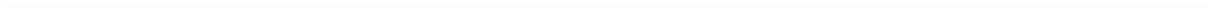
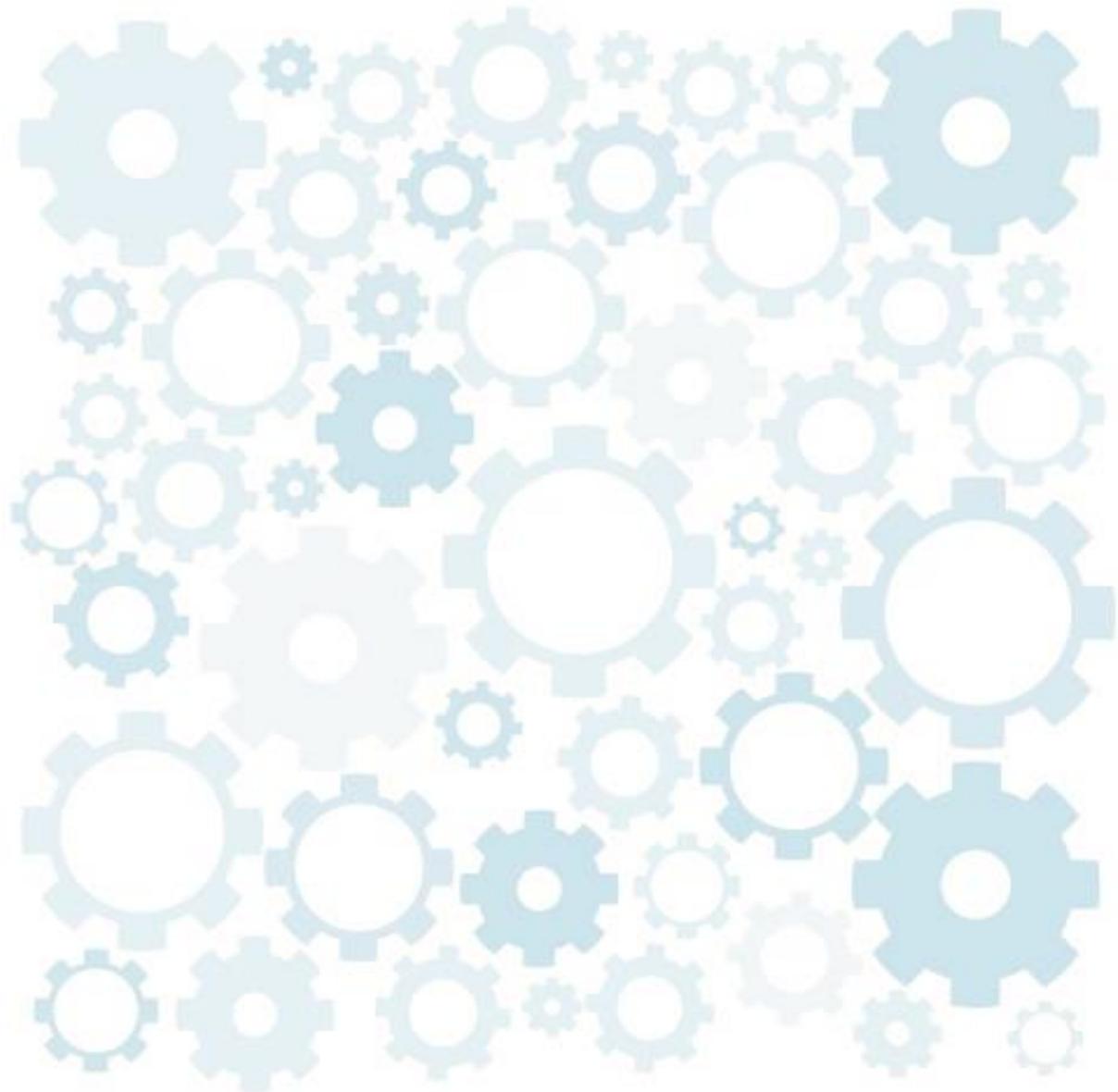


# **What people have told us about health and social care**

**A review of our evidence October - December  
2018**

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## Overview: What people told us this quarter

**People want health and social care support that works for them – helping them stay well, get the best out of services and manage any conditions they face. Our job is to find out what matters to the public and to help make sure their views shape the support available.**

Between October and December 2018, Healthwatch England received 11,864 people's experiences and views of health and social care from our network. We collate these experiences and views to understand what people are saying. This briefing outlines our findings for the last three months and how we're using this information to help shape health and social care policy and practice.

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## What did people speak to Healthwatch about this quarter?

Below is a summary of the issues – new and established – that we identified in the evidence gathered this quarter. Later in the report we explain in more detail what people told Healthwatch about each of these areas.

### Doctors surgeries, dentists, pharmacists, and other primary care support

#### What's new this quarter?

People are finding it difficult to get their medication when they need it.

#### What do we continue to hear?

- It is not always easy to get an appointment to see a GP.
- Communication between GPs and patients can be poor.
- It is difficult to register and/or make an appointment with a dentist.
- Poor quality dental work can lead to further treatment.

### Hospital care including urgent and emergency care

#### What's new this quarter?

- Some people felt they waited too long before being discharged from hospital and others felt they were discharged too soon.
- People are not always able to choose where they receive treatment.
- Experiences of receiving support in A&E for mental health emergencies can be poor.
- People are having difficulties finding somewhere appropriate to park when arriving at hospital.

#### What do we continue to hear?

- People continue to wait too long for treatment in A&E.
  - The quality of medical treatment in hospitals is good although customer care may not be.
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- People are waiting too long for appointments and operations at hospitals.
- Parents and carers are not supported while they wait in A&E.
- Follow-up communication and information sharing can be limited and untimely.

## **Social care**

### **What's new this quarter?**

- There is variation in the quality of care delivered to people in their homes.
- The cost of care home services is not always clear and transparent.
- Families are finding it hard to get care plans reviewed when they believe their relatives' care needs appear to be unmet.

### **What do we continue to hear?**

- People need to know how to access information about care assessments, care homes and care at home.
- Some people have difficulty finding the most appropriate home care services for themselves or a loved one.
- More variation in stimulation for care home residents is needed.
- Levels of training among staff need to be improved, particularly for dementia care.

## **Mental health**

### **What's new this quarter?**

- Some groups of people face difficulties in accessing support because they do not meet the necessary criteria.

### **What do we continue to hear?**

- There is no straightforward pathway to access support for mental health challenges.
- Children and adults are waiting a long time to get the support they need.

## **People with limited family and social networks**

Our research has highlighted issues regarding people with limited family and social networks. Here are some common issues people told us about:

- Those with mental health concerns have a need for extra support, particularly with managing medication.
- There is a lack of safe housing for people recovering from addiction leading to some people becoming homeless.
- There is insufficient additional support to help those with memory problems ensure they attend appointments.

- People need support to overcome social isolation.
- People without transport find it difficult to attend appointments at short notice.

## **In Focus: Problems with medication**

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### **What people are telling us**

People have spoken to Healthwatch this quarter about issues they've experienced with their GP and pharmacist when trying to get the medication they need.

### **Problems with prescribed medication**

Difficulty in getting GP appointments can mean that people don't get diagnosed and prescribed with the medication they need, as quickly as they need it.

We also heard from people whose medication had been changed without them knowing and others whose new medication caused them to experience allergic reactions or had conflicted with their existing prescription. In other serious cases, people said they were given the wrong medication altogether by their GP.

People often told Healthwatch that they felt these problems occurred because their GP didn't listen to them. Some said they felt disappointed with their GP's attitude, lack of empathy and disregard for their views.

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### **Personal story: Incorrect medication**

"I see my GP every 3 months for my Depo contraceptive injection. I went yesterday and I saw a different GP. She told me that my notes state I was given a Vitamin B12 injection instead of my contraceptive last visit. She checked the stock and confirmed that I was in fact given Vitamin B12. I had to take an emergency pregnancy test, which was negative, but I could still be pregnant. I must wait for 4 weeks and have another pregnancy test before I can have my contraceptive injection. I've had 3 months of being without contraceptive cover because of their mistake."

Healthwatch Kent

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### **Personal story: Unexpected changes to medication**

"Caller is a patient at [name of GP practice]. The practice has stopped all her medications and told her that she needs a blood test. She regularly has blood tests in hospital and her consultants have previously written to her GP asking them to continue to prescribe. She had a meds review very recently. She has said she is happy to have a blood test, but is running low on medications including painkillers and needs them to be prescribed urgently. She has struggled to get medications in the past and has sometimes ended up getting the hospital to prescribe them instead, but does not understand why her meds have been stopped this time."

Healthwatch Haringey

## People having difficulties in accessing their medication

We heard from people who had the right prescription, but pharmacies didn't have their medications in stock when they tried to collect them.

Not being able to get medication as soon as it's needed can leave people feeling stressed and anxious, but it can also have other effects. For some it can make dealing with acute pain and infections more difficult, whilst others are left struggling to manage a broad range of chronic conditions such as eczema, poor mental health and cancer.

Moreover, we heard people say their pharmacy gave them different medication from the medication they were prescribed by their GP.

People told us how experiencing these problems with their medication had prolonged their recovery and, in more serious cases, had a negative impact on their long-term health and wellbeing.

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### Personal story: Problems with supply of medication

"Poor service, really long waits when waiting for prescriptions and most of the time don't have my medication in stock and they don't tell me and give me the opportunity to take it all somewhere else, not have to return there!"

#### Healthwatch Rochdale

"I spent some time in [service provider] due to illness. My issue was that I was ready to be discharged and allowed to go home after having been visited by the pain management team, who gave me a prescription for medication. But 4 hours later I was still there waiting for medication to come from the pharmacy. I have no idea why this process took so long. Surely a better way would be to go get the prescription at my own pharmacy."

#### Healthwatch Wakefield

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### Personal story: Pharmacy dispensing the wrong medication

"... [name of pharmacy] delivered the wrong prescription to [name of person], who is 87 years old. She contacted them immediately, advising the tablets were different to normal to be told they were the same but with a different name and to take as advised. She was taking the wrong medication for 15 days and feeling worse every day. [name of person] became increasingly poorly, to the point she was hardly unable to get up from her chair. Her daughter googled the tablets she was taking, to find they were not correct. There was a sticky label over the original name of the medication which was different to what was on sticky label. [name of person] went to her GP who did tests and found that the medication she had taken was dangerous to her health. The chemist is looking into this and her doctor advised she was lucky not to have continued taking them as she could well have suffered kidney failure and possibly death. This is the second time [name of pharmacy] have delivered the wrong medication to this lady. On a previous occasion she was given the wrong medication and was taking Prostate meds which resulted in low blood pressure."

#### Healthwatch Kent

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## The policy context: Problems with medication

Getting medication right is clearly an important part of effective treatment, but from a policy perspective it is also heavily linked to people's broader perceptions of how effective and efficient the NHS is. From the feedback we have received we have highlighted four ways in which access to medication can shape opinion of the NHS. These will be of particular interest to health and social care policy makers and professionals:

- **Building trust in a modern, truly integrated NHS**

Our conversations with the public suggest that people are in favour of being able to order repeat prescriptions online. They recognise this as part of broader efforts to bring their interaction with the NHS in line with how they use other services.

However, feedback on digital interactions with the NHS suggests problems with online orders are common. Those affected often then make additional comments about the NHS's ability to run a modern service. In particular, when it results in the wrong dosage being issued or new drugs conflicting with existing medications, people have questioned whether the NHS can deliver on more advanced services, such as personalised medicines.

Whilst comments in the last quarter largely focused on medications in relation to primary care, access to medications when leaving hospital have been a running theme over a long period of time. People report that poor communication between hospitals and primary care is making it difficult to get access to newly prescribed medications without having to make an additional trip to see the GP. As a result, people often say that they feel services are not well integrated.

To prevent confidence in an integrated and modern NHS being undermined, it is important to ensure good customer service around access to medications. This needs to be built on services showing they can consistently get the basics right, and working together to provide a seamless experience for people.

- **Availability of medications**

Feedback this quarter has highlighted how when medications aren't available it can have a negative impact, and in some cases a very serious effect, on people's care. Whilst the number of examples shared with Healthwatch this quarter were comparatively low, they were higher than usual. This also reflects [reports in the press](#) in recent weeks which suggest that the country is indeed facing supply issues with around 80 common medications (record high was 91 medications in Nov 2017). In response the NHS has agreed to pay more for medication where necessary, adding the items to the 'price concessions list'.

There is heightened public awareness of this issue at the moment with the additional concerns around medications supply in the event of a no-deal Brexit. It is therefore crucial that the NHS understands and communicates why there are pressures on certain drugs. Where effective short-term 'fixes' are implemented these need to be shared across services so the system as a whole is best placed to manage demand.

The Department of Health and Social Care has introduced a statutory instrument to enable pharmacists to dispense alternative medications to those in short supply without the need to go back to the prescribing clinician. This step will help reduce the impact on patients, who are often the ones who have to go back to the doctor, and reduce the burden on GPs

having to cope with additional demand on appointments. However, there are certain cases where prescribing alternative medications is not simple, or even possible, so it is vital that GPs and patients work together to find solutions.

- **‘Postcode lotteries’**

In response to broader funding pressures, in recent years Clinical Commission Groups (CCG) have introduced policies to help reduce expenditure on medication. This has seen some CCGs restrict certain medications they consider ineffective, switching to cheaper alternatives and stopping prescribing things patients access over the counter.

In an effort to ensure these policies are applied equitably across the country, NHS England (NHSE) and NHS Clinical Commissioners (NHSCC) have developed national guidance based on clinical evidence and public consultation. Work conducted by Healthwatch showed that people broadly supported the programme because they expect the NHS to manage its resources efficiently, even if it means they have to pay for over-the-counter products they may previously have got on prescription.

[See our response to the original consultation.](#)

However, concerns have been raised by many Healthwatch in the last quarter that CCGs are deviating from the national guidance. In other cases where NHS bodies have chosen not to follow national guidance, NICE guidance on IVF being a relevant example, they are required to present their own clinical evidence as to why. CCGs often do not do this, which ultimately challenges the value of national guidance.

Whilst Healthwatch recognises the national guidance on prescriptions isn't legally binding, in order to prevent 'postcode lotteries' we would suggest that individual CCGs be required to present their own independent clinical evidence in support of their decision. This should ideally be backed up with independent consultation with their community on any proposals.

- **Purchasing practices**

Whilst our research has shown that the public broadly support the changes to prescriptions mentioned above, in return they made it clear they want the NHS to demonstrate it is doing more to ensure efficient purchasing practices when buying medications from pharmaceutical companies.

In November NHSE and NHSCC announced the latest phase of changes to prescriptions stating how much money it could save. However, the announcement did not update the public on how much money the previous changes have saved already. It also did not include an update on how much the NHS itself has managed to save by negotiating better deals when purchasing medication.

One example of high purchasing prices that has been brought to the attention of Healthwatch is the cost of Liothyronine (T3), which is used to treat underactive Thyroids. Following responses from the public to the original consultation, the NHS does still prescribe this drug. However, concerns have been raised with us by individuals and organisations that CCGs have been seeking to restrict use since [price rises in recent years](#). This matter has been investigated by the Competition and Markets Authority but [costs remain significantly higher than in the EU](#). Given the public attention on this drug it would be a prime candidate for the NHS to demonstrate how it is working to ensure they are paying the best possible price for medications on the country's behalf.

The DHSC [announced](#) in December that the health service is set to save £1 billion on the medicines bill in 2019. It is important to ensure this message is getting through to people in their day-to-day interactions with the NHS.

## In Focus: Empathy

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### What people are telling us

One of the recurring themes we continue to hear about across all service areas is how important it is for people to be cared for with empathy. This quarter, we've heard about GPs who appear to disregard people's concerns, and who seem to be unable to understand how they feel.

Continuity of care is more important to certain groups than others. Some people tell us that they would like to see the same primary care professional to ensure continuity and a more personal approach. People who have complex issues would like to discuss them with someone who can build an understanding of their personal needs so that they can feel more comfortable sharing sensitive issues. People have also told us that the brevity of appointments does not help and that they are too short to explain complex conditions sufficiently.

However, although negative experiences still occur, we have also started to hear more positive examples of people with mental health conditions who've felt that their GP has shown empathy regarding their condition and has helped them find the support they need.

At the start of the year we heard about a lack of empathy in secondary care services, specifically A&E. People told us that they believed that the pressures presented by staff shortages meant professionals did not show enough empathy towards them as patients.

We have also received similar feedback about staff shortages and high turnover of Community Psychiatric Nurses (CPNs). Similarly to GPs, this means people cannot develop the relationships they want with professionals. We hear of similar issues within a social care setting such as care at home or care homes although to a lesser extent than primary or secondary care services.

There appear to be specific groups of people where this is even more apparent because of their circumstances. We have heard that there is a perception among prisoners that prison staff lack empathy and have a poor understanding of mental illness, making it harder for prisoners to get mental health support.

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### Personal story: An empathetic approach can encourage patients to seek medical advice at the earliest opportunity

"I recently attended the doctors not feeling well at all... I saw a particular doctor and I turned out to be more poorly than what I attended with, she was so helpful, kind and understanding I was extremely distressed and anxious she was calm and gentle explained everything calmly and kindly and got me the care I needed at the hospital. She gave me extra time after surgery and I'm ashamed and embarrassed at seeing doctors and if she hadn't been so wonderful with me I could have ended up not going to hospital and ended up much more poorly. Also, the receptionists have been brilliant with an urgent prescription and ringing me back... so very

grateful thank you everyone.”

## Healthwatch Leeds

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### **The policy context: Empathy**

Comments about staff make up a significant proportion of the positive feedback left about the NHS and social care, with people expressing how kind they are and often describing the care as ‘the best in the world’. This is despite people being aware of, and raising with us in their feedback, the clear pressures facing the health and social care workforce.

Other organisations, including the King’s Fund, have suggested that the continued positivity toward the health service in recent years may be precisely because of the pressures. People are perhaps adjusting their expectations because they value the core principles of the NHS but can visibly see how stretched people are.

This hypothesis would fit with how people have tended to report their stories to Healthwatch in previous years, with people revealing areas for improvement only when we take the time to really explore their experiences. However, with empathy, or the lack of, a growing theme in people’s feedback it suggests that things might be changing.

This theme needs further exploration and we will continue to monitor the situation closely. In the meantime, for the benefit of policy makers and professionals, we have outlined a few examples of how a lack of empathy is manifesting itself and the impact this could have on the NHS and social care:

- **People feel staff do not have the time to listen to them or take their concerns seriously**

Both the Secretary of State and the NHS Long Term Plan prioritise greater focus on prevention and spotting conditions earlier. Healthwatch research suggests that people support this approach, and increasingly expect the NHS to be more of a wellbeing service rather than focusing on treating people when they get sick.

One key to this is ensuring patients always feel able to seek help and are dealt with appropriately when they present with a question or concern. However, when staff are too busy people perceive this as evidence that their individual needs are not a priority or that their concerns are being dismissed without proper explanation or thorough examination. This can result in people leaving comments suggesting they are less likely to seek advice or help in future. This outcome would be bad for both people and the health and care system as a whole, as early warning signs of more serious problems may be missed.

- **People feel they don’t have a relationship with any particular professional**

We have talked previously about the need for better continuity of care, and this is being supported by big system wide projects such as improved record sharing, which should reduce the number of times people have to retell their story. However, this only addresses part of the problem.

Certain groups of people, in particular those with chronic conditions, place greater emphasis on the need for continuity than others. These individuals often talk about wanting to build a relationship with a single professional who understands their needs and can help them navigate the rest of the health and social care environment. This is an

important part of creating a very human interaction with what is a massive and very complex system. In the past this desire for this named point of contact has been interpreted as always having to be the GP, but Healthwatch feedback consistently suggests people want this to be the most appropriately qualified person for the job. In many cases this could be a specialist nurse or mental health professional who has more specific specialist knowledge about the condition.

- **People don't feel clinicians can relate to their experience of conditions**

Although clinicians are the experts in diagnosing and suggesting technical treatment options for different conditions, these are not the only factors affecting patients' decisions. We know from our work on mental health in particular that, whilst people have welcomed the increasing focus and investment, what people want is more support from people who have experience of living with a condition. This growing desire for more peer support needs to be given full consideration as the NHS considers its plans for the future of the workforce. Whilst peer support should never be a replacement for clinically trained professionals, used in conjunction it could help provide a greater level of empathy in the support offered by the NHS.

- **The potential for technology to de-humanise interactions**

Our research has constantly shown that people welcome the greater use of technology by the NHS and recognise this is a much needed move to bring the health service in line with how people are able to interact with services in other sectors. However, it is also true that some of the [research](#) raises concerns about how this might lead to less human interaction with services and that this might exacerbate people's experience of lack of empathy. This serves as a reminder for policy makers and those working on the roll-out of new systems to ensure they are focusing on how they reduce administrative burdens to enable professionals to concentrate on providing the human interaction people need when accessing health and care support.

## Where does our data come from?

Our evidence contains data from 85 publications collected from 39 local Healthwatch, and includes the views of 6,331 people. We received 23% fewer reports this quarter, which is partially due to the Christmas period.

Our insight is also informed by an additional 5,533 individual pieces of feedback received directly from the public. These include views people shared with 47 local Healthwatch at engagement events, or that they shared over the phone, online or in person. The amount of feedback we are receiving continues to increase; we received over three times as much this quarter as we did during the same period last year.

## What are people telling us about primary care?<sup>1</sup>

15 local Healthwatch reports covered primary care this quarter and incorporated the views of 1,428 people. In addition, we received 2,490 individual pieces of feedback from members of the public about primary care through the Healthwatch network. This accounts for 45% of all the individual feedback we received.

### Doctors Surgeries

Eleven of the reports local Healthwatch shared included feedback from 866 people about doctors surgeries. We also received 2,136 individual pieces of feedback which accounted for a third (39%) of feedback overall. People shared both positive and negative stories about their experiences of GP care.

What is new this quarter?

#### Patients having issues with their medication

This quarter, we received more feedback on issues with medication, as discussed in the 'In Focus' section above.

#### What do we continue to hear?

- **People struggle to make appointments with a GP**

Just over half (51%) of the people we heard from this quarter who spoke about GP services talked about booking appointments. Many struggle to see a doctor as soon as they need to. In one case, a father said he thought about booking monthly appointments for his daughter just in case she needed them, and then cancelling if she didn't.

Not only is this a burden on people trying to see a GP, but it may also take appointments away from people who really need them.

- **Poor communication between GPs and patients**

We continue to hear from people about difficulties communicating with GPs. People say that they feel doctors display a general disregard for their views and how they feel. As a result, many feel unwelcome at their GP surgery and anxious about visiting again in future.

### Personal stories: Patients do not feel listened to by GPs

"... the doctors fail to address the root causes of your problem and typically want you in and out as fast as possible. Frequently told 'you've got a virus, go home!' and if you are firm that there is something wrong, they just prescribe something you don't need instead of referring you up the medical chain to detect the problem... I know my body and wish the doctors would trust me... if the GP can't identify what it is after 5 visits in two months with the same problem, then they really ought to be referring it onto a specialist. Telling me I am wrong, after listening

<sup>1</sup> The following services are included in the primary care category; General Practice, Dentistry, Pharmacy, NHS 111 and Opticians. The majority (86%) of our primary care feedback relates to GP services.

for 5 seconds in that moment to my chest and airways has not stopped the fact I've had a cough for 5 months and feel extremely fatigued... This was not just one experience with one doctor, but my experience with three doctors..."

### Healthwatch Leeds

"Caller's child has a severe protein allergy (PKU). When they went for his flu jab last week the nurse asked if they were allergic to egg. When they said 'yes' she said that the vaccination they'd had for the last nine years had contained egg. They also discovered that they'd previously been given medication containing protein. The caller's child has been with the practice for 18 years and feels their condition should be flagged at every visit. Lack of continuity - seeing a different GP each time doesn't help and they have to explain all over again."

### Healthwatch Northumberland

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## Healthwatch in practice

Following a merger of three local GP practices, Healthwatch Sunderland engaged with 99 patients to find out their thoughts on the newly-formed practice. While feedback was largely dependent on patients' experiences of their original practice, more than a third (37%) of all negative feedback related to the telephone system. As a result, the practice recognised that the current telephone system wasn't robust enough to manage the volume of patients trying to contact the practice. This led to the practice sourcing a new telephone system to better manage the increased volume of calls and help patients communicate with the practice when they want to.

### Healthwatch Sunderland

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## Other Primary Care Services

The other reports we received this quarter which discussed people's experiences of primary care (four) included feedback about dentistry and pharmacy, incorporating feedback from around 562 people.

We also received 354 individual pieces of feedback from members of the public through the Healthwatch network, the majority of which (57%) related to dental services.

## What is new this quarter?

### Pharmacy: People struggle to receive their medication on time, if at all.

More people have spoken to us about experiencing problems with accessing their medication for several reasons that we describe in the in-focus section above.

## What do we continue to hear?

- **Dentistry: People are having problems registering and getting appointments with a dentist**

We continue to hear about the difficulties people face registering with a dentist, and

specifically finding practices taking on NHS patients. People also told us that they find it hard to get emergency dental care quickly.

- **Dentistry: People are receiving poor quality dental care and then sometimes require additional treatment to put it right**

People spoke to us about having to have extra treatment to fix errors made during previous appointments, often at their own expense. This not only leads to disputes between patients and dentists about costs, but the dental problems themselves can also prove hard to resolve. We heard about serious cases where poor dental treatment caused damage and infections to healthy teeth.

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### **Personal story: Difficulty accessing emergency care**

“If a dentist from hell existed this would be it. I have tried to get an emergency appointment constantly. Was told to repeatedly call back. After 2 weeks there is an appointment available only to be told it had to be confirmed by the dentist. Apparently, you can only get an emergency appointment with your own dentist. My dentist was on holiday for 1 week and fully booked the following week. At no point was I told this during the two weeks I repeatedly called... Cannot believe how inconsiderate fellow humans can be when they have the ability to help and have a duty of care.”

**Healthwatch Birmingham**

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### **Personal story: Poor dental treatment**

**We also received positive feedback about dentists this quarter.**

Besides having the ability to book appointments with ease, people have said how being able to communicate well with practice staff, receive clarity about treatments and costs, and dentists doing their best to be gentle during procedures can make all the difference in helping them feel comfortable about visiting the dentist in the future.

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### **Personal story: High quality dental care**

“My dentist is really caring and takes the time to face me when she needs to speak instead of standing at the back of the treatment chair as I am hearing impaired. The staff at reception are helpful. They help with form filling.”

**Healthwatch Kent**

“Having attended for routine hygiene appointment but really worried about a recent implant that after accidentally biting on it, the crown had caught under my gum & was so incredibly painful & uncomfortable. I was outside of Emergency hours but the receptionist made a request & the staff gave up their lunch break to provide outstanding care & resolved the issue immediately, resulting in instant relief. I am so incredibly grateful to both for helping me & it is absolute given that this practice will do all it can to provide the best possible care for their patients.”

**Healthwatch Bedford Borough**

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## What are people asking us about primary care?

Last year, 707,816 people accessed Healthwatch advice and information online or contacted us with questions about local support. This quarter 182 people asked us about primary care services. These are the most common questions Healthwatch are asked about primary care:

- How to find a GP
- How to register with a practice
- How to change to a new practice
- How to complain about their GP
- How to access a relative's medical records
- How to find mental health-friendly GP services

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### Personal story: Mental health support from GPs

“Individual with bipolar contacted us looking for recommendations for GP practices who are known to provide good mental health support, as they were removed from xx GP practice register by the practice without their consent. They have been told they were de-registered due to 'abuse', however feel that the reception staff don't know how to deal with vulnerable patients and this can mean their reaction to reception staff has been seen as 'abusive'. They were refused contact with their GP who had been giving them good support over the last few years, and the practice also refused to provide any handover to a new GP practice.”

#### Healthwatch York

“I am moving away to university and need help finding a GP who is Mental Health friendly as many doctors are reluctant to prescribe the medication I am currently taking.”

#### Healthwatch Milton Keynes

# What are people telling us about secondary care?<sup>2</sup>

As usual, we heard a lot of feedback about people's experiences of going to hospital and other specialist facilities this quarter. We received 10 reports from local Healthwatch which included feedback from 896 people on this subject, as well as 2,018 additional individual pieces of feedback about it. About a third of the people (36%) who shared their views with Healthwatch this quarter spoke about going to hospital.

## A&E and urgent care

Local Healthwatch have produced one report this quarter about A&E and urgent care departments, informed by 55 people's experiences. We also received 291 pieces of individual feedback about these topics, representing 5% of all individual feedback this quarter.

We heard slightly more positive than negative feedback, which is likely to be because of the level of care people receive from urgent and emergency services.

## What is new this quarter?

### People wait too long before being discharged and others are discharged too soon

We have heard again this quarter from people who have experienced delays being discharged from A&E. People said they felt they spent too long either waiting for an assessment, for information about follow-up treatment, or for transportation to take them home. In one case, a person left hospital of their own accord and unaccompanied because they hadn't been able to see a psychiatrist after being admitted overnight.

However, we've also heard of instances where people have been discharged too soon and then either returned to A&E or ended up at another hospital's emergency department.

### Poor treatment for people in mental health crisis

We keep receiving more and more feedback about the poor care people experiencing mental health emergencies are receiving in A&E. People have told us that they don't feel listened to or that the care they received helped them to get better. Not everyone who went to A&E with a mental health crisis was able to speak with a mental health professional, and others were given contradictory information by different members of staff. We heard from others that they were given a higher dosage of their medication and discharged without being advised as to what to do next.

## What do we continue to hear?

- **Poor communication and information sharing**

The way staff behave and speak to patients has a huge impact on their experience and the overall quality of care they feel they have received. Although we continue to hear positive

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<sup>2</sup> Secondary care services relate to A&E and urgent care services as well as hospital services such as maternity, ophthalmology, cancer services and cardiology.

feedback about the quality of care and patience demonstrated by most members of staff, we also heard about some ways in which things could improve.

We've heard about families and carers who weren't notified when a loved one was discharged from hospital, and about people who had received conflicting advice and information from professionals. People told Healthwatch that follow-up treatment doesn't always happen as planned, presenting issues when hospitals later can't access up-to-date information about patients.

- **Longer waiting times and lack of support for parents and carers while waiting**

We have received more negative feedback about waiting times in this quarter, which might be because more people use the service during the winter. People said they'd like to know more about where they are on waiting lists, and for there to be a screen in waiting rooms through which they're called to their appointments. Parents and carers told us that they felt unsupported whilst waiting and that there wasn't anywhere for them to go to get refreshments close by.

People seem less frustrated when they are updated about their wait and delays are explained.

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### **Personal story: Delays getting emergency treatment**

"... An ambulance was called for sick diabetic child. The ambulance arrived 1hr later and took them to A&E. They waited in A&E for 4/5 hours and then admitted to ward 32, they then had wait on a bench for a further 4 hours. Son's ketones were high and were sent home. My son has special needs and the doctor said that he can be seen in an emergency. When I contact the practice to make an appointment, the receptionists make it very difficult."

**Healthwatch Bradford**

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### **Personal story: Praise for A&E staff**

"... My baby was very ill and unresponsive so we took him to A&E where he was seen immediately. The nurses and doctors were amazing. They treated him quickly, did all sorts of checks and tests on him. But at the same time they made sure we knew what was going on and took the time out to make sure we were ok. Everything happened so quickly and really smoothly. The staff couldn't do enough for him and us and we can't thank them enough. He is totally fine now!"

**Healthwatch Wakefield**

## Hospitals

Nine reports we received from local Healthwatch this quarter talked about 841 people's experiences of hospitals. We also received 1,563 individual pieces of feedback, covering 54 hospital services. This represents 31% of all individual feedback received.

### What is new this quarter?

#### People are not always able to choose where they receive treatment

Everybody is entitled, where possible, to choose where they are treated, but not everybody knows this and not all professionals make this clear to people. We heard this quarter from people who wished to be treated elsewhere, including one person who was much happier with their experience following a change of hospital.

However, in some cases it's limited availability of services that decides where people are treated. We heard from a number of people in Northumberland having to go to Berwick Hospital because services, such as children's phlebotomy, aren't available in their regions. This experience is common across the country, and particularly in rural areas, such as Cornwall. People in these areas might find that they have to be transferred between hospitals, as it isn't possible for them to just be treated in one place.

#### People are having difficulties parking when arriving at hospital

More people have told us about their concerns with parking at hospitals and other secondary services this quarter. We have heard from over 60 people about parking at 35 locations across England. People are mainly concerned by the fact that they can't find a parking space and, as a consequence, arrive at their appointment late or "stressed". We also heard about insufficient disabled parking. One person told us that there is such little parking that they have to park outside and push their wheelchair-bound husband up a hill to get back to the car.

People have also commented on the high - and increasing - cost of parking. We have also started to hear about overcomplicated car parking machines that do not cater for differing technological abilities.

#### Feedback from professionals: Unsuitable working environment for nurses

Feedback from a nurse in Cornwall gives an insider look into what it feels like to be a nurse in the NHS. The nurse describes the working environment as unsuitable to care for patients properly and sometimes when they complain nothing is done about it. We've heard from patients that low staff levels are sometimes obvious, which makes them more sympathetic regarding waiting times.

## What are people asking us about hospitals, urgent and emergency care?

This quarter 109 people asked us about hospitals and urgent and emergency care. These are some of the questions Healthwatch have been asked:

- How do I access support for long term conditions outside of hospital?
- What do I do if I have been waiting a long time for a referral or operation?
- What are the contact details of local hospital services?
- How do I make a complaint about hospital services?
- What type of support is available following discharge from hospital?
- What support is available for expectant mothers?
- How do I get information about dementia support?
- How do I get medical treatment without going to A&E?

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### Personal story: Empathy with nurses

“... [some nurses] managing more than one ward, some managing three wards at a time, only supposed to manage one...12-hour shifts without breaks, always under staffed. Ovens not emptied - food left in oven [for] over 24-hours and then potentially served to patients. Not suitable for patients’ needs. Not a good response from supervisor, just told to deal with it. Host refused to give food as could have resulted in food poisoning. Anxiety from not knowing what wards need covering - stress levels very high... not given full training before going on the wards... complaints not taken forward. Not enough equipment... such as bin bags. Staff not listened to... Disciplined for speaking to patients too long. Nurses get backlash from jobs not being done correctly.”

Healthwatch Cornwall

### What do we continue to hear?

- **Quality of medical treatment is good but not everyone receives good customer care**  
We consistently hear praise and gratitude for hospital staff and medical treatment. We also hear negative feedback, such as complaints about rude staff, but that many people feel sympathetic to professionals who are under pressure. The feedback indicates that the more staff can do to make people feel listened to, the more satisfied they are with their experience.

We have heard good examples about the quality of treatment in hospitals in Wakefield where staff ‘always go the extra mile for you with no bother at all’ and care is individual and enough time is given to each patient.

- **Long waiting times for appointments and operations**

We hear a lot about outpatient care and appointments with hospital services. Issues people experience include: notifications about appointments not being sent in a timely fashion, and missing referral notes and patient records. People have received letters on the day of their appointment, or have turned up to be told their appointment has been cancelled. In some cases, hospitals then refer people back to their GP, making their wait for treatment longer. As a result of these issues, some people are waiting beyond the NHS target of 18 weeks for operations. We have previously heard from people who have had more than two operations cancelled.

## What are people telling us about social care?<sup>3</sup>

Half of the reports we received this quarter (44) related to social care, capturing the views of 2,010 people. This included 37 reports about visits to care homes. We also received 352 pieces of individual feedback from members of the public about social care. Most of our feedback in this area is about either care homes or care provided in people's own homes.

### What is new this quarter?

#### Variations in care delivered in people's own homes

People shared a number of complaints about home care providers with Healthwatch this quarter. We heard about care workers changing their visiting schedule without giving people notice, cancelling visits altogether without letting people know, and failing to give people their medicine. When these issues arise, some families decide to change care provider, which can lead to further stress and delays getting people the help they need.

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### Personal story: Inconsistent care

"I have had ongoing issues with [name of home care agency] since August 2018. The carers are very unreliable. When my relative was discharged from hospital with a visual impairment, care package was increased to 3 visits a day, but they only came twice on the first day and not at all on the second day. Relative is frail with diabetes and dementia. Carers should have come at 7am, but did not arrive until after 8am. No one ever came for the lunchtime visit. I have complained but the matter has not been resolved. Relative is about to be discharged from hospital again and need guarantee that their care will be consistent. I think this is a systemic issue with [name of home care agency]."

#### Healthwatch Haringey

#### Poor transparency regarding care home costs and difficulties having care home packages reviewed

People spoke to Healthwatch this quarter about a lack of transparency when it comes to care home costs, with continuing healthcare and 'lifestyle payments' feeling unclear. We also heard

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<sup>3</sup> The following services are included in the social care category; care homes, home care, assisted living, social care assessment and equipment services.

from families struggling to get care home packages reviewed when their personal care needs are not being met.

### What do we continue to hear?

- **Variation in activities for care home residents and levels of training among staff**  
We continue to hear about the lack of planned activities and stimulation for care home residents, as well as a mixed level of training and awareness among care home staff, particularly in relation to dementia.
- **Lack of consistent and accessible information about home care services**  
People continue to talk to us about having trouble accessing the most appropriate home care services, with some needing help to set this up for themselves or a family member.

### Healthwatch in practice

Having visited their 100th care home, Healthwatch Bucks showcased how some of the care homes they visited within the last six months had listened and acted on their findings.

In addition to helping make care homes feel more homely for residents, Healthwatch Bucks also successfully encouraged care home staff to attend dementia awareness and communication training, and to create dementia champions. These efforts have helped residents living with dementia feel better supported and live more the way they want to.

#### Healthwatch Bucks

### What are people asking us about social care?

This quarter 127 people asked us about social care support. These are the most common areas Healthwatch are asked about:

- How to access care at home services for elderly or those with long term conditions
- How to choose the right care home
- How to get equipment installed or repaired in the home
- How to access respite care
- How to get information on care packages available
- How to access supported accommodation
- How to get a social care assessment

### What are people telling us about mental health?

We received 11 reports, which included 1,524 people's views on mental health services this quarter, 38% more than last time. However, we only received 242 individual pieces of feedback about mental health (7% fewer than the previous quarter).

### What is new this quarter?

## Some groups of people do not meet the eligibility criteria for some support services

Our feedback this quarter indicates that some groups of people face difficulties accessing support because they do not meet the necessary criteria for it. We heard from two men who said that their gender limited their support options, with staff deeming it inappropriate to include men in group sessions, such as art therapy.

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### Personal story: People left without support

“I have been referred from one service to another. I don't fit the specific criteria for certain services, and there is no-one to fill the gaps. I have been left with no support... I was told by my psychiatrist that I would get therapy but it never happened - professionals tell you one thing and set the expectations but then it is never delivered. I was also told that I would be suitable for MBT (an Art Based Therapy). However, despite being suitable this wasn't offered to me because the rest of the group was made up of girls. I was denied therapy that could have helped, just because I was male.”

#### Healthwatch Milton Keynes

Others have struggled to gain access because they have more than one diagnosis, speak a different language, have a condition that is too severe or have specific communication needs such as a British Sign Language interpreter.

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### Personal story: Lack of understanding about people's needs

“I have autism and experience mental ill health. I was offered very little support during my pregnancy. I didn't fit the specific criteria so I was offered no mental health support. Instead, I was passed around from one department to the next. Police and Health professionals need more training surrounding autism and mental health.”

#### Healthwatch Milton Keynes

## What do we continue to hear?

- **Waiting times – need for interim support and information**

We continue to hear about long waiting times across mental health services, most commonly for formal assessments and follow-up treatment. Sometimes people are bounced between different services, which mean they're waiting longer to get support. Other times, people who are already in contact with services are kept waiting for routine appointments. People also struggle to get through on the phone to mental health crisis services, from which they require an urgent response.

We heard from one mother whose daughter was still on a waiting list for treatment for an extreme eating disorder. She has been admitted to hospital twice but is still waiting for specialist support.

- **Poor communication, and limited information about and delayed access to support**

We often hear that limited information is given to people, particularly whilst they're awaiting diagnosis or mental health support. People are told to expect letters in the post and calls from services, but these often don't happen for some time.

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Most people have no idea what mental health services are available in their area, and this isn't helped by a lack of information about support on offer. We've heard that professionals and members of the public are unaware of services that can help people in need.

Many services are moving to self-referral, but this can be a confusing process. We've had lots of people ask us how to do this after their GP has told them to self-refer.

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## **Personal story: Limited access to mental health support**

"It is extremely difficult to get quick therapeutic counselling services unless you can pay for them (which is extremely expensive). The NHS needs to be able to retain staff better to improve this."

### **Healthwatch Milton Keynes**

"A gentleman contacted our signposting service on behalf of his wife who is trying to access IAPT and had her initial assessment. She was then directed to crisis support; however, what she needs is ongoing support with her depression. Since the assessment, they have been transferred back and forth from IAPT to Crisis support. They have limited knowledge of who to speak to who could sort their issue."

### **Healthwatch Lewisham**

"I have autism and I experience mental ill health. There is no point of contact for me when I am in crisis. I need somebody who I can build a relationship with, who I can turn to when I need them. Instead I get offered support in 6 months' time with a stranger."

### **Healthwatch Milton Keynes**

## **What are people asking us about mental health?**

This quarter 53 people asked us about mental health care. Here are some of the most common questions Healthwatch are asked:

- How can I get help to understand the pathway for mental health support?
- How do I find out about CAMHS?
- How do I get an early diagnosis for an Eating Disorder?
- How do I access to non-medical support for mental health conditions?
- What support is available for veterans and victims of trauma, including bereavement and sexual abuse?
- How do I complain about mental health services?
- How do I access befriending services?
- How do I get support in my own language?

## People who find it difficult to be heard: What are their experiences?

In previous quarters, we have looked at specific tangible communities that struggle to be heard, such as people who are homeless and prisoners. This quarter, we have chosen to look at a more far reaching group that cross multiple communities – people with limited family and social networks.

We received three local Healthwatch reports, which included the views of 162 people who find it difficult to be heard, and we also heard 168 pieces of individual feedback.

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### People with limited family and social networks

This quarter, we have heard from 37 people who have limited family and social networks about some of the problems they face accessing health and social care.

#### Common themes

##### Trouble managing mental health conditions in isolation

It can be hard for people who are isolated to deal with mental health issues. Those we heard from said they needed someone to talk to and some kind of peer support. We also heard from people who said they couldn't always manage their medication effectively without help.

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#### Personal story: Impact of problems accessing medication

“The client contacted us [Healthwatch Calderdale] due to long term problems with medication for his mental health conditions being issued late by his pharmacy, which in turn leads to deterioration in his mental health, suicidality, rough sleeping and hospital admissions... The client lives on his own, and due to his mental health problems, has weekly contact with the Community Mental Health Team to support him, as if he forgets to take his medication he ends up back in hospital. For the last year the... pharmacy has not been issuing his medication on time, it has regularly been 4 to 5 days late... He doesn't want other people to have the same problems, and wants to make a complaint about the... pharmacy as their attitude has been 'It happens' and then it happens.”

#### Healthwatch Calderdale

#### Housing for those with mental health challenges

People with mental health conditions who have limited support networks may require additional help with finding a safe place to live. However, we've heard over the last quarter two instances where a recovering addict was placed in accommodation where drug dealing and crime was a problem. This resulted in them leaving the premises and becoming homeless. In turn, this led to their conditions deteriorating and presenting them with significant challenges in accessing health and care services. Such cases are illustrations of why NHS and social care services must work with other public sector organisations to ensure people's health, safety and broader wellbeing needs are met.

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## **Personal story: Impact of unsuitable housing**

“A young tenant of a supported housing association had complained to his landlord about drug dealing in the stairwell. He said many tenants were intimidated and the dealing was affecting his own recovery from addiction. The landlord had not resolved the issue and he had been targeted by the dealers. As a result, he is now sleeping rough. He has a support worker who has helped but reports that neither his landlord nor the local authority will help. He has also reported it to the local authority safeguarding team. Unfortunately, despite repeated attempts to call the client back he has not answered his phone.”

**Healthwatch Lambeth**

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## **Personal story: Lack of support for people who are homeless**

“... I suffer from anxiety and depression. I am living on the streets at the moment. I have registered as homeless with [name of service provider] but they said I have made myself homeless as they previously gave me a place to stay. I am a recovering addict and this place was full of people with addictions... My room was broken into and all my things were stolen. There were needles and drug paraphernalia left in my room. I could not cope with this and left, when I went to [name of organisation] they refused to help me as they said I made myself homeless.”

**Healthwatch Sunderland**

## **Need for clear, ongoing communication**

Maintaining continuous communication is essential for those who experience memory problems and have a limited family or social network. We hear that small changes could make a significant difference to people, such as appointments scheduled automatically at regular intervals, and reminders sent to people beforehand.

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## **Personal story: Lack of support for people who are homeless**

“... When I make an appointment with the GP it is essential they remind me of the appointment by text, I would often miss my appointments and get dates and times mixed. I have got a memory problem, medication problem and problem with numbers. About 2 years ago I raised this issue with GP and he got angry with me, he said you patients waste my time and come here with other issues. Still difficult to get appointments, waiting in the queue and then no appointments available.”

**Healthwatch Birmingham**

## **Transport for people living alone**

We heard from people living alone who have no support network and no way to access transport. For these people, travelling to appointments, particularly ones scheduled at short notice, can be really challenging. People feel that there is little empathy amongst service providers for individuals in these circumstances.

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## APPENDIX

### Volume of insight collected from October to December 2018 (Q3) compared to July to September 2018 (Q2).

	No. of local Healthwatch reports Q3 2018/19 <sup>4</sup>	% of local Healthwatch reports Q3 2018/19*	% of local Healthwatch reports Q2 2018/19	Number of individual feedback Q3 2018/19	% of individual feedback Q3 2018/19	% of individual feedback Q2 2018/19
Primary care	15	18%	23%	2490	45%	41%
Secondary care	10	12%	30%	2018	37%	34%
Social care	44	52%	32%	352	6%	7%
Mental health	11	13%	7%	242	4%	6%
Other	7	8%	15%	431	8%	12%
<b>Total</b>	<b>85*</b>	-	-	<b>5,533</b>	<b>100%</b>	<b>100%</b>

\*Total number of publications.

<sup>4</sup>This is the number of reports that contain information on the service areas listed some reports cross multiple service areas which means the sum of the reports will be greater than the total publications

## About us

### **Healthwatch is here to make care better.**

We are the independent champion for people who use health and social care services. We're here to find out what matters to people, and help make sure their views shape the support they need.

There is a local Healthwatch in every area of England. We listen to what people like about services, and what could be improved, and we share their views with those with the power to make change happen. We also help people find the information they need about services in their area.

We have the power to make sure that the Government and those in charge of services hear people's voices. As well as seeking the public's views ourselves, we also encourage services to involve people in decisions that affect them.

Our sole purpose is to help make care better for people.

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## Contact us

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