

# INSULIN USERS' PERSPECTIVE PROFILE

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June 2017



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**Molly Lepaska**

Health Action International

Published by

**Health Action International**

Overtoom 60 (2) | 1054 HK Amsterdam

The Netherlands | +31 20 412 4523

[www.haiweb.org](http://www.haiweb.org)

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The ACCISS Study is supported by The Leona M. and Harry B. Helmsley Charitable Trust and Stichting ICF. The analysis included in this report is that of the authors alone and does not necessarily reflect the views of the Helmsley Charitable Trust or Stichting ICF. All references and conclusions are intended for educational and

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# **Insulin Users' Perspective Profile**

# Contents

- Acknowledgments .....3**
- Acronyms .....3**
- 1. Introduction .....3**
  - 1.1 The ACCISS Study ..... 3
  - 1.2 Insulin in Real Life ..... 4
- 2. Methods.....4**
  - 2.1 Limitations of the Study ..... 5
- 3. Results.....6**
  - 3.1 Demographic Information..... 6
  - 3.2 Insulin Use and Delivery Devices ..... 6
    - 3.2.1 Types of Insulin Being Used .....7
      - 3.2.1.1 Satisfaction with Current Insulin .....7
      - 3.2.1.2 Respondents who have Used Multiple Insulins ..... 8
      - 3.2.1.3 Preference to Switch Insulin ..... 9
    - 3.2.2 Insulin Delivery Devices .....10
    - 3.2.3 Life with Insulin: Flexibility and Adaptability ..... 11
    - 3.2.4 Daily Challenges of Insulin Use.....13
  - 3.3 Accessing Insulin.....13
    - 3.3.1 The Price of Insulin .....14
    - 3.3.2 Insulin Availability.....15
    - 3.3.3 Insulin Reliability .....16
      - 3.3.3.1 What Do You Do if You Can't Access Insulin? .....16
  - 3.4 Diabetes Associations and their Role in Insulin Access .....17
  - 3.5 Lack of Knowledge of the Insulin Companies and Types of Insulin .....18
    - 3.5.1 Changing Insulins and Brand Loyalty .....19
  - 3.6 Doctors and Their Role in the Choices of Insulin Users .....19
  - 3.7 Beyond Insulin: The Price of Diabetes.....21
    - 3.7.1 Diabetes and Insulin Awareness ..... **22**
- 4. Discussion and Further Research Needs ..... 22**
- 5. Conclusions ..... 24**
- References ..... 25**
  
- Annex 1. Insulin User Questions..... 27**
- Annex 2. Where Respondents Reported Getting their Insulin From ..... 28**

# Acknowledgments

I would like to acknowledge all of the individuals who helped me to find contacts and complete these surveys, particularly, Chalerm Sak Kittitaku, AIDS Access; Denis Kibra, HEPS; Jenny Hirst, IDDT; Dr. Kaushik Ramaiya, Shree Hindu Mandal Hospital; Louise Kyle, AHS; Alpha Oumar Diallo, CDC; and Dr. Subrata Chatterjee, GE Power India Limited, Stephanie Boyle, AYUDA.

# Acronyms

ACCISS	Addressing the Challenge and Constraints of Insulin Sources and Supplies
DR	Dominican Republic
Eli Lilly	Eli Lilly and Company
IDF	International Diabetes Foundation
IIF	International Insulin Foundation
HIC	High-income country
LMIC	Low-and middle-income country
RAPIA	Rapid Assessment Protocol for Insulin Access
UK	United Kingdom
US	United States

## 1. Introduction

### 1.1 The ACCISS Study

Today, approximately 100 million people around the world need insulin, including all people living with type 1 diabetes and between 10-25 percent of people with type 2 diabetes. Although insulin has been used in the treatment of diabetes for over 90 years, globally more than half of those who need insulin still have difficulties accessing it. Without insulin, people living with type 1 diabetes will die. Many more will suffer from diabetes-related complications, like blindness, amputation and kidney failure, and, ultimately, premature death.

There are many complex issues that affect access to this life-saving medicine, creating inequity and inefficiency in the global insulin market. The innovative global study, Addressing the Challenge and Constraints of Insulin Sources and Supply (ACCISS), sets out to identify the causes of poor availability and high insulin prices and develop policies and interventions to improve access to this essential medicine, particularly in the world's most under-served regions. The three-year study involves a unique group of leading international experts as members of the study's advisory and technical groups. ACCISS is co-led by Margaret Ewen at Health Action International, David Beran from Geneva University Hospitals and the University of Geneva, and Richard Laing from Boston University School of Public Health.

The study is being carried out in three phases. The first phase was mapping the global insulin market from various angles. In phase 2, a greater understanding on insulin manufacturers and the distribution chain was sought, as well as further understanding on insulin access from the

perspective of those who use it and the doctors who prescribe it. This report is part of this work. All profiles can be accessed on the ACCISS Study section of Health Action International's website: <http://haiweb.org/what-we-do/acciss/>.

## 1.2 Insulin in Real Life

Some of the key barriers to access to insulin already identified include high prices of insulin (particularly analogue versus human insulin) and the domination of Eli Lilly and Company (Eli Lilly), Novo Nordisk, and Sanofi who currently hold around 90 percent of the global insulin market (1). However, to gain a more comprehensive picture of the insulin landscape, it is important to also investigate insulin from the user's perspective – how it is used on a daily basis, where people actually get their insulin from and how much they pay for it, how they feel about what they are using, and how much (if any) impact national diabetes associations, doctors or marketing by manufacturers might have on users insulin knowledge or choices. Looking at the real life applications of insulin use is important in implementing any strategy to improve insulin access in the future.

Insulin user input is critical because diabetes is a condition that is said to be managed by the person living with the condition 95 percent of the time (2). Qualitative research has been used in the past in many studies to help illustrate the issues that affect those living with type 1 and type 2 diabetes and to improve care (3-8). In low- and middle-income countries (LMICs), interviews have been used to record the barriers to care through particular cultural or socio-economic lenses (9 -13). In the 2000s, the International Insulin Foundation (IIF) developed the Rapid Assessment Protocol for Insulin Access (RAPIA) that looked at access to insulin in low-income countries from various perspectives, including interviews of type 1 diabetes patients regarding access to and cost of treatment (14). Barriers to insulin access in LMICs have also been researched via the doctor's perspective (15, 16). Outside of academia, interviews and storytelling have been employed to promote insulin access and raise awareness about living with type 1 diabetes by organisations such as the 100 Campaign and T1 International, and in the US, Glu which asks those with diabetes to directly input data into their online database (17 – 19).

The aim of the interviews is to look specifically at insulin use and access from the perspective of the insulin user, across both types of diabetes, to develop preliminary insight on some of the critical issues in accessing their insulin. To do this, ACCISS conducted informal interviews with insulin users from June – October 2016 to understand more about the experiences, challenges to access and use, as well as the opinions and perceptions about the insulin they use.

## 2. Methods

Interviews with insulin users were conducted via phone, Skype, Google Hangout, direct email, and more formally through printed questionnaires.

To find potential insulin user respondents, contacts from 20 countries were emailed (Bangladesh, Barbados, Brazil, Burkina Faso, Canada, China, Dominican Republic (DR), Ethiopia, Guyana, Kenya, India, Mexico, Moldova, Russia, Tanzania, Thailand, United States (US), United Kingdom (UK), Uganda and Vietnam) between June and September 2016. Primary contacts were found through a variety of personal and professional contacts, the ACCISS Advisory Group, country diabetes organisations from the ACCISS Network list and the

International Diabetes Federation (IDF) website, and the IDF's World Diabetes Day events calendar website from 2015.

The only requirements for those interested in participating in this study is that they be over 18 years of age (or a parent of a child with type 1 diabetes) and have at least one hour of time to either speak on the phone (or online platform such as Skype or Google Hangouts) or respond to an email questionnaire, available in English, Spanish, French, Kiswahili, and Thai (Annex 1). The phone interviews were conducted in English, with the exception of one done via a surrogate interviewer in Thai. Some of the email questionnaires were completed by the users, others were completed by proxy. All questionnaires were anonymous.

Questions in the email questionnaire covered the following subjects:

- Biographical information
- What insulin the respondent is now using (or has used in the past) and how they use it
- Insulin preference and satisfaction
- Where they get their insulin and the price they pay for it
- The availability and dependability of insulin
- The challenges with using insulin
- Other challenges of living with diabetes
- Their knowledge of the insulin manufacturers Eli Lilly, Novo Nordisk, and Sanofi and differences between analogue and human insulin and how these might affect their insulin knowledge or choices
- Diabetes associations they belong to

## **2.1 Limitations of the Study**

This was a convenience sample of respondents. Because the respondents were referred by contacts, they tended to live in similar areas of the country or in similar circumstances (e.g. all go to the same clinic, all are members of the same organisation, all work at the same company). While efforts were made to ensure some diversity, these interviews do not reflect the thoughts of all people living with diabetes in these countries and therefore cannot be considered representative or generalisable.

Although the questions were used as a guide, the phone interviews were semi-structured, and often did not directly address each question. After phone and email interviews clarification and follow-up was made if necessary. For the printed questionnaires that were distributed via one main contact and returned as scanned copies, responses were taken at face value. Everything was self-reported, so that should be considered when looking at the data. Because of this, the report rarely uses exact numbers. This report should be used as guide for further, more formal research into the experience of insulin users.

## **2.2 Ethical Considerations**

Individual responses were anonymised and all interviewees were asked to sign a consent waiver, however some did not complete the waiver prior to this report being prepared. No identifying factors other than country name, diabetes type and insulin type are in the study.

### 3. Results

In total, 36 people were interviewed in 11 countries: UK (five), US (two), Canada (two), Mexico (one), Uganda (one), DR (four), Tanzania (12), India (three), Burkina Faso (three), Mali (one), and Thailand (two). Although every effort was made to connect via phone or Skype interviews, due to language and schedule barriers, only ten interviews were conducted over the phone, Skype or Google Hangout. These took place in the US, Canada, the UK, Mexico, Thailand and Uganda. All others were done using email or phone questionnaire (including two from the UK via email). In Tanzania, the DR, and the UK, more surveys were received than all other countries (12, four, and five respectively) due to greater interest. Some of the data may be skewed because of this.

#### 3.1 Demographic Information

Of the 36 people interviewed, 18 had type 1 diabetes, 18 had type 2 diabetes. One labelled their status as “MODY” (Maturity onset diabetes of the young), which for the purposes of this report is included in the type 1 diabetes category. Ages of participants ranged from five to 79 years and the mean age was 45.8 years. Of the participants, the number of years of living with diabetes ranged from ‘just diagnosed’ to 46 years, with a mean of 16.7 years of living with diabetes.

Table 1. Number of respondents per country, by diabetes type.

Country	Type 1 diabetes	Type 2 diabetes
US	2	0
Mexico	0	1
UK	4	1
Uganda	0	1
DR	4	0
Canada	2	0
Tanzania	2	10
India	0	3
Burkina Faso	2	1
Mali	1	0
Thailand	1	1
<b>Total</b>		
11 countries	18	18

#### 3.2 Insulin Use and Delivery Devices

Survey respondents living in LMICs were more likely to use human insulin, while those living in high-income countries (HICs) were more likely to use analogues. Lantus® and Actrapid® were the most commonly used insulins. Most survey respondents reported being happy with the insulin they were currently on. Only two explicitly expressed dissatisfaction with the insulin they were using. However satisfaction with insulin does not necessarily mean that respondents did not

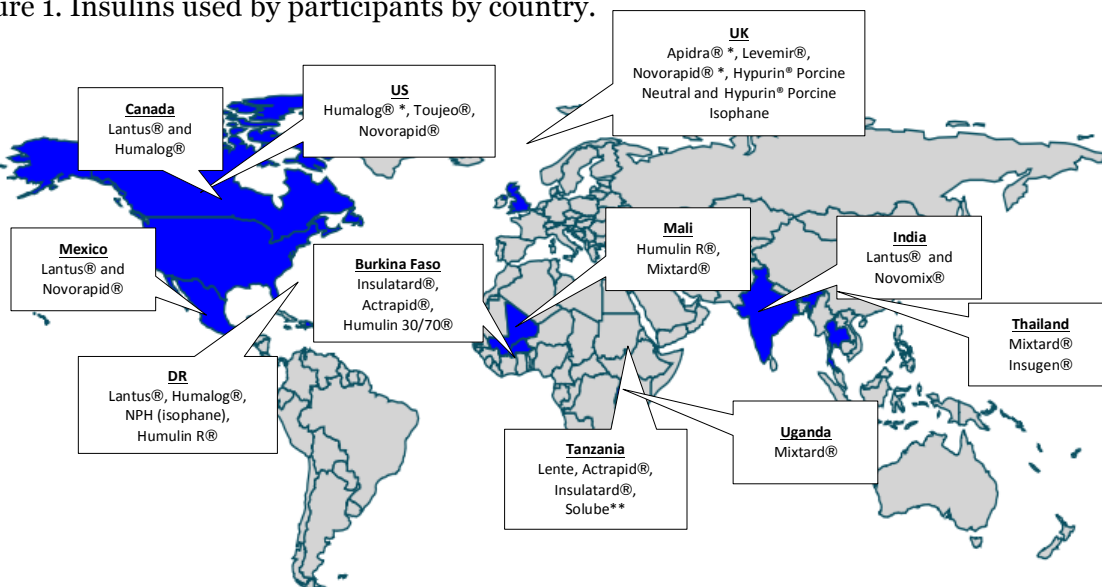


report struggling with other issues around insulin management. The majority of the survey respondents across all countries were still using syringes and vials, with pens as the second most highly used delivery system. Insulin pumps were only used by three of those interviewed. While the survey focused mainly on insulin and not delivery devices, only a few respondents reported real issues of using vials and syringes versus other delivery methods.

### 3.2.1 Types of Insulin Being Used

As Figure 1 shows, all but one of the survey respondents in a HIC was on analogue insulin. Those in LMICs were predominately using human insulin, except for one respondent in Mexico (Lantus® and Novorapid®), two in the DR (Lantus® and/or Humalog®), and three in India (Lantus® or Novomix®). In India, survey respondents were working for a company that provided free insulin to their employees and their families. In the DR, two respondents using analogue insulin received it via their diabetes foundation. The most commonly used insulin was Actrapid®, but this might be because there were many respondents from Tanzania that came from the same hospital. Excluding Tanzanian respondents from the results, Lantus® was the most used insulin, with eight users (representing India, Canada, Mexico, and the DR). The least used insulin was Toujeo®, Hypurin® Porcine Neutral and Hypurin® Porcine Isophane insulins (one person each).

Figure 1. Insulins used by participants by country.



\*Insulin pump users

\*\* On the questionnaire, some respondents wrote 'solube' and some 'actrapid' so they are counted here as two insulins

#### 3.2.1.1 Satisfaction with Current Insulin

Most respondents indicated that they were generally satisfied with the insulin they were using. Further, most had been using their current insulin for an average of 8.4 years. This equalled about half the average time respondents in the study had been living with diabetes (16.7 years). The longest duration on one type of insulin was 40 years, and the shortest was just a few days. While most were satisfied with their insulin, this did not mean that they didn't struggle with other aspects of their insulin management. Only one respondent answered that they were

completely satisfied with insulin, including management, and thus did not have any other challenges with their diabetes since starting on insulin.

*Since I have started using insulin I have no problems with diabetes I am feeling [better] than before.* Tanzania type 2 diabetes (Actrapid® and Insulatard®)

While many insulin users discussed their feelings about their current insulin, a few respondents also commented on what they felt when they first used insulin. An individual living with type 2 diabetes expressed difficulty in overcoming the fear of injection, while another living with type 1 diabetes since a young age communicated the challenges related to adjusting to a complex new schedule of diabetes management with insulin injections.

*At first of I was very afraid of using insulin and very afraid of needles. [It] probably took me one day to adjust and after that, I found out that everything was in my mind (regarding the pain) and quickly overcame the pain. Lantus® doesn't hurt but feels hot when you inject it.* Mexico type 2 diabetes (Lantus® and Novorapid®)

*During the first year of my diabetes I also used a less fast acting insulin during the day so I could go to school without having to inject. My parent and the health care providers figured out a plan for me to use to avoid taking insulin during the day and I ate specific foods during lunch. The next year, (grade 4) I took Humalog® at school– going to the bathroom for lunch, and basically eating the same thing everyday. As I got older started to adapt but still used Humalog® and Lantus®.* Canada type 1 diabetes (Lantus® and Humalog®)

Others expressed their contentment with the insulin they were using, but the answers were more nuanced, for example because they either hadn't tried other types of insulin, or conversely that they had tried other insulins and felt dissatisfied with the results.

*I'm happy but I don't know anything else – used to [my regime] and adjusting insulin when something big changes. I'm pretty happy.* Canada type 1 diabetes (Lantus® and Humalog®)

*Happy on my insulin regime but have read a lot about the two insulins combination (long acting and short acting) that would be closer to your own body control.* US type 1 diabetes (insulin pump - Humalog®)

*I have used porcine insulin for nearly 40 years. I was put on genetically modified or “human” insulin for four and half years (1987 to 1992) then went back on porcine insulin starting in 1992. So I have been using porcine insulin, in total for nearly 40 years.* UK type 1 diabetes (Hypurin® Porcine Neutral, Hypurin® Porcine Isophane)

### **3.2.1.2 Respondents who have Used Multiple Insulins**

Half of those interviewed (16) said they had used types of insulin other than the ones they were currently on. All nine of the respondents from HICs had been on more than one insulin regime. Two had switched from an analogue mix (long- and rapid-acting analogues) to the insulin pump (rapid-acting analogue only), one had switched from pork insulin to the insulin pump (rapid-acting analogue), and one had switched from the pump (rapid-acting insulin) back to a

combination of analogue insulins, and one had used all types of insulin and was currently on pork insulin. All others in HICs had switched from human insulin to analogue. Only seven of the total 27 in LMICs responded that they had used more than one insulin. Five had switched types of human insulin (for example from Mixtard® to Lente) and two had used analogue insulins and now were using human insulin. A small number of respondents did not know about other types of insulin or answered that they hadn't heard of others, or would prefer something based on advice from a doctor.

### **Analogues to Other Analogues**

*I went off the [insulin] pump while I was on vacation and my pump broke. I really liked the freedom that Lantus gave me. US type 1 diabetes (Novolog®, Toujeo®)*

### **Pork to Human to Analogue**

*I've used animal, human and analogue (insulin). I started on beef insulin – it is crude around today's standards. Human insulin is noted as a drug allergy (for me). I get dreadful swelling of my hands when I use it. Because it's not documented (in studies, as a side effect) no one believed me. UK type 1 diabetes (Apidra®)*

### **Human to Analogue**

*When I was first diagnosed I was on Humulin R® and N® then when Humalog® came it was pretty awesome as I don't have to wait for 30 mins to kick in. I started taking Lantus® about two years ago. Canada type 1 diabetes (Lantus®, Humalog®)*

### **Human to Pork**

*I've always had excellent results when on porcine insulin. The years I spent on genetically modified or human insulin I lost all my warning signs of low blood sugar, my blood sugars would drop rapidly and without warning. I would also get very high blood sugar no matter how I tried to control and manage the condition my diabetes became more and more unstable. I lost my confidence and my health deteriorated. UK type 1 diabetes (Hypurin® Porcine Neutral, Hypurin® Porcine Isophane)*

### **Human to Human**

*First [the insulin user] took two different insulins that needed to be mixed but it was much more difficult for [the insulin user] to do the mixing on their own, so now [the insulin user] takes pre-mixed insulin. Relative of Uganda type 2 diabetes (Mixtard®)*

## **3.2.1.3 Preference to Switch Insulin**

While most of the respondents were satisfied with the insulin they were using, a few were not. One indicated that they were just dissatisfied with their insulin in general, but did not indicate they wanted to switch insulin types.

*[My current regime] does not give good control. [I am] generally unwell, [have] loss of sensation to feet and an infection at the injection site.* Tanzania type 2 diabetes (Lente and Soluble)

Five respondents specifically indicated they would prefer to switch to another form of insulin (although this did not necessarily mean they were unhappy on their current insulins). Four out of the five respondents were in LMICs. All of the five indicated they would want to switch to an analogue insulin (those named were Levemir®, Lantus®, and more generally a rapid-acting insulin). While not all of these respondents indicated if they had used these types before, all were receiving insulin from diabetes associations or foundations. The insulin user in Mali stated the reason for the desired switch was due to effectiveness, while one of the users in the DR stated that they would prefer to switch to insulin that was “better known.”

*There are many things that we miss, such as effective insulin. Given the condition we accept what we are offered but if possible would prefer Novolog (Novorapid®) insulin.* Mali type 1 diabetes (Humulin R®, Mixtard®), has used Novorapid® before.

*I would like insulin to be changed to options that are better known and used more on the (existing) market.* DR type 1 diabetes (NPH and Humulin R®)

*Whatever the insulin I was taking the last year (during the study – thought to be Toujeo®)...I would prefer that. It got to a point where I was almost only using the long acting insulin and didn't have to take the shorter acting insulin (during meals).* UK type 2 diabetes (Novorapid® and Levemir®)

### **3.2.2 Insulin Delivery Devices**

Most of this group of respondents were still using insulin in vials with syringes. Although this was more of the case in LMICs, insulin users in HICs were also using them, at least in combination with pens. After vials and syringes, ten people reported using pens, either in combination with vials and syringes or on their own. Of the nine people interviewed in HICs, three were on insulin pumps, and three still used syringes exclusively (one was for pork insulin, and one was a mix of syringe with vials and cartridges). There were no insulin pumps used in the respondents spoken to in LMICs.

*[I use] the pump, although I started off injecting and switched around 2006/2007.* UK type 1 diabetes (Novorapid®)

*[I use] syringes with cartridges as I'm a very active with my job and it's the easiest way for me.* Canada type 1 diabetes (Lantus®, Humalog®)

For the respondents who spoke more in depth about the insulin delivery devices, a few discussed having to overcome the fear of injecting insulin (see also 3.2.1.1) or said they were still struggling with their perceptions of needles/injections.

*At first going on insulin was not so easy – but she has learned to inject herself with the insulin and it much easier (now).* Relative of Uganda type 2 diabetes (Mixtard®)

*[The insulin I use is] ok but on another side it is dangerous to inject always. Tanzania type 2 diabetes (Lente and Soluble)*

One respondent in the UK had just taken part in a year-long trial where vials and syringes were used rather than pens. Although the respondent thought that pens were easier, the main criticism of the vial and syringe was not using the needle, but measuring the insulin into the syringe.

*[I am] reasonably happy with [my insulin]. I have recently come off a year-long devote trial- it's a trial where they evaluate an extremely long acting insulin. They believed I was actually on the insulin. During the study I had to go back to using a vial and syringes and it is much easier to use pens than to measure out the amounts via the syringe. UK type 2 diabetes (Novorapid\* and Levemir\*)*

For one respondent in the UK, the type of insulin she used was decided by her delivery device and the availability of a continuous glucose meter (CGM).

*I am now on an insulin pump with a glucose meter. I'm using [analogue] insulin only in the insulin pump and also use the CGM at the same time. I will only use [analogue] insulin with "the loop" of the CGM and the pump working together. I do not inject analogue. I believe it is too volatile to use without the CGM. UK type 1 diabetes (Apidra\* insulin)*

### **3.2.3 Life with Insulin: Flexibility and Adaptability**

Although these were not in-depth interviews, this study aimed to uncover insulin user perceptions of flexibility and adaptability of insulin routines and what, if any, challenges users experienced. As reported by the respondents, the average number of insulin units used each day by those with type 1 diabetes was 35.9 units per day and 36.4 units per day for type 2 diabetes (this is just under the WHO's defined daily dose of 40 IU <http://apps.who.int/medicinedocs/en/d/Js4882e/8.6.html> ). The average number of injections per day across all users was 2.8 injections. In general, analogue users injected their insulin more times per day than users of human insulin (excluding pump users).

Of 36 respondents, 14 said they felt free to adapt the amount of insulin they took every day, and 22 said they strictly followed the instructions set by their doctor. Those who felt they were 'free to adapt' included all people in HICs and five people in LMICs. In general, those who strictly followed their doctors' orders in terms of insulin doses (versus those who felt free to change their insulin regime themselves) were overwhelmingly users living with type 2 diabetes and all living in LMICs.

*I feel fully flexible with my treatment. They really turn it over to me. I was reading something about the first people to use insulin and read that even with the very first users it has always been something that has been self-driven. US type 1 diabetes (Humalog\*)*

*I very rarely adapt my schedule. I eat the same thing everyday. Mexico type 2 diabetes (Novorapid\*, Lantus\*)*

*[I feel] no freedom to change [my insulin regime] Generally [I am] unwell [with] loss of sensation to my feet and have an infection at the injection site. Tanzania type 2 diabetes (Lente and Solube)*

*The doctor prescribes and it is strictly defined by the doctor. Thailand (Mixtard® 30/70)*

Despite many feeling strictly tied to their regimes, in total 27 respondents said that they either always or sometimes felt as they had flexibility within their daily life and routine, although many in LMICs especially perceived challenges within this flexibility in terms of diet and travel particularly.

*I have as much flexibility as I need and want. I take part in regular exercise. I have been a regular runner for the last 26 years and have been a member of a running club. As long as I have the right supplies with me I have no problem with taking part in running/races/walking etc. With regard to my daily routine I have worked full time in a busy job for many years. I have just taken early retirement –and I am still busy helping out family with childcare and doing gardening and keeping busy so I have no problem with my daily routine. I eat out with family and friends but always check menu first to ensure that there is something suitable and I also ensure that other people are aware of my condition (i.e. so that they know I can't "skip" meals or eat at unsuitable times. UK type 1 diabetes (Hypurin® Porcine Neutral and Hypurin® Porcine Isophane)*

*Very flexible – I can still live my life. It doesn't really affect my day-to-day [uses vial and syringe]. Canada type 1 diabetes (Lantus®, Humalog®)*

*For the meals I follow the same diet (not too much fat, sugar not in high quantity). I use a motorcycle and in the evenings go running or play basketball. Mali type 1 diabetes (Humlin R®, Mixtard®)*

*Overall is convenient. But I experience some difficulty if you have to travel and key is the insulin contained with ice. This is so inconvenient. Also sometimes I forget to take insulin. Thailand type 2 diabetes (Mixtard®)*

*It's so hard to have diabetes because it limits me to have and explore a lot of food and drinks I would love to have and also the type of food I have to take is boring and the same everyday. Tanzania type 1 diabetes (Insulatard®)*

*It is a challenge to use insulin every day. Diet is another challenge where by sometimes you are in places where you can't get the food you are allowed to have. Sometimes eating in time is a challenge. Tanzania type 1 diabetes (Mixtard® and Actrapid®)*

*My challenges will be 3 meals a day and a fear of sugary foods. Burkina Faso type 1 (newly diagnosed). (Humulin® 70/30)*

*My normal routine suits nicely but during travel is difficult. India type 2 diabetes (Novomix®)*

*Sometimes it is difficult to use insulin when traveling due to daily routine at work Tanzania type 1 diabetes (Mixtard® and Actrapid®)*

### 3.2.4 Daily Challenges of Insulin Use

Insulin management, as part of diabetes care requires daily diligence. Many respondents discussed this commitment: from remembering to take insulin every day and accepting the ups and downs of insulin use; to the additional challenges it adds, such as daily vigilance and changes to diet. Some had come to accept it, despite some feelings of being overwhelmed or frustrated.

*I've come to a good level of acceptance with diabetes. Initially I thought that if I get the formulas right and took the medicine as I was supposed to it would be great and it would all just work out. What I've learned is that you just have to do the best you can and hang on. Whatever happens you have to just do. It was a big moment because you have to let go of that and allow yourself to know it won't always be perfect and it won't always even be good. US type 1 diabetes (Humalog®)*

*I feel like I've lived a charmed life on diabetes. But still there are challenges – such as in the bleakest moments trying to get the doctors and clinicians to understand the 24 hour commitment to care and what it takes to manage the condition. UK type 1 diabetes (Apidra®)*

*We as insulin dependents we need to be responsible for our health, to ensure our blood sugar level is maintained and not to fall to the other related complications, kidney failure and other complications and for men, erectile dysfunction. Tanzania type 2 diabetes (Lente, Solube)*

*If you are diabetic, accept the fact. Do the 'dos' to enjoy the life. You will live more than others with good part of life. India type 2 diabetes (Novomix®)*

For others, the daily maintenance could also cause apathy and boredom, which could lead to a decline in insulin use or management.

*After being on insulin for a while now in a way I have become comfortable and are not watching my numbers as closely and am forgetting to take care of myself and putting in my body what I need. Mexico type 2 diabetes (Lantus®, Novorapid®)*

*I don't want to take the medicines. I feel bored and have to control my diet. Thailand type 2 diabetes (Mixtard®)*

### 3.3 Accessing Insulin

Beyond insulin use and the challenges to the daily routine, most respondents also reported challenges paying for and/or accessing insulin consistently. This ranged across all country income levels except in the UK, where the government healthcare system pays for all diabetes treatment and users receive reliable treatment and care. Outside the UK, respondent countries that reported receiving free insulin, all except for India, reported that insulin was not 100 percent reliable from their main source, or they experienced other difficulties in accessing insulin such as a long travel distances or a long wait time to receive the insulin.

### 3.3.1 The Price of Insulin

For many, the high price of insulin was a part of managing the condition. A user from the US explained how the cost of insulin and related supplies was just something their family planned into their yearly budget.

*I can't imagine not having access to insulin. It is incredible how expensive it is. I've come to accept that in there is a high diabetes ceiling (in terms of costs) and that for our expenses there is always a certain amount of our money that will go to it. I pay about US\$500 a year for diabetes supplies outside of what is covered by insurance. Never had to buy insulin outright. US type 1 diabetes (Humalog®)*

#### **Respondents Not Paying Out-of Pocket for Insulin**

Out of 30 respondents, 18 said they received free insulin at least some of the time. This included five from the UK who receive all diabetes-related supplies free from the government. Thirteen of those receiving free insulin were living in LMICs. Of these, eight received insulin from diabetes associations, three from their company's health centre (in India), two from the government, and one reported receiving insulin via family insurance benefits (see Annex 2).

*It's free as I have a medical exemption certificate from the NHS (National Health Service). UK type 1 diabetes (Novorapid®)*

*Insulin is free if it's available through the health unit. If it is not available there, it costs US\$7.28 (25,000 Ugandan shilling) per vial at the private pharmacy (in Kampala). It can also be possible to get it through the diabetes association when it's unavailable for US\$4.37. But to do this, the diabetes association collects US\$0.87 a month, which you must pay every month, regardless of if you get insulin from them or not. Relative of Uganda type 2 diabetes (Mixtard®)*

*My insulin is available via a (local organisation) every month at the hospital in Mali. I buy [insulin] at the pharmacy when it is late. Mali type 1 diabetes (Humlin R®, Mixtard®)*

#### **Respondents Using Insurance**

In total, eight insulin users said they were using insurance to supplement or cover their insulin costs. Two were in the US, two in Canada, three in Tanzania, and one in Thailand. For those in the US and Canada, three reported struggling with co-pays and deductibles on their insurance.

*I have insurance (Pharmicare) which varies per province. You pay for your deductible which is based on your tax return from two years previous. My deductible is around US\$750 (per year). The deductible puts a strain on our [household income]. All diabetes costs have to be paid until you reach the limit of the deductible. Canada type 1 diabetes (Humalog® and Lantus®)*

*I have insurance so I only have a US\$5 co-pay on each 10 ml vial of Humalog. I pay US\$700 per month in health insurance for me and my 2 boys. Without insurance Humalog® would be apx. \$350 per bottle. I also purchase back-up Levemir® vial for US\$5 co-pay. US type 1 diabetes (Humalog®)*



*[Get insulin covered through] NHIF – [otherwise I would pay] approximately US\$33.15 (72,000 Tanzanian shillings) if paid from my pocket. Tanzania type 2 diabetes (Lente, Solube)*

*Insurance partially covers my insulin. I pay between US\$70 and US\$90 for both the Novolog® and Toujeo® pens (1 box plus 2 pens). US type 1 diabetes (Novolog®, Toujeo®)*

*[My biggest challenge is] insurance company and hoops to jump through to make sure you are getting what you want/need. The insurance companies don't want to give you more than they have too. US type 1 diabetes (Humalog®)*

### **Respondents Paying Out-of-Pocket**

Ten of the respondents said had to pay for insulin out-of-pocket all the time. In the case of Mexico, the user paid for their insulin out-of-pocket because they preferred to use insulin that was recommended from their doctor. Prices, which were self-reported, ranged from US\$357 for Lantus® pens in Mexico to US\$9.36 for Lente insulin in Tanzania.

*I don't find a lot of people taking this insulin (Lantus®, Novorapid®). They have raised up the price too much the past few years, you don't hear too much in Mexico about changes [to other insulins]. Usually I buy my insulin (out of pocket) at Walmart. If you buy 3 pens, Walmart will give you the 4<sup>th</sup> free so you save 25%. Mexico type 2 diabetes (Novorapid® and Lantus®)*

*[From] 2006 – 2013 I was purchasing from Medical Shop. It was US\$7 (480 rupees) x 5 for cartridges using every month. 2013 August onwards [I am] getting [insulin] free of charge from our company which my son is working for. India type 2 diabetes (Lantus®)*

### **3.3.2 Insulin Availability**

Most survey respondents reported getting their insulin most frequently from pharmacies (Annex 2, Table 1). About half as many respondents received insulin either from a hospital or health centre or their diabetes association/ work health centre. All of those receiving insulin from their diabetes association/work health centre received insulin for free (Annex 2, Tables 2 -3).

*If [the insulin user] gets insulin for free during monthly check-ups, [the insulin user] must travel 15km to visit the health unit. You must visit the doctor to get insulin. Sometimes if you are lucky they give two bottles of insulin at a time if it is available. If [the insulin user is] getting insulin from the private pharmacy, then I will buy it in Kampala. Relative of Uganda type 2 diabetes (Mixtard®)*

*I receive insulin every month [picked up from the nearby pharmacy]. [I'm] supposed to get four vials, but my insurance will only allow me three vials – I use at least three vials every month. US type 1 diabetes (Humalog®)*

*[The insulin] is administered by [the diabetes foundation], if not available, the pharmacy. DR type 1 diabetes (NPH, Humalog®)*

*I go to Walmart that is in my town. I have had to travel outside of my town when they didn't have insulin anywhere in town. Sometimes I have to go from one Walmart to another (two or three) to find my insulin. Mexico type 2 diabetes (Lantus®, Novorapid®)*

*Prescription from the GP then any chemist will dispense it but I usually get it from Boots (pharmacy). UK type 1 diabetes (Hypurin® Porcine Neutral, Hypurin® Porcine Isophane)*

### **3.3.3 Insulin Supply Reliability**

For some respondents insulin might be free or available at health centres or pharmacies, but it did not guarantee they would receive it at the time they would need it. Some respondents mentioned having to wait from a few days, up to many months for their insulin. This was only a problem in LMICs.

*It's hard to say how dependable insulin [supply] is –in the years it goes up and down. Sometimes for 3 -4 months it is available and then they go 6 months without it. In Uganda there is a focus on other illnesses and so the demand (by health services) for insulin goes down and there is less insulin available. Relative of Uganda type 2 diabetes (Mixtard®)*

*It is not always reliable and you often have to wait days to get it. Mali type 1 diabetes (Humlin R®, Mixtard®)*

*The insulin is free but there are times when you receive it late. Thailand type 2 diabetes (Mixtard®)*

In HICs, reliability of supply was not an issue.

*It is free so that is not an issue and the pharmacy has never been out of stock. Even if they were they could order some and it would arrive the next day. UK type 1 diabetes (Novorapid®)*

*As my life and health are dependent on Porcine insulin and only one company produces it, I live in fear of it not being available. UK type 1 diabetes (Hypurin® Porcine Neutral and Hypurin® Porcine Isophane)*

*Feel lucky not to have faced this issue. One time someone stole my bag (with insulin inside) and I had to go to the doctor to get a new prescription or it would have cost me \$500 out-of-pocket. US type 1 diabetes (Toujeo®, Novorapid®)*

#### **3.3.3.1 What Do You Do if You Can't Access Insulin?**

For those who could not reliably access their insulin, three said they would visit private pharmacies or the diabetes association to find insulin, one kept tablets on hand just in case (for type 2 diabetes) and two said that they would 'adjust their diet.'

*[The] biggest challenges are consistent availability of insulin by the Government Health Plan and also affordability of insulin and supplies in the private pharmacies. I know many people who just go without insulin when it is not available for free as they cannot afford it in the private sector. ). Relative of Uganda type 2 diabetes (Mixtard®)*

*Sometimes insulin is not available and I have to have money to buy it. Tanzania insulin user (Actrapid\*, Insultard\*)*

*If I can't find [insulin] then I have to talk to the doctor about finding one that is cheaper. DR type 1 diabetes (Lantus\* , Humalog\*)*

*Often the brand of soluble/lente is not available. I tried my best to adjust my diet while looking or waiting for availability. Tanzania type 2 diabetes (Lente, Solube)*

### **3.4 Diabetes Associations and their Role in Insulin Access**

National or local diabetes associations/foundations had a role in insulin supply for respondents in four countries within this study. In three countries (DR, Mali and Burkina Faso) they were providing insulin to their members. In one, Uganda, they were helping to subsidise the costs when the government did not provide insulin, but members had to pay a monthly fee to the association. The insulin that was provided seemed to be primarily human insulin, but according to survey respondents, some analogues had also been provided. One respondent also went to a diabetes association for blood testing.

*Not a member but have taken labs through a diabetes organisation and they post the best results (of blood tests there). Mexico type 2 diabetes (Lantus\*, Novorapid\*)*

In addition to providing insulin, associations also offered empowerment and education to its members. Respondent in both the UK and the DR (who both came from sources connected to diabetes associations/foundations) talked about the benefits to the organisations that they were a part of – especially regarding empowerment and education.

*Diabetes is a condition you have to live with - life with diabetes or no life from diabetes. DR type 1 diabetes (NPH, Humulin R\*)*

*I feel proud of my diabetes. DR type 1 diabetes (NPH, Humulin R\*)*

*[My organisation is] always very helpful and they provide all the help and assistance I have ever needed. I do not feel I am missing any other services. UK type 1 diabetes (Hypurin® Porcine Neutral and Hypurin® Porcine Isophane)*

*They are always teaching me new things and I feel like I have a family of people there who can help me if I need it. UK type 1 diabetes (Novorapid\*)*

When asked if there was an interest in changing insulins, only those who were receiving insulin from diabetes associations answered with knowledge of specific brands that they preferred to use (these quotes were also mentioned in section 3.1). Further, the survey showed that 75 percent of those who had knowledge about the companies Eli Lilly, Novo Nordisk and Sanofi also were members of diabetes associations. This could indicate that people who join diabetes associations are more knowledgeable about diabetes, or it could speak to a certain relationship between diabetes associations and the insulin manufacturers.

*I would like insulin to be changed to options that are better known and used more on the (existing) market. DR type 1 diabetes (NPH and Humulin R®)*

*There are many things that we miss [in Mali], such as effective insulin Mali type 1 diabetes (Humulin R®, Mixtard®), has used Novorapid® before.*

### **3.5 Lack of Knowledge of the Insulin Companies and Types of Insulin**

Despite the influence and insulin market share of the three largest insulin manufacturers (Eli Lilly, Novo Nordisk and Sanofi), most survey respondents did not know very much about them (across insulin type and country of residence). Most respondents knew the brand name of the insulin they used but at the same time, did not necessarily know the company that manufactured it. For example, of the survey respondents who were interviewed on the phone, most had to look at the box of their insulin to find the name of the manufacturer.

#### **Knowledge of the Eli Lilly, Novo Nordisk and Sanofi**

Insulin users were asked if they had ever heard of the any of the three largest insulin manufacturers Eli Lilly, Novo Nordisk and Sanofi. In general, far less respondents had heard of any of these companies. Of 31 respondents, 19 had not heard of any of them. Twelve said they had heard of at least one, only four indicated that they were familiar with all three. Of the 12 who had heard of at least one of the companies, nine were members of national or local diabetes associations. Five of the 12 were from HICs and seven were from LMICs. Type of insulin did not affect knowledge - six were using human insulin, six were using analogue insulin.

Of the three companies, the one that was mentioned most was Novo Nordisk, with seven respondents acknowledging the company, one user from Tanzania even stating ‘Novo Nordisk is the best as per my experience’, and then Sanofi (five respondents ) and Eli Lilly (three respondents).

*Eli Lilly and Novo Nordisk I have heard of. I suppose my only worry with smaller companies is if they are able to maintain a reliable supply. UK type 1 diabetes (Novorapid®)*

*I don't have an opinion either way about [the pharmaceuticals]. I can't say they are bad or good. Canada type 1 diabetes (Humalog® and Lantus®)*

*I am somewhat familiar [with the largest insulin manufacturers]. I'm more interested in what the doctor has to say than the name of the company. US type 1 diabetes (Toujeo®, Novorapid®)*

#### **Knowledge of Insulin Type**

Similar to the knowledge of the manufacturers of insulin, only ten respondents indicated that they knew the differences between analogue, human and animal insulin. Most could not correctly identify differences, except for those in the UK who were all members of an association that advocates for access to human, animal and analogue insulins. In general, people only knew vaguely what the differences were.

*[I've] heard that the analogues work quicker. Had an aunt who used human and had to take insulin way before a meal. US type 1 diabetes (Humalog®)*

*I know that they exist but don't really know the differences. I know the ones that are supplied for free in Mexico are not human insulin. Mexico type 2 diabetes (Lantus®, Novorapid®)*

### **3.5.1 Changing Insulins and Brand Loyalty**

In terms of willingness to change insulins, brand loyalty seemed more important than company loyalty. Of the 20 who answered the question, 17 respondents indicated they would be willing to use insulins from “smaller, lesser known companies.” Only three said they had ‘no preference’. Most indicated that they were open to trying other insulins, but would need assurances, for example, ‘that it was the type they needed’, or they would be willing to try, but “with reservations”. Of those willing, the largest reason given for considering new insulin was a recommendation from their doctors or other assurances that the insulin was ‘good.’

*I would [have] reservations [about changing insulins] because I'm used to what I use and because I trust [what I'm using]. Anything else would be a risk. The origin doesn't interest me, it's what I'm using that's keeping me healthy. Canada type 1 diabetes (Humalog® and Lantus®)*

*I know Novo Nordisk and Sanofi. If the occasion rises for insulin of any form, I would grab it and use it with great joy. Mali type 1 diabetes (Humulin R®, Mixtard®)*

*Would be open to other insulins from other companies. I would hope that anything allowed on the market would hold up. Would trust any company that was selling insulin to do a good job. US type 1 diabetes (Humalog®)*

*[I will take] whatever treatment works better. Thailand type 2 diabetes (Insugen®)*

*No preference (on type). I trust what my doctors say. What they say I should do, I will do. Mexico type 2 diabetes (Lantus®, Novorapid®)*

## **3.6 Doctors and Their Role in the Choices of Insulin Users**

Across all respondents, doctors seem to have a big influence in the lives of people living with diabetes in terms of insulin. But at the same time, many of the respondents, especially those living with type 1 diabetes or in HICs seemed self-empowered to make decisions about their own daily routine and control, for example, one user from the US said:

*I see the doctor every 6 months...the doctor is not that 'hands on', meaning if there are other tests or management stuff I want to do, I need to ask them for it. If I have any questions, I can always email my doctor.*

However, this same user reported being very influenced by his/her doctor's advice when it came to her choice in insulin:

*When I was on Lantus®, my insurance company once tried to force me to go on a cheaper version that my doctor said ‘might or might not work’ so I had my doctor write an override letter to the insurance company to ensure I had access to Lantus®.*

This same user later switched to new insulin as well under doctor recommendation:

*My doctor recommended that I switched to Toujeo® around 9 months ago because I was not always exact in the times that I was taking Lantus® and [he said it] lasts longer than Lantus and stays in your system. I still take it every 24 hours, but haven’t had any issues with it. US type 1 diabetes (Toujeo®, Novorapid®)*

### **Time Spent with Doctors**

To get a sense of the time people spent with their doctors and how it varied across countries, the respondents were asked how many appointments they typically had with a doctor or health care professional per year. Out of 31 respondents, visits to health professionals averaged 5.7 times per year. In general, those living in HICs visited health professionals less than those living in LMICs. The average number of health professional visits per year in LMICs was 7.0, but in HICs, the average number of visits was 2.4 per year. However, despite seeing doctors less in person, most in HICs reported being able to email their doctors.

*[I see the doctor] every six months officially but can email as necessary. I also get my blood tests every six months. UK type 1 diabetes (Apidra®)*

*Every two months if I [am] really unwell I can see a doctor more often. Tanzania type 2 diabetes (Lente, solube)*

*I have the freedom to adapt. I am helped greatly by the diabetes specialist nurse at the hospital who is amazing about treating me holistically. I can ask for help around small things, like how to safely use the gym, how to adjust the background dose and what trends I am showing. I am never judged. The consultant not so much. UK type 1 diabetes (Novorapid®)*

The time people spend with their doctors or health care professionals can offer positive and negative opportunities for doctors to impact upon insulin users management, particularly because ‘doctor’s recommendation’ was noted as a key factor in insulin users deciding to change their insulin to a new brand.

*When I first found out I had diabetes, I asked the doctor of the company I worked for to introduce me to the president of the diabetes association so that I could ask her to recommend the best doctor she knew. The doctor used to be the President of the diabetes association and he recommended that I use insulin. He said that in America they give a pill and the Europeans start right away on insulin and I said if that’s the best, I’ll take it. When I go to the doctor he doesn’t change me or recommend something else. And I’m not concerned with changing what I’m on now. Mexico type 2 diabetes (Lantus®, Novorapid®)*

*Medical doctors [must] educate the public regarding the importance of using insulin instead of tablets. You can live with diabetes so long as you use insulin properly and regulate the units depending on sugar levels within consulting a doctor. I thank [my doctor] who did teach/council me on how to live with diabetes. Tanzania type 2 diabetes (Actrapid®, Mixtard®)*

Although doctors seemed to have a big impact on insulin users, survey respondents who relayed negative or critical feelings about their doctors did not necessarily feel negative about their condition in general. In Thailand, not having access to consistent care was considered a challenge.

*I see the doctor every three months, but it is never the same doctor. I would prefer to see the same doctor for continuous treatment.* Thailand type 2 diabetes (Mixtard®) In the UK, the perceived failures of the health system were looked at as an opportunity for self-empowerment.

*I feel like doctors very rarely tend to start the dialogue with who you are and what you want to achieve (from your treatment). If they did this, you would know what your outcome would be for yourself. Choices are premade. It's a common failing that health service providers answers to questions that are never asked.* UK type 1 diabetes (Apidra®)

*I would like all health care professionals to be made aware that natural animal insulins are still available and I would like these insulins to be offered to all people newly diagnosed with diabetes as an option to take. And I would like to see animal insulin offered to people who already have diabetes and are not getting good control on human and analogue insulins so that everyone is aware that there is another excellent alternative.* UK type 1 diabetes (Hypurin® Porcine Neutral, Hypurin® Porcine Isophane)

*The world's worst thing is when people say that "a doctor looks after your diabetes". People must be able to look after their own diabetes and be empowered to do so.* UK type 2 diabetes (Novorapid® and Levemir®)

### **3.7 Beyond Insulin: The Price of Diabetes**

While insulin prices are one of the biggest challenges to accessing insulin, other important factors mentioned included the cost of syringes, test strips, doctor's visits, and travel. These factors have been identified and discussed elsewhere including in studies conducted by the IIF. In this section, the impact of the cost of these other factors on a person's ability to buy insulin are highlighted. For example, in both Uganda and Thailand, users reported receiving their insulin free but for the most part having to buy their own syringes.

*I do not pay for insulin. But I pay US\$14.05 (500 baht) for needles (every 3 months).* Thailand type 2 diabetes (Mixtard®)

*Insulin supplies are also expensive. Sometimes they give syringes (1-2 at a time) but sometimes you have to buy. They used to be US\$.15 shillings per syringe but now it cost US\$.30 (per syringe).* Relative of Uganda type 2 diabetes (Mixtard®)

Additional costs involved with obtaining insulin include travel and costs of health care consultations. For example, in Mali, despite insulin being free, the insulin user surveyed stated that he/she must pay for two doctor consultation prior to receiving insulin. In addition to these extra costs to access insulin and get it into the body, long travel times and waits at health centres can cut into work time for those in trying to access their insulin.

*My tracking (of my diabetes) feels like a lot. There are many things that we miss, such as effective insulin, the travel, the distance and the obligation to pay US\$.83 (500 CFA francs) per appointment. Mail type 1 diabetes (Humlin R\*, Mixtard\*)*

*My challenge...is that it is far away (320 km) to get to the facilities. Tanzania type 2 diabetes (Lente and Solube)*

*Each visit at the hospital you have to wait a long time due to the long queue of patients waiting to see the doctor. When I travel by bus it takes me one hour (2 hours roundtrip) to get my insulin. You also have to pay for needles. Thailand type 2 diabetes (Mixtard\*)*

*I usually make an appointment for myself 1 or 2 times a year with both a diabetes doctor and a cardiologist. I pay out-of-pocket. Visits cost around US\$49.31 (1000 pesos) each. Mexico type 2 diabetes (Lantus\*, Novorapid\*)*

### **3.7.1 Diabetes and Insulin Awareness**

Many insulin users reported struggling with a lack of education and understanding around insulin, both for those living with diabetes as well as for their families, friends, colleagues and communities in general. In some cases, respondents said this stigma affected their health.

*[There is a] lack of understanding from my family, public, patients and because of that I always feel anxious and stressed out. Tanzania type 2 diabetes (Lente and Solube)*

*Diabetes is on the increase and there is no awareness – the focus is on other [conditions and illnesses] and there is little emphasis put on diabetes. In terms of the perception of diabetes it depends on the person and the location. Deep down in the villages people do not understand diabetes (as an illness) as the person looks healthy (not sickly) and hard to understand the future complications. Relative of Uganda type 2 diabetes (Mixtard\*)*

*[In terms of perceptions about diabetes in Mexico] it seems like people have the feeling there is a connection between diabetes and diabolic. There is a perception that once you got it you are touched by the devil. Something else that happens in Mexico – regularly people take pills. Once people start taking insulin, they people see it as “too late” or the time when it is very close to more serious complications. When I went on insulin – I was very enthusiastic of getting on insulin. Mexico type 2 diabetes (Novorapid\* and Lantus\*)*

*UK needs better education about insulin use, what it is and how to use it. Many don't know the basic profile of how insulin works. Diabetes benefits massively from a coaching approach. The diabetes charities do it only as a one-off, with no follow up as to what happens two and half weeks later. There needs to be a system that provides backup to people, trusted sources of information. UK type 2 diabetes (Apidra\*)*

## **4. Discussion and Further Research**

Looking at the data collected from the interviews, it is apparent that access to insulin is complex, just like diabetes itself, and many elements from the user perspective warrant further investigation. Although this report reflects just a small set of data, it does point to certain trends.



## **Insulin Use and Vials**

Most insulin users indicated satisfaction with the insulin they were currently using. However, this did not mean that they didn't still perceive many challenges to insulin management. Based on this limited data source, there did not seem to be an overwhelming demand for different insulins, but there was a need for better access to insulin and insulin management tools.

In terms of how people use insulin, most of this group of respondents were still using insulin in vials with syringes. Although this was more of the case in LMICs, insulin users in HICs were also using them, at least in combination with pens. Looking into preferences for insulin delivery devices might warrant further review. Particularly because pharmaceutical companies continue to develop insulin containing devices and these devices now make up over half the patents for insulin in the US market (20), often creating price barriers for many. Last year the ACCISS Study report on prices (21) revealed that insulin in vials versus pens or cartridges was lower for all human insulins, although not all analogues. The price report coming out this year will shed more light on the price variations.

## **Insulin Price, Availability and Reliability**

Across all respondents from all countries except the UK, insulin users struggled to pay for their insulin and/or insulin related supplies. Although the issues range from struggles with co-payments and deductibles in the US and Canada, to out-of-pocket costs when the government provided insulin is not available in Uganda, all illustrate the real issue of high insulin prices for those living with diabetes and their families. This study, as many have before, shows that there is a crucial need for insulin prices to be reduced. Supply reliability and availability must also be improved. This year, the ACCISS Study will release two reports on insulin price, availability and mark-ups to further underscore this case. ACCISS tools coming in the second part of the year will be released to assist those looking to improve these issues in their own countries.

## **Diabetes Associations and their Role in Insulin Access**

From empowerment and education to providing insulin and diabetes supplies, diabetes associations can provide a critical service for those living with diabetes. Their positive impact should not be understated. Looking at the respondents in this survey, those who were members of diabetes associations seem to have a much greater knowledge of types of insulin and the largest three insulin manufactures. This could indicate that people who join diabetes associations were more knowledgeable about diabetes, or it could speak to how the relationship between diabetes associations and insulin companies affects its members. Eli Lilly, Novo Nordisk and Sanofi all work with some diabetes associations via their diabetes initiatives, or directly to donate insulin and supplies, fund education programs and doctor trainings. To get a better picture of the impact these companies can have on diabetes associations, and the communities they service, more research should be done. The ACCISS Insulin Initiatives Profile, to be released in 2017 will help to uncover some of the impact these initiatives have on diabetes communities.

## **Lack of Knowledge of the Diabetes Companies and Insulin Brand Loyalty**

Despite the influence and market share of the three largest insulin manufacturers (Eli Lilly, Novo Nordisk and Sanofi), most survey respondents were not knowledgeable about them (across insulin type and country residence). Most knew the brand name of the insulin they used, but not necessarily the company that manufactured it. In general, knowing this did not seem a

priority to the respondents of this survey. Further, most did not know the differences between human, analogue or animal insulin, or could not identify the types accurately.

In terms of willingness to change insulins, brand loyalty seemed more important than company loyalty. This is something important to study further, and underlines the impact that the insulin brand names have and the argument for using international non-proprietary names, rather than brand names on products. Most user respondents did not oppose other brands, but there still was a large perception of potential inferiority. This seemed in accordance with the results of a market research study conducted by dQ&A, that found that as long as biosimilar companies can secure approval, perform effectively and offer a cost reduction, users would be willing to consider them (22). In 2017, ACCISS will release reports on regulatory paths for biosimilar insulin approval, and further information about biosimilars will be available in the ACCISS toolbox for people living with diabetes.

### **Doctors and their Role in the Choices of Insulin Users**

Across the countries, doctors seem to have a big influence on the insulin selection of people living with diabetes. Many insulin users in this study relied solely on their doctor to make their insulin choice. Even some of those who seemed self-empowered to make decisions about their own daily routine and control were influenced by their doctor's advice on which insulin to use. While there has been research that outlines how contact between the pharmaceutical industry and doctors' affects prescribing practises (23, 24) research is still needed on how they impact the decisions and perceptions of insulin users. The ACCISS study is investigating the role and perspectives of physicians on the barriers to access to insulin to shed light on this topic.

### **Considerations of Patient Costs – Beyond Insulin**

For those in need of insulin, access to insulin is the foundation to building a successful management plan. However, insulin is only brick in the building of a robust diabetes management plan and, therefore cannot be considered in isolation. While insulin price is noted as one of the biggest challenges to accessing insulin, other important factors mentioned were the costs of syringes, glucose test strips, doctor's visits, and cost and time it takes to travel the pharmacy, doctor's office or health centre. This echoes the work of the IIF, which found that insulin price, in many cases, is not biggest barrier to access to treatment. By reducing insulin prices, the hope is that the overall price of diabetes management will begin to be reduced. This year, ACCISS will be looking at the calculating the cost of care for those with diabetes.

## **5. Conclusions**

The data from this report points to certain trends in how insulin is used on a day-to-day basis, particularly on where users receive their insulin from, the relationship users have with their doctors and the perception of their treatment. It also points to the shared struggles that insulin users, across countries and type of diabetes, go through and the opportunity it presents to work together to further the cause of access to low-cost, high-quality insulin for all.

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# Annex 1. Insulin User Questions

## ACCISS Study's Insulin Users Interview Project

Thank you for agreeing to participate in the ACCISS Study's Insulin Users Interview Project. We view those who use insulin as the top experts in the field and are very grateful your time. As already stated this interview will be used primarily to complement the technical work of the ACCISS Study. Your answers will remain anonymous and we will identify you through the country in which you live. Please fill this out to the best of your ability. You can leave questions blank if they do not apply to you.

1. Do you have type 1 or type 2 diabetes?
2. What is your date of birth?
3. When were you diagnosed (year)?
4. What kind of insulin do you use now (what is the name and/or type, and/or the company that make it)?
5. How long have you been using it?
6. How do you inject it into your body? (using a syringe and vial, pen, pump, etc.)
7. What other types of insulin have you used?
8. How do you feel about your current insulin regime?
9. Based on what you have already taken, what would you prefer to take? Which insulin did you feel like you had the best results from?
10. Based on what you have heard from others or read about, is there another insulin that you wish you were on instead?
11. Where do you get your insulin from?
12. How much do you pay for your insulin (per month) (If you are receiving insulin now for free, but have paid for insulin in the past, you can include this in your answer)?
13. How often do you purchase/obtain your insulin?
14. How far do you have to travel to purchase your insulin?
15. Is your insulin supply always dependable?
16. What are your biggest challenges you have with obtaining your insulin (or insulin supplies)?
17. What do you do if it is not available or not affordable?
18. What is the average amount of units do you use per day?
19. How many injections do you take per day?
20. Is the amount of units of insulin you take set by your doctor strictly or do you feel like you have freedom to adapt the amount of insulin you use?
21. Based on your current insulin regime, how much flexibility do you feel like you have within your daily routine (meals, exercise, travel, etc.)
22. How is your health in general, are you currently suffering from any complications?
23. How often do you see a doctor, nurse or other medical professional for your diabetes? Who do you see?
24. How many times do you test your blood sugar (at home) (per day, per week, or per month)?
25. How often is your blood sugar level tested in a clinical setting and what tests are used?
26. How do you feel about your diabetes in general? What are your biggest challenges?
27. Have you heard of the insulin companies Eli Lilly, Novo Nordisk and Sanofi? If yes, would you have a preference to receive insulin from these companies rather than smaller, less known insulin companies.
28. Do you know what the differences between animal, human and analogue insulins are?
29. Do you receive donated supplies, insulin or other support from insulin manufacturers or other organizations or foundations?

## Annex 2. Where Respondents Reported Getting their Insulin From

Table 1. Pharmacies.

Country	Payment Method	Distance less than 10KM?	Dependable (y/n)*
USA	Insurance	Yes	Yes
USA	Insurance	Yes	Yes
Mexico	Pay	Yes	No
UK	Free	Yes	Yes
UK	Free	Yes	Yes
UK	Free	Yes	Yes
UK	Free	Yes	Yes
Canada	Insurance	Yes	Yes
Canada	Insurance	Yes	Yes
Tanzania	Pay	No	Yes
Tanzania	Insurance	No	No
Tanzania	Insurance	No	No
Tanzania	Pay	No	Yes
Tanzania	Pay	Yes	Yes
Tanzania	Pay	Yes	No
Tanzania	Pay	N/a	Yes
Burkina Faso	Free**	N/a	Yes
Burkina Faso	Free**	No	Yes

\* For 'no' answers, respondents indicated that insulin was unavailable at least one time.  
 \*\*Although respondents said they collected their insulin from the pharmacy they indicated it was free of charge via support of an diabetes organisation.

Table 2. Hospital or Health Centres.

Country	Payment Method	Distance less than 10KM?	Dependable (y/n)*
UK	Free	Yes	Yes
Uganda	Free	No	No
Tanzania	Pay	No	Yes
Tanzania	Insurance	Yes	Yes
Tanzania	Pay	No	Yes
Tanzania	Pay	No	Yes
Tanzania	Pay	Yes	Yes
Thailand	Free/Insurance	No	Yes
Thailand	Insurance	No	No

\* For 'no' answers, respondents indicated that insulin was unavailable at least one time.

Table 3. Diabetes Association or a Company Health Centre.

<b>Country</b>	<b>Payment Method</b>	<b>Distance less than 10KM?</b>	<b>Dependable (y/n)*</b>
Dominican Republic	Free	No	No
Dominican Republic	Free	Yes	Yes
Dominican Republic	Free	Yes	Yes
Dominican Republic	Free	Yes	Yes
India	Free	Yes	Yes
India	Free	Yes	Yes
India	Free	Yes	Yes
Burkina Faso	Free	N/a	Yes
Mali	Free	No	No

\* For 'no' answers, respondents indicated that insulin was unavailable at least one time.