

healthwatch

Blackburn with Darwen



Type 1 – DNA Responses

Healthwatch Blackburn with Darwen

2019/2020

About Healthwatch Blackburn with Darwen

Healthwatch gives people a powerful voice locally and nationally. At the local level, Healthwatch Blackburn with Darwen helps local people get the best out of their local health and social care services. Whether it's improving them today, or helping to shape them for tomorrow, Healthwatch BwD is all about local voices being able to influence the delivery and design of local services.

Healthwatch was created under Health and Social Care Act, 2012. We are part of a network of local Healthwatch organisations which help to ensure that the views and feedback from patients and carers are an integral part of the design and delivery of local services.

Find out more at: www.healthwatchblackburnwithdarwen.co.uk

Disclaimer

Please note this report relates to the findings from 39 individuals in Blackburn with Darwen and East Lancashire. Our report is therefore not a representative portrayal of the experience and views of young people with Type 1 diabetes, only an account of what was represented at the time.

Date of Project

Engagement activity took place **October 2019 to March 2020**.

Background and Rationale

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). The findings of this work are included within this report available on our website -

http://www.healthwatchblackburnwithdarwen.co.uk/sites/default/files/report_-_experiences_of_the_transition_to_adult_services_for_young_people_with_t1d_-_final_version.pdf

Healthwatch Blackburn with Darwen followed this work up with a further review of young people's responses, particularly from young people who currently do not attend clinic appointments to understand the reasons for their lack of attendance and engagement with their Type 1 diabetes care.

Based on this feedback, Healthwatch Blackburn with Development has developed a set of recommendations for the Diabetes Transition team at ELHT. These are summarised within this report.

Issues raised by 'Did Not Attend' (DNA) respondents

-  Sometimes I can't attend as I can't get there - depend on parents to get to clinic 
-  I'm not a good diabetic, I don't handle it well. I suffer from depression and my walking is bad. 
-  Hard to get to clinic because I can't walk without a struggle with my legs and asthma 
-  Worried, scared most times 
-  Lack of relationship with hospital staff - feel judged, don't like way they talk to me, patronising, stress at me 
-  I know my own body no diabetic is the same "I know deep down I need to get a grip" 
-  Everything is fine, I attend all my appointments, everyone is great!!! 
-  Confusing as one week would get a letter to go to the old clinic and then the next appointment would be for the new clinic 
-  The nutritionist's team is not flexible with food, feel like I'm being told off 
-  I can manage my diabetes by myself 
-  Positive - "My emotional wellbeing person has been the most helpful staff member" 
-  Don't like the way the specialists talk to me and treat me. 
-  I miss half lessons at school to get here on time. 
-  I have to take leave from work to get here. 

Other issues raised

- Parental involvement - consider alternative options for appointments. 64% of respondents rely on family to take them to the clinic.
- Distance and time to get to clinic problematic for respondents making their own way to clinic - for some it requires several changes of public transport
- Cost of car parking an issue for 15% of all respondents and availability of parking sometimes seen as an issue. “The cost of parking builds up as having to attend every 3 months.
- 84% of all respondents stated that the time and location were fine but this was not the case for the DNA respondents
- 33% of all respondents were worried about coming for appointments. Patients seem to have a high fear factor of being judged, especially if they feel they are not managing well.
- 19% of all respondents did not take up offer of emotional wellbeing support and 5% were not offered this support. “Some of the diabetic team did put me off due to their attitude, they don’t live with this condition and have no idea”.
- 33% of all respondents did not feel they were managing their condition as well as they could. “I’m trying but it isn’t controlled. Balancing it with seeing friends and education is hard.”
- 38% of respondents are worried about their future living with diabetes.
- Flexibility of time and location would be appreciated. Drop-in clinics were a popular alternative
- Not one size fits all - maybe offer mix of video appointments, drop-in clinics, home visits to be able to be flexible to young people needs? in clinics were a popular alternative

Recommendations

- Prioritise involvement of emotional wellbeing team (from 12-14 upwards).
- Further investigation into correlation between when diagnosed and DNA rate - is this higher for those who have been diagnosed later on in childhood and who have not built the same relationship with the team?
- Start conversations about transition early (12-14 onwards) with clear transition plan developed for individuals based on their needs and emotional readiness.
- Implement a keyworker approach based on individual's relationship with the team to support them through transition - it is clear from feedback from respondents that they build up relationships with particular individuals in the team.
- Clarity of communication - for both young people and families. Make it easy to understand for young people - could the team involve young people in developing the resources with the development of a participation group?
- Better promotion of the app - several respondents were unaware of it.
- Regular conversations between appointments - text or over social media to see how they are doing - take pressure off individuals if they are feeling they are not doing particularly well and reduce their fear of attending appointments.
- Consider flexibility of time and location of appointments particularly for those furthest from the 2 clinics e.g. Pendle, Hyndburn, Ribble Valley.
- Face to face is the most popular option for appointments but offer flexibility of other support mechanisms - video calls/text service/peer support/social media groups.
- Consider developing a participation group (similar to CAMHS) for those who are keen to be involved in the service and who want to work with the team to make changes and support other young people.
- Anything that could be done about car park cost?!
- Transport support - dial a ride type options/the free bus shuttle? Linking in with schools and colleges transport?
- Other factors - waiting room more young people friendly with wifi, information sheets they can relate to and more young people friendly reading material (not homes and gardening!)

TRUST RESPONSE

Re: Response to Healthwatch Lancashire and Blackburn with Darwen report on Diabetes transition: the experience and provision of local services for young adults.

Results of the report were given to Dr Chris Gardner, Consultant Paediatrician and Deputy Medical Director for East Lancashire Hospitals NHS Trust.

“Healthwatch volunteers and staff are thanked for the work undertaken to support the Trust in highlighting positive findings from patients and their families, as well as highlighting some areas for improvement. We take all feedback seriously and work hard to ensure all our patients and their relatives have a good experience when using the Trust’s services.”

After reviewing the comments from patients and the recommendations made by Healthwatch Lancashire and BwD, we want to advise that:

- One of the positive aspects of the COVID Pandemic is that advances in remote consultations have made many of the ideas within the report more achievable. It is good to see that this innovation will be welcomed by our patients.
- We are encouraged by the many positive comments about the support which the team is able to give, however the report provides powerful insights into reasons for non-attendance at clinic, and the fear factor. The team will look at their approach to patients to understand how this can be specifically addressed to enable our patients to take advantage of the support on offer.
- We will aim to create an action plan to address the issues raised in the report to advance the service further.