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Diabetes is one of the fastest growing health crises of our time. Over 317, 000 people are living with diabetes in Scotland and that number continues to grow.



Diabetes is Serious: Diabetes care and support during the pandemic and beyond

This year marks 100 years since the discovery of insulin, one of the twentieth century's greatest medical discoveries which has saved millions of lives. From the Scottish doctor who won a Nobel Prize for its discovery, through to the development of the insulin pen, Scotland has led the way in advances in diabetes care and technology.

Scotland has also become an international leader in diabetes research, thanks to the data from the online diabetes portal, SCI-diabetes. SCI-diabetes enables access to real time data at a national, regional, local and individual level on the care people are receiving and their health.

It's thanks to that data, alongside our recent survey of over 1000 people living with diabetes in Scotland, that we have a uniquely full picture of the care and support people living with diabetes over the past two years.

The past two years have been a time like no other. The pandemic brought unprecedented challenges to us all, none more so than our hard-pressed healthcare professionals. It also highlighted just how serious diabetes can be. As well as the increased risk of diabetes complications from not being able to access regular check-ups, a diabetes diagnosis carries with it the risk of serious outcomes from coronavirus.

The pandemic highlighted how serious the condition is, with people with diabetes devastatingly accounting for 20% of hospital deaths in Scotland during the first wave of the pandemic.

This data gives us a crucial window into diabetes care and support in Scotland. Importantly, it also gives us the evidence to reflect on what works - and just how serious a diagnosis diabetes still is.



I am finding it difficult to work from home, look after my child, keep on top of house work, eat properly and keep my diabetes under control'

Diabetes Scotland survey respondent



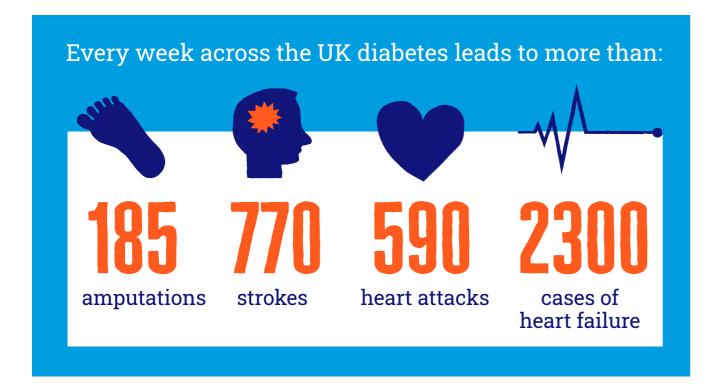
What does the most recent evidence tell us?

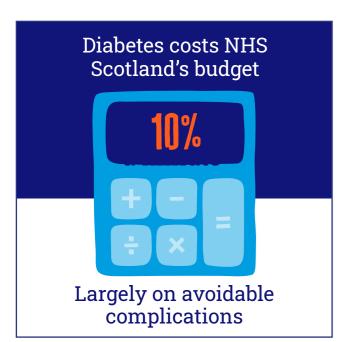
- Diabetes is one of the fastest growing health crises of our time, with 317,000 people living with diabetes in Scotland – a growth of 5000 on the previous year. Rates of diabetes are rapidly increasing, with diabetes diagnoses more than doubling in the last 20 years. A large part of this rise is due to the growing rate of type 2 diagnoses.
- People living with diabetes have key annual healthcare checks to ensure they don't develop devastating complications. The survey shows that key care processes dropped during the pandemic, with only about 10% of over 18s receiving all key care processes. This is a drop from about 30% for type 1s and 40% for type 2s from the previous year.
- Access to the right diabetes technology, like insulin pumps, can be lifechanging and allow much easier control of your diabetes. While numbers of young people with type 1 diabetes using insulin pumps have grown in recent years, the data shows that still only just over 10% of over 18s in Scotland use these. This means the overwhelming majority rely on injection therapy. The access to this life-changing technology ranges hugely across Scotland, with just 24% of young people in Grampian with a pump compared to over 60% in Lothian and Orkney.
- In our recent survey of over 1000 people living with diabetes, one in ten people told us they were having trouble affording the things they need to manage their diabetes.
- Cases of life-threatening diabetic ketoacidosis (DKA) have been steadily increasing in Scotland, with those from less affluent areas most likely to be hospitalised or die.
- The gap in diabetes outcomes for the richest and poorest in Scotland is widening.
- 1 Due to the predominant use in secondary care, the data has a focus on type 1 diabetes.
- 2 https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/vital-events/general-publications/weekly-and-monthlydata-on-births-and-deaths/deaths-involving-coronavirus-covid-19-in-scotland/related-statistics
- 3 Scottish Diabetes Survey 2019
- 4 As above
- 5 As above

The cost of diabetes

With the right support and good management, people with diabetes can live healthy lives. However too often we see the condition lead to avoidable, serious complications such as amputation, strokes and heart attacks.

Before the pandemic, one in five hospital beds in Scotland were occupied by a person with diabetes, and diabetes costs 10% of NHS Scotland's budget, at around a billion pounds. 80% of this is on avoidable complications, which highlights why the drop off in care processes is a cause for concern.





Effective management with the right support for people with diabetes and their healthcare professionals can prevent or delay complications from developing, meaning a better quality of life for people with diabetes and a vastly reduced cost to the NHS and wider society.



Parents of children with Type 1 live in constant fear of over-night hypoglycaemic events - because they can be very traumatic if it's a severe episode and, at worse, fatal. This obviously has had a huge impact on the quality of sleep for all of us and on our stress levels.' Focus group participant



The increased risks of Covid for people living with diabetes has had a real impact on people's mental health and wellbeing, adding to the difficulties of managing a relentless condition whilst routine appointments and visits to healthcare professionals have been postponed or cancelled.



My NHS care has been amazing but it has been 2 years since I have seen a doctor/nurse in person just a 5 min phone call in July.



Like many people I haven't seen or heard from diabetes team or gp since last March. I know appts have been suspended but a wee phone call from someone to check how we are doing would have been appreciated - kind of feels that we don't matter.



When people with diabetes do not have access to the information, treatment and care planning support they need to manage their condition well, then their health outcomes are worse - with increased risk of diabetes related complications as well as hospital admission or unfortunately death due to coronavirus.



We need to ensure patients are not feeling isolated and frightened for their well-being... [My] health care concerns are mounting leading to mental health issues and [I] basically feel ignored and unimportant.



NICE recommends ways to monitor and improve the health of peoplefor example their HbA1c, foot checks, and blood pressure monitoring

As ever, we work closely with our healthcare professionals and understand the challenges facing all clinicians working in diabetes care to clear the backlog. Recalls should be based on clinical need, and although biometric parameters such as a person's last recorded HbA1c offer easier methods of prioritisation. other factors should be included such as pregnancy planning, mental health concerns, new-onset or worsening foot or eye disease.

⁶ NCVIN (2020) Footcare Activity Profile 2016–19

⁷ Digital (2019), National Diabetes Audit 2017–18 Report 2A: Complications and Mortality

⁸ NHS Digital (2020) National Diabetes Inpatient Audit 2019

⁹ Hex, N., et al (2012) Estimating the current and future costs of Type 1 and Type 2 diabetes in the United Kingdom, including direct health costs and indirect societal and productivity costs. Diabetic Medicine. 29 (7) 855-862

¹⁰ Diabetes Scotland Survey, 2021. Unpublished.

Inequality and diabetes

To tackle health inequalities and reduce the strain on our NHS, we must also consider those key areas out-with the health system that impact on our health such as rising rates of poverty. Fundamentally, to address health inequality we must interrupt the process of treating people and then sending them back to the conditions that made them ill in the first place.

The landmark Marmot Review, published in 2010 and followed up in 2020, gave a clear outline of the cross-government actions needed to address the social determinants of health. These are the non-medical factors that impact on our health and life chances; broadly, the conditions in which we are born, live and grow. The Scottish Government is making determined progress on many of these, not least as part of its ambitious plans to tackle child poverty. However, we have much further to go.

Recent evidence from Edinburgh University also revealed widening inequalities in type 1 diabetes care across Scotland. The study, funded by Diabetes UK, showed that cases of life-threatening diabetic ketoacidosis (DKA) have been steadily increasing since 2004, with those from socially deprived areas most likely to be hospitalised or die as a result.

This inequality gradient exists in type 2 diabetes too. Living with overweight and obesity accounts for between 80-85% of a person's risk of developing type 2 – and obesity rates are highest (and growing) among those from the most deprived communities.

This is not about lifestyle choices – a range of external factors make it difficult, often impossible, for people on low incomes to make healthy choices. Ultimately, the amount of money that someone has in their pocket dictates what they can buy.

OF DISPOSABLE INCOME would need to be spent on food to meet the UK government's Eatwell Guide costs. For households in the lowest income decile.

Social security levels also do not currently allow families to make informed, healthy choices. And almost 1 in 10 people in Scotland live with the constant worry of running out of food.

It shouldn't be the case that the greatest burden of diabetes falls on our least affluent communities - and it need not be the case.



I know what I should be eating and what technology I should be using. I can't afford any of that. It's completely unfair.



1 IN 10 PEOPLE

told us they were having trouble

affording the things they need to

- 11 https://www.eurekalert.org/news-releases/929785
- 12 https://www.healio.com/news/endocrinology/20210902/repeat-dka-more-common-for-younger-people-women-and-the-with-poor-mental-health
- 13 Diabetes and obesity rates soar | Diabetes UK
- 14 http://www.healthscotland.scot/health-topics/diet-and-healthy-weight/obesity
- 15 https://www.thequardian.com/society/2021/feb/19/new-universal-credit-claimants-forced-skip-meals-covid





The gap between the richest and poorest is widening with people living in poverty are over twice as likely to get type 2 diabetes and over two and half times more likely to experience serious complications

Everyone deserves free and equal access to the right treatment for them

Diabetes technology makes the day-to-day management of diabetes easier for many. It provides more frequent, better quality glucose readings through continuous glucose monitoring (CGM) and flash glucose monitoring (Flash), helping children, young people and adults with diabetes to manage their blood glucose levels better. This is a critical part of preventing serious complications from diabetes.

Insulin pumps provide the regular insulin a person needs throughout the day and night, helping to keep their blood sugar levels more often in their target range. Potentially the most exciting development in some time, a hybrid closed-loop system allows your insulin pump to 'talk' to your continuous glucose monitor (CGM). This continuously monitors blood glucose levels and calculates the amount of insulin required. Then, it automatically adjusts your background, or basal, insulin based on your blood sugar readings – essentially, an artificial pancreas.

We know, however, that many people living with diabetes are still not getting access to the life-changing technologies they can most benefit from, even when they meet the criteria. The 2020 survey shows us that still only around 10% of the adult population are using tech.

Recent evidence from England and Wales also shows that there are also growing inequities in the use of diabetes technologies, particularly among children from more socially deprived areas and Black children.

This year marks the 100th anniversary of the discovery of insulin and Scottish academics have played central roles in diabetes discoveries ever since. However, we're nowhere near to making those treatments and technologies available for all who need them.



I so hate injecting insulin doses. They hurt.



Even if you meet the criteria to get diabetes technology, it doesn't guarantee you access. It's also a postcode lottery due to huge variation in provision across health boards. While some people are in the position to pay for tech, buying it – and ongoing costs – can be hugely expensive. And it's simply not right that some have this life-changing support. while others don't, based on their ability to pay or where they live.



[Closed loop technology] is an excellent piece of kit... It's like having a transplant without going through the surgery and anti-rejection drugs

Throughout the pandemic people's access to care and support from their diabetes healthcare teams has been understandably limited, meaning their ability to effectively self-manage their condition has been more important than ever.

Use of diabetes technology has proved invaluable for people with diabetes who have access to it and local health care teams during the pandemic, with 84% of people who responded to a recent Diabetes UK study who use technology agreeing that it helped self-management of their condition during the pandemic.

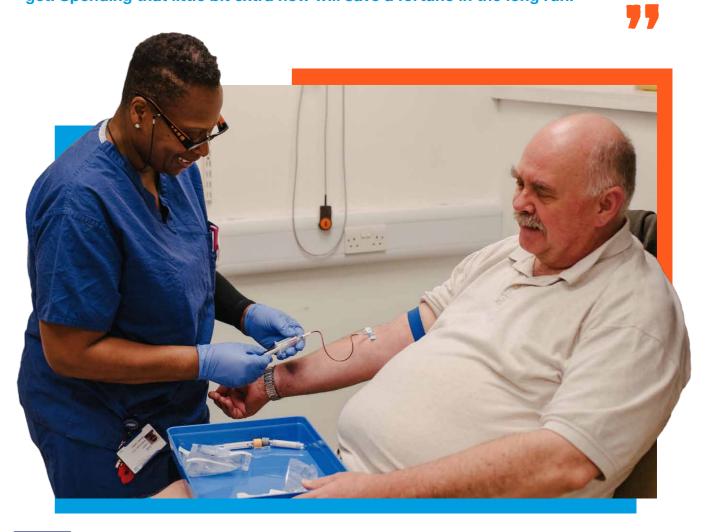


I've been on a pump for approx. 10 years and Libre for 6. I self-funded the Libre for a long time before it being prescribed. The pumps I've been given, I had no say or choice in which is not individual care for patients needs or circumstances.

Is it affordable for me as a single parent with 2 disabled children, no its definitely not, I've made big sacrifices to be able to pay for it. I find a way because I can't afford to have long term complications and not be around for my children.



I have asked [my healthcare team] 'What is the cost [..] compared to a night in ICU due to DKA or kidney disease?' and get no answer. Managing type 1 diabetes is like having another full-time job. Closed loop is the closest thing to a cure we can get. Spending that little bit extra now will save a fortune in the long run.



¹⁷ Effect of Flash GlucoseMonitoring on Glycemic Control, Hypoglycemia, Diabetes-Related Distress, and Resource Utilization in the Association of British Clinical Diabetologists (ABCD) Nationwide Audit, available online here: www.care.diabetesjournals.org/content/dia-

¹⁸ National Paediatric Diabetes Audit (NPDA) National report 2019/20: Care processes and outcomes

Everyone deserves free and equal access to the right treatment for them

Healthcare professionals working in type 1 diabetes care where people with diabetes have been using technologies like Flash and CGM, have been able to deliver a higher quality of remote care such as HbA1c and time in range. This in turn allows them to provide more tailored support to people with diabetes.

The Scottish Government has made a clear commitment to build on the innovations seen during the pandemic. In diabetes, this means ensuring more people living with diabetes are given access to technologies that support better self-management and effective delivery of care by their healthcare teams. Diabetes technology can make delivery of care in all areas easier, including in social care settings where people may need assistance to communicate and manage their diabetes.

We've seen significant improvements in diabetes care and support since the discovery of insulin, but it's not available to all – particularly those who could benefit most. The use of diabetes technology could significantly reduce the strain on the NHS in the long term, including preventing avoidable complications such as heart problems and strokes. As such, we need to see every health board commit to providing patients with the technology they nee



I would like to see more investment in newer technology rather than purely the cheapest option, also giving patients more choice. I'm waiting to have a further discussion with my consultant with the hope of being moved to a more up to date pump so I can fully utilise a closed loop system with the CGM I fund myself.

A system that is life changing for us, a much better chance of leading a 'normal' life with less fear of future complications. I'm committed to investing in my health and future which in turn will undeniably cost less for the NHS in the long run.

I, like so many other people living with diabetes, ask that the NHS invest in our care and diabetes management so we can reduce the long term cost to the NHS and have the opportunity to fully manage our diabetes to the best of our ability using more up to date technology that is already out there which would allow us to do that.





Conclusion

Coronavirus has put unprecedented pressure on the healthcare system and exacerbated widening inequalities.

And we know that the NHS faces yet another hugely challenging winter ahead. As we look to recover and build back to a better system and a fairer Scotland. evidence from the diabetes community from 2020 gives us a unique insight into how we can future proof our healthcare system.

Diabetes is a rapidly growing health crisis, but there is much opportunity to change this.

By ensuring people can access the technology that would allow them to manage their condition more effectively and tackling the conditions that lead to wholly avoidable rates of type 2 in our least affluent communities, we can get closer to a world where diabetes does no harm. The prevalence of diabetes and its growing nature means that if we get this right, it could transform the landscape for healthcare and help more people live well.

We look forward to working with stakeholders, government and Parliament to build on the findings of this report and to ensure lasting change is taken forward.

¹⁹ Julia Fuchs, Roman Hovorka, 2020 COVID-19 and Diabetes: Could Diabetes Technology Research Help Pave the Way for Remote Healthcare?

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For enquiries relating to this report or any of its content, please contact scotland@diabetes.org.uk



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