

Report of the

WHO discussion group for people living with diabetes

virtual meeting
30-31 March 2023





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Abbreviations and acronyms

GDC	Global Diabetes Compact
HCP	health care professional
NCD	noncommunicable disease
T1DM	type 1 diabetes
T2DM	type 2 diabetes
WHO	World Health Organization

Overview

Globally, over 422 million people live with diabetes. In April 2021, the World Health Organization (WHO) launched the Global Diabetes Compact (GDC), an initiative aiming to make sustained improvements in type 2 diabetes (T2DM) prevention and care for people living with all forms of diabetes. The engagement of people living with diabetes is a priority area for WHO. Previous engagements include a series of focus groups and informal regional consultations. Building upon these engagements, and also aligning with key principles outlined in the WHO framework for meaningful engagement of people living with noncommunicable diseases, and mental health and neurological conditions, the GDC held a discussion group on 30–31 March 2023 for people living with all forms of diabetes. The event was entirely designed by people living with diabetes. Sixty-four individuals representing 28 countries attended the two-day virtual event to discuss the realities and challenges of living with diabetes, access to essential medicine and supplies, digital health for diabetes and diabetes education and promotion.

Key learnings from the discussion group reveal that the intersectional experiences of stigma, food insecurity, non-individualized treatment, education access, digital literacy, proximity to health care facilities, lack of reliable data and policies developed and implemented without the inclusion of people living with diabetes all contribute to barriers to care and self-management, ultimately impacting health outcomes. Recommendations from people living with diabetes for WHO include: the inclusion of people living with diabetes in decision-making roles and in all WHO activities that impact them, the promotion of health systems and care models that encourage collaboration between people living with diabetes and health care professionals and the continued development of reliable and accurate data sources and educational material on diabetes that accurately reflects the diabetes experience.

Introduction

In April 2021, WHO launched the GDC, a global initiative aimed at reducing the risk of T2DM and ensuring that all people diagnosed have access to equitable, comprehensive, affordable and quality treatment and care (1; 2). The GDC also helps inform broader WHO efforts towards the achievement of global coverage targets for diabetes established at the Seventy-fifth World Health Assembly (3). The engagement of people living with diabetes is a priority area for the GDC. Previous WHO engagements for people living with diabetes include:

1. 2022 – WHO focus group for people living with diabetes;
2. 2022 – WHO informal regional consultations for people living with noncommunicable diseases (NCDs) and mental health conditions in the African Region, Region of the Americas, European Region, Eastern Mediterranean Region, South-East Asia Region and three forums in the Western Pacific Region (4); and
3. 2021 – WHO informal consultation of people with lived experience of diabetes.

Key learnings from these engagements helped inform:

1. An article on the WHO key informant language survey of people with lived experience of diabetes (5);
2. The WHO framework for meaningful engagement of people living with noncommunicable diseases, and mental health and neurological conditions (hereby referred to as “the Framework”) (6).

Key principles and enablers of the Framework include inclusivity, institutionalizing meaningful engagement and redistributing power towards people with lived experience (6). In alignment with these principles, the GDC held a discussion group for people living with all forms of diabetes on 30–31 March 2023. The goals of the event were to learn from the experiences of the global diabetes community and to inform the design of relevant WHO programming and the development of future WHO technical products, where relevant.

Participants

Participant selection

Participants were invited through an open call shared broadly across WHO networks. Expressions of interest links were distributed in English, Spanish and French to encourage participation from underrepresented regions and communities. Applicants were screened based on lived experience of diabetes, country (prioritizing applicants from low- and middle-income countries) and gender identity to ensure diverse and fair representation.

Participant demographics

Sixty-four individuals representing 28 countries attended the two-day event. Overall, 71% of attendees live with type 1 diabetes (T1DM), 26% live with T2DM and 3% live with other forms of diabetes. The majority of participants identify as female and represented 73% of attendees.

Countries represented

Argentina	Indonesia	Spain
Australia	Israel	Switzerland
Brazil	Kyrgyzstan	Uganda
Canada	Lebanon	Ukraine
Chile	Mexico	United Kingdom of Great Britain and Northern Ireland
Costa Rica	Nigeria	United Republic of Tanzania
Ecuador	Pakistan	United States of America
France	Portugal	Zimbabwe
Ghana	Singapore	
India	South Africa	

Insights from participant demographics

There was balanced regional diversity among all participants, including from across the WHO African Region. While the event did have an increased attendance by people living with T2DM compared with previous WHO activities, it remains challenging to engage this community. This remains a GDC priority area for future learning.

GDC should also seek more diverse gender perspectives in future events, including male identifying and non-binary individuals, to better understand how gendered experiences in diabetes impact overall management and health outcomes.

While all WHO participatory age groups (18–65+) were reflected in this event, youth perspectives (18–24) and aging perspectives (65+) were less represented. WHO would also benefit from learning from these age groups in future activities.

Despite representation from all WHO regions, there were significantly fewer expressions of interest received from, and overall attendance by, individuals representing the WHO Eastern Mediterranean and South-East Asia regions. Additionally, there were no representatives from the Small Island Developing States of the Region of the Americas or Western Pacific Region, suggesting greater attention to engagement and advocacy efforts in these areas for future events.

Co-designing with people living with diabetes

For this engagement, the GDC did not develop a preset agenda or propose preferred topics for discussion. Rather, to ensure inclusivity and to redistribute power towards people with lived experience, the event was entirely designed, from its inception, by people living with diabetes. A lived experience planning committee was established with members representing individual and country perspectives of Ecuador, Lebanon, Pakistan, Portugal, South Africa, Spain, United States of America and Zimbabwe (Fig. 1). All facilitators have lived experience of either gestational, T1DM, T2DM, or other forms of diabetes. Collectively, the facilitators were also able to communicate in English, Spanish, Arabic and Portuguese to aid in small-group discussion. The event was moderated by two GDC team members who both live with T1DM. The following steps outline the process taken for co-designing the two-day event agenda:

1. GDC collected preliminary discussion topics through 202 submitted expressions of interest from people living with diabetes;
2. GDC team identified common themes across all submitted discussion topics;
3. Lived experience planning group reviewed common themes and highlighted four themes for discussion;
4. Lived experience planning group developed two discussion questions for each topic; and
5. GDC slightly adjusted the proposed questions as needed to ensure open-ended framing and to promote sustained discussion (Fig. 2).

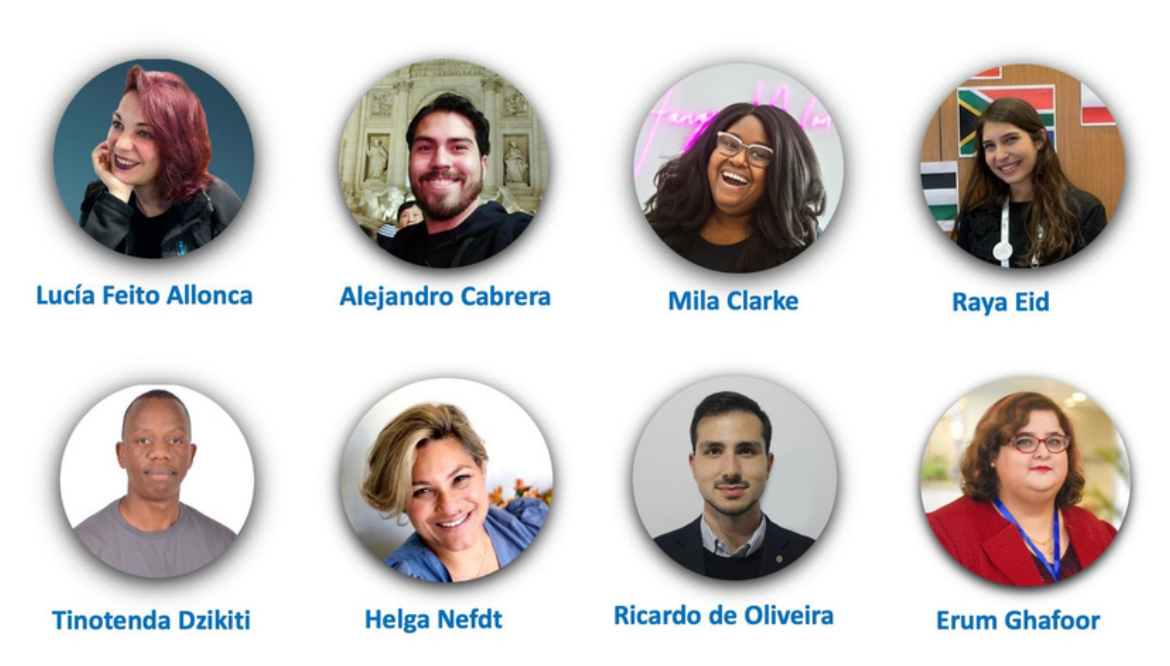


Fig. 1: Members of the lived experience planning committee

Fig. 2: Discussion themes and questions developed through the co-design process



Theme 1 Living with diabetes: realities and myths

What is it like to live with diabetes in your community? What are your main challenges? What would you like to see improved?

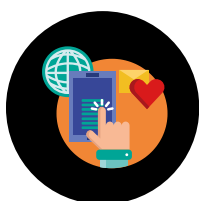
What are the greatest misconceptions about diabetes that you experience? How or from whom do you experience or receive these misconceptions?



Theme 2 Access to essential care and medicine: equity and opportunities

What does health equity mean to you? How does health equity, or a lack of, in your local community impact your experience of diabetes?

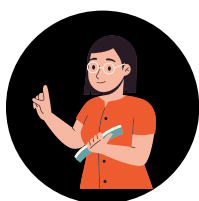
How do you believe that equity and essential care can be obtained for all people living with diabetes?



Theme 3 Digital health for diabetes

What is your experience using digital health for your diabetes management? What types of digital tools are available in your country? What digital tools do you wish you had access to? How would this change your diabetes management?

What do you believe are ways to make digital health and diabetes technology more accessible to people around the world? What people or groups should be involved?



Theme 4 Diabetes education: prevention and promotion

How did diabetes education affect your early or current diabetes experience? Do you think diabetes education could have changed or improved this experience? If so, how?

How can diabetes education be improved in your community or country? What types of support systems for people with diabetes would benefit your community?

Key learnings

Living with diabetes: myths and challenges

Participants shared their individual perspectives on living with diabetes and the associated challenges and experienced myths that impact their lives in their local contexts. These challenges are often interconnected and contribute to barriers to care and self-management. For example, challenges with access to essential medicine seem to be not only predicated on financial constraints or lack of availability of needed supplies, but also on the correlating experiences of stigma, discrimination and diabetes education, particularly at the primary health care level, which impacts self-management. Based on participant experiences, the following key challenges were identified: access to and affordability of quality care, healthy food, essential medicine and supplies; stigma and discrimination in the diabetes experience; and existing resources and government policies that do not meet individual needs.

Access to and affordability of quality care

The majority of participants experience challenges, beginning at the diagnosis stage. These challenges impact the overall diabetes experience, including self-management and, in some cases, health outcomes. Most frequently, challenges occur at the primary health care level. The common thread across these experiences includes non-individualized interactions with primary health care professionals (HCPs), including physicians, nurses and extended care teams, who seemingly have limited time, knowledge and/or specialized training in diabetes management. Specifically, experiences with primary HCPs include:

- non-individualized treatment
- lack of holistic care and whole person considerations for quality of life
- judgement, blame and stigmatizing language used by HCPs, which leads to fear of seeking care
- limited HCP understanding of treatment approaches for T1DM and T2DM
- lack of timely diagnosis, especially with gestational diabetes and T2DM.



“People are asking, ‘Should I take my medication if I can’t feed myself properly?’ [There is] often not enough insulin to cover what people are eating. When people go for check-ups, they are stigmatized by HCPs who say we are not looking after ourselves properly, so people are reluctant to go for their check-ups. There is a lack of empathy from HCPs.”
– person living with diabetes, anonymous

An additional challenge noted among participants is difficulty accessing health care facilities and needed services. This is particularly common for those living in rural areas and in regions where there is limited availability of primary care physicians, health care facilities, laboratory testing centres and diabetes specialists, including endocrinologists. However, these challenges were also noted for people living in high-income countries, such as Canada, where some indicated wait times of up to six months to see an endocrinologist. In these contexts, challenges with accessing needed health care services directly impact self-management, including access to needed supplies or essential medicines.

“To avoid diabetes complications and late diagnosis, it is critical to raise awareness and educate people living in rural areas about type 2 diabetes prevention. More testing centres in small towns are needed, as are awareness campaigns and programmes.”
– person living with diabetes, anonymous

The most common indicated challenge among the participants is the price and availability of essential medicine and supplies. Some participants are rationing essential medicine, such as insulin, due to prohibitive cost barriers. For others, there is limited availability of diabetes technology that can potentially aid in self-management. Food insecurity and limited access to affordable and healthy options are also challenges that impact barriers to care. Among participants, this seems to be consistent in low-, middle- and some high-income countries.

“Being unemployed I cannot afford the treatment and I have to choose between the use of insulin or test strips.” – person living with diabetes, anonymous

“I have the right to eat healthy food. But sometimes it is difficult to choose between medicine or food.” – person living with diabetes, anonymous

Stigma and discrimination

Participants shared how cultural and social stigma and discrimination are pervasive at every level of the diabetes experience, including in health services, education, schools, relationships and employment. This experience is particularly common among women with diabetes, especially in the areas of marriage and pregnancy. Some participants noted struggles with job security when those around them learn about their diabetes diagnosis. Others noted that stigma is particularly heightened and common when communities of colour experience care from HCPs. Stigma, particularly about T2DM, can actually lead to delayed diagnosis and early complications as the general belief that diabetes is caused by food choices or lifestyle behaviours ultimately contributes to how people with diabetes manage their condition and engage with the health care system.

Fundamentally, it is important for societies to be knowledgeable about the multiple factors behind diabetes and the differences between T1DM and T2DM management, including related co-morbidities.

“In conservative societies, people with type 1 diabetes are not allowed to have children. Marriage is regarded as the most difficult challenge for a diabetic woman. It is difficult to feel accepted in society and women face alienation and stigma. Due to this, the women have an extra burden to prove themselves while managing a chronic condition to be able to feel accepted and understood.” – person living with diabetes, anonymous

Existing resources and government policies

Many existing government policies are developed without the input of people living with diabetes. For many of the participants, these policies do not meet the needs of the individual and often create additional barriers to care. For example, some people mentioned policies that offer some essential supplies (e.g. insulin) but not others (e.g. test strips for blood glucose monitoring), despite the two essential supplies being interconnected in self-management for many people living with diabetes.

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“There is legislation that means care is covered for all people with diabetes. However, this is just on paper. Insulin is covered, but test strips are not. This needs to change as many families are not able to afford test strips. Resources are distributed poorly. People with diabetes are eligible to receive a support package, but the person must prove they have diabetes and this needs to be done every year. This is done in hospital, which is a great cost to the state, but it is required to obtain subsidies.”
– person living with diabetes,
anonymous

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“Government or organizations offering free insulin, test strips, or diabetes technology should consider providing everyone with a minimal standard of care. For example, some doctors administer 30/70 premixed insulin injections, which can cause complications and lower a patient's quality of life. When it comes to holistic diabetes care, consider quality of life, which is a major challenge in low- and middle-income countries.”
– person living with diabetes,
anonymous

From the participants' perspectives, few countries have or implement minimal standards of care for people with diabetes. The lack of in-country diabetes data registries, policy development without the input of people living with diabetes, and the particular challenges faced among people with diabetes in humanitarian and emergency crises also highlights the need for improved government coordination and resources among all relevant stakeholders, including people living with diabetes. Some participants also emphasized the influence of political determinants during humanitarian crises that impact access to essential medicine. They stressed that when decisions are made at the highest level, it results in a trickle-down effect that has a big and lasting impact on the lives of people with diabetes.

Access to essential care and medicine: equity and opportunities

The most popular topic requested by participants was access to essential care and medicine, as submitted through the expressions of interest. Although this theme has been discussed in previous WHO engagements for people living with diabetes, and also briefly addressed in the previous section, the urgency remains a high priority for the community. Ongoing discussions are critical to continued WHO learning on how to support Member States in addressing this issue. The common threads across participant experiences relate not only to accessing essential diagnostics, treatments, medicines and care but also to the seemingly still insurmountable variables of food insecurity, discrimination, mental health challenges, insufficient or ineffective health coverage and how comorbidities impact access to care.

Concepts of health equity varied among participants. Some stressed that health equity is simply *“the right to eat healthy food”* or *“the right to afford insulin”*. Others took the liberty of developing powerful definitions of health equity based on their lived experiences of diabetes:

“Health equity is a fair and just opportunity to achieve your highest level of health, culturally competent, affordable and accessible care that gives patients the freedom to choose. It is bio-individual, accessible treatment that removes systematic barriers to health.”
– people living with diabetes, anonymous

On how to address the challenges of health equity in the diabetes experience, one key recommendation was the inclusion of people living with diabetes, in order to help develop relevant and effective policies. This includes placing people with diabetes in decision-making positions and ensuring people with diabetes have a voice through continued engagements and opportunities to drive access and equity solutions forward.

“I have received different treatment because of the colour of my skin. I have seen situations where one kid was being educated about continuous glucose monitors while a child of colour diagnosed at the same time wasn’t. People make assumptions that communities of colour can’t afford certain devices and they receive poorer access to education.”
– person living with diabetes, anonymous

Participants also provided additional recommendations for WHO to help Member States address challenges with accessing essential care, supplies and medicines for people living with diabetes:

- Increase leadership from global organizations such as WHO and the International Diabetes Federation on addressing access to care issues;
- Increase health equity by educating people about the systems that need to be changed, including greater lived experience empowerment and understanding of existing laws on health, food, advertising, housing and education;
- Explore the creation of specific guidelines for people with diabetes that address barriers to care and also consider variables such as financial opportunities, food access and education;
- Encourage more research and evidence-based publications on health inequity in diabetes through a lived experience lens; and
- Support the development of more competent primary health care models equipped to support people with diabetes.

Digital health for diabetes

Participants had the opportunity to feed into discussion questions about digital health for diabetes. Many participants, particularly those living with T1DM, often use the terms “digital health” and “technology” interchangeably. Within that context, the terms often reflect experiences with specific diabetes technology such as insulin pumps, smart pens and continuous glucose monitoring devices.

Experiences with and recommendations for digital health

Some participants describe themselves as early adopters of digital technology for diabetes while others have difficulty accessing basic digital tools due to lack of local availability. Others mentioned that they do not have access to basic glucose meters so the thought of digital tools for management seems irrelevant. Existing apps are also used to support diabetes management through exercise guidance and carbohydrate counting.



“During COVID-19, my HCP team was looking after me online including through WhatsApp consultations. Physical consultations related to my amputation were hard to do online but other than that everything else diabetes related could be done online. I appreciate more time spent online and have continued the online consults even now.”

– person living with diabetes, anonymous



“In Ghana, access to tools such as laptops and phones is scarce, so talking about digital health is a problem”
– person living with diabetes, anonymous

Although existing text/SMS health platforms mostly focus on other public health issues, some participants mentioned digital health solutions for COVID-19 as potential comparative models for diabetes. With COVID-19, digital health tools became more widely available but not as widely accessible for all due to lack of or poor internet connectivity, limited or unreliable mobile phone availability and digital competence as limiting factors in adoption.

Many participants emphasized the inclusion and consideration of the needs of people with T2DM and gestational diabetes in the development of digital tools for diabetes. Additional attention should also be placed on people in rural areas, where health needs tend to be more pressing and immediate. Others emphasized that the use of digital tools is not only informative to diabetes management, but also supports self-advocacy. However, due to conflicting advice, many people fall into traps of myths and misconceptions and fall out of the continuum of care until there is a crisis.

Some indicated that progress with digital health tools cannot be made unless progress is first made with basic utilities and skills, such as stable electricity in rural areas, mobile phone and laptop availability, internet access and computer and digital literacy.



“There needs to be a safety component to digital tools. There needs to be some kind of regulator to check for misinformation and authenticate. Another unregulated area is social media misinformation about diabetes. Having a reporting system would be good.” – person living with diabetes, anonymous

How to make digital tools more accessible to people around the world

Participants emphasized that industry and policy makers should be part of the solution to make digital health and technologies more accessible and affordable. This requires a level playing field for all people. Discussions about digital health access need to include perspectives from people living in low- to middle-income countries who are struggling to access basic medicine and care. Diabetes educators should also be actively involved as they can help teach and prescribe digital health tools and technology. Peers, community networks, conferences and multidisciplinary teams are also important groups to include in the development of digital health tools to support adoption and use.

“

“A positive of increased access to digital health is being able to have a diversity of voices at meetings like this. It is important for us as a community to be united and connect and build one voice together, enhanced through opportunities brought by technology like this.”

– person living with diabetes, anonymous

Diabetes education: promotion and prevention

Some participants shared reflections on how, in some contexts, diabetes education has moved from a rigid, “old knowledge” and “fear-based” approach to one that is more flexible and open-minded. Others mentioned that, in their experiences, some diabetes educators still perpetuate stigma through information that is not supportive or helpful to the diagnosis or management experience. In these instances, peer support and advocacy continue to fill the gaps for needed and reliable diabetes education.

“

“My first educational experience was at the hospital. My doctor had poor bedside manners. It was traumatizing and created fear of physical pain.”

– person living with diabetes, anonymous

“

“I was just given a diet chart to follow. There was no information about correction doses or how to manage day-to-day challenges.”

– person living with diabetes, anonymous

The common theme among most participants is that reliable, personalized and compassionate diabetes education remains a struggle, as some HCPs have limited time and limited training on the differences between T1DM and T2DM management, medications and the use of diabetes technology. People with T2DM shared that the education and advice provided by HCPs, educators and care teams tends to be more generic and stigma ridden. For some, this contributes directly to diabetes burnout, stress and denial about the condition, perhaps indicating a link between diabetes education experiences and mental wellness.

“

“People with T2DM get very little information and leave the hospital very confused, whereas more resources are available for people with T1DM.”

– person living with diabetes, anonymous

For the majority of participants, better diabetes education could have improved the diabetes experience at the diagnosis stage. For some, the lack of diabetes education led to avoidable diabetes complications. The delivery of information by HCPs and support teams should include compassion, respect and understanding. It should be reliable, personalized and centred on the whole person. Other participants suggested a move away from top-down education from HCPs to one that is individualized and driven by the community in order to support more effective approaches to self-management, especially in the early days of the diagnosis experience.

The overwhelming consensus from the participants is that diabetes education should be easily accessible for people in all geographic regions, especially those in rural settings and those with disabilities, including visual and hearing impairment. Diabetes educators, people with diabetes *and* HCPs should partner together and collaborate to develop training programmes on diabetes education within health care systems. Led by people with diabetes, governments should develop and implement health policies that increase funding in the training of diabetes educators and HCPs to support prevention programmes for people at risk of T2DM.

Ultimately, participants stressed that diabetes education should be multilingual, culturally appropriate and devoid of stigma.

“

“We need diabetes education in our own languages – not only translated into our languages but also into human words.”

– person living with diabetes, anonymous

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“Most information is online and there are geographic locations where there is no access to high-speed internet or mobile devices.”

– person living with diabetes, anonymous

“

“Back in the day, we received information to prevent our death. Diabetes education should be to guarantee quality of life. We need updated and continuous diabetes education related to different stages of life.”

– person living with diabetes, anonymous

“

“We need better support groups. We have to make sure that diabetes education is understood. We need diabetes education in our health systems. There's access but not everyone can pay out of pocket. WHO should promote that public health systems have diabetes educators.”

– person living with diabetes, anonymous

Summary and recommendations

The WHO GDC is well positioned to apply key learnings from people living with diabetes to support best practices of meaningful engagement. The following high-level recommendations are based on learnings from the discussion group and can be applied to ongoing and future WHO diabetes-related efforts, including specific applications to workstreams, activities, technical products and progress towards global coverage targets, where relevant:

- WHO GDC engagements should be co-designed and co-developed with people living with all forms of diabetes, with special attention paid to those whose perspectives have been marginalized, and with greater representation from low- and middle-income countries.
- WHO must increase its efforts to undertake and develop specific strategies to encourage greater regional representation of diabetes lived experience across WHO South-East Asia, Eastern Mediterranean and Western Pacific regions as well as Small Island Developing Countries.
- Efforts must be taken to better understand barriers to participation and engagement experienced by people living with type 2 diabetes.
- WHO should promote health systems and care models that encourage collaboration between people living with diabetes, diabetes educators and health care professionals at the primary care level.
- WHO should include people living with diabetes in decision-making roles and in the development of future WHO technical products and guidelines that address barriers to access to essential medicines and care.
- WHO should be a trusted global source for reliable data and educational material on diabetes that accurately reflects the diversity of diabetes experiences.

References

1. Global Diabetes Summit [website]. Geneva: World Health Organization; 2021 (<https://www.who.int/news-room/events/detail/2021/04/14/default-calendar/global-diabetes-summit>, accessed 7 June 2023).
2. Resolution WHA74.4. Reducing the burden of noncommunicable diseases through strengthening prevention and control of diabetes. In: Seventy-fourth World Health Assembly, Geneva, 24 May–1 June 2021. Resolutions and decisions, annexes. Geneva: World Health Organization; 2021:7-11 (<https://apps.who.int/iris/handle/10665/352594>).
3. First-ever global coverage targets for diabetes adopted at the 75th World Health Assembly [website]. Geneva: World Health Organization; 2022 (<https://www.who.int/news-room/feature-stories/detail/first-ever-global-coverage-targets-for-diabetes-adopted-at-the-75-th-world-health-assembly>, accessed 7 June 2023).
4. Regional reflections. analysis from informal regional consultations with people living with noncommunicable diseases and mental health conditions. Geneva: World Health Organization; 2023 (<https://apps.who.int/iris/handle/10665/366977>).
5. Hunt D, Lamb K, Elliott J, Hemmingsen B, Slama S, Scibilia R, Daniels KW, Mikkelsen B. A WHO key informant language survey of people with lived experiences of diabetes: media misconceptions, values-based messaging, stigma, framings and communications considerations. *Diabetes Res Clin Pract.* 2022;193:110109. doi: 10.1016/j.diabres.2022.110109.
6. WHO framework for meaningful engagement of people living with noncommunicable diseases, and mental health and neurological conditions. Geneva: World Health Organization; 2023 (<https://apps.who.int/iris/handle/10665/367340>).

Annex. Event agenda

WHO discussion group for people living with diabetes

Agenda

Day 1: Thursday 30 March 2023

14:00 to 17:00 CET

Time	Topic	Speakers
14:00–14:05	Welcome	James Elliott and Ida Ahmadpour WHO GDC
14:05–14:15	Opening remarks	Dr Bente Mikkelsen Director, NCD Department, WHO headquarters
14:15–14:25	WHO Global Diabetes Compact (GDC) – updates	Dr Bianca Hemmingsen Medical Officer, MND/NCD, WHO headquarters
14:25–14:35	WHO framework for people living with noncommunicable diseases, mental health conditions, and neurological conditions – updates and opportunities	Dr Guy Fones Unit Head, GCM/NCD, WHO headquarters
14:35–14:40	Setting the scene	James Elliott and Ida Ahmadpour WHO GDC
14:40–14:45	Break	All
14:45–15:20	Breakout session 1 – Living with diabetes: realities, myths and challenges Discussion questions: <ul style="list-style-type: none"> What is it like to live with diabetes in your community? What are your main challenges? What would you like to see improved? What are the greatest misconceptions about diabetes that you experience? How or from who do you experience or receive these misconceptions? 	Facilitators: Lucía Feito Allonca, Spain Alejandro Cabrera, Ecuador Mila Clarke, United States of America Tinotenda Dzikiti, Zimbabwe Raya Eid, Lebanon Helga Nefdt, South Africa Ricardo de Oliveira, Portugal
15:20–15:40	Summary of breakout session 1	Facilitators
15:40–15:45	Break	
15:45–16:20	Breakout session 2 – Global access to essential care and medicine: equity and opportunities Discussion questions: <ul style="list-style-type: none"> What does health equity mean to you? How does health equity, or a lack of, impact your experience of diabetes in your community? How can health equity and essential care be obtained for all people living with diabetes? 	Facilitators: Lucía Feito Allonca, Spain Alejandro Cabrera, Ecuador Mila Clarke, United States of America Tinotenda Dzikiti, Zimbabwe Raya Eid, Lebanon Helga Nefdt, South Africa Ricardo de Oliveira, Portugal
16:20–16:40	Summary of breakout session 2	Facilitators
16:40–16:50	Open forum	All
16:50–17:00	Close for the day	James Elliott and Ida Ahmadpour WHO GDC

WHO discussion group for people living with diabetes

Agenda

Day 2: Friday 31 March 2023

14:00 to 17:00 CET

Time	Topic	Speakers
14:00–14:05	Welcome and reflections	James Elliott and Ida Ahmadpour, WHO GDC
14:05–14:15	Digital health for diabetes	Surabhi Joshi, Technical Officer, DHI, WHO headquarters Per Hasvold, Digital Health and Innovations department, WHO headquarters
14:15–14:50	Breakout session 3 – Digital health and diabetes Discussion questions: <ul style="list-style-type: none"> What is your experience using digital health in your diabetes management? What types of tools are available in your country? What digital health tools do you wish you had access to? How would this change your diabetes management? What do you believe are ways to make digital health and diabetes technology more accessible to people living with diabetes around the world? What people or groups should be involved? 	Facilitators: Lucía Feito Allonca, Spain Alejandro Cabrera, Ecuador Mila Clarke, United States of America Tinotenda Dzikiti, Zimbabwe Raya Eid, Lebanon Helga Nefdt, South Africa Ricardo de Oliveira, Portugal
14:50–15:20	Summary of breakout session 3	Facilitators
15:20–15:30	Break	
15:35–16:10	Breakout session 4 – Diabetes education – prevention, promotion and support Discussion questions: <ul style="list-style-type: none"> How did diabetes education affect your early or current diabetes experience? Do you think diabetes education could have changed or improved this experience? How? How can diabetes education be improved in your community or country? What types of support systems for people with diabetes would benefit your community? 	Facilitators: Lucía Feito Allonca, Spain Alejandro Cabrera, Ecuador Mila Clarke, United States of America Tinotenda Dzikiti, Zimbabwe Raya Eid, Lebanon Helga Nefdt, South Africa Ricardo de Oliveira, Portugal
16:10–16:30	Summary of breakout session 4	Facilitators
16:30–16:40	Open discussion: Changing mindsets	All
16:40–16:45	Summary and next steps	James Elliott and Ida Ahmadpour, WHO GDC
16:45–17:00	Event close	James Elliott and Ida Ahmadpour, WHO GDC

