

What is important to children, young people and families about the way Complications from Excess Weight (CEW) clinics provide their services?

Thurston,

Themes from engagement

Emma Rigby and Lindsay Starbuck August 2023

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About the design of this report

Creativity was used in the engagement sessions we ran to make them fun and engaging. In one of the sessions young people made paper aeroplanes. We have therefore used these images in the report about the engagement. The different journeys the aeroplanes take reflect the different experiences and journeys the young people and families shared as part of this work.

Acknowledgments

We would like to thank all the young people and families who attended the engagement sessions and all the clinics that we worked with to set up and run the workshops. This work was funded by NHS England.



Executive Summary

To inform the development of new, specialist complications of excess weight (CEW) clinics 39 young people and 38 parents took part in engagement events around the country, based in five of the clinics. The events took place in early 2023. Young people ranged in age from six to seventeen, and were approximately split on gender. Half of attendees were from White British backgrounds with the rest from a range of other ethnic groups.

Some consistent themes emerging from the engagement included the importance of the clinic environment (how welcome and comfortable families felt), the importance of having both in person and on-line options for different parts of the clinic journey, some confusion over the service offer and the need for more clarity, the challenges offered by logistics around timing, attendance and travel, and the value placed on the opportunity to engage with each other, schools and other external services.

Being clear what a CEW clinic is seemed a critical message; young people and families need to know what to expect. A better and more universal understanding of how the clinics are focused not only on weight loss and other clinical complications but also mental health distress and the young people's own personal goals seemed key. Being listened to by staff in the CEW clinic was important to young people and parents they valued the opportunity to be heard.

Despite the clarity of these themes, there were also differences within groups and between the sessions. This highlights the need for a responsive, person centred approach (and one that is youth friendly). Overall the engagement sessions also suggested that it was quite difficult to reflect about the whole experience at a rather early stage in the development of the clinics, that clinics might need more support with how to engage with clients on an ongoing basis, and that the discussions highlighted the importance of clinical leadership and team culture in setting the context for individual clinics. A number of practical recommendations are made that might help in the short term, including introducing welcome packs.



Background

To inform the development of new clinics for treating 'Complications from Excess Weight' (CEW clinics), NHS England funded the Association for Young People's Health (AYPH) to seek the views of young people living with excess weight and their families.

A previous round of engagement in 2021-22 worked with children, young people and their families to help determine the priority outcomes for the clinics. Now that the clinics are up and running, this second round of engagement in early 2023 was designed to elicit views on the ways in which the service is delivered. A third round later in the year will explore the different staff roles at the clinics and multidisciplinary team

working. Understanding the perspective of the young people attending the clinics is critical to getting the model right.

As engagement rather than formal research the aim of this work was to get a sense of the range of views held by the children, young people and families using the clinics, and to allow them a voice in the debate around the benefits and challenges of different service delivery models. Their views will not necessarily be representative of all those attending clinics, but they ensure we do consider provision from their point of view as the clinics evolve.

About the engagement

Five engagement sessions were facilitated between January and March 2023. Five different CEW clinics were selected to take part via an open expression of interest process in the autumn of 2022. The aim was to have a broad range of children, young people and families involved. AYPH and NHS England jointly decided which areas to run the events in seeking to ensure PPV sessions ran in places testing different models of working and with a good geographical spread.

The sites selected to take part were all from different NHS regions. Each area also had a different model of CEW provision including clinics which were running online, face to face, hub and spoke, single hub, split site and network models.

A total of 39 young people and 38 parents were involved in the Patient and Public Voice (PPV events across the sites in this round. The age of the young people ranged from 6 to 17 years. We met 21 young women and 18 young men. Most family members

attending were mothers but we also had grandmothers, fathers and siblings attending in total 10 male relatives and the rest female. Half of the young people and parents attending identified as White British with the remaining attendees coming from a range of ethnic groups including Asian, Black African, Black British, Black Latin American, Mixed ethnicity and other White ethnicities. Attendees had a range of access needs. Interpretation was required in two of the sessions, a number of the young people were neurodivergent or had learning difficulties or disabilities, some attendees had restrictions to their mobility and some experienced anxiety. Many of the young people had experience of using multiple health services either in relation to their weight or other long term conditions and many of the families were managing complex interactions with health services, schools and other services.



Methods

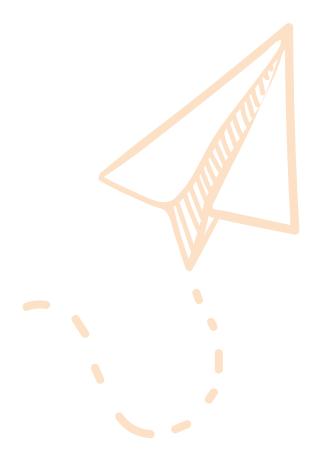
The focus of the engagement events was to understand young people and their families' perspectives on the different delivery models of the clinics. At the beginning of each session, we informed participants about the different ways CEW clinics worked in different locations. We designed a methodology that focused on the main aspects of difference in the CEW clinic models – access, travel, location and communication (a full list of the topics discussed can be found at Appendix 1). We also facilitated open discussions about what happened at the clinics and children and young people's preferences in terms of how services are run.

Four sessions took place face to face – three in NHS venues and one in an independent venue. One session took place online to reflect the focus on online delivery in that clinic. Sessions ran for 1.5-2 hours. In each session we started with introductions and fun icebreaker exercises followed by an outline of the purpose of the engagement. After these introductory elements, we ran parallel sessions with young people and parents, which allowed us to identify distinct themes from young people and parents.

NHS England staff were present at each session to share information about other clinics and the CEW model and observe the discussions. Staff from the CEW clinics were also present at each session to provide wrap around support for attendees. At the start of each session we stressed that staff present from the service really wanted to learn about ways to improve the service to try and avoid concerns from attendees about criticism of the service. We also provided alternative routes for feedback via direct conversation with AYPH staff at the meeting or via email.

All young people and families were supported to attend by their respective clinics. AYPH provided travel expenses including covering costs of taxis and other modes of transport in advance when required. Every young person and family attending received a £20 multi store voucher to thank them for their engagement.

At the sessions a range of art materials were available for young people to use, and discussions and activities were made as interactive as possible. With a wide range of ages and needs, the two experienced AYPH staff running the sessions adapted the methods as required to fit online and face to face delivery and the other needs of the groups. The access needs of participants were reviewed by CEW staff and communicated to AYPH before the sessions. CEW staff supported young people and families who found being with the whole group overwhelming for all or part of the session. Finally in two areas some young people were unable to attend the clinic session but wanted to participate. The youth/family worker in both places used the methodology to undertake one to one interviews with these young people.



Themes from the engagement

The importance of the clinic environment

All five clinics ran in different ways. Some were primarily in hospitals whilst others used community and youth spaces. In some areas more than one venue was used for clinic appointments and the amount of online engagement varied from clinic to clinic. Some operated primarily online and others entirely face to face.



Something to do with your hands like drawing or playing with something like clay/putty or a fidget toy.

Young person





As a young person you don't feel like you fit in either of these spaces, there is no middle ground so they feel less inclusive.

Young person

Young people appreciated some of the clinics' facilities such as smoothie bikes, virtual reality headsets and support animals as well as games to play and interesting things to read. Many of them mentioned the importance of something to help ease anxiety. This included a range of fun, interesting and distracting activities on offer as well as the importance of quiet spaces which were not overwhelming. Free wifi was also important as was a space to get healthy food or a kitchen.

For older young people the need for specific youth oriented space was highlighted and they shared the feeling that they didn't fit in either the child or adult spaces. Overall, the clinic space is important to help reduce anxiety and support young people's attendance.

Parents talked about the need for a *welcoming* space with friendly, approachable staff. They recognised the importance of spaces which were relevant and welcoming to children and young people of different ages. For example, play workers and play spaces were important for those with younger children to ensure parents could communicate with clinicians.



(should be) divided by young people's age.

Parent





Waiting area for multiple clinics – horrid.

Parent





Nice and welcoming energy and you don't feel you will be negatively questioned.

Young person



Some parents shared how waiting areas for multiple clinics could be challenging, highlighting the potential for sensory overload.

The clinical environment was key to making both young people and their families comfortable. Everyone stressed the importance of not feeling judged. There was also a desire for age appropriate spaces where young people feel recognised.



Online versus face to face services

There were strong opinions across the groups about whether remote online/telephone or face to face appointments were preferred. In the two clinics which were delivered almost entirely face to face there was little appetite for online options. In the clinics where some online/telephone contacts were used there were a range of views.

Some families and young people really appreciated the opportunity to meet online and this was particularly important for those who lived very far away from the clinic. Virtual contact was also appreciated for rapid responses particularly for parents outside of regular appointments (see section on logistics). However, some young people were



I'm ok doing it virtual but I prefer to have one session in person to start ...so I get comfortable.

Young person





Not everyone has a laptop with a camera set up.

Young person



strongly against online appointments and pointed out that it shouldn't be assumed that everyone will have the technology or privacy required.

Some face to face contact was important for everyone we spoke to and there was the sense that face to face contacts can help to develop trust whilst virtual contact could be important for the more regular appointments with clinic, both thus playing different and complementary roles.



Can be more engaged when in person, face to face is important but you need virtual to enable more frequent contact.





Some parents shared a perception that young people were more actively involved in face to face meetings than those that are virtual. Overall there was a sense that different young people and families required different ways of communicating. Participants reported that face to face contact was key in the early stages to build relationships and trust. After that young people and families need to be involved in decision making about the balance of online versus face to face sessions in their own care.

Understanding the service offer

Across the five clinics there was a considerable difference in young people's and parents' understanding of what the CEW clinics were. This was partly due to how long they had been in contact with the clinics but also a lack of information about what to expect. Clinics shared a range of information in different ways but this had not always provided families and young people with a clear understanding of the CEW clinic, its purpose and how it would work for them.



Some people don't like (to be) caught off guard — would be good to know what is going to happen at the first appointment.

Young person



on my first face to face there was a lot of people which was a bit overwhelming.

Young person





Getting to know you as a person is important which can make me feel more comfortable.

Young person



a picture of the doctor before the clinic with their name and a survey at the first session to say what they liked and disliked. The main purpose of those early interactions from young people's perspective was to help get to know the team and build trust as well as the potential for sessions to be informative for them.

Continuity of staff was really important and seeing the same staff person each time was prioritised consistently. In addition young people spoke about the fact that they would often see lots of professionals together. For some this was overwhelming but for others this was preferred to seeing everyone separately.

Information about what happens at the clinic, how many people they would meet with and other details was very important to participants. Knowing what to do in between clinic appointments was also seen to be vital – there was a significant proportion of young people and families who were not sure about what they should be doing.

Young people highlighted the need to understand better what happens at the clinics. They also highlighted the importance of support for their parents and family. They had suggestions for ways in which clinics could improve including virtual tours, videos of the clinic where you get to meet the team,



No I don't know what I am meant to be doing in between clinics.

Young person





Written down version helps to understand as there are a lot of things going on in the clinic.

Young person



Young people were not all clear about what they should be doing in between clinics. They spoke about the importance of communication after the clinics so they could remember everything that was talked about. Some young people also asked for emails to be sent to them as well as their parents. Others, particularly at the younger



Home visits have been really good (they) went on walks with my young person.

Parent





lack of cohesion between professionals (clinic is) great but linking message lost somewhere.

Parent



end of the spectrum, wanted all communication to go through their parents.

Parents felt positive about the work that happened outside of clinic appointments, particularly with youth and family workers. They appreciated having all the clinicians in one place and contrasted this with other health services. However, some parents felt that there wasn't always a clear structure to the support, including not knowing what to do between clinics or when the next contact would be.

Parents felt that it was important to have opportunities to speak with clinicians on their own. This would allow them to ask questions and express any concerns that may be difficult to do in front of young people.





Can't share my worries with her.

Parent





(I need a space to be) open about everything

Parent



It was clear from the engagement events that there is a need to clearly communicate the clinical offer to both young people and their families. There was a lack of understanding about the approach (being largely behavioral rather than medical), the process (long term with a significant amount of individual work outside of clinical setting) and the intended outcome (weight loss or improving health/complications related to excess weight).

The logistics of attending

We discussed logistics with all young people and parents including clinic location, waiting times, the frequency of appointments and travel. There were varied experiences based on where people lived in relation to clinics and how this distance impacts the amount of time required to attend.



It was only a few weeks after I got referred to be seen.

Young person





Pay for petrol and parking – more expensive if you stay longer.

Young person



Young people told us they had to take time out of education to attend appointments, although some were less concerned about this than others. Most of the young people we spoke to said they didn't have much control over appointment times. Older young people were aware of and concerned about the cost of travelling to appointments — public transport, parking, taxis. The younger young people were more aware of the time it took to get to appointments and how difficult it was to find the clinic on the first visit.



I was referred 6-7 months before my first appointment.

Young person



When it came to waiting times between referral and first appointment, young people had a wide range of experiences. They also shared different experiences when we asked how long the clinic appointments lasted – everything from 30 minutes to 4 hours. At some of the sites, young people felt that their contact with the clinic was too spread out and sometimes lacked a clear purpose. At others, young people had regular contact, often with a youth or family worker. Overall young people felt that regular contact could help their engagement and motivation with the process.



If I have to make changes, it's hard to keep up the motivation and it's easy to forget about it (can remember for maybe one week).

Young person

Parents and carers were acutely aware of the financial implications of attending clinics. As well as young people needing to take time off school to attend, parents need to take time off work to support their young person to attend. They felt it was important to have a say in appointment times or at least have a good amount of notice so they could make arrangements at work.



Travelling a long way is a nightmare have to have whole day off school...my daughter hates it.

Parent



time out of work difficult.

Parent



The opportunity to have them out of school hours was important so education was not disrupted.

Many young people and their families had to travel considerable distances to attend CEW appointments at great cost. For some families, significant changes had to be made such as changing their job in order to attend clinics. For others travelling by public transport or getting to the hospital in time to get a parking space was both time consuming and costly.



We got lost on the way!.

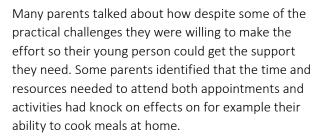
Young person





Knowing when next appointment is – need to give notice at work.

Parent



Clarity about the regularity of appointments, h ow these fitted into people's lives and making them easy to book were all highlighted by participants.



It is far us but it's definitely worth the travel as we have no other services like this where we live.

Parent



The importance of engagement with each other, schools and other services

Although it was not specifically part of the structure of our sessions, the ability of the clinics to advocate for young people and families with schools and other services was highlighted as particularly important. Participants also had a lot to say about opportunities for peer support.



I would like a space for just young people so they get a chance to become friends without staff.

Young person







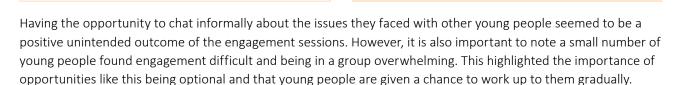
Good we understand each other – similar experiences shared – very important and helpful.

Parent



More talking to younger people like today would help a lot of people come out of their shell.

Young person





"More support at school, pastoral support is not actually helpful.

Young person



Nice to know other people are on the same journey as me.

Parent



All parents were positive about the engagement session and reported that it had been really important to meet other parents. In more than one engagement session they mentioned being on a similar journey together and the comfort they got from knowing they aren't going it alone.

Although the content of the PPV sessions focused primarily on the different models of CEW clinics, young people regularly spoke about their negative experiences in school. Parents felt that staff advocating for their young person and family at school was very helpful. Parents were also appreciative of how the clinic put them in touch with a range of other services they weren't aware of such as; youth clubs, mental health support and an all male gym.



ok missing occasional day of school for health. School have been pretty good with it. Clinic made contact with the school.

Parent



(There's) nowhere else to get help.

Parent



Participants felt that some advocacy with schools was necessary for them to better understand how their excess weight affects their health and support their access to CEW appointments in school time. Peer to peer support was also highly rated — where regular systems were in place this was motivating and enjoyed by young people. Where this wasn't in place almost all of those attending PPV sessions said more engagement with their peers would be supportive.

The role of clinical leadership and team culture



young person knew what was happening and was engaged in the process from the start.

Parent





The staff were very kind with him and helped him manage his anxietyeven when taking blood which was a brand new experience for him.

Parent

Another theme highlighted in the sessions was staff. Parents in particular highlighted the importance of the relationships they and their young people had with clinical staff. How well supported young people and their families felt by their local CEW team had a significant influence on how they perceived the service overall.

The most positive feedback came from young people and families who experienced the process as collaborative and tailored to their needs. A large proportion of the young people accessing CEW clinics are neurodivergent and/or experiencing mental health issues so when staff worked with them sensitively, it was particularly appreciated parents.

At the other end of the spectrum were families who felt that the service had been imposed on them. Both

young people and parents talked about experiencing stigma and blame around weight, both inside and outside of the clinical environment. Those for whom child protection orders and parenting assessments had been put in place felt judged and scrutinised rather than supported.

Additionally, some parents highlighted how discouraging it was when health advice was given without taking into consideration their family's actual circumstances.



I thought we were getting supported.

Parent





I once got told to shop daily how are you supposed to do that? She's not my only child.

Parent





I haven't asked for this so why am I under scrutiny?

Parent



The benefits of nonjudgmental and supportive services for both young people and their families were reflected in the feedback at our engagement events. For a health intervention based on behavior change, it felt particularly important that young people and their families were included in the process rather than having a sense of it being imposed upon them.



Reflecting on the experience of engagement

• Early stage of engagement with CEW clinics:

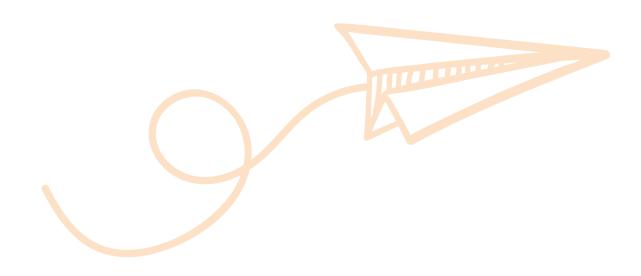
For some of the young people and families the engagement event took place at the start of their CEW journey and they had had little experience of the CEW clinic at the time we spoke to them. The sessions were facilitated so that they could focus on what they wanted to discuss rather than a comment on what they were receiving from the service.

Experience of arranging PPV events:

There was a range of experience across the CEW teams of running engagement events with children and families. There was a lack of confidence in some areas and an under estimation of the challenge of recruiting children, young people and families to attend and the time that this takes. We met with all teams several times in the run up to each event. Key to success was having a lead staff member to coordinate the recruitment and liaise with AYPH staff. Despite the challenges we had good attendance at all sessions and all teams were appreciative of the opportunity to have a session and welcomed the feedback they received.

• Importance of engaging with other young people and families:

For some young people and families this was the first time that they had had the opportunity to meet together with others going through the same experiences as them. The feedback at the end of the session about whether they enjoyed meeting with other young people and parents was overwhelmingly positive. However, one young person in one of the larger sessions had found the session challenging. Two young people in one of the sessions found it extremely challenging to be in the same space as other young people but stayed supported by CEW staff for the whole session. After the session the parents stressed the importance of their young person having opportunities to get out of the house and into more social settings.



Conclusions and recommendations

Throughout the five engagement sessions and across the different topics we discussed with young people and their families there were some overarching messages. Young people and their families want:

- nonjudgmental, supportive services where they feel included in their own care
- tailored one-to-one support
- opportunities to meet with their peers who have had similar experiences, and
- a holistic approach that focuses on all aspects of their health, especially when they have experienced stigma, shame and bullying.

Although some aspects will be specific to CEW clinics, these are in line with what young people with long term conditions tell us they want to see from health services in general.

We have also drawn out a number of specific, practical recommendations for the consideration of the CEW clinics that could be implemented immediately:

- The need for a clear and simple welcome pack for young people and for parents/carers – for example, it would be good to include photos, practical information about how to find the clinic and an overview of the offer
- Understanding how young people and families prefer to engage with the clinic: In early sessions using a survey or a conversation to understand the young person and families preferences about how they engage with the clinic including online, in person; appointment times; how far they have to travel and best appointment times.
- Understand the cost of attending clinic for families and provide clear guidance about how to claim for travel expenses.
- Understanding the child's context: It is important to ensure that there is understanding about how well each child (and their family) are engaging with school or college as a context for being able to benefit from the clinic. The situation may be a positive or negative support. Building in advocacy with schools is important to support engagement with the clinic and avoid school attendance or other issues having a negative impact.
- Investigate online and other tools that can help families and young people manage appointment times
 availability of choice about appointment times to see clinicians was important.

The honest feedback we received highlighted the importance of an approach to delivering CEW clinics which is person centered with ongoing structures for engagement built in. Whilst these sessions did not focus on having warm, supportive and friendly staff, the young people and parents know this is essential. The positive relationships young people were able to develop with youth/family workers was particularly appreciated. Building trusted relationships with staff in the clinic and supportive peer relationships with each other seems key to CEW interventions and ongoing access to health services.



APPENDIX 1

Topics discussed with participants at engagement events

1. ACCESS

- speed of being seen
- how often do you want contact
- how long you are at the clinic for
- seeing the right staff member
- seeing the same staff person each time

2. TRAVEL

- how far to travel
- how long it takes
- accessible by car/public transport/other
- cost of travel/parking

3. LOCATION

- in a hospital
- in a community setting
- virtual
- how welcoming the venue is
- the facilities at the venue

4. COMMUNICATION

- Knowing what you need to do in between clinics at home
- Having clear communication in person
- Having information by email or online

About AYPH

The Association for Young People's Health works to understand and meet the particular health and wellbeing needs of 10–25 year olds. To find out more about our work visit www.ayph.org.uk

Contact: info@ayph.org.uk @AYPHcharity