TACKLING THE COSTS OF DIABETES
Over 400 million people currently live with diabetes.  
One in two is undiagnosed.  
Screening for type 2 diabetes is important to ensure early diagnosis and treatment to reduce the risk of serious complications.  

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Paying for diabetes

Health has been called the first of all liberties. The **Universal Declaration of Human Rights** (UDHR, Article 25) mandates that everyone has the right to the highest attainable standard of physical and mental health. Universal Access stipulates that access to healthcare must be guaranteed for all people on an equitable basis. Today it is estimated that 415 million people live with a form of diabetes - type 2 diabetes constituting 90-95% of the total number of cases. A diagnosis of diabetes requires individualized medical care alongside the availability of life-saving medication. That is, if the person with diabetes has become aware of their condition. Nearly half of the millions of people living with diabetes today do not know they have the condition and of those that have been diagnosed, one person will die of diabetes every seven seconds.

It is time to stop ignoring diabetes. For far too many, the cost of the human right required to prevent or live with diabetes has become out of reach. According to a recent study, (Worldwide trends in diabetes since 1980: a pooled analysis of 751 population-based studies with 4.4 million participants. *Lancet.* 2016; 387:1513-30) the global annual cost of diabetes is more than USD 800 billion, and yet, the global targets set by the 2011 UN High-Level Meeting on Noncommunicable Diseases (NCDs) to halt the rise in the adult prevalence of diabetes at its 2010 levels, in all probability, will not be met. That same study reports that only nine countries for men and 29 countries for women, mostly in western Europe, have a 50% or higher probability of meeting the global target.

Uncertainty and tragedy hallmark the rise in diabetes. Because the cost associated with the burden of care and treatment for diabetes has reached such an extreme level it is likely that many national healthcare systems will be forced into bankruptcy. Further, diabetes, both in prevalence and in number of adults who develop the condition, has increased much faster in low-income and middle-income countries than in high-income countries. Experts say the surest way to stem the tide of the diabetes epidemic is to address soaring global obesity rates, foster healthy nutrition at every life stage and examine how genetics and environment play a role. For this to happen, targeted support and preventive strategies for these populations are necessary. In the meantime, affordable and comprehensive diabetes care, accessible where and when needed, including low- and middle-income countries, is a basic human right for all people living with diabetes today.
This month, *Diabetes Voice* is dedicated to investigating, revealing and discussing, with a heightened sense of urgency and responsibility, the price we are all paying for diabetes today, both literally and figuratively.

Ping Zhang, Health Economist at the Centers for Disease Control and Prevention and João da Rocha Fernandez, IDF’s Health Economist discuss **cost-effective and cost-saving interventions** to reduce the future economic burden of diabetes. David Beran, researcher and lecturer at the University of Geneva and Geneva University Hospitals, and his co-authors, examine the challenge and constraints to insulin access today, declaring our need to act on behalf of the 50 million people who require insulin but have difficulties accessing it (*Insulin in 2016: challenge and constraints to access*). In, *Diabetes in the Young, School Performance and KiDS*, our authors discuss cognitive function and school performance in children with type 1 and type 2 diabetes, the importance of treating and caring for diabetes in school, and how the *IDF Kids and Diabetes in Schools (KiDS)* project is helping to foster school environments that create a better understanding of diabetes and support students with diabetes.

In *Diabetes in Society*, we asked people living with diabetes or caring for people with diabetes what diabetes costs them in real terms, and how this cost and burden has affected them physically and emotionally. Whether you are a poor farmer who has been diagnosed with type 2 diabetes requiring insulin and care for early stage retinopathy in Rwanda, or a 12-year-old girl who has developed type 1 diabetes in the United States, the costs exacted upon each family can be equal in relation to total income. Both the farmer and the parent of the girl will, we can imagine, ask themselves: how will I pay? How will I (help her) survive?"

And finally, Rhys Williams, in his last article (*Estimating the national and global costs of diabetes*) for the publication as Editor-in-Chief, revisits the methods used to calculate the costs of diabetes and re-evaluates our current position on costs and how we may need to revise our economic expectations of a future in which diabetes itself and its complications are prevented. In Professor Williams’s words, “That, after all, is what we are here to do.”

Elizabeth Snouffer is Editor of Diabetes Voice
Eyes on diabetes will be the International Diabetes Federation (IDF) World Diabetes Day (WDD) campaign for 2016. WDD 2016 activities and materials will promote two key messages:

• Screening for type 2 diabetes is important to modify progression of the disease and reduce the risk of complications.
• Screening for diabetes complications is an essential part of managing type 1 and type 2 diabetes, and gestational diabetes (GDM).

WDD 2016 will highlight the feasible and cost-effective solutions that exist to help identify people with undiagnosed type 2 diabetes or at risk of developing diabetes in the future.

IDF has estimated that globally as many as 193 million people, or close to half of all adults living with diabetes in 2015, are unaware of their diabetes. Most of these cases are type 2 diabetes. The earlier a person is diagnosed, the earlier treatment and management can be initiated, which can improve chances of preventing harmful and costly complications. A person with type 2 diabetes can live for several years without showing any symptoms, during which time high blood glucose is silently damaging the body. There is therefore an urgent need to screen, diagnose and provide appropriate care to people with diabetes.

Diabetes is a leading cause of cardiovascular disease, blindness, kidney failure and lower-limb amputation. Over one third of all people currently living with type 1 and type 2 diabetes will develop some form of eye disease during their lifetime. These complications can be prevented or delayed by maintaining blood glucose, blood pressure and cholesterol levels as close to normal as possible. Many complications can be detected at an early stage through screening, enabling more effective, timely treatment which is associated with the delivery of better outcomes. WDD 2016 will highlight the importance of integrating screening for diabetes complications into ongoing primary care for people living with diabetes.

Supporting materials for WDD 2016 will be released from May through to September to help campaign stakeholders and the wider diabetes community prepare for activities on November 14, 2016.

Posters, visuals and banners promoting the key messages of the campaign are now available for download from the World Diabetes Day website - www.worlddiabetesday.org
Online interactive education modules to enhance diabetes care worldwide

The International Diabetes Federation (IDF) announces the launch of its online interactive modules developed to ensure that the best possible diabetes healthcare education is available to healthcare providers and other professionals in a flexible, self-paced environment. IDF’s online modules are designed with the latest learning technologies available to healthcare professionals wherever they practice in the world, giving professionals in more remote communities the opportunity to provide optimal healthcare for people living with diabetes. Currently, available modules include: Introduction to diabetes; and Overview of diabetes management. A third module: Understanding diabetic retinopathy will be released in June 2016.

IDF’s online modules are a strategic initiative directed to help healthcare providers improve the screening, treatment and management of the millions of diagnosed and undiagnosed people who live with diabetes. In 2015, the IDF Diabetes Atlas estimated that one in 11 adults has diabetes (415 million) and one in two (46.5%) adults with diabetes is undiagnosed. Three-quarters of people with diabetes live in low- and middle-income countries.

The rapid global growth in all types of diabetes means there is an urgent need to increase the diabetes education and care capacity of healthcare professionals so that they can provide the current best practice treatment to people with diabetes, especially in low- and middle-income countries. IDF’s online modules have been developed for a broad range of professionals connected to healthcare, diabetes and health services:

- Healthcare professionals who work in isolated and remote settings.
- Healthcare providers, managers, social workers, healthcare assistants interested in diabetes.
- Non-governmental/charity organisation staff involved in developing diabetes care projects in low- and middle-income countries.
- Healthcare professionals working with directorates of health services, central and state governments and officials engaged in health services at national-, state- and local-level government institutions.

The online modules are accessible through D-NET, IDF’s online diabetes network for health professionals.
The International Diabetes Federation (IDF), in collaboration with the Diabetes and Ramadan (DAR) International Alliance has developed new Ramadan guidelines which were published and distributed on April 6, 2016. The comprehensive content in the IDF-DAR Practical Guidelines (144 pages) will help ensure that healthcare providers (HCPs) have the most up-to-date information to achieve optimal care of people with diabetes observing Ramadan. It is estimated that worldwide more than 80 million people with diabetes fast during Ramadan.

Ramadan, a holy month of Islam, will start on Monday, 6th June, 2016 and will continue for 30 days until Tuesday, 5th July. Ramadan is observed by Muslims worldwide as an obligatory annual observance, during which abstinence from eating, drinking and use of oral medications is required from sunrise to sunset everyday. Insulin injections have no nutritional value and are allowed, regardless of whether they are given by the subcutaneous, intramuscular, or intravenous route.

The IDF-DAR Practical Guidelines provide HCPs with relevant background information and practical recommendations to enable them to help people with diabetes participate in fasting during Ramadan while minimising the risk of acute complications such as hyper- or hypo-glycaemia. The guidelines cover several key topics, including epidemiology, the physiology of fasting, risk stratification, nutritional advice and medication adjustment. One of the recurring themes throughout the guidelines is the importance of a personalized approach of care and education within a diabetes management plan.

Fasting for people with any type of diabetes poses significant risks and, therefore, specific education about diabetes and fasting, careful monitoring and HCP guidance are key. To download a copy of the guidelines, please click the following link: http://www.idf.org/guidelines/diabetes-in-ramadan
Refugee report: living with diabetes in war

Nizar Albache

Diabetes can be difficult in normal situations, but it becomes a real challenge during war. War deeply affects the lives of people with diabetes. At a humanitarian level people in war may be killed, injured or imprisoned. They may lose a member of their family, lose their home, or become displaced inside or outside their home country. Refugees require urgent help including fulfilling their need for shelter and food.

People with chronic illness depend on medications, but in war medical centres such as hospitals may be destroyed and healthcare systems may collapse. Also, emergencies such as trauma and injuries are the priority during war, while chronic conditions like diabetes are often neglected because long-term care during war is considered a luxury and something that the state authorities will not provide. Examples of sub-standard diabetes care may include poor access to insulin, inadequate food supply, and lack of attention given to the risk of diabetes complications including nephropathy and retinopathy. People with diabetes in the Middle East are suffering from multiple conflicts and severe economic hardship, with very poor access to medical care.

The Syrian war, which began five years ago, has led to an excess of ten million refugees of which half live in neighbouring countries in camps. More than 400,000 are estimated to live with type 2 diabetes. At present, we have access to the following statistics which reflect the number of refugees with diabetes: Lebanon: 130,000; Jordan: 140,000; Turkey: 120,000; and Iraq: 15,000. The number of refugees with diabetes in Europe or in other countries is still unknown.

Fortunately, there are many organisations working in very difficult conditions and helping to build healthcare systems adapted to existing war conditions. Temporary medical centres are being set up, and staffed with well-trained healthcare teams to cope with emergencies and chronic conditions, including diabetes. Providing essential life-saving medication and care to victims of war living with diabetes is a duty of the international community.

In the IDF-MENA Region we have already developed practical measures to help all refugees with diabetes. Our committee has initiated the following activities:

- Provide insulin to Syrian camps for people with diabetes particularly children with type 1 diabetes (donated by Life for a Child and Insulin for Life).
- Organizing and facilitating medical workshops for nurses and physicians.
- Planning and carrying out fundraising campaigns.

The committee’s future plan is to extend our activities to all refugees in neighbouring countries by coordinating its efforts with other international and humanitarian organizations. We are optimistic we can extend our support to other countries including Sudan, Afghanistan, Yemen and Iraq.

Nizar Albache is the Regional Chair for the IDF Middle-East and North Africa Region.
Obesity explosion in China’s children and teenagers

China has a growing health problem and partly to blame, according to a recent study, is a high fat, high sugar, low-fibre diet and lack of physical activity. Traditional diets have been replaced with the more aspirational western diet causing a spike in childhood and adolescent overweight and obesity in China’s rural provinces. The study, *Trends in overweight and obesity among rural children and adolescents from 1985 to 2014 in Shandong, China*, examined the trends in overweight and obese rural children and adolescents over the past 29 years.

A total of 27,840 rural students aged 7–18 years were included in this study. Body mass index cut-off points recommended by the Working Group on Obesity in China (WGOC), the International Obesity Task Force (IOTF) and the World Health Organization (WHO) were used to define overweight and obesity. Using WGOC criteria, for boys, the prevalence of overweight and obesity increased from 0.74% and 0.03% in 1985 to 16.35% and 17.20% in 2014, and, for girls from 1.45% and 0.12% in 1985 to 13.91% and 9.11% in 2014, respectively. A similar increasing trend was observed by IOTF and WHO criteria. Poor diets high in fat and sugar, and lack of physical activity are blamed as the source for the explosion in weight gain and obesity.

The authors of the study speculate that childhood overweight and obesity will continue to increase in future decades in Shandong Province, and that similar increases will be found in other regions of China.

Socioeconomic status (SES) may also play an important role in the development of obesity in China’s children. Low SES is associated with aspects of lifestyle such as access to healthy food and patterns of physical activity. Studies from developed countries have shown that high SES youths are less likely to be obese than their lower SES counterparts. In contrast, in developing countries such as Indonesia, Brazil and China, high SES youths are more likely to be obese than their lower SES counterparts. The authors point to the rapid socioeconomic and nutritional transitions of China, which have led to a more obesogenic environment.

Considering the rapid development of China’s rural economy, prevalence of childhood overweight and obesity is likely to increase. China is set for an escalation of cardiovascular disease and type 2 diabetes that will increase healthcare costs, disrupt the economy and destroy lives. The authors of the study call on policy-makers and experts to take notice of these trends and enact obesity interventions in rural areas.

For more information - 
http://care.diabetesjournals.org/content/39/2/179.full
An increase in physical activity for the US population could save billions

In an oral abstract presentation, “Economic cost of type 2 diabetes attributable to physical inactivity in the United States in 2012”*, researchers looked at the direct medical costs of type 2 diabetes attributable to not meeting physical activity guidelines and to physical inactivity in the United States and found that billions of dollars (US) could be saved if adults were to engage in physical activity, a major primary preventive strategy to lower the risk for developing type 2 diabetes.

This cross sectional study used physical activity prevalence data from the 2012 Behavioral Risk Factor Surveillance System (BRFSS). These data were combined with the prevalence and cost data of type 2 diabetes (in 2012) to estimate the cost of type 2 diabetes attributable to not meeting physical activity guidelines, and to physical inactivity in 2012. Sensitivity analyses were carried out by varying the prevalence of not meeting physical activity guidelines from 30%-70%, and by varying the average annual cost of type 2 diabetes from USD 4,394 (for a person younger than 45 years) to USD 11,825 (for a person older than 65 years).

The prevalence of the US population meeting physical activity guidelines and engaging in no leisure time activity were 50% and 30% respectively in 2012. The average annual cost attributable to type 2 diabetes in the USA, was USD 7,888 per person. The cost of type 2 diabetes in the USA in 2012, attributable to not meeting physical activity guidelines was estimated to be USD 18.6 billion, and that attributable to physical inactivity was estimated to be USD 5.9 billion. Based on sensitivity analyses, these estimates ranged from USD 10.36 billion to USD 27.9 billion for not meeting physical activity guidelines and USD 3.3 billion to USD 8.87 billion for physical inactivity.

The authors concluded, “Type 2 diabetes has grown to epidemic proportions in the USA and physical activity levels in the population continue to remain low, although it is a major primary preventive strategy for diabetes. Physical activity promotion, particularly at the environmental and policy level should be a priority in the US population.”

*From the American Heart Association’s Epidemiology and Prevention/Lifestyle and Cardiometabolic Health 2016 Scientific Sessions. March 1, 2016.
ESTIMATING THE NATIONAL AND GLOBAL COSTS OF DIABETES

Rhys Williams

This article sets out to do a number of things. First, it will revisit the rationale and methods of estimating the national and global costs of diabetes as included in the early editions of IDF’s Atlas. It will also comment on the ways in which these methods have developed in more recent editions and outline a number of potential misinterpretations of disease-specific cost data. It will then take stock of ways in which we might move on in our thinking about economic aspects of diabetes and diabetes care and how we may need to revise our economic expectations of a future in which diabetes itself and its complications are prevented. In the light of this, it will make suggestions as to how future editions of the Atlas might be developed to further increase the usefulness and scope of information on the economics of diabetes and diabetes care.

Atlas economic estimates - past and present

The first estimates for the cost of diabetes, by individual country and for the world, were included in the 2nd edition of IDF’s Diabetes Atlas. That Atlas chapter set out two formulae first put forward by the Swedish health economist Bengt Jönsson.

One of these formulae estimated the cost of diabetes care. The other estimated the cost of care for people with diabetes. Both formulae used the same three variables, P, R and THCB but in different relationships to one another. P represented the prevalence of diabetes in any given country, R the ratio of the cost of care of a person with diabetes compared with the cost of care of a person without diabetes (taken to be 2 or 3, i.e. twice or three times the cost of a non-diabetic person) and THCB was the total health care budget of that country. The global cost was the total of all country costs.

Jönsson’s advocacy of two formulae recognised the need to distinguish between, on the one hand, the total cost of medication, equipment, investigations, activities and so on directly related to diabetes (the cost of diabetes care) and, on the other, these costs plus those which follow on from the presence of diabetes when the healthcare event is not directly attributable to diabetes - for example the extended length of hospital stay and increased intensity of care when a person with diabetes is admitted to hospital for a hip replacement compared with an age- and gender-matched person without diabetes admitted for the same condition (the cost of care for people with diabetes). The latter, of course, is greater than the former (indeed, it can be as much as twice the former).

The methods used to estimate costs in the more recent editions of the Atlas use a more sophisticated formula than those of Jönsson. These methods are clearly explained in a recently published article. The 7th edition of the Atlas, however, does not clearly state whether the estimates listed are of the costs of diabetes care or the costs of the care for people with diabetes. The implication is that they are of the latter which would be the logical choice-
the “real” (i.e. total) costs of diabetes.

The 2nd edition of the Atlas also included estimates of the apportionment of costs between hospitalisations and other healthcare events and the apportionment of costs between different complications, although these were not given for every country (but combined, for 25 Latin American and Caribbean countries). Such data were not included in more recent editions.

The rationale for cost estimates of diabetes and their inclusion in the Atlas

So called “cost of illness” studies have a long history. The first for diabetes were carried out in the USA in the 1960’s. Most have distinguished between direct and indirect costs. The former are those which can be attributed to the costs of preventing, diagnosing and treating the condition and its complications. The latter (which are fearedly difficult to estimate with any accuracy) are the costs of lack of productivity resulting from absence from work, disability or early death as a consequence of the condition. These costs can be estimated from the point of view of the individual, the family, the healthcare sector or society as a whole. Studies differ as to the balance between direct and indirect costs because methods differ and national circumstances differ. However, features which all such studies have in common are:

- The cost of diabetes is substantial.
- It is rising.
- The main component of direct cost is that of hospital admissions relating to complications (both acute and chronic).
- In societies with universal healthcare coverage free at the point of delivery, the main cost to the individual and the family is indirect cost.

The original purpose of cost of illness studies was to enable decision makers to prioritise resource allocation between various conditions. Put simply, the contention was that more resources should be devoted to the prevention and treatment of the most “expensive” diseases, all other things being equal.

The rationale for the inclusion of diabetes cost estimates in the Atlas, however, was as another expression, in addition to prevalence and incidence, of the “burden” of the condition and, in particular, as a means of emphasising the cost of potentially preventable complications. In the more recent Atlas editions, costs have also been used to illustrate the global inequities in diabetes healthcare with high-income countries devoting disproportionate levels of healthcare resource compared with low- and middle-income countries both in terms of total national health expenditures and funds spent on individuals with diabetes.
The misuse of economic information

These quite legitimate intentions in relation to costs estimates have, unfortunately, the potential for some fundamental misconceptions. First, there is the naïve belief that, if we succeed in preventing diabetes complications, we will, somehow, “save money” for health services or society as a whole. It is important to realise, however, that, if complications are prevented, healthcare expenditure will not necessarily fall. Rather, these resources will be transferred to other uses, mostly, probably, within the healthcare sector. Some of these uses will be diabetes-related, some will be for other conditions.

Second, there is the potential misconception that individuals with diabetes are a burden on society and that, since we already spend so much money on their care, we should not increase that expenditure since that would further increase inequalities within the healthcare sector. (I.e. R, if it is already 2 or 3, should not be increased further.)

If we continue to emphasise high diabetes costs we need to give some positive and realistic economic messages if we are to provide a balanced argument which will convince decision-makers that changes need to be made.

Striving for a more positive balance

The most convincing positive economic message, as emphasised in the article by Fernandes and Zhang in this issue, is that there are many diabetes interventions which are cost-effective and some which are cost-saving (“cost-reducing” would be a better term). Many of these interventions are technologically quite simple. For example, comprehensive foot care, lifestyle modification for the prevention of type 2 diabetes and several others.
of absence from school, under-achievement at school and reduced employability after leaving school for children with diabetes. There are a few studies of this important field but not many. In addition, there are diabetes-related indirect costs for those in essential, non-workplace societal roles (home-making, child-rearing etc.) which have seldom, as far as I am aware, been estimated.

**Atlas economic estimates - possible future additions?**

As suggestions for the Atlas Editorial Committee planning the 8th edition I would put forward the following:

- Include both estimates (cost of diabetes care and the cost of care for people with diabetes) and explain the difference between them or, at least, if one only is included, be specific as to which one has been chosen;
- Encourage empirical estimates, in a variety of resource settings, of the ratio of costs of care for people with diabetes compared with people who do not have diabetes.
- Provide more detail of the apportionment of direct costs between, for example, hospital admissions for complications and those for the prevention of complications.
- Explore trends in these proportions over time. Are we getting on top of the costs of preventable complications or not?

**The wider future - bracing ourselves for a shock**

As we succeed, as we must, in preventing type 2 diabetes, delaying the onset of type 1 diabetes and preventing the majority of complications, we need to realise that this will, not necessarily, reduce the cost of diabetes but might well increase it. The expenditure that will be required to achieve these preventive and therapeutic goals may well be more than we spend now in our “fire-fighting” activities of dealing with complications when they arrive. Prevention may well be better than cure but it is not necessarily cheaper.

Even if we “cure” both type 1 and type 2 diabetes in the future, as well we might, we shall have to pay for that cure (“those cures”, more likely). Our aim, and this may seem obvious, is not to reduce the price of diabetes but to spend whatever resources we need to spend in more appropriate ways.

Of course, if the cost of diabetes rises, we should not resent this and we should not resist it. If we prevent diabetes and its complications, even at high cost, we shall be reducing or preventing completely the price that individuals and families pay - the physical and psychological price as well as the economic price. That, after all, is what we are here to do.

**Rhys Williams** is Emeritus Professor of Clinical Epidemiology, Swansea University, Swansea, UK and Editor-in-Chief of *Diabetes Voice.*

**References**

COST-EFFECTIVE AND COST-SAVING INTERVENTIONS FOR PREVENTION AND CONTROL OF DIABETES

João da Rocha Fernandes and Ping Zhang

Diabetes imposes large economic burdens on national healthcare systems across the world. In 2015, the International Diabetes Federation (IDF) estimated that 415 million adults aged 20 to 79 years had diabetes and USD 673 billion was spent to treat diabetes and its related complications. This accounted for 11.6% of the total health expenditure worldwide. By 2040, the total number of people with diabetes is estimated to reach 642 million and the total health expenditure on diabetes is expected to exceed USD 802 billion.¹

Many effective interventions are available to reduce the future economic burden of diabetes by improving the management of type 1 diabetes, and preventing or delaying type 2 diabetes and diabetes-related complications. Cost-effectiveness analysis is a method for assessing the gains in health from different interventions relative to their costs. The cost-effectiveness of an intervention is often measured by the incremental cost-effectiveness ratio (ICER), which is calculated by dividing the difference in costs in monetary units by the difference in expected health gains between the intervention being assessed and another comparing intervention or status quo. Health gain outcomes can be expressed in natural units such as number of diabetes cases or diabetes complications prevented, or by using overall outcome measures such as years of life gained (YLGs), disability-adjusted life years avoided (DALYs), or quality-adjusted life years (QALYs).

Figure 1 illustrates how results from cost-effectiveness analysis can be used to aid resource allocation decisions. A indicates a “cost-saving” intervention (more benefit at a lower cost), and an X indicates a “harmful” (more harm at a higher cost) intervention, compared with the current practice. A ? indicates that decision makers are required to balance the additional cost with the additional benefit based on their willingness to pay for an additional unit of health improvement. For example, in the United States USD 50,000 per QALY is the conventionally accepted “price” to pay for a newly introduced intervention.² Using this threshold, the intervention would be considered cost-effective if the intervention costs less than USD 50,000 per QALY and not cost-effective if the intervention costs USD 50,000 or more per QALY.

The cost-effectiveness of interventions used for prevention and control of diabetes has been evaluated by many researchers, but mainly in high-income countries. Here we summarized the results from two recent reviews using an accepted price of USD 50,000 per QALY.
PRIMARY PREVENTION OF TYPE 2 DIABETES

Interventions that were targeted to those with high risk for type 2 diabetes included structured lifestyle intervention (diet and physical activity promotion programmes following a curriculum) and medications such as metformin. These interventions can prevent or delay type 2 diabetes and its complications, which can translate into better quality of life and longer life expectancy. Balancing the costs and benefits associated with the interventions, both structured lifestyle and medication interventions are cost-effective.

Key findings:

• Structured lifestyle interventions among people at high risk for type 2 diabetes are cost-effective over standard lifestyle recommendations. Reviewing the results from 16 studies showed that the median ICER was USD 13,761/QALY.3
• Group-based (one coach per group of participants) programmes are more cost-effective than individual based (one coach per participant) programmes and could be cost-saving. Group-based programmes presented a median ICER of USD 1,819/QALY, while individual programmes had a median ICER of USD 15,846/QALY.3
• Taking metformin is a cost-effective way to prevent type 2 diabetes among people at high risk. The median ICER was USD 9,700/QALY.4

SCREENING FOR TYPE 2 DIABETES

Type 2 diabetes can be asymptomatic, and the gap between a person developing type 2 diabetes and being diagnosed can be 4-7 years.5 Screening for type 2 diabetes can detect cases early, allowing early treatment of patients and potentially reducing the likelihood of developing diabetes complications, and incurring associated health care costs, increasing life expectancy and improving quality of life. The cost-effectiveness of screening for undiagnosed type 2 diabetes depends on the risk level of the target population.

Key findings:

• The ICER observed in studies analysed varied widely based on patient age, from USD 46,800 to USD 70,500/QALY.4
• Routine screening for undiagnosed type 2 diabetes among high-risk populations is cost-effective compared with no screening.4

Glucose control

The hallmark of diabetes is elevated blood glucose levels. Randomized clinical trials showed that intensive glycaemic control can reduce diabetes microvascular complications (nephropathy, retinopathy, and neuropathy), increase life expectancy, and improve quality of life. Intensive glycaemic control is cost-effective compared with less intensive glycaemic control.

Key findings:
• Among people with type 1 diabetes, intensive insulin treatment (target: 6%-7% HbA1c) compared with less intensive insulin therapy (target: 10% HbA1c) is cost-effective with a median ICER of USD 28,900/QALY.4
• Among all people with diabetes, intensive glycaemic control (target: 7.2% HbA1c or fasting plasma glucose [FPG] <6mmol/L) compared with less intensive glycaemic care (target: 10% HbA1c or FPG <15 mmol/L) is cost-effective with a median ICER of USD 3,400/QALY.4

Diabetes self-management education

Diabetes is a complex chronic disease that requires active involvement of patients. Diabetes self-management education (DSME) provides an opportunity for people with diabetes to gain the knowledge, skills, and motivation to effectively manage their condition, and thereby avoid or postpone the onset of serious and costly complications. DSME is cost-effective or cost-saving compared with no DSME intervention.

Key findings:
• Among people with type 1 diabetes, DSME is likely to be cost-effective compared with no DSME (USD 4,000/YLG).
• Among people with type 1 diabetes, DSME is cost-saving.4

Diabetes-related complications

Diabetes increases the risk of developing several complications, such as kidney disease, vision loss, and cardiovascular disease (CVD). These complications impact patient quality of life and cost national health systems billions of dollars a year. By preventing and treating these complications, quality of life can be improved and health resources saved.

Key findings:

Screening and prevention
• Screening for microalbuminuria and treating patients with ACE (angiotensin-converting-
enzyme) inhibitors or irbesartan to prevent end-stage renal disease could be cost-saving compared with no screening/treatment.²

- Screening for diabetic retinopathy can be cost-saving compared with no screening.⁴

- Comprehensive foot care (including foot inspection, appropriate footwear, treatment, and education) to prevent ulcers in people with diabetes is cost-saving compared with routine foot care.⁴

**Treatment**

- Immediate surgery to treat damage to the retinas caused by diabetes is cost-effective compared with deferred surgery, with an ICER of USD 2,900/QALY.⁴

- Comprehensive foot care to prevent ulcers is cost-saving compared with usual care.⁴

**Treating other risk factors for diabetes-related complications**

- Intensive blood pressure control using ACE inhibitors among people with type 2 diabetes and hypertension is cost-saving compared with less intensive control.

- Taking a statin is cost-effective to prevent CVD among people with type 2 diabetes with or without CVD history compared with no statin use.³

- Smoking cessation therapy among people with type 2 diabetes is cost-effective compared with no smoking cessation therapy.³

Very little information is available from low- and middle-income countries (as classified by the World Bank⁶) about the cost-effectiveness of interventions used for the prevention and control of diabetes. In the initial review by Li et al, of the 56 studies identified from 20 countries, only one was from a middle-income country, and none were from low-income countries.⁴ In an ongoing review of the cost-effectiveness of interventions for the primary prevention of type 2 diabetes and gestational diabetes (conducted by IDF to be published in 2016)⁷, of the studies conducted in 52 different settings, only four were in middle-income countries, and none in low-income countries.

In the absence of direct data, evidence on the cost-effectiveness of diabetes interventions from high-income countries can provide some useful guidance on prioritizing interventions for low- and middle-income countries, with appropriate cautions. In general, ICERs for an intervention will be lower for low- and middle-income countries than for high-income countries, because the effectiveness of an intervention is likely to be similar while the cost is likely to be lower due to lower costs associated with personnel and medical services. Thus, the ICERS reported for high-income countries can serve as the upper bound of ICERS expected for low- and middle-income countries. Regarding the willingness to pay for a unit of health improvement, the World Health Organization recommends using three times the value of a country's per capita gross domestic product (GDP).⁸ For example, a country
with a per capita GDP equivalent to USD 5,000 would use an ICER of USD 15,000 as a cut-off for cost-effectiveness. Using this as a general rule, a country can determine whether or not an intervention is likely to be cost-effective in their location based on the reported ICERs from high-income countries.

In summary, diabetes imposes a large economic burden on healthcare systems globally, and it is likely that this burden will continue to grow in the foreseeable future.

Fortunately, effective interventions are available to prevent or delay type 2 diabetes and diabetes-related complications. Evidence from high-income countries indicates that most evaluated interventions are not only effective but also cost-effective or cost-saving.

However, applicability of these conclusions in middle- and low-income countries will need to be confirmed by future studies. Widely implementing effective interventions, especially cost-saving interventions, could lower future healthcare expenditures associated with treating diabetes and its complications.

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Insulin was discovered in 1921, first used by an individual with type 1 diabetes in 1922 and then became widely available in the “Western world”. Challenges of access to insulin have been documented and these relate mainly to issues of availability, price and affordability, particularly in low- and middle-income countries.¹ For example, insulin was only available in 20% of facilities where it should have been present in Mozambique (in 2003) and in Mali insulin cost the equivalent of USD 11 per vial (in 2004).² In some high-income countries challenges with affordability have been reported.³ There is a need to examine availability in both the public and private sectors, as this will have an impact on cost to the individual.

Although about half of people requiring insulin have difficulties accessing it (estimated to be about 50 million people worldwide), there has been a relatively weak response from the United Nations, governments worldwide and civil society. To address this gap, Health Action International in collaboration with the University of Geneva and University of Geneva Hospitals and Boston University School of Public Health launched the Addressing the Challenge and Constraints of Insulin Sources and Supply (ACCISS) Study in January 2015.

Results to date

Insulin is included on the World Health Organization’s Model Essential Medicines List highlighting its importance as a medicine.³ The ACCISS Study found that of 100 National Essential Medicine Lists nearly all countries list both intermediate-acting and short-acting human insulin. This same report found that, in the literature, the proportion of people with type 2 diabetes treated with insulin is generally between 10% and 25%.

A review of the business literature found the global insulin market was valued at USD 20.8 billion in 2012. Novo Nordisk, Sanofi and Eli Lilly collectively have almost 90% of this market share by value. The remaining 10% is divided between 39 smaller insulin manufacturers. This dominance of the market is also reflected in trade data with Germany (Sanofi), Denmark (Novo Nordisk), and France (Eli Lilly) collectively representing 85-96% of total exports in 2004-2013. Approximately 50% of global imports of retail insulin were to the USA, UK, Germany, and Japan (2004-2013) and about 60 countries imported insulin from only one country for at least one year meaning that they are potentially vulnerable to any disruption in supply.

Unlike many medicines for cancer, HIV and other conditions, intellectual property is not a barrier to accessing insulin as there are no patents on any formulations of human insulin. Patents on currently available analogue insulins already on the market in the USA and Canada have expired or will soon expire. However, one issue of concern is the increase in patents on delivery devices.⁴
Different prices were identified for human and analogue insulin from government tenders and for people with diabetes in the public and private sectors. Table 1 shows the range and median prices of 10 ml of insulin in the different sectors. In comparing human and analogue insulin within the same sector, analogue insulin is at least 2.4 times more expensive than human insulin. Differences between the tender price and patient price in the public sector can be linked to various add-on costs. The add-on costs in both sectors (mark-ups, tariffs, taxes etc.) are being further investigated in 2016, but, looking at available data, the majority of countries have no import tariffs on retail insulin and the proportion of countries without tariffs has increased since 2004 from 52% to 77%. Value Added Tax (VAT) on insulin ranged from 0% to 24%. Average VAT levels were 8.3% in Organization for Economic Cooperation and Development (OECD) countries; 4.6% in non-OECD high-income; 7.0% in both upper- and lower-middle income countries; and 7.0% in low-income countries. These add-on costs, as well as wholesaler and pharmacy mark-ups and other charges in the supply chain, increase the overall financial burden on individuals.

What needs to be done?

The ACCISS Study aims to complete key work in the areas of understanding biosimilar regulations and the challenges faced by biosimilar insulin manufacturers in expanding market reach. Data on insulin availability, prices and add-ons, will complement existing price data to give a fuller picture of the price and availability of insulin. This will help inform interventions to ensure that countries and individuals are accessing insulin at the lowest price possible.

The ACCISS Study also made a call to action on the issue of access to insulin, which included:

- Funding for innovation in the delivery of diabetes care and insulin;
- Ensuring that insulin is included in Universal Health Coverage benefit packages (as the Sustainable Development Goals include the push for Universal Health Coverage);
- Development of a regulatory framework for biosimilars and insulin, that ensures access to quality-assured, safe, efficacious, and cost-effective insulin;
- Guaranteeing human insulin in vial form will

Table 1 - Median prices per 10ml of insulin at different levels of the health system (USD)

<table>
<thead>
<tr>
<th>Price per 10ml 100 IU/ml</th>
<th>Public sector</th>
<th>Private sector</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Tender price human</td>
<td>Tender price analogue</td>
</tr>
<tr>
<td>Minimum</td>
<td>2.24</td>
<td>6.88</td>
</tr>
<tr>
<td>Maximum</td>
<td>43.51</td>
<td>81.67</td>
</tr>
<tr>
<td>Median</td>
<td>5.99</td>
<td>34.20</td>
</tr>
<tr>
<td>Ratio analogue: human</td>
<td>5.71</td>
<td>5.89</td>
</tr>
</tbody>
</table>
As we approach the centenary of Leonard Thompson first receiving insulin in 1922, all those active in the area of diabetes owe it to those in need of insulin to act on this global issue.

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Additional resources
For those interested in the topic the ACCISS Study organised a panel discussion on the issue of access to insulin. The video is available at: http://haiweb.org/what-we-do/acciss/whd_insulin/. In addition, the detailed profiles from this research can be found at: http://haiweb.org/what-we-do/acciss/research-findings/.
School is a vital part of life for children, who spend up to a third of their time in varying educational institutions from the age of 4 to 5 years through to young adulthood. Children and adolescents who develop diabetes, either type 1 diabetes (T1D) or type 2 diabetes (T2D), must manage their chronic health condition not only through diabetes self-management strategies with families and friends, but also in the complex and changing setting of school. While school for most individuals is a supportive and nurturing environment, many healthy children find school difficult with pressures around education, relationships and social development. The addition of diabetes may add an enormous burden to a negative experience of school for some children, and may raise issues for the child, their parents and the school and teaching and school staff. This article looks at the impact of diabetes on school performance. We also describe the Kids and Diabetes in Schools (‘KiDS’) project that aims to foster a supportive school environment to create a better understanding of diabetes by children, their families and school staff with the aim of optimising the experience of school for young people with diabetes.

Diabetes and cognitive function

Along with academic achievement, primary and secondary education for school children and adolescents aims to promote maturity and cultivate many other aspects of personal development. Academic achievement has a major impact on measurable education performance with an effect on future employment and life opportunities as an adult. The effect that diabetes in childhood has on cognitive development has been of major concern since the start of treatment with insulin.

Persistent hyperglycaemia over several years after diagnosis is linked strongly to the risk of micro-vascular complications such as retinopathy, neuropathy and nephropathy: children who are diagnosed early in life have a greater risk of time associated abnormal glycaemia risk. Therefore, younger children with type 1 diabetes are at greater risk for the long-term complications of diabetes. In the 1980’s and 90’s, this prompted a radical rethink in the approach to diabetes in the young. “Intensive insulin therapy” and intensive glucose control (a glycated hemoglobin (HbA1c) level less than 7%) were promoted in order to minimise the development and severity of later vascular complications. In higher income countries this approach has been extended further with the use of insulin pumps and continuous glucose monitoring (CGM). However, even in low- and middle-income countries with poor healthcare resources, there is often a need to manage diabetes during the school day, either with the administration of insulin injections, monitoring of blood glucose and overseeing appropriate nutrition. This often places an enormous burden on school staff who need to understand diabetes in children and adolescents and undergo training in the practical aspects of diabetes management.
School staff may be reluctant to take on these added tasks for the child with diabetes. It is important to reassure them with simple education on diabetes management and how to assist the student with diabetes should complications or adverse situations arise in the school setting. School visits by an experienced paediatric diabetes educator to educate and inform can be essential in these circumstances. Unfortunately, the adoption of intensive glucose control may result in an increased risk of developing frequent and/or severe hypoglycaemic episodes, with marked variability in blood glucose levels. These episodes result in cerebral hormonal and metabolic disturbances that may carry a high risk of the development of diabetes-related cognitive dysfunction.¹,²

T1D has been reported to affect various components of cognitive function in adults - intelligence, attention, psychomotor speed, cognitive flexibility, and visual perception.³ However, the reported effect on these cognitive functions, for the majority of small numbers affected, is relatively small in magnitude, with mental slowing being the fundamental cognitive deficit associated with T1D.⁴ Toddlers and children with T1D also show similar effects on cognitive dysfunction.⁵,⁶ These effects emerge early in the course of poorly controlled diabetes with defined effects, particularly on intelligence and psychomotor speed. They appear to be more pronounced in children diagnosed at a young age, and the brains of children may be more susceptible to the marked variation in blood glucose particularly under seven years of age. This age group is reported to be at a higher risk of developing more severe cognitive deficits than those who develop diabetes at an older age.⁷ It has also been reported that in adolescents diagnosed before age six years showed clinically significant impairments in a wide range of cognitive domains, compared with only 6% of those diagnosed later, and 6% of people without diabetes.⁸

There is concern that erratic blood glucose control particularly in very young children diagnosed with diabetes (<7 years) does affect cognitive function, and although this may be relatively minor based on standard assessment scales, it raises the concern that the overall impact on schooling may be diminished in people who develop diabetes early in their youth.

**School performance**

What then is the effect of having diabetes on school performance? The answer to this question is difficult, in part because there are a limited number of well-conducted studies.

Perhaps more importantly, it is extremely difficult to tease out the effect of diabetes on brain function and academic achievement itself from the impact of living with diabetes, which brings with it many psychological and social issues that are known to affect school performance.
Dalqhuist and her colleagues from Sweden linked the Swedish Diabetes Registry to national education information data to relate diabetes to school outcome, based on the leaving marks at the end of secondary school education (~16 years age). The mean numerical school marks for teenagers were slightly, but statistically significantly, lower than those of the non-diabetic children, with the lowest scores among children with diabetes diagnosis before the age of 2 years, although this did not reach significance. In a further analysis of the linkage, they determined that diabetes in childhood had a statistically significant negative effect on final grades at 16 years of age in compulsory school and theoretical programmes in older young adults (age 19 years) in upper secondary school. Again, children with early-onset diabetes (0-4 years), suffered a significantly greater disadvantage as a result of the disease in compulsory school. In terms of later life and employment, individuals with diabetes at age 29 years were less likely to be gainfully employed however this was not statistically significant. Prompted by these findings, the group from Perth, Western Australia examined the school performance of children with T1D in comparison to their peers, exploring changes over time, and the impact of clinical factors on school performance. Two important findings emerged; firstly, following adjustment for confounders (carers’ education and school attendance) no difference was observed between those with T1D and their peers across any of the educational domains analysed. Secondly, an association of moderate size was observed between persistently raised blood glucose control and poorer school performance, but not hypoglycaemia described in the clinical records. T1D was associated with decreased school attendance (~ 3% fewer days attended per year), which has been noticed in other centres. It appears, therefore, from limited observations that, overall, having diabetes can negatively influence school performance in some children and adolescents, by both affecting cognitive functioning and behavioural development and also social adaptation. However, on average this appears to be a relatively small effect. Therefore, the school experience and ultimately the performance of many children will be as expected for their family and cultural background. However, for some children and teenagers, as they progress through school, the impact can be massive with major difficulties. This effect of diabetes is mediated through several components: hypoglycaemia (especially in children diagnosed before they enter primary education), overall poor glycaemic control, loss of school time, practical interference with
with school activities, social isolation, lack of self-esteem and conflict with family, peers and teaching staff.

Caring for diabetes in school

Schools play an important role in prioritising safety, and protecting rights of children with diabetes. However, for many children and their families the lack of knowledge among the school teaching staff about diabetes can cause isolation, discrimination and bullying of the child. Adequate and appropriate care of diabetes needs to continue for children and adolescents in the school setting, and this relies on acceptance of the diabetes by teaching and school staff as well as awareness of the issues around diabetes management.

Many high- and middle-income countries have developed education and advocacy information for their local schools and regional and national education authorities. This is used by health professionals to support schools in caring for the child with diabetes in the natural school environment. Visits to the school by diabetes educators and nutritionists are routine, not just for instruction and guidance of individual children with diabetes, but for general information sharing and advocacy. While most schools, particularly small primary education schools will have just one child in their student population, larger secondary schools, particularly in regions of high incidence of T1D and/or T2D, may have several children with diabetes enrolled. The school also becomes a major agent in health promotion and public health matters, relating particularly to the prevention of obesity and T2D, both in the school population and later adult life.

Several countries have introduced a legal requirement that schools must be able to appropriately support children with diabetes, necessitating that school staff are adequately trained in insulin administration and blood glucose monitoring. However, for the majority of schools who take on active management of diabetes, it relies on the goodwill of teachers and other school staff, as well as assistance from the child’s family to support the child with diabetes, as well as effort to support the school by the child’s family. Organisation and effort is needed by all concerned to make this work well in the child’s interest and, by and large, all parties concerned can reach a successful plan. The plan needs constant review and updating as the child progresses through school and until the children are sufficiently able and mature to take on the practical role themselves.

Unfortunately, many countries in the world do not have support staff, either from the clinic or the school, nor information material readily to hand, and struggle with constant update of information and support material. The lack of development of material produced in various languages is also a major hindrance in producing practice-based information appropriate for the
required cultural context. Health professionals and school staff are therefore at a major disadvantage in supporting the child.

In March 2005, IDF released a position statement on the Rights of the Child in the School declaring that children have the right to manage their diabetes without being excluded or discriminated against in the school setting.\textsuperscript{12} The position statement calls for all children with diabetes to have an individualised diabetes management plan developed in a collaborative approach with healthcare providers, school staff and the family. This position statement is currently in the process of being updated and a new version will be released by the end of 2016.

Examples of numerous guidelines and educational materials on diabetes in schools for teachers, parents and children are available from many countries. Despite these initiatives, evidence suggests that many children and adolescents with diabetes continue to face barriers to education, and endure discrimination and stigma, in particular in low- and middle-income countries. School and national policies frequently do not recognize the special needs of a child living with diabetes. Lack of assistance needed to monitor blood glucose, administer insulin and treat emergency situations (e.g. hypoglycaemia) can result in the child being excluded from school activities. Some schools believe they reserve the right to deny access to a child with diabetes and even when allowed to matriculate, some children are barred from participating in extracurricular activities. Ignorance and misconceptions about diabetes held and fostered by school staff, fellow students and parents of other students are often at the root of such stigma and discrimination. Children and adolescents feel that they are treated differently in school because they have diabetes, leading some of them to hide their disease. Furthermore, the school may not provide clean and adequate space to support self-management tasks such as testing blood glucose, storing snacks, injecting insulin or storing equipment for injections or lancets for blood glucose testing. A recent review identified education of staff and peers as one of the key priority areas to improve the care of children with T1D in the school setting.\textsuperscript{13}

Strategies are therefore required to help children and teenagers and their families to cope with diabetes in school, and also to inform and assist the teaching and administrative staff responsible for the pupils with diabetes. If a child with diabetes, at whatever age, has a “good start” at school, it will positively affect
their future ability and capacity to manage their diabetes for life.

Angie Middlehurst is the Education Manager for IDFs Life for a Child Programme.

Daniela Chinnici is the IDF Project Coordinator for The Kids and Diabetes in schools (KiDS) project.

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References

KiDS: an international standard for supporting children with diabetes in school

To support intensive management of diabetes in school there is a need to improve knowledge and education in teaching professionals. In September 2013, in collaboration with the International Society for Paediatric and Adolescent Diabetes (ISPAD) and Sanofi Diabetes, IDF launched the Kids and Diabetes in Schools (KiDS) project to foster a school environment that creates a better understanding of diabetes and support for children and adolescents with diabetes. The KiDS project has been designed as a worldwide initiative to provide a culturally relevant tool for young people with diabetes and their teachers to optimise the school experience, in a variety of media formats and languages.

A key component of the KiDS project is to specifically educate teachers and those who interact with children at school about diabetes and its management (differentiating T1D and T2D), as well as the risk factors for T2D and the benefits of healthy lifestyles.

The aims of this multi-stakeholder programme are:

• To foster a safe and supportive school environment for children with type 1 diabetes to manage their diabetes and prevent discrimination;

• To raise awareness about type 2 diabetes prevention and the benefits of healthy food choices and physical activity among school-age children.

Feasibility studies were established in India and Brazil in 2013, with buy-in from local health practitioners, lay representative bodies, education representatives, public health organisers and local and regional governments.

The pilot intervention consisted of the development of a ‘Global Diabetes Information Pack for Schools’ supported by an international multi-disciplinary technical advisory committee. The pack is composed of modules for teachers, parents of a child with diabetes, parents and children (6 to 13 years). This Global Pack has been adapted and tailored to meet local needs and be culturally and socially relevant and acceptable. In the pilot intervention, 1,393 school staff and 38,000 students were trained in India and Brazil to use the Diabetes Information Pack, followed by educational sessions in class. Centralized training for school director and for nutritionists took place respectively in Delhi and Sao Paolo. Following suitable training, the pack was widely distributed through the implementing partners’ online network and social media. The pack is not intended to replace the advice of healthcare professionals and should always be accompanied by educational sessions.

To determine the impact of the project, a qualitative evaluation was performed in 10 schools in Brazil and India.13 Three main themes emerged from the preliminary results of introducing the KiDS project:

• Increased knowledge about diabetes by education staff;

• Fostered awareness about diabetes and openness to discuss diabetes;

• Created a consciousness not to restrict the learning and other school opportunities for children with diabetes.
High satisfaction with the KiDS training and resources was also reported by families and teaching staff. In a number of cases, schools implemented measures to encourage healthier food choices and more physical activities. The results of the project confirm the effectiveness of a simple intervention in improving the experience of children with diabetes in schools and in promoting healthier lifestyles. They emphasise the need for a comprehensive diabetes education programme in schools. The KiDS project demonstrated success in two different settings suggesting it can make an important contribution to addressing the needs of children and adolescents with diabetes in school at a global level.
HOW DOES THE COST OF DIABETES AFFECT ME AND MY FAMILY?

People with diabetes incur medical costs that can range anywhere from 2 to 5 times greater than people living without diabetes. The extent to which they have to bear these costs or a proportion of them will depend upon the health system where they live and receive care. These costs are not dependent upon one single medication, treatment, surgery or therapy taken over the course of weeks or months; the treatment and therefore, the costs incurred are for life. People with diabetes require more medical visits, quarterly diagnostic testing, specialist care, expensive life-saving medications, and a range of devices including at least one basic blood glucose testing meter and test strips. People with diabetes also have a higher degree of being admitted to the hospital, and are often at risk for complications, and other health problems, many of which also are autoimmune disorders.

We asked people from around the world living with diabetes how the cost of treating and managing the condition affected them and their families. Among all their stories is one common thread, specifically difficulties related to accessing medical care and treatment and the fear and anxiety related to running out of life-saving medicines and supplies, such as insulin.

Many discuss the burden on their families and the financial sacrifices made for what is often, very basic diabetes care. Contributors from Western economies mention insecurities about the ability to purchase and meet guidelines in order to keep devices like insulin pumps or continuous glucose monitors which require thousands of dollars, or coverage from government health services/premium insurance companies.

While these new technologies are key to meeting intensive insulin therapy targets, they are not available to most people living with diabetes today. Mostly our contributors worry what they will be forced to do if there is an increase in medication price, loss of a job or when receiving charitable donations, fearing the medical assistance may stop.

Although we asked our contributors to focus on costs in real-terms, everyone mentioned “indirect costs” such as lack of opportunity, early retirement, exiting school early, adjusting residence for better treatment or travelling long distances for care. The price of living with diabetes also included a general lack of understanding about diabetes from the public leading to discrimination, and bullying, often resulting in despair and isolation.

Our hope is that the voices on these pages resonate with our readers, and foster a greater understanding of the financial and psychological burden of living with diabetes in our world today.
I COULD ONLY AFFORD TO TEST MY BLOOD GLUCOSE ONCE A MONTH

I am an 11-year-old girl living in Thissamaharama, Sri Lanka which is a five-hour drive from the capital city of Colombo. I was diagnosed with type 1 diabetes at the age of one and a half in 2007. The nearest general hospital to me is about 45 minutes drive away where I have been seeing my consultant paediatrician once a month ever since my diagnosis was made. I receive my basic medical supplies such as insulin free of charge from this hospital as the National Health Service in Sri Lanka is free. However, the hospital was not able to issue me a glucometer (for blood glucose testing) and strips. So instead of checking my blood glucose on a daily basis, I was only able to do so once a month during my trip to the hospital clinic.

In early 2016, my paediatrician referred me to the Diabetes Association of Sri Lanka (DASL) in Colombo for further follow up and management of my diabetes. At the association, I am given syringes, glucometer, strips and lancets free of charge. Also, my medical reviews are covered for free at DASL.

My father is unemployed and has been disabled for 30 years following an accidental fall from a coconut tree. I have four sisters, but our mother left us for another man when I was seven years. Two of my older sisters are married and they live in separate homes from me. My third sister is currently in a probation home for young mothers. My younger sister (6 years old) and I live at home with my father. Our total family income is 6,000 Sri Lankan Rupees [USD 40] a month which includes government contributions. We live in a house which was donated to us by kind foreigners as our old house was destroyed by the December 2004 Indian Ocean tsunami that hit our area.

DASL Medical Team Observations: Miss Thilini is from a poor socio-economic background. She has no close relatives and no one who will offer financial assistance. Despite these financial, medical and emotional constraints she seems to be enjoying her sport activities and attends school regularly.

She was initially on rapid acting insulin however; we have now changed her insulin therapy to a pre mixed preparation. Her latest blood result is an HbA1c of 8%.

Miss Thilini is an 11 year old school girl who was diagnosed with type 1 diabetes in 2007 at age of 1 1/2 years.
A FIRST AND THIRD WORLD COMPARISON

My 15-year old daughter Alexandra has had type 1 diabetes for nearly eight years now. She was diagnosed on June 25th, 2008, at the age of seven, when we lived in Ghana, West Africa.

We had no insurance, but as retired American expatriates, we were “rich enough” to afford insulin, syringes, lancets, a blood glucose meter and glucose strips. Our initial outlay for supplies cost our family about 133.50 US dollars (all other costs in US dollars); the (imported) blood glucose meter and strips were 102 dollars, insulin was 20 dollars and a bag of 10 insulin syringes cost $1.50. Later on, my daughter was switched to more expensive analogue insulin while doing multiple daily injections (MDI). The cost for buying five insulin pens each was about 100 dollars and 100 pen caps cost another 20 dollars.

Today, living in the US, where my daughter has medical insurance, I can see that the costs for the same insulin are astronomical, comparatively. In some cases, five times as much as we paid in Ghana. In my mind, that makes absolutely no sense. We lived in a third world country, able to obtain the same exact product, at a fraction of the cost - without insurance!

For the average Ghanaian family, diabetes supplies, albeit life-saving, are financially out of reach. For the average American family, in the absence of medical insurance, the same thing applies.

I am thankful my daughter has insurance. But if we did not, we’d move back to Ghana, in order to keep my daughter alive. Given the rising costs of insulin, we’d have no other choice.

Barbara Zigah, the mother of Alexandra who was diagnosed with type 1 diabetes in 2008 at age seven years.

MY MOM QUIT HER JOB TO CARE FOR ME

When people first heard about my type 1 diabetes, the first thing that popped up in their minds would be the burden on my family, financially, and the cost of my medical necessities. No doubt, it is clear that my life with diabetes forces my family to spend a huge amount of money.

My family is not so affluent and this is not a favourable circumstance for the ideal management of type 1 diabetes. My family spends a quarter of our income on buying basic medical necessities for me. In addition, my mother must purchase high glycaemic foods and snacks to protect me from severe hypoglycaemia. This extra cost is another heavy burden because my mom was forced to quit her job to take care of me. Now, she has less money to spend.

For me, a life with type 1 diabetes has other implications that are as difficult. At first, my schoolmates thought I was sick with influenza, but when they discovered I had type 1 diabetes, they jeered at me and saw me as a monster. I became disheartened. I began to hate myself. I felt bizarre and peculiar in other peoples’ eyes.

There are other issues, too, that I consider a great cost. It is hard to get over the sickness when having a hypoglycaemic episode or when my blood glucose runs high. I become dizzy and tired, and the situation lasts for quite a long period of time. When I encounter these episodes, I often need to lie down. This obviously affects my daily routine.

A life with type 1 diabetes costs more than most people can guess.

Gabriella Chong, 16 years, diagnosed with type 1 diabetes in 2005, Hong Kong
WHEN I WAS 13 YEARS, I COULDN’T GET INSULIN

My name is Ines, and I was born on December 20, 1989 at Nyakabanda/Kigali in Rwanda. I developed type 1 diabetes when I was 10 years old. When I was diagnosed, I didn’t really understand the burden of diabetes. I had one parent who was taking care of me, but when she died after three years, I couldn’t take care of myself and had no one to help. My diabetes started to get worse. My blood glucose levels were always high because I couldn’t get insulin.

After a while I heard about the Rwanda Diabetes Association (RDA) and I was told to join. At that time, I started getting my insulin for free, but because I didn’t really understand the treatment and the importance of insulin in my body, I took my insulin sporadically.

After some time, I started getting really sick. In 2012, I was so sick that I had to drop out of university that I just started. At that time, the doctors told me that I had a serious kidney problem and it was a complication of my type 1 diabetes because I had not been taking care of myself. I started looking for information on diabetes and that is when I really understood that I have always underestimated my situation.

With my kidney problem, I got even worse because I was unable to pay for my insulin and kidney medication. One day I met Jason Baker of the Marjorie’s Fund at the RDA, and he was talking to young adults with type 1 diabetes (24 years plus) about type 1 diabetes. I decided to reach out to him and told him my story which I am glad I did! Jason was compassionate and promised to try to help in any way he could. Since that time, he has been helping me with medication bills.

Now that I better understand diabetes and know the importance of insulin and how it is critical to get the needed insulin in my body, I took control of my blood glucose levels. I have made it my mission to help and educate other young people with diabetes so that not one of them will be like me and realize the situation too late.

Ines Mukarwego, 27 years, was diagnosed with type 1 diabetes in 1999. She lives in Kigali, Rwanda.

I STILL FACE DISCRIMINATION FROM MY NEIGHBOURS AND RELATIVES

My name is Amitha and I’m 24 years old. I was diagnosed with type 1 diabetes at the age of twelve years in 2004. I have been a registered patient at the National Diabetes Centre (NDC) in Rajagiriya, Sri Lanka since June 2014.

My father is a farmer and I live with my two brothers and my parents at home. We live in a small town called Akurasse which is a four hour
bus ride from the capital city of Colombo. My eldest brother developed difficulties in walking when he was young and today, he is completely bed-bound. He also lives with type 1 diabetes.

A few years ago I developed the same symptoms as my brother. We were both investigated and subsequently treated for Vitamin B12 deficiency and Friedreich’s ataxia - a rare disease that causes progressive damage to the nervous system. In support of our need for treatment, donations were given to us by the Diabetes Association of Sri Lanka (DASL).

My second brother has not shown any symptoms for any disease so far. He is a driver and works full-time. My mother stays at home as she is the main carer for us. Our monthly family income is approximately 20,000 Sri Lankan Rupees (140 US Dollars). I receive all medical supplies and travelling money from the NDC.

I started a Higher National Diploma in Information Technology at a Vocational Training Centre close to my hometown. I had to discontinue this course of study halfway through the programme as I found it difficult to travel to my classes. Even so, I completed a certificate course in Microsoft Office. Even though I finished school, I had to face a lot of discrimination and bullying throughout my time there. Today, I still face discrimination from my neighbours and relatives. However, I can manage myself around the house and I’m independent with my activities of daily living.

**DASL Medical Team Observations:** Amitha is a very pleasant girl who comes for her medical reviews and supplies every three months with her father. She has been given insulin, syringes, glucometer, strips and lancets from DASL. We are aware she has a lot going on in terms of financial and emotional stress. However, she always manages to keep her wits about her and never ceases to smile.

When she initially came to us, she was on very high doses of a pre mixed insulin preparation. We have managed to cut it down and have gained a rapport with her. We feel she looks forward to her visits here. Her latest blood reports reflect this as they have been satisfactory, with an HbA$_{1c}$ of 8.3%.

_Amitha Udayangani, 24 years, diagnosed with type 1 diabetes at age 12. She lives in Akurasse, Sri Lanka._

**FEAR OF LOSING MY INSULIN PUMP**

Kia ora, welcome to New Zealand, land of the kiwi, made world famous by the movie, Lord of the Rings. There are approximately 25,000 people with type 1 diabetes living in our developed country and in some ways we’re humbled by the fact we have funded access to life-saving supplies. On the other hand, people with diabetes in New Zealand are absolutely frustrated about the neglect in our medical care.

The situation with our glucose meters is a fine example of how we’re overshadowed. New Zealand suddenly went sole-supply and major brands rapidly exited the country - all our great blood glucose meters disappeared and are no longer funded. The uproar that ensued made no difference. It may seem like a trivial issue, but my sense of security was rattled and this has been a significant step backwards.

On a positive note, the most incredible advance is that we now have government funded insulin pumps, but the excitement stops there. The qualifying process is unjust and keeping designated funding is stressful. In order to get an insulin pump, you need to have a diagnosis of hypo-unawareness or be written off as having poor control. If you have great blood glucose levels, it can be harder to get funded. What creates a great deal of fear are the diagnostic
test results requirements needed to keep my pump. I must have three consecutive HbA1c results below 7%, precisely three months apart before May next year in order to keep my pump. I worry about this every single day; I constantly check my levels and feel emotional if my blood glucose is high because again, like my old glucose meter, I don’t want to have my pump taken away. My HbA1c is assessed after nine months, then two years, so it’s a lot of pressure. I’m always told that I’m not defined by numbers but obviously this isn’t the case here. We also know that absolutely anything can affect our glucose levels, including stress. I’m just finishing my Masters degree, so there are times when my eating schedule is erratic and my blood glucose levels can be unpredictable. I was panic stricken for those first nine months about whether I was going to be able to keep my pump.

Finally, I had a glimmer of hope. The Ministry of Health released a five-year plan entitled “Living Well with Diabetes.” Their promise was to “maximise the benefits of technology.” Could my dream of continuous glucose monitors (CGM) (not available) and improved BG meters be coming? Unfortunately, no. The 33-page document has a total of 1.5 pages dedicated to type 1 diabetes, with little mention of the devices so vital for optimal diabetes management.

For four years running we’ve been voted ‘the best country’ in the world and in some areas, we are. In a diabetes context, we’re not quite there yet.

Carrie Hetherington, 27, diagnosed with type 1 diabetes in 2008, Auckland, New Zealand

RELYING ON FAMILY TO COVER THE COSTS

I live in Beijing and have lived with type 2 diabetes for 29 years. I was diagnosed with type 2 diabetes at age 50, nine years before I retired from my middle school teaching position. In those nine years, I was treated with oral anti-diabetic drugs. Soon I needed to rely on insulin injections and have taken insulin for the past 18 years.

Over the years, I have developed microvascular complications (nephropathy, retinopathy and neuropathy) and I also suffer from many other chronic diseases, including hypertension, coronary heart disease, chronic bronchitis, and osteoporosis. The average salary for a teacher when I was teaching was Chinese Yuan Renminbi (RMB) 600-700 (92-108 US dollars) per month. Unfortunately, I retired five years earlier than the normal retirement age because of my type 2 diabetes.

I spend around 500 RMB (77 US dollars) each month on blood glucose strips due to my unstable blood glucose levels. I went to the
endocrinology outpatient department every month although the cost for my examination was covered by Medicare. I have relied on support from my parents and family for a significantly large proportion of my medication costs.

After the Chinese government began its current medical insurance policy, the level of reimbursement for outpatient costs rose to 20,000 RMB (3,075 US dollars) per year. In my case, I have to spend all the insurance money on my medicines, including insulin. I visit the outpatient department once per month but I usually finish the 20,000 RMB by October, which means I have to spend my own money for the rest of the year.

Mrs Zhu, 79 years, diagnosed with type 2 diabetes in 1987, Beijing, China

WORRY IS A BIG PART OF MY LIFE WITH DIABETES

Over the 30 years I have lived with type 1 diabetes, the fear of not having enough insulin, test strips and not being able to keep my continuous glucose monitor (CGM) creates a lot of stress. I also worry about adequate health insurance to cover diabetes care even though I currently have coverage. The fact that my life depends on insulin therapy has created this anxiety and fear. Maybe in my case it is unnecessary as I don’t live in a third world country; maybe some people would judge my worry as irrational, but I don’t think so.

I remember when insulin R or N was about 20 US dollars per vial in 1985. It was also available without a prescription. Blood glucose test strips have always been expensive, but insulin has gone up more than 15 times in price over the 30 years I’ve lived with type 1 diabetes. I am fortunate that my insurance covers insulin, but I feel concerned for people who do not have access to insulin therapy. People should not be dying because they can’t afford insulin—a drug that has been around for close to 100 years!

I was recently diagnosed with rheumatoid arthritis (RA) which requires very costly medication. Like type 1 diabetes, rheumatoid arthritis is an autoimmune disease. When you have one autoimmune illness, you are much more susceptible to getting another. RA has given me another monthly cost for medication and care. Costs add up fast when you take so many medications like I do. Changes for self-employed people (at least in New York state) under Obamacare have had both positive and negative effects for me. There is no out-of-network coverage available to people who buy their own insurance. This makes it extremely costly to see many doctors that I have used for years who do not accept my insurance now.
Aside from financial worry and insurance coverage, there are emotional costs which I have had to work on overcoming. I remember how fearful I was when I started my first job after college. I was taking long-acting insulin at the time (NPH) and sometimes, during meetings close to lunchtime, I would start dropping very low. I didn’t want my boss to know at first but I also didn’t want to pass out either. It created a lot of mental stress.

Risa Pulver, 50 years, diagnosed with type 1 diabetes in 1985, USA

SELLING OFF FARM ANIMALS TO COVER DIABETES COSTS

My name is Jonathan Mutabaruka from Rwanda. I am 52 years old and the father of five children. I was diagnosed in 2010 with type 2 diabetes.

After diagnosis, I was prescribed tablets (metformin and glibenclamide) to improve my blood glucose which didn’t help much because at the next clinical visit after one month my blood glucose was high. I was put on insulin therapy which I am still using today.

After my diagnosis, I started a long and very hard journey. It was emotionally difficult for me and my family to cope with this chronic illness, and the cost to take care of my health took a huge toll on my family’s financial situation.

Before diabetes, our economic situation was good because I could cover all the basic expenses for my family. I live in a village and my source of income is farming and breeding. From the time I was diagnosed with diabetes, I had to sell one of my breeding animals in order to pay for diabetes consultations and medication fees. After a while, I just ran out of animals to sell. With this cost for my health, it became nearly impossible for me to meet my children’s needs including their school fees. Because of the medical costs related to my diabetes, I feel my children are not having an enjoyable life. We had to cut down on entertainment costs and purchases enjoyed by the family. I feel like my children are missing out on their childhood. Recently, my daughter told me that she is going to study to become a doctor so she can cure me of my diabetes. Fulfilling my family’s dreams is becoming out of reach because my productivity reduces over time while my diabetes needs are growing day after day.

Thanks to the “Mutuelle de Santé” (local health insurance in Rwanda), I am getting some of the help I need at a reduced price. It is still hard to afford everything, but at least there is hope.

Jonathan Mutabaruka, 52 years, diagnosed with type 2 diabetes in 2010, Rwanda
Don’t miss the chance to help shape the future of diabetes

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