



DIABETES IN THE EU BETWEEN AWARENESS AND ACCESS TO CARE

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Diabetes remains a major public health concern despite the efforts to increase awareness and reverse its relentless spread in Europe.

As a complex condition with a multitude of expressions and causes affecting all genders, generations, and socioeconomic groups, diabetes has been on policymakers radars and a lot has been done in prevention and in improving access to diabetes care for patients.

The forthcoming proposal of an EU health data space will come in handy, as it could reinforce the use of data and the recently set up national diabetes registries.

In this series of articles, EURACTIV takes a look at the state of play in diabetes treatment and prevention as well as at challenges in improving the quality of care and outcomes. -

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Improving access to diabetes care will fit into EU's health data space

By Gerardo Fortuna | EURACTIV.com



Woman using a blood glucose meter and a smartphone. One in ten Europeans suffer from diabetes. [SHUTTERSTOCK/MICROGEN]

Diabetes patients will be among the beneficiaries of the much-awaited European health data space, according to policymakers and health stakeholders.

In the coming months, the European Commission will seek to create a trustworthy, patient-centred EU's health data space – a cornerstone of the European Health Union plan to reshape the way health is dealt with across the EU.

Expectations are high for this upcoming legislative proposal which promises to unlock the potential of digitalisation in improving hospital systems and enabling patients to have access to better care.

Among the main beneficiaries could be people with diabetes, a disease which one in ten Europeans suffer from and is envisaged to affect 80 million Europeans by 2045 if proper measures to tackle it are not undertaken.

For the Croatian Christian-democrat MEP Tomislav Sokol, diabetes is one of the biggest public health problems and the EU could address via the European health data space.

“We are putting pressure on the Commission to come up with a concrete legislative proposal [on health data space],” he said at a [recent](#)

[event](#), adding that amendments in the European Parliament will improve the initiative by making the data space a reality for diabetes patients too.

At the same event, the health data space was put in correlation to diabetes registries by Andrzej Rys, deputy director-general at the Commission's DG SANTE. “We believe in the ambition we really should bring digital health to the 21st century,” he said.

DIGITALISATION OF REGISTRIES

Despite the lack of proper competencies on health, the EU can still support the harmonisation of

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healthcare standards across the bloc and support member states in achieving their healthcare objectives.

“The use of data in the area of healthcare is one of those areas where the EU can – and I believe will – provide an added value,” said MEP Sokol.

With the health data space proposal, the EU executive will try to simplify the exchange of and access to health data for different use cases, including healthcare provisions, digital health services and research.

“This includes the quality of registries and electronic health records. We very strongly support accessible medical devices as well as the use of smartphones and other IoT devices,” said the Commission’s Rys.

For the Commission, electronic health records, strictly in line with the GDPR rules, will help improve access to quality care, achieve cost-effectiveness of care delivery and contribute to the modernisation of health systems.

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 automatisisation.

SECONDARY DATA

However, the proposal will raise the problematic issue of secondary use of health data, meaning the way data created and registered for health services or related activities can be used for purposes other than the reason for which they were originally collected.

“We would like to increase access and security of primary data but on other hand, we have also the secondary health data which we believe should be more accessible,” said Rys.

The re-use of health data as secondary data poses problems because of the fragmented digital infrastructure, but also because there is still uncertainty on artificial intelligence (AI) liability in health and there are limited provisions of data for training AI.

Cross-border health data portability and the possibility to enjoy the benefits of the health data space across all member states is another important topic that needs to be addressed by the Commission.

“The EU can do what it can to remove obstacles to this cross border use of data,” said MEP Sokol, mentioning the need for cross-border clinical trials and research as well as the use of European reference networks.

The European Commission has decided against imposing geographical restrictions on the establishment of so-called ‘data sharing services,’ as part of ambitious new plans laid out in the executive’s landmark Data Governance Act.

AUTOMATISATION AND ACCESS

According to Rys, automatisisation is another key area in increasing the quality and access to data.

Likewise, Robert Heine, executive medical director for diabetes at the pharmaceutical company Ely Lilly, said that health data need to be

collected automatically in order to have the double benefit of giving patients access to data and reducing the burden on the healthcare system.

“I don’t think we can ask people to enter data manually anymore. This also should ensure a higher quality of data collection,” he said.

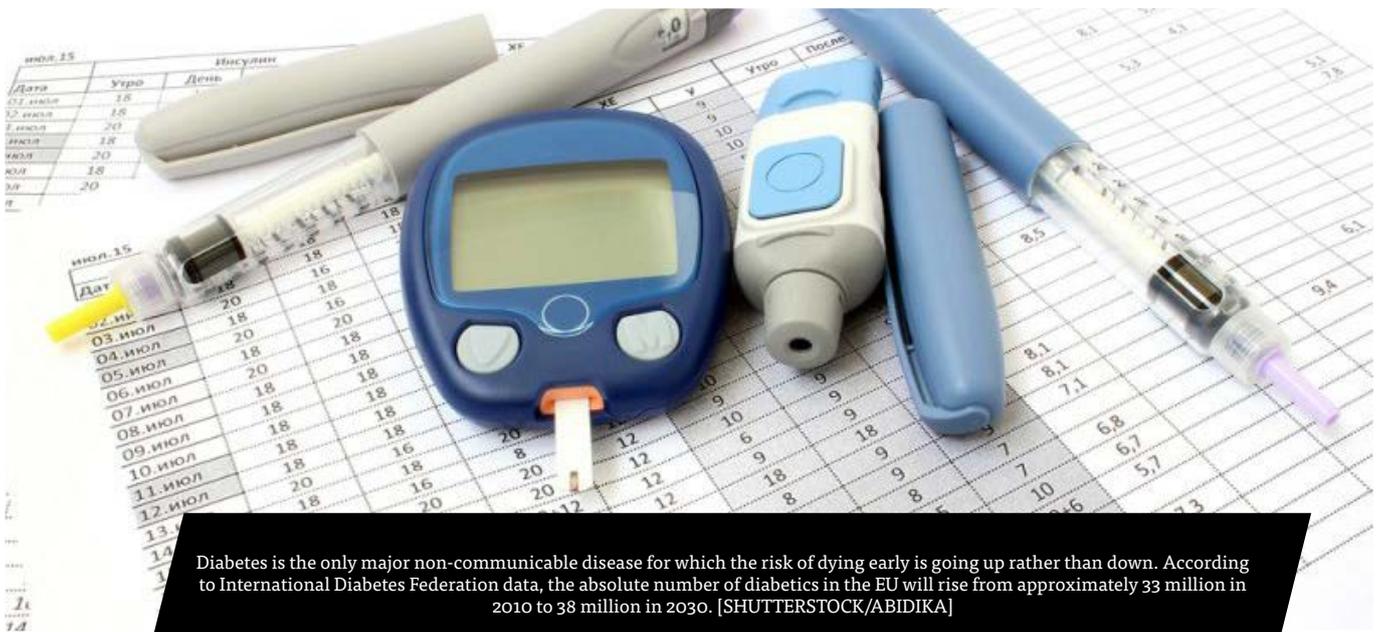
However, access to care and, in particular, lack of diagnosis and treatment remain the thorniest problems when it comes to diabetes, according to Bente Mikkelsen, director of WHO’s department for non-communicable disease.

“Globally, we know that 50% of people with type-2 diabetes who need insulin don’t get what they need. And this happens 100 years after the discovery of insulin,” she said.

INTERVIEW

WHO: Real data, not 'guess' needed for equal access to diabetes care

By Clara Bauer and Giedre Peseckyte | EURACTIV.com



Diabetes is the only major non-communicable disease for which the risk of dying early is going up rather than down. According to International Diabetes Federation data, the absolute number of diabetics in the EU will rise from approximately 33 million in 2010 to 38 million in 2030. [SHUTTERSTOCK/ABIDIKA]

Ensuring that all people diagnosed with diabetes have access to equitable, comprehensive, affordable and quality management cannot be done without the use of data, according to a World Health Organisation expert.

Bente Mikkelsen is the director of the non-communicable disease department at the World Health Organization (WHO) headquarters. She spoke to EURACTIV's health reporter Giedre Peseckyte.

What should be done to prevent new diabetes cases?

In a nutshell, reducing the risk factors and improving the prevention. Governments should facilitate and support access to healthy diets and physical activity and people should be informed about the importance of dietary habits and healthy lifestyles.

But is there enough awareness in society? How much do people know about the disease?

Diabetes is one of the oldest diseases but there's still a lot of misconception about its nature. For many it seems very simplistic, so people don't really understand the multi-organ disease that diabetes is.

Over time, diabetes can damage the heart, blood vessels, eyes, kidneys, and nerves. Diabetes has an impact on the eyes – it is a major cause of blindness. Diabetes also impacts the cardiovascular system with an increased risk of heart attacks and strokes. Impaired blood flow combined with nerve damage in the feet increases the risk of foot ulcers and limb amputation.

There is still a need for awareness-building in all countries. WHO and partners make an effort to increase awareness globally, therein Europe, through the [Global Diabetes Compact](#),

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the Global Diabetes Compact Forum with its growing numbers of partners and also through People Living with Diabetes.

Beyond these increasing numbers, are there more cases that are just simply undiagnosed?

When you look at the lack of diagnosis worldwide, four out of five adults with undiagnosed diabetes live in low and middle-income countries. The recently released IDF data estimate that around one-third of people living with diabetes in Europe are undiagnosed.

How important is it to diagnose diabetes early then and how can this be ensured?

It's not possible to give evidence on exactly how early the diagnosis should be in order to measure the improvement of outcomes. This is one of the gaps in research.

However, earlier diagnoses of people with type 1 diabetes should be promoted worldwide due to prevent deaths of delayed diagnoses and high prevalence of diabetic ketoacidosis at diagnosis.

Talking about patient needs, there are many multiple treatments available for diabetes. But are they reaching patients and how different is the situation in different countries?

The number of people living with diabetes quadrupled since 1980 and we know it is on the rise. At the moment, we have more than 420 million people living with diabetes and it is estimated there will be 643 million in 2030, as many as 784 million in 2045.

This increase is also combined with an increase in premature mortality, meaning dying before

70 years of age. When you look at the lack of access to medicines and technology, it is estimated that 50% of the people with type 2 diabetes who need insulin don't get that on a regular basis.

And then, only a small extent of the diabetes diagnosis, screening and care is included in the primary health care system. This is too weak.

That is why we are very grateful for the World Health Assembly resolution on Diabetes this year that commit all member States to give Diabetes priority and for WHO to work on accessibility and affordability for insulin and other Diabetes medicines and medical devices.

Did the pandemic have an impact on this too?

During the COVID-19 pandemic, diabetes patients were one of the groups at most risk for getting severely ill and dying. We conducted a survey that showed 60% of countries had partially or fully disrupted health care services for the treatment of diabetes and diabetes-related complications.

What about registries for diabetes? This is being discussed a lot and countries seem to have a different take on this.

Data is important and we need data to take action. What we are looking at, in general, is facility-based data and data included in the health information system. At the moment, we have very scattered data.

I think we will, in the coming years, discuss this more intensively as we develop tools for collecting facility-based data for all diseases, but also linked to the global diabetes targets that we have suggested for the WHO member states to discuss this year.

So what should a diabetes register look like?

This is something we need to come back to. The format should accommodate various settings. And I look forward to having this discussion with our Global Technical Advisory Group on diabetes that will give advice to WHO.

But I would like to say that without data, it's very difficult to build accountability and also to help ensure that diabetes is diagnosed, treated and controlled.

Our vision is to reduce the risk of diabetes, and also to ensure that all people who are diagnosed with diabetes have access to equitable, comprehensive, affordable and quality management. And to reach this target, we need to measure, we cannot only guess.

There is a globally agreed target to halt the rise of diabetes and obesity by 2025. What should be done in order to do so?

Halting the rise in obesity and diabetes is possible. Partnerships between governments and civil societies and all non state actors will be key to supporting policy implementation necessary to halt the rise. The recommended policy actions for preventing obesity and diabetes are aimed at increasing physical activity and uptake of a healthy diet.

We need academicians, we need non-governmental organizations, we need people living with diabetes, also stepping up and helping us to, to some extent, change the language. We also need to push on education such as speaking of diets in schools and kindergartens.



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