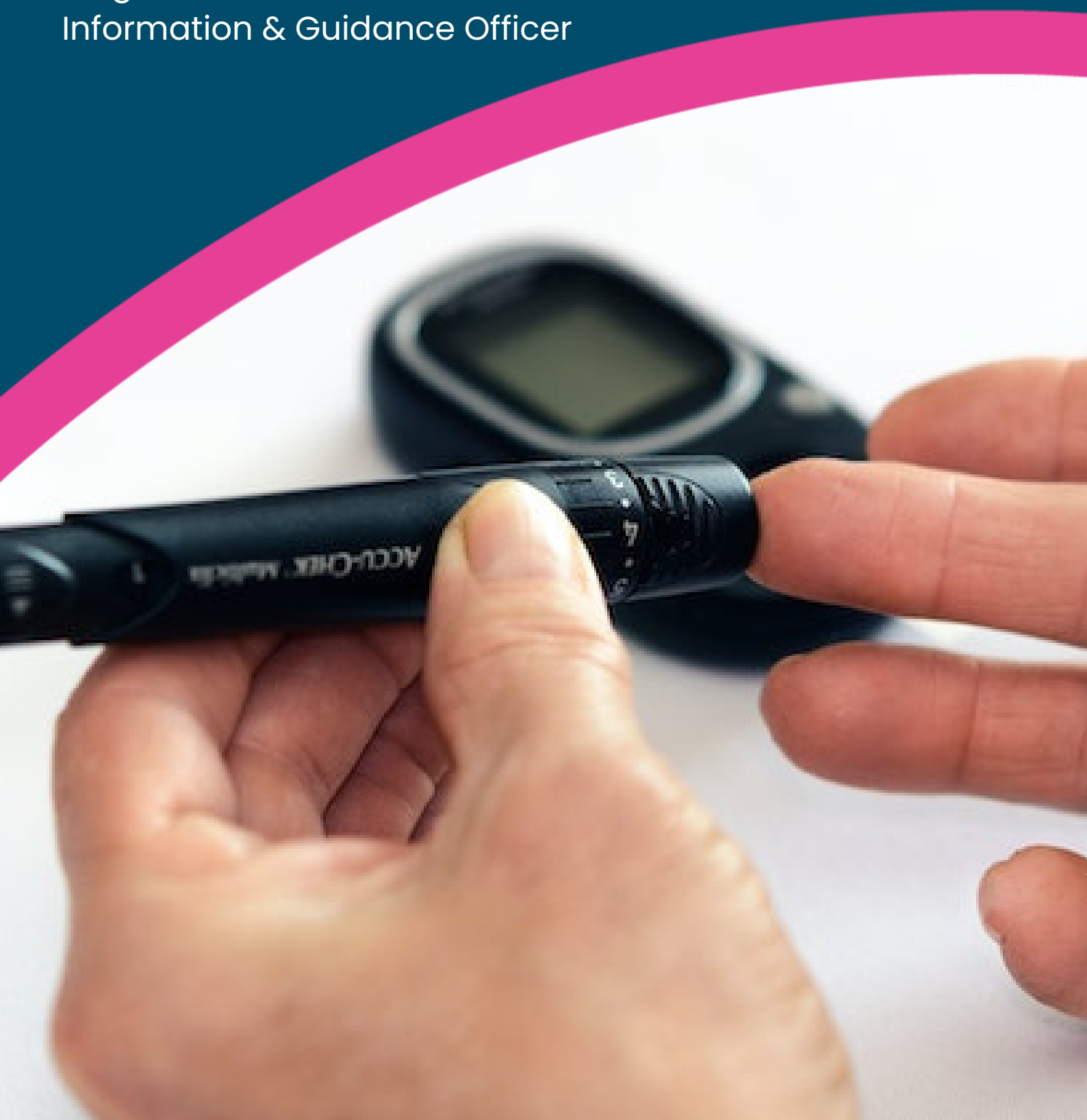


Experiences of Living with Diabetes in West Essex

October – December 2023

Fergus Bird

Information & Guidance Officer



Experiences of Living with Diabetes in West Essex



Produced by Healthwatch Essex
Fergus Bird
Information & Guidance Officer
October - December 2023

Contents

1.0 Introduction	3
1.1 Healthwatch Essex	3
1.2 Topic Background	3
1.3 Acknowledgements	4
1.4 Disclaimer	4
2.0 Purpose	5
2.1 Engagement methods	6
3.0 Key Findings and Recommendations	25
4.0 Conclusion	27
5.0 Terminology and Acronyms	28

1.0 Introduction

1.1 Healthwatch Essex

Healthwatch Essex is an independent charity which gathers and represents views about health and social care services in Essex. Our aim is to influence decision makers so that services are fit for purpose, effective and accessible, ultimately improving service user experience.

One of the functions of a local Healthwatch under the Health and Social Care Act 2012, is the provision of an advice and information service to the public about accessing, understanding, and navigating health and social care services and their choices in relation to aspects of those services.

The Healthwatch Essex Information and Guidance team are dedicated to capturing the health and social care experiences people in Essex are encountering daily. The team respond to enquiries relating to health and social care and are equipped through training, to offer specific information to the public or other professionals. The team are well placed to listen, reflect on and support people to share difficult experiences such as the one's shared in this report.

1.2 Topic Background

According to the International Diabetes Federation, there are about 537 million people with diabetes worldwide.

Predictions for the future do vary, but in June 2023, academics publishing in The Lancet Diabetes & Endocrinology journal claimed cases could top 1.3 billion by 2050. While the fastest growing numbers are in low and middle-income countries, the UK is by no means immune to the increase.

Diabetes UK states that 1 in 15 people in the UK have diabetes (over 4.3 million), with registration figures for 2021-22 up by nearly 150,000 from 2020-21.

Around 90% of people with diabetes have type 2, and around 10% have type 1.

1.3 Acknowledgements

Healthwatch Essex would like to thank the hundreds of people who engaged with us, participated in this project, and completed the survey.

Our thanks are also made to those individuals who took the time to speak with us and share their personal stories.

We would also like to thank our many partners, contacts, and networks who worked with us to share the project and survey throughout all of West Essex and help generate such a strong level of interest and feedback.

1.4 Disclaimer

Please note that this report relates to findings and observations carried out on specific dates and times, representing the views of those who contributed anonymously during the engagement period. This report summarises themes from the responses collected and puts forward recommendations based on the experiences shared with Healthwatch Essex during this time.

2.0 Purpose

As diabetes cases continue to rise, there will be an increasingly significant burden placed on both primary and secondary healthcare providers.

This report aims to take advantage of listening to and understanding what people living with diabetes in West Essex are experiencing and identify areas where the systems that are supposed to be in place are not functioning as they should.

By ensuring we learn from this and make all necessary adaptations, we can insulate our resources from becoming overwhelmed.

Timely diagnosis and screening are crucial for effective diabetes management. However, challenges such as limited access to healthcare facilities and awareness contribute to delayed diagnoses.

Modern day lifestyle choices including diet and exercise, with increasing levels of obesity are contributing significantly to this increase.

Diabetes management involves lifestyle modifications, oral medications, insulin therapy, and, in some cases, surgical interventions. Patient education and adherence to treatment plans are essential for successful outcomes.

The integration of technology, such as continuous glucose monitoring (CGM) systems and telehealth services, has shown promise in improving patient outcomes and increasing access to care.

Disparities in access to healthcare services, particularly in rural and underserved areas, hinder the early detection and management of diabetes.

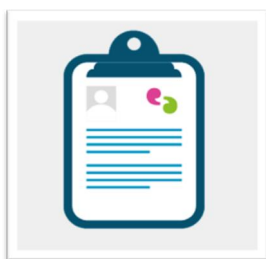
Insufficient awareness about diabetes and its management, coupled with a lack of patient education, contributes to suboptimal treatment adherence and outcomes. The economic burden of diabetes is substantial, with costs associated with medication, monitoring supplies, and hospitalizations. Strategies to address cost barriers are crucial for improving patient access to care.

2.1 Engagement methods

Participants were contacted through the Healthwatch Essex website, through local West Essex based Facebook groups, the Healthwatch Essex newsletters, our own Facebook page, Instagram account and Tik-Tok. Word of mouth also played an important role along with promotion of the project via our extensive networks.

Our partners, other organisations and working groups in West Essex, together with our volunteers and many individuals inside and outside of the NHS and Essex County Council helped and supported our efforts to engage with and reach as many people throughout the area as possible.

They were engaged with in two ways:



Survey

A survey was created to gain perspective and insight from residents who have had experience of living with Diabetes.



Interviews

Individual interviews were conducted to collect personal stories from members of the public. Interviews took place by telephone during November and early December 2023 and all participants gave their consent to have their interviews recorded. Participants were willing for their experiences to be shared within this report, however, to ensure their anonymity and confidentiality of information they provided, all names used are pseudonyms to protect identities.

2.2 The Survey

The survey consisted of 11 core questions, mixing multiple choice questions and 'free text' information boxes enabling the participants to expand on their answers. There were an additional three demographic questions.

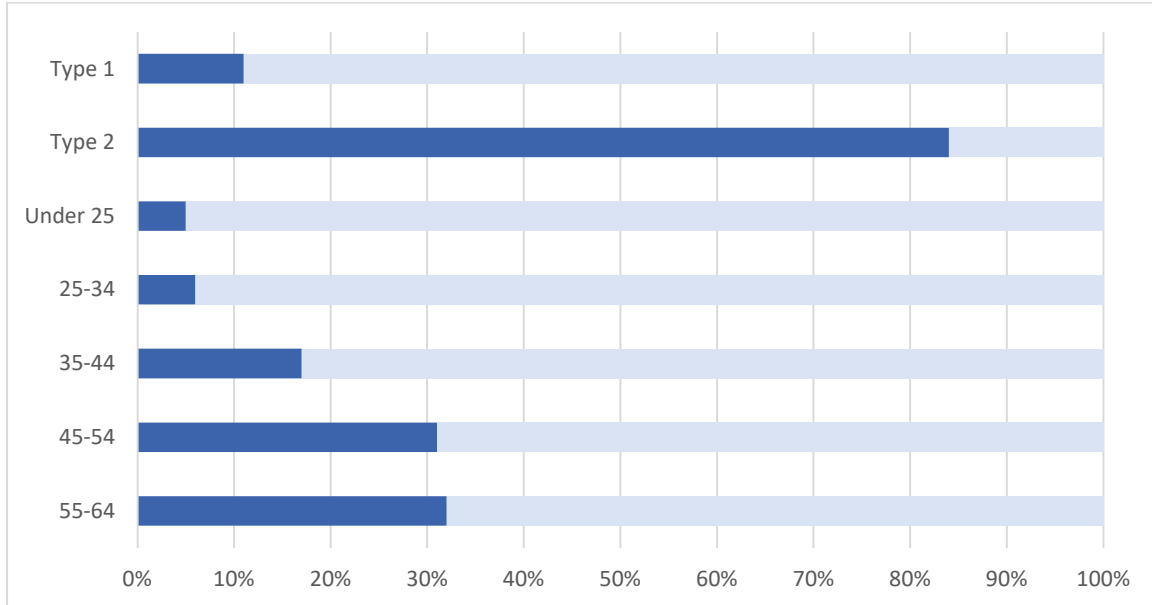
It was devised to encompass:

- Symptoms
- Initial information and advice
- Ongoing support
- Education and self-management
- Technology

The survey was primarily in an online format but was also available to be printed off and filled out manually as required. The Information and Guidance Team at Healthwatch Essex were also available if the survey needed to be completed in any other format, such as over the telephone. The questions, and responses are shown below:

Q1

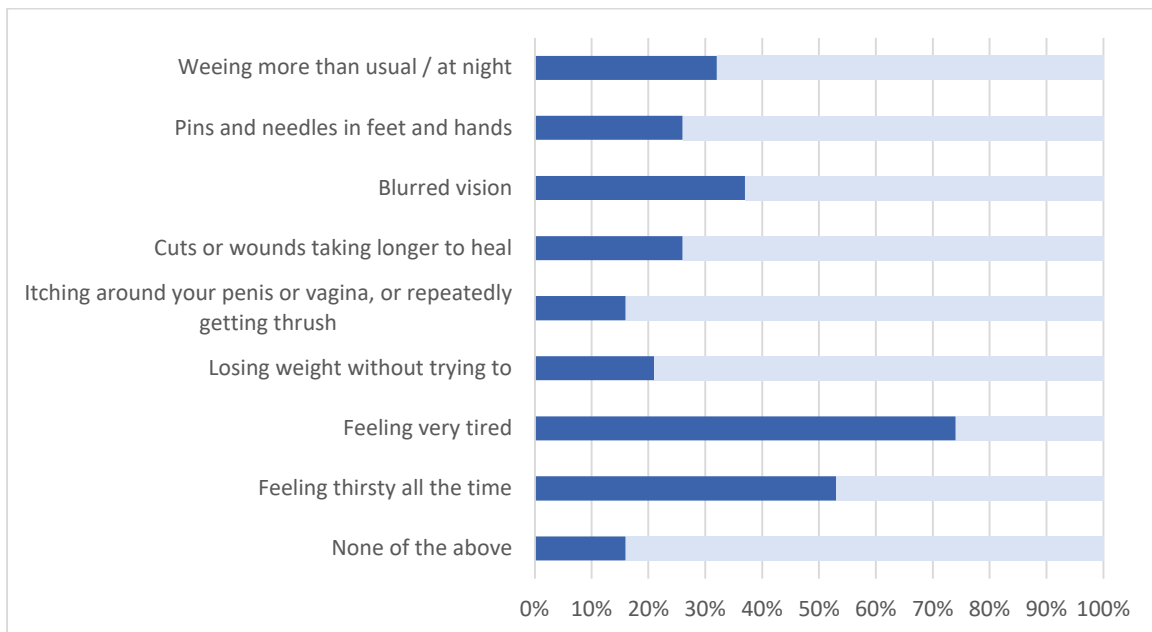
Do you have Type 1 or Type 2 Diabetes, and at what age were you diagnosed?



Our respondents broadly mirror the national averages.

Q2

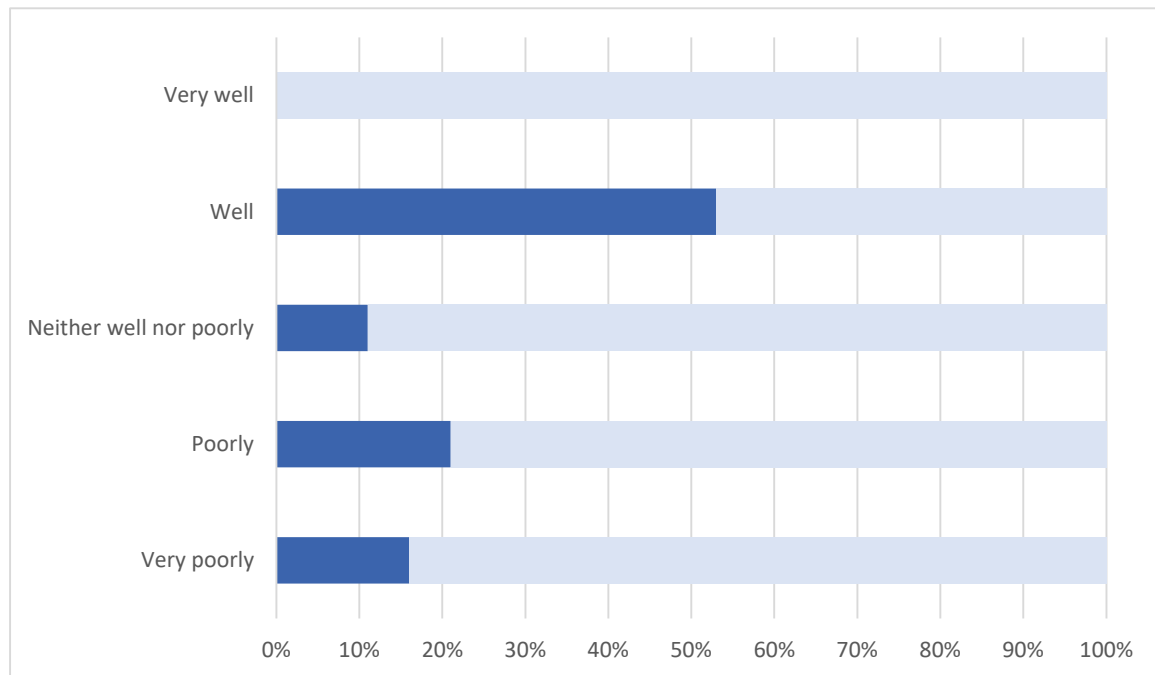
Before your diagnosis, which of the symptoms below did you think were possible signs of Diabetes?



Although all the options we offered in the survey were known about, most were only recognised by around 15-35 percent of people, and 16% weren't aware of any of them.

Q3

When you were first diagnosed, how well informed and supported did you feel by your GP/other healthcare professional?



Although nobody felt they were 'very well' informed and supported, over 50% felt it was good. However, 37% saying it was done poorly or very poorly shows significant room for improvement.

Q4

Please tell us more about why you chose this answer.

Below is a representative sample of responses:

'I got no help at all, I was referred to a group which was closed due to lockdown, footcare which was done via the phone, it was just an awful experience.'

'I had a general knowledge as a third generation Type 2, so professionals assumed I was knowledgeable - and while I am to some degree, it's still new to me.'

'My son was diagnosed during lockdown so our experience, I'm sure, was not the norm.'

‘I received good information following my type 2 diagnosis after having gestational diabetes three times.’

‘The nurse who gave me the diagnosis laid out everything that I needed to do and the path that diabetes took in the long term if I didn’t manage the condition. My GP was very proactive back then regarding monitoring and offering the medication and support that I needed.’

‘Firstly, I was told to go on a diet and six months later another doctor was horrified that I was on a diet and told me I should have gone on medication immediately.’

‘I left hospital following surgery after six days with very little comprehension of what diabetes was. My local surgery arranged an emergency appointment not only with doctor but also with nutritionist.’

‘I was telephoned by a doctor, who gave me no information except that I would get a nurse appointment and eye appointment! I’m 83 and knew nothing about diabetes except something to do with sugar! I live alone and was worried to death.’

‘I was aware of pre-diabetes and had read information online and from books about dieting putting diabetes into remission. I did this myself without help. I was offered drugs but wanted to avoid them if possible.’

‘I have screening, which is useful, but I have to wait between blood tests to work out if I’m getting it right.’

‘The GP advised on the different medications prescribed.’

‘Both my parents had diabetes and so I was told that I knew what to do.’

‘I was given the choice of whether to take medication (although strongly advised medication was best) and sent on ‘understanding and living with your diabetic diagnosis’ and monitored for approximately six months before moving to yearly check-ups.’

‘I was given really simple booklets that told me nothing, a course to go on that was poorly run, told see you in a year, and no follow up given for more than three years.’

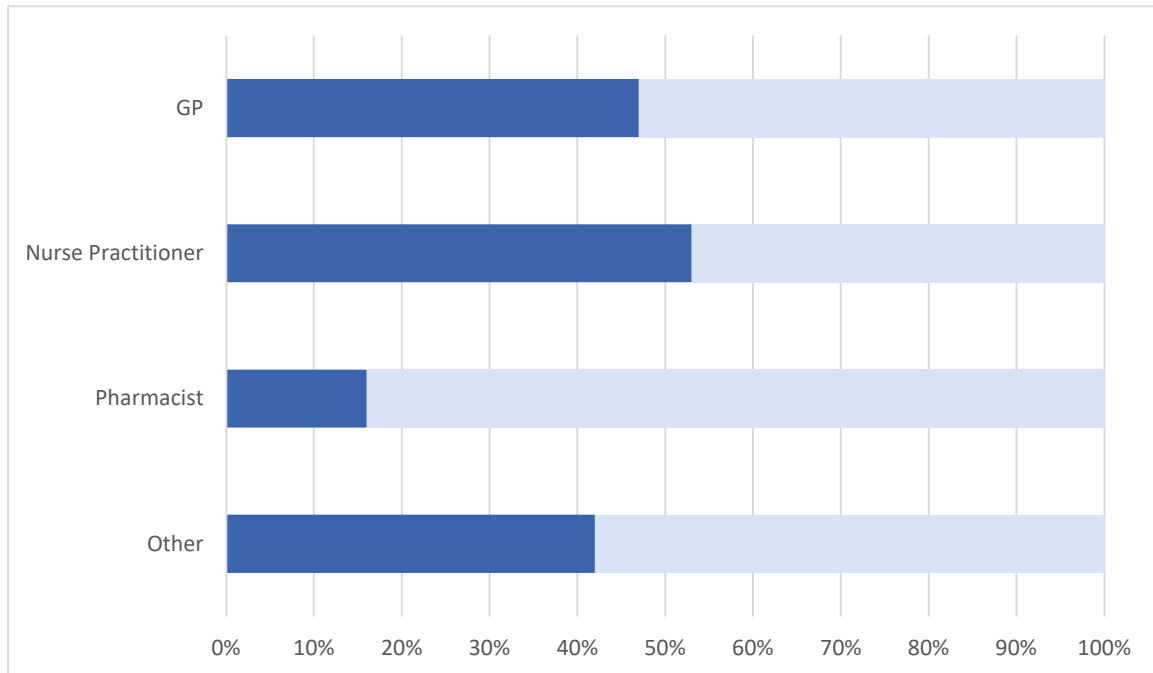
‘I was told nothing.’

‘It was a long time ago, but the diabetic nurses were helpful.’

‘I was initially diagnosed by an HCA who was not at all sensitive on delivering the information and actually left me feeling very scared. I then, at the same visit, was referred to a nurse who was much more thorough and understanding.’

Q5

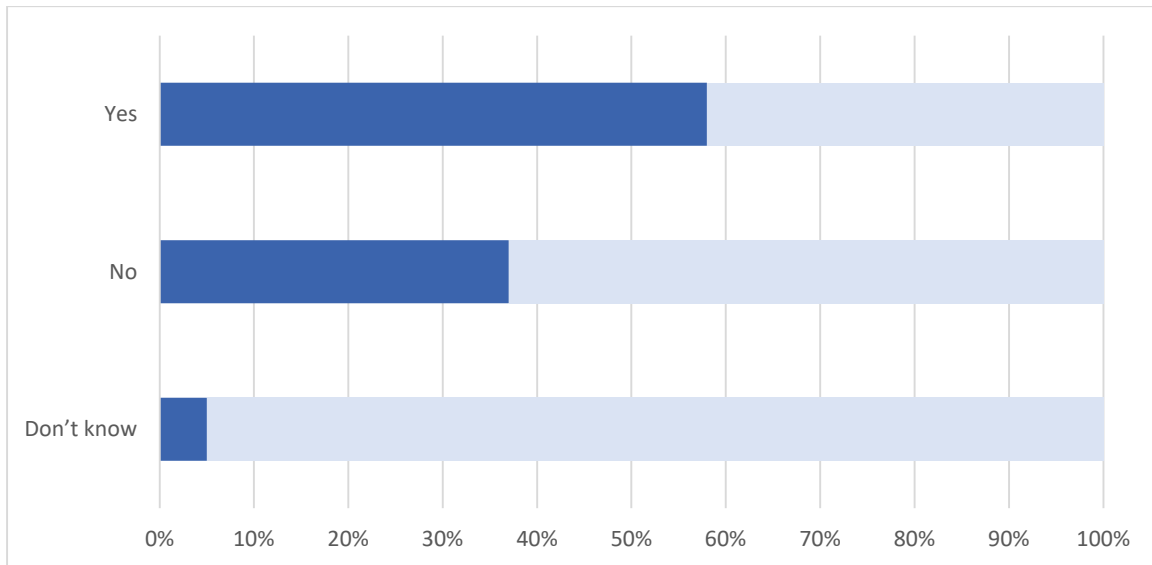
Who of the following has given you direct advice and support since your diagnosis?



‘Other’ included Diabetes UK, podcasts, Zoom meetings, ‘no-one’, Facebook groups, healthy eating websites, sugar information websites, You Tube videos, etc.

Q6

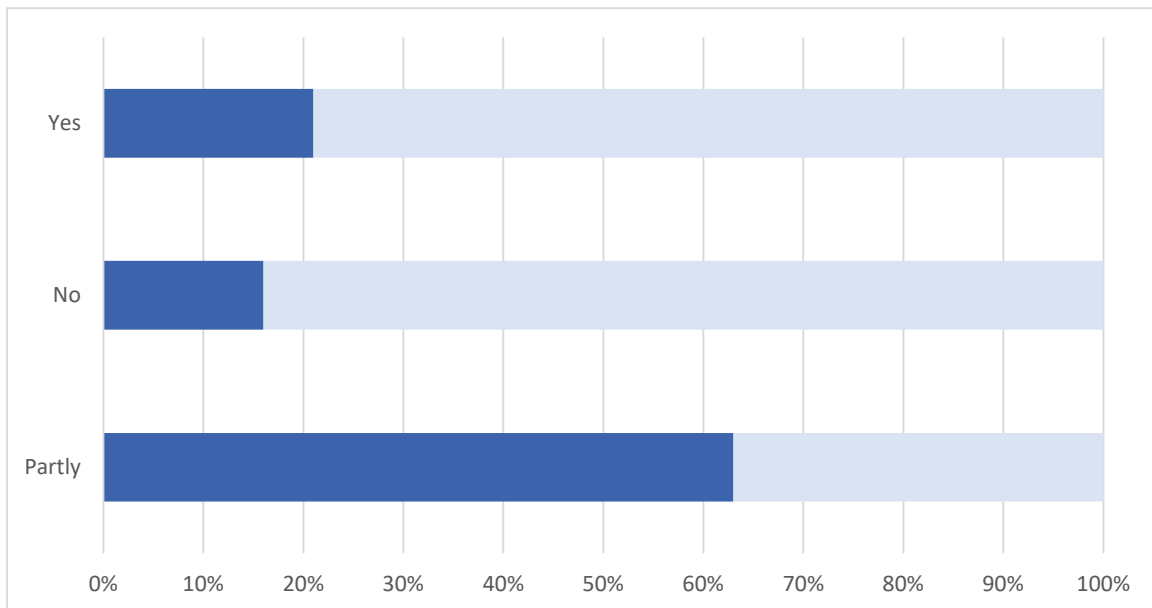
Were you offered a programme of structured education (either online or face-to-face)?



There is a clear opportunity to improve in this area.

Q7

Do you feel confident that you are able to self-manage your condition?



More background on these responses is given in Q8 below.

Q8

Why do you feel that way?

Here's a sample of the answers given:

‘There has been a medication shortage since covid, and this has meant that I have been without medication at times and the constant changing medications has had a negative effect on my diabetes leaving me with a bad episode of thrush.’

‘I try my best but sometimes I slip up.’

‘I have a general knowledge.’

‘My son has been amazing and started to inject himself a year and a half before moving up to secondary school this September.’

‘I do not regularly test my blood sugar levels and have six monthly appointments with my GP who is a diabetes specialist at my surgery. Also, six monthly catch ups with the diabetes nurse although I’m sometimes unsure if I am controlling it well enough.’

‘As well as the information the GP practice gave me, I have continued to grow my own knowledge of my condition, by reading articles, books, reports etc.’

‘I’ve given up as the doctor nor pharmacist cannot find the right pills for me.’

‘Even though I have completed the DAFNE course it contains an awful lot of information to take in.’

‘There is not enough information.’

‘I have managed to control my Hba1c, and my annual check-ups have been ok but I feel stressed and anxious if I’m not feeling well, not knowing if it’s just getting older, the stress of being a carer or not managing the diabetes’.

‘Sometimes it’s quite difficult to get an appointment or telephone call with the Diabetes Nurse.’

‘I learnt a lot from my father who had diabetes. Over the years I have gained more knowledge and taken various courses, including an Open University course.’

‘I’m not confident that a yearly blood test is sufficient to monitor my Hba1c levels.’

‘The course was basic and poorly delivered. I got no real information from the nurse.’

‘I just feel more knowledgeable of things and my body.’

‘I know what I have to do but I worry constantly now about everything I eat and drink and feel quite powerless about it all, even though I have made significant lifestyle changes.’

Q9

What has been the greatest help and the greatest challenge to you in managing your condition?

‘The greatest help was an understanding GP. The biggest challenge is sourcing medication.’

‘The greatest help is reading online with diabetes UK, the greatest challenge, Addison House in Harlow. I have never had a day where I felt well since I started metformin in 2018.’

‘The Diabetes UK website has been the greatest help.’

‘Addenbrookes have been very helpful. The greatest challenge are the prescriptions from the surgery, they are often wrong; either wrong medication or number of items requested.’

‘HbA1c checks and eye tests are helpful, the challenges are that without checking bloods daily I am unsure if I am controlling it well enough.’

‘Diabetes UK forums have been very helpful, being able to speak to others going through the same as I am.’

‘The biggest challenge is that as the disease has progressed over 15 years my control is getting harder and harder, yet the ability to get the tech I need from the NHS to help to control it better just isn't available to me. I'm currently self-funding a CGM but will shortly not be able to afford it. The CGM has made a huge impact on being able to manage my blood sugar in real-time, which has had a positive effect on my HbA1c. This needs to be available to all insulin users on the NHS to help prevent future complications of diabetes.’

‘Finding a doctor that cares about my condition is the biggest challenge.’

‘DAFNE has helped but I realize it will take time. My biggest challenge has been to be given funding for a CGM glucose monitor. It has been seven months, and I am still without one.’

‘The greatest help is the Diabetes UK web site forum.’

‘Crash dieting and losing weight put my diabetes in remission and being very careful since has kept it stable but I have trouble working out if I can relax now and again without doing any damage.’

‘Self-funding for a Libre2 CGM is both the biggest help and challenge.’

‘Help comes from hearing from professionals involved with up-to-date information. The challenge is people thinking I have diabetes because I ate too many sweets. Some HCPs have less knowledge than I do, and it is embarrassing to have to update them. I am not or have ever been overweight but have a strong family history of diabetes.’

‘Internet for both being helpful but also creating concern.’

‘Not being able to speak to someone at the surgery for queries and concerns is a challenge.’

‘Help comes from looking online, speaking to others and attending webinars that give real practical information.’

‘Challenges were no real guidance, no reassurance, no check ins except for annually (but after being left for over 3 years first).’

‘Being able to research for myself is the greatest help.’

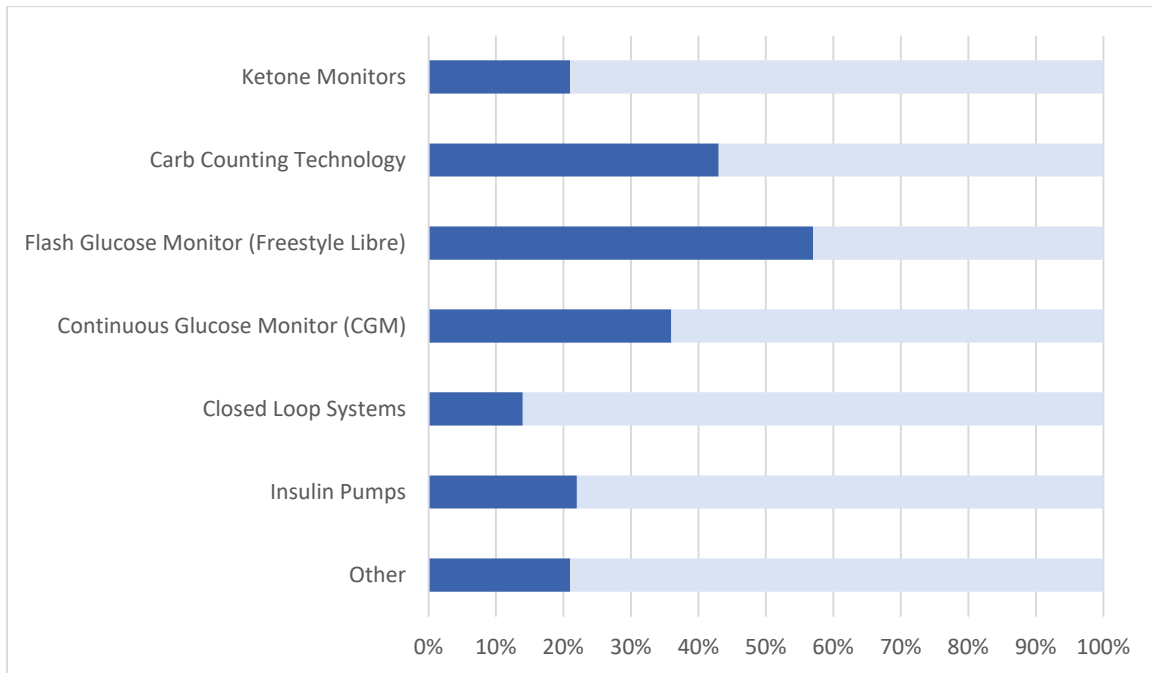
‘Greatest help is the nurses.’

‘The biggest challenge lies in managing sugars with the stress and exhaustion.’

‘The nurse practitioner who has followed up with me since diagnosis has been the best help.’

Q10

Which of the following technologies are you aware of that can help you self-manage your diabetes?



Nearly all the specific responses to ‘Other’ were that they didn’t know about any of them.

Q11

Have you been offered any of this technology free of charge?

These are a representative selection of responses:

‘I have never been offered any help.’

‘No!!’

‘There has been nothing.’

‘Yes, the CGM but it took some time.’

‘I asked and was told I didn’t need to monitor! I strongly disagree with this.’

‘No, I was told I have to buy anything like that.’

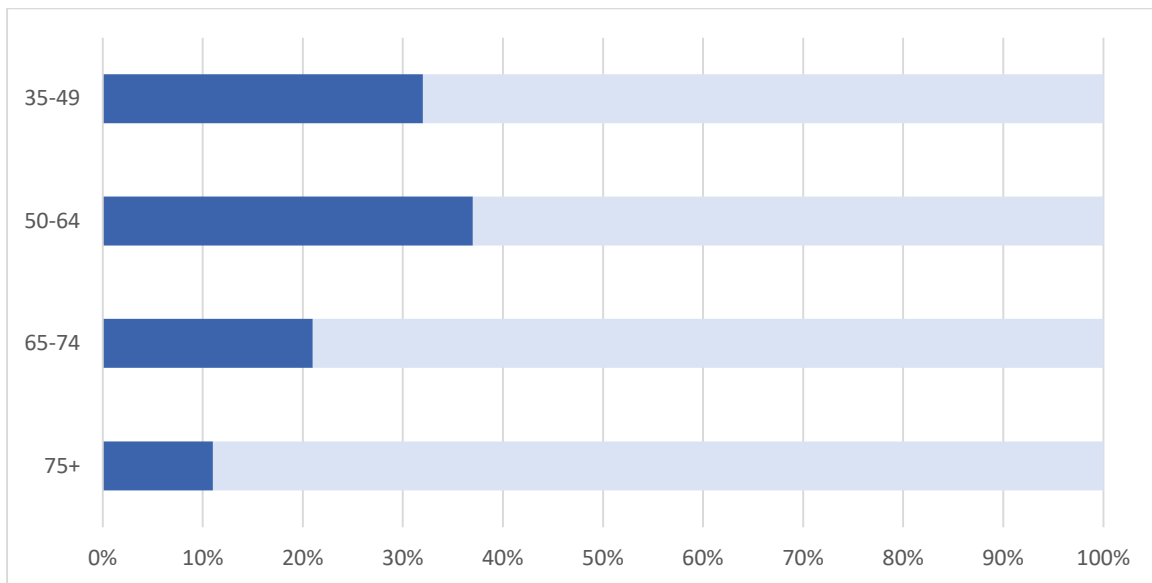
‘Yes.’

‘No, I was only told about the blood sugar testing kit and advised to buy my own off Amazon by the surgery, which I thought was a bit unprofessional.’

‘No, I am self-funding what I can afford.’

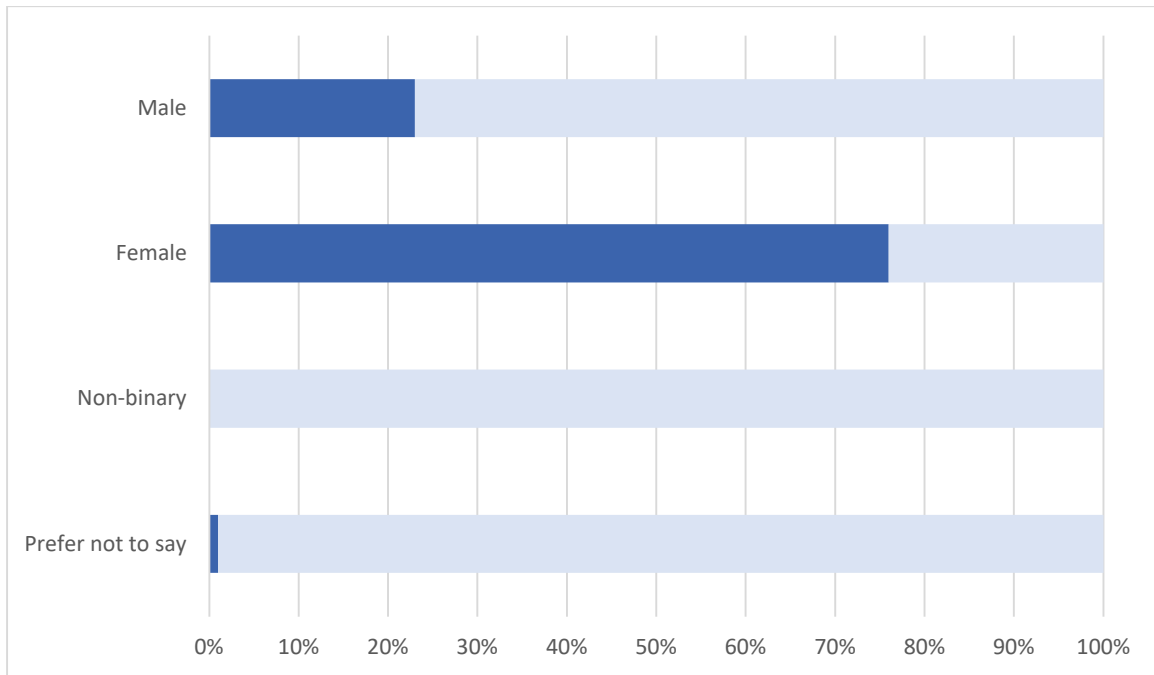
We also explored participant demographics in our engagement.

Age group

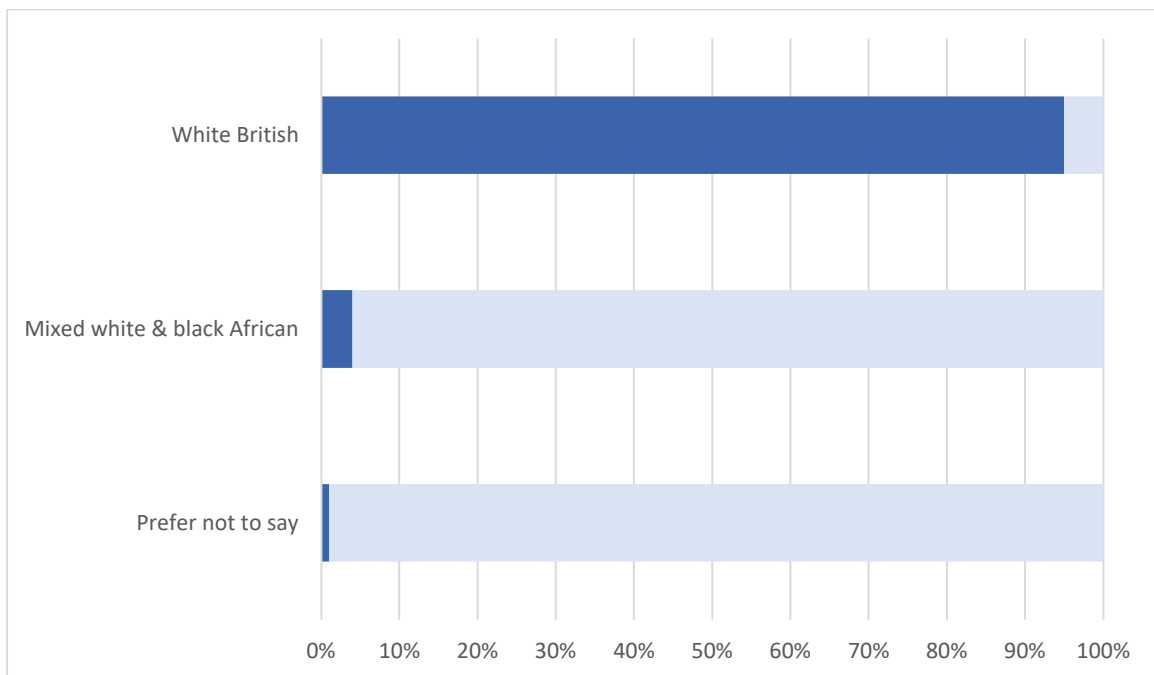


There were no participants below the age of 35

Gender



Ethnicity



2.3 Interviews

Many people offered to talk to us directly and tell us about their stories in depth. We would like to thank everyone who took the time to talk to us and share their experiences, helping us to produce this report. From those that we have spoken to, we would like to highlight three case studies reflecting the lived experience of people in West Essex.

Case Study 1

Margaret*

'I've been diagnosed prediabetes for, I don't know how many years, but quite honestly it meant nothing to me. I thought diabetes was just sugar, that sort of thing. So, I think there's room for improvement there definitely.

Then after a blood test a I was phoned by a doctor. She just said, 'You're diabetic now'. Just like that, nothing else. She couldn't give me any more information, and I didn't want to stay on the phone any longer. I'm 83. I live on my own.

You know, I'm still angry about that. Since then, I've had an appointment with the nurse following that conversation, but only because I chased it and demanded it. This was about three months ago.

She was very nice. She said had I got any questions, and I said I've got a list of about 20, but she said, well, they're all in this book. So, I said fine, if they're all in that book, I won't waste your time anymore. I came home and read the book and found it very unhelpful!

In any case, as it turned out, that appointment was after I'd had another blood test, and I wasn't diabetic at all. I was down to 42 in about three weeks, because I if I want to do something, I'll do it. I'll stick to it. So, I think that is all a little bit muddled. As nice as she was, I could have asked lots of questions, but I just believed it was all in the book.

But then I went on the best place in the world - thediabetic.com forum. You can ask anything. You don't feel a fool because you don't know. Everybody's in the same boat. Absolutely wonderful, I can't praise it enough.

Initially it was like a bombshell. But I think I think the real problem with my case was, I don't know how many years ago, two or three, I can't tell you, but when I was prediabetic. I wasn't told anything, there was nothing explaining what it meant. Nothing saying if you don't do this, this and this, you will be diabetic in the future. You end up thinking it's your own stupidity for not asking. But why should you have to ask? You should be told.

Case Study 2

Kate*

'I was diagnosed with gestational diabetes in 2012 into 2013 and then I was borderline, so prediabetes, after my son was born. Then my next son came along a year later. So, I then again for 2013 to 2014 had gestational diabetes. And then from 2014 I had prediabetes basically. Then my youngest was born in 2018, so 2017 to 2018, again I had gestational diabetes. But this was much harder to manage the last time, and I used to have to take quite a lot of insulin. Throughout the day, kind of like four or five times. So, I've kind of managed it for probably about 11 years, and through varying degrees.

I would have to go kind of every two weeks to hospital, to a diabetic midwife appointment. I would also see a consultant and I would see a dietician - the support was quite good.

It's kind of hard to manage. I mean, the thing was it was very much about your diet control, your insulin control and getting exercise and so kind of that was something I'd focus on. And I would also test throughout the day. I'd probably test about five times a day, so when I got up in the morning, after breakfast, after lunch, after dinner, and then before I went to bed and I would have to keep a log of all these readings were along with what I'd eaten, so I had to keep food diary every day as well.

I had my baby and didn't go back to the clinic anymore. I was managed by my GP. I don't have a testing machine, so my testing machine was only ever used when I was actually pregnant. So as soon as I had my baby I wasn't testing anymore, and so I suppose it's a little bit harder to manage as you're not kind of conscious of where your blood sugars are at any given time, and I think out of sight, out of mind. I go for a check on my feet and my blood pressure and my circulation and stuff once every six months or a year, and I have my eyes tested, so I do do that part.

But recently my levels have kind of started to move up again. The last time was just outside of the range that they wanted them to be. But if I'm really honest, it's really hard to stay motivated, someone like me with quite young children, it's really hard to kind of say I'm not going to eat what everyone else is eating. And I'm still quite young, I'm 44. I've managed diabetes for the last ten years, and sometimes if I'm really honest, it's a bit where you don't want to do it for one day or one week or whatever. You don't want to have to think about it, but I do have a real understanding that the only person that's being hurt in that situation is myself. You become your own worst enemy.

So that's kind of where I am. I don't test regularly, just every kind of six months and I try to be healthy as much as I can.

When I'd had my last baby, I would have been classed as clinically obese. I've managed to lose a little bit of weight. I did manage to lose more weight but then I've managed to put some of it back on again, but still probably four, four and half stone from where I left off.

I don't really have any knowledge of the tech available now, but I know that it's progressed a lot. I obviously got a reader ten years ago, which was basically prick your finger, put it on a testing strip.

I am open to any options, even if I had to do that again. I guess if I was kind of aware that it would help me, I would be absolutely willing to put that effort in. I just feel like we need to be on top of it a little bit more. We have three really young children and we both work full time. You know, it's really busy for us but I feel like that's not an excuse. I want to be here for my kids for as long as possible and I do understand that diabetes and its side effects can be a life limiting disease. And I just feel like I've still got my whole life to live. I would be open to kind of technology, whatever the recommendations were for someone you know, like me with my diabetes background.

But no one has basically told me anything. I've spoken to my diabetes nurse before, and she said we'll speak to the diabetes GP. However, it's really difficult because the diabetes GP is lovely, but she only works one day a week so literally it takes months to get an appointment, but I would be willing to kind of do a little bit of research into the technology and find out what it does.

But you can't hide from the decisions that you're making.

If I'm really honest, I will get a text telling me I need to see my diabetes consultant. I'll phone up and there's no slots available. I say my diabetes review is due and I just wonder if I can make an appointment. And then they're like, your GP doesn't have any appointments, so can you phone back again and then it's on you then to try and phone back in two months' time and see if she's got any availability, and you could go through that quite a few times till you actually managed to get a slot. And so, you're a year down the line you know, and you become slightly complacent. You think 'Oh I feel fine, I'm sure everything's okay', but then your level's crept up a little bit, and it's crept up a little bit more, and although I hold my hands up and I do have to take responsibility for myself, I just feel like if it's a bit more proactive and I was seen every three months, then I absolutely would have pulled my socks up, you know, kind of give yourself a kick up the bum and start looking after yourself. So that's quite frustrating in that way.

It's something that plays on my mind but I'm not extremely anxious about it. But I do know that I need to be concerned about that. I'm a bit more aware that it does have some serious side effects. You know you can lose your sight, you can lose your limbs, and all this kind of stuff and so I am very aware that my kids are really young - ten, nine and five - and I need to look after myself.

And I think that that's where the worry comes from and that's where you need to find out what you can do to make it as managed as possible. I realise that education is the key and I know what I should be eating and drinking. I know I don't do it all the time. So, what can I put in place that I'll give me that kind of information. I need to know where I am at any given time.

And then I think with that information comes the more informed choices that you make. Because you see what happens you know it's in black and white, and you could see if you're eating or drinking certain things what it does to you. And then I think that information gives you that real encouragement to make those choices and make them well, and I think while you don't see it and you're not testing it almost doesn't seem quite real.

Because you're not seeing things in any kind of real time. Things that are happening to your body. You just think oh I'm fine, but actually you're probably not.'

Case Study 3

Graham*

'It all started with me fainting in the shower. They decided to give me a blood test and from that blood test they found that I had diabetes. My doctor said to me, 'why aren't you in a coma?' I said, 'I feel fantastic, I don't feel any different to normal right now.'

I very much believe over the years that I've been type 2 diabetic, which is quite a number of years now, that everyone is different, and everyone's tolerances are different. I was told I should have been in the coma. Sometimes I think they're starting to agree with me that everyone's tolerance is a different and stop putting people in the same box. But I'm still carrying on. I'm still alive and I've not lost any limbs, yet.

I went on one of these courses that they did in our local area. It didn't teach me much about it. I must admit I'm a stubborn old git, so it's very difficult to keep my attention all the time. For the last, probably year, I should have been on insulin, but I refuse to inject myself. I can't stand needles. I'll keep going till I die, but I don't think I'm going to die from diabetes.

I'm not managing it, because somehow my body is managing it. I'm still urinating quite frequently during the night but that's the only real side effect I'm getting from having it.

I've had to get a blood test done. I had to go to our local hospital. It had changed a bit and they're meant to be putting me on a pill. But when it comes, God knows. They seem to run three to six months behind.

I do feel that I'm not being looked at closely enough. I am incredibly tolerant, and if they can find out why I'm so tolerant, that could maybe help others. My case may be unique, but I'm sure there's other people in my situation that have got extremely high sugar levels whenever they're tested.

I've made adjustments to my diet, but I still like my doughnuts to be honest, but not every day. I'll have a Kit Kat, maybe daily. But otherwise generally my food intake is very, very different to when I was first diagnosed. They put me on a diet for six months and they said it should help, but when I saw my doctor again, I saw a different doctor at my surgery, and he said you should have been given different advice.

But recently, I haven't had anything from the surgery from the last nine months to say go and book an appointment. I get an annual sight test, and I normally get a letter from the NHS to tell me when the appointment is, so that carries on every year. They haven't told me I've got any issues. The feet used to be the diabetic nurse, and every time she did my feet, they were OK. The nerve endings started going, but when she does the pulse test into my feet they've been fine again. I probably haven't had one of those for a couple of years now really, because the surgery haven't bothered getting in touch.

The only things I've seen about technology helping diabetics is what you see on TV with those things that you're put onto. But that only lasts for two weeks now, and it's about £140! But also, I don't think that's going to help because it's at such a high level when I'm tested. This is why, over the years I've come to the conclusion that not everyone should be put in the same box. Everyone's physiology is different. We've all got a fixed number of cells, and some have got a few more cells than others and this is why I think in my case, I should be looked at by people who know what they're talking about and what they're doing to find out why my sugar levels come out so high.

I'd just love to know why I feel fine, and what's going on inside. Why am I different, that's what I'd like to know. There's got to be something different about me. That's allowed my sugar levels to be so incredibly high, but if you look at me walking down the road walking the dogs, you wouldn't know any different.'

Case Study 4

Ben*

'In March this year, I had a CT scan at the Princess Alexandra Hospital and had to have a Whipple procedure. As part of this operation, I had to have my pancreas removed. My diabetes is type 3.

So that was obviously a lot to take on board. You know, it's not just being diabetic, but it's everything else that's going on with your health. Immediately after my surgery, whilst I'm still in hospital, I did have a visit from a diabetic nurse. Unfortunately, to be honest, I was in such a state after the surgery that it didn't really go in. And then I was released out of hospital after six days.

I've had various consultations with dieticians and with the diabetic team, and I have subsequently done what they call a DAFNE course, which is dose adjustment for normal eating, which was five weeks online and online training and also a Zoom type 3 one hour training package. That certainly helped tremendously. I've got type 1/type 3 and I'm entitled to one of the things that go on your arm. It gives constant monitoring, which is called a Dexcom G7. I was notified in October that funding has been made available for that. However, I have subsequently had no interaction with these people at all for five weeks.

I have tried. The phone is always on answerphone and the Harlow one, because they didn't have a contact number, I had to go to their switchboard and they just put me through to some support answer phone, which wasn't really what I was trying to get.

I have a letter from the Essex Partnership University Trust in Epping. It was to my doctor, and they just sent me a copy the letter and it says I 'will continue to be followed up at the GP. His clinic funding for Dexcom G7 has been approved via Princess Alexandra Hospital and should be followed up in their clinic.' But unfortunately, they didn't leave a contact.

My GP was absolutely fantastic. They got me in touch with a dietician again and they have followed me up regularly, making sure that I'm now on their system to ensure that all the future diabetic treatments, i.e., the foot checks, the annual blood checks, that's all on their system now. So they'll be chasing me up to go along to do that. So, I'm very pleased with them.

The DAFNE course was very, very helpful. It really did give you an idea of counting carbs and giving your adjustment accordingly. To be honest, try to go on that. It was a little bit of knowledge that certainly helped tremendously. It's an excellent course although I'm not a great fan of online training, but the face to face meetings are all starting in the New Year and I intend to go back to work on the first or second.

To say again about the GP, they have been brilliant, absolutely awesome. It shocked me massively, but some people who might not be as robust as me might well have taken it really badly, especially if they're on their own.'

**names have been changed to protect participant anonymity.*

3.0 Key Findings and Recommendations

Key Findings

Initial diagnosis

- The majority of people feel well treated by their GP surgery.
- However, there remains a significant number who feel poorly treated.
- Lack of sensitivity, information and explanation is regularly cited.

Education and self-management

- The majority are offered an education program when diagnosed.
- However, some found it very poor and others were not offered anything.
- In turn, this leads to lack of confidence in self-management for many, including worry, confusion and anxiety. Too many sufferers still do not know enough about their illness.
- People have a strong need for support and reassurance, and many want to be seen by a nurse or GP much more often.

Technology

- Latest tech is widely known about and very useful to those that have it.
- Lack of funding for technology equipment rules it out as an option for many.
- Only 1 in 10 of our respondents have been offered any free tech equipment or services.

Prescriptions

- There remains an inconsistency of supply of medication.
- Regular changes in medication.
- Difficulties and worries about injecting are common.

- Difficulty getting on with many of the medication options.

Recommendations:

Education, education, education

- With the high numbers of people suspected to have undiagnosed diabetes or prediabetes, it is vital that the population is given as much information on the symptoms as possible to help ensure numbers of early diagnoses and prediabetes diagnoses are as high as possible.
- In many cases (especially with early diagnosis), diabetes can be reversed, but in often this will only happen if people are given time to understand and fully grasp the significance of what they have. With support, encouragement and education, reversal numbers can increase dramatically.
- Effective self-management makes living with the illness more effective for everyone. Ensuring the education is put in place to help people do this will have a positive impact on their lives and reduce strain on the NHS diabetes services.

Support

- As a long-term condition for people of all ages, diabetes can be a very lonely experience. Stretched resources mean that sufferers aren't seen as regularly as they often should. The lack of understanding from friends, employers and the public in general can leave people exasperated, especially when they have to continue a 'normal' life with all the daily stresses.
- Advice on charities such as Diabetes UK, and other online support groups should be given out as standard. There are plenty of organisation such as Healthwatch that would be able to work on programmes of local support, including vetting the more informal groups so they can be recommended.

Technology

- There have been (and continue to be) significant improvements in technology solutions in recent years. GPs and other diabetes healthcare professionals must be up to date and aware of these in order to tailor any recommendations to patient throughout their diabetes journey.

- Technology that is free should be offered to all along with practical support and advice on just how effective it can be in managing the condition long term.
- All avenues need to be explored to find ways to make more technology free to people with diabetes. Whether this is finding suppliers of better value-for-money solutions, or increasing technology budgets, the long term strategy will bear fruit.

4.0 Conclusion

Diabetes is not going away. Modern day lifestyles and diets are ensuring that. All the professional bodies, researchers, charities and healthcare professionals recognise that it is going to increase in numbers with almost no upper limit.

However, the solutions to appease the huge strain to come are there for the grasping. The building blocks and foundations are already there and mostly in the right place.

Education is one of those. Before, during and after diagnosis. It must be offered consistently, appropriately, and in time. But the education itself must be of real quality. Former patients, current patients and family carers must play a part in designing courses, both face to face and online. They must not be too simple or too complex. The right balance will motivate people to take it on and beat it or control it. rather than it controlling them.

Education also links to another foundation - technology. Understanding what's available, how to use it, not to be scared of it, and how transformative it can be in controlling your symptoms will help thousands upon thousands of people. We see technology usage at home increasing in healthcare (simple examples of blood pressure monitoring for example), and there is a huge opportunity not to be missed here. Every angle and option should be investigated to establish a best practice program of technology monitoring and management - the long-term benefits cannot be underestimated, but the challenges need to be addresses now.

The third and final pillar is support and emotional understanding. So many people struggle to continue to battle this illness for year after year. Seeing family and friends indulging, enjoying some alcohol, eating cakes, while you have to abstain is difficult, and relapsing is all too easy - especially when the effects are often not immediately visible. People feel stupid for not asking the right questions, for not understanding their condition well enough, and for not controlling their diet and taking enough exercise. This is only made more difficult when you are seen by your healthcare professional once a year. Emotional support, together with advice and

guidance, can help on every level. This needs to come from inside and outside the NHS and includes local authority, charities, VCS, primary care, hospitals, opticians, pharmacy, mental health and so on. Indeed, it encompasses everything that an integrated care system should be.

5.0 Terminology and Acronyms

DAFNE - Dose Adjustment for Normal Eating.

Factor V Leiden - a mutation of one of the clotting factors in the blood.

GP - General Practice or General Practitioner

HbA1c - average blood glucose (sugar) levels.

HCPs - Healthcare Professionals.

IAG Team - Healthwatch Essex's Information & Guidance Team.