

# NHS YOUNG RESEARCHERS

*Communication, Trauma, and Weight:  
making sure “sickness to prevention”  
works for all young people*

## Report 2025/2026



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# SICKNESS 2 PREVENTION EXECUTIVE SUMMARY

The NHS young researchers are a group of young people aged 16-25 who, since April 2025 have come together to explore the 10 Year Health Plan, and design research that aims to address what we feel is missing from the plan. As a subgroup we have focused on the “**Sickness to Prevention**” part of the plan.

Over the first few months Barnardo’s together with NHS England engaged us in a series of online and in person sessions to inform us about the 10 Year Health Plan, its purpose and the core recommendations it contained. Using our diverse range of experiences and knowledge, including lived experience of the healthcare system, we identified, through a series of discussions, what we felt were the key gaps in the plan. For us this was all underpinned by whether or not young people really felt listened to in healthcare spaces.

This report therefore seeks to address our core question:

## **DO YOUNG PEOPLE FEEL LISTENED TO WHEN ENGAGING WITH NHS SERVICES ABOUT THEIR PHYSICAL AND EMOTIONAL NEEDS, IF NOT HOW DO WE IMPROVE THIS?**

Our larger question is split into three key themes with a focus on:

**COMMUNICATION**

**TRAUMA**

**WEIGHT**

We developed an online survey with a mixture of qualitative and quantitative questions. The survey went live on the 31st October 2025 and closed on the 20th November 2025. **147 young people from across England responded during this time.**

Qualitative responses were analysed thematically. As this project centers youth voice, team members also had the opportunity to spotlight certain areas that particularly resonated with them or which they felt were important to share, even if only a few young people talked about it. This method fit with our overall message and ethos, that every young person's story deserves to be listened to.

Across all themes we found that young people often don't feel listened to in healthcare settings. The extent to which young people feel heard is inequitable with factors such as age, gender, ethnicity, disability, experience of trauma and weight can all be linked to feeling unheard. The impact of feeling unheard on a young person is diverse ranging from days missed of school, misdiagnosis, worsening health, a mistrust of health professionals and even experiencing medical trauma.

**72% of young people feel that who they are negatively impacts how NHS staff listen to them**  
**65% of young people feel that their previous experience of healthcare has made them less confident' accessing them again in the future**

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## **TIA LOUISA ( / )**

I am 25 years old, from London. I work across the Civil Service, and with various charities supporting vulnerable young people. I am also a Care Leaver who spent 16 years growing up in the foster system – navigating complex issues such as abuse, poor health & mental health and the challenges and inequalities that came with navigating these systems. Care experienced young people face more hardship on average, leading to statistically worse outcomes and more strain on public services. I am passionate about championing vulnerable voices and improving preventative measures.

## **GAIA CAWLEY (SHE/HER)**

I am 25 years old, based in the West Midlands and will be embarking on a PhD exploring harmful cultures and young people. As a young survivor of gender-based violence and a lately-diagnosed Dyslexic, I am passionate about amplifying youth voice, breaking barriers and encouraging systemic change.

## **ANNA FREED (SHE/HER)**

I am 25 years old, from London, and work in the heritage sector. I am multiply disabled, and experienced barriers to accessing healthcare due to misogyny, ableism, and fatphobia. I am passionate about making sure proposed ‘preventative’ services work for all young people and our different constellations of needs.

## **TEAGIE (SHE/HER)**

I am 23 years old, from the North of England and am interested in addressing inequalities in healthcare.

## **PHILIPPA HORROBIN (SHE/HER)**

I am 18 years old, from the North West and am multiply disabled. I am concerned with the lack of space (both within the healthcare system and in academic research) for underrepresented groups. My main passion lies in making sure all voices are amplified and ensuring that all individuals are given the opportunity to share their lived experiences!

## **ELLE LAPPIN (SHE/HER)**

Hi, I am Elle aged 21 years old from Liverpool. I have been part of youth voice projects since I was 15. It is important that young people are represented and have a say in decisions made about them. Currently I am studying Politics and Social Policy at university.

## **MUHAIMEEN AL-ISHRAQ (HE/HIM)**

HELLO! I’m Ishraq and 17. Coming from a marginalised ethnic group who suffers from a lack of basic healthcare, I am really passionate about bridging the gap between accessing help and communities that are often overlooked. Seeing the ways in which the NHS has impacted these communities has pushed me to improve

## **CAOIMHE KEANEY (SHE/HER)**

I am 18 years old, from the East of England and am currently studying for my A-levels. As someone with a chronic illness, I have had a range of experiences interacting with healthcare services (many positive but some very negative) and I want to improve the experience for young people who may otherwise ‘fall through the cracks.’

This research is grounded in lived experience. Designed by young people, for young people. Our starting point was therefore based on the question “What is missing from the Sickness to Prevention section of the 10 year health plan?”. Our list was long, but all our ideas were underpinned by the common theme about whether young people really felt listened to and confident accessing health services. Our rationale was that multiple policies and services can be developed, but none of these will ever be effective, if young people aren't listened to, taken seriously or feel confident accessing them. We narrowed our focus to three key areas:

## **(1) Youth voice**

We felt like a key gap in the 10 year health plan was “secondary prevention”. We linked this strongly to youth voice and wanted to explore whether ‘being listened to’ was a barrier in prevention or secondary prevention being achieved for young people.

## **(2) Trauma**

We felt like the 10 year plan didn't look at ‘prevention’ on a broad enough scale; failing to account for the array of systemic issues that can contribute to poor health. We believe that a cohesive and cross department government approach is needed to tackle broader issues such as (but not limited to) child poverty, homelessness and trauma. We know from lived experience, the impact trauma can have on a young person's physical and mental health and wanted to explore the challenges and solutions to preventing trauma both inside and outside of a medical setting.

## **(3) Weight**

We found the focus on ‘obesity’ problematic for a variety of reasons, including the lack of recommendations to address inequalities in healthy food and safe exercise access. But we also found another issue, whilst fatness is often talked about, medical fatphobia isn't, and we wanted to understand young peoples views on the proposed ‘Complications of Excess Weight clinics’.

Research is like weaving a patchwork quilt. Weaving together each individual, unique story to create an overall picture. This picture is presented as themes, trends and headlines all aimed to give you insight into the key issues young people are facing and the potential ways we can try and solve them. However, the young people that shared their experiences with us made it clear that statistics and generalisations often caused the issues for them and they wanted to be seen, heard and respected as individuals, not patients, not numbers, but people. Every young person is unique and so is their story. Solving this problem is not just a matter of addressing the headlines but ensuring that each and every young person feels listened to, cared for and has confidence that when they need them, health services will be there ready to listen to them.

.A patchwork quilt has become both a metaphor for the system and our approach to this project. The pages that follow hold key statistics, headlines and themes, but they also hold individual stories and experiences, told in the words of the young people they belong to. Some stories belong to just one young person, but we have included them anyway.

Why? Because traditional research often overlooks the outliers of a trend. But we want to challenge that thinking. Does one young person's negative experience not matter because the trend line says most are positive? Should one young person's bravery to share a challenging experience with us be overlooked just because some themes come up more? Our answer is NO.

Every young person that has contributed to this report unique and the young researcher behind every page approached this research from a different angle. Every page of this report is therefore slightly different. The design of this report reflects our key message **EVERY YOUNG PERSONS UNIQUE STORY MATTERS, IF JUST ONE YOUNG PERSON GOES UNHEARD, THEN THE WHOLE SYSTEM BEGINS TO FALL TO PIECES.**

If just one patchwork from the quilt below were removed, the entire blanket would fall to pieces as fraying edges and loose threads get pulled and moved, and more and more pieces would fall. This is a metaphor for the Current healthCare system. When one young person waits too long, one young person feels unheard, then the whole system begins to fall to pieces.



Drawn by Teagle

REMOVING JUST ONE PATCH, REMOVING JUST ONE STORY, MEANS YOU DON'T SEE THE FULL PICTURE

17 SURVEY QUESTIONS

6 QUANTITATIVE

11 QUALITATIVE

3 KEY THEMES

147 RESPONSES

147 STORIES

147 YOUNG PEOPLE

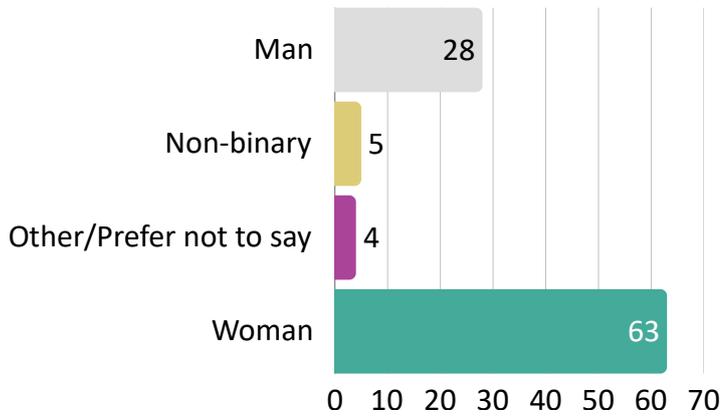
REPRESENTED ON THESE  
PAGES

- QUANTITATIVE QUESTIONS TO GET A SNAPSHOT OF THE CURRENT SITUATION
- QUALITATIVE QUESTIONS TO EXPLORE, EXPERIENCES, IMPACTS AND SOLUTIONS
- RECOMMENDATIONS DRAWN FROM YOUNG PEOPLE'S LIVED EXPERIENCE

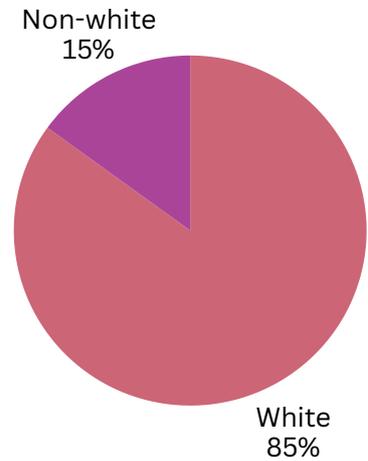
- STATISTICAL ANALYSIS
- THEMATIC CODING
- CASE STUDIES & SPOTLIGHTING

# SICKNESS 2 PREVENTION DEMOGRAPHICS

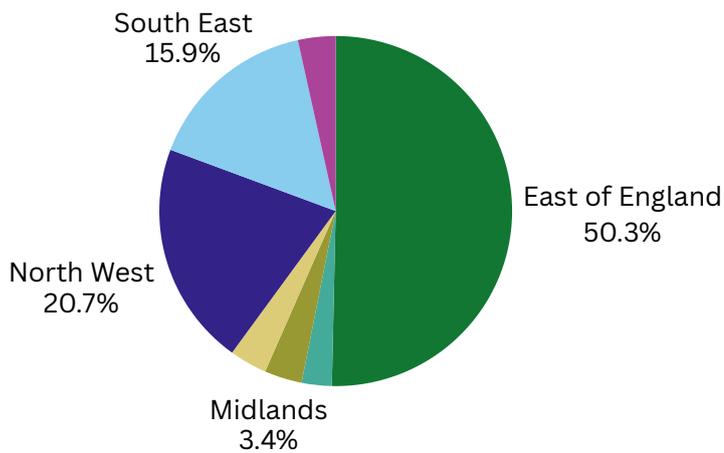
## PERCENTAGE OF GENDER



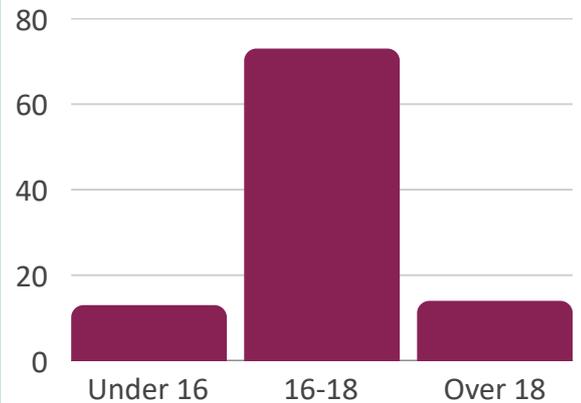
## PERCENTAGE OF ETHNICITY



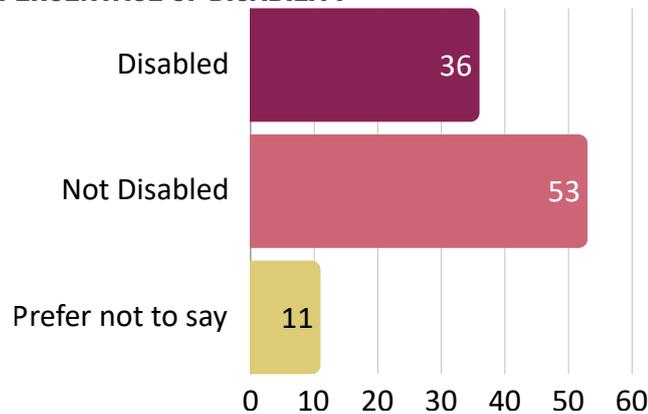
## PERCENTAGE OF NHS REGIONS



## PERCENTAGE OF AGE



## PERCENTAGE OF DISABILITY



# WHAT DOES VOICE AND BEING LISTENED TO MEAN TO YOU?

Young people were asked an open-ended question exploring what ‘voice’ and ‘being listened to’ means to them, whether they feel listened to within healthcare services, and how this could be improved. Responses highlighted that being listened to is not a single or uniform experience, rather it is shaped by factors such as identity and communication needs, as well as by the outcomes of care.

**3%**

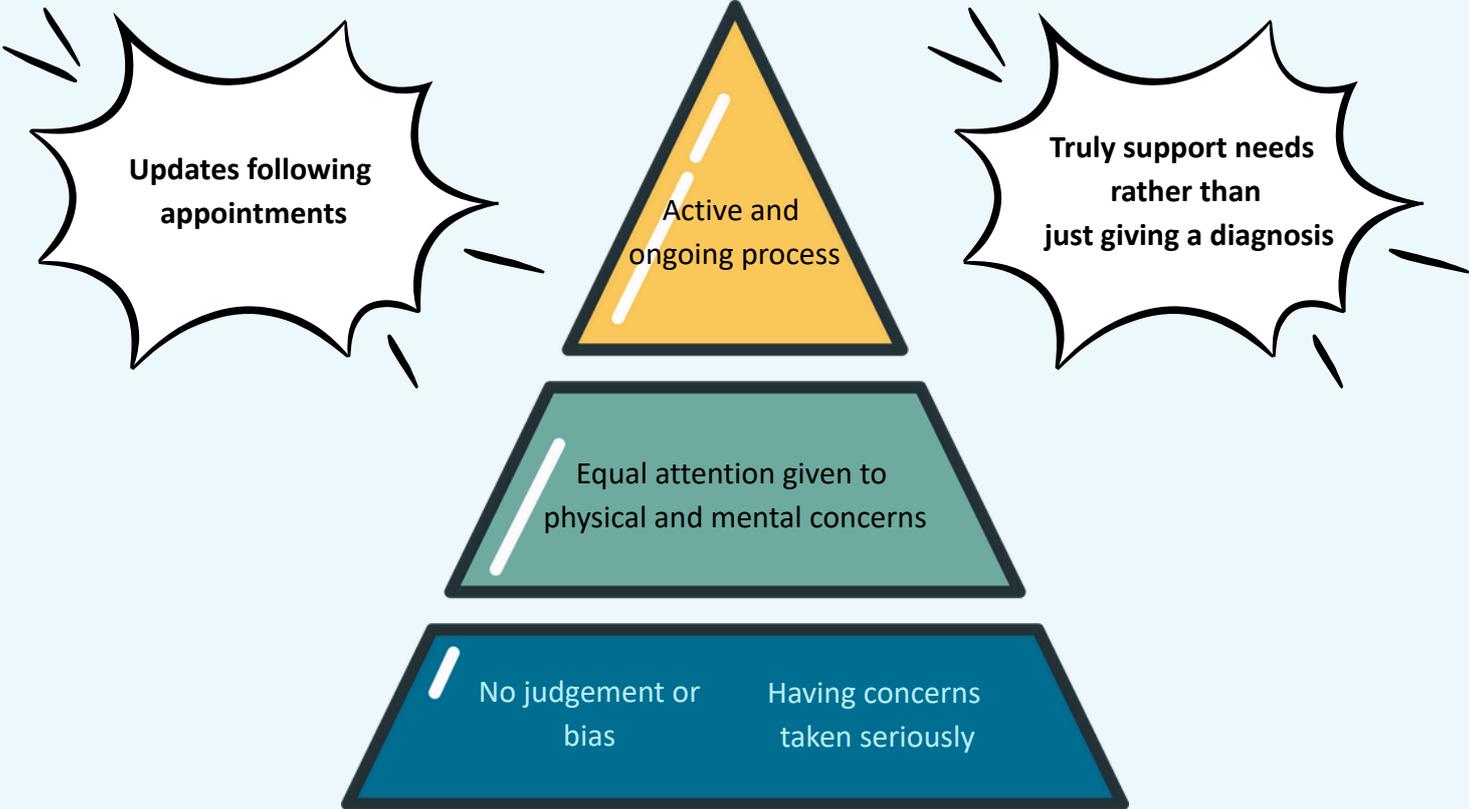
Described positive previous experiences



**33%**

Described negative previous experiences

This disparity suggests significant weaknesses in the design and delivery of healthcare services for children and young people, with many feeling that their views are not taken seriously, even in matters directly affecting their own care.

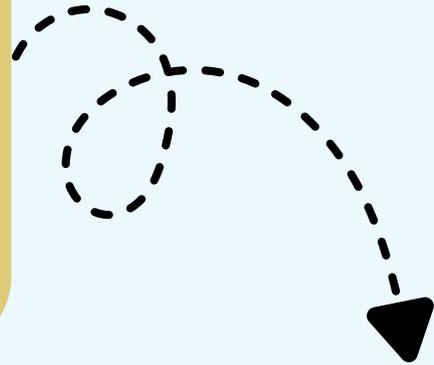


Young people consistently framed listening as something that is not only measured whilst they are in direct contact with a healthcare professional but also how their views are then acted upon.

Both disabled and non-disabled respondents articulated similar expectations around listening.

## Disability:

- Of the negative responses recorded, 56% were from people identifying as disabled (as opposed to 36% of total respondents)
- Whilst it may be true that disabled people access more health services, the overrepresentation of disabled respondents among negative experiences suggests disproportionately worse experiences, not merely higher service use.



*'It has affected my treatment plan, what is written on my notes and how certain doctors perceive me'*

## Neurodiversity:

- 36% of respondents who explicitly mentioned neurodiversity, processing differences, or communication needs explicitly described negative listening experiences.
- Among respondents who did not mention these needs, around 13% explicitly described negative listening experiences.
- Young people who raised neurodiversity or communication needs were also substantially more likely to describe feeling unheard.
- This indicates that listening is closely tied to whether healthcare systems recognise and adapt to different communication styles.

## Gender Identity:

- In the responses, women were substantially more likely than men to explicitly describe negative listening experiences.
- Around 21% of women described negative listening experiences compared with around 7% of men.
- Responses often linked being unheard to credibility, mostly around pain and ongoing health concerns, suggesting that gender may influence whose voices are taken seriously.

*'Because I'm a woman my problems are automatically unimportant'*

*'My strong accent makes me feel bad as though is it hard for them to understand me'*

## Ethnic Background:

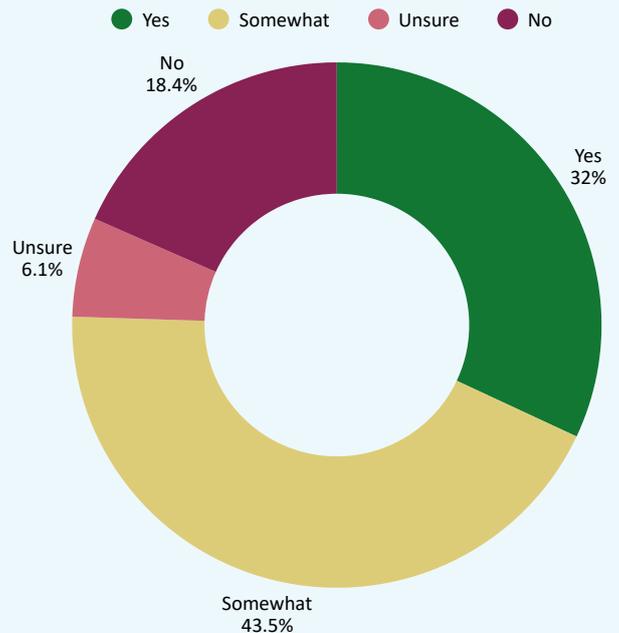
No consistent statistical differences were observed by ethnicity though sample sizes for some ethnic groups were small.

## Structural Barriers:

- A lack of knowledge about the different ways in which illnesses present on non-white people
- Difficult to communicate due to lack of patience with understanding accents
- General points around 'background [making] it hard to be understood'

## DO YOUNG PEOPLE FEEL CONFIDENT ACCESSING HEALTH SERVICES? (E.G. GP, WALK-IN CENTRE, SCHOOL NURSE, ETC.)

The highest proportion of respondents 44% (64/147) responded “Somewhat, I know which services/ support options are available, but I feel that if I access them, my concerns will not be listened to”.



Overall 68% of respondents did not choose “yes” showing that there needs to be improvements and support in place to help young people feel confident when accessing health services such as attending appointments at the GP, Walk-in Centre, School nurse.

32% (47/147) of respondents said “yes” that they feel confident when accessing health services.

The smallest proportion - 6% (9/147) of respondents said that they were “unsure” of feeling confident when accessing health services.

18% (27/147) of respondents said “no” that they feel confident when accessing health services.

## WHAT COULD HEALTHCARE PROFESSIONALS DO TO MAKE YOUNG PEOPLE MORE CONFIDENT ENGAGING WITH THEM? WHAT HAS ALREADY MADE YOUNG PEOPLE FEEL MORE CONFIDENT?

There were 147 respondents. 27 people said no to Q1a. 10 people were unsure.

110 people provided responses that can be categorised under 4 themes.

The themes are:

- Theme 1: Communication, Listening and Being Taken Seriously - 61 results
- Theme 2: Access to Services and Accessibility Arrangements - 26 results
- Theme 3: Information, Education and Other Factors - 16 results
- Theme 4: Transparency and Support at appointments - 7 results

In particular:

- Theme 1 focuses on communication where solutions and information are provided, young people being listened to and taken seriously by medical professionals
- Theme 2 focuses on Access to Services & Accessibility Arrangements, Changes to services, appointments, contact details and waiting times, location / knowing where healthcare services are
- Theme 3 focuses on better information, more education and training on accessing health services
- Theme 4 focuses on more transparency by medical professionals and support at appointments such as having a trusted person at appointments with

### 2 KEY QUOTES FROM EACH THEME:

"listen to me.  
believe me. try  
to understand"

"Listening to your viewpoint  
thoroughly. Taking a person  
centred approach. Listening  
to women's views"

"Multiple doctors have not fully investigated symptoms that turned out to be part of a more serious condition, acknowledging these and not brushing them off repeatedly would make me feel more confident when engaging with healthcare professionals"

"Services not  
available  
enough"

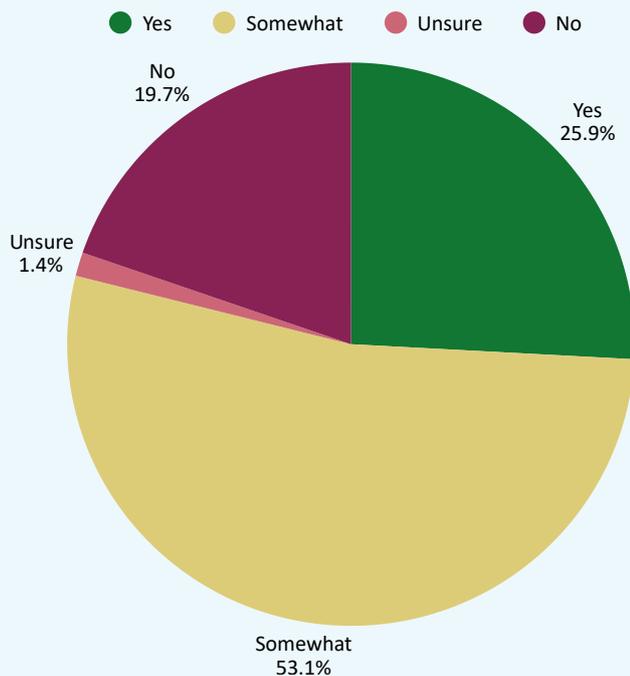
"Having my  
parent/carer  
advocate on my  
behalf"

"we need more education on  
accessing health support"

"Being more open and not  
googling my symptoms in  
front of me"

"Have more transparency in knowing what to expect when making an appointment, attending and then follow up care - have more training in interacting with disabled people. There is a different doctor each time that you have to explain your history to"

## DO YOUNG PEOPLE FEEL LISTENED TO WHEN ACCESSING HEALTH SERVICES?



Overall more than half of respondents (53%) when answering Do you feel listened to when accessing health services? said “somewhat”. A similar percentage/proportion of respondents said yes (26%) or no (19.7%). Only 1.3% of respondents said that they were unsure.

26% (38/147) of respondents said “yes” that they listened to when accessing health services.

The smallest proportion - 6% (9/147) of respondents said that they were “unsure” of feeling confident when accessing health services.

19.7% (29/147) of respondents said “no” that they do not feel listened to when accessing health services.

Q3 - ISHRAQ

**“HAVE YOU EVER EXPERIENCED A LONG WAIT BETWEEN TRYING TO ACCESS SUPPORT AND RECEIVING THAT SUPPORT?”**

DESPITE MANY PEOPLE’S PRECONCEPTIONS, THOUGH THERE WAS A CORRELATION BETWEEN LONGER WAIT TIMES AND NEGATIVE PERCEPTIONS OF THE NHS, THIS WAS NOT AS EXAGGERATED AS WE FIRST ANTICIPATED



More information on page 35

OUT OF THE 20% WHO DID NOT HAVE ISSUES WITH WAIT TIMES:

- 51.7% STILL REPORTED HAVING HAD A NEGATIVE PERCEPTION OF THE NHS POST-TREATMENT.

WHILE ON AVERAGE, THE 16.6% WHO WAITED OVER 2 YEARS TO ACCESS SUPPORT:

- CONTAINED, EXPECTEDLY, A HIGHER NUMBER OF PEOPLE WHO HAD NEGATIVE PERCEPTIONS OF THE NHS POST-TREATMENT (83%)

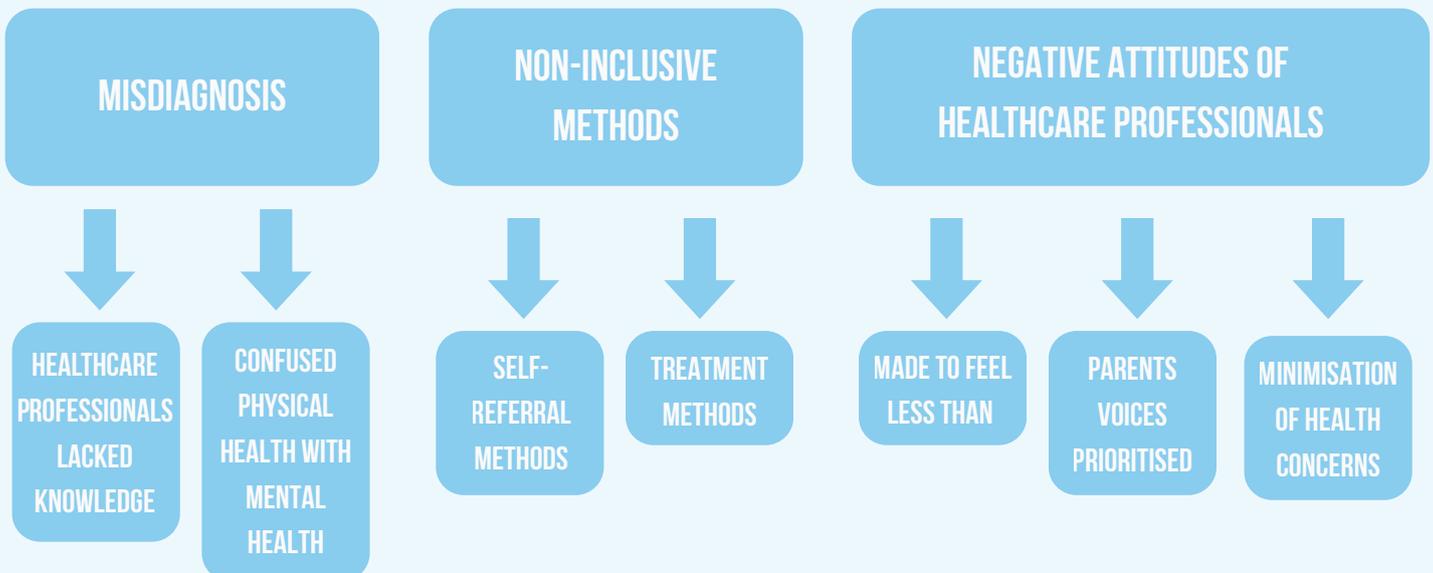
HOWEVER A 31.3% DIFFERENCE SUGGESTS THAT WHILE WAIT TIMES IS A FACTOR TO THEIR PERCEPTION OF THE NHS, THERE MUST BE OTHER UNDERLYING FACTORS GIVEN OVER HALF OF THE AFOREMENTIONED PARTICIPANTS REPORTED FEELINGS OF EMBARRASSMENT, DISRESPECT AND FUTILITY.

## DID YOUNG PEOPLE FEEL LISTENED TO WHEN ACCESSING SUPPORT AND HOW WERE THEIR CONCERNS ACTED ON?

### OVERARCHING THEME

INCONSISTENT AMOUNTS OF SUPPORT

### THEMES & SUBTHEMES



### INCONSISTENT AMOUNTS OF SUPPORT

The overarching theme that emerged in the data was that the quality of support young people received when accessing NHS services varied significantly. For some young people, the support was fast-paced and they were seen to by healthcare professionals accordingly. However, the majority of respondents reported a lack of or delayed support. Young people felt this was due to long waiting lists, failing referrals, their condition worsening, staff shortages/changes, and/or being passed between services.

*“My concerns were acknowledged, and the professionals involved took appropriate action to address them, which helped me feel supported and understood.”*

*“It took me 8 years for my condition to be taken seriously enough that after moving doctors surgeries three times, I final[ly] got a specialist referral to the hospital”*

## MISDIAGNOSIS

Of the young people who reported receiving inadequate or delayed support, several stated that not being listened to by professionals led to the misdiagnosis of their conditions.

*“Took multiple professionals years to listen to my concerns of my issues not being allergy-based but physical, only recently diagnosing the issue.”*

Young people felt this was because healthcare professionals lacked knowledge of conditions, forming the first subtheme. This was a common experience for those accessing services related to women’s health:

*“I had hair loss and I asked if it was due to my periods as I was also anaemic, and the GP (he was a man) said no and didn’t even entertain the idea. Turns out it was hormonal... There needs to be more knowledge and care regarding women’s health”*

According to some young people, professionals frequently mistook physical health for mental health when they attempted to identify the root of the problem:

*“Tried to blame physical health problems solely on mental health difficulties”*

## NON-INCLUSIVE METHODS

Young people reported that current methods within the NHS were not inclusive or accessible. This was the case for both self-referral methods and treatment methods.

Several young people described experiences where the format of self-referral methods, such as having to phone in, acted as barriers and consequently prevented them from receiving help. This could have been prevented if services had listened to the young people’s individual needs and offered other options:

*“When accessing CAHMS for triage advice, no. I had gone to them for being suicidal and attempting, the advice they gave of calling a suicide helpline I contested as I kept going mute so could not physically speak to ask for help or call emergency services - they offered no alternatives and did not contact again with any form of follow up.”*

Some young people described not feeling listened to by professionals when it came to choosing the right treatment method for them:

*“I find it difficult to convince doctors to investigate a condition or to consider a different method of tackling it.”*

## NEGATIVE ATTITUDES OF HEALTHCARE PROFESSIONALS

Concerningly, this was a large theme across respondents, with many young people detailing incidents where they felt healthcare professionals had not taken their health concerns seriously or downplayed the severity. Young people described being laughed at, patronised, and treated as though their opinions weren’t important. These negative experiences also extended to family members advocating for them:

*“Belittling my mother who kept explaining what was wrong and made her sound like an idiot”*

*“It’s also uncomfortably condescending the way many doctors talk to patients, it’s supposed to be a position of care and they make you feel like a burden.”*

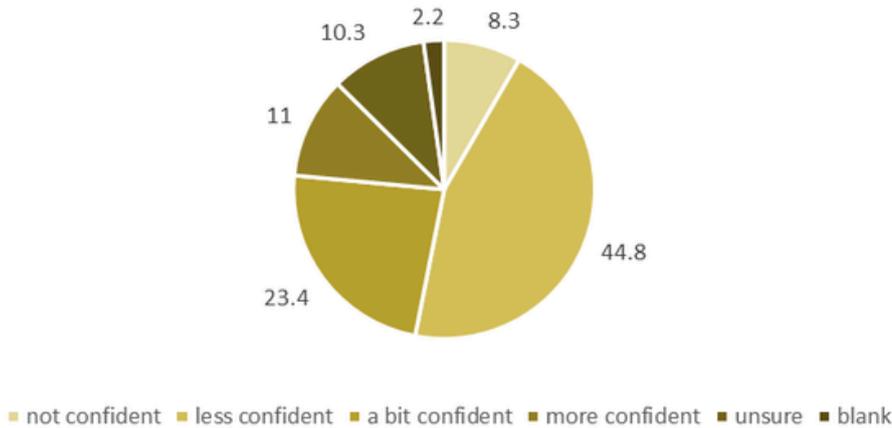
*“Many of my issues were brushed off by Doctors and Nurses as teenage girl syndrome even when they were more serious and I had to visit multiple times to have them listen to me.”*

Minimisation of healthcare concerns particularly occurred with Women’s Health issues, with young people reporting being gaslit by professionals and told that their issues were jimply “hormonal”.

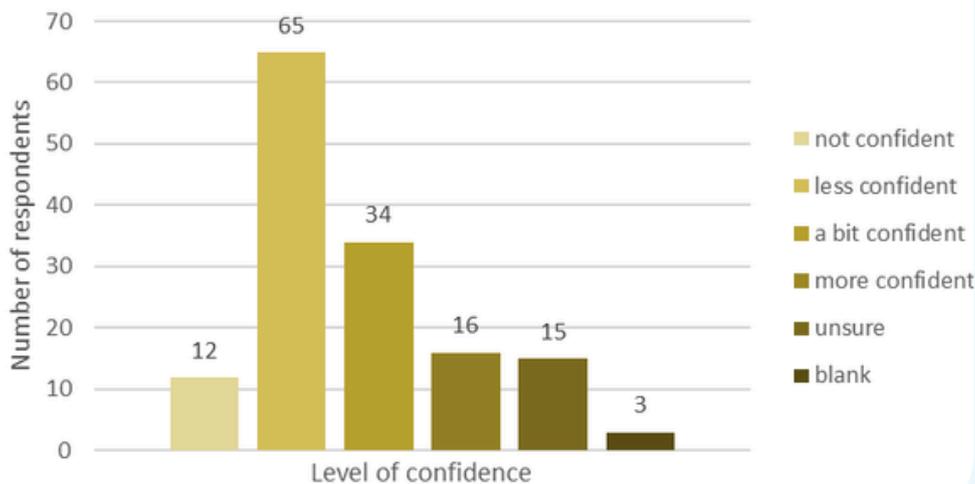
# HOW DOES INTERACTING WITH HEALTH SERVICES AFFECT YOUNG PEOPLE'S CONFIDENCE ?

# SICKNESS 2 PREVENTION COMMUNICATION

Have your previous experiences accessing health services made you feel more or less confident to access them again?  
(% of respondents)



Have your previous experiences accessing health services made you feel more or less confident to access them again?

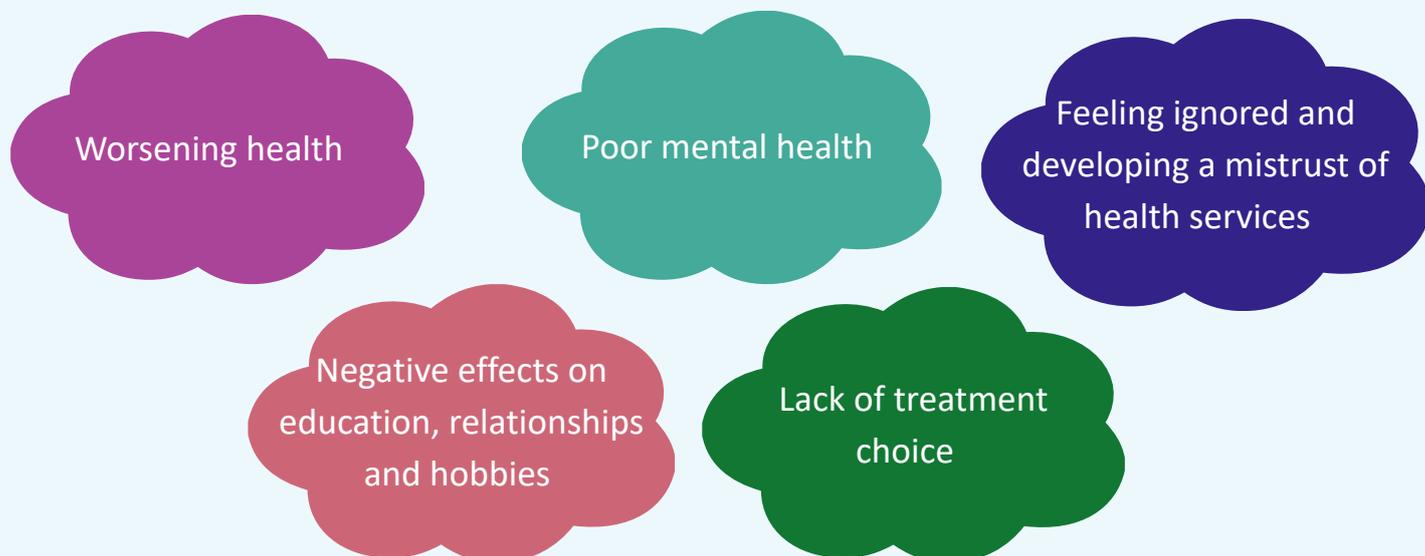


- Only 11% of respondents felt “more confident” accessing health services based on previous experiences.
- The majority of respondents had their confidence reduced by previous experiences accessing health services.
- Most felt “less confident” based on their interactions and experiences surrounding health services.
- Note: there is a certain ambiguity around the wording of the question - how did respondents quantify “a bit confident” and did they perceive it to be positive or negative?

## DEMOGRAPHICS: FOOD FOR THOUGHT

- Of the small number of under-18 responses, 100% of 13 year olds and 50% of 12 year olds felt “less confident”.
- Participants in the East, London, Midlands, North West and South East all had “less confident” as their single largest category with only North East & Yorkshire and the South West having responses tied across multiple categories.
- Similar levels of respondents who identified as “white” (44.7%) and respondents who identified as a person of colour (42.1%) felt “less confident”.
- However, whilst 13% of those who identified as “white” felt “more confident”, 0% of respondents who identified as a person of colour felt “more confident”.

## WHAT IS THE EMOTIONAL AND PHYSICAL IMPACT OF LONG WAIT TIMES AND NOT BEING LISTENED TO ON YOUNG PEOPLE?



Within the 10-year health plan, we felt like there was a lack of focus on secondary and tertiary prevention within the NHS. Whilst we support a commitment to trying to prevent health issues from occurring in the first place (primary prevention) we would argue that for many children and young people, the timeframe for primary prevention has passed, meaning a broader perspective on the issues affecting young people's access to prompt treatment and support (secondary prevention) is needed. Timely access to the right healthcare services and subsequent treatment can help to mitigate the harm caused by a health issue, including harm to a child's wider social, emotional and educational development. However, growing waiting lists, combined with young people feeling unheard when they do eventually access them, can mean that for many young people, early intervention isn't a reality. The issue is widespread across health services, with nearly 40,000 young people waiting for over two years for mental support ([Taylor 2024](#)), whilst 8,000 children are waiting over a year for elective treatment, despite an 18-week target and over 40,000 young people waiting over a year for community health services ([RCPH, 2025](#)). Long wait times have been linked to poorer health outcomes and lower satisfaction with care received (Limri, 2025), but current understanding of the impact of wait times for children and young people is poor, with the RCPH (2025) arguing that any progress on waiting lists is 'glossing over' children and young people's health services. We aimed to bridge this gap in current understanding by exploring the physical and emotional impact of wait times, including those attributed to feeling unheard following the accessing of services, on children and young people. Our research shows that whilst waiting, young people experience worsening health, poor mental health outcomes, experience significant challenges in school and social settings and develop a mistrust of healthcare services.

## WORSENING HEALTH

Many young people described how their experience led to the health condition they were trying to access support for getting worse. This included experiencing avoidable pain and the escalation of health issues, with some being told that the damage incurred whilst waiting would be irreversible. For some young people, these impacts were due to their health condition going unmanaged whilst they were on the waiting list:

*"As my condition wasn't being managed properly, my physical health declined a lot. This affected my mobility greatly, and I couldn't really leave the house. Both of these negatively impacted my mental health"*

## LACK OF TREATMENT CHOICE

Research has demonstrated that choice can be important in healthcare settings, helping people to feel like their perspectives are heard and valued ([Barnett et al. 2008](#)). Choice can also enable people to access alternative treatments if they feel like one option isn't working, and allow treatment to be tailored to a person's specific needs and preferences. For children and young people, choice can enable them to feel autonomy over a medical issues, that often make them feel out of control. However, young people described how long wait times were removing this choice leaving them stuck on treatment they don't feel is working and they no longer want to be on:

*"21 months later I am still on propranolol and I feel as if anything it's made me worse, I think I'm mentally in a better place but the medication itself heightens my physical symptoms if I reduce the amount I take .....I feel stuck on medication I'm unsure I even want to still be on and that the decision to put a 14 year old on medication was rushed and I took any help I could get at the time because I was desperate and I knew the waitlist was far too long for me to cope."*

## GETTING WORSE BUT STARTING OVER

Young people also described how they transitioned into adult services during their wait for support, causing both further delays and increased difficulty in getting the treatment they needed.

*"As someone with multiple chronic illnesses, I am getting slowly worse and have found it increasingly difficult to get treatment as I have been graduated from peds"*

# WIDER IMPACTS

## EDUCATION, HOBBIES AND RELATIONSHIPS

Young people's health is not isolated from the rest of their lives. Quick access to the right treatment and support can not only prevent health conditions from progressing but also reduce their impact on a young person's social, emotional and educational development. Young people described how worsening health whilst they waited led to them missing multiple days off school and college, being struck off from work due to taking too many sick days, having to drop out of sports teams and clubs and having restrictions on their social lives due to concerns around their safety.

*"I haven't had the right support in primary, high school or college because I am waiting for an autism examination"*

*"When I finally did get support, I realised how much it would have helped earlier."*

## IS THIS REAL? IS THIS SUPPORT FOR ME?

The prompt diagnosis of a medical issue can open up access to a range of supportive treatments that can help a young person to not just live with their medical condition, but thrive. However, young people explained how long waiting lists and sustained challenges in getting medical professionals to take their concerns seriously were blocking their access to such support. This included young people not having access to support plans whilst in school, as their diagnosis took the full length of their education, and confusion about whether they could use supports such as crutches, despite them improving their mobility. Long waits also led young people and those around them to question the validity of their symptoms, which young people found incredibly distressing.

*"I haven't been able to go out with my friends as much, and when I do I have to plan recovery days afterwards. And then healthcare professionals don't believe me when I'm literally breaking down crying because I'm in so much pain I feel like I've been set on fire. It's horrible. You do start to question whether it is all in your head, but that wouldn't explain the pain, would it? And I have had issues not knowing whether it is ok to use a walking aid with my condition, because I don't know what my condition is. Eventually I gave in and started using a crutch on days where my legs are bad but my arms are fine."*

*"It felt frustrating, as it almost felt as if people thought that I was just putting it on, when in fact I was majorly struggling."*

## POOR MENTAL HEALTH

**65%** OF YOUNG PEOPLE WHO REPORTED SIGNIFICANT ADVERSE IMPACTS TO THEIR MENTAL HEALTH WHILST ON A WAITING LIST HAD NEVER ACCESSED MENTAL HEALTH SERVICES BEFORE

Young people reported experiencing significant negative mental health impacts as a result of their experiences including suicidal ideation, self-harm and psychosis. Young people further described how they experienced high levels of stress, felt worthless, had persisting low mood and had significant disruptions to their sleep. Of the young people who described a mental health impact, only 35% reported either currently or previously accessing support for their mental health. This is concerning as it suggests that young people could be developing new issues either as a result of their medical issue or as a result of their wait time.

*"My mental health got a lot worse as a result of physical health difficulties to the point where I didn't want to go out of the house due to feeling ashamed and embarrassed. It also led to self-harm and suicidal thoughts"*

## A MISTRUST OF HEALTH SERVICES

Young people described how their experiences had led to them feeling ignored, like they were a burden, like nobody cared about them and like they couldn't ask for help or trust services in the future. Some young people described how they felt like their problems were not serious enough to try and access help and that their experience had a negative impact on their confidence in asking for support. Early detection and intervention is imperative in preventing health conditions from worsening. This in turn is important in preventing long term adverse impacts on a young person's development, including limiting disruptions to their education and social development.

Therefore, young people's experiences of not receiving support and not feeling like their concerns were taken seriously may not only lead to significant personal, social and educational impacts in the short term - but long term distrust of services may impact their confidence in accessing prompt preventative care in the future.

*"I felt like I didn't want to reach out for help if I had any concerns regarding my health in the future"*

*"I felt as if I wasn't enough to be listened to and that there will always be someone worse than me, I have it easy"*

## 72% OF YOUNG PEOPLE FEEL THAT WHO THEY ARE NEGATIVELY IMPACTS THE WAY NHS STAFF LISTEN TO THEM

One of the NHS's core values is that **'everyone counts'**, meaning that nobody is *"excluded, discriminated against or left behind"* (NHS constitution for England). Despite this, discrimination still remains prevalent in health services with inequalities relating to protected characteristics leading to disparities in health outcomes and healthcare experiences ([Bamrah et al. 2025](#)). We asked young people whether they felt like 'who they were' impacted the way NHS staff listened to them. Unfortunately, 72% of young people felt that who they were negatively impacted how healthcare professionals listened to them.

### AGE

Some young people felt like they were spoken down to, not listened to and taken less seriously because they were young whilst other felt like they were treated as being 'too adult'

"they speak down to you as a child in some cases"

Young people felt like the medical professionals in the room preferred to talk to the adults accompanying them, rather than to them.

they more prefer to talk to an adult than the actual child

Some young people felt their concerns were written off as just been a 'young person thing', 'teenage thing' 'puberty thing' 'hormone things' instead of their symptoms being investigated properly. Many also felt their symptoms were too quickly dismissed as being 'anxiety' despite no tests or checks being run.

### DISABILITY

Disability means that doctors think that **I** cannot speak or they have to baby me

Young people with disabilities explained that they sometimes felt patronised and spoken down to. Some felt like healthcare professionals avoided speaking to them and instead spoke to those accompanying them because they were disabled/

they speak to my mum instead of me because **I** use a wheelchair

One young person explained how they felt frustrated that their communication difficulty was not noted so they had to explain this to every medical professional they visited.

Some young people felt like medical professionals were accommodating their disability.

"Yes because they are more patient with me since **I** am neurodivergent"

## GENDER

Young women felt like their voices were unheard and their symptoms dismissed without any proper tests or investigations, simply because they were young women.

**I** feel as a young female my voice and opinion is very much undermined"

Young women felt particularly dismissed when trying to discuss reproductive issues and that their pain was never taken seriously enough.

my female reproductive health and pain not being taken seriously enough"

Young people with gender diverse identities felt like their care had become too politicised and this impacted how they were listened to in healthcare settings.

Being **LGBTQ+**, especially gender non-conforming, has made many medical professionals treat me as though **I** am stupid or incapable of making decisions for myself.

## RELIGION

Some young people felt like assumptions were made about them because of their religion which meant their concerns weren't listened to in an objective way by healthcare professionals.

## PREVIOUS MEDICAL HISTORY

Young people feel like their previous medical history can negatively impact how new health concerns are listened to.

This is a particular concern for young people with previous mental health diagnoses who then feel like physical health symptoms are dismissed, and young people with complex medical histories. Two young people's stories are presented below:

**I** think that my background of **NHS** notes affects how professionals speak to me as **I** have used the services a lot and have been told that **I** am 'too complex' or that **I**'m beyond help

**I** have my mental health diagnosis on my medical records and when accessing physical health services for completely different reasons, **I** have been told my physical health is all in my head and not true because of my mental health diagnosis when **I** did have genuine problems

## ETHNICITY

Young people feel there is a lack of awareness about how medical issues presented on non white bodies and this made it challenging to get their concerns taken seriously

## HOW YOUNG PEOPLE FEEL LIKE THEY ARE SEEN.....



## HOW YOUNG PEOPLE WANT TO BE SEEN.....



Drawn by Teagie

**TO WHAT EXTENT DO YOUNG PEOPLE FEEL LIKE THEIR CAREGIVERS SUPPORT THEM IN ACCESSING HEALTH SERVICES?**

**82% OF YOUNG PEOPLE FELT LIKE THEIR CAREGIVERS SUPPORTED THEM IN ACCESSING HEALTH SERVICES BY PROVIDING.....**

**PRACTICAL SUPPORT**

Caregivers provide support, booking appointments, taking young people to appointments and helping with treatment, including picking up prescriptions

**COMMUNICATION SUPPORT**

Helping young people track their symptoms and communicate their concerns to medical professionals

**ADVOCATING**

For some young people their caregivers play an advocacy role in healthcare settings

**SUPPORT FINDING AND ACCESSING SERVICES**

Caregivers encourage young people to find and access health services, and support them to do this.

**A LACK OF SUPPORT WAS ATTRIBUTED TO...**

**CAREGIVERS.....**

- Dismissing young people's symptoms
- Having a lack of understanding about how neurodiversity presents in different genders
- Holding a belief that they should be responsible for their own healthcare

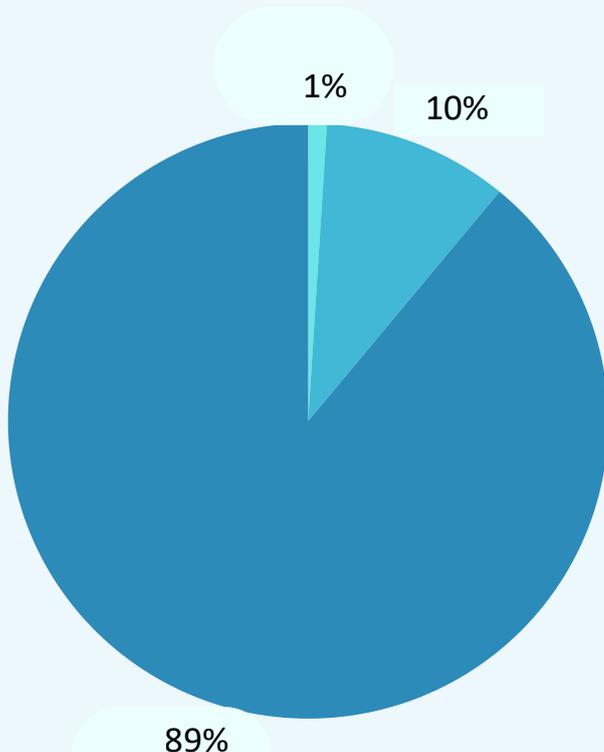
**YOUNG PEOPLE.....**

- Feeling more comfortable accessing healthcare services alone
- Not wanting to worry their caregivers about health issues

**BEING A YOUNG CARER**

Some young carers describe how their carers are unwell, and therefore they are unable to support them. Some of these young people describe how one caregiver provides more support than the other.

## IF YOU HAVE BEEN ADMITTED TO HOSPITAL IN THE LAST 12 MONTHS, WERE YOU TOLD ABOUT MARTHA'S RULE?



Whilst there were only 62 responses to this question, the vast majority (55) were not told about Martha's rule, suggesting a significant gap in communication to and awareness from patients. This could indicate that current approaches to informing patients about Martha's Rule may be inconsistent, limiting its potential effectiveness as a safety mechanism. Only one respondent answered yes to this question, highlighting again that knowledge of Martha's Rule among respondents is extremely limited.

## IF YOU WERE TOLD, DID YOU UNDERSTAND WHAT IT WAS?

Only one respondent to the survey was actually told and this person says they were only given a leaflet. Prior to being admitted, this young person had watched the news, potentially suggesting prior knowledge that helped them to understand as opposed to purely the experience at the hospital.

## WHAT IS MARTHA'S RULE AND WHY IS IT IMPORTANT?

- Martha's Rule centres around the right for patients, families and carers to request a rapid review if they are worried that a patient's condition is getting worse and their concerns are not being listened to.
- It is important in empowering both young people and their families and ensure their voices are always heard in the management of conditions.
- A lack of communication around this could further weaken trust of healthcare professionals and prevent accurate diagnoses

# RECOMMENDATIONS:

## SICKNESS 2 PREVENTION COMMUNICATION

(1) **Create a comprehensive 'communication' protocol for healthcare professionals working with children and young people.**

The 2023 *'You're Welcome': Establishing Youth-Friendly Health and Care Services'* report outlined 8 key standards for achieving youth-friendly health services including standards for interacting with young people in healthcare setting. Our findings from this report indicate that these standards are not being met. We would like guidance to be revised and some more practical steps taken to implement changes that will reform healthcare experiences for children and young people.

**The Lemur protocol could be used as a starting point:**

**L - Look** at a young person when you are talking to them and direct questions and explanations at them

**E - Explain** all decisions and keep them updated with their care

**M - Make time** for young people to ask questions and share any worries

**U - Understand** how the medical problem is affecting a young person on a broader level

**R - Remember, report, refer**

- Remember to check for young people's consent
- Report any concerns or disclosures from a young person at the first sign of an issue
- Refer young people to support

However, a more comprehensive protocol is needed taking into account young people with diverse communication styles (including non-verbal communication). This includes increased awareness about different forms of communication and ensuring at every healthcare setting, there are the resources available to ensure all young people can be communicated with (e.g. a BSL interpreter, a longer appointment for those who need more processing time, the use of assistive communication devices). The role of caregivers also needs to be considered. Some young people will both want and need caregivers' support to a much older age (even following the transition to adult services), and this should be accommodated.

(2) **Increase support for young carers.** Including practical support with transport to and from appointments and picking up prescriptions as well as communication and emotional support.

(3) **Tackle the use of dismissive language**

<p>“It’s probably all in your head” “I think you're faking it” “It can’t really be that bad”</p>	<p>All these phrases are dismissive of a young person's experience</p> <p>Our research found that young women disproportionately report being told or made to feel like they are ‘faking it’ or that their symptoms are ‘all in their head’ demonstrating a gender bias in how symptoms and pain are perceived in young people.</p> <p>1 in 4 young people may experience a ‘medically unexplained’ or ‘functional’ symptom, but even in these cases, the young person isn’t ‘faking it’ but rather a variety of factors have come together to produce a very real symptom for that young person (GOSH, 2020).</p>
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## (4) Expand the current ‘waiting well’ provision for children and young people

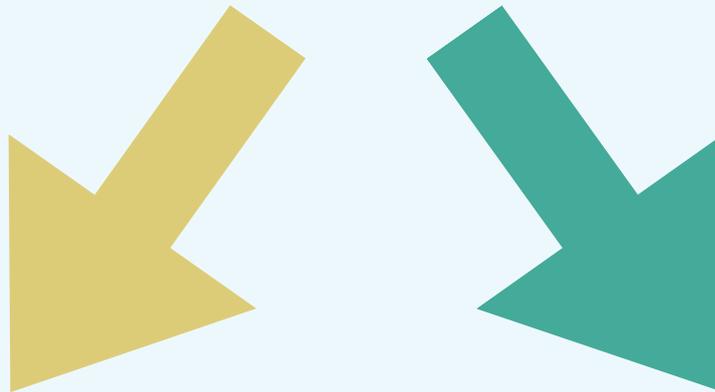
Several NHS trusts have developed a “Waiting Well” offer to help young people and the people who care for them whilst they wait for an appointment.

Manchester University NHS Foundation Trust - CAMHS service

- Self-help resources
- Social prescribing to community-based sources of support
- CAHMS contact numbers
- Numbers to use in an emergency situation

NHS England (2024) also outlined an action for trusts to provide ‘waiting well’ or self-care resources in their report “Closing the gap: actions to reduce waiting times for children and young people”. This guidance stated that young people and their carers should be offered resources such as leaflets. They also provide a link to resources that can aid the alternative prioritisation of paediatric waiting lists.

We would like to see the ‘waiting well’ provisions expanded so they address some of the key concerns raised by young people in this report.



See the next page for a  
breakdown of our ideas

See the design of a new  
communication tool for children  
and young people to use (end of  
trauma recommendations)

Area that waiting well provisions need to address	Ideas for how this could be achieved
<p>(1) Children and young people experience worsening health symptoms whilst on the waiting list.</p>	<p>How can the condition of children and young people on the waiting list be measured effectively?</p> <p>Whilst a deterioration in a young person's condition may be identified through repeated visits to healthcare settings, admissions or the need to access emergency services, this won't be the case for all young people. Many young people are waiting 'quietly' on waiting lists, not for months, but for years, whilst experiencing worsening physical and mental health, missing vital days of school and dropping out of their hobbies. Therefore, a critical aspect of a waiting well provision needs to be the improved monitoring of children and young people on waiting lists.</p> <p>Our idea</p> <p>Regular surveys of a young person's conditions to monitor:</p> <ul style="list-style-type: none"> <li>• Symptoms (including if any new symptoms have started or if symptoms are progressing)</li> <li>• Pain</li> <li>• Impact on quality of life</li> </ul> <p>For those with digital access, there could be a section of the NHS app which would enable CYPF to document the progression of symptoms at specific points (e.g. after a month, 3 months, 6 months). Information could also be collected on the medical problems' impacts on aspects of a young person's life, such as education and hobbies.</p> <p>Digital poverty needs to be considered, however, especially as children and young people living in poverty are more likely to experience poor health and wait longer for services ( The Kings Fund, 2024). So alternative versions, such as paper surveys or automated phone surveys, could be used.</p>
<p>(2) Preventing poor mental health whilst on the waiting list</p>	<ul style="list-style-type: none"> <li>• Provide more resources to CYPF about supporting a young person's mental health whilst on a waiting list</li> <li>• Avoid making comparisons about "how bad" a young person's symptoms are or implying they are faking it</li> <li>• A system of regularly checking in could also help young people to not feel forgotten whilst waiting</li> </ul>
<p>(3) What support can be put in place whilst a young person waits</p>	<ul style="list-style-type: none"> <li>• Coordinating across health, social care and education departments so accommodations and support can be put in place whilst a young person is waiting</li> </ul>

**(4) Increase support for children and young people 'on the move'**

For many young people, moving can cause a further challenge to accessing support and cause them to repeatedly be at the bottom of the waiting list.

- 'Your rights' - providing CYP with more information about their rights within healthcare spaces
- Establishing a 'home' base for young people, where possible, so referrals and waitlists are centralised
- New waiting lists to account for the time already passed
- Caution taken over referral to community services (which can also have waiting lists of up to 24 months)

**(5) Tackle Discrimination in ALL Healthcare settings**

- Expand training so there is an awareness of how conditions present in non-white bodies - a textbook doesn't go far enough
- Specifically, there is a need to look at how women's reproductive health is treated and approached

Care-experienced children and young people face some of the most profound and persistent inequalities in the UK. Despite their strength and resilience, the systems designed to protect them often respond only when harm has already occurred. This reactive model contributes to poorer outcomes, increased long-term costs, and preventable pressure on public services.

## DISPROPORTIONATE ADVERSITY AND OUTCOMES

The data paints a consistent and troubling picture:

- **39% of 19–21-year-old care leavers are not in education, employment, or training (NEET)—three times** the rate of their peers (13%). [[committees...liament.uk](#)]
- By age 27, **only 22% of care leavers are in employment**, reflecting systemic barriers that persist into adulthood. [[committees...liament.uk](#)]
- **1 in 3 care leavers become homeless** in the first two years after leaving care. [[committees...liament.uk](#)]
- **50% of children in care meet the criteria for a mental health disorder**, compared with 20% of all 8–25-year-olds. [[committees...liament.uk](#)]
- Looked after children and **care leavers** are between four and **five times more likely** to attempt suicide in adulthood [[neglected-minds.pdf](#)]

Long-term research reinforces these disparities. In England, **25% of care-experienced young people had no employment or education participation eight years after leaving school**, compared to just 4% of all school leavers.

These inequalities stem from compounding trauma, instability, and unmet emotional and health needs throughout childhood - needs that, if addressed earlier, could significantly improve outcomes for those individuals and reduce future public spending.

## THE INTENSIFYING MENTAL HEALTH CRISIS AMONG YOUNG PEOPLE

Mental health needs among children and young people continues to rise sharply:

- In 2023, 1 in 5 young people aged 8–25 had a probable mental health condition. [[youngminds.org.uk](#)]
- 78,577 young people waited over a year for NHS mental health treatment in 2023/24, with 44% waiting over two years, often deteriorating while on the waiting list. [[youngminds.org.uk](#)]

These pressures fall heaviest on vulnerable groups such as care-experienced young people, who already have higher levels of mental ill-health and far less access to consistent, long-term therapeutic support.

## MENTAL HEALTH FUNDING: THE URGENT NEED FOR INVESTMENT

Despite growing need, only 8% of the NHS mental health budget is allocated to children and young people's services.

While CYP mental health spending has grown by an average of 7% annually since 2017/18, this increase still falls short of demand and fails to correct decades of underinvestment. [[kingsfund.org.uk](#)]

Increasing CYP mental health funding would:

- Strengthen early intervention, reducing crisis presentations
- Address high rates of mental ill-health among care leavers
- Prevent escalation of unaddressed trauma into adulthood
- Reduce systemic pressures across healthcare, housing, social care, and justice
- Deliver long-term economic benefits through improved employment, education, and wellbeing outcomes

As someone who spent 16 years in the foster care system and who now works across the Civil Service and charitable sector supporting vulnerable young people, I have seen both sides of this issue. Our current approach is too often reactive, costly, and ineffective. Early, preventative interventions, particularly through well-funded mental health services are essential if we are to break cycles of disadvantage. Investing in prevention today is the surest way to reduce inequality and build a healthier, fairer and cost effective future for all.

**CHILDREN AND YOUNG PEOPLE MAY REPRESENT 25% OF THE POPULATION, BUT THEY ARE 100% OF OUR FUTURE.**

“IF YOU HAVE EXPERIENCED TRAUMA OR A TRAUMATIC EVENT AND WANTED TO SEEK HELP, WHAT WERE THE MAIN BARRIERS THAT PREVENTED OR DELAYED YOU FROM SEEKING HELP FROM NHS SERVICES?”

## TYPES OF BARRIERS

### EMOTIONAL

**43%** OF REPORTED BARRIERS

This suggests that internal emotional states play a major role in delaying or preventing help-seeking.

However, it would be naïve to treat these as purely “personal” problems. Many of these emotions (shame, fear of judgement, difficulty speaking) are shaped by expectations of how services will respond. In other words, they are psychologically internal but socially produced.

### TRUST & SAFETY CONCERNS

**32%** OF REPORTED BARRIERS

This is striking. These are not vague anxieties - they are experience-based or belief-based concerns about harm, dismissal, or lack of understanding within NHS services.

This shifts the narrative from “Young people are reluctant to seek help” to “A substantial proportion anticipate that services may not be emotionally safe or validating”

### SYSTEM & ACCESS

**25%** OF REPORTED BARRIERS

Waiting times are the single most common individual barrier, but when grouped, system/access issues are smaller than relational and emotional factors combined.

A simplistic policy response might focus only on reducing waiting lists. THE data suggest that even perfect access would not solve the core problem if young people still expect judgement, dismissal, or misunderstanding.

### DEMOGRAPHICS

OF THE 147 TOTAL SURVEY RESPONDENTS, 102 EXPERIENCED BARRIERS - WHICH IS 69.9%. OF THESE 102:

101 WERE YOUNG PEOPLE AGED 11-25,  
82 WERE YOUNG PEOPLE AGED 11-18

OF ALL THE CARE EXPERIENCED YOUNG PEOPLE WHO RESPONDED, 100% OF THEM EXPERIENCED AT LEAST ONE BARRIER, 87.5% EXPERIENCING MORE THAN ONE BARRIER

ONE OF THE EIGHT CARE-EXPERIENCED RESPONDENTS AGED OUT OF CHILDREN'S SERVICES WHILE WAITING FOR SUPPORT. ALTHOUGH SMALL, THIS ONLY REFLECTS THOSE WHO ACCESSED THE SYSTEM AT ALL - THE TRUE SCALE OF TRANSITION GAPS MAY BE HIGHER FOR YOUNG PEOPLE WITH SOCIAL CARE EXPERIENCE

\*Keep in mind, participants were allowed to report more than one barrier - we took this into consideration.

**DO YOUNG PEOPLE FEEL NHS PROFESSIONALS UNDERSTAND TRAUMA AND ITS IMPACTS? (IN BOTH MENTAL AND PHYSICAL HEALTH CONTEXTS)**

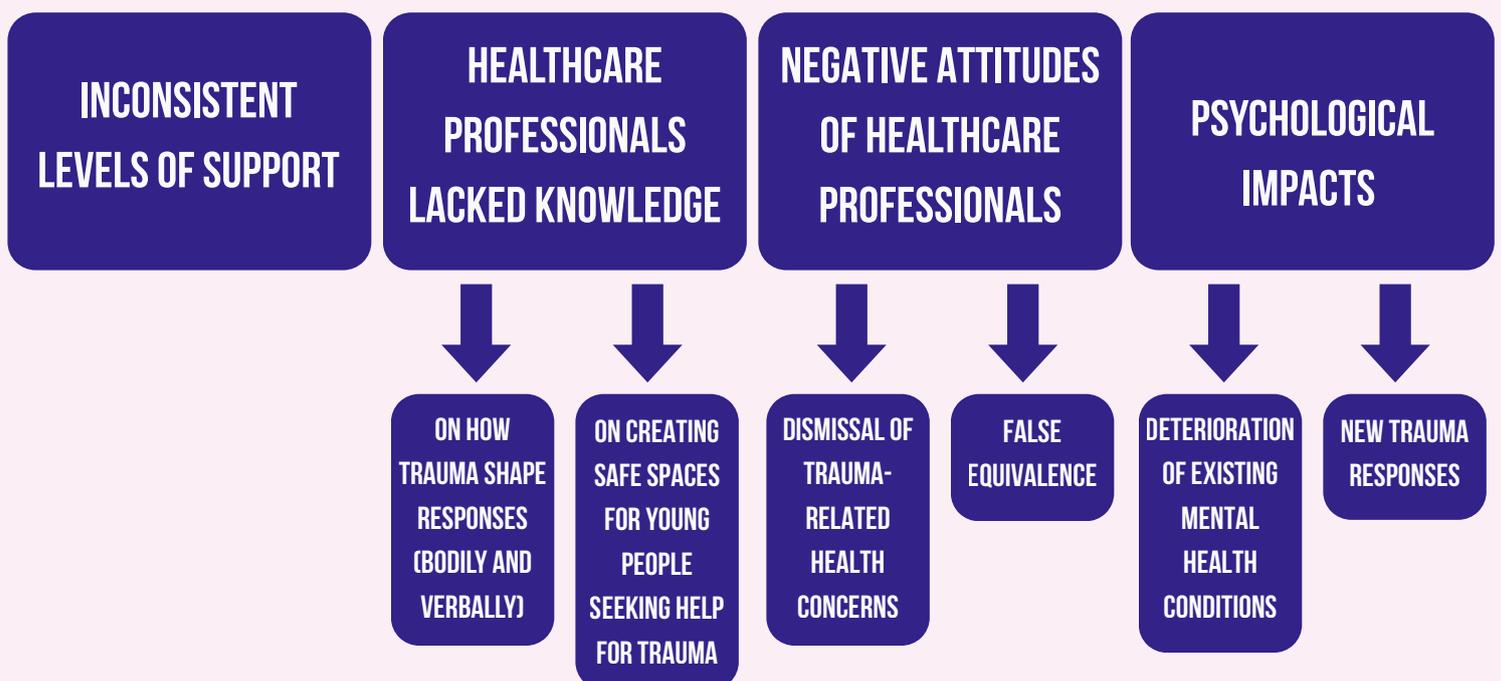
Though there was a mixed consensus among the 90 young people who answered this open-ended question, most did not feel as though healthcare professionals within the NHS fully understood trauma, nor its various impacts. Three main themes were identified: **(1) Inconsistent levels of support, (2) Healthcare professionals lacked knowledge** and **(3) Negative attitudes of healthcare professionals**. The diagram below shows the subthemes included in these overarching areas.

*"I think certain doctors have been very sympathetic but others don't seem to consider this at all when interacting with patients"*

*"Sometimes I feel I have to explain or justify my reactions instead of being understood automatically as someone affected by trauma."*

*"Most focus mainly on symptoms without recognising how past experiences can shape trust, communication, and responses to treatment."*

**THEMES & SUBTHEMES**



## INCONSISTENT LEVELS OF SUPPORT

An important theme that emerged in the data was the inconsistency of trauma support that young people received when accessing NHS services. Young people stated that staff members were often more understanding of trauma if they were younger and/or had previous lived experience of trauma. Additionally, some young people described how being passed between different services, departments and individual staff members negatively impacted how well their trauma was understood and managed - with one person describing this process feeling "like a gamble". The word "gamble" shows the lack of confidence young people have in the NHS to ensure high-quality trauma support every time, with the expectation that they may not receive what they need or want.

Factors that influenced quality of support:

- Age of staff
- Staff with lived experience
- Different departments/staff members
- The child-to-adult services transition

*"I did feel listened to at my local GP, and when accessing children's care. But when I had to access adults' care (a specific department rather than just paediatrics) I felt dismissed and not listened to"*

## HEALTHCARE PROFESSIONALS LACKED KNOWLEDGE

### ON HOW TRAUMA SHAPES RESPONSES

Young people highlighted that trauma can manifest in different ways and can influence how they physically and verbally express pain:

*"...In physical health, I don't think NHS staff realise that chronic pain affects how you express your pain. People with chronic pain often have to fake being in less pain than they are to stay sane and to go out in public at all."*

Previous abusive experiences may also cause young people to alter their behaviour, to avoid future ridicule or harm:

*"Trauma around getting upset (e.g. being hit or insulted for crying, especially at a young age) will affect how a person expresses pain. They will probably avoid crying at all costs. This does not mean they are not in pain."*

Trauma can also negatively impact young people's ability to advocate for themselves. These struggles often have a knock-on effect on the support they receive from NHS professionals:

*"You can be far more hesitant to engage, yet professionals put it down as 'not willing to engage' even though you really need support."*

### ON CREATING SAFE SPACES FOR YOUNG PEOPLE SEEKING HELP FOR TRAUMA

Experiencing trauma can make everything harder when accessing NHS services - from trust and communication, to physically being in the room. Young people mentioned how some approaches by professionals can feel emotionally unsafe:

*"They pushed and pushed and pushed about why I did it. They didn't seem to realise that this would only make me unable to talk to them, as they no longer felt like a safe person to share with."*

One young person pointed out that the layout of a building and having to wait in the same area as everyone else can be additionally challenging for those experiencing trauma:

*"I think they understand some things but whenever I've went to hospital for putting myself in danger, we always have to wait in the normal children's waiting room. I feel there should be one especially for struggling people that is private."*

## NEGATIVE ATTITUDES OF HEALTHCARE PROFESSIONALS

### DISMISSAL OF TRAUMA-RELATED HEALTH CONCERNS

Many young people felt as though healthcare professionals did not listen to them about their trauma or take it seriously:

*"Some of my friends or family have had far worse experiences of misunderstanding or being dismissive"*

Young people mentioned that trauma is sometimes downplayed or written off as another common symptom or issue:

*"I feel like they push everything for younger people towards "anxiety", or "low mood", instead of listening and understanding."*

### FALSE EQUIVALENCE

Even when their trauma was acknowledged, some young people felt their individual traumatic experiences were approached and managed in the same way as other cases. This made young people feel as though they were not a priority or as important as others:

*"[They] treat everyone who's experienced trauma as if they've undergone the same trauma"*



## PSYCHOLOGICAL IMPACTS

### DETERIORATION OF PRE-EXISTING MENTAL HEALTH CONDITIONS

Young people described how their trauma not being understood by professionals led to the worsening of pre-existing mental health conditions. This was the case even in mental health contexts. Being referred to the 'wrong' services also increases the risk of young people being without support for longer:

*"I got moved from a psychiatrist into trauma counselling, even though I said that I was unable to talk about it, this pushed me into a deeper episode and then I ended up in 'Anxiety Management'?"*

### NEW TRAUMA RESPONSES

Healthcare professionals not listening to young people about their trauma can trigger new trauma responses. New trauma responses that young people described experiencing included self-doubt, shutting down, over-explaining:

*"[I'm] constantly unsure whether what I was reporting was serious enough"*

*"When they act normal and expect me to just answer straight away or "Be fine," it makes me shut down."*

IF YOUNG PEOPLE COULD CHANGE ONE THING ABOUT THE WAY THE NHS HELPS THOSE WHO HAVE EXPERIENCED TRAUMA, WHAT WOULD IT BE?



*"Just be compassionate and kind, it's easy for someone who hasn't experienced trauma to say "it'll be okay, just get over it" but if you have experienced trauma you'll know that it changes you and all aspects of your health...it never goes away..."*

*"I think there needs to be more clear open communication and also more specific therapy, I had to fight for more specific therapy for trauma"*

*"Every young person should be spoken to at least once a term. whether its at school or doctors, they should be having check ups every half term just to see how there doing."*

*"More range/choice in the people who oversee your care e.g. choosing people who you feel listened by"*

*"I think there should be more consistency, kindness, and follow-up, so young people feel supported throughout the whole process, not just at the first appointment."*

*"Trauma doesn't happen in a vacuum. Context matters. A young person's identity, culture, lived experience, and level of independence shape how they understand what has happened to them and how ready they are to seek help."*

*"Allowing them to fully explain themselves and share as much as they want before asking questions... interjecting with questions can disrupt that and immediately make us feel unbalanced and anxious"*

*"Require less influence from parents but still have some sort of adult safeguarding in place."*

*"I'd make trauma-informed training mandatory for all staff, not just mental health specialists. Young people often first encounter the NHS through GPs, A&E, or school-based nurses. It would also help if services worked more consistently together, so young people don't have to repeat painful experiences each time they meet a new professional."*

*"I wish they'd slow down and take time to actually know me instead of treating me like just another person on a list. "*

## WHAT DOES THE NHS NEED TO DO TO REDUCE OR PREVENT YOUNG PEOPLE FROM EXPERIENCING MEDICAL TRAUMA?

Medical trauma is a concept that has been defined in a multitude of ways; encompassing both physical and psychological trauma. In the context of this report the young people who shared their experiences with us talked broadly about two different concepts relating to medical trauma:

### “MEDICALLY RELATED TRAUMA”

Young people refer to trauma as a result of experiencing illness or injury, invasive or long term medical treatments, interactions within medical settings and the physical hospital environment itself. This includes experiences of feeling unheard, dismissed and not listened to. These experiences broadly align with Young et al (2021;740) definition of medical trauma being “exposure to a series of medical events related to injury, illness, painful or invasive medical interventions and or other hospital experiences that may be perceived by the child and/or caregivers as threatening, overwhelming or frightening”. For the purpose of this report this will be referred to as “medically related trauma” highlighting its specificity to trauma relating to medical conditions, treatment, and interactions within medical spaces. The majority of experiences young people shared with us fit within this category.

### “TRAUMA RELATING TO HARM, ABUSE OR MALPRACTICE”

Young people also refer to trauma as a result of malpractice, mistakes, abuse and harm that have occurred both inside and outside the medical environment. This includes stories of young people who felt unheard when disclosing familial abuse to healthcare workers, leaving them in a vulnerable situation. It also includes young people who shared experiences relating to harm and abuse in medical settings and the impacts of medical mistakes. For the purpose of this report this will be referred to as “trauma relating to harm, abuse and/or malpractice”. Harm, abuse, malpractice and failings to safeguard are all incredibly serious issues with life long consequences for everyone involved and are issues that need to be carefully reviewed to build a comprehensive understanding of what has occurred.

Medical trauma can be an incredibly difficult topic to discuss due to the significant social, psychological and physical impacts for those involved. Sometimes medical trauma comes as a direct result of negligence, where a person or trust is responsible for causing unnecessary harm or failing to protect a young person from harm. “Medically related trauma” can be a particularly challenging topic as this often comes as a result of routine practices in medical setting or as a direct result of a young person experiencing an illness or injury and therefore the perceived harm young people feel may have occurred inadvertently with little to no fault of anyone involved. It can therefore, be challenging to understand how to address it or make space for these conversations in healthcare.

Therefore, for anyone reading this section we urge you to come into this conversation with an open mind, something which the young people who shared their experiences with us ask you to do also:

*“It means admitting that people have the capacity to cause harm in the first place. The more we are transparent about the possibility of everyone causing harm, the more we can approach it with openness.”*

In some of the stories young people share they express large amounts of anger and frustration at those involved in their care - we ask you to take this at face value - young people who are hurting, confused and angry at the experiences they have had to go through at such a young age.

Many young people explained that they were aware of the pressures staff were under and didn't blame them as they knew they could have no impact on external factors such as wait times. We know many professionals may feel as helpless as young people as to what they can do to help - but together we believe that we can change the system. These recommendations from young people are therefore a call to action to the people in power to create a system which has the time and resources to listen more, to understand more and to communicate more effectively with the young people who access it.

## HOW CAN THE NHS REDUCE OR PREVENT YOUNG PEOPLE FROM EXPERIENCING MEDICALLY RELATED TRAUMA?

### 1. Listen more and make an effort to understand young people as individuals

Young people ask that medical professionals slow down and take the time to get to know them as a person and not just a patient. They also ask that NHS staff spend time understanding young people's concerns, and how they are feeling and take this seriously.

“ Spend time with your patients. Understand them, know their name”

“ Take time to understand and listen to what they are experiencing”

### 2. Treat young people with kindness and compassion

Young people explained that they wanted to be approached with an understanding that they were also first and foremost a person and should be shown kindness regardless of their characteristics. Young people also asked that medical professionals showed kindness when young people expressed signs of trauma as a result of medical experiences.

“ be gentle and open, don't treat us like the ones who caused our trauma”

“ Be nice and considerate and treat everyone equally no matter their sex, ethnicity or identity”

“ Be compassionate, not condescending. We are human beings not burdens.”

### (3) Listen when they try to talk about trauma that has occurred in a medical setting and take quick action

Young people ask that medical professionals listen when they talk about trauma they have experienced in a medical setting and take these concerns seriously, as some young people currently feel like they are being dismissed. Young people gave the following recommendations:

- Notice the signs of trauma early and ask questions if there are any concerns
- Young people experiencing emotional distress as a result of their healthcare experiences asked that medical professionals put time aside in appointments to check in with young people about how they are feeling, identify issues early and refer to support services early. They also asked that medical professionals were more aware about the potential emotional impacts of appointments, tests and treatment

#### **(4) Improved communication and transparency around care**

Young people explained that they wanted to be more informed about their healthcare and the decisions that were being made and that this transparency around care would have prevented trauma from occurring.

“Be more communicative with patients. Patients deserve to have clinical decisions explained to them”

*Young people made explicit reference to medical students and that they should always be asked if it is okay for a medical student to observe rather than just assuming they have a right to be involved with a young person's care. Young people explained that whilst they understood the need for learning, they had experienced situations where they were undergoing invasive or highly sensitive procedures and in these contexts, it was particularly inappropriate to bring in medical students without prior consent.*

“I was informed half way through a procedure that students had been brought in to observe while I was under local anaesthetic and had private areas exposed. I felt like it wasn't a question if they could be part of my treatment but just a courtesy to tell the teenage girl on the table that a bunch of people were watching her”

#### **(5) Take young people seriously**

#### **(6) Tackle discrimination**

#### **(7) Be aware of how frightening a hospital environment can be**

*This is something to be aware of when designing new hospitals. Particular attention is needed on how the physical environment can be made less frightening for children and young people.*

“I don't think they could do anything hospitals are a scary place for young people”

## TRAUMA RELATING TO HARM, ABUSE AND/OR MALPRACTICE

(1) Young people recommended for medical settings to make supportive resources more accessible to young people, including:

- *Making pathways to reporting harm or abuse more obvious and accessible for a young person*
- *Creating pathways to access more anonymous forms of support. One young person suggested putting posters in medical settings outlining the reporting process and ways in which support could be accessed.*

### The impact of asking the 'right questions'

Disclosing traumatic experiences can be deeply challenging for young people, and healthcare services form an integral part of safeguarding and supporting children and young people when trauma, abuse, harm or malpractice occurs, either inside a medical setting or outside of it. Young people often don't know how to start these conversations, or don't know who or where it would be safe to have them. Drawn from lived experience within the team, it was discussed how vital being asked the right questions could be in enabling a young person to disclose what had happened to them, something 70% of the young people who shared their stories with us agreed with. For some, this was linked to broader points made surrounding increased awareness of what constitutes harm or abuse in both medical and social settings, with young people explaining that the right questions could have led them to realise that what happened to them was wrong earlier. Some young people shared positive experiences of disclosure in healthcare settings and explained how, when medical professionals took time to ask them questions, it made them feel safe and like someone cared, enabling them to open up and disclose what was happening to them.

Young people explained, however, that even when the right questions were asked, they still didn't feel safe or comfortable disclosing and explained how it often took them a long time to trust and feel safe around new people. As a result, the recommendations for more time to be spent with young patients to fully get to know and understand them could not only help young people to feel more comfortable in healthcare settings but could also be a lifeline in creating a trusting and safe space for a young person to open up about what has happened to them.

“**Y**es, **I** think if someone had asked me the right questions and taken the time to really listen, **I** would have felt safer to open up and ask for help sooner. **S**ometimes it's hard to talk about what you're going through, especially when you're young and not sure how people will react. **I**f staff had shown more understanding, patience, and care and asked questions in a gentle and non-judgmental way it would have made me feel more comfortable and confident to share what was really happening. **F**eeling safe and believed makes a huge difference when trying to get support.”

**(2) Raising awareness about medical trauma and validating all forms of trauma**

Young people also highlighted that increased education around all forms of trauma, including harm or abuse that may occur in the home, would be beneficial in helping them understand that what was happening was wrong - as some young people explained they did not realise what was happening to them until much later on.

*"Make it easier to access anonymous support or have posters around **NHS** buildings of where you can access support for trauma immediately"*

*"act on issues sooner rather than letting it get to a drastic point"*

*"Ensure young people are aware of the signs of mistreatment / abuse in both medical and social scenarios"*

**(3) Stop making mistakes**

Some young people had experienced harm as a result of medical mistakes and misdiagnosis.

**(4) Provide swift intervention if a young person discloses harm or abuse (both inside or outside a medical setting)**

*"When they tell you someone in their homelife is hurting them or doing things, **LISTEN**. This would have saved me from so much, if they had listened."*

**TAKE YOUNG PEOPLE SERIOUSLY  
THE FIRST TIME, EVERY TIME.**

**AN URGENT REVIEW IS NEEDED INTO THE DISCRIMINATION  
YOUNG WOMEN FACE IN HEALTHCARE SETTINGS**

**OUR RESEARCH HAS FOUND THAT YOUNG WOMEN...**

Experience trauma as a result of being denied pain relief for invasive procedures

**Are more likely to have their pain and symptoms dismissed**

Are often given unsuitable resources - such as information books based solely on male presenting autism

Are more likely to be told or feel like they are faking it or that all their symptoms were in their head

Often have reproductive issues and pain overlooked

Face challenges around consent when going through sensitive medical procedures

Frequently feel dismissed and not taken seriously simply because they are a **woman**

**Tackling discrimination in healthcare - our thoughts:**

More medical research is needed to create a more modern, informative curriculum that is inclusive to minority groups.

Targeted prevention - reviewing the curriculum in order to provide a high quality level of education that meets the needs of a modern and evolving society, will then hopefully provide better outcomes for those from marginalised and minority groups, putting less strain on services as a whole as needs are met earlier on reducing the chances of secondary conditions being developed and needing further long term support

## RECOMMENDATIONS:

### FOR SUPPORTING YOUNG PEOPLE EXPERIENCING TRAUMA:

#### 1. Embed Trauma-informed Care in National CYP Standards and Metrics

Expand the NHS 10-Year Health Plan's commitment to improving children and young people's mental health access and outcomes by embedding trauma-informed care principles into national standards, key performance indicators and Integrated Care Board (ICB) performance frameworks for CYP services.

#### 3. Require Mandatory Trauma-Informed Training for all NHS staff

Introduce mandatory trauma-informed training designed for all NHS staff working with children and young people, including primary care, emergency departments, mental health services, community services, schools' mental health teams and allied professionals (e.g., health visitors). Training should include modules tailored to developmental stages and contexts.

#### 5. Trauma-Informed Commissioning and Financial Incentives

Use commissioning frameworks and incentive structures introduced by the 10-Year Plan to reward providers that deliver high-quality, trauma-informed care for CYP, including reduced waiting times and demonstrable improvements in experience and outcomes.

#### 2. Trauma-Informed Early Identification to Support Timely Access

Mandate trauma-informed screening as part of routine early assessment for CYP across primary care, school-linked support services and mental health access points to ensure faster identification of trauma-related needs and more timely referral to appropriate support services.

#### 4. Co-Design with Children & Young People with Lived Experience

Require services to co-design trauma-informed pathways with young people with lived experience and include them in governance, training design, and quality review processes.

**FOLLOW YOUNG PEOPLES RECOMMENDATIONS TO PREVENT AND REDUCE TRAUMA IN MEDICAL SETTINGS**

Recommendation	Explanation
<p><b>Collaborate with young people to co - design a training programme for healthcare staff to address the common issues young people raise as causing medical trauma</b></p>	<p>Young people who shared their experiences explained how ‘increased training for staff’ would help to reduce or prevent medical trauma. These young people explained how key features of this training should be around:</p> <ul style="list-style-type: none"> <li>• Age-appropriate communication</li> <li>• How health conditions present in non - white bodies</li> <li>• Education about health conditions and how characteristics such as gender, ethnicity or sexuality may affect this</li> <li>• Training on what to avoid [to prevent young people from experiencing trauma]</li> </ul> <p>Collaborating with young people to design this programme would be essential to ensure it was tailored to specifically address the challenges young people face in healthcare settings.</p>
<p>“More age-appropriate healthcare training”            “Train their staff in communication skills”            “Research and understand how illness presents with non-white people”</p>	
<p><b>Collaborate with schools to demystify healthcare and provide age-appropriate education about harm, abuse and where to access support</b></p>	<p>Young people that increased collaborations with schools could help to demystify healthcare and the support that was available. As part of this, young people said they would like to see an increased awareness about harm and abuse both inside and outside medical settings, including clear signposting to support, so children and young people are aware when things happen to them that are wrong.</p>
<p>“Ensure young people are aware of the signs of mistreatment / abuse in both medical and social scenarios”            “Needs more interaction and training within schools”</p>	
<p><b>Have clearer pathways for reporting issues and accessing anonymous forms of support</b></p>	<p>Young people suggested having posters in NHS settings with signposts to pathways for reporting as well as support. Young people also explained that access to anonymous supportive resources could also be useful.</p>
<p>“Make it easier to access anonymous support or have posters around NHS buildings of where you can access support for trauma immediately”</p>	

Develop a new communication tool to help children and young people in healthcare settings  
Below is a provisional design which aims to address issues raised by young people across the themes of  
trauma and youth voice.

Drawn by Teagle

## About Me

I really enjoy / my hobbies are.....



Things I want you to know about communicating with me.....

- Please talk to me and explain all the decisions
- I get nervous so please be patient with me

How this is affecting me.....

- I've been let go from work because of the amount of sick days I'm taking
- I've had to give up sport
- I keep missing school
- I can't get any help because I don't have a diagnosis

I'm worried about.....

- the treatment
- being on a busy hospital ward
- not knowing what is wrong with me
- talking to a new medical team
- Being ignored as I've had bad experiences in the past

Since my last visit / while I've been waiting....

My pain has...

My symptoms are...

I've been struggling with..

I want to talk to you about....

2

1

3

4

5

1 Young people explained that they wanted healthcare professionals to take time to understand them as a **person** as well as a patient. They also shared the impacts that wait times and their health conditions were having on wider aspects of their life, including education, hobbies and socialising. These sections, therefore, aim to give a healthcare professional insight into what a young person enjoys doing and how their health issue is affecting them on a broader level. We hope this would enable a healthcare professional to understand more about a young person whilst also inform and build a more holistic image of the challenges they are facing, which could inform treatment plans.

2 Young people shared their frustrations at how their communication needs were not shared between medical teams, leading to every appointment feeling difficult. We therefore suggest that there is a section where young people can explain to healthcare professionals anything they would like them to know about communicating with them. Whilst beneficial for all young people, this feature would particularly help children and young people with communication difficulties and ensure that decisions around their care are explained in a way that is appropriate for them.

3 Young people shared that healthcare settings were often traumatic for them, simply due to being overwhelming and daunting places. They also suggested that one way of overcoming this was regular check-ins with young people about how they are feeling. This section would therefore enable young people to share what they were worried about, which would enable healthcare professionals to allay fears, potentially spot arising issues early and support a young person in the healthcare setting. This could also allow young people to share more sensitive concerns without having to repeat them verbally to healthcare professionals.

4 Young people shared how their health changed whilst they were waiting for an appointment. They also found repeating their story multiple times challenging, particularly when visiting a multitude of different specialities. This sections would therefore allow young people to document and track their symptoms over time, explain what they are struggling with and explain any changes that have occurred. This section could help in a few ways:

- 1) Supporting young people to explain what they are experiencing where verbal communication may be challenging - enabling their voice to be centred
- 2) Giving a healthcare professional detailed insight into what the young person is experiencing, including how it is developing

Young people explained some significant additional issues they acquired whilst waiting for an initial appointment, diagnostic tests or treatment. If this section was made 'live' so a young person could keep track of how they were feeling over time it could also enable healthcare professionals to identify arising significant issues before they went any further.

5 Young people's voices being centred in their care is the central aspect to ensuring they feel cared for and listened to. A section such as this could enable young people to identify key things they would like to discuss in an appointment.

## SURVEY QUESTIONS

### JUSTIFICATION

Fatness is a major focus of the Sickness to Prevention theme in the NHS 10-Year Plan, with five pages dedicated to ‘tackling the obesity epidemic,’ 30% of the pages dedicated to the shift. In discussions with NHS England, Complications from Excess Weight (CEW) Clinics were presented as the primary intervention for young people. Pilots CEWs, which launched in 2021, aimed to provide more personalised care around fatness, and trial GLP-1 medications and other non-surgical interventions for under 18s. The NHS is running its own evaluations of the CEWs’ efficacy with the ENHANCE Project, which will involve inclusion of interviews with ‘parents and young people’ using the service.

As such, it felt imperative to ask young people as a whole, beyond those with direct contact with CEWs, about their opinions. It also felt relevant to try to capture the impact of conversations about weight, which will inherently be a precursor to any referral to a CEW clinic, as well as being the point where some young people and families will reject specialist referrals - these voices are just as important to capture as those who did accept referral during the pilot period.

### QUESTIONS

The third section of the survey focused on weight, opening with a content note for respondents:

*“This section discusses weight. This section is optional, and you can skip it if you want to. We understand that weight is a sensitive topic. If you do choose to answer, please only share what you are comfortable with and remember you can skip a question or the section at any time. Please see below for contact information for support.”*

It comprised two quantitative questions, grouped together, and one qualitative question:

*Question 14a Have NHS Staff discussed your weight with you? (check all that apply)*

- *Yes - unprompted*
- *Yes - I brought it up*
- *No - I have not discussed weight*
- *It was related to the health condition we were discussing*
- *It was not related to the health condition we were discussing*

*Q14b The age you were:*

- *When I was over 18*
- *When I was under 18*
- *When I was under 16*
- *When I was under 13*

*Q15. How do you feel about the concept and name of ‘Complications of Excess Weight (CEW) Clinics’ which would be aimed at people under the age of 18?*

Questions 14a and 14b were designed to gather data on the amount of young people who have discussed weight with a healthcare professional, when this happened, whether it was prompted by them or the professional, and whether the young person felt it was relevant to the health issue they were discussing. Question 15, the qualitative question, investigates young people’s opinion on CEWs. Based on published information from a Lunch and Learn session<sup>1</sup>, this description of CEWs was given to respondents:

*‘CEWs are for young people aged 2-18 who have conditions associated with weight (which can be physical or mental health conditions), and are designed to be a ‘holistic’ non-surgical option for weight loss. Currently they are being run in slightly different ways, but the first CEWs focused on low calorie and low carbohydrate diets, a GLP-1 medication (in the same medication family as Ozempic), as well as identifying and removing barriers to weight loss within the young person’s household.’*

A link was also provided to ENHANCE’s ongoing consultation around renaming the clinics, to further amplify young people’s voices on the topic.

<sup>1</sup> NHS England (2022) *April Lunch and Learn Summary*. <https://www.england.nhs.uk/london/wp-content/uploads/sites/8/2022/09/CEW-Clinics-FAQ-document-V2.0.pdf>

## TERMINOLOGY

This report will utilise the word fat to describe overweight/obese people, and obesity as a whole. In line with approaches to reclaiming 'fat' by body neutrality and positivity activists and scholars,<sup>2</sup> fat is used here as a neutral, descriptive term.

Survey language, however, referred to 'weight' without mention of obesity, as reclamation of 'fat' is in its early stages, and popular alternatives used to self-describe, like 'plus size', might have seemed overly euphemistic in a medical context. This did mean that a handful of respondents disclosed they had weight conversations with health professionals relating to being underweight. This limitation is made clear throughout.

*'reclaiming the word  
fat is about  
reclaiming our very  
bodies, starting with  
the right to name  
them'*

AUBREY GORDON, FAT  
ACTIVIST AND SCHOLAR

## RESULTS

Of the 143 respondents who provided usable responses to the survey, 132 responded to all or part of the weight sub-section. Of these respondents, 64 (48%) explicitly disclosed having a weight conversation with a health professional, and 68 (52%) did not. In shorthand, these groups are referred to as the 'weight' group and 'non-weight' group, respectively.

A limitation of these sub-groups compared in these results is that they are not drawn from a demographic question around fatness, but use the unambiguous disclosure of conversations around weight as a proxy (i.e. ticking either 'yes - I brought it up', or 'yes - unprompted'). Some in the non-weight group ticked one boxes in the checklist regarding weight conversations (e.g. 'it was not related to the condition we were discussing'), but based on some who provided qualitative responses, this seemed to be because respondents assumed they needed to check a box to progress the survey.

The draft survey did include a way to distinguish respondents who had conversations about being a 'normal' weight or underweight, but this was not properly transferred to the Microsoft form. As such, not all conversations about weight would be about fatness, with some making this explicit in their qualitative responses. Further research, co-produced with fat young people specifically (especially those who have declined CEWs or other Weight Management Service referrals), is encouraged.

## WEIGHT CONVERSATIONS

### AGE

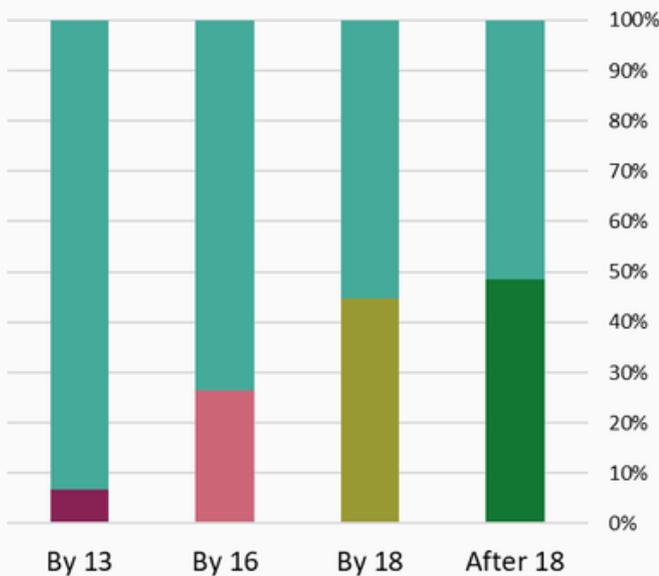
***1 in 14 will have a conversation about weight with a healthcare professional before they are 13.***

***1 in 7 of those who will have weight conversations with a healthcare professional will have had one before they turn 13.***

<sup>2</sup>Gordon, A. (2020) *What We Don't Talk About When We Talk About Fat*. New York: Beacon Press.

# SICKNESS 2 PREVENTION WEIGHT

Percentage who had a conversation about weight by a certain age



The childhood statistics may be lower than recorded rates of fatness among young children,<sup>3</sup> but speak to healthcare professionals' general willingness to bring up the topic with young children and tweens.

After the age of 18, the percentage of those who have had a conversation about weight is higher than the percentage of adults who are considered overweight or obese, even assuming all those who skipped this section chose to do so because they have never had a conversation about weight. This suggests that healthcare professionals are also raising weight with younger adults who are at a 'normal' or 'borderline' BMI.

This could further indicate the presumption that increased rates of fatness have been caused by a lack of awareness of healthy habits is false.

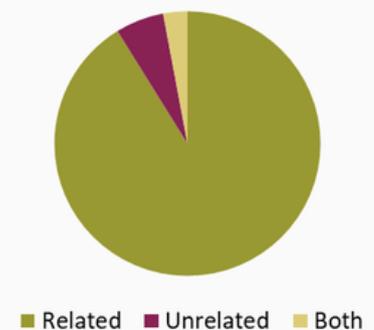
## PROMPTING AND RELEVANCE

Almost all young people who had conversations about weight felt it was related to their health condition. Without further information, it is impossible to know the accuracy of these assessments, but does initially suggest healthcare professionals are regularly contextualising weight conversations, and that young people have absorbed and accepted this reasoning. However, further qualitative research would be welcomed here, given research with fat adults that suggests they experience irrelevant and inaccurate perceptions about their weight during their care.<sup>4</sup>

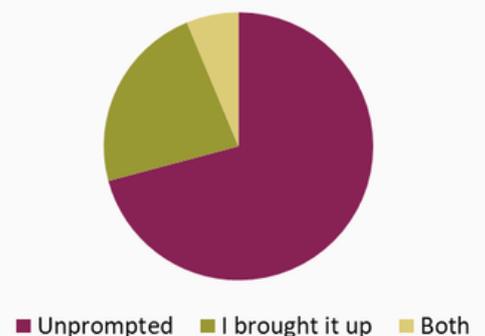
However, these results do suggest that most young people are not seeking weight-related healthcare when these conversations occur. 77% of young people report these conversations about weight were initiated unprompted by the healthcare, including two thirds of those who were under 13, and 70% of those who were under 16. Given overall concerns about self-image issues among young people and teenagers, and that many young people brought up these issues when articulating concerns about CEW Clinics (see page xx) it seems relevant to question the appropriateness of these interventions.

Further qualitative research about the nature of these conversations, how they were initiated, and their impacts could be especially relevant should the NHS wish to expand CEW Clinics, which would likely result in primary care professionals initiating these conversations more frequently with children and teenagers.

Was weight relevant to the health condition you were discussing?



Was weight brought up by you or by the healthcare professional?



<sup>3</sup> NHS England Digital (2024) Health Survey for England. (<https://digital.nhs.uk/supplementary-information/2024/hse-child-single-year-of-age-bmi---ad-hoc-analysis>)

<sup>4</sup> Phelan, S. M. *et al.* (2015) Impact of weight bias and stigma on quality of care and outcomes for patients with obesity. *Obesity Reviews* 16, 319–326.

## DEMOGRAPHIC DIFFERENCES

It was not possible to compare some demographics due to small samples, but there are other areas where demographic differences are likely to exist, e.g. the racialised history of fatphobia, and a lack of awareness about the reduced applicability of metrics like BMI impact Black people.<sup>5</sup>

But certain groups were more likely to report discussions about weight with their healthcare providers:  
**Young people assigned female at birth (AFAB; 47%) vs those assigned male at birth (AMAB; 31%)**

**Disabled young people (56%) vs non-disabled young people (35%)**

**Young people who have accessed mental health services (53%) vs those who have not (47%)**

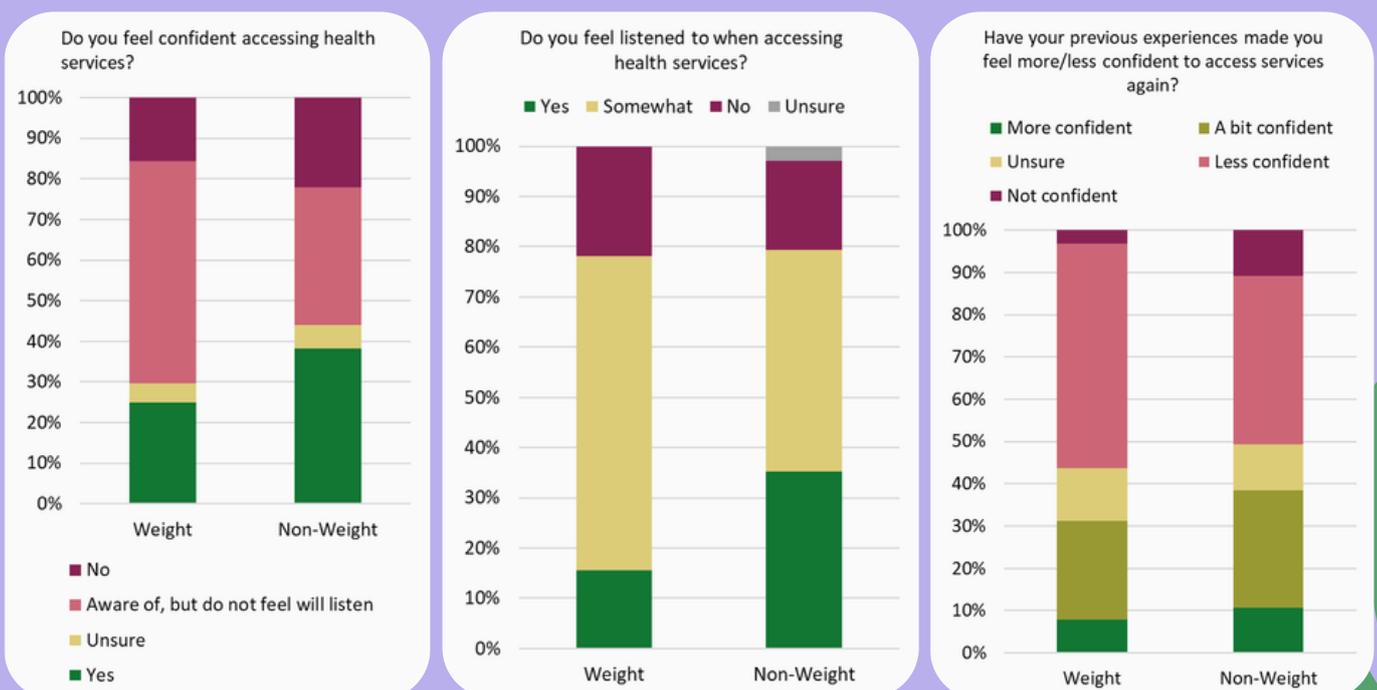
As expected from earlier statistics, young people in the weight sub-group were older, but the full age-range surveyed is represented; the youngest respondent was 12.

Whilst the increased discussion of weight with disabled young people could be partially justified by population statistics around fatness in England, the disparity between AFAB and AMAB young people does not reflect reality; AMAB people are slightly more likely to be fat for almost all of their lifetimes.<sup>6</sup> This could suggest medical misogyny plays a role in who doctors discuss weight with, and could tie into the gendered impact of poor self-image and eating disorders.

## WIDER HEALTHCARE IMPACTS

Creating these sub-groups allowed examination of the potential impact of these conversations on wider healthcare experience. Young people in the weight sub-group, despite skewing older, feel less confident accessing services, less listened to during interactions, and less confident because of past interactions. Due to a small sample size, it is difficult to control for other demographic variables, but preliminary analysis suggests that differences between weight subgroups remain when these are controlled.

Overall, this data suggests these conversations, regardless of intention or contextualisation, have a negative impact on young people and alters their overall perception of healthcare. This would align with surveys of fat people and their experiences of fatphobia in medical settings, who are also more likely to persistently avoid healthcare as a result.<sup>7</sup>



<sup>5</sup> Strings, S. (2019) *Fearing the Black Body*. New York: NYU Press, New York.

<sup>6</sup> Stiebahl, S. (2025) *Obesity Statistics*. [researchbriefings.files.parliament.uk/documents/SN03336/SN03336.pdf](https://researchbriefings.files.parliament.uk/documents/SN03336/SN03336.pdf).

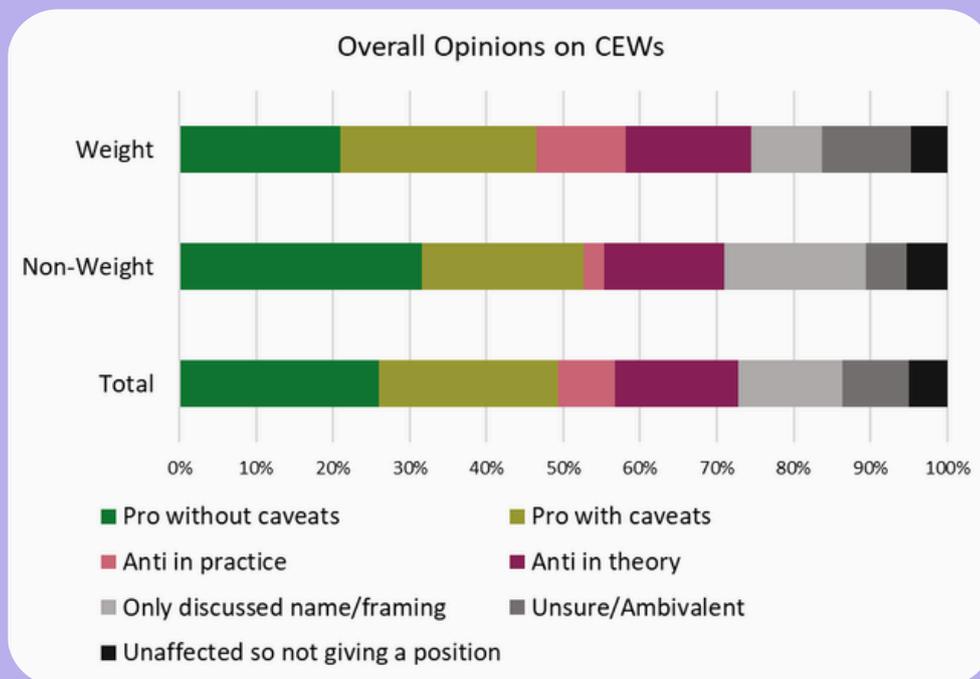
<sup>7</sup> Mensinger, J. et al. (2018) Mechanisms underlying weight status and healthcare avoidance. *Body Image* 25, 139–147.

## OPINIONS ON CEW CLINICS

As the penultimate section in the survey, fatigue in providing qualitative data appears in the brevity of many responses to the questions on CEW Clinics (CEWs). The fact CEWs remain an early pilot could also impact limited engagement. Responses were divided into pro-CEWs, anti-CEWs, and inapplicable.

Young people in both groups had a net positive perception of CEWs, however there was a marked difference between the weight and non-weight subgroups. Whilst similar numbers in both groups were anti-CEWs in general (i.e. they should not exist), the weight group were more likely to be anti-CEWs due to concerns about their execution, or pro-CEWs with caveats.

Where reasoning was given for positive viewpoints, this was often merely a few words, namely that they thought it was necessary and/or helpful for the service to exist. However, where both ‘for’ and ‘against’ responses went into detail, it was surrounding their concerns regarding the practice or framing of the clinics - these are grouped by theme regardless of whether they came from an individual who was overall pro-CEWs or overall anti-CEWs.



### NAME AND FRAMING

Several young people specifically responded to the name of the CEWs, and others both for and against the service also expressed concerns about the name and wider framing of the CEWs. A handful liked the name, suggesting it seemed non-stigmatising and medically accurate.

However, the majority of those who raised the name had negative perceptions, feeling it was stigmatising and could cause shame or embarrass a young person.

*‘I feel that the name “Complications of Excess Weight (CEW) Clinics” could sound quite negative or judgmental, especially for young people. Using words like “excess weight” and “complications” might make some feel ashamed, embarrassed, or singled out, which could stop them from wanting to get help. Many young people already struggle with body image and confidence, so the name could unintentionally make things harder. I think it would be better to have ... something that feels more positive and encouraging, like “Healthy Futures Clinic” or “Wellbeing and Nutrition Support Service.”’*

- A YOUNG PERSON WHO HAD NOT HAD A WEIGHT CONVERSATION

Respondents rarely went into depth about why this wording specifically was distressing, and only a few suggested alternatives. There was no consensus, but a suggestion to focus on health was common; indeed, this survey chose to avoid the word obesity due to its general dislike in community, but this was the exact alternative suggested by one respondent!

## APPROACH

Respondents had various concerns about the methodology of clinics, fearing that their approaches were either harmful, ineffective, or both.

There were often different perspectives around what diets actually lead to weight loss, but respondents believed calorie restriction was ineffective or had wider impacts on young people academically or when trying to engage in exercise that outweighed any benefit. Notably, one of the young people raising these concerns, as well as concerns about potential to induce disordered eating, was part of a local consultative group for a pilot CEW; the fact they felt the need to respond here and note may indicate they did not feel listened to during the consultative process.

*'I ... advised on the set up of [a CEW clinic]. I had big concerns regarding risks of eating disorders and carbohydrates are a really important energy source so can affect cognition, injuries and ability to participate in sport/daily activities.'*

- A YOUNG PERSON WHO DISCLOSED THEY HAD HAD CONVERSATIONS ABOUT WEIGHT

One of the most common concerns, often the only one a young person listed, was the proposed use of GLP-1s for under-18s. If they elaborated, they indicated they felt this was unsafe and unethical.

*'I think a weight loss program is good, but I don't think it should be pushed onto children & I don't think using medication to lose weight is a good idea no matter the person.'*

- A YOUNG PERSON WHO DISCLOSED THEY HAD HAD CONVERSATIONS ABOUT WEIGHT

Others had concerns around how young people would be referred to CEWs, fearing undue pressure or involuntary referral to the service. Some felt it should be a last resort for young people, and be fully medically justified, and others emphasised the need for young people (i.e. with Gillick competence) to have full autonomy over when it is raised and during the process to minimise potential harmful impacts they foresaw CEWs having. One person instead worried about the transition to adult services and missing out on the holistic approach of the service if they were referred as an older teen.

Finally, a respondent who was in favour of services raised frustrations with dietician services they have accessed in the NHS, who have been unable to offer suggestions for neurodivergent individuals with food sensitivities. Ideally, the holistic approach CEWs have should mean there is support for conditions like ARFID, but, given concerns around coerced referrals above, it is essential that this is not the only pathway for young people to access support with neurodivergence-related dietary issues.

*'Please take people's sensory needs into account. I have lots of sensory issues with food, and a lot of the time eating healthy just isn't an option for me. It's eating safe foods ... or nothing at all.'*

- A YOUNG PERSON WHO DISCLOSED THEY HAD HAD CONVERSATIONS ABOUT WEIGHT

## IMPACT

Many were concerned about the impacts of the framing and practices of CEWs, even if they thought the service was medically beneficial. Given that many expressed concerns about the name being stigmatising, it seems likely that young people envision there is a risk of these negative impacts from the moment the CEW clinics are mentioned to a young person.

Themes that emerged included exacerbating existing body image, shame, and self-esteem issues among young people, and the potential to exacerbate or cause eating disorders. Given documented issues around fat people accessing eating disorder support,<sup>8</sup> this fear is especially worthy of consideration - are there mitigations in place to prevent eating disorders, and are there care plans in place should an eating disorder emerge after care at CEWs?

Interestingly, those against CEWs as a concept in both subgroups tended to provide reasons relating to these potential impacts for young people, suggesting they felt these outweigh any potential benefits, if they believe there to be benefits at all.

*'While I understand the necessity ... I know many young people who have a difficult relationship with food, and I can struggle myself, for them even passing comments from GPs and other healthcare professionals have done far more bad than good. I would be nervous about how the patients would be treated and the rhetoric used without consideration of this.'*

- A YOUNG PERSON WHO HAD NOT HAD A WEIGHT CONVERSATION

*'This should not be accessible to anyone under the age of eighteen, at such a fundamental part of development, children should be taught how to eat in a way that listens to their body and is intuitive. I think this is a pipeline to a generation of disordered eating that will be difficult to come out of.'*

- A YOUNG PERSON WHO DISCLOSED THEY HAD HAD CONVERSATIONS ABOUT WEIGHT

*'I feel that the holistic approach focusing on diet, medication, and removing barriers is a beneficial way to run the clinics ... However, I feel that placing such a large focus on weight to young children may lead to unhealthy relationships with food and weight loss as they grow into adulthood. Additionally, the potential ability to dismiss health concerns as weight related may pose a barrier to treatment.'*

- A YOUNG PERSON WHO DISCLOSED THEY HAD HAD CONVERSATIONS ABOUT WEIGHT

all   
bodies  
ARE  
good  
bodies

<sup>8</sup> Harrop, E. N. et al. (2023) "You Don't Look Anorexic": Atypical Anorexia Patient Experiences of Weight Stigma in Medical Care. *Body Image* 46, 48–61.

## WEIGHT AND CEWS: RECOMMENDATIONS

### CO-PRODUCE TRAININGS FOR PRIMARY CARE PROVIDERS

In the National Youth Strategy, the government have committed to prioritising young people in future research. One focus area we'd recommend is to conduct co-creative qualitative research to research the impact of weight-related conversations and interventions in healthcare to develop training and guidance for healthcare professionals. This should centre young fat people and fat activists who may challenge existing assumptions in the NHS, and capture experiences at different intersections of marginalisation. It should go beyond the scope of ENHANCE by including people who have chosen not to engage with CEW Clinics and other weight management services, and aim to reach those who have avoided healthcare because of fatphobic experiences.

### WORK TO NORMALISE 'FAT', BUT MIRROR INDIVIDUAL LANGUAGE CHOICES

As fat activists have chosen to reclaim the term, any other alternative to 'obesity' the NHS might suggest will appear euphemistic or medicalised in these circles (and 'excess weight' was shown here to be an unsuccessful alternative among young people). Assuming a similar trend to disability activism, it will eventually become the dominant term to describe fatness. Normalising 'fat' in medical settings and daily life require major cultural shifts in how we talk about fatness in the NHS and wider society. However, this would align with recent changes that have de-medicalised language in NHS communications to be more accessible, and could precipitate an internal shift away from terminology intrinsically tied to BMI. Such a shift could also create more racially inclusive conversations about weight and health.

Whilst no consensus exists, there should be a focus on mirroring individuals' self-descriptors - to speak from lived experience, we are aware of where we sit on the BMI scale of obesity, and showing respect for our own language choices would be a step to building trust during weight-related interventions.

### CEW CLINIC REFERRAL GUIDANCE

Whilst CEWs exist, CEW Clinics should develop information leaflets and scripts for healthcare professionals who are introducing the concept to young people and carers. These should have neutral framing and provide contacts for support if the young person finds the conversation or information distressing.

Recommend that professionals provide no further prompting on the topic, to allow for the referral to be young person-initiated, either via an online portal or by restarting the conversation themselves.

### WAIT BEFORE YOU TALK ABOUT WEIGHT

In lieu of the full training recommended above, this acrostic is inspired by respondents and lived experience about how healthcare professionals should approach conversations about weight:

**W - Why are they here?** Is weight relevant? Is weight loss going to be helpful in the short-term for this health concern? Are they are likely to able to lose weight in the short-term with this concern?

**A - Are they already aware?** Are previous conversations noted in their records? Do they seem anxious or upset if you mention updating their height and weight information or try to pre-empt the conversation?

**I - Is this a good time?** Do they seem like they are in a good mental state? Do you know if they have a support system? Do you have resources ready that you can signpost them to if they become distressed?

**T - Talk and Timeline.** Talk about weight neutrally, avoid personal opinions or pithy maxims and tips. Provide a clear timeline for the earliest time weight might be raised by this service again (i.e. not their next appointment). Make a note of the conversation and the timeline in their records.

## YOUTH VOICE

- (1) Collaborate with young people on a 'communication protocol' to ensure every young voice gets heard
- (2) Think LEMUR when interacting with a young person
- (3) Expand current waiting well provisions for children and young people
- (4) Expand awareness, training and resources to tackle discrimination
- (5) Increase support for young carers and young people 'on the move'

What needs to be explored further?

- The experiences of young people in care or care leavers
- Specific research needed into how different 'groups' experience healthcare and what can be done to address this inequality

## TRAUMA

There is an urgent need to explore the experiences young women have in healthcare settings and tackle gender based inequalities in care

Collaborate with young people to further explore the causes of medical trauma and co-design initiatives addressing them

Integrate lived experience within service design so there is an increased understanding of how trauma impacts young people, how it affects them accessing healthcare and how healthcare services can be improved to provide better support for young people following a traumatic event.

## WEIGHT

- (1) Work to normalise 'fat', but mirror individual language choices whilst no consensus on terminology exists
- (2) CEW Clinics need to create guidance for referrals to ensure conversations are non-pressured and neutral, with leaflets for young people and their carers so they access unfiltered information on the Clinics.
- (3) WAIT Before You Talk About Weight

What needs to be explored further?

- Co-produce qualitative research on the impact of conversations around fatness in the NHS, with fat young people and fat advocates. Capture intersectional experiences across race, gender, and disability.
- Use this to develop training and guidance to improve experiences in the NHS.

The 2023 'You're welcome' standards aimed to improve the quality of and access to healthcare services for children and young people. Our report has demonstrated that there is still significant work to be done to ensure these standards are achieved and most importantly that young people feel the benefit of them. The standards include criteria on ensuring young people are involved in their care, obtaining consent, making young people feel welcome and expanding training with a focus on 'cultural competence, consent and communicating'.

Despite this, the young people who shared their stories with us told us that; they didn't feel heard in healthcare settings, their continued to be issues around consent, particularly with medical students, and inequalities in treatment was raised as a core issue with young people asking for NHS staff to have more awareness on how to communicate with them and how health issues present in different bodies. Our research aimed to not just understand the challenges young people are facing but also to understand what solutions they would like to see implemented. Therefore, we hope the recommendations outlined in this report can be used as a step forward to implementing co - created solutions to the systemic barriers young people face to accessing healthcare.

The fact some of the recommendations set out in this report echo those set out nearly 3 years ago demonstrates that something is not working. We would like this report to be a call to action for policymakers that change is needed. Young people don't feel listened to in healthcare spaces. There are unfair inequalities in care. Creating healthcare services that young people feel confident accessing and fully listened to in is imperative, not just for preventing the multitude of adverse affects on a young persons life but also ensuring that a generation of young people don't grow up with a deep mistrust of the services that should be their to help them.

For more information about the NHS Youth Forum and Young Researchers, visit  
<https://www.barnardos.org.uk/nhs-youthforum> or email us at [NHSYouthForum@Barnardos.org.uk](mailto:NHSYouthForum@Barnardos.org.uk)

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