MEPs Mobilising for Diabetes

Blueprint for Action on Diabetes in the European Union by 2030
Contents

FOREWORDS

EXECUTIVE SUMMARY

UNDERSTANDING DIABETES

No population group is immune to diabetes

Diabetes affects us all

There is a path to flattening the diabetes curve, reducing costs and inequalities and improving the quality of life of people living with diabetes

POLICY ENVIRONMENT

EU policy context

The global policy context

Synergies with WHO Regional Office for Europe

The WHO Global Monitoring Framework on Non-Communicable Diseases (NCDs) and the 2030 Sustainable Development Goals

The national policy context

PRIORITIES AND RECOMMENDATIONS

1. Reduce the risk

1.1 Raising awareness and eradicating discrimination

1.2 Creating enabling environments addressing modifiable risk factors and the social, cultural and environmental determinants of health to reduce the risk of developing diabetes and diabetes-related complications

1.3 Supporting early action (including screening, early diagnosis and therapeutic inertia)
2. Integrate care

2.1 Strengthening primary care

2.2 Fostering better integration between and amongst the different levels of care

2.3 Promoting patient-centred care and value-based healthcare

3. Enable access to quality care

3.1 Ensuring access to diabetes care (care, medicines, supplies and technologies)

3.2 Providing adequate support as well as structured and peer-to-peer diabetes education throughout the life course

3.3 Increasing health literacy and ensuring no-one is left behind

ENABLERS

Engage and involve people living with diabetes

Harness the power of digitalisation and data

Promoting an accelerated move towards digitalisation of health services

Fostering the adoption of innovative tools and technologies to support PwD

Promoting and supporting the development of harmonised Europe-wide data frameworks, including diabetes registries

Conduct research into all types of diabetes, from basic science to translational and behavioural research, for actionable insights

WHAT WOULD SUCCESS LOOK LIKE?

CONCLUSION

ACKNOWLEDGMENTS AND ENDORSEMENT

REFERENCES
Since the discovery of insulin nearly 100 years ago, advances in diabetes treatments and therapies have transformed the lives of people with diabetes (PwD), notably reducing the daily burden of its management.

Newer technologies, including those driven by artificial intelligence, have the potential to further improve the quality of life of PwD and help identify and diagnose people at risk of developing Type 2 diabetes and diabetes-related complications early. However, medical and technological advances alone are not enough to fix the diabetes challenge. It is also critical to acknowledge the complexity and the seriousness of diabetes, its impact on the quality of life and well-being of over 32 million PwD in the EU and the financial burden it represents for health systems and society at large.

A paradigm shift with greater emphasis being placed on a holistic approach to diabetes is required, addressing stigma and discrimination and promoting person-centred, value-based and integrated care.

This Blueprint identifies policy opportunities and recommendations to implement this holistic approach. It outlines the societal and legislative changes that are critical to reducing the risk for people of developing Type 2 diabetes and diabetes-related complications as well as those required to ensure appropriate measures and support are in place for healthy life choices and to provide equitable access to care for all. The Blueprint also highlights the role of technology and digitalisation in diabetes prevention, management and care, and the obvious choice that diabetes represents for spearheading the digital health transformation.

Systemic changes are needed to flatten the diabetes curve. Central to this is the need for diabetes to be addressed as a priority by policy makers at national and European levels. The establishment of the MEPs Mobilising for Diabetes (MMD) Interest Group, that builds on the work of the EU Diabetes Working Group and the long-standing engagement of PwD themselves, aims to provide bold leadership to encourage and support the societal, structural and organizational changes that are needed to address the diabetes challenge.

MMD is pleased to provide a political platform to support the diabetes community and to elevate its united voice at the European level.

MEP Sirpa Pietikäinen and MEP Christel Schaldemose, Co-Chairs, MEPs Mobilising for Diabetes
More than 32 million people live with diabetes in the EU – one in ten adults. The impact of this life-long condition on their health and well-being is often underestimated, not to mention its substantial economic burden on health budgets – estimated at about 9% of EU health expenditure in 2019.

The Blueprint for Action on Diabetes in the European Union is the cornerstone of the activities of the MEPs Mobilising for Diabetes (MMD) Interest Group. It is also a critical tool for everyone, at national and European level, who is committed to improving the policy response to the growing burden of diabetes in Europe.

Written from the perspective of people living with diabetes (PwD), the recommendations in this Blueprint cover the whole spectrum of actions to be implemented to improve their lives in Europe. These recommendations are articulated around three key priorities: reducing the risk of developing Type 2 diabetes and diabetes-related complications, integrating care and enabling access.

This Blueprint represents the united voice of the diabetes community and outlines recommendations that need to be implemented over the next ten years in order to flatten the diabetes curve, improve the lives of PwD and reduce health inequalities across Europe.

Dr Niti Pall, Chair, IDF Europe
IDF Europe manages the MMD Secretariat
Diabetes comprises many disorders characterized by high glucose levels in the blood. No population group is immune to it. In 2019, it was estimated that 59 million people were living with the condition across Europe, including more than 32 million in the European Union.

It is a complex and progressive condition that requires systemic and innovative changes to turn the tide – changes in care delivery approaches but also policy changes that will promote enabling and equitable environments for health and ensure fairer and more affordable access to medicines, technologies, ehealth and education. Despite the many daily challenges, with the right care and uninterrupted access to the appropriate treatments, tools and technologies, PwD can lead long, healthy and fulfilling lives.

Diabetes affects society as a whole. Direct diabetes medical costs (which accounted for 9% of total health expenditure in Europe as a whole and within the EU) and indirect costs (including absenteeism, disability, and premature mortality) keep increasing and impose a substantial economic burden on society.

Yet, there is a path to reducing the incidence of diabetes and improving care for better health outcomes for all. This requires implementing a whole spectrum of actions that seek to improve the understanding of the complexity of the condition, recognise the importance of placing PwD at the centre of their care and provide equitable and affordable access to diabetes care and support programmes.

Three priorities and sub-priorities have been identified to achieve this, articulated around three pillars: reducing the risk of developing Type 2 diabetes and diabetes-related complications, integrating care, and enabling access. Recommended EU policy actions to overcome these challenges are provided within each priority.

Many people do not know what diabetes is or do not think it is serious until it affects them or someone close to them. Raising awareness is, therefore, a key step towards reducing the risk of developing Type 2 diabetes and/or diabetes-related complications that might develop over time. Improved knowledge about diabetes will help to eradicate stigma and discrimination, two significant barriers to effective prevention and care. Risk reduction will also be achieved through the implementation of policies that support health-enabling environments, tackle social and health inequalities and promote early action. This is a key component of risk-reduction strategies, notably addressing the challenge posed by the 41% of Europeans (38% of EU citizens) living with diabetes, who have not been diagnosed, and are, therefore, at increased risk of diabetes-related complications.

Integrated care has been identified as one of the main priorities for people living with diabetes and those at risk. To ensure a coordinated approach across multiple providers, primary care systems need to be strengthened; there needs to be closer interaction and coordination between and among the different levels of care and most importantly, the person living with diabetes has to be placed at the centre of their care.

People with diabetes can live life to the full. This requires, however, the ability to access the medicines, supplies, technologies and care they require on an uninterrupted basis. People across Europe face significant inequalities in access to care. This has been exacerbated by the recent advances in treatment options and new technologies and tools. Action is required across a number of dimensions to promote access and reduce inequalities – alongside the move towards patient-centred and value-based care. It includes more wide-ranging, pan-European evaluations of the effectiveness of interventions; improved education and support for both PwDs and healthcare professionals (HCPs); and increased health and digital literacy.
The action plan is supported by three cross-cutting enablers that promote further engagement of PwD, the digital transformation of healthcare and investment in research.

Specifically, a paradigm shift is required in the way healthcare is developed and implemented to engage PwD as equal co-designers and co-decision makers.

The digitalisation of care and broader use of data will be critical to bending the diabetes curve over the next decade. They open the door to the deployment of the most advanced and innovative prevention and education initiatives, treatment and care practices for better health outcomes and optimised health systems. However, they raise a number of questions and challenges that need to be addressed prior to their widespread deployment. These include, for example, the risk of widening the digital divide, the need for transparent governance and the potential for ethical and liability issues.

The COVID-19 pandemic has shown the vital importance health plays in upholding the sustainability and competitiveness of the European Union, as well as the central role of research. Tackling the diabetes challenge will also mean conducting further research into the prevention and management of diabetes and its complications and ways of improving all diabetes treatments. Underpinning this will be the need to more clearly identify the factors influencing the impact of good practices for diabetes care in Europe, which have perhaps prevented the effective deployment of existing policies and programmes.

This blueprint is a guide and a commitment to support policies and programmes that will contribute to flattening the diabetes curve, reducing costs and inequalities as well as improving the quality of life of PwD. It also aims to build resilient health systems that are better equipped to care for people living with chronic diseases, including diabetes.
Understanding Diabetes

No population group is immune to diabetes

Diabetes is characterised by its complexity and the multiplicity of its expressions and causes. It affects all genders, generations and socio-economic groups, in rural and in urban areas across the globe.

Factors influencing certain types of diabetes might not affect others. Type 1 diabetes (T1D), for example, is an autoimmune disease (whereby the immune system destroys the body’s insulin-producing cells) which often emerges in children and younger adults, although it can also develop at any age. Type 2 diabetes (T2D) is often wrongly thought of as a self-inflicted condition, assuming that personal behavioural choices are the primary determinants of our chances of developing the condition. T2D is in fact the result of complex interactions between environmental, lifestyle, clinical and genetic factors. None of these causes are either necessary or sufficient for disease development.

The WHO’s 2019 Classification of Diabetes Mellitus describes 14 different types of diabetes, of which Type 1 and Type 2 are the most common (the latter accounts for about 90-95% of all diabetes cases). A lifelong and progressive condition, diabetes is also a risk factor for many other non-communicable diseases (NCDs), such as cancer, cardiovascular and renal diseases, and can cause devastating complications such as diabetes retinopathy, neuropathy and foot disease.

THE FACTS

About an equal proportion of men and women develop diabetes during their lifetime.4

The Europe Region has one of the largest numbers of children and adolescents (0-19) with T1D in the world (around 300,000, of whom about 165,000 in the EU alone) and the highest number of new cases every year (31,100, of whom around 16,200 in the EU), with incidence at its highest in Finland, Sweden, Norway5 and Sardinia.6

The diabetes prevalence in people older than 65 years is double that of those under the age of 65 (20%), equating to 31 million people.7

Hyperglycaemia in pregnancy (HIP) is one of the most common medical conditions affecting women during pregnancy. An estimated 19% of live births in Europe may be impacted by HIP.8

Children born to women with HIP are at very high risk of obesity, early onset T2D and cardiovascular disease. HIP perpetuates the risk of diabetes into the next generation.9

* Hyperglycaemia in pregnancy (HIP) includes both gestational diabetes (GDM) – diabetes which develops during pregnancy – and diabetes in pregnancy (DIP), which refers to pregnant women with pre-existing diabetes, or who are diagnosed with hyperglycaemia that was first diagnosed during pregnancy and meets the WHO criteria of diabetes in the non-pregnant state.
Diabetes affects us all

Diabetes represents a major burden on individuals, health systems and society at large. In Europe, one in eleven adults live with diabetes; and this figure stands at around one in ten in the EU. Of those living with diabetes in the EU, around 38% have not been diagnosed and are at high risk of developing harmful and costly complications.

Diabetes affects the lives of those living with it, their carers, friends and family. It carries a huge economic burden for societies. In 2019, direct diabetes costs made up an estimated 9% of total health expenditure in the whole Europe region and in the EU. In addition to causing major suffering and unsustainable health expenditure, diabetes also reduces work productivity and increases the risk of premature mortality.

Strategies to lower the risk of developing the non-autoimmune forms of diabetes and optimising management across all types of diabetes benefit everyone’s health and well-being. In fact, strong evidence suggests that health promotion initiatives and policies addressing the environmental, cultural, and socio-economic determinants of health not only benefit PwD and those at risk, but also the general population. Preventing or delaying the onset of diabetes and its complications will allow for huge savings that could in turn be allocated to other priorities, including investment in improved management and care across all disease areas.

It is time to shift from a culture focused on treatment and management to one focused on risk reduction, quality of life and well-being.

THE FACTS

59  Across Europe, 59 million adults were living with diabetes in 2019, of whom 32 million were in the EU.\(^\text{11}\)

The number of PwD across Europe as a whole continues to rise and is forecast to increase to 66 million by 2030, and to 35 million in the EU.\(^\text{12}\)

41  It is estimated that 41% of European adults with diabetes were undiagnosed in 2019 (24.2 million). This figure stood at 38% in the EU (12.6 million).\(^\text{13}\)

On average, diabetes reduces life expectancy in people aged 40-60 by 4-10 years and independently increases the risk of death from cardiovascular disease, renal disease and cancer.\(^\text{14}\)

In 2019, close to one third of diabetes-related deaths were in people under the age of 60 and diabetes and its complications accounted for 8.5% of all-cause mortality.\(^\text{15}\)

In 2015, PwD accounted for the third largest number of potentially avoidable hospital bed days spent in Europe among chronic diseases.\(^\text{16}\)

In 2019, the total diabetes-related cost to healthcare systems in the EU was around €100bn.\(^\text{17}\)

This makes up an estimated 9% of total health expenditure.\(^\text{18}\)

About 75% of this expenditure is due to preventable complications of the disease.\(^\text{19}\)
There is a path to flattening the diabetes curve, reducing costs and inequalities and improving the quality of life of people living with diabetes

New discoveries such as that of insulin 100 years ago, new treatments and technological innovations have radically transformed the diabetes landscape, reducing the daily burden of diabetes for people living with the condition. Ground-breaking research is looking into the prevention of T1D and cell and gene therapies as alternatives to current treatments. Artificial Intelligence is revolutionising many aspects of diabetes management such as blood glucose control and insulin delivery and has shown great promise in diagnosing people earlier and improving diabetes education, support and management. PwD have long been involved in driving such improvements in diabetes management and care. Also, in more recent times they have been engaged in developing these technological innovations themselves.

Despite these advances, there is still a long way to go and some major challenges remain. Why is T1D on the rise in Europe, especially in Nordic countries? And what causes it to develop in the first place? Why is T2D still increasing, mainly in Southern and Central European countries? And why are health outcomes still often worse than expected despite the availability of a broader range of medicines, increasingly precise glucose monitoring and other technologies?

This Blueprint outlines the priorities that need to be addressed over the next ten years to collectively bend the diabetes curve, improve the lives of people living with diabetes in the EU and reduce health inequalities as well as the societal and financial burden for all.

The priorities are articulated around three pillars, supported by three enablers, shown below.

<table>
<thead>
<tr>
<th>PRIORITIES</th>
<th>ENABLERS</th>
</tr>
</thead>
<tbody>
<tr>
<td>REDUCE THE RISK</td>
<td>Engage and Involve PwD</td>
</tr>
<tr>
<td>• Raising awareness and eradicating discrimination</td>
<td>Harness the Power of Digitalisation and Data</td>
</tr>
<tr>
<td>• Creating health-enabling environments</td>
<td>Conduct Research for actionable Insights</td>
</tr>
<tr>
<td>• Supporting early action</td>
<td></td>
</tr>
<tr>
<td>INTEGRATE CARE</td>
<td></td>
</tr>
<tr>
<td>• Strengthening primary care</td>
<td></td>
</tr>
<tr>
<td>• Fostering better integration of care</td>
<td></td>
</tr>
<tr>
<td>• Promoting patient-centred care</td>
<td></td>
</tr>
<tr>
<td>ENABLE ACCESS</td>
<td></td>
</tr>
<tr>
<td>• Ensuring access to diabetes care</td>
<td></td>
</tr>
<tr>
<td>• Educating PwD</td>
<td></td>
</tr>
<tr>
<td>• Increasing health literacy and leaving no-one behind</td>
<td></td>
</tr>
</tbody>
</table>
The MEPs Mobilising for Diabetes (MMD) group is instrumental in elevating diabetes on the EU political agenda, promoting understanding of the multi-faceted nature of the condition and dispelling common misperceptions. Through close collaboration with the Commission/Council/individual Member States (MS), MMD seeks to foster EU policy measures and action around the priorities highlighted above.

MMD builds on a long history of European advocacy, including the long-standing commitment of many Members of Parliament. The St. Vincent Declaration more than 30 years ago was a key milestone. It resulted from a meeting in St. Vincent (Italy) which gathered representatives from patient organisations and Ministries of Health from all European Countries under the aegis of the World Health Organisation and the International Diabetes Federation Europe (IDF Europe).

The Declaration outlined a series of goals and targets to be achieved to tackle the diabetes epidemic. It was also a key trigger of the first EU Diabetes Working Group, which held its first meeting back in April 2003 and pursued its action until the late 2010s, with engagement and support of organisations such as IDF Europe, the Foundation of European Diabetes Nurses (FEND), Primary Care Diabetes Europe (PCDE) and the Alliance for European Diabetes Research (EURADIA).

“The MEP Diabetes Interest Group is a key frontline sentinel to stimulate and monitor pioneering action of the EU Institutions in favour of people living with diabetes acting in strict conjunction with the European diabetes community. Given the overall benefits of high-quality diabetes care, its endeavour will result in a major benefit not only for people with diabetes, but for the European population as a whole.”

- Massimo Massi-Benedetti
  (IDF Europe President, 1997-2003)
Policy Environment

EU policy context

2020 brought health to the forefront of everyone’s mind, which has prompted unprecedented policy action. The European Commission is seeking to build a strong European Health Union that protects EU citizens, equips EU Member States to better prevent and address future pandemics while improving the resilience of Europe’s health systems, all of this guided by the 2030 Agenda and its Sustainable Development Goals (SDGs).

With a budget of €5.1 billion, the EU4Health programme is the European Union’s largest health programme ever, in monetary terms.

Health is also central to several other EU initiatives, including:

- The research programme, Horizon Europe
- The EU Green Deal and the Farm to Fork Strategy

It will also benefit from other EU policies such as the Digital Education Action Plan (2021-2027), which aims to foster the development of a high-performing digital education ecosystem and enhance digital skills and competences for the digital transformation.

Within the Directorate General Santé, a number of initiatives are currently under way including:

- Europe’s Beating Cancer Plan
- The EU Pharmaceutical Strategy
- The development of a European Health Data Space
- The Health Technology Assessment Regulation

Health policy is also deployed through agencies including the European Medicines Agency and the European Centre for Disease Prevention and Control. While the latter’s role has primarily focused on communicable diseases, the COVID-19 pandemic is leading to a review of its role in NCDs as well and to a general call to strengthen both agencies.

It is critical to ensure that diabetes is high on the agenda of the various EU institutions to ensure that it is integrated into all new initiatives/programmes/proposed legislations.
The global policy context

Synergies with the WHO Regional Office for Europe

2020 also saw the adoption by the WHO Regional Office for Europe and the European Commission of a joint declaration seeking to strengthen policy dialogue and technical cooperation on public health. This will be a new opportunity to harness synergies between the priorities of the European Commission and the new WHO European Programme of Work, “United Action for Better Health” and its four flagship initiatives to enhance impact.

Three common priorities are of specific interest to the diabetes community:

1. Strengthening effective, accessible, resilient and innovative health systems to ensure universal access to affordable and quality health systems.

2. Reducing the impact of NCDs with a focus on cancer through addressing risk factors (such as tobacco, alcohol and unhealthy diets), as well as the environmental determinants of NCDs and mental health conditions.

3. Promoting sustainable food systems and health through improved food safety and supply, including the promotion of sustainable and healthy diets for all and the transition to sustainable food production.

The WHO Global Monitoring Framework on NCDs and the 2030 Sustainable Development Goals

Actions by MMD will also be aligned with:

- The WHO Global Monitoring Framework on NCDs which tracks progress against nine Voluntary Targets to be achieved by 2025, and includes three directly relevant targets for diabetes:
  - A 25% relative reduction in the overall mortality from cardio-vascular diseases, cancer, diabetes and chronic respiratory diseases.
  - A halt in the rise in diabetes and obesity.
  - An 80% availability of the affordable basic technologies and essential medicines, including generics, required to treat major NCDs in both public and private facilities.

- The United Nations 2030 Sustainable Development Goals, which include two main relevant targets:
  - Target 3.4: Reduce by one-third premature mortality from NCDs through prevention and treatment and promote mental health and well-being.
  - Target 3.8: Achieve Universal Health Coverage (UHC), including financial risk protection, access to quality essential healthcare services and access to safe, effective, quality and affordable essential medicines and vaccines for all.

The national policy context

Within the European Union, public health is a shared competence, by which EU MS define and deliver their national health services and medical care, and the EU seeks to complement national policies by means of a health strategy.

The distinct reality that exists in each EU country, coupled with the varied organisation of health systems, means that health action must also be tailored to each European Member. A key component to drive and measure the outcomes of action on diabetes is the development and implementation of national diabetes plans and diabetes registries, which are still not in place in several EU countries.
1. REDUCE THE RISK

Flattening the diabetes curve and improving the quality of life of those living with diabetes is possible. With the right care, a person living with diabetes can lead a long and healthy life, with full realisation of their personal expectations. We know what to do. Yet, the actions that can have the most impact – measures to lower the risk for people of developing diabetes and of developing diabetes-related complications for those who live with it are still often not in place, are too limited in scope, or face significant barriers in their implementation.

1.1 Raising awareness and eradicating discrimination

Awareness is the first pillar of any action designed to lower the risk of people developing diabetes and its complications. Awareness is a pre-requisite for action – changing behaviour, seeking care, identifying risk factors and referring for screening, for example. Despite the staggering numbers of PwD and those at risk, there remains a general lack of awareness about diabetes among the public, some health professionals and many policy makers.

Awareness requires visibility. The (deafening) silence around diabetes is strongly associated with stigma. This stigma results from various misconceptions surrounding the causes and management of diabetes. It is also a legacy of the past, when diabetes led to untreatable, devastating complications for the person being diagnosed. Stigma hinders prevention campaigns, creates barriers at nearly every step of the way and engenders discrimination beyond the health system – at school, in the workplace, and in many other daily activities. The fear of judgment and discrimination can discourage individuals from undergoing screening, delay diagnosis and negatively affect diabetes management. In turn, this leads to an increased risk of complications and worse health outcomes. Stigma imposes silence and shame where there should be support and hope. If the diabetes community will not speak of the condition, that support can be even harder to find.

“Stigmatisation can lead to poor psychological and clinical outcomes. Those involved in diabetes care must ensure that people living with diabetes are treated as people first and use language to generate positive relationships. The right words can go a long way”.

- Prof Tatjana Milenkovic, IDF Europe Board Member

There is an urgent need to shift from the simplistic and erroneous assumption that diabetes is a lifestyle disease, which places the responsibility on the individual. There is a path to changing the story. We must acknowledge the complexity of the disease, the influence of obesogenic environments, the impact of social inequalities and the psychological burden of a life-long condition that requires round-the-clock management. It also means providing support to people to engage in self-management in the long term.
HOW CAN EU POLICY ACTIONS HELP OVERCOME THESE CHALLENGES?

- Support public and professional awareness and education campaigns at European and national levels outlining the many facets of the condition, its causes and long-term effects.

- Ensure that all EU actions and documents – across all work areas – reflect the most up-to-date evidence (especially with regard to modifiable risk factors and risk reduction measures) and present an accurate picture of diabetes. This can be achieved through stronger EU engagement with diabetes-focused patient, HCP and research organisations.

- Encourage, under the European Pillar of Social Rights, the review and harmonisation of employment policies across MS to ensure PwD are no longer subject to employment discrimination based on an obsolete system for the assessment of current therapeutic and technological innovations in diabetes management.

1.2 Creating enabling environments addressing modifiable risk factors and the social, cultural and environmental determinants of health to reduce the risk of developing diabetes and diabetes-related complications

Although lifestyle alone will never cause diabetes, policies addressing the condition’s modifiable risk factors, such as those promoting active living and access to healthy foods and those encouraging manufacturers to produce healthier offerings, will help reduce the risk or delay the onset of T2D and diabetes-related complications for many people.

Ensuring EU citizens are empowered to make, and are economically and physically able to access, healthy choices and to lead an active life is critical. This requires governments and local authorities to develop measures fostering health-enabling environments and addressing the social and economic determinants of health. ‘Health-in-all-policies’ approaches can also design and build healthier communities through better housing, planning, employment and other social policies, although there are many barriers to implementation that need to be examined further.
“Nowadays, the most important risk factors are social inequalities, poverty, climate change and the food industry”.
- José-Manuel Boavida, President of the Portuguese Diabetes Association (APDP)

Health education and awareness need to start early. Children must be provided with health education from an early age, through to the end of their secondary education, fully integrated as part of the school curriculum. Schools must also lead the way as healthy living spaces – from fostering physical activity and encouraging all opportunities for an active lifestyle, including walking and cycling to school (through the provision, for example, of adequate parking space for bicycles) to providing access to healthy food in canteens and vending machines and preventing exposure to unhealthy influences.

**HOW CAN EU POLICY ACTIONS HELP OVERCOME THESE CHALLENGES?**

- Ensure the Farm to Fork strategy provides Europeans with access to healthy, affordable and sustainable food, promote a Europe-wide front-of-pack labelling system allowing consumers to make informed choices, and encourage the manufacture of healthier foods.

- Support the implementation of environmental and infrastructure regulations and projects (urban planning and transportation policy) which promote active living at the national level, supported in particular by the European Social Fund and the European Regional Development Fund.

- Foster harmonisation of measures across EU Member States further restricting marketing of high fat, sugar and salt foods to children, and encourage additional national fiscal measures supporting initiatives fostering healthy living.
1.3 Supporting early action (including screening, early diagnosis and therapeutic inertia)

In the EU, over 38% of PwD are undiagnosed. By the time of diagnosis, many have already developed one or more complications. Additionally, given the silent and progressive nature of T2D, early detection and prompt diagnosis are critical to avoiding long-term complications such as cardiovascular diseases, renal diseases and retinopathy. Not only are these complications potentially devastating from a personal viewpoint, but they are also hugely costly to health systems.

Screening people for diabetes and diabetes-related complications will help in ensuring 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.

“Up to half of all cases of diabetes are undiagnosed. It can sometimes be diagnosed several years after onset, leading to severe complications which include heart attack, kidney failure, stroke, blindness, and amputation.”

- Prof. Nebojsa Lalic, IDF Europe Chair-Elect

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. HCPs must be supported and encouraged to follow guidelines more closely to tackle therapeutic inertia. In many countries, the intensification of treatment has been shown to lag significantly behind the point when it should have been initiated, thereby leading to potentially preventable complications.

Healthcare systems must also be re-organised to support more frequent monitoring of the effectiveness of the strategies deployed at all stages of the condition, improve the education of PwD and the trust between the person living with diabetes and their healthcare provider.

Gestational diabetes places increased risk for the mother and the child to develop T2D in later life. Women with hyperglycaemia detected during pregnancy also have a higher risk of developing adverse pregnancy outcomes. Follow-up of mothers and babies must also be included in all risk-reduction strategies, and women living with diabetes before pregnancy must receive adequate antenatal care.

HOW CAN EU POLICY ACTIONS HELP OVERCOME THESE CHALLENGES?

- Support the development and implementation of a National Diabetes Plan in all EU Member States, which includes a risk reduction and screening component. The use of a common screening tool across Europe should be encouraged to promote data and best practice exchanges.

- Promote the exchange of best practices across MS and encourage the implementation of incentive programmes at primary care level to support systematic screening.

- Encourage the digitalisation of health services in MS and the adoption of new tools and technologies allowing for more effective monitoring and action to reduce the risk of diabetes-related complications and improve quality of life.
2. INTEGRATE CARE

Integrated care can be defined in a variety of ways and from various perspectives. For our purpose it relates, as per the WHO Regional Office for Europe’s definition, to a person-centred health system which promotes “the comprehensive delivery of quality services across the life-course, designed according to the multidimensional needs of the population and the individual and delivered by a coordinated multidisciplinary team of providers working across settings and levels of care”.

As with many other chronic diseases, PwD may require access to a variety of HCPs – general practitioners (GPs), endocrinologists and diabetologists, diabetes specialist nurses, dieticians, exercise physiologists, psychologists, etc. Through its ability to deliver continuity of care in a coordinated way, across multiple providers, integrated care has the potential to make a significant impact on the management of people at risk of developing or living with diabetes. It is also a pre-requisite to driving the empowerment of PwD, ensuring high quality of care, good health outcomes and high quality of life and well-being, and fostering health system sustainability.

2.1 Strengthening primary care

Primary healthcare is the first level of contact between HCPs and individuals. Primary healthcare professionals are not only responsible for much of T2D management but are also ideally placed to identify people at risk and help address modifiable behavioural risk factors. Although they are critical components of an integrated care system, primary care systems remain underdeveloped in many regions and countries. An under-resourced primary care system, under-funded, under-staffed and/or lacking expertise across disciplines is a major obstacle to effective diabetes risk reduction strategies and management and contributes directly to a care deficit and higher disease burden for PwD.

Investing in primary care infrastructure, ensuring adequate staffing levels and skills, providing comprehensive education to primary HCPs on identifying this multi-faceted condition, recognising and providing the support (inclusive of the psychological one) required by people living with diabetes throughout their life, and training them on self-management are critical to ensuring PwD lead long and healthy lives. The same is true of the need to develop multidisciplinary consultations including screening.

“...The multidisciplinary and interdisciplinary primary care team is an essential pillar in the provision of diabetes care, research and education and also addressing the social determinants of health at a national policy level and cascading down to local delivery.”

- Anne-Marie Felton, Foundation of European Nurses in Diabetes (FEND) President

HOW CAN EU POLICY ACTIONS HELP OVERCOME THESE CHALLENGES?

- Support an extensive review and overhaul of national models of care with a focus on investment in primary care through the Recovery and Resilience Facility, guided by the European Semester process, to reduce inequalities across EU MS, and improve the resilience of EU health systems.

- Implement a task shifting approach, supported by the education and training required to develop adequate expertise and competence, and foster a harmonisation across the EU of specialist diabetes nurses’ role and scope, for example, the ability to prescribe diabetes medicines.

- Support upskilling of primary care professionals across EU MS.
2.2 Fostering better integration between and amongst the different levels of care

Many people with diabetes are at risk of developing or live with other chronic conditions and/or diabetes related complications (e.g., heart disease, stroke, cancer, renal failure, retinopathy, etc.). For the most part, European healthcare systems are not optimally set up to manage complex, chronic diseases such as diabetes, nor are they necessarily designed with people’s needs in mind. Rather, they are often organised into silos according to specialities/care levels. As such, people often have to find their own way to navigate the healthcare system, trying to coordinate the care they receive in different parts of the system – an additional challenge for an already-demanding condition.

Not only can this hinder the effectiveness of the care received, or even access to the required care, but it also often generates higher preventable costs, resulting from delayed interventions and the development of diabetes-related complications, for example.

A high quality of life for PwD requires fully functional, integrated care between all care levels. The need for duplicated tests and multiple appointments, the effort required in managing polypharmacy, early identification of complications can all be reduced by ensuring a central point of contact between the person living with diabetes and care professionals and setting up a repository of patient information, easily accessible to all involved in a person’s care.

This should be accompanied by clear and transparent guidelines on care pathways, detailing, the decision-making process for care to take place at primary or secondary level, and the trigger points for referrals between care levels.

Another key aspect to optimal effectiveness of diabetes care is ensuring multidisciplinary teams are well structured, fully resourced and well-coordinated.

HOW CAN EU POLICY ACTIONS HELP OVERCOME THESE CHALLENGES?

• Support national health systems in designing and adopting integrated care models adapted to their national requirements.

• Establish a European Integrated Care Outcomes Observatory as part of EU4Health or the strengthened ECDC mandate. This would foster the collection of data supporting best practices in integration of care and specific interventions, as part of a common European data framework.

• Encourage research on integrated care models including the development of guidelines and best practices surrounding the management of people living with co-morbidities, for example people living with cancer and diabetes, as part of the Europe’s Beating Cancer Plan/EU4Health Programme.

2.3 Promoting patient-centred care and value-based healthcare

Underpinning all improvements in diabetes care is the need for the person living with diabetes to be placed at the centre of their care. The value of care must also be assessed not only on the value it brings to health systems, but also taking into account health outcomes that matter to people availing themselves of care. In other words, by design, healthcare systems should strive to improve the value brought to PwD.

Reflecting the different priorities of distinct stakeholders, this, first of all, means shifting from a model based primarily on the cost of a medicine, technology or intervention and towards a model focusing on health outcomes. This also means incorporating a
broader set of measures including well-being and quality of life in an assessment of the value of a medicine, technology or intervention, and tackling wasteful and low-value clinical care, operational waste and governance-related waste.\textsuperscript{26}

Part of this includes generalising the use of Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs) and ensuring that the voice of PwD is represented in all decisions, such as the design of research agendas and participation in health technology/reimbursement assessments. A good example of this is the work carried out by the International Consortium on Health Outcomes measurements on the concerns and experiences of PwD, which might provide a basis for further research in this area.\textsuperscript{27}

This also means collating a broader set of data on the real-world effectiveness of interventions, including the cost-effectiveness of prevention measures and of new innovations. In parallel to this, it is vital to identify barriers hindering the implementation of these effective interventions and innovations, which may include intrapersonal factors, interpersonal processes, institutional factors, community factors and public policy.\textsuperscript{28}

Increased digitalisation of healthcare systems and the development of more integrated systems of care and care pathways are necessary pre-requisites to the expansion of value-based systems. Both improve the efficiency, effectiveness and resilience of health systems and help empower PwD to make informed decisions and improve their ability to manage their treatment and care. They also have the potential to reduce costs and free resources. The latter can then be re-allocated to improve access for all to existing and newer medicines and technologies, bring about an expansion of prevention programmes etc.

Implementing a patient-centred and value-based system of care is also a key component of the move towards the full realisation of personalised care, whereby an individual and its healthcare team are able to engage with a knowledge-based, fully informed and meaningful co-decision process. Building on patient-centred care, itself fostering a multi-disciplinary team approach, and the development of guidelines and protocols, personalised care also involves the use of precision medicine (based on the identification of phenotypic and genotypic markers) that would help better target ideal (and non-ideal) therapies.

HOW CAN EU POLICY ACTIONS HELP OVERCOME THESE CHALLENGES?

- Securing the adoption of the Health Technology Assessment Regulation, ensuring that a value-based framework is incorporated in all assessment protocols.
- Fostering the exchange of best practices among EU MS to promote the use of value-based measurements, building on the example of the Organisation for Economic Co-operation and Development (OECD) PaRIS initiative (Patient Reported Indicator Surveys), with a view to reducing inequalities in Europe.
- Encouraging the development of a common framework across the EU to determine a set of outcome measures that matter most to PwD. This could be used during health technology assessments as well as in guiding research and policy, by allowing disease monitoring and risk assessments, identification and spread of best practices in health and social care; and strengthening the assessment of health and social care systems performance.
3. ENABLE ACCESS TO QUALITY CARE

Achieving the best possible health outcomes and enjoying the highest possible quality of life for PwD is contingent upon their ability to access the medicines, supplies, technologies and care they require on an uninterrupted basis. The COVID-19 pandemic has clearly demonstrated the inherent inequalities in access to care across and within EU countries, themselves leading to significant inequalities in health outcomes for European citizens.

3.1 Ensuring access to diabetes care (care, medicines, supplies and technologies)

Adding to the existing inequalities in access to care (linked to the accessibility and availability of HCPs, geographical location, education etc.), recent advances in treatment options, including new medicines as well as new technologies and tools have placed an increased strain on the ability of healthcare systems to ensure equal access to the most appropriate treatment for all. This is a result of the costs of these novel treatments/technologies, coupled with a lack of the resources and knowledge necessary within national healthcare systems to assess their cost-effectiveness. This also derives from the challenges related to digital and health literacy and increasingly, the organisational rethink of health systems that is required to take advantage of new, digital solutions. Newer treatments and technologies also present challenges to PwD and HCPs alike, who may require more education and training on how to use new formulations and devices and how to understand and act on ever larger data sets, and generally deal with the challenges of these innovations.

In practice, this means some therapies or technologies may only become available in some EU countries several years after they first get adopted in other MS, or will only be accessible to those with a certain type of diabetes, of a certain age, income and/or literacy levels, etc.

The additional psychological burden brought about by those advances, such as the perception that data needs to be acted upon immediately, must not be neglected and access to the appropriate support and care must also be improved.

Innovation need not be an additional cost. Innovative tools, treatments and technologies have the potential to reduce overall health expenditure, or maintain health expenditure at similar levels, while extending or improving care. This is done by reducing waste, lowering the risk of developing complications and improving health outcomes.
The current pace and disruptive nature of innovation means a concerted approach within the European Union is required to evaluate the value and benefits of new treatments/technologies, bearing in mind the need for patient-centred care, and ensure faster and fairer deployment of new treatments and technologies across all EU countries, regions and PwD.

“Living with type 2 diabetes, we are sometimes judged to have the easy diabetes and getting access to the technologies that would make a real difference to our health outcomes and quality of life can be a struggle. It is not just about losing weight and exercise.”
- Ken Tait, Person living with Type 2 diabetes, Diabetes Advocate

HOW CAN EU POLICY ACTIONS HELP OVERCOME THESE CHALLENGES?

- Secure the adoption of the Health Technology Assessment Regulation, ensuring an ambitious scope for assessments of new diabetes medicines, tools and technologies including the broader use of real-world evidence.
- As part of the Pharmaceutical Strategy and upcoming pharmaceutical legislation:
  - Conduct a review of Intellectual Property frameworks for diabetes medicines development as well as public investment in Research & Development
  - Assess options relating to the pricing of medicines across EU countries
  - Encourage distribution throughout the EU of medicines and technologies having obtained a central marketing authorisation for faster and broader access
  - Foster more transparency around procurement practices and greater collaboration among MS
  - Encourage greater competition and product substitution wherever appropriate, ensuring full transparency for PwD and their HCPs
  - Support broader engagement between the EU, individual MS and health systems and the private sector (providers and payers) to ensure access to innovation that will benefit PwD and healthcare systems
- Support MS in implementing effective financing schemes and best-practice management strategies.
3.2 Providing adequate support as well as structured and peer-to-peer diabetes education throughout the life course

Diabetes is a condition essentially managed by those living with it. **Alongside access to medicines, technologies and care, comprehensive education is required for optimal management** and reducing the risk of complications. PwD need to understand their condition in order to be empowered to take an active role in their care, to make informed decisions together with their healthcare team, and to have the motivation to keep up with the round-the-clock management of their condition over many years.

Although **self-management education** is generally recognised as critical for a long and healthy life with diabetes, it is still very often neglected or lacking in scope. **HCP self-management training has also been shown to be effective** in ensuring better uptake, implementation and effectiveness of self-management programmes, but is rarely offered as matter of policy.²⁹

As a matter of course, all newly-diagnosed people should be given structured diabetes education in a one-on-one or group setting, as required and as soon as possible, no longer than one or two months after diagnosis. **Because diabetes is a progressive disease, education should be provided not only at the time of diagnosis but on an ongoing basis throughout a person’s journey with the condition.** Subsequent education should be offered by specialised diabetes educators, when there are any changes in treatment or when targets for glycaemic control are not met.

**Peer-to-peer education, coaching and support are rarely embedded in healthcare services**, despite their proven effectiveness in bringing together a community, providing psychological support, fostering behavioural changes and improving health outcomes.

Diabetes is a chronic disease that places a huge **psychological burden** on people living with it, their families and carers/relatives, and this is often neglected. Depression is two to three times more common in PwD than the general population.³⁰ **Access to adequate psychological support must be integrated as a key component of diabetes care.** It is also critical to train HCPs in recognising the need for this support and providing them with the tools to deal with this psychological aspect.

"Diabetes is a condition that affects the mind just as much as it does the body. It’s time that we recognise that and start providing and normalising support for all aspects of diabetes, including the psychological and emotional. Being responsible for your own care 24/7 is a massive undertaking, and providing support throughout that journey should be fundamental."

- Cajsa Lindberg, person living with T1D, former President of the Swedish Diabetes Association

**HOW CAN EU POLICY ACTIONS HELP OVERCOME THESE CHALLENGES?**

- **Foster best-practice sharing across MS on effectively integrating self-management training and the training of HCPs in supporting and motivating PwD within an integrated system of care.**

- **Support the integration within national health systems of peer-to-peer support programmes as part of the diabetes education programme.**
3.3 Increasing health literacy and ensuring no-one is left behind

Health literacy is described as “the personal characteristics and social resources needed for individuals and communities to access, understand, retrieve, appraise and use information, services and information communication technologies (ICT) to make decisions about health. Health literacy includes the capacity to communicate, assert and enact these decisions” (WHO).

Access to care and education is indispensable to leading a healthy life with diabetes. But for those who cannot take advantage of it, managing diabetes remains an insurmountably complex task. A low degree of health literacy has been associated with poorer diabetes management and health outcomes.\textsuperscript{31,32,33} Conversely, higher health literacy has been associated with better glycaemic control.\textsuperscript{34} Those lacking health literacy may find it difficult to understand dietary recommendations and educational material, calculate their required insulin intake, or use technology to maximise outcomes. It may also negatively affect their ability to access the necessary health services and understand complex care pathways. Several factors influence health literacy, not least socio-economic background and age.

In an increasingly digital world, low levels of health literacy are compounded by low digital literacy levels and unequal access to the tools required to avail oneself of the digital health revolution. Within the EU, access to broadband varies widely across and within MS, as does access to equipment and skills. Health and digital literacy become prerequisites to building trust in, and ensuring equitable access to, innovative technologies that may lead to better health outcomes. Health is a basic human right, and guaranteeing that no one will be left behind through adequate investment should be a key priority within the European Union.

HOW CAN EU POLICY ACTIONS HELP OVERCOME THESE CHALLENGES?

- Leverage initiatives under the European Pillar of Social rights/health promotion efforts under the EU4Health programme to support initiatives building health literacy capacity across European MS, including further training of HCPs in identifying, and communicating with people with limited health literacy.

- As part of its focus on enhancing digital skills within Digital Europe, ensure that digital literacy initiatives have a broad scope encompassing health systems components, and foster best-practice sharing across MS on effective programmes to improve digital literacy.

- Include a health component as part of the European Digital Education Hub to monitor the skills required to gain full access to digitalised health systems and services.
Enablers

Achieving success in the implementation of the priorities outlined in this document can only happen through a concerted effort across three areas:

- **The greater involvement and engagement of PwD** in all aspects of diabetes research, risk reduction programmes and care.

- **The digitalisation of health systems and broader use** being made both of the data generated generally across the healthcare system and diabetes-specific data through the digital tools and technologies increasingly common in the treatment of PwD.

- **Conducting research** in the diabetes field, centred not only on developing treatments, but also on analysing clinical outcomes and the effectiveness of specific prevention and management interventions for actionable insights and policy action.

As experts, PwD are also best placed to determine what health outcomes matter most to them, and what their main unmet needs are. They have also been at the forefront of life-changing innovations (e.g., the DIY movement – a community of PwD who started developing advanced automated insulin delivery systems which had not yet been developed, approved or launched commercially) and have a key role to play in helping governments fast-track the adoption of new technologies. Raising their voice will also ensure that unmet needs are properly considered and all research and development activity is focused on achieving meaningful outcomes.

Engage and Involve People living with Diabetes

Diabetes is a chronic disease like several others, with which it shares many risk factors. Its life-long, relentless self-management is like no other though, and PwD have to become experts in managing their condition. However, all too often, decisions surrounding their care take place without their meaningful engagement. A paradigm shift is required in the relationship between PwD and the healthcare system.

HOW CAN EU POLICY ACTIONS HELP OVERCOME THESE CHALLENGES?

- **Promote engagement with PwD** during consultation processes, definition and implementation of new work programmes and policies and other initiatives at the EU level such as Horizon Europe, the EU4Health programme Annual Work Plans and Steering Committee, Europe’s Beating Cancer Plan, and within MS.

- **Support the integration of PROMs/PREMs** as part of clinical trials data and mandate the involvement of PwD in all EU-funded projects.

- **Integrate people living with diabetes** within all EU agencies and as part of the European Health Technology Assessment framework.
Harness the Power of Digitalisation and Data

Promoting an accelerated move towards digitalisation of health services

COVID-19 has brought into sharp relief the different levels of digitalisation and preparedness to increased digitalisation of healthcare systems across different EU MS. It has also highlighted the need for more responsive, advanced and innovative healthcare systems.

Diabetes is a condition that makes much use of numbers, calculations and data, and which requires lifelong, 24/7, self-management by the person living with the condition, with infrequent input from HCPs. Technology and digitalisation are natural tools for managing the condition. Diabetes is therefore a natural choice for spearheading the digital health revolution.

By streamlining activities, reducing waste and facilitating the monitoring of the impact of various interventions, digitalisation opens the door to the deployment of the most advanced and innovative prevention and education initiatives, treatment and care practices for better health outcomes and optimised health systems.

Increased digitalisation will not only help improve the quality of life of PwD and reduce the incidence of T2D but it will also decrease the cost of diabetes-related healthcare expenditure, free up health system resources through lower diabetes incidence and fewer or less severe complications, and broaden access to health through cost savings and the ability to reach previously underserved communities such as people in rural areas.

Digitalisation, and one of its supporting tools – artificial intelligence – also comes with a series of potential pitfalls – for example, what is the exact role and remit of artificial intelligence-led tools and systems; what is the likelihood of face-to-face human interactions being displaced by new technologies, aspects that many in the diabetes community have shown concern about. Addressing these issues is essential in order to foster acceptance of, and trust in, such new tools.

An added benefit will be to boost European innovation and strengthen the EU’s structural competitiveness.

HOW CAN EU POLICY ACTIONS HELP OVERCOME THESE CHALLENGES?

- Support investment into the digitalisation of health services in Europe, guided by Digital Europe’s key objectives, to contribute to improved resilience of EU health systems, and also supported by the EU4Health programme and EU structural funds.

- Foster the adoption of innovation and advanced therapies through improved monitoring and data collection shared across EU countries.

- Set European and national specific and numerical targets for improving diabetes-related outcomes and ensure the data system captures this across the patient care pathways.
Fostering the adoption of innovative tools and technologies to support PwD

Diabetes is a hugely complex disease to manage. People living with T1D and those with T2D on insulin therapy must check their blood glucose throughout the day and adapt their treatment accordingly. Going for a walk or a jog, having a cup of coffee, breast-feeding a baby – all need to be taken into account when managing diabetes, especially T1D.

People with T2D who are not treated with insulin also need to manage their blood sugar levels effectively throughout the days and weeks by seeking to eat foods that trigger fast/large spikes in blood sugar in moderation, generally following an appropriate medication strategy and increasing physical activity, which helps lower blood glucose levels.

The price to pay for sub-optimal blood glucose levels for the individual is potentially very high – this includes life-disabling complications such as blindness and amputations, cardio-vascular and renal disease, amongst others.

Recent advances in medicines and technologies have the potential to make a real difference to the quality of life and well-being of PwD. Real time continuous glucose monitoring systems (CGMs), and more recently intermittently scanned CGMs, for example, are helping to maintain better blood sugar levels and prevent dangerous hypoglycaemic events. New insulin delivery systems, such as connected pens, help keep track of the insulin amount injected throughout the day. Artificial intelligence is paving the way for safer, more finely-tuned closed-loop systems (artificial pancreas), with the potential to take away much of the heartache of daily diabetes management.

The adoption of innovation is, however, constrained by a number of factors, key amongst which are the delay in the assessment by national regulatory agencies of the benefits of these innovations, and the (perceived) cost of newer drugs and devices. Support and guidance to increase the quality and accessibility of digital tools to improve self-management are also required.

HOW CAN EU POLICY ACTIONS HELP OVERCOME THESE CHALLENGES?

- Support the development of an EU-wide Accelerator Programme focused on diabetes and co-morbidities, either standalone or as part of a broad Health Technology framework, and ensure the adoption of the EU Health Assessment Technology Regulation.
- Leverage a common EU data framework for faster adoption of new technologies.
- Support allocation of funding to research on the impact of digital technologies on diabetes self-management and behavioural changes for improved diabetes prevention and management.

“With better insulin and access to a continuous glucose monitor, I found my way back to sports that I had given up after diagnosis, and I became even more passionate than I was before.”

- Maartje Roskams, Person living with T1D, Diabetes Advocate
Promoting and supporting the development of harmonised Europe-wide data frameworks, including diabetes registries

The COVID-19 pandemic has also highlighted the lack of standardised data collection and data sharing across MS. This lack of comparable data hampers the development of a collective and coordinated response across the Union in a time of crisis; in non-crisis times, it represents a major barrier to the development of more resilient health systems.

"Many regions in Europe lack quality of care data or fail to translate existing data into policy actions. Better data gathering and guidance for regional/national translation is one of the most important areas where Europe can make the difference. Let’s align on the ambition to improve diabetes outcomes!"

- Prof. Chantal Mathieu, European Diabetes Forum (EUDF), Chair

The development of harmonised Europe-wide data frameworks will enable the collection of data and knowledge that can be translated into policy actions, to best influence diabetes prevention, management, and care across Europe, in line with the objectives of a European Health Data Space.

Encouraging the set-up of national diabetes data registries in all European countries and collecting data across the Union around a commonly-agreed set of indicators, including patient-reported outcomes, will allow for faster and more comprehensive analysis of effective interventions in terms of both management and prevention. It will also allow for better resource allocation, facilitate the integration of care and the deployment of innovation and help tackle wasteful clinical care, operational waste and governance-related waste. According to an OECD report on Tackling Wasteful Spending on Health35, for example, the number of hospital discharges for diabetes ranged for 10 to 57 per 1,000, dependent on the country surveyed.

The increased collection of personal data through such tools as CGMs and the creation of European frameworks have the potential to bring real benefits to PwD and health systems, as detailed earlier. Nevertheless, they also raise a number of questions and challenges. For the European Health Data
Space, it is essential that a strong, transparent governance approach is promoted, which includes all relevant stakeholders. The initiative’s governance model and its deployment must guarantee that all data will be secure and that it will preserve the rights of the individual. Special attention must be given to ensuring the ethical use of the data as well as the modalities of this usage (how, by whom, for what purposes, with what implications) and determine its ownership (notably, but not exclusively, in the context of user-generated data through CGMs and other monitoring devices).

As mentioned earlier in this document, addressing the digital divide and digital literacy needs of both PwD and HCPs will also be required to ensure equal access to health and reduce inequalities for all across the European Union.

HOW CAN EU POLICY ACTIONS HELP OVERCOME THESE CHALLENGES?

- **Make diabetes a flagship initiative of the European Health Data Space** to demonstrate the feasibility of coordinated diabetes data registries for use in best-practice exchanges, to support healthcare reforms and care delivery and to support research into the effectiveness of clinical interventions and prevention programmes.

- **Promote access to data to stimulate diabetes research and encourage the translation of data and registries into policies to improve care.**

- **Ensure that all relevant issues relating to the increased digitalisation and use of data, such as ethical, privacy and liability consideration as well as their integration in the process of care delivery, are addressed in the set-up, further development and usage of European and national data frameworks and further digitalisation of health services.**

**Conduct research into all types of diabetes, from basic science to translational and behavioural research, for actionable insights**

COVID-19 has highlighted the vital role health plays in ensuring the European Union’s economic sustainability and competitiveness, and in shaping a fairer society. Research is the cornerstone of future improvements in diabetes prevention and management, and in light of the recent pandemic and the burden of diabetes across Europe, must be strengthened.

Through its research programme, Horizon Europe, as well as EU4Health and various other initiatives designed to improve the resilience of health systems (for instance, through structural funds and other initiatives), it is critical that the EU supports the following research areas to gather actionable insights to be translated into policy action:

**Preventing diabetes and improving treatments**

- Research on the prevention of T1D (e.g., immunotherapy including development of vaccines) and the management of both T1D and T2D (addressing the destruction of insulin-producing cells, or reversing insulin resistance through gene therapy, for example).

**Prevention of T2D and diabetes-related complications**

- The link between diabetes stigma and health outcomes, and effective solutions to tackling stigma.


- Evaluation of social interventions and the promotion of local initiatives in prediabetes and in diabetes.
Management of Type 1 and Type 2

- The effectiveness of key interventions including group support, novel tools, technologies and other areas of innovation.
- Clinical outcomes in integrated care systems.

Research into best practices supporting improved management and prevention of diabetes and its complications must also be supported by an in-depth updated analysis of factors that positively or negatively influence the implementation of good practices for diabetes care in Europe. This is all the more important given that many of the interventions, policies and initiatives that have been developed over the past 30 years have perhaps not achieved, or not fully achieved, their expected outcomes.

**HOW CAN EU POLICY ACTIONS HELP OVERCOME THESE CHALLENGES?**

- Ensure Diabetes is included in all key EU-funded research programmes as a stand-alone component as well as in broader research on NCDs and people living with co-morbidities.
- Ensure that all new research into management and prevention is supported by a broad research framework on the key factors influencing the implementation of good practices in diabetes care and prevention in Europe.
What would success look like?

Targets help trigger action, drive momentum, and spur engagement, and are necessary tools for measuring success. Not achieving pre-determined targets is also a useful measure of the need to re-assess policies and examine barriers to their implementation. As such, this Blueprint proposes success to be measured against two indicators:

1. The integration of key policy recommendations within EU legislative action and other EU initiatives.
2. A set of health indicators and healthcare system practices, reflecting the policy recommendations outlined in this document.

Integration of Key Policy Recommendations in EU Legislative Action and other Initiatives

<table>
<thead>
<tr>
<th>Year</th>
<th>EU Policy/Initiatives</th>
</tr>
</thead>
<tbody>
<tr>
<td>2021/2022</td>
<td>Recognition of the need for all new, centrally authorised diabetes medicines and technologies to be made available in all EU countries</td>
</tr>
<tr>
<td>2022</td>
<td>Diabetes as a flagship initiative of the European Health Data Space</td>
</tr>
<tr>
<td>2022/2023</td>
<td>Parliamentarian Resolution</td>
</tr>
<tr>
<td>2023</td>
<td>A proportion of EU Structural Funds allocated to fostering health promotion and diabetes prevention in a majority of EU countries</td>
</tr>
<tr>
<td></td>
<td>Further development of EU HTA framework: diabetes included as a key area of assessment and integrating principles regarding value-based healthcare</td>
</tr>
<tr>
<td></td>
<td>Strong diabetes research focus as part of Horizon Europe</td>
</tr>
<tr>
<td>2024</td>
<td>EU-wide screening tool and framework for people at risk</td>
</tr>
<tr>
<td>2025</td>
<td>EU-wide common specific and numerical targets for improving diabetes-related outcomes</td>
</tr>
<tr>
<td>2030</td>
<td>National diabetes registries in place or under development in all EU countries</td>
</tr>
</tbody>
</table>

Health Indicators/Health System Practices

<table>
<thead>
<tr>
<th>Year</th>
<th>Healthcare indicators and frameworks</th>
</tr>
</thead>
<tbody>
<tr>
<td>2025</td>
<td>A significant improvement in the number of people in the EU meeting HbA1C targets compared to a 2020 baseline (with an ideal target to be reached being above 75%) Meet diabetes component of GCM on NCDs</td>
</tr>
<tr>
<td>2026</td>
<td>A significant improvement in the proportion of people at risk of diabetes to be screened in all EU countries (against a baseline in 2020/2021) All newly-diagnosed people living with diabetes able to access self-management education within one month of diagnosis</td>
</tr>
<tr>
<td>2027</td>
<td>All relevant primary and secondary care professionals to be trained in supporting self-management and people with low literacy levels</td>
</tr>
<tr>
<td>2030</td>
<td>Meet SDG targets 3.4 and 3.8</td>
</tr>
</tbody>
</table>
More than 30 years ago, the St. Vincent meeting brought the urgency of taking action on diabetes to the fore. Through the St. Vincent Declaration, it secured the commitment of many European governments.

Since then, much has been achieved, not least through the engagement of PwD themselves, patient and HCP organisations, many other organisations across the diabetes community, and many policymakers at the national and European level (such as the EU Diabetes Working Group).

However, much remains to be done. The MEPs Mobilising for Diabetes’ Blueprint for Action on Diabetes to 2030 is a guide and represents a renewed commitment to supporting policies and programmes that will contribute to flattening the diabetes curve and reducing costs and inequalities. It also aims to build resilient health systems that are better equipped to care for people living with chronic diseases, including diabetes.

The ultimate goal of this blueprint is to improve the lives of PwD in the short term. Longer-term, the focus must be on eradicating the condition altogether.
Acknowlegments

Steering Committee
Dr Niti Pall, Chair, IDF Europe; Prof Nebojsa Lalic, Chair-Elect, IDF Europe; Prof Massimo Massi-Benedetti, Former Chair, IDF Europe.

Writing Team
Elisabeth Dupont, Regional Manager, IDF Europe; Sabine Dupont, Senior Policy Consultant; Cajsa Lindberg, Senior Consultant.

Contributors
MMD and the International Federation Europe would also like to thank the following organisations for contributing initial content and/or reviewing and providing feedback on the document:

- Diabetes Association Netherlands
- Diabetes DE, Germany
- European Diabetes Forum (EUDF)
- Fédération Française des Diabétiques (FFD)
- Foundation of European Nurses in Diabetes (FEND)
- Finnish Diabetes Association
- Polish Diabetes Association
- Portuguese Diabetes Association (APDP)
- Primary Care Diabetes Europe (PCDE)
- Romanian Diabetes Federation
- Slovenian Diabetes Association

Editing and layout
Lisa Dolan and Katie Greybe

Support
This publication was made possible thanks to unrestricted grants from the European Diabetes Forum and EFPIA to IDF Europe for the management of the MMD’s Secretariat.
References

2 The Lancet Commission on diabetes: using data to transform diabetes care and patient lives, DOI:https://doi.org/10.1016/S0140-6736(20)32374-6
5 Ibid
8 Ibid
9 Ibid
10 Ibid
11 Ibid
12 Ibid
13 Ibid
14 The Lancet Commission on diabetes: using data to transform diabetes care and patient lives, DOI:https://doi.org/10.1016/S0140-6736(20)32374-6
18 Ibid
22 Diabetes, Obesity and Metabolism 18: 401–409, 2016. Clinical inertia with regard to intensifying therapy in people with type 2 diabetes treated with basal insulin K. Khan†1, A. Nikolajsen2, B. L. Thorstedi, M. Andersen3, M. J. Davies1 & S. K. Pauli4,†
24 A Strategy for Health Care Reform — Toward a Value-Based System.Michael E. Porter, Ph.D. n engl j med 361;2;nejm.org july 9, 2009
25 Manag Care Spec Pharm. 2019;25(3):324-31, Identifying Outcome Measures for Type 2 Diabetes Value-Based Contracting Using the Delphi Method, Lynn M. Nelson, PhD; Elizabeth C.S. Swart, BS; Chester B. Good, MD, MPH; William H. Shrank, MD, MSHS; Rochelle Henderson, PhD; Chronis Manolis, RPh; and Natasha Parekh, MD, MS
Disclaimer: The objectives and actions outlined in this document have been reviewed by the MMD co-Chairs. However, certain actions and perspectives may not necessarily reflect the views of individual Members of the Interest Group or the views of different political parties.