60th Annual Meeting

European Association for the Study of Diabetes

9 - 13 September 2024

Madrid, Spain

EASD 2024

International Diabetes Federation Europe

IDF Europe Symposium at EASD 2024

PERSONALISATION OF CARE – THE WAY FORWARD

September 12, 2024

Air Liquide HEALTHCARE

Air Liquide Healthcare is a partner of this symposium

Programme

On September 21, IDF Europe held a symposium on "Personalisation of Care" during the European Association for the Study of Diabetes (EASD) 60th Annual Meeting.

The event brought together people living with Type 2 (T2D) and Type 1 diabetes (T1D), healthcare professionals (HCPs) from different specialties and a policymaker to explore what personalisation of care means for different stakeholders. The goal of the symposium was to gather different perspectives to define the key elements of personalised care and discuss key barriers to, and enablers of, care personalisation. The event set the stage for deeper conversations on how to effectively identify and address the needs of people living with diabetes (PwD) through innovative approaches and ultimately improve their health outcomes and quality of life

Speakers

T2D Advocate
Juan Antonio Giménez Bastida

General Practitioner
Pinar Topsever

Endocrinologist
Oliver Schnell

T1D Advocate
Cajsa Lindberg

Endocrinologist
Sufyan Hussain

Policymaker
Pilar Aparicio Azcárraga

Psychologist
Katharine Barnard-Kelly

Endocrinologist
Antonio Ceriello

Welcome & Introduction

IDF Europe Regional Chair
Nebojša M. Lalić

Moderator

IDF Europe Board Member
João Raposo

Wrap up & Closing Remarks

IDF Europe Chair Elect
Tadej Battelino

Key takeaways

WHY PERSONALISATION OF CARE?

Tailoring diabetes management to the unique needs, preferences and circumstances of PwD is critical to help them make relevant lifestyle changes, manage transitions throughout life , cope with comorbidities and address the mental health challenges associated with living with a chronic condition that requires 24/7 management.

KEY ASPECTS OF PERSONALISED CARE

- **Adaptability:** it should be possible to adjust care outside of standardised protocols.
- **HCPs' role:** HCPs should take into consideration PwD's lived experiences, involve them in shared decision-making and adopt a holistic approach to their care.
- **PwD empowerment:** health literacy, empowerment and confidence are key to PwD actively engaging in their care and trusting the value of their lived experience.

COMMUNICATION AND PSYCHOSOCIAL SUPPORT

- HCPs need to recognise the **connection between the body and the mind** and use patient-reported outcomes (PROMs) and patient-reported experience measures (PREMs) to understand what matters to PwD.
- Good **communication skills** are essential for HCPs to listen attentively to PwD, although a **lack of time** often limits this.
- HCPs should be equipped with tools to address the **psychosocial aspects of diabetes** during consultations.
- HCPs should stay updated on the latest **innovations in diabetes treatment**.

DIGITALISATION AND TECHNOLOGY

- Digital tools can **streamline HCPs' tasks**, freeing up time to focus on what matter to PwD.
- The scope of **electronic health records** (EHRs) should be extended to support and inform personalised care.
- Digital apps can support PwD in managing their diabetes, although **interoperability and data-sharing** remain a challenge.
- **Digital solutions** need to be **localised**, easy to use and adapted to PwD's needs and **language** to be effective.

HEALTH SYSTEM ORGANISATION

- Primary care is key to care personalisation due to its **proximity to the community** and knowledge of PwD.
- **Integrating primary care** with specialised diabetes centres, **empowering diabetes nurses** and **ensuring continuity of care** with the same HCP team can improve personalisation.
- Strengthening primary care services for **early diagnosis and regular follow-ups** can support effective and personalised diabetes care.

Welcome and Introduction

IDF Europe Regional Chair, Prof. Nebojša M. Lalić, opened the symposium, welcomed everyone and emphasised the importance of advancing personalisation of care to reduce the burden of diabetes and its complex management.

The first part of the symposium was structured around four conversations on what personalisation of care really means to PwD and what is needed to drive it; the importance for HCPs to get to know healthcare system users; the need for transforming healthcare systems for optimal care personalisation; and the main barriers to, and enablers of, personalisation of care.

DIALOGUE 1: What does personalisation of care mean and what is needed to drive this?

Dialogue between PwD

During the first dialogue, T2D and T1D advocates, Juan Antonio Giménez Bastida and Cajsa Lindberg, shared their personal experiences of living with diabetes and the impact that access to, or lack of, personalised care had on the management of their condition.

Juan was diagnosed with T2D in 2020 after testing his blood glucose levels with his father's glucose meter during a time when, due to the COVID-19 pandemic, access to regular check-ups was restricted. Since his diagnosis, he has made significant lifestyle changes, all self-driven and managed: ***"All the changes I made were performed based on my personal decisions."*** Without personalised advice, Juan learned how to adjust his diet, incorporate physical activity in his daily activities and use technology to effectively manage his condition. He also discovered how different foods affect his glucose levels, noting that this may vary from person to person and subsequently highlighting the importance of access to personalised nutritional advice. In Juan's experience, ***"The health system in Spain lacks personalisation of care for T2D."***

Cajsa was diagnosed with T1D in 2002 and has had varied experiences with care personalisation. At the time of diagnosis, the lack of personalisation made managing her diabetes difficult and **"took a toll on me both physically and mentally."** She highlighted the importance of personalised care during life transitions, such as moving from paediatric to adult care or switching self-management devices. Despite challenges, she also had positive experiences with personalised care, including access to a real-time continuous glucose monitor (rtCGM) in 2012 to manage hypoglycaemia unawareness, which was uncommon at the time. Later, during her cancer treatment, her diabetes management was adapted to prioritise her overall health. After recovery, she appreciated that "more time was given with my endocrinologist to address all my endocrine conditions together. I was considered as a whole person."

Defining personalisation of care

After sharing their perspectives, Juan and Cajsa defined care personalisation as a multidisciplinary approach tailored to the unique needs, preferences and circumstances of each individual living with diabetes. According to them, personalised care requires answering fundamental questions to meet the specific needs of PwD.

They highlighted key aspects of care personalisation, including:

ADAPTABILITY

While some level of standardisation is necessary, there must also be some flexibility to adjust treatment (e.g. care targets, medical technology, medications) and the format of consultations based on an individual's life circumstances to better meet PwD's needs at that point in time.

HCP ROLE

For HCPs, personalising care involves:

- Having confidence in their expertise while recognising the value of PwD's lived experience.
- Taking a holistic approach, bringing PwD into the discussion and including them in decision-making processes to ensure that their care is aligned with their unique needs.

PwD ROLE

For PwD, effective personalisation requires:

- Courage to navigate power imbalances and hierarchies in healthcare settings, asking for what they need and trusting that their lived experience matters.
- Health literacy, empowerment and an understanding of the healthcare system, which is often developed over time, building the confidence to engage in shared decision-making.

There needs to be some level of standardisation in diabetes care obviously, but there also needs to be more room for adaptation to meet PwD's specific needs and desired targets.

– Cajsa Lindberg

DIALOGUE 2: Getting to know healthcare system users, how do you make a science of it?



Dialogue between a psychologist, a general practitioner and an endocrinologist

During the second dialogue, Dr. Katharine Barnard-Kelly, Dr. Sufyan Hussain and Dr. Pinar Topsever discussed the importance of getting to know healthcare users to provide personalised care.

From the perspective of a psychologist, Dr. Barnard-Kelly highlighted the importance of acknowledging patient-reported outcomes to understand what truly matters to PwD in managing their condition and what resonates with their individual lived experiences. She emphasised the fact that PREMs and PROMs are essential tools for improving both the physical and the mental well-being of PwD: ***"The pancreas is not separate from the rest of the body and the mind"***. Dr. Barnard-Kelly called for a more holistic approach to care and noted that this is particularly challenging within a system that focuses on acute physical care.

Reflecting on the tasks of primary care physicians (PCPs), Dr. Topsever emphasised their critical role in empowering PwD, particularly those living with T2D, by providing personalised information to help them manage their condition. PCPs are uniquely positioned to do this, as they are closely connected to the community and have in-depth knowledge of PwD's clinical history. Dr. Topsever also highlighted the growing importance of EHRs and investments in healthcare systems digitalisation. Initially used for reimbursement purposes, EHRs are now increasingly being leveraged to improve care quality. ***"The next step is to use those records to deliver more personalised, person-centred care."***

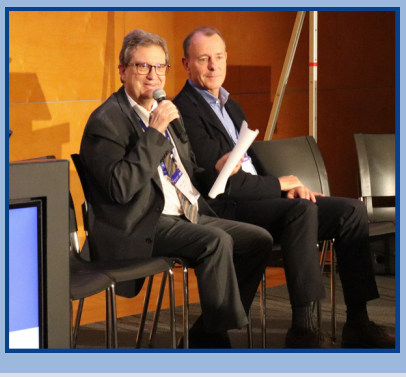
As an endocrinologist and a person living with T1D, Dr. Hussain stressed the need to eq*uip HCPs with the right communication skills to listen to PwD and truly understand their needs.* ***"Doctors are often very distracted by the multitude of tasks they need to manage during a 20/30-minute consultation,"*** Dr. Hussain explained. This can detract from their ability to listen attentively. Good communication and listening skills can help HCPs understand the complexity of PwD's lives and provide motivation for behavioural changes that can lead to improved health outcomes. Dr. Hussain also highlighted the potential of digital innovations to help streamline tasks. Technology can be used to support HCPs by consolidating and visualising PwD data to reduce distractions during consultations. He concluded by stressing the importance of "relation continuity" as opposed to "information continuity". Being followed by the same team of HCPs throughout time is key to effective care personalisation.

DIALOGUE 3: Transforming and standardising healthcare systems for optimal care personalisation

Dialogue between HCPs from different healthcare systems

During the third dialogue, Prof. Schnell and Prof. Ceriello discussed how the configuration of healthcare systems can influence personalisation in diabetes care.

Prof. Schnell explained how healthcare systems can leverage digital apps to tailor diabetes treatment to PwD's needs. He highlighted the example of the **Digital Health Application (DiGA) programme in Germany**, which allows HCPs to prescribe digital health apps for diagnosing, treating and managing various chronic conditions. However, Prof. Schnell emphasised the fact that, to fully harness these innovations, there is a critical need for improved interconnectivity. Currently, while these digital tools provide support to people living with diabetes and other chronic conditions, they do not allow for data to be shared with HCPs, hindering their potential for effective care personalisation.



Prof. Ceriello presented an overview of healthcare systems in various countries, illustrating how various models of diabetes care organisation and delivery can support personalisation. He highlighted Italy as an example, demonstrating how **integrating specialised diabetes centres with primary care** can help providing personalised care. The role of diabetes nurses in the UK, who are in some cases allowed to prescribe diabetes medicines, was also described as a key element supporting care personalisation.

Breaking barriers – Enabling change

Perspectives from a policymaker

Concluding the first part of the symposium, Dr. Aparicio, who represented the policymaker's perspective, shared insights on barriers to, and enablers of, care personalisation.

Dr. Aparicio emphasised the **importance of a strong primary care system**, especially in countries like Spain, where the prevalence of diabetes is high. She emphasised the critical role of **continuity of care** and access to **early diagnosis and regular follow-ups** throughout PwD's life course to enable effective care personalisation. Dr. Aparicio also explained how the interconnected network of healthcare centres across Spain allows for effective **data sharing** and that this system is being successful in preventing hospitalisation for diabetes-related complications.

Panel Discussion and Q&A

Following the various sessions illustrating the perspective of various stakeholders, speakers gathered on the stage to address questions from the moderator, Prof. João Raposo, and the audience.

Question from the moderator: *In healthcare, we often rely on data and numbers to guide our approach. How do we balance standardisation with the need for more personalised care? How can we identify individuals who may not align with the "average" and ensure their unique needs are met?*

Dr. Aparicio: *Both approaches should coexist. We need public health policies that address the entire population, while also ensuring effective personalised care at every level of the healthcare system, not just in primary care. This is why continuity of care is crucial.*

Question from the moderator: *Should we train all HCPs to provide different care to different people?*

Dr. Barnard-Kelly: *In my experience, there isn't always a correlation between quality of life and HbA1c or time in range. PwD may have optimal numbers but still feel extremely challenged in achieving that. We can personalise care for everybody. In the UK, we support HCPs with evidence-based resources across the psychosocial spectrum for them to use and share with PwD. As psychologists, our role is not only to support PwD but also to help HCPs be confident and competent in addressing psychosocial issues. Data shows that this can be integrated into regular consultations without extending their duration.*

Dr. Topsever: *Digitalisation in healthcare offers great benefits for follow-ups and managing complex conditions, but it should empower both PwD and HCPs. It should not add complexity, create extra work or increase anxiety. Trust in HCPs is also built through continuity of care, which is a key role of primary care.*

Prof. Ceriello: *We try to personalise care, but a key barrier is the limited time HCPs can dedicate to each PwD. This is a problem in every country, driven by a lack of resources and HCPs shortages. A shared solution should be found at European level through collaboration between all stakeholders.*

Remark from the audience: *Data shows that 40% of PwD experience diabetes distress. However, many do not have the space or the vocabulary to describe what they are experiencing. Do we need more psychological support? Perhaps not. But we do need to ask more questions about psychology during consultations, as some PwD may not know that they are experiencing diabetes distress.*

Prof. Schnell: *In some European countries, like Germany, access to care and medication is generally not an issue. However, there is a significant gap between real-world treatment and guidelines. New treatment approaches are often underutilised. I believe HCPs should stay informed about new treatment and diagnostics. There needs to be a shift in mindset – not waiting passively for education, but taking personal responsibility to stay up to date with the state of the art.*

Question from the audience: *At the time of diagnosis, the relationship and the communication between HCPs and PwD is critical both in terms of what is communicated and how it is communicated. This interaction has a strong impact on how PwD will manage their condition. This also applies to digital tools. How is the language used in digital applications accounting for this?*

Prof. Schnell: *There is still a long way to go. Digital solutions need to be localised. The use of language is very important with these tools. In some cases, they are still not able to capture the right language and to tailor it to PwD's needs. These tools should not be too technical, they should be easy to use, simple and intuitive. This still needs to be improved.*

Question from the moderator: *How can HCPs manage the vast number of apps available for diabetes management, and what should they do if PwD present an app they are unfamiliar with?*

Dr. Hussain: *HCPs should learn from them to better understand what tools are available and how they could help other PwD. It should be seen as a resource. Technology is going to change our roles, how we interact and what we do, but it cannot replace some human tasks. Hopefully, it will be able to help with challenges such as resource allocation, timing and staffing. Interoperability is essential, and data should be patient-owned to foster trust among users.*

Question from the moderator: *Which outcomes are relevant for PwD?*

Cajsa Lindberg: *Fundamentally, the physical health is important, but also the mental health and how that impacts our diabetes management. Our daily life has a huge impact on our ability to manage diabetes. Simply listening to what PwD are saying is already effective. The problem is how to standardise this. As an example, with a youth organisation we used a questionnaire that PwD could fill in before a consultation with their HCP to guide the conversation. HCPs were able to read it and understand what they needed to talk about in order to optimise their diabetes management.*

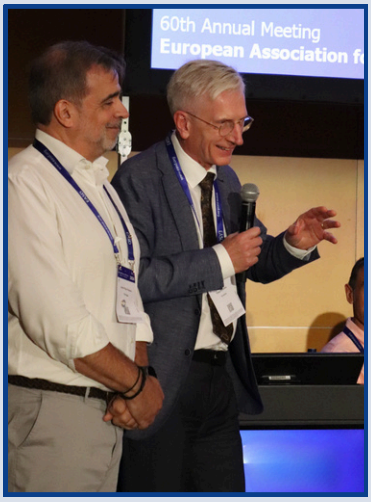
Question from the moderator: *Health systems need to adopt digital solutions, but the pace of innovation is often faster than the approval process of health ministries and regulatory agencies. How can health systems effectively incorporate new digital solutions quickly while ensuring and measuring their quality for personalised care?*

Dr. Aparicio: *Technology is supposed to improve the lives of PwD and the work of HCPs. However, there are many risks related to quality, ethics, privacy and the sensitivity of health information. Introducing these innovations presents a major challenge, and I hope the European Union can support all countries in addressing this issue. There is much work to be done. For healthcare systems to provide quality care, robust data is crucial. However, managing the vast amounts of data effectively is a challenge due to limited human resources. We need to consider how to use this data effectively. It is not only about quantitative data but also understanding the experiences of PwD through PROMs and PREMs, which are essential for improving care quality.*

Prof. Ceriello: *Identifying ways to monitor and assess the quality of digital solutions is also crucial. More research is needed, and several studies are ongoing. The perspective of PwD should also be included in this process.*

Closing Remarks

After the panel discussion, IDF Europe Chair Elect, Prof. Tadej Battelino emphasised the **need for solutions to advance personalised care** and improve HCPs education to effectively support people living with chronic conditions such as diabetes. He highlighted the **potential of artificial intelligence**, the need for **standardised EHRs** across Europe and the **integration of health systems**. Prof. Battelino also stressed the fact that **early access to care**, **early identification** and access to the best available therapies are crucial for personalised care. He concluded by calling for **increased political focus on diabetes** at the European level and inviting all stakeholders to support IDF Europe's efforts to find meaningful solutions for PwD.



Next steps

This symposium marked a significant first step in our work on personalisation of care. By gathering the perspectives of several stakeholders, we have now set the stage for more in-depth conversations on each of the key aspects of this important topic. Based on the insights shared at the symposium, IDF Europe will, over the coming months, organise a series of activities to further explore them in collaboration with all relevant stakeholders. From podcast episodes to events, publications, and more, **IDF Europe warmly invites all members of the diabetes community to join and be an active part of this important conversation.**

Before the symposium, IDF Europe began developing content on this topic, publishing its very first **podcast episode**, featuring a conversation about personalisation of care between the symposium moderator, Prof. João Raposo, and T2D Advocate, Erik Werson.

LISTEN TO THE PODCAST:

International Diabetes Federation
Europe

IDF Europe wishes to thank all the speakers and attendees who joined the event and our partner, Air Liquide Healthcare, who helped make the symposium happen.

We look forward to continue collaborating with our community as we drive forward these essential conversations.

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