

What we are hearing

Quarterly Report: July-September 2024



Contents

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

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

3rd party reported compliments – green background

3rd party reported negative feedback – pink background

Concerns and complaints in own words – blue background

Cover photo by Marc Markstein via unsplash

Introduction

What we do

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

Healthwatch York:

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

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

This Report

We have put this report together based on what you have shared with us in the 3 months from 1 July to 30 September 2024. This report gives a flavour of the issues and themes this quarter.

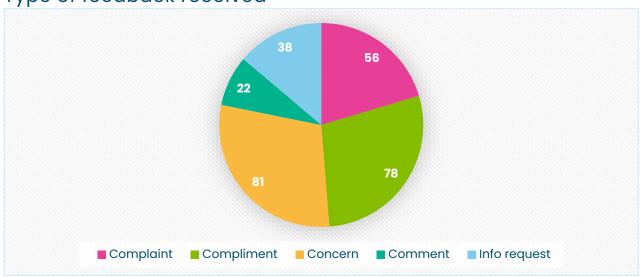
The service areas highlighted in this report are as follows:

- Hospital services
- GP services
- NHS dentistry
- Mental health services
- Social care services

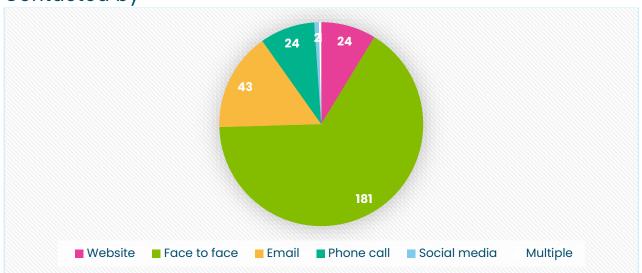
Overview of contacts received

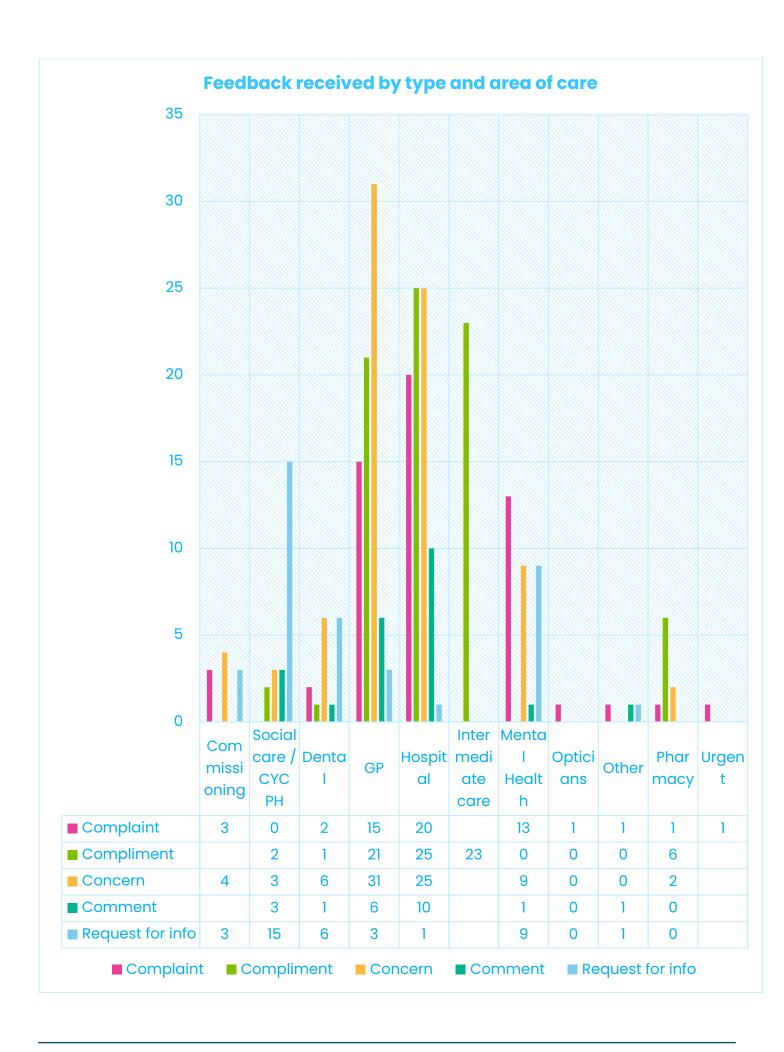
From July to the end of September 275 people contacted us directly to ask for information / advice or share their feedback.

Type of feedback received









Key themes by area of care

Hospital

We received 25 compliments about hospital care.

My surgeon has done her absolute best from what was a very difficult and complex cancer diagnosis which left me after two surgeries with a great outcome regarding the incision placements. She left no stone unturned via scan procedures which I am truly grateful for. I can't thank her enough for giving me the best journey on what is going to be a long hard road to recovery. The nurses on this unit are amazing and their care is outstanding.

"Excellent A&E staff."

Person went to A&E in a mental health crisis. The A&E staff were excellent. They made sure the person was never left alone and knew who to talk to if needed, but without being intrusive. They did everything they should to ensure the person was safe and helped with their physical health issues while waiting for the mental health team. They arranged a chaperone to be with her when she saw the doctor and she felt safe and listened to.

"Excellent service."

Person has been under Audiology for a number of years and finds them brilliant. He knows that it can take time to get a referral via the GP, but has found since he has been a patient, they have been great. He goes every three months to get his hearing aids retubed and they ensure he has access to the latest technology.

Themes from compliments included:

- Kind, compassionate and personalised care (in A&E, the Magnolia Centre, Audiology and from the heart failure team)
- Staff doing their best despite the challenging environment
- High quality aftercare
- Clear, timely communication

We also received 20 complaints and 25 concerns, 10 comments and 1 information request. Within these the key themes were:

- Poor care, including failing to provide basic care
- Inappropriate discharge plans
- Misdiagnosis
- Problems with staffing levels at the weekends
- Failure to provide test results
- Poor communication and failures to recognise access needs
- Staff attitudes

"Stage 4 cancer diagnosis given by phone"

Person's cousin has had COPD and breathing issues for the past two years. They noticed a scar on her lung two years ago, but didn't do any follow up scans or tests. When the person has been in hospital for breathing problems, they were told it was infections. Two weeks ago an x ray identified something and the person was sent for a CT scan and then a PET scan. They were phoned to say it was cancer, it was in the same place as the scar in their lungs but had spread to their spine was stage 4 and terminal. All of this was told over the phone with no time for them to process it or ask questions. When the person went in for a biopsy, their cousin asked if the family (including the person's four sons) could talk to someone face to face, but they were told they were short staffed so it wasn't possible. When they asked again they were told there was nothing more to say. The person is now in hospital and for the first 24 hours wasn't offered any pain relief even though they were in significant pain. The person and family still haven't been given the

opportunity to talk to someone face to face about the diagnosis, prognosis and what happens next.

Personal Story: "Awful experience which led to a blood clot on the brain"

I would like to complain about the maternity services which I can only describe as a living nightmare. Our lovely 23 year old granddaughter had her baby girl three weeks ago which should have been the best time of her and her partner lives but sadly wasn't. Our granddaughter had an epidural which went drastically wrong after days and going backwards and forwards to above department her husband woke to her having seizures (never had one before). She was rushed to hospital where I can only describe the next four days as living hell. No neurologist on site? No scan for days as it was a bank holiday? Couldn't have her newborn with her unless family slept at her bedside? She ended up on a renal ward as no bed availability on correct ward where she was finally diagnosed with a blood clot on her brain which had caused the seizures. (Problem with the epidural caused this). Even though she is now home on heavy duty medication she needs 24 hour supervision. This is not what anyone should endure. Our NHS should have the correct staff available at all times. Emergency health problems DO Not only occur during normal working hours. Why is this happening?

Shared via email

"Challenges in accessing treatment leaving staff hysterical"

Woman went to the optician and was told she needed laser treatment on her eyes. They sent her a link to access this. She swears the link said something like "click to book." She kept trying to book a 2pm appointment but it kept saying 2am. She assumed this was an error. She didn't get a letter to confirm her appointment so her daughter called on the day. The phone was answered by a laughing woman "oh, we've got another one. You think you've booked an appointment. It's our CRAZY system." Her daughter responded "But we clicked to book." Still laughing she said "no, you're not booked, don't bring her in. You've just told us you want a referral." Which she feels does beg the question 'why doesn't the link say click here to refer into the service' rather than to book, and why make you choose a time? Daughter realises she was laughing because it was so ridiculous and she must be answering the phone all day, but this all felt inappropriate and not really a laughing matter. It needs resolving and communication needs to be improved. Also this must be adding to the admin burden, tying up resource to answer patient questions. Eventually after this got a letter confirming an appointment, but why isn't this sent as soon as booking is attempted?

"Poor care and inappropriate discharge plans"

Man had a bladder and prostrate procedure at York Hospital. He returned home and experienced severe bleeding. His wife took him to Scarborough A&E where he waited (in pain and bleeding) for 12 hours. Scarborough said he had to be transferred to York as that was where the procedure happened. He was and at York the consultant said it was normal and sent him home. The bleeding continued overnight "our home looked like a slaughterhouse". His wife called the paramedics who called the GP who called the consultant who said to go back to York Hospital. He was admitted on Monday. On Tuesday he was very confused, agitated and had a slight droop to his mouth. The doctors thought it might be a stroke, so sent him for a scan which showed no stroke. They also checked with the stroke team who said it wasn't a stroke. On the Wednesday he couldn't sit up or swallow and his family were told this sometimes happens when someone has neurological issues (which he does). On Thursday his family were called and told to go in as he was unresponsive. They were told if his heart stopped they could not restart it (he had heart failure). The family suggested it could be an infection as he had had them and sepsis before. The doctor said

they couldn't treat with antibiotics until it was confirmed, which it later was. He was in ICU for a week. 24 hours after coming out of ICU the family were told the doctors were going to discharge him - this was miscommunication as they meant he was medically fit to be discharged but other things would need to be put in place. But the family didn't know this and thought they meant they were sending him home to a first floor flat when he couldn't get out of bed! The family would have liked clearer communication and would like him to be transferred to Whitby or Bridlington for reablement before going home. They live in Whitby and his daughter lives in Bridlington. They are finding the travel to York exhausting.

GP Services

There were 21 compliments for GPs and GP practices.

I go to York Medical Group at Tower Court. I have complex issues. I know the staff and they are brilliant. I see the same GP and he goes out of his way to help. Sometimes I have to wait, but I don't mind and continuity is so important. I see one of two GPs and they both know my history.



I had to go for dressing changes twice weekly following an operation. All nursing staff at Gale Farm excellent and put me at ease explaining things. On the one occasion they had to get a doctor to look at the wound he was good too and took time to explain what was wrong and how to treat. Despite having to go to Acomb as no nurse at Old Forge in my village I could not have had better treatment and caring manner

"Excellent care."

Person moved to York from Halifax. They had been to the GP in Halifax who told them their issue was to do with their hormones and didn't do anything further. The GP at Dalton Terrace was concerned and sent them for tests which showed a pituitary tumour which had spread. They had further scans and surgery in Hull which saved their life. The GPs at Dalton Terrace have continued to be excellent. They always read the patient's file in advance and know what the person needs and refer on if that is necessary.

Themes from compliments included:

 Great access, from being seen more quickly than expected to being offered home visits as needed

- Good communication between GP practices and community pharmacy to provide fast access
- Continuity of care, especially for people with long term conditions

We also received 15 complaints, 31 concerns, 6 comments and 3 requests for information. Within these the key themes are:

- Health concerns not being taken seriously
- Failure to diagnose underlying health issues
- Problems with accessibility of practice sites
- Problems using the online form
- Long waiting times to be seen, even when health issues are urgent
- Transport concerns

Personal Story: "Poor physical access."

It is very difficult getting into the grounds and then to the surgery of the Haxby practice. It is unsafe for someone with limited vision. There is a pathway from the Haxby side but the path stops abruptly at some grass and then you have to weave through cars and the car park 'road' to get to the practice. It is very dangerous. There is a path from the Wigginton site, but to get to that, you have to cross the entrance to the car park which is even more dangerous.

The person has raised the issue with the practice, but has not heard back about whether anything will change.

"Online form requires you to lie."

Person is very frustrated with the online form which either tells you to call 999 or your request isn't urgent. They talked to a receptionist when their request was deemed non-urgent and

was told just to tick a few more boxes. It is extremely frustrating that you have to lie to get attention.

"Ignored urgent issue."

Person woke with severe chest pains at 6am. They rang the GP at 8am but were told it wasn't urgent and they would get an appointment in 2 – 3 weeks. So the person rang NHS 111 and were told to go to A&E immediately. A&E were brilliant. When the person got there, 111 had called ahead so they were prioritised. The staff were excellent and felt there was a right branch blockage but couldn't find the reason.

"Misdiagnosis and lack of treatment."

Person's mum was told she had asthma for six years and given a series of inhalers, but none of them helped. She then went private as she was frustrated. She was told it wasn't asthma, she had atrial fibrillation and she was referred to a cardiologist. However because a diagnosis of asthma was still on her records a GP refused to prescribe the medication the cardiologist had recommended. This despite the fact that she had never had asthma!

Mental Health services

We received no compliments, 13 complaints, 9 concerns, 9 requests for information and 1 comment. Within these the key themes were:

- Poor staff attitudes and a lack of empathy with people experiencing mental ill health and / or gender dysphoria
- Failures to provide care and people feeling 'abandoned' by services
- Long waiting times for care
- · Services failing to make contact as promised
- Challenges in accessing ADHD and Autism assessments for children and adults
- Need for a local sleep service and a clear pathway for supporting people experiencing problems with sleep

"Mixed experience of mental health care."

Woman had a breakdown in early January 2024 linked to a number of traumas she had experienced in the past 10 years. She contacted the mental health crisis line who told her she should 'just get on with it' and after she considered suicide that she 'needed to think positive'. They were no help at all but did, eventually, refer her to the community mental health team who have been more helpful. With the CMHT she is starting stabilisation and then will get access to trauma therapy.

Personal Story: "Don't listen - terrible care."

My son was admitted after {attempting suicide} although he had been diagnosed with psychosis, they decided to take him off meds. This even though I told them many times what was going on in his head. He is now discharged had no therapy no meds and no further on since he started with the mental health team except {attempting} suicide three times. They don't seem to care.

Shared via email

"Inconsistency about support and medication for sleep."

Woman is struggling with a child who can't sleep. Her daughter aged 13 had struggled to sleep. Her daughter is autistic and has help from CAMHS. She had been on a waiting list since March and has now been told there is no sleep service in York. She also said that the transition to adulthood with mental health services and sleep support is a nightmare. She has three children who are all autistic and all have issues with sleep. Her eldest child was prescribed melatonin which really helped. But when he reached 18, he was told that they don't prescribe melatonin for adults. He was given a three day supply and that was it. It took him 2 - 3 hours to relax and so he started self medicating with alcohol which later led to him having to seek help for addiction. The person's second child was also prescribed melatonin and still is even though she is 18. But when the person asked about melatonin for her 13 year old, she was told no. The child's lack of sleep is significantly affecting her, her schooling and the rest of the family. It is absolutely awful and she feels like there is no help.

"Poor communication."

Person self-describes as a high functioning manic depressive and is autistic. They were in touch with TEWV pre lockdown and had an autism assessment in summer 2019. Since then they have heard nothing. They were told that they would be seen in 6 - 8 months after the assessment. After lockdown they chased this up and were told it would be two years, but no one has been in touch.

"Awful services in York led to son's suicide."

Woman feels her son was abandoned by services in York particularly when he turned 18. He did get some support from Lime Trees, but after 18 he felt abandoned and that the psychiatrist he saw did not care. The only people who helped him were the ambulance staff who took him to hospital after suicide attempts and the police. The crisis team did visit him in hospital the day after a suicide attempt, but they said that he was OK to be discharged and didn't need support. Three days later he was back in hospital after another suicide attempt. The son's father kept a diary of the issues for his son, but when he shared it with TEWV staff he was told that as his son was over 18 it was 'none of his business'. The family found the mental health staff very arrogant and heard 'in my x years of experience' a number of times. However, none of the staff could help despite their experience. Two of the son's contemporaries also took their own lives, having not received any help from York's mental health services.

Personal Story: "Unable to get a referral."

Despite having many traits of ADHD identified via myriad questionnaires on the profiler tool they wrote me off straight away as my ADHD is not a danger to me or anyone else so I have all this information but nowhere to take it as a I can't get a referral. Waste of time.

Shared via our website

Personal Story: "Issues with the Do-It profiler."

My husband just filled in the do it profiler and there only seems to be 3 questions about self harm, family court and hospital treatment that when answered lead to no assessment. Is this really the ONLY criteria for an ASC or ADHD assessment? If you then go to further sections there are sections you can't get through unless you tick a box even if none of the boxes are relevant. Some of the questions are ambiguous which is terrible for ND people. Then even when you score highly and have symptoms then you still can't get a referral. Again I ask is this really what is happening here? We're trying to get him a referral for an ASC assessment. This was flagged when he got his ADHD assessment. We also want to use Right to Choose. We've filled in stuff but seems no further along in getting referred. Can anyone help as your website is really confusing, badly designed, patronising and stunningly unhelpful. My husband spent about 60 minutes filling in lots of stuff and is no further along in getting a referral. This process is unhelpful, discriminatory, confusing, irritating, ableist and as far as I can tell, pointless.

Shared via email

Dentistry

We received 1 compliment about dental care.

Quick review from my wisdom teeth removal today. Doctor and nurse were fantastic honestly. I have such an hidden fear when it comes to having a dental needle in my mouth... My visit today was like no other visit to a dentist in 50 years never have I had a dentist talk though the process like the doctor did far less pain and afterwards I almost didn't even think I had an injection. The nurse was again great in every way right down to the list of things to do and not to do. I truly appreciate the way these guys are so good with people skills and very skilled in the work they do.

We received 6 concerns and 2 complaints. We also received 6 information requests and 1 comment. These mainly related to help to find an NHS dentist in York.

Within these the key themes are:

- Lack of NHS dentists in the city
- Long waiting times to be seen
- Problems in getting referrals due to not having an NHS dentist
- Poor communication from practices who stop providing NHS dentistry
- Problems with affording private dental care

"New dentures required."

Woman rang for advice about her 101 year old mother who is living independently but has lost her false teeth. Their previous dentist went private and they can't afford it. She has tried to find somewhere to help but the only option she has been given costs £2,000.

Personal Story: "Delayed dental appointment"

I have an NHS dentist, who I was meant to be seeing every three months, however, my dentist has left and now my next appointment has been offered for over a year's time. How can this be allowed, why is it that other NHS services are so heavily scrutinised yet dentistry is just allowed to be so poor?

Shared via email.

"Can't get a referral to Leeds dental hospital."

Woman has previously been referred to Leeds dental hospital for significant work that wasn't possible in a high street dentist. Since then she and her husband have been removed from their dentist's register and so now are not registered at a dental practice. However, she needs further dental work that requires a referral to the Leeds dental hospital again. But without being registered at a dentist, this is proving impossible. They have tried NHS 111 but on seeing an emergency dentist she has been told that the dentist can't refer her as she is not a registered patient.

"Need to see an NHS dentist."

Person has had treatment for oesophageal cancer which required a tube down their throat. They were warned this could impact on their teeth and that has happened and they are having issues with their teeth breaking. Their previous dentist went private and they can't afford it. They now want to see an NHS dentist to get help.

Social care services

We received two compliments about social care.

We went (to Able to Enable) on Saturday and they were excellent. I was very impressed with their knowledge, lack of pushiness in terms of sales – much more about trying to find you the best fit, but very aware these are expensive items, and the guy we dealt with Mike had a very good manner and awareness of disability etc. Overall I would highly recommend.

We received 3 concerns and no complaints. We also received 15 information requests and 3 comments. Key themes from these include:

- Wanting more information about dementia support in the community
- Wanting information about community support for people with long term health conditions
- · Lack of support for people with autism and those caring for them

"Lack of support for profoundly disabled children."

Person is a grandparent to a profoundly disabled child. She feels that apart from one perfunctory phone call to the child's mother, no-one has seen the child, there have been no carers and only one respite break a month. There seems to be very little support or service. When a company came to service the hoist, they were amazed that it was still in place as it was so old and could be seen as dangerous.

"Concerns about care home."

Person's mum lives in a York care home. When they visited they found her sat in her own urine on one occasion. She is rarely wearing her own clothes. Sometimes the clothes she wears are too small for her.

Things we're aware of

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

- Challenges for families of neurodivergent children around education, health and wellbeing
- Waiting for social care support
- Support and services for people living with long Covid
- Difficulties accessing HRT and other menopause support for those experiencing early menopause
- Long waiting times for assessments for ADHD and autism
- Long waits for hospital care

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

We also want to hear from young people aged 16-25 about their experiences of accessing health and care. Take our survey to share your views direct by visiting:

https://www.smartsurvey.co.uk/s/CCYork/

NHS 111 (Option 2) User Feedback

We have also asked for feedback about NHS 111 option 2. In September 2024 we shared this request via social media platforms and received 3 responses. The 'snapshot' feedback highlights several key issues:

Inappropriate initial assessment with a focus on physical health questions and not directly relevant to mental health concerns. A generally rushed and impersonal approach, lacking empathy and understanding.

Ineffective Crisis Team referral with delayed or no follow-up from the crisis team. A lack of timely intervention and support during a mental health crisis.

Inadequate support and guidance with generic advice like 'watch TV' or 'run a bath' for individuals experiencing severe mental health episodes with limited understanding of the specific needs and challenges faced by people with mental health conditions.

Difficulty in accessing timely GP appointments, hindering ongoing care.

A lack of person-centred care with insufficient attention to individual needs and circumstances; a need for more compassionate and empathetic support. There was a focus on providing solutions and distractions rather than active listening and emotional support."

We would welcome any further feedback about NHS 111 option 2. You can also feed into national work on this – read more in the National section of Current surveys and consultations on page 24.

Current surveys and consultations

Local

Humber and North Yorkshire Cancer Alliance cancer awareness survey

People in Humber and North Yorkshire are being invited to share their attitudes, awareness and understanding of cancer in a regional survey carried out by York St John University on behalf of Humber and North Yorkshire Cancer Alliance.

The objectives of the cancer awareness (CAM) survey are to:

- Measure the public's awareness of the symptoms and risk factors of cancer as well as the barriers to seeking help
- Gain a deeper understanding and insight of cancer awareness within the region's differing communities and populations
- Benchmark the region's varied populations in terms of their cancer awareness and understanding of symptoms

The survey launches in October and is open until mid-December. The results are due to be published in March next year.

Healthwatch York are delighted to be supporting this work, and sharing the link for the survey here: https://bit.ly/CancerAware24
Please mention Healthwatch York as the organisation you heard about this from!

Humber and North Yorkshire ICB – We need to talk

From 14 October the local NHS across Humber and North Yorkshire is embarking on **We Need to Talk** – a four-week conversation about the future of the NHS in our area.

For further information and details of how to get involved visit: www.ourNHS.org

The survey can be found here: https://www.smartsurvey.co.uk/s/OurNHS/.

You can also request further information and a paper copy of the survey by calling 01482 672156 or by writing to (no stamp required):-

NHS Humber and North Yorkshire ICB
FREEPOST RTTL-HSBE-BLHL
Health House
Grange Park Lane
Willerby, HULL
HU10 6DT

National

The Department of Health and Social Care has recently launched the **Change NHS** consultation.

"Our NHS is broken, but not beaten. Together we can fix it."

We want to have the biggest ever conversation about the future of the NHS. Your views, experiences and ideas will shape a new 10 Year Health Plan for England.

This is open to everyone. If you are a member of the public or someone who works in health and care in England, visit https://change.nhs.uk/en-GB/projects/start-here, to tell us how the NHS needs to change.

If you are contributing as a representative of an organisation, complete the organisation's questionnaire here: https://change.nhs.uk/en-GB/folders/organisations

NHS England – Mental Health Crisis Care 111 survey

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

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

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

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

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

Why we do this

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

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

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

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

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

healthwatch York

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