What we are hearing

Quarterly Report: April-June 2026

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 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

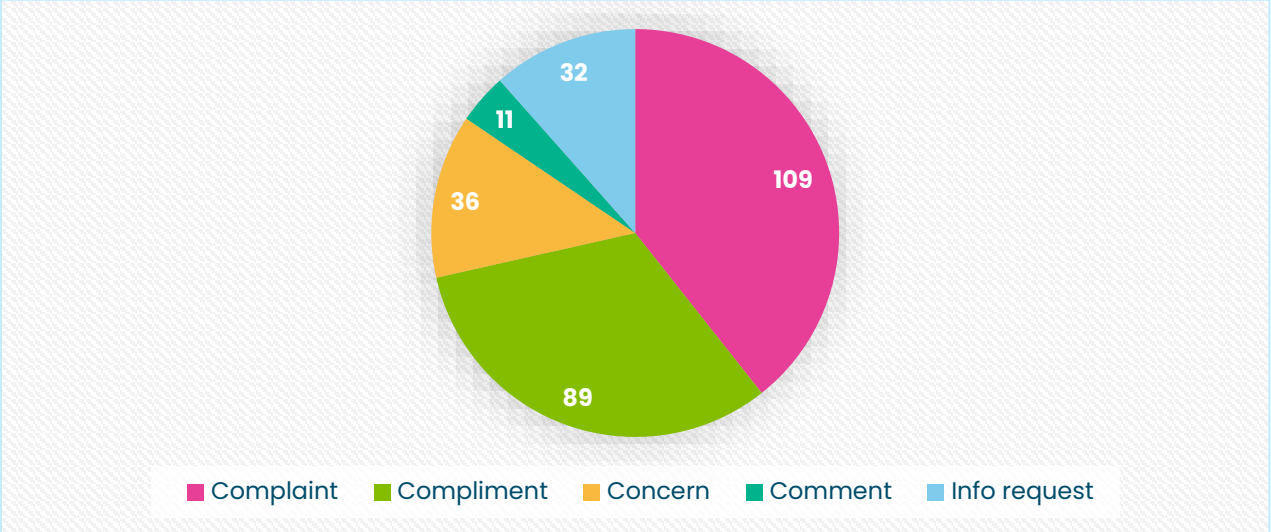
We have put this report together based on what you have shared with us in the three months from 1 April to 30 June 2026. This report gives a flavour of the issues and themes this quarter. The service areas highlighted in this report are as follows:

- Hospital services
- GP services
- Mental health services
- Dental services
- Social care and council services
- Neurodiversity support (from across the above categories)

Overview of contacts received

From April to the end of June 2026 **277** people contacted us directly to ask for information / advice or share their feedback.

Type of feedback received



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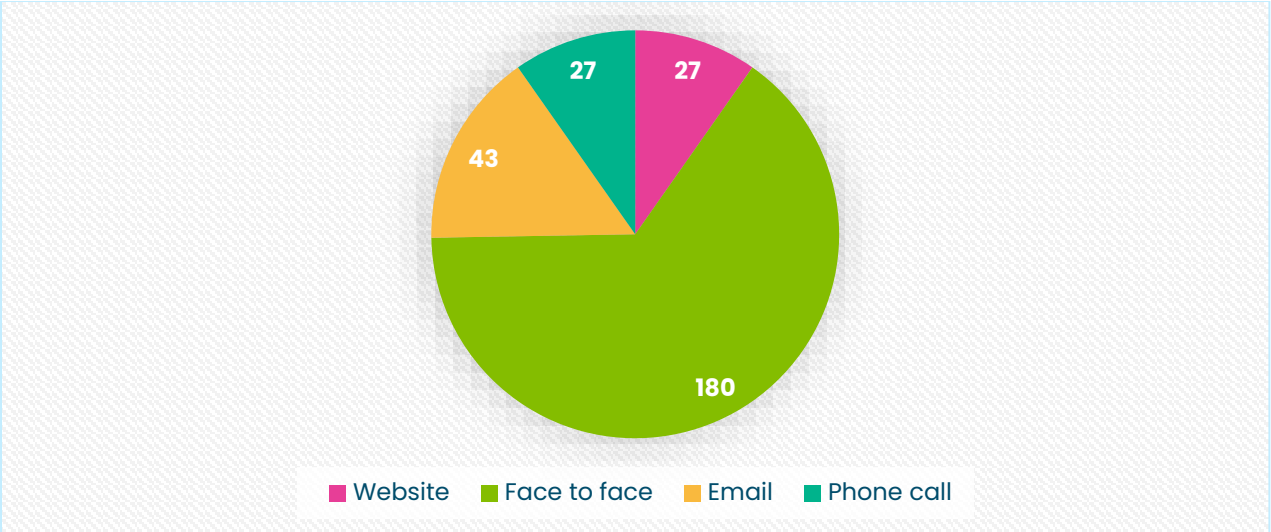
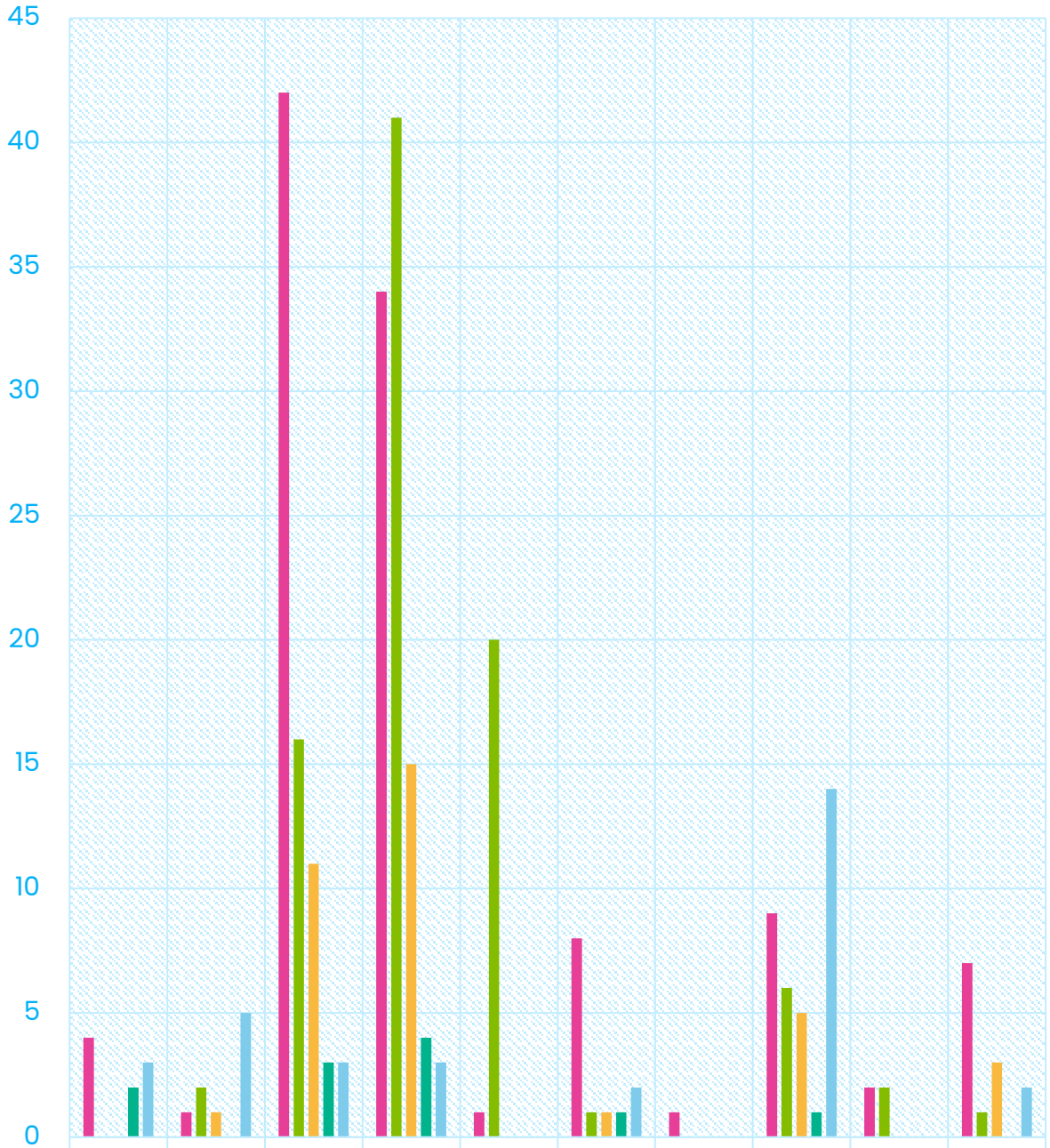


Feedback received by type and area of care



	Commissioning	Dental	GP	Hospital	Intermediate care	Mental Health	Opticians	Other	Pharmacy	Social care / CYC
Complaint	4	1	42	34	1	8	1	9	2	7
Compliment		2	16	41	20	1		6	2	1
Concern		1	11	15	0	1		5	0	3
Comment	2	0	3	4	0	1		1	0	0
Request for info	3	5	3	3	0	2		14	0	2

Key themes by area of care

Hospital

We received 41 compliments about hospital care.

> My daughter has breast cancer and has been treated and supported by the Magnolia Centre and Leveson Centre and they have been fabulous. She had a lumpectomy and a reconstruction and has some radiotherapy planned as well as endocrine treatment. It has all been very good. Also the free parking is very welcome as she has a number of appointments and is a single mum so needs to save where she can. It is appreciated.

> My husband came out of hospital after a heart operation. He could only come home because the hospital team supported us to make sure he could have the antibiotics he needed at home. They brought all the equipment he needed and talked me through how to use it. For the first few days they came every day and then less as I was more confident. They even gave him a clever device that could give him the antibiotics while we were out, so we were able to go out and about. I felt supported by everyone and their help gave us an extra 18 months of good time before he died.

I was diagnosed with arthritis and have seen the specialist nurse and consultant in the rheumatology department. They were excellent. I was then put on patient initiated follow up (PIFU) and that's been great. I was in touch recently as I had more pain. They saw me quickly and gave me some good advice. They offered one treatment which I didn't want so offered something different.

I fell while out with the dog. I managed to walk home and then went to A&E. I arrived at 9.30am on Wednesday and was seen by a very good doctor at 11am. They went through a series of questions and thought I'd broken my arm. They got an orthapaedic surgeon to come and look and he agreed (he was also very good). I was sent for an x-ray which confirmed what they thought. It wasn't a bad break, so the surgeon gave me an anaesthetic in my arm and reset it. I was then taken to somewhere in A&E where they put plaster on. I was out of the hospital by 1.30pm by which time A&E was very busy. I then had an appointment at the fracture clinic a few days later when they checked everything was OK and put a new cast on and I could choose the colour! They thought it was all OK and booked another appointment for a further 10 days. It was all excellent.

I came for an operation on my leg. They were very good, explained everything clearly and the pre operation call was very useful. They also took into account my additional needs which was excellent.

Themes from compliments included:

- Being seen more quickly than expected.
- High quality care, especially in A&E, rheumatology, the Magnolia Centre, neurology and ophthalmology.
- Supporting people beyond their hospital stay to be as independent as possible.

We also received 34 complaints, 15 concerns, four comments and three requests for information. Within these the key themes were:

- Communication and access problems.
- Failure to recognise and meet individual needs or make reasonable adjustments as required.
- Family members not being kept up to date with discharge plans.
- Missed diagnoses and poor experiences of care.

Personal Story: "Communication is hit and miss."

"The communication while in hospital and at discharge is very hit and miss. It is like pulling teeth trying to get information as a relative. You can see the staff are overstretched. We want to help, but can't talk to anyone to find out what we can do."

Personal Story: "Fallen off the list."

"My husband is 90, has advanced prostate cancer and is starting with memory problems. He used to be seen regularly by the Magnolia Centre, had his PSA tested annually but now he seems to have been forgotten. He did have a call from the urology nurse recently so it seems like he is back on their books, but he hasn't had a PSA test for two years and it would be good to know if anything has changed. It really feels as though things will only happen if I chase them as he can't do that. But it is very frustrating."

Personal Story: "Communication is very poor."

I am struggling to get an answer from urology. I have rung twice and asked for a manager to ring me, but have heard nothing. I was sent an appointment for a procedure. I couldn't make the date so contacted them and rearranged. I then had the procedure which was very good. However, I then got a letter, copying in my GP, to say I had not attended the appointment - this was the appointment that I rearranged so no longer existed. I now have that on my record when I did attend the rearranged appointment. It is very frustrating.

Personal Story: "Missed chronic gallbladder problems."

I was in awful pain and went to A&E. I was there for six hours and they just told me to go home and take Gaviscon. The pain didn't go, so a few weeks later I rang 111. It took them 36 hours to call back and they said take paracetomol. It continued and I went to my GP who said it was just indigestion. But I was doubled over in agony. Eventually I went to the Nuffield and paid to see someone who immediately said it was a problem with my gall bladder. They did a scan and found it was badly infected. Because of the pain, I paid to have it removed privately. I didn't trust the NHS.

Personal Story: "Two letters sent on the same day with different information."

I received two letters from the hospital at the same time. Both had the same date. One told me about an appointment they had booked for me and the other told me that the appointment they had booked had changed. This does not appear to be very efficient!

Personal Story: "Poor communication spoiled a positive experience."

I had to have three biopsies and the staff were excellent. They were thorough and explained what they were doing and why. However, I then needed an MRI. I told the staff that if they tried to put things in my arm, it wouldn't work. They didn't listen and then had problems. It was extremely uncomfortable and an awful experience. Then there was a lack of communication between ENT and radiology. In the end someone in ENT did get it sorted out, but it wasn't good. I am here today to have conversations about some planned procedures and they have been good. But I have ME, fibromyalgia, neuro fibromatosis and other things and I do struggle. I do find some staff wonderful and others not. I had an ultrasound once when a staff member walked in, did the ultrasound and walked out without saying anything. It feels like they are looking down their nose at you. I have also been refused patient transport.

Personal Story: "Inappropriate food."

We have been visiting a dying friend on the ward. He can no longer eat much - ice cream or mousse at best - and yet he is continually brought meals he can't eat. It is unfortunate for him as he would love to eat the food and can't and also a waste of money as he can't eat the food that keeps appearing. Surely something should be done about this.

Personal Story: "Mixed experience."

I recently had my first child at York Hospital. It was the first time I've been in hospital and so I found it a difficult experience. It did not feel personalised. The midwives and pre-natal classes are good, but I felt there is a lot of scaremongering where they talk about still birth and other things. The fear stayed with me from that time on and I didn't find it helpful. As I was worried, I asked if I could go and visit the maternity wards etc. in advance, but they said it wasn't possible as only people with mental ill

health could do that. They told me to watch a video, but I didn't find that helpful. In the end I had an emergency c section. The staff supported me with that, although initially I did feel I was rushed into the labour room before I was ready, just because it was empty. The worst part was after I gave birth. They put me in a ward with my baby. She kept crying and even though they told me I needed rest, I tried to get up to comfort her as I was so aware of the other women and babies trying to sleep. In the end the midwife said she'd take my daughter and comfort her so I could get some sleep. That first night also I was left alone, at 8pm, all family have to leave. Just when I needed them most, they weren't allowed to be there. I found that inhumane. Then a week after we went home, I was back in hospital with sepsis. I was in hospital for five days for that while they got on top of it. They still don't know the source of the sepsis.

Personal Story: "Endoscopy without sedation/anaesthetic despite LD nurse involvement."

My nephew has been waiting for five months for an endoscopy. His family got in touch with the Trust's York learning disability nurse when it was said he needed one as they felt that he would need sedation or a general anaesthetic to have the procedure. She agreed and was very helpful, liaising with the dept. However, they went ahead without anything and my nephew had a melt down. We have tried to contact the department to rearrange the procedure in a way that works for my nephew, but we have not heard from them. We've contacted PALS, but they say they won't talk to me any more in order to protect my nephew's interests. When I said I wanted to escalate my concern to a complaint, they said it would delay his treatment. There is something wrong and he needs the endoscopy. I don't know why it is taking this long or why it wasn't done with sedation or an anaesthetic in the first place.

Personal Story: "No help from ward staff after moving ward."

My mum was on AMU and had a specialist physiotherapy outpatient appointment in the hospital the following day which she didn't want to miss as she had waited a long time for it. She explained to the staff and they said they would help her and it would be no problem. However, during the night, she was moved to a surgical ward. The staff there said they wouldn't help her as she wasn't a surgical patient. She had been in bed for two days so did need help and was very cross when the staff didn't help. She did manage to get herself ready and did get to the appointment no thanks to the surgical ward staff.

Personal Story: "Premature discharge."

They discharged my mother before she was ready on Friday and on Tuesday she had to come back to hospital as she could not be at home. When she was readmitted she was readmitted to a surgical ward. She is due to have surgery in the summer and we are now waiting to see if it is possible for the surgeon (this is a very specialist procedure) can do the operation earlier or if they are happy for someone else to do it sooner. The issue is to do with her bowels - she either had faecal incontinence or constipation and carers can't cope with it. In the past a district nurse came to give her an enema, but there was no-one to help her clean up the consequences of the enema and she is a wheelchair user so can't do it without help. So she is in hospital at the moment. When she is well she can look after herself, but not when she is not well.

Personal Story: "Nothing offered for condition."

Was sent for MRI the day after a 10 hour wait in A&E with suspected cauda equina. Not offered any treatment or suggestions on how to manage pain.

Family expected to provide full care in hospital

Person's mum is 92 and has a diagnosis of dementia. She has been cared for on an acute elderly ward (28). Her daughter lives in Scotland. She has been in York for an extended period to support her Mum during her hospital stay. She feels the care was better in A&E than on the ward. She feels that she and her brother have been left to nurse their Mum despite her being in hospital. They are having to feed her and offer water and believe without them doing this she would be left without - they have also supported other patients on the ward. On one occasion the patient was given her medication in a little pot. Her daughter was told staff did not have time to make sure that she took it so she would have to do that. She has had to change her Mum when soiled without help, a process that takes two hours each time. Despite spending seven hours on the ward one day the daughter was asked if she could come in earlier the next day to look after her Mum. On another occasion the daughter was asked if she knew about John's campaign and was told 'it means you can be here 24 hours to look after your mum' and 'we could do with the help'. She says she is on her knees mentally and no recognition is given to how difficult it is to sit with someone who is delirious for seven to eight hours at a time. She has found access to staff for updates very difficult. She worries about discharge as there is no communication (her mum is improving physically but not mentally). She feels very concerned about what would happen to her mum if she and her brother were not there. She worries about what will happen when they can't be there long term as they both live around five hours away.

GP Services

There were 16 compliments for GPs and GP practices.

> I've been having pains in my hip and leg and had phoned my GP practice who arranged for an appointment for me at Cornlands Road. I had to take time off work and get a lift there, but it was worth it. The GP was thorough and examined me, poking and prodding and making me do movements to show what hurt. He identified that I have sciatica and talked me through what I need to do, prescribed me some stronger pain killers to use when I have a flare and was very good.

> I went to my GP who noticed a lump on my forehead which he thought looked 'angry'. It wasn't why I had gone to the GP, but he thought it was worrying and he referred me to York Hospital. I had an appointment within three weeks and they checked it out and arranged for me to have it removed. They could not have been kinder or more efficient.

> At my last GP appointment, the GP asked if they could use AI to do the notes from the consultation. I agreed and the notes were far better than the previous appointment I had with the same GP.

> The GP practice has got it right. The online system is very good and you often get a response within two hours. I have diabetes and the care comes from the GP practice which is excellent. They are also good at doing Covid vaccinations.

> My GP called me back within a few days because of a query over a test I had done. She texted me about 8am for an appointment that morning at 11am. Marvellous service and she was running well to time also.

Themes from compliments included:

- Efficient and timely responses
- Digital and online systems working well
- Thorough assessments of people's health needs and concerns
- Kind, compassionate and non-judgemental care.

We also received 42 complaints, 11 concerns, three comments and three requests for information. Within these the key themes are:

- Difficulties making appointments.
- Poor support for women's health issues.
- Communication problems.
- Failure to provide timely support with urgent conditions.
- Challenges with accessing blood tests.
- Problems with repeat prescriptions and medication reviews.

Personal Story: "Issues not taken seriously and patient not listened to."

My daughter has had years of crippling periods and awful pain. It affects her mental and physical health. She has had really bad experiences of seeking help at the GP practice. She was told it was due to rough sex, which isn't true. They did refer her to the hospital and she had a laproscopy which found nothing, so they dismissed her even though the symptoms haven't changed. At one point the GP said it could be IBS, but in two years she's had no follow up to that. She did have a coil fitted, but that hasn't helped. She did try different contraceptive pills but they all had different impacts for her, particularly on her mental health. At one point they tried to force her to take medication that she didn't want to - one of the side effects was anxiety, which she already was experiencing - and did not listen to what she was saying. We know she has a high pain threshold but it is getting to the stage where she is having to take time off work as the pain is so bad.

Personal Story: "Inappropriate information on form and no results."

I had had some tests done and the GP practice said there was a slight inflammation of my liver so I needed another blood test. When I went to pick up the blood form on it by reason it said 'suspected alcohol abuse'. That is not true and the receptionist knew it. She said it was a default setting. But why would that ever be put on a blood test form at all?

Personal Story: "Changed an appointment at the last minute."

My husband had an appointment at {name of} surgery. He got a call an hour before the appointment to say the location had been changed to {name of surgery}. We don't have a car, so he had to walk and it took him that long to get there. He got there five minutes late and they were going to refuse him the appointment. He explained and thankfully someone saw him.

Personal Story: "Not easy to get in touch."

I find the online form very difficult to do. If you phone up it takes ages and you are often tenth in the queue. Then if you do get an appointment, you are sent all over York. I find some of the receptionists, especially at {name of surgery site}, quite rude. Once when I had to go there I was running a little late due to traffic. I rang to tell them and when I got there five minutes late they said I'd have to rearrange the appointment. I also contacted the practice with an issue for my young daughter but they didn't seem interested and said they'd be back in touch in three or four weeks.

Personal Story: "Issues with repeat prescriptions."

I ordered a repeat prescription as early as I could - two weeks before. A week later as I was about to run out of the medication, I got a message saying I needed a review. But that will take me weeks to arrange by which time I will have run out of the medication. In these cases, why do they not give me the next prescription and tell me I need a review before I order again. This would mean I have enough medication to last until I have the review. It seems wrong to let me run out of medication before telling me I need a review.

Personal Story: "Difficult to get an appointment."

I always find it difficult to get an appointment. First I can't use the online system, so always phone up. If I ever go into the practice they try to get me to use the online system but I find it really difficult. And when you get an appointment, it isn't always with a GP. I also had a prolapse and am waiting for them to take the pessary out. At a previous GP practice I could just go in, but now I have to go on a waiting list and they never tell you how long it will take.

Personal Story: "Given up on trying to get an appointment."

I find it really difficult to get an appointment with the GP surgery. Then, when you do get an appointment they phone you and often I am at the supermarket or somewhere else where it is difficult to talk and when I don't have my notes in front of me. I was also once offered an evening appointment in {area of York}, but I live in {area of York} and it is not easy to get there. I also find the online form incredibly difficult to fill in. All of this means I have given up trying to get an appointment and instead use Chat GPT to find out what is wrong with me. I've even given up trying to order prescriptions as it is so complicated and not clear which system you should use from Systmone, the NHS App or Patient Knows Best. It is so confusing and you get messages on one about the other. I can't deal with any of it.

Personal Story: "Online form issues."

Over the weekend, my wife developed a urinary tract infection. Because symptoms started with delirium yesterday, when I filled in the new {name of surgery group} online form, I was only given the option of calling 999. I did manage to speak with a very helpful receptionist, who has arranged an urgent call with a GP, but this necessitated me actually going to the surgery. It seems that {name of surgery group} are making the portal even less use than previous iterations.

Personal Story: "Change to timing of bone density scan with no conversation."

I have osteopenia and previously had bone density scans every two years. I haven't had one since 2022 and contacted the GP about it to find that a GP who had never met me had changed it so that I have a scan every three years. That said it is now 2026 and I still haven't had one..

Personal Story: "Excellent hospital care - after GP ignored the issue."

I had tonsilitis and contacted my GP. They didn't get in touch with an appointment and it got progressively worse. It got very bad and I rang 111 who said to go to the urgent treatment centre at the hospital. They were excellent, saw me quickly and admitted me to a ward for IV antibiotics. One of the nurses said I looked awful. I felt very bad taking up a bed, but there was no choice. If only the GP had seen me as if they had, I would not have needed to end up in hospital in that way.

Personal Story: "Long wait for an appointment due to ringing the wrong number."

I requested an appointment via the online form and gave my current mobile number for them to use to get in touch. I waited for nine weeks before a GP rang. They explained that a number of people had tried to ring, but the number was out of use - they were using my old mobile number which was on my record, but not the phone number I'd asked them to use. The only reason I got a call was because an excellent GP realised what the problem was as it had happened with other people before when people were identified as 'serial cancellers'. They then arranged an appointment for me which was very good. The surgery is brilliant and the nurses and doctors are excellent. The issue is just the system of getting an appointment. And I know I should update my mobile number on my record, but when I had been asked to give a number to call and had done, I thought they would use that number.

Personal Story: "Don't do blood tests in the surgery."

I can't get a blood test at the surgery. They say to go to the hospital, Askham Bar or the stadium. But I can't get there.

Mental Health services

We received one compliment about mental health care.

> Before my wife's UTI manifest as an infection, she suffered from an acute psychotic episode. Clearly the UTI was at least partly responsible. I had to ring 111 and spoke with a lovely lady who passed me onto the mental health crisis team. The gentleman with whom I spoke there was equally helpful. He offered to contact both {name of GP practice} and Huntington House. I missed a call from Huntington House, which has not been returned yet and I suspect that the GP with whom I spoke this morning has attributed everything to the UTI. It is good to know that things CAN work...

We received eight complaints, two requests for information, one concern and one comment. Within these the key themes were:

- Struggles to access timely dementia assessment and support.
- Difficulties accessing ongoing NHS care if you choose to go private for speedier assessments.
- Challenges finding and accessing the right help.

Personal Story: "Mixed experience."

> My husband has been diagnosed with Alzheimer's and dementia with Lewy Bodies. In the end we paid privately to get the diagnosis. We then went to the memory clinic, but they said because we'd got the diagnosis privately there was nothing they could do and we were on our own. Even when our GP contacted them, they said we were 'out of the NHS system' and there is no more help. Yet, I am really struggling to cope.

Personal Story: "One year waiting list."

My mum went to the GP for some initial tests for suspected dementia. They think she does have dementia and have referred her to the memory clinic but the waiting list is a year long and so much could have changed in that time. No-one told us if there is anything else she or we can do in the meantime, just wait!

Personal Story: "Very hard to get help."

I was with someone who was really struggling with their mental health. We didn't know where to turn. I asked the police and they said to contact the crisis team. I phoned them but they couldn't help at all. It was awful and I didn't know where to turn.

Won't accept a GP referral.

A GP with 15 years of experience was trying to refer a young person to CAMHS because of self-harm. They tried three times but each time the referral was rejected. They were told that the school wellbeing service should be able to help - which they couldn't. In the end the GP has referred it to safeguarding.

Social care and council services

We received one compliment about social care and council services.

> Falls prevention is excellent. They came to my home and installed grab rails on the stairs and checked I was OK. Top marks.

We received seven complaints, three concerns and two requests for information. Key themes from these include:

- Challenges arranging support for fluctuating conditions and that fits with people's lives.
- Concerns about the costs of care; difficulties paying the contributions required.

Personal Story: "Wrong time for carers and often discharged."

My mum has a number of health conditions and is a wheelchair user. When she is well, she can look after herself with no issues. However, there are times when she does need support. We have been in touch with adult social care but the problem is that they close her case when she is well, and then we have to start again when she isn't. Also she is active and enjoys going out in the evening, particularly to choirs. However, often carers come at 7 or 8pm and want to put her to bed. That is far too early for her. And being in bed can be quite uncomfortable, so she doesn't want to go before she needs to. It can be very frustrating.

Personal Story: "Nothing for people who are deaf and have dementia."

My mother was in a care home when she died at 96. She had inherited deafness from being young and much later developed dementia. The care services in York are not ready to support someone in my mother's position. The care home were brilliant and did all they could. But nothing was suitable for a deaf person. The best she could have was someone one to one and the staff did that and were great. After she died they even said they were planning a sensory garden for people like her. However, at the care home, in hospital and at the GP none of the care was geared towards someone in her position and it should be. At hospital I was told she should have something green at every meal. That was to preserve as much of her sight as possible. But that didn't happen in the care home. She had problems with her teeth and ended up with a pureed diet, but there was no green. The care home staff tried to help but kept hitting rules they couldn't do anything about. Before she went into care she had someone to take her out once a week for two hours, via mental health, which was brilliant and exactly what she needed. That stopped after she was discharged from mental health support and there was nothing else. She just didn't fit into any categories and we couldn't get the support she needed. This reduced her quality of life and significantly impacted on me as her daughter and carer.

Personal Story: "Issues with carers and cost of care."

The main issue I have is the current costs. I'm on universal credit yet I am assessed as needing to pay £105 a week towards my care. The PIP care component I receive is £75. This means I have to use my mobility money to pay for my care. The maximum should be that the council is only allowed to take the PIP care money. They should not be allowed to take the money for mobility equipment or food and bills. It's not safe. I'm trying to manage without carers because of the unaffordable packages the council make for people on universal credit.

Dentistry

We received two compliments about dental care.

> I have just been to the dentist as I have a problem with my wisdom tooth. Normally I hate going to the dentist, but they make it so easy and not the awful experience I have had before. They can't do enough for you and I can't fault them.

We received one complaint, one concern and five information requests.

Within these the key themes are:

- Lack of NHS dentists in the city and challenges accessing timely healthcare because of this.
- Difficulties paying for private treatment.
- Significant challenges accessing urgent dental treatment.

Personal Story: "No NHS dentists."

> My daughter is on Universal Credit and had some problems with her teeth. She is also being treated for cancer. She tried to find an NHS dentist but no-one could take her on. She has had to go privately and I have paid as she really needed to see a dentist.

Personal Story: "Need a dentist to enable me to have a heart operation."

> I need heart surgery following the fitting of a pacemaker. But I need a certificate from a dentist before the surgery is booked, but I don't have an NHS dentist and can't afford to go private. Can you help?

Personal Story: "Any dentists taking on NHS patients?"

My partner and I are looking for an NHS dentist in York. He has been via 111 for an emergency, but then they could only do work on one tooth, even though two of his teeth were hurting. I have tried calling all over, but I can't find anywhere taking patients on without a long waiting list.

Personal Story: "Trying to find an NHS dentist."

I am trying to find the nearest dentist to York that is taking on new NHS patients. The information on the NHS website is not accurate and I have tried many, many dentists to no avail. I was informed that you might be able to advise. Looking forward to hearing back from you.

Neurodiversity support

We received one compliment about neurodiversity support. This related to voluntary sector support.

> I have been on a course with Daisy Chain and have had group and one-to-one support. They are excellent. They really understand about neurodivergence (I have ADHD) and are really great at listening. I would recommend them to anyone who needs the support..

We also received six complaints, two comments and two information requests from across all sectors. Key themes from these include:

- Staff across health and care settings failing to understand neurodivergence.
- Difficulties accessing assessments and ongoing support through the NHS.
- Long waits for assessments and support.

Personal Story: "Bad experience of CAMHS."

> I am 16 and have been in touch with CAMHS since I was 12. I am autistic and think I may have ADHD, but they are refusing to do an assessment. I have also asked for medication - sertraline - as I am really struggling, but they always say no. I have been about mental ill health and they just tell me it is low mood when I know it isn't. My mum did pay for me to get support from the Retreat, but CAMHS said if I was under them I couldn't get support from anywhere else in case there were mixed messages. But the Retreat provides NHS care and works in partnership with TEWV, so how can that be mixed messages?!

Personal Story: "Awful."

Someone I am supporting was a patient at {name of surgery}. They were more than awful. The person is neurodivergent and they were made to feel like they were a compulsive liar and that they were too demanding. No one at the surgery understands about neurodivergence and the person was left worse than before they went to the GP practice. They have now changed practice and the new practice has done a full medication review, something they had needed for years, and they now feel supported and understood.

Personal Story: "No shared care for ADHD medication."

I currently have a private ADHD diagnosis through ADHD Certify and have been receiving treatment and medication through them. However, I have been unable to find a GP willing to accept shared care, meaning I cannot access NHS prescribing and would need to continue paying privately for treatment, which I cannot afford anymore. But the medication has been life changing for me. I attended a GP appointment to see my options. As everywhere I've read up on has said to do Right to Choose. But I was informed there's a local NHS ADHD pathway was explained to me that had a long waiting list but would accept my private care. However, as I may be moving out of the York area soon, I was advised that I would be removed from the waiting list or discharged from the service if I moved. So I'd be back to square one. When I then asked about a Right to Choose referral to ADHD360, I was told this pathway was only for people without an existing diagnosis. However, this leaves me in a difficult position, as the only option currently available to me appears to be continuing private treatment, despite being unable to afford it. The medication has genuinely been life changing for me, so I am feeling very anxious about losing access to treatment while also not having another clear pathway available. At the moment, I feel unsure what I am supposed to do next.

Personal Story: "Can't get an assessment."

I have had to pay for my grandson to get an assessment for autism/ADHD as CAMHS have rejected him. He is quiet and doesn't make a fuss, but he clearly has issues and needs some help. But the school and CAMHS have just said he doesn't need anything. It is so frustrating.

Personal Story: "No shared care for people with ADHD."

I was on the Retreat waiting list in 2021 and I still haven't heard. Instead I opted for Right to Choose. Thankfully the organisation I went with is continuing to provide medication after I found none of the GP practices in York will do shared care. Do they not know the damage they are doing and the increased costs for the NHS in not doing this. I would need so much additional support if I couldn't get my medication. I would struggle to work as well.

Personal Story: "Help for grandchildren."

I think my grandchildren (from different families) are autistic or have ADHD or both. They have both got bladder and bowel issues and allergies and seem to have other signs. However, the nursery for one has been very supportive, but not for the other. A health visitor once said that one was just being lazy and will grow out of it! They did not understand and were unhelpful. Do you know anyone who could help as my daughters are really struggling.

Personal Story: "Mixed Experience."

Generally the GPs I have seen have been good and treat me holistically. However, the first GP I saw about ADHD was very dismissive. They asked why I wanted a diagnosis at 'my age', said ADHD was for school children. It got to a point where I asked to see a different GP. Since then I've had no problems. I generally see the same GP and they are very good.

Things we want to hear more about

Through the feedback we've received recently we want to hear more about:

- Waiting for social care
- Financial assessments for social care support
- Experiences of technology and AI in healthcare
- Discharge from hospital
- Experience of screening health checks for men
- End of life care
- Giving up on seeking health or care support due to poor experiences of services.
- Inaccuracies in your records due to admin or communication issues

We welcome your feedback on all aspects of health and care. But we would particularly welcome hearing from you about your experiences of any of these areas of care.

Recent reports and publications

Healthwatch York Annual Report: Speaking up for better care

We are pleased to share our Annual Report for 2025-26, which highlights how your experiences of health and care have shaped and influenced decisions about services in York,

Contact us for a printed copy or view it on our website here: https://bit.ly/HWYAR25-6

Summer magazine
In this edition we focus on palliative care and end of life services in York, as well as sharing news and updates. Contact us for a printed copy or view it here: https://bit.ly/HWYSummer26

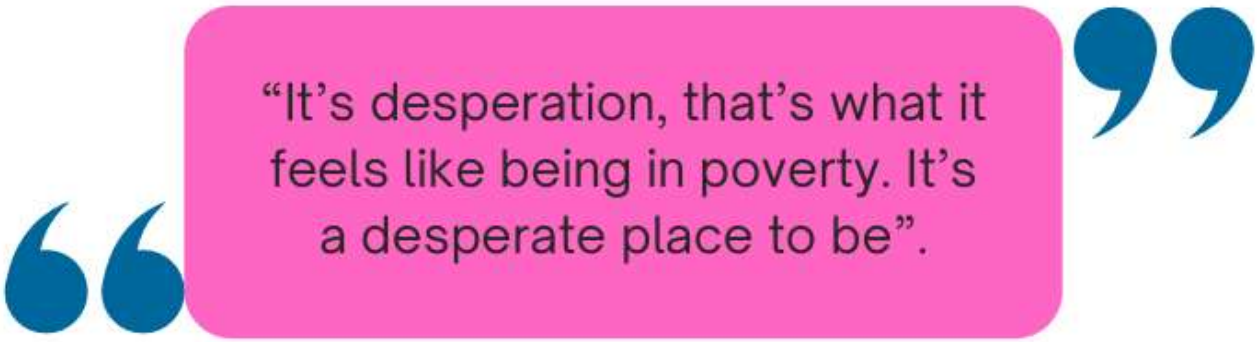
Mental health and wellbeing guide 2026
Contact us for a printed copy or view it here: https://bit.ly/DemG25

Care Home reports
Our volunteers aim to visit a care home every month through our Care Home Assessor programme. Our latest reports can be found here:

Connaught Court Care Home: https://bit.ly/Connaught0826
Somerset House Care Home: https://bit.ly/Somerset0826

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

Desperation of Poverty Life
Alongside partner organisations in the city, we were proud to be part of this project. The aim was to explore experiences of the local welfare safety net – schemes and support in the city beyond the national benefits system. The project was designed, facilitated and analysed by people with direct experience of accessing the welfare system. This approach better reflects the real experiences of those most affected. Read the full report here: https://bit.ly/DoPL2026



Current surveys

Children and young people's mental health and neurodiversity survey
Are you a child or young person in York waiting for mental health or neurodiversity support? Has a child or young person you know tried to access mental health support or a neurodivergence assessment (autism or ADHD) in York in the last two years?

Our surveys to capture people's experiences are still open. Please share your experiences and help us understand what is happening for you and your family – we will use what we hear to help improve services:

For young people: https://www.smartsurvey.co.uk/s/camhscyp26/

For families and carers: https://www.smartsurvey.co.uk/s/CAMHS26/

If you would rather talk to us about your experience, please get in touch: **healthwatch@yorkcvs.org.uk** or call 01904 621133.

As well as hearing from children, young people and families, we want to hear from professionals, so please complete our anonymous survey if that is you: https://www.smartsurvey.co.uk/s/SENCO26/

We've also had some feedback related to child to parent violence. We know this can be a difficult subject to discuss. But we want to understand more about people's experiences. We also want to hear about any services and support people have found helpful in these circumstances. We'd welcome any feedback on this. You can contact the team through any of the usual routes. We have also set up an anonymous comments box on whispermeter. This guarantees we have no access to any information that could identify you. Find it here: https://whispermeter.com/feedback/CtPV_tell_us

Technology and AI in healthcare

We have launched a survey to find out about your views, knowledge and experience of using (or not) some of the digital ways to access health information including the NHS App, GP practice online services and Patient Knows Best. We also want to know what you think about the use of AI (artificial intelligence) in healthcare.

If you would like to take part, the survey is available here: https://www.smartsurvey.co.uk/s/DigitalHealth26/

If you would like more information or a paper copy of the survey, please contact healthwatch@yorkcvs.org.uk.

There is also a survey for healthcare professionals to share their views on digital access and AI use: https://www.smartsurvey.co.uk/s/ME1S2F/

Waiting Well In Social Care

We are working with the Administrative Fairness Lab at the University of York on a National Institute for Health and Care funded research project exploring *Waiting Well in Social Care*. The study focuses on people's experiences of waiting—for example, waiting for a needs assessment, for a care and support plan, or for care to begin.

We are looking to speak with people who have current or recent experience of waiting for social care to take part in a one-to-one research interview. The study hopes to identify ways the process could be improved in the future, increase awareness.

If you have experience you would like to share, please get in touch: healthwatch@yorkcvs.org.uk.

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 ED or Emergency Department.)
ADHD	Attention Deficit Hyperactivity Disorder – now recognised as a single condition with three types, inattentive, hyperactive-impulsive, and combined.
AMU	Acute Medical Unit – a short stay ward that assesses and treats people in some hospitals
CAMHS	Child and Adolescent Mental Health Services. In this area, these are provided by TEWV (see below).
Chat GPT	An Artificial Intelligence (AI) powered chat bot that generates text, speech and images in response to prompts.
CYC	City of York Council
ENT	Ear, Nose and Throat – a medical specialty focused on issues affecting the ears, nose, throat, head and neck
IV	Intravenous – a process that puts fluids, medications and nutrients directly into people's veins
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.
Osteopenia	Osteopenia refers to lower-than-usual bone mineral density, making them weaker and more likely to break. It is considered a pre-cursor to osteoporosis, a more severe loss of bone density.
PALS	Patient Advice and Liaison Service – a free service provided by local hospitals. They can help with questions, concerns and complaints about hospital care.

Patient Knows Best	A secure platform used by services like the hospital to hold patient records.
PIFU	Patient Initiated Follow-Up – an approach to organising ongoing care without scheduling routine follow-up care.
PIP	Personal independence payment – a benefit for disabled people and people with long term health conditions who need extra help with daily living activities.
PSA	Prostate specific antigen – a PSA test checks the levels of PSA in your blood. High levels can indicate a prostate condition.
SystmOne	A secure platform used by services like GP practices to hold patient records.
TEWV	Tees, Esk and Wear Valleys NHS Foundation Trust. They hold the contract for delivering NHS mental health services for York and North Yorkshire.
UTI	Urinary Tract Infection – A UTI is an infection in any part of the urinary system. This includes the kidneys, bladder, ureters and urethra.

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