What people told us about health and social care

A review of our insight and evidence
January - March 2019

This quarter we gathered

775

views, experiences and stories

This insight also reflects our **community partnership** work

To find out more about this work visit our Partnerships page. We also publish a full Community Partnership update each quarter.

Our priorities for 2018/19 were:

Primary and Community Care

Children and Young Peoples mental health and wellbeing

Adult Social Care

Hot Topics

This quarter we also engaged people in discussions about the NHS Long-Term Plan and local plans – this will be reported on separately

Why not sign up to receive our monthly "Heads-up" briefing to stay in touch with local changes in health and care
(Visit our website and complete the sign-up box to the bottom right of the page)

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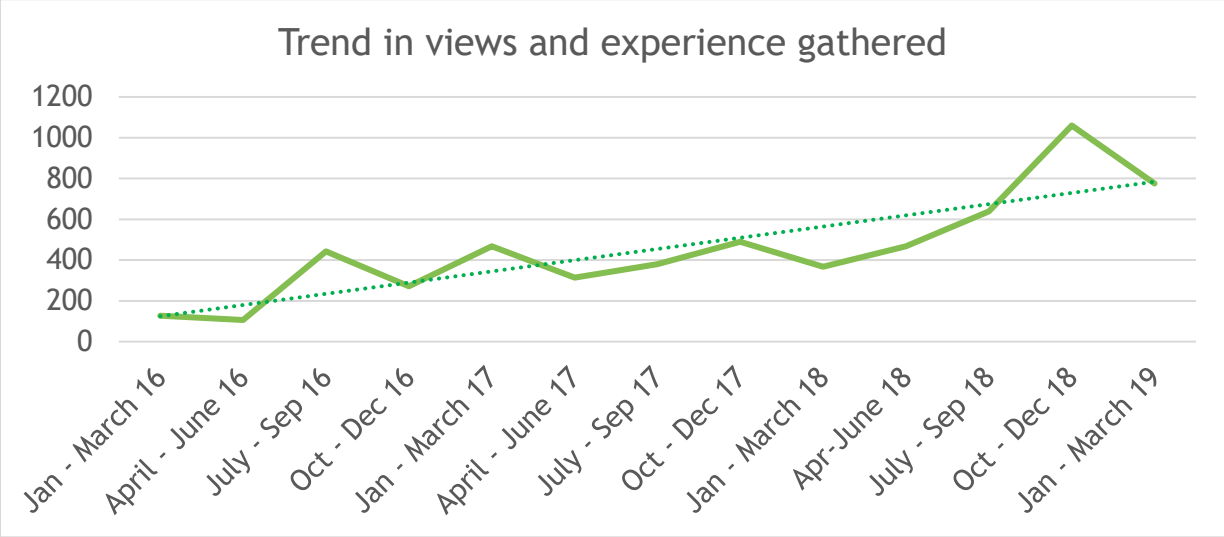
it starts with YOU

healthwatch West Sussex

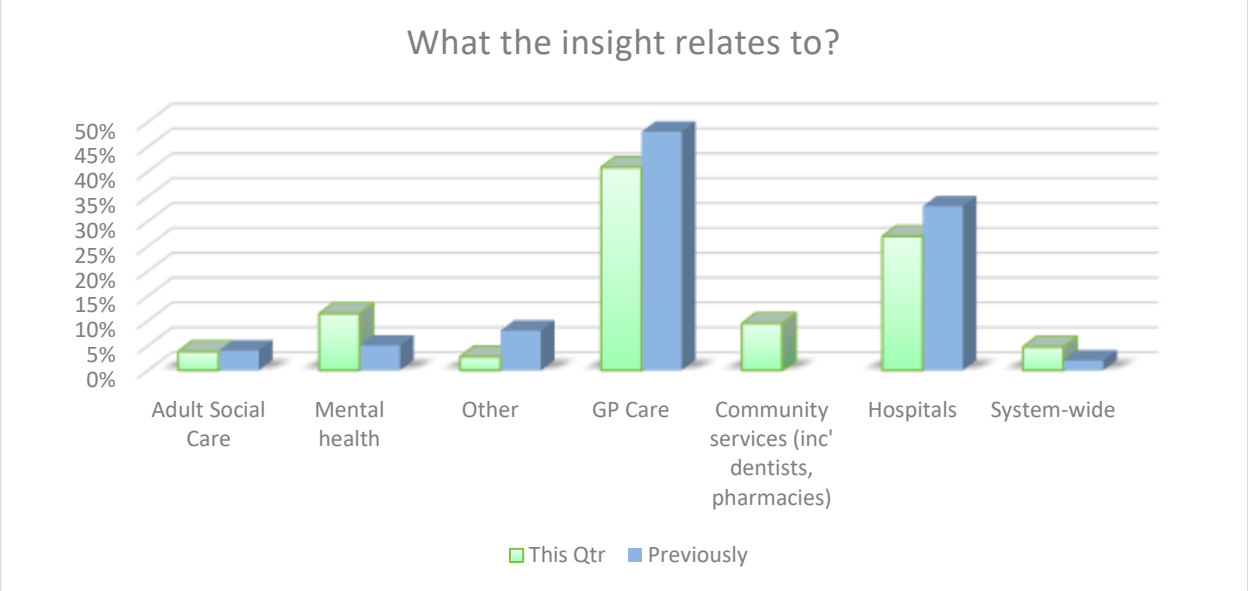
At a glance

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.

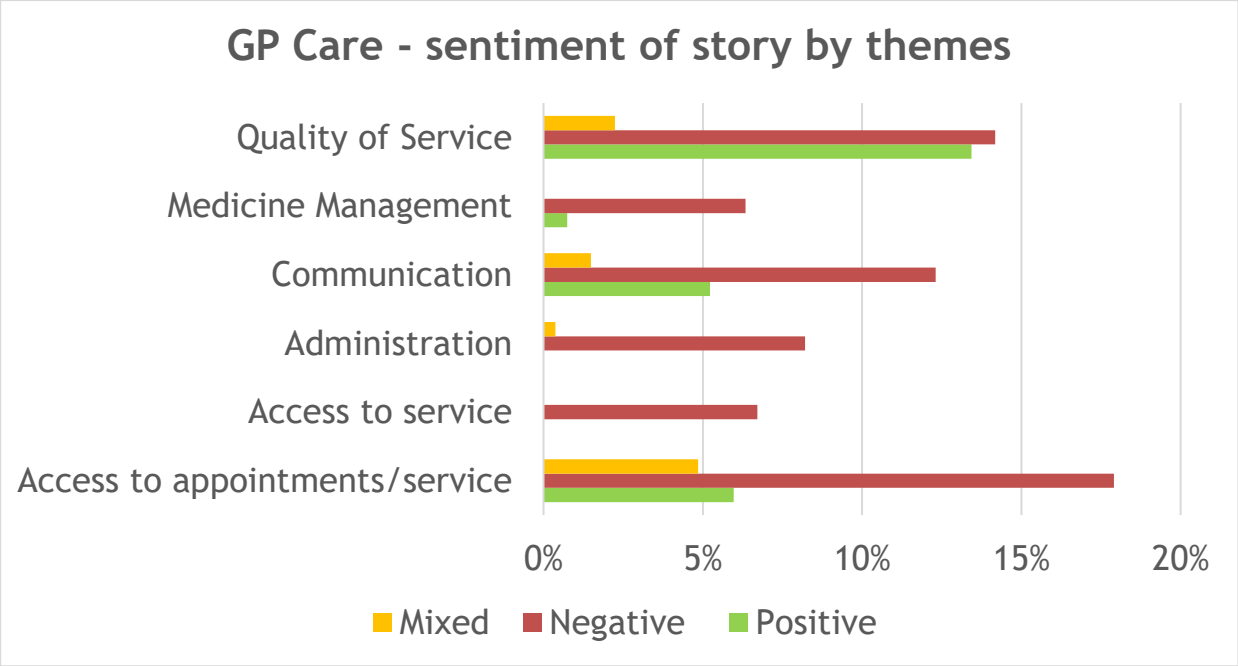
775 people shared experiences and views with us between January – March 19.



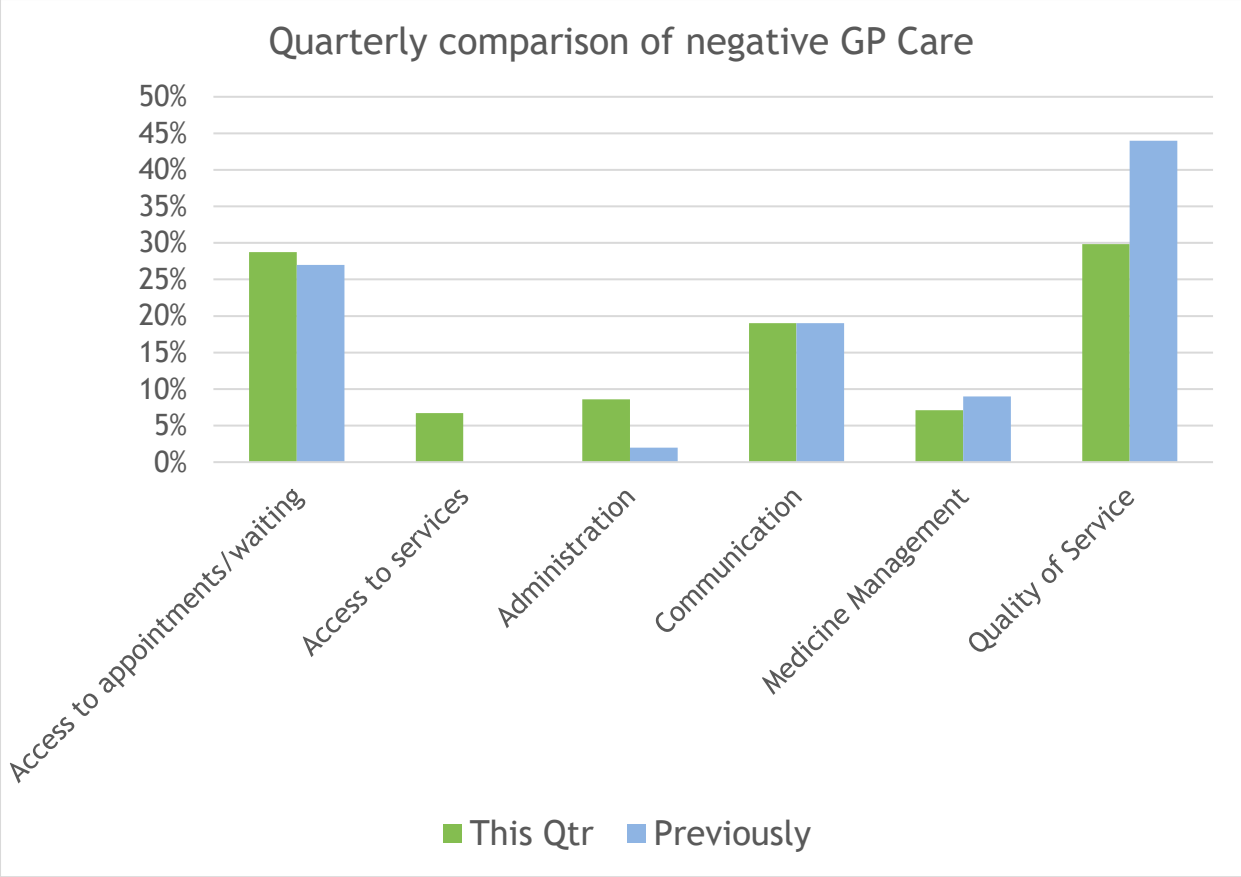
We look here at what people are saying, and how we're using this information to help shape health and social care policy and practice.

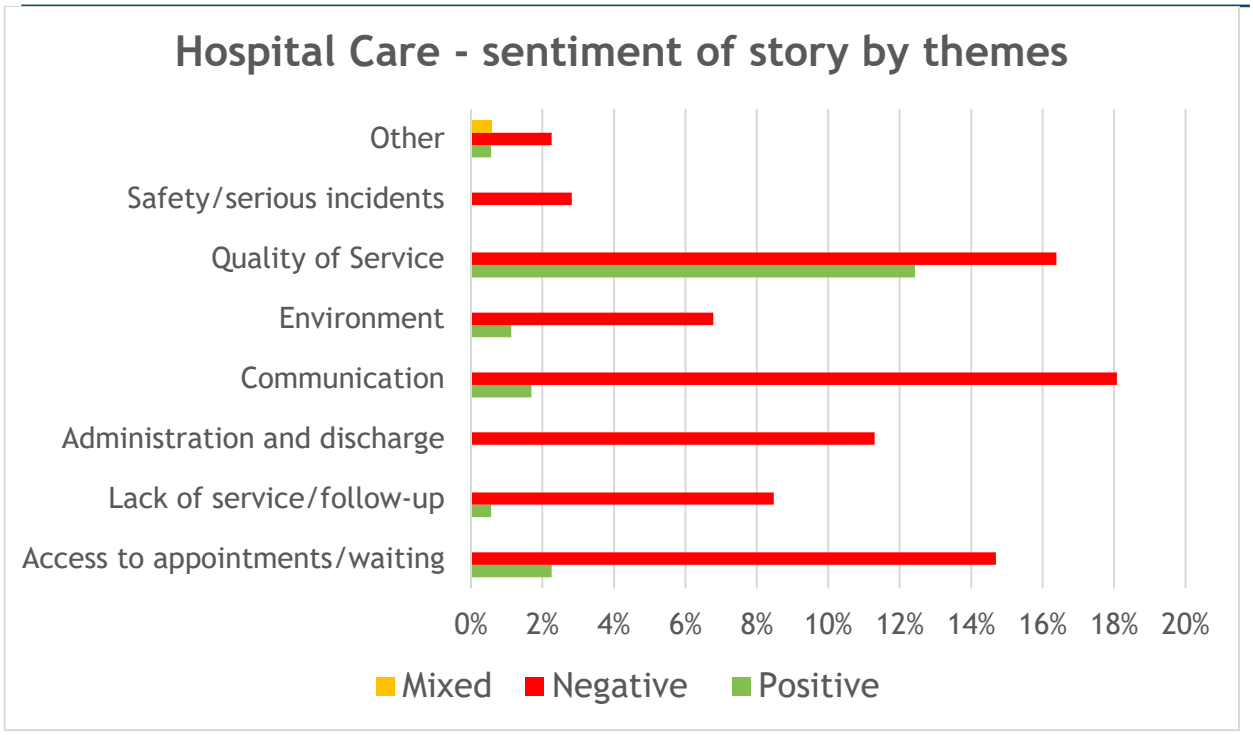


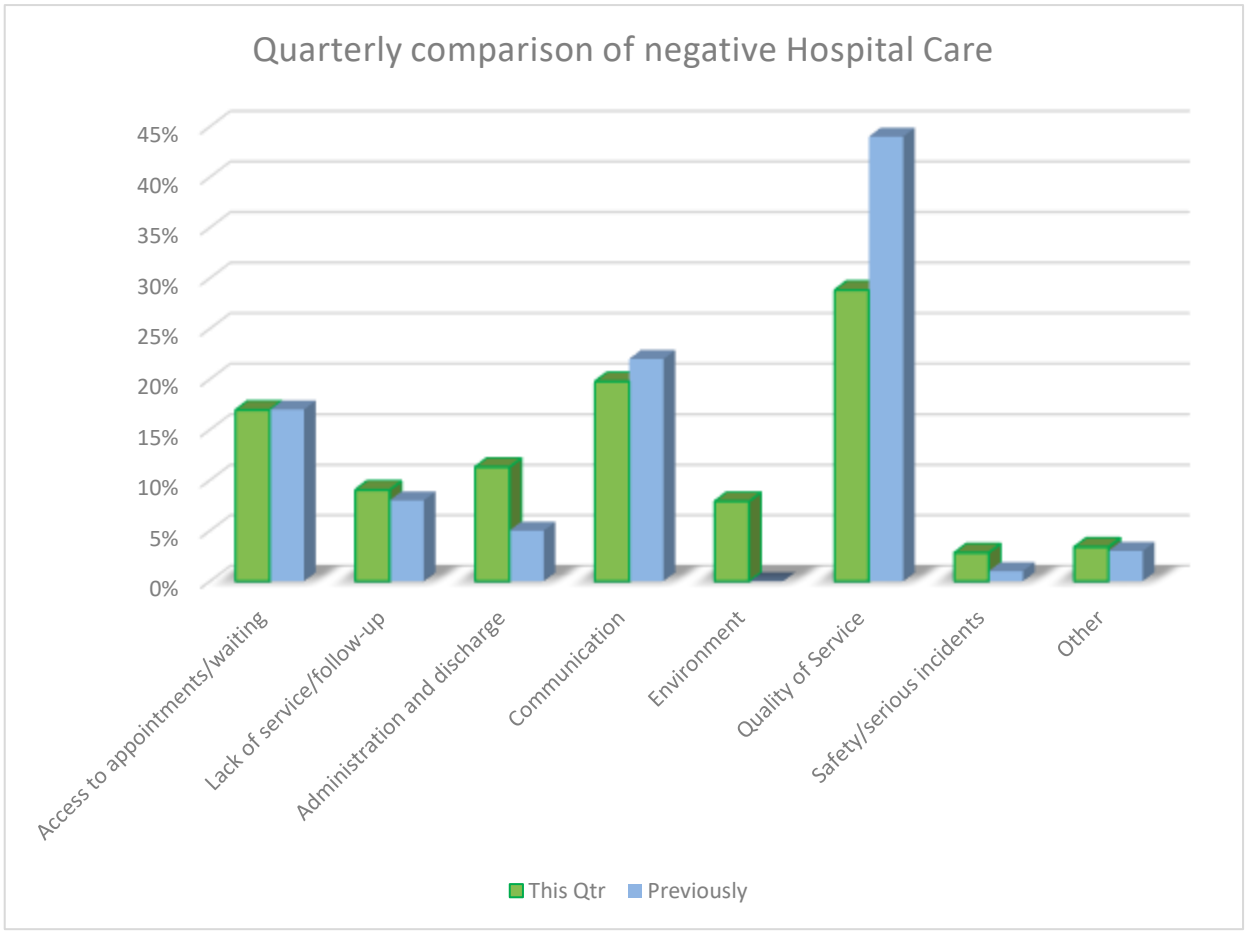
We have separated the GP Care from the community care this quarter, hence the lack of data for community care in the previous quarter, as this was combined with GP care.



The trend continues to show a dissatisfaction in getting access to GP care. The chart below compares the themes to the previous quarter.




Hospital Care - sentiment of story by themes
Other
Safety/serious incidents
Quality of Service
Environment
Communication
Administration and discharge
Lack of service/follow-up
Access to appointments/waiting
0%
2%
4%
6%
8%
10%
12%
14%
16%
18%
20%
Mixed
Negative
Positive


Quarterly comparison of negative Hospital Care
45%
40%
35%
30%
25%
20%
15%
10%
5%
0%
Access to appointments/waiting
Lack of service/follow-up
Administration and discharge
Communication
Environment
Quality of Service
Safety/serious incidents
Other
This Qtr
Previously

What people saying?

GP care **This is one of our Priorities for 2018/19**	
Emerging themes	Many people are still talking in terms of trusting their GPs, but we have heard a growing number of people expressing little faith anymore in the NHS. Some from missed diagnosis, others stemming from a frustration at not getting any support. Through sponsoring an Indian Heritage event in Crawley, we heard how important it is to Asian women to have their appointments with a female Asian GP. "Many Asian people have changed GP to See Doctor (name given). As she is one of the few Asian GPs."
Ongoing themes	We continued to hear that access to GP appointments remains the most negative theme but there are still practices where local people report no problems in getting appointments in general. • People also expressed a lack of understanding of the processes in getting access to their GP. Many commenting on how this feels overly repetitive and time consuming. • There can also be a mis-match between information on NHS 'Find a GP' website and what a GP Practice states is their catchment area. • There is a lack of knowledge of the **improved access** since the introduction of evenings and weekend appointments. Communication comes up time and again in relation to how this impacts care or decision on where to access care.
What are we doing?	Our Board will be keeping GP Care as a priority for 2019/20. We're looking at how we can best add value, particularly with changes coming through the NHS Long Term Plan. One of these changes is the creation/contracting of *Primary Care Networks (PCNs)*. NHS England explain these as: *building on the core of current primary care services and enable greater provision of proactive, personalised, coordinated and more integrated health and social care*. Contracting with PCNs aims to move from reactively providing appointments to proactively caring for people and communities. Our Chair is part of a group working on introducing a community hub for Midhurst and surrounding villages, that will do just this. We're producing a video to give local people more details about this and its benefit.

Access to appointments

Doctor (name given) is very, very good. He creates a rolling double appointment for me each month, as he knows I've not got much support with my autism. He's always running late but no one minds because he's talking to people. He listens.

Contrast between GP practices in Haywards Heath

Susan said of her experience "I have **great difficulty** getting through on the telephone and you have to phone. You can be on the phone for 2-3 hours."

Barbara who goes to another practice reported, "**You would think that with the new housing we would have more problems getting a same day appointment.**"

At community event in Bentswood, we met Frank who told us that there wasn't a health provision in the area and local people register with Northlands or the Dolphins Surgeries, which means a lot of travelling. He suggested there could be a drop in session locally, say once a week. This he said could help for preventing health problems.

Understanding processes

Pamela shared "the receptionist asks what the issue is and then the triage nurse asks you *again* what the problem is, and then when you see the GP you are asked *again* what the problem is. Could they not write down the first time what the issue is and pass on? The NHS is like a never ending round of asking the same question and you giving the same answer. There's a lack of communication.

A patient at a Worthing practice said, "there aren't evening appointments and you have to wait two weeks to see the same GP." When we surveyed people in a Littlehampton surgery, very few were aware they could get an evening or weekend appointment.

Harry said his GP surgery was very good and he could get an appointment quickly. He then went on to say he thinks the online appointments are too complicated to use and he is an IT professional! Others also said they find the online systems confusing and difficult.

Fiona said "I do not understand why I am given the option of an emergency appointment when I would just like to talk to someone or show them photographs. I recently had a telephone consultation for a rash. I was told I had Chicken Pox! I didn't have this, as I know what it looks like. So, after two telephone calls I asked for an emergency appointment to get to the bottom of things."

Hospital (secondary) care **Aspects of this insight may come under our Hot Topic Priority for 2018/19**	
Emerging themes	One patient told us that "having an Inflammatory Bowel Disease (IBD) nurse you can contact gives me more control and helps avoid becoming too ill, or having to attend A&E, as the nurse is able to speak to the consultant and organise treatment." This quarter people reported issues with environmental and equipment issues in different hospitals. We heard more stories relating to going home from hospital (discharge) and a lack of support in the community, this quarter than previous three months. This may reflect winter pressures or a general indication of lack of community support? **Food for thought:** David was scheduled to have a procedure at Royal Sussex County Hospital. He has been told he needed 'a responsible adult' to drive him there and back, plus to hang around for about 4 hours. He asks: how is this supposed to work for people that live alone? According to the paperwork, this responsible adult should also stay with him overnight. He feels this is utterly unrealistic for most people that aren't in a relationship or have relatives nearby. With a changing demographic this is likely to present more patients with a challenge.
Ongoing themes	We continued to hear of issues with Southlands eye clinic. However, the Trust has told us that a new Matron has joined the clinic, and this should have a positive impact on the service. Cancelled appointments remain an issue for patients across a range of hospital services. For some, cancelling appointments seems to have become the norm. Getting communication right features at the heart of many stories.
What are we doing?	Environmental insight helps us, when planning our hospital *Enter & View* visits and we share this insight with the Care Quality Commission to inform their inspections. Our *Liaison Representatives* will be discussing the cancellation concerns and communication with individual Trusts and we will want to ensure hospital letters include contact details.

Environment

James has visited several hospitals due to musculoskeletal conditions, "I attended the private part of the Princess Royal orthopaedic hospital about 5 years ago. It was clean, smelled clean and tidy. 'Even the chief came around'. In 2018, I attended the same hospital now run under the NHS and the cleanliness had fallen – it smelt unclean and had tissues lying around and blood on the floor."

Healthwatch comment: We've had a dedicated team of *Authorised Representatives* visiting the Princess Royal Hospital, following a very disappointing *Patient-Led Assessment of the Care Environment* (PLACE) visit. Our team has worked directly with their Estates Director and we've seen much improvement and a change in the staff attitude towards maintaining the environment. Issues we have raised have been addressed or a plan has been put in place.

Donna shared that she had waited 36 hours at St Richards hospital for a bed and was then put into a really small room without a bed.

"They really do need to do something about the parking charges. In the past, I paid as I left so only paid for the time I needed. Now I have to pay as I arrive and do not know how long I need."

Issues with appointments/operation dates

Peter explained that he received a call from a 'very cheery' secretary to cancel his surgery. The person explained to him that they had to cancel the whole day's list due to a lack of day surgery beds. He went on to say that "when I asked when it would be rescheduled, she couldn't say, as she had to ring and cancel all the other patients first. No other information was given. I was then rushed into Worthing Hospital and ended up having the surgery there. When I rang Princess Royal Hospital to let them know I'd had the operation the secretary was very rude. She said it was very inconvenient and got very stroppy. Yet they cancelled the op with barely any notice! Seems to be two rules – the patient isn't allowed to cancel but the hospital can cancel whenever they like. Also wasn't sure the reason she gave was accurate – having to cancel a whole day's list because no beds? Really? What had happened to them all? Felt we were being fobbed off."

"I go to Crawley Hospital for diabetic checks and have to wait for a long time for a 'feet check'. The appointment is made, then cancelled and I then wait another 2-3 months", Margaret told us.

An elderly patient's daughter told us that her mother was under the orthopaedic team at Southlands Hospital. They have received "a series of cancelled appointment letters from the service over several months and have resorted to private treatment due to waiting time and pain." The letter stated that due to 'unforeseen circumstances the appointment needed to be rescheduled'. They received nine cancellations letters in total during the six months they were waiting. The daughter said that each of the letters caused anxiety and confusion. Also, the letters did not give a number to call to discuss the matter or change the appointment date.

Communication

Sophie who lives with a long term and complex condition, told us, "I had a really positive experience with the Bladder and Bowel Service. The nurse had not only researched my condition prior to my appointment but also then referred to (details given) during the consultation. I have never been treated with such respect and empathy before."

In contrast to Sophie's experience, Raj shared his experience. "I had severe pain due to Inflammatory Bowel Disease (IBD). My GP told me to go to A&E. I was treated there as though I was making a fuss over a bit of stomach ache. I overhead a nurse say, '*people think they can just turn up for any old thing – can't do that in India'*. However, I ended up being admitted due to a severe inflammation."

Also, patients report wastage in the NHS because they are not listened to. Roger told us that he had a problem with his right hip and was referred for an x-ray. Once, at the hospital, they took x-rays of his left hip, which he tried to argue with, but they were taken anyway. They found nothing wrong and there was no follow-up, just a referral to a physio, where he explained the pain was in his right hip. The physio requested an x-ray of the right hip- where they found advanced osteo-arthritis. He refused to go back to the original hospital. His hip replacement operation was cancelled twice and he had to eventually go out of County to have it replaced.

"I've been wearing hearing aids forever and have yearly check-ups. At the last one, it was suggested that I discuss the different hearing aids that were now available, as technology has moved on. I said 'OK, tell me'. They said, 'Oh no. You have to make an appointment'. I said, 'OK, make me an appointment'. They said, 'We can't. You have to be referred by your GP'. I couldn't believe it. How stupid. I was there, being told to have a conversation and couldn't, as I needed to be referred to these people by my GP before the chat could happen! What a waste of time and energy. So anyway, I get referred – wasting my time and the GPs and I end up back in the same clinic. Crazy!

Mental health **Children & Young Peoples' mental health is one of our Priorities for 2018/19**	
Emerging themes	More people are sharing the negative impact wider society has on their mental health, such as the benefits processes. We've started to use our resources, developed with young people and others, through some targeted engagement with young people and families. Accordingly, we have begun to hear more lived experiences.
Ongoing themes	We continued to hear that people: • Struggle to get support for their mental health in the community • Are being referred to A&E when facing a mental health crisis and how this is not the right place for them.
What are we doing?	Healthwatch England has provided funds to support engagement in West Sussex on the NHS Long Term Plan, which includes focus group activities. We've decided to focus our group work around adult mental health.  We are seeking to meet with commissioners and Sussex Partnership NHS Foundation Trust to examine the community support strategy. This will give us the opportunity to bring to the table the insight local people are sharing. We're following the work of the Independent Review Panel and oversight group, looking at children and young peoples' emotional resilience. We'll shortly be using our insight to sense-check the panel's draft key lines of enquiry, to see if these can provide it with valuable insight, so that future Sussex-wide services are right for local people.

Case study
We met Joyce, who suffers from chronic pain and depression, at a Job Centre Fair. She told us she was keen not to be seen as a *victim,* but finds the demands involved with claiming Universal Credit affect her mental health recovery.

Joyce went on to tell us that the pressure of sanctions, when she is struggling to survive, became overwhelming, particularly as she is barely managing financially and often can't afford food. She feels the food banks aren't designed for her.

To attend appointments, she said she often misses classes at the Recovery College. Joyce said she must apply for jobs and attend interviews when she's not ready to and is finding the whole process too much.

"*The process just makes me feel that I'm just not trying hard enough. My self-esteem has plummeted. I feel trapped in a very negative cycle, where I fear fines and sanctions and I'm a failure and should just pull myself together. The energy that goes into claiming benefits means I'm too depleted to put the mask on and socialise with my friends and this is making me become very isolated.*"

Joyce said the system doesn't consider how ill health gets in the way of moving forward. Questions like, 'Why are you not looking for work? Or What have you been doing? cause a lot of harm. There seems to be no awareness of how depression and pain affect a person's ability to function, or how long it takes a person to do anything.

This pressure has left Joyce feeling, she said, 'on the verge' and this frightens her, as she has a lot of medication at home.

Healthwatch comment: we spoke to several Job Centre employees, all of whom shared they were aware of the impact their processes had on people and some felt totally unable to support their clients. They said they were unaware of where to direct people for support. We were able to give details of voluntary organisations to information centre employees to help them to signpost those needing extra support, particularly with their mental health.

Social Care

This is one of our Priorities for 2018/19

Emerging themes	People have expressed concern that their voice is not being listened to and whilst we have heard this previously, it was something we have heard particularly loudly this quarter.
Ongoing themes	We continued to hear that people that have concerns over the assessment for adult services or charging. More people shared positive feedback about the support and benefit they gain from community organisations and groups. Many being recognised as safe spaces, and good sources of information and peer support.
What are we doing?	Our Board will be keeping Adult Social Care as a priority for 2019/20. We're looking at how we can best add value, particularly with changes coming from the West Sussex County Council's transformation programme.

Communication

Sally lives with Parkinson's disease. She struggles with her speech, particularly on the telephone but was able to tells us face-to-face she was unhappy with the support she is getting. As her social care package wasn't enough to meet her needs, she moved to a care home funded by the local authority. At the time, there was a limited choice of home due to her age. She told us she isn't getting her medications as prescribed and therefore must self-medicate, and that the food is insufficient. We asked if she has raised her concerns with the local authority and sally said she has and had a review but again feels she is not listened to by social workers. She would like support to have her voice heard. Sally has a Parkinson's nurse who is supportive but feels she needs advocacy to assist her in communicating with health and social care.
(We gave her details of advocacy services.)

Charging

We met an elderly lady, who told us that she pays privately for care but is also being charged by West Sussex County Council (WSCC) for brokerage fee of £5 per month, as her husband was referred to a service. However, she told us that they had found the services themselves and mentioned it to WSCC team.

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.

We also help people find the information they need about services in West Sussex.

We here to help you on the next step of your health and social care journey – wherever it is taking you.

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.

You can review how we performed this quarter in our latest Performance Report.

Contact us

Healthwatch West Sussex CIC is a Community Interest Company limited by guarantee and registered in England & Wales (No. 08557470) at Pokesdown Centre, 896 Christchurch Road, Pokesdown. BH7 6DL.

Healthwatch West Sussex works with Help & Care to provide its statutory activities.

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