Patient focus
– A snapshot of why we are in business

Derek Gardiner has type 2 diabetes and lives in the UK
We need to listen to lead
Christian Kanstrup, senior vice president in Novo Nordisk, offers his view on what makes Novo Nordisk a patient centred company and highlights some of the activities put in place to engage more closely with people living with diabetes.

A new DAWN™ for type 2 diabetes
Kathy Kovacs Burns, a passionate patient advocate from Canada with type 2 diabetes, shares her thoughts on what can be done to raise the voice of people with type 2 diabetes and how pharma companies can become better at listening.

“Together we can turn type one into type none”
Meet Tanner Barton who has type 1 diabetes and is part of Novo Nordisk’s new ‘patient expert panel’ whose purpose is to involve people with diabetes more actively in drug discovery and development.

Hey, that’s #NotMyType!
Do you know the differences between type 1 and type 2 diabetes? Take the #NotMyType test to find out!

The patient journey
This infographic takes you through a number of phases that people living with diabetes may experience. Read personal statements from across the globe.
Shifting gears to improve person-centred healthcare
Becky Furuta has type 1 diabetes, races professionally for Team Novo Nordisk and offers her views on patient centricity.

Diabetes in children: a family matter
When a child is diagnosed with type 1 diabetes, the entire family is affected as everyone must adjust to a new way of living. See how an initiative in Ethiopia is offering support to families through the Changing Diabetes® in Children programme.

Engaging the ones who know patients best
Read about a new approach to patient involvement in clinical research that puts nurses and study coordinators at the forefront.

Beyond regulation to respect patients’ rights
See how a human rights assessment led to new initiatives being taken to improve reporting of product safety issues in certain parts of Africa.

A tale of two cities
Two-thirds of the 415 million people with diabetes live in and around cities. See what a partnership programme is doing to address the challenge of urban diabetes.

The people driving sustainability
“We can be miles away from the patient – and yet, we are not”
Mogens Thorsager Jensen heads up a special department that evaluates if Novo Nordisk is living up to its values – hear his view on how well patient centricity is embedded in the company.

Control is more than a number
A study shows gaps in how doctors and people with diabetes perceive ‘diabetes control’ – see why this matters to achieving better health.
We need to listen to lead

Christian Kanstrup, senior vice president in Novo Nordisk, offers his view on what makes Novo Nordisk a patient centred company and highlights some of the activities put in place to engage more closely with people living with diabetes.

In August of this year, I returned to Denmark to start my new job as senior vice president for Marketing, Medical Affairs and Stakeholder Engagement. I’d just come from China where I’d spent the previous two years leading our Chinese affiliate, working closely with public officials, healthcare professionals and people living with diabetes and haemophilia. This is a job that takes you close to the people we are in business for.

As part of our values-based management system, the Novo Nordisk Way, we state that ‘We create value by having a patient centred business approach.’ However, one of the first things I told people when I came back was that you cannot find any pharmaceutical company that would claim they are not patient centred. We needed to ask ourselves, ‘What makes Novo Nordisk able to say that we are a patient centred company?’

Long-term focus

I believe Novo Nordisk stands out in the way we integrate patient centricity into our business decisions. That is the basis for running a pharmaceutical company in my view. Since 1923, our focus has been on diabetes and over the years we have added haemophilia, growth disorders and obesity to this focus.

What is common across the therapy areas we work in is that they are all chronic diseases. This means we are serving the patient not only today or tomorrow, but decades into the future. With this kind of time frame, our business decisions must be a balance between short-, medium-, and long-term and must align with the long-term needs of treating chronic diseases.

Living with a chronic disease can pose many challenges. To truly understand these, we listen to patients, their caregivers and patient organisations to understand their daily challenges, needs, and wishes, and engage them as equal partners in developing innovative and sustainable solutions for better healthcare. We do not have all the answers, but as a leader in diabetes care, we have an obligation to listen. And together we can uncover new solutions for better healthcare.
insights to help improve quality of care and life. For example, we have taken the 360° insights from the DAWN2™ study in 17 countries on board in our diabetes education, support and training activities.

“We listen to patients, their caregivers, and patient organisations to understand their daily challenges, needs, and wishes, and engage them as equal partners in developing innovative and sustainable solutions for better healthcare”

So for me, Novo Nordisk’s long-term focus and our ability to listen are two things that make us special. Someone once said, “language is abstract, life is real.” I very much agree, so I want to move from telling what patient centricity is to me to showing it by giving a voice to colleagues, business partners – and of course patients.

Listening to patients
The journey of a new pharmaceutical product, from the lab to the patient, takes about 10 to 13 years. The patients’ experiences can add value from the very beginning. This year a specialised unit within Novo Nordisk’s Research & Development (R&D) was established. In the article Together we can turn type one into type none, we introduce the new R&D Patient Partnering unit and show how it is asking for patients to become involved in drug discovery and development.

Equally important for long-term success is patient involvement in our clinical trials. Retaining patients throughout trials lasting several years helps to ensure high quality results. The article Engaging the ones who know patients best shows our new approach to listening and integrating the patient voice into clinical trials.

Patients and doctors do not always understand the world the same way, and this may affect the efficiency of treatment and care. Therefore, we do research not only on the effect of our products, but also on perception of ‘control’. In the article Control is more than a number, we show the gap in how doctors and people with diabetes perceive ‘diabetes control’ and why this matters to achieving better health.

Insights gathered from our human rights assessment are driving new initiatives to improve product safety reporting. The article Beyond regulation to respect patients’ rights looks into the lack of reporting systems and how colleagues are making efforts to increase awareness of what to do about it.

In Ethiopia, the article Diabetes in children: a family matter shows the challenges that families face when a child is diagnosed with type 1 diabetes and how the Changing Diabetes® in Children programme offers support.

And in A tale of two cities, the Cities Changing Diabetes programme addresses how type 2 diabetes is impacting the lives of urban citizens.

Raising the patient voice
In this issue we feature Becky Furuta, Tanner Barton and Kathy Kovacs Burns who are all living with diabetes. Becky has type 1 diabetes, races professionally for Team Novo Nordisk and offers her views on patient centricity in the article Shifting gears to improve person-centred healthcare.

Tanner talks about life as a professional swimmer, his dedication to working with type 1 children and young people and his views on pharma companies and patients working together.

Lastly, we have Kathy Kovacs Burns, a passionate patient advocate from Canada with type 2 diabetes. In A new DAWN™ for type 2 diabetes, Kathy shares her thoughts on raising the voice of people with type 2 diabetes and how pharma companies can become better at listening.

Thanks, Kathy, we do need to continue to do more to make sure that being patient centred is more than just nice words. This is why we at Novo Nordisk have a special department called Facilitation that monitors and helps guide the company on living up to our values. In this issue’s People Driving Sustainability, Mogens Thorsager Jensen, corporate vice president for Facilitation, reveals how well patient centricity is embedded in practice in the company.

I hope this issue of TBL Quarterly shows the value of greater patient inclusion and makes the case for working together, from the beginning and with long-term commitment.

Christian Kanstrup
Senior vice president
Marketing, Medical Affairs & Stakeholder Engagement
Novo Nordisk
A new DAWN™ for type 2 diabetes

Kathy Kovacs Burns is a passionate patient advocate from Canada living with type 2 diabetes. Here, she talks about what patient centricity means to her, what can be done to raise the voice of people with type 2 diabetes and how pharma companies can become better at listening.

Could you tell a bit about yourself?
First of all, I have been living with type 2 diabetes for the past 27 years which has taught me a lot about self-management. I am also an advocate for people with type 2 diabetes and other chronic conditions and work with several patient coalitions, including the International Alliance of Patients’ Organizations.

I work for Alberta Health Services in Alberta, Canada employing more than 100,000 staff including healthcare professionals who are dedicated to engage with patients, families as well as peers and other clinical staff to improve Patient-and-Family-Centred care and outcomes. And I am also a professor in public health where my focus is on how to translate health research into policies and practice.

What is patient centricity to you?
It means to always consider the patient as the main focus of healthcare planning and delivery, and include a broader 360° degree perspective of the person’s network, including family, school, work place and community.

It is also about engaging with patients to understand their needs and include them as equal partners in developing solutions for better care. This is a key recommendation coming out of the DAWN2™ study.

What is the DAWN2™ study?
DAWN2™ is a global study exploring the unmet needs of people with diabetes, as well as family members and healthcare professionals.1 It takes a 360 degree approach to understanding the psychosocial aspects of living with diabetes, education and self-management considerations, and societal attitudes.

As part of the study, I represent the International Alliance of Patients’ Organizations, of which my patient coalition organisation in Canada is a member, and have provided input on all aspects of the DAWN2™ study including the role of family members. I work with the global DAWN™ network and advocate for how we can translate the insights from the study into practice. For example, the Canadian Diabetes Association is now incorporating evidence from the study into their guidelines and other initiatives.

People with type 2 diabetes seem to be less vocal in the public debate compared to type 1 – why is that? And what can be done to raise their voice?
There is still a stigma attached with having type 2 diabetes because it is more often than not associated with lifestyle. It has negative undertones making it challenging for people with type 2 diabetes to disclose and raise their voice, but I have chosen to do it anyway.

I believe we should be more vocal about type 2 diabetes and address the negative attitudes which inhibit people with type 2 diabetes to speak up about their needs. We need to make the discourse more positive and focused on active self-management, having a good quality of life and contributing to society in a meaningful way.

What can pharma companies do to better ‘walk the talk’ of patient centricity?
I think all pharma companies can learn from the DAWN2™ study because it offers unique insights into the views of patients, their families and healthcare professionals. Pharma should listen to these insights to better understand how to support patients’ needs and increasingly consider psycho-social issues, not just medical needs.

Earlier, patient organisations had a hard time working with the industry, but this is slowly changing. To truly walk the talk, pharma companies need to invite patient organisations to have a seat at the table, for example in clinical trials, in health technology assessments and in the development of patient education tools. This is the only way we can create mutual understanding about what will work best for meeting the needs of people with diabetes and changing practices or influencing health policies.

1. With more than 15,000 people participating across 17 countries, DAWN™ is the largest study ever conducted to understand the psychosocial issues and needs of people with diabetes. The study was conducted as a collaboration between the International Diabetes Federation, the International Alliance of Patient’s Organizations, Novo Nordisk and others. For more information, see dawnstudy.com
Taking a 360° view of diabetes care: diabetes and discrimination

DAWN2™, a global study exploring the unmet needs of people with diabetes, family members and healthcare professionals, shows that discrimination remains an issue. See some of the facts here.1

1 OUT OF 5
PEOPLE WITH DIABETES FEEL DISCRIMINATED AGAINST DUE TO THEIR CONDITION

22% OF FAMILY MEMBERS BELIEVE THAT PEOPLE WITH DIABETES EXPERIENCE DISCRIMINATION

33% OF FAMILY MEMBERS BELIEVE THAT DISCRIMINATION IS A SOCIETAL ISSUE

ONE IN THREE HEALTHCARE PROFESSIONALS BELIEVE THAT DISCRIMINATION IS A SOCIETAL ISSUE

TOGETHER WE CAN STOP DISCRIMINATION BY INCREASING PUBLIC ADVOCACY AND AWARENESS ABOUT THE REALITY OF LIVING WITH DIABETES

1. The DAWN2™ study surveyed more than 15,000 people in 17 countries, listening to the voice of people with diabetes, family members and healthcare professionals. For more information, see dawnstudy.com
“Together we can turn type one into type none”

In the research phase of a pharmaceutical product, scientists work to discover new molecules that will ultimately turn into a new drug to improve the lives of people who need it. But what role can these people play at this early stage? Historically, their involvement has been limited, but this is changing.

For many years, professional talks in the pharmaceutical Research & Development (R&D) phase were reserved for scientists and healthcare providers while patients only played a role as ‘research subjects’ once a drug made it to the clinical development process. This may seem perplexing considering the fact that patients are the ones living with the chronic condition every day. And that their insights might inform decisions made by the scientists in the lab if they had a better chance to engage. Fortunately, this has started to change.

Globally, patients – and their related advocacy groups and patient organisations – are taking an increased interest in becoming more involved in drug discovery and development. In Europe for example, the EUPATI initiative\(^1\) is working to strengthen the capabilities of well-informed patients and patient organisations to be effective advocates and advisors in medicines research.

1. For more information, see patientsacademy.eu/index.php/en

Walking the talk

In August 2015, Novo Nordisk began exploring more active patient involvement with the establishment of a specialised unit within Strategic R&D called ‘R&D Patient Partnering’. This unit is a direct response to the increasing ask for more involvement from patient leaders globally and of Novo Nordisk’s appreciation of the benefit to engage with patients to create drug of value for them.

To unfold and pursue the potential positive impact, R&D Patient Partnering has embarked on a number of strategic initiatives. One is the establishment of a ‘patient expert network’ in all present and future therapy areas. All the panel members are patient leaders, eg people who are themselves patients, in addition to being the collective voice of entire patient groups or populations.

Tanner Barton is one of these experts. Tanner has type 1 diabetes and is a local chapter leader and international spokesperson for JDRF, the Juvenile Diabetes Research Foundation in the US.\(^2\) He has been selected for Novo Nordisk’s R&D patient expert network because of his extensive work with children, youngsters and adolescents and related insights into the impact that type 1 diabetes has on this group.

TBL Quarterly met with Tanner to get his viewpoint on how listening directly to the experiences of people with the condition and internalising them throughout the R&D process could foster a positive change.

Tanner, tell a little bit about yourself?

I am a student at Ball State University, Muncie, Indiana, United States, majoring in Health Science and Spanish. Additionally, I am also a competitive university swimmer at the NCAA Division I level, competing in the 100 and 200 butterfly. I have been passionate about swimming since I was seven years old. I also take pride in advocating for all type 1 diabetics, since I have been living with type 1 diabetes for over 12 years.

How does diabetes affect your everyday life?

I carry my ‘diabetes bag’ with me wherever I go. This bag includes my insulin, test kit, strips, snacks etc. Even though I do not let my diabetes control me, this bag constantly reminds me that I have a chronic condition.

2. For more information, see jdrf.org
My life has definitely changed since 2 September 2003, when I was diagnosed with type 1 diabetes.

**What has been your motivation to join JDRF?**
I experienced different emotions after my diagnosis. Although diabetes initially troubled and angered me, I refused to let it control my life. All along, it has always been very important for me to take ownership of my disease. ‘Diabetes does not define me’ is my credo. This is why I joined JDRF. JDRF is working to make diabetes less of a burden for diabetes patients and their ultimate ambition is ‘to turn type one into type none’ which means to find a cure for type 1 diabetes.

**What is patient centricity to you?**
It is about you, as a person feeling important and valued as an individual, that people are paying attention to your needs, your personal ambition and that they have a genuine, authentic caring attitude about diabetes management.

**JDRF is largely engaged in type 1 diabetes research: what is your reaction on the partnership Novo Nordisk is starting to build with your community?**
To be honest, my initial thought was: ‘why would Big Pharma want to hear what I have to say?’ I was a bit sceptic … but I was also enthusiastic and curious.

Shortly after my visit to Novo Nordisk’s R&D site in Seattle, I found that the team really listened to my innermost intentions and thoughts. They paid great attention to detail and they not only focused on the disease and the product, but also on how to improve the lives of all their patients.

Also, I found that curing diabetes is a priority to Novo Nordisk and written into their mission statement which gives us, type 1 diabetes patients, hope – and it holds Novo Nordisk accountable!

**What is your personal take moving forward?**
We definitely have a shared agenda in fighting a chronic condition; it is comforting to know that pharmaceutical companies, like Novo Nordisk, truly care about our daily lives and perspectives.

For example, when we started our workshops with the scientists, type 1 diabetes was regarded as a metabolism condition defined by an absolute lack of insulin. After our discussions, other concerns, like the psychosocial burden of diabetes, have been recognised inherent in the condition and sometimes worse than the disease itself – even when the disease is well-managed.

As a young adult living with type 1 diabetes – and for all the young adults living with a chronic disease – knowing that pharmaceutical companies are focusing their efforts on patient engagement is inspiring and it makes us feel that we are valued as individuals. If we succeed in having this closer co-understanding – knowing what the patient needs are, which is as just as important as what the disease is – I believe we would be more appreciative of pharmaceutical companies.

**To your experience, are we on the path of doing something new here?**
Yes, I think Novo Nordisk is ahead of the ballgame. I have not heard of other pharmaceutical companies doing this to the same extent. I like how Novo Nordisk asks burning questions that truly elicit candid responses. I am really excited to be involved in your R&D efforts, and this is why I’ve accepted to be the first patient expert network member.

If you want to know more, contact Global Head of R&D Communication and Patient Partnering, Camilla Krogh Lauritzen, CKLA@novonordisk.com
Everyone deserves respect. Unfortunately, it isn’t always lack of good intention that makes us come up short. For the millions of people living with type 1 and type 2 diabetes, disrespect is often the result of misinformation and stereotypes. Here’s just the tip of the iceberg:

**Woman with type 2 diabetes, Japan, age 47, 10 years with diabetes:**
“I have been discriminated against due to my diabetes. My husband’s relatives don’t understand, my friends don’t understand, and I face discrimination in looking for a job. Trying to explain about it has been useless.”

**Man with type 1 diabetes, Italy, age 41, 29 years with diabetes:**
“People around us need to understand that diabetes isn’t contagious, and that we have the same rights as healthy people.”

Step up and take the #NotMyType challenge. Pst! The correct answers are on the following page.

1. This type of diabetes is an autoimmune disease meaning that the body’s immune system attacks insulin producing cells and the person therefore needs to take insulin daily to survive.
   A. Type 1 diabetes  B. Type 2 diabetes  C. None of them  D. Both of them

2. Advancing age, obesity, poor diet, family history, physical inactivity and ethnicity are risk factors for this type of diabetes.
   A. Type 1 diabetes  B. Type 2 diabetes  C. None of them  D. Both of them

3. This type of diabetes accounts for 85–95% of all diabetes cases in high-income countries.
   A. Type 1 diabetes  B. Type 2 diabetes  C. None of them  D. Both of them

4. This type of diabetes cannot be prevented.
   A. Type 1 diabetes  B. Type 2 diabetes  C. None of them  D. Both of them

5. Symptoms for this type of diabetes often appear suddenly.
   A. Type 1 diabetes  B. Type 2 diabetes  C. None of them  D. Both of them

6. Chronic complications such as eye disease, heart disease and kidney diseases are associated with this type of diabetes.
   A. Type 1 diabetes  B. Type 2 diabetes  C. None of them  D. Both of them

7. Diet and exercise is relevant for this type of diabetes.
   A. Type 1 diabetes  B. Type 2 diabetes  C. None of them  D. Both of them

8. This type of diabetes is a consequence of individuals not taking ownership of their health.
   A. Type 1 diabetes  B. Type 2 diabetes  C. None of them  D. Both of them

9. This type of diabetes is usually diagnosed in children although the majority of patients are adults.
   A. Type 1 diabetes  B. Type 2 diabetes  C. None of them  D. Both of them

10. There is no cure for this type of diabetes.
    A. Type 1 diabetes  B. Type 2 diabetes  C. None of them  D. Both of them

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Correct answer: A. Type 1 diabetes
In type 1 diabetes, the immune system attacks the insulin-producing cells in the pancreas until it cannot produce insulin. Therefore it must be injected instead. Type 2 diabetes is different because the body is able to produce insulin but either this is not sufficient or the body is unable to respond to its effects.2

Correct answer: B. Type 2 diabetes
Advancing age, obesity, poor diet, family history, physical inactivity and ethnicity are all risk factors for type 2 diabetes. People with type 2 diabetes can remain undiagnosed for many years, unaware of the long-term damage being caused by the disease.2

Correct answer: B. Type 2 diabetes
Type 2 diabetes accounts for 85–95% of all diabetes cases in high-income countries. The number of people with type 2 diabetes is growing rapidly worldwide. This rise is associated with economic development, ageing populations, increasing urbanisation, dietary changes, reduced physical activity, and changes in other lifestyle patterns.2

Correct answer: A. Type 1 diabetes
As opposed to type 2 diabetes, type 1 diabetes is an autoimmune disease which cannot be prevented. In type 1 diabetes, the immune system attacks the insulin-producing cells in the pancreas until it cannot produce insulin.2

Correct answer: A. Type 1 diabetes
Type 1 diabetes often develops suddenly and can produce symptoms such as abnormal thirst, frequent urination, extreme tiredness, constant hunger and sudden weight loss. Symptoms for type 2 diabetes most often take longer to appear or be recognised.2

Correct answer: D. Both of them
Consistently high blood glucose levels can lead to chronic complications such as eye disease, heart disease and kidney diseases. This is the case for both type 1 and type 2 diabetes. The impact of these complications is costly both in human and economic terms.2

Correct answer: D. Both of them
Diet and exercise is relevant for both type 1 and type 2 diabetes. People with type 1 diabetes need to follow a structured self-management plan, including insulin use and blood glucose monitoring, physical activity, and a healthy diet. People with type 2 diabetes may be able to manage their condition through a healthy diet and increased physical activity or oral medication. However, if they are unable to regulate their blood glucose levels, they may be prescribed insulin.2

Correct answer: C. None of them
Type 1 diabetes is an autoimmune disease and cannot be prevented. Obesity is believed to be the main risk factor for developing type 2 diabetes, however, many people cannot stably lose weight by themselves and therefore need assistance with weight management.2

Correct answer: A. Type 1 diabetes
Type 1 diabetes can affect people of any age. It usually occurs in children or young adults although the majority of patients living with type 1 diabetes are adults. The number of people who develop type 1 diabetes is increasing. The reasons for this are still unclear but may be due to changes in environmental risk factors, early events in the womb, diet early in life, or viral infections.2

Correct answer: D. Both of them
There is currently no cure for type 1 and type 2 diabetes. However, research aimed at finding a cure is being conducted.2

9–10 correct: In the words of Aretha Franklin – R.E.S.P.E.C.T!
6–8 correct: Well done – you deserve some respect!
3–5 correct: On the right track but you could do better!
0–2 correct: Hey, you need to step it up!
The patient journey

Each patient is unique, however, many go through a range of generic phases with ups and downs. Follow the journey and read how people with diabetes experienced the different stages.¹

Onset of symptoms

Before I was diagnosed, I didn’t really pay attention to my diet and I seldom exercised. I often felt dizzy, urinated frequently, and lacked energy. When it turned out to be diabetes, I was very worried.

Man with type 2 diabetes, age 44, China

I went through a long and frustrating process before I was diagnosed with type 1 diabetes, as I didn’t fit in the box in terms of my symptoms.

Woman with type 1 diabetes, age 41, Denmark

Diagnosis

None of us understand what diabetes is. There are no information and prevention measures. Because of that, I was not diagnosed until I developed a severe form of diabetes, and therefore had to take high doses of medication. People need to be informed about the initial symptoms. The earlier the disease is diagnosed, the greater the chance of a full and fruitful life.

Man with type 2 diabetes, age 40, Russia

Interference with daily life

In the past years I’ve had to stop three different leisure time activities due to my health. This has resulted in being bitter and cross about many things. One feels that one isn’t a ‘part of society’ anymore.

Man with type 2 diabetes, Denmark, age 57

It’s all up to me. I have good days and bad days. Most times I seem to not want to believe I am diabetic and just push it aside then I feel guilty and scared because I am not taking better care of myself. It’s a never-ending circle.

Woman with type 2 diabetes, age 54, Canada

It’s hard to constantly have to take medicine and do injections. It encumbers daily life.

Woman with type 2 diabetes, age 62, Turkey

Adapting to change

Taking control of ongoing self-management

What moved me was when my family quit eating certain foods because I had to. Finally, my diabetes was slowly but effectively controlled under the care and help of my family. Since then, I have more confidently faced the hardship that this disease has brought.

Man with type 2 diabetes, age 53, China

I think I learned to cope quite quickly because I had good support from my doctors. When I got an insulin pump it became a lot easier because I didn’t have to rely on injections. Of course I always have to think about what I eat, but I don’t feel that there are any limitations.

Man with type 1 diabetes, age 44, Denmark

Everyone deals differently with diabetes, but some are really suffering from it and some don’t have any adverse effects at all. I live as a normal human being. I have everything under control and bother no one with it.

Man with type 2 diabetes, age 73, the Netherlands

I can do whatever a person without diabetes can do. There are no limits; of course it is not all good for me, but neither is it for everyone else without diabetes. I have chosen that the disease should not control me. I consider having diabetes as having the life of a rope walker; you can live a great life if you are in balance – I can live a long and happy life.

Woman with type 1 diabetes, age 34, Denmark

I took some time to get used to changing my lifestyle habits, but it was worth it, because I see the future differently, and I pay even more attention in order to live longer with my loved ones.

Man with type 2 diabetes, age 67, France
The medical community has come a long way in measuring diabetes health. But what happens when numbers do not go far enough to capture a complete picture? A new study shows that perceptions matter even more so when people’s lives are the topic of discussion.

A difference in perceptions can be humorous. There is a television commercial in which a large battle ship is tearing through rough stormy waters and the captain is on the radio urging an unidentified ship to change course to avoid a collision. Met with continued resistance, the captain finally threatens to take extreme measures if the ship does not move. “This is a lighthouse, mate, your call” is the reply.

When it comes to people’s health, a difference in perception between doctor and patient has less humorous consequences. Results presented at both the European Association for the Study of Diabetes (EASD) and the World Diabetes Congress show that there is a significant gap between how doctors and people with type 2 diabetes uncontrolled on basal (long-acting) insulin each view ‘control’.

But what is ‘control’? If people with diabetes are to be more central in their treatment, it is essential that everyone agrees on what it means to be ‘in control’.

**Defining control**

In the 1970s researchers discovered a method of measuring the average concentration of sugar levels in the blood, called plasma glucose concentration. The method involves looking at the amount of a particular protein molecule in red blood cells called haemoglobin A1c, or HbA1c for short.1 The concentration of the HbA1c molecule indicates how well sugar is being transitioned out of the blood and used by the body.

Then, in 1993, the Diabetes Control and Complications Trial showed that keeping blood sugar levels as close to normal as possible, determined to be 7% concentration, slows the onset and progression of eye, kidney, and nerve diseases caused by diabetes. In fact the trial demonstrated that any sustained lowering of blood glucose helps, even if the person has a history of fluctuating levels.2

With the results, the periodic monitoring of HbA1c levels provided healthcare professionals with a useful way of documenting the degree of control of how well sugar is being used by the body (glucose metabolism) and helped guide treatment for people with type 1 and type 2 diabetes.2

HbA1c provided the ability for blood sugar level control to be measured and has since become a widely accepted standard used by the medical community. However, research linking HbA1c control to the barriers and challenges people with type 2 diabetes face in maintaining a normal HbA1c still had a way to go. Big gaps persisted in understanding why so many people were not reaching HbA1c levels set by their doctors and had challenges ‘being in control’.

**Seeing control from both sides**

The Perceptions of Control study led by Meryl Brod, PhD, aimed to develop a better understanding of just how doctors and patients perceived what it means to be in control of diabetes as well as the obstacles and impact that being uncontrolled has on a patients’ lives.

The study gathered information from 300 doctors and 1,307 people with type 2 diabetes treated with basal insulin from the UK, Sweden and Switzerland. The group was divided into those people with type 2 diabetes that had well-controlled HbA1c levels and those who did not (295 and 1,012 respectively).3

One of the main findings was that the definition of control went far beyond the traditional medical concepts used by doctors.

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The doctors surveyed in the study believed HbA1c, diabetes complications and hypoglycaemia were the best definitions of diabetes control. Though people with type 2 diabetes who are uncontrolled on basal insulin also used medical concepts in their definition of control, many of the main definitions included a much broader range of daily factors, such as the number of insulin units they are taking, energy levels, predictability of life and time spent thinking about diabetes (see ‘Gaps in perceptions of control’ info box 1).

Lead investigator on the study, Meryl Brod, explains the potential challenges to improving treatment when definitions are not aligned.

“I think the major implication is that communication between the doctor and the patient is at cross purposes. As a result, patients can feel misunderstood and discouraged and doctors miss the opportunity to work with the patient to have a realistic treatment plan that works for the patient and their life circumstances,” says Meryl. “Additionally, when healthcare professionals focus only on getting HbA1c down, the patient does not really fully grasp the importance of control as they are defining control in terms of the broader factors.”

Beyond how control is defined, a wide perception gap was also found to exist between patient and doctor when it comes to the obstacles that make control difficult and the impact of not being in control (see ‘Gaps in perceptions of control’ info box 2 and 3).

“If the doctor does not understand what are the particular challenges and obstacles that a given patient has to being in control, then they are not able to have a realistic treatment plan for the patient to be in control,” explains Meryl. “It is important to remember that several of the obstacles to control are actually factors which are outside of a healthcare professional’s sphere of influence or medical role, such as work schedules. However, if they are aware of these obstacles, they are then in a position to work strategically around medical solutions with the patient. Patients need realistic strategies that work for their lives to be in control and doctors need to understand the obstacles to help with the strategy.”

You never know until you ask

The results from the Perception of Control study point out opportunities to improve the health and well-being of people with type 2 diabetes. A key starting point is the dialogue between doctor and patient. With an increased acknowledgment of the differences in perceptions of control between doctor and patient, better support and clearer communication can result.

Meryl believes the insights could be very beneficial to improving diabetes health and tools could be developed from what has been learned from the Perceptions of Control study.

“I think a simple check list that healthcare professionals could give patients, asking what are the obstacles for them to being in control, can serve as the basis for a discussion between doctor and patient on how to realistically overcome the obstacles,” says Meryl. “Overall, having a more open dialogue during consultations may provide more insight into these critical factors which could improve diabetes management and lead to more effective individualised treatment plans.”
The mission of Team Novo Nordisk is to inspire, educate and empower people affected by diabetes. Professional cyclist Becky Furuta talks about patient centricity through the eyes of a competitive athlete.

Becky Furuta is a competitive cyclist for Team Novo Nordisk, a global all-diabetes sports team of cyclists, triathletes and runners, spearheaded by the world’s first all-diabetes professional cycling team. She lives in Boulder, Colorado, in the US and she was diagnosed with type 1 diabetes in 2007 during the pregnancy of her second child.

In the eight years since her diagnosis, Becky is back in competitive cycling (getting up at 4.30am every day to train), is a busy mother of two, a fulltime healthcare policy consultant and a cyclist and ambassador for diabetes.

TBL Quarterly had the pleasure of speaking with Becky to find out her views on putting people with diabetes closer to the centre of treatment and care.

What is patient centricity for you?
It’s a participatory approach to healthcare. The old model relies on the healthcare system but now we are more knowledgeable and want a seat at the table. It’s a more collaborative approach, after all, sometimes solutions can be driven by the patient.

How can healthcare put the person in the centre of their care?
There needs to be a culture shift in how healthcare professionals, the system and patients interact. Some are adapting more than others. When I want my doctor to check on my recent blood glucose measurements, he goes to the cloud.

I think electronic records are a big opportunity. Now we are provided with clinical summaries and lab reports but ultimately there should be more accessibility and the sharing of healthcare data is not always fluid, especially when healthcare professionals are not centralised or clustered.
The emergency room is a good example of where healthcare data sharing can break down. I had an emergency room visit and found it very challenging for the staff to access my health records and get all the right information about me as a person with type 1 diabetes.

Data and record sharing can also improve treating the person as a whole. Once I went to a physiotherapist after an injury and thought how helpful it could be for this information to be shared with my doctor. If it was shared, my doctor would know that I would be getting less than my normal level of exercise and this might require changes in my treatment.

Where can healthcare companies play a role?
Healthcare companies need to tell stories about how they will improve patients’ lives. It is important that these stories go beyond numbers. The benefits are what patients recognise and can relate to. I am an athlete and if a diabetes device that I need to have with me does not fit in a pocket on my cycling jersey, it is not a benefit.

Companies can engage in more dialogues with patients and get a better understanding of the inconveniences of people with diabetes. A big one that always comes to mind for me is the hassle of having to carry around so much stuff.

How has your life changed since you joined Team Novo Nordisk?
Athletics in general are empowering, and perhaps even more so when you have a challenge like diabetes. It’s easy to get sucked into feeling like a ‘patient’. For a long time, in fact, I was hesitant to even disclose that I had diabetes because I didn’t want to be perceived as someone sick or unwell – even though I was fit, strong and healthy.

My racing has certainly kept me in good shape, both physically and mentally, and being a part of the team has made me even more aware of just how important it is to be open about living with diabetes. Every time I see my teammates, I am reminded of what diabetes can look like, and what we can do with active management. I want others to see that, too … especially young people who might be self-conscious about having diabetes.
Diabetes in children: a family matter

Type 1 diabetes is a lifelong condition, most often diagnosed in children and young adults. Treatment involves daily injections of insulin, regular exercise, proper nutrition and emotional support. A huge responsibility for anyone, even more so for a young child.

When a child is diagnosed with type 1 diabetes, the entire family is affected as everyone must adjust to a new way of living. With the right level of support, family members can play a central role in helping their children manage their treatment with confidence.

In Ethiopia, Getamesay’s son, Christian, has type 1 diabetes. Since he was diagnosed at age three, Getamesay has adopted his son’s life style. He’s helped create a home where diet and Christian’s daily treatment needs are routine.

“If Christian did not have type 1 diabetes, I might not give such concern for types of food we buy,” says Getamesay. “Instead, my life has been adjusted according to his need.”

A new routine
At the time Christian was diagnosed, life had been quite different. There was strain between Getamesay and his wife and things were far from routine. After the diagnosis, life became even more stressful for both parents.

“The new responsibility was a lot to cope up with,” says Getamesay. “Shortly after Christian’s diagnosis we became separated. We agreed that I should take sole responsibility for Christian.”

In the beginning, the daily adherence to Christian’s diabetes treatment was difficult. He was also concerned about the availability and affordability of insulin, test strips and glucometers to measure and monitor Christian’s blood sugar level. Christian was soon enrolled in the Changing Diabetes® in Children programme at Tikur Anbessa Hospital in the city of Addis Ababa. Through the programme, he was able to get the insulin and monitoring supplies without cost.

“We were lucky the Changing Diabetes® in Children programme, under the Ethiopia Diabetes Association, had started up,” says Getamesay. “Being a minibus driver and earning a meagre income made it impossible to afford the cost of care for Christian.”

There were other challenges Getamesay had to face in the early years. As a minibus driver, he was frequently away from home. To support the daily management of Christian’s diabetes, Getamesay invited his sister to move in. When Christian started school, he had the ongoing task of informing teachers and staff about hypoglycaemia and Christian’s treatment needs.

Getting the right support
The focus was clearly on Christian and ensuring that his health and wellbeing were good. But Getamesay was facing needs of his own, getting support to help him adjust to life as a parent to a child with type 1 diabetes.

Getamesay sought support and was fortunate to find the Parent and Child Forum at the Tikur Anbessa Hospital’s Changing Diabetes® in Children clinic. At forum meetings, parents like Getamesay learn about type 1 diabetes and how to manage their children at home.

1. Hypoglycaemia, also known as low blood sugar or low blood glucose, is when blood sugar decreases to below normal.
But most importantly, the parents share their challenges, fears and success stories openly and learn from each other.

“It was good for me to learn that there are parents who shared the same experiences and were willing to support each other,” says Christian. “The support given to me is significant and it would be difficult for me to deal with being there for Christian without the support.”

In addition to sharing and discussing life as a parent to a child with type 1 diabetes, a counsellor is invited to help parents overcome the practical and emotional challenges that come with being a parent to a child with type 1 diabetes.

Misrak Tarekegn, who works for the Ethiopia Diabetes Association and acts as project manager for the Changing Diabetes ® in Children clinic, explains that the forum meetings are usually an impactful and therapeutic experience for parents.

Misrak explains: “Suddenly, parents don’t feel alone and become more involved in their children’s diabetes. This boosts the confidence of the children and they no longer feel isolated either. When a parent is not involved, the whole burden of taking care of diabetes rests on children, and they may not take care of themselves very well.”

An eye-opener
What is initially eye-opening for parents is the discovery that there is a considerable number of children with type 1 diabetes living in Addis Ababa. The numbers continue to increase as stories spread about how the forum has helped improve care and overall health of the children.

“We have seen an increase in the number of children who come to the association [Ethiopia Diabetes Association] for education,” says Misrak. “Of great importance is that we can also see that the number of children who experienced diabetic ketoacidosis has decreased.”

Diabetes specialists are invited to the meetings to both educate and assure parents that every child can thrive with diabetes. A dietician also joins to clear up myths about diet and provide informed guidance about what their children should be eating.

Through the Parent and Child Forums, Misrak has witnessed parents taking on a more engaged and confident role in helping their children. Though the journey can be hard.

“Many of the meetings are quite sentimental. I remember when a mother narrated her path from denial to acceptance and many of us were crying because it was so difficult,” says Misrak. “The story was so powerful that some mothers who didn’t have a child with diabetes got involved and continue to support the forum.”

For Getamesay the forum meetings have been a life-saver. “Without the support I’ve received, I do not know how I would have dealt with this situation. Christian is now eight years old, healthy and cheerful. I am so grateful to the support of Novo Nordisk through the Ethiopian Diabetes Association,” says Getamesay.

About Changing Diabetes ® in Children
Novo Nordisk, together with a range of partners, established the Changing Diabetes ® in Children programme in 2009. The programme’s primary aim is to improve delivery of care to children with type 1 diabetes in resource-poor settings. Today, it has reached more than 13,000 children in nine countries in Africa and South Asia.

More information and materials are available at novonordisk.com/cdic

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2. Diabetic ketoacidosis is a life-threatening problem that affects people with diabetes. It occurs when the body cannot use sugar (glucose) as a fuel source because there is no insulin or not enough insulin. Fat is used for fuel instead. When fat breaks down, waste products called ketones build up in the body.
Engaging the ones who know patients best

Ensuring good conditions for people with diabetes who participate in clinical trials is key for a successful outcome. A five-year trial is setting new standards for patient involvement in clinical research by putting nurses and study coordinators at the forefront.

Sharon Tovey works as a nurse and she knows her patients well. She knows their medical history and how to best adjust their treatment. But she also knows the people behind the disease, their feelings and concerns and even the names of their children, spouses and cats.

Sharon is not your typical kind of nurse working at a general practitioner or at an emergency room. For the past seven years, she has worked as a research nurse, specialising in diabetes at the clinical research centre at Southmead hospital in Bristol, UK.

**What is clinical research?**

Clinical research is a crucial part of the development process for human medicine. It is done to document the efficacy, safety and optimal use of the medicines to people who need them.

In the process, patients collaborate with nurses, physicians and pharmaceutical companies to develop new knowledge, improved medicine and technologies. Ensuring the best conditions for patients and the research sites conducting the trials is key. If not, people are more likely to leave the study which can negatively affect the validity of the trial results.

In 2010, Novo Nordisk was faced with its largest and longest clinical trial to date involving approximately 9,000 type 2 diabetes patients in 32 countries over a five-year period. The trial, called LEADER®, is undertaken to study cardiovascular outcomes in one of Novo Nordisk’s drugs¹ and has an ambitious goal to retain 99% of all patients until the trial’s end.² So it was decided to try a new approach.

**A new approach**

In clinical research, a doctor – also known as the investigator – conducts the clinical trial in collaboration with a sponsoring pharmaceutical company. The investigator is the primary link between the company and the research site, however, he or she is not always the one having the daily contact with patients. This is where the research nurse often comes into the picture.

“We wanted to learn more about the view of the patients – what motivates them and what concerns they might have and build this into the design of the trial – so we thought why not let the ones

“A patient does not want to be seen as a research subject, but as a whole person. They are people with normal lives who want to be listened to”

who often know the patients best play a more active role?” says Jan Kildeskov, Senior Director of Study Programmes in Novo Nordisk, who was heading up the original team spearheading the company’s new approach to working more closely with nurses in clinical research.

According to Jan, this was not without challenges. It was a shift from a purely science driven top-down approach towards a collaborative partnership that put increased focus on communication and relationship building which required a more cross-functional skillset. “In the beginning, we spent a lot of time convincing people that this was the way to go. But it was worth the investment,” he adds.

1. Cardiovascular disease is the major cause of death in diabetes, accounting for more than 50% of all diabetes fatalities. The LEADER® trial is assessing cardiovascular outcomes and relevant clinical parameters with liraglutide in type 2 diabetes.
2. Patient retention normally ranges from 60-85% (Sahoo, “Patient Recruitment and Retention in Clinical Trials: Emerging strategies in Europe, the US and Asia”, 2007, Business Insights Ltd).
Putting nurses and study coordinators at the forefront

In Bristol, Sharon has felt the new approach on the ground: “I have been deeply involved from the very beginning.” She also sits on the LEADER® Patient Retention Panel, which is group of study coordinators and study nurses who give Novo Nordisk advice on patient retention activities and communication with patients in general.

“A patient does not want to be seen as a research subject, but as a whole person. They are people with normal lives who want to be listened to – and in the panel we are giving them a voice and changes are happening as a result of it,” Sharon adds.

One of the people who have played a key role in making these changes happen is Lori Berard. Lori is Nurse Manager at the WRHA Health Sciences Centre Winnipeg Diabetes Research Group in Canada, and she chairs the LEADER® Patient Retention Panel. She also sits in the Global Expert Panel of the LEADER® trial and is the National Study Coordinator in Canada.

“The key learning is that by engaging the people working closest to the patients, you get better results for everyone”

“Treating the patient as a VIP

As part of their work in the Patient Retention Panel, Lori and Sharon identify gaps, exchange ideas with the other research nurses and develop a range of initiatives and tools to improve conditions for patients and their caregivers – all based on input they get from listening to them.

“Our approach is that we want to ‘treat the patient as a VIP’ and find ways we can make their lives easier and keep them motivated throughout the trial,” says Sharon. “One thing we have done in the UK is to set up regular patient meetings where we invite in external speakers to talk about retinal screenings for example. People can bring their partner and share experiences over tea and coffee. I have never done this for other trials.”

Another initiative to improve communication with patients is a regular newsletter which includes articles on what is new in diabetes research, tips about exercise and general updates on the trial.

The end of the beginning

After five years, the LEADER® trial is now coming to an end and is on track to meet its retention target. But how do you then say goodbye to patients in the best possible way?

“People in clinical trials get better than normal care and some are concerned about their continued care when the trial stops,” says Sharon. “Therefore we have developed guidelines for how we can best support this transition by making it an integral part of the last six months of the trial.”

To Jan, saying goodbye to LEADER® only marks ‘the end of the beginning’ because it has shown a new way for how Novo Nordisk can work more actively with nurses in clinical research going forward. Lori and Sharon are obviously pleased about this.

“Our experiences have shown us that there is a different way of doing large trials and we have created a model that sets new standards for patient involvement. The key learning is that by engaging the people working closest to the patients, you get better results for everyone,” says Lori.
Sometimes domestic laws do not protect all human rights and in challenging contexts they may not be enforced. In such cases, a company’s responsibility to respect patients’ rights must go beyond these laws. In Novo Nordisk, a human rights assessment has led to new initiatives being taken to further improve reporting of adverse events from areas with vague or missing local safety reporting requirements.

How do you inform and instruct patients about reporting of adverse events in countries where there is a lack of medication, healthcare professionals and no well-functioning national reporting systems in place?

This was the task that Betina Østergaard Eriksen was faced with when she started her work as deputy QPPV in Novo Nordisk in 2014. QPPV is short for Qualified Person for Pharmacovigilance and Betina sits in Global Safety, the department responsible for the safety of Novo Nordisk’s products. Most of her work is focused on pharmacovigilance which is the science and activities related to the detection, assessment, understanding and prevention of adverse events or any other drug-related problems.

“Novo Nordisk has one set of pharmacovigilance procedures in place covering all countries worldwide and lives up to all existing legislations. However, even though we have solid global procedures in place, there are big differences in reporting patterns from different countries. Areas like the USA, Japan and EU have advanced national reporting systems in place while many developing countries have different local conditions, like limited access to medication, insufficient number of healthcare professionals and less well-functioning national reporting systems, resulting in lower adverse event reporting from these countries,” says Betina.

Making sure that people using Novo Nordisk’s products can report adverse events may therefore not be as simple as ‘just’ following the law. This also became clear when the company conducted a human rights impact assessment in 2014.

What’s business got to do with it?
States have obligations under international human rights law to respect, protect and fulfill the human rights of people under their jurisdiction. This has not changed. But with the growing role and impact of corporate actors, now a global standard exists that specifies the responsibilities that businesses have to respect human rights.

Novo Nordisk is committed to meeting its responsibility to respect human rights as defined by the UN Guiding Principles on Business and Human Rights, which is the global standard. At its core is proactive due diligence. “It is like thinking of almost worst-scenario-impacts to people in our operations, products and business relationships, and proactively prevent and manage them before they occur,” says Kasumi Blessing, global project manager in Corporate Sustainability.

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1. An adverse event is defined as any unfavourable and unintended sign, symptom or disease temporally associated with the use of a product.
2. For more information, see: who.int/medicines/areas/quality_safety/safety_efficacy/pharmvigi/en
3. For more information, see: ohchr.org/EN/PublicationsResources/Pages/ReferenceMaterial.aspx
Novo Nordisk initiated its first comprehensive human rights due diligence by starting with an impact assessment looking at global processes and functions. One of the work streams has been initiated by Global Safety.

“In the assessment, we looked at patient safety beyond liability and focused on how we in areas with challenging local conditions could optimise adverse events reporting from patients and healthcare professionals,” says Betina.

**Challenges in Sub-Saharan Africa**

One of the areas Novo Nordisk decided to focus on was its Middle Africa business region which is comprised of 49 countries mainly located in Sub-Saharan Africa.

A well-functioning system to report product safety issues safeguards the public through efficient and timely identification, collection, and assessment of medicine-related adverse events and by communicating risks and benefits to support decision-making about medicines at various levels of the healthcare system.

According to a United States Agency for International Development (USAID) report, the lack of policy and regulations in Sub-Saharan Africa limits enforcement of medicine safety monitoring and reporting. Out of 46 surveyed countries, only two collected more than 100 reports per million population in 2010 per year.4

One reason for this is the low capacity of the health workforce. In Sub-Saharan Africa, there are only 10 health workers per 10,000 people compared to an Organisation for Economic Co-operation and Development (OECD) average of 129.4

But companies can and should still do something. As a result of the human rights assessment, Betina is now working with a group of colleagues from different business areas to identify local initiatives to optimise reporting of adverse events.

**First steps to improve**

To implement initiatives on the ground, Betina teamed up with Krishnananda Nayak, who works as Regulatory Affairs, Quality Assurance and Pharmacovigilance Manager for Novo Nordisk’s Middle Africa region.

Nayak acknowledges that it is a challenge that many countries in the region do not have an infrastructure in place to support pharmacovigilance requirements. “Some countries for examples have national web portals dedicated to this, but they are not updated,” he says. “In addition, Novo Nordisk only has sales personnel present in 16 out of the 49 countries in Middle Africa which makes it even more challenging to obtain the information.”

Together with his team, Nayak has started a range of activities. First focus has been on improving awareness and training of employees in Middle Africa as part of the introduction training course as well as sessions on quality and safety reporting in quarterly and annual sales meetings. Together with the Medical department, he has also initiated a monthly newsletter on the topic and made sure that there is a pharmacovigilance contact and phone number on the business card of all sales employees.

In an attempt to create more awareness for the people using Novo Nordisk’s products, an email address will also be printed on all the promotional material used in Middle Africa. Dedicated mobile numbers to receive safety information are currently established in Nigeria, Ghana, Kenya, Zimbabwe, Namibia, Botswana, Mauritius and Ivory Coast and more countries are expected to be added to the list next year.

Further, Nayak – in collaboration with the Medical and Marketing department – has developed ‘leave behind’ cards and stickers to be used at pharmacies and physician’s clinics to increase awareness.

“We believe it is not that people do not want to report safety information, but rather they do not know that safety information is vital and has to be reported,” says Nayak. Hence the focus is to develop ways and means to assure product safety and provide better diabetes care.

These may seem as small steps but they are hugely important in making it easier for patients and doctors to report on potential adverse events.

“Today the magnitude of the issue is unknown, including the impact it has on patients’ quality of life, non-adherence to treatment and costs to the healthcare system. If we know more, we as a company are better able to strengthen product safety and advise doctors using the products – and ultimately this is likely to result in better outcomes for patients.

**For more information on Novo Nordisk’s work with respect for human rights, read the company’s position on human rights here:** novonordisk.com/about-novo-nordisk/novo-nordisk-in-brief/positions/human-rights.html

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A tale of two cities

Cities concentrate people, and in doing so, cities can also concentrate risks and hazards to health – this is evident in the case of type 2 diabetes. Two-thirds of the 415 million people with diabetes live in and around cities.¹

The form and composition of cities – their size, density, diversity and complexity – provide tremendous opportunity for understanding the drivers behind type 2 diabetes, thus making cities a focal point for developing interventions that can break the rising curve of diabetes. Getting to these solutions requires an understanding of how societal factors and individual behaviour associated with urban living influence an individual’s risk of developing type 2 diabetes.

In November 2015, the partners behind the Cities Changing Diabetes programme, including University College London, Steno Diabetes Center, city partners and Novo Nordisk, completed a yearlong assessment in the programme’s five study cities. Anthropologists and public health researchers took to the streets in Copenhagen, Houston, Tianjin, Shanghai and Mexico City to begin uncovering the social factors and cultural determinants that make some people more vulnerable to the development of type 2 diabetes.

Going forward, the insights gained from the Cities Changing Diabetes research will guide the development of local actions to tackle the diabetes epidemic in cities. Prompted by the findings, Novo Nordisk has pledged to invest 20 million USD of expert resource and research funds by 2020. In 2016, Vancouver and Johannesburg will become the next cities to join the programme and contribute to the international pool of evidence.

Here are a few of the field notes from two of the cities located in opposite sides of the world, showing that whether living in Shanghai or Mexico City, availability of healthy food options, access to healthcare services and the financial burden of type 2 diabetes are impacting the lives of urban citizens.

For more information, see theguardian.com/cities-changing-diabetes-partner-zone/2015/nov/24/study-of-urban-diabetes-international-perspectives and youtube.com/user/citiesdiabetes
DESTINATION MEXICO CITY
MEET IZTAC

Iztac is a 44-year-old woman from the borough of Iztacalco in Mexico City. She has two sons and two grandsons, and they all live in a simple building near a main street with heavy car and foot traffic. On one corner of her street is a primary school, and there is a metro station nearby. Along the street are the customary roadside food stalls selling quesadillas and tacos.

Since she was seven years old, Iztac has been blind in her left eye, and her right eye only has 15% visibility. This makes it hard for her to read and write. Her type 2 diabetes, which was diagnosed 10 years ago, has led to and exacerbated her vision loss. Iztac sees diabetes as just ‘another disease that you get’, because since childhood she has been ‘living with disease’, referring to both her vision and mobility problems due to a leg injury as a result of being run over.

Even though diabetes tires her and causes pain in her feet, both of which affect her work performance, Iztac sells bottled gas door to door each day. She has had episodes where her blood sugar level has dropped during her workday and she has had to be given medical attention, meaning that she was unable to continue working. When she has only a little money available, she buys a chocolate bar and a soft drink to raise her blood sugar level and carry on working.

Her current situation means she cannot maintain a healthy diet due to lack of time and money, even though she knows it is important for those with diabetes. In general, Iztac feels that her diabetes is a consequence of living with stress due to family and working problems, a fact that she believes is inherent in the city and its dynamics. Her view is that labour exploitation, noise, hurry and widespread insecurity also lead to stress and later cause health issues. Mexico City is a setting ‘that makes you ill’, according to Iztac.

“You can give me a nice talk about nutrition, but no, … I won’t be able to stick to it … Partly for economic reasons, partly because sometimes you just pick something up from the street vendors … In my case, because I’m diabetic, it’s bad for me not to eat, and so sometimes I just have tripe tacos and coke … With that, I can go all day.”

DESTINATION SHANGHAI
MEET LIU

Liu is a well-groomed 70-year-old man. He is retired and lives together with his wife and son, who has returned from studying abroad.

Diabetes has cost Liu his left foot. His foot was amputated 30 years ago after a small wound on his toe developed into a large ulcer – this is a common complication of diabetes. He is now confined to a wheelchair as a result of his disability. This experience has left him disappointed with the medical system available to people like himself. He has suffered a lot as a consequence of diabetes, but this does not stop him from engaging in medical care and looking after his health.

Consequently, Liu is keen to prevent and control any diabetes-related complications, and keeps himself informed about what challenges can arise as well as how he can treat or avoid them. He believes that diabetes is caused by lack of exercise or by dietary habits such as eating fried foods or consuming excessive sugar. Furthermore, he holds the view that a big risk factor for developing diabetes is genetic predisposition.

Although he and his wife each receive 2,500 Chinese yuan (just below 400 USD) a month from their pensions, this is not enough to meet their needs. So to support his family’s needs, Liu sells newspapers, cigarettes and soft drinks on the streets in his neighbourhood. “My son has returned from studying abroad and doesn’t have a job as yet, so I have to earn money.” Fortunately for Liu, he has the support of many of his neighbours, who keep in regular contact with him and help Liu carry things up and down the stairs at his home.
How do you make sure that company values are not just nice words but something that employees across the globe live in their daily work? We asked Mogens Thorsager Jensen who heads up a special department in Novo Nordisk called Facilitation to get a better understanding of how well the company is living up to one if its core values of having a ‘patient centred business approach’.

Could you describe your role as corporate vice president of Facilitation?

Our team consists of ten full-time and 12 part-time facilitators whose job is to evaluate how well our organisation is living up to Novo Nordisk’s values-based management system, the Novo Nordisk Way, expressed in our Novo Nordisk Essentials. These are ten statements that guide the way we work and we conduct 60–65 facilitations a year worldwide.

I have my 25th anniversary in Novo Nordisk this year. It is my 7th job in the company and before I headed up departments like Strategic R&D and Investor Relations. My current role is to manage the ten full-time facilitators and then I am also responsible for reporting regularly to Executive Management and the Board of Directors who are very interested in the trends that we can identify – both the things that go well but also where we can improve.

What is special about the way Novo Nordisk does facilitations?

Every pharma company is talking about patient centricity but the trick is the way you walk the talk. Many companies around the world have different follow-up systems but in most cases, they rely on line management or the HR function. We as facilitators are not part of HR and we are not line management, so we can come in as impartial auditors and observe things in a slightly different and unbiased way.

I also believe that our method is quite unique. We do not have a rigid questionnaire with question A, B and C. Instead, we have very open and qualitative interviews where we try to make people feel at ease – this is not an interrogation! It is a conversation where we always start by relating to the individual and what he or she is doing.

Novo Nordisk’s essential 1 says ‘We create value by having a patient centred business approach’ – how do you evaluate how well a unit lives up to that?

A facilitation interview leads to a discussion about many things and it is our job as facilitators to do the linking to the essentials. To find out how patient focused a unit is, a typical question would be ‘tell me the last time you met a patient?’ or ‘do you have any activities that could increase your focus on patients?’

By talking to many people – we are normally two facilitators and interview between 15–20% of employees in a unit – we get to a qualified assessment of what works well and what could be improved.

What do employees find challenging about being patient centric?

I am well aware that this comes easier for some units. If you are a small sales affiliate with most employees working in the field, obviously you have very high patient focus because you meet doctors almost every day. In a headquarter function like my own, it can be more of a challenge. However, patient focus is a mind-set. We can be miles away from the patient – and yet, we are not. We work on different levels but all for the same cause. Facilitators must always be aware of the context, and we would not necessarily rate an affiliate higher than what we would a staff function.
What are some of the challenges of your job?
One challenge is how do we know what is ‘good patient-centric behaviour’ because we as facilitators do not go out and ask patients directly. However, we only employ facilitators with a lot of experience who have a good understanding of Novo Nordisk, the environment we work in, and the issues that patients are concerned about.

Another challenge is that in some cultures it is more difficult to get people to open up, but our facilitators are trained for this. Occasionally it can also be challenging to get the management team on board because at the end of the day it is them being evaluated and there will be findings of different severity. But it is only because we want to make sure that we improve and that our values are not just something we have written on a glossy page.

What happens if a department ‘scores low’ on patient centricity?
We sometimes issue minor findings, for example we facilitated a unit which was very high performing in general, but could spend more energy on increasing their patient focus. We recommended things they could do to get a better impression of what it means to be a patient, such as invite a patient in or have someone from R&D to come and talk about unmet needs. They happily accepted it and are implementing initiatives as we speak.

How can Novo Nordisk become more patient centric?
That’s a tall order, so I don’t think I can point to one specific action. However, one key aspect is when we get new people on board in the company. Already when we talk to people in job interviews, we should get a sense of why they want to join Novo Nordisk and why they are engaged about the things we do – it should never just be for the money.

You can watch a short movie about facilitations here: video.novonordisk.com/video/4855300/global-facilitation-making-sure-we-live

THE ESSENTIALS
1. We create value by having a patient centred business approach.
2. We set ambitious goals and strive for excellence.
3. We are accountable for our financial, environmental and social performance.
4. We provide innovation to the benefit of our stakeholders.
5. We build and maintain good relations with our key stakeholders.
6. We treat everyone with respect.
7. We focus on personal performance and development.
8. We have a healthy and engaging working environment.
9. We optimise the way we work and strive for simplicity.
10. We never compromise on quality and business ethics.
About Novo Nordisk and the Triple Bottom Line

Headquartered in Denmark, Novo Nordisk is a global healthcare company with more than 90 years of innovation and leadership in diabetes care. This heritage has given us experience and capabilities that also enable us to help people defeat other serious chronic conditions: haemophilia, growth disorders and obesity.

We believe that a healthy economy, environment and society are fundamental to long-term value creation. This is why we manage our business in accordance with the Triple Bottom Line business principle and consider the financial, environmental and social impact of our business decisions.

The best way to comment on any article is on:
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For a deeper look at how Novo Nordisk works with sustainability visit our website at: novonordisk.com/sustainability