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Consultation report on the experiences of Children and Young People who were admitted to Acute Paediatric wards due to mental health issues.

Feedback from focus groups with young people aged 13-19 across the Humber and North Yorkshire ICS

Prepared July 2023

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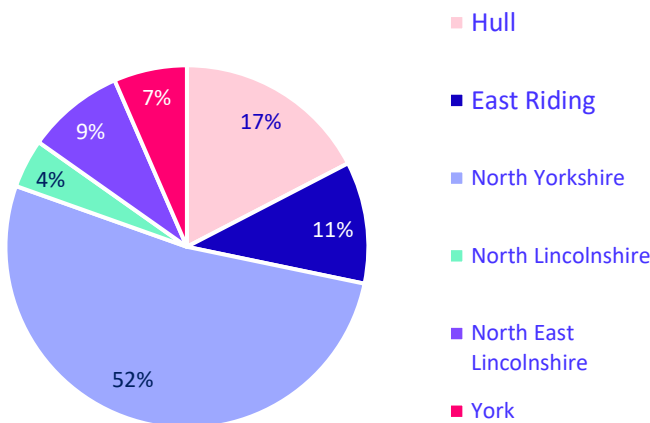
Introduction

This report presents qualitative data and verbatim feedback obtained from young people who have experienced an admission to an acute paediatric ward with mental health needs, within the Humber and North Yorkshire Integrated Care System (ICS) geography in recent years.

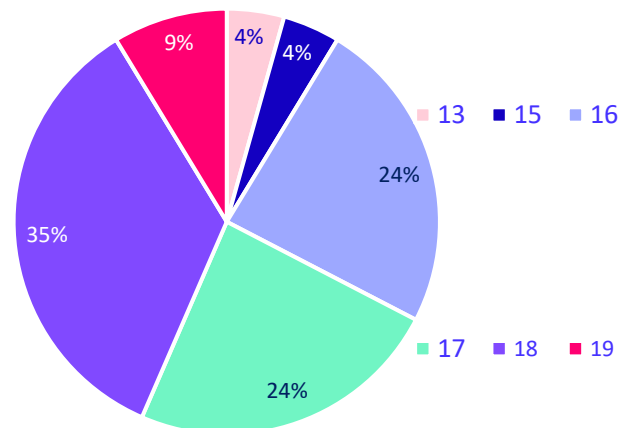
The objective of this research is to identify key areas where improvements can be made to enhance the overall care and support provided to children and young people facing mental health challenges and reduce the number of young people with mental health needs requiring an admission to an acute paediatric ward.

The feedback is categorised under three headings: 'Before', 'During', and 'After' an admission to an acute paediatrics ward. Under each heading feedback is then further categorised by 'What worked well', 'What didn't work well', and 'Even better if...'. Additionally, perspectives on the new distraction boxes initiative and on the potential implementation of a health passport were also discussed.

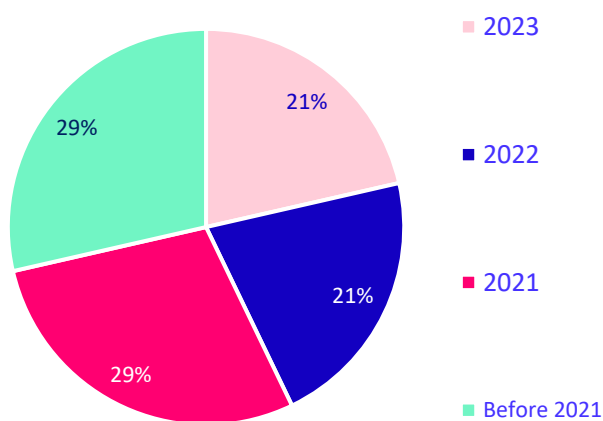
Locations of those taking part in focus groups



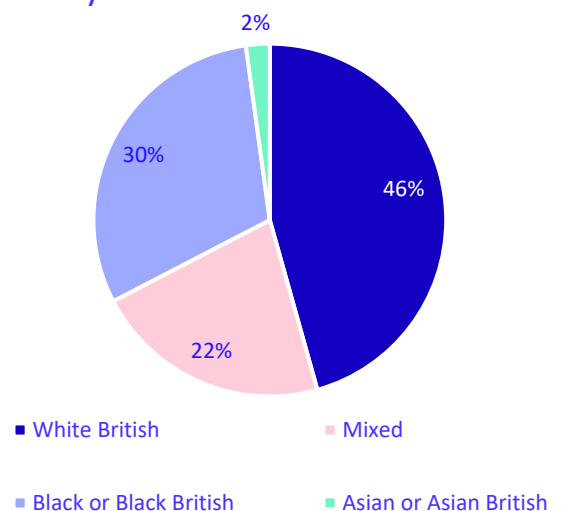
Ages



When was your most recent hospital stay?



Ethnicity



Approach

The engagement approach for this research was coproduced with a core group of seven young people aged 16 to 21, with combined experience of disability, neurodivergence, growing up within the care system, poverty, homelessness, LGBTQ+, eating disorders, and suicidal ideation and intent, and two of the young people involved had direct experience of an admission to an acute paediatrics ward with mental health needs. The group's insights were invaluable to pitching this engagement approach to the target audience of young people aged 13-19, from across Humber and North Yorkshire, with experience of an admission to acute paediatrics for their mental health needs.

The agreed approach involved a preliminary online survey, followed by a series of focus groups. The young people were presented with different engagement proposals, including one traditional comms approach and three alternative proposals utilising social media platforms. The group unanimously agreed to work in partnership with HEY Mind but advised on tweaks to the proposal, particularly around the effectiveness of the specific social media platforms and instructed us to redirect the allocated budget for Snapchat to instead focus predominantly on TikTok advertising.

All wording and imagery was coproduced with the core group of young people, who had final sign off on wording and how it looked. They then tested the survey on a variety of devices and provided feedback on layout and where text could be condensed to increase the user-friendliness of the survey, particularly for young people with additional needs.

The questions for the focus groups were also agreed with the young people, who requested an easy-to-follow structure and supported the idea of breaking down the focus group into sections based on 'before', 'during' and 'after' an admission, using the same simple and clear questions of 'What worked well?', 'What didn't work well?', and 'Even better if...?'

After the first focus group it became clear that the responses to 'Even better if...?' under the 'Before' heading did not necessarily indicate what might have prevented an admission, so it was agreed with the core group of young people to ask the additional question of 'What might have prevented you from needing to go into hospital?'

Engagement

The success of the TikTok advertising led to 111 young people expressing an interest in attending the focus groups. It was easy to identify the timings of the TikTok adverts from flurries of emails at specific times from young people expressing an interest in the focus groups. Consent forms were then sent to those young people to further identify their eligibility for the focus groups.

Some of the young people who applied for the focus groups had experience of an inpatient admission, instead of acute paediatrics, and with their consent their details will be passed onto the inpatient engagement leads.

Of the 111 young people interested in the focus groups, 49 young people were found to be suitable and were invited to attend a focus group. 46 of those contributed to this research, sharing their feedback at either one of six focus groups or one of three one-to-one discussions (offered only to those unable to attend any of the planned focus groups).

Challenges

The initial proposal involved utilising engagement leads within the acute settings to support with identifying young people to feed into this research and gathering feedback from them. However, efforts to identify engagement leads within the acute settings to support this work was unsuccessful, leading to increased pressure on Humber and North Yorkshire Health and Care Partnership's Mental Health, Learning Disabilities and Autism Collaborative Programme's Children and Young People's Engagement and Coproduction Manager, to undertake a piece of work unsupported. As a result, this work has taken longer than expected to achieve the goals in the initial proposal.

The language and wording for both the engagement promotion and the consent form presented a significant challenge. It was difficult to assess suitability of young people for this research due to the differences in language used by young people and by services, which led to confusion around the meaning of terms such as "acute", "paediatrics", and "inpatient".

Whilst the TikTok advertising, as directed by the young people, was hugely successful in reaching a large number of young people, some were out of area or not suitable for this piece of work. Due to unfamiliarity with TikTok advertising it is reasonable to assume that specific targeting exceeded the geographical patch, perhaps due to algorithms or the advert being shared by individuals. However, on the whole, feedback from the young people out of area about their experiences before, during and after an admission to an acute paediatrics ward with mental health needs, indicated a similar experience to those within the Humber and North Yorkshire footprint. This report will therefore be shared with regionally and nationally as well as across our ICS.

Another challenge was due to the email address included on the promotion. The core group of young people advised that using the Mental Health, Learning Disabilities and Autism Collaborative's generic email address of hnf-tr.hnymhpmo@nhs.net was too confusing and difficult to read and would create a barrier for young people if it was used on the promotional posters and adverts. Young People have recommended a more appropriate email address e.g. CYPbeheard@nhs.net. Therefore, it was agreed to use the Children and Young People's Engagement and Coproduction Manager's email address instead. However due to the scale of engagement, a significant amount of the Children and Young People's Engagement and Coproduction Manager time, that had not been accounted for, was spent on managing the administration needs of this engagement. Many of the young people who expressed an interest expressed anxieties about this research and had numerous questions about the focus groups, and responding to these was extremely time consuming. However, this supportive approach did ensure many young people expressing an interest were able to take part and the numbers consulted through focus groups was higher than initially expected (expectation was approximately 20-25 young people when the research was planned). The higher number of participants has ensured the findings are more robust.

The final challenge was due to using MS Teams for the focus groups and one-to-one discussions. A lot of time was wasted during the allocated time in addressing the barriers some young people were facing in accessing Teams, and in navigating the many instances of lost connection, loss of sound, loss of image, and the majority of respondents needing to log off and back on again at least once. This was extremely frustrating for everyone involved and compromised the collection of some of the feedback shared.

Themes

Although the target geography of this report was Humber and North Yorkshire, several young people from out of area applied to take part in a focus group, and through conversations with those young people, several experiences were shared with themes that aligned with the experiences of the young people within the Humber and North Yorkshire ICS footprint. However, those young people did not attend a focus group and their comments are not included in this report.

Though this report is structured on the three phases of support, before, during and after an admission, there are some clear themes running throughout including:

- Communication barriers between healthcare professionals and the young people and their families
- Lack of clarity of process
- Lack of support for family
- Feelings of fear, anxiety and stress
- A sense that the health professionals do not care.
- Young people's views not heard and reflected in their care plans
- Barriers to accessing the right support at the right time
- Feelings of shame and guilt
- The need for an informative online resource for patients and their families
- Identified training needs for healthcare professionals to better understand diverse cultural and ethnic backgrounds and deliver inclusive care.
- A lack of sensory aids and resources to create a more calming and comfortable environment.

The following verbatim quotes are just a snapshot as there were too many comments to have included them all. For every quote included, there are another 10 not included but those included are those that best represent the views of young people.

Any names in this document with a * indicate that the name has been changed for confidentiality.

Before an admission

What worked well?

I tried to get help, well my mam and my nana tried for me, and was on a waiting list but in the end I had to go to A&E because I wasn't eating and my body weight was low. Everyone worried about my heart rate, and they rushed me in. I think I was there like two nights or something but then I went to Mill Lodge instead. So I think going to A&E works well.

I got support from my faith leader. He is a great man. He was good and kind. He was always there to listen. And I felt free talking to him. So he helped me a lot. Without him I might not be here.

I was getting help from the youth workers at the youth centre I go to and I already had a CAMHS worker.

Seeing a private therapist but they need to slash cost or offer the same for free on the NHS.

My family were really great at providing help to me.

What didn't work well?

Before I went to the hospital for my mental health, when I finally got accepted for the fact that I really needed medical attention I was scared. I was so scared. I didn't know what to expect. I was worried about what it is gonna be like, the treatment and everything, and how society look at you, that you're getting medication, you're getting medical attention based on your mental health and it is gonna look like you're a psycho or something.

CAMHS is a joke! There was somebody at youth parliament saying that anybody who is self-harming would be seen by CAMHS but that's a lie. They knew I was self-harming but still didn't see me.

When you do get admitted they all say, 'Why didn't you access support before?' but I tried, and nobody would help me. It's only when you actually try to kill yourself that they're even interested.

Initially, when I was diagnosed with them, you know, mental health issues, I had a therapist, so that's when I started having discussions with him about my mental health. I liked him and that kind of support, but I was only allowed so many sessions. I trusted him and he knew everything about me, and I thought I was going to keep getting help but then all of a sudden it's like 'off you go, you've had your lot now!'.

Having nobody to talk to, and nobody who knew what it felt like. I was anxious and so afraid to speak up about my mental health crisis.

I only had the support coming from my family who prayed a lot about me, about my health, mental health challenges. They found out that I wasn't coping well with my studies. I also wasn't in a very good mood for a longer period of time than normal. So, it was just my family around. My friends deserted me. I was on a waiting list for support, but I was waiting and waiting. When I got referred, they said it would be six weeks but six weeks passed and I heard nothing. I did think about going private, but I didn't have enough money. My family didn't have enough money for that.

So called crisis support! Nobody listened to me or my family until I tried to kill myself.

I wasn't getting any support, just my family. I did try to get support, but I kind of backed down because I didn't get anywhere, which was making me more depressed, and I felt it would be much easier for those who understand me, which are my family, to relate to me and for them to communicate on my behalf. I felt it to be much too difficult for an outsider to get help because I am not from the UK. They say the help is there but we couldn't find it, so I am sceptical.

The wellbeing team at school referred me for counselling but I was on the waiting list for an autism assessment so they wouldn't accept me because I would need to see a specialist counsellor and they didn't have one, so then school referred me for the disability team, but they wouldn't accept me because I didn't have a diagnosis, so I was in an impossible situation.

Being on waiting lists and most of the times being told that I should have been expected to start receiving my treatments, but then I kept getting disappointed and the waiting list gets longer but there's no transparency on the parts of the health providers.

I think funding was an issue at the time so I couldn't get a therapist on the NHS when I needed it, but I was able to, you know, fund it myself, but it's not a fair system because I had that option but not everyone does.

My family wanted to give me the maximum support and care that I deserve but didn't know how. They couldn't prevent me going to the hospital because they are not trained. I needed doctors and nurses to make me better, but they just see you as a patient and you're not the only one, so there can't be that special attention compared to your family.

Even better if....?

If there was something maybe online before you get admitted to the hospital, something like to get tips or what you should expect. Just to make it clear what you're going for, what will happen, and that just because you're seeking medical attention for your mental health doesn't mean that you're a psycho or something. Something to prepare you for what you will experience and see over there, because it is scary. Yeah. If they'd been something like that it would have been much more helpful. At least it will reduce the level of people being scared and not knowing what to expect.

If it wasn't a battle for the whole family to get the help you need. I saw what it did to my family and that made me feel so guilty for causing a ton of stress on the people I love. It needs to be easy to get help. Don't wait until people are literally trying to die because they can't take it anymore.

I would have preferred it to be a kind of face to face experience to meet the mental health professional and then talk about my experience, but then also an online channel with the same person because sometimes you go there and you're waiting and waiting, even when you're at the top of the waiting list, you still have to wait, and then you see someone different and they don't know the things you've already told someone else, and all that takes time.

A mental health service delivered by all the providers I think could have been better, where there's more flexibility in scheduling.

Mental health services with a therapist who can see you the moment you're in crisis.

Have better options like if I can't go in person, I can just connect to my doctor from my house, maybe through Telehealth.

So I think the institutions and the staff should try to be a bit transparent with their patients and let them know when they can start the treatment and like the other options that are available while they're waiting.

The doctors and nurses that see patients on a daily basis could help to train families on how to support children and teens in that situation, because they're the ones who can give you the love and affection you need but they feel discouraged to go to the hospital because they are excluded by the fact that the family are not well trained, they are not professionals in that field.

What might have prevented you needing to go into hospital?

If CAMHS actually did anything!

Better things put in place by the government. So, make some form of support available quickly for people with mental health care needs, not leaving them waiting and waiting in crisis.

If I'd successfully killed myself!

If services actually listened to you and believed you, instead of assuming you're okay and you're just attention seeking.

If services agreed to see me and help me instead of dismissing me for being on a waiting list and not having a diagnosis yet.

Access to mental health experts like right from the start instead of having to convince a GP that you actually need more than antidepressants.

During an admission

What worked well?

Naomi, she was another patient and became one of the most important things that's happened in my life. I got a best friend there and she really helped me get through my meals and my health issues.*

The nurses were lovely, and I could tell they cared about me getting better

I guess I was lucky I had a health care provider that actually put me first. He asked for my say on solutions to the issues and spoke in a language that let me see it in a way I would understand, and if there was anything he said that was technical, he explained what he was trying to say using things that I'm familiar with, using them as examples, and at every moment he kept asking "Do you understand or should I go back?". And even when my parents were there, he spoke to me directly. He gave me options. He asked me "Would you prefer this, or you prefer this? Would you want it this way or you want it this way?".

I got given this book to say whatever I want, and the doctor made sure I understood every bit of what they were saying and was ready to go back at any point if I said I don't understand.

The other people on the ward who made friends with me and encouraged me.

What didn't work well?

A good number of times I understood what the consultant was saying but at times, you know, I didn't understand. And yes, it's quite unfortunate they didn't spare me some time to explain those details to me.

I hated the fact that I'd literally be right there in front of the staff, and they ignored me and just talked to each other or to my parents like I'm nothing and it's none of my business what they're doing to me.

Having no privacy

They used words what me and my mum didn't understand like section 4 and section 2. We had to google it.

They clearly don't understand autism or sensory overload. I felt so triggered by the sounds and the lights and they just got annoyed with me.

Patients crying and screaming and being held down by staff. It was horrible and very triggering. I will never forget that sound.

I was made to feel guilty for taking up a bed.

I know there are issues where patients don't get listened to, and there's very high technical languages that they use, so the patients don't really get to understand, and there are some issues where they prefer speaking to the parent because they feel the parent knows what's best for the child, forgetting that the child will actually know what's best for them.

You could tell some of the hospital staff maybe had a relationship issue, or family issues and things like that. And then you got to notice that they directed their anger or aggression or whatever to the patients, and it affected their relationship and the treatments they give to their patients, which is very wrong.

Maybe I shouldn't have said this here, but one of the reasons why I was uncomfortable there was because of the treatment I got from most of the nurses because of my colour and my accent. I felt they were giving more attention or special attention to the white people but because I'm an African American, I didn't have the right complexion or accent so perhaps they felt I was less of a human. So, most of the time when I wanted help and needed them the most, I would see them pass by, giving other people special attention, while I'd be there looking right at them and it felt uncomfortable.

Even better if....?

The medical doctors should pay more attention to the patients, like focus on the patients. They should discuss more things about the patients' mental health with the patients, not the other way around where they discussed these things with our parents you know and then they don't let us know what is really gonna happen or what their thoughts are about us or what they intend to do. I think that we should be the first to know all the details even before our parents.

They could have like really short animations about things like what a section 4 is or a section 2, so if the doctors and nurses don't have time to tell you it so you understand you could just watch that instead.

If they understood autism better and sensory triggers. They need ear defenders, weighted blankets, better lighting, and things to distract patients.

They could manage people's emotions better and remember that it's frightening and stressful from where we're sitting and we don't know all the things they know about what's going to happen, so try to be more understanding and supportive.

Trust us to know what is best for us and what is going to work for us and what won't. You don't even know us so don't assume you know best. We've lived with ourselves since we were born and not even our parents know things about us if we decide not to tell them. Try to remember that.

I just think that it's the best to and I'd really love the doctors to be open with the patients, so the patients understand every fact about their health, the healthcare plan, and whatever that's bothering or concerning them about the health of the patients.

So, I think health care providers should bring themselves down to our level and speak so everyone can understand.

Listen more, don't assume you know exactly what the young person needs and work with the young people that decide together what is best for them. Talk about it with them.

Yes, I think they should treat everyone equally, irrespective of their colour. Ethnicity shouldn't be a reason to treat people differently.

I know staff are made to be trained professionally based on mental health, on the kind of treatment to give to patients, on how to give the treatment and things like that. But I feel when it comes to mental health, they need more training on the human-interest kind of relationship. It's the stuff like on emotions and being more understanding, more on tolerance, on patience and more of those attributes. So, I think most of the staff should be taught and should be trained on being patient and tolerant and whatever stuff they have going on in their own personal life, learn to keep whatever anger or issues you have at home, keep it outside before

you attend to any patients. Instead of adding to their pain, try to bring yourself down, to put yourself in their shoes. Try to experience what they're going through, and then I think you'll get to attend to them better in that way.

Train people who have had specific mental health challenges and recovered from their mental health issues to provide specialist support, because they were in similar shoes so they know best ways to walk those people through the recovery process.

Have a counsellor or someone who has been through it themselves available on the ward 24/7 to listen if you want to open up about your feelings but can't tell your family. And if you can't sleep you could talk to them instead of being alone in your head in a spiral of negative thoughts and feelings. Sometimes when you're that scared and that angry you just need to talk things through with a person who isn't part of your family and isn't going to judge you.

During assessments I think the professionals should really take time to fully listen to the patient when they evaluate them instead of making all kinds of assumptions, then kind of tweak the treatments in order to fit, not just deciding that because someone came in with a similar situation, they will use the same approach to solve it. Basically, what worked for them might not work for me. The approach needs to be as individual as we are.

I feel one of the main things they should do is, if possible, I don't know if such things are already being checked, but all staff should be secretly watched to see if they are able to treat everyone equally irrespective of the colour of their skin, the race, the ethnicity, even financial status. And I think there should be training for most of the staff because most of them, I feel like they are there just for the money. So, if such training is not done, I think a lot of people like me out there will find it very difficult visiting hospitals because although they might not boldly say to your face 'you're not welcome here' but from their behaviour and their attitude on a daily basis, you know you're definitely not welcome. So, I feel when this training is done and proper sanctions have been put in place where anyone who is found to break such rules is being dealt with severely, I feel the rest will definitely see that example and they'll be able to know how to behave properly and treat everyone equally.

Have a complaints box where you can quickly write a note and put it in the box without possibly writing your name or who you are.

After an admission

What worked well?

Good support from home treatment service

I'd made friends so sometimes I could discuss some of my health issues with the friends I made, like Peter, who was a patient like me while we were there. Through text messages and phone calls.*

I had contact of healthcare providers and contact of fellow patients. You don't have to be reduced to being alone. When you leave, you can still get in contact with them. That's what I did.

When they referred me to a particular site, I searched it out and researched it and contacted them whenever I needed to find solutions until I got the answers what I was looking for.

The keyworker service helped a lot.

Ripon Community Mental Health Team.

I went back to my therapist, you know, I think he's the only one I actually got support from.

So, there was an opening that was possible if I wanted, I could go to this place my therapist told me about for sessions to calm down and relax your body and you know, let it all out. I liked being given the choice but I'm still with the mental health team at the moment.

My family have been amazing and I'm still under CAMHS, who are helping me.

What didn't work well?

Communication! I didn't know what was going to happen next, my family didn't know, my therapist didn't know. Anyone my family asked said something different, it was a mess.

Even though they knew I was suicidal, I was just left to get on with life like nothing had happened. If it wasn't for my family I wouldn't still be here now.

They force talking about your care when you leave the hospital, but I think it's greatly affected by the kind of relationship you had while in the hospital and mine was not a good relationship.

I was expecting a routine check-up from the doctor where they have to call, even if not regularly, at least once in a while to check out and know how you're faring, to ask 'Are you doing better?' but I didn't really get that.

Being left to fend for myself and losing my job because I'd had too much time off, so my mental health got worse, and I took another attempt on my life and I ended up back in hospital.

Even better if....?

After discharging the patients, there should be follow up calls to check up on this patient to ensure that this patient is really recovering.

A follow up appointment with all the health workers from the hospital and my therapist, and any other people all together so everybody knows the same information about what's already happened, what treatment you've had, and what follow ups there should be.

Check that the patients get reintegrated back into this society positively. That they're getting along with their life and living normally.

It's really, really essential for the health professionals to keep in touch with their patients afterwards, and also provide groups that would also help. It would make sense because especially peer support will help. Being able to talk to someone who is of your age range and who also relates to the kind of situation you are in.

We have to talk about the relationship we have with healthcare workers. While in the hospital all the healthcare workers need to build a friendly relationship, not too intimate, not too personal, but a bit less professional and strict. If they create a better relationship in the hospital, afterwards children and teenagers will have more trust to talk to them honestly after leaving the hospital.

If the hospital were calling at least once in a while to give you a routine check to know how things are going, it would definitely be really nice. But I didn't get that. Not necessarily daily or weekly, but at least just for someone to call you at least once a month to know how you're responding to treatment.

Have more people like you to contact people when they get out of hospital to ask how you feel and if you're OK, and what it was like for you, because this is what I've always wanted. I wanted someone to hear me out, where I can share my thoughts and my experiences without being judged. To feel comfortable around people because I feel like they understand me and what I've been through.

Additional Questions

Currently acute wards across Humber and North Yorkshire are preparing distraction boxes, with resources to keep children and young people occupied while in hospital, with things like colouring books, mindfulness activities, fidget toys, etc.

What do you think about that idea?

Would those distraction boxes have helped you when you were in hospital?

And do you have any suggestions about what else could be in those boxes to help children and young people on an acute ward?

Yes, they sound good. I think it would work really well because you have nothing to do and time passes real slow, so that would make it more interesting and take your mind off what you're going through.

Noise cancelling headphones would be helpful for some people because some people when they are going through a mental health crisis at that moment, they might just prefer being alone and not having to listen to everything going on in the ward. You see and hear some things that aren't very nice on the wards and you're already anxious and triggered by your own stuff, and some of them could really enjoy listening to music, so I think that really makes sense.

People who have mental health challenges might find something very meaningful to their lives, or something that could make a lot of meaning to them at that situation. Some extra things like inspiring words, maybe Bible verses, you know. Yeah, those things could be very inspiring. Could be very encouraging. It could hit someone's mind at a particular spot that you know could be a turnaround, like a turning point for that person.

In a mental health crisis those things could be very useful or bring meaning, so bottom line is it's gonna be very, very useful.

Will books be in the boxes too? I think they should be. I like to read to escape my reality, but I didn't know I was going into hospital, so I didn't have any of my own books with me.

Positive messages to keep you upbeat.

Drawings or paintings from other kids and messages in a book, about what's helped them. Like a secret message from somebody who has been through what you're going through, so they know how you feel and can give you advice through the book or help cheer you up.

So, I think the distraction boxes are perfect. It's really gonna be like interesting and helpful to at least once in a while distract our minds and our thoughts from whatever we are going through at that moment. And it reminds me of when I was in the hospital, and I was proper desperate for something to take my mind off things and shush my racing thoughts.

Games like Uno or cards. Like when I was in hospital I was amazed with another patient because she was so upbeat and encouraging of me, and it was like that for like three to four days, but I probably wouldn't have even spoken to her if she didn't ask me to play cards with her. She's actually my best friend now through that.

A game, like something to bring people together to learn to accept each other, so like human bingo and have to find someone wearing red, or someone with a birthday in December, and things like that. I mean the staff as well. I think that would make people talk to each other more so they don't feel like they're on their own, and I'm all for it.

A distraction box would have helped me quite a lot to be fair. Nobody wants to be in there and people get proper stressed out so anything that's gonna chill you out is worthwhile in my eyes. Time drags in there if you haven't got anyone with you and it's impossible to sleep so give anyone the choice to lay there doing nothing except taking in everyone else's stress, or take their mind off it with colouring, positive affirmations, origami, things like that, obviously they're gonna choose to take their mind off their problems aren't they.

Arts and crafts stuff and maybe Plasticine or Playdoh.

They could have things to help with sensory issues like weighted blankets, ear defenders, sunglasses, calming oils that smell nice, kaleidoscopes, fidget toys, Squishmallows, etc. to help calm us down.

Sketchbook and pencils.

QR codes to websites that can help you feel better or with games you can play.

There is also some work happening at the moment to develop a Health Passport as a way of young people recording their wishes and feelings, any disabilities or support need they may have, the medication they are on, etc. The Health Passport would help to keep track of any treatment plans and any extra information about their hospital stay. Plus, it would mean that young people wouldn't have to repeat the same information over and over again, to different healthcare professionals because they could just read the Health Passport instead.

What do you think of that idea?

Would a Health Passport have helped you when you were in hospital?

And do you have any suggestions about what else it should include?

Just any other information that would be of concern to the patients, like what will happen when they are discharged.

It could have previous prescriptions in it too, so they know what you've already tried.

The parents' thoughts would be ideal for the patient's health passport, just so that the patient would be aware of whatever decisions their, his or her parents made without their, his or her knowledge.

A daily diary between the patient and the and the professional, with notes about what happened, medication, treatment discussed, so if the patient can't remember or didn't understand they can go back to it later.

It could be an online platform where you can communicate with the doctors, share your views, record routine visitations from either the doctors or the nurses, share what works for you and what you want as part of your options, say if you're physically fit, if you have support at home, stuff like that.

Yeah, that sounds like a really great idea because it will really, really help in taking away that stress of going through the story all over again. And then the treatments, like the previous treatments, and other professionals that the patient has met, I think that should also be included there, so that the new professional

can reflect on what the last professional did and know the kind of treatments or the kind of process and the kind of help that will be better for the person.

I love this idea because by the time I left hospital I was sick of telling my story so many times.

The passport could be an app so you could have it on your phone and every time a new doctor, nurse, dietitian, or whatever, works with you, you don't have to start from scratch and tell them your whole life history. You could put it in the app once so every health worker could read that before they talk to you.

I like the idea of it being an app. It could have your medical history and the list of all the different consultants and what they've said, the times you need to take your medication and an alarm to remind you.

Information the doctors and nurses need to know like if the person has eaten or not, about the person's diet, allergies, and other things.

There could be a thing to rate the doctors and the nurses like you give them 4 stars, or 5 stars, or something like that, where at least with that you can be able to judge their performance, you know, OK, if it's within a certain range, it's not doing well, and if it's below average or above average something like that. So, for example, a particular nurse who is having one star or no stars all the time, the hospital would definitely know there is a problem with that nurse, because everyone cannot be against one particular person if they're all in the hospital at different times. So, I think if such a thing is put in place where the patient is able to rate the performance of the doctors and the nurses, it would go a long way.

Conclusion

Summary of recommendations from CYP

The following is a summary of the recommendations identified in this report which need to be actioned. A commitment was made to the young people taking part in the focus groups that we would feedback to them on how the recommendations were actioned, so they know their input made a difference which was very important to them. Some of the young people would also be willing to work with staff to develop things in the recommendations e.g. animations for training, health passport etc.

Improved Communication

- Listen to CYP and talk to them not just the parents.
- Ensure CYP are involved in all aspects of their care planning.
- Better support for parents to support the young person.
- Improved information on process/pathways for CYP and Parents
- Resource pack on what happens when you go into hospital for mental health needs.
- Short animations that young people and parents can watch to explain things
- Transparency and better communication on waiting times
- Use clear understandable language and check young people and parents understand the information and their options.

- Compliments/complaints box on ward so young people can share experiences quickly and improved opportunities for CYP to provide feedback after discharge to improve services for other young people.
- Develop Health Passports/App
- Day diary so CYP could share their thoughts and questions with staff on the ward
- Consistency of care to reduce changes in workers when a therapeutic relationship has been established.

Improved training for Acute and A and E staff

- CYP mental health training
- Improved training for healthcare professionals to better understand diverse cultural and ethnic backgrounds and deliver inclusive care.
- Training on Autism and sensory issues
- Improved equalities training

Improved and increased access to Early Intervention.

- Improved digital access to support not just face to face.
- Flexibility on length of support depending on need e.g., counselling not being restricted to a set number of sessions.

Improved support on the ward

- Access to a counsellor or someone who can listen when CYP need to talk about their mental health.
- Resources for CYP on wards including distraction boxes, ear defenders/noise cancelling headphones and weighted blankets.
- Improved communication (see recommendations above)

Improved aftercare

- Improved access to support after discharge
- Clarity for CYP and parents of what happens next and clear information on the plan for support after discharge.
- Clear information on what to do if things get worse again.
- Quick access to support if things get worse again.
- Peer support and group support
- Check in from GP/hospital/camhs to check progress after discharge.
- Ensure other organisations supporting the CYP and family know what the plan is e.g. therapists, schools, GP etc.
- More aftercare from community services

Next Steps

This report will be presented to the HNY CYP Acute Steering Group, and the HNY CYP Mental health Steering group and partners will cascade through their own organisations, internal meetings, steering groups and partnerships. Services are expected to action the findings and the recommendations in this report. They will report back to these groups on how they are actioning the feedback and the recommendations so young people can know how their input has made a difference. The report will also be shared with all Healthwatch organisations across the ICS.

These recommendations will inform the use of funding available to make improvements identified.