Diabetes care at the test of digital age
Digitalisation and integrated care can offer a new range of solutions for improving the quality of diabetes treatment and even securing better patient outcomes.

The use of digital tools in diabetes care, which requires constant control, represents an interesting case study at the dawn of the EU’s health data revolution fuelled by the ambitious project of a European Health Data Space (EHDS) recently proposed by the EU executive.

In this series of articles, EURACTIV explores the options available for diabetes patients that can be untapped by digitalisation and a data-driven approach to healthcare.
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Digital tools to play key role in transition to data-driven diabetic care

By Clara Bauer and Gerardo Fortuna | euractiv.com

Diabetes registries collecting patient data and new digital tools directly used by patients are considered by stakeholders some of the best options to improve the quality of diabetes care ahead of the EU’s health data revolution.

About 32.3 million adults were diagnosed with diabetes in the EU in 2019, and while countless people struggle to get help managing their condition, some are never diagnosed.

A set of policy recommendations drafted by the European Diabetes Forum (EUDF) insists on the importance of digitalisation, data registries, and integrated care to change the approach to diabetes management and improve patients’ quality of life.

Digitalisation, in particular, promises new developments in diabetes care after the recent unveiling of the much-awaited
European Health Data Space (EHDS), which is expected to revolutionise the European healthcare system as we know it.

“We are in the pocket of our patient: we never had such a good opportunity to be so close to our patient,” explained Peter Schwarz, a doctor at the University of Dresden, at the launch of the policy recommendations.

According to him, this new digital potential also brings new challenges and the need to rethink how digital tools are used to address the need of patients.

“Digitalisation is not about providing new opportunities for physicians or about providing new ways to store data. It is a big chance to address the need of our patients,” he stressed.

For instance, making these new apps accessible to all patients remains a thorny issue.

“The question of whether a certain service is available to everybody who needs it is very important. We don't want to run the risk that [the service] cannot be used by the most vulnerable parts of the population,” said Stefan Schreck, deputy director-general at the European Commission’s health service DG SANTE.

He added that a key policy aim of the EU executive for all the initiatives in this area is about not widening the gap between those in a better position to access these digital tools and those not that exposed.

In the recommendations, the EUDF experts suggested the development of a best practice access pathway, including processes to enable or accelerate access to digital health apps harmonised at the EU level.

**Interoperability and patient involvement**

Another aspect that needs to be addressed is the interoperability between the many apps available on the internet, particularly if patients decide to move from one digital tool to another.

To have a relevant use of the apps, Finnish MEP Sirpa Pietikainen also pointed out that interoperability between apps and public healthcare systems must be ensured. This aspect is addressed in the EHDS proposal, which is expected to make the exchange of data between the different management systems and across borders easier.

Pietikainen also mentioned the importance of “bringing patients to the app’s process”. In other words, apps need to be accessible for everyone and not only for people used to technology or technical devices.

She said that isolated and old people are the “target group that should benefit most of these apps”, as well as from digital devices and remote doctors’ visits; otherwise, it would lead to a digital gap.

Schreck also welcomes the involvement of diabetes people in the development of these apps. “It is clear that digital tools need to be designed in such a way that patients like to use them,” he said.

Cajsa Lindberg, who is living with diabetes, shared her feelings on the different applications that already exist. “The most successful ones are the ones that are automatic, and data doesn't have to be logged.”

She also explained that “diabetes is a disease where your decisions are made every few minutes. Therefore, the most successful apps are the ones that help people “in the moment”.

According to her, people living with diabetes and diabetes associations should be involved not only in the development of apps but also in other aspects of diabetes disease management. “The biggest mistake you can make is not involving people with diabetes” she said.

**Data protection**

However, the priority remains protecting patients’ data which requires a “strong data security regulation that we more or less have in Europe”, said Pietikainen, who also mentioned the “strong responsibility” of the companies storing data.

“I see tremendous possibilities of the data space for the benefits of people”, she concluded.

The trust component remains crucial for the digital space uptake, as the European Commission highlighted in presenting the EHDS proposal. The EU executive suggested the need for an additional layer of security protection compared to the already robust EU’s privacy framework.

“We know very well that often the GDPR is interpreted in different ways in different member states, which makes the transport of data more complicated,” said Commission’s Schreck.
“The important thing is that there is a balance between sacrifices you make in sharing your data and the benefits you get back,” the Lindberg pointed out.

**Untapping the potential of registries**

Diabetes registries also play an essential factor in determining successful future policies and, together with electronic health records, are also included in the EHDS proposal.

National and even sub-national diabetes registries are used mainly for surveillance, clinical management or improving the quality of care, and they could benefit from digital automatisation.

Diabetes registers can inform decision-makers in real-time on health care resource allocations with an added value to the quality of diabetes care.

“It needs to be a sense of urgency to make this work,” Robert Heine from pharma company Ely Lilly said, suggesting the importance of establishing a European forum where all health data registries can be discussed.

Schreck mentioned some projects already at hand in the European Union, such as the European Cancer Information System and the European Rare Disease Registry platform.

“These cannot be used directly for diabetes but can give some inspiration for how to set up a registry and for what can be done at the European level to assist people in the member states to set up such registries and to ensure the collection of data across borders,” he concluded.
Integrated care can break silos in treating diabetes, says health expert

By Gerardo Fortuna | euractiv.com

Languages: Deutsch

People living with diabetes must be put “in the driver’s seat” of their treatments thanks to the integrated care concept, a health expert told EURACTIV.

Integrated approaches to healthcare aim to avoid silos in the course of a certain treatment or a variety of treatments, increasing cooperation between different actors and healthcare providers to better deliver holistic care for patients.

Such an approach can be particularly valuable for people with diabetes, as they often deal with a range of specialists and healthcare workers, from cardiologists and primary doctors to caregivers and eye doctors.

Organising the care pathway bycentring the person with diabetes is key, according to Chantal Mathieu, professor of medicine at KU Leuven university and chair of the European Diabetes Forum (EUDF).

“Sometimes cardiologists say ‘do A’ while nurses say ‘do B’ – and it’s very confusing to the person living with diabetes,” she told EURACTIV.

The pandemic has proven the benefits of a concerted approach as opposed to working in silos. “Having integrated care means having the person with diabetes in the driver’s
The seat of everything that is happening with him or her,” she said.

Together with new technologies and data collection, integrated care was one of the three policy recommendations drafted by the EUDF following a year-long project that saw a collaboration of more than 45 experts.

“We had selected these three spearhead working points before the pandemic as we thought they would have been the biggest needs and the emergency confirmed them among the most important ones,” she said.

For instance, the pandemic showed how data and registries are essential. In the first year of COVID-19, “we were flying blind and probably doing the wrong things sometimes,” Mathieu said, ascribing this to the lack of available information about the virus at the time.

“Having data on who has diabetes – but also making this data work – can guide policies as well as determine how much resources you need to put in,” she added.

**Make integrated care work**

Education and information can also play a role in the uptake of the integrated care approach as medical and paramedical schools train young doctors, nurses, and dietitians of the future.

Some schools have already introduced integrated care in the curriculum, Mathieu pointed out, citing the example of her own university, KU Leuven.

In the professional environment, incentive systems can contribute to better integration in health care, she suggested. Belgium, for example, provides an incentive of €80 per year to bring primary care physicians and endocrinologists together.

According to Mathieu, another crucial element to enabling this approach is bringing people with diabetes to the forefront of discussions on care and listening to their inputs.

Digital tools have contributed to empowering people living with diabetes over the past 10 years with the explosion of new technologies such as sensors allowing to measure glucose continuously or insulin pumps.

People with type one diabetes can also use apps and digital platforms to make decisions on their treatment or simply be helped in getting involved in a healthy lifestyle.

“Convincing people living with the disease about the importance of new technologies is perhaps the easiest bit. It’s convincing policymakers but also healthcare professionals, which is not so easy,” said Mathieu.

**‘Healthier together’ and beyond**

The European Commission has recently launched an initiative called ‘Healthier together’ to support member states in reducing the burden of addressing non-communicable diseases (NCDs) in the EU.

The initiative, which will be funded by €156 million from the 2022 work programme for EU4Health, will cover diabetes, together with other NCDs such as cardiovascular diseases, cancers, and chronic respiratory diseases.

“We’re very proud that the initiative includes diabetes specifically. We don’t want diabetes just to be considered a mere risk factor for cardiovascular disease: it is a disease itself,” she said.

As a disease affecting more than 60 million people in Europe, she added, it deserves proper attention specific to the needs of people living with diabetes.

Aside from the new impetus on NCDs, EU policymakers seem to be changing their approach to health – even discussing the possibility of providing Brussels with more powers on the matter.

“I would hope that the next generation will see Europe playing a bigger, leading role in how healthcare is organised, with a vision about where things should go,” Mathieu concluded.
Diabetes is a rapidly accelerating public health crisis demanding immediate policy attention. It’s an emergency hiding in plain sight: In Europe today, 1 in 11 adults (or 61m people) live with diabetes; this is more than the population of Italy.

Francesc Xavier Cos Claramunt is the Chairman of Primary Care Diabetes Europe (PCDE). Bart Torbeyns is the Executive Director of European Diabetes Forum (EUDF).

Based on 2021 data, approximately 1 in 20 Europeans (or 21.9 million people) were living with undiagnosed diabetes and were not receiving any treatment. By the time of diagnosis, many have already developed one or more complications.

Early detection of diabetes is important, as timely and adequate diabetes management could prevent or delay complications, comorbidity, poor quality of life and premature death, as such contributing substantially to decreasing the burden of diabetes for individuals, health systems and societies.

We can prevent or delay complications by ensuring access to high-quality diabetes care, by supporting diabetes patients’ self-management and implementing care models that integrate proactive diabetes management with person-centred, personalised care. Diabetes registries, which collect, track, and analyse patient data are an essential tool for improving the quality of diabetes care and securing better outcomes for people with diabetes.

Type 1 diabetes

Type 1 diabetes (T1D) is the most common chronic disease in children and adolescents. The European
Region has the highest number of children and adolescents living with T1D (295,000) as well as the highest incidence annually with 31,000 new cases per year. The incidence of T1D is increasing in Europe by more than 3% per year.

A large proportion of people with T1D are diagnosed under dramatic circumstances in the emergency rooms, presenting with abnormally high blood sugars and a dangerous, sometimes fatal, condition called diabetes ketoacidosis (DKA). Detecting T1D before symptoms occur is possible through a simple blood test. Screening for T1D would provide people the time to prepare for the diagnosis, develop a plan for further monitoring with their doctor and avoid serious adverse events and hospitalization.

Studies also show that screening for T1D also has positive long-term effects on the course of the disease, with blood sugar levels more often in the normal range. Very high blood sugar levels increase the risk for complications such as kidney disease, heart disease and eye disease.

The prevalence of complications is often underestimated in children and adults with newly diagnosed T1D. For instance, more and more data highlight the recurring existence of risk factors for heart disease also in newly manifested T1D and underlines the need for effective cardioprotective measures from disease onset. Several reports in adolescents and young adults with T1D demonstrate signs of cardiac dysfunction at young ages. Greater focus on cardio protection is warranted in both adolescents and adults with T1D.

Type 2 Diabetes

Given the silent and progressive nature of Type 2 Diabetes (T2D), early detection and prompt diagnosis are critical to avoid long-term complications such as heart diseases, kidney diseases and eye disease. Not only are these complications potentially overwhelming from a personal perspective, but they are also hugely costly to health systems.

Screening people for diabetes and diabetes-related complications will help ensure that the relevant action is undertaken early (e.g., initiation of education and treatment) thereby delaying, or reducing the risk of developing, the condition and/or its complications. While the investment in upfront screening and risk-reduction campaigns might be significant, the case for the cost-effectiveness of prevention has been clearly demonstrated.

Furthermore, targeted screening for type 2 diabetes may be considered, in particular among adults with overweight, obesity, high blood pressure, high cholesterol, or other relevant risk factors. Screening of people at high risk of developing diabetes should be integrated with high blood pressure and hypercholesterolemia screening programs within primary care. Selective screening for diabetes and prediabetes is also recommended for patients with established cardiovascular disease.

Gestational diabetes

Gestational diabetes places an increased risk for the mother and the child to develop T2D and/or T1D later on in life. Detection of women with hyperglycaemia during pregnancy is crucial as they have a higher risk of developing adverse pregnancy outcomes and neonatal problems. Follow-ups of mothers and babies must also be included in all risk-reduction strategies.

In many countries screening for gestational diabetes among pregnant women has been implemented based on guidelines. These guidelines differ according to screening approaches and criteria for gestational diabetes, which results in various screening practices across and within EU countries. To improve the quality and outcomes of gestational screening, guidelines may need to be updated and aligned, and good practices could be exchanged.

Call To Action

Early diagnosis must go hand-in-hand with early action. Newly diagnosed people must gain access to the most adapted interventions (e.g., training and education, lifestyle intervention programmes), medicines, technologies and care, immediately, and for as long as they need them.

We call for the development and implementation of National Diabetes Plans in all EU Member States, which should include a risk reduction and screening component. As the European Diabetes Policy Puzzle shows, there are profound differences among EU countries from a policy perspective, as well as weak implementation standards and poor KPI results. The use of digital tools that allow the compiling of data from screenings across Europe should be encouraged to promote data and best practice exchanges.

With an increased interest from the European Commission, the European Parliament, and the Member States to work on Diabetes, we call for a holistic & integrated approach on diabetes screening, with specific KPIs in different common domains, fully leveraging the opportunities and momentum available in the current policy environment.