

The Diabetes Improvement Plan and Scottish Diabetes Survey 2019

Introduction

This narrative contextualises key data from 2019 Scottish Diabetes Survey against the national priorities set out within the Diabetes Improvement Plan. A brief overview as to how the survey informs the work of the Scottish Diabetes Group and the wider diabetes community in progressing these priority areas is provided.

We would like to acknowledge the considerable amount of work that has been done by the entire diabetes community across Scotland in collecting the data within the survey and more importantly for using this information to drive improvements in care. We would also like to specifically thank the data analysts, subgroup chairs, national co-ordinators and other members of the Scottish Diabetes Group who support the Scottish Diabetes Survey and this accompanying narrative.

The 2019 Scottish Diabetes Survey

The Scottish Diabetes Survey provides an annual comprehensive view on diabetes care across Scotland summarised at national and NHS Board level. The Scottish Diabetes Survey 2019, report that:

- There were 312,390 people diagnosed with diabetes in Scotland at the end of 2019 which represents 5.7% of the population. Crude prevalence of diabetes ranged from 4.9% to 6.8% across NHS boards.
- 10.7% of people were recorded as having T1 (T1) diabetes and 87.9% with T2 (T2) diabetes. 1.4% of people were recorded as having “other” types of diabetes, including maturity onset diabetes of the young (MODY) and unknown diabetes type.
- Of those with a recorded body mass index (BMI), a total of 64.5% of those with T1 diabetes and 87.1% of those with T2 diabetes were overweight or obese.
- 90.5% of those with T1 diabetes and 91.1% of those with T2 diabetes had an HbA_{1c} recorded in the previous 15 months. Of these, 26.5% and 55.3% respectively had a result < 58mmol/mol.
- 83.7% of those with T1 diabetes and 88.6% of those with T2 diabetes had their blood pressure recorded in the previous 15 months. Of these, 41.4% and 31.4% respectively had a systolic blood pressure <130 mmHg and a diastolic blood pressure ≤80 mmHg
- Cholesterol was recorded in 83.0% of people within the previous 15 months, and the target of ≤ 5 mmol/l was achieved in 71.0% of those with T1 diabetes and 78.8% of those with T2 diabetes.
- 18.9% of those with T1 diabetes and 15.7% of those with T2 diabetes were recorded as being current smokers.
- 3.6% of those with T1 diabetes and 9.7% of those with T2 diabetes had a record of myocardial infarction, and 2.9% and 7.6% respectively had a record of cardiac revascularisation.
- 1.4% of those with T1 diabetes and 0.6% of those with T2 diabetes have a record of having end stage renal failure.

- 84.4% of people with T1 or T2 diabetes had a record of eye screening in the previous 15 months.
- 56.5% of people with T1 diabetes and 64.7% of those with T2 had their foot scores recorded in the previous 15 months.
- 0.8% of those with T1 diabetes and 0.5% of those with T2 diabetes had a record of having had a major lower limb amputation.

The Scottish Diabetes Survey provides a one page health board specific summary outlining individual performance against the national average for some of the key measures within the survey. Health Boards through their Managed Clinic Networks are asked to review the information presented in the 2019 survey and use this to inform how best to deliver ongoing improvement in diabetes care.

The Diabetes Improvement Plan

The Diabetes Improvement Plan highlights eight national priority areas, agreed through consultation with the diabetes community, to improve the experience and clinical outcomes for people living with diabetes. These priorities are:

- Prevention and Early Detection of Diabetes and its Complications
- Type 1 Diabetes
- Person-Centred Care
- Equality of Access
- Supporting and Developing Staff
- Inpatient Diabetes
- Improving Information
- Innovation

While very comprehensive, the data available within the Scottish Diabetes Survey lends itself to some priority areas more than others. There is rightly a focus on measures related to screening, disease monitoring and outcomes, however for other areas, such as in-patients and pregnancy, data from other sources may be used to drive improvement.

A cornerstone of diabetes care in Scotland is SCI-diabetes which provides a shared electronic patient record for supporting the treatment of people with diabetes. Over the last 5 years we have added functionality that helps clinicians and governance teams identify areas for improvement at an individual patient, practice, secondary-care clinic, regional and national level. These tools also help us to assess the impact of any changes that are being implemented to improve care. The SCI-diabetes team continues to work closely with the Scottish Diabetes Group to identify metrics and develop visualisations that will allow teams to track progress made in each of the priority areas in the Diabetes Improvement Plan. Work continues to strengthen the extensive data linkages that SCI-Diabetes has for example with diabetes technologies and pregnancy services to increase the support provided to people with diabetes.

Priority 1 - Prevention and Early Detection of Diabetes and its Complications

To establish and implement approaches to support the prevention and early detection of type 2 (T2) diabetes, rapid diagnosis of type 1 (T1) and to implement measures to promptly detect and prevent the complications of diabetes.

Prevention and early detection of type 2 diabetes

The implementation of the *Framework for the Prevention, Early Detection and Early Intervention of Type 2 Diabetes* has provided a focus on enhancing weight management services for people newly diagnosed with T2 diabetes and people with a diagnosis of pre-diabetes, previous gestational diabetes (GDM) and those at risk.

Historically it has been challenging to collect data on weight management outcomes due to the inequity of service provision but the framework has supported the development and implementation of National Core Standards for Adult Weight Management. A mandatory core dataset linked to these standards was implemented in October 2019 to support evaluation and ongoing monitoring of the framework interventions and outcomes.

Additional data fields are now available on SCI Diabetes to enable capture of information there has been a diagnosis of pre-diabetes and to record where T2 diabetes is now in remission. Work is underway to develop a new SCI Prevention platform which will enable data capture specific to the prevention framework in addition to the SCI Diabetes platform.

Screening and Disease Surveillance

Regular screening and monitoring is key to ensuring the prompt detection of diabetes complications and allows for early and aggressive intervention. For adults living with diabetes, there are nine processes of care that should be checked on an annual basis – these are HbA1c, BP, weight, smoking status, screening, renal function, albuminuria, cholesterol, retinal and foot screening. The 2019 Scottish Diabetes Survey reports that the number of adults who have had all nine processes of care recorded is 34% and 40% for T1 and T2 diabetes respectively. While this is similar to 2018, the level of monitoring has been decreasing since 2014.

Albuminuria testing and foot screening remain the two most challenging areas. The 2019 Scottish Diabetes Survey reports that the number of adults who have had albuminuria screening recorded is 63.5% and 65.8% for T1 and T2 diabetes respectively. While there has been little change in albuminuria testing levels for people with T1 diabetes there has been a noticeable decline in the number of people with T2 diabetes getting Albuminuria testing in recent years.

The 2019 Scottish Diabetes Survey reports that the number of adults who have foot screening recorded is 57% and 65% for T1 and T2 diabetes respectively. Recording in T2 diabetes has dropped dramatically since changes in Quality Outcome Framework were introduced (from a peak of 80%). It is of concern that individuals with T1 diabetes are more likely to attend diabetes specialist clinics, but are less likely to get their feet examined despite being twice as likely to develop a foot ulcer compared to people with T2 diabetes.

With the ongoing COVID crisis it is vital that we revise care models to ensure they meet the challenges of healthcare delivery with the restrictions that are likely to be in place for some time. It is also an opportunity to consider how we utilise community hubs to develop a robust approach to screening and the surveillance of long term conditions, such as diabetes, to address the decline in monitoring as detailed above.

Foot Health

The Ulcer Management System available on SCI-Diabetes has been developed to support recording of foot ulceration. This has resulted in over 5,000 ulcers being recorded with an overall prevalence of around 1.7%. There are however a wide range of results across health boards, ranging from 1.6 to 3.9% for T1 diabetes and 1.1 to 2.2% for T2 diabetes. Health boards are being encouraged to record all new episodes of ulceration and to complete a final outcome on completion of treatment using the Ulcer Management System. As engagement in the process improves, the variation in prevalence is expected to decline.

Rates of amputation have declined with 0.3% of all people with diabetes having had a history of major amputation. However in previous surveys, minor amputations were included in the statistics and so it remains unclear whether progress is being made. This is a critical area as from separate data, we know that this is a particularly vulnerable group with half to two thirds of people with diabetes dying within 5 years of an amputation and 20% within 2 years of a foot ulcer.

Priority 2 - Type 1 Diabetes

To improve the care and outcomes of all people living with type 1 diabetes

Glycaemic Control

Intensive glycaemic control reduces microvascular complications, cardiovascular disease and premature mortality in people with type 1 diabetes. The 2019 survey reports that only 26.5% of people with type 1 diabetes have an HbA1c <58 mmol/mol (the national HbA1c target). After many years of increase, it is disappointing to note that the percentage of people meeting the HbA1c target has fallen between 2018 and 2019. Similarly, despite marked reduction in the percentage of people with very high HbA1c (>75 mmol/mol) over the past few years, there has been a small rise between 2018 (31.1%) and 2019 (31.6%). We know, from the work of the SDRN epidemiology group, that HbA1c is strongly influenced by age and socioeconomic deprivation. It will be useful to explore barriers to meeting HbA1c targets in future versions of the survey, as this may help inform targeted intervention in groups not currently benefiting from current care models and therapeutic modalities.

Diabetes Technologies

The 2019 Scottish Diabetes Survey shows that the use of insulin pump therapy has increased every year since 2013 and this trend continues. It is worth noting that insulin pump use in adults is currently 11.3% which is still significantly lower than many other developed nations. Future versions of the survey should focus on barriers to initiation of pump therapy in adults.

Insulin pump therapy in those under the age of 18 is at the highest level (38.9%) since these data were first collated and is likely to be a key factor in the substantial improvements in HbA1c observed in Scottish children over the past decade.

Although not reported in the current survey, flash glucose monitoring use has increased substantially over the past 2 years and more detailed data with respect to the uptake and effects of flash monitoring would be welcome additions to future versions of the survey. Real-time continuous glucose monitoring has increased in the last few years but still only used by a very small proportion of people with T1 diabetes in Scotland. Information of this would also be a welcome addition to future versions of the survey.

There is little doubt that diabetes technologies have had a transformative effect for many individuals with T1 diabetes but we must ensure that access is equitable and does not result in greater widening of inequalities in diabetes outcomes.

Foot Health

The 2019 Scottish Diabetes Survey highlights that individuals with T1 diabetes need greater prioritisation of their foot care. People with T1 diabetes have twice the rate of active foot ulcers (2.7% vs 1.4%), twice the prevalence of ever having had an ulcer (8.4% vs 4.2%) and have a higher amputation rate than those with T2 diabetes.

Priority 3 - Person-Centred Care

People with diabetes enabled and empowered to safely and effectively self-manage their condition by accessing consistent, high quality education and by creating mutually agreed individualised care plans

Supporting Self-Management

Timely and appropriate access to high quality patient education supports people living with diabetes by promoting self-management, improving well-being and aids optimisation of glycaemic control. The 2019 Scottish Diabetes Survey highlights that 21.3% and 4.8% people over the age of 18 with T1 diabetes and T2 diabetes respectively have completed level 3 structured education. While there is likely to be a degree of under reporting of completion of structured education, particularly for T2 diabetes there is significant scope for improvement.

We continue to work across all aspects of the health and social care communities, including our partners in the third sector, to promote accessibility to educational opportunities to all people with diabetes and their carers. There is a need to address the barriers to education, such as geography, deprivation or ethnicity, and offer education opportunities at the right time, with appropriate support in a range of formats.

We have committed to the development of a toolkit of resources for T2 Diabetes, which can be accessed depending on personal need no matter where you live in Scotland. Websites, Social Media platforms and on-line learning (individual or group) have developed significantly but we need to ensure we are inclusive and person centred in the models we develop.

My Diabetes, My Way is an interactive diabetes for people living with diabetes which provides information on diabetes, online learning and access to diabetes clinic results to support them to manage their condition more effectively. Clinical teams continue to promoting this resource and encourage people to register for *My Diabetes, My Way* leading to an increase in people using this. At the end of 2019, the number of people living with diabetes who are registered with *My Diabetes, My Way* was 47,343 people (an increase on 17.9% in the previous year) of which 26,361 people have used this website to access their clinic results.

Diabetes in Pregnancy

While there is currently no pregnancy specific data within the Scottish Diabetes Survey this is something we are looking to address and we hope to be able to include some key pregnancy related measures in the diabetes dashboard in due course.

A key focus in this area has been improving data in relation to diabetes related pregnancies with ongoing work to link SCI-diabetes to the obstetric systems used in NHS Scotland. A core dataset for process and outcomes of gestational diabetes has also been established as part of the T 2 prevention framework.

Priority 4 - Equality of Access

To reduce the impact of deprivation, ethnicity and disadvantage on diabetes care and outcomes

Ethnicity

The 2019 Scottish Diabetes Survey shows that information on ethnic group was available for 82.3% of the registered population with T1 and T2 diabetes. This has risen significantly from 56% in 2009 and has increased gradually year on year. Information on ethnicity has been useful in informing the outputs from epidemiological research and will help us to understand whether ethnicity impacts upon current outcomes for people with diabetes in Scotland.

Disengaged from diabetes care

The Scottish Diabetes Survey provides information on disengagement with diabetes services (defined as no record of HbA_{1c} and no retinal screening in the preceding 15 months). The 2019 survey reports the rate of disengagement continues to be highest in people aged 18 - 25 at 9.5% and 14.0% in T1 and T2 diabetes respectively. This is significantly higher than the rate of disengagement for people over the age of 26 which is 5.0% and 3.8% in T1 and T2 diabetes respectively. This information is helping to inform care models and in particular consider extending the age range for transition services up to the age of 25.

The Diabetes Improvement Plan outlined the potential role that *My Diabetes, My Way* may have to target disengagement. Future work looking at the deprivation status, ethnicity and geographical location of users will help inform how we may improve digital inclusion and also mitigate against the risks of digital exclusion. This is particularly important as diabetes services increasingly move to virtual care

models. To ensure equitable access to online and virtual resources we would encourage all health care professionals to ensure that enrolling people with diabetes in *My Diabetes, My Way* as a key step in their care.

Deprivation

The Scottish Diabetes Survey at present does not have information on deprivation however this is included within the diabetes dashboard and given the impact deprivation has on health outcomes we will look to include this within future surveys.

Priority 5 - Supporting and Developing Staff

To ensure healthcare professionals caring for people living with diabetes have access to consistent, high quality diabetes education to equip them with the knowledge, skills and confidence to deliver safe and effective diabetes care.

Staff Development

Although the Scottish Diabetes Survey does not provide data on this priority we are cognisant that delivering high quality care requires high quality professional education for everyone supporting diabetes care. There is a wide range of knowledge and skills required throughout healthcare in Scotland and we need to be mindful that different professional training needs can vary depending on location and population need. A national training course for newly appointed Diabetes Specialist Nurses has been developed and this methodology is being considered as an opportunity for the wider multi-disciplinary diabetes teams. A training needs analysis for our multi-disciplinary diabetes teams Scotland-wide is being undertaken explore this further.

We continue to work in partnership with our patient groups, third sector, Health Boards, NHS Education for Scotland, our Universities and Higher Education authorities as their input will be paramount as we optimise Healthcare Education. As the professional roles and responsibilities change within the health and social care system we remain committed to assist the delivery of high quality diabetes teaching, learning and professional development in line with the strategy outlined in our Diabetes Improvement Plan.

To support the Think, Check, Act and Check, Protect, Refer (CPR) for Feet Campaigns online education modules were developed and these continue to be promoted to staff working within the hospital setting to increase their knowledge in these areas.

A dedicated post, the National CGM Support and Training Lead has been established to support boards to embed this technology into clinical practice. This post has supported the development of the CGM Patient Pathway and Education Resource and training in local areas on the new technologies as they develop.

In relation to diabetes foot care there is scope to develop diabetes specialist podiatrists and link podiatrists in the community to deliver more of the direct ulcer care independently. Work is ongoing to ensure that the Capability Framework for Integrated Diabetic Lower Limb Care is available in an interactive on line format to

allow clinicians to self-assess themselves in all areas of Diabetes Lower Limb care and identify training needs.

Priority 6 - Inpatient Diabetes

To improve the quality of care for people living with diabetes admitted to hospital by improving their glucose management and reducing the risk of complications during admission

Inpatient Diabetes Dashboard

At present there is limited inpatient data reported within the Scottish Diabetes Survey due to the information not being routinely collected on SCI-Diabetes. There are plans to address this as experience from NHS Boards where local systems are established demonstrates that timely access to real time inpatient data can drive improvement.

To support the development of an inpatient diabetes dashboard there is a requirement for secure data capture in each health board with IT linkage of admission, discharge and transfer messages from the hospital Patient Administration System, SCI diabetes and blood glucose monitoring systems. The inpatient dashboard will capture diabetes patient demographics, length of hospital stay, foot risk, and foot ulceration in hospital, blood glucose data, mortality and critical incidents (inpatient Diabetic Ketoacidosis (DKA), inpatient Hyperosmolar Hyperglycaemic State (HHS), technology failures, hospital acquired foot ulceration, insulin errors and hypoglycaemia).

Inpatient Diabetes Foot Care

A recent national inpatient diabetes foot audit demonstrated that more patients were getting their feet checked when in hospital and there was an increase in use of foot protection compared to the previous audit in 2013. The number of ulcers as a consequence of being an in-patient did not decrease, but this may reflect greater awareness and detection of the problem.

A local audit identified that more than half of all inpatient DKA episodes were precipitated by unrecognised foot infections. Work is ongoing to actively encourage the implementation of the CPR for Feet campaign across all care settings and encourage the use of the quality, fit for purpose and cost effective pressure redistribution devices.

Priority 7 - Improving Information

To ensure appropriate and accurate information is available in a suitable format and effectively and reliably used by all those involved in diabetes care.

Diabetes Dashboard

SCI-Diabetes, our clinical management and information system, is world-leading, and continues to enable us to track the effects of health policy on the delivery of care and outcomes for the 312,390 people with diabetes in Scotland.

The Diabetes Dashboard, launched in June 2019, has been developed within SCI-diabetes to improve access to information. The dashboard provides diabetes teams with timely access to information on meaningful outcome measures and key pathways of care for children and adults with diabetes at a local, regional and national level. The dashboard allows teams to readily identify their current performance and supports improvements in real time by providing easy to interpret information with drill down ability to support individual care at practice/centre level. The dashboard allows for comparisons to be made between different populations across Scotland to support sharing of best practice and learning from others.

The Diabetes Dashboard continues to evolve in response to clinical need with new metrics being added for example in patient care, pregnancy.

Priority 8 – Innovation

To accelerate the development the development and diffusion of innovative solutions to improve treatment, care and quality of life of people living with diabetes.

Diabetes Technologies

In partnership with NHS Scotland procurement the framework for technologies involved in diabetes care has been revised.

Working closely with the Scottish Health Technologies Group the clinical and cost effectiveness of Flash Glucose monitoring (Freestyle Libre) was assessed which support a standardised approach to access this innovative product. Ongoing collaboration is helping assess its effectiveness of this product in a 'real world' setting and is informing the ongoing roll out across Scotland.

Scottish Diabetes Technologies & Innovations Group

Measuring innovation is clearly challenging and as such there is no data within the Scottish Diabetes Survey which readily assesses the innovation landscape across Scotland. The focus of this work is to promote networking and mechanisms to support innovation and to increase the pace of adoption of proven innovations.

In partnership with the Chief Scientist Office the Scottish Diabetes Technologies & Innovations Group is ensuring Scotland can maximise the opportunities around data, technologies and innovation to improve diabetes care and outcomes in Scotland. This forum allows for sharing information to facilitate collaboration and acts as a source of expertise and signposting.

Linking with NHS Scotland's wider innovation work streams this group is leading on several diabetes specific initiatives. These include evaluation and potential adoption of technologies such as the bionic pancreas as well as projects aimed at improving in-patient diabetes care and foot ulcer prevention. In addition several Scottish based groups are looking to develop health informatics and artificial intelligence (AI) solutions to improve risk stratification, communication and improve person centred care models.

Conclusions

The 2019 Scottish Diabetes Survey, once again, shows the extensive local, regional and national data we have within Scotland. Key messages from the survey include, the number of people with diabetes continues to increase. There has been progress with the proportion of people with T1 diabetes accessing new technologies. Previously reported progress on improved glycaemia has been limited in 2019 and remains a key priority.

Main future developments will focus on making the data more transparent and usable at local level in expectation that this would then drive improvement. Data will inform the refresh of the Diabetes Improvement Plan and ongoing work to develop further data linkages, and will also allow detailed assessment of diabetes pregnancy and in-patient care and outcomes. All of which will help inform future care models and address health inequalities.