

DIABETES UK – RESPONSE TO CONSULTATION ON THE DRAFT PROGRAMME FOR GOVERNMENT OUTCOMES FRAMEWORK

Prepared by:

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Who are we?

Diabetes UK is the leading health professional and research charity in Northern Ireland for people living with diabetes. We support people living with diabetes in Northern Ireland through our peer support groups, the *Our Lives Our Voices* programme as well as our Helpline and Forum.

We also campaign and work in partnership with government agencies, education institutions, healthcare professional and other third sector organisations to deliver improvements in the care and treatment of people living with diabetes.

Alongside people living with diabetes, carers, healthcare professionals, the Department of Health and the HSC Board, we are a key partner in the Diabetes Network for Northern Ireland.

Diabetes in Northern Ireland

As of 2021, there are just under 105,000 people in Northern Ireland with a diagnosis of diabetes. When a person has diabetes, they will have one of several serious and life-long conditions affecting a person's blood glucose and insulin levels:

- Approximately 9,500 people in Northern Ireland have **type 1 diabetes**, a condition where they cannot make insulin at all. Type 1 diabetes cannot be prevented or delayed, and what causes type 1 diabetes to develop is not known. While type 1

diabetes is often diagnosed later in life, it is the most common form of diabetes in children.

- Approximately 90% of people with diabetes have **type 2 diabetes**. When a person has type 2 diabetes, the insulin they make cannot work effectively or they cannot produce enough of it. This means their blood glucose levels keep rising. Approximately 70-80% of cases of type 2 diabetes can be prevented or delayed. The risk factors for developing type 2 diabetes include age, ethnicity, family history and being overweight. For these reasons type 2 diabetes is most commonly found in older adults.
- In 2018/19, just over 2,200 women in Northern Ireland had **gestational diabetes**, which develops during pregnancy. When a woman has gestational diabetes, it is due to the hormones she is producing making it hard for her body to use insulin properly. Gestational diabetes usually goes away after giving birth however it is possible for a woman to develop type 2 diabetes following a diagnosis of gestational diabetes, and less commonly some women develop type 1 diabetes.

There are other, rarer forms of diabetes and the numbers in Northern Ireland for these conditions are low.

It is estimated that approximately 10% of Northern Ireland's total health and social care budget is spent on diabetes-related complications – equating to approximately £1m per day.

General comments on the draft Programme for Government Outcomes Framework

Diabetes UK Northern Ireland welcome the publication of the Northern Ireland's Programme for Government Draft Outcomes Framework, and additionally welcome this consultation into the draft Outcomes Framework by the Executive office.

We particularly welcome the outcome of *We all enjoy long, healthy, active lives* as it is this outcome which, if met, should best support people living with diabetes in Northern Ireland. Also of relevance to our work are *Our children and young people have the best start in life* and *We have a caring society that supports people throughout their lives*. We look forward to contributing to future action plans on those outcomes.

To support these outcomes, Diabetes UK Northern Ireland call for:

1. Recurring investment in the Diabetes Network for Northern Ireland

Diabetes UK is a key partner within the Diabetes Network for Northern Ireland, working alongside the HSC Board, the Department of Health and people living with diabetes. The Diabetes Network was established in 2017 to drive and support the implementation of the Diabetes Strategic Framework – the main diabetes strategy for Northern Ireland.

Under this Programme for Government, the Diabetes Network will both directly and indirectly contribute to the outcomes of *We all enjoy long, healthy, active lives; We have a caring society that supports people throughout their lives and Our Children and young people have the best start in life.*

The Diabetes Network has rightly celebrated many successes within its priorities, including in Structured Diabetes Education, diabetes in pregnancy, foot care, and recently in the provision of insulin pump therapy.

Despite this, it is our view that further successes have been hampered by a lack of commitment to recurring and sustainable funding, beyond one-year funding cycles. This has historically led to HSC Trusts' inability to commit to the longevity of services in their localities due to funding uncertainty. Resultingly, this has often made important sustainable change championed by the Diabetes Network, and committed to in the Diabetes Strategic Framework, very difficult. Some commitments in the Strategic Framework remain outstanding and, are dependent on long-term and sustainable investment from the Department of Health.

We urge the Executive Office, working with the Department of Finance, to commit to a multi-year budget to enable recurring investment in crucial public health programmes which are under the direction of the Department of Health, in this case, to the Diabetes Network.

2. Greater investment in and emphasis on the prevention of type 2 diabetes

Of the 105,000 people living with diabetes in Northern Ireland, 90% live with type 2 diabetes. Diabetes UK estimate that 70% to 80% of type 2 diabetes can be delayed or prevented. The COVID-19 pandemic has also compounded the risk of mortality for the 80% of people with type 2 diabetes who also have obesity. Considering this, the case for sustainable and recurring investment to diabetes prevention services could not be clearer.

The Diabetes Prevention Programme was established in 2018 with a commitment of funding for three years, from Confidence and Supply monies. With that three-year funding cycle due to come to an end this year, we have urged the Department of Health to maintain funding to the Diabetes Prevention Programme in the coming year and beyond at a level which will contribute to reducing the number of people diagnosed with type 2

diabetes each year and contributing to the outcome of *We all enjoy long, healthy, active lives*.

We therefore urge the Executive Office, working with the Department of Finance, to enable the funding required for the Department of Health to continue the Diabetes Prevention Programme, through a multi-year budget programme.

However, with the preventable nature of many cases of type 2 diabetes and the subsequent cost of diabetes-related complications to the Northern Ireland Executive of approximately £1m a day, prevention of type 2 diabetes also requires a comprehensive and multi-departmental approach alongside the prevention of obesity. It is therefore ***important that the prevention of type 2 diabetes is recognised and underpinned in current and future cross-departmental and existing frameworks***, such as (but not exhaustive to) *Making Life Better* and *A Fitter Future for All* under the Department of Health; the *Strategy for Sport and Physical Activity* under the Department for Communities; and the *Children and Young People's Emotional Health and Wellbeing in Education Framework* and *Nutritional Standards for School Food* under the Department for Education.

3. Greater emphasis on mental health support for people with diabetes

Diabetes are complex and demanding conditions with potentially debilitating consequences. People with long-term conditions (LTCs) such as diabetes are twice as likely to experience mental health problems as the general population. People living with different types of diabetes often tell us the overwhelming nature of the condition can also affect the mental wellbeing of those close to them, such as parents, carers, and family members.

Diabetes UK believe the relationship between routine diabetes care and mental health is essential and must be strengthened. LTC services that incorporate emotional and psychological support can help people improve both their physical and mental health, reduce pressure on HSC services, and save money – but people with diabetes have told us that the provision of such services is extremely patchy in Northern Ireland.

To ensure that people with diabetes live *long, healthy, and active lives* and that people with diabetes live in a *caring society that supports them*, it is crucial that emotional wellbeing is a routine part of care for LTCs, with a person-centred approach and greater signposting to support services, from the point of diagnosis for the rest of their lives.

To achieve this, the ***Department of Health must ensure there is training and education for healthcare professionals to identify the mental health needs of people with long-term physical conditions***. Alongside this, the ***Department must also enable healthcare***

professionals' awareness of what mental health services are available for people with LTCs, and similarly, greater awareness of the impacts of LTCs among mental health professionals.

4. Better data collection through Northern Ireland's inclusion in the National Diabetes Audit

Data collection is a crucial component in the development of policy and services. In England and Wales, a National Diabetes Audit (NDA) has existed since 2003 which provides a comprehensive national picture of diabetes care in those jurisdictions. Scotland has a similar audit called SCI-Diabetes which enables benchmarking and comparison with the rest of Great Britain, and the Republic of Ireland is developing its own diabetes audit, using NDA and SCI methodology.

This leaves Northern Ireland lagging as the only region in these islands not having a comprehensive system of data collection on diabetes care and support. The lack of a diabetes audit in Northern Ireland makes it very hard to extrapolate data in a structured format to mirror that of other regions for the purposes of benchmarking and comparison and to also establish a baseline.

Northern Ireland's participation in the NDA, alongside England and Wales, was first promised by the then-Health Minister Michelle O'Neill in the Diabetes Strategic Framework in 2016. Following a critical assessment of type 2 diabetes care and support by the Northern Ireland Audit Office (NIAO) in 2018, the NIAO urged the Department of Health to begin participation in the NDA as soon as possible. In the Department's response, it accepted the NIAO's recommendation. As of 2021, this has still not happened.

To provide the data to ensure people with diabetes live *long, healthy, and active lives*, ***we again strongly urge the Department of Health to act upon previous commitments and commence participation in the NDA as soon as possible.***

5. Early identification of type 1 diabetes

Too many children in Northern Ireland are not diagnosed with type 1 diabetes until they are in diabetic ketoacidosis (DKA), a life-threatening condition that requires emergency medical attention. During the coronavirus pandemic, healthcare professionals have reported an increase in children presenting in emergency departments with DKA. Diabetes UK have developed the 4 Ts, which are the most common symptoms of type 1 diabetes, to make sure more children are diagnosed early.

1. Going to the **Toilet** more often than usual
2. Being insatiably **Thirsty**
3. Increased **Tiredness**
4. Getting **Thinner**

It is important that children and young people get a quick diagnosis and early treatment and becoming seriously ill with DKA is avoided.

Diabetes UK urges the Department of Health and the Public Health Agency to work cross-departmentally with the Department of Education and the Education Authority, in co-production with people with diabetes and Diabetes UK, to increase awareness of the 4 Ts in schools and other educational settings – in line with the Programme for Government outcomes of *We all enjoy long, healthy, active lives* and *Our children and young people have the best start in life*.

5. Enshrining the principles of co-production in policymaking

It is disappointing to note that there is little detail on co-design and co-production in the draft Programme for Government Outcomes Framework – and co-production has not been mentioned at all. This despite an explicit recommendation in section 4.6.10 of the *New Decade, New Approach* agreement that “*Engagement with civic society and the principles of co-design and co-production must underpin the development of the Programme for Government, budget and strategies*”.

While we acknowledge the time, effort, and sincerity of the PfG team to engage with the voluntary and community sector and users of services through NICVA and All-Party Assembly Groups, consultation is not co-production or co-design and we urge the Executive Office to detail how the Programme for Government will be co-produced with stakeholders.

The Department of Health, as committed to in 2016’s *Delivering Together* document, in 2018 published *Co-production Guide: Connecting and realising value through people* which defines and supports the application of a co-production service across the health and social care system. We urge the Executive Office to adopt these principles of co-production in the policy and service development of the entire Northern Ireland Executive under the direct leadership of the First and deputy First Ministers.

For more information

For more information on this response, please contact:

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