

Testing times: restrictions accessing test strips and meters for people with diabetes



Introduction

For many people testing their blood glucose levels is an essential part of managing their diabetes. This is usually done with a finger prick blood test using a blood glucose meter that shows the blood glucose level at the time of the test. Not everyone needs to test, but if they do they should have access to test strips and the meter they need. People with Type 1 diabetes and others, especially if treated with insulin, are likely to need a good supply of test strips so they can manage their condition and keep themselves safe and well. People with Type 2 diabetes often find that testing supports their self-management of the condition.

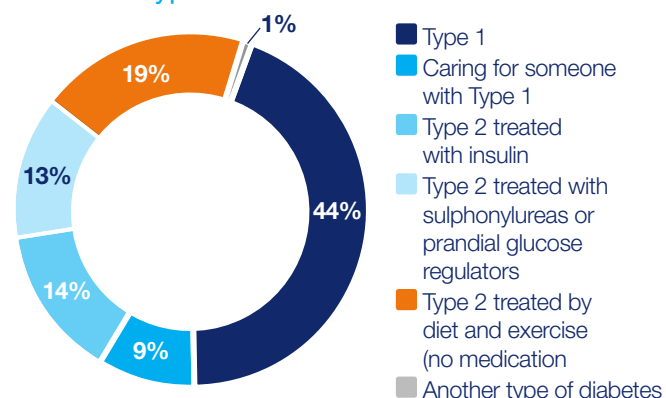
We're concerned that people with diabetes are having their test strips and meters restricted. Whilst developments in blood glucose monitoring are moving fast, and new (less invasive) technologies are likely to be available in future, people with diabetes currently still need access to test strips and meters. We've conducted three surveys since 2013 to monitor the restrictions and assess the impact on people with diabetes. Previous surveys found that the restrictions had a considerable negative impact on the ability of people to manage their diabetes. Responses showed people were concerned for their immediate safety and wellbeing and for their future health.

This report features data from our most recent test strips survey conducted in spring 2016 and the 15 Healthcare Essentials survey carried out in the autumn of 2016.

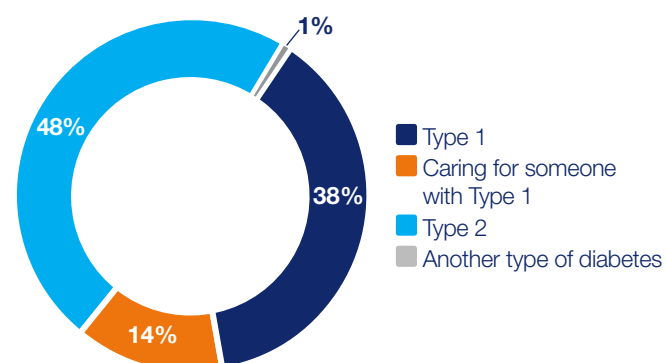
The 2016 test strip and meters survey

During March – May 2016 over a thousand (1,248) people responded to an online survey about restrictions to prescribing of test strips and meters. Of these, 547 (44%) had Type 1 diabetes and 561 (45%) had Type 2. A further 115 (9%) cared for someone with Type 1 (mostly parents). Of those with Type 2, 199 (or 203, including cared for) people (35%) were treated with insulin, so 69% of all the respondents to the survey were treated with insulin (or cared for someone who was). A further 16% were treated with sulphonylureas or prandial glucose regulators – for which self-monitoring of blood glucose is recommended – especially when driving.

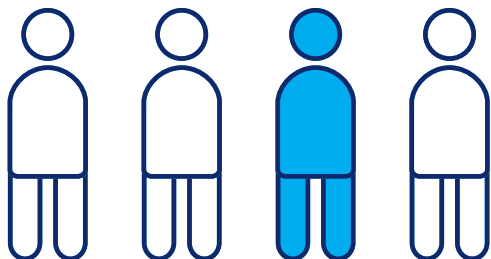
Survey respondents by diabetes and treatment type



Survey respondents who have been refused or had restrictions on their prescription of blood glucose test strips by diabetes type



1 in 4 people with diabetes face restrictions to their test strips



We found 27 per cent of people had been refused a prescription for blood glucose test strips, or had the number of test strips on their prescription restricted, within the past year. Of these, 52 per cent had (or cared for someone with) Type 1 diabetes. This is of particular concern as NICE recommends that all adults with Type 1 diabetes should routinely self-monitor their blood glucose levels, and test themselves at least four times a day, including before each meal and before bed. For people who are frequent drivers, taking regular exercise or who are at high risk of hypos this could increase to around 10 times a day².

In autumn 2016 the Diabetes UK 15 Healthcare Essentials survey also found that 25 per cent, of nearly 6,000 respondents who tested their blood glucose, had not been prescribed enough test strips for their needs³.

The reasons people were given for the removal or reduction of test strips on their prescription

Budget constraints or 'excessive testing' were often the reasons given to people to explain why the restriction was occurring. People with diabetes found these restrictions stressful and had to make difficult decisions about when to test or not.

Comments we received included:

- “ I was told they were expensive and we should test less. Only need to test four times a day. We use a pump so need to test every two hours. ”
- “ They said I had my allowance for the month. ”

“ There is a blanket limit on the number of test strips available to diabetics across the CCG. ”

How restrictions affect people

Answers from our surveys showed restrictions on test strips had a considerable impact on people's ability to manage their diabetes and keep themselves safe:

“ I can only test a certain amount of times a day which worries me as I have had problems with hypos that I needed help with from others and when I'm ill I can't test more when needed. ”

“ It greatly reduced my ability to change my insulin dosage and carbohydrate intake to maintain blood sugar levels within accepted parameters. ”

“ As a pump user I need to monitor numerous times a day. I also need to drive to work which also necessitates testing. I have run out of test strips at times. ”

One woman, who was 32 weeks pregnant, had been left a voicemail stating her test strip prescription was going to be reduced from 300 to 50 test strips. This meant she could not test as often as she needed to for the safety of herself and her unborn baby. It also doesn't meet NICE guidance in pregnancy. She also drove a car, so needed to test to meet the legal requirements of the DVLA guidance.

Because of restrictions people were forced to make difficult decisions about when to test or not, and sometimes had to ration the number of times they tested. As a result many had bought or considered buying test strips from pharmacies or online, where the quality cannot be guaranteed. It also comes at financial cost.

“ I had to reduce my testing. Hypo awareness has depleted again. ”

“ Nearly run out of strips and had to buy them on eBay. ”

“ I find it hard as I live on a pension to buy them and so have to use them sparingly. ”

“ It means to me that I have to take about £10 a month to buy my own test strips and as I am on a very low and restricted income that's very hard to do. ”

Safety

The DVLA has guidance on testing to make sure drivers with diabetes are safe when they get behind the wheel. We're worried this guidance isn't always being considered by GPs when prescribing test strips. Respondents to our survey frequently commented that they were being given too few test strips to meet the DVLA legal requirements.

“ I now have to purchase strips, as DVLA guidance requires me to test before driving and every two hours whilst driving. ”

“ The GP didn't understand that as a driver doing 40,000 miles per year that I needed more strips to test in line with regulations. ”

“ I showed the renewal for my license and they agreed I could have them. ”

For people treated with insulin who drive large vehicles (HGV – Group 2 licences), this could threaten their livelihood as they are required to show evidence that they are testing regularly in order to renew their licence every year.

Impact on primary care

We have observed that receptionists and other practice staff are very often preparing prescriptions.

With the increasing demand for GP appointments and workload at GP surgeries increasing year on year this is not surprising.

But a recurring theme in this survey's results, and from feedback we get through our Helpline, was the impact of the lack of understanding of diabetes by these staff and their interpretation of local policies.

Very often people reported that when they challenged a restriction their prescription was reinstated.

“ Doctor's receptionist told us we test too often – made complaint to surgery. ”

“ I had to get my diabetes specialist nurse to ring my GP receptionist who was the one who questioned my use of strips on several occasions. ”

“ I feel annoyed that every week or so I need to keep ordering and that I need to justify myself to a surgery person that knows nothing about what we go through. ”

It is important that clinical decisions affecting people's care and management are made by doctors in consultation with the person with diabetes.

Impact on primary care

Managing diabetes requires a huge amount of time and effort. Restrictions only make things harder. Our survey found people frequently commented that test strip restrictions damaged their quality of life. Often only a certain amount of test strips are prescribed or for only a restricted number of weeks. This leads to a great deal of time spent going backwards and forwards to GP and pharmacies and always having to remember to put in and collect prescriptions. There is also the inconvenience of extra trips if more test strips are used because of instances like illness.

“ This feels like the worst thing about having diabetes – the constant battle and the ins and outs of GP and pharmacy. ”

“ It's just a pest. I now need to order and collect a prescription monthly, or sooner depending on any issues that crop up. I am glad they increased it, which is enough for one month, but I don't have any back up and they are reluctant to prescribe more frequently. ”

“ It's time consuming having to do repeat prescriptions for test strips as I need to do the repeats more regularly than the repeats for the insulin and needles which come in larger sizes to last longer. ”

“ It is very stressful always having to go back and battle with them. I have to remember to check stocks and, as it takes two weeks to get a prescription, the process to get the prescription means I have to start every two weeks. It makes living with diabetes feel like a real chore and that people are against me when I'm trying my best to improve my health. ”

Impact on quality of life

In addition to restrictions on test strips, 66 per cent of respondents to the recent survey were given no choice of blood glucose meter and had been switched to a different, cheaper meter, without any discussion with them. Of these, 25 per cent were not happy with the meter provided. For instance, the meter was too large to easily carry around or didn't upload the data to a computer.

“ Meter is useless, can't test discretely, can't test in the dark, battery dies quickly, can't upload meter readings to a computer. ”

“ They said I had to change strips to a cheaper meter even though I'm on omnipod pump so I need freestyle strips. ”

“ They said test strips too expensive for my particular meter, so wanted me to change to a meter that used cheaper strips. However they didn't actually tell me, just waited for me to complain that my repeat prescription had not been issued, leaving me without any strips to use. ”

Restrictions for people with Type 2 diabetes

Worryingly many people with Type 2 diabetes were incorrectly being told they do not need to test. This is clearly not the case if their diabetes is treated with insulin, and diabetes medication which can cause hypoglycaemia, particularly to make sure DVLA guidance is met.

The following responses from people with Type 2 diabetes highlight this disturbing situation:

“ Told testing not required despite being a driver on glicizide. Practice nurse totally unaware of DVLA and testing requirements. Strips reinstated by GP. ”

“ I have been told as a Type 2 there was no point in having a test meter or strips. ”

“ This was stressful and upsetting. Made me feel like I was doing something wrong and being a nuisance. ”

Challenging restrictions

People with both Type 1 and Type 2 diabetes report that, when they challenge restrictions, their prescription is usually reinstated. We're concerned that people have to challenge in order to get access to an often essential piece of kit for managing their diabetes effectively. We're also concerned about the effect on overloaded GP surgeries and the time spent by both people with diabetes and primary care staff sorting out restrictions made in error through misunderstanding, or misapplication, of local policies and guidance.

The benefits and needs for testing blood glucose levels should be discussed at a person's annual review (and if a person's situation changes during the year). How many test strips and what meters people are given should be agreed then by the person with diabetes and their GP or specialist team (refer to position statements for further information). Find out more about Diabetes UK's position statement on self-management of blood glucose levels at www.diabetes.org.uk/what-we-say

What should be done?

Rationing blood glucose test strips is unsafe and puts the health of people with diabetes at risk. It is a false economy, storing up long-term costs for the NHS because diabetes complications are extremely expensive to treat.

The restriction of test strips and meters to people with diabetes is driven by the need for short-term cost savings and rarely by the needs, or clinical benefit, of people with diabetes. This can cause immediate and long-term health problems for people with diabetes, undermining their ability to self-manage and take control of their condition. It can affect safety, quality of life and when test strips are bought privately it transfers the financial cost from the NHS to people living with diabetes and their carers.

Dangerously, in some cases that have come to our attention, DVLA guidance, legislation and NICE guidance is not being met.

We're calling for strong action and guidance at a national level across the UK to make sure that everyone with diabetes gets the kit they need to self-manage their diabetes effectively. People with diabetes should not have to fight for this when they are already managing a condition that requires constant attention.

Local policies should allow sufficient choice and flexibility for individual circumstances to be taken into account when prescribing test strips and meters for people with Type 1 or Type 2 diabetes. People with diabetes should be involved in creating local policies and consulted about the impact this will have on them.

We urge people with diabetes to challenge restrictions to their prescription for test strips and meters if they feel that their needs are not being met and their ability to self-manage their condition undermined. Find out more from the Diabetes UK support pack at www.diabetes.org.uk/advocacy

Recommendations

NHS England should make sure that GPs and CCGs are not restricting access to test strips and meters for people with Type 1 diabetes, or people with Type 2 diabetes when treated with insulin. This puts people at risk of hypoglycaemia which can threaten their safety and lead to costly hospital admissions. Another risk is hyperglycaemia which can lead to hospital admissions and undermines people's ability to self-manage and avoid costly longer-term, life-threatening complications.

NICE should review guidance on self-management of blood glucose for people with Type 2 diabetes and recognise that people who are self-reporting benefit should be supported to monitor their blood glucose.

In Scotland, SIGN guidelines for people with Type 2 diabetes should also be reviewed to make sure that people treated with insulin and people who are self-reporting benefit should be supported to monitor their blood glucose.

In Wales the Diabetes Clinical Lead and All Wales Diabetes Implementation Group should promote and share our report with all health boards.

In Northern Ireland blood glucose test strips should be provided as recommended by the Chief Medical Officer in 2013 for people living with Type 1 diabetes to support successful management of their condition. In addition it should be recognised that the Driver and Vehicle Agency (DVA) require people living with Type 2 diabetes to test appropriately when driving and sufficient test strips should be provided to allow people to comply with the driving regulations.

References

- 1 NICE Type 1 diabetes in adults: diagnosis and management. www.nice.org.uk/guidance/ng17/chapter/1-Recommendations#blood-glucose-management-2
- 2 Diabetes UK 15 Healthcare Essentials survey 2016

More information

If adults with Type 1 diabetes or their carers are experiencing restrictions on test strips, blood glucose meters, ketone meters or Continuous Glucose Monitoring technology they can contact the following for support:

Diabetes UK Advocacy Service

The Diabetes UK advocacy service is here for all people with diabetes, their family, friends and carers to help with issues connected to diabetes. We give you the information and support you need to make sure you know your rights, understand your options and help you get your voice heard.

Web: www.diabetes.org.uk/advocacy

Telephone: 0345 123 2399*, Monday to Friday, 9am–7pm

INPUT Patient Advocacy

A charity supporting patients' access to diabetes education and technology, for more information and assistance.

Web: www.inputdiabetes.org.uk

Telephone: 0800 228 9977

Juvenile Diabetes Research Foundation (JDRF)

A Type 1 diabetes charity, improving lives until we find the cure. They fund research to cure, treat and prevent Type 1 diabetes, including a major initiative to perfect the artificial pancreas, a technology that could revolutionise treatment of Type 1 diabetes.

Web: www.jdrf.org.uk

Type 1 Technology. A guide for adults with type 1 diabetes, 2016. Diabetes UK, INPUT, JDRF: www.inputdiabetes.org.uk/wp-content/uploads/2016/10/Type1techAdults.pdf

