What people are telling us

A summary (January – March 2020)

Introduction

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

- Key issues the public have told us about primary, secondary, mental health and social care support.
- The top questions people are seeking advice about.

This report covers the period January – March 2020 and is informed by 30,421 people's experience of care. This period covers the start of the COVID-19 pandemic.

What issues cut across health and care?

Read how a **lack of support whilst waiting for treatment** is affecting people's experiences, and about the **initial impact of the COVID-19 pandemic.**

Speak Up 2020

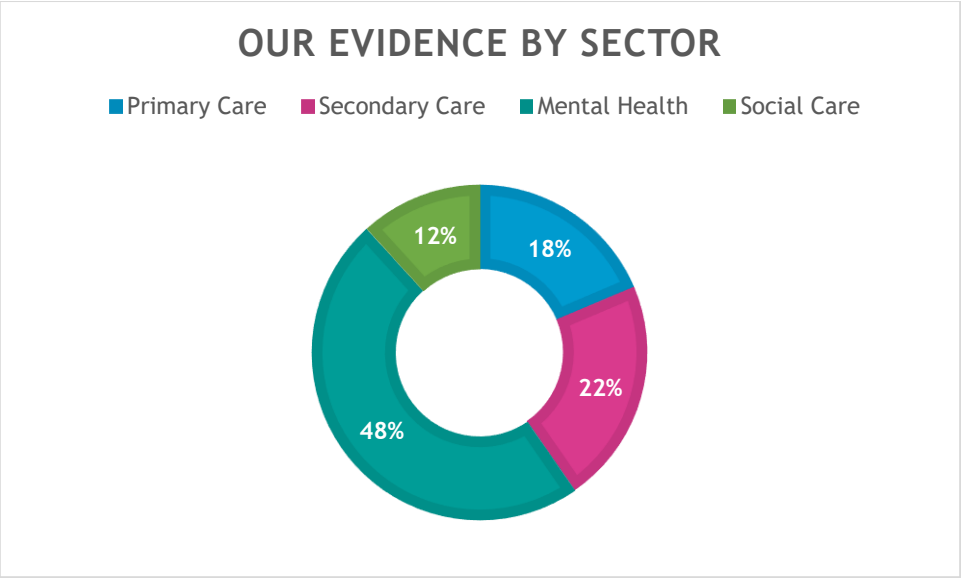
Read about the findings of our January '#SpeakUp2020' campaign to find out about people's experiences of care.

What's happening in my sector?

Look at our primary care, secondary care, mental health and social care snap shots to see the ongoing concerns people would like services to address. These sections and the recommendations have been developed from feedback shared with us before or at the very start of the pandemic.

The evidence that informs this report

27,160 people's views drawn from 170 Healthwatch reports published to our reports library about local NHS and social care services, as well as individual feedback from the public. The graph below shows the proportion of all our evidence by sector.



The top questions people are seeking advice about

1. How do I make a complaint?
2. How do I access advocacy support?
3. What services are available for me to access support with my mental health?
4. How can I access out of hours services?
5. How can I find a local GP?
6. What are my options if I need care?

Issues that cut across health and care

Find out about the issues that people raise in every area of care.

What happens while you wait?

Before the COVID-19 pandemic started, we heard the impact delays were having to people's experiences of care involving:

- Getting an appointment
- Surgery
- Assessment
- Support or treatment
- Being on a waiting list
- Waiting in the hospital or GP surgery to be seen

However, to meet the substantial increase in patients as a result of COVID-19, the NHS implemented a blanket postponement of many routine treatments. We will undoubtedly see a spike in this issue. It will also continue to be an issue for some time as the NHS looks to get back on track with waiting lists.

People have been sharing experiences of what it is like to wait for longer times than expected for appointments with us for some time. This insight may provide some valuable suggestions to providers about how they can help people have positive experiences and be reassured during extended waiting times.

Our evidence has shown that people may not mind waiting if they are given information about how long it will be until they see someone and if it is updated on a regular basis. People also value information on how they can support themselves in the meantime. If waiting in hospital or GP waiting rooms, people want to have reasonable facilities, including water, other refreshments and comfortable chairs.[1]

Steps that people say would have helped improve their care:

[1] See *What Matters to people using A&E*, Healthwatch England, February 2020

- Provide updates and communicate to people about how long they can expect to wait for an appointment, support, surgery or treatment.
- Tell people what support or action they can take in the meantime to manage their health condition.
- Provide regular updates to reassure people that they have not been removed from the waiting list.
- Provide estimated waiting times in hospitals and GP surgery waiting rooms so people know what to expect.
- Improve the comfort of waiting areas and provide refreshments.

How long do I have to wait?

Due to abdominal pains a man contacted NHS 111 who signposted him to an urgent care centre. After waiting two hours to be seen, he was given a 9am 'ambulatory care' appointment at the local hospital for the following day. When he went to hospital, the receptionist told him that she didn't have a record of his appointment and told him to wait. Over an hour later, the man asked the receptionist for an update. She said she couldn't see his details on the screen and told him to wait again. The man was seen shortly afterwards and had various checks before being sent through to another area and told to wait. After a while, he had a further examination and was told to wait again. A trolley with sandwiches came around to everyone in the waiting area except him. He later discovered that this was because he had abdominal pains, but no one explained this to him. After waiting four hours the man spoke to someone again about his wait. He had previously informed staff that he was a full-time carer for his wife so couldn't be away too long and he reiterated this. He was again told to wait. After waiting for five hours he told a nurse he was going home. She responded that he had to wait until he was seen by a doctor to release him. After a further 20 minutes, he signed a release form and left.

"I felt fobbed off every time I asked hospital staff about the time I had to wait. There was nothing to read and no information on waiting times. Initially there were no cups at the water dispenser".[2]

[2] 1642_6958, Healthwatch North Tyneside

Other cross cutting issues:	Steps that people say would have helped improve their care:
Poor administration	• When services return to normal, ensure that correct information about appointment dates and times are provided to people. • Communicating whilst people wait for referrals is essential so that they do not continue to chase them up. This will help to identify where administration errors may occur which delay referrals.
Staff attitudes	• Remind staff of the importance of taking time to listen to people to understand their needs. Being mindful to be empathetic and not dismissive is especially important to vulnerable people, those who face language barriers, and people with multiple conditions. • Emphasise the importance of offering personalised care, with people getting choice and control over the way their support is planned and delivered.
Lack of communication between services	• Review the current communication channels between services, if any, to ensure that they address any difficulties and better integrate services.

The impact of the coronavirus pandemic

In March 2020, as the coronavirus pandemic unfolded across the country, people started to share with us their questions, views and experiences of health and social care during this time.

These are some of the key issues that people told us about:

Information for everyone

People highlighted how important it is for information to be clear and accessible to everyone – especially as government advice was developing and changing quickly.

We heard that people were particularly struggling to find information in British Sign Language, Easy Read format, and other community languages. People also raised concerns about accessing up-to-date information for other groups – including Roma, Gypsy and Traveller communities, and people who are socially isolated and do not use the internet.

Managing long term conditions

People expressed worries about managing their long-term health conditions, and asked questions about what to do or expect from the services they would usually access during this time.

These issues presented even more of a challenge for people who struggled to get through to their GP practice on the phone or had not yet received any information about the changes to their local services. This made it difficult and stressful for people to access their repeat prescriptions – especially if they were not able to use online systems as an alternative.

Some people with existing health conditions told us they were finding it difficult to understand which advice applied to them, including advice about shielding. While some people believed they should be shielding didn't receive the letter telling them to do so, others received the letter unexpectedly.

Social care support

People who rely on home care raised concerns about getting the support they need – particularly if their care support workers or family carers became unwell. We heard that people were unsure about whether care workers should be wearing personal protective equipment (PPE) when providing care at home, and if so, where they could get it from.

We also started to hear about the impact of social distancing measures on the respite support available:

"In the initial announcement, children with special educational needs were going to continue to go to school. We have been firmly told by the school today that our child should not be attending. While I completely understanding what the government is trying to do, I'm not sure how we are going to manage. We have respite provided by my parents

(who are both over 70) and community groups – but all of this has stopped now. We manage well with this support but do rely on it. I am anxious about the future now."[3]

Praise for health and social care professionals

As always, we have heard how much people appreciate health and social care professionals when they or their family receive great care.

"My father was rushed into A&E. He was treated as soon as he arrived, tested for coronavirus as he had a chest infection. Staff had masks, gloves and aprons on until they got the results. As a family, we were treated with respect and kept informed of what was going on."[4]

While these are some of the main issues we heard about during March 2020, we continue to review all the feedback we receive about people's experiences of health and social care during the coronavirus pandemic. Our plans are to investigate hospital discharge and the impact of COVID-19 on social care.

We are keen for the Healthwatch network to continue engaging and capturing views on a wide variety of issues – from the experiences of people who have had routine treatment cancelled and may now face an extended wait, to those who have been using new digital systems to interact with care. Ultimately, we want to make sure we capture the good that has come out of the health and social care system's response to COVID-19, but also ensure that any gaps are closed as quickly as possible.

[3] Healthwatch York, 1693_3950

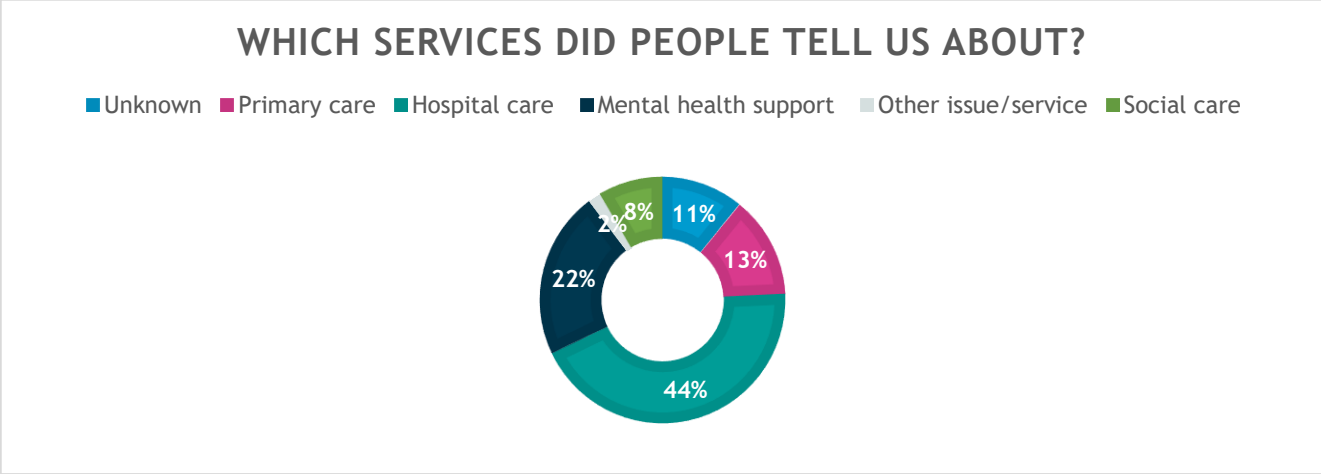
[4] Healthwatch Bedford Borough, 1704_5640

Speak Up 2020

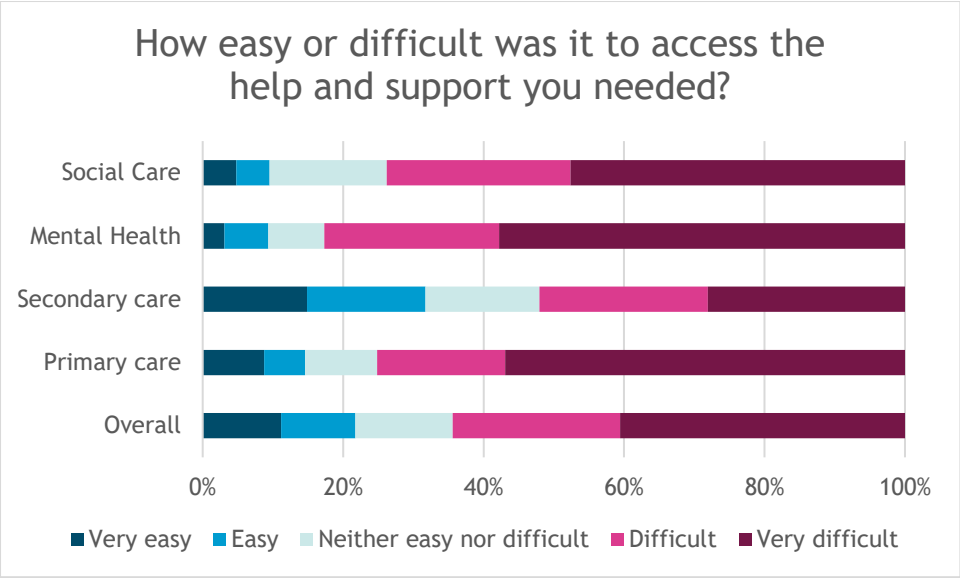
In January we undertook the '#SpeakUp2020' campaign to get people's views on the top priority areas that the network is working on: mental health, social care, and hospital care, as well as other services and issues. We hosted a short survey on the Healthwatch England website and received 1,044 responses from people living all over England.

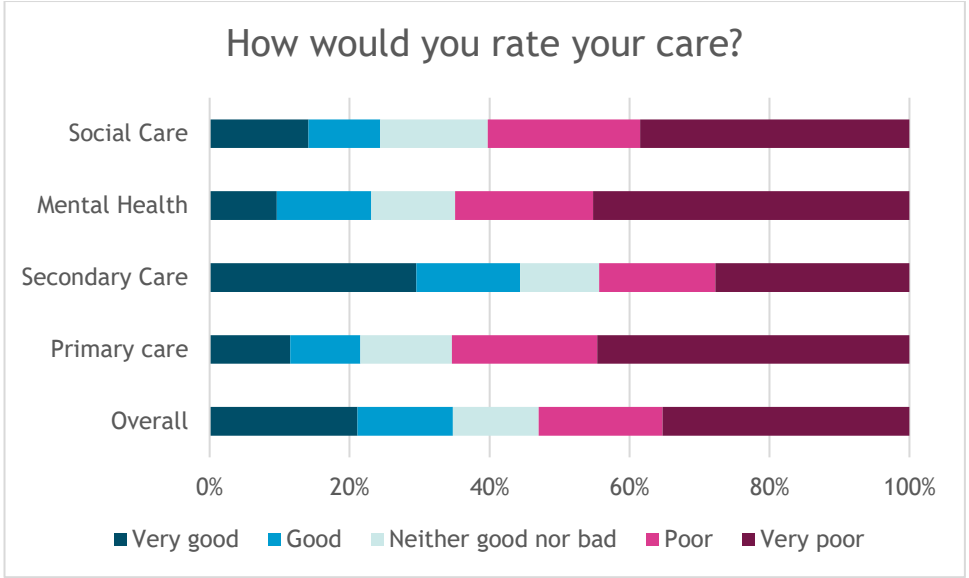
Of these people:

- 78% were women
- 74% were heterosexual
- 31% were aged 65 or over
- 12% were from Black, Asian and Minority Ethnic backgrounds
- 33% were disabled
- 49% had a long-term health condition
- 20% were carers



The survey asked people to tell us about their experience of accessing the help and support they needed, how they rated their care, and their experience of further treatment or care.





These charts show that survey respondents who had sought treatment from secondary care had better experiences than people who needed treatment from mental health or primary care providers. Four out of five people who needed support from mental health services found it difficult or very difficult to access it, compared to half of people who needed to access secondary care.

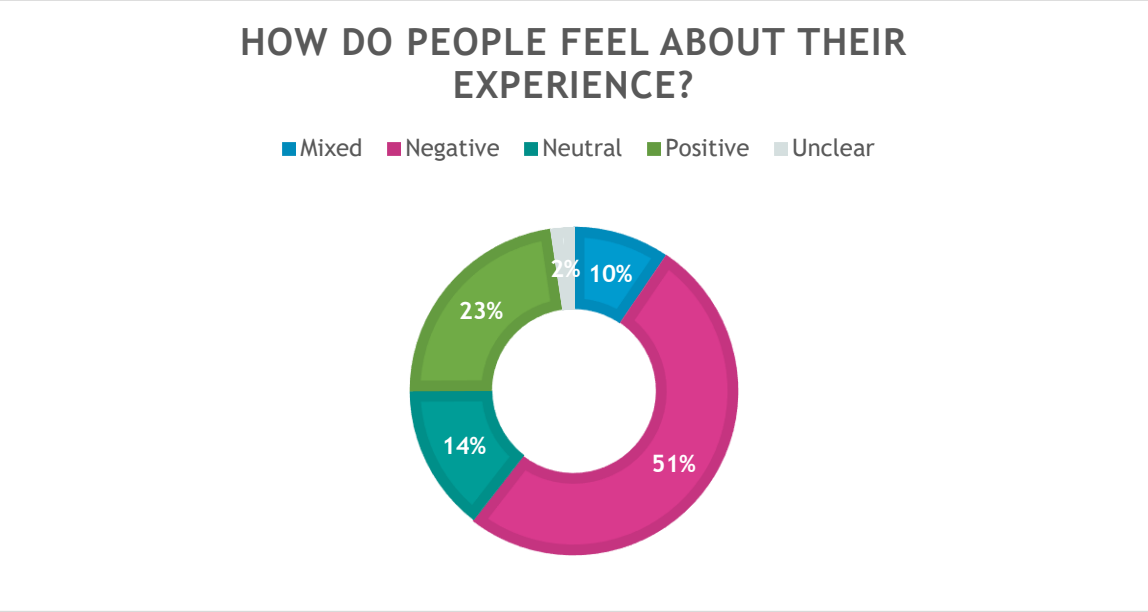
"I was desperately depressed, anxious and suicidal. My doctor referred me to a mental health team. The team CANCELLED five appointments before I actually got to see them."[5]

[5] Quote from the survey

Ongoing issues by service area

Primary care

5,666 people's experiences informed this section.



Service area:	Ongoing issues:	Steps that people say would have helped improve their care:
General Practice	Difficulties in getting an appointment	• Offering more dates in advance for online appointments. • Better telephone systems to reduce time left on hold, and prevent people being turned away after travelling to GP to book an appointment in person. • Ensuring that people know about extended access programmes.

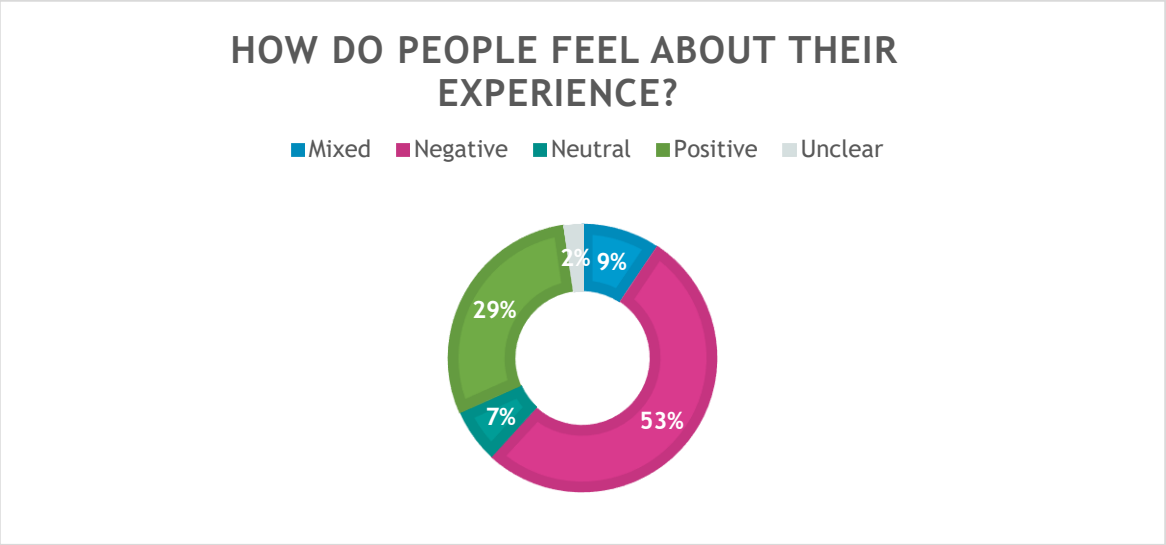
Dentistry	Access to NHS dentistry	• Increase the availability of dental appointments.
	Clarity about the cost of NHS dentistry	• Be transparent about costs prior to treatment. • Promote sources of help with finances e.g. NHS Low Income Scheme, to help people avoid delaying treatment.

"I'm struggling to get an appointment at my GP practice. I tried calling and was on hold for over 45 minutes on one occasion and 37 minutes another. When I go into the practice, they say I must call at 8am in the morning, but by the time I call all the appointments have gone. I'm a diabetic and need my prescription updated but the receptionist just says to call the next day. Getting fed up with this."[6]

[6] [6] HW Warwickshire, 1685_2853, 2/2/2020

Secondary Care

6,618 people's experiences informed this section.



Service area:	Ongoing issue:	Steps that people say would have helped improve their care:
Urgent and emergency care	Lack of patient transport	• Individual circumstances, such as inability to pay for taxis, should be considered. • Better coordination of patient transport and investment in its provision.
	Difficulties accessing NHS 111	• Provide clear and realistic information on what to do or who to call, if a person is unable to talk to someone on the phone.
Hospitals	Lack of understanding around how to complain	• Provide clear information about how people can make a complaint.

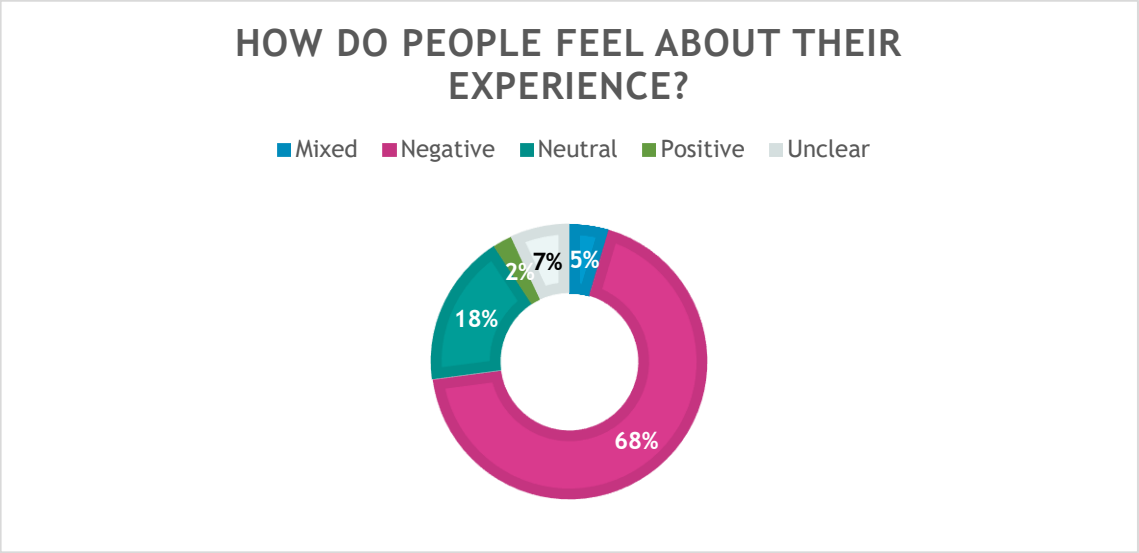
How do I get home after being discharged?

"A person told us about their experience of being discharged from A&E, following admission by ambulance. They say they were told that there was no patient transport provision. They were concerned that they only had their nightwear and slippers and no purse, and that they would have had to take multiple buses to get back home."[7]

[7] Healthwatch North Yorkshire, 1785_3325

Mental health services

14,561 people's experiences informed this section.[8]



Ongoing issue:	Steps that people say would have helped improve their care:
Family involvement	• Clearly outline the expectations of care with all people who are involved in someone's care. This will improve communication between health professionals and the public, as well as empower people to feel involved in their care.
Holistic support	• Remind staff of the importance of taking time to listen to people to understand additional factors that may be exacerbating their issues. • Consider working alongside integrated health and social care teams.

[8] This figure is larger than usual due to a local Healthwatch report about the mental health needs of young people based on a sample of 11,950

Disagreement with diagnosis	• Encourage clear communication about how a diagnosis was made. • Allow for discussion with the person and loved ones involved.
Medication management	• Provide regular medication reviews to monitor side effects and allow discussion of additional worries with the person taking medication.

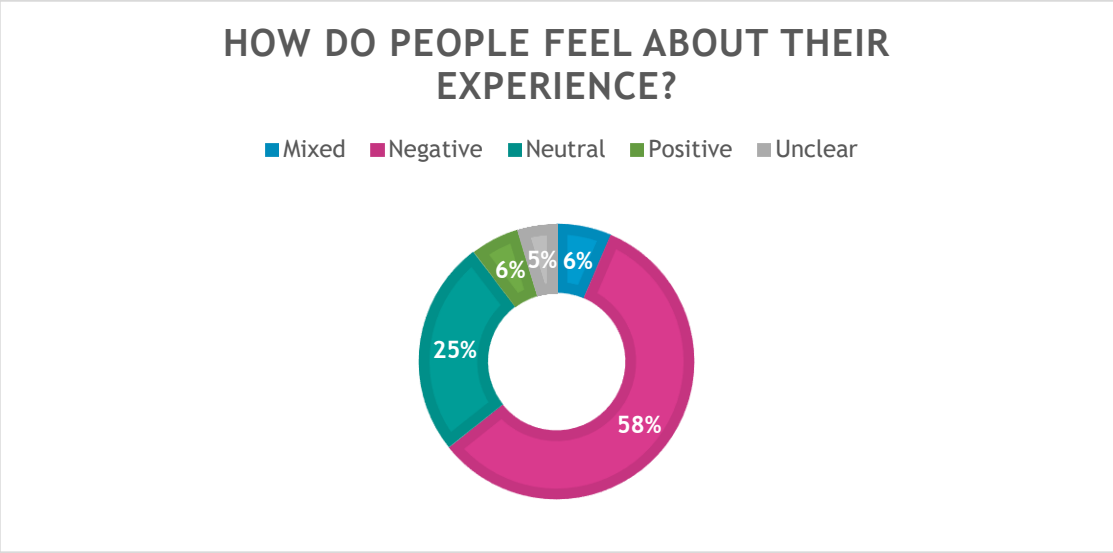
My psychiatrist won't change my medication

"Someone contacted us as they would like to make a complaint about their psychiatrist's unwillingness to consider a change of medication. The medication was making them drowsy and they couldn't work as a result. They are too frightened of the withdrawal symptoms to consider changing their medication regime without medical supervision."[9]

[9] Healthwatch Hertfordshire, 1705_3104

Social care

3,576 people's experiences informed this section.



Ongoing issue:	Steps that people say would have helped improve their care:
Paid carers aren't always providing good quality care	• Ensure all paid carers are aware of the basic standards of care they are expected to provide and how families can contact them outside normal working hours. • Ensure that domiciliary care companies can continuously improve the quality of care they provide. • Parliamentarians should listen to the care sector to understand why paid carers might not always provide good standards of care ahead of social care reform.

Experience of poor-quality care

"A woman receiving domiciliary care following an operation told us about problems with one care worker who had offered to empty the chemical commode. Although she tried to explain to the care worker that the commode could only be safely emptied by a specialist company, the care worker took the full commode up to the bathroom and brought it down half full. When the woman's grandson came home, he found that they had spilled the contents in the bathroom, landing and up the stairs, and that the care worker had used towels to mop up the mess and then put the soiled towels over clothes drying on the banister. The carer also put their hand on the woman's chest when she tried to get up and told her to sit down. The woman did not like this."[10]

[10] Healthwatch Hillingdon, 1617_5794