

**Experiences of the transition
to adult services, for young
people with Type 1 Diabetes**

March 2020



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About Healthwatch

Healthwatch Lancashire (HWL) and Healthwatch Blackburn with Darwen (HWBwD) were established in April 2013 as part of the implementation of the Health and Care Act 2012.

Healthwatch England acts as the national consumer champion for all local Healthwatch organisations, enabling and supporting HWL and HWBwD to bring important issues to the attention of decisions makers nationally.

A key role of HWL and HWBwD is to champion the views of people who use health and care services in their local area, seeking to ensure that their experiences inform the improvement of services.

HWL and HWBwD are constantly listening, recording and reporting on the views of local people on a wide range of health and care issues, ensuring that people in the county are able to express their views and have a voice in improving their local health and care services.



Executive Summary

Healthwatch Lancashire and Healthwatch Blackburn with Darwen were asked by the East Lancashire Hospital Trust (ELHT) to conduct a survey focusing on the experiences of young people diagnosed with Type 1 Diabetes (T1D).

In total, Healthwatch spoke to 34 young people attending the T1D clinics at the Royal Blackburn Hospital (24 people) and the Burnley General Hospital (10 people.) The questions they were asked were designed to investigate their experiences of the transition to adult services. ELHT wanted to focus on this 'transition period' as it can be a particularly fraught and challenging time for young people as it falls during a time when they may be experiencing other life changes. Improper diabetes management for this age group has been partially blamed for the UK mortality rate being higher than that of Europe⁹.

ELHT provided demographic information for the current 'transition group' within East Lancashire: 290 patients aged 15-24, split almost 50/50 between male and female. Demographic information for the Healthwatch survey: the majority of respondents were aged 16-18 and 75% were white/British and 22% Indian/Pakistani/Bangladeshi/other. Unfortunately we did not have the gender information for ten respondents.

77% of the respondents to this survey found the transition to adult services to be a positive experience. 62% felt positive about attending appointments, 85% said nothing put them off attending and everyone understood the purpose of the appointments, although 48% felt anxious prior to attending their appointments.

There were four individual respondents who stood out as being both anxious about their appointments and being aware that they were

not managing their T1D. Most respondents are aware when their T1D is under control and are comfortable and confident enough to be honest in the Ready, Steady, Go questionnaire. However, 1/3 download their meter readings and 1/3 are worried about their future living with T1D. Nurses and Doctors/Consultants are the most valued in providing support and respondents also value nurse and Doctor/Consultant led appointments. 94% felt that appointments focus on their personal needs.

Education and information that respondents would like to see tended to focus on advice and guidance for their future. A 'perfect service' for the young people who answered this questionnaire, would consist of quick, timely and local appointments with all the relevant staff present, where everyone was understanding, friendly and caring.



Project rationale -

Exploring the experiences of transition to adult services, for young people with Type 1 Diabetes

Healthwatch Blackburn with Darwen (HWBwD) and Healthwatch Lancashire (HWL) in collaboration with East Lancashire Hospital Trust (ELHT) Diabetes Service and Public Participation Panel created a survey designed to explore the experiences of transition to adult services, for young people diagnosed with Type 1 Diabetes.

What is Type 1 diabetes (T1D)?

Type 1 diabetes is a serious, lifelong condition caused by high blood glucose levels which happens when your body can't produce enough of a hormone called insulin.

*"When you have Type 1 diabetes, your body attacks the cells in your pancreas that make insulin, so you can't produce any insulin at all."*¹

People with T1D need daily injections of insulin in order to keep their blood glucose levels under control.²

How many people have T1D?

According to the JDRF T1D charity:³

- There are approximately 400,000 people with T1D in the UK, which includes 29,000 children.
- Incidence is increasing by 4% each year.
- The UK has one of the highest rates of T1D in the world.

The transition from paediatric care to adult services

East Lancashire Hospitals Trust Children's Diabetes Service have established a Transition Service for 16-19 year olds alongside one adult diabetologist, two adult DSNs and two dieticians in our transition clinics. These professionals have specifically allocated time funded by the paediatric service to ease the transition to Adult Services.

The transitional move into adult T1D services can be a particularly *"traumatic period"* for young people who may *"fall between services."*⁴ This transition often takes place during a time of broader change within a young person's life, such as a move to university or work, becoming more independent, moving away from parents and carers and experimenting with alcohol, sex and drugs.⁵

According to a recent study⁶, the average age of transition is 19.5 - 20.1 years, with 80% of all patients being transitioned by the time they are 21. The study also found that 1/3 of the young people being 'transitioned' did not feel adequately prepared.

Transition: *"The purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult orientated health care systems."*⁴

Self-management of T1D

One of the most difficult aspects of the transition period is young people learning to self-manage their diabetes.

Psychosocial changes that tend to occur at the same time can make this period particularly challenging for young people.

Psychosocial changes include⁴:

- Erratic eating and exercise.
- Poor adherence to insulin regime.
 - Risk taking behaviour.
 - Family stressors.
 - Self-image problems.
 - Missed appointments.
- Binge drinking and smoking.

Mortality rate for people with T1D

Statistics provided by Diabetes UK show that approximately 500 people living with diabetes die prematurely every week in England and Wales.⁷ People aged between 35-64 who have T1D are 3 to 4 times more likely to die prematurely, than those without the condition.⁷

They are also⁸:

- More than twice as likely to be admitted to hospital.
- At least one in ten people in hospital has diabetes at any moment in time.
- More likely to experience prolonged stays in hospital (resulting in about 80,000 bed days per year.)

Mortality rate for young people with T1D

A study conducted by University College London (UCL) found that young people in the UK are more likely to die from type 1 diabetes than in the rest of Europe as a result of improper diabetes management.⁹

“The death rate in the UK amounts to 37 deaths from type 1 diabetes out of every 100,000 people aged between 15 and 24. If the mortality rate in the UK were the same as in Europe, there would be 17 fewer deaths from type 1 diabetes among young people every year.

Russell Viner, lead author of the study, suggests that a number of factors may be responsible for the high mortality rate, including higher levels of poverty and healthcare issues.

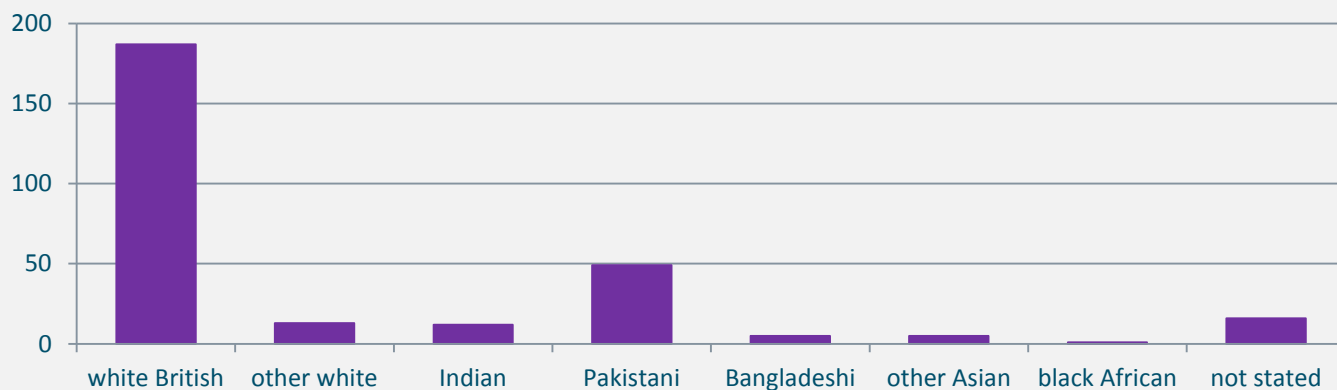
“This is a significant concern given that we know diabetes control is poor. This is going that next step and saying that death is rising.”⁹

Demographic information provided by East Lancashire Hospitals NHS Trust (ELHT)

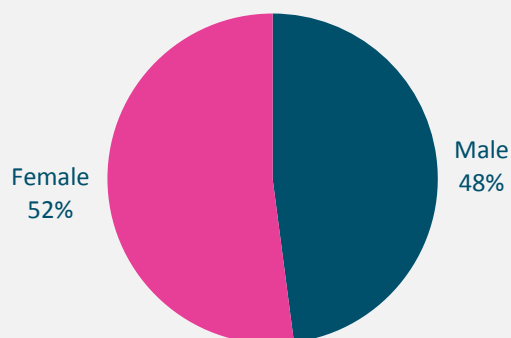
The following demographics for the **Transition Group** were provided by the ELHT to support this research project.

The Transition Group within East Lancashire consists of 290 T1D patients aged between 15-24 years.

Ethnicity of patients



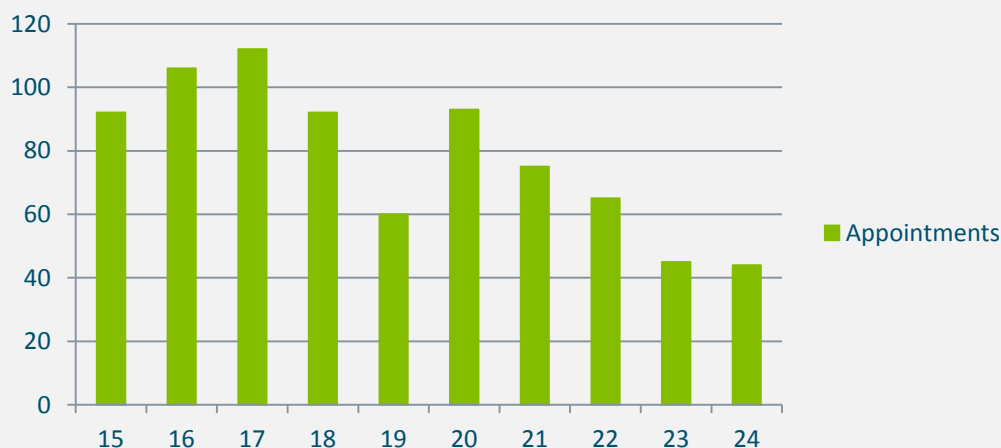
Gender of patients



The majority of T1D patients identify as 'white British', which is in line with the ethnic make up of East Lancashire as a whole (according to the 2011 Census.)¹⁰

The gender of T1D transition patients is split 52% female to 48% male.

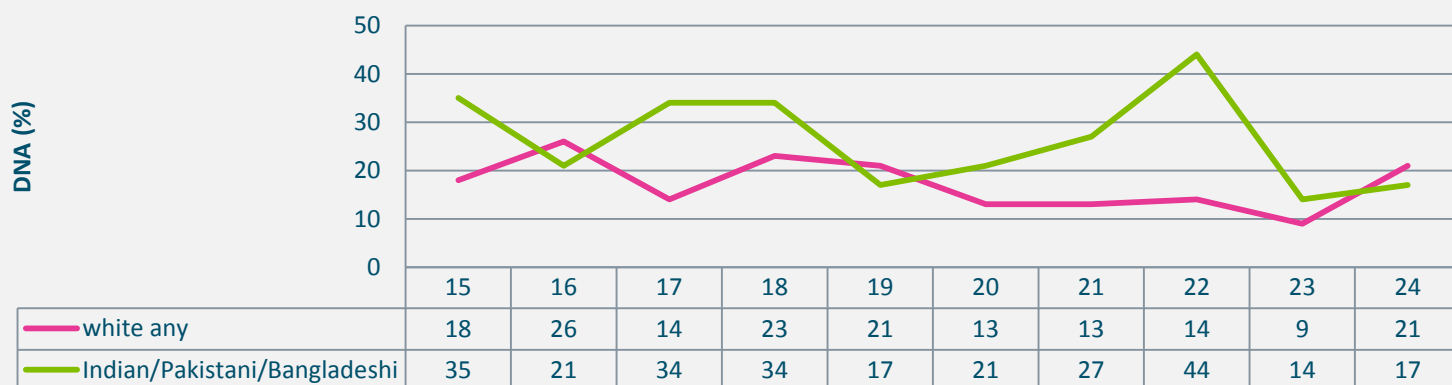
Number of annual appointments by age of patient



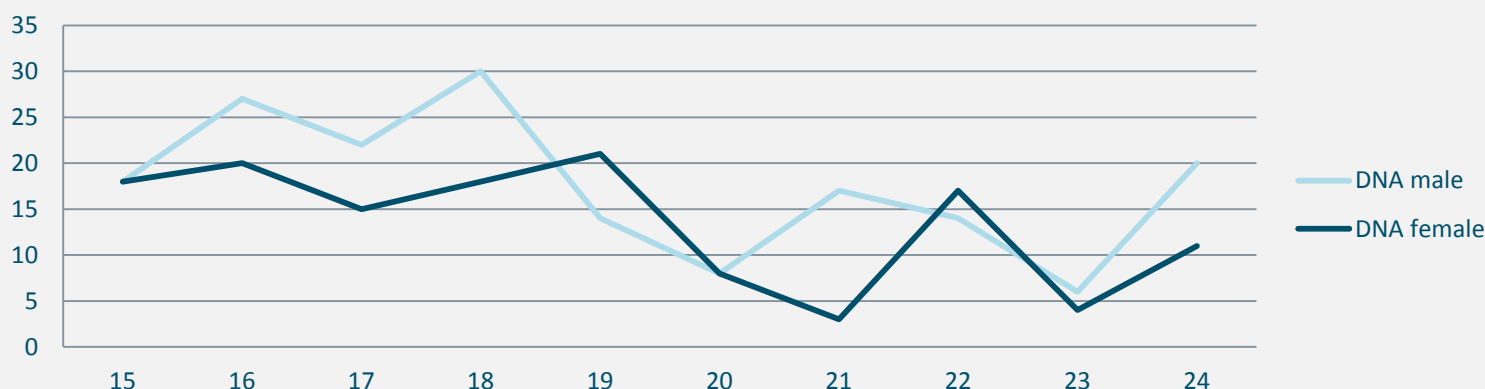
DNA - Did Not Attend demographic information for East Lancashire

The demographic data for DNA provided by ELHT, shows a higher number of patients from an Indian, Pakistani or Bangladeshi background do not attend their appointment, when compared with patients from a white ethnic background, with a peak of DNA at age 22.

DNA by ethnicity and age



DNA by gender and age



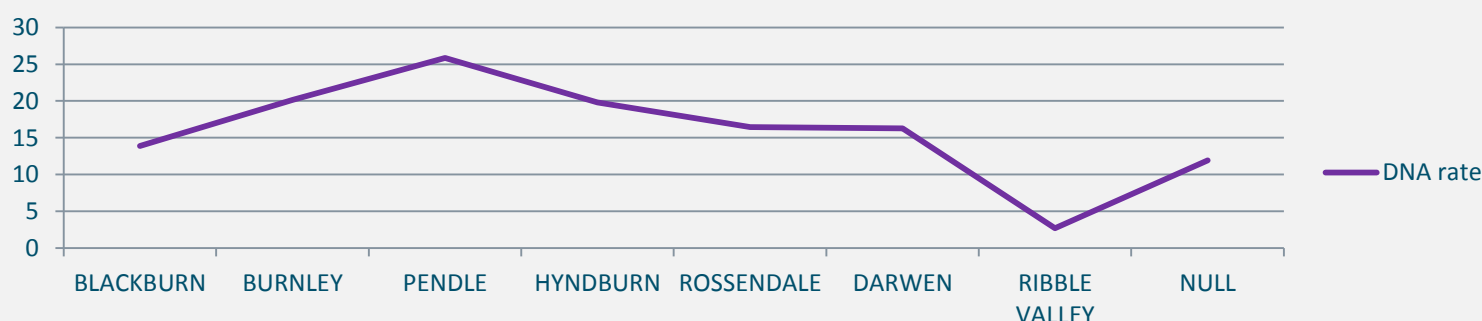
Overall more males DNA than females.

There is a spike in DNA for females at age 19 years and again at 22 years.

For males, DNA spike at age 18 years.

Pendle has the highest rate of DNA, the Ribble Valley has the lowest.

DNA rate by locality



Methodology

This project ran from October 2019 to February 2020.

34 people participated in this research.

24 were interviewed at the Royal Blackburn Hospital and 10 at Burnley General Hospital.

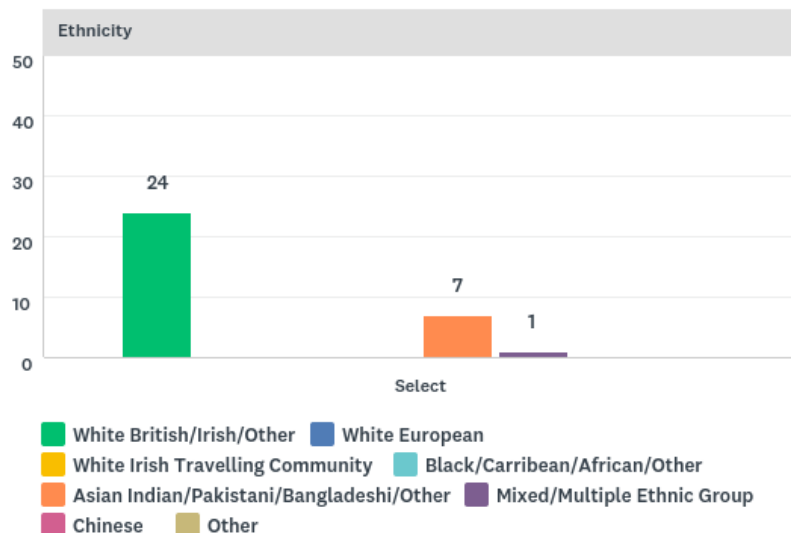
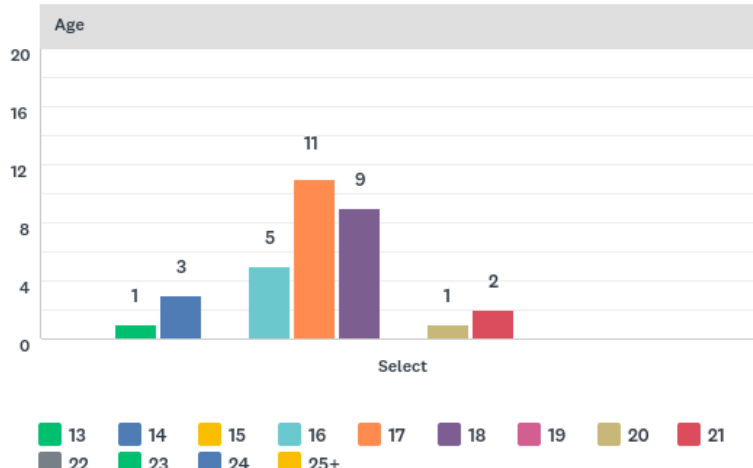
Survey questions

1. Which diabetes clinic do you attend?
 2. How do you get to the clinic?
 3. How easy do you find the journey?
 4. Are the days and times of your clinic appointment convenient?
 5. How did you find the move from the children's clinic to the transitions clinic?
 6. How do you feel about attending clinic appointments?
 7. Do you attend all your clinic appointments?
 8. Has anything put you off from attending appointments regularly?
 9. How soon after your appointment time are you seen?
 10. How do you feel about the number of appointments in a year?
 11. Does the way the diabetes team communicates with you about appointments and care meet your needs?
 12. What do you think the purpose of your appointment is?
 13. How much do you prioritise/focus on managing your diabetes, compared to other aspect of your life?
 14. How well do you think you are managing your diabetes?
 15. How do you know when you are in control of your diabetes?
 16. Do you worry about your future living with Diabetes T1?
 17. Please explain your response, including what support the Diabetes Team could offer.
 18. Are you confident/comfortable to be honest in your responses in the Ready, Steady, Go questionnaire?¹¹
 19. Do you download your meter readings to help with managing your diabetes?
 20. Do you regularly upload/share your meter readings for the diabetes team to review?
 21. How helpful do you find the following in managing your diabetes:
nurse led appointments?
consultant led appointments?
dietician?
Emotional Wellbeing Team?
 22. When it comes to managing your diabetes, who do you value the most in the diabetes team in supporting you? Please explain which qualities you value in staff and why?
 23. Are appointments focused on your personal needs/interest and do you feel you can lead the conversation at your appointment?
 24. Can you suggest anything that can be improved at your clinic appointments?
 25. Would you find the following beneficial as an alternative to a face to face appointment?
Skype/Facetime/video calling/phone
 26. What are your thoughts on the clinic environment?
 27. Which of the following would you use?
Drop in clinics/social media groups/text service
 28. What education and information would you like to help manage your diabetes, and how do you want this information?
 29. What would a perfect service to support you with your diabetes look like and who would be involved?
- Respondents were then asked to provide their age, ethnicity, the town where they live and their gender.

Demographics

There were 34 responses to the Healthwatch survey, this page provides the demographic characteristics. 24 people were attending the clinic at the Royal Blackburn Hospital and 10 were attending the Burnley General Hospital.

Unfortunately as some of the surveys were completed online by participants, not all the data fields or questions were completed. As a result there are 10 participants for whom we do not have their gender or their location.



57% of participants were male
43% were female*
78% were aged 16-18 years

75% were White/British
22% were Indian/Pakistani/Bangladeshi/other

Most people find it easy to get to their appointments

65% are taken to their appointments by friends or family

Most feel there are the right number of appointments per year

85% said that the date and time of their appointment was convenient for them

When attending appointments, 83% are seen on time or within 30 minutes

*This data is incomplete for 10 participants

The transition clinic and attending appointments

How did you find the move from the children's clinic to the transition clinic?

77% of participants found it a positive experience, with only 13% experiencing worries or problems.

10% hadn't moved to the transition clinic and were still using the children's clinic.

"Really hard - so much so that I'm still with the children's team! I don't like new stuff and especially if I'm in a routine with people. I don't think I'd come by myself without my mum."

"It was really good. When they did the move it was good. There was an adult consultant there and a children's consultant at the same time so I could get used to them. The only problem was the children's dietician and diabetes nurse were never there which is important when you're getting used to someone new. In the children's clinic I could never get hold of the nurse. Now in the adult clinic I can always get in touch with them. I can always speak to them."

How do you feel about attending clinic appointments?

62% of the participants said they feel positive about attending their appointments.

Phrases they used included; not bothered, happy and confident.

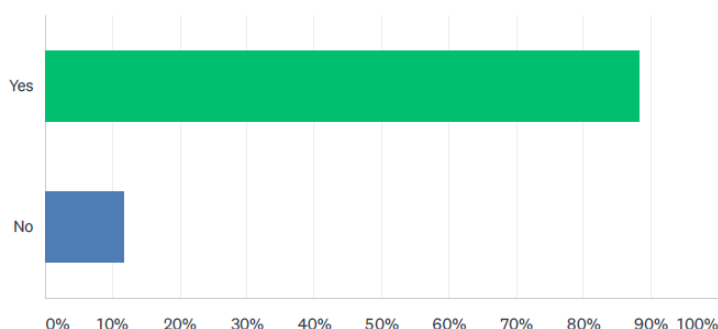
48% said they felt worried or anxious about attending appointments. In particular they felt worried about how they are doing [managing their diabetes].

One participant expressed concern over mental health issues:

"I feel like I can't talk to the nurses and staff about mental health problems."

Q7 Do you attend all your clinic appointments?

Answered: 34 Skipped: 0



The reasons given for not attending appointments:

- Can't get a lift.
- The timing doesn't suit.
- I have something on at college at the same time.
- If I'm ill.
- Sometimes I can't be bothered.

Appointments and managing T1D

85% said there was nothing that put them off attending appointments.

The 15% who said they were 'put off' gave the reasons as:

- Anxiety
- 'Being ill'
- Having 'something else on'
- Worrying about 'getting told off'

All of the respondents said they were happy with how the team communicated with them.

"Email reminders to upload results are helpful."

"I would like to be able to talk more about how I feel."

What do you think the purpose of your appointment is?

1. To check that my T1D & blood sugar levels are under control.
2. It's a check up and to identify any problems I'm having.
3. To see if I am coping with my T1D.

How well do you think you are managing your diabetes?

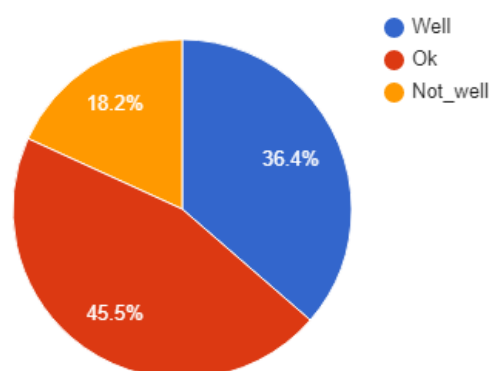
"Not the best I could be."

"More so now I'm on a pump. It's a life changer."

"I think I'm doing ok, it's not great all the time and I do have dips where I'm not managing it well but overall quite happy."

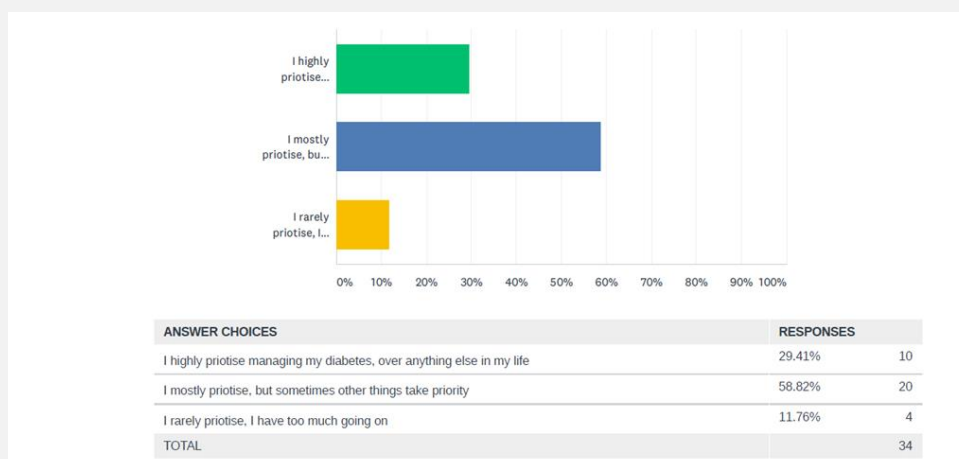
"When I'm out it is hard. School and college meals don't have labels and popular meals aren't healthy."

How well do you think you are managing your diabetes?



Prioritising the management of T1D

How much do you prioritise or focus on managing your diabetes, compared to other aspects of your life?



Of the four people who said they ‘rarely prioritise’:

- They all attend the Royal Blackburn Hospital.
- They all said they feel worried about attending their appointments.
- One person said they don’t attend all their appointments - *“Sometimes I can’t be bothered.”*
- None of them felt they were managing their diabetes properly.

However, despite this, three respondents don’t worry about their future living with T1D.

- Three people don’t download their meter readings or share them with health professionals.
- They were all unhappy with the waiting room - *“It could be bigger”, “I was anxious about sitting with people.”*
- There was no useful feedback about what would help them manage their T1D.
- When they were asked what a perfect service would look like:
 - *“Mum would sort it all out.”*
 - *“Speaking to other teens about it.”*
 - *“I wouldn’t come, but my mum makes me.”*
 - *“I think it’s fine as it is.”*

Demographic characteristics of these respondents:

Ages: 14 years, 16 years, 18 years, 18 years

Ethnicity: 3 respondents = white
1 respondent = Asian

Gender: 2 males*

*Data was not available for the gender of two of the participants..

Being in control and worries for the future

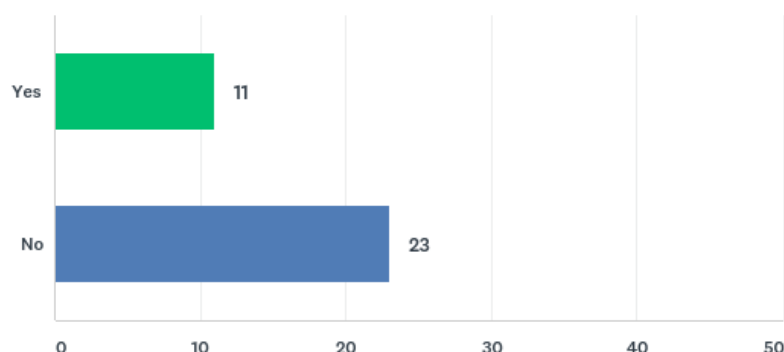
How do you know when you are in control of your T1D?

- “consistency”
- “feeling well”
- “feeling better in myself”
- “energised”
- “bloods will be in range”
- “feel happy”
- “love a green line”
- “not too many highs and lows”

How do you feel when you are not in control of your T1D?

- “dizzy, shaky, blurred vision”
- “stressed and tired”
- “I don’t feel well and my energy is low”

Q16 Do you worry about your future living with Diabetes Type 1?



I am worried about my future, because:

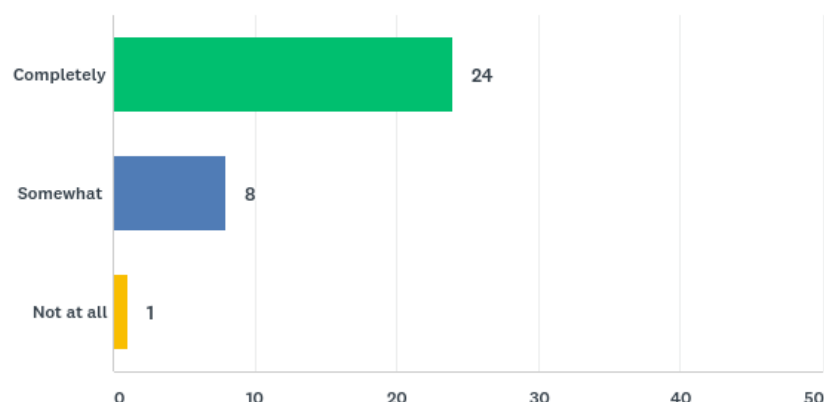
- If I move abroad, there’s no NHS.
- How will I get to appointments if I’m working?
- What if I can no longer manage my T1D?
 - I struggle to look after myself.
 - I have to start preparing for the future.
 - There are “more ways to die”.
 - I will be moving away to Uni.
- How will Brexit affect the availability of medicines?

I am not worried about my future, because:

- I’ve managed my T1D for 15 years.
- “It’s routine. I control the diabetes, it doesn’t control me.”
 - There will be new technology.
- There will be new developments in medicine.
 - I keep to all my appointments.
 - I’m too young to worry yet.
 - I see my Mum coping with hers.
- Working in the fitness industry is a benefit.

The Ready, Steady, Go questionnaire

Q18 Are you confident/comfortable to be honest in your responses in the Ready, Steady, Go questionnaire?



The overall impression is that the respondents understand they need to be honest and open in order to improve. They also felt staff were trustworthy.

Those who did not feel confident or comfortable in their responses, commented that they felt shy, or were nervous and worried about being judged. Some participants said that they lie in their responses.

When I was in the children's clinic I would pretend because they would tell you off and not understand. They would have a go at you. In the adult clinic I can tell them anything that is going on and I don't feel nervous when they look at it. They focus on the positives and what has gone well. They're there to be open and honest with us. They're not diabetic so say "help us to help you."

"If I'm not doing as well on something I would want to not tick it."

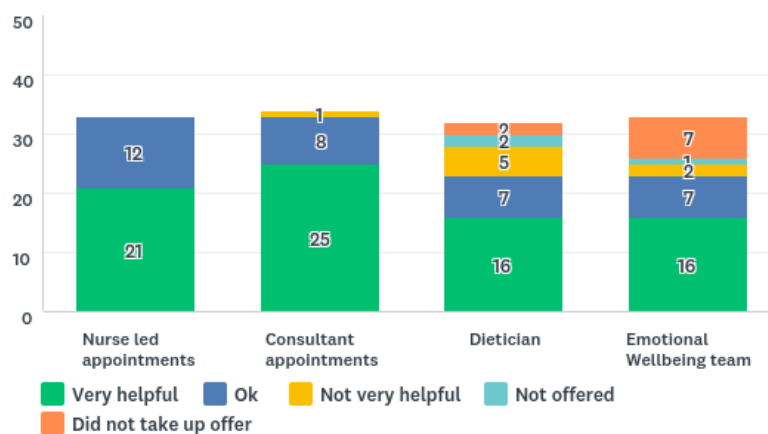
"Sometimes I lie and don't tell them the complete truth. Nervous cuz I know I've not done great."

Support for managing T1D

32% of the participants download their meter readings to help manage their diabetes.
68% do not download them.

44% of participants regularly upload or share their meter readings for the diabetes team to review.
56% do not - although some left comments to say they do this during their appointments.

Q21 How helpful do you find the following in managing your diabetes:



Who do you value the most in supporting you?

1st - Nurse

2nd - Dr/Consultant

3rd - the whole team

4th - Dietician

What qualities do you value in staff and why?

- Knowledge
- Non-judgemental
- Making me feel comfortable
- Emotional support
- Down-to-earth and easy to talk to
- Flexible and easy to contact
- Understanding, caring and friendly
- Being treated like an adult

Improving appointments

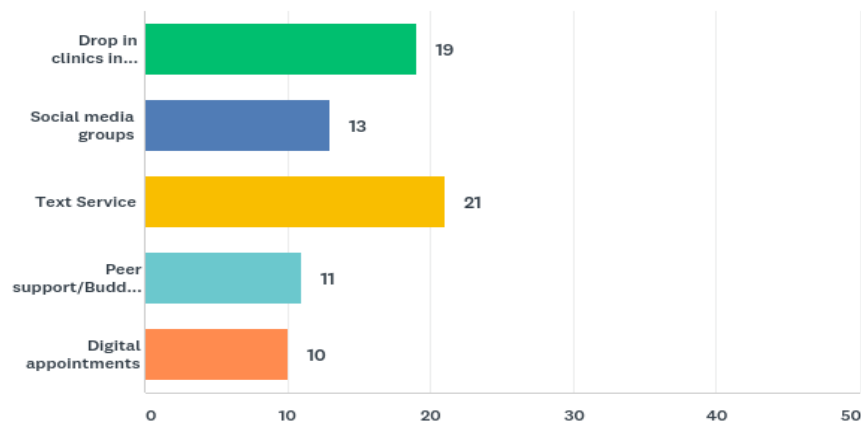
94% felt that appointments focused on their personal needs and interests and that they were able to lead the conversation.

14 people would prefer a phone call as an alternative to a face to face appointment.

12 people would prefer video calling.

Although in the comments that were left, most people would still prefer a face to face appointment

Q27 Which of the following would you use?



Do you have any suggestions for how we can improve clinic appointments?

- Fewer appointments.
- Quicker appointments.
 - Better timings.
 - Being seen on time.
- An opportunity to talk to the emotional wellbeing team.
 - To make them 'fit around you'.
- An Action Plan (to know what the team are planning to discuss.)
 - More seating.
- Better communication.

What would you like to see?

What education and information would you like to help manage your diabetes?

- Information to help me 'do what I want to do in my life'.
- Have all the relevant information available on social media or a website.
- A website for the transition clinic.
- Relevant apps.
- Advice about travel.
- Information about driving.
- Information about going to university.
- How to manage your T1D and other conditions that can occur because of it.
- What to expect during your teenage years.

What would a perfect service look like?

- It would be quick and all the staff would be present at the same time.
- There would be convenient appointment times.
- Waiting times would be shorter.
- There would be an option for home visits.
- Everyone would be understanding, friendly and caring.
- You would be able to speak to other teens about their experience.
- Always having appointments with the same healthcare professionals.
- More access to the emotional wellbeing team.
- It would be closer to home.

"Probably what they already do but with weekend care with diabetes nurses. They know where you work and your personal life. They know what can affect your diabetes."

"This and everyone here. I love everyone here, I get on with them all."

Conclusion -

What are the experiences of the transition to adult services, for young people with Type 1 Diabetes?

Rationale behind the research

The transition to adult services can be a particularly difficult period for young people with T1D, as it takes place during what is usually a time of change for teenagers generally. This survey was designed to explore young people's experience of this transition from child to adult services, within East Lancashire.

There were 34 responses to the survey. Unfortunately, as some surveys were completed online by respondents, some people did not complete all of the questions. As a result, we do not have the gender for ten respondents, making any comparison between females and males unreliable. It also means that we cannot compare the demographics of this study with the wider demographics for the East Lancashire transition group (see p8).

Clinic appointments

Overall most respondents had no difficulty getting to their appointments, they felt that they have the right number of appointments and the date and time was usually convenient.

All respondents were happy with the current methods of communication and they understand the purpose of their T1D appointments.

Generally respondents feel that their clinic appointments do focus on their personal needs and interests.

Suggestions about how to improve clinic appointments included having fewer of them (despite most respondents saying they were happy with the current number of appointments), being seen on time and appointments being quick. Better communication about the appointments and what will happen or be discussed during the appointment, as well as a more personalised approach would also be appreciated.

The move to the transition clinic

When moving from the children's clinic to the transition clinic, $\frac{3}{4}$ of respondents found it a positive experience. Just over half (62%) also felt positive about attending their clinic appointments. Any concerns arise as a result of anxiety over how they are managing their T1D, such as what the blood results will show and what the corresponding reaction of the healthcare professionals will be. Some of the respondents are concerned that professionals will be 'judgemental' and 'not understand'.

The reasons given by four individuals for regular non-attendance of appointments, were mainly that their clinic appointments clashed with other activities that they wanted to do. It is difficult to establish whether this is a genuine concern over being able to rearrange other activities or whether it is a reluctance to prioritise clinic appointments and T1D management.

85% said that nothing puts them off attending their appointments, but a minority do worry about what will happen when they attend and are concerned about 'being told off'.

Managing T1D

The majority (82%) feel that they are managing their T1D either well or 'ok'. As there is a similar percentage of respondents who regularly attend their appointments (85%) it suggests that there is a positive relationship between attending appointments and feeling as if you are able to manage your T1D. Research¹² shows that regular attendance at clinic appointments results in more effective glycaemic control.

The four individual respondents who stated that they do not prioritise managing their T1D also showed concern about attending clinic appointments and felt that they are not managing their T1D. Despite this, three of these individuals said that they are not worried about their future living with T1D, giving reasons as parents taking responsibility for their T1D and seeing T1D as an inconvenience and not really 'an issue'. Worryingly this seems to highlight a reluctance to take responsibility for the management of their T1D and a denial of the impact this could have in the future.

Almost everyone we spoke to was aware of how they feel when they are in control of their T1D and how they feel when they are not. 2/3 of respondents were not worried about their future with T1D as they feel they have it under control.

Communicating with health professionals

70% of respondents are completely confident in using and responding to the Ready, Steady, Go questionnaire, 24% felt 'somewhat confident' and only 1 person said they didn't feel at all confident.

Only 32% regularly download their meter readings, although 44% say they upload or share their meter readings with health professionals.

Respondents said that phone or video calls would be an acceptable alternative to clinic appointments, but most would still prefer face to face appointments. 2/3 would be happy to use texts or drop-in centres, less popular were social media groups, peer support groups and digital apps.

Support from health professionals

Nurses and Doctors/Consultants are the most valued for providing support and helping respondents manage their T1D. The qualities that young people value in a health professional are feeling understood, being treated with respect and being listened to in a non-judgemental manner. They also value practical support, such as health professionals who can provide information about T1D, who have knowledge of the young person as an individual and who are flexible and easy to contact.

What would a 'perfect' service look like?

The final two questions asked the young people what they would like the service to provide. They would like information that can support them to do the things they want to do in life and in the future, such as travelling, driving, going to university and advice about what to expect as a young person living with T1D.

A perfect service would consist of quick, timely, local appointments where all the necessary staff were present and everyone is understanding, friendly and caring. There would also be a wider support network that provided emotional health support and peer support.

References

¹<https://www.diabetes.org.uk/diabetes-the-basics/what-is-type-1-diabetes>

²<https://www.nhs.uk/conditions/type-1-diabetes/about-type-1-diabetes/>

³<https://jdrf.org.uk/information-support/about-type-1-diabetes/facts-and-figures/>

⁴[file:///dcfs1/FolderRedirection\\$/debbie.banks/Downloads/EoE%20Transitional%20Care%20for%20Young%20People%20with%20Diabetes%20\(2\).pdf](file:///dcfs1/FolderRedirection$/debbie.banks/Downloads/EoE%20Transitional%20Care%20for%20Young%20People%20with%20Diabetes%20(2).pdf)

⁵<https://www.england.nhs.uk/wp-content/uploads/2016/01/diabetes-transition-service-specification.pdf>

⁶<https://link.springer.com/article/10.1186/s40842-019-0078-7>

⁷ https://www.diabetes.org.uk/about_us/news/premature-deaths-diabetes

⁸ https://www.diabetes.org.uk/resources-s3/2017-11/diabetes_in_the_uk_2010.pdf

⁹ <https://www.diabetes.co.uk/news/2015/apr/type-1-diabetes-mortality-rate-higher-in-uk-than-most-of-europe-95680226.html>

¹⁰ <https://www.lancashire.gov.uk/lancashire-insight/population-and-households/population-and-households-2011-census/population-by-ethnicity/#:~:text=The%20usual%20resident%20population%20of%20the%20Lancashire%2D12%20area%20was,ethnic%20people%20in%20the%20county.>

¹¹<https://www.uhs.nhs.uk/OurServices/Childhealth/TransitiontoadultcareReadySteadyGo/Transitiontoadultcare.aspx>

¹² <https://www.hindawi.com/journals/jdr/2018/9572817/>

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