DIABETES IS SERIOUS

DiABETES UK
KNOW DIABETES. FIGHT DIABETES.

Recovering diabetes care: preventing the mounting crisis

CONTENTS

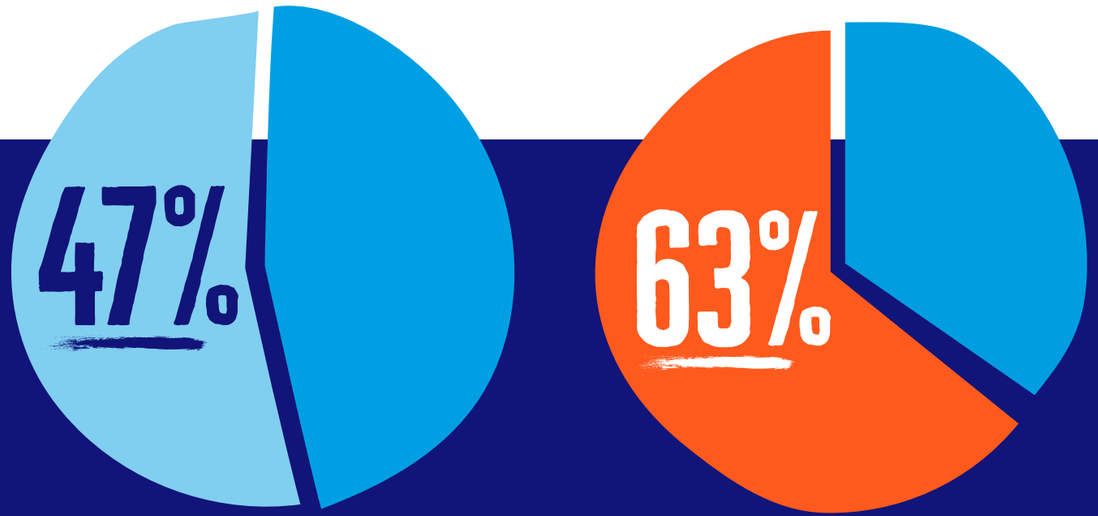
Diabetes can't be switched on and off. It's with you constantly. So imagine not being able to get the essential checks, care and support you need to get by, day to day. That's what some people with diabetes are facing right now. But by speeding up recovery of diabetes care, we can speed up recovery of the NHS, and do that in a way that addresses the unequal impact of the coronavirus (covid-19) pandemic on people's health, supports the elective recovery plan and prevents longer-term harm.

- Almost half (47%) of the 10,000 people with diabetes responding to our recent survey told us they had difficulties managing their condition during 2021.
- Three in five (63%) of people who had experienced difficulties attributed this at least in part to not having sufficient access to their health care team, rising to 71% in the most deprived areas of the country.
- One in six respondents have had no contact with their diabetes healthcare team since before the pandemic.
- National audit data shows that decreases in the numbers of people receiving vital diabetes checks during the pandemic, and more recently, are much greater in areas of higher deprivation.

Over the last year we have seen a lack of priority and urgency given to recovering diabetes care and again and again people with diabetes have found themselves at the back of the queue.

People from the most deprived areas of the country have had particularly poor access to essential care which can prevent serious illness and early mortality from the cardiovascular complications of diabetes. This is not acceptable or sustainable. Neglect of diabetes care stores up problems for later and impacts on all parts of the NHS system.
It impedes recovery of elective care when people are not fit for surgery or need longer hospital stays due to poor health of their condition.

Whilst the Government's focus has been focused on recovering elective care, we now urgently need a national recovery plan for long term conditions to prevent the consequences of delayed diabetes care for both the NHS and people living with diabetes.



of people had difficulties managing their condition during 2021.

of those experiencing difficulties attributed this in part to not having sufficient access to their health care team.

"I have had one telephone appointment since 2019, where blood glucose was discussed. In my opinion this is especially poor as I have a number of complications."

Survey Respondent

"I was told I would have a check in three months in December 2020 – I am still waiting."

Survey Respondent

1 IN 3

people had

NO CONTACT

with their diabetes healthcare team during 2021.

1

WHY IS DIABETES SO SERIOUS?

4.9 MILLION PEOPLE

are now living with diabetes in the UK, equivalent to one in 14 people.

More people than ever are living with diabetes:

- 4.9 million people are now living with diabetes in the UK, equivalent to one in 14 people[1].
- Diabetes registrations have almost doubled in the last 15 years[2].
- An estimated 850,000 people in England have undiagnosed type 2 diabetes[3], which will have increased during the pandemic[4].
- There are more than 13.6 million people at increased risk of type 2 diabetes and other serious health conditions in the UK right now[5].
- A significant number of younger people are now living with type 2 diabetes – 4% of the total. There are 122,780 people with type 2 diabetes under 40 years, and over 1,500 of them are under 19 years old[6].

Diabetes is a hidden condition. You might not be able to see it. But, if left untreated or undiagnosed, it can cause serious harm. It can affect every part of your body, damaging the cardiovascular system, blood vessels and organs:

- Every week diabetes leads to more than 190 amputations[7], 770 strokes, 590 heart attacks and more than 2300 cases of heart failure[8].
- One in six hospital beds are occupied by a person with diabetes[9].
- Diabetes costs 10% of the NHS budget, 80% of which is spent on treating preventable complications[10].

The pandemic showed us more than ever how serious the condition is, with people with diabetes devastatingly accounting for one in three deaths from covid-19 in England during the first wave[11]. This is a trend which has continued even in people with diabetes who have been vaccinated, though with much smaller numbers[12].

Diabetes registrations have almost

DOUBLED

IN THE LAST 15 YEARS

The pandemic has also impacted on non-covid-19-related deaths – the Office for National Statistics (ONS) have reported a significant excess in deaths in people with diabetes[13].

- During the period March 2020 to January 2021 in England and Wales there was an excess of 2,696 deaths in people caused by diabetes, representing a 24.7% increase compared with the five-year average prior to the pandemic.
- Diabetes was the third highest cause of excess death in this period – excluding deaths from covid-19.
- Deaths in people with diabetes due to causes other than covid-19 were above average in each month between July to December 2021.
- The impact of excess deaths in people for reasons other than covid-19 was highest on people in the most deprived areas.

Key to the care and support people with diabetes should receive are the eight 'care processes' recommended by NICE, for example blood sugar measurement (HbA1c), foot checks, and blood pressure monitoring[14]. These regular checks are crucial for early identification of risks and informing the care and treatment required to prevent devastating and costly cardiovascular complications.

10%

of the NHS budget is spent on diabetes care

80%

of which is spent on treating preventable complications.

Delivery of these care processes is associated with reduced:

- mortality[15]
- emergency admissions[16]
- amputations[17]
- and diabetic retinopathy.[18]

Over a seven-year period, people with type 1 and type 2 diabetes who had received all their annual care processes had better outcomes, including lower mortality, reduced progression to heart failure and reduced progression to renal replacement therapy[19]. More recent evidence around care processes has added to this, showing that people with diabetes who have fewer routine care processes have higher mortality[20].

NICE also recommends that adults with diabetes should meet three key treatment targets, which measure HbA1c, cholesterol and blood pressure. Evidence shows that people who meet these treatment targets are less likely to develop complications[21]. Increasing the number of people meeting these treatment targets would save lives as well as saving the NHS millions of pounds.

Recommendations: investing in preventative care and treatment

As the Government looks to reform healthcare by investing up front in prevention, routine checks for people living with diabetes must be considered a priority, as they play an important role in preventing and delaying costly complications. This will require investment in the GP workforce and health care staff working in a wide range of roles in primary care, investment in specialist diabetes care and investment in IT infrastructure and integration of care.

Integrated Care Systems (ICSs) provide an opportunity to shift investment locally to preventative treatment and care. As they look to reduce inequalities and integrate care, ICSs must put diabetes front and centre of their Health and Care Plans.

Between March 2020 to January 2021 diabetes caused an excess

2,696 DEATHS

and was the

THIRD HIGHEST

cause of excess death in this period*

***Excluding deaths from covid-19**

2

THE IMPACT OF THE PANDEMIC ON DIABETES CARE

Disruption of routine diabetes care

The experiences of people with diabetes

Earlier this year we conducted a survey which gathered insights from over 10,000 people with diabetes about their experience during the pandemic. Our research painted a deeply worrying picture with large swathes of the diabetes community struggling to cope with their condition, yet too many still without access to vital care and support. It also showed disturbing inequalities, with people from the most deprived areas being the hardest hit in almost every measure.

Nearly one in ten survey respondents (9%) had difficulties managing their diabetes during 2021 but have not had contact with their healthcare team since the pandemic began in March 2020. Those from the most deprived areas were more likely to have experienced difficulties managing their diabetes with 56% of people in the most deprived quintile saying they had experienced difficulties compared to 44% in the least deprived.

> **“I have several health complications some of which are diabetes related. I have not been proactively chasing on these issues due to the covid pressure on the NHS and suffered as a consequence.”**
>
> Survey Respondent

The majority (63%) who reported having difficulties managing their diabetes during 2021 referred to a lack of access to care and support by their diabetes healthcare team as the reason, rising to 71% of those in the most deprived quintile. Some people may have delayed seeking care due to fears of contracting the virus or putting pressure on the NHS. In another survey of people with type 1 diabetes, 40% reported that they had held back from contacting the NHS about their diabetes during the pandemic even though they needed support[22].

We also know that many have had problems accessing care:

- 62% of our survey respondents said that they had found it slightly or much more difficult – 40% much more difficult – to contact their diabetes healthcare team during 2021 than before the pandemic.
- Nearly a third (29%) told us they had no contact with their healthcare team about their diabetes during 2021 and one in six people (18%) had not had any contact since before the pandemic.
- People in the most deprived quintile were nearly twice as likely to have had no contact with their diabetes healthcare team since the beginning of the pandemic than those in the least deprived – 23% compared with 12% – and 44% of those in the most deprived quintile reported they had found it much more difficult to contact their healthcare team during 2021 than pre-pandemic, compared to 36% in the least deprived areas.

To live well with diabetes and avoid complications all people living with the condition need:

- Regular reviews with a health care professional, including the NICE recommended care processes and a conversation to agree a care plan.
- Access to education about diabetes and how to manage it.
- Emotional and psychological support embedded in diabetes care with access to more specialist support when needed.
- Access to diabetes technology to support self-management of the condition as appropriate.
- Weight management support when needed, including appropriate referral to specialist weight management services.
- Facilitated peer support.

40%

reported they had found it much more difficult to contact their healthcare team during 2021 than pre-pandemic.

Overall, one in four had at least one consultation cancelled that had still not taken place by the end of 2021. Of those who were still waiting for a cancelled appointment to take place, nearly a third said that they had been waiting between one and two years. And one in ten had been waiting over two years.

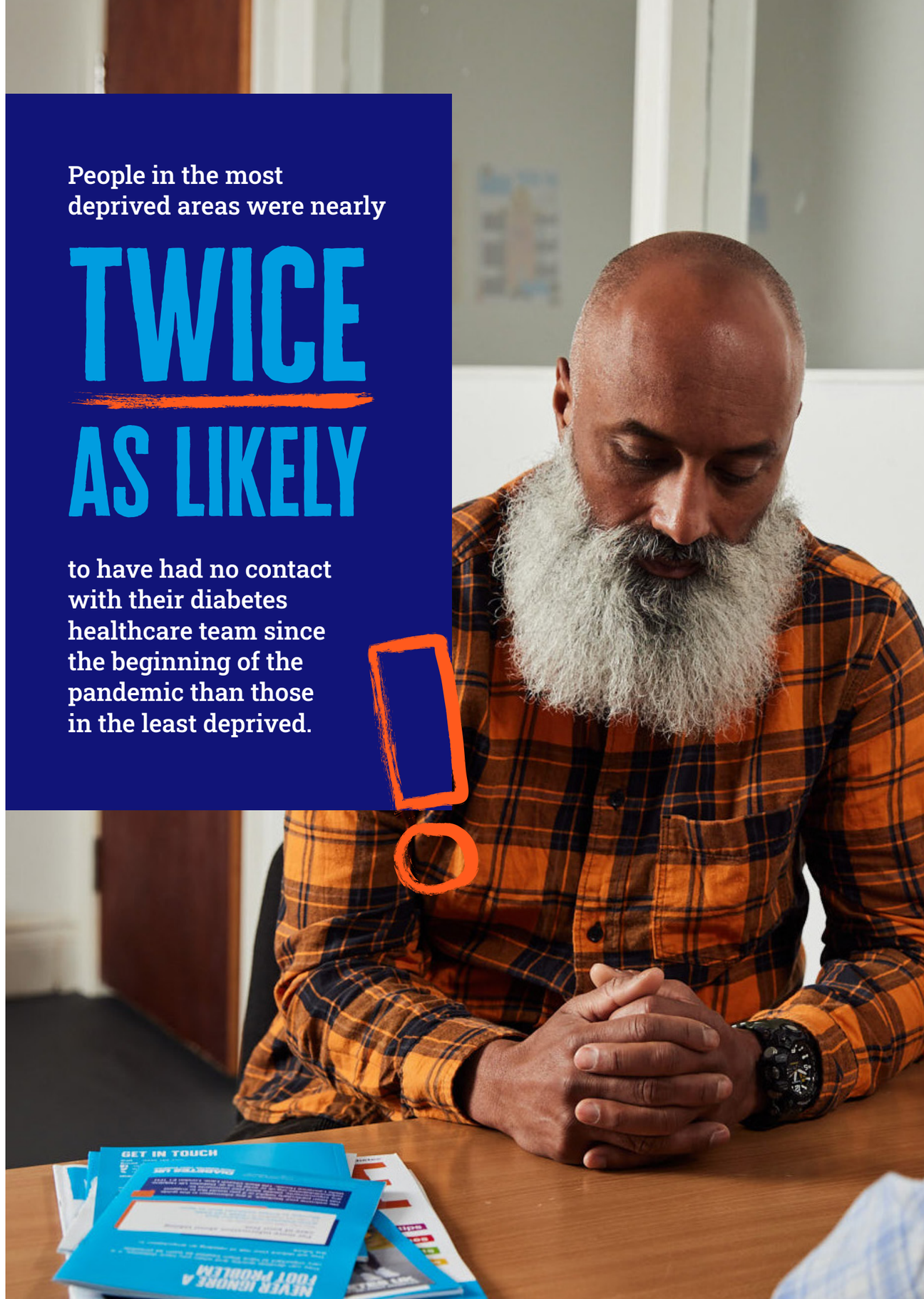
People's experiences have barely improved since we reported last year and this is during a period when, at least some of the time, health services were supposed to be recovering. Concerns from people with diabetes about the impact of delays on their diabetes management have been exacerbated.

> **I was diagnosed in December 2019, shortly before the pandemic started. I should have attended an education session for newly diagnosed diabetics during the spring of 2020 but this has never happened. Consequently, I don't feel that I really understand the condition nor how to manage it. My HbA1c reading has increased from 51mmol in November 2019 to 104mmol in November 2021 but I don't understand why this is.**
>
> Survey Respondent

People in the most deprived areas were nearly

TWICE AS LIKELY

to have had no contact with their diabetes healthcare team since the beginning of the pandemic than those in the least deprived.

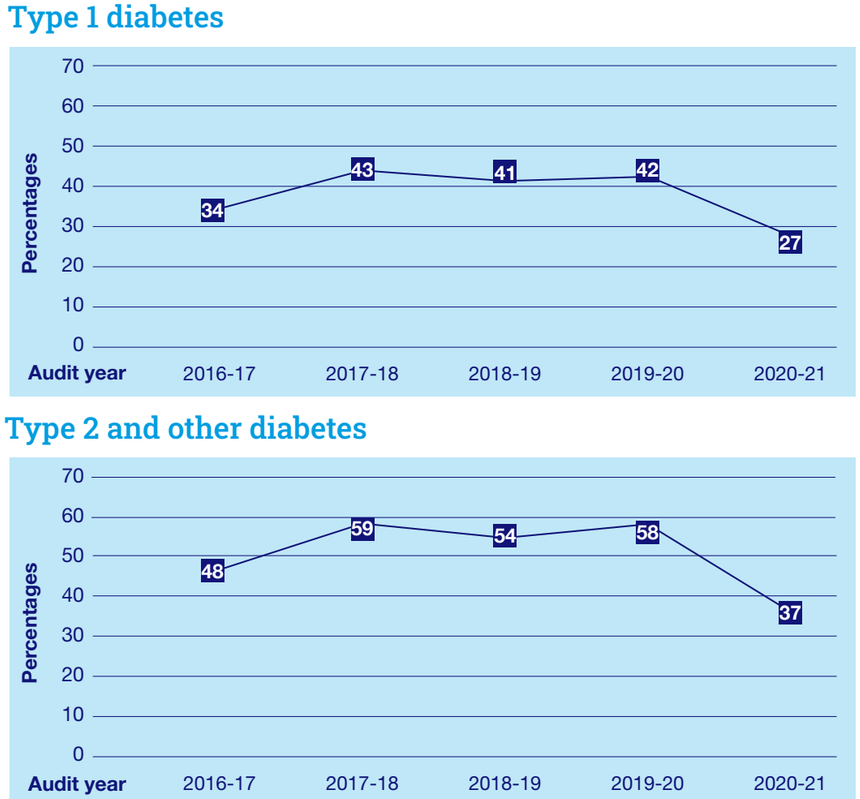


Data on missed checks and targets

Before the pandemic, diabetes care was generally showing positive improvement. National Diabetes Audit data shows that in the three-year period prior to the start of the covid-19 pandemic, the proportion of people with diabetes in England receiving all eight diabetes care processes increased[23], but then it fell markedly during the pandemic for both types of diabetes:

- In 2020/21 27% of people with type 1 diabetes received all eight care processes, compared to 42% in 2019/20. This represents a 35% reduction in the proportion of people receiving all eight of these important checks.
- 37% of people with type 2 or other diabetes received all eight care processes in 2020/21, compared to 58% in 2019/20. This is a 37% in the proportion of people receiving all of these checks.

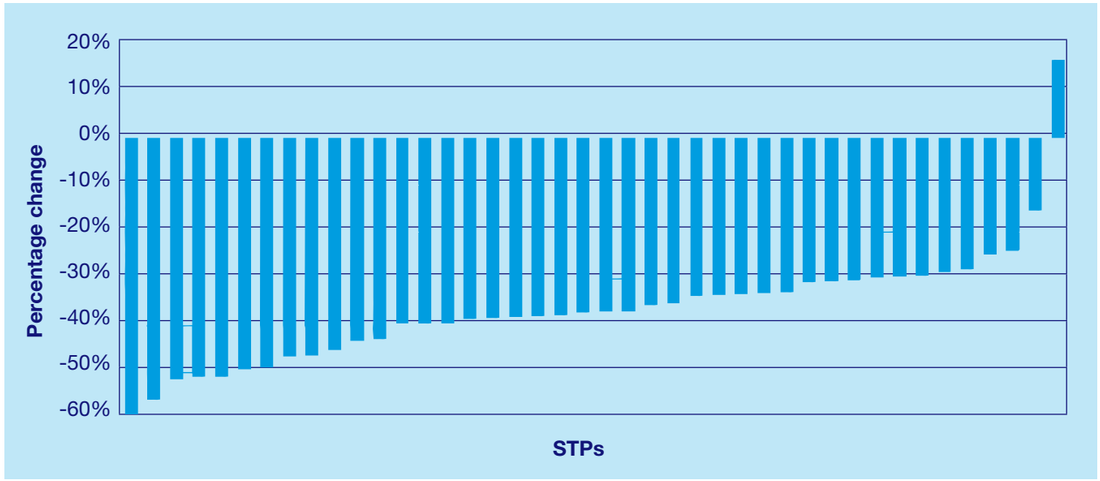
Figure 1: Percentage of people with diabetes in England receiving all eight care processes, 2016–17 to 2020–21



Source: NHSE&I internal analyses of National Diabetes Audit 2019/20 and 2020/21 data.

There was significant variation in the percentage change in the proportion of people with type 2 and other types of diabetes who received all eight care processes in 2020/21 compared to 2019/20 by STP, ranging from -59% to 17%.

Figure 2: Percentage change in proportion of people with type 2 diabetes/ other who received all eight care processes in 2020/21 compared to 2019/20, by STP



Source: NHSE&I internal analyses of National Diabetes Audit 2019/20 and 2020/21 data.

Most worryingly there were greater decreases in eight care process delivery for people with type 2 diabetes living in the most deprived quintile (39%) compared to the least deprived quintile (34%) and for those with type 1 diabetes (37%-34%).

The latest available data – Jan to Sept 2021 – shows that while there is some recovery it is much too slow. There is still a significant gap in people receiving the eight care processes since the same period before the pandemic with only 27% of people with type 2 (and other) diabetes receiving these and 17.7% of people with type 1. A gap of 9% and 4.5% respectively[24].

In addition to the eight care processes, people with diabetes should receive screening for eye problems caused by diabetes – diabetic retinopathy. Again, there was a large drop in people receiving this during 2020–21 compared to pre pandemic[25]. However there has been a programme of diabetic eye screening initiatives in 2021–22 to catch up with this backlog, with 99% of eligible people with diabetes being offered retinal screening in 2021–22.

Digital inclusion: leaving no one behind

The pandemic has also driven a move towards digital healthcare. This works well for many people and can improve access for some. But people in poverty are at risk of digital exclusion and those most at risk of exclusion from digital healthcare are often from groups who already experience the greatest inequalities in healthcare and access[26].

A number of respondents to our survey talked about difficulties with using technology. Others said that hearing problems made telephone appointments impossible for them.

Poorly implemented digital healthcare can exacerbate existing health inequality and steps will need to be taken to eliminate this risk[27]. Healthwatch has set out five principles for post-covid digital healthcare[28].

Contacting anyone by computer is very difficult for me due to failing eyesight and osteoarthritis in hands which causes fingers to tremble. Living on a fixed income precludes purchase of up-to-date equipment.

Survey Respondent

The pandemic has thrown up intense new pressures for our patients and we are extremely concerned about the real burning impact of poverty. Some of our patients do not even have the basics necessary to manage their diabetes, including a patient who couldn't afford a fridge to store their insulin, this makes good diabetes control practically impossible.

Dr Kate Fayers and Dr Hermione Price,
Consultant Diabetologists, Southern Health NHS Foundation Trust, West Hampshire Community Diabetes Service

Five principles for post-covid digital healthcare

1. **Maintain traditional models of care alongside remote methods and support people to choose the most appropriate appointment type to meet their needs.**
2. **Invest in support programmes to give as many people as possible the skills to access remote care.**
3. **Clarify patients' rights regarding remote care, ensuring people with support or access needs are not disadvantaged when accessing care remotely.**
4. **Enable practices to be proactive about inclusion by recording people's support needs.**
5. **Commit to digital inclusion by treating the internet as a universal right.**

Information taken from Healthwatch England

Recommendations: recovery of routine diabetes care

While the Government has driven forward a multi-billion pound elective recovery plan to address the backlog of planned care and surgery, the essential ongoing care and support for people with complex long term conditions such as diabetes has been overlooked. The Government must urgently bring forward a national recovery plan for routine primary care so that people with diabetes can access the vital support they need to keep themselves well and to prevent the short and long-term consequences of delayed care for the NHS and people living with diabetes.

In recent years investment in diabetes care and prevention, through the NHS Long Term Plan, has led to significant improvements in some areas, but the covid-19 pandemic has stalled, and started to reverse, progress in some aspects of care. The forthcoming refresh of the NHS Long Term Plan is needed to further embed and extend the investment in improvement of diabetes care which was making good progress before the pandemic.

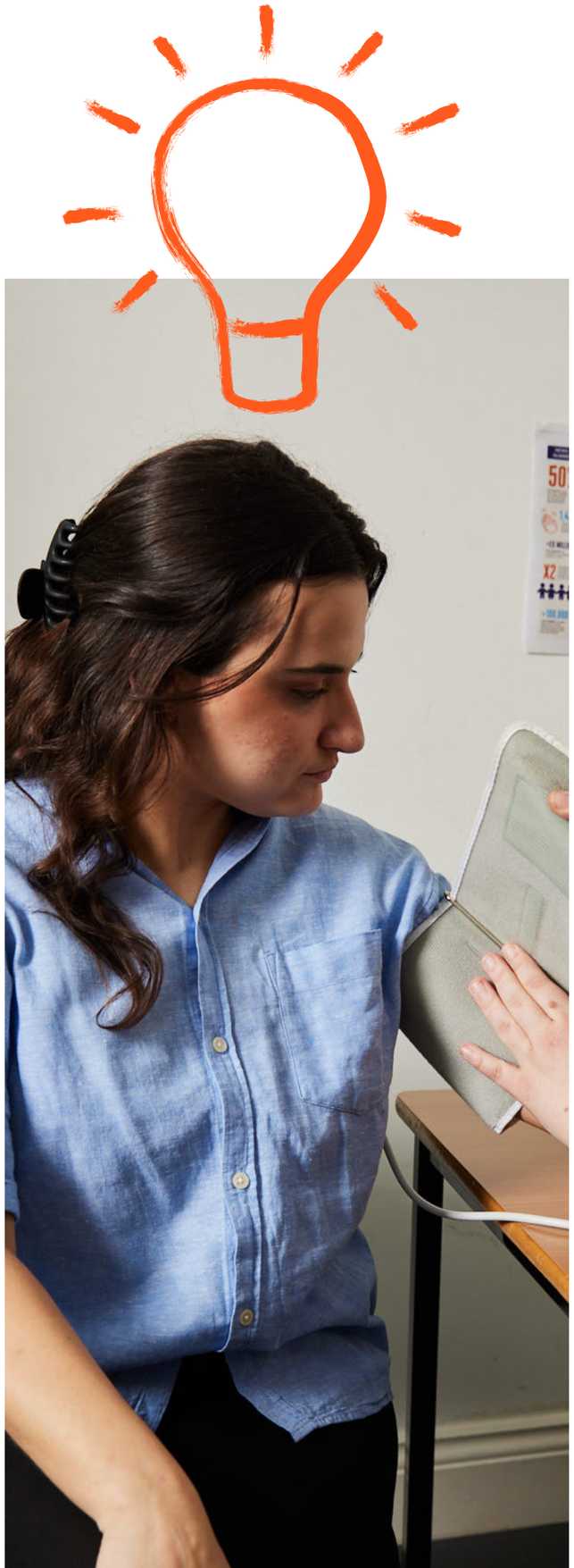
Telephone appointments are no use to people like me with hearing problems.

Survey Respondent

ICSs should urgently draw up plans to catch up on the diabetes backlog, restoring the identification, monitoring and provision of management support for people with all types of diabetes to pre-pandemic levels. They should increase the number of people with diabetes receiving the eight care processes to meet NICE recommended treatment targets, ensure all those who have not been seen for more than a year are urgently reviewed and take action to ensure equitable recovery, as the greatest decreases in routine reviews were in areas of highest deprivation. They must also ensure strong clinical leadership is in place to support the coordination and improvement of diabetes services across both place and system level.

ICSs should also prioritise tackling the inequalities in diabetes outcomes experienced by those from deprived communities and those from ethnic minority groups. To underpin this work quality data needs to be available to inform the action local systems take to remove the barriers that cause structural discrimination, variation, and inequalities in diabetes outcomes.

As delivery of care is transformed, ICSs should take action to ensure digital inclusion implementing Healthwatch principles for digital healthcare.



Missed diagnoses of type 2 diabetes

In the first year of the pandemic the increase in diagnosed cases of type 2 diabetes dropped by two thirds compared to pre-pandemic years[29]. In the first wave of the pandemic there were an estimated 5.2 million fewer HbA1c tests carried out in people who did not have diabetes – these are blood tests used to screen those at high risk of type 2 diabetes or make diagnoses of the condition[30]. Reduced rates of diagnosis were particularly evident in older people, men, and in those from deprived areas[31].

These shortfalls in diagnoses are greatly concerning as the earlier people are diagnosed, the sooner they can get support and treatment to reduce their risk of complications and also potentially go into remission. An estimated one in three people newly diagnosed with type 2 diabetes already have complications[32] and so delays in diagnosis are potentially very serious, and a missed opportunity to prevent cardiovascular disease. Evidence suggests that substantial health benefits can be gained if everyone with conditions that increase cardiovascular disease risk could be diagnosed, with detection of undiagnosed diabetes producing greatest benefits[33].

NHS health checks can identify those at high risk of type 2 diabetes as well as driving earlier diagnosis. During the pandemic delivery of these were greatly reduced. The proposed review of the NHS Health Check service provides an opportunity to make these even more effective. It will be important to ensure that health checks are particularly targeted in areas of high deprivation in order to level up opportunities for prevention of type 2 diabetes and reduce the risk of cardiovascular complications through earlier diagnosis.

Recommendation: missed type 2 diagnoses

ICSs should support primary care teams to urgently identify and review those at high risk and with potentially undiagnosed type 2 diabetes. The role of community diagnostic centres in supporting this should be explored.

Impact on self-management

Living with diabetes and avoiding the complications can be a constant juggling act and for many people living with diabetes the pandemic compounded the difficulties of constantly having to manage the condition. Supported self-management is central to effective diabetes care.

Compared to before the pandemic

60%

found it more difficult to maintain positive mental health during 2021.

Emotional and psychological support

People with diabetes are twice as likely to suffer from depression, and more likely to have depression for longer and more frequently[34]. It has been widely reported that the pandemic exacerbated mental health problems and the NHS Confederation has warned of a 'second pandemic' of depression, anxiety and eating disorders due to shortfalls in mental health services[35].

- About half (48%) of GPs and practice nurses responding to a survey reported more mental health concerns in people with diabetes than before the pandemic and 30% reported significantly more mental health problems in their patients with diabetes[36].
- In our recent survey nearly a quarter of people (24%) said that not having sufficient access to emotional and psychological support during the pandemic was a reason for having difficulties with managing their diabetes.
- Compared to before the pandemic, 60% said that they had found it slightly or much more difficult to maintain positive mental health during 2021, with over a quarter saying it was much more difficult.
- People from more deprived areas were more likely to have been having difficulties in managing their diabetes and 33% of people in the most deprived areas who reported difficulties in managing their diabetes said that they did not have sufficient access to emotional and psychological support compared to 25% in the least deprived.

Now, more than ever, urgent action is required to support the increasing emotional and psychological needs of people living with diabetes. This must be seen as an integral part of diabetes care to support people better manage and live well with their condition.

> **"Since the start of the first lockdown, my mental health has not been good and I have been binge eating sweets, biscuits, chocolate and crisps. I have put on a significant amount of weight and my average blood glucose levels are very high."**
>
> Survey Respondent

Access to diabetes technology

Wearable diabetes technologies help improve clinical outcomes while simultaneously providing a better quality of life for people who use them[37 38]. In our recent survey, 79% of those using diabetes technology agreed that it had helped them to manage their diabetes during the pandemic, but not everyone who could benefit from these life changing technologies gets access, even when recommended by NICE:

- Audit data shows that access is limited – and particularly for people living in areas of high deprivation and those from minority ethnic groups[39].
- Around 70,000 people living with type 1 diabetes meet the NICE criteria for insulin pump therapy, but just 20,000 people are using one[40].

We have welcomed the recent revised diabetes guidelines which recommend extending access to Flash and CGM technologies for people with diabetes and urge local health systems to adopt these[41].

> **I have never had access to any tech and am always told I do not fit any criteria and shut down on the few occasions I've asked, with no further information or suggestions. I have very recently started self-funding a Libre which is a big financial commitment for me but has proven to be truly life changing.**
>
> Survey Respondent

Weight management support

For people with both type 2 and type 1 diabetes who are living with obesity, weight loss can considerably improve their health and help prevent cardiovascular complications by reducing HbA1c, cholesterol and blood pressure[4243].

- Half of the respondents to our recent survey said that they had found it slightly or much more difficult to maintain a healthy weight during 2021 compared to before the pandemic with one in five saying it was much more difficult.
- Over a quarter (28%) of people in the most deprived quintile had found it much more difficult to maintain a healthy weight compared to 19% of those in the least deprived.
- 42% of respondents who had experienced difficulties managing their diabetes during 2021 said it was at least in part due to not being able to get as much exercise as normal and 34% said their eating habits had changed.

For some people with type 2 diabetes, significant weight loss can lead to remission of their diabetes[44]. We welcome the pilot services being run by NHS England to evaluate ways of delivering a low-calorie diet intervention similar to our DiRECT research and hope to see a wider roll out of that and other weight management programmes. We are very concerned about recent reports of Government cuts in funding for some weight management services which is a backwards step.

> **I had to home-school my two young daughters and wasn't able to exercise as usual. The stressful, tiring days then led me to overeat as a way of coping.**
>
> Survey Respondent

OVER ONE QUARTER

of people in the most deprived quintile had found it much more difficult to maintain a healthy weight, compared to 19% of those in the least deprived.

50%

of people said that they had found it slightly or much more difficult to maintain a healthy weight during 2021 compared to before the pandemic.

Peer support

Going forward self-management support will be even more vital in light of the huge backlog of care and a burnout and depleted workforce. Drawing on the information and peer support resources available through local communities, third sector organisations can play an essential part in the recovery.

Recommendations: self-management support

As part of their Health and Care plans, ICSs should ensure that people with diabetes have access to diabetes education, mental health support and weight management services, including a mix of digital and face-to-face support, ensuring that everyone can access support that is culturally appropriate and meets their needs and that they monitor disparities in access and provision. ICSs should also work with diabetes service providers, local communities and third sector organisations to ensure people with diabetes can access peer support.

ICSs must ensure that all people with diabetes, regardless of postcode, ethnicity or economic status have an equal opportunity to access diabetes technology in line with NICE guidelines, ensuring clinicians working in diabetes are supported to take part in relevant training on diabetes technology.

ICSs should ensure suitable diabetes specialists are embedded within IAPT-LTC (The Improving Access to Psychological Therapies (IAPT) Pathway for People with Long-term Physical Health Conditions) services.

The Government's Mental Health Recovery Plan did not address the increased challenges faced by people living with long-term health conditions. This must be addressed in the promised long term mental health plan and the Government should invest in a sustainable mental health workforce to meet these needs.

Children and young people with diabetes

Healthcare professionals report a recent increase in both type 1 and type 2 diabetes in children and there is emerging evidence that covid-19 could trigger diabetes[45].

In our recent survey, 18 to 25-year-olds were the age group most likely to say that they had difficulties managing their condition in 2021 (80%). Furthermore, where they were experiencing difficulties this age group were also most likely to report that they did not have sufficient access to emotional and psychological support from their diabetes healthcare team and that they were negatively affected by both anxiety, worry or stress.

The 2019–20 National Paediatric Diabetes Audit (NPDA) shows that even pre-pandemic the proportion of children and young people with type 1 diabetes assessed as requiring additional psychological support was increasing from 39% in 2018–19 to 44% in 2019 –20[46]. There was also considerable variation in HbA1c target outcomes amongst children and young people with type 1 diabetes between localities and differences in outcomes related to social deprivation and ethnicity. Those living in more deprived areas lag behind those in the least deprived areas and minority ethnic children and young people are less likely to achieve lower HbA1c targets or be using a diabetes technology that could support their management – black children are least likely to be using an insulin pump. Alarmingly, this inequality has grown for six years in a row[47]. Those living in more deprived areas were found to have a higher risk of retinopathy and other early signs of complications, need additional psychological support, and have higher HbA1c levels.

Young people are less likely to reach the HbA1c target and receive care processes post-transition to adult care compared to pre-transition[48]. Hospital admissions data from NHS England analysed for the 2019/2020 ‘Get It Right First Time’ report show a worrying spike in the number of DKA admissions for children and young adults between the ages of 15 and 25 when they are transitioning to adult care[49].

A key contributing factor to this sharp rise is the unevenness in current transition pathways and the lack of support services to reach out to those who are not engaged in their care. There is some evidence of best practice in transition, but the 2020 GIRFT report found that transition services are often unavailable or under resourced[50]. We welcome recent initiatives by the NHS England Diabetes and Children and Young People teams to pilot improvements.

More children and young people are developing type 2 diabetes, but few people know the signs and symptoms, so they don't know if they are at risk. Currently, we don't know how many children and young people are living with undiagnosed prediabetes and insulin resistance, so it is vital that we raise awareness, so they can get the care they need.

Dr Dita Aswani, Consultant Paediatrician specialising in Diabetes and Weight Management, Sheffield Children's Hospital and North East and Yorkshire CYA regional diabetes lead, NHSE.

Healthcare professionals working in paediatric diabetes teams report an increase in the numbers of children and young people with type 2 diabetes. Type 2 diabetes in children is considered to be more aggressive than in adults, with more rapid onset of complications at a younger age threatening long-term health and quality of life in adulthood. Early diagnosis and access to good care for children and young people with type 2 diabetes should be a high priority for ICSs. A 'spotlight' audit report on children with type 2 diabetes[51] found the majority of children and young people with type 2 diabetes were living in the most deprived areas in England and Wales (71%) and were from minority ethnic groups (65%).

Recommendations: better support for children and young people

ICSs should ensure that care for children and young people with type 1 and type 2 diabetes is planned and coordinated across paediatric and adult care, ensuring that all are supported to meet treatment targets through getting regular health checks, access to psychological support and equal access to diabetes technology.

Given the growing numbers of children and young people with diabetes, it will be important to ensure that the forthcoming refresh of the NHS Long Term Plan includes sufficient funding to provide the best care for children with type 1 and type 2 diabetes and for the prevention of type 2 diabetes in young people.

3

SUPPORTING SYSTEM RECOVERY AND RESET

Supporting healthcare professionals to recover diabetes care and drive improvement

Whilst staff shortages were an issue even before the pandemic[52], it has had a massive impact on those working in the NHS and further impacted workforce pressures:

- Workforce burnout was described by many providing evidence to a Health and Social Care Committee enquiry last year as the highest in the history of the NHS[53].
- A recent RCGP survey found that 34% of GPs expect to leave the profession within 5 years, which could mean the loss of over 14,000 GPs to the workforce[54].
- Projections from the Health Foundation suggest that by 2030/31, a 40% increase in the health care workforce would be needed to meet demand pressures and recover from the pandemic – double the growth seen in the last decade[55].

People with diabetes need a skilled workforce who have support for their own wellbeing to deliver good care. This will be essential in building back a better system that works for people with diabetes and health care professionals.

Workforce burnout was described by many in a recent parliamentary inquiry as the HIGHEST in the history of the NHS.

Integrated diabetes care

Good diabetes care is where the delivery is seamless between specialist and primary care, and where planning, delivery and learning is joined up around the person with diabetes[56]. Integrated IT systems can allow seamless sharing of clinical information across systems and facilitate timely communication and can also increase the individual's involvement in their own healthcare. Such systems may avoid duplication and hence expenditure[57].

- Less than half (44%) of specialist diabetes services responding to a survey by the Association of British Clinical Diabetologists (ABCD) last year thought that their services –primary and secondary care – work in a joined-up way.
- Nearly half said that there were no plans to integrate their IT systems with primary care in the next year and that this was due to lack of priority (39%) or lack of funding (28%)[58].

Recommendation: integrated care

ICSs working with Primary Care Networks (PCNs) should take the opportunity they have to better integrate diabetes care, facilitating specialist input to primary care and supporting joined up care through integrated IT systems.

ICSs should identify a clinical lead for diabetes care and draw on their expertise to plan integrated diabetes care and type 2 prevention. Diabetes clinical networks can facilitate learning and improvement across the local system.

71%

of respondents to recent PCDS survey felt the pandemic had significantly impacted their practice's ability to provide routine diabetes care.

Primary care

As the NHS struggled to recover from the pandemic last year, primary care, and particularly routine care for people with long term conditions like diabetes, has been challenged over and again by setbacks and extra demands. Most recently at the end of last year the shortage of blood vials, followed by the emergency response to the Omicron variant, led to routine care for people with diabetes being deprioritised again. The heightened demand pressures on GPs mean that planned appointments have still not recovered to their pre-pandemic levels[59].

Nearly three quarters (71%) of respondents to a survey by the Primary Care Diabetes Society felt that the pandemic had significantly impacted their practice's ability to provide routine diabetes care and checks for those with diabetes and screening for type 2 diabetes[60].

Restoring diabetes care locally will require investment in primary care, including health care staff working in a wide range of roles to support general practice and facilitate improved integration between primary and specialist care, including:

- mental health practitioners working in IAPT LTC services
- pharmacists
- social prescribers
- community-based specialist diabetes teams
- community diagnostic centres.

Recommendation: primary care workforce

The Long Term Strategic Framework for Health and Social Care Workforce planning must take account of the anticipated rise in the numbers and complexity of needs of people living with diabetes and invest in a wide range of roles to support primary care and ensure that all health care professionals have a basic level of diabetes education.

> **"The failure to restore primary care provision urgently and safely to at least pre-pandemic levels in a sustainable manner could adversely impact people's physical and mental health and place additional burden on the already overburdened healthcare system."**
>
> Conclusion to PCDS survey report[60]

Specialist diabetes and inpatient care

The growing general medicine and emergency workload of specialist diabetologists working in hospitals impacts negatively on integrated models of care. This was highlighted during the pandemic when care was focused on emergency medical cases, resulting in significantly reduced contact with people with diabetes in both inpatient and outpatient settings.

There is often a lack of knowledge about diabetes and its treatment amongst the wider workforce. Almost one third of inpatients with diabetes have a medication error during their hospital stay[61].
Poor management of diabetes when in hospital has a devastating impact on an individual's healthcare and often leads to delays in other vital procedures such as surgery.

Diabetes inpatient care teams are crucial for providing quality care for people with diabetes in hospital. They are key to offering expert knowledge and care plans to support quick turnaround of patients in A&E and other specialties such as cardiology, renal and surgical which prevents deaths and delays. They help to make hospital stays shorter and safer for people with diabetes.

We know that even before the pandemic, inpatient diabetes teams were being disbanded[62], and whilst Diabetes Specialist Nurses (DSNs) are key to coordinating care and educating the wider workforce, 18% of hospitals still do not have a DSN service[63].

Whilst there some signs of recovery in inpatient diabetes care, specialist diabetes teams report considerable difficulties in funding for outpatient services which will impact on their ability to recover the backlog in care for people with type 1 diabetes and for those with all types of diabetes who need specialist input to their care.

Recommendations: inpatient care and specialist support

ICSs should continue to invest in and support the development of specialist inpatient teams so that all hospitals can ensure minimum standards of care and people with diabetes are safe in hospital.

ICSs should ensure that people with type 1 diabetes can access the specialist support they need.

4

PREVENTION OF TYPE 2 DIABETES

Addressing obesity and the social determinants of health

Many risk factors can impact someone's likelihood of developing type 2 diabetes, including age, family history and ethnicity – the more of these risk factors a person has, the higher their risk of developing the condition. The most significant modifiable risk factor is obesity. In 2018–19, 87% of people newly diagnosed with type 2 diabetes were in the overweight or obese BMI categories[64].

The UK is now the third most overweight country in the G7. In England 67% of men and 60% of women are living with overweight or obesity[65]. The pandemic has impacted on obesity rates and last year saw the largest increase in childhood obesity since records began.

Reducing obesity is essential for reducing the prevalence of type 2 diabetes and addressing inequalities in health outcomes. The prevalence of obesity is much higher in those from the most deprived areas (35%) than the least deprived (22%)[66]. People with type 2 diabetes are also more likely to live in the more deprived areas – the prevalence of type 2 in the most deprived areas of England and Wales is 24%, compared to 15% in the least deprived[67].

Having a wider waist circumference, another risk factor for type 2 diabetes, is also associated with area deprivation[68]. Other modifiable risk factors for type 2 diabetes such as physical activity, stress, and smoking are also strongly correlated with deprivation.

Interventions that rely on individuals' agency have been found to be less effective and less equitable than population-level interventions in tackling major risk factors for ill health[69]. No single policy intervention will be sufficient, there are numerous steps that can be taken by governments, industry and local health and care systems. To truly turn the tide on the rising rates of obesity and type 2 diabetes we need to improve the income, housing, employment conditions, and the local environments we live in.

Many of the levers for addressing risk factors for type 2 diabetes sit outside the health system. ICSs have an opportunity to address health inequalities and influence the wider determinants of health, as they bring together the NHS, local authorities and community partners[70]. ICSs should address health inequalities and influence the wider determinants of health ensuring the NHS plays a full part in broader social and economic development together with local authorities and community partners.

It is also essential to address the way that food is produced, sold and promoted and shift industry towards a model that supports access to healthy food for everyone. Last year the Government made some positive steps and pledges towards addressing the unhealthy food environment, including new restrictions on promotions and advertising of unhealthy products. While new policies are on the horizon which further address the food environment, progress is slow. The Government must go even further and faster, including building on the recommendations of the National Food Strategy to address increasing obesity levels by considering additional fiscal measures to incentivise food and drink manufacturers to make their products healthier and tackle the 'junk food cycle'.

There is also an urgent need to reduce diet related inequality and the Levelling Up White Paper was a missed opportunity to address this.

Recommendation: addressing the issues underlying increased risk of type 2 diabetes

The forthcoming Government White Paper on addressing disparities in health should include proposals from the National Food Strategy, ensuring that everyone has access to healthy food.

In addition, the forthcoming White Paper on Health Disparities should set out a cross Government strategy to tackle health inequalities by addressing the social determinants of health, including poverty, that underly and compound the unequal impact of diabetes. It should also include plans to increase the resource available for social prescribing in communities, address digital access issues and face-to-face delivery of healthcare services. The recommendations from the recent NHS Race and Health Observatory report into ethnic inequalities in healthcare[71] should also be addressed.

Preventing type 2 diabetes in individuals at highest risk

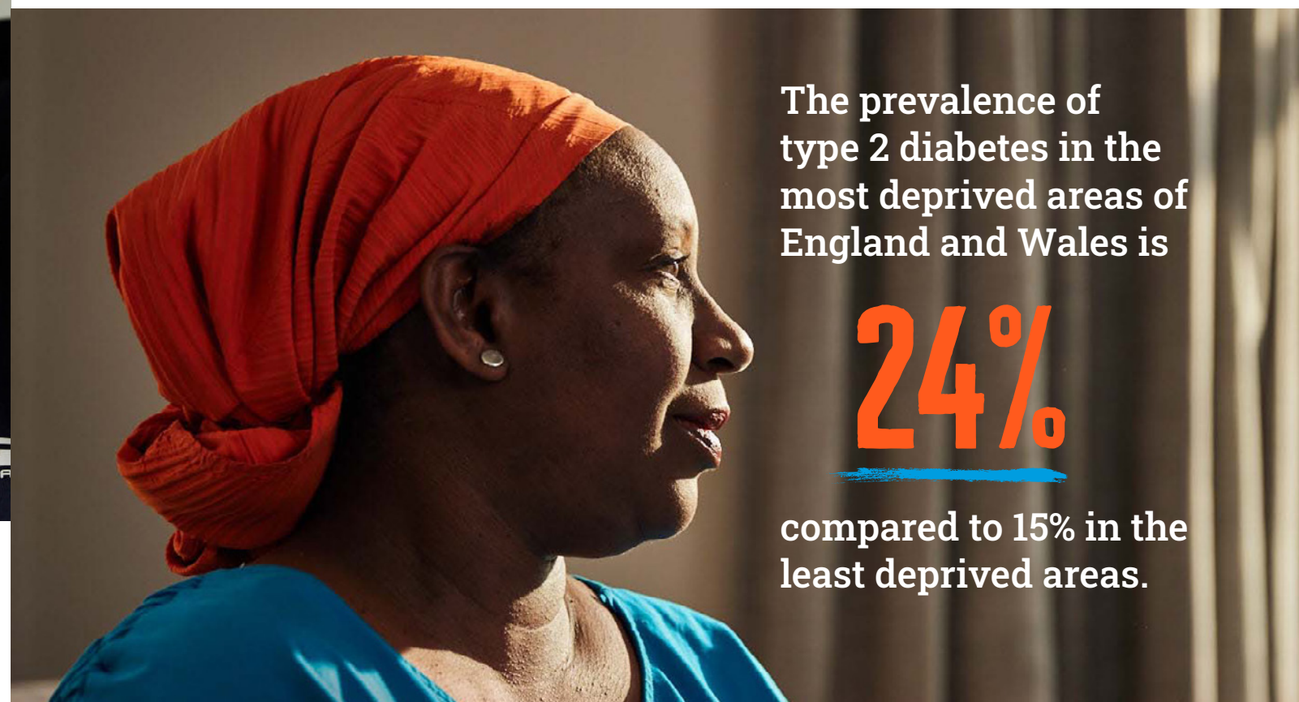
A massive 13.6 million people are currently at increased risk of developing type 2 diabetes and other serious health conditions. Amongst people who are at high risk of developing type 2 diabetes, around half could delay or prevent the onset of the condition with the right kind of support[72]. Investment in the NHS Diabetes Prevention Programme (NHS DPP) in recent years has supported thousands of people to take action to reduce their risk[73].

As people from South Asian, Black African, and Black Caribbean backgrounds are two to four times more likely to develop the condition, frequently at a younger age and lower BMI than White Europeans[74], it is important to increase referrals to the NHS DPP for these groups and people living in more deprived areas.

We welcome the Government's commitment to bring forward a new requirement for NHS England and Improvement to introduce a yearly prevention spend[75] to invest in tackling major preventable diseases such as diabetes and look forward to hearing more details about this.

Recommendation: increasing referrals to the NHS Diabetes Prevention Programme

As we recover from a pandemic where the numbers of people at high risk of type 2 diabetes will have risen along with obesity levels, local health systems should support primary care to increase referrals to the NHS Diabetes Prevention Programme, ensuring all who could benefit can access it and particularly targeting areas of high deprivation.



5

CONCLUSION AND SUMMARY OF RECOMMENDATIONS

We are at a moment of significant change to the healthcare system as the Health and Care Bill comes into force later this year and this report has outlined many opportunities to transform diabetes care in a way that reduces cost for the NHS and improves the lives of people living with or at risk of diabetes.

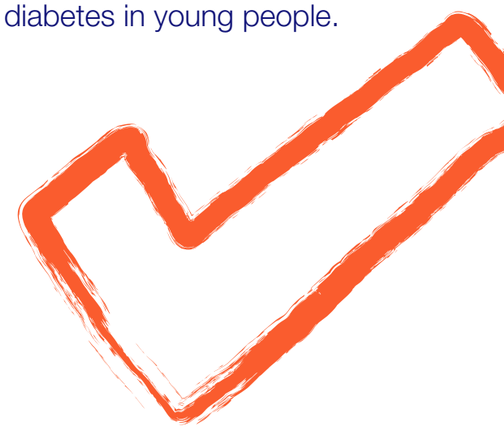
Covid-19 put unprecedented pressure on the healthcare system and people living with diabetes. As the NHS focuses on recovery, and as new local organisations take responsibility for the health system in in England, it is important to recognise the seriousness of the condition and the opportunities to prevent cardiovascular complications and premature mortality. Greater investment is needed in both prevention of type 2 diabetes and the care of those living with diabetes. We need investment in technology for local systems and for people to manage their condition more effectively, investment across primary care and in specialist diabetes professionals, and investment in weight management, mental health and peer support to enable people with diabetes to live well and prevent the serious harm that diabetes can do.

Recommendations to government

1. As the Government looks to reform healthcare by investing up front in prevention, routine checks for people living with diabetes must be considered a priority, as they play an important role in preventing and delaying costly complications. This will require investment in the GP workforce and health care staff working in a wide range of roles in primary care, in specialist diabetes care and in IT infrastructure and integration of care.

2. The Government must urgently bring forward a national recovery plan for routine primary care so that people with diabetes can access the vital support they need to keep themselves well and to prevent the short and long-term consequences of delayed care for the NHS and people living with diabetes.

3. The forthcoming refresh of the NHS Long Term Plan should further embed and extend the investment in improvement of diabetes care which was making good progress before the pandemic. Given the growing numbers of children and young people with diabetes, it will be important to ensure in the forthcoming refresh of the NHS Long term plan that sufficient funding is available to provide the best care for children with type 1 and type 2 diabetes and for the prevention of type 2 diabetes in young people.



4. The Government's Mental Health Recovery Plan did not address the increased challenges faced by people living with long-term health conditions. This must be addressed in the promised long term mental health plan and the Government should invest in a sustainable mental health workforce to meet these needs.

5. The Long Term Strategic Framework for Health and Social Care Workforce planning must take account of the anticipated rise in the numbers and complexity of needs of people living with diabetes and invest in a wide range of roles to support primary care and ensure that all health care professionals have a basic level of diabetes education.

6. The forthcoming Government White Paper on addressing disparities in health should include proposals from the National Food Strategy, ensuring that everyone has access to healthy food. In addition, this White Paper should set out a cross Government strategy to tackle health inequalities by addressing the social determinants of health, including poverty, that underly and compound the unequal impact of diabetes. It should also include plans to increase the resource available for social prescribing in communities, address digital access issues and face-to-face delivery of healthcare services. The recommendations from the recent NHS Race and Health Observatory report into ethnic inequalities in healthcare should also be addressed.

Recommendations to Integrated Care Systems (ICS)

1. ICSs should urgently draw up plans to catch up on the diabetes backlog, restoring the identification, monitoring and provision of management support for people with all types of diabetes to pre-pandemic levels. They should increase the number of people with diabetes receiving the eight care processes to meet NICE recommended treatment targets, ensure all those who have not been seen for more than a year are urgently reviewed and take action to ensure equitable recovery, as the greatest decreases in routine reviews were in areas of highest deprivation. They must also ensure strong clinical leadership is in place to support the coordination and improvement of diabetes services across both place and system level.

2. As they look to reduce inequalities and integrate care, ICSs must put diabetes front and centre of their Health and Care Plans. These plans should ensure that people with diabetes have access to diabetes education, mental health support and weight management services, including a mix of digital and face-to-face support, ensuring that everyone can access support that is culturally appropriate and meets their needs and that they monitor disparities in access and provision. ICSs should also work with diabetes service providers, local communities and third sector organisations to ensure people with diabetes can access peer support.

3. ICSs should also prioritise tackling the inequalities in diabetes outcomes experienced by those from deprived communities and those from ethnic minority groups. To underpin this work quality data needs to be available to inform the action local systems take to remove the barriers that cause structural discrimination, variation, and inequalities in diabetes outcomes. As delivery of care is transformed, ICSs should take action to ensure digital inclusion implementing Healthwatch principles for digital healthcare.

4. ICSs should support primary care teams to urgently identify and review those at high risk and with potentially undiagnosed type 2 diabetes. The role of community diagnostic centres in supporting this should be explored.

5. ICSs must ensure that all people with diabetes, regardless of postcode, ethnicity or economic status have an equal opportunity to access diabetes technology in line with NICE guidelines, ensuring clinicians working in diabetes are supported to take part in relevant training on diabetes technology.

6. ICSs should ensure that care for children and young people with type 1 and type 2 diabetes is planned and coordinated across paediatric and adult care ensuring that all are supported to meet treatment targets through getting regular health checks, access to psychological support and equal access to diabetes technology.

7. ICSs working with PCNs should take the opportunity they have to better integrate diabetes care, facilitating specialist input to primary care and supporting joined up care through integrated IT systems. ICSs should also ensure suitable diabetes specialists are embedded within IAPT-LTC services.

8. ICSs should identify a clinical lead for diabetes care and draw on their expertise to plan integrated diabetes care and type 2 prevention. Diabetes clinical networks can facilitate learning and improvement across the local system.

9. As we recover from a pandemic where the numbers of people at high risk of type 2 diabetes will have risen along with obesity levels, local health systems should support primary care to increase referrals to the NHS Diabetes Prevention Programme, ensuring all who could benefit can access it and particularly targeting areas of high deprivation.

6

APPENDIX AND REFERENCES

Diabetes UK survey methodology

Diabetes UK ran an online survey for people living with diabetes or a close connection to diabetes between 17 January to 7 February 2022.

Participants were living with diabetes or the parent or carer of someone living with diabetes; living in England; and aged over 18 – though parents and carers could answer on behalf of someone living with diabetes under the age of 18. Respondents were asked a range of questions about their experience of living with diabetes and diabetes care, primarily during 2021 and in some questions since March 2020.

A small number of questions invited free text and was the source of quotes from people with diabetes in this report.

10,040 complete, eligible responses were submitted and included in the analysis. The provision of gender, ethnicity and location data was optional. The numbers and demographic breakdown of respondents used in this report are outlined below. 5863 survey respondents provided post code data, enabling us to provide a breakdown of responses by deprivation quintile based on the 2019 Index of Multiple Deprivation for lower-layer super output areas.

Ethnic group	Number	% of total
White	8,323	96.61
Mixed/ multiple ethnic groups	69	0.80
Asian/Asian British	114	1.32
Black/ African/ Caribbean/ Black British	79	0.92
Other ethnic group	30	0.35
Total	8,615	100

Index of multiple deprivation quintiles	Number	% of total
1 – areas of most deprivation	937	15.98
2	1,101	18.78
3	1,228	20.94
4	1,274	21.73
5 – areas of least deprivation	1,323	22.57
Total	5,863	100

Age	Number	% of total
18–25	198	1.97
26–45	1,070	10.66
46–65	4,084	40.68
66 and over	4,688	46.69
Total	10,040	100

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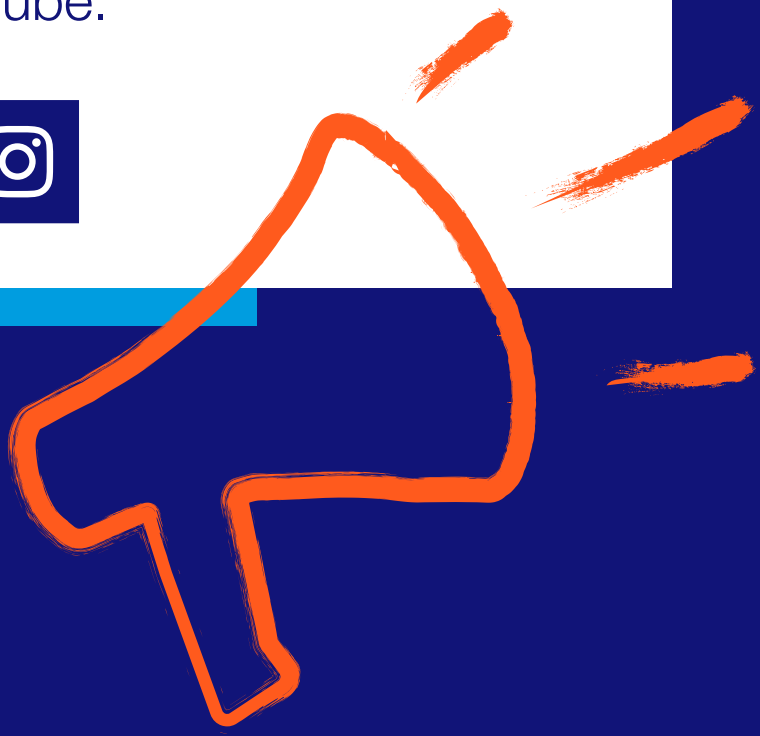

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