

# What we are hearing

Quarterly Report: January-March 2025



# Contents

Content warning: contains reference to mental ill-health, breakdown, trauma, self-harm, suicide and suicidal ideation, anxiety, distress, struggles with daily living, family breakdown.

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Key: Compliments in own words – no background, speech bubbles 3<sup>rd</sup> party reported compliments – green background 3<sup>rd</sup> party reported negative feedback – pink background Concerns and complaints in own words – blue background

Cover photo by Healthwatch York

# Introduction

### What we do

Healthwatch York is your way to influence local health and social care services – hospitals, care homes, GP surgeries, dentists, pharmacies, home care services and many others. We make sure your voices are heard by those who buy and deliver local health and care services.

Healthwatch York:

- Provides information about local services to make sure you know how to access the help you need
- Signposts you to independent complaints advocacy if you need support to complain about a service you have received
- Listens to your views about local services and makes sure these are taken into account when services are planned and delivered

Every month we hear from people across York about your experiences of local health and care services. Where requested, we signpost and / or provide helpful information about their options. We share what we hear anonymously with the people who buy and deliver those services.

### **This Report**

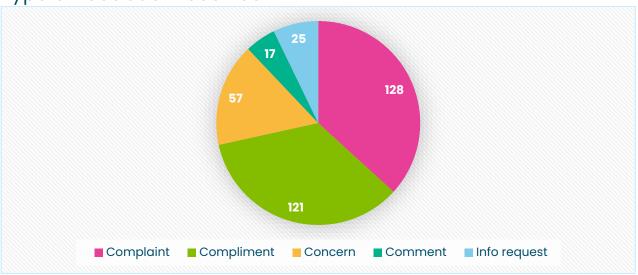
We have put this report together based on what you have shared with us in the 3 months from 1 January to 31 March 2025. This report gives a flavour of the issues and themes this quarter.

The service areas highlighted in this report are as follows:

- Hospital services
- GP services
- Mental health services
- Social care services
- Dental services
- Neurodiversity support

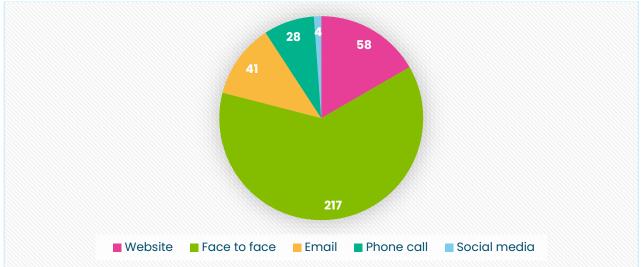
# **Overview of contacts received**

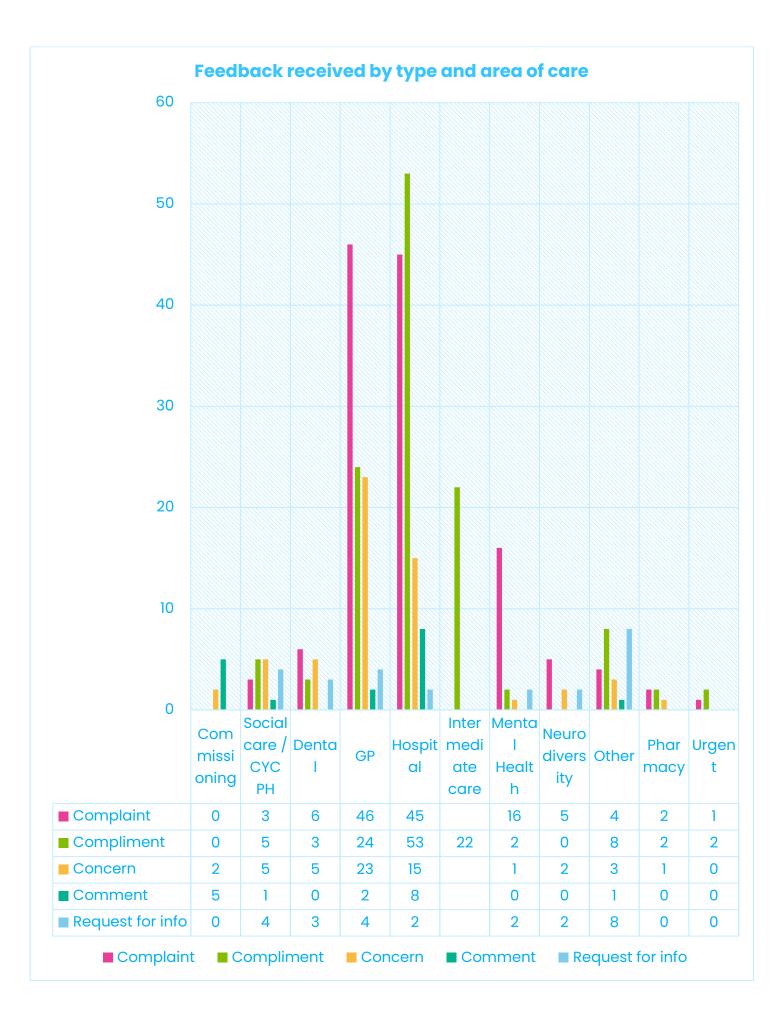
From January to the end of March 2025 348 people contacted us directly to ask for information / advice or share their feedback.



Type of feedback received

#### Contacted by





# Key themes by area of care

# Hospital

We received 53 compliments about hospital care.

I went for a colonoscopy last week after doing a bowel screening test at home. The whole process from getting the testing kit to the follow up after the colonoscopy was fantastic. The speed was good and the way it was handled was outstanding. The hospital staff were caring and informative.

> I have type 2 diabetes and moved from the south here in 2011. I have had wonderful care and support. I think if I'd stayed in the south I would have lost my sight by now.

I lost partial vision suddenly in my left eye. I was referred urgently by my optometrist to York hospital. I was contacted less than 30 minutes after he sent the request, seen about 45 minutes after that and had thorough scans and eye tests and saw the consultant. Out in two hours. Everyone was kind and

professional and explained clearly what they were doing. Though the waiting areas were fairly crowded they took the time needed and didn't rush. I am so thankful every day for our NHS (especially after having lived in the US for 30 years.)

Themes from compliments included:

- Shorter waiting times than expected
- High quality care
- Excellent, caring staff

We also received 45 complaints, 15 concerns, 8 comments and 2 requests for information. Within these the key themes were:

- Poor attitudes to people with a history of addiction
- Long waiting times
- Administrative problems with booking appointments
- Concerns about staffing levels and quality of care
- Lack of information on discharge about what happens next

### Personal Story: "If this could be cancer..."

My daughter, who is 35, was referred by her GP to the hospital as she had some issues. An MRI found that there is something on her pancreas and a possible lesion on her liver. Cancer has been mentioned, but the hospital has refused to refer her to Leeds for a biopsy (which can't be done in York). They said that she needs to lose weight and stop smoking first. But if this could be cancer, surely they should be doing the biopsy as soon as possible. The GP challenged the hospital's decision, but she is still waiting in January after the MRI in November. The last time we heard she was on a two week fast track referral but nothing has happened. She is still in a lot of pain and is very worried.

### Personal Story: "Just something they have to do."

My mother-in-law has had a stroke. The hospital ward wasn't great as the staff are very abrupt and didn't treat her like a person, just something they have to do.

### Personal Story: "I have a lot of questions."

Generally I have had good experiences of the hospital. But recently I was sent to A&E with a heart problem. It took 10 hours for me to be seen. I wouldn't have minded so much, but the chairs in A&E are very uncomfortable. The doctor I saw was good, and they referred me to a cardiologist, but there is a 52-week wait for that. The doctor sent me a letter to say I have a furred left ventricle. I have a lot of questions about this and what it means for other medications etc. But I only got a letter with no information about what to do if I have questions or concerns. It would have been a lot better if they had rung up or told me who I can ring for advice.

### Personal Story: "So degrading and awful."

I had to go to A&E last week. I had been vomiting for four days and had started to vomit blood. They treated me like I had leprosy. I was left sitting on a chair for 14 hours without any pain relief or anything. I was then admitted and was in hospital for six days. It is so degrading and awful how they treat me. I hate going and never want to go to the hospital again. But I know I have to as I have a number of conditions (acute pancreatitis, liver problems and right kidney isn't working properly). Just because I was an addict and have had problems, they treat me differently to other people and don't treat me like a human. I know I need to go back for tests, but I can't face it.

#### Personal Story: "Worsening month by month."

It is now a year since I was referred to Neurology and still no outpatient appointment. Meanwhile my symptoms are worsening month by month.

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## **GP Services**

There were 24 compliments for GPs and GP practices.

My mum needed to see a GP. I called the practice and there wasn't an appointment that day (Friday) but they arranged for her to go in on Saturday. The GP was really good. They took time to listen to the problems and said to go for a blood test. After they got the blood test results they rang to explain the problems and to prescribe steroids which we collected from the local chemist. They were great. In fact they have always been excellent.

My GP is excellent and goes over and above. I have complex health conditions and a few times I've had an appointment and they've said to follow up in a few days, then the GP calls that or the next day to say they've been thinking and they want to arrange a test or something. It really makes me feel they care. Also I had one appointment and mentioned the condition. The GP asked if they could book another appointment the next day instead to

give them time to read up about the condition so they felt more prepared. I offered to talk them through it, but they said they wanted to look into it. I was so reassured and it gave me so much confidence in them and the care I was getting. I can't fault the practice.

> I had pancreatitis which led to me becoming a diabetic. I then had a bout of gastro enteritis. I wanted to know if I should keep taking the Metaformin or not. I rang the GP practice and explained that I just needed a quick answer. They took the details and a GP rang me within five minutes. They said to stop taking the Metaformin and start again when I'd kept

some water down for half a day. It was exactly the answer I needed and was really quick. They are a great GP practice and I've always had a good service.

Themes from compliments included:

- Fast, effective diagnosis and ongoing support
- Warm, caring staff
- Able to get appointments as needed

We also received 46 complaints, 23 concerns, 2 comments and 4 requests for information. Within these the key themes are:

- Transport issues for patients of multi-site practices
- Difficulties with making appointments, including challenges with the online form
- Problems with repeat prescriptions
- Concerns about delays to diagnosis and lack of information at point of diagnosis

### Personal Story: "Your life in the hands of some admin failures."

I have a repeat prescription that I request online. And some issues that I need to investigate. A couple of weeks ago I went to collect my meds only to be told my doctor wants a review. Thinking that's my way in I ask for an appointment since I have a few other problems. Receptionist says I have to fill in the online form... Problem is that I work full time long days. When I get home to fill in the form it is always disabled and says it will come back next day in the morning. No wonder they post messages that they experience a high volume of urgent appointments. I wish I'd change GP but I have a feeling that they are all the same now. Very disappointing. And very disturbing having your life in the hands of some admin failures.



### Personal Story: "Not really feasible."

Every time I get a face to face appointment it is at {name of} surgery which is only accessible from {area of York} by public transport by taking a bus into town and a bus out to {area} which takes over an hour and is not really feasible if you're unwell. I have friends who need weekly dressings and who have to get to {area} as there is no nurse at {area} to do it which seems madness considering the aging population in the village. Surely they could send a nurse for a couple of hours a week.?

### Personal Story: "She can't get past the receptionist."

My mother, 92, has had one knee replacement (14 years ago) and could do with another. Consequently her mobility is much reduced leaving her unable to walk far. She needs to see the GP to talk about her knee and mobility but cannot get an appointment - she can't get past the receptionist! So she can't get a Disabled sticker for a supporter's car and she may be missing out on benefits because she needs to see the doctor to get a diagnosis.

#### Personal Story: "Wish they'd taken it more seriously sooner."

I went to the GP a number of times with something on my skin on my forehead. They kept saying it was a wart and giving me things to treat it with. However, I eventually was referred to the hospital. And it was a nasty skin cancer that needed an operation to remove. I really wish they'd taken it more seriously sooner. I'm still here but I was very worried.

### Personal Story: "That was it."

I was diagnosed with haemochromatosis late last year. It is a genetic condition and I went to the GP after my mum had been diagnosed to see if I had it. Initially I had a test and was called back to go for a genetic test. After the first test the doctor asked me if I knew about the condition. I said I'd Googled it and he left it at that. Then after the genetic test when he called back he was on the phone for 32 seconds to tell me that I had the two genes and so had the condition. He then said he'd made an urgent referral to the specialist and that was it. This is a life changing longterm condition and at no point did he explain anything about it. One element of the condition is that you shouldn't drink alcohol, but he didn't tell me that. Neither did he tell me how long the referral would take (I still haven't heard and it is January). At one of my mum's appointments with the same GP she mentioned that I was worried, but he said I shouldn't be as they'd caught it early. But he didn't tell me that. I am very disappointed.

#### Personal Story: "It is not possible."

My husband is 89 and had a call from the GP to say he needs to do his blood pressure and have a blood test. They said they can no longer do blood tests as they aren't being paid to do it. So my husband has to go to the Community Stadium, hospital or Askham Bar. For someone who is not very mobile and needs to use public transport it is not possible. When he said this, they just asked if someone can drive him to Askham Bar! There needs to be an option for someone who can't go to the other venues. My husband won't be the only one. In fact my friend's mum, who is 92, was told the same and her daughter has to take her. They should know from a person's notes what is and isn't possible.

## **Mental Health services**

We received 2 compliments about mental health care.

I have had mental ill health for a long time and have had good support from the NHS and other organisations. I found horse therapy particularly good.

We received 16 complaints, 1 concerns, and 2 requests for information. Within these the key themes were:

- Dismissive attitudes from staff
- Difficulties getting access to the right care and support
- Concerns about care not being trauma-informed
- Long waiting times for support
- Administrative challenges and poorly written reports

### Personal Story: "I cannot take much more."

I just wanted to let you know that I am still having serious problems with the crisis team and CMHT. All day today I have been on and off the phone to the crisis team I called 111 and spoke to a lovely man. He put me through to the crisis team this was about 1pm. I spoke to a lady in the crisis team and told her I did not want to be here anymore and that I had plans to end my life and she said because it was before 5pm I needed to contact the CMHT so she had asked them to phone. {Woman} from the CMHT did eventually call about 2pm and I told her how I felt she said she would go away and speak to the rest of the team and get back to me, I heard nothing until about 4pm when another lady called me and she said that because it was nearly 5pm I needed to go to the Haven. I have called the crisis team again just now and told them I cannot take much more and the crisis team have said they cannot help etc. when I have asked about being referred to the home treatment team that gets refused. The CMHT are still offering me no proper help for my CPTSD even though I am having nightmares on a night and cannot sleep. I give up even asking for help anymore. Earlier I had messaged my mum and told her I was going to go and jump off a bridge she found me, but she sent that message over to the manager in CMHT and all the CMHT said was "I'm glad you found her." I do not know what I need to do to ask for help from anyone anymore.

### Personal Story: "Awful."

The only thing Orca House does well is breaking promises. They don't care what happens to the families in their care just as long as they don't actually have to follow anything up or God forbid do some paperwork. After nagging daily for four months, I finally got a letter I'd requested and it wasn't even basic English. It was clearly just a bunch of copy/pasted phrases and half weren't even relevant to the child. I sent it back and asked them to proof read it and they changed one sentence. One! I need to submit this with legal documents and my five year old would have done a better job. Absolutely disgusted with the whole system. It's a joke and the kids that desperately need the care it supposedly offers are absolutely screwed.

#### Personal Story: "Only advice was to have a bath."

I was in the homeless hostel having just come out of Foss Park. I was at my worst time for my mental health and contacted the CMHT saying that I had been harming myself and was thinking of taking my life. They suggested I should have a bath. It was awful and no help at all. You have to be at death's door to get any help.

### Personal Story: "Staff need much better training."

I went to the GP as I was having mental health issues {Spring 2024}. They referred me to trauma therapy (EMDR). I had an assessment from a mental health team who agreed that would be the best treatment but there was a waiting list of six months. In October I hadn't heard anything and my trauma issues had increased, so I contacted my GP again. They said they'd chase up the referral. I got a letter as I'd changed my phone number to explain I was on the waiting list. I rang them to give them my new number.

Then I got a phone call from a withheld number. Because of my history I find withheld numbers triggering (my abusive partner used to use a withheld number to call me). I did some breathing exercises and did answer the phone. I explained to the person on the phone but they just said 'at least you answered, most people don't answer the call'. They then went on to tell me that there was a long waiting list but that other people also needed help and made me feel quite worthless.

So I was still on the waiting list and they offered online support. I said I didn't want that and was quite short as I was struggling. After the call, I felt bad and rang back to apologise. The receptionist was helpful but said that he didn't know who I spoke to but would ask the team and pass on my message. He then rang back with a very different tone to say he'd passed the message on.

I do feel that the staff need much better training about dealing with people who need mental health support. Also if they are going to call on a withheld number, they should put that in a letter or text message to explain and say when they will ring. Then people can prepare. Or if that isn't possible, they need to find a way to let us know who is calling or have a code, so call with three rings and then ring back so people know who it is. It should not be the case that their contact triggers people who already have issues.

## Dentistry

We received 3 compliments about dental care.

Recently visited and have joined their affordable plan. My dentist was really patient with me and took time to explain things. I then booked to have a filling and from start to finish the procedure was painless and comfortable. The front of house team is attentive and supportive and went the extra mile

to accommodate my appointment with urgency. Very pleased with my moved to this practice.

We received 6 complaints, 5 concerns and 3 information requests.

Within these the key themes are:

- Lack of NHS dentists in the city
- Unaffordable costs of private care
- Challenges accessing care for potentially vulnerable groups and individuals

#### Personal Story: "No NHS Dentists."

No dentists apart from one taking new patients in York, meaning no access to an NHS dentist for a majority of pregnant people for example which is my case and can't wait several years as the maternity exemption certificate expires in one year and nine months.

## Personal Story: "Appalled at this situation."

My daughter (17) fell and broke her front tooth and the other is now wobbly. I managed to get an emergency appointment for her via NHS 111 but they said they can't do any further work, but that work is needed. My dentist retired, and while the practice is still doing NHS treatment, they said there is no room for me and my daughter with the NHS dentists. It is so frustrating. I have found another dentist who will take my daughter on, but only for the two months until she is 18. But she will need someone to check what is happening with her teeth. I have worked in the NHS for 50 years and am appalled at this situation. I went to [name of practice] this morning as I'd heard a dentist there was taking NHS patients. The receptionist basically laughed at me and said those places were filled really quickly as they'd had a queue outside when people found out.

### Personal Story: "Taken me 13.5 years."

I have been trying to get an NHS dentist and it has taken me 13.5 years for me and my son. He has only seen a dentist twice in his 14 year old life so far. Thankfully a new dentist has opened and we have got on the books. I haven't been yet, so can't comment on whether it is good or bad, I am just relieved to be seeing someone.

#### Personal Story: "I could not have afforded it."

I am on Universal Credit and have had a lot of problems with my teeth. It got so bad I had to go private and the treatment cost £125. Thankfully a friend paid for me as I could not have afforded it. I just can't get an NHS dentist in York.

## "Desperate to find somewhere that will help."

Person has very loose upper dentures which will only stay in place for two hours at most. They have tried 20 dentists in and around York, but none are taking on new NHS patients. She is bipolar and the issues with her dentures are triggering her mental health issues. She is desperate to find somewhere that will help.

## **Social care services**

We received 5 compliments about social care.

My mum was really struggling, but two and a half weeks ago she went into York Manor Care Home. It is lovely and she is settling in well. The staff are great. It is such a weight off my mind as I know she is being looked after very well and is happy. Before I had to go round almost every day and was never sure what I would find. Now I can visit, and have quality time with her as I know she will be OK.

We received 3 complaints and 5 concerns. We also received 4 information requests and 1 comment. Key themes from these include:

- People looking for information about dementia support
- Lack of clarity around finances and financial assessments
- Difficulties resolving concerns about care

### Personal Story: "Someone else will suffer if I have a wash."

I have just developed metastatic breast cancer which is affecting my ability to use my arms and dress myself. I was referred by my local council to a care agency and I knew something was wrong the moment I met the first member of staff. They all avoid eye contact. None of them introduce themselves. The agency runs care homes as well as provides home care. This is supposed to be a palliative care package that can function if I become unable to express myself or communicate. The first woman who came in didn't know how to operate a bath lift. And she was asking if a rail to hang a towel on was a coat hook.

Then my assigned carer came. She was really good but very disconnected and I couldn't understand why. She looked panicked all the

time. She kept saying "I've got to get everyone out of bed!!" The second time she came the slot was one hour for me to have a bath and change of clothes. She told me that if she stayed for the hour then somebody would not be got out of bed until 11.15am. I felt ashamed to ask for her to stay for the hour even though this is my care contract and the council has paid for them to do an hour. Every day this woman has to get these people out of bed late and it clearly upsets her.

It really upset me that my first experience of social care for people with terminal cancer was to be made to feel guilty about asking someone to help me change my clothes and wash me. I was visualising someone in agony because of me whilst I soak in my bath. That's why I couldn't do the bath. I already feel bad about asking people to help with personal care. Being openly told someone else will suffer if I have a wash was just bloody awful. She said she was in this great rush and so late but then she stood in my kitchen for 15 minutes filling out an online form saying that I refused the wash. By the time she left she could have done the wash.

### "His quality of life is very limited..."

Person is very concerned about a person with a learning difficulty who is in shared housing with a care provider. They are a man in their 20s or 30s and shares a house (with care) with a 60 year old woman with Down's Syndrome and possible dementia. There is one to two carers for them, but this often means the woman gets the majority, if not all the care, and the man mostly stays in his room. His often doesn't want to go home and spends most of his time in his room. Despite raising concerns, nothing has happened and the person is concerned for the man's long term health and feels he would be much better either living with someone else or on his own.

## **Neurodiversity support**

We received no compliments about neurodiversity support.

We received 5 complaints and 2 concerns. We also received 2 information requests. Key themes from these include:

- Long waiting times for accessing diagnosis
- Challenges in accessing education due to health issues
- Concerns about transitions from children's services to services for adults
- Lack of multi-agency working for those with the most complex needs

# Personal stories: "He is struggling and I am struggling...but there's nothing"

My son is 26 and has a number of mental health issues. We also think he is autistic, but he hasn't got a diagnosis. He has had contact with TEWV and the crisis team. But they have discharged him and said he is too difficult for them to help. They said they think he is autistic, but haven't done anything about it. Last year the police said they would refer him to safeguarding because he was groomed in the past, but nothing happened. Every time he is sectioned we have a meeting. They see that he is struggling and I am struggling and they say we need support. But nothing ever happens and there is nothing. I know he can be hard work, but there is no-one to help us. He often talks about taking his own life. Once he rang the crisis team and spoke for an hour to a woman who was good and talked about everything he needed, but then nothing happened or he was offered something online, but he can't do things online. He needs one-toone help and someone who will take the time to understand him and help him get the support he needs, but there isn't anyone willing to do this. Our GP has been very helpful, but there is a limit to what they can do.

### Personal Story: "All shared care agreements are being stopped."

I wondered if any collective action was being taken in relation to the removal of all shared care agreements by Humber and North Yorkshire ICB for ADHD review and medication. My issue concerns all adults who already have a diagnosis of ADHD completed by a private psychiatrist. The GP then entered into a shared care agreement where you have your annual review with the psychiatrist. My son and I have now been informed that all shared care agreements are being stopped and there is the option to remain on a private pathway (and pay for all medication yourself – I can't afford this) or to be referred to The Retreat for medication reviews. I have contacted the Retreat and understand that the waiting list for medication reviews is 18 to 24 months. Meaning that the integrity of the annual review will not be met and GPs then may not continue to prescribe.

#### Personal Story: "Basically there was no support."

My daughter is 19. She is autistic and has an EHC plan. She is studying and had been doing well, but her mental health has deteriorated as it has taken a long time for her to get any adult mental health support. There was a large struggle to get any support when she transitioned to adult services. Basically there was no support. She did have a social care assessment, but it took six months for me to get a copy and they said they can't get involved until the mental health team has done its work. I would really like to see a case coordinator involved for young people transitioning to adult services. There should be a case conference when a young person is 15 with everyone involved to look at what needs to happen over the next five years. That doesn't happen. There are annual reviews but we, as parents, have to push for people to be there and things to happen. When I asked about case coordination, I was told that lots of people are involved. But that is the problem, there needs to be someone with an overview who looks at someone's needs holistically. That isn't happening.

### Personal Story: "They couldn't help."

My daughter is 11 and really struggled in lockdown. She managed to go back to school for most of year 5, but only managed a few days in year 6 when she wouldn't go to school and then wouldn't leave the house. She has been diagnosed as autistic (privately) and was referred to CAMHS. They assessed and discharged her. They said that all they could offer was talking therapies and as she didn't speak in the assessment, they couldn't help. They thought the school could help, but they couldn't and she won't go to school. One of the significant problems is that any intervention is far too late. So I did manage to get an EHCP and she was referred to {a specialist unit within a mainstream school} but at best she will engage for between 5 and 45 minutes. If this had been available before, maybe she would have been able to continue going to school. But by the time she went she had been out of school for at least a year when she wasn't interacting. The help needs to come when the struggles start, not years later. I have had to give up work and it is all taking its toll on me. I am on a waiting list for counselling.

#### Personal Story: "I don't know what is happening."

I saw my GP in 2021 and they got me to fill in a form to see if I should be sent for an autism assessment. I did and as far as I know I was referred. Then the same in 2022 for ADHD. But I have never heard anything back. I don't know what is happening. The process is not transparent. I have contacted the Retreat by email and gone there twice and no-one can tell me if I'm on the waiting list and where I am. I need these assessments so I can get on with my life. It is an awful situation



# Things we're aware of

Through the feedback we've received recently, we are aware of:

- People waiting for social care support
- Support and services for people living with long Covid
- Concerns around support available for people with ME / Chronic Fatigue
- Difficulties accessing HRT and other menopause support for those experiencing early menopause
- Long waiting times for assessments for ADHD and autism
- Long waits for hospital care

We welcome your feedback on all aspects of health and care but would particularly love to hear from you about your experiences of any of these themes.

# **Recent Reports**

We have recently relaunched our Care Home Assessor programme. We have now published four reports:

Ebor Court: <u>https://bit.ly/EborCourt25</u> Birchlands: <u>https://bit.ly/Birchlands25</u> Riverside Care Complex: <u>https://bit.ly/RiversideCC25</u> Rawcliffe Manor: <u>https://bit.ly/RawcliffeM25</u>

And we'd love to hear from you if you have any feedback about care homes in our city.

# **Current surveys and consultations**

## **National surveys**

### NHS England – Mental Health Crisis Care 111 survey

Have you accessed mental health crisis care via the NHS 111 mental health service?

If you have used the service, NHS England would like to hear your feedback about your experiences and the support you received. This will help them to identify areas for improvement and ensure that the service is meeting the needs of people in crisis and providing the highest quality of care.

If you would like to take part, please visit this website to take the survey:

https://www.engage.england.nhs.uk/survey/1d60f9bb/consultation/in tro/

If you require an alternative format of this survey, please contact <u>england.adultmh@nhs.net</u>. The survey closes 15 July 2025.

# Why we do this

We believe that the best health and care services put people at the heart of their work. We put this report together to help local services hear more about your experiences of health and care in our city, and can use this to help shape what they do next.

We also want to encourage more people to speak up about their experiences, whether good or bad. It is important to celebrate those providing excellent care. It is also important to highlight what could be improved – when we share what doesn't work, we provide those delivering and buying care with an opportunity to make services better.

This report also gives more insight into the work we do through our signposting, information and advice service. This service exists to:

- help people find out about services and support available to them
- provide information that can help people understand their options and make decisions about health and care
- provide a listening ear to anyone who has had a difficult experience

We hope you find this report of interest, and please get in touch if there is anything we can help you with.

## healthwatch York

Healthwatch York Priory Street Centre 15 Priory Street York YO1 6ET

www.healthwatchyork.co.uk t: 01904 621133 e: healthwatch@yorkcvs.org.uk I @healthwatchyork f Facebook.com/HealthwatchYork