

DIABETES IS SERIOUS

Diabetes care:
is it fair enough?

DIABETES UK
KNOW DIABETES. FIGHT DIABETES.

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INTRODUCTION

More than **5 million people** across the UK live with the challenges of diabetes, day in, day out. Diabetes is relentless. It requires constant decision-making and careful self-management to stay well with the condition. For too many people, diabetes still leads to serious complications and even, sadly, early death.

Every week diabetes leads to more than

184 AMPUTATIONS¹

770 STROKES

590 HEART ATTACKS

2,300 CASES OF HEART FAILURE²

With the right care and support, many life-altering diabetes-related complications can often be prevented. The National Institute for Care Excellence (NICE) recommends eight routine checks for people with diabetes, which have been shown to reduce the chances of developing these complications.³ However, not everyone with diabetes has equal access to this vital healthcare. Less than half of people with diabetes in England (47%) received all of their vital checks in 2021 to 2022, compared to 57% before the pandemic. And the rate of completion was

significantly lower for those in the most deprived quintile.⁴

Emerging evidence suggests that the ongoing disruption to routine care may be leading to excess mortality in people with diabetes. Evidence for England shows that compared to pre-pandemic, in 2022, there were more than 7,000 excess deaths involving diabetes, 13% more than expected and the majority of these were not attributable directly to coronavirus (covid-19). Worryingly, the situation has only worsened in the first part of 2023, with 1,461 excess deaths between January and March, three times as high as the same period in 2022. Urgent action is needed to reverse this trend and support everyone living with diabetes to live well with the condition.⁵

There were more than **7,000 EXCESS DEATHS**

involving diabetes in 2022, **13% more than expected.**

As well as these devastating excess deaths, we are concerned that fragmented access to routine care will have other major implications for people living with diabetes and for the NHS. Without ongoing care and management, people with diabetes are at increased risk of hospitalisation, due to complications.

In December 2022, the NHS England Board determined that disruption to routine and emergency care due to the coronavirus pandemic resulted in significant increased demand and mortality.⁶ The Board recommended that Integrated Care Systems (ICS) should be supported to prioritise secondary prevention as part of their strategic plans, a call that we at Diabetes UK echo.

At the start of 2023, we surveyed more than 13,000 people living with diabetes or caring for someone with diabetes across the UK about their experience during 2022. This report focuses on the experiences of the 11,000 respondents from England, and separate information will be available for Northern Ireland, Scotland and Wales. The survey revealed that almost half of respondents (48%) experienced difficulties managing their diabetes in 2022, highlighting the need for greater support for people living with diabetes.⁷



Non-Covid related excess mortality over the past year was primarily driven by cardiovascular disease (CVD), liver disease and diabetes, and the sustained period of high urgent and emergency care (UEC) demand is understood to be driven primarily by respiratory disease and CVD of which diabetes is a major risk factor.



NHS England Board paper, December 2022



MORE THAN A THIRD

of respondents found it difficult to make appointments for their diabetes check ups.

MORE THAN HALF

who had tried to get emotional or psychological support, faced difficulties doing so.

Diabetes UK survey findings (England only)

- Almost half of people who responded to our survey (48%) experienced difficulties managing their diabetes in 2022.
- The most common cause attributed to these difficulties, at least in part, was a lack of access to their diabetes healthcare teams, which half of respondents (50%) cited.

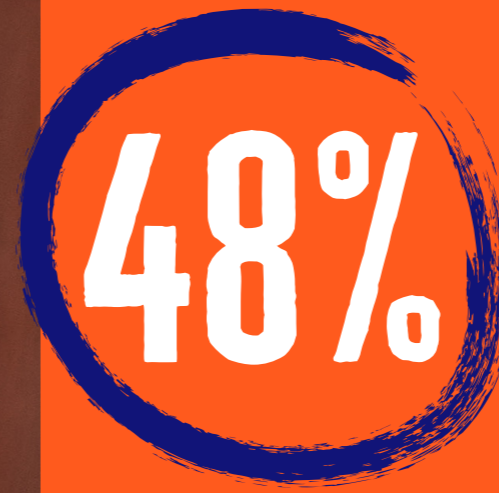
- More than a third (38%) of respondents found it difficult to make appointments for their diabetes check ups.
- More than half (52%) who had tried to get emotional or psychological support, faced difficulties doing so.
- People in the most deprived quintile were nearly 50% more likely to have had no contact with their healthcare team in over a year, compared to those in the least deprived.



There is so much we can do to educate and treat people earlier in the course of type 2 diabetes to reduce risk of complications and to support those with type 1 and other types of diabetes to lead a full life. Many staff currently feel that they are not providing the care they wish to with the pandemic recovery pressures. The burden to the individual and NHS of not getting this right is huge.



Diabetes Clinical Lead



of people who responded to our survey experienced difficulties managing their diabetes in 2022.





50%

attributed difficulties managing their diabetes, at least in part, to a lack of care and support from their diabetes healthcare team.



30%

cited insufficient access to emotional and psychological support.

Other causes attributed to these difficulties were:

- **37%** not being as physically active or able to exercise as normal
- **28%** increasing costs of living
- **27%** eating habits changed.

UNFAIR ACCESS TO DIABETES CARE

Existing inequalities within diabetes care and prevalence

The impact of diabetes is not felt equally, there is inequity in every aspect of diabetes, from risk to outcomes, treatments to technology. For instance, people from South Asian, Black African, and Black Caribbean backgrounds are two to four times more likely to develop type 2 diabetes, frequently at a younger age and lower BMI than White Europeans.⁸

Deprivation is a key factor in diabetes inequality, with 24% of people diagnosed with type 2 diabetes living in the most deprived areas, compared to 15% in the least deprived.⁹ And people with type 1 diabetes in more deprived areas are more likely to have a high HbA1c, a measure for average blood glucose levels.¹⁰

Deprivation and diabetes

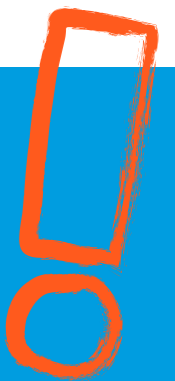
Our 2023 survey looked at the impact of diabetes on people's lives and their experience of accessing care in 2022. It found that those in the most deprived quintiles were more likely to have faced difficulties managing their diabetes, maintaining their health in the face of rising living costs and getting access to the healthcare they needed.

We found that...

- 1 in 3 people in the most deprived areas found it difficult to contact their diabetes healthcare team in 2022, compared to 1 in 4 in the least deprived.

- 1 in 10 people in the most deprived areas reported no contact with their healthcare team in over a year. And were almost 50% more likely to have had no contact in this time than people living in the least deprived areas.
- Those in areas with highest levels of deprivation were more likely to have experienced difficulties managing their diabetes (57%) than those with the lowest levels (45%).
- People living in areas of higher deprivation were more than twice as likely to attribute these difficulties, at least in part, to the rising cost of living, 41% compared to 17% in the least deprived areas.
- People in the most deprived areas were also more likely to cite changes to their eating habits (34%) and physical activity (43%) as a reason for their difficulty managing their diabetes than those in the most affluent areas (23% and 34% respectively).

1 IN 3



people in the most deprived areas found it difficult to contact their diabetes healthcare team in 2022, compared to 1 in 4 in the least deprived.

These results underline the stark inequalities in diabetes care and management, which ultimately lead to worse health outcomes for those in the most deprived areas. Routine diabetes care reduces the likelihood of developing life-altering complications and early mortality. So it is extremely concerning to see that those from deprived communities are more likely to report not having had contact with their healthcare team and having found it difficult to make appointments.

The rising cost of living is a threat to public health, and these results reaffirm that they will be hardest felt by those in the most deprived communities. The ability to maintain a healthy diet and to be physically active are vital not just to prevent type 2



Having no help when struggling with my diabetes has caused me a lot of stress which also has an impact on my blood sugar control. Letters were sent with an appointment, then a week later I received a letter to say it had been cancelled, this happened on three occasions in a row.



Lesley, North East and Yorkshire

diabetes, but also in the management of all types of diabetes. So it's extremely concerning that the rising cost of living is making this more challenging. Failure to act to improve diabetes outcomes and reduce the prevalence of type 2 diabetes risks undermining the government's aims to increase healthy life expectancy and reduce ill-health related labour market inactivity. A whole system approach is needed to reduce obesity, to ensure everyone can afford to maintain a healthy diet, and that people have access to green spaces and safe, active travel routes.

Our recent report on the current cost of living crisis, **The Hidden Cost**, showed that 66% of people with diabetes or at risk of type 2 diabetes have cut back on essentials like food or energy, or have gone without entirely.¹¹ For instance, by switching off the fridge – impacting both food and medication storage, eating cheaper but less healthy food, cooking less, or having to use a food bank. To prevent long-term health scarring, we need a guarantee that no one will have to go without essentials and that everyone will have access to well-resourced care.

Geographical variation

In 2022, The Health and Care Act replaced existing Clinical Commissioning Groups (CCGs) with larger Integrated Care Boards (ICBs), to create opportunities to integrate care and to enable local areas to respond to the needs of their communities. Work is now needed to tackle the huge variation that exists within ICBs in policies, priorities and outcomes, by sharing learning across

these wider areas to improve healthcare across the entire ICB.

Data from the National Diabetes Audit (NDA) in England reveals huge differences in the percentage of people receiving all of their vital diabetes checks in 2021 to 2022 across different areas. While some areas have restored their diabetes care to above pre-pandemic levels, the majority have not, with the lowest performing areas seeing only 1 in 10 people with diabetes get all of their checks.¹²

47%
of people across England diagnosed with diabetes received all of their care processes in 2021 to 2022.

Local variation in NDA data

- Across England, 47% of people diagnosed with diabetes received all of their care processes in 2021 to 2022.
- However significant variation exists between ICBs, with just 25% of people with diabetes receiving all eight care processes in the lowest performing area (NHS Shropshire, Telford and Wrekin ICB), compared to the highest rate of 62% (NHS Suffolk and North East Essex ICB).
- Data broken down at Primary Care Network (PCN) level reveals an even

starker degree of variation. The percentage of people with diabetes who received all their care processes varied from 10% in the lowest performing PCN to 86% in the highest, a range of 76%.

- Within one ICB, the completion rates between its PCNs ranged from 18% at the lowest to 79% at the highest.
- Just 15% of PCNs (162) have restored the number of people receiving all of their checks to pre-pandemic levels, with 85% (1,110 PCNs) still lagging behind their 2019 to 2020 completion rate.¹³

This analysis reveals that the average (mean) care process completion data across England and the relatively large geographical footprint of ICBs are masking a much more concerning and unequal picture. One where the vast majority of local 'neighbourhood' areas are struggling to recover these vital routine diabetes checks.

The impact of the pandemic continues to be felt across the NHS, as services struggle to cope with the backlog alongside unprecedented demand and workforce shortages. Learnings should be taken from areas where services have been able to recover and where the majority of people with diabetes received their checks. Prioritising routine care for people with long-term conditions is vital to secondary prevention, enabling early interventions to support people to stay well, stay in work and avoid the need for further healthcare. Therefore, ICBs should put routine care at the forefront of their plans now, to reduce pressure on health and social care services in the future.

IMPACT OF MISSED ROUTINE CARE ON OTHER SERVICES

Diabetes management impacts on every aspect of a person's health, including comorbidities and other healthcare needs. Without routine care to support people with diabetes to stay well, the consequences are felt, not just by individuals and their diabetes healthcare teams, but across the breadth of the NHS. The majority of NHS spending on diabetes is spent treating diabetes-related complications, including heart disease, stroke and sight loss.¹⁴

Almost 16% of survey respondents said they had elective surgery with the NHS in the previous two years. **While waiting for this surgery, 23% said it became more difficult to manage their diabetes.** Significant numbers also had to visit their GP (22%) or A&E (13%) for the condition that they were waiting to have an operation for.



Getting diabetes care and treatment right could have transformative effects on NHS pressures. Vast amounts of the NHS budget is spent on managing complications of diabetes, that are often easily preventable. Similarly, giving people with diabetes access to the right care at the right time has the power to transform lives.

Rose Stewart,
Consultant Clinical
Psychologist, Wales

Furthermore, 9% of survey respondents told us they were currently on a waiting list for elective surgery. Of these people, **more than 1 in 10 (13%) had their surgery delayed because of their HbA1c levels.** HbA1c is a measure of average blood glucose levels over two to three months and is an indicator of how someone's diabetes is being managed. A high HbA1c can increase the risk of post-surgical complications, so it is essential that people have support to manage their diabetes ahead of any planned surgery. These avoidable delays to surgery can lead to deterioration in other health conditions and ultimately, result in worse health outcomes and greater need for NHS care.

Andy's story

A couple of weeks after I was diagnosed with type 2 diabetes, I had an appointment to speak to a diabetes nurse at the surgery. But it was cancelled on the day, and I was told it would be three weeks till the next available appointment. This was totally unacceptable, I'd been diagnosed two weeks prior and hadn't had any consultation or been able to speak to my doctor. Eventually, I had a telephone consultation with the diabetes nurse, who gave me some generic information about diabetes and directed me to the Diabetes UK website.

I then had a telephone consultation with a doctor, who put me on metformin, but I had more questions at the end of it, than at the beginning. There's no care plan. **I'm most disappointed about not being able to meet face-to-face and have a conversation about my diabetes.**

My coping has come from being proactive and doing independent research rather than relying on the NHS to do what they should be doing. They just don't seem to have the time or resources to offer the level of care that is needed.



Anthony's story

It feels as if I get less care than I used to, and no one seems to have a proper understanding of my diabetes.

Back in January 2020, I was due a check-up but the appointment was cancelled and moved to March for a telephone appointment. This happened again and again, and I didn't receive any further communication about appointments after that.

Prior to the pandemic, I had constant monitoring of my eyes as there were some concerning little blood vessels. I believe the lack of contact and support contributed to me developing retinopathy as I didn't have an eye appointment for two years. We know that covid was a challenging period but not having that external assessment and not being monitored properly really impacted me and no plans were in place should I develop any complications. It was known that I had high blood pressure and I was approaching my early 40s but important conversations and future planning just didn't happen.

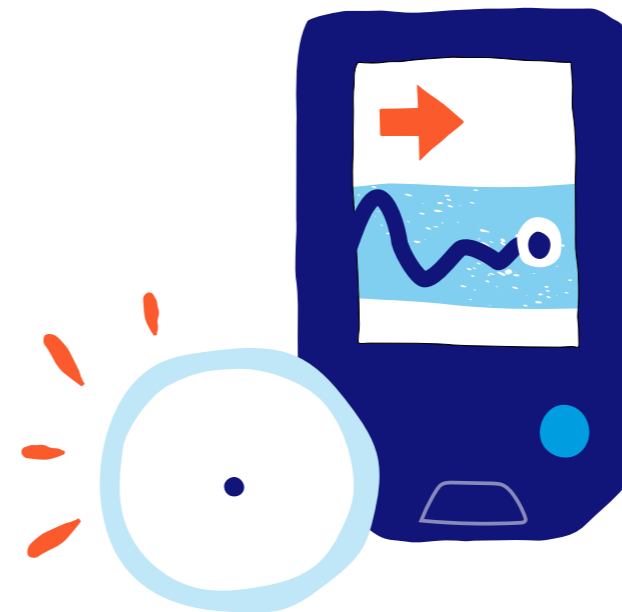


The retinopathy has impaired my sight and also affected my health. I've not been as active as I usually would be and when I try to be active it makes matters worse. So since last June, I've put on a bit of weight and my health has suffered.

Diabetes is a complex condition. The repercussions over time are very serious, and as I have found life-altering. There needs to be a commitment to managing my condition properly.

DIABETES TECHNOLOGY

Diabetes technology has a vital role to play in the future of diabetes care. Glucose monitors, insulin pumps, hybrid closed loop and smart pens can all facilitate improved diabetes management leading to better short and long-term health outcomes. The NHS has made huge progress to increase access to diabetes technology in recent years, seeing the majority of people with type 1 diabetes move from finger pricking, to using a flash glucose monitoring (Flash) or continuous glucose monitor (CGM).



In England, 84% of people using diabetes technology agreed it helped them to manage their diabetes in 2022, and 79% said it improved their wellbeing. And 61% told us that diabetes technology made remote consultations with their diabetes team easier.

New NICE guidance on Flash and CGM in 2022 made recommendations to build on the progress, widening eligibility to include everyone with type 1 diabetes, and for the first time, some people

84%
of people using technology, agreed it helped them to manage their diabetes in 2022.

79%
said it improved their wellbeing.

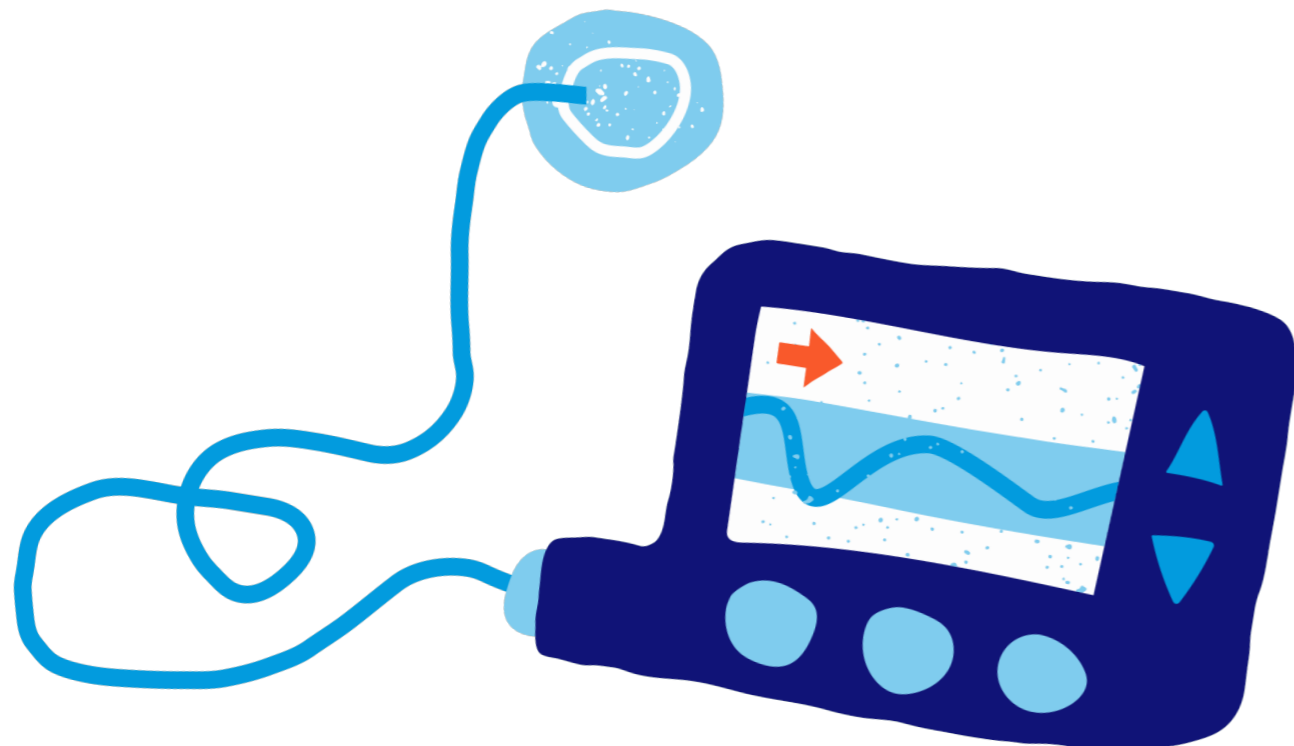
with type 2 diabetes, who inject insulin multiple times a day. The new guidance also made clear that people with type 1 diabetes should be able to choose the right monitor for them.

However, many people who could benefit continue to miss out. Audit data indicates that people who are eligible for technology under existing NICE guidance do not always have access to the technology that could help them. Around 50,000 people who are eligible for an insulin pump are not currently using one. While some will choose not to use certain technology, we know that many are not aware of it, believe they are ineligible or face barriers to access. Amongst people with type 1 diabetes, our survey showed that there are high levels of interest in technology that people are not currently using.

“
I know a pump would improve my control of diabetes. Being denied every time I go to clinic because my control is too good is dispiriting.”

Mark, lives with type 1 diabetes

Technology	I am currently using this	I don't currently use this but am interested in it	I don't use this and am not interested in it
Flash	72%	10%	12%
CGM	26%	46%	14%
Insulin pump	23%	34%	31%
Hybrid closed loop	5%	37%	24%





FAIR DIABETES

CARE FOR THE FUTURE: RECOMMENDATIONS

Recommendations for the government

1. The upcoming Major Conditions Strategy should focus on secondary prevention to support people with long-term conditions to stay well, including setting out plans to increase access to routine diabetes appointments.
2. The Major Conditions Strategy should recognise diabetes as a major driver of health inequality and make recommendations to reduce inequity in diabetes risk, care and outcomes.
3. The Major Conditions Strategy should take steps to embed an integrated care model across diabetes and mental health care pathways, to improve the emotional and psychological support for people living with the condition.
4. The government should implement the 2020 obesity strategy in full and without further delay, including the restrictions on junk food marketing.



Diabetes is sadly with us for life and we need a future proof care plan not just a plaster to cover the immediate wounds. ”

Matt, lives with type 1 diabetes

Recommendations for ICBs

1. As laid out in the current NHS priorities and operational planning guidance, ICBs should detail their plans for the prevention of ill-health within their Joint Forward Plans “paying due regard to the NHS Long Term Plan primary and secondary prevention priorities, including a continued focus on...diabetes.”
2. Addressing the inequalities in access to diabetes care and prevention support through the National Diabetes Prevention Programme should be at the heart of every ICB’s strategy to improve health and reduce inequalities.
3. ICBs should set out in their Joint Forward Plans how they will catch up on the diabetes backlog, restoring the identification, monitoring and provision of support for people with all types of diabetes to pre-pandemic levels. Specific focus should be given to ensuring those who have greatest clinical need, and those who have not been seen for more than a year are urgently reviewed.
4. Plans should set out what action will be taken to ensure equitable recovery, as the greatest decreases in routine reviews were in areas of highest deprivation.
5. ICBs should commit to investment in system and network level diabetes clinical leadership to support the integration, coordination and improvement of diabetes services across both place and system level.

CONCLUSION



Inconsistent diabetes care and ongoing disruptions to care delivery are leaving people struggling to manage their condition and compromising their long-term health, impacting not just their physical health but also their wellbeing. Getting diabetes care right now will help to mitigate the ever-increasing pressure on the NHS, preventing and reducing diabetes complications that can require expensive treatments, surgery or hospital admissions and sadly can result in early deaths. While in some areas diabetes care is fast recovering and has even shown improvement on pre-pandemic levels, most are not. People with diabetes in deprived areas are less likely to be receiving the care they need, and more

likely to be facing difficulties with their condition, exacerbating the health inequalities that already exist for those in the most deprived communities.

With the right care and support, people living with diabetes can lead healthy, productive lives. Support to face the daily challenge of managing diabetes can make all the difference, improving long-term health outcomes and emotional wellbeing. Collaborative and ambitious action between the government, NHS England and ICBs could shift the focus of healthcare to empowering people with long-term conditions to stay well, rather than treating the devastating and complex consequences down the line.

APPENDIX AND REFERENCES

Appendix A: Survey methodology

Diabetes UK ran an online survey for people living with diabetes or a close connection to diabetes between 25 January to 20 February 2023.

Participants were living with diabetes or the parent or carer of someone living with diabetes, living in the UK. Respondents were asked a range of questions about their experience of living with diabetes and diabetes care, primarily during 2022.

In England, 11,304 complete, eligible responses were submitted and included in the analysis. The provision of gender, ethnicity and location data was optional. 8,448 survey respondents provided postcode 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.

	1 (most deprived areas in nation)		2		3		4		5 (least deprived areas in nation)		Total	
	N	%	N	%	N	%	N	%	N	%	N	%
England	1267	15%	1583	18%	1809	21%	1872	22%	1917	23%	8448	100%

Appendix B: Variation within ICBs

The table below is based on the most recent National Diabetes Audit, 2021 to 2022, broken down by ICB to show the percentage of people receiving all eight of the NICE recommended annual care processes. PCN figures are assembled from underlying practice level data. It shows:

- The percentage of people who received all of their NICE recommended care processes.
- The range between the PCN with the highest completion rate for all eight checks and the PCN with the lowest completion rate within the ICB.
- The difference in completion rate of all eight checks in 2021 to 2022 compared to pre-pandemic 2019 to 2020.



ICB	NHS Region	Percentage of people who received all 8 care processes 2021/22	Difference between highest and lowest PCN completion rates in 2021/22	2019/20 to 2021/22 difference in percentage of people receiving all 8 care processes at ICB level
NHS Shropshire Telford and Wrekin ICB	Midlands	25.4%	44.8%	-19.2%
NHS Coventry and Warwickshire ICB	Midlands	32.1%	51.2%	-13.2%
NHS Cheshire and Merseyside ICB	North West	37.2%	40.7%	-16.5%
NHS Staffordshire and Stoke-on-Trent ICB	Midlands	37.7%	34.6%	-19.6%
NHS Mid and South Essex ICB	East of England	37.8%	38.5%	8.6%
NHS Northamptonshire ICB	Midlands	37.8%	40.0%	-12.4%
NHS Kent and Medway ICB	South East	38.9%	40.3%	5.6%
NHS Greater Manchester ICB	North West	39.0%	56.6%	-19.8%
NHS Cornwall and The Isles Of Scilly ICB	South West	40.3%	30.3%	-12.4%
NHS North Central London ICB	London	43.1%	51.7%	-14.6%
NHS Black Country ICB	Midlands	43.3%	38.6%	-20.1%
NHS Hampshire and Isle Of Wight ICB	South East	45.1%	41.2%	1.6%
NHS Bristol North Somerset and South Gloucestershire ICB	South West	45.2%	36.8%	-15.7%
NHS Leicester Leicestershire and Rutland ICB	Midlands	45.8%	35.0%	-6.2%
NHS Nottingham and Nottinghamshire ICB	Midlands	46.3%	29.6%	-12.3%
NHS Dorset ICB	South West	46.3%	33.7%	-10.1%
NHS Lincolnshire ICB	Midlands	46.4%	34.8%	-12.5%
NHS South Yorkshire ICB	North East and Yorkshire	46.6%	50.0%	-11.9%
NHS Herefordshire and Worcestershire ICB	Midlands	46.7%	32.7%	-11.9%
NHS North East and North Cumbria ICB	North East and Yorkshire	47.0%	42.7%	-12.8%
NHS Bedfordshire Luton and Milton Keynes ICB	East of England	47.4%	36.6%	-11.3%
NHS Derby and Derbyshire ICB	Midlands	47.8%	25.6%	-13.8%
NHS Lancashire and South Cumbria ICB	North West	47.8%	40.0%	-10.7%
NHS Humber and North Yorkshire ICB	North East and Yorkshire	48.4%	35.5%	-10.0%
NHS Norfolk and Waveney ICB	East of England	48.7%	33.6%	-10.7%
NHS Hertfordshire and West Essex ICB	East of England	49.1%	34.9%	-6.4%
NHS South West London ICB	London	49.4%	42.5%	-9.7%
NHS Gloucestershire ICB	South West	49.8%	21.9%	-10.7%
NHS Surrey Heartlands ICB	South East	50.0%	37.8%	-16.7%
NHS South East London ICB	London	50.5%	60.5%	-10.9%

ICB	NHS Region	Percentage of people who received all 8 care processes 2021/22	Difference between highest and lowest PCN completion rates in 2021/22	2019/20 to 2021/22 difference in percentage of people receiving all 8 care processes at ICB level
NHS Birmingham and Solihull ICB	Midlands	50.7%	48.6%	-17.4%
NHS Cambridgeshire and Peterborough ICB	East of England	50.9%	40.2%	-6.8%
NHS Devon ICB	South West	50.9%	29.4%	-7.2%
NHS West Yorkshire ICB	North East and Yorkshire	51.2%	53.9%	-11.6%
NHS North East London ICB	London	51.9%	57.6%	-11.4%
NHS Somerset ICB	South West	52.1%	22.4%	-13.2%
NHS Sussex ICB	South East	52.7%	38.4%	-11.1%
NHS Bath and North East Somerset Swindon and Wiltshire ICB	South West	52.7%	31.6%	-8.3%
NHS Frimley ICB	South East	55.4%	27.3%	-13.5%
NHS North West London ICB	London	57.3%	50.2%	-3.3%
NHS Buckinghamshire Oxfordshire and Berkshire West ICB	South East	57.5%	48.6%	12.2%
NHS Suffolk and North East Essex ICB	East of England	62.5%	58.1%	-7.1%

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