obtain the machine as a loan or donation, but the cost of cartridges are too high or not available locally</p>
<i>Other</i>	The HbA1c test is performed in some laboratories where their methods has not been

<i>challenges</i>	<p>standardized and there is no adequate control of the reagents, so the results are often false. In some occasions, we think that the results are modified by the laboratory technician because values are reported within the normal range when the real values are very high</p> <p>With different point of care equipment in the market, there is an urgent need to for standardization of results as the coefficient of variations differ significantly</p> <p>Standardization is a major issue. Labs here use machines from various vendors, results vary</p> <p>Lack of point of care HbA1c devices in all health facilities</p> <p>Compliance of patients doing their HbA1C as at when due</p> <p>Patients do not follow up in time and indulge in other ayurvedic and homeopathic treatments Our patients have the necessary knowledge, however the psychosocial and socioeconomic situation has a lot of influence on these results</p> <p>Understanding the of role of HbA1c is poor in both the health workers and the patients. This leads to patients not honoring their appointments and going for long periods with poor control before intervention</p> <p>Little information in the analysis of the HbA1c test</p> <p>Our team members have only read about the HbA1c machine and have no hands-on</p>
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	<p>practice</p> <p>Phasing out projects that have been supporting the kids with provision of HbA1c testing</p> <p>The need to decentralize testing to other health facilities</p> <p>Expanding coverage to support more patients</p> <p>The hospital cannot afford to get A1C machine because the poor patients we serve will not afford the cost of testing</p> <p>Lack of government commitment towards the management of patients with diabetes</p> <p>Standardization is another concern as machines following international standardizations are very expensive</p> <p>Health workers appreciating the role of HbA1c in patients</p> <p>Teaching young patients the importance of carrying out testing every three months</p> <p>Having cash for customs clearance of packages</p> <p>Accurately forecasting number of cartridges needed</p>
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3. **Appendix C: Descriptions of barriers faced by patients in accessing HbA1c testing**

Theme	Description
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Costs	<p>Low socioeconomic status is a major barrier when it comes to getting HbA1c performed</p> <p>When our centre has shortages, we have encouraged patients to access the test outside our centre, but they wouldn't do it due to cost</p> <p>Poverty is the biggest barrier. There are some patients at our center who cannot afford to pay even the discounted rates.</p> <p>Many young people with diabetes cannot afford to pay out of pocket for their HbA1c testing. They prefer to come for their fasting blood glucose test every three months.</p> <p>Many of our youth and children cannot take the test every three months and some do it only once a year</p> <p>All of our young patients have never done HbA1c test because is not available and they do not have the money to access it privately</p> <p>Our young diabetics have never done the HbA1c test. Their glucose control is only analysed from capillary and venous glycemia</p> <p>The problem arises for those who graduate the LFAC program over 26 years of age. 100% of them drop the test for financial reasons.</p>
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Accessibility	<p>They live out of the city where testing capabilities are located</p> <p>Most of the people who live rurally are families with limited economic resources. In some areas of the country, access to these tests is null and in others, if there is a machine to do the exam, they do not have the necessary reagents. In any case, it depends on the hospital they can access.</p> <p>Our centre provides HbA1c testing for free but sometimes we cannot afford this and the patients are obliged to wait. Despite the free testing, the cost of the transport are sometimes limiting the patients to come to the hospital.</p> <p>Some don't have resources to pay for transport to the centre to get the tests</p>
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4. Appendix D: Comparing availability of HbA1c testing to blood glucose measurement and insulin in primary health centres

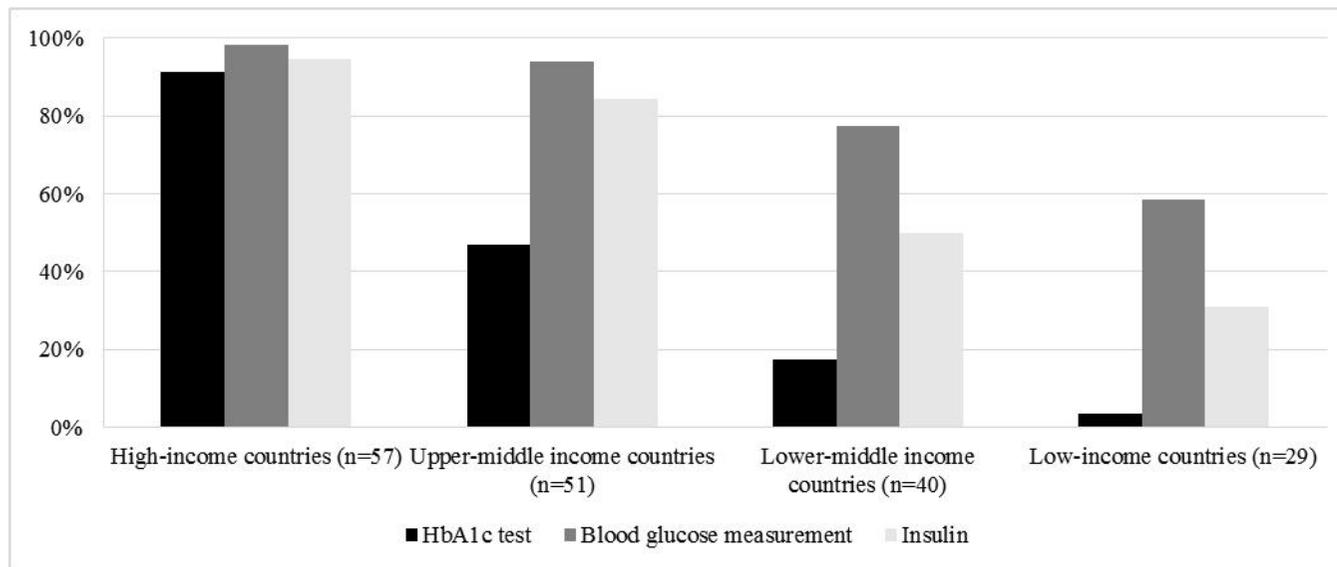


Figure created with data from WHO diabetes country profiles^[1]. General availability of blood glucose testing defined as > 50% presence at health-care facilities.

References

1. **World Health Organization (WHO)**. Assessing national capacity for the prevention and control of noncommunicable diseases: report of the 2015 global survey [Internet]. 2016 [cited 2020 Jan 1]; Available from: <https://apps.who.int/iris/bitstream/handle/10665/246223/9789241565363-eng.pdf?sequence=1>

5. Appendix E: Type 1 diabetes prevalence for young people <19 years age in countries surveyed

Country	T1D estimates (0-19 y)
Azerbaijan	1,847
Bangladesh	5,350
Bolivia	834
Burkina Faso	580
Burundi	343
Central African Republic	32
Democratic Republic of Congo	1,275
Dominican Republic	196
Ecuador	710
Eritrea	107
Ethiopia	2,127
Ghana	1,209
Guatemala	4,333
Guyana	4
Haiti	110
India	171,281

Jamaica	180
Liberia	178
Maldives	38
Mali	306
Mauritania	130
Mexico	26,578
Nepal	4,621
Nigeria	2,954
North Korea	1,941
Pakistan	1,754
Philippines	3,897
Republic of Congo	265
Rwanda	631
Sri Lanka	2,623
St Lucia	23
Tajikistan	829
Tanzania	1,984
Togo	289

Uganda	2,253
Uzbekistan	2,534
Vietnam	2,574

References

1. **International Diabetes Federation.** Type 1 diabetes estimates in children and adolescents Type 1 diabetes (0-19 y), in 1,000s, IDF Diabetes Atlas 9th edition [Internet]. 2019 [cited 2020 Jan 7]; Available from: <https://www.diabetesatlas.org/data/en/indicators/12/>
2. **Patterson CC, Karuranga S, Salpea P, Saeedi P, Dahlquist G, Soltesz G, Ogle GD.** Worldwide estimates of incidence, prevalence and mortality of type 1 diabetes in children and adolescents: Results from the International Diabetes Federation Diabetes Atlas, 9th edition. *Diabetes Res Clin Pract* 2019;157 [PMID: 31518658 DOI: 10.1016/j.diabres.2019.107842]