

Early Onset Type 2 Diabetes: Lived experience insights report

Health Innovation Network
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1. Executive Summary

1.1. Background

NHS England (NHSE) have released national funding to all Integrated Care Boards (ICBs) as part of the 'T2Day: Type 2 Diabetes in the Young' Programme aimed at improving care for people with early onset type 2 diabetes (EOT2D). EOT2D is defined as the development of type 2 diabetes (T2D) below the age of 40 years.

In south east London, EOT2D is disproportionately more common in those from Black (33.4%) and Asian (22.4%) ethnic backgrounds when compared to the south east London population, as demonstrated in the tables below [1, 2]. The inequality is even more stark in individuals aged under 25, with those from black ethnic backgrounds representing 42.3% of those diagnosed with EOT2D.

Ethnicity	Type 2 diabetes, aged 18-39		Type 2 diabetes, aged 18 - 24	
	No.	%	No.	%
Asian	987	22.4%	31	11.7%
Black	1474	33.4%	112	42.3%
Mixed	225	5.1%	14	5.3%
Other	244	5.5%	12	4.5%
Unknown	180	4.1%	17	6.4%
White	1303	29.5%	79	29.8%
Total	4413		265	

Ethnicity by percentage of south east London population	
Asian	9.5%
Black	19.5%
Mixed / other	10.8%
White	60.2%

Table 1: Proportion of early onset type 2 diabetes by age group and ethnicity in south East London. Data from South East London EOT2D dashboard QOF 12-month reporting 23/24, accessed 15.08.24 [1]

Table 2: Ethnicity by percentage of South East London population. Data from Office for National Statistics, accessed 13.12.24 [3].

In addition, people with EOT2D in south east London are more likely to be from the most socio-economically deprived areas. The SEL ICB EOT2D dashboard indicates that 65.6% of those aged 18-39 living with type 2 diabetes are from index of multiple deprivation quintiles one and two [1].

People with EOT2D are much less likely to have all annual care processes completed (54.9%) when compared to the whole T2D population in SEL (SEL ICB diabetes dashboard). They are also less likely to achieve the three NICE treatment targets for blood pressure, cholesterol and HbA1c control (17.9%) when compared to the whole T2D population in SEL [1].

Previous research indicates that people with EOT2D have significantly higher mortality and morbidity compared to people diagnosed above the age of 40 [4, 5].

The lived experience insights workstream gathered insights from people in south east London (SEL) living with T2D aged between 26-39 about their experience of diabetes care. The aim of this was to inform the next steps of the project which would look to improve care experience and outcomes for this group, through improving engagement with primary care, supporting services and diabetes care, clinical optimisation and local pathway improvement. This report presents the findings and

recommendations drawn from the focus group, interviews, and online survey which took place between May and June 2024.

1.2. Findings

Thirty-one participants took part in either an interview or focus group and 70 participants completed a survey. Most participants were female, aged between 35 to 39 years old and identified as Black or Black British, Caribbean or African ethnicity. The majority lived in Southwark and were employed full time. Their age of diagnosis was most commonly between the ages of 31 to 35.

The majority of participants described a negative experience of diagnosis and would have liked more time with a healthcare professional and a better understanding of the condition and its management. Diagnosis of and living with diabetes was associated with negative emotions and some attributed this to feelings of low mood and poor mental health. Stigma associated with a diabetes diagnosis led to feeling embarrassed and unable to share a diagnosis. This resulted in feelings of isolation and decreased wellbeing, as well as reduced self-management and attendance at diabetes care appointments.

"Because of my age... I feel embarrassed or I feel a bit, um, anxious when I have to reach out to someone for help"

Participants felt that increased and tailored (to age and individual) support and information is needed, reinforced by a positive and motivational approach. There was clear appetite to better understand and manage diabetes which could be supported through more information, additional appointments and being able to monitor blood glucose levels. Peer support may help with understanding and reduce feelings of isolation. Trust in the information provided, knowing where to go for it, feeling supported and receiving feedback and answers were all considered to be important.

"Sometimes I look at the age groups...sometimes I may be the...youngest person there, I think to myself...is there something different wrong with me?"

Through the survey 33% of respondents selected that a healthcare professional at their GP practice had talked to them about their mood or mental health (33% responded no, 4% preferred not to say) and 49% had been told about, or offered a referral to, mental health support services. Participants felt being asked directly about their mental health would provide better support.

"If you ask explicitly how is your mental health? Like how you coping with everything? Then that opens up the conversation. But if you're not really asked directly, you're not really going to talk about it"

When asked whether a healthcare professional at their GP practice had talked to them about other things that might affect health and wellbeing such as what you eat and drink, jobs, money, housing, family and friends etc., 51% felt this has been raised and 29% were offered further support.

Of the survey respondents who indicated they were a person who could become pregnant, and felt comfortable to answer questions relating to pregnancy (this was 46% of respondents), 84% were aware that type 2 diabetes can have an impact on pregnancy and 31% had had a conversation about pregnancy planning or contraception with a health care professional at their GP practice.

When relating positive experiences participants described feeling that they had enough time in an appointment, that explanations of tests and why they were being done and what the results meant had occurred, and that they had opportunity to ask questions and receive answers. This resulted in feeling supported and cared for. Training for health care professionals should be provided to enhance their existing skills, confidence and awareness of the difference in approach needed for this age group.

Survey respondents felt that the following options would make them feel more confident and able to self-manage their diabetes:

- More education/better understanding
- Digital apps/online services
- Being able to do test and checks (usually done at GP) at home
- Being able to monitor blood glucose (blood sugar)

“Changing the stigma that T2 people are just fat, lazy and eat badly. This has a huge impact on my mental health when I discuss being T2 with others”

1.3. Recommendations

Improve diagnosis experience

- Provide an ‘enhanced’ appointment at the point of diagnosis to ensure individuals are provided with sufficient time and clarity.
- Consider a set of appointments at diagnosis and which staff roles need to be involved. For example, a longer first and second appointment, two to three months apart, allowing time to provide essential information, support motivation to make changes and attend courses, and to check understanding.
- Review structured education offer and consider options to tailor and/or tailored to a younger audience. Examples include Digibete for 18-25 years and MyDESMOND EOT2D.
- Review literature and information provided at the point of diagnosis to ensure it is relevant to this population. Develop a single source of information such as a webpage to signpost young adults to resources and links for support, and reduce the potential for misinformation.

Provide training and support for health care professionals

- Ensure health care professionals providing diabetes care complete training to enhance their existing skills, confidence and awareness of the difference in approach needed for this age group (e.g. Leicester Diabetes Centre’s Eden ‘Early Onset Type 2 Diabetes’ education package).
- Training should include topics such as age-pertinent information about diagnosis of diabetes, cardiometabolic management, medication, approach to appointments, being mindful of stigma and avoiding compounding this, psychological and social considerations, pregnancy and contraception, information about services such as the path to remission programme, structured education, and health and wellbeing services.
- If considering use of additional roles to support pathways, ensure adequate training for their roles and responsibilities is provided to improve staff confidence and competency, and trust and engagement of people with EOT2D.

Address stigma and negative connotations associated with diagnosis and living with type 2 diabetes

- Provide adequate psychological and emotional wellbeing support, ideally provided by an appropriately trained individual.
- Provide direct access to psychological support in a young adults’ clinic.
- Consider opportunities for peer support within this age group to address stigma and isolation and reduce potential for misinformation.
- Health care professional education provided should include information about stigma and how to avoid compounding this.

Increase ‘time’ offered to young adults

- Increase the regularity of support provided, particularly in the initial stages of a diagnosis when targets and medications may not be optimised, and an individual is learning how to manage and navigate change.
- Consider ways in which contact times can be increased, in addition to annual reviews, for example through peer support, use of staff roles with behaviour change/motivational skills, digital support options.
- Investigate potential for offering continue glucose monitoring (CGM) to support learning and management of blood glucose.

Review pathways for prevention and early diagnosis

- Implement a search of people coded with non-diabetic hyperglycaemia (NDH) under the age of 40 to review HbA1c status and/or ensure they are offered and supported to attend NHS Diabetes Prevention Programme (NDPP) programme.
- Review appropriateness and effectiveness of pathway and support provided when someone is coded as having NDH, including steps to tailor education provided (NDPP) for younger audience.
- Consider case finding to ensure early intervention wherever possible. Search for people under the age of 40 with increased blood glucose or HbA1C recorded suggesting possible diabetes.

Continue to involve people aged 18-39 with lived experience of type 2 diabetes

- Continue insights gathering and co-design work with people aged 18 to 39, alongside any implementation of the recommendations made above to ensure further work and changes made are done so relevant to the needs of this population.
- Engage with community organisations and investigate alternative methods of recruitment to reach people who are not engaging with healthcare services or attending annual check-ups.

2. Background

National funding has been made available by NHS England to all ICBs for the T2Day: Type 2 Diabetes in the Young Programme, a 2-year initiative (for 23/24 and 24/25) aiming to improve care for people with early onset type 2 diabetes (EOT2D). The programme aims to improve care across 4 key areas:

1. Verifying diagnosis of type 2 diabetes
2. Supporting preparation for pregnancy or access to contraception in women with type 2 diabetes where relevant
3. Cardio-metabolic risk management and medicines optimisation
4. Addressing unmet psychosocial needs and overall wellbeing

ICBs were able to decide the final approach and delivery of the NHSE programme within their area, in line with the service specification set out by NHSE, providing details of suggested and required component parts of the model of delivery. SEL ICB have commissioned the Health Innovation Network (HIN) South London to work with them to support and deliver this work to improve care and outcomes for people aged 18-39 who are living with type 2 diabetes.

In south east London, EOT2D is disproportionately more common in those from Black (33.4% vs. 19.5%) or Asian (22.4% vs. 9.5%) ethnic backgrounds when compared to the south east London population, which is demonstrated below in table 1 and 2 [1, 2]. The inequality is even more stark in individuals aged under 25, with those from black ethnic backgrounds representing 42.3% of those diagnosed with EOT2D.

Age	19 - 24		25 - 29		30 - 34		35 - 39		Total	
Ethnicity	No.	%	No.	%	No.	%	No.	%	No.	%
Asian	31	11.7%	95	17.1%	262	21.9%	599	25.0%	987	22.4%
Black	112	42.3%	200	35.9%	375	31.3%	787	32.9%	1474	33.4%
Mixed	14	5.3%	33	5.9%	57	4.8%	121	5.1%	225	5.1%
Other	12	4.5%	32	5.7%	82	6.9%	118	4.9%	244	5.5%
Unknown	17	6.4%	31	5.6%	38	3.2%	94	3.9%	180	4.1%
White	79	29.8%	166	29.8%	383	32.0%	675	28.2%	1303	29.5%
Total	265		557		1,197		2,394		4413	

Table 1: Proportion of early onset type 2 diabetes by age group and ethnicity in south East London. Data from South East London EOT2D dashboard QOF 12-month reporting 23/24, accessed 15.08.24 [1]

Ethnicity by percentage of south east London population	
Asian	9.5%
Black	19.5%
Mixed / other	10.8%
White	60.2%

Table 2: Ethnicity by percentage of South East London population. Data from Office for National Statistics, accessed 13.12.24 [3].

In addition, people with EOT2D in south east London are more likely to be from the most socio-economically deprived areas. The SEL ICB EOT2D dashboard indicates that 65.6% of those aged 18-39 living with type 2 diabetes are from index of multiple deprivation quintiles one and two [1].

IMD	Persons	%
1	1069	24.2%
2	1827	41.4%
3	739	16.7%
4	374	8.5%
5	236	5.3%
Unknown	168	3.8%
Total	4413	

Table 3: Proportion of EOT2D by index of multiple deprivation (IMD) quintile, data from South East EOT2D dashboard, QOF 12-month reporting 23/24, accessed 15.08.24 [1].

People with EOT2D are much less likely to have all annual care processes completed (54.9%) when compared to the whole T2D population in SEL (SEL ICB diabetes dashboard). They are also less likely to achieve the three NICE treatment targets for blood pressure, cholesterol and HbA1c control (17.9%) when compared to the whole T2D population in SEL [1].

In SEL there are approximately 4400 people aged between 19 and 39 living with type 2 diabetes. The number of people within this population per practice ranges from 5 to 170 (for larger partnership practices/groups). Despite the small number of patients per GP practice, prevalence is increasing [6] in SEL from 2021 to 2024 the number of patients recorded as having EOT2D has increased from 3,743 to 4,413 [1].

A steering group was convened to agree the approach to the programme of work. This group reviewed data, pulling together a population health dashboard for young adults with T2D, and considered existing work in SEL focussing on this cohort with a view to build on this and utilise any existing resources. From this, several workstreams were established. The lived experience insights workstream gathered insights from people living with T2D aged between 26-39, to look at how to improve experience and outcomes for this group, through improving engagement with diabetes care, clinical optimisation and local pathway improvement, with a focus on primary care.

To explore lived experience, this insights gathering exercise took a mixed methods approach. A rapid approach to explore insights was undertaken with interviews, a focus group and survey delivered in May and June 2024 and analysis in July 2024. Alongside insights from other project workstreams, this understanding will inform the next steps of the project in determining possible interventions or improvement changes that could be implemented across SEL.

This report uses the conventions of social science reporting: “a few” is used to indicate views which were mentioned infrequently, and “many” or “most” for views which are more frequently expressed. The use of “some” reflects the balance between these views which were mentioned by some participants, i.e. more than a few but not the majority of participants. This report focuses on perceptions and proportions used in the reporting should be considered indicative, rather than exact. Verbatim quotes are used throughout the report to demonstrate a viewpoint expressed during the qualitative work in the participant's own words.

3. Approach

3.1. Purpose and scope

The purpose of this work was to understand lived experience of type 2 diabetes care and in doing so provide insight to inform guidelines, recommendations and/or design of an intervention. The overall aim is to improve diabetes care and engagement with primary care and supporting services for people living with type 2 diabetes aged between 26 and 39 years. Adults with type 2 diabetes aged 18-25 were not included as insights from this group have previously been sought via the 'Type 2 Take 2' Programme of work in Southwark and Lambeth.

Gathering lived experience insights aimed to:

- Learn about the participants experience of being diagnosed, what was good and what could be improved.
- Understand barriers and challenges faced by this population group in living with type 2 diabetes.
- Understand barriers and challenges faced by this population group in attending diabetes care appointments.
- Discover the ways in which this population group feel barriers could be overcome and diabetes care could be improved.
- Determine whether social and psychological needs are being assessed, and appropriate support offered.
- Determine whether contraception and planning for possibility of pregnancy is raised within appointments (pregnancy preparedness).

3.2 Design

This was an insights gathering exercise designed to explore lived experience of type 2 diabetes care and inform future work. The process used a mixed methods approach consisting of interviews or a focus group, and/or a survey (Table 4: Summary of data collection methods). People aged between 26 and 39 (inclusive) living with type 2 diabetes in SEL were invited to take part.

Collection method	Description	Analysis
Interviews and focus group	People were invited to attend either individual interviews or a focus group to share their experience of type 2 diabetes care. People were recruited via text messages sent from their GP practice or information shared via Healthwatch, Diabetes UK and the HIN.	Interviews and focus groups were recorded and transcribed. Themes were coded in Excel based on the evaluation objectives.
Online survey	People were invited to complete an online survey instead of, or in addition to, an interview or focus group. This explored experience of diabetes care and opinions for improvement.	Responses to the online survey were exported to an Excel spreadsheet and analysed using descriptive statistics.

Table 4: Summary of data collection methods

4. Findings

Quantitative and qualitative data were collected and analysed. Sample size is as follows:

- Interviews and focus group: 31 participants overall (29 in interviews, 2 in a focus group)
- Survey: 70 responses overall

4.1. Overview of participant populations

4.1.1 Recruitment and attendance

Approximately 1150 text messages were sent from GP practices directly to individuals within the target population inviting them to take part in the project. This number is estimated as there may have been messages sent that were not confirmed with the HIN. Information and invitation to be involved were also shared via the HIN's Partners with People newsletter, southeast London Borough Healthwatch teams and the Diabetes UK involvement team. Potential participants were asked if they would like to take part in a one-to-one conversation or group discussion. They were also offered the opportunity to complete an online survey in addition to, or instead of, taking part in an interview or focus group. They were offered £30 for taking part in either an interview or focus group and the opportunity to enter a prize draw for a chance to win a £100 shopping voucher for completing the survey.

Interviews and focus group:

An information sheet was provided prior to sign up explaining the purpose of the work and what taking part involved. 86 individuals provided their information to be contacted about taking part in an interview or focus group.

Everyone who provided details was contacted via their preferred method to provide information and confirm involvement. When contacted, individuals were asked to choose their preferred option of focus group or interview. Interviews and focus group were offered online, via MS Teams. Purposive sampling was used for following up those who did not respond to try to ensure a representative sample of the SEL population. Information and a consent form were sent with the confirmation of agreed interview or focus group date and time. Individuals with type 1 diabetes or who lived outside of SEL were not included as we sought the views of people accessing primary care for their type 2 diabetes care in SEL. Table 5 presents the number of participants booked in for interview or focus group and subsequent attendance.

	Booked	Attended	DNA
Interview	30	26	4
Focus group	11	2	9
Initial total	41	28	13
<i>Re-booked to interview after not attending focus group</i>	3	3	0
Final attendance total		31	

Table 5: Booked and attendance

Online survey:

Seventy-eight survey submissions were received, of which 70 were completed from people within the correct age range accessing type 2 diabetes care in SEL. Of those completing the survey, 30 also attended an interview or focus group.

4.1.2 Demographic characteristics of participants

Some demographics have been combined or not included in the total number as the number of participants were too small (e.g. less than 5) to be presented separately or to be reported on in this report, as this would compromise anonymity.

Most participants were female, aged 35-39 years old and just under half identified as Black or Black British, Caribbean or African. The majority of participants were from Southwark which correlates to the known numbers of recruitment messages sent out in each borough. Almost half of the participants we spoke to were employed full time.

Interviews and focus group:

Thirty-one participants took part in an interview or focus group (29 in interviews, 2 in a focus group). Demographics of participants who took part in an interview or focus group are presented in Table 6.

Characteristic	Number	%
Gender		
Female	21	68
Male	10	32
Ethnicity		
White	10	32
Asian / Asian British & Mixed / multiple ethnic groups	7	23
Black / Black British, Caribbean or African	14	45
Age group		
26 - 34	14	45
35 - 39	17	55
Location		
Bexley, Bromley, Greenwich, Lambeth, Lewisham	9	29
Southwark* ¹	22	71
Occupational status		
Employed	19	61
Seeking employment, carer, student, other	12	39
Age of Diagnosis*²		
25 and under	8	32
26-30	6	24
31-35	11	44

*¹The highest number of messages sent directly to people with EOT2D was in Southwark

*²25 participants provided their age of diagnosis

Table 6: Demographic breakdown of participants attending and interview or focus group

Online survey

Seventy participants completed the online survey, their characteristics are presented in Table 7.

Characteristic	Number	%
Gender		
Female	47	67
Male	22	31
Ethnicity		
White	22	31
Asian / Asian British	13	19
Black / Black British, Caribbean or African	28	40
Mixed / multiple ethnic groups & other ethnic group	7	10
Age group		
26 - 29	7	10
30 - 34	24	34
35 - 39	39	56
Location		
Bexley, Bromley, Greenwich, Lambeth, Lewisham	24	34
Southwark* ¹	46	66
Occupational status		
Employed	44	63
Seeking employment, carer, student, other, prefer not to say	26	37
Age of Diagnosis		
25 and under	14	29
26-30	10	20
31-35	18	37
36 - 40	7	14

*¹ The highest number of messages sent directly to people with EOT2D was in Southwark

Table 7: Demographic breakdown of participants completing an online survey

Comparison to SEL

In comparison to the demographics of the wider SEL population, slightly more female and Black or Black British, Caribbean or African participants were recruited. Most other demographic characteristics were similar.

Characteristic	Number	%
Gender		
Female	2335	53
Male	2077	47
Ethnicity		
White	1303	30
Asian	987	22
Black	1474	33
Mixed	225	5
Other	244	6
Unknown	180	4
Age group		
19-24	265	6
25-29	557	13
30-34	1197	27
35-39	2394	54

Table 8: Demographic breakdown of participants 19-39 with type 2 diabetes in SEL

4.2. Experience of diagnosis

4.2.1. Interview/focus group

Individuals most commonly described their experience of being diagnosed with type 2 diabetes (T2D) using words such as 'shocked', 'confused', 'stunned', 'unexpected', 'worried', 'overwhelming', 'traumatic' and 'scary'. Many also spoke about their expectation and concern that the condition would worsen, they would develop associated complications and expressed feelings of inevitability that they wouldn't have a good life anymore.

I'd only ever heard bad things about type 2 diabetes because...and so obviously it's scary...when I got diagnosed with type 2 diabetes, I was like, I'm never gonna have a normal life again...I was just like, oh my life's over [participant 29]

Some participants reported the diagnosis being 'unsurprising' due to a family history of T2D but were surprised that they had been diagnosed at a young age. For others a diagnosis was not completely unexpected as they had previously had gestational diabetes (GDM), non-diabetic hyperglycaemia (NDH) or 'knew' something wasn't right due to symptoms.

In contrast a few participants were told that GDM was temporary and so were confused and upset when subsequently diagnosed with T2D. Diagnosis came out of the blue for some when having a blood test or attending hospital for something else.

Whilst a few described a 'straightforward' diagnosis or expressed apathy about it, participants generally reported having a negative experience.

I was never actually told that I was diabetic...until a couple of months later I got a letter saying come in for your annual diabetes check [participant 21]

This was because they felt the diagnosis was not clear, took a long time to be confirmed, or was not explained well.

I feel like my sort of journey to diagnosis was quite confusing to be honest [participant 22]

Support offered or provided at the time of diagnosis was variable. Speaking with participants it was difficult to clearly establish what support had been offered, what referrals had been made and what information had been provided. Many talked about referrals to courses, sessions and workshops. Those mentioned included DESMOND, Oviva, weight management, dieticians, and exercise/gym, however the majority still felt that the information provided and their understanding of diabetes and how to manage it could be better.

I feel like a lot of different things were discussed, but nothing was really... no information was given like I still don't know what I should be aiming for as a reading [participant 22]

Lack of support, information and understanding were common themes when participants were describing the support they received at or around diagnosis. Many participants didn't feel that there was much support or information provided and still did not understand the condition or management of it. The support frequently recalled was being given medication and/or advised to change their diet and being 'left to it'.

It was not really good experience for me and putting me on medication and they told me to exercise, eat well...that was it [participant 20]

It was like you've been diagnosed. We're giving you medication. That's it. And so yeah, that was the diagnosis [participant 18]

Due to this perceived lack of guidance participants went online or turned to peers for information including work colleagues, family and friends, particularly those living with diabetes. Some participants felt they had existing knowledge from the experience of their family and friends and others spoke about having to 'work things out' for themselves. For some this was a long time after diagnosis.

There wasn't any real like guidance given...I didn't really understand anything to be honest with you. I just knew that my [family member] takes insulin and I've got to take a tablet. So it's not that bad, but if I was to lose weight, then maybe it would go away. That was kind of how I was for a good couple of years until like, I decided myself to kind of like educate myself about, like, my condition [participant 15]

A few participants felt disappointed and disheartened that the focus of their diagnosis, and subsequent diabetes discussions about diet, was on weight and weight loss, rather than on managing blood sugar levels. Participants spoke about it being difficult to understand what they can and can't eat, and that advice given was not practical or realistic. Some spoke about not initially knowing that carbohydrate turned into sugar and so couldn't understand why their changes to cut back on sugar were not having an impact on their blood glucose.

It was also raised that assumptions were made about levels of knowledge. For some it was assumed they already had knowledge and information due to a previous diagnosis of GDM or NDH and felt this impacted on the amount of information they were provided with when diagnosed, whilst others spoke about assumptions about a lack of knowledge which resulted in feeling patronised.

I've gone to so many nutritionists, so I do have an understanding on food. But...that's more for weight management...Education and information about how food impacts on blood sugar levels, not necessarily just around weight loss. I think the focus is always weight which is... annoying [participant 10]

Throughout conversations participants acknowledged the amount of work GP practice staff have to do, the pressures they are put under with short appointment times and wider NHS pressures, and how this impacts on care provided. Some were also aware of a limited number of diabetes specialists being available at their GP practice, with one diabetes nurse being referred to as a 'one man band'. Whilst this availability created challenges for some, others felt they benefitted from continuity of care and a more holistic approach with someone knowing their full history.

It was actually my GP that diagnosed me, but he's a good GP but obviously he's, you know, constrained with time [participant 31]

I do feel that the diabetes nurses at my specific surgery, are quite stretched and the appointments are very kind of rushed [participant 14]

Positive experiences described, following (an often negative) diagnosis, centred around adequate time and clarity being provided; participants receiving an explanation of why this may have happened and what happens next, and feeling like they were able to ask questions and receive answers. A supportive environment, feeling cared for and a clear point of contact or named contact for queries and support was also seen as positive.

And because she gave me a lot of, you know, you can manage it, you can like, this is a lifestyle. Like she was always really positive all the way through... So yeah, I got quite a lot of support from my specialist [participant 26]

4.3. Barriers and challenges living with type 2 diabetes

4.3.1. Interview/focus group

Participants were asked about their own barriers and challenges, and those that other young adults (18-39) may experience. There was no clear distinction between individual and general challenges, therefore those expressed have been grouped together.

Stigma

Participants talked about the stigma attached to type 2 diabetes, particularly being diagnosed at a young age. Stigma resulted in reluctance to share a diagnosis or speak to other people due to feelings of embarrassment and self-consciousness, which for some impacted on their acceptance of having T2D and feelings of isolation.

There's a lot of shame and stigma attached to it. And amongst people my age and it's something that is preventable or maybe like a moral failure, so I'm kind of by myself, isolating myself a lot more, or feeling like I'm trying to hide a part of myself, or to manage it on my own [participant 16]

This included their own perceptions of the condition, for example feeling that acknowledging a diagnosis of diabetes was confirmation of not living well or healthily, being seen as vulnerable and not wanting to be seen as someone who is sick. A few felt embarrassed and disappointed as they felt it was their fault.

Look what you've done to yourself [participant 5]

Most spoke about the perceived views of others, including family and friends, which included belief that others view T2D is a 'self-inflicted disease' and would think 'you caused it for yourself'. This was related to assumptions about lifestyle

You're just fat and you're just unhealthy...you need to stop eating chocolate and sweets and start eating greens and fruit [participant 25]

and perception of disease, in particular T2D, being associated with older age groups.

I didn't really tell anybody that I had diabetes cause first of all, it feels like it's [an] older like it's a more mature disease...a lot of people that I knew growing up that had diabetes were a lot older...so I was embarrassed about that [participant 7]

Mental and emotional wellbeing

The impact of a diagnosis and of living with diabetes on emotions and mental health was frequently raised. Feelings of being down, disheartened or depressed were expressed.

Sometimes when I think that I have the illness, I hate myself...I feel down like depressed sometimes [participant 20]

There was worry about the future, what the long-term impacts might be and there was concern about complications and how they would cope with these. Some found information online scary, and this influenced denial and thinking about worst care scenarios. For those who had family members with complications or ill health because of diabetes, this was scary and caused anxiety. Whilst considering

the future was motivation to make changes for some, for others it influenced their acceptance of T2D and negatively impacted on motivation.

When you really look into it and the long term effects it has, if you don't manage it, it's quite scary and some people might not wanna face that. So, it's easier for them to just turn a blind eye and live as they are. So perhaps there's an element of not wanting to think about the future or the possible consequences [participant 9]

Keeping motivated to make changes, maintain a healthy lifestyle and avoid comfort eating was also a challenge for some. This particularly related to times of stress when less healthy options seem easier to make. Many were also aware of the impact of stress on blood glucose levels with one participant describing a loop of: stressful period - comfort eating sugary things - impact on health - feelings of guilt - stress effecting blood sugar levels. Maintaining motivation was also reported as challenging when there is not feedback available about progress or the feedback received is negative despite feeling that changes have been made.

Everything basically affects your blood sugar...I can't win...there'll be times when I've gone to have my like 3 monthly check up and I'm like, no, I've done really well and they're like, nope, still high [participant 15]

I'm going to have that piece of chocolate cake, cause why bother trying to be good if all I'm doing is starving myself and it's not making a blind bit of difference [participant 18]

Medication

Many participants would like to not have to take medication. There were challenges reported with forgetting to take medication, being 'bad at taking medication on time' and remembering whether or not they had taken it. Concern about the potential need to take insulin in the future was also raised. For those with other existing long-term conditions diabetes was not always the priority. There was frustration with having to add another medication and the way diabetes medication sometimes negatively interacted with their existing medication.

Side effects of medication, in particular metformin, were a challenge with descriptions of 'absolutely diabolical' and 'destroyed my insides' being used. The need to use the bathroom more regularly was particularly challenging when out of the house, at college or work. For some this affected how frequently they took medication, for example not taking it if they have to go into to the office or on a long journey.

I would love my blood sugar to come down, but I can't use the meds because I'm having really bad reactions to it so I can't use it [participant 10]

Not understanding medication and why it is being taken was also a challenge.

I don't really know why I'm taking medication or what it's for or what could happen if I continue taking this medication [participant 7]

Monitoring blood glucose

Participants who checked their blood sugar levels found this helpful in managing their diabetes, but the lack of confidence and understanding of what the numbers indicate was a barrier.

I'm checking but I don't know what I'm checking for [participant 31]

The pain and visible signs of finger pricking were off putting and embarrassing to some.

I would like to know, you know, if there's any improvement with the sugar levels, but ... the fact that I do it and then I see all these like needle marks in my fingertips. You know it, it just makes it feel like maybe I'm a... (drug user) or something...even though I know I'm not [participant 24]

Participants also spoke about the practicalities of using a blood glucose meter and/or needing to inject insulin around others or away from the privacy of home. This included forgetting to take or not taking a monitor out with them and also feeling embarrassed about checking blood glucose levels, with it being something you do not want to be seen doing, especially at a younger age.

You have to get it (glucose monitor) out, put it somewhere and then oh, you're diabetic. You know, you don't really want people knowing your business... I think that's the biggest challenge [participant 23]

Food and drink

Food and drink were common themes mentioned when discussing how diabetes had impacted on life. Making changes to eating habits was a challenge for most. Participants described a heightened awareness of food, being conscious and cautious of what they are eating all the time. For some this included being scared of eating certain things due to the impact it may have on blood sugar levels. Having to cut out food, being restricted and not being able to eat the things they want to eat or drink were all frustrations. Not previously having knowledge about the high sugar content of alcohol was mentioned in the context of socialising and 'bad' foods were seen as an easier, cheaper option and more readily available.

It is really difficult, especially if you're used to living and eating and being a certain way. It's a massive life change [participant 9]

The influence of peers, as well as advertising and the media, was also cited as a barrier to making changes.

It's easier to see junk food and it's more attractive than your healthy foods [participant 12]

It (making changes) is hard work and obviously a lot of younger people influenced by what's around them and their friends and that kind of stuff [participant 17]

Participants spoke about making lifestyle changes, in particular to eating habits, and were aware of and acknowledged their own responsibility in making changes to manage their blood sugar levels.

I don't really make substitutions as I probably should do [participant 7]

My HbA1C has kind of gone creeping up. So, it's been me as well not managing it [participant 17]

Social interactions

Linked closely to the theme of food and drink, the impact on relationships and going out with friends and family, and in other social situations such as office gatherings was highlighted. Including eating out less, not being able to be spontaneous and having to plan in advance how, where and what they are going to eat and drink.

Spontaneous isn't even an option for me [participant 14]

Participants talked about having to be 'careful' when going out and one spoke about considering whether they have been 'good enough' to go out. Choosing not to go out felt like letting others down which affected mental health. Being restricted in what foods and drinks you can have and not being able to have the same as others felt awkward for some and made them self-conscious.

I feel very restricted because I'm like, what can I eat, what can't I eat? [participant 10]

Participants also spoke about feeling judged by friends and family if they chose to have something sweet, or that people disapproved of their choices. They related this to other people's understanding of diabetes, including being encouraged to eat cake commenting 'what will it do' and unhelpful remarks being made.

That's one thing people always talk about. You're diabetic, so that means your foot can get cut off [participant 23]

Knowledge and information

Not having sufficient knowledge to manage diabetes was raised as a barrier. This included feeling that not enough information had been provided by health care professionals and sourcing the 'right' information for themselves was challenging and time consuming. A few participants spoke about the way in which information is presented and the language used being prohibitive for people and not catering for different ways of learning, cultures and disabilities.

When I've gone to look up websites and stuff, there's a lot of like jargon around it [participant 15]

Challenges with accessing or attending educational sessions offered included lack of childcare, not being able to attend during working hours and feeling that support and information is not presented for their age group. A few people expressed frustration that they would like to do something, but alternatives had not been offered.

I haven't attended, but how it's been presented, it's like it's presented as a as if it's for older people [participant 16]

Being the youngest in a group was also an experience of attending the NHS Diabetes Prevention Programme (NDPP) or similar, which for one individual re-enforced a view that due to age they had time and could begin to make changes at a later time.

I went on to a program and it felt unusual because the people on the program were much older than me...And I felt a bit odd and out of place there because I was the only person my age and 'cause I've got this in my head that I've got youth on my side [participant 11]

Physical symptoms

Participants spoke about tiredness affecting their day to day, making it hard to exercise and lowering productivity levels. Others also spoke about experiencing pain or symptoms but not knowing whether these were side effects of medications and/or hyper- or hypoglycaemia and not knowing 'why' they were feeling this way. Some participants also talked about being hyperaware of feelings and sensations and being concerned that these were indicating complications associated with diabetes impacted on some.

Things that have always been there - I sort of second guess [participant 21]

Personal resource

Time to concentrate on making changes was a barrier, the two main reasons being work and for those caring for children, the needs of children being the priority.

It's like you don't think about yourself when you're looking after (your child). So, I haven't managed it (diabetes) as well as I should have managed it all [participant 17]

For those who worked shifts or who had busy, long days reported finding it difficult to eat regular healthy meals and often resorted to snacking. There was also conflict between being told they had to eat meals regularly or at certain times by health care professionals and feeling able to accommodate this within working daily life.

Money and the cost-of-living crisis was a factor mentioned by many participants as a barrier to accessing gym or exercise classes and in being able to make healthier food choices. For some it was also a barrier to being able to monitor their blood sugar levels as they would like to use continuous glucose monitoring, but as this was not provided, cost was prohibitive. Participants acknowledged the benefit of not having to pay for diabetes medication and one participant shared that, because they no longer took diabetes medication they had to pay for other prescriptions, and this was a challenge.

4.4. Barriers and challenges in attending diabetes care appointments

4.4.1. Interview/focus group

Almost all the individuals we spoke to were attending the diabetes care appointments that were offered to them, with the reported frequency of the appointments varying between individuals. There was varying knowledge of an annual diabetes review and what that involved. In general, most attended because they felt they had to for their health and whilst not necessarily wanting to go, or knowing why they were going, they understood it was important to attend. It was also felt attending was the only way to know what was going on, to know where their blood glucose level is and if anything is wrong. Whilst most attended the appointments offered there was still uncertainty about what they 'should' be being offered, how frequently they ought to be attending and why some of the tests are being done.

For those who did not attend appointments they felt they had not been offered one, it was not their top priority at the time (childcare/work/study more important) or were unable to leave the house due to other health reasons. People with multiple conditions were seen by health care professionals more frequently and it was difficult to separate out comments about diabetes appointments as tests and checks were often done opportunistically when being seen for other reasons.

Appointment times

Timings of appointments were important, particularly for those who worked, who felt that appointments being first thing or last thing to minimise impact on the working day, or even on evenings or weekends, would be helpful. Appointments in the middle of the day or at short notice were difficult to attend. Availability of appointments was cited as one of the biggest barriers with available slots taken quickly and limited times and days available to see diabetes specialist clinicians.

*It's finding time with (the diabetes nurse), so if I for example can't make that particular appointment, it's a bit of an **** trying to get another appointment with (them) [participant 10]*

Booking process

The process of booking appointments was also raised as challenging with some participants preferring to book online or through an app and having the autonomy to view options and choose their own appointments. If an appointment was offered or made for an individual the ease of communication between participant and surgery to book or change an appointment was also important. Having multiple appointments in various locations was also raised as challenging, with preference being for one appointment. Appointments were described as 'scattered'.

It's quite broken down and it can be a bit time consuming [participant 11]

Associated emotions

For some, feelings of embarrassment about speaking to practice staff were barriers to booking appointments.

Because of my age... I feel embarrassed or I feel a bit, um, anxious when I have to reach out to someone for help, especially if I have to do it over the phone [participant 4]

Emotions associated with attending diabetes care appointments was also a barrier. They felt sad about attending, worried about going and expecting bad news.

Found it a bit scary...you don't want to be told that things are going bad [participant 20]

They spoke about not really knowing what was going to happen at appointments, needing to build themselves up and needing to 'steel' themselves to advocate for themselves.

Should I ask for this time or should I just let it go and just do my own thing and find my own help and resources [participant 16]

Others also spoke of embarrassment in attending the GP practice and feeling ashamed of their eating habits, avoiding sugar a few days before the appointment.

the anticipation is not good, (at the practice) sometimes I look at the age groups...sometimes I may be the...youngest person there, I think to myself...is there something different wrong with me [participant 24]

Appointment approach

Participants also described negative experiences of review appointments which resulted in them being reluctant to attend. For example, feeling reprimanded:

A discussion telling me that I'm not doing good enough...I find them intimidating because it's almost like it's always focused on what you're doing wrong...and not what you're doing right...it's not encouraging. It's almost as if instead of the support, it's being judged and scolded [participant 14]

Or that the appointments felt like a 'tick box' exercise without any discussion:

I feel like it's a bare bones thing...it's a report that they're reading [participant 4]

It was like 5 minutes, in, out, done. It wasn't...how you coping with it? Is there anything that that's worrying you? Is there anything that with medication or stuff like that, there's no questions at all [participant 25]

4.4.2. Survey

Ninety per cent of respondents reported to have been to their GP for a diabetes check up in the last 12 months, with 10% reporting 'no' or 'I don't know'. The top reasons selected (from a list) for not attending included 'I am too embarrassed to go', 'no one contacted me about needing a check-up' and 'I have been to a diabetes check-up appointment but it wasn't at my GP practice'. Also selected was 'I was not able to get an appointment' and 'I have not needed to go'. Another reason provided was they were due an appointment.

When asked 'what makes it difficult for you to attend diabetes appointments at your GP practice?' **timing and availability** of appointments was reported as the biggest barrier, particularly due to work schedules and childcare.

I work full time and mostly run during work hours, booking is difficult and there is a long wait [response 22]

Mental health was also a barrier for some with anxiety, depression, fear and agoraphobia mentioned, along with the **stigma**, shame and embarrassment associated with having and their management of diabetes and acceptance of the diagnosis.

Accepting that I have diabetes each time I'm reminded to visit the GP [response 19]

When I know my diabetes isn't very well controlled [response 29]

Physical health barriers and forgetting appointments were also reported. A few also reported feeling they would like **more engagement from health care professionals** as they were not feeling listened to or taken seriously and having to find out information for themselves.

I have had blood samples, but little follow up with the GP. Getting an appointment is hard, have definitely felt alone since diagnosis and been doing a lot of research/learning alone [response 55]

Twenty eight percent (28%) of responses to this question indicated no barriers to attendance.

Nothing. The people in my surgery are very helpful [response 45]

Nothing, my GP practice is always helpful [response 54]

4.5. Ways in which diabetes care could be improved

4.5.1. Interviews and focus group

Ease of access and availability of appointments

Participants spoke about challenges in booking or changing appointments and in limited availability both relating to time and days. They suggested appointments that are early or late so that the amount of work time affected is minimised. Availability after hours or Saturday appointments i.e. outside of (standard) working hours would also be welcomed. Autonomy to choose their own appointments, rather than be sent one or offered one available by a reception team, was important, particularly for those who had experienced challenges in changing their appointment or felt nervous or embarrassed about phoning the practice/speaking to someone. Online booking was suggested as well as the option to do appointments online if a convenient in-person appointment was not available (the challenge of needing blood tests was acknowledged).

if they could make it more available online, but I guess it's almost impossible because they have to do blood tests [participant 10]

Participants found (text) reminders for appointments very useful, particularly when appointments are booked in advance.

Also relating to accessibility, one participant mentioned a dislike of public bathrooms, impacting on their likelihood of submitting a urine sample when at the surgery. They would prefer to do a urine sample at home prior to the appointment and bring it in. There was also embarrassment associated with having to give information and a urine sample at front desk with others around.

Prevention and earlier intervention

Some participants would have liked information and education about diabetes earlier on in life and a few felt diabetes could have been prevented if they knew about it earlier on. One participant spoke about different cultures and attitudes towards health, feeling that they were raised without awareness as being 'fat' was seen as positive as it was evidence of good living. It was suggested that more awareness was important to help them avoid developing diabetes, for example using a social media campaign providing information that made people aware of the importance of being healthy and going to checks, but without alarming them.

We could educate people through the power of social media, which would then benefit us as a society. So then we wouldn't need to have to go to, you know, a doctor's appointment to say, well, I think I've got this wrong [participant 2]

Awareness of symptoms for the public, but also for other health professionals, was highlighted as being important so that these could be picked up and diagnosed earlier. An example provided was sexual health clinics having more awareness about recurrent thrush as a symptom of diabetes.

We teach people that if you feel something is wrong with your body, don't sit there in silence [participant 2]

Participants who had NDH felt the information provided or available at this point could have been better, particularly knowing what they knew now about diabetes complications.

When I was told that I had prediabetes literally, I was just told...I know I could have done something myself, but I just, I just didn't understand it [participant 3]

Approach to appointments

More information about appointments and what they would involve, including explanations about why the tests and checks are being done was seen as positive. Many felt that knowing more about what's involved and why it is being done would help with motivation and reduce anxiety about attending. This also included more explanation about medication, why it is being taken, what it does and whether there are any side effects. Individual tests were not discussed however a few participants mentioned that they did not know why their feet were being checked and would like more information about what was being done and why. It was suggested this would be helpful early on in a diagnosis.

It was suggested that more structure would help, such as having a clear plan outlining the number of appointments to attend, who they would be with and what they will be checking. It was also suggested that being provided with a medication and blood glucose timeline, about where they are now, where they should be and what happens regarding medication moving up or down the timeline could help

with understanding and motivation.

It was also important to many participants to better understand the results of the tests that were being done and showing progress over time.

Sometimes I'll do a blood test, but I don't really have anybody kind of going over the results with me and like explaining it to me and you know, just kind of maybe comparing it to like where I was before or something like that to just show the improvement so that I could understand it for myself a little bit better [participant 7]

Participants also spoke about the disconnect between being told or knowing what to do and actually putting that into practice. For example, participants spoke about being told to reduce sugar and knew they needed to, but didn't know how to do this. It was felt that discussing practical and realistic changes and tips would be helpful.

I want to do everything for me to, like, be free for medication, but I don't know how [participant 20]

More regular check ins and monitoring

Participants felt that a lack of information and support impacted on motivation to make change and that this could be overcome with more regular contact.

Maybe people don't take it seriously because they don't get that support...If I can't find information online, I would like to be able to speak to someone about it and not wait 2 weeks [participant 26]

Most participants felt that more regular check-ins to see how they were getting on would be beneficial. Participants thought this would make them feel more cared for and supported and felt that with more regular contact, they would be able to have a better understanding of diabetes and how to manage it, be able to ask questions that they wanted answers to, but also to make them more accountable for their actions and any plans that were put in place.

I think maybe if there was a little bit more contact or personal touch, people might want...to do more about their diabetic care because they feel like, OK, well, I have to be accountable [participant 9]

Being able to share what they had done and then have feedback was important for some and it was highlighted that if there is a long time between appointments recall becomes an issue and it is harder to have a good conversation about what you have and haven't done. It was felt that regular check ins would help with understanding what actions had a positive and negative effect blood sugar levels and would help with breaking down goals into more manageable, progressive ones.

I just ignored the fact that I had diabetes and didn't necessarily act on it in the ways that I should have, and I do feel if there was more follow up appointments available at the time. Maybe I could have got my head around it a lot sooner [participant 14]

It was suggested that contact didn't have to be an in-person appointment and could work well if offered as an online check-up so people could more easily attend and be checked on remotely in between tests. Participants spoke about support from pharmacists, and also via apps which had been helpful. Trust and confidence in a clinician's knowledge and the information they were receiving was highlighted as important (i.e. the support did not have to come from a GP or nurses specialist).

[I] think GPs need more people to help with getting through to people and supporting people on that journey [participant 26]

Participants spoke about the potential for an app, or an online option or portal, that would help them monitor and manage their diabetes, but that also allowed them to interact with health care professionals. Something easy that you don't have to be too 'tech savvy' for. Functionality suggested included recording or logging what they have done, to help with scheduling and planning, reminders or alarm system for medication and booking and attending appointments, being able to see or monitor progress, a food diary, food and alternatives or swaps (ensuring it reflects diverse cultures and what people 'actually' eat), as well as useful articles and information about living with diabetes. It could also be an online community for peer support or something that helps people to feel like they are not alone. It was also suggested management could be turned into a game with fake prizes or badges on the phone. Many also spoke about being able to submit or report information that can then be seen by a GP (or HCP), reviewed and feedback provided.

But it's good for my own benefit logging it and being able to go back and see it and be like, right, ok, that spikes my blood sugar, that didn't. And then kind of making the adjustments myself. But if there was somebody there to kind of like review that as well and kind of bounce off, I think that would maybe be easier [participant 14]

Understanding and monitoring blood glucose levels

Many participants thought it would be helpful if they were able to measure their blood glucose as they thought it was important to be able to be more aware, to monitor and see progress of blood glucose levels. This would help them to learn and know what to do and what was working or not.

You can look back at it and say, well my life was this way, or I was doing these things throughout this time my sugar level was down [participant 23]

It gave me that kind of and starting point or that basis that helps me to...know if I have this in the morning, this is more likely to spike my blood sugar, if I have this, those sorts of things [participant 9]

Some had bought their own glucometers. Ideally testing kits or CGM would be on prescription, especially at the beginning or early in diagnosis. Information about blood glucose levels and HbA1c and understanding the numbers was seen as important.

Even though it's (HbA1c) on the NHS app, you still don't really know what is what [participant 30]

Participants felt that the prescription of CGM would be most beneficial and that this would overcome having sore fingers and help those with a fear of needles. One participant spoke about moving to insulin and that the only positive thing is being able to monitor their blood glucose better now they are provided with CGM.

They help so much. And that is one thing I'd say like I feel like everyone with diabetes should have, but they don't give it to everyone [participant 23]

Another participant spoke to us about how they found CGM much easier, more convenient and it made them more likely to make lifestyle changes, but cost was a barrier. They have a glucometer but doesn't use it as the process takes too long and they forget to take it out.

I found (trailing of CGM) was helpful to monitor my diabetes and I think also me knowing what my blood sugars are, made me more likely to change things that I was doing [participant 17]

A positive approach

Participants felt that a more positive and encouraging approach to appointments would foster more motivation to attend appointments and engage with care, rather than feeling like they are being 'told off' and told what they are doing wrong.

I feel like if it's more focused on the things that I'm doing right, it would kind of make me want to improve the things that I'm not quite doing as well as I could be on [participant 14]

This was also reflected in comments made about lifestyle change discussions, in particular relating to food and drink, that preference would be to be provided with suggestions for alternatives about the things that they should have less of, rather than being told what they can't have. Some participants felt that this would help in a practical sense, knowing what changes could be made, but also to manage emotional response (pushing back on being told what you can and can't do).

Just knowing that there's other things cause at that age just being told like you can't do this, you can't do that... I was just like, I'm gonna do it anyway [participant 15]

Participants felt that they didn't hear any positive things about managing diabetes, that there is too much 'doom and gloom'. A few reported that even friends or family they thought of as managing well would be told they are not doing well enough. Some suggested that positive 'real life' case studies would be beneficial and that sharing stories of people doing well, that they could relate to, would provide motivation, hope that progress can be made, and that there are some things that can be controlled.

Some participants were also aware of being able to go into remission however for the most, this had not been discussed at diabetes appointments, for example, one participant had learnt about it from a colleague at work. Many were keen to know more about this and whether it was possible.

I feel like a lot of people when they're diagnosed diabetic type 2 and we all think that it's a life sentence and like there's not enough information out there about remission and that you can get rid of it [participant 12]

A holistic approach

Feeling listened to was raised as being important to foster motivation and engagement:

Other people my age might be put off, put off engaging with their health care as well because we might not feel listened to as well...you have to advocate for yourself and how exhausting that can be [participant 16]

Positive experiences were expressed by participants who felt they had trust and a rapport with their diabetes clinician. Seeing the same person who knows an individual and their history was described as beneficial as they understand and know what's going on, can see improvements and suggest changes. One participant felt lucky as they were able to call the GP practice when they needed to and had a particular clinician they could go to, recognising that that was not the case for everyone.

My doctor's gone out of her way to really build a rapport with me over the last 10 years [participant 10]

A few participants expressed frustration when they felt the time had not been taken to understand them or their situation. They felt it was important to find out what someone already knows to avoid being patronising and so that conversations can be productive. It was felt that everyone should be looked at as an individual, and personal circumstance such as work and childcare taken in to account. It was

suggested everyone needs their own targets and referrals and support should be based around that, not just generic advice provided.

Work with me to make a plan that's realistic for me and not a textbook [participant 22].

A few participants reported being 'pretty happy' with the care they receive. These comments generally linked to feeling cared for, having a good relationship with a diabetes specialist clinician where they felt able to ask questions, having test/checks explained and receiving feedback about the results. Having previously had negative experiences and feeling like they were on a 'conveyor belt' one participant spoke very highly of a more recent experience and when asked what was good explained:

They actually sat me down and said to me what she was doing and what it was actually for. She sat down and said to me, look, this is what's the cause, this is what's the issue, we need to get this resolved...she actually took the time. She was catering for the person rather than the generic...What I felt last time was that they was just ticking the drop down boxes. She actually took the time and the effort to actually review everything and explain [participant 25]

The importance of feeling able to speak and be listened to was also reflected by some final comments made.

I think this is like the most I've ever talked about my diabetes...because normally at the GP it's not as interactive as this and I feel like this sort of interaction is nice [participant 24]

It's actually helped speaking to someone really, about it that actually wants to know. Who's interested in how it's actually affected someone [participant 25]

Self-education

Participants acknowledged the need for self-learning as the NHS does not have time to 'spoon feed' people, but that health care professionals could clearly signpost them to good sources of information. There was a large appetite for knowledge about, and understanding of, diabetes and how to manage blood sugar levels. The importance of information being easy to access, in one place and in different formats to suit learning needs and levels of education was highlighted. As well as considering different language and cultures. Participants generally felt that information needs to be plain and simple, easy to digest and relevant to young people. Possible shorter attention spans were also highlighted as needing to be accommodated.

Participants were motivated by different things and felt that having one place to go for information, where they could then choose the things that mattered to or motivated them, would be helpful. For example, being told about the potential complications of diabetes had impacted negatively on mental health and influenced denial/acceptance for some.

But it's also giving somebody the right tools and equipment to be able to do that and they're not all gonna be the same for that individual because of their lifestyle and because of the way they've lived, they're upbringing [participant 2]

Avoiding misinformation

Many spoke of having lots of unanswered questions and wanting somewhere to go or someone to talk to when these questions crop up in between appointments. This included questions about diabetes such as what type 2 diabetes is and whether it can change to type 1 diabetes, and also questions about day to day life such as filling out forms asking about medical conditions, having certain beauty treatments or getting a tattoo. A fact sheet was suggested rather than searching online where it was felt

this are sometimes contradicting stories.

Although many felt that an online resource or app would be acceptable some also felt written information would be helpful to take home, particularly after the first appointment to help them to digest the information.

Peer support

Participants spoke about feelings of shame and embarrassment and not feeling able to speak with friends and family. This caused feelings of isolation and managing diabetes alone felt like a burden. It was suggested that opportunities of peer support such as a lived experience champion (similar to a mental health model), a group setting or forum would provide a better support network. Many participants thought that being able to talk to other people of the same age, going through the same thing or at the same stage of their 'diabetes journey' would help with understanding, loneliness and addressing stigma. A space, such as a local community group, where a group can come together to connect, do activities, have fun, talk about concerns, learn and understand other people's perspectives of what's going on and how diabetes can be managed was seen as beneficial. A few also thought it would be helpful to have a medical professional present or therapist to talk about diabetes, answer questions and how it can affect your life.

I went on the Desmond course, I was the youngest person there...I would have loved to kind of feel like you're going through that journey with someone else...But people don't understand when you're diagnosed really young...you can still make changes [participant 26]

4.5.2. Survey

Improvements in the **flexibility, availability and timing of appointments** was the most common theme that survey respondents felt would help them or make them more likely to attend appointments. This was focused on accommodating life and work schedules such as having early or late appointments and weekend appointments, as well as shorter waiting times and more availability.

I attend all my appointments as best I can fit them round my work schedule, but appointments available on a Saturday would help [response 28]

Ease of booking such as incorporating online booking and improved **accessibility** such as phone or video appointments and reminders were highlighted as important, as well as more regular appointments, better efficiency in appointments, and better access for disabilities.

Tests and checks relating to diabetes could be carried out in one appointment rather than a million appointments [response 48]

Comments made about how appointments could be improved mostly focused on **increased contact and interactions**. More regular appointments with better availability/accessibility (including receiving reminders/prompts) and more time within appointments were seen as improvements.

A lot of information is discussed so a follow up call/check in after the diabetes check-up would be useful [response 52]

They could be more regular and more in-depth, reviewing medication properly [response 35]

In addition to this, **more information** being provided about diabetes management and lifestyle changes would be an improvement, particularly taking a holistic view, tailored to the needs or other conditions of the individual

To be honest, since being diagnosed I have been going at it alone. There has been some box ticking appointments, but non-existent in terms of information, what it means etc. [response 55]

I would like more information regarding how to manage my condition, but I understand that the doctor has a small amount of time for each appointment [response 34]

It is also important that this information is accessible as well as one respondent told us one challenge was understanding the terminology used in appointments.

Peer support or a group was suggested as a helpful way more information could be provided

The team are helpful but provide the bare information. I assume as to not overwhelm people, so I think a group session where you can talk to others would be really useful [response 28]

Addressing stigma around diabetes was also raised by respondents as something that needs to be considered to support mental health and motivation to manage.

More talking about it. Feel like it's shameful [response 7]

Changing the stigma that T2 people are just fat, lazy and eat badly. This has a huge impact on my mental health when I discuss being T2 with others [response 56]

The survey also asked what would make them feel more confident and able to self-manage their diabetes. Respondents were given a list and we able to select all that applied to them. Table 9 presents the number of times each option was selected

Table 9: Options to improve self-management

Option	Count
More education/better understanding	40
Digital apps/online services	40
Being able to do test and checks (usually done at GP) at home	38
Being able to monitor blood glucose (blood sugar)	32
Other (please specify)	14

Within 'other' suggestions included:

- Access to new medicines/interventions
- Understanding how different conditions impact on the other(s)
- Access to support/someone to speak to outside of appointments e.g. when blood glucose isn't stable
- Discussing management other than weight loss, taking the whole person into account (e.g. considering women's health)
- Diet/lifestyle changes information and advice
- Access to continuous glucose monitors
- Group sessions (shared experience, accountability, with similar aged individuals)

4.6. Support for psychological and social needs

4.6.1. Interviews and focus group

Throughout conversations participants shared mental health concerns in general, the impact diabetes has on their mental health and acknowledged the impact their mental health has on managing diabetes.

I've always said to them like my mood is not great, which is why I don't feel like I monitor my diabetes and do what I should with my diabetes as well as I should because I've got a lot of stuff on my mind [participant 17]

Participants were asked if a healthcare professional at their GP had spoken to them about their mental health in relation to diabetes or during their diabetes appointments. Participants had generally not been directly asked about their mood or mental health during diabetes appointments. If they had been asked it was usually because they had existing mental health concerns and those who had accessed mental health support had done so for other reasons. Most participants felt they knew how to access mental health support, but options mentioned were limited.

Participants felt being asked directly about their mental health would provide better support.

If you ask explicitly like how is your mental health? Like how you coping with everything? Then that opens up the conversation. But if you're not really asked directly, you're not really going to talk about it [participant 7]

They also suggested they would like to have more awareness of services and how to access them, with support offered particularly around diagnosis to help reduce the stress and fear that may cause.

It can be a very stressful, especially when you first get your diagnosis, you could feel like all your whole life is over and it did cause a lot of anxiety for me personally [participant 8]

Many participants also felt it would be helpful to know that there was someone they could call or speak to. Some felt it would be beneficial to speak with someone specifically about diabetes and that perhaps having a specific service would result in a reduced waiting time.

Somebody that you can talk to that is kind of trained on diabetes and understands everything like a medical perspective [participant 14]

The potential for peer support or group support was also strongly suggested as the importance of a platform for sharing views, tips, feeling heard and speaking to other people who understand or 'get it', don't make you feel different and are experiencing similar situations was raised. This was particularly important if people didn't have or feel able to speak to friends or family.

Having a community of people that, like, understand, like what I'm like, where I'm coming from and what I'm going through [participant 15]

Participants were also asked about other things that might affect their health and wellbeing. Diet, eating, exercise and weight were mentioned frequently however participants generally felt that other social needs were not raised at appointments. One person had been referred to a lifestyle coach (by a pharmacist) which they had found beneficial.

They always only talk to me about food and stuff like that. They don't talk to me about anything else...It's always like the doctors look at me and it's always got to be food related [participant 29]

Participants were aware that stress and possible causes of stress such as jobs, study, bereavement, caring responsibilities and finance could impact on their ability and motivation to manage diabetes and blood glucose levels. Money in particular was cited as problematic when wanting to buy healthy food

and eat healthily and participants were thankful that they did not have to pay for medication.

There were few suggestions made about how social needs could be supported other than ensuring a support system is in place and asking directly about other things which may be impacting their diabetes management.

I think a bit more understanding about how it's not always just your diet or your diet can't be maintained all the time because of certain other aspects [participant 17]

4.6.2. Survey

Thirty-three per cent (33%) of respondents selected that a healthcare professional at their GP practice had talked to them about their mood or mental health (33% responded no, 4% preferred not to say) and 49% had been told about, or offered a referral to, mental health support services. The majority were referred to or were told about talking therapies (IAPT). MIND or other charities, leaflets or written information about mental health or an app or online support service were the other selected options. Twenty seven percent (27%) accessed additional mental health support services. Of those who did not access further support (21%) reasons given included appointments not being at a suitable time, not thinking it would be helpful or was needed, being too embarrassed or nervous to go, a long waiting list, appointment(s) cancelled, or no follow-up made.

When asked whether a healthcare professional at their GP practice had talked to them about other things that might affect health and wellbeing such as what you eat and drink, jobs, money, housing, family and friends etc., 51% felt this has been raised and 29% were offered further support. Additional support offered most frequently recalled was weight management services and dietician referrals. A few (n=10) selected that diabetes structured education had been offered and n=6 selected the diabetes remission programme. Other additional support recalled included peer support, social prescribing or health and wellbeing coaches, and physical activity groups or classes. Thirty-four per cent accepted the offer of additional support. Some felt that more support could be offered and there was a lack of support about 'other issues that can affect a person taking care of themselves'.

I think further information needs to be given in relation to the other things that can affect your diabetes for example stress [response 34]

4.7. Raising contraception and planning for possibility of pregnancy

4.7.1. Interviews and focus group

The majority of participants felt that contraception and planning for possible pregnancy had not been raised during diabetes appointments and there was little knowledge about the impact of diabetes on pregnancy. Existing knowledge tended to be due to previous pregnancy and developing GDM where the impact of diabetes was discussed in hospital, from their own reading, or because a family member or friend with diabetes had been pregnant.

Contraception was always pushed rather than the conversation around getting pregnant or having a baby [participant 14]

Few people we spoke to had discussed pregnancy and contraception in relation to diabetes with a health care professional at their practice. When it had been raised by the practice this was due to starting a medication that would need to be stopped if they became pregnant, and to ask them to inform the GP if they were planning to become pregnant. Otherwise, it appears conversations were raised by people with type 2 diabetes.

We acknowledge that an individual may already be on a contraceptive and be a reason for the topic not

being raised at diabetes appointments.

4.7.2. Survey

Participants were asked if they were a person who could become pregnant. If they responded yes, they were presented with questions relating to pregnancy. Those who responded no or indicated that they would prefer not to answer questions relating to pregnancy moved on to the final questions.

Forty-six per cent (46%) of respondents (n=32) felt able to respond to questions about pregnancy and contraception. Of this:

- 84% were aware that type 2 diabetes can have an impact on pregnancy
- 31% had had a conversation about pregnancy planning or contraception with a health care professional at their GP practice
- 28% had been provided with information about what to do if they were planning to become pregnant (59% had not been provided and 13% were not thinking about becoming pregnant)
- 19% had been provided with information about what to do if they are/become pregnant (56% had not and 25% reported to not be pregnant)

Respondents were also asked whether they had been referred to a specialised service if they were planning to become pregnant or were pregnant. Thirteen per cent (13%) selected that yes, they had been referred, with 38% responding no (the remaining were 'no response' or it was 'not relevant').

5. Conclusions

Thirty-one participants took part in either an interview or focus group and 70 participants completed the survey. Most participants were female, aged between 35 to 39 years old and identified as Black or Black British, Caribbean or African ethnicity. The majority lived in Southwark and were employed full time. For those who reported their age of diagnosis, this was most commonly between the ages of 31 to 35.

A few participants told us that their diagnosis of type 2 diabetes was straightforward. However most described a negative experience. This appears to be due to a lack of structure and clarity in the diagnosis leaving them confused and unsure how to manage. Whilst participants did recall receiving some resources and referrals, the majority still expressed that they would have liked more support and information at this time. This suggests information being provided is not being received/absorbed by the individuals and/or is being provided at the 'wrong' time. Lack of support, information and understanding were mentioned in most interviews and so reviewing the point of diagnosis could be a high impact area for improvement.

A diagnosis of diabetes and living with diabetes were associated with negative emotions and participants attributed this to feelings of low mood and poor mental health. Participants felt that it would be beneficial for mental health to be directly asked about to prompt them to talk about it, as some felt they would not raise concerns otherwise. Stigma associated with a diabetes diagnosis led to feeling embarrassed and unable to share a diagnosis. This resulted in feelings of isolation and decreased wellbeing, as well as reduced self-management and attendance at diabetes care appointments. This included a participant's own perception and belief about diabetes as well as of those around them. For some this included feeling judged by healthcare professionals. There is opportunity to address associated stigma, negative connotations and feelings of inevitability (life is over, things will get worse)

through the approach to appointments, information provided and via peer support.

Many felt that having more opportunity to speak with people of the same age, with the same condition, would be beneficial and improve confidence, to share experience, learn from each other and reduce feelings of isolation. For those who attended structured education, it was felt that this was directed at an older age group compounding feelings of being different. There may be potential for opportunities to offer peer support through existing pathways such as group consultations for a specific age range and engaging with local community groups or diabetes UK to signpost to appropriate group support, as well as considering tailoring structured education for young adults.

Participants were aware of their own responsibility in making changes however felt that there was a lack of practical knowledge and support. Participants knew that they needed to manage their blood sugar levels but did not know how to do that in day-to-day life. It was clear that this population group would appreciate more time being provided and clearer structure to their diabetes care. Participants spoke frequently about their desire to have more information and to understand and manage their diabetes better and felt that more regular contact would be beneficial to support them to do this. There was a suggestion to have more frequent appointments or check in points and the opportunity to ask questions when they had them. This doesn't necessarily need to be an in-person appointment with a GP or diabetes nurse, but a form of contact where feedback and support is received. Participants suggested that, as long as there was trust in the individual and their knowledge, there was not a need for the person to be clinical. This could provide opportunity to consider how other roles, or digital options, could support an individual's diabetes management.

Overall participants felt that psychological and social wellbeing, as well as contraception and pregnancy planning was not raised by health care professionals within diabetes care appointments. More structure and time provided may help to ensure that these topics are raised appropriately. The ability to monitor blood glucose levels was also seen as positive for many as they felt this would help them learn about what impacts on blood glucose levels. Availability of continuous glucose monitoring free of charge would be welcomed. Whilst there are clear restrictions in this area through NICE guidance, there could be potential to investigate a pilot in this area to understand the impact of being able to monitor blood glucose on the management of it.

A clear theme throughout was the desire for a more supportive and motivational environment rather than what is perceived to be a punitive one, being 'told off' at appointments with the focus on what they have been doing wrong. Being provided with practical alternatives rather than being told what they couldn't do was seen as a more motivational approach. This includes the potential for remission, where appropriate. There was also a wish to avoid the focus being on weight all the time. Participants spoke about wanting to hear positive case studies and success stories and to be able to see their own progress. It was also felt that having more information about appointments would support motivation and likelihood of attendance, knowing why they are attending, what they should expect and to allow for preparation. This links with the desire of participants for a more holistic approach to care. The importance of considering an individual's personal circumstance and how this may impact on their motivation and ability to make changes and manage their diabetes was highlighted. Reviewing appointment structures and potential approaches (such as Year of Care) to provide more time to enable this approach would be beneficial.

There was also acknowledgement of the capacity of primary care and a willingness to find out their own information. Participants spoke about having to find things out for themselves but that this was challenging and time consuming and increases the risk of potential misinformation. It was suggested that having one place to go for information would be helpful, which could be online or via an app, but that knowing where to look for information, that was trusted, easily accessible and relevant was important.

Flexibility, availability and timing of appointments was also a challenge they felt could be addressed. Timing of appointments was particularly relevant for those who worked and/or were a parent or carer. Restricted days and times that appointments are offered are a barrier and appointments that were outside of working hours would be beneficial. Ease of booking was also highlighted as being important in attending appointments, with suggestions to be able to book and change appointments online as well as via the phone. There should be flexibility in the way in which appointments can be booked and changed to accommodate preferences and consideration could be given to increase the booking options available, for example availability of online booking or the use of the NHS app. Whilst this was an important theme raised and one which should be reviewed it is not specific to this population and so no recommendation has been made regarding this.

Participants also reflected on how they would have liked to have had information earlier. People who had been diagnosed with NDH didn't feel like they had been provided with support at this stage and had not understood the consequences of not making changes at that time. There is potential to address this through ensuring sufficient time is allocated when an individual is diagnosed with NDH to explain what it means and what they need to do to manage it and in supporting attendance at the NDPP where possible. Consideration could be given to the acceptability of NDPP programme for young adults and also in identifying people who are at risk of developing T2D at a younger age to ensure early diagnosis and management.

It is important that training and support is provided to healthcare professionals along with any of the considerations provided above.

6. Limitations

This lived experience insights gathering exercise successfully collected qualitative data from 31 participants through interviews and a focus group and collected 70 responses to the survey, with representations from all six south east London boroughs. However, there were some limitations:

- The majority of people with type 2 diabetes aged 26 to 39 in SEL was not directly sent information inviting them to take part in the process and a large proportion of those sent messages chose not to take part.
- The majority of direct messages sent from primary care to people with EOT2D was in Southwark and this is reflected in the demographics of the group who took part. We understand there is a similar approach to diabetes pathways across SEL however we are not able to say these insights are representative of people with EOT2D in other boroughs
- The timeframe in which this exercise was done limited the methods of recruitment and of collecting data, for example we were unable to recruit through community organisations and were unable to arrange in person focus groups
- All methods of data collection were done online via survey or MS Teams
- The majority of the people with EOT2D we engaged with reported to be attending diabetes care appointments. We were unable to collect perceptions from people with type 2 diabetes who tend not engage with their diabetes care.
- People with EOT2D were invited to sign up to speak with the HIN and/or complete the survey. Thirty of the participants completing the survey also took part in an interview or focus group.
- People with EOT2D who engaged with the process may be subject to selection and/or response bias.
- All participants needed to be able to read and speak English.

7. Recommendations

7.1 Improve diagnosis experience

- Provide an 'enhanced' appointment at the point of diagnosis to ensure individuals are provided with sufficient time and clarity
- Consider a set of appointments at diagnosis and which staff roles need to be involved. For example, a longer first and second appointment, two to three months apart, allowing time to provide essential information, support motivation to make changes and attend courses, and to check understanding
- Review structured education offer and consider options to tailor and/or tailored to a younger audience. Examples include Digibete for 18-25 years and MyDESMOND EOT2D
- Review literature and information provided at the point of diagnosis to ensure it is relevant to this population. Develop/source a single source of information such as a webpage as a place to signpost young adults to where they can find resources and links for support, and reduce the potential for misinformation

7.2 Provide training and support for health care professionals

- Ensure health care professionals providing diabetes care complete training to enhance their existing skills, confidence and awareness of the difference in approach needed for this age group (e.g. Leicester Diabetes Centre's Eden 'Early Onset Type 2 Diabetes' education package)
- Training should include topics such as information about diagnosis of diabetes, cardiometabolic management, medication, approach to appointments, being mindful of stigma and avoiding compounding this, psychological and social considerations, pregnancy and contraception, referrals and supporting services such as remission, structured education, health and wellbeing services.
- If considering use of additional roles to support pathways, ensure adequate training for their roles and responsibilities is provided to improve staff confidence and competency, and trust and engagement of people with EOT2D

7.3 Address stigma and negative connotations associated with diagnosis and living with type 2 diabetes

- Provide adequate psychological and emotional wellbeing support, ideally provided by an appropriately trained individual
- Provide direct access to psychological support in a young adults' clinic
- Consider opportunities for peer support within this age group to address stigma and isolation and reduce potential for misinformation
- Health care professional education provided should include information about stigma and how to avoid compounding this

7.4 Increase 'time' offered to young adults

- Increase the regularity of support provided, particularly in the initial stages of a diagnosis when targets and medications may not be optimised, and an individual is learning how to manage and navigate change
- Consider ways in which contact times can be increased, in addition to annual reviews, for

example through peer support, use of staff roles with behaviour change/motivational skills, digital support options

- Investigate potential for pilot in offering CGM to support learning and management of blood glucose

7.5 Review pathways for prevention and early diagnosis

- Implement a search of people coded with NDH under the age of 40 to review HbA1c status and/or ensure they are offered and supported to attend NDPP programme
- Review appropriateness and effectiveness of pathway and support provided when someone is coded as having NDH, including steps to tailor education provided (NDPP) for younger audience
- Consider case finding to ensure early intervention wherever possible. Search for people under the age of 40 with increased blood glucose or HbA1C recorded suggesting possible diabetes

7.6 Continue to involve people aged 18-39 with lived experience of type 2 diabetes

- Continue insights gathering and co-design work with people aged 18 to 39, alongside any implementation of the recommendations made above to ensure further work and changes made are done so relevant to the needs of this population
- Allocate time and resource to lived experience involvement
- Engage with community organisations and investigate alternative methods of recruitment to reach people who are not engaging with healthcare services or attending annual check-ups

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