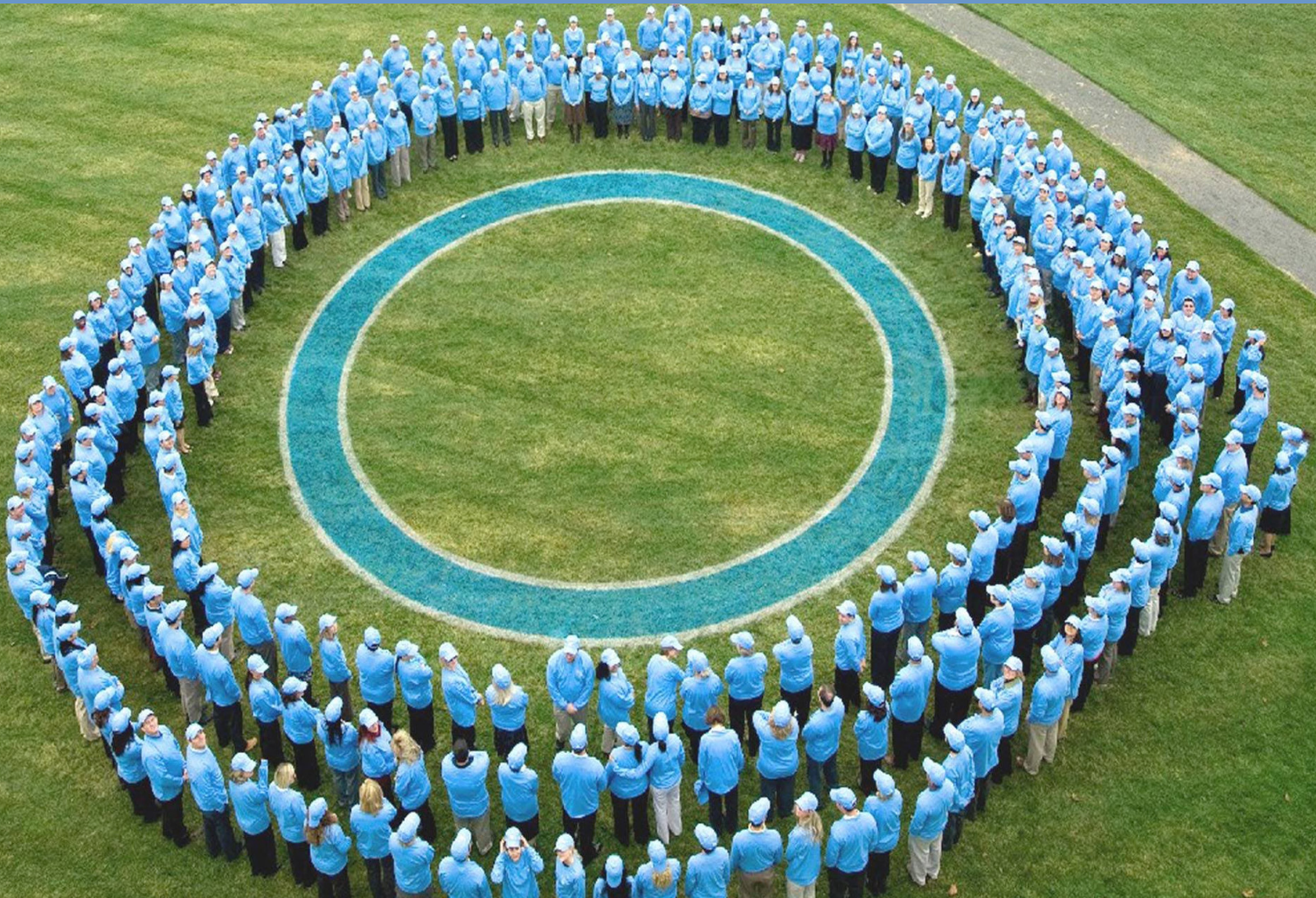




**International
Diabetes
Federation**



THE PRIORITIES OF THE BLUE CIRCLE VOICES NETWORK

Highlights of the first BCV consultation



EXECUTIVE SUMMARY

The first BCV consultation was a success participation-wise: **82 participants from 43 different countries** of all IDF regions (86% of the members of the network at that point in time) took part in it. **Most of the respondents came from urban settings** (87%); with a higher participation from women (61%) than men (39%), which reflects the gender structure of the network.

Just **under two-thirds of respondents have T1D (62%)**, followed by people with T2D (18%), carers/relatives of people with diabetes (14%), women with a history of GDM (5%) and people with other types of diabetes (1%).

All respondents unanimously agreed with the three IDF priorities (improving health outcomes for people with diabetes, preventing the development of T2D and stopping discrimination against people with diabetes).

Top of the network's agenda was undoubtedly access and affordability of medicines/devices and medical care, which were mentioned by almost half of all respondents. Education was

of slightly less concern, mentioned by 37% of respondents ahead of prevention (9% of answers) and discrimination (6% of answers).

Highlighting the critical situation of access to medicines worldwide, **more than half the BCV respondents had experienced issues in accessing prescribed medicines/devices**, with 28% having problems in finding a doctor in their area.

While affordability is also a well-known barrier to access to diabetes medicines and care globally, **fewer BCV respondents experienced difficulties in affording their medicines/devices (39%) than did experience problems accessing them**. Affording medical care was even less of an issue, although it still affected about a quarter of all participants. Nevertheless, and knowing the critical need for patients with diabetes to have adequate and regular access to their prescribed medicines/devices, it was striking that **16% of BCVs were forced, at some point, to abandon their treatment due to the unaffordability** of their prescribed medicines/devices.



82 Participants
from 43 countries

39%
experienced
difficulties in
affording
their medicines



1/3 believe that
governments should
take action on access

Diabetes education and diabetes awareness were both perceived as key to ensuring good diabetes management, stemming the epidemics and fighting stigma. These are initiatives which, however, **appear to have largely been either neglected or ineffective in achieving their goals.** Many respondents considered education/awareness-raising to be of relatively low quality, with the exception of health care professionals (HCP) education, considered by 40% of respondents to be good or excellent. This compares with just one third of respondents rating diabetes education for children as good or excellent and 24% rating it as such for education for adults. At the other end of the scale, just 15% of respondents each believed public awareness and education of carers to be good.

BCV perceptions regarding research into a cure/better treatments and the prevention of T2D diabetes and complications also showed a lack of confidence in their quality and effectiveness. Only screening for GDM was considered to be of good quality, but this masked highly polarised views, with an equal number of BCV members believing it to be good or excellent as did find it poor or very poor. Most other areas of prevention were considered of suboptimal quality.

Despite many awareness campaigns over the years, between one fifth and one quarter of all respondents said that discrimination was often or always an issue in relation to their gender (21%), when trying to access employment (21%) or in the workplace (25%). This went up to 41% of respondents in a school setting, and **51% of people with diabetes trying to access health insurance.**

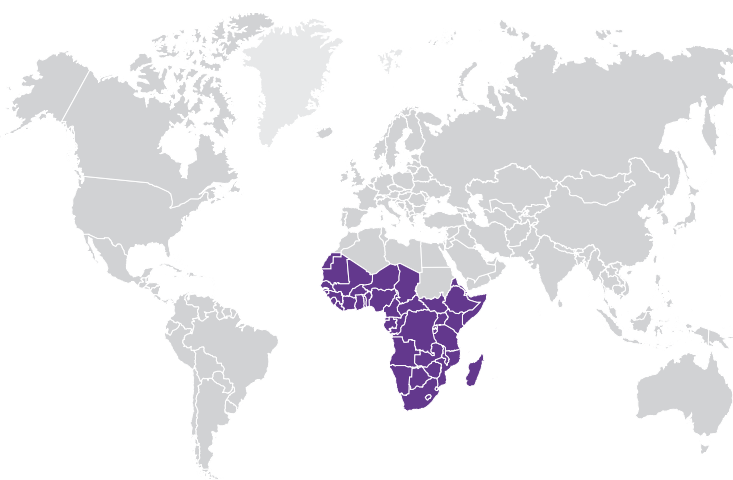
One third of the respondents believed that governments are the institutions that should be taking action in presenting solutions to the challenges they faced, followed by diabetes associations, HCPs and patients themselves. The requested action on the part of governments tended to focus mostly on the need for improved access and affordability of medicines and care. **Diabetes Associations were also seen to have a role to play, particularly in the field of education and awareness building.**





REGIONAL HIGHLIGHTS

AFRICA (AFR)



Twelve respondents from six African countries took part in the consultation.

African respondents placed a lot of emphasis on the challenge of accessing and affording medicines and devices. Seventy-five per cent of them had had difficulties accessing medicines/devices and 66% had experienced difficulties in affording them, which was compounded by the fact that the majority of respondents did not receive any reimbursement. This led to a quarter of respondents having had to abandon treatment at some point. In response to these challenges, the participants strongly promoted the view that government action

was required. Education was rarely seen as good across the continent but was regarded as a necessary tool to help stem the flow of the disease as well as help people to better manage their condition. Education provided to children was a particular area of concern, with two-thirds of respondents rating it as poor or very poor, as was awareness of diabetes by the general public. Some respondents also pointed to a divide between urban and rural areas.

“Most people with diabetes know very little about the disease. Basic education on the condition will go a long way in helping patients cope with the condition” (Tanzania);

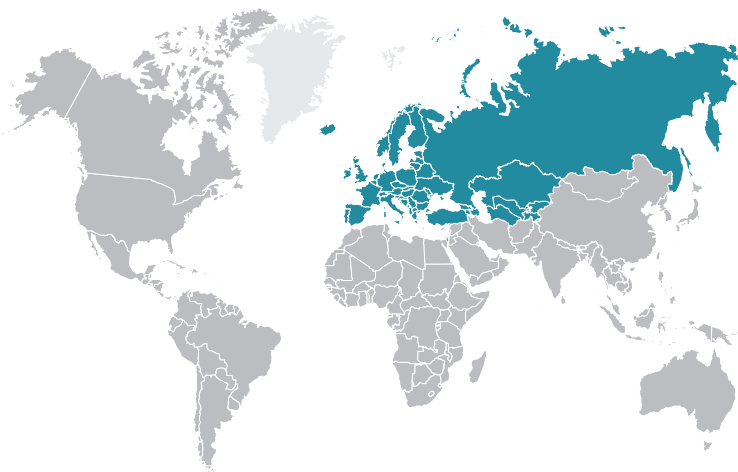
“Education is still a major problem in the rural areas of Cameroon” (Cameroon).

Discrimination was not perceived as a major issue, except in trying to obtain health insurance, where more than half the respondents mentioned it was always or often an issue.

Prevention measures were at best perceived to be of average quality. One exception was the research for better treatments for all types of diabetes, which was seen as poor.



EUROPE (EUR)



Thirteen respondents from nine European countries took part in the consultation.

Generally, access and affordability of medicines/devices and medical care were less of an issue in Europe than in most other regions, perhaps linked to the fact that the majority of respondents were recipients of reimbursement for their care expenses. Some 85% of respondents never experienced any difficulties finding a doctor and 77% did not have difficulties purchasing medicines, although 54% reported issues in accessing them.

Diabetes education was generally seen as being average or good, with the worst area being seen as education provided to carers/relatives, with 54% of respondents rating it as

poor or very poor in contrast to HCP education rated by a similar proportion as being good.

Other than in the area of gaining access to health insurance, cited by 38% of respondents as always or often an issue, discrimination was not generally regarded as a major issue in EUR and no one perceived gender-related discrimination as often being an issue.

Prevention of diabetes and its complications was seen as being of average quality in EUR, except for the areas of T2D research, GDM screening and promotion of healthy environment, which were regarded as good.

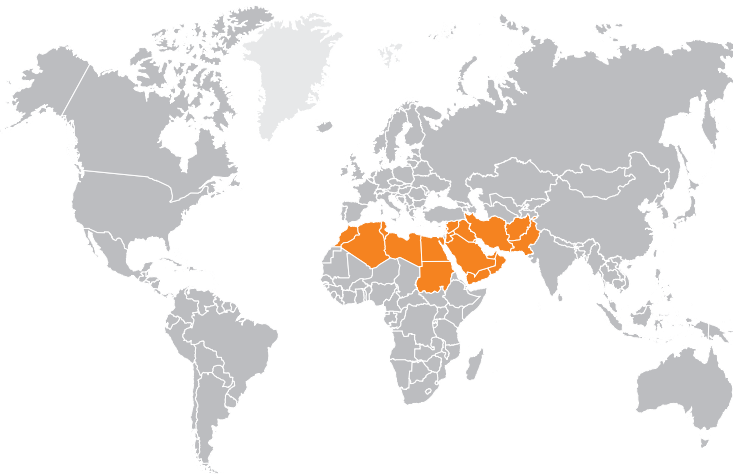
One of the main challenges for the respondents appeared to be the ability to live a normal life despite their diabetes. Patient groups and peer education were seen as having a key role to play in supporting people with diabetes.

“Peer education, which is an organization of Turkish diabetes association has fruitful and successful outcomes” (Turkey).

Government action was also viewed as a key requirement, especially in the area of reimbursement of new technologies and devices.



MIDDLE EAST AND NORTH AFRICA (MENA)



Thirteen respondents from eight MENA countries took part in the consultation.

Similarly to EUR, very few respondents from MENA appeared to have problems with access and affordability of care, although nearly 50% of participants did not receive reimbursement for their care. Some 85% of MENA respondents did not have problems finding a doctor in their area and 92% did not have any difficulties paying for the consultation, and 77% did not have problems accessing or paying for prescribed medicines and devices.

As in EUR, respondents in MENA believed that education for HCPs was generally good (seven respondents qualified it as good or excellent against just one rating it as poor and five as

average). By contrast, more than half the participants thought that the education of relatives/carers was poor or very poor (seven respondents) – a similar number to those believing that the education of children was poor. Opinions were spread more widely regarding the education of the general public – five respondents qualified it as average; five as good and three as poor or very poor. One respondent in Egypt also added that awareness was perhaps not as high in rural areas as in urban settings. A similar picture was in evidence regarding the education of adults with diabetes.

MENA was the region that scored best in terms of discrimination. Two-thirds of respondents reported that discrimination relating to gender, accessing employment or once in the workplace were never or rarely an issue. Discrimination was seen as occurring more frequently in schools or in relation to health insurance.

It was also the region that scored the second highest in terms of prevention of diabetes and its complications.

Part of the solution in the MENA region was seen as been dependent on fostering healthy lifestyles (particularly healthy eating through labelling) and improving screening to prevent the rise of T2D across the region.

NORTH AMERICA AND CARIBBEAN (NAC)

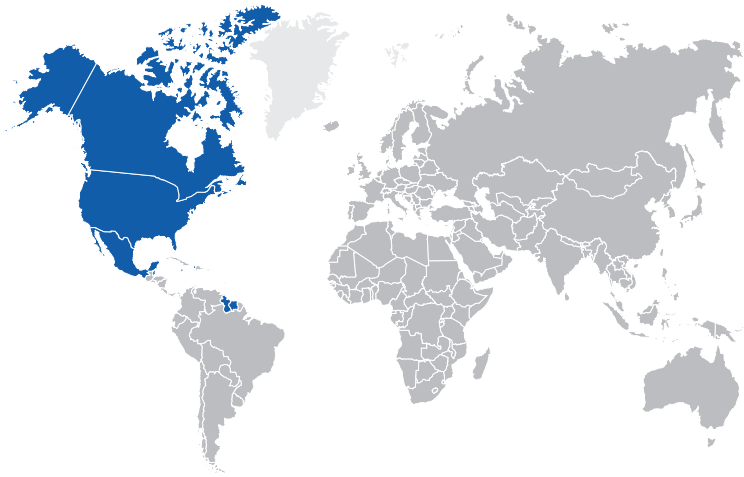
Thirteen BCVs from five NAC countries took part in the consultation.

Accessing and affording prescribed medicines and devices was a significant issue in NAC. More than half the respondents had difficulties accessing them, and 38% had had problems paying for them. NAC was also the region with the highest proportion of respondents having problems finding a doctor (61%).

“Insulin is expensive, cost of diabetes care is expensive...access isn’t a problem affordability is a major issue” (US respondent);

“If you are not working, you will find it difficult to purchase certain medication” (Barbados).

The quality of education in the region and by topic was perceived to be quite inconsistent.



Some 31% of respondents believed education provided to children to be excellent or good (a similar number thought it poor or very poor) and 38% considered HCP education to be good (with a further 38% rating it average); just 15% believed it to be good when it came to adult education.

A similar proportion considered education for relatives to be good, against 69% who qualified it as poor or very poor. Education for the general public was perceived as universally poor or very poor (77% of respondents).

“There is no planned program for education” (Guyana respondent);

“The media in the US always get diabetes wrong, therefore the people of the US tend to think of diabetes mis-information as fact” (US respondent);

“Education is better for type 1s than type 2s. Type 2s largely see their general physician who may not know much about diabetes, particularly as new treatments and drugs come out at an astounding speed” (US respondent).

Discrimination was perceived to be at its highest in relation to access to health insurance and at school, where respectively all 13 and nine respondents felt that it was sometimes/often/always an issue.

As with most other regions, research into a cure/better treatments, diagnosis and prevention measures were generally perceived to be of poor quality, with the notable exception of screening for GDM.

SOUTH AND CENTRAL AMERICA (SACA)



Fifteen participants from six SACA countries took part in the consultation.

Close to three quarters of respondents had no problems accessing medical care, but accessing prescribed medicines was an issue

for two thirds of them as was paying for their medication (60%) and consultations with their doctors (40%). SACA was also the region with the highest number of participants having stopped their treatment due to unaffordability (27%). Several comments also pointed to severe inequalities within the countries.

“Access to diabetes treatment in my country is at a critical stage, with a lack of resources in many regions” (Brazilian respondent);

“I have had no trouble getting supplies from the government in my region. But I know that in some regions of Brazil the supplies are not enough” (Brazil).



All areas of education were perceived to be poor or very poor by a vast majority of respondents. Education for children was the area rating the highest, with only two-thirds of respondents rating it as poor or very poor, against 87% of negative responses for education of the general public.

“There are no education campaigns on diabetes, nor about prevention. There is a great lack of knowledge” (Argentina);

“The diabetes associations help people with education, but Brazil is huge” (Brazilian respondent);

“Everybody talks about education as being a key factor in improving the management of diabetes, but nobody does anything concrete about it” (Chile);

“Diabetes education for adults is much less extensive than the education for children with T1D; it is also very bad in rural areas” (Costa Rica).

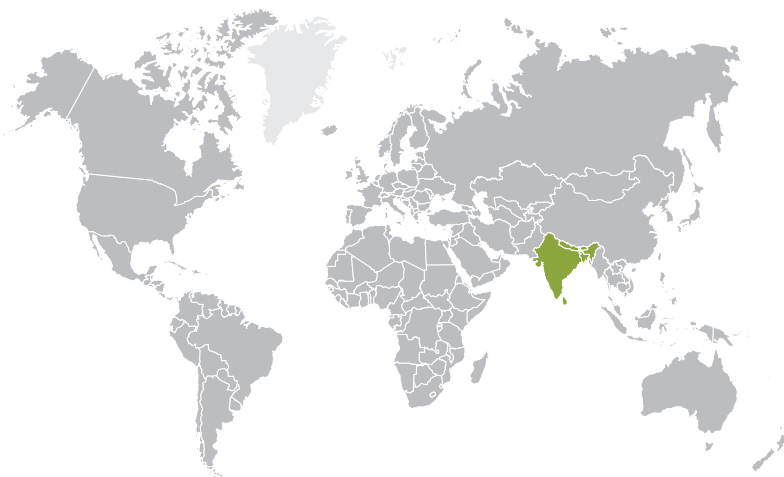
A majority of respondents believed that discrimination at school and in relation to gaining health insurance was always or often an issue (53% and 60% respectively). Discrimination in other areas was not perceived to be as prevalent.

“Many times, it is the lack of knowledge of the society that generates exclusion and discrimination against people with diabetes” (Argentina);

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

Research, prevention of diabetes and its complications were not generally viewed as being undertaken in a satisfactory manner. Three areas were singled out as poor: quality of research for T1D, T2D and other types of diabetes, and T2D prevention.

SOUTH EAST ASIA (SEA)



Only three respondents from this region participated in the consultation.

Therefore, the results may not be indicative of the real situation in SEA.

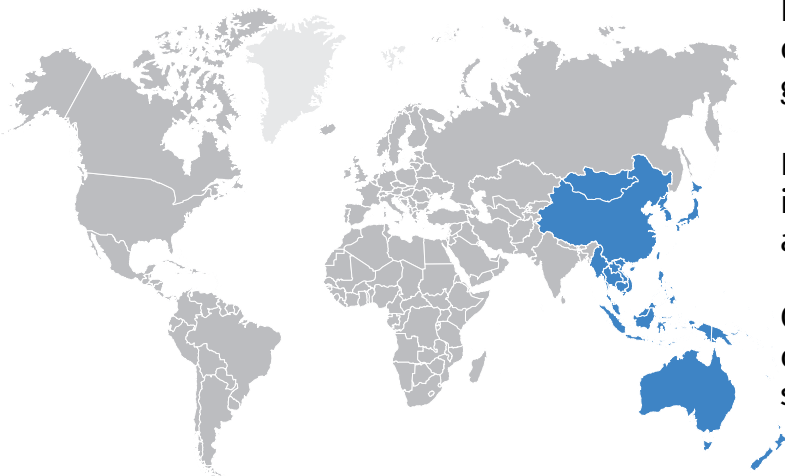
The respondents had no issues accessing or affording medical care or medicines. However, they also stated that their experience might not reflect the situation in the region.

Education, across all areas, was generally seen in a better light than in other regions, especially when it came to HCP education.

Discrimination was never perceived as an issue in SACA, except for discrimination in access to employment which was rarely a problem.



WESTERN PACIFIC (WP)



By contrast, discrimination was a serious concern in the region, except in the area of gender-based discrimination.

Eight of 11 areas of prevention of diabetes and its complications were rated by respondents as good overall.

Quality of research for T1D and for other types of diabetes, and quality of T1D diagnosis were seen as of average quality.

Thirteen participants from seven WP countries took part in the consultation.

More than three quarters of respondents did not have an issue finding medical care or paying for medicines, devices and consultations. However, 40% had difficulties in accessing prescribed medicines and devices.

Excluding SEA, WP was the region scoring the highest in terms of education, with education for children, adults and HCPs in particular being regarded as good.





GLOBAL CONCLUSIONS

The conclusions of this report are based on the views expressed by the Blue Circle Voices, and are meant to provide a perspective on the key issues and challenges being encountered by the network's members, rather than painting an exact picture of the world situation relating to access to diabetes medicines/care, education and discrimination. Nevertheless, the BCV have been chosen because of their broad experience in their country, affording them a good overview of national realities.

Highlighting the fact that despite national commitments to ensuring universal health coverage by 2030 (SDG 3.8), many governments across the world still do not offer reimbursement for diabetes care, or are unable to guarantee access to essential medicines, even when theoretically available, the ability to access prescribed medicines and devices and pay for them was the main concern of the participants in this consultation.

Limited access to medicines and devices was an issue across the world, irrespective of income levels and settings; even in the most affluent societies, this was at times a problem. Affordability issues meant that 39% of respondents to this survey had difficulties affording medicines/devices and 16% had stopped taking their treatment at some point.

Accessibility of medical care was an issue for just a quarter of the respondents in this consultation. However, many comments pointed out that it can be very difficult to access specialised diabetes care – especially in rural settings. Clearly more needs to be done to help address this, and IDF will continue to advocate for improved access to diabetes medication and care across the world.

Diabetes education was regarded as the second most important challenge for people with diabetes, and was generally considered to be lacking, except when it came to HCP education, which was broadly perceived to be adequate. Nevertheless, many respondents stressed the need for the education of primary care professionals to be improved, especially in the light of ever evolving treatment opportunities. This is an area which IDF has already started to address through the launch of the IDF School of Diabetes and will continue to work on in collaboration with our network.

There was also a widely shared belief among the BCV network that **relatives/carers do not receive the education required for them to provide adequate care.** The value of peer support and patient networks was outlined as a potential solution to improve patients'



education, raise awareness of diabetes generally, and help fight discrimination.

Many comments suggested that general public awareness was quite poor around the world. Low public awareness has an adverse effect on individuals' ability to best manage their disease and the opportunities to identify individual risk while at the same time failing to address stigma and prejudice. Clearly, action at the national level is required in order to achieve the WHO target of 0% increase in diabetes prevalence by 2025. As part of its objectives to improve diabetes awareness and help stem the diabetes epidemic, IDF is committed to working with its network, notably through its World Diabetes Day campaign.

Measures to prevent diabetes and its complications were rarely seen as being of decent quality. One notable exception was screening for GDM. It is clear that governments around the world need to improve the effectiveness of research, screening and prevention campaigns. The promotion of healthy lifestyles was cited as a cost-effective measure for governments to take to improve the prevention of diabetes and its complications.

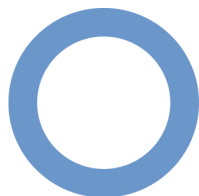
Respondents clearly felt that discrimination exists for people with diabetes across the board, but they seemed to be slightly less concerned about this than about the other topics – with the exception of discrimination on access to health insurance. This might reflect the composition of the network; IDF will be conducting more in depth studies to confirm this evidence.

The consultation also suggested clear inequalities between regions; access and affordability were markedly bigger issues in AFR, NAC and SACA than in EUR, MENA and WP. The number of participants from SEA did not allow for meaningful analysis.





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