



Healthwatch Kingston

Pulse check report:

Services for people with diabetes

Survey and Focus Group - October to November 2021

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healthwatch
Kingston upon Thames



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1. About Healthwatch Kingston

Healthwatch Kingston upon Thames is your local health and social care champion. If you use GPs and hospitals, dentists, pharmacies, care homes or other support services in your area, we want to hear about your experiences. We are independent and have the power to make sure NHS leaders and other decision makers listen to local feedback and improve standards of care. We can also help you to find reliable and trustworthy information and advice. Last year, the Healthwatch network helped nearly a million people like you to have your say and get the support you need. Healthwatch Kingston upon Thames is part of a network of over 150 local Healthwatch across the country.

We're here to listen to the issues that really matter to people in the Royal Borough of Kingston upon Thames and to hear about your experiences of using local health and social care services. We're entirely independent and impartial, and anything you share with us is confidential.

Healthwatch uses your feedback to better understand the challenges facing the NHS and other care providers and we make sure your experiences improve health and care for everyone – locally and nationally. We can also help you to get the information and advice you need to make the right decisions for you and to get the support you deserve.

It's really important that you share your experiences – whether good or bad, happy or sad. If You've had a negative experience, it's easy to think there's no point in complaining, and that 'nothing ever changes'. Or, if you've had a great experience, that you 'wish you could say thank you'. Remember, your feedback is helping to improve people's lives. So, if you need advice, or you're ready to tell your story – we're here to listen.

2. Introduction

There are believed to be about 8,000 people in Kingston who have been diagnosed as having diabetes and national trends indicate that there could be around a further 2,000 in the Borough who have the condition but are unaware.

The 3 most common types of diabetes are:

- Type 1 - this is often associated with younger people but can occur at any age. It is known as an autoimmune condition which means the body's immune system has mistaken the cells that make insulin as a threat. This means that a person with type 1 diabetes will need to manage their condition with multiple daily insulin injections from diagnosis. We still do not fully understand what causes type 1 diabetes.
- Type 2 - This occurs when the insulin made by the pancreas is unable to work properly (this can be due to 'insulin resistance') or the pancreas cannot make enough insulin, meaning that blood glucose levels keep rising. A pancreas under continued stress to make more and more insulin can become so 'exhausted' that it is unable to meet the insulin demand. Type 2 diabetes is treated firstly with advice on diet, physical activity and lifestyle. If blood glucose is still raised, then medication will be needed (this could be tablets or injections).

In both type 1 and type 2 diabetes it is important to aim to keep blood glucose as close to the target range that has been agreed to help reduce the chances of health problems due to the diabetes.

- Gestational diabetes (GDM) - this is diabetes that occurs in some pregnancies. It is usually seen at 28 weeks of pregnancy but can happen as early as 16 weeks. It occurs because of increased insulin resistance due to pregnancy hormones. It is treated with diet together with Metformin tablets and / or insulin injections if necessary. In most women it will disappear after the birth of the baby. A blood test is taken 6 - 13 weeks after birth to confirm this. Women who have had GDM are

much more likely to develop type 2 diabetes sometime during their life and can have a screening test each year. They are advised to follow a healthy diet and lifestyle to help reduce this risk.

Diabetes should not prevent anyone from living a full and active life. However, living with diabetes and managing daily can be challenging and can have an effect on psychological well-being. Diabetes can also lead to some complication if blood glucose levels are above target ranges over significant periods of time.

3. Research methodologies

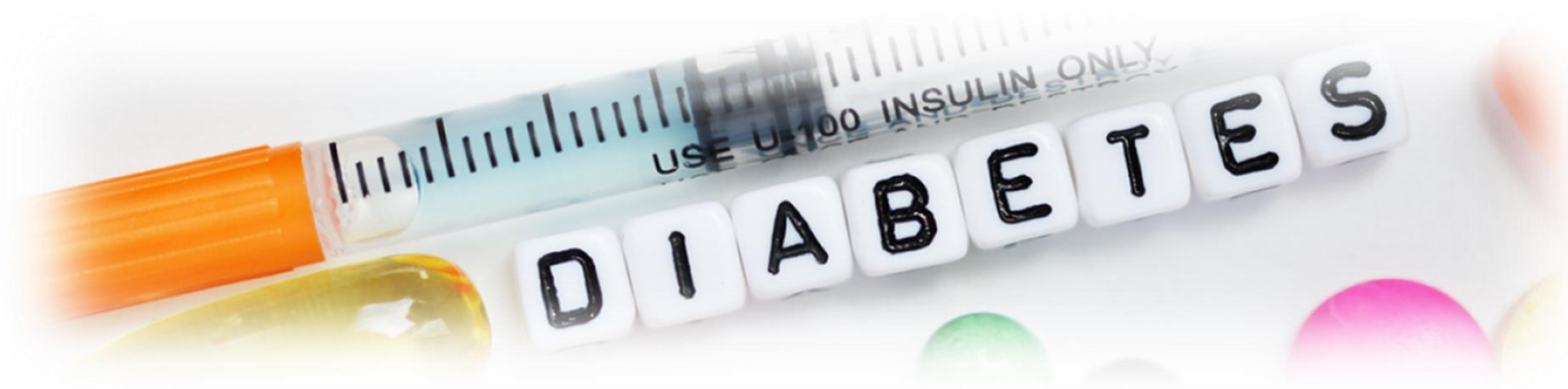
Healthwatch Kingston, working with Diabetes UK, wanted to encourage Kingston residents to talk about their experiences of services. We sought the views of people with diabetes to help services work better for the people who use them.

The findings from this Healthwatch Kingston Pulse check are drawn jointly from a focus group discussion, held in association with the Kingston branch of Diabetes UK, as well as returns to an online survey which was featured on the Healthwatch Kingston website for the months of October and November 2021. In total 40 respondents (23 survey respondents/17 focus group attendees) between the ages of 25 to over 80 expressed their views, the majority of whom were approximately pensionable age. We also provide examples of what people shared with us.

Methodologies used to collect data for this compilation report included:

- Online survey, promoted via our [website](#), social media and local health and social care stakeholder communications
- Targeted engagement with a local community self-help group on 20 October 2021.

Healthwatch Kingston would like to note an unexplained divergence between focus group experiences of diabetes services and responses shared via our survey relating to quality of care received (see page 13).



4. Local service offer

To find out about support available for people living with and affected by diabetes in the Royal Borough of Kingston upon Thames, and also support for professionals go to the [Healthwatch Kingston All About: Diabetes services](#).

5. Key messages

- A. Of those participating in the focus group discussion there was a ratio of 3 to 1 of those with Type 2 over participants with Type 1. This was similar with survey respondents, where there were more people diagnosed with Type 2 diabetes (57%) than Type 1 diabetes (43%). Irrespective of this, there were believed to be considerable inconsistencies between

GP surgeries in the way diabetic conditions were being treated and supported. Where patients had been referred to the Diabetic Day Unit at Kingston Hospital there was considerable admiration for the support received by patients.

- B. Covid-19 had impacted on diabetes treatment, with a reduction in annual eye tests changing to every two years, at least for the period of the pandemic. The knowledge of diabetes issues among GP practice staff was questioned by participants.
- C. This varied between practices but seemed to represent “a postcode lottery”. Annual diabetes checks at surgeries were in many cases seen as being a “tick box” exercise for the benefit of the practice as opposed to being of genuine assistance to the patient. However, a minority of patients expressed the view that their annual check and the associated discussion with surgery personnel was of benefit to them.



The annual diabetic check should be more than a box-ticking exercise for the GP practice. I felt this was so in my case - no useful advice/information provided to me.”

- D. In the absence of the expected information and advice being forthcoming at surgery level, many patients felt the need to do their own research which included on-line sources, patient support groups and learning from others with the condition who seemed best able to offer practical advice. This led to patients feeling that they knew more about their condition than the personnel accessible to them at GP level.



I know more than the nominated health professional.”



They don't know very much.”

- E. Whilst patients accepted that diabetes care represented the patient taking control of their condition, this depended upon a partnership of care between patient and doctor. But it was felt that many medical professionals lacked awareness of research such as the [Newcastle diet trials](#) and [Surrey University starch intake study](#). Too few people in the early stages of being told that they had diabetes were referred to the available NHS services. Respondents said they “felt all alone” in coping with diabetes. Participants however, noted better experiences of specialist services.



Despite budget cuts and other challenges, I can only praise the whole (Diabetes Day Unit) team - from the person who answers the phone, right through to the specialist nurses and consultants. I feel safe with them.”

- F. Respondents said they felt uncertain as to whether they were on the right medication or the correct dosage. Advice on medication was sometimes inconsistent but pharmacies were praised for frequently being helpful. There was a feeling among several that their prescriptions could be based on cost rather than the suitability of a drug and this led to a feeling of mistrust in some quarters. With a high link between diabetes and blood pressure it was acknowledged that getting blood pressure medication right could be a matter of some trial and error. One respondent shared experience that their district nurses were not confident providing insulin, and in addition could only visit twice a day when they were in fact needed at every meal.
- G. Annual podiatry and the return to annual eye testing were seen as helpful. Retinopathy issues were a concern among patients and the respondents were pleased to note that if early stages could be identified, the frequency of eye checks would automatically be shortened from every two years.




Pediatric team for Type 1 diabetes at Kingston Hospital are excellent.”

- H. Some respondents spoke highly of the value they achieved from such a meeting, particularly related to food and dietary matters. However, several of the respondents said that they gain no benefit from their Annual Review sessions at their surgery. A lack of proper discussion with knowledgeable practice personnel was seen as the major concern.

 *No feedback from annual check.”*


- I. Having diabetes was seen as a source of continuing worry for many patients. It had to be consistently on the mind, but there was ample evidence that this could spread to more intensive mental health issues, if support was not seemingly available. It was accepted that with Type 1 there was a consistent need for “a more disciplined life”. In both Type 1 and Type 2 the condition was seen as a “social handicap”, especially when meeting people who had no understanding or felt that the diabetic person was just “acting strangely” where meals and other eating were concerned.

 *I’ve had Type 1 diabetes for 46 years nearly, the care I receive from Kingston Hospital is exceptional. I’m on an insulin pump and any problems I can email or call the team. I also have access to the diabetes nurse at my GP surgery. They can’t help me re my insulin pump as its too specialist, but she carries out my health checks and I can talk to her about any concerns. I have excellent care with both, having had Type 1 diabetes for so long, since a child, I know I’m at risk of complications, but I feel I have the right care available to try and limit those risks.”*

- J. Diabetic patients would like to receive more personalised dietary advice.

 *Dietician(s) should have a better understanding of culture.”*

K. Currently some of the available information seemed contradictory. Better communication to those with diabetes was seen as necessary, not least to alleviate anxiety about food. Patients felt “typecast” by medical professionals and others as having diabetes because they had previously over-indulged in eating. This was not regarded by diabetes patients as either fair or true as many, especially with Type 2, had never been excessive overweight. A participant in the focus group talked about how slim they were and that as many services focus on weight loss, they were struggling to find the right support.

 *I am very happy with my service in primary care but with the amount of change and `information that takes place for all clinical conditions it feels that it would be good to be reviewed, even if it was between 3-5 years, by a specialist.”*

 *I am a lot more cautious but otherwise OK.”*  *Fell down sometimes when I reflect over condition.”*

 *My mother’s diabetes gives me anxiety as I’m her carer. I don’t want to miss any time and it is too late to do anything.”*

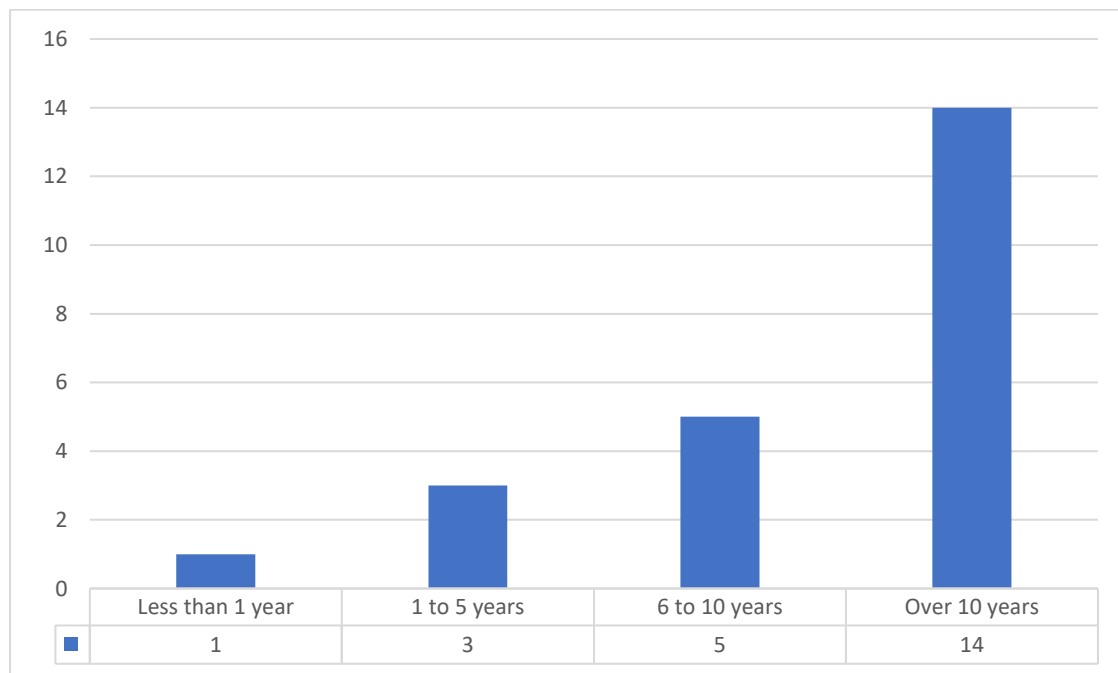
L. Exercise was recognised by the respondents as playing an important role in tackling diabetes. Covid-19 had led to the closure of leisure centres and consequently several respondents said they had been walking more to compensate.

 *Should be more disciplined. I get tired.”*

However, with earlier dark nights this was seen as a habit that would be less likely to continue and returning to leisure centres would increase. There were feelings of guilt that participants should be doing more exercise but they said that other commitments “got in the way”.

- M. Some 40 per cent of the respondents said they would make use of diabetes-specific supervised exercise classes if these were reinstated post-pandemic.

6. Pulse check survey findings

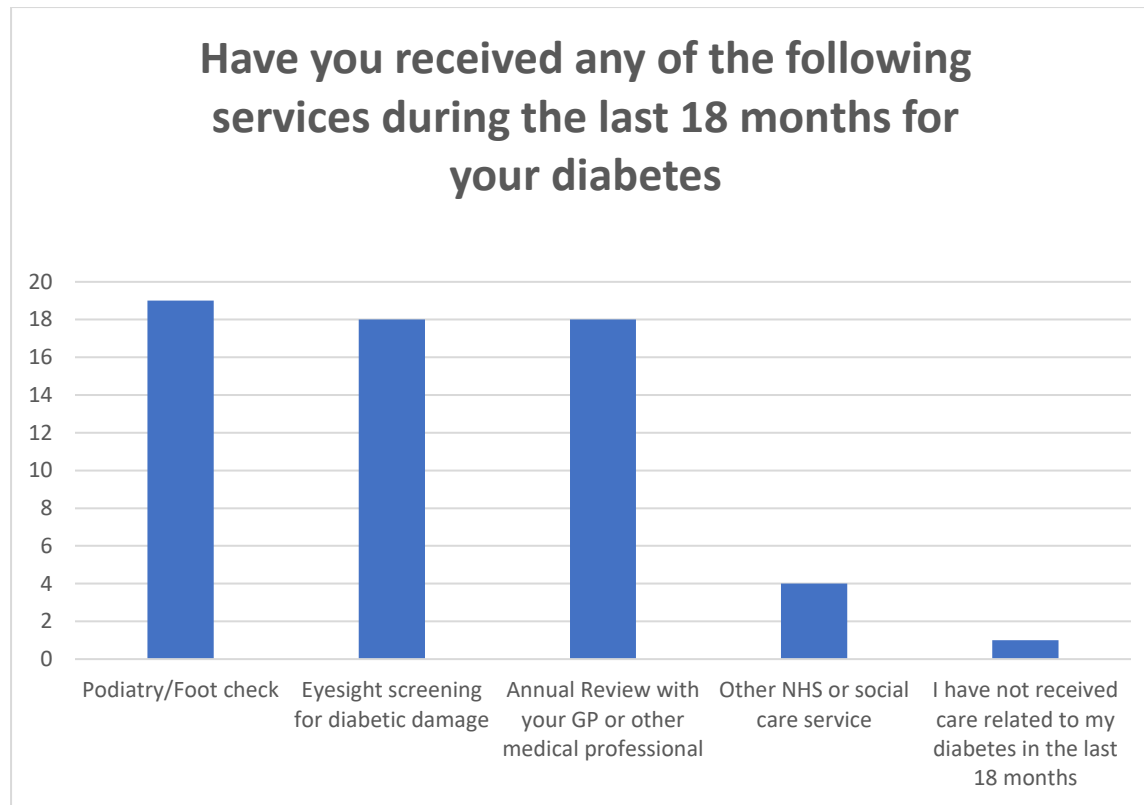


How long diagnosed?

We asked the 23 survey respondents to the Pulse check survey, approximately how long they had been diagnosed with diabetes.

Most people (19 / 83%) said either ‘6 to 10 years’ or ‘over 10 years’.

Ten (43%) out of the 23 people were diagnosed with Type 1 diabetes and thirteen (57%) were diagnosed with Type 2 diabetes.



Service needs and medication

Our Pulse check survey asked people what their main diabetic medicine was.

Most respondents (12 / 39%) were taking Metformin followed by those taking Insulin (10 / 32%). Gliclazide was the third noted diabetic medication taken by respondents (5 / 16%), with 4 people (13%) saying they took 'other' diabetic medicine (Dapagliflozin, Forxiga, Januvia and Sitagliptin were mentioned).

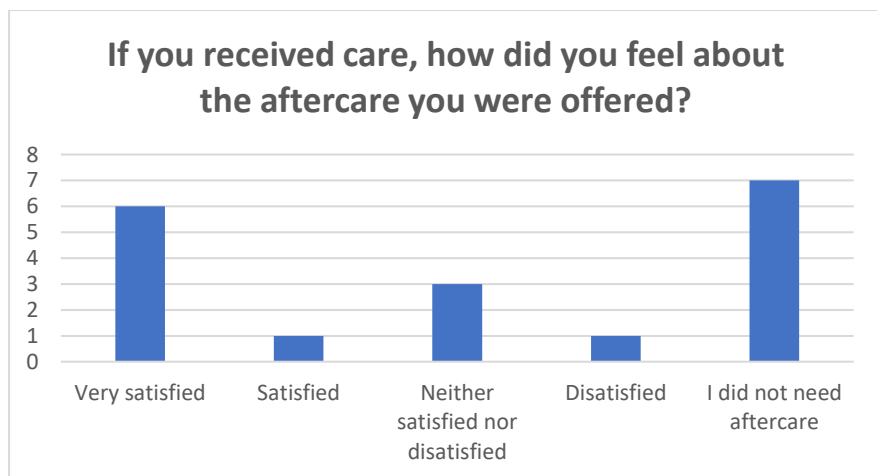
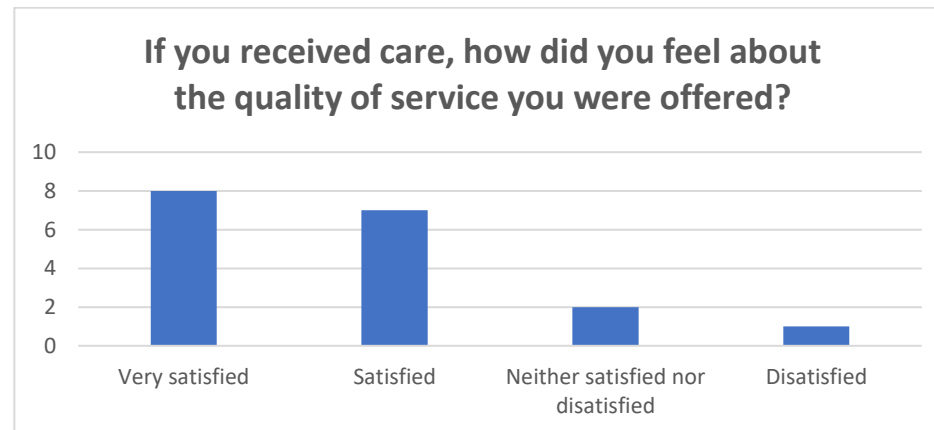
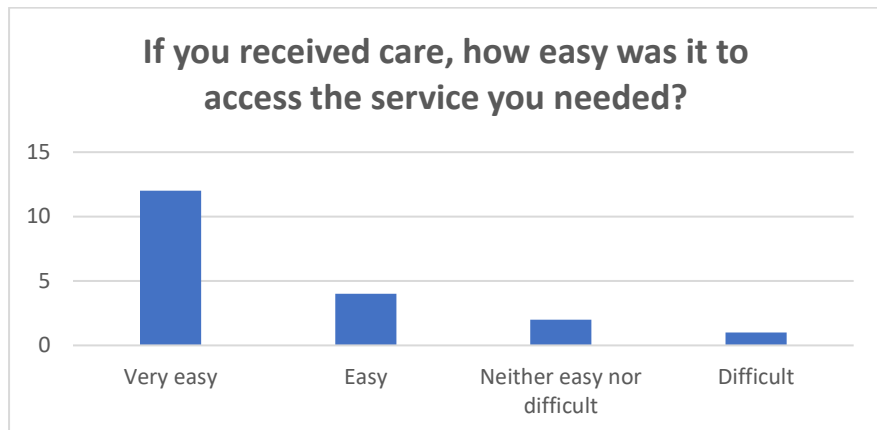
Concerningly, focus group participants were uncertain about being on the right medication.

Most respondents (20 / 87%) said in the past 2 years they had made a request to their GP to be referred to more specialist diabetes care and advice than was available at their surgery.

Unsurprisingly, respondents indicated a need for specialist diabetes care and support in three key areas: Podiatry/Foot check; Eyesight screening for diabetic damage; and Annual Reviews.

Access, quality, and aftercare

We asked people that received care how easy it was to access the service they needed, how did they feel about the quality of the service they were offered, and how they felt about any aftercare they received. This is how people responded overall:



Where 3 respondents have identified difficulty or dissatisfaction, Healthwatch Kingston will anonymously discuss this with the provider.

We asked people where they sourced information about diabetes. The table below illustrates that both the ‘Kingston Hospital Diabetic Day Unit’ and ‘Diabetes UK and other printed publications’ were the main ‘go to’ places. It is more likely, however, that those seeking information from ‘Kingston Hospital Diabetic Day Unit’ have more complex needs.

Main source of diabetes information	No. who answered	Percentage
Diabetes UK Kingston group	5	14%
Kingston Hospital Diabetic Day Unit	8	22%
GP	6	17%
Social media and websites	6	17%
Diabetes UK and other printed publications	8	22%
Other	3	8%

Being kept informed by medical professionals

Most respondents (15 / 65%) felt their medical professional kept them informed about their condition and any long-term complications. There were 4 people that were ‘unsure’, and worryingly, 4 others that answered ‘no’ to this question.

Mental and physical health and wellbeing

The link between use of anti-depressants and diabetes is well evidenced. We wanted to find out more and asked people, ‘Has diabetes impacted your mental health?’. 11 people said, ‘yes’, 8 said, ‘no’ and 4 were ‘unsure’. Those that said ‘yes’ worried.

 *I feel down sometimes when I reflect over condition.”*

 *My mother's diabetes gives me anxiety.”*

We also asked, ‘How frequently do you exercise with a professional, to improve your diabetes care and general health?’.

13 people said ‘never’, 2 said ‘occasionally’, 2 reported they exercised ‘once a week’ and 6 shared that they did so ‘more than once a week’.

Healthwatch Kingston notes there is access to the NHS Diabetes Prevention Programme - a nationally commissioned, locally delivered service that Kingston patients can attend. The service offers several sessions patients attend with diet / exercise / education on trying to prevent pre-diabetes becoming diabetes. If you are interested in getting involved in either, please contact your GP. [Find out more.](#) There is also the [‘Get Active’ Exercise Referral Programme](#) available through your GP.

We learned that there were exercise classes in Kingston specifically for people with diabetes, but these have stopped. It appears this service is missed with a negative effect to one respondent’s health and wellbeing:



I used to attend some well-run exercise classes specific to the needs of those of us with diabetes. These were first at the Kingfisher Centre and then moved to Kingsmeadow. These stopped for understandable reasons when Covid came along, but I hope we can hear soon that these will be restarted. I have really missed this and feel that my general health has declined over the last two years.”

Diabetes has historically been seen as solely an issue related to diet. In recent years it has been acknowledged as not the only issue - genetics, bad luck, mental and physical stress, and co-morbidities (15 respondents said they have another long-term medical condition) have all become factors.

While reporting about the impact of a loss of a service, the Pulse check community survey also asked, ‘ Since being diagnosed with diabetes, are there things you can no longer do? The next page shares what people told us.

Things I can no longer do since being diagnosed with diabetes:

“Walking long distances - tied to increased blood pressure, for which I now take medication”

“Being able to just grab food!” “Loss of appetite, memory loss , depression, tension, tiredness.”

“No, diabetes has never stopped me.” “Food has been impacted, being out and about.”

“Yes - drinking and eating.” “Having to eat whatever my mother likes.”

“Should be more disciplined. I get tired.” “My diet is restricted.”

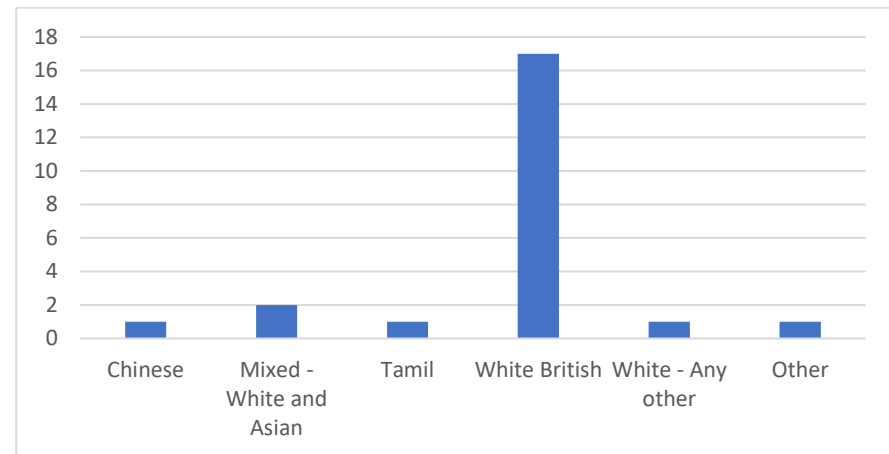
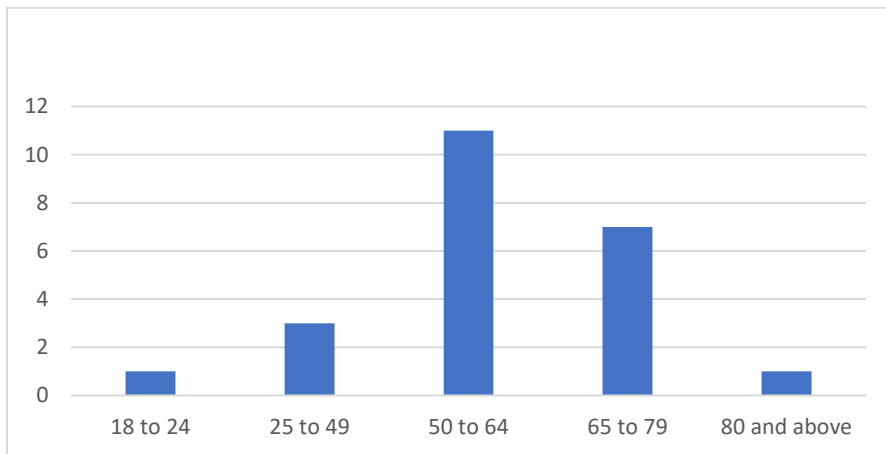
“Bath between sensor changes as it disconnects. I need to disconnect before going on a theme park ride.”

“Eating whatever I like - e.g. cakes, pastries, sweets etc.” “Eat a lot of cake.”

“Having to count amount of carbohydrates for every meal.” “I miss certain meals.”

7. Health Inequalities

To help reduce health inequalities, Healthwatch Kingston has committed to ‘moving towards’ better representation in our engagement work and is promoting a collaborative approach with voluntary sector organisations and with support from local community champions. The demographic data shows there were 10 male (43%) and 13 female (57%) respondents. All 23 noted they were the same gender identity as assigned at birth. Age/ethnicity numbers (26% non-‘White British’) are provided below:



8. Thank you and next steps!

Healthwatch Kingston would like to thank everyone that has shared their experiences with us. Everything we say and do is informed by what local people tell us. We will publish this report on our [website](#) and share with Healthwatch England, the Care Quality Commission, the Royal Borough of Kingston upon Thames, south west London Clinical Commissioning Group, Voluntary and Community sector and other stakeholders.



Tell us what you think about NHS and social care.

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