What we heard in 2025

healthwatch
York

Contents

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

Key: Compliments in own words – no background, speech bubbles

3rd party reported compliments – green background

3rd party reported negative feedback – pink background

Concerns and complaints in own words – blue background

Cover photo of part of the Snook trail by a member of the Healthwatch York team

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 day 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

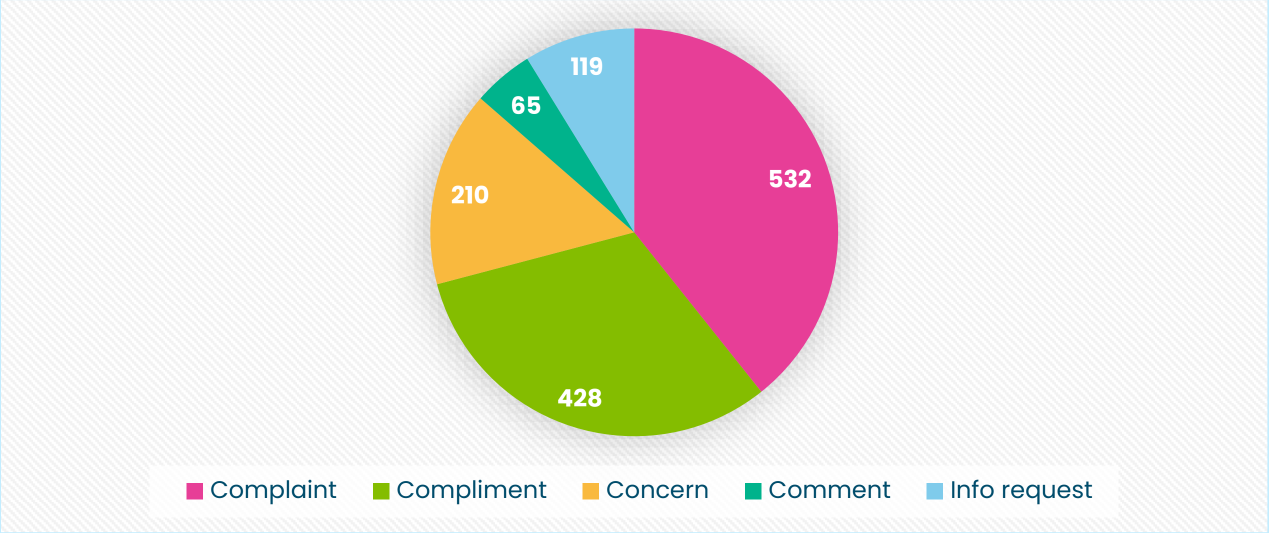
We have put this report together based on what you have shared with us from 1 January to 30 December 2025. This report gives a flavour of the issues and themes we have heard this year. The service areas highlighted in this report are as follows:

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

Overview of contacts received

From January to the end of December 2025 **1354** people contacted us directly to ask for information / advice or share their feedback.

Type of feedback received



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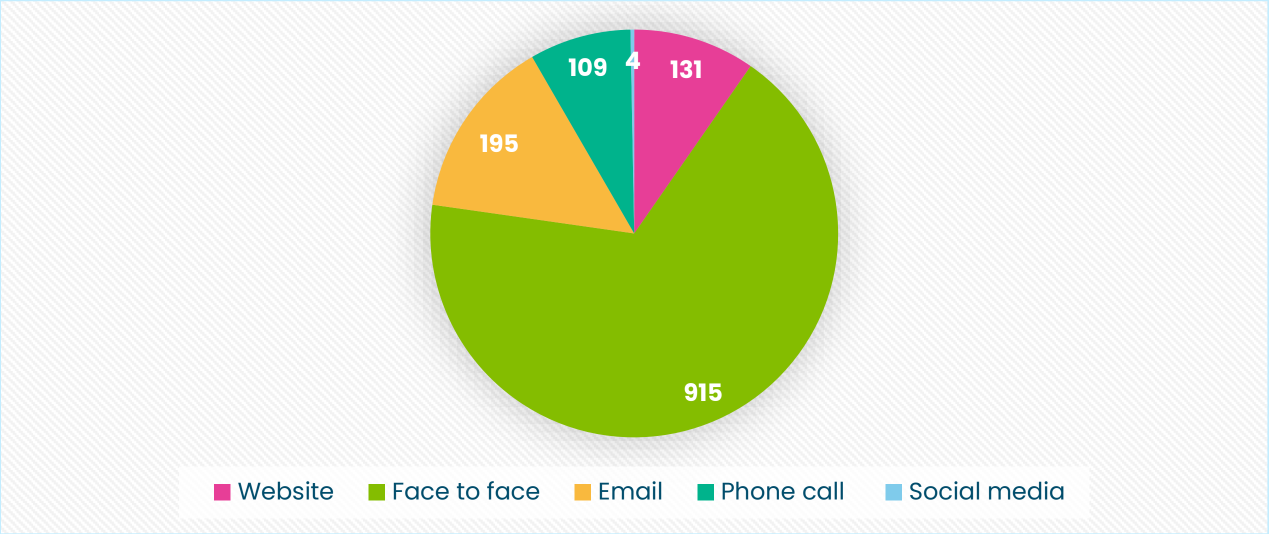
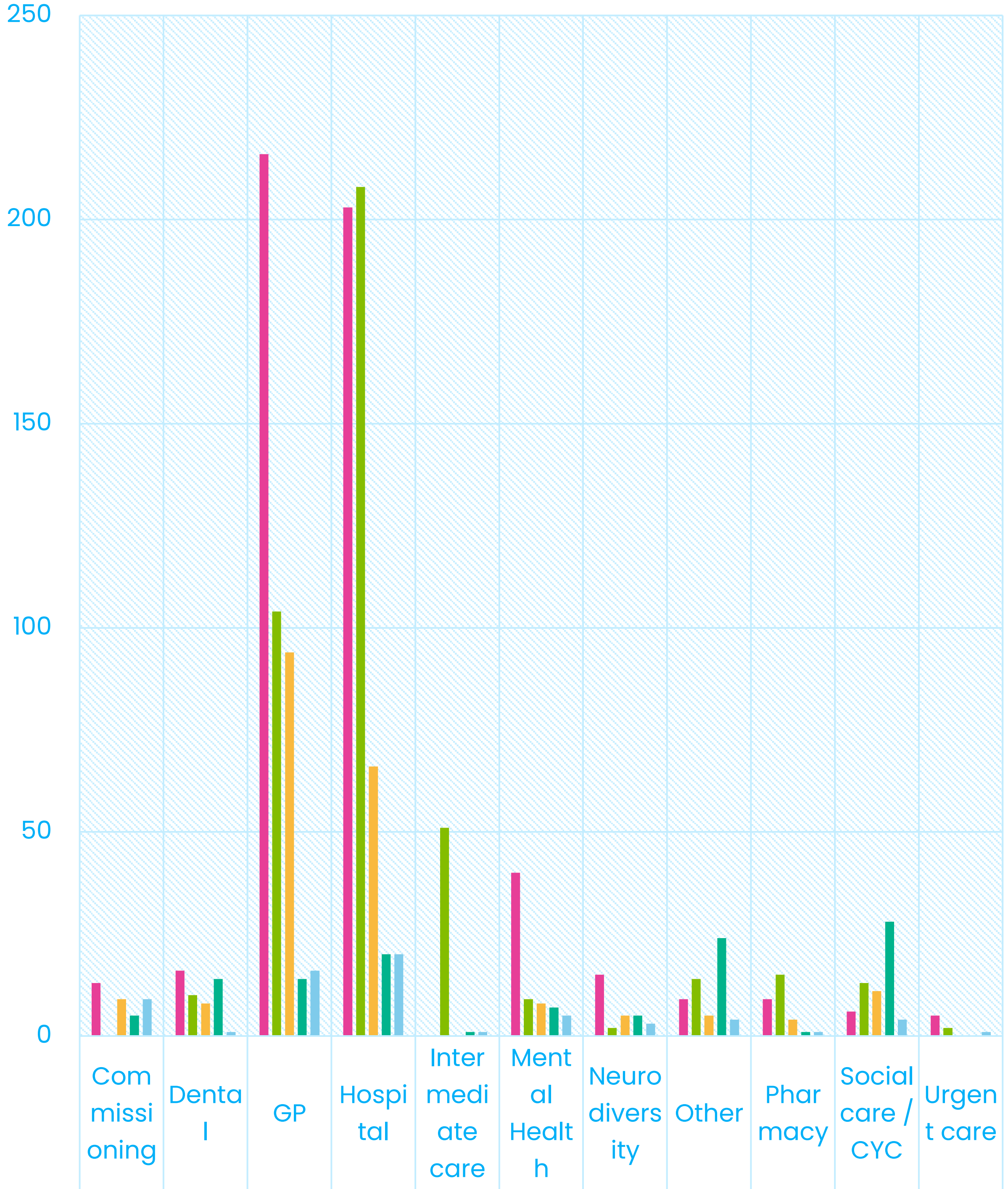


Feedback received by type and area of care



	Commissioning	Dental	GP	Hospital	Intermediate care	Mental Health	Neurodiversity	Other	Pharmacy	Social care / CYC	Urgent care
■ Complaint	13	16	216	203	0	40	15	9	9	6	5
■ Compliment	0	10	104	208	51	9	2	14	15	13	2
■ Concern	9	8	94	66	0	8	5	5	4	11	0
■ Request for info	5	14	14	20	1	7	5	24	1	28	0
■ Comment	9	1	16	20	1	5	3	4	1	4	1

■ Complaint ■ Compliment ■ Concern ■ Request for info ■ Comment

Key themes by area of care

Hospital

We received 208 compliments about hospital care.

> My dad fell and damaged his arm. He was in quite a lot of pain and so went to A&E. While it was very full and said there was a four-hour wait, he was seen within 35 minutes, sent for an x-ray (which was also very quick as there wasn't a queue), seen by a doctor and given a splint. The whole visit took less than an hour and a half including a second opinion as one doctor wasn't sure if there was a hairline fracture and wanted to check with a colleague. It was brilliant. All the staff, including those on the desk, were lovely.

> I have been in touch with the Autism Liaison Service at the hospital about a forthcoming operation. They are fab. They helped me to do a health passport. They have helped me to find out where I am on the waiting list for the surgery and made sure that the person doing my pre-op saw my passport and so met my reasonable adjustments. The person for the pre-op said it was the first time they had seen that kind of passport. They are also going to talk to the staff on the ward I will be on after my operation. They have been brilliant.

> I have type 2 diabetes and moved here from the south 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.

> Excellent birth experience. The whole experience from start to finish was amazing. The staff on labour ward, G2 and the room where I got induced were unbelievable. They couldn't do enough for you, every step they made sure you were okay and your needs came first.

Themes from compliments included:

- Excellent compassionate care, particularly from A&E, the day care unit, the Magnolia Centre and the eye clinic.
- Being seen and treated quicker than expected.
- Clear communication including good explanations of treatment needed and any follow up required.

We also received 203 complaints, 66 concerns, 20 comments and 20 requests for information. Within these the key themes were:

- Communication problems including failure to make reasonable adjustments.
- Unsafe discharge
- Lack of holistic care where people have more than one long term condition.
- Concerns about the lack of support for particular health conditions including ME/CFS, PoTS, hEDS.
- Poor staff attitudes and stigmatising behaviour.

Personal Story: "Interpreting tablets don't work."

I have been to the hospital many times and often they can't find the interpreting tablets or they don't work as the wifi is not good enough. I ask for an interpreter, they say they will book one, but lots of times I get there and there is no interpreter.

Personal Story: "Given the wrong antibiotics."

I was admitted to hospital with bronchitis. My medical notes stated that I was allergic to a particular antibiotic, but I was given that antibiotic and I nearly died. It was extremely frightening for me and my partner and I still have flashbacks.

Personal Story: "No scan results for five months."

I had an MRI scan in July about my heart and possible worsening heart failure. I still haven't had the results. When I had the scan they said it could take eight to ten weeks for the results, but they weren't sure. I rang my consultant's secretary last week and they said they'd had the scan since mid September and she would arrange for an appointment for me next year. But my anxiety levels are higher than ever while I am waiting. I have always had anxiety but this is something else. I've gone to my GP for help and seen the mental health worker but now I can't even face that as I just want my scan results.

Personal Story: "Reception staff are not well trained."

When I went to A&E the receptionist challenged me saying I should have gone to my GP. I had a ruptured appendix which required an operation the same day. The receptionist was lacking understanding, kindness and compassion. They need better training.

Personal Story: "Very blunt consultant was not helpful."

I went to the hospital for an appointment with a neurologist as I had been wobbly. He told me to walk up and down, which I did. He then told me I had epilepsy. He asked how I had got to the hospital and said if I'd come by car, I could not drive home or drive again as I was a danger to others. I was really shocked by this and by the way he told me. There was no softness. Thankfully my wife had come to the hospital and could drive me home. But it took me a while to come to terms with having the condition and also the way I was told.

Personal Story: "It is the worst hospital in the country."

My friend was taken by ambulance to York Hospital. She waited for 13 hours in A&E but she didn't want to wait any more, so went home. Soon after getting home she was worse and called an ambulance again. She died in the ambulance on the way back to hospital. It is awful.

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: “No treatment for PoTS.”

I spoke to my Cardiologist today, and he basically said that York hospital can't treat PoTS patients. He said his guidance hasn't really been clear, he is being told he can see them but not treat them which feels wrong for him, and it is, obviously. He said the closest place is Sheffield but they are refusing to take his patients. So it seems York Hospital feels like there are too many PoTS patients but it seems to me an opportunity to expand that service not take it away...when they have a very enthusiastic PoTS specialist. It's not our fault that we are a drain on their service, but the treatment makes a huge difference to our functioning levels and our level of disability which is obviously a good thing for us and the country.

Personal Story: “If this could be cancer...”

My daughter 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: “No interpreter in A&E.”

Last week my friend was in a lot of pain and I went with him to A&E. On arrival we explained that we are both deaf and needed an interpreter. We were waiting nine hours and never got an interpreter. It was a waste of time. No one even tried to help.

Personal Story: "Poor care after emergency."

My father had a large bleed in the brain. He was transferred from York A&E to Hull for emergency surgery. He spent 26 days in ICU and neuro ward before being transferred back to York for rehab. York put him on a respiratory ward when he has no respiratory issues, under a respiratory consultant who tried to discharge him within 12 hours of arrival. My father has evident neurological issues he needs rehab for. But no assessments were conducted, no communication was undertaken with family, and no relevant specialist was aware. When we raised this to the ward the duty doctor said they would try and speak to Hull and the stroke ward at York to sort it. But they went home instead while we sat there. No doctor was available on the ward at all after that. Absolutely appalling lack of basic care and communication from staff. My father needed cognitive tests and a care plan and then his release would have been fine. But there was no concern or recognition of this from the ward.

Personal Story: "Wasted time and money."

I came into A&E yesterday and had an 11 hour wait. When people came to call the names of the people waiting, they didn't come far enough into the waiting room or speak clearly enough so lots of people, me included, didn't know if our name had been called and we'd missed our turn. Later they said I needed an endoscopy and told me to come back today. I did, only to find that they can't do it today, but they are worried about me going home as it's urgent - but not urgent enough to do today! They therefore have to find me a bed to stay overnight and can't even guarantee they will do the endoscopy tomorrow. What a waste of NHS time and money - and my time!

GP Services

There were 104 compliments for GPs and GP practices.

> I've had ME/CFS for five years and have found it very difficult to find medical support. Having just had my annual review, I wanted to commend my GP for their help and reassurance. Though they admit to knowing very little about my condition, they still listen to my concerns and come up with suggestions that might help (in this case, a blood test and a referral to another doctor). Having someone who seems to genuinely care and tries to help makes a huge difference.

> 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 day 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 confidence in them and the care I was getting. I can't fault the practice.

> My neighbour was a new patient at Dalton Terrace. He is in his 80s and on joining was invited to lots of health checks. As a result he was referred to a specialist and has ended up having a double heart bypass. He had no symptoms but thanks to Dalton Terrace's checks this all happened before he had any issues. If it had been another surgery he would probably have had a heart attack.

> I was withdrawing from alcohol and in a mental health crisis and the GP was fantastic. They helped me detox and got me the medication I needed within two hours. I had gone in to ask about pain, but they saw what I needed and helped immediately as well as referring me to rheumatology as a priority. The doctor was young, up to date and knew how to help. They also arranged an appointment for the next week so they could see how I was doing. I was so lucky, they saved my life.

Themes from compliments included:

- Friendly, helpful and supportive staff.
- Able to get appointments as needed.
- Offering flexibility and personalised care to meet need.
- Prompt referrals into hospital services.

We also received 216 complaints, 94 concerns, 16 comments and 14 requests for information. Within these the key themes are:

- Problems with communication including failure to make reasonable adjustments and inappropriate communication of diagnoses.
- Difficulties getting timely support and diagnosis.

- Challenges with communication and care planning between GPs and other health services.
- Concerns about having to travel across the city for appointments with multi-site practices.
- Frustration with administrative processes and IT systems not working.

Personal Story: "Diagnosis by text."

My aunt was diagnosed with stage 3 kidney disease by text message. There was nothing else, no information, no opportunity to talk to anyone, just a text. It is appalling.

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: “No interpreter.”

I booked an appointment for my three-year-old son. I am a BSL user, which the surgery knows. However, there was no interpreter - they said it was because the appointment was last minute, but they didn't even offer a video service. While there I needed to book a further appointment and explained about the BSL interpreter, but they couldn't confirm the date for the appointment and therefore they can't book an interpreter. It feels like a fight every time.

Personal Story: “Our medical records need to reflect reality.”

I was surprised to log into my online portal to discover I'd had a medication review which included considering my mental health and risk of self-harm.... the coding suggests I had a phone conversation which I didn't and in no medium was I asked about intended self-harm etc. despite a depression review also being coded. If they had asked, I would have told them I have some self-harm ideation but would find it really hard to hurt myself. I'm incredibly concerned about people who physically can harm themselves whose reviews have also been fudged...

Personal Story: “Extremely poor response regarding getting a death certificate.”

My mother-in-law died at home early on Wednesday morning. She had Alzheimer's and this is what she wanted. My husband, her son, was there and it was peaceful. He rang 111 to ask about getting a death certificate and was told they would pass it on to the GP. Once the GP had opened he went in and they said it was OK, and they had the details. So, he rang the funeral director and said he'd call back when the GP had been. At 2.30pm a GP from the surgery rang as they should have visited that day to see how she was. My husband explained and they said to leave getting a death certificate with them. At 3pm the undertaker rang to chase up. My husband rang the GP and the receptionist said that GPs can't certify a death and that he should ring 111 or 999. He rang 999, apologised and explained and they were very angry and said it was something the GP should do. At 5pm the GP practice rang and said if you don't hear anything before 6pm to ring 111. At 6.24pm the GP arrived and was there for a maximum of five minutes. They did apologise. They said they would send the death certificate, but on Monday we are still waiting and know we have to register the death in a certain time and are worried we will miss it.

Personal Story: “Good when you get there.”

The GPs are all fantastic but the system is atrocious. The practice is poorly run and disorganised including the communications. They sent a text addressed to me to my wife. And they put on my mum's record that she is a heavy smoker when she has never smoked and would never smoke. It could have affected her healthcare and travel insurance. She had to fight to get them to change it. It is not good enough.

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 the village by public transport by taking a bus into town and a bus out to {area}. This 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 to do it here which seems madness considering the aging population in the village. Surely they could send a nurse for a couple of hours a week?!

Mental Health services

We received nine compliments about mental health care.

> I had been adamant I was never going to the mental health hub. But I was having a meltdown recently and either had to sit in a park or go to the hub. I went and they were really lovely. The man I spoke to really nailed it. The conversation was just enough. He talked about the support available and suggested I go back to talk more. I did and he has arranged for me to see the person he thinks would be able to help most. I am really pleased and now feel it is somewhere I can go if I need to.

> Over the past six to seven months I have noticed that the crisis team seem to be better at responding to me when I call. In that time they haven't told me that I was being childish, that I need to go to sleep and they haven't hung up the phone on me. They seem more receptive and will listen more.

> I had problems with my memory and was referred to TEWV for some tests. They were very thorough, including doing two brain scans, and reported that there was nothing wrong. They told me about things I could do to help improve my memory and I have been doing those. They have been very good.

We received 40 complaints, eight concerns, five comments and seven request for information. Within these the key themes were:

- Difficulties in accessing services after poor experiences.
- Concerns about staff attitudes.
- People feeling unsafe and without access to care.
- Long waits for dementia support.

Personal Story: "Long delays for referral."

My mother in law went to the GP thinking she might have dementia. It took two years before she saw someone. Then she saw a registrar and had two follow up appointments with a nurse and then nothing. No one told us about Dementia Forward or any other places we can get support.

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: "Hospital experience worse than being ill."

I was in Foss Park last year after I had a breakdown. The staff weren't interested and were really cold towards me. I thought it was one of those hidden camera things where they were seeing your reaction to them being awful, but it wasn't. I didn't know who my key worker was, they didn't really provide any care, they didn't diagnose me and I didn't feel safe. One day I walked out and went home and it was as if no-one cared or was bothered. I did go back but then I was discharged, given some medication and put on to the crisis team. Eventually I got a diagnosis of bipolar and felt that I was bullied to take medication. I don't feel I got much support. I found acupuncture which has helped more than anything else. I also got support from the Haven who were good. The two mental health nurses at Haxby Medical were really good too.

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: “Awful experience of the crisis line.”

I had to call the crisis team last night because I was self-harming again. I really didn't want to call them but I had no choice. So I spoke to 111 and 111 was lovely she put me through to the crisis line. A few minutes later a lady in TEWV crisis team answered. When I told her I was struggling and had been self-harming etc. her response was "well you've been like this a while haven't you so I don't know what your problem is." She then said she would go away and read my notes so she put me on hold. I waited over half an hour on hold so in the end I hung up because I didn't even know if she was going to come back to the phone. An hour later she called me back and then said "Sorry I can't remember what we was talking about so can you repeat it again." So then when I said to her that she was the one who said she was going to go away and read my notes she said "Yes I've read your notes and it looks like you have been offered a lot of stuff so again I don't know what your problem is." She also said I had been offered the "managing your emotions" work which I told her I have agreed to do but that isn't gonna help me right now when the CMHT will not even tell me when I can start this. She then started getting really nasty so I hung up.

Dentistry

We received 10 compliments about dental care.

> Thank you for referring me to Mydentist. They have seen me three times and the dentist is lovely. They did a check up, took the roots of two teeth out and have done a root filling. They've booked me in for another visit to talk to me about alternatives for my teeth and mouth. They have been brilliant.

> 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 16 complaints, eight concerns, one comment and 14 information requests.

Within these the key themes are:

- Lack of NHS dentists in the city.
- Challenges in meeting costs of private care.
- Reports of poor treatment and failure to remedy problems
- Challenges accessing care for potentially vulnerable groups and individuals

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.

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: "Can't get a dentist."

My daughter and I have had problems with our teeth but can't get any help. My daughter has false teeth which no longer fit her as she has lost a lot of weight. They are hurting her now. I am having a lot of jaw pain, which my GP says is my teeth. But again I can't get any help.

Personal Story: “No NHS dentists.”

I live in York, I have two broken teeth causing me constant pain and an abscess I have no spare money and no transport the only emergency dentist with availability is in Leeds. I live on painkillers as I can’t get help.

Personal Story: “My friend needs an NHS dentist.”

My friend (80+) has a number of health issues and really needs to see an NHS dentist. It is a long time since she went to her dentist and thinks they have thrown her off the list. Can you help?

Personal Story: “'Cost of dental treatment not covered by NHS.”

Since speaking to you I have had the treatment we discussed at the [name of] practice, some privately and some under the transition prices while my dentist was awaiting NHS registration. She now has this registration, but I have had to return to consult her as there are more problems with other teeth. I have always looked after my dental health but I am assuming that, as part of the ageing process, treatments given earlier in life are deteriorating. My dentist has recommended one tooth is extracted and another has the root canal redone. The second they can only offer privately and I am aware from earlier attempts that the NHS dental hospital do not consider me sufficiently high priority to give me treatment. She say she expects the root canal to cost about £900, the rough figure I paid for other treatment earlier in the year. This is very expensive, particularly when it a repeated payment. I have looked to see if there is any insurance scheme I can join that would reduce the cost of these repeated one-off payments. All that [name of scheme] offer is a scheme that will cover the first £300 in any year. If I want to keep my teeth, can you suggest any ways I can mitigate these sky-high prices.

Personal Story: “Can't get an NHS dentist.”

I have had some problems with my teeth and had to go private. But it was so expensive. I really need to see an NHS dentist, especially if I am in pain again.

Personal Story: “Trying to find an NHS dentist.”

I only moved to York two years ago and have not been able to find an NHS dentist that will take me on. I have never had any problems with my teeth before but since being unwell I have had 2 fillings. I feel this is really unlucky timing for me because I am currently struggling to work so therefore have limited funds (currently in receipt of ESA & PIP which brings me out with around £700 per month.) I have called 111 to ask what dentists in my area are taking on nhs patients and they just mentioned a few dentists I have already contacted (at the best they have waiting list of up to three years). I have tried to discuss this with my doctor and explain how worried I am about this but they could not provide any help. I have researched things and found that because I am receiving ESA it makes me eligible for free dental care. I have emailed my current dentist surgery saying this and they say they are private and can not help. They are now saying I am due a hygiene check and also a dentist check, I'm not sure why I have to have both.... I just need to look after my teeth at the moment because, whilst being unwell, my dental health has deteriorated. Hygiene appointment will cost me around £60 and added expense for dentist appointment. If I don't have the appointments and pay the money then they will strike me off the list. I feel this is so unfair and I have nowhere to turn for help!

Social care and council services

We received 13 compliments about social care and council services.

> 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.

> I have got a Blue Badge as a result of sight and mobility problems. The Council has arranged for me to also have a frame, a handrail in the shower and a wheeled trolley. The service was excellent. They have also arranged for me to get help with putting my bins out.

We received six complaints, 11 concerns, four comments and 28 requests for information. Key themes from these include:

- Challenges in making suitable care arrangements.
- People looking for information about dementia support
- Lack of clarity around finances and financial assessments
- Difficulties resolving concerns about care

Personal Story: "SEND provision is not good."

> My daughter is SEND and over 18. There is no support at all. That said, the SEND hub has opened and that looks like it might help. I really hope so as before there was absolutely nothing. We really need advice on staying in education and benefits.

Personal Story: "Not supporting my mum."

My mum has Parkinson's and Lewy Body dementia linked to her Parkinson's. She is very limited in what she can do now and has carers regularly. It seems that she mostly just sits and watches TV or is in bed. She struggles to eat without spilling her food, can't remember to take her medication and is struggling. She is a smoker and keeps dropping lit cigarettes. I think it is only a matter of time before she sets something on fire. I've tried to raise this with her GP and to get a formal diagnosis of dementia, but they aren't interested and definitely won't come and visit her. I have talked to the Council but they said there are no social workers so she can't have one. She did go into care for a few weeks, and she looked so much better. But she said she wanted to leave (as they wouldn't let her smoke inside) and they said she had capacity so she could. I am struggling with my health and so can't really support her, but it seems like that is what the GP and Council expect me to do. But I can't. One GP told me to move away! But I can't do that either. I don't know what to do.

Personal Story: "No help at all."

I did have a care plan and regular carers. But after the OTs came to visit, I have had no support. The OT thought I needed more help, but I have had nothing since September. I said I needed someone to help with cleaning, making the beds, ironing etc, and they said they would get me help. But again, I have heard nothing. I need someone to help me open my post, but no-one is helping - it is so hard to get a PA when you live in the villages as it isn't worth it for them.

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. I knew something was wrong the moment I met the first member of staff. They all avoid eye contact. None 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...

Personal Story: "What is there to support people with dementia?"

My husband has dementia and I am looking for activities in York. A friend's husband also has dementia and Parkinson's, is there anything for him in York?

Personal Story: “Struggling for support as a connected carer.”

I am the carer for my 13-year-old grandson. He has been with me since Spring 2024 when he was brought round by social care. I was told I was looking after him as that is what he wanted. He has ADHD and autism and has issues with alcohol and drugs. I had no choice and since then I have had no support. When I raise issues with the social worker they are no help and they keep changing. I had one social worker for eight days! I have just had a demand of £1,000 from HMRC as I hadn't filled a foster carer form in, but no-one told me I had to or how to do it. I still can't get any help, I am just told 'that's not my job'. I rang in a crisis on a Friday and was told that my social worker wasn't there, they'd send an email and she'd get back to me on the following Thursday when she was back in the office. It really isn't good enough. If I was a foster carer I would have had training and an induction, but because he is my grandson I have had nothing. I feel like I'm now the babysitter and our relationship has changed. I used to be his grandma and we had a good relationship, but that's gone as I'm now the one telling him he has to go to school.

Neurodiversity support

We received two compliments about neurodiversity support.

> The Retreat was fantastic at diagnosing me with ADHD and autism. The aftercare was good too. I have six grandchildren who are neurodivergent. They live in different places and we are having to pay privately to get them diagnosed. I wish they could get the service I got from the Retreat.

We received 15 complaints, five concerns, three comments and one information request. Key themes from these include:

- Challenges accessing help whilst waiting for a diagnosis.
- Difficulties in beginning the assessment process.
- Concerns about the removal of shared care arrangements for ADHD medication.

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

[Is] any collective action 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: “Struggling to get an appointment to be able to be referred for an autism/ADHD assessment.”

I was diagnosed with ADD when I was younger and I am struggling with everyday life. I feel I need an assessment for ADHD/autism. However when I asked my local GP surgery, they said that they were on Opal 4 so I would need to contact NHS 111. However, they also said I need to see a GP so I am stuck. But I am really struggling. I know the referral will take time, but the longer it takes to even see a GP the more difficult it feels.

Personal story: “Challenges to get care for child with suspected autism/ADHD and eating issues.”

My son (9) is probably neurodivergent but hasn't got a diagnosis. He has had traumatic experiences at school and has increased eating issues from July 2024 to the point now where he will only drink, not eat. I have been trying to get help since July. I asked my GP first and they refered him to a psychiatrist, but they said he was too complex for them to support. We saw CAMHS last September but they said they can only help with the eating issues if he completely stopped eating. The GP has made two referrals to the York paediatric team and one to Leeds, but on each occasion the referral was rejected as they said it was a mental health issue. Although I think there are some physical issues too, but no-one will listen. The play therapist he has seen says he needs to see a trauma therapist. The SENCO at his school told him not to tell me about some of the traumatic things that had happened as they were worried I would complain. He now has significant trust issues about school and hasn't been to school for a year. I know there is something wrong, but my son can't verbalise it and I have run out of who to turn to. Can you suggest anything or help?

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.

Impossible to get on the waiting list for autism and ADHD assessment, despite various attempts over nine years.

Person under the care of Community Mental Health Team was advised by them to seek autism and ADHD assessments. They were sent the pre-assessment forms four times, filled them in and returned them each time, was told they were being being referred and were on the waiting list. But two years later their GP told them they had never been added to the waiting list.

At that stage, their only option was the do-it profiler, but nothing came of it because at that stage they were not in one of the at risk groups. A week later, they would have been in a risk group, but they couldn't go back and revisit it, so lost their chance. They became very unwell and were admitted as an in-patient to a mental health hospital out of area. Whilst they were an in-patient they eventually got to see their medical records. They were shocked by how much wrong information they contained.

Reports in 2025

Quarterly reports

This report has been collated based on the four quarterly reports we published in 2025. These original reports can be found here:

January to March: https://bit.ly/HWYQJ-M25

April to June: https://bit.ly/HWYQA-J25

July to September: https://bit.ly/HWYQJ-S25

October to December: https://bit.ly/HWYQO-D25

Themed reports

In 2025 we published the following reports:

Listening to Neurodivergent Families: https://bit.ly/NDFamilies0125

Core Connectors – Young People's Experiences of Health and Care: https://bit.ly/CoreConnect0125

GP website audit report: https://bit.ly/GPwebaudit25

GP access audit report: https://bit.ly/GPaccessaudit25

Women's Health: https://bit.ly/Womens25

Care Home work

We recently relaunched our Care Home Assessor programme. Our latest reports can be found here:

Birchlands: https://bit.ly/Birchlands0225
Riverside Care Complex: https://bit.ly/Riverside0125
Rawcliffe Manor: https://bit.ly/Rawcliffe0325
Mossdale: https://bit.ly/Mossdale0425
South Park: https://bit.ly/SouthP0525
The Oaks: https://bit.ly/TheOaks0725
Ivy Lodge: https://bit.ly/Ivy0825
The Lodge: https://bit.ly/TheLodge1025
Amarna House: https://bit.ly/AmarnaH1125

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

Information and Signposting

We updated our Dementia Guide in 2025 – find the latest version here:

Dementia Guide June 2025: https://bit.ly/DemG25

Want more? Read our **magazines**:
Summer 2025: https://bit.ly/SummerM25
Autumn 2025: https://bit.ly/AutumnM25

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. We believe they can and should 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.

Glossary of terms used

Term	Definition
A&E	Accident and Emergency (also referred to as ED or Emergency Department.)
ADD	Attention Deficit Disorder – a term that used to be used for inattentive ADHD.
ADHD	Attention Deficit Hyperactivity Disorder – now recognised as a single condition with three types, inattentive, hyperactive-impulsive, and combined.
CAMHS	Child and Adolescent Mental Health Services. In this area, these are provided by TEWV (see below).
CMHT	Community Mental Health Team.
CYC	City of York Council.
ESA	Employment and Support Allowance – a benefit for disabled people / people with a long term health condition that impacts on their ability to work.
Foss Park	Foss Park is a 72-bed hospital that provides adult and older people's mental health services for York and North Yorkshire, including crisis teams and dementia care.
HMRC	His Majesty's Revenue and Customs.
ME	Myalgic encephalomyelitis, also called chronic fatigue syndrome or ME/CFS, is a long-term condition that affects different parts of the body. The most common symptom is extreme tiredness. The cause of ME/CFS is unknown. ME/CFS can affect anyone, including children.
MRI	Magnetic Resonance Imaging – a scanner that uses strong magnetic waves to provide images of organs in the body.
Orca House	Orca House is TEWV's (see below) community base in York for children and young people's services. Many people refer to it as York CAMHS (Children and Adolescent Mental Health Services).

OPEL 4	Operations Pressure Escalation Level Four - OPEL 4 or a black alert is the highest level of stress and activity in health services. The OPEL levels are a method used in the NHS to measure stress, demand and pressure. NHS England classes Level 4 as a ‘serious incident.’
OT	Occupational Therapist.
PA	Personal Assistant – someone who provides care support and is directly employed by the person being supportive or their representative.
PIP	Personal Independence Payment or PIP is a benefit for disabled people / people with long-term health conditions who need extra help with daily living or mobility.
PoTS	Postural Tachycardia Syndrome is a condition where your heart rate increases very quickly after getting up from sitting or lying down, making you feel dizzy and light-headed.
SENCO	A Special Educational Needs Co-ordinator is a qualified teacher who’s responsible for leading the school’s provision for special educational needs and the support offered to students with SEN (special educational needs) – which includes things like autism, dyslexia and ADHD as well as physical and sensory impairments.
SEND	Special Educational Needs and Disabilities - A child or young person has special educational needs and disabilities if they have a learning difficulty and/or a disability that means they need special health and education support.
TEWV	Tees, Esk and Wear Valleys NHS Foundation Trust. They hold the contract for delivering NHS mental health services for York and North Yorkshire.

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