# Diabetes Ireland

# Pre-Budget Submission 2023

Diabetes™ Ireland

September 2022

This document has been prepared by Diabetes Ireland (including Diabetes Ireland Advocacy Group) and consulted with the HSE National Clinical Programme for Diabetes and National Clinical Programme for Paediatrics and Neonatology (Diabetes), and the Cross Parliamentary Group on Diabetes.

# DATA & HEALTH INFORMATION

1) Development of a National Diabetes Registry.
2) Development and implementation of a National Paediatric Diabetes Audit.

## HIGH QUALITY OF CARE: MULTIDISCIPLINARY APPROACH

3) Ensure continuing progress of Enhanced Community Care programme and development of diabetes specialist hubs and access for all.
4) Ensure regular access to multidisciplinary diabetes teams in acute hospitals in paediatric and adults diabetes services.
5) Ensure access to mental health specialists.

## ACCESS AND REIMBURSEMENT

6) Ensure reimbursement of medicines for women with gestational diabetes (GDM).
7) Extend eligibility for Flash Glucose Monitoring to adults with diabetes based on clinical need.

8) Ensure timely access to diabetes education.
9) Ensure timely access to diabetes technology based on clinical need.
10) Provide easier access to Mortgages for people with diabetes.

## HEALTH AND WELLBEING

# Contents

# Budget 2023 Introduction

Diabetes Ireland is highlighting the current gaps in diabetes care in Ireland and is calling on the Government to take immediate actions to improve diabetes healthcare services, improve the quality of life for people living with diabetes, and reduce the long-term costs to the health service of diabetes complications. Currently, **we have no data and health information required to provide accurate budget estimates and appropriate health-service planning**. Thus, the first step to **improve health-service delivery in Ireland is to invest in data and health information provision, so the accurate financial needs recognition can be done**. Therefore, **the development and implementation of a national diabetes registry and a paediatric diabetes audit are the priority needs of the Pre-Budget Submission 2023 that require immediate funding**.

## Up to €1 billion spent on diabetes, half a billion on complications

Although up to date economic burden is unknown, knowing that total health expenditure in Ireland in 2019 was €23.8bn (€17.6 bn funded by the government), and using percentage estimates from 2006 and 2009-11 (4-6%), we envisage that between €700 m to €1 billion has been spent on diabetes care annually, with an estimated 50% of the budget (CODEIRE study) spent on avoidable complications and hospitalizations.

**Above estimates are, however, vague due to the lack of a diabetes registry.**

Diabetes is a serious global public health issue which has been described by the World Health Organisation as one of the top ten most challenging health problems in the 21st century with a high individual, social and economic burden[1]. According to the International Diabetes Federation Diabetes Atlas 2021 Ireland is ranked 7$^{th}$ in the world for diabetes related health expenditure per person[2]. The economic burden of diabetes on the Irish health care system is becoming a major challenge for the government and the Health Service Executive (HSE)[3].

As **a leading cause of morbidity and mortality, affecting an estimated 300,000 people in Ireland[3,4], and the most prevalent chronic condition in people between 45 to 74 years of age, diabetes places a significant burden on society and presents a growing challenge for the national economy[6]**. The economic estimates provided below are, however, not up to date and vague, further implying the necessity of having access to appropriate data and health information.

According to research comparing health-service use between people over 50 with and without diabetes (data from years 2009-2011), diabetes was associated with an 87% increase in outpatient visits, a 52% increase in hospital admissions and a 33% increase in emergency department attendances[6].

Although we have no diabetes registry or way to monitor the costs associated with diabetes, the CODEIRE study (2006) suggests that costs associated with diabetes consume between 4% and 6% of the annual healthcare expenditure in Ireland (€377.2 million to €580.2 million in 2006)[7]. If the same percentage (4-6%) is applied to the healthcare expenses in 2019 (€23.8 bn overall health expenditure, of which €17.6 bn was funded by the government)[8], we envisage that the government spend between €700m to €1bn on managing diabetes and its complications annually.

With overall health-expenditure (including out-of-pocket expenses and private care), costs associated with diabetes were from approx. €1 bn to €1.4 bn. In 2021, the International Diabetes Federation estimated that almost $1.1 bn has been spent on diabetes in Ireland in 2021[2]. Most of the costs (approx. 50% according to the CODEIRE study) were associated with hospitalisations and treatment of complications[7].

**To avoid costly and unnecessary diabetes complications, investment should be made in best available care. There is much evidence that more frequent medical review reduces health costs by preventing acute and chronic complications and inpatient hospital admissions. Without this level of care for all people with diabetes, acute and chronic complications are increasing, thus, a reorganisation of the current delivery of diabetes care is warranted:**

- For appropriate budget estimates, there is a need to further evaluate the economic costs of diabetes-related healthcare expenses in Ireland.
- There is a need to invest now in better diabetes management (diabetes education, access to best treatments and technology, and health-care professionals' expertise and resources) to avoid costly diabetes complications and hospitalisations.
- The priority for diabetes care in Ireland is to develop and implement a national diabetes registry and a paediatric diabetes national audit.

# What is Diabetes?

Diabetes is a lifelong condition characterised by high blood glucose levels, that occur when the pancreas is no longer able to make insulin (Type 1 diabetes), or when the body cannot make good use of the insulin it produces (Type 2 diabetes). Insulin is a hormone – a substance of vital importance - it acts like a key to open the doors into cells, letting sugar (glucose) in. If there is either no insulin letting sugar get into cells, or sugar does not get into cells efficiently, the sugar builds up in the bloodstream, causing high blood glucose levels.

It is commonly understood that there are two "types" of diabetes, "insulin deficient" (where the body does not produce enough insulin to manage blood glucose), and "insulin resistant" (where the body is unable to make effective use of the insulin in the bloodstream). These are commonly known as "Type 1 Diabetes" and "Type 2 Diabetes" respectively, but there are more than a dozen different types of diabetes. The division between the types is also based on the treatment – the vast majority of Type 2 diabetes cases are treated by lifestyle modification (nutrition, exercise) and/or glucose lowering tablet/injections. But an increasing number of people with Type 2 diabetes have to inject insulin and need similarly frequent glucose levels control and management – the treatment used in Type 1 diabetes from diagnosis.

**Living with diabetes is life-long, requires medical treatment, continuous control, assessment, and review, and for those on insulin – glucose control, intense diabetes self-management with dozens of medical decisions regarding insulin dosing and interventions a day**. All of it just to be safe and be able to maintain 'normal' and healthy lives, and help to avoid serious and harmful medical consequences, both severe [diabetic ketoacidosis (DKA), severe hypoglycaemia] and long-term complications (limb amputations, blindness, kidney failure and dialysis, cardiovascular events and even death). **To maintain healthy lives, despite normal day to day diabetes management, people with diabetes require access to medicines and technology used in diabetes care, the expertise of health-care professionals, diagnostic equipment, psychology supports, and education, support, and motivation to self-manage their condition well.**

| Group | Requires |
|---|---|
| People with insulin deficient (e.g. Type 1) diabetes | Regular expert diabetes review by multidisciplinary team (endocrinologist, diabetes nurse specialist, dietitian, psychologist) and referral pathway to other healthcare professional specialist areas. |
| People with insulin resistant (e.g. Type 2) diabetes, who have no complications | Regular review by community professional staff (doctor, nurse, dietitian) and referral to other community specialists e.g. podiatry and retinal screening. |
| People with insulin resistant (e.g. Type 2) diabetes, who have complications | Access to diabetes specialist multidisciplinary teams to address the resultant complex issues. |
| Women with diabetes during pregnancy | Specialist obstetric and diabetes care before and during the pregnancy to protect their and their child's health. |

# The needs of people with diabetes

People with diabetes need access to high standards of care, expertise, treatment aligned with clinical recommendations, reimbursement of medicines to maintain good health and quality of life. The actions we are calling on the Government are person-centred, cost-effective, and easy to implement.

| Needs and actions |
| --- |
| **PRIORITY NEED: DATA AND HEALTH INFORMATION:**<br>  <br>1) Development and implementation of a National Diabetes Registry is needed if we are to aspire to a delivery of high-quality diabetes care for all.<br>2) Development and implementation of a National Paediatric Diabetes Audit. |
| **HIGH QUALITY OF CARE: MULTIDISCIPLINARY APPROACH**<br>  <br>  <br>3) Ensure continuing progress of Enhanced Community Care programme and development of diabetes specialist hubs and access for all.<br>4) Ensure regular access to multidisciplinary diabetes teams in acute hospitals in paediatric and adult diabetes services, according to the national guidelines and models of care.<br>5) Ensure access to mental health specialists. |
| **ACCESS TO TREATMENTS AND REIMBURSEMENT**<br>  <br>  <br>6) Ensure reimbursement of required medicines for women with gestational diabetes (GDM).<br>7) Extend eligibility for Flash Glucose Monitoring (FGM) to adults with diabetes based on clinical need. |
| **HEALTH AND WELLBEING**<br>  <br>  <br>8) Ensure timely access to diabetes education.<br>9) Ensure timely access to diabetes technology based on clinical need.<br>10) Provide easier access to Mortgages for people with diabetes |

These actions align with the Sláintecare ten-year plan for reforming the Irish health system towards universal healthcare which aims to create a system where care is provided based on need, not ability to pay[9].

These actions also support the HSE National Clinical Programmes for Diabetes (Paediatric and Adult) strategy for managing diabetes (current & future cohorts of people living with diabetes) based on effective daily self-management and avoiding the development of chronic complications which in turn will make huge savings for the government.

**Diabetes Ireland is calling for implementation of these actions as a matter of priority to support the ever-increasing diabetes population**. These needs and actions require political support and long-term, year-on-year funding commitments for immediate implementation. This pre-budget submission outlines some initial steps we can take in the short term to aid and support the development of this strategy.

The four basic needs of people living with diabetes and their families, and four pillars of diabetes care are to:

I. **KNOW THE DATA AND ACCESS HEALTH INFORMATION**
II. **RECEIVE QUALITY CARE: MULTIDISCIPLINARY APPROACH**
III. **ACCESS BEST TREATMENTS AND MEDICINES (REIMBURSEMENT)**
IV. **MAINTAIN GOOD HEALTH AND WELLBEING**

Data are key to informed decisions. To improve diabetes care in Ireland data provision is necessary; only then can appropriate interventions and decisions be made. The entire diabetes community, including health care professionals and the Health Service Executive (HSE) National Diabetes Clinical Programmes for Adults and Paediatrics, the Cross Parliamentary Group on Diabetes, as well as people with diabetes (Diabetes Ireland, including Diabetes Ireland Advocacy Group), prioritise reliable data and health information as the only solution for improvement in all other pillars. Data is fundamental to generating change, thus **the priority ask of this Pre-Budget Submission 2023 is to invest, develop and implement a National Diabetes Registry and the National Paediatric Diabetes Audit. Only with the use of data, three other pillars (quality of care, reimbursement and health and wellbeing) can be improved.**

# Four pillars of diabetes care – summary of needs

## I. THE PRIORITY NEED: DATA AND HEALTH INFORMATION

### 1) National Diabetes Registry

**What is the need?**

Development and implementation of a National Diabetes Registry will provide a database to track the prevalence of diabetes, help to plan staffing resources, determine the cost of providing care and improve outcomes.

**Budget 2023 Ask: Funding to initiate the development of a registry.** € HSE / Minister of Health to Estimate cost.

**Why Fund This?** The lack of a National Diabetes Registry hinders the HSE's ability to plan for diabetes, an increasingly common and costly chronic condition.

**If Not Funded:** The HSE continues to blindly manage diabetes, and health-service delivery planning - we do not understand the cost implications of policy decisions.

**Highlights**

1. We do not know how many Irish people have diabetes, its complications, nor where they live in the country.
2. We can only estimate national-level figures by using prevalence rates in other countries (e.g. Scotland)
3. Lack of a registry is highlighted at European level as major deficiency of our service (rank: 20 of 30) since 2014.
4. Establishment of a registry would help with tracking the prevalence of the condition, measuring clinical outcomes, and cost of care and, most importantly enable better planning for delivery of services.
5. The registry could be a template for other chronic diseases.

### 2) National Paediatric Diabetes Audit

**What is the need?**

Development and implementation of a National Paediatric Diabetes Audit (NPDA), as outlined in the NPDA Feasibility study (2022) to improve diabetes outcomes, highlight areas of good practice, identify deficits, and promote improvement in the quality-of-care delivery and data-driven resource allocation for children and adolescents with diabetes.

**Budget 2023 Ask**: Funding for next steps as outlined in the Feasibility study. € HSE to Estimate

**Why Fund This?** The National Office for Clinical Audits has completed the feasibility study and funding is required to initiate the next steps.

**If Not Funded:** The HSE continues to blindly manage diabetes, and health-service delivery planning.

**Highlights**

1. Equal access to high quality standardised care required for all children with diabetes regardless of geographical location.
2. Development and implementation of the National Paediatric Diabetes Audit will enable better planning for delivery of services, tackle discrepancies and improve the outcomes and quality of care in children and adolescent with diabetes.
3. Starting from paediatric diabetes, it is planned to be expanded to all people with type 1 diabetes, and next to all people with diabetes in Ireland.

## II. OTHER NEEDS: QUALITY OF CARE: MULTIDISCIPLINARY APPROACH

### 3) Enhanced Community Care and diabetes specialist hubs

**What is the need?**

Continue delivery of comprehensive specialist community diabetes teams under the Enhanced Community Care Programme (Sláintecare), which helps make community healthcare services more effective in managing chronic conditions including Type 2 diabetes.

**Budget 2023 Ask: Ringfence the funding committed to employing the remaining 70% of posts required for diabetes services previously** included in HSE Winter Plan 2020

**Why Fund This?** Community diabetes care is provided in line with the National Framework for the Integrated Prevention and Management of Chronic Disease.

**If Not Funded…** Hospital resources remain under pressure from diabetes-related appointments and preventable acute complications.

**Highlights**

1. Comprehensive community specialist teams will support GP colleagues to manage people with more complex diabetes issues in a community setting.
2. Care for diabetes, chest and heart conditions is integrated. Multiple hospital appointments in different departments are avoided.
3. Pressure on hospitals is reduced and the community setting may be perceived as more patient friendly.
4. Money has been allocated for posts which have long been identified as necessary.
5. The Enhanced Community Care (ECC) programme is available for people covered by the GMS (General Medical Card Scheme). We ask for access to ECC programme for those paying for their GP care privately, as outlined by the principles of Sláintecare (and universal health coverage) for provision of care to those based on needs.

### 4) Multidisciplinary teams in ambulatory diabetes clinics

**What is the need?**

Better resourcing of multidisciplinary diabetes teams, as part of the long-term health-services planning based on epidemiological data and local needs to fulfil the necessary capacity and respond to the needs of people with diabetes. A National Diabetes Registry to inform health-services planning essential to improve resources in multidisciplinary teams in ambulatory diabetes clinics.

**Funding to initiate the development of a registry.** € HSE to Estimate cost.

**Why Fund This?** The lack of a National Diabetes Registry and long-term health-services planning in ambulatory care hinders the HSE's ability to effectively plan for diabetes care, an increasingly common and costly chronic condition. Lack of investment in multidisciplinary teams puts at risk health of people with diabetes treated in ambulatory setting.

**If Not Funded…** The HSE continues to blindly manage diabetes care, maintain the long waiting lists and no access to diabetes education and technology for people living with diabetes receiving their care at a hospital level.

**Highlights**

1. Hospital-based teams require staffing resources to ensure the quality of care
2. Due to interdisciplinary character of diabetes, requiring input from clinicians, nurses, dietitians, mental health specialists, podiatrists, MDT is the core of any hospital-based team for provision of diabetes education in self-management, structured diabetes education, diabetes advice based on persons with diabetes needs, provision training in the use of diabetes technology
3. We do not know how many Irish people have diabetes, its complications, nor where they live in the country and what staffing resources are sufficient to deliver high quality care.
4. Establishment of a registry and a long-term health-service plan in ambulatory care would improve diabetes care at the hospital level.

## 5) Ensure access to mental health specialists

**What is the need?**

Development of and access to psychology services for people with diabetes.

**Budget 2023 Ask: A funded plan to increase psychology support in diabetes teams.** HSE to estimate the costs.

**Why Fund This?** There is more than a 95% deficit in adult diabetes psychologists nationally (2018); there are only a few diabetes paediatric psychologist services available outside of Dublin.

**If Not Funded…** Lack of effective psychological support in diabetes has been clinically linked to a higher incidence of depression, anxiety, eating disorders, and other mental health disorders. It has also been linked with poorer diabetes outcomes, including complications and reduced employment opportunities.

**Highlights**

1. Good mental health and wellbeing are crucial in successful diabetes management.
2. Diabetes-related issues, such as diabetes distress and burnout can lead to deterioration in mental health and poorer diabetes management.
3. Prevalence of depression, anxiety and eating disorders is much higher in those with diabetes than in their healthy peers.
4. More psychology posts would facilitate support of acceptance of diagnosis, improvement of diabetes self- management and addressing mental health comorbidities, assisting, and training of diabetes teams and to offer people living with diabetes and their families equal and equitable access to psychological services.

# III. OTHER NEEDS: ACCESS TO TREATMENT AND REIMBURSEMENT

## 6) Reimbursement of medicines for women with gestational diabetes (GDM)

**What is the need?**

Restore funding supports to women with gestational diabetes (GDM).

**Budget 2023 Ask:** HSE/PCRS to estimate

**Why Fund This?** Essential that women with Gestational Diabetes (GDM) test glucose levels frequently and take glucose lowering tablets or deliver insulin, if necessary, to avoid potentially serious health consequences for Woman & Baby. Access to funding supports for duration of pregnancy (approx. 3 months of pregnancy) ensures best practice care for women with GDM.

**If Not Funded…** Unmanaged gestational diabetes is associated with higher health risks to both the mother and unborn child.

**Highlights**

1. Women with GDM at higher risk of pregnancy complications.
2. Infants at risk of higher birth weight and complications, including stillbirth.
3. Approximately 7,440 women develop GDM each year.
4. Increase in prevalence by 10-100% over last 30 years.
5. Essential that women with GDM test glucose levels frequently, take prescribed glucose lowering tablets or inject insulin if necessary to avoid pregnancy risks.
6. Delivery of best practice care impeded due to unforeseen costs.

## 7) Reimbursement of Flash Glucose Monitoring

**What is the need?**

Extend eligibility for Flash glucose monitoring to all people with diabetes, based on clinical need.

**Budget 2023 Ask:** HSE/PCRS to estimate

**Why Fund This?** This technology allows people using insulin to more effectively manage their blood sugar levels, and has been clinically demonstrated to reduce diabetes-related hospital admission.

**If Not Funded…** Preventable serious diabetes complications will continue to harm those on insulin and consume HSE resources.

**Highlights**

1. Adults with diabetes over age 21 cannot access Flash glucose monitoring – this is estimated to be 75% of the Type 1 diabetes population.
2. Many pay out-of-pocket, which significantly affects their personal budget and raises frustrations.
3. People with diabetes have been calling for wider access to this device since 2018.
4. Flash Glucose monitoring allows users to see a more comprehensive profile of blood glucose levels to help people with diabetes and clinicians to make more informed diabetes management decisions which improves quality of life.
5. As a consequence, it improves diabetes management, outcomes, and quality of life.

# IV. OTHER NEEDS: GOOD HEALTH AND WELLBEING

## 8) Timely access to diabetes education for people with Type 1 diabetes

**What is the need?**

Confirmation that further funding will be provided to continue to establish DAFNE centres and funding for the provision of diabetes insulin pumps specialist nurses is also provided.

**Budget 2023 Ask:** HSE to estimate

**Why Fund This?** Structured education is the cornerstone of good diabetes management and Insulin pumps are required as a treatment option in certain circumstances.

**If Not Funded…** Many more hospitalisations due to severe hypos, DKA and treatment of diabetes complications

**Highlights**

1. Diabetes education is the most important aspect of diabetes self-management, however, 55% of adults with Type 1 diabetes do not have access to DAFNE diabetes structured education.
2. 61% of adults with Type 1 diabetes do not have access to insulin pump therapy as a treatment option
3. DAFNE is the cornerstone of diabetes management for people on MDI or Insulin pumps.
4. DAFNE education has been proven to reduce hospital admissions significantly in the 12 months following completion.

## 9) Timely access to diabetes technology

**What is the need?**

Funding to provide diabetes clinics with trained specialist (technology) nurses.

**Budget 2023 Ask:** HSE to estimate

**Why Fund This?** Diabetes technology improves quality of care, life and improve diabetes outcomes in the diabetes population as a whole, as outlined in several national and international population-based studies.

**If Not Funded…** Many more hospitalisations due to severe hypos, DKA and treatment of diabetes complications

**Highlights**

1. Insulin pump uptake in adults with Type 1 diabetes in Ireland is as low as 7% while internationally uptake averages between 15-20%.
2. Insulin pump therapy should be offered as a treatment option based on thought-through discussion between the person with diabetes and diabetes team and should be considered based on clinical need.
3. Continuous or Flash Glucose Monitoring should be offered to any person with Type 1 diabetes, as outlined in the NICE guidelines, and international and national recommendations.

## 10) Provide easier access to mortgages for people with diabetes

**What is the need?**

Policy changes to support a scheme whereby people with diabetes will be able to secure a mortgage after being denied by three insurers.

**Budget 2023 Ask:** €0

**Why Fund This?** Living with diabetes must not prohibit anyone from purchasing a family home because their management of diabetes has been deemed "too risky" to insure.

**If Not Funded…** Some people with diabetes will be unable to purchase a home.

**Highlights**

1. Currently the insurance industry, based on the results of a medical assessment, has the final say as to whether they wish to offer mortgage protection to a person being treated with insulin.
2. The proposed scheme states that an individual who has been turned down by three insurance companies will be given a waiver by the mortgage provider which is covered in law.
3. Gives person with diabetes the opportunity to purchase home.
4. Huge advances in diabetes treatment and medications have reduced the level of risk.

# Four pillars of diabetes care – detailed information

## I. DATA AND HEALTH INFORMATION

**Data is key for health services planning, medical development and improving outcomes for those living with diabetes.** Epidemiological estimates, economic evaluation, medical and patient-reported outcomes have an essential role in helping clinicians, researchers, decision makers and health service planners provide the best possible service to those who need it, prevent outdated or inappropriate practice or undesired outcomes[10]. Data also support people with diabetes to make the right choices for better health and wellbeing and provide policymakers with evidence to take decisions based on patient needs and an understanding of current public health trends. Epidemiological data enable health-service planners make accurate decisions regarding resource allocation (nationally and locally) and improvements in the capacity of ambulatory and community diabetes clinics and teams[10-14].

Ireland is among a few countries in Europe without a diabetes registry or clinical audits[15]. In Ireland, the same issues for decades are over stretched and under-resourced health services, in particular in areas other than Dublin[10,11,14]. The lack of capacity and trained staff affects access to basic needs of people living with diabetes: regular, reliable diabetes care, access to modern treatments and medicines, and overall affects the standards of care. To improve diabetes care in Ireland data provision is necessary; only then can appropriate interventions and decisions be made[11,13,14]. The entire diabetes community, including health care professionals and HSE (National Diabetes Clinical Programmes for Adults and Paediatrics), as well as people with diabetes (Diabetes Ireland, including Diabetes Ireland Advocacy Group), prioritise reliable data and health information as the only solution for improvement in all other pillars. Data is fundamental to generating change, thus **the priority ask of this Pre-Budget submission 2023 is to invest, develop and implement a National Diabetes Registry and a National Paediatric Diabetes Audit.**

### 1) National Diabetes Registry

**What is the need?**

Development and implementation of a National Diabetes Registry will provide a database to track the prevalence of diabetes, help to plan staffing resources, determine the cost of providing care and improve outcomes.

**Budget 2023 Ask: Funding to initiate the development of a registry.** € HSE / Minister of Health to Estimate cost.

**Why Fund This?** The lack of a National Diabetes Registry hinders the HSE's ability to plan for diabetes, an increasingly common and costly chronic condition.

**If Not Funded:** The HSE continues to blindly manage diabetes, and health-service delivery planning - we do not understand the cost implications of policy decisions.

**Highlights**

1. We do not know how many Irish people have diabetes, its complications, nor where they live in the country.
2. We can only estimate national-level figures by using prevalence rates in other countries (e.g. Scotland)
3. Lack of a registry is highlighted at European level as major deficiency of our service (rank: 20 of 30) since 2014.
4. Establishment of a registry would help with tracking the prevalence of the condition, measuring clinical outcomes, and cost of care and, most importantly enable better planning for delivery of services.
5. The registry could be a template for other chronic diseases.

**Diabetes Ireland is calling for the creation and implementation of a National Diabetes Registry**. Health services that aspire to deliver high-quality diabetes care need to know who lives with diabetes in their locality. There is no accurate figure available for the number of people living with diabetes in Ireland. Initial steps towards this were previously funded, but funding was subsequently suspended with COVID-19. **The HSE / Minister of Health would need to estimate the costs of this (largely IT) project.**

The lack of a National Diabetes Registry represents a significant problem for our health service as we attempt to tackle diabetes, an increasingly common and costly chronic disease[10,11,15]. Establishment of a registry **would help with tracking the prevalence of the condition, measuring outcomes and cost of care and planning for future services**. A National Diabetes Registry also has the potential to provide an architecture and approach for the subsequent development of a **national chronic disease registry**.

In 2014, **Ireland was ranked 20th of 30 European countries** in a Euro Diabetes Index survey with the lack of a diabetes registry highlighted as a major deficiency[15]. This deficiency came into sharper focus recently when **the health service was unable to easily identify the diabetes population** as part of the COVID-19 vaccination programme.

Based on recent prevalence data from Scotland (taken from the Scotland Diabetes Survey 2020[16]) which maintains a National Diabetes Registry and can easily identify the diabetes population and track the prevalence of diabetes year on year, it is estimated (based on 5.8% of the total census population of Scotland) there are estimated 297,165 people living with diabetes in Ireland using the 2022 census[17].

| Country | Total (census) Population | Total Diabetes Prevalence | Type 2 Diabetes Prevalence | Type 1 Diabetes Prevalence |
|---|---|---|---|---|
| **Scotland (2020)** | 5,463,300 | 317,128 | 278,239 | 34,087 |
| **% of total population** | 100% | 5.8% | 5.1% | 0.6% |
| **Ireland (vague estimate) based on Scottish %** | **5,123,536** (CSO, 2022) | **297,165** | **261,300** | **30,741** |

We are calling for the development of a National Diabetes Registry that **would help with tracking the prevalence of the condition, measuring outcomes and cost of care and planning for future services**.

## 2) National Paediatric Diabetes Audit

**What is the need?**

Development and implementation of a National Paediatric Diabetes Audit (NPDA), as outlined in the NPDA Feasibility study (2022) to improve diabetes outcomes, highlight areas of good practice, identify deficits, and promote improvement in the quality-of-care delivery and data-driven resource allocation for children and adolescents with diabetes.

**Budget 2023 Ask**: Funding for next steps as outlined in the Feasibility study. € HSE to Estimate

**Why Fund This?** The National Office for Clinical Audits has completed the feasibility study and funding is required to initiate the next steps.

**If Not Funded:** The HSE continues to blindly manage diabetes care, and health-service delivery planning.

**Highlights**

1. Equal access to high quality standardised care required for all children with diabetes regardless of geographical location.
2. Development and implementation of the National Paediatric Diabetes Audit will enable better planning for delivery of services, tackle discrepancies and improve the outcomes and quality of care in children and adolescent with diabetes.
3. Starting from paediatric diabetes, it is planned to be expanded to all people with type 1 diabetes, and next to all people with diabetes in Ireland.

Ireland has **a high incidence of Type 1 diabetes - the most prevalent chronic condition in children and adolescents**. Continuous and **integrated multidisciplinary patient support is required to empower patients and caregivers to maximise self-management skills of the child and their parents/carers in order to achieve optimal diabetes control, which has been definitively shown to reduce the risk of acute and long-term diabetes-related complications**[18]. No national paediatric diabetes audit (NPDA) exists in Ireland, and available data originate from single-centre, stand-alone, or retrospective studies.

The lack of reliable data precludes healthcare professionals from making informed decisions about how to improve services and means that disparities in paediatric diabetes care are neither identified nor prospectively addressed. **A national audit of paediatric diabetes will highlight areas of good practice, identify deficits, and promote improvement in quality-of-care delivery and data-driven resource allocation. The need for an NPDA was specifically emphasised in the Model of Care for All Children and Young People with Type 1 Diabetes**[19].

In 2022 a feasibility study was published by the National Office of Clinical Audit which **highlighted the impact of national audits on clinical outcomes, as well as the contextual factors that have influenced audit implementation and how these factors might translate in a diabetes context**. The report describes the configuration of paediatric diabetes services nationally and the patient journey from diabetes diagnosis through ambulatory care to the transition to young adult services. It also **highlights areas of variability that might be amenable to audit and quality improvement.**

The multidisciplinary team resources available to children with diabetes nationally are reviewed and current practice across services for measurement and reporting of the key performance indicator (KPI) of glycated haemoglobin (HbA1c) described. Learnings from international audits and registries highlight the need for resources for data collection, that **the accuracy and efficiency of data collection is optimised by the use of electronic systems, integrated into healthcare and that data-driven decision-making and quality improvement are fostered by systematic data collection**[18].

We want to continue to use the knowledge gathered in the feasibility study to develop and implement an effective, detailed and informative National Paediatric Diabetes Audit, which could be then expanded to all Type 1 diabetes services and finally Type 2 diabetes services audits. The ask is to provide funding to NOCA **to develop and implement a paediatric diabetes audit which can be extended into adult services in future years.**

# II. QUALITY OF CARE: MULTIDISCIPLINARY APPROACH

**Diabetes care requires multidisciplinary approach**, as outlined in multiple national and international clinical recommendations[20-22]. Diabetes management is not only based on medical treatment (clinician – endocrinologist, diabetologist, GP), but on **nutrition (dietitian), diabetes education (diabetes nurse specialist/advanced nurse practitioner), behaviour change and mental health support (psychologist), foot care (podiatry)** etc [20-22]. Diabetes can affect all parts of body, therefore **every person with diabetes should be screened for early symptoms of retinopathy, nephropathy or neuropathy, cardiovascular disease, and if complications appear – should be referred to a specialist**, i.e. a podiatrist, nephrologist, or cardiologist[10].

**Access to multidisciplinary teams is essential for appropriate diabetes education and training to use advanced diabetes technology**: insulin pumps or automated insulin delivery systems. Expertise and multidisciplinary approach of the team: whether treating a person with uncomplicated type 2 diabetes in community care, a person with type 1 diabetes in ambulatory care or a person with diabetes-related complications – is essential in provision of recommended standards of care. **Offering regular access to multidisciplinary care to all people with diabetes in Ireland is the key to reduce diabetes-related complications and improve the quality of life of people with diabetes[3]**. We request the Government to:

i. Ensure continuing progress of Enhanced Community Care and development of diabetes specialist hubs and access to it to any person with diabetes in community care
ii. Ensure regular access to multidisciplinary diabetes teams in acute hospitals in paediatric and adult diabetes services, according to the national guidelines and models of care
iii. Ensure access to mental health specialists in ambulatory and community care.

## 3) Enhanced Community Care and diabetes specialist hubs

**What is the need?**

Continue delivery of comprehensive specialist community diabetes teams under the Enhanced Community Care Programme (Sláintecare), which helps make community healthcare services more effective in managing chronic conditions including Type 2 diabetes.

**Budget 2023 Ask: Ringfence the funding committed to employing the remaining 70% of posts required for diabetes services previously** included in HSE Winter Plan 2020

**Why Fund This?** Community diabetes care is provided in line with the National Framework for the Integrated Prevention and Management of Chronic Disease.

**If Not Funded…** Hospital resources remain under pressure from diabetes-related appointments and preventable acute complications.

**Highlights**

1. Comprehensive community specialist teams will support GP colleagues to manage people with more complex diabetes issues in a community setting.
2. Care for diabetes, chest and heart conditions is integrated. Multiple hospital appointments in different departments are avoided.
3. Pressure on hospitals is reduced and the community setting may be perceived as more patient friendly.
4. Money has been allocated for posts which have long been identified as necessary.
5. The Enhanced Community Care (ECC) programme is available for people covered by the GMS (General Medical Card Scheme). We ask for access to ECC programme for those paying for their GP care privately, as outlined by the principles of Sláintecare (and universal health coverage) for provision of care to those based on needs.

The HSE Winter Plan 2020 included provisions to commence a targeted reform programme, in line with the vision set out by Sláintecare, known as the 'Enhanced Community Care Programme' (ECCP). This programme aims to resource and scale-up community healthcare services including specialist chronic disease (Diabetes; Cardiology; Respiratory) services in line with the National Framework for the Integrated Prevention and Management of Chronic Disease[9,23].

**Diabetes Ireland welcomes and gives its full support to these reforms in care and requests that the allocated funding be ringfenced and not reduced in any way. We also ask to ensure access to ECCP to people not covered by the General Medical Scheme, who currently pay for their GP care privately.**

As part of ECCP initiative, funding has been secured to appoint specialist community diabetes teams to cover all community health networks across the country. These specialist diabetes teams are comprised of:

- Clinical Nurse Specialists Diabetes Integrated Care
- Senior Dietitians (Diabetes)
- Staff Grade Dietitians (Diabetes Prevention)
- Clinical Specialist, Senior and Staff Grade Podiatrists (Foot Protection)

Community specialist diabetes teams will work to support their colleagues in General Practice to develop and implement ambulatory care pathways and to manage complex diabetes care, and associated co-morbidities, within the community setting (where appropriate) and in line with the Model of Integrated Care for Type 2 Diabetes[10,23].
The diabetes community support this model of integration for all people with diabetes and is calling for **fast tracking of community diabetes teams appointments and to ensure that funding to employ the remaining 70% of planned posts is ringfenced for 2023**.

**Access for all people with diabetes**
We also ask to **ensure access to specialist community diabetes teams**, as well as **expanding the ECCP for all people with diabetes, including those who are not covered by the GMS Scheme**, so the access to healthcare is provided based on needs, not financial eligibility. Nearly one third of people with diabetes over 50 years of age cannot access the Type 2 Diabetes Cycle of Care programme. Although there are no data available to estimate the number of people eligible for the ECC programme based on their clinical need, but not holding a GMS card, we expect that similar numbers (35 to 40,000 people) who were not eligible for the Type 2 Diabetes Cycle of Care programme will continue to be forced to pay for their diabetes care privately[24]. The lack of access and free provision of care may result in people with uncomplicated diabetes still be seen by hospital-based diabetes team (no cost associated) or have no access to proper diabetes care at all.

## 4) Multidisciplinary teams in ambulatory diabetes clinics

**What is the need?**

More resources in multidisciplinary diabetes teams, as part of the long-term health-services planning based on epidemiological data and local needs to fulfil the necessary capacity and respond to the needs of people with diabetes. A National Diabetes Registry to inform health-services planning essential to improve resources in multidisciplinary teams in ambulatory diabetes clinics.

**Funding to initiate the development of a registry.** € HSE to Estimate cost.

**Why Fund This?** The lack of a National Diabetes Registry and long-term health-services planning in ambulatory care hinders the HSE's ability to effectively plan for diabetes care, an increasingly common and costly chronic condition. Lack of investment in multidisciplinary teams puts at risk health of people with diabetes treated in ambulatory setting.

**If Not Funded…** The HSE continues to blindly manage diabetes care, maintain the long waiting lists and no access to diabetes education and technology for people living with diabetes receiving their care at a hospital level.

**Highlights**

1. Hospital-based teams require staffing resources to ensure the quality of care
2. Due to interdisciplinary character of diabetes, requiring input from clinicians, nurses, dietitians, mental health specialists, podiatrists, MDT is the core of any hospital-based team for provision of diabetes education in self-management, structured diabetes education, diabetes advice based on persons with diabetes needs, provision training in the use of diabetes technology
3. We do not know how many Irish people have diabetes, its complications, nor where they live in the country and what staffing resources are sufficient to deliver high quality care.
4. Establishment of a registry and a long-term health-service plan in ambulatory care would improve diabetes care at the hospital level.

**A complete multidisciplinary team (MDT) is key to the delivery of high standard and quality care for people living with diabetes**[10]. Due to **interdisciplinary character of diabetes, requiring input from clinicians, nurses, dietitians, mental health specialists, podiatrists, MDT is also the core of any hospital-based team for provision of diabetes education in self-management, structured diabetes education, diabetes advice based on persons' with diabetes needs, provision training in the use of diabetes technology** (in particular continuous/flash glucose monitoring, insulin pumps) and **mental health support**[21,22,25,26].

The numbers of consultant endocrinologists, diabetes nurse specialists, dietitians and psychologists are low and **the vast majority of clinics in Ireland are under-resourced**. As outlined in the National Survey of Diabetes Care Delivery in Acute Hospitals 2018, 'The current national WTE of consultant endocrinologists is estimated to be 72% lower than recommended minimum levels. Substantial staffing deficits were also identified across other disciplines with a national WTE percentage deficit of 95% in psychologists, a 74% deficit in dietitians, a 32% deficit in podiatrists and a 19% deficit in specialist diabetes nursing staff'[27].

Although the situation has slightly changed since 2018, in particular in dietetics, nursing and psychology post, the **deficits still exist and are still significant**. These deficits were highlighted as part of the survey conducted by the National Clinical Programme for Diabetes in 2018[27], since then, however, staffing resources, local prevalence and needs have not been monitored.

In paediatric diabetes care the situation is a bit better, but very large gaps in MDT resources were identified in Children's Health Ireland and the South/South West Hospital Group across the full MDT, as outlined in the recently launched National Paediatric Diabetes Audit Feasibility Study Report 2022[18]. For example, gaps in dedicated paediatric diabetes psychosocial care were identified across all Hospital Groups.

**Insufficient resources significantly affect care delivery.** While technological devices are funded in Ireland, limited MDT staffing levels to provide the required education and support result in extensive waiting lists for children for whom this treatment would facilitate optimal medical care[18]. Furthermore, children currently using these devices **are not receiving the amount of support and education required for their optimal use, and when transferring to adult services, might not receive the required specialist care, as one-third of Irish diabetes clinics is not even offering the follow-up care for pump therapy, not to mention the possibility to commence the pump[24]**.

**Challenging transition from paediatric to adult diabetes care**

According to the NPDA, smooth transition processes were in place in several centres, but many reported delayed access for patients transitioning to adult services and some reported that co-located adult diabetes services did not accept transition patients who were using diabetes technology (insulin pumps)[18]. Based on locally asked Parliamentary Questions, **waiting lists to access adult diabetes services for adolescents and young adults with diabetes are counted in years in some areas of Ireland[28,29]**. Limited availability of technology-trained adult diabetes clinics and rejection of adolescents transitioning from paediatric services affect the waiting times and overwhelms clinics in the whole country. **The lack of continuity of care puts young adult health at risk, deteriorates or not progress with diabetes management, and is a significant gap of Irish diabetes care delivery, increasing the risk of unnecessary hospitalisations due to severe complications of diabetes, and associated costs.**

We ask to revise the current staffing resource levels, employ long-term health-services planning based on epidemiological data and local needs to fulfil the necessary capacity and respond to the needs of people with diabetes. The lack of understanding of the gaps, no comparison between the clinics and treatments used and their medical outcomes, is a consequence of the lack of a diabetes registry and standardised processes for measuring the outcomes. We ask that funding be made available to the HSE and NOCA for the development and implementation of the National Diabetes Registry and the National Paediatric Diabetes Audits which will improve future health-service planning in Ireland.

## 5) Ensure access to mental health specialists

**What is the need?**

Development of and access to psychology services for people with diabetes.

**Budget 2023 Ask: A funded plan to increase psychology support in diabetes teams.** HSE to estimate the costs.

**Why Fund This?** There is more than a 95% deficit in adult diabetes psychologists nationally (2018); there are only a few diabetes paediatric psychologist services available outside of Dublin.

**If Not Funded…** Lack of effective psychological support in diabetes has been clinically linked to a higher incidence of depression, anxiety, eating disorders, and other mental health disorders. It has also been linked with poorer diabetes outcomes, including complications and reduced employment opportunities.

**Highlights**

1. Good mental health and wellbeing are crucial in successful diabetes management.
2. Diabetes-related issues, such as diabetes distress and burnout can lead to deterioration in mental health and poorer diabetes management.
3. Prevalence of depression, anxiety and eating disorders is much higher in those with diabetes than in their healthy peers.
4. More psychology posts would facilitate support of acceptance of diagnosis, improvement of diabetes self- management and addressing mental health comorbidities, assisting, and training of diabetes teams and to offer people living with diabetes and their families equal and equitable access to psychological services.

**Good mental health and wellbeing are the core of all aspects of life and are crucial in successful diabetes management**. People living with diabetes face the burden associated with the condition every hour of every day. It requires continuous self-management and the necessity to make multiple medical decisions daily. This **burden is reflected in the significantly higher incidence of depression, anxiety, and other mental health disorders, including eating disorders in the diabetes population when compared to other populations**[30-32].

Some specific diabetes-related issues, such as **diabetes distress and burnout, lead not only to significant deterioration in mental health but also to poorer diabetes management and outcomes**. This in turn can lead to **reduced motivation and capacity to deal with the responsibilities associated with diabetes which can result in a higher incidence of depression and the development of expensive diabetes-related complications and a reduced quality of life**[30-33].

In the current social and economic circumstances within Ireland, **the physical and mental health of people with diabetes of all ages is not at the top of any agenda**. Although recognised by the HSE, psychosocial support in diabetes care is not formally embedded as part of diabetes management and not in line with diabetes-related health-services delivery in Ireland.

Presently, there is a 95% deficit of diabetes psychologists in adult diabetes services in acute hospitals and there is no access to dedicated diabetes psychology services in primary care[27]. Moreover, opposite to enhanced community care hubs in cardiac care, which include mental health specialists as part of the multidisciplinary team, resource planning for diabetes have not included psychologists and mental health specialists as part of wider multidisciplinary specialist community hubs teams[23].

As outlined in the National Paediatric Diabetes Audit Feasibility Study Report 2022, for children and adolescents with diabetes, there is limited access to 5 paediatric psychologists (2.2 WTE for the whole country) within national HSE paediatric diabetes services. Three of them (1.5 WTE) are based in Dublin, one in Mullingar (0.5 WTE) and one in Limerick (0.2 WTE). The gaps in dedicated paediatric diabetes psychosocial care were identified across all Hospital Groups[18].

With so little resources available, **the gap in access to psychological support for people living with diabetes in Ireland is significant, whereas the need to assess and deal with the psychological burden is substantial.** To address this huge gap, Diabetes Ireland wants to see funding made available to provide posts which play critical role in:

a) Supporting adjustment to an acceptance of the diabetes diagnosis.
b) Improving diabetes self-management through supporting behaviour change and adherence to diabetes care regimens and therefore reducing the prevalence of diabetes-related complications and mortality.
c) Addressing mental health comorbidities (e.g. depression, anxiety, diabetes distress, eating disorders) through individual and group psychotherapeutic intervention, as people living with diabetes are at much higher risk of serious mental health disorders.
d) Providing complex psychological formulation and neuropsychological assessment.
e) Assisting and training the diabetes MDT in psychological aspects of diabetes, recognition of psychological challenges and basic support provision.
f) Offer people living with diabetes and their families equal and equitable access to psychological services based on need, not ability to pay or geographical location, as in line with Sláintecare priorities.

We ask for recognition and investment in mental health care and support for people with diabetes who are at much higher risk of depression, anxiety and eating disorders due to the burden associated with diabetes treatment. A funded plan to increase psychology support in diabetes care is required.

# III. ACCESS TO TREATMENT AND REIMBURSEMENT

Everyone with diabetes: Type 1 or Type 2, except for women with gestational diabetes, is eligible for inclusion in a Long-Term Illness (LTI) scheme. It entitles every person with diabetes to receive diabetes medications (insulin, oral hypoglycaemic agents etc.) and medications for associated conditions such as some blood thinners, cholesterol lowering and blood pressure medication. Other diabetes supplies, such as pens/syringes lancets, blood glucose monitoring strips, insulin pump infusion sets, continuous glucose monitoring sensors etc., if required, are also included and free of charge once prescribed.

**The reimbursement of medicines is critical for people living with chronic condition, as well as free health-service delivery (diabetes appointments, reviews, screening etc.)**. In Ireland, there are still a few gaps affecting people living with diabetes. Therefore, we ask for:

- Reimbursement of medicines (blood glucose test strips, glucose lowering tablets, insulin etc) for women with gestational diabetes (GDM) for the duration of pregnancy.
- Reimbursement of Flash Glucose Monitoring (FGM) for people with diabetes over 21 based on clinical need.

## 6) Reimbursement of medicines for women with gestational diabetes

**What is the need?**

Restore funding supports to women with gestational diabetes (GDM).

**Budget 2023 Ask:** HSE/PCRS to estimate

**Why Fund This?** Essential that women with Gestational Diabetes (GDM) test glucose levels frequently and take glucose lowering tablets or deliver insulin, if necessary, to avoid potentially serious health consequences for Woman & Baby. Access to funding supports for duration of pregnancy (approx. 3 months of pregnancy) ensures best practice care for women with GDM.

**If Not Funded…** Unmanaged gestational diabetes is associated with higher health risks to both the mother and unborn child.

**Highlights**

1. Women with GDM at higher risk of pregnancy complications.
2. Infants at risk of higher birth weight and complications, including stillbirth.
3. Approximately 7,440 women develop GDM each year.
4. Increase in prevalence by 10-100% over last 30 years.
5. Essential that women with GDM test glucose levels frequently, take prescribed glucose lowering tablets or inject insulin if necessary to avoid pregnancy risks.
6. Delivery of best practice care impeded due to unforeseen costs.

Diabetes Ireland is calling on the government to **provide access to insulin, glucose lowering tablets, and blood glucose strips free of charge for women who develop Gestational Diabetes (GDM**) for the duration of pregnancy. Since a decision by the then government in 2013/14, women who develop GDM are no longer entitled to reimbursement for blood glucose test strips under the Long-Term Illness Scheme and if they do not have a GMS card, they are required to pay for their blood glucose strips themselves, costing up to €80 per month, the maximum amount under the drugs payment scheme. Many women cannot afford this additional, unforeseen cost which can impede the delivery of best practice care for women with GDM.

Each year in Ireland approximately 7,440 women develop GDM[3]. The International Diabetes Federation reports that one in six (16.7%) pregnancies are affected by diabetes worldwide and the majority (80.3%) are classified as GDM[2]. Figures generally point towards an increase in prevalence by 10–100% over the past 30 years. These women can often be treated mainly by nutrition intervention, however, a significant number of women with GDM have to take glucose lowering tablets or inject insulin. They also have to control their glucose levels to avoid unnecessary complications[34].

Women with GDM are at higher risk of developing serious complications such as pre-eclampsia, perineal trauma, or emergency caesarean delivery. Infants of women with GDM are at increased risk of higher birth weight with associated complications such as neonatal hypoglycaemia, jaundice, birth trauma and even stillbirth. **Due to these higher risks and associated complications it essential that women with GDM monitor their blood glucose levels frequently during their pregnancy so that they and their diabetes team can individualise their treatment safely and appropriately[34].**

The mainstay of treatment for GDM is lifestyle intervention and this is highly effective in some women. Intervention is even more important due to almost 10-fold higher risk of developing type 2 diabetes in women with GDM when compared to women without GDM[35]. Therefore, this group requires further screening, and access to best available care from the onset of GDM. Some women require insulin, tablets and extra monitoring of blood glucose levels[34] and currently in Ireland they have to pay for those out of pocket.

We are calling for required medicines: blood glucose strips and/or insulin and/or glucose lowering tablets to be made available to women diagnosed with Gestational Diabetes free of charge for the duration of their pregnancy.

## 7) Reimbursement of Flash Glucose Monitoring

**What is the need?**

Extend eligibility for Flash glucose monitoring to all people with diabetes, based on clinical need.

**Budget 2023 Ask:** HSE/PCRS to estimate

**Why Fund This?** This technology allows people using insulin to more effectively manage their blood sugar levels and has been clinically demonstrated to reduce diabetes-related hospital admission.

**If Not Funded…** Preventable serious diabetes complications will continue to harm those on insulin and consume HSE resources.

**Highlights**

1. Adults with diabetes over age 21 cannot access Flash glucose monitoring – this is estimated to be 75% of the Type 1 diabetes population.
2. Many pay out-of-pocket, which significantly affects their personal budget and raises frustrations.
3. People with diabetes have been calling for wider access to this device since 2018.
4. Flash Glucose monitoring allows users to see a more comprehensive profile of blood glucose levels to help people with diabetes and clinicians to make more informed diabetes management decisions which improves quality of life.
5. As a consequence, it improves diabetes management, outcomes, and quality of life.

Since 2018, access to Flash Glucose monitors has been restricted to people with Type 1 diabetes under aged 21 years unless there were "exceptional circumstances" which resulted in approximately three quarters of the Type 1 diabetes population in Ireland refused access. Yet other more costly glucose sensing technologies (Continuous Glucose Monitoring – CGM) are available[36]. **This limited access is not reflective of sensing technology choice seen across Western Europe where it is now commonplace for FGM to be an option for all people with type 1 diabetes, and some people with Type 2 diabetes, regardless of age, but based on clinical need[37,38]**.

Flash Glucose Monitoring replaces routine 'finger-stick' self-monitoring blood glucose (SMBG) for people with diabetes and provides a 24-hour continuous profile which also helps people with diabetes and their clinicians to make more informed diabetes management decisions. SMBG only provides a one moment snapshot of glucose levels. This technology allows people using insulin to more effectively manage their blood sugar levels, and there is a substantial body of clinical evidence demonstrating that the system safely improves clinical outcomes and quality of life for people with diabetes as well as reducing healthcare system resource utilisation, such as costly hospitalisations[36,39-41].

Based on real-world data from diabetes registries, wide implementation of sensing technology improves population health[39,40]. **For example, there is now a substantial body of clinical evidence including Randomised Controlled Trials (RCT), real world and observational studies demonstrating that FGM system safely improves clinical outcomes for people with diabetes.** The Association of British Clinical Diabetologists (ABCD) audit involving 102 UK diabetes centres with over 10,000 users' data collected, reported that FGM users had significantly less paramedic call outs, hospital admissions and episodes of severe hypoglycaemia in the 7.5 month follow up period – admissions for hypoglycaemia reduced from 120 to 45 and admissions for hyperglycaemia/ DKA reduced from 269 to 86, comparing 12 months pre–FGM initiation to 7.5 months post[41]. The cost of a hypoglycaemia admission in Ireland is in the region of €1000 and puts significant burden on Irish hospitals. In addition, Irish based clinical evidence has been provided by a number of Irish diabetes centres plus a submission to the HSE (PCRS) by Diabetes Ireland which highlighted that adult with diabetes using the technology privately showed a 66% reduction in their blood glucose strip usage[3]. **This mounting clinical evidence on the reduced hospitalisation costs and the massive improvements in the quality of life for people with diabetes should be a considerable factor in the decision to expand access to FGM.**

The National Institute for Health and Care Excellence (NICE) in England published updated glucose monitoring guidelines in March 2022 for people with diabetes. The recommendations are all people with Type 1 diabetes have access to either FGM or CGM, so have a choice of continuous glucose monitoring dependant on their needs and preference, and for people with Type 2 diabetes using insulin intensively and meeting certain criteria FGM should be offered. NICE found FGM to be cost effective in both these cohorts[37,38]. Currently available 2018 Irish National Clinical Guideline No. 17 for Adults with Type 1 diabetes contextualises many parts of the previous Type 1 NICE guidelines, so we foresee the access to technology section will be updated to reflect NICE's more recent and broader recommendations anyway in line with the new NICE guidelines[42]. **Access to glucose sensing technology for people with type 1 diabetes is a clinical recommendation of all international diabetes societies[21,37,38,43,44].**

Diabetes Ireland was asked to prepare a Patient Submission of Evidence, as part of the Health Technology Assessment (HTA) for FGM. Although the full HTA did not go-ahead Diabetes Ireland surveyed people with diabetes and their experiences accessing and using FGM in 2021 anyway, and 754 people (Type 1, Type 2 diabetes, health-care professionals) took part. The results were stark in terms of improvements in mental health and diabetes burden – 88% of participants felt less overwhelmed by the demands of living with diabetes when compared to finger pricking. **56% of those currently using Flash self-fund but many could not continue due to affordability and many '*had to choose between paying for good health and paying bills*'.** From a HCP perspective 92% believe that Flash should be reimbursed for all people with diabetes in Ireland based on clinical need. There is a process, laid out by the HSE, to allow exceptions to the current FGM reimbursement, based on clinical need, however 74% HCPs report many are rejected without any valid reason provided[35]. Parliamentary Question asking for the rejection status of applications for FGM for people over 21 stated that the proportion of rejected application is increasing annually from 35% in 2018 to 51% in 2020 and 100% in 2021[45].

We understand the manufacturer, Abbott, company producing FGM (FreeStyle Libre) has made an application for their next generation device FreeStyle Libre 2, with optional alarms, to be added to the HSE Continuous Glucose Monitoring pricing agreement, not FGM. We would welcome this addition to the currently available glucose sensing technologies and are hopeful Ireland will align to a broader access seen across our European neighbours allowing people with diabetes of all ages a choice of technology to meet their clinical needs.

We are **calling for Flash Glucose Monitoring to be made available to all people with diabetes, who use MDI or an insulin pump (Type 1, Type 2, etc.) to manage their diabetes based on the clinical need. FGM is reimbursed for people with Type 1 diabetes in all Western European countries** with a mass of international evidence of improving diabetes care and outcomes, not reimbursed to people with diabetes in Ireland, despite clinical recommendations and its effectiveness. This will improve quality of life for the individual and further aid prevention of costly diabetes complications and make short and long-term savings for the health service.

# IV. GOOD HEALTH AND WELLBEING

Diabetes is a chronic condition, which, if treated according to the clinical guidelines and recommendations does not have to cause complications and other significant burden. People with diabetes can work in any roles, have families, and live full, 'normal' lives. The burden of living with diabetes is huge and significantly increases the risk of diabetes related psychological comorbidities, such as depression, anxiety, burnout or eating disorders as compared to healthy population. There is also a vicious circle of mental health and effectiveness of diabetes management. When mental health is affected, it affects the medical outcomes and management and affects the quality of life. As well as mental health support, the key to optimal self-management and diabetes outcomes is also high-quality diabetes education, which gives people with diabetes skills necessary to live with their condition. There is also a mass of evidence acknowledging the role of diabetes technology in improving the quality of life and wellbeing. Therefore, we in Diabetes Ireland ask for the:

- Timely access to diabetes education, in particular structured education programmes such as DAFNE to those with Type 1 diabetes.
- Timely access to diabetes technology for all people with diabetes based on the clinical need.
- Provide easier access to mortgages for people with diabetes.

## 8) Timely access to diabetes education for people with Type 1 diabetes

**What is the need?**

Confirmation that further funding will be provided to continue to establish DAFNE centres and funding for the provision of diabetes insulin pumps specialist nurses is also provided.

**Budget 2023 Ask:** HSE to estimate

**Why Fund This?** Structured education is the cornerstone of good diabetes management and Insulin pumps are required as a treatment option in certain circumstances.

**If Not Funded…** Many more hospitalisations due to severe hypoglycaemia episodes, DKA and treatment of diabetes complications

**Highlights**

1. Diabetes education is the most important aspect of diabetes self-management, however, approximately a half of adults with Type 1 diabetes do not have access to DAFNE diabetes structured education.
2. 61% of adults with Type 1 diabetes do not have access to insulin pump therapy as a treatment option
3. DAFNE is the cornerstone of diabetes management for people on MDI or Insulin pumps.
4. DAFNE education has been proven to reduce hospital admissions significantly in the 12 months following completion.

**Over half of adults living with Type 1 diabetes do not have access to DAFNE diabetes structured education, a vital training in enabling self-management of insulin dependent diabetes and one third of adults with Type 1 diabetes do not have access to insulin pumps as a treatment option**[42]. This impacts upon not only newly diagnosed adults with diabetes,

those who are living with diabetes for decades, but also for many young adults transferring from paediatric to adult Type 1 diabetes care, often feeling left behind lacking any structured education at a pivotal moment of change in their lives. People with Type 2 diabetes have bigger choice of structured education programs (Discover, DESMOND, and CODE), people with Type 1 diabetes can only access structured education via a dedicated DAFNE centre[3,46].

Although **The National Clinical Guidelines for Adults with Type 1 diabetes state that structured education program, for example DAFNE, should be offered to all adults with Type 1 diabetes, and in particular 6-12 months after diagnosis, it also highlights that over half (55%) of the adult type 1 diabetes population do not have access to diabetes services providing access to these specialised Type 1 diabetes programmes[3,42]**. In 2018, there were 7 accredited DAFNE centres in Ireland with a plan for 11 additional centres in line with implementing the National Clinical Guidelines for Adults with type 1 diabetes. So far in 2022, additional centres have been established, including 2 private clinics, bringing the total to 16 (14 in public clinics). We want to ensure that the remaining centres become DAFNE licensed in 2023.

DAFNE (Dose Adjustment for Normal Eating) structured education is the cornerstone of diabetes management for adults with Type 1 diabetes. The National Clinical Guidelines for Adults with Type 1 diabetes states that the clinical evidence DAFNE training provides results in a reduction in hospital admissions, "fewer long-term complications as a result of improved glycaemic control, reduced number of episodes of diabetic ketoacidosis (DKA) resulting in hospital admission, improved psychological adjustment to living with diabetes, improved undertaking of diabetes self-management behaviours, improved clinical outcomes"[3,42,47]. Too many adults living with Type 1 diabetes, however, still do not have access to DAFNE diabetes structured education, a vital training in enabling self-management of insulin dependent diabetes.

**Diabetes Ireland is calling on government to ensure that funding to complete the current rollout of DAFNE Structured education centres continues in 2023. If DAFNE is not offered, then multidisciplinary teams with expertise in diabetes education should be available.**

## 9) Timely access to diabetes technology

**What is the need?**

Funding to provide diabetes clinics with trained specialist (technology) nurses.

**Budget 2023 Ask:** HSE to estimate

**Why Fund This?** Diabetes technology improves quality of care, life and improve diabetes outcomes in the diabetes population as a whole, as outlined in several national and international population-based studies.

**If Not Funded…** Many more hospitalisations due to severe hypos, DKA and treatment of diabetes complications

**Highlights**

1. Insulin pump uptake in adults with Type 1 diabetes in Ireland is as low as 7% while internationally uptake averages between 15-20%.
2. Insulin pump therapy should be offered as a treatment option based on thought-through discussion between the person with diabetes and diabetes team and should be considered based on clinical need.
3. Continuous or Flash Glucose Monitoring should be offered to any person with Type 1 diabetes, as outlined in the NICE guidelines, and international and national recommendations.

Diabetes technology has advanced in the last five years to make a real difference in improving quality of the lives of people with diabetes and reducing the cost of hospital admissions. Access to diabetes technology in Ireland is far behind the Western world, including our neighbours in the United Kingdom[21,37,38,41].

**National uptake of insulin pumps in Ireland is exceptionally low at 10.5%, compared to the internationally uptake averages between 15-30%**. Although insulin pumps are reimbursed in Ireland, availability and uptake are poor in comparison to other Western countries where the reimbursement is offered. In 2016, **7% of adults with Type 1 diabetes and 34% of children and adolescents were using insulin pumps.** This is a lot less than for example in Germany (>50% of children, 34% of adults), Sweden (70% of children) or UK (15% in adults in 2015)[48]. Although pumps are available in Ireland for the last 20 years, so should not be called 'new technology', **one-third of Irish adult diabetes clinic do not offer training to commence insulin pump therapy, nor follow up care, what significantly affects uptake, awareness, and transition process of adolescents and young adults with diabetes[25]**. Uptake of pumps is much higher in this group, and the lack of the follow up care in local clinic, and the need to refer someone on pump to a centre with particular 'expertise' cause delays and long waiting lists, as mentioned previously. Among the main barriers to provide care for people on pumps or willing to commence insulin pump therapy are insufficient resources, lack of capacity, expertise, awareness, and personal beliefs of health care professionals[26].

With the dawn and emerging evidence for automated insulin delivery systems (insulin pumps which continuous glucose monitoring and special algorithms to automatically deliver insulin based on needs)[49,50], the low uptake of pumps should be tackled, as clinical evidence on the benefits of insulin pump therapy is vast and have demonstrated improved glucose control, reduces glucose variability, reduction in hypoglycaemia events and significant improvement in quality of life[44,51-53], and clinical evidence for automated insulin delivery systems are superior to any other technology. **With the advances in the development of sensor augmented closed loop "smart" insulin pumps the barriers to pump access present in significant problem for the health service in catching up to current international best practice in diabetes management.**

Continuous/flash glucose monitoring is easier to implement, however, the uptake is still limited in Ireland. Flash glucose monitoring is only available to people under 21, and for older cohorts – only if clinical need is well described. However, 74% of health-care professionals who took part in the survey on accessing FGM in Ireland highlighted that their applications on the grounds of significant clinical needs are frequently not accepted, even with no reason provided. It raises frustration among health-care professionals who are best placed to decide on the most appropriate medical treatment for their patients[36].

**Diabetes technology is the reality and future of diabetes management.** NICE guidelines 2022 state that all people with type 1 diabetes should be offered FGM or CGM early after diagnosis[37], and people with type 2 diabetes with clinical need (i.e. on insulin) should be offered FGM[38]. **International clinical recommendations which are based on multiple real-world data (diabetes registry, audits), and clinical trials, outline that every person using insulin should use continuous or flash glucose monitoring instead of standard finger-pricking.**

Therefore, we ask for further investment in diabetes teams (resources) and training of health-care professionals, as well as easier provision of diabetes technology to those who need it most. We expect that the national diabetes registry and clinical audits will prove the effectiveness of diabetes technology on people's health (medical outcomes) and the quality of life. Diabetes registry and audit will also highlight the deficits in resources, which are crucial for diabetes technology distribution and uptake. We ask for better health-services planning, delivering and implementing a National Diabetes Registry.

## 10) Easier access to mortgages for people with diabetes

**What is the need?**

Policy changes to support a scheme whereby people with diabetes will be able to secure a mortgage after being denied by three insurers.

**Budget 2023 Ask:** €0

**Why Fund This?** Living with diabetes must not prohibit anyone from purchasing a family home because their management of diabetes has been deemed "too risky" to insure.

**If Not Funded…** Some people with diabetes will be unable to purchase a home.

**Highlights**

1. Currently the insurance industry, based on the results of a medical assessment, has the final say as to whether they wish to offer mortgage protection to a person being treated with insulin.
2. The proposed scheme states that an individual who has been turned down by three insurance companies will be given a waiver by the mortgage provider which is covered in law.
3. Gives person with diabetes the opportunity to purchase home.
4. Huge advances in diabetes treatment and medications have reduced the level of risk.

Diabetes Ireland regularly receive **enquiries from people with diabetes in relation to difficulties in accessing mortgage protection and life cover.** When quoted, people with Type 1 diabetes can expect to pay 200-450% more on their mortgage protection cover, depending on their diabetes management, while those with Type 2 diabetes can expect to pay 50-200% more. If it is a joint mortgage, only the person with diabetes will be loaded.

It is sometimes possible for a person with Type 1 or Type 2 diabetes to get a quote for Mortgage Protection Life Insurance depending on the history and how well the person is managing his/her condition.

Different Life Insurance Companies and different Insurance Brokers will deal with applications in different ways. At the outset information will need to be provided by the applicant on the diabetes type, when diagnosed, last two professional HbA1c readings which should be under 53mmol/mol (or 7%), Body Mass Index, information on any diabetes related complications, blood pressure, cholesterol and smoking/nicotine usage etc.

If the applicant meets the initial criteria, a Personal Medical Attendants Report (PMA) or a full medical report from the applicants own doctor or an independent doctor will be sought. Although Diabetes Ireland is not happy with the set criteria on which the medical examination and ratings system is based, we are not advocating for change of the criteria. Instead, Diabetes Ireland is proposing a Scheme whereby an applicant living with diabetes having be declined for Mortgage protection / Life Insurance by three different Life Insurance Companies would be granted a "Waiver" by the Mortgage Provider, which would mean that the Mortgage Provider would not refuse to grant the mortgage in these circumstances. It is our understanding that this is already provided for under current law but requires systematic agreement of the Mortgage Providers to be put into effect on a formal basis and not as currently on a case-by-case basis.

This would be a gamechanger for many people with diabetes enabling them to purchase a family home. **With the huge advances and improvements in diabetes treatment and medications now available the risk of poor claims experience is much less than it was 5-10 years ago, and the risk will continue to reduce as treatments and medications are continually improved**. We now have Continuous and Flash Blood Glucose Monitoring systems which have transformed the management of diabetes.

It is well established that optimal blood glucose management reduces the risk of complications and allow people with diabetes to achieve a normal life expectancy free from these complications.

**Diabetes Ireland is asking the Government, Department of Finance and the Minister for Finance to engage with the Banking and Payments Federation Ireland to develop a standardised protocol as outlined.**

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## Diabetes Ireland Head Office:

**19 Northwood House,**
**Northwood Business Campus,**
**Santry, Dublin 9, D09DH30**
Phone: 01 842 8118
Email: info@diabetes.ie

## Dublin Care Centre

19 Northwood House
Northwood Business Campus,
Santry, Dublin 9, **D09DH30**
Phone: 01 842 8118
Email: carecentre@diabetes.ie

## Cork Care Centre

Enterprise House
36 Mary Street
Cork, T12 H6NH
Phone: 021 427 4229
Email: charlotte.pearson@diabetes.ie

## Western Regional Office

1 Wine Street, Sligo
Phone: 071 914 6001
Email: wro@diabetes.ie