TRANSFORMING THE DIABETES JOURNEY – adopting a life course approach for citizens' improved well-being and healthcare systems' resilience in the European Union

What is diabetes?

Diabetes is a group of chronic metabolic disorders characterised by **elevated levels of blood glucose**. High blood glucose levels directly cause micro- and macro-vascular complications.

It is a **highly complex condition**, whose onset involves different mechanisms, facilitated by risk factors. The World Health Organization (WHO) recognizes **more than 10 forms of the disease**.



No one is immune to diabetes, which may affect people from all walks of life, at any point in their life.

TYPE 1 DIABETES (T1D) is an auto-immune disease, whereby the body destroys insulin-producing cells (β-cells) in the pancreas. People living with T1D need insulin injections to survive.

TYPE 2 DIABETES (T2D) is the single most common form, accounting for about 90% of all cases. It develops due to a combination of unmodifiable (genetic, physiological, environmental) and modifiable, behavioural risk factors.

GESTATIONAL DIABETES (GDM) is a form of diabetes which develops during pregnancy, when the body does not produce enough insulin to meet the additional metabolic needs of the person giving birth and foetus.

Why should diabetes be a health priority in the European Union (EU)?

Diabetes is a measure of inequalities among EU citizens, which it also exacerbates, as well as a marker of healthcare system resilience



Diabetes represents a huge and growing individual and societal burden

Diabetes is the root cause of many other conditions

Why should diabetes be a health priority in the European Union (EU)?

DIABETES REPRESENTS A HUGE AND GROWING INDIVIDUAL AND SOCIETAL BURDEN

1 in 10 adults
34m people live with diabetes in the EU [1]

1/3 of PwD are **undiagnosed** [1]

Some **200,000 children and adolescents** live with **T1D** in the EU (14% of the world total) [1]

€119bn
Diabetes-related health expenditure (EU, 2024) [1]

3/4 of diabetes costs result from diabetes-related complications [2]

Diabetes leads to productivity losses, undermining EU's competitiveness [3]

GDM increases the risk for the person giving birth and the child to develop **T2D** later in life [4]

Diabetes is increasingly borne by younger generations, **with a rise in young onset T2D (<40yo)** [5]

Diabetes is exacerbated by the **ageing of population** [6]

Diabetes is a **complex condition, rooted in the exposome during PwD's life**, and **compounded by the healthcare ecosystem's response**.

Suboptimal diabetes prevention and management generate **high carbon emissions** [7]

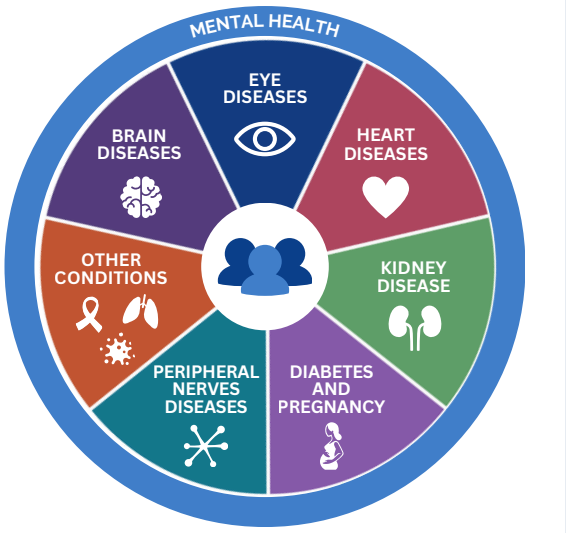
DIABETES IS THE ROOT CAUSE OF MANY OTHER CONDITIONS

Diabetes is a hugely complex condition to manage, requiring **coordination across many specialties and care levels** as well as robust and **constant self-management**.

PRIMARY & COMMUNITY CARE | **SECONDARY CARE** | **TERTIARY CARE**



Cardio-vascular (CVD) and renal diseases, blindness and amputations are some of the direct consequences of its **ineffective management**, and represent the real cost of the disease. The younger a person is diagnosed with T2D, the more serious the complications are likely to be.



[8]

1/3 of PwD develop **CVDs** [9]

80% of **end-stage renal disease** is caused by diabetes/+ hypertension [10]

1/3 of PwD develop **diabetic retinopathy** [11]

Up to 1/2 of PwD have **peripheral neuropathy** [12]

Beyond physical complications, the relentless nature of diabetes management coupled with **stigma** and **discrimination** often create significant **mental health issues** for PwD.

PwD are **2-3x** more likely to experience depression than people without diabetes [13]

Its impact on individuals and healthcare systems is generally underestimated due to **misperceptions** of its seriousness **and low direct mortality**.

DIABETES IS A MEASURE OF INEQUALITIES AMONG EU CITIZENS, WHICH IT ALSO EXACERBATES AND A MARKER OF HEALTHCARE SYSTEM RESILIENCE

The **socio-economic determinants of health** have a disproportionate impact on the risk of developing diabetes and adverse health outcomes.

Other determinants such as sex, gender and age are variables leading to massive **disparities in risks and outcomes**, for example, linked to differing health-seeking behaviours, risk profiles and access to care, which are exacerbated by the lack of dedicated research.

Huge **inequalities** in access to, availability and affordability of, quality care, medicines and treatment exist among and within EU countries, resulting in vastly **differing quality of life and health outcomes for PwD**.

Effective diabetes prevention and management require a comprehensive **health-in-all policies approach** as well as **concerted action** across both social and health care systems. This is contingent on a multi-faceted approach being implemented – targeted research funding and scope, healthcare systems' digitalisation and person-driven integration, adoption of innovative approaches in healthcare delivery as well as innovative medicines, tools and technology, an educated workforce and patient empowerment.



How can the European Union transform the diabetes journey for European citizens' improved well-being and healthcare systems' resilience?

Transforming the diabetes journey is predicated on understanding the close interconnectedness between individual health factors (e.g. genetics), **the exposome** (broader, external influences – social, commercial, economic, and environmental determinants – and the biological response to it) **and the healthcare ecosystem itself** (research, access and delivery) in order to develop a comprehensive health-in-all policy framework, combining public health and individual approaches with a re-think of healthcare delivery systems, supporting person-centred, personalised care across the life course.



It needs to be built through EU-driven action, supported by culturally and settings-adapted national implementation. Such an approach which would consider the broad external environment as well as the person throughout their life, rather than individual conditions in silos, would greatly contribute not only to improving the quality of life and health outcomes of people living with diabetes and other NCDs but also to supporting healthier and fairer environments and reducing the burden on healthcare systems, thereby bolstering their sustainability and resilience.

In so doing, action on diabetes can underpin a move towards a more equitable and sustainable society and be a key driver of social and economic progress.

ADDRESSING THE MAIN DRIVERS OF POPULATION HEALTH – ACTING ON THE EXPOSOME

According to the World Health Organization, healthier environments could prevent almost one quarter of the global burden of disease.[14] **Environmental health** (physical environment, environmental stressors and climate change) has now been shown to have a major bi-directional relationship with diabetes and other NCDs, and healthcare systems themselves. **Unsustainable agriculture**, with high usage of chemicals and production of food with lower nutritional values, also has a clear negative impact on both human health and climate change.[15] Heavy consumption of highly processed foods, **driven by commercial determinants**, combined with food deserts and swamps, also negatively affect people's ability to follow healthy diets, a key driver of T2D.[16] **Developing policies supporting health-enabling environments, such as healthier built environments, while also addressing the food offering** (from better agricultural practices through to food labelling, product composition and taxation) **would go a long way towards lowering the risk of diabetes**.

The social determinants of health also play a strong role in influencing health, estimated to account for between 30-55% of health outcomes,[17] and significantly contribute to health inequalities and disparities, which are particularly evident in the context of diabetes.

PERSONALISING ACTION – UNDERSTANDING DIABETES

Too little is currently known regarding the genetics affecting the development of diabetes, the drivers of disease progression and treatment responses, and many unmet healthcare needs still exist. **More research is required both to profile and stratify people living with diabetes to personalise treatment approaches.**

ADAPTING TO THE LIFE COURSE – IMPLEMENTING A CROSS-CUTTING APPROACH

Health determinants combined with actions and decisions taken at various stages of the life course influence disease progression, quality of life and health outcomes. ***Pre-conception***, the environment in which the foetus develop has a long-term impact on the person.[18] Throughout the rest of the life course, early and tailored actions are required across major milestones. ***Early screening*** is a pre-requisite to identifying people at risk of developing diabetes and potentially lowering their risk to develop the condition, or delaying its onset. ***Early action*** enables better management of glucose and other risk factors. It is critical to lowering the risk of future diabetes-related complications and has been shown to have long-term benefits.[19] ***Children and teenagers*** require an adapted response, notably through the provision of additional psychological support, **while managing older adults means, taking greater consideration of some factors** such as their home setting, cognitive and general health status.[20, 21]

A life-course approach considering PwD's needs in a holistic fashion at key stages of their lives is required to optimise well-being, health outcomes and quality of life, and reduce inequalities.

TRANSFORMING THE HEALTHCARE SYSTEM RESPONSE – ADAPTING TO NEEDS THROUGH PERSON-CENTRED, INTEGRATED AND INNOVATION-DRIVEN APPROACHES

As was illustrated by the COVID-19 crisis, **healthcare systems are ill equipped to deal with chronic diseases**, and still operate with a cure rather than prevention mindset. **Adapting to the needs of people living with chronic diseases**, such as diabetes, who often have to deal with more than one condition **across the life course, requires healthcare systems to take a radically different perspective and adopt an integrated, personalised and person-centred rather disease-oriented approach, including, for people at risk, before they develop any chronic condition**.

A prerequisite to this is understanding PwD's needs and preferences to be able to support them in achieving optimal health outcomes, as the condition evolves and people's circumstances change.

Key enablers of care integration supporting novel care pathways are the improved use of data, the digitalisation of healthcare systems and the use of artificial intelligence (AI), digital tools and digital technologies.

Another key component of the healthcare system response is its ability to deliver uninterrupted, equitable and affordable access to medicines, technologies and care. At present, great inequalities persist in access to health services within and between EU countries as well as in medicines and technologies. Barriers to access are numerous such as shortages of healthcare professionals, weak or under-resourced primary care, availability and affordability of medicines and technologies, and differing health-seeking behaviours by gender and among vulnerable populations.

Empowering and engaging PwD – the lynchpin of transformative action

Critical to transforming the diabetes journey is to ensure that PwD are given a voice in anything that affects them from defining research needs to participating in reimbursement decisions. To deliver on this, a review of governance structures at all levels, supported by improved awareness and education for HCPs, PwD and all diabetes stakeholders. **Only through such concerted and comprehensive engagement and involvement can a meaningful impact be made for individuals and the society at large.**

EU POLICY RECOMMENDATIONS

1 ADDRESS THE MAIN DRIVERS OF POPULATION HEALTH

- Improve environmental health
- Address the fundamental determinants of health
- Support health and digital literacy

2 RAISE AWARENESS AND TACKLE INDIVIDUAL MODIFIABLE RISK FACTORS

- Raise awareness from an early age (schools)
- Act at community and primary care levels
- Address stigma and discrimination through guidelines on evidence-based and respectful communication for institutions, HCPs and the general public

3 TRANSFORM HEALTHCARE DELIVERY THROUGH A LIFE COURSE APPROACH AND ACT EARLY THROUGH ADAPTED SCREENING INITIATIVES

- Map and share best prevention practices & define effective screening criteria, approaches and systems for screening of people at high-risk of diabetes and other NCDs
- Explore targeted support and adapted interventions at different stages of people's lives
- Promote access to quality, comparable data across the EU. through the development of registries and a Diabetes and Health Observatory, providing an extensive repository of best practices and approaches to tackling diabetes and other NCDs

4 ENSURE AFFORDABLE AND EQUITABLE ACCESS TO THE RIGHT TREATMENT AT THE RIGHT TIME, IRRESPECTIVE OF GEOGRAPHY, AGE & OTHER PERSONAL CIRCUMSTANCES.

- Develop framework and conditions to guarantee early, affordable and uninterrupted access
- Improve primary HCP training
- Ensure adequate self-management education
- Explore common EU approaches to medicines development and procurement

5 SUPPORT MS IN OVERHAULING NATIONAL HEALTHCARE SYSTEMS, AND FINANCE TRANSITION AND RESEARCH INTO THE MOST EFFECTIVE STRATEGIES TOWARDS:

- Adopt innovation and promote digitalisation
- Develop person-centred, integrated care pathways – at individual disease level and across comorbidities – with strengthened primary & community care
- Draft, implement and monitor national diabetes plans and strategies.

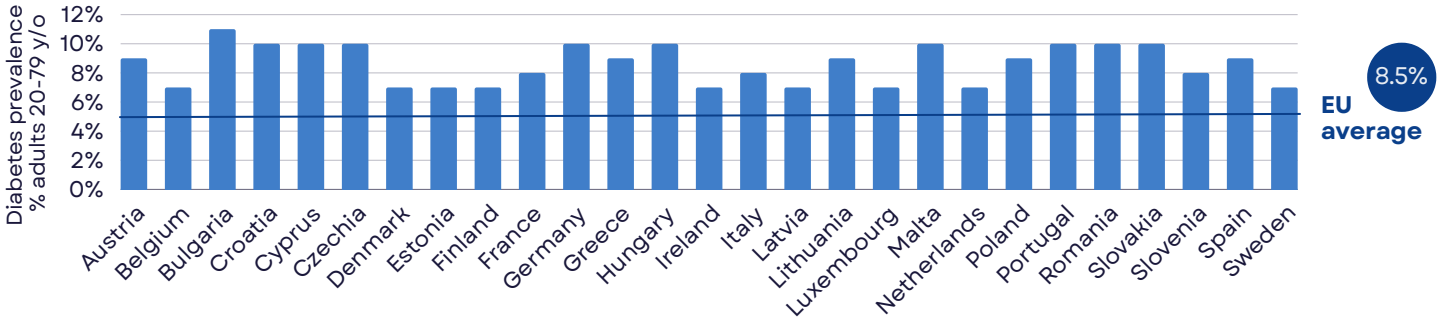
6 ENCOURAGE INNOVATION AND RESEARCH INTO UNMET HEALTHCARE NEEDS

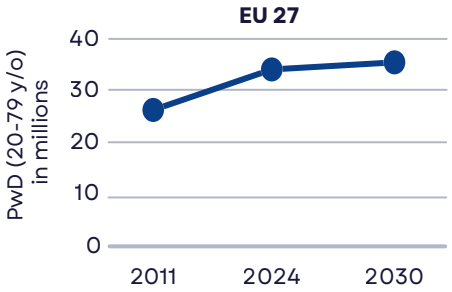
- Boost funding for basic science into the mechanisms of diabetes and the development of more targeted treatments as well as for translational science and behavioural insights
- Set up a Diabetes & NCDs Research Mission, alongside the lines of Europe's Beating Cancer Plan.
- Launch a European Accelerator for Innovation and Digital Transformation, focused on rapidly bringing to market and deploying within the EU national health systems the most advanced and innovative prevention and education initiatives, treatment and care practices for better health outcomes and optimised health.

All of this needs to be supported by full engagement and empowerment of people with lived experience and civil society, embedded as a matter of principle in all legislative, policy and healthcare-related actions.

THE EU DIABETES PREVENTION AND MANAGEMENT LANDSCAPE

DIABETES PREVALENCE





Children & adolescents with T1D (0-19 y/o)

200,000

Diabetes-related deaths **285,000**

People with undiagnosed diabetes

26.4% **(9m people)**

Average expenditure per person

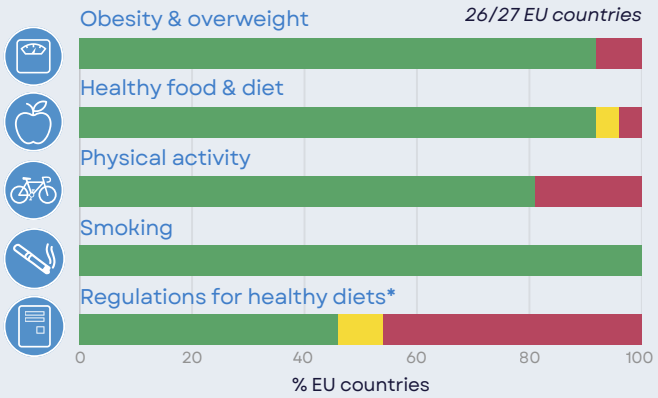
€3,500

DIABETES PREVENTION

Yes | With variations | No

One of the key pillars of T2D prevention is the implementation of **health-enabling policies**. Across the EU, more needs to be done for these to be fully implemented. At least one country, rising to 12 countries for regulations for healthy diets, do not have those in place.

**Regulations for healthy diets include binding measures such as sugar taxes and bans on advertising unhealthy food and beverages to children.*



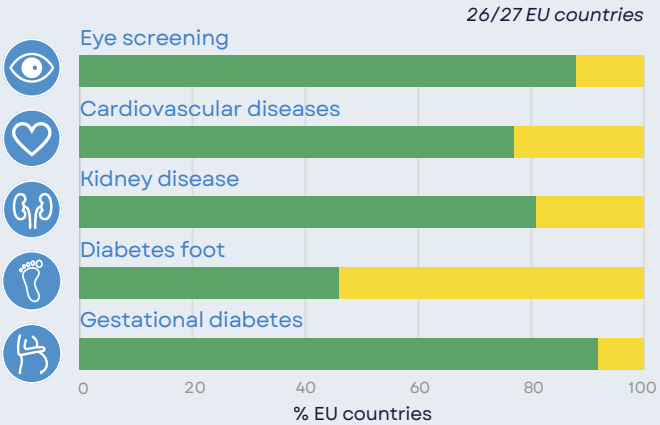
DIABETES MANAGEMENT

Yes | With variations

Diabetes management has one main objective – lowering the risk of acute and chronic diabetes-related complications, while maintaining the highest possible quality of life. This is achieved through controlling glycaemic levels and managing co-morbidities as well as through preventative approaches aiming to prevent organ and tissue damage. A prerequisite to effective diabetes management is access to the medicines and technologies required to control blood glucose levels and other risk factors and administer medicines as well as self-management education and an integrated, person-centred and personalised approach to care.

Regular **screening** is essential to identify potential complications early and prevent their progression.

Screening for complications



Psychological support is a key component of diabetes care and management. However, PwD in about 24 EU countries do not have full access to psychological support due to a lack of specialised HCPs and/or the cost of services not being reimbursed.

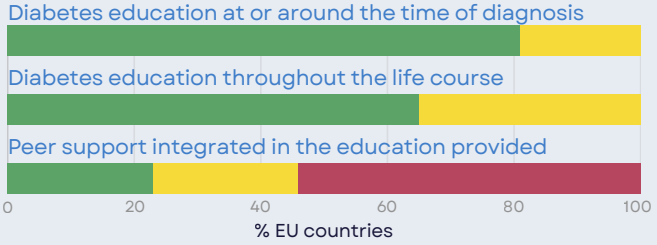
DIABETES MANAGEMENT

Yes | With variations | No

Diabetes is a chronic, life-long and incurable disease. Its management is highly complex, with the need to balance nutrition, physical activity and medication (often poly-pharmacy), 24/7. The vast majority of people living with T2D are treated in primary care, with limited support from healthcare professionals, which they may see only 2 or 3 times a year. People living with T1D or on insulin treatment may have to make an extra 180 decisions a day. Self-management is therefore a crucial element of diabetes management.

Self-management education

26/27 EU countries



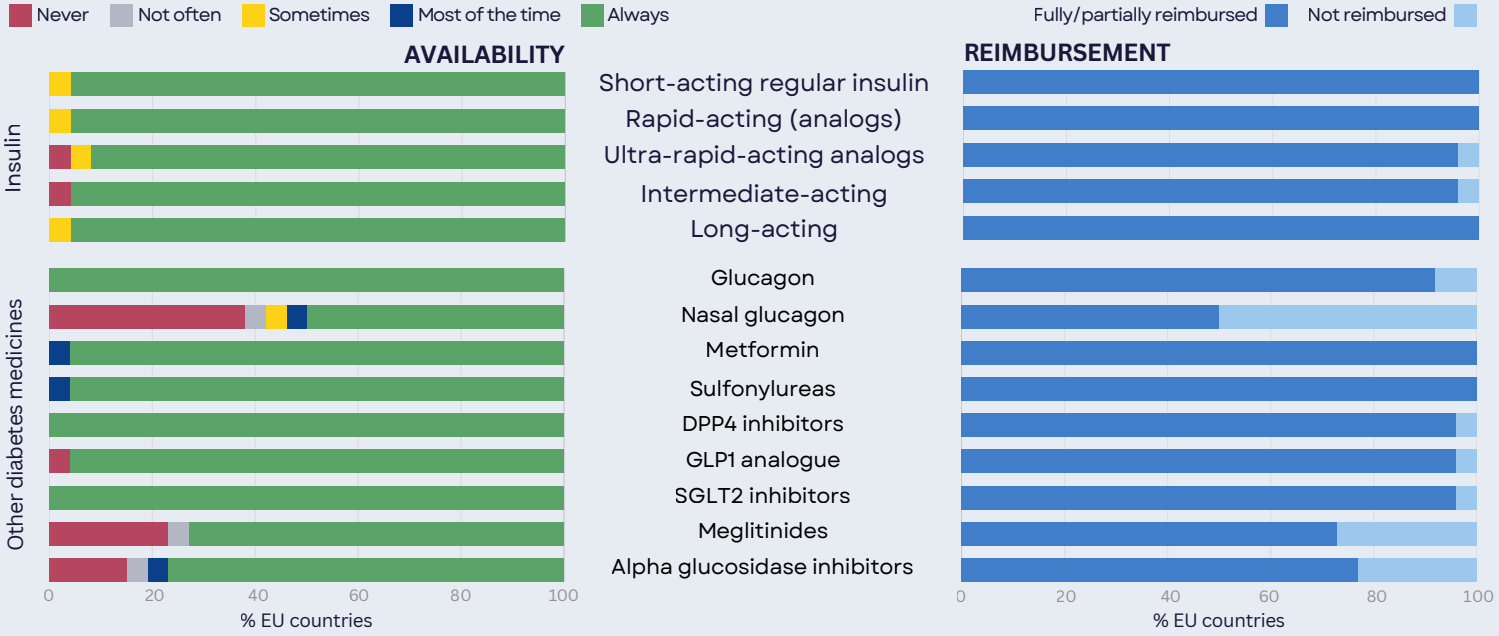
Self-management education is not provided systematically in at least five to nine EU countries.

Peer support is effectively integrated in diabetes education in six countries.

ACCESS TO MEDICINES, TECHNOLOGIES AND SUPPLIES

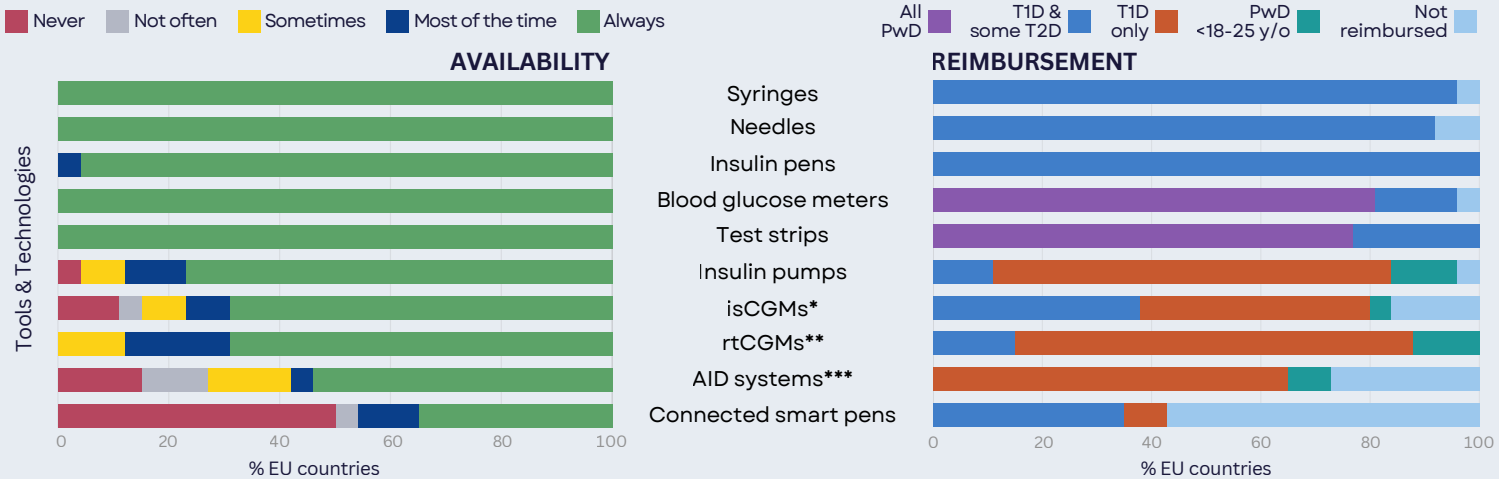
26/27 EU countries

Access to medicines is generally not an issue in EU countries, although shortages do occur, both for basic products such as insulin, as well as for newer medicines, such as GLP-1s. Affordability is subject to more variability.



PwD must check their blood glucose several times throughout the day and adjust their treatment accordingly. Access to reliable tools for monitoring blood glucose is therefore crucial for managing their condition effectively and preventing life-threatening complications.

In the past, blood glucose monitoring tools have largely been reserved to people living with T1D or on intensive insulin treatment. Recent studies have demonstrated the benefits of tighter control for people on once-daily insulin treatment as well as those on oral medications, and several EU countries have extended their provision of glucose monitoring tools.



*Intermittently-scanned continuous glucose monitors

**Real-time continuous glucose monitors

***Automated insulin delivery systems

HEALTHCARE SYSTEMS READINESS

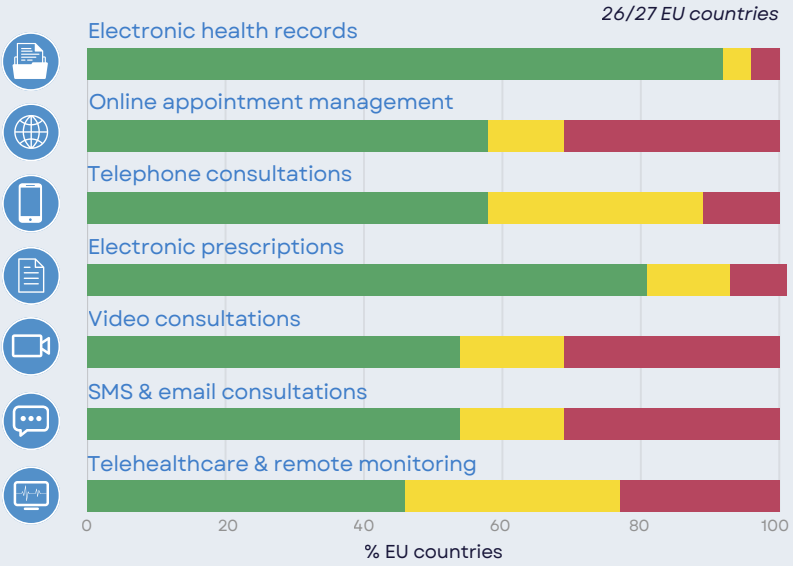
E-health services

Yes | With variations | No

Novel approaches to the delivery of care supported by digital tools such as web portals, apps, telemedicine and digital therapeutics can be used to improve diabetes management, facilitate interactions between PwD and HCPs and support access to information.

Only about nine EU countries provide systematic access to a wide range of e-health services for all PwD.

Apps to prevent/manage diabetes are recommended in about 18 EU countries but they are only sometimes reimbursed in four countries.



National Diabetes Plans

National Diabetes Plans are comprehensive frameworks developed by governments and health authorities to address the growing burden of diabetes within countries. They typically include diabetes prevention and treatment strategies, but they can also incorporate strategies on early diagnosis, routine care, reduction of complications, support for research and innovation, and PwD education. NDPs can be stand-alone and address diabetes specifically or as part of broader NCD strategies.

YES

Stand-alone **In some reagions*

- Croatia
- Czechia
- Finland
- Greece
- Italy*
- Malta
- Netherlands
- Portugal
- Romania
- Slovakia
- Slovenia

Partly integrated

- Austria
- Cyprus
- Poland

Fully integrated

- Spain

UNDER DEVELOPMENT

- Belgium
- Estonia
- Hungary
- Lithuania
- Luxembourg

NO

- Bulgaria
- Denmark
- France
- Germany
- Ireland
- Latvia
- Sweden

NDPs should be tailored to the unique context of each country to ensure that interventions are relevant and effective in providing person-centred care for all PwD. NDPs should also include monitoring and surveillance mechanisms to facilitate data collection on their implementation and measure the effectiveness of diabetes-related interventions.

National Diabetes Registries

National Diabetes Registries (NDRs) enable the systematic collection of data about PwD and their care. They are typically used to monitor PwD's health outcomes and/or the performance of diabetes care over time. NDRs can include detailed information about PwD demographics, medical history, treatment plans, laboratory results and outcomes related to their diabetes care and management.

YES

- Croatia
- Denmark
- Finland
- Latvia
- Sweden

FOR SELECTED GROUPS*

- Austria
- Belgium
- Czechia
- France
- Germany
- Hungary
- Ireland
- Italy
- Luxembourg
- Netherlands
- Poland
- Portugal
- Romania
- Slovakia
- Slovenia
- Spain

**Age, diabetes type, treatment*

NO

- Bulgaria**
- Cyprus**
- Estonia
- Greece
- Lithuania
- Malta**

***Under development*

NDRs are essential tools for HCPs, researchers and policy makers to ensure the availability and provision of high-quality diabetes care based on personalised and data-driven decision making.

International Diabetes Federation Europe

IDF Europe is the European chapter of the International Diabetes Federation (IDF). We are an umbrella organization representing 75 national diabetes organisations in 46 countries across Europe. We are a diverse and inclusive multicultural network of national diabetes associations, representing both people living with diabetes and healthcare professionals.

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