

# COVID-19: What people are telling us

A summary April - June 2020

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## Our approach to equality, diversity, and inclusion

We believe that everyone should have a fair and equal experience of health and social care. We recognise that some people and communities face multiple layers of disadvantage and discrimination, and that their views and needs are often not represented where they should be. Healthwatch England has published an Equality, Diversity and Inclusion work plan for 2020-21. Going forward, we are working to ensure our insight better represents the diversity of the communities we serve. Our Equality, Diversity and Inclusion work plan.

## Introduction

### **COVID-19 has had an unparalleled impact on us all.**

Over a few days in March, millions of NHS appointments were paused or moved online, hospitals quickly discharged patients to free up beds, and those most clinically vulnerable to COVID-19 were told to “shield” at home.

The Government began a nationwide campaign to reduce the risks presented by a virus about which little was known. A multitude of guidance was also issued, which was often changed at short notice.

While the crisis unfolded, Healthwatch did not stop our work. We mobilised staff and volunteers to advise a concerned public, and we alerted services to the issues that were confusing or preventing people from getting the care they needed.

Professionals are now working to get services back up and running before winter, while also preparing for a potential second COVID-19 wave.

From the stories shared with us, it’s clear that people are immensely grateful for the sacrifices NHS and social care staff have made and their dedication to keeping us safe. However, we can learn from issues, such as:

- The need for up-to-date information in languages or formats people understand, explaining how to protect themselves and their loved ones

- Better communication about how to access available services, and what the next steps are if support must be paused
- Problems accessing certain treatments and services, especially dental care
- Concerns about processes, such as the confusion around 'Do Not Attempt Resuscitation' forms without sufficient discussion in the early stages of the pandemic
- Queries about accessing testing for COVID-19
- Challenges with digital appointments because some people could not access them or felt uncomfortable using them

Although we can't provide all the answers, services must learn from and respond to people's experiences. Feedback from the public is helping services find their way and they stand ready to do more. The job facing health and care staff is incredibly demanding - but if people do not speak up about what is working and what is not, that job would be even harder.

- Sir Robert Francis QC, Chair of Healthwatch England

## About this report

Each month, thousands of people share their experiences with us about NHS and social care services. This report provides NHS and social care leaders with a summary of:

- Key issues the public faced because of the COVID-19 pandemic, and how this affected their experiences using health and social care.
- The feedback we have received on: primary care; secondary and urgent care; mental health services; social care; and community and other services - including patient transport, equipment services and charitable or voluntary services such as the National NHS Responder Scheme, and more.

This report covers the period April-June 2020 and is informed by 19,717 people's experiences of care. This is an increase of 12% compared to the same quarter last year

### What evidence informs this report?

19,717 people's views taken from 150 Healthwatch reports published to our reports' library about local NHS and social care services, as well as individual feedback from the public.

The proportion of all our evidence by sector:

- 60% Community and other
- 18% Primary care
- 14% Social care
- 9% Mental health

- 5% Secondary and urgent care

## Who are we hearing from?

The following information provides a snapshot of the people who completed our national survey about their experiences of health and social care, during April – June 2020.

- 76% were women, and overall 87% were cisgender.
- Nearly three-quarters were aged between 50 and 79 years.
- 70% told us they were White British, English, Welsh, Scottish or Northern Irish.
- Nearly three-quarters identified as heterosexual.
- 28% were carers.
- 41% had a disability; 68% had a long term health condition.

## Top advice the public are seeking

People turn to Healthwatch locally and online when they do not know how to get the information they need about services.

Between April and June 2020, these are the most commonly viewed advice and information articles people came to Healthwatch to find out about, based on Healthwatch England's website page views:

### Top 10 most viewed articles

1. What does shielding mean? 49,327 unique page views

2. What's the difference between social distancing and self-isolation? 11,210 unique page views
3. How can you find an NHS dentist? 6,191 unique page views
4. Do you need help with travelling to NHS services? 2,924 unique page views
5. Should I see a pharmacist instead of a doctor? 3,221 unique page views
6. Help making a complaint 2,615 unique page views
7. Registering with your GP: Understanding your rights 2,463 unique page views
8. Coronavirus is affecting my mental health, what can I do? 2,211 unique page views
9. Someone I love has died, where can I find support? 1,624 unique page views
10. Planning care at the end of life 1,320 unique page views

The top question the public were seeking answers to was 'What does shielding mean?' - this article had over 51% of our total unique page views

## The impact of the COVID-19 pandemic

What did people tell us at certain stages of the lockdown?

### Lockdown begins

As COVID-19 numbers started to climb in March 2020, the Government announced measures to help the country respond. All non-urgent NHS treatment was postponed, GPs moved rapidly to remote working, and people with certain health conditions were asked to shield themselves. By the end of March, the country had entered lockdown.

### Changes to routine and planned care

Many people contacted their local Healthwatch with queries about a wide range of services they would usually access, including routine blood tests, medication reviews, community nursing for wound care, and podiatry. In many cases, people were concerned and unable to find the information they needed to understand what they should do or expect from services at the time. We also heard from people whose planned treatments, scans and operations had been postponed. As a result, many were struggling with pain management – especially since they were unable to access their usual physiotherapy or exercise activities. People felt stressed, frustrated, and ignored due to a lack of clear and consistent communication about what the next steps for their treatment or care would be.

My husband's orthopaedic appointment this morning was cancelled. He received a text, then a phone call and a letter which arrived after his appointment, but never mind. When



he spoke to the consultant's secretary, he was advised that when the coronavirus outbreak is over, he will need to make an appointment with his GP to be re-referred. She did say that he won't have to wait as long as he's already on the list... This seems like a waste of the GP's time in that case - why the re-referral? This would mean thousands of unnecessary GP appointments across the area.

Healthwatch Sunderland

## Shielding measures

We heard from many people about issues around shielding. Some people who had existing health conditions and thought they should be shielding didn't receive a letter advising them to do so, making it difficult to understand which advice to follow, and who to contact for help. People also faced challenges proving their circumstances to their employer if they had not received a shielding letter. Those who were shielding told us about difficulties in accessing transport to their hospital treatment or appointments, which were going ahead despite the disruption to services. Transport, including patient transport services, was often reduced or could not guarantee sufficient distancing from other people. For some people, the cost of attending one or more hospital appointments was too expensive to arrange private transport, especially if the hospital was far from home.

## What have we learned?

- People need clear, accurate and consistent information about their care and the services they use - particularly when

services have to change in response to events like the pandemic.

- People's experiences of hospital appointments do not start and end at the hospital doors – their journey begins at home, so transport arrangements must be considered. This is especially important while public transport is reduced, or people feel unable to use it.

### Access to prescription medications

People told us they were struggling to get through to their GP or pharmacy by phone, and others experienced delays in getting hold of their medication. Some people reported inconsistencies and a lack of information about how local GP practices were linking with pharmacies to issue and process prescriptions. This caused stress and anxiety; particularly for people with long term conditions, if they were running out of supplies. However, as local systems and community support services became more established, we received less feedback about these issues – indicating that these services were helping people to access their prescriptions in new ways that minimised contact and risk.

I'm a cancer patient and have been facing problems with getting my prescriptions from my GP. I recently made a clear and precise request for a repeat prescription and mentioned that two items would run out on today's date and I am in isolation due to the COVID-19 situation. The requested items were not supplied but extra items were... I had spoken to the receptionist about the prescription on four occasions that week, so I just can't understand the error... I'm in a lot of pain

and I think the cancer has returned. My CT scan has been postponed for a minimum of two months due to COVID-19 and I'm really worried.

Healthwatch Hillingdon

## Lockdown begins to ease

In June, the lockdown restrictions started to ease. People were allowed to meet outside and in small groups, whilst maintaining social distancing. Those living alone (but not shielding) were allowed to form a support bubble with one other household. Non-essential shops and places of worship also began to reopen.

## Worries about the future

As plans to ease the lockdown were announced, we started to hear concerns from some people about the prospect of returning to work and going back out into busier public spaces. Since the beginning of July, we started to hear more concerns from people about NHS services restarting, and possible delays. People have raised questions about how services can reopen safely, reported problems accessing services that are supposedly already open for business and expressed frustration at some NHS services being slow to reopen compared to other sectors of the economy. We will continue to monitor this feedback for our next quarterly report.

## Testing for COVID-19

In June, we started to receive more feedback about testing. Whilst some people found visiting a testing centre easy and efficient, we also heard that the online booking process was difficult for some to use. There were concerns about the accessibility of testing centres for people with hearing impairments, as well as care home residents, staff and their family members.

I was offered COVID-19 testing due to my symptoms. I booked the test online, it was not very straightforward and could be confusing for those not familiar with online booking... I was offered numerous slots for that same day, so I booked one. When I arrived, there was no one else there. I was directed around to two different check-in areas, then to testing. The test was taken with the window down. It was very quick and efficient; the whole thing was done in 10 minutes. I was surprised at the high number of staff and how empty it was. I received my results by text within 24 hours. With this much capacity, I think many more people could be tested.

Healthwatch Warwickshire

## What have people been telling us throughout?

Looking at collective public feedback from across England, there are a number of areas which were particularly affected by the COVID-19 pandemic.

### Lack of accessible information for everyone

Throughout the pandemic, we heard about the difficulties of finding up-to-date information in the languages or formats people need – especially when advice from the Government was frequently changing. People told us they struggled to find information in British Sign Language (BSL) – and this was reflected in the lack of a BSL interpreter for the Government’s daily briefings. Similarly, people could not find information in Easy Read format, as well as in other languages spoken in their communities. We heard about some of the additional challenges faced by deaf people interacting with health services, including difficulties accessing BSL interpreters and a lack of other reasonable adjustments to meet their communication needs. Other groups, including Roma, Gypsy and Traveller communities, and people who are socially isolated and not online also had concerns about accessing up-to-date information.

## **What have we learned?**

- Accessible information and meeting people’s communication needs must be considered from the start and should not be an afterthought. It is unacceptable for health advice not to meet the Accessible Information Standard at any time, but especially during an emerging public health crisis.
- Not everyone accesses information through the most widely-used channels. To reach more people whose first language is not English, information must also be shared through trusted sources, such as community centres and groups.

## Rapidly busting myths: Do Not Attempt Resuscitation (DNAR) forms

During early lockdown, we heard concerns about service providers seeking to apply DNAR forms to patients without sufficient discussion or explanation with the individuals and their families. Whilst these concerns were limited in number, they were alarming. Along with public pressure, multiple organisations wrote to adult social care providers and GP practices at the end of March, including; the British Medical Association; Care Provider Alliance; Care Quality Commission; and the Royal College of General Practitioners. Healthwatch escalated this issue in early April to the Department of Health and Social Care and NHS England and, within 24 hours, NHS England wrote to all parts of the system on 7 April to reiterate that decisions about DNAR forms “should only ever be made on an individual basis and in consultation with the individual or their family”.<sup>1</sup> Healthwatch England advised on local issues by producing a briefing the next day, to provide guidance for local Healthwatch across England.

## Emergency dental care

Before COVID-19, Healthwatch regularly heard from people who were struggling to find a dentist in some parts of the country. Since the start of the pandemic, this problem has become challenging for even more people. While routine appointments were on hold, people did not know how to access emergency dental care – causing them extra stress while experiencing acute dental pain or other serious symptoms.

In June, as dental practices started to reopen for routine appointments, we heard that the information being provided from some services was inconsistent or confusing, leaving people unsure about whether they were running again, and what treatment would be available. Some people reported being told to call their dental practice by NHS111, only to be redirected back to NHS111 by the dental practice's voicemail message. We also heard about some cases of dentists applying additional charges to patients to cover the cost of PPE, making dental care even less accessible. It was not clear from our evidence whether people ended up paying for private treatment or were paying more than the NHS treatment band costs.

However, since the beginning of July, people have started to tell us they feel they have no option but to go private if they want to receive treatment for what their dentist has deemed non-emergency treatment. We will continue to monitor this feedback for our next quarterly report.

## Digital and telephone care

As a result of the COVID-19 pandemic, there has been a significant shift towards more care being delivered via digital and telephone appointments. We received positive feedback about this, with many people finding it a convenient and efficient way to speak with their healthcare professionals – particularly if they live in a rural area.

However, we know that these kinds of appointments do not work for everyone. We heard concerns about the accessibility of remote care for people with additional



communication needs, as well as people who do not use the internet. People also told us that digital or telephone appointments and assessments are not always suitable for people living with dementia, autistic people, and those with learning disabilities. For example, some older people with learning disabilities found video calls in their homes scary and intrusive. Many need help to get online, and the people supporting them are not always able to provide this.

Without alternative options for those who need them, the shift to digital and telephone care risks leaving many people behind.

As a registered patient, I booked online for a video appointment... A text arrived from the doctor at my appointment time. I clicked on it, was able to use the video app in seconds, and there was my doctor on my phone! I never thought it would work. He liked it as he could see me which might help a bit with diagnosis. He issued a prescription which was sent electronically to the chemist for me to collect same day. Very lucky to have this service!

Healthwatch Bucks

## What have we learned?

Healthcare services should embrace technology but should not be exclusively digital.



## Access to B12 injections

Accessing vitamin B injections was another challenge throughout the pandemic. Although some people received injections, either as normal or at a different GP practice, we also heard that in many areas there was an inconsistent approach to providing this treatment. Some people told us their treatment was changed from injections to tablets, despite this not being a suitable alternative for their condition. This also made them doubt the level of knowledge of their healthcare professionals. In other cases, people were advised to purchase alternatives over-the-counter or online – leading to concerns about the risks involved, without people receiving sufficient information or clinical monitoring. People told us about the worrying symptoms they were experiencing as a result of not receiving vitamin B12 treatment – including extreme tiredness, confusion, low mood and hair loss. Some felt that their symptoms were not taken seriously enough by their healthcare professionals.

## Care homes

Our insight on care homes demonstrates very mixed experiences across the country. People raised concerns about access to testing and PPE in these settings, as well as for home care workers and informal carers. People's feedback highlighted that while family and friends were unable to visit their loved ones in care homes, timely and regular communication from care home staff really mattered – especially surrounding discussions about advance care

planning or if the resident was approaching the end of their life.

The importance of communication in care homes Two members of the public shared their personal experience with their local Healthwatch, one positive, and one negative - demonstrating the impact communication or a lack thereof can cause.

#### Positive experience:

“I hold power of attorney for my mother who is in a care home. The manager called me to discuss end of life care during the coronavirus pandemic. My mother has signed a DNR already and has capacity to do this.

The manager asked if I would want my mother to be cared for in the hospital or at the care home if she got coronavirus. I was told that the care home had drawn up plans to care for COVID-19 residents in a separate room and that I would be able to visit my mother if I wore PPE. I was very pleased to hear this as my fear was my mother dying in hospital alone.

I am very grateful to the care home for drawing up these plans.”

Healthwatch Warwickshire

#### Negative experience:

“My mum is currently living in a care home. She has been there since the start of the year after a fall at home. She was

supposed to go back home with home carers before lockdown, but this was postponed... I am very upset with the care home. I found out my mum had COVID-19 four days after she began to deteriorate. I received a call from the care home telling me and any other close family members to video call my mum as it wasn't looking very hopeful that she would survive the virus. This was the first I knew that my mum had symptoms. I am very unhappy with this care."

Healthwatch York

## The hidden impact on families and carers

Families and carers have faced huge challenges due to the closure of respite and day centre services during this time. The lack of respite has left many feeling stressed, isolated and forgotten about. Research published by Carers UK in April showed that 70% of unpaid carers were providing even more care due to the pandemic, and 55% felt overwhelmed by their caring responsibilities and were worried about burning out in the weeks ahead.

People who care for someone living with dementia told us that the lack of social contact and stimulation had caused a deterioration in the health of the person they care for. We also heard about the difficulties some people faced helping the person that they care for to understand and remember the lockdown measures and why they could not go out as usual. Families and carers told us they felt uninformed and unprepared when the person they care for was discharged

from a hospital stay, due to a lack of communication or clear information from the hospital.

Healthwatch England is currently undertaking a national project on hospital discharge during the pandemic. This work is exploring how well the rapid discharge guidance worked for patients and their families and carers.

My father was discharged from a hospital stay after cardiac treatment and with probable COVID-19. My mother, who is 78, has been caring for him. She was advised to wear a mask and gloves but not provided with any instructions about how best to use PPE so has been using household items... Once at home my father fell twice and had to be helped up by my mother, so isolating from each other was not possible. He has since been readmitted to the hospital.

- Healthwatch Northamptonshire

## What have we learned?

- Families and carers have been providing even more care than usual during the pandemic - but this often goes unnoticed, and many need more support.
- The usual respite that carers rely on for a break, such as day and evening services, have all been cancelled, putting an extra strain on families.
- Ensuring communication between care home staff, residents and their family and friends is key, particularly while visiting restrictions are in place. Where appropriate, this should include involving residents' families or next of kin in decision making about their care.

## Praise for health and social care workers

Throughout the pandemic, we have heard about how much people appreciate the hard work of health and social care professionals during this time of unprecedented challenges. In particular, we noted an increase in positive experiences of urgent and emergency care services - with the amount of positive feedback increasing to 45%, compared to 36% last quarter. Whilst the reduced number of people attending A&E is likely to have reduced waiting times, people have also praised healthcare staff's professionalism and care - highlighting how reassuring this was, particularly as many had been reluctant to attend these services in the first place.

One patient describes their trip to the hospital as advised by their GP, after experiencing some cardiac symptoms. I didn't want to go to the emergency department, as I felt I could be wasting their time during this busy period. When I arrived, the waiting area was completely empty, although there was a steady stream of ambulances arriving outside. My wife was told to go home and wait there for me as part of their coronavirus protocols. I didn't wait long before being seen. The doctor was thorough, listened to me, and I felt reassured by the use of PPE and the protocols which were in place to keep me away from other patients during my visit. I was sent home, reassured that I had had a thorough examination and that I could go back if I needed to. Thank you, NHS staff, for making time for me at this busy time."

Healthwatch Sunderland

## The impact on people's mental health

Since the start of lockdown, we have heard about the effects of the pandemic on people's mental health and wellbeing. Factors such as loneliness and social isolation, bereavement, employment and financial stress, and anxiety about both COVID-19 and other health conditions have all had a negative impact. We also heard that some autistic people were feeling more anxious due to not being able to follow their usual routines.

Overall, we receive predominantly negative feedback about mental health services; this has remained the case during the COVID-19 pandemic. For some people, the changes to the services they would usually access have left them feeling abandoned - with infrequent telephone appointments not meeting their needs. We heard that some people found talking to a stranger on the phone very difficult and wanted more regular, consistent support by phone, or face-to-face contact - particularly if they were close to crisis point.

I had an appointment for an assessment with a specialist psychotherapy service at the beginning of April that was cancelled. No other support was offered, I was just told that I could ring the crisis team and out of hours team. I don't feel able to do that as I don't know what the process would be, and I have auditory processing difficulties that make telephone contact very difficult. I have been left at crisis point with no named person to contact, no care coordinator, just medication and being under the care of my well meaning GP who can't do anything else to help me.

Healthwatch Sheffield

## What have we learned?

- The mental health impacts of the pandemic are affecting both existing service users and non-service users. Mental health services will require investment to support people in both the short and long-term.

## Technology in response to the pandemic

### What can we learn?

As previously noted, the pandemic has seen the digitisation of many health and social care services overnight, combatting the lockdown restrictions which were in place. While we learnt that digital appointments don't work for everyone, and services should not be exclusively digital, it's important healthcare services embrace technology for those who find it an efficient way to communicate. Our work on the two projects below demonstrates new ways of services working to embrace this shift to the digitalisation of healthcare; Doctor Zoom, and the COVID-19 contact-tracing app. We share what we can learn from the rapid roll-out of virtual NHS consultations, and the importance of involving patients from the start when setting up new services.

### The doctor will zoom you now

Healthwatch England recently partnered with Traverse and National Voices to undertake research exploring people's experiences of remote appointments since the start of the pandemic. You can read more about the project or read the report.

Based on in-depth interviews with the public, we've developed some tips to help you improve people's experiences of virtual health and care appointments. To be



clear, these tips are about making changes where services can and are able to. We will be doing further work in the autumn looking at healthcare for those whom digital options do not work.

## Nine tips to improve digital consultations

1. Provide a precise time window for appointments.
2. Check that the person is in a confidential and safe place to have the phone or video call.
3. Understand the person's level of confidence using technology and give people a choice of how to communicate.
4. Proactively check what the patient needs, clarify what is happening next, and who is responsible for the next stages of care.
5. Slow down the pace of the consultation, demonstrate active listening.
6. Use the chat function in video calls to make the appointment more interactive; share links to information; and summarise next steps.
7. Don't ask people to provide information you already have access to.
8. Give guidance about how the appointment will work; offer demonstrations; provide an opportunity for a test run or provide some training.
9. Seek feedback about people's experiences and use this to improve the service.

You can also read our top tips for patients on how they can get the most out of their virtual consultations - you can read more.



## COVID-19 contact-tracing app

In May and June, the contact-tracing app initiative was piloted on the Isle of Wight, aimed at supporting a safer transition out of the lockdown and preventing a resurgence of the virus. Members of the public initially expressed a high level of support for the app and willingness to engage with the trial, as shared with Healthwatch Isle of Wight.

However, the local Healthwatch reported a shift in public opinion, following a lack of communication about the results of the pilot, and how improvements would be made as a result. Many are now frustrated with the Government's efforts and communications.

From our past research, we know that most people are happy for the NHS to use personal data to improve health, especially if they are certain that the data will be kept anonymous and will only be used for the specific purpose to which they have given consent.

Throughout the app's development, Healthwatch England has made the case that to ensure the app's success, the public will need to feel confident about understanding the answers to the following questions around the privacy of the app:

- What data will the app capture?
- How will it be captured?
- How will it be used?
- Who will have access?
- How long will they have access to it?
- What happens to anyone who misuses the data?

In August, the NHS released a revamped COVID-19 contact-tracing app for testing. Read our response to this news.

You can read more about our involvement with the contact-tracing app and further recommendations, as we look at how the new app addresses many of the concerns people have when it comes to their data privacy and security. [Read more](#)

## How do people feel about their care?

Here we provide an overview of how people feel about their care. We do this by using sentiment scores by sector, using data reported by local Healthwatch. This outlines whether the public feel mainly positive or negative about the care they receive, or whether they have neutral or mixed views.

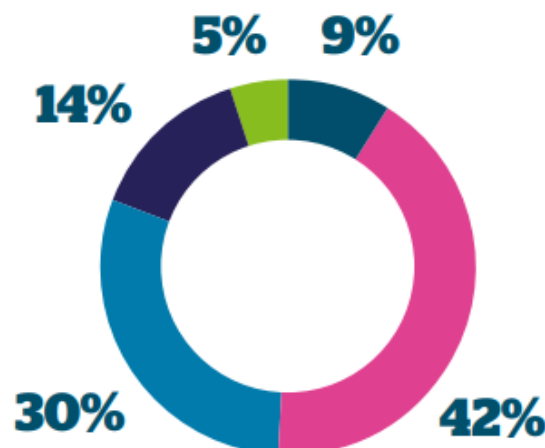
We have noted an increase in positive experiences of urgent and emergency care services - with the amount of positive feedback increasing to 45%, compared to 36% last quarter.

**Key**



### Primary care

2,666 people's experiences informed this section

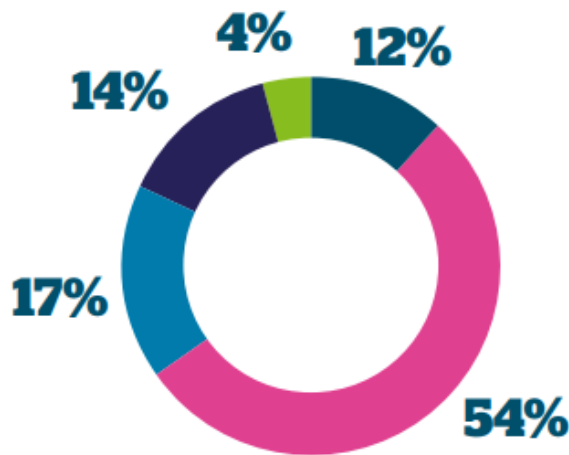


Key

- Positive
- Negative
- Neutral
- Mixed
- Unknown

### Secondary care

1,103 people's experiences informed this section

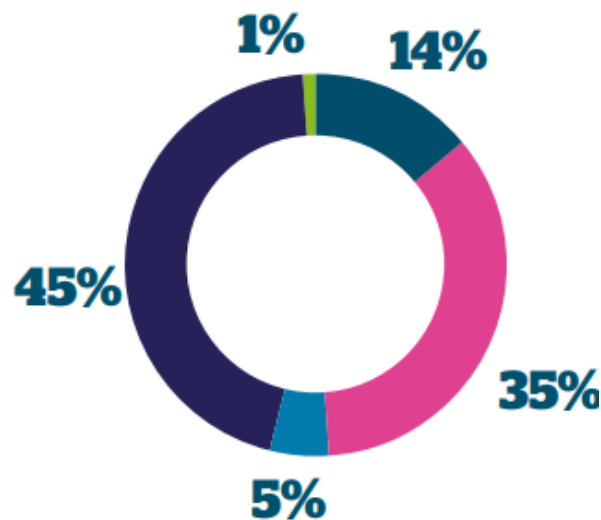


Key

- Positive
- Negative
- Neutral
- Mixed
- Unknown

### Urgent care

1,103 people's experiences informed this section

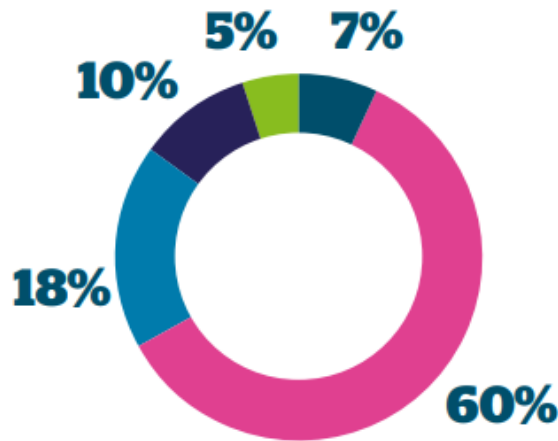


Key

- Positive
- Negative
- Neutral
- Mixed
- Unknown

### Mental health

1,762 people's experiences informed this section

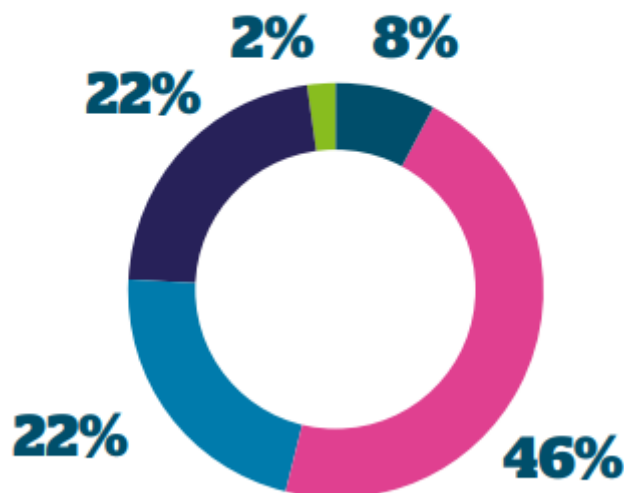


Key

- Positive
- Negative
- Neutral
- Mixed
- Unknown

### Social care

1,631 people's experiences informed this section

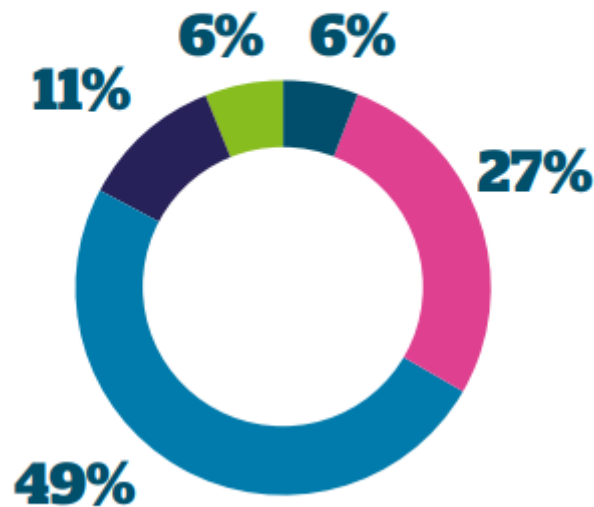


Key

- Positive
- Negative
- Neutral
- Mixed
- Unknown

## Community and other services

**12,462** people's experiences  
informed this section



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