

# Understanding a young adult diabetes service's accessibility: Have virtual appointments helped?

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**Abbreviated title:** Understanding a young adult diabetes service's accessibility

**Key points:**

- Challenges with diabetes management as a young adult can lead to poorer health outcomes later in life.
- There are many barriers to young adults accessing diabetes care, culminating in high 'Did Not Attend' (DNA) rates for this patient group.
- Barriers include practical barriers, psychological barriers and patients' experiences of their relationship with the diabetes team.
- Virtual appointments can help overcome some barriers to young adults accessing diabetes care but not all.
- Flexible service provision is valued by young adults living with diabetes, and services should aim to balance this with ensuring that patients' needs are adequately met.
- There are a multitude of ways that services can be more accessible to this population in relation to appointment scheduling and content, demonstrating an understanding of the links between diabetes and mental health, and adapting service provision more widely.

## **Abstract**

Diabetes mellitus is characterised by hyperglycemia, requiring strict management regimes to avoid associated health complications. Diagnosis and/or management of diabetes during young adulthood can be particularly challenging, potentially contributing to significant psychological distress and struggles with management, culminating in poor physical and mental health outcomes. This service evaluation sought feedback from young adult patients (19-25 years old) on diabetes service accessibility and to understand the impact of offering virtual appointments during the Covid-19 pandemic. All young adult patients (n=101) were invited to complete an online questionnaire about their experience of service accessibility and offered the opportunity to discuss their feedback in a telephone interview. Data was collected from 15 patients. Analysis using content and thematic analyses revealed three main themes regarding service accessibility: practical barriers, psychological barriers, and patients' relationship with the diabetes team. Recommendations are made for several service developments concerning appointment scheduling, appointment set-up, and developments around service provision more widely. Further research is needed to gain a wider range of feedback to inform future developments and should prioritise patient involvement to increase patient response rate.

## **Key words**

Service evaluation, diabetes, service accessibility, remote/virtual appointments, young adults

## **Introduction**

Diabetes mellitus is a group of metabolic diseases that feature hyperglycemia and affect the lives of 1 in 15 people in the UK.<sup>1</sup> Most people with diabetes are diagnosed with Type 1 or Type 2 diabetes. Complications from both, and the implications of poor management, can contribute to premature morbidity and mortality.<sup>2</sup>

The emergence of, and experience of living with diabetes (predominantly Type 1) in a time described as “*emerging adulthood*” (ages 19-25),<sup>3</sup> can be particularly challenging. This period has been identified in the western world as a time whereby sociocultural factors, such as extended education, may provide further opportunities for identity exploration and development post-adolescence. Living with diabetes, therefore, may place extra burden on individuals during an already turbulent time, due to competing priorities and navigating this challenging period alongside diabetes management.<sup>4-6</sup> Higher rates of psychological distress have been identified in young adults with diabetes<sup>7</sup> and such distress is predictive of future poor clinical and psychological outcomes.<sup>8</sup>

This period also coincides with the transition between paediatric and adult diabetes services, with research indicating that challenges of diabetes management during this period also contribute to poor physical health outcomes.<sup>5;9;10</sup> Furthermore, whilst support from diabetes services is important to ensure adequate education around management, and to undertake medical checks<sup>5</sup>, irregular or non-attendance of appointments is common<sup>11</sup>, with reports of patient dissatisfaction with adult care-providers.<sup>12;13</sup>

Bedford Hospital Diabetes Service’s young-adult clinic provides care to people aged 19-25 with diabetes, and was set up to support the transition between paediatric and

adult diabetes services. Patients accessing this service are expected to attend a minimum of two appointments per year: an annual review with their medical consultant, and an appointment with the diabetes specialist nurse (DSN) six months later. This exceeds the expectations of the National Institute for Health and Care Excellence (NICE) guidance for diabetes management for adults, which stipulates the need for an annual medical review,<sup>14</sup> but offers less than paediatric diabetes services where a minimum of four appointments per year is expected.<sup>15</sup> Further support is available from the multidisciplinary team (MDT), including a dietician and clinical psychologist.

Normally, diabetes appointments would take place at the hospital. However, in response to the Coronavirus (Covid-19) outbreak and in line with national guidance,<sup>16</sup> since March 2020, appointments have been undertaken virtually (via video consultation or telephone call). Following easing of the restrictions, some face-to-face consultations have resumed when a clinical need has been identified.

Prior to the pandemic, the MDT identified a high number of DNA appointment outcomes. They expected these figures to improve with a shift to virtual appointments, due to the convenience for patients of not having to attend hospital. It was anticipated that virtual appointments would increase attendance, particularly for those who had left home for university or were employed, by eliminating travel to the hospital. However, initial in-house data collected in October 2020 suggested there had been little improvement in the attendance rate following the introduction of virtual appointments. A commitment to increasing attendance and reviewing the acceptability of virtual appointments for patients prompted the team to consider evaluating service provision, with the aim of 1) understanding patients' perspectives

on the accessibility of the service and 2) their perspectives on virtual appointments, in order to 3) inform service development.

## **Method**

### *Design*

This study was designed in collaboration with the diabetes MDT. Despite efforts made to consult with patients about the design, this wasn't possible as the clinical psychologist received no responses from patients. As this was a service evaluation, NHS ethical approval was not required. Approval was granted by the departmental Clinical Director and General Service Manager, as advised by the hospital's Research and Development Department.

### *Participants*

Participants were recruited from the young adult diabetes clinic, using opportunity sampling. All patients under the care of the clinic (n=101) were invited to share feedback.

### *Measures and materials*

Information about the service evaluation was distributed to patients via email and letter. After providing informed consent, data was collected using a questionnaire hosted online. This method was used to facilitate anonymous feedback and efficient widespread reach. The questionnaire asked individuals to share contact details if they would like to provide further qualitative feedback. Telephone interviews with the first author were used to ask follow-up questions to consenting participants to gain more in-depth understanding of their feedback.<sup>17</sup> Data collection was a multi-staged iterative process (see Table 1).

[INSERT TABLE 1]

### **Data Analysis**

Content analysis (CA)<sup>19</sup> and thematic analysis (TA)<sup>20</sup> were used to analyse the data at different points during data collection. As more data was collected, an overlap between CA and TA was identified<sup>21</sup>. CA was used to quantify the themes within the questionnaire data during the interim analysis.<sup>19</sup> These themes were rich, and qualitative data provided in the completed questionnaires helped to make sense of the numbers, given some disparity in the emerging statistics. Once data collection was complete, TA was used to identify and analyse overall patterns within the data.<sup>20</sup> Furthermore, given the range of views provided, the themes produced by more in-depth TA offered a richer summary of the feedback. Therefore, themes resulting from TA are presented alongside statistics produced by CA.

### **Summary of results**

The questionnaire was sent to 101 patients. Despite 22 people responding, seven had only completed the first question (whether they had attended their last annual review). Of these, 17 had attended their last annual review (77%), and five had not.

Fifteen respondents answered the whole questionnaire to be used in the data analysis (response rate of ~15%). Of these, two had not attended their last annual review (13% of 15), representing the group of patients the service was most keen to hear from. Three of the 15 people completing the questionnaire were contacted for a follow up telephone interview (20%).

TA identified three main themes, each with a number of sub-themes (see Table 2), which are described below. As the CA initially identified some of these themes, quantitative data (where existing) is presented in the text below in relation to the themes.

[INSERT TABLE 2]

### **1. Practical barriers**

The feedback identified a number of practical barriers preventing appointment attendance; travel and work were key subthemes. Many participants identified issues associated with travel to the hospital as barriers to attending appointments, alongside the time needed off work. As a solution, one participant suggested, *“instead of being sent a specific date and time, some options could be listed for a response, in order to make it easier to find the most suitable day/time for appointments”*.

Eighty-five percent shared that virtual appointments facilitated appointment attendance. Participants overwhelmingly reported that virtual appointments have been *“more convenient”*, *“very efficient and easy to access”*, removing some of the practical barriers as there is *“no need to travel or take time off work”* and enabling the option to be *“able to be at work and just quickly take 5 minutes out to talk rather than having to leave early”*. Remote appointments were also easier to attend for those with mobility difficulties and young children.

However, despite improving accessibility in these ways, 15% of patients reported that virtual appointments hindered attendance. Feedback identified that *“access to laptops and Wi-Fi might be a problem”* for virtual appointments, and new pressures



could be introduced, such as having *“to organise my own foot checks”*, which can *“create added level of anxiety”*. These findings highlighted a dilemma between the preference for face-to-face appointments and the practical benefits of virtual appointments, e.g., *“I prefer having face-to-face appointments, however for convenience (avoiding the need to travel/arrange time off work etc); virtual appointments have worked really well for me”*.

Patient preferences for future appointments were mixed; 69% of respondents requested a mixture of both face-to-face and virtual appointments, with a particular emphasis around *“flexibility of appointments”* and *“having the option”*, depending on appointment type (e.g., consultant versus dietician). Whereas, 31% requested a full return to face-to-face appointments. No-one reported wanting only virtual appointments.

## **2. Psychological barriers**

Some participants reported psychological barriers to attendance, with subthemes of forgetting (n=4), anxiety around appointments (n=2), and mental health (n=2).

Forgetting was attributed to reasons such as the timing of communication from the team; *“the letter [was] so far in advance”*, and lack of choice; *“I didn’t pick the date”*. Participants shared helpful ideas for managing this, such as sending out a reminder *“text message on the day”* or *“letters [as] a helpful reminder”*, as well as members of staff calling when patients are *“not being on the video chat”*.

Anxiety could be a barrier to attending hospital appointments and virtual appointments may have helped as, at home, patients *“feel more comfortable...it makes the experience feel less clinical and I feel more confident and comfortable to*

*share my concerns*". When considering virtual options, there were differing views about how video and telephone calls affect this; some felt *"being able to see people is important"*, and others felt *"awkward on video calls"*.

An important link between diabetes and young adults' mental health was also highlighted, with patients voicing *"not feeling motivated to take control"* of diabetes and struggling to understand *"how deep an impact diabetes was having"*.

### **3. Relationship with team**

Across feedback, participants referred to experiences of their relationship with the diabetes team and the impact this could have on engagement. Sub-themes identified included: rapport (n=3), the focus of appointments (n=1), perceived level of input (n=3), the team's understanding of mental health (n=1), and the visibility of the team (n=2).

Rapport with team members was highlighted with both positive adjectives, e.g., *"friendly and approachable"*, *"supportive and understanding"* and negative adjectives, e.g., *"dread"*. One participant noted that the move to virtual appointments appeared to have brought an unhelpful shift to being *"more focused in appointments and less discussion"*. This could link to other reported impacts, such as patients being more likely to *"forget to ask questions"*, and the reflection that *"check-ins or MDT meetings [might be helpful] virtually, but seeing a professional in person can make me feel more understood"*.

Another important factor was patient's perceptions on the level of input they were receiving from the service. Feedback comprised of both feelings of satisfaction and

dissatisfaction. Despite some participants noting how virtual appointments left them feeling less connected with the team, one participant felt that “*virtual appointments have allowed [DSN] to be involved in meetings with other professionals - joined up care never happened before*”. One participant also highlighted the importance of the team understanding the impacts of diabetes on mental health and the learning process of the clinician and patient about this (Table 2). Finally, two participants identified not clearly understanding the service, team, and support available, making it difficult to access appropriate support (Table 2).

## **Discussion**

This service evaluation aimed to understand patient perspectives on the accessibility of a young adult diabetes service, experiences of virtual appointments, and preferences for future service provision. Results indicated a multitude of factors that might be barriers to service access; practical barriers (travel, work, and technical issues), psychological barriers (forgetting, anxiety around appointments, and mental health) and patients’ experiences of relationships with the diabetes team (rapport, focus of appointments, perceived level of input, team’s understanding of mental health, and visibility of the team).

The results speak to the complexities of managing diabetes at this life-stage, particularly competing priorities and the psychological burden of diabetes,<sup>5,6</sup> as well as the challenges of transition to an adult-service model of care (e.g., less frequent appointments), which can contribute to dissatisfaction in the level of input offered.<sup>12,13</sup> Results also further understanding of how patients have found virtual appointments; both the benefits (e.g., ability to fit appointments around other commitments, the convenience of appointments at home, and opportunities for joined-up care) and

drawbacks (e.g., feeling disconnected and lack of support from the team). These findings align with the suggestion that services should remember, *“one size does not fit all”*, and the importance of flexible service provision.<sup>22</sup> However, although flexibility could prove valuable, it is important to ensure that appointments are prioritised by patients when required (e.g., patients allow sufficient time for their appointment) to ensure their needs can be adequately met.

Participants shared some of the psychological barriers to attending appointments and the impact diabetes can have on their mental health, with one participant emphasising the importance of the team demonstrating an understanding of mental health in order to provide more tailored person-centred consultations. This follows NICE guidelines,<sup>14</sup> which state that diabetes professionals should have *“appropriate skills to identify and provide basic management of non-severe mental health problems in people from different cultural backgrounds”*. This is supported by research identifying patients’ desires for professionals to better understand the impacts of living with diabetes<sup>4</sup> and, more widely, the issues around frontline medical staff not being equipped with adequate mental health training.<sup>23</sup> Feedback suggests disparity within the team in making use of mental health knowledge to tailor diabetes care, which may indicate an area for team training or development that could be facilitated by the in-house clinical psychologist.

However, whilst this service evaluation is able to further understanding of various barriers preventing young adults accessing their diabetes service, the limited responses, particularly from people not currently accessing the service, alongside the partial completion of a number of questionnaires, must be recognised. Therefore, whilst the data facilitates understanding of perspectives on current service provision,

findings may not be representative of all patient experiences. The lack of patient involvement in the evaluations design may have contributed to this, and future research should prioritise patient consultation around how best to engage this population in research activity.

Despite the response rate for this evaluation appearing to be relatively low (~15%), in comparison to response rates to other evaluations at the hospital, this rate is favourable (Outpatient Department had a response rate of 1.8% for the Friends and Family Test in June 2021). This raises wider questions regarding how best to gain feedback on service provision, and whether patients perceive value in providing feedback. It was hoped that circulating some initial data could address this, helping patients to see that their voices were being heard, and encourage further feedback. Future research should consider whether there are alternative means of gaining feedback that are more amenable.

### **Conclusion and clinical implications**

A number of actionable outcomes have arisen from the results that could contribute towards a more accessible service. Changes suggested in relation to service provision, including the scheduling and undertaking appointments, are described in Table 3. Changes made should be reviewed by the service to inform continuous service development and improvement.

[INSERT TABLE 3]

In conclusion, this service evaluation identified some of the barriers to young adults accessing diabetes care, as well as some suggestions for ways in which this service

could become more accessible. It is hoped that implementation of some, if not all, of these change ideas could improve clinical outcomes and ensure the service provides effective, person-centred care.<sup>24</sup>

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Table 1: Data collection process

Steps	Procedure
Step 1	76 patients who had provided a contact email address for service-related correspondence were emailed information about the evaluation by the second author or DSN in May 2021. This email also contained a link to a consent form and questionnaire. Letters with the same information were also sent to all 101 patients under the service.
Step 2	Telephone interviews were undertaken with individuals who had shared their contact details in the questionnaire for this purpose.



Step 3	The first author undertook preliminary analysis of the data from both the questionnaires and telephone interviews. This was collated into an interim summary document to share with patients.
Step 4	Given the documented low response rates to questionnaires (25-30%) <sup>18</sup> all patients originally contacted via email were contacted a second time via email to share the summary and encourage further feedback from those yet to participate – unfortunately, there were no further responses to the questionnaire once the initial summary of the data was circulated.
Step 5	Telephone calls were also made by the DSN and second author to patients identified by the service as struggling to engage (n=8) in line with the service policy, with the aim of inviting them to arrange an appointment and to participate in the service evaluation – unfortunately no contact was possible.

Table 2: Themes and subthemes with example quotes

Theme	Subtheme	Quotes
Practical barriers	Travel	<p>“Travelling to the hospital might make it difficult to attend the appointment. For those that don’t have easy access to transport the journey and planning necessary might deter them”.</p> <p>“Travel on public transport isn’t the most reliable”.</p> <p>“...parking [at the hospital is] scarce, too expensive...”.</p>
	Work	<p>“Inconvenient appointment times... as it does not recognise a normal working day”.</p> <p>“Clinics running on certain days,..., and this makes it difficult to get time off work”.</p>
Psychological barriers	Forgetting	<p>“I don’t remember, I probably forgot”.</p> <p>“Easier to forget when the video calls are as I didn’t pick the date”.</p>
	Anxiety around appointments	<p>“I think sometimes when I go to the hospital I get anxious. When I’m at home I feel more comfortable... it makes the experience feel less clinical and I feel more confident and comfortable to share my concerns”.</p>
	Mental health	<p>“Not feeling motivated to take control of your condition”</p> <p>“How deep an impact diabetes was having on me”</p>
Relationship with team	Rapport	<p>“...friendly and approachable”.</p> <p>“Appointments so far have been supportive and understanding - the team have been quite open when I've had worries of me being able to reach them with concerns while having virtual appointments - I really appreciated that”.</p> <p>“For a long time, I just went to my routine appts and dreaded them and thought I'd be met with this punitive stance...”</p>
	Focus of appointments	<p>“When we are looking at numbers not setting things that are unrealistic for me”</p>

		<p>“Feel like we're here to talk about this - more focused in appointments and less discussion”</p>
	Perceived level of input	<p>“...can text with little questions if needed, we've set up regular weekly contact to check in... [DSNs] willingness to collaborate with other NHS services &amp; learn about &amp; acknowledge my mental health needs has been genuinely life changing...”.</p> <p>“As a fairly recently diagnosed Type 1, I think I would have benefited from more frequent check ins/ support”.</p> <p>“I have had a review from a doctor online however I have only had a brief phone call with a nurse and dietician. Due to covid this means I don't really feel I've had much support from the hospital service”.</p>
	Team's understanding of mental health	<p>“I think the consultants have a good understanding of diabetes &amp; its physical complications &amp; treatments. But they lack the understanding of the mental health aspects that affect these things. Mental health issues are so prevalent in T1 diabetics &amp; this needs to be incorporated into standard diabetes care”.</p> <p>“Ignoring the numbers, and focusing on how I feel - that's really made a difference. rather than being told I'm going to die or lose my legs.. Instead talk about energy to see friends... see nephew... particularly with consultants there's a focus on the numbers and ticking the boxes of what is done in a review rather than treating you like a person with complex needs”.</p>
	Visibility of team	<p>“Having more of an idea of what support there is as a diabetic patient would be really good. I don't know who's on the team really”.</p> <p>“Didn't know that it was a young adult service. Which I advocate for a lot”.</p>

Table 3: Recommended actionable outcomes

Area for change	Change idea
Scheduling appointments	Offer patients flexibility in clinic times (e.g., if possible, offering an afterhours clinic) and/or allowing patients to pick an appointment slot, rather than being allocated one.
	Where possible/appropriate; offer patients the option of face-to-face or virtual appointments.
	When offering virtual appointments, check patient access to necessary technology (e.g., Wi-Fi for video appointments).
	Given the length of time between appointments; send reminder texts on the morning of the appointment (and/or letters ahead of this) and make follow-up calls if patients DNA.
Undertaking appointments	Take time to set up the appointment with the patient (e.g., the structure and what to expect from appointment) and leave time for general discussion to aid rapport building (particularly in virtual appointments).
	Encourage conversations with patients about the relationship between diabetes and their mental health early in consultations.
Changes to service provision	Consider whether the MDT would benefit from additional training around diabetes and mental health (e.g., from the team clinical psychologist).
	Ensure new patients are informed about the nature of a young adult diabetes service and are aware of the full MDT and their roles in supporting their care.
	Consider offering a consistent full MDT approach to diabetes care e.g., offering patients their annual review with a consultant, but rotating nurse, dietician, and clinical psychology appointments as standard in between. Alternatively, all members of the MDT could be scheduled to be available on clinic days to see the patients there and then, rather than referring on and having to make other appointments.