

The European Diabetes Forum (EUDF): a forum for turning the tide on diabetes in Europe

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Abbreviations

EASD European Association for the Study of Diabetes

EUDF European Diabetes Forum

Diabetes is a rapidly accelerating public health crisis demanding immediate policy attention. It is an emergency hiding in plain sight: in Europe today, estimates show that 1 in 11 adults, or 61 million people, live with diabetes; this is more than the population of Italy [1]. And the epidemic of diabetes does not show any sign of abating. Its prevalence is expected to grow a further 13% in the European region by 2045. Diabetes remains one of the most undertreated and underestimated of all common medical conditions. Society has no real sense of what living with diabetes means: the sheer scale of the health indicators one must constantly track and trace; the omnipresent threat of complications; the fear and anxiety about the future [2]. The disproportionate impact

of COVID-19 on people with diabetes has highlighted the severity of the crisis. Earlier in the pandemic, for instance, as many as one in three COVID-19-related deaths were of people with diabetes [3]. Diabetes also poses unique stresses to health systems and economies. This is not just in terms of direct medical expenditures, now €170 billion and rising, but also, in an age of health staff shortages, of allocating health resources. Diabetes also engenders indirect costs, including diminished productivity, absences due to sickness, disability, early retirement and premature loss of life [4]. Moreover, type 2 diabetes is increasingly affecting people at a younger age, and the disease is more aggressive at a younger age [5]. With regards to childhood onset of type 1 diabetes, the Europe region has the highest number of children and adolescents with type 1 diabetes: 295,000 in total [1]. This only magnifies the total burden.

However, all too often stakeholders, like the scientific and medical communities, but also people living with diabetes and industry, approach policy makers from different angles and with different focus points, thus diluting the overall message and allowing policy inertia.

EUDF

After several years of preparation and exploration of the needs in Europe by Dr John Nolan (European Association for the Study of Diabetes; EASD), the European Diabetes Forum (EUDF) was founded as a non-profit organisation under Belgian law in 2019 by EASD, EFSD (European Foundation for the Study of Diabetes), FEND (Foundation of European Nurses in Diabetes) and JDRF (Juvenile Diabetes Research Foundation). After the launch, PCDE (Primary Care Diabetes Europe), SFD (Société Francophone du Diabète), IDF Europe (International Diabetes Federation Europe) and ISPAD (International Society for

CM represents the European Association for the Study of Diabetes (EASD), JS represents the Juvenile Diabetes Research Foundation (JDRF), SDP represents the European Foundation for the Study of Diabetes (EFSD), A-MF represents the Foundation of European Nurses in Diabetes (FEND), XC represents Primary Care Diabetes Europe (PCDE), CdB represents the International Society for Pediatric and Adolescent Diabetes (ISPAD), J-FG represents the Société Francophone du Diabète (SFD), BH represents the International Diabetes Federation Europe (IDF Europe), AF is the chair of the Strategic Forum on integrated care, RH is the chair of the Strategic Forum on data and registries and represents the European Federation of Pharmaceutical Industries and Associations (EFPIA), PS is the chair of the Strategic Forum on digitalisation, and BT represents the European Diabetes Forum (EUDF).

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Pediatric and Adolescent Diabetes) joined EUDF as members. The EUDF has pharmaceutical and medical technology companies as supporting collaborators (www.eudf.org).

EUDF is a platform to bring together stakeholders from across the diabetes landscape in Europe to present a harmonised voice on the needs of the diabetes community to governments, regulators, payers and others. It is the EUDF scope to influence future policy and engage with political leaders and decision makers around Europe to advance the agenda of diabetes and advocate policy change to enable the healthcare systems to cope with the diabetes pandemic. During the COVID-19 pandemic, there was less political attention to non-communicable diseases such as diabetes. EUDF action may be even more critical after the COVID-19 pandemic and the financial constraint that may ensue it.

The mission of EUDF is to ensure the translation of research and clinical evidence into policy actions towards better diabetes care at a national level. Apart from working at the European level, EUDF also supports the translation of the efforts at the European level to national and regional initiatives. At present, several national/regional forums are realised or are being realised, two successful examples are the Belgian and Romanian Forums (www.belgiandiabetesforum.be; www.forumdiabet.ro).

So far, three main areas of policy focus have been identified: technology, digitalisation and empowerment of self-care; data and registries; and integrated care.

EUDF actions: creation of Strategic Forums

To make the objectives tangible, EUDF established three Strategic Forums over the course of 2021 to generate policy recommendations. Chairs for each Forum were presented by the member associations of EUDF based on their specific expertise and appointed by the board of EUDF. All member associations and supporting collaborators were then invited to propose experts for each Strategic Forum (approximately 15 per Forum). Each Strategic Forum defined its work plan and key deliverables, following a ‘Situation–Complication–Resolution’ approach [6]. The Strategic Forums were supported by an independent agency to facilitate the work meetings and ensure the execution of the work plan. All members and chairs worked as volunteers.

EUDF Strategic Forum-proposed solutions for achieving better outcomes in diabetes care in Europe

Integrated care represents efficiency and value for money, and it needs to be at the foundation of diabetes healthcare in every setting and country in Europe Care integration has already previously been identified as having an important impact

on the quality, efficacy and efficiency of diabetes management [7]. While a number of models and pilot programmes have shown the benefits of integrated care in diabetes, the experience for many patients and health professionals is that there are still significant deficits in the level of integration across care systems [8]. In part this reflects divergent organisational infrastructures, determinants and resources for diabetes care across Europe. The failure to enhance care integration results in inefficiency and suboptimal clinical performance, driving up care costs and increasing the health burden on people living with diabetes.

This behoves us to rethink and redesign care in ways that are better suited to the needs of people with diabetes, in particular focusing on identifying a framework to ensure a patient-centred approach across the life span [9]. Consideration should also be given to the use of technology, addressing inequalities in diabetes care and ensuring that psychosocial as well as metabolic health outcomes are addressed. For health professionals, the focus should be on supporting integrated care models and pathways, introducing strategic and personalised care models, rather than following routines, and enhancing communication skills. At the system level we should consider how to construct transferable principles that can be applied across divergent health systems. This includes system-level learning models and strategies to incentivise care integration [10].

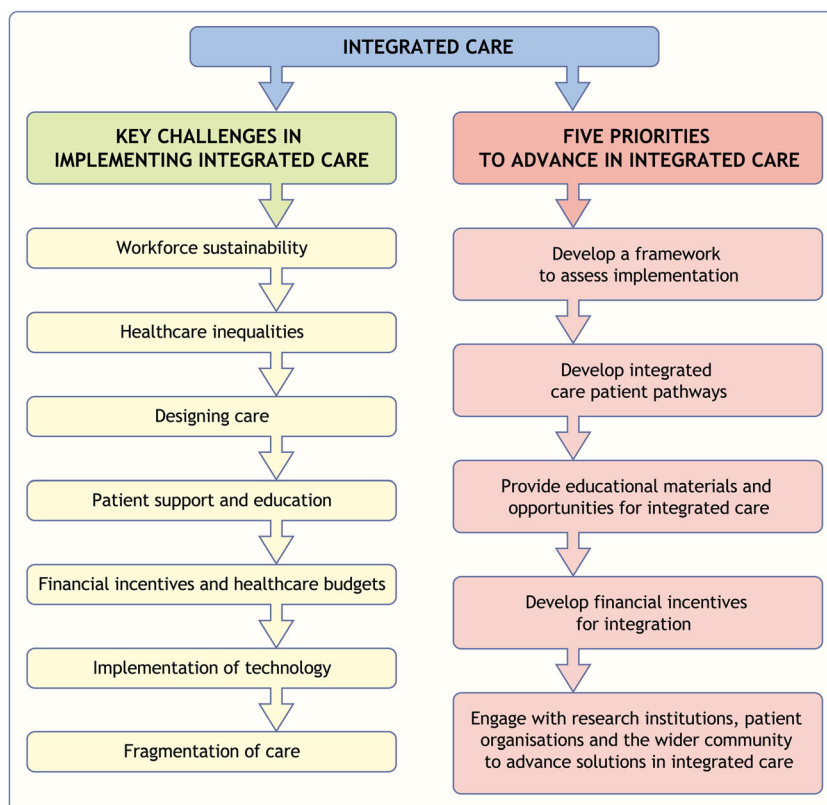
With this in mind, the EUDF proposes strategies to improve integration in all care settings, including implementing assessment models, developing patient-centred pathways for diabetes care, revamping educational curricula and putting incentives in place to encourage cooperation and teamwork within and between primary and secondary care settings (Fig. 1). The recommendations are described in detail on the website of EUDF (<https://www.eudf.org/our-work/recommendations/integrated-care/>).

It takes more than just a registry to improve care, we need to use data to raise awareness and initiate action to improve outcomes for people living with diabetes

The diabetes community in Europe has launched several programmes and actions over the last decades, including the St Vincent Declaration, with the intent to improve the outcomes of care [11, 12]. These were ambitious projects with challenging treatment goals. Unfortunately, these initiatives resulted in incremental improvements that were far less than required or hoped for [13]. In most countries the outcomes of care could not be monitored because of the absence of quality registries [14]. At present, most data on diabetes in Europe are estimated, rather than robust, with the exception of a few countries and regions in Europe [15–17]. These registries could provide us with valuable scientific data but often are not sufficiently applied to measurably improve diabetes care.

We need to learn from these experiences and avoid making the same mistakes. One of the key learnings is that it takes

Fig. 1 Challenges and priorities to advance in integrated diabetes care. To achieve integrated diabetes care, several challenges need to be overcome. We propose five priorities that need to be realised in order to advance integrated diabetes care



more than just a registry to improve care. First, there needs to be the recognition by healthcare decision makers that changes are essential. Second, a dedicated team needs the authority to initiate the development of a local/regional data registry and lead and manage this registry with the mandate to drive change where needed to improve the well-defined and agreed upon outcomes of care. Third, following a successful regional effort, we need the roll-out of a broader European registry.

Diabetes registries are essential to enable a more evidence-based and data-driven approach to diabetes management. Registries may ensure quality control and better adherence to guidelines, track performance across clinics or regions and help identify the reasons for variation in outcomes, and inform the delivery of care and treatments, which can reduce costly complications. An example of how such registries could look like is the global paediatric SWEET registry (www.sweet-project.org).

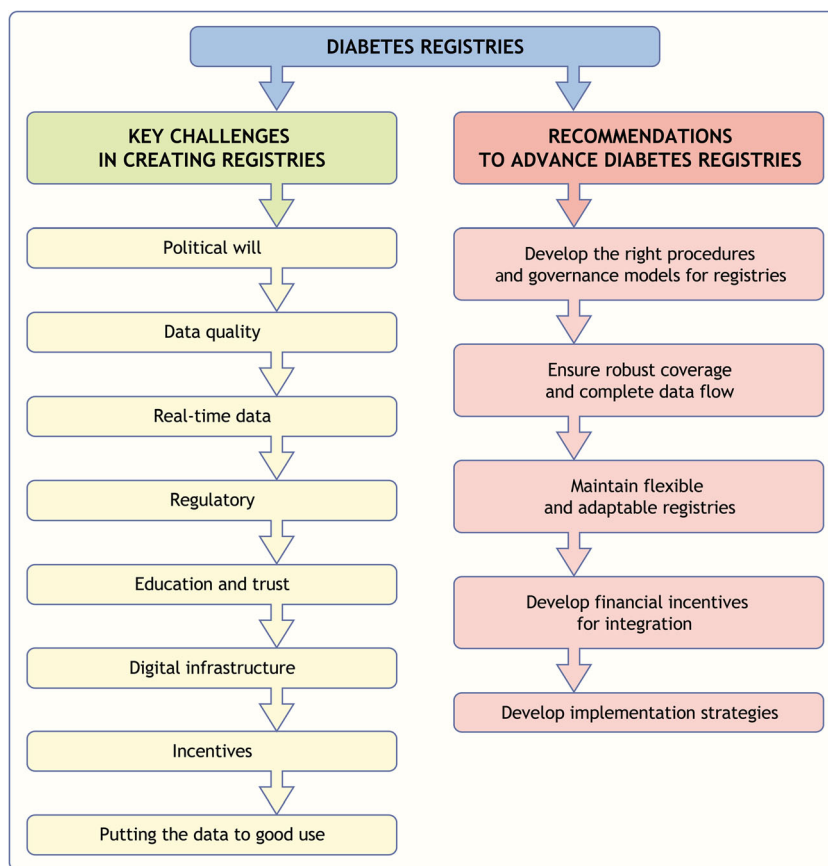
Policy makers, health authorities, healthcare professionals, industry and people with diabetes must work together to advance the development of registries throughout Europe where they do not exist, or to expand and strengthen those where they do. The EUDF has set out recommendations (on the governance of registries, on procedural aspects like data input or the indicators that should be included and implementation strategies) to help make this happen (Fig. 2). The recommendations are described in detail on the website of EUDF (<https://www.eudf.org/our-work/recommendations/data-and-registries/>).

Creating an environment where successful digital solutions can easily be shared throughout Europe to support their people with diabetes We are currently observing two distinct trends around the use of digital tools in diabetes care [18]. On the one hand, we see inertia among physicians when it comes to using and introducing digital tools. On the other hand, the development of intuitive digital tools triggered by patient needs is very rapid. The landscape has changed dramatically and there is now a very fast-growing number of best-practice solutions in Europe. Often, these solutions are used only in a very small environment.

There is evidence that digital support in the form of an app or an online programme can help in improving the empowerment of people with diabetes, which leads to better self-management and finally to improved decision-making by people with diabetes [19, 20]. It is essential to equip people with diabetes with the knowledge and tools they need to better manage their condition. Smartphones have long become integrated into people's day-to-day lives, an integral part of the way people work, shop and socialise.

Improving the self-management capacities of people with diabetes is key to achieving a high level of compliance to therapy (matching behaviour to medical advice), improved health outcomes and a better quality of life with reduced long-term complications. Here, digital tools, including mobile apps, can serve as the patient-facing interface for digitally enabled care, giving people with diabetes and their care teams tools to manage their condition through better day-to-day support, greater

Fig. 2 Challenges and recommendations to advance diabetes registries. This figure identifies key challenges for the establishment of diabetes registries, and proposes recommendations to advance the realisation of diabetes registries. Importantly, no hierarchy in recommendations is suggested in this figure



flexibility and more connectedness with healthcare providers, which can help enable remote monitoring and more data-driven decision-making [21].

Many countries in the EU are already starting to devise policy solutions to support health and diabetes apps. We suggest creating an environment where solutions that prove successful for people with diabetes in one country can easily be shared with other countries, stakeholders and organisations to support people with diabetes, starting with those that have proved effective, and help them broaden their reach into Europe. The EUDF hopes to accelerate this process with recommendations on developing a user-centred app, implementing a best-practice access pathway for apps and supporting the integration and uptake of high-quality apps into the health ecosystem (Fig. 3). The recommendations on digital care are described in detail on the website of EUDF (<https://www.eudf.org/our-work/recommendations/diabetes-technologies/>).

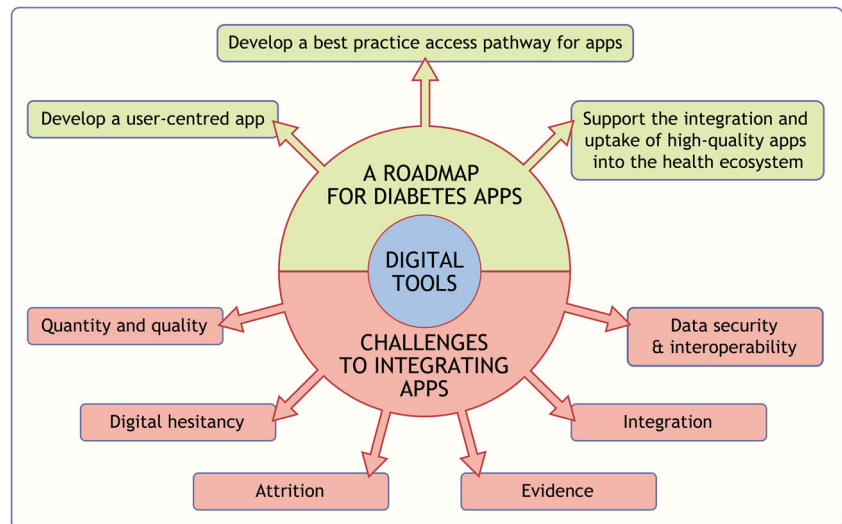
The path forward: action needed

From its inception, EUDF has been working with WHO and WHO Europe to align messages and discuss priorities. EUDF welcomed the Global Diabetes Compact of WHO [22] and has been accredited as a ‘non-state actor’ for WHO Europe.

While endorsing the coverage targets proposed by WHO, we want to refine them further to European standards and introduce coverage targets for diabetes into the European Diabetes Report, thus promoting diabetes care in Europe.

There are currently several opportunities in the European policy environment to advance the proposed solutions. In June 2022, the European Commission launched a comprehensive roadmap, ‘Healthier Together – EU non-communicable diseases initiative’, to guide and support member states in addressing the burden of highly prevalent non-communicable diseases [23]. The Healthier Together initiative covers five disease areas, including diabetes. From June 2022 onward, the implementation phase of the EU non-communicable diseases initiative will start with the support of EU-level funding instruments. EUDF and its members gave input on the priorities of the initiative and provided examples of best practices. Now EUDF’s work continues on a member state level for a successful implementation of the best practices. Countries and stakeholders are able to apply for support and funding for the implementation of their selected policy projects and interventions, using EU-level funding instruments, of which EU4Health [24] is the primary one. In addition, a Joint Action on cardiovascular disease and diabetes has been launched, funded under the 2022 EU4Health Work Programme [25]. Member states should submit their proposals to the European Commission for the development

Fig. 3 Challenges and recommendations to advance apps in diabetes care. Digital tools occupy a central place in diabetes care. Challenges and recommendations to the development and use of apps in diabetes care in Europe are shown



and implementation of the Joint Action, which is expected to kick off in 2023. EUDF will continue to engage on these opportunities and stimulate country experts and partners to contribute to the country implementation and propose specific projects.

Conclusion

Diabetes is one of the greatest health challenges Europe faces today. However, there are reasons to believe we can face up to and overcome this challenge if we deploy the tools available and take the concrete policy actions needed. All major diabetes stakeholders in Europe now come together in the EUDF to generate policy recommendations and ideas for implementation. Spearheading these solutions in integrated care, registries, and digitalisation and self-care will promote a more data-driven and person-centric approach to healthcare and diabetes management that should pay off in terms of fewer complications, improved quality of life and more efficient use of clinical resources.

The EUDF will continue to serve as an expert partner to promote these efforts, acting as a forum for a collaborative campaign for policy change. Our vision is to achieve better outcomes for people with diabetes and enable healthcare systems to cope with a devastating epidemic that can no longer be swept aside. The time to act is now.

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