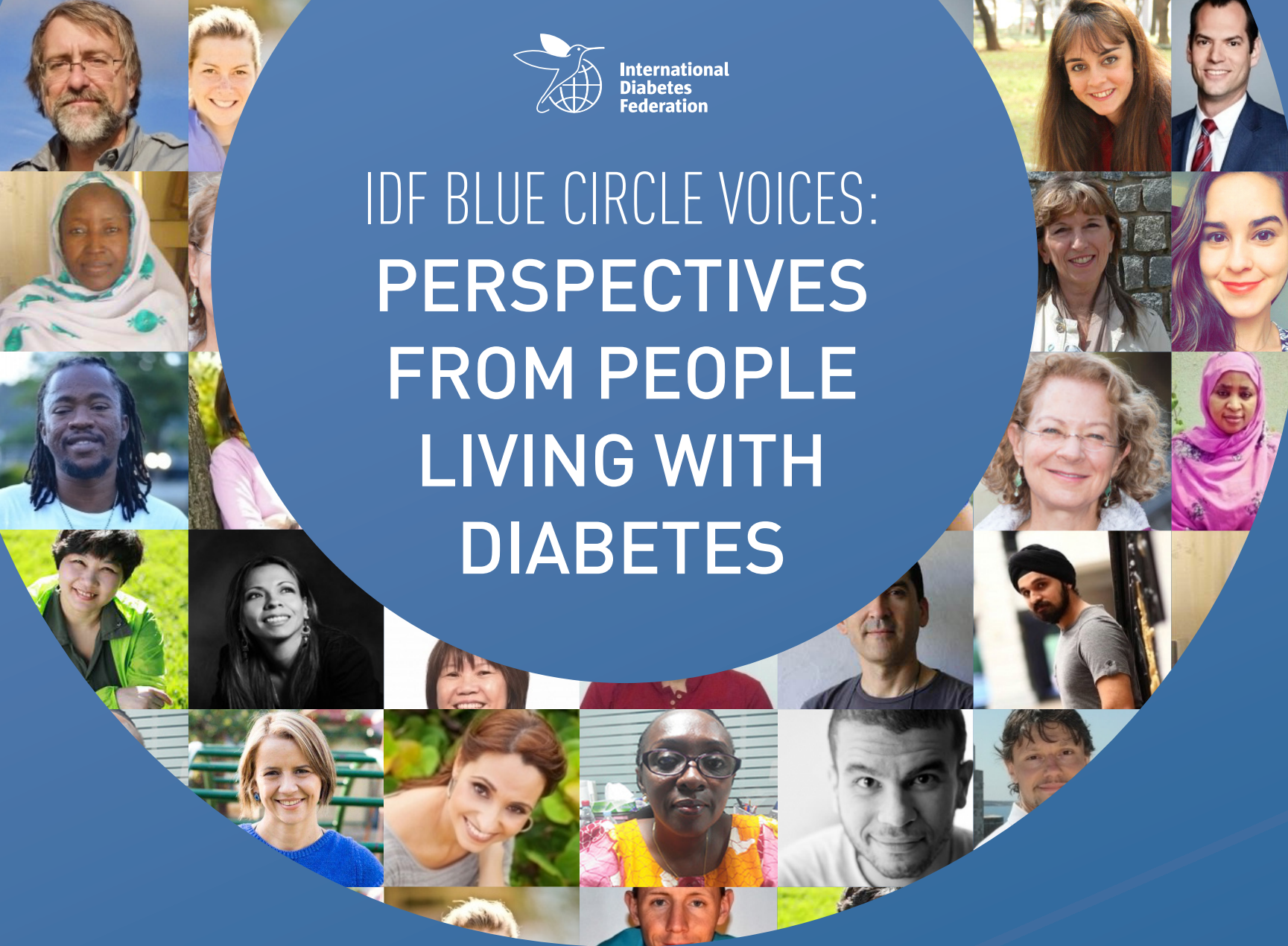




International  
Diabetes  
Federation

# IDF BLUE CIRCLE VOICES: PERSPECTIVES FROM PEOPLE LIVING WITH DIABETES



The International Diabetes Federation (IDF) is an umbrella organisation of over 230 national diabetes associations in 165 countries and territories. IDF is the Global Voice of People with Diabetes, representing the interests of the growing number of people with diabetes and those at risk. IDF has been leading the global diabetes community since 1950. IDF's mission is to promote diabetes care, prevention and a cure worldwide.

[www.idf.org](http://www.idf.org) | [advocacy@idf.org](mailto:advocacy@idf.org) | © 2017

## THE BLUE CIRCLE VOICES NETWORK

The Blue Circle Voices (BCV) is an IDF initiative that aims to represent the interests of people living with, or affected by, diabetes, through a worldwide network of members and other stakeholders. The BCV network draws upon the experiences of people with diabetes, acts as their global voice and provides them with an opportunity for expression. This network focuses on a variety of issues and challenges that people with diabetes encounter in our world today. More information about the network can be found here:

[www.idf.org/our-network/blue-circle-voices.html](http://www.idf.org/our-network/blue-circle-voices.html)

## BACKGROUND

Diabetes is one of the largest global health emergencies of the 21<sup>st</sup> century. In 2015, it was estimated that one in eleven adults (415 million) had diabetes worldwide. A further 318 million adults had impaired glucose tolerance, which puts them at high risk of developing type 2 diabetes in the future.

IDF estimated that in 2015, five million annual deaths were attributable to diabetes, more than those from HIV/AIDS, tuberculosis and malaria combined.<sup>1</sup>

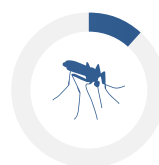
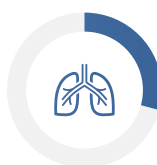
In addition to having a substantial economic impact on countries and national health systems, diabetes also places a large financial burden on individuals and their families due to the cost of insulin and other essential

In November 2016, IDF carried out its first consultation with the BCV network to determine the priorities of, and challenges faced by, people living with diabetes. More information on the results can be found here: [www.idf.org/images/site1/content/Highlights-first-BCV-Consultation.pdf](http://www.idf.org/images/site1/content/Highlights-first-BCV-Consultation.pdf). More than 80 BCV members from all seven IDF regions responded to this consultation, providing a broad picture of their key concerns and challenges, which are outlined in this document.

diabetes medicines and supplies<sup>2</sup> and poses a number of challenges relating to a person's daily life, emotional well-being and perceived quality of life.

In 2011, the UN and the international community held the first High Level Meeting on the Prevention and Control of NCDs, recognising the need to prevent the diabetes epidemic from growing. In 2013, all countries unanimously agreed on nine NCD targets to be achieved by 2025, including a 0% increase in diabetes prevalence. The urgent need to fight NCDs is also reflected in the Sustainable Development Goals adopted in 2015, with the overarching goal of reducing premature mortality from NCDs by 30% by 2030.

### Adults who died from diabetes, HIV/AIDS, tuberculosis, and malaria



# IDF'S CALL TO ACTION

IDF calls on all governments to honour their commitments to ensuring universal health coverage by 2030 and step up action to achieve the WHO target of a 0% increase in diabetes prevalence by 2025, for which only five countries were on track by 2016. IDF also encourages governments to take all other relevant measures to improve the health outcomes of people with diabetes, prevent the

development of type 2 diabetes and its associated complications and stop discrimination against people with diabetes. National governments cannot act alone, and therefore IDF also calls to account other stakeholders, including the private sector and international organisations, to support government actions. Some of the recommended courses of action are as follows:

## 1 Access and Affordability

- Reduce the cost of medicines and supplies through improved supply chain and procurement practices, the promotion of competition for multi-source products, and the development of equity pricing
- Improve physical availability in all settings including through investments in cold chain distribution
- Develop equitable insurance schemes

## 2 Education

- Improve education of existing health professionals on diabetes and other NCDs
- Promote the education of people with diabetes and their carers at the time of diagnosis and throughout their life
- Implement awareness campaigns to increase the knowledge of the general population about diabetes and how to prevent the onset of type 2

## 3 Type 2 Prevention

- Implement locally-adapted comprehensive lifestyle programmes, especially for people at risk
- Encourage fiscal policies and other public health measures to promote healthier diets
- Consider the use of cost-effective medication strategies for type 2 diabetes prevention, alongside comprehensive lifestyle programmes

## 4 Discrimination

- Adopt the principles of, and disseminate, the *IDF's International Charter of Rights and Responsibilities of People with Diabetes*
- Develop information campaigns and tools to increase diabetes awareness and reduce stigma
- Provide teachers and school staff with the knowledge and tools required to stop discrimination against children with diabetes

<sup>1,2</sup> IDF Diabetes Atlas 7th Edition, 2015

# THE PRIORITIES OF PEOPLE LIVING WITH DIABETES

## Priority Issue 1 **Ensuring access to, and affordability of, medicines and care**

### THE BCV VIEWS

The ability to access prescribed medicines and devices and pay for them is, by far, BCV members' main concern. This highlights the fact that, despite national commitments to ensure universal health coverage by 2030 (one of the UN Sustainable Development Goals agreed upon in 2015), many governments across the world still do not offer reimbursement for essential diabetes care, or are unable to guarantee access to essential diabetes medicines at the point of use, even when theoretically available. Limited access to medicines and devices is an issue across the world, irrespective of income levels and settings; even in the most affluent societies, this is at times a problem. Access to medicines and primary healthcare is also a significant issue worldwide, especially in rural settings.

The vast majority of our diabetes patients face huge financial problems and many other issues with access to care.

BCV member from Morocco

### THE ISSUES

The lack of access to affordable essential diabetes medicines and care is a huge challenge, putting people at risk of developing severe and costly complications, and premature death. IDF estimates that many of the five million annual deaths attributable to diabetes could be prevented with proper access to medicines and supplies. People with diabetes require medicines to control their blood glucose levels, blood pressure and blood lipids, supplies and equipment to monitor their blood glucose levels, and a healthcare system that is able to provide integrated and comprehensive care to all parts of the country. A recent IDF publication, *Access to Medicines and Supplies for People with Diabetes – a global survey on patients and health professionals' perspectives*, showed that only one in five low-income countries had access to essential diabetes medicines<sup>1</sup>, which compares with four in five high-income countries.

<sup>1</sup> WHO Essential Diabetes Medicines: short-acting insulin, intermediate-acting insulin, gliazide, glucagon and metformin. ([http://www.who.int/medicines/publications/essentialmedicines/20th\\_EML2017.pdf?ua=1](http://www.who.int/medicines/publications/essentialmedicines/20th_EML2017.pdf?ua=1))

Close to half the BCVs have access and affordability issues

## Priority Issue 2 **Improving diabetes education for healthcare professionals and people living with diabetes**

### THE BCV VIEWS

BCV members consider diabetes education provided to people living with diabetes and general awareness-raising campaigns to be at best inadequate, or even at times misinformed. Education provided to carers and relatives is regarded as being of even poorer quality, and not allowing them to ensure adequate care. Diabetes education for healthcare professionals, meanwhile, is broadly seen as being adequate. Nevertheless, many BCV members stress the need for the education of primary care professionals to be improved, especially in the light of ever-evolving treatment opportunities.

Everybody talks about education as being a key factor in improving the management of diabetes, but nobody does anything concrete about it.

BCV member from Chile

### THE ISSUES

Best practice medical care for diabetes throughout the world recognise education as an essential component of quality diabetes care that achieves positive health outcomes<sup>1</sup>. Diabetes education is all the more important in that the management of this chronic disease, where multiple daily decisions are required to balance food, physical activity and medication, is handled primarily by the people living with diabetes themselves and/or their carers. Additionally, care requirements will change during an individual's life cycle and diabetes disease process. Successful self-management requires comprehensive and personalised initial diabetes education both at the time of diagnosis and throughout a person's life course. Special attention needs to be directed to education for the carers of people with diabetes, particularly those who cannot understand or undertake the requirements for self-management<sup>2</sup>. Additionally, with a high number of people with, or at risk of diabetes only ever getting access to a primary care physician, excellent basic diabetes education for healthcare professionals is required to ensure optimal health outcomes.

<sup>1</sup> *International Standards for Education of Diabetes Health Professionals*  
<sup>2</sup> *IDF Global diabetes Plan 2011-2021*

Self management education for people with diabetes is not an option; it is an imperative

# THE PRIORITIES OF PEOPLE LIVING WITH DIABETES

## Priority Issue **3** *Prioritising type 2 diabetes prevention efforts*

### THE BCV VIEWS

Measures to prevent diabetes and its complications are rarely seen by BCV members as being of decent quality. One notable exception is screening for gestational diabetes (GDM), which in many countries takes place more regularly than other forms of prevention. BCV members believe that governments around the world need to improve the effectiveness of research, screening and prevention campaigns. The promotion of healthy lifestyles is cited as a cost-effective measure to improve the prevention of diabetes and its complications. This also includes public campaigns to raise general public awareness.

### THE ISSUES

Type 2 diabetes often develops over several years and may remain asymptomatic until complications occur. This means that it is crucial to raise public awareness as a way of identifying individuals at risk, as well as tackling the disease and establishing good control early to prevent complications such as cardiovascular disease, retinopathy and kidney failure. IDF estimates that diabetes was responsible for USD 673 billion in healthcare spending in 2015 worldwide. This represents 11.6% of the total amount spent on health by countries<sup>1</sup>, with diabetes-related complications the major driver of diabetes health expenditure. IDF also estimates that up to 60% of type 2 diabetes cases can be prevented by addressing key modifiable risk factors for type 2 diabetes such as physical inactivity, inappropriate nutrition and obesity. Cost-effective solutions exist to tackle these risk factors but are not always implemented effectively. This includes intensive lifestyle modification involving the adoption of healthy diets and increased physical activity, as well as the use of certain medications for primary prevention and other public health measures to promote healthier behaviours.

<sup>1</sup> IDF Diabetes, Atlas 7th Edition, 2015

“ In my country, people die because of lack of awareness. BCV member from Nigeria ”

! In 2015 diabetes was responsible for USD 673 billion in healthcare expenditure worldwide

## Priority Issue **4** *Eradicating discrimination against people living with diabetes*

### THE BCV VIEWS

Discrimination is a fact of life for many people living with diabetes. This takes several forms, from discrimination at school or in the workplace, which is often attributed by BCVs as stemming from a lack of understanding of the disease, to discrimination linked to gaining access to employment, care and medicines, or based on gender. Limited access to health insurance is an area seen as particularly prevalent and challenging.

### THE ISSUES

Beyond the simple issue of social justice, the type of discrimination outlined often has a negative impact on the ability of people with diabetes to manage their condition effectively, seek and/or gain access to quality healthcare, play an active role in society, and take advantage of opportunities which many take for granted, such as getting married. As a lifelong disease requiring complex daily decisions, successful self-management is vital to effective diabetes care. Tackling the issue of discrimination and engaging and empowering people with diabetes, as well as their families and communities, in the management of their own diabetes and in diabetes prevention and care is critical to reverse the current burden of diabetes.

“ Unfortunately, due to lack of knowledge, sometimes parents remove their children from the school, or the schools do not want to accept the child because of it. BCV member from Ecuador ”

! Discrimination does not just affect quality of life but also influences health outcomes



