



International
Diabetes
Federation
Europe



MEETING REPORT

First Meeting of IDF Europe's
T2D Platform

March 2024



We thank our partners for their support !



Over the last few decades, citizen engagement has increasingly been acknowledged by private and public stakeholders alike as vital in designing initiatives and solutions that truly meet their needs and preferences across all aspects of their lives. In the healthcare field, it is a cornerstone of quality care. **Engaging people with lived experience** improves shared decision making and supports self-management. Incorporating lived experiences in healthcare design and health-related policies can significantly enhance healthcare delivery. Looking at research, involving people with lived experience ensures that research focuses on outcomes that meet people's expectations, needs and preferences and helps broaden the dissemination of research findings amongst the general public.

People living with Type 2 Diabetes (T2D) represent 90-95% of the total number of people living with diabetes (PwD). Despite this, this community has little visibility in the public and political arenas. To address this, IDF Europe recently initiated a programme designed to encourage a stronger T2D voice. This initiative is part of IDF Europe's broader PwD platform.

At the end of 2023, IDF Europe Member Associations expressed their interest in joining forces to support the programme, after which they were invited to nominate candidates potentially interested in raising their voice at national and pan-European levels.

As a first step, IDF Europe held a **meeting to further understand the barriers and motivation to T2D engagement in advocacy work**; identify synergies at national and European levels; and develop, in collaboration with PwD, a training programme to equip them with the skills required to become strong advocates and give them the confidence to represent their community at national and pan-European levels. Some 35 participants from 22 European countries joined this inaugural meeting in Brussels on March 16 and 17. The meeting's main aim was to provide attendees with an opportunity to connect with each other and to build a community that would identify its own strengths and needs, share challenges and experiences, co-create its own training curriculum, identify opportunities to engage, and brainstorm future activities.





After a round of introduction to break the ice for those participants who had not been able to attend the welcome dinner the day before, the meeting's first session on March 16 was designed to allow participants to understand the **value that engagement** of people with lived experience brings to different stakeholders such as healthcare professionals, diabetes associations, researchers, policy makers, industry, and other PwD, themselves.



- Prof. Nebojša Lalić presented the **healthcare professionals'** perspective and outlined how the partnership between PwD and HCPs can support more effective advocacy action towards better access to healthcare and to the latest diabetes treatments. Prof. Lalić also stressed the value of the PwD voice in improving care in discussion with their HCPs.



- Sehnaz Karadeniz, member of the Turkish Diabetes Foundation, representing the views of **diabetes associations**, highlighted the critical role of PwD in shaping associations' strategies, participating in workshops and projects as well as supporting their advocacy efforts.



- Sabine Dupont, Director of Strategy and Policy of IDF Europe, mentioned that participation in **diabetes research** ensures that research outcomes are relevant to people living with T2D. and can therefore address their unmet medical needs.



- Elisabeth Dupont, Regional Manager of IDF Europe, pointed out that engaging with **policy makers** can lead to policy decisions that better reflect the needs of those living with T2D, leading to improved healthcare policies and support systems

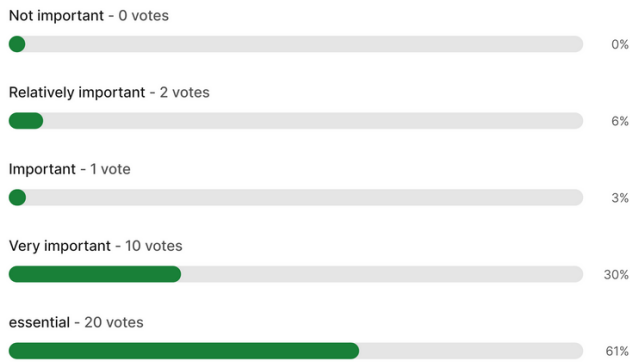


- Melissa Pen, Director of Patient Engagement R&D in the Industry sector, emphasised the fact that **industry** acknowledges individuals with T2D as experts in their own condition and stressed the value they derive from PwD's insights into their unmet needs, notably when developing new treatments and devices.



- Kostas Tagkalos, a T2D advocate who has participated in several IDF Europe projects, said that **engaging with other PwD** can contribute to an improvement in one's own understanding of the disease and talked about the rewarding feeling of helping others who might be struggling and feeling alone with the disease and its management.

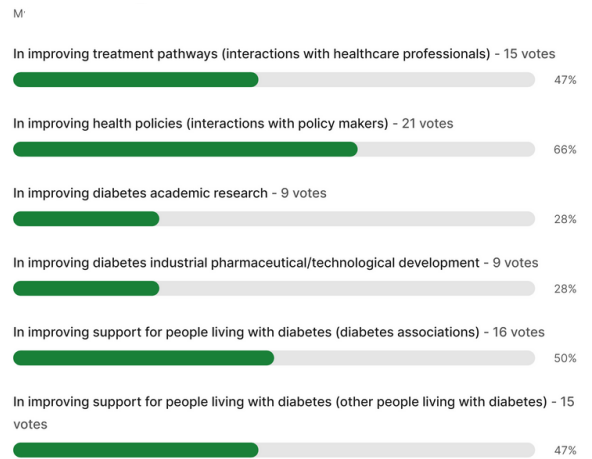
Having heard these short testimonials, do you feel the voice of people living with diabetes is important to drive changes:



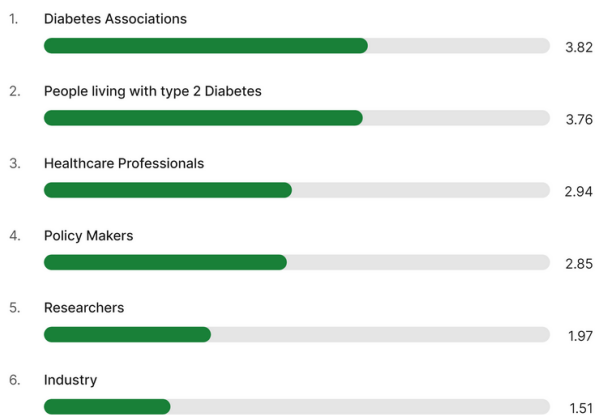
Participants had the opportunity to provide **immediate feedback** on topics brought up during the testimonials. When asked whether they felt that the voice of PwD is important to drive change, over 90% of them indicated that it was very important to essential.

When asked where they saw the most value in including the voice of PwD, opinions varied greatly. Almost 70% believed that improving health policies was the most important area where the voice of PwD should be utilised. This was followed by improving support for PwD by engaging with diabetes associations and other PwD. Participants also rated improving treatment pathways by interacting with healthcare professionals highly.

Where do you see the most value in bringing the voice of people living with diabetes (in general – not where you could have the most impact):



Where do you think you could contribute the most (Please rank the options from the highest to the lowest priority):



Lastly, participants provided a ranking of advocacy activities to which they would be interested in contributing. Participants expressed most interest in interacting more with their diabetes organisation and other people living with T2D. Many were also interested in advocacy activities targeting healthcare professionals and policy makers.

Despite the evident need for engagement and involvement of people with lived experience, several challenges and barriers still hinder meaningful engagement.

To address these limitations, a strong voice is needed. The second session of the meeting aimed to **understand the motivations, barriers and needs of people living with T2D** to raise their voice and engage in activities that would ultimately benefit their community.

PwD can have a different set of motivation, barriers and needs when engaging with different stakeholders. Insight from participants can be summarised as follows.

Healthcare Professionals



Motivation to engage: understand the condition, gaining individualised advice on diet and management

Barriers: accessibility, lack of support from the healthcare system.

What is needed to engage: moderated platform for information exchange between HCP and PwD.

Policy Makers



Motivation to engage: help facilitate policy changes that drive change.

Barriers: stigma, lack of resources and knowledge on how to communicate with them.

What is needed to engage: roadmap outlining communication strategy and education on statistics.

Diabetes Associations



Motivation to engage: need for information on management and recent developments in the field.

Barriers: lack of awareness.

What is needed to engage: direct support and way to keep in touch with fellow advocates.

People with Diabetes

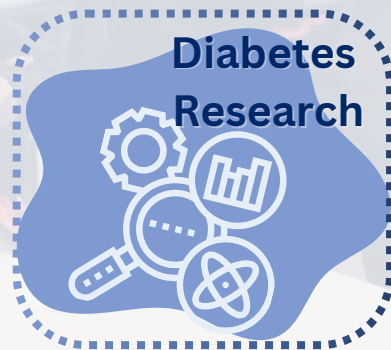


Motivation to engage: help other PwD by raising awareness of diabetes and share experiences.

Barriers: stigma and discrimination, internal and external through society.

What is needed to engage: create an opportunity for PwD to share experiences.

Diabetes Research



Motivation to engage: mutual sharing of information, first to learn of new findings.

Barriers: lack of awareness and time to invest.

What is needed to engage: raise awareness of the existence of such projects and how to participate



As part of the discussion on how to enhance advocacy efforts, Ashley Ross, a professional coach moderating the meeting, explained the concept of the “inner critic,” the inner voice of doubt that reinforces limiting beliefs and can constrict growth and prevent people from stepping out of their comfort zone. This aimed to provide participants with strategies for personal growth and effective communication and further empower them in their advocacy efforts.

Building on this second session, IDF Europe asked the participants to identify, first individually, then collectively, topics and skills for a training curriculum that would support their engagement in advocacy activities. Participants’ input is summarised in the table below:

Guidelines and strategic thinking	Storytelling and communication skills	Social Media skills	Improved knowledge on diabetes	Other suggestions
A structured strategy to address different areas of advocacy e.g. how to approach policy makers	How to frame messages while ensuring consistent and targeted messaging	How to use social media effectively	More scientific/medical information on diabetes and its complications	A “buddy programme” which pairs people with more experience with people with less experience
Tools to improve statistical literacy (understanding and reasoning with data)	How to Improve presentation skills, <u>verbal</u> and written communication	Video editing on the phone	Up-to-date information on recent scientific developments in treatment and management of diabetes	Fundraising knowledge
A compendium of best practices in advocacy		How to create content for social media	More information on nutrition and diets related to diabetes	A platform on which they can communicate with fellow advocates

The second day of the meeting began with participants **reflecting** on their learnings and questions from the previous day :

☁ Are there any insights from yesterday you would like to share?



Many participants identified the sharing of experiences as being extremely valuable. Most of them added that they would value future opportunities to remain connected and be able to exchange with one another on a regular basis.

☁ What does advocacy mean to you?



When asked about their understanding of **“advocacy”**, the most common answer was **“support”**. Advocacy was perceived as a tool to help (themselves and) others, a way to improve understanding and awareness of diabetes and increase the voice of PwD.



A subsequent **session on storytelling** emphasised the importance of personal narratives and provided a systematic approach for constructing them. Attendees learned how to navigate through the key stages of storytelling (introduction, conflict, resolution, and conclusion). This session aimed to equip participants with the techniques required to effectively convey their stories, enhancing their ability to engage and connect with others. Participants also had the opportunity to exercise their storytelling skills by conducting roleplays in which they, as T2D advocates, had to convince other stakeholders (healthcare professionals, policy makers, or industry representative) to support their cause.





IDF Europe showcased **engagement opportunities** for participants, such as:

- Speaking at events/conferences
- Providing video or written testimonials for our communication campaigns
- Joining an editorial board for upcoming IDF Europe publications
- Meeting with policy makers
- Taking part in patient advisory panels in the context of scientific research projects or industry supported projects or IDF Europe focus groups on relevant topics of interest

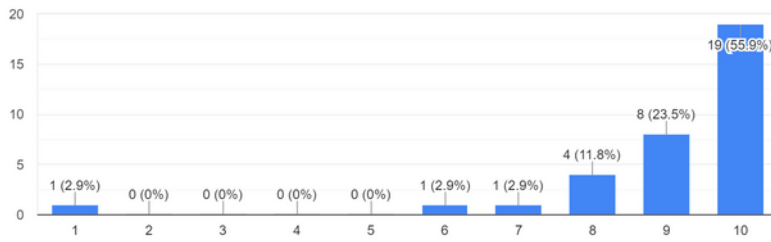
Kostas Tagkalos, a long-time T2D advocate, outlined the various engagement opportunities in which he had been involved, retracing his journey with IDF Europe over the last three years. This included his experience as a member of patient advisory groups in research and education projects, speaker at policy events at the EU parliament and other diabetes-related-events, and member of editorial boards for IDF Europe publications.

Regarding the specific question of how to **expand the network**, participants suggested:

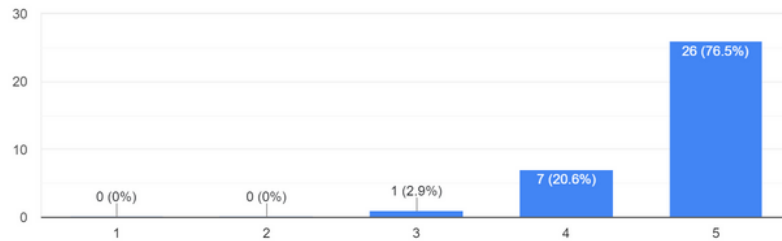
- Holding frequent meetings within the platform where members can suggest and refer PwD
- Utilising existing groups on social media such as Facebook to find more members
- Collaborating with people of influence who live with T2D such as celebrities or other influencers
- Organising more events with T2D members involving stakeholder groups



How satisfied are you with the event?



How satisfied are you with the networking opportunities at the event?

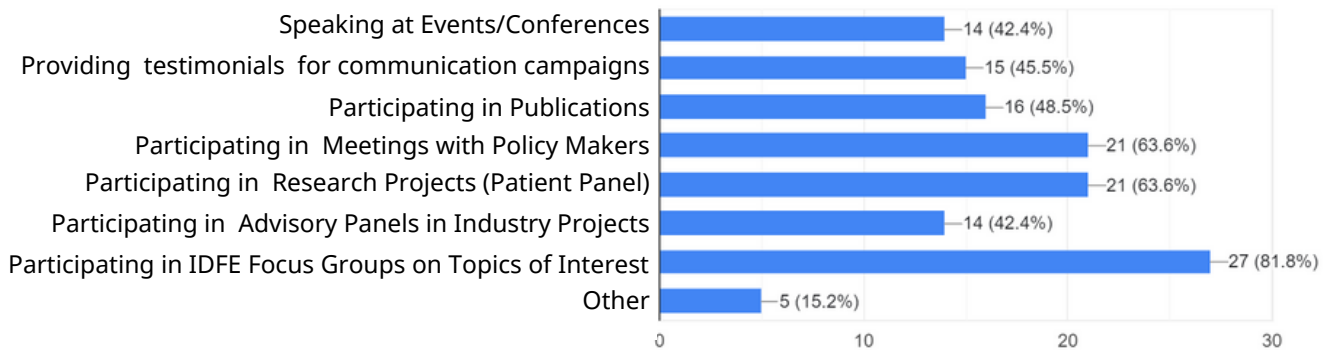


Participants' feedback on the event was very positive and when asked about satisfaction with the event and networking opportunities, participants indicated a high level of satisfaction as shown below.

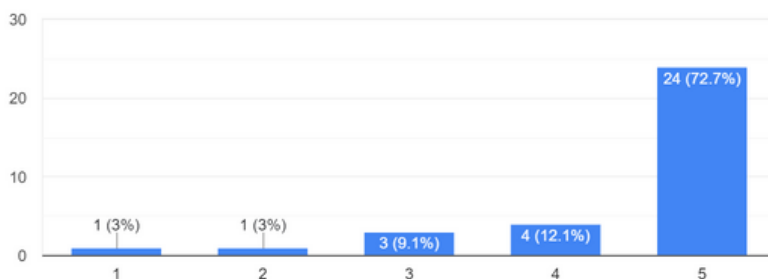
More than 87% were very satisfied with the event and over 76% rated the networking opportunity and the exchange of experiences with fellow people living with T2D as being the most valuable part of the meeting.

When asked about future engagement, more than 80% of the participants expressed an interest in participating in IDF Europe activities such as focus groups and more than 60% expressed an interest in taking part in research projects and in meetings with policy makers.

After having attended the meeting, which of the following activities would you be interested in participating in?



How likely are you to engage more with your national diabetes association after the event?



Many of the participants also voiced their desire to engage more with their national diabetes associations.

NEXT STEPS

Following this event, IDF Europe plans on taking the following steps:

1 One-on-one discussion with participants

IDF Europe wishes to further understand the individual experience and motivation of participants, as well as their strengths, interests and availability for further engagement as well as their needs and suggestions. This will help inform our strategy to include members in projects that align best with their capabilities and interests.



2. Creating a web portal for information exchange

At the group's request, IDF Europe will create a space where platform members can exchange information, experiences and stay connected. This will also include a repository of relevant resources (publications, etc.). This portal was requested by a majority of T2D members, with a view of building their sense of community. The web portal will be on the IDF Europe website for easy access and exclusive to T2D platform members.

<http://> 

3. Co-creation of a training curriculum based on feedback received during the meeting and during previous focus groups, as well as on experiences/best practices of diabetes associations/IDF Europe members, partners and other patients' groups

- Establishment of a steering committee
- Research on other patient engagement programmes and trainings
- One-to-one online meetings with diabetes associations that have developed a similar engagement programme for people living with T2D
- Survey/interviews of various stakeholders to identify their reasons and ways in engaging with PwD
- Drafting of the curriculum
- Implementation of the pilot training programme (online webinars and working group sessions, in-person meetings) and presentation of the programme at the time of the IDF Europe RC meeting
- Evaluation and adaptation of the training as/if required
- Making the training available to members



NEXT STEPS



4. Organisation of online “exchange of experience” meetings (or other online touch base meetings) to keep the momentum generated at the meeting in Brussels and nurture the “community feeling”



5. Involvement of T2D platform members in IDF Europe projects

IDF Europe wishes to strengthen the voice of people living with T2D by directly including them in research projects. This could include participation in editorial boards for publications, involvement in panels of PwD for EU-funded projects etc.



6. Identification of opportunities to engage with policy makers/share testimonials at events

Many members voiced a desire to take part in such activities and IDF Europe will look to identify opportunities and stakeholders relevant.



7. Expansion of the platform and improving recruitment of new members

IDF Europe wishes to have 50 active members by the end of 2024, ensuring diverse perspectives, skills and opinions, and geographical representation as well as broad community engagement and long-term sustainability.

We thank all participants for taking on the challenge to co-develop this initiative with us and to contribute to its next steps. We also thank our Member Associations for nominating participants and/or supporting the initiative.

We also wish to thank Ashley Ross for his moderation and insightful sessions on storytelling and inner critics, as well as our partners, Lilly Diabetes and Novo Nordisk for their support and trust.

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The meeting gave me another perspective in advocating for T2D issues.

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“

We need to meet, keep in touch, so we can all improve the lives of people living with type 2 diabetes.

”

“

I learned a lot, met wonderful people. I am truly happy that I can be a part of the T2D Platform.

”

“

We have a story to be told and if we go home and don't do anything about the issue [of diabetes], nothing is going to happen.

”

“

Despite many of us having very different journeys, I feel less isolated now.

”



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