
What people told us about health and social care

A review of our insight and evidence
October - December 2018

This quarter we gathered

1060

views, experiences
and stories



Our priorities for 2018/19 are:

Primary and
Community Care

Children and Young
Peoples mental
health and
wellbeing

Adult Social Care

Hot Topics

We'll also be
engaging people in
discussions about the
NHS Long-Term Plan
and local plans.

This insight reflects
our **community &
partnership** work.



To find out more about this work visit
our [Partnerships](#) page

Why not sign up to receive our monthly “Heads up” to stay in touch with local changes and news in health and care
(Visit our [website](#) and complete the sign-up box to the bottom right of the page)



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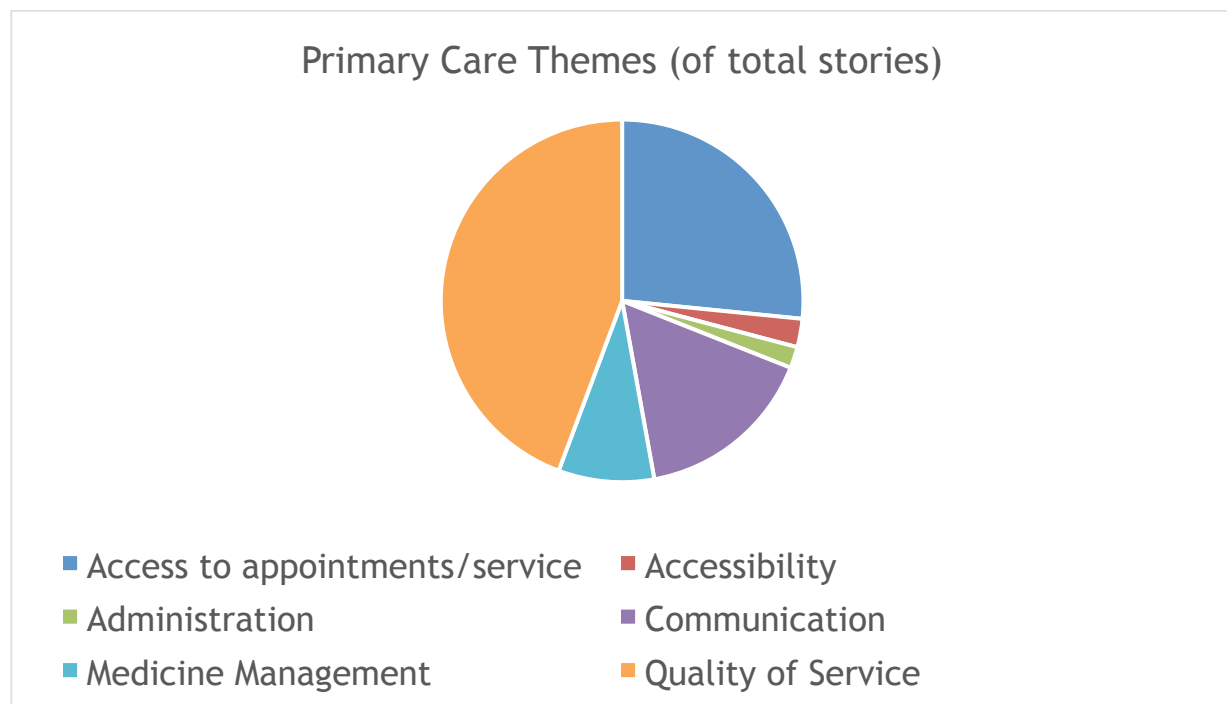
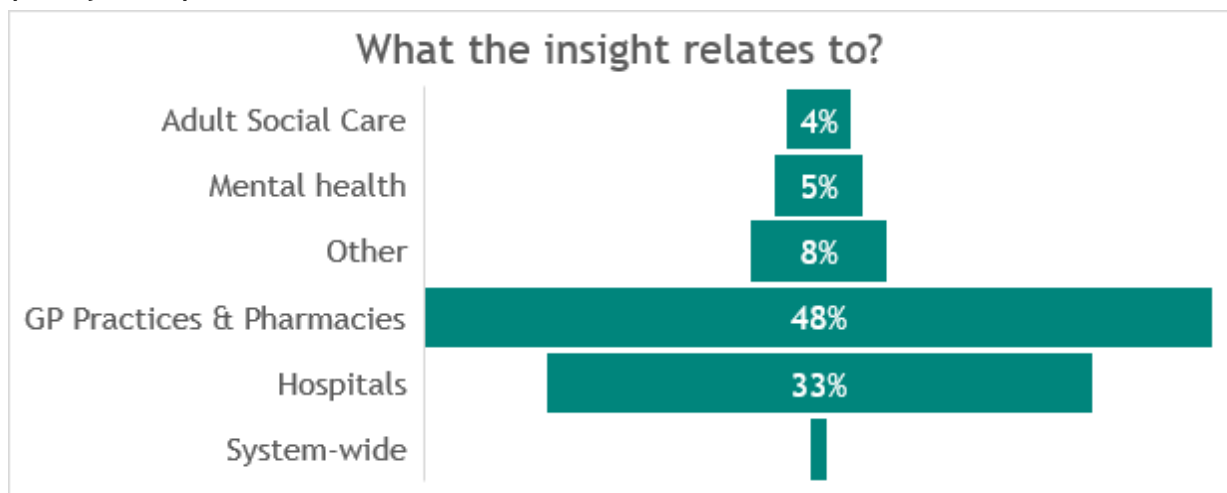
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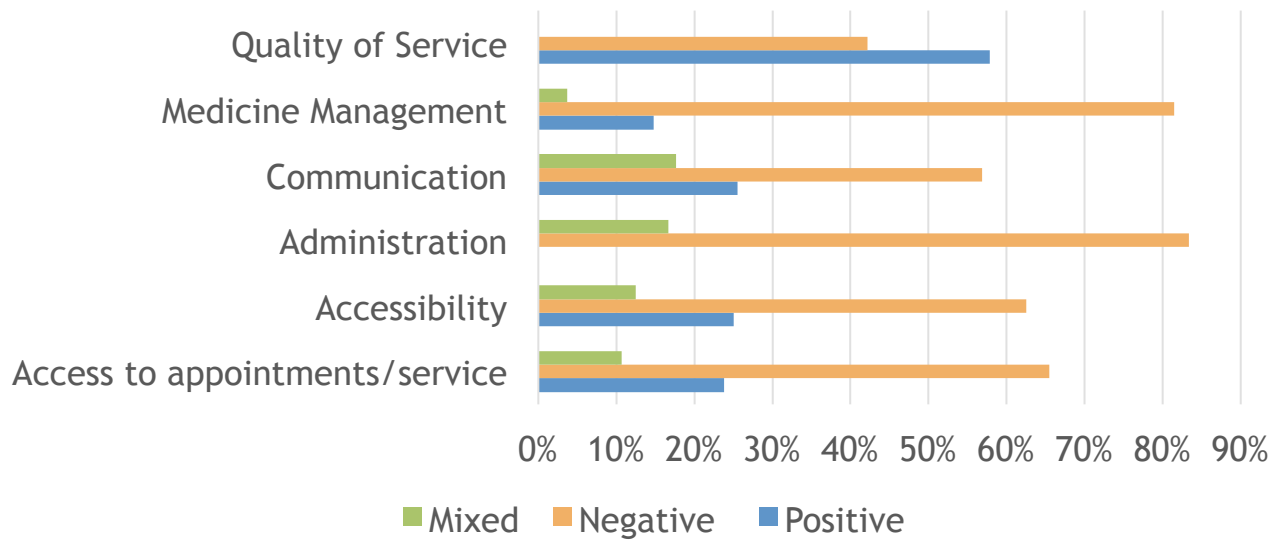
At a glance

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 and experiences shape the support available.

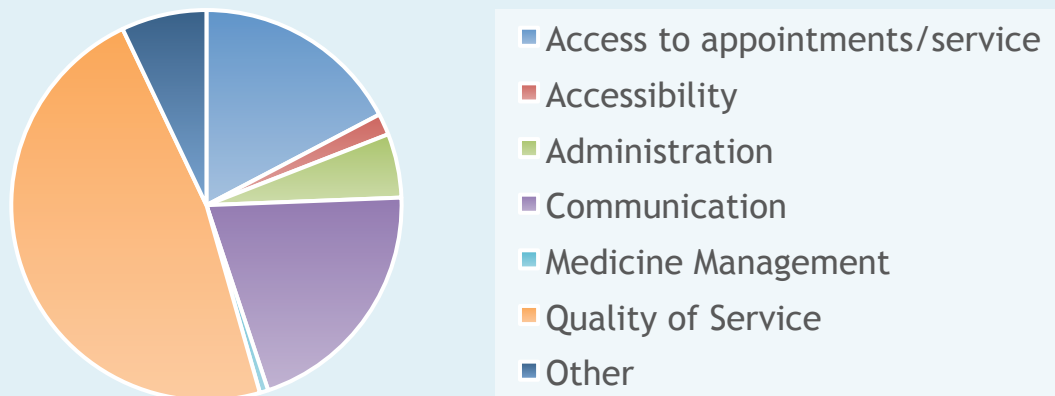
1060 people shared their experiences and views with us between October - December 2018. This briefing takes a deeper look at what people are saying, and how we're using this information to help shape health and social care policy and practice.



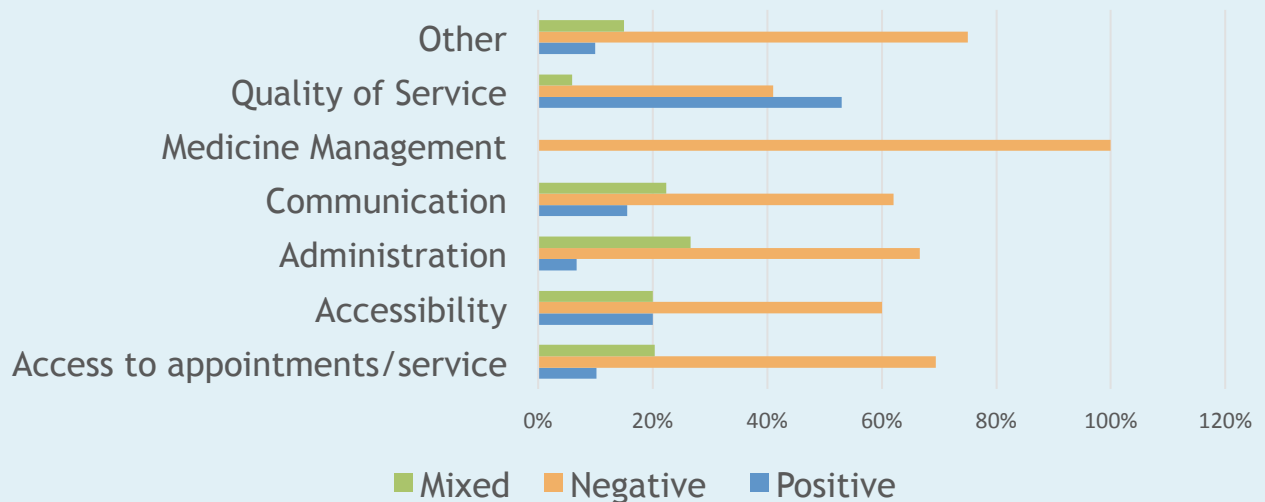
Primary Care - sentiment of story by themes



Hospital Care Themes (of total stories)



Hospital Care - sentiment of story by themes



Where does our data come from?

Our insight and evidence includes data collected from face-to-face activities and events, helpdesk enquiries, online feedback, emails and observations. We also gather insight through working in partnership with other organisations who work closely with the residents of West Sussex communities.



What are people saying?

Primary care This is one of our current priorities	
Emerging themes	Through our pharmacy raising awareness campaign we have seen a much high percentage of positive comments, many stemming from our observations when visiting nearly all the pharmacies in West Sussex
Ongoing themes	<p>We continued to hear:</p> <ul style="list-style-type: none"> • Access to GP appointments continues to be by far the most common theme from our insight on General Practice. Stories detailing the challenges patients face, including the cost of physically getting to appointments, difficulties getting through on the phone and waiting times • Accessibility concerns, whilst only a small percentage of the total primary care insight, show these as being significant for patients with protected characteristics (see case studies) • At the heart of much of the negative comment is communication. It is clear, that if more care was taken when speaking to people, and more proactive conversations were introduced giving options/managing expectations, this would result in far better patient and practice experiences (see case studies) • Medicines Management continues to present challenges for local people.
What are we doing?	<p>The General Medical Council have consulted on their draft Decision-making and Consent - Supporting patient choice about health and care Guidance (ended 23 January 2019). This sets out a whole range of guidance for health professionals around communication, and how to have meaningful and appropriate conversations with people. We'll be promoting the outcomes of this work, when available.</p> <p>We'll be trialling our questionnaire on accessing GP appointment (including questions on missed appointments) in Littlehampton, during the next quarter. We're confident this will offer valuable insight in to this challenging area.</p>



Case studies

Access to appointment

A Bognor Regis resident shared with us the difficulties they had in trying to cancel an GP appointment, resorting to email in a final attempt not to waste the appointment. *I have been trying to cancel my husband's appointment without success. I was on in a call queue from 9am till my phone ran out of charge at 9.46. Whilst holding, I went to the website as I thought I'd be able to cancel it there instead. WRONG. As I am not the patient I couldn't access the Appointments system. This is obviously one of the main reasons' appointments are not being kept - we just cannot get through to cancel them! In these days of automated phone systems surely another option can be added solely for the purpose of cancelling appointments! My husband will now be marked as not attending an appointment (which could have gone to someone else) just because there was no way of getting through to cancel. Just a suggestion to make the appointment system more efficient.*

Highlighting accessibility issues

Sarah told us she had been registered with her surgery for three years after moving to West Sussex. She's quick to point out that her family have received a *fantastic service* but that she has by comparison had a *shoddy service*.

Sarah is deaf and was asked by the healthcare professional where her interpreter was. She explained that she did not want one for the Doctor appointment as she felt confident she could communicate using a pen and notepad. Fortunately, Sarah is very familiar with the Accessible Information Standard and recognised it would have been the practices responsibility to arrange the interpreter, knowing her communication and support needs.

As well as setting the wrong tone the situation was made worse by Sarah having to wait over an hour, having checked using the check-in screen. *During this time nobody came to communicate with me. I found this isolating, worrying and highly frustrating because I could see enough to know that other people were coming into the waiting area and disappearing to appointments.*

Having made enquiries, Sarah was eventually seen by a GP, who gave no apology for the wait. The staff already knew Sarah's hearing and vision issues, and she felt it would have been reasonable for them to try to locate her, had there been a problem with her appointment. This would be classified as making a reasonable adjustment under the Equalities Act 2010. Despite Sarah's communication wishes and abilities, the GP refused to write notes and therefore Sarah felt unable to continue with the appointment.

Sarah had the confidence to raise her concerns to the Practice Manager, who was able to explore the situation and together they have improved their shared understanding of her communication wishes and needs, which in turn will make future appointments more productive for both her and the GP/staff.

Communication and understanding

We were fortunate to hear from both a relative of someone living with anxiety and other mental health conditions, and their GP. From the patient's viewpoint the wait for a GP to call them back but not getting a call until the afternoon just increased their anxiety. GPs shared that they proactively leave calling their patients, who they know have mental health issues to the afternoon when they have more time to talk to them. We've been able to share the impact this is having and suggested frontline staff support the GPs by reassuring the patient that they will get a call back after lunch when the GP will have much more time to listen and support them.

The importance of having consistent language. When a patient went in to make an appointment, they asked the receptionist about the new extended GP access. *The staff member looked blank and said 'The What?'* The patient explained that they had read somewhere that people could now visit a doctor in the evenings or at weekends. The staff member laughed and said *'Oh no! That's the overflow appointments'* and went on to explain that they can book patients into the overflow session when all other appointments are filled. The Saturday morning sessions are for people who need appointments but can't come in during the week - like for smear tests or asthma / diabetes checks.

Flu clinics

This has been a challenging year for delivering the flu vaccine due to supply issues. This case is given to help providers planning for next year's clinics.

Paula told us: I attended a planned Saturday-morning flu clinic (in a Worthing based Practice). Although the building is shared by several services, the flu clinic was the only service in operation that morning, so the building was empty and unused otherwise. After parking my car, I noticed a queue of (mostly elderly) people snaking out of the front door and across the car park. When I got to the front of the queue, I noticed the queue was to the desk for booking-in, but the counter stretched for many feet down the empty building. I took it on myself to suggest to the people waiting that they form a line along the edge of the counter - therefore ensuring the line was inside the building and that people weren't waiting in the bitter cold. It seemed strange to me that the staff were not managing the queue better and that frail and vulnerable people were left to stand for a long time, in the cold.

The actual service was quick, well organised and efficient. Under 65's went to one room and 65+'s another. The reception desk was being manned by a Senior Partner, who seemed to be extremely busy. There were staff without badges (so it was not clear what their role was normally) at the room doors helping people to prepare, but no-one in the waiting / queuing area offering support. It would have been good to see Patient Participation Group members helping and controlling the queue.

Hospital (secondary) care

Aspects of this insight may come under our Hot Topic priority

<p>Emerging themes</p>	<p>More people are sharing feedback about:</p> <ul style="list-style-type: none"> • the eye clinic services at Southlands hospital is much more organised and less stressful. • Expectant mothers' experiences of consultant-led maternity care (for multiple babies) compared to midwife care
<p>Ongoing themes</p>	<p>We continued to hear that:</p> <ul style="list-style-type: none"> • Cancelled appointments continue to be an issue for patients across a range of hospital services, leading to long waits to see specialists or to get treatment (see case study examples) • Accessibility and creating the right environment for all patients to be able to share in decision making remains an issue for people (see case study example) • Handling of complaints and delayed responses remains concerning • Trust responses to serious incidents are still causing concern
<p>What are we doing?</p>	<p>We're reporting separately on observations and patient feedback from Southlands Hospital visits.</p> <p>We're sharing the maternity stories with the Better Births' project leads to inform service development across Sussex.</p> <p>We've spoken to Western Sussex Hospitals NHS Foundation Trust (WSHFT) and were told there had been recruitment issues, which has led to cancellations but recently most, if not all key consultant posts had been filled. This should start to have an impact on appointments and make for a more positive patient experience. We would like to continue to hear from patients, who have or are being referred for hospital services, to understand what is working well and what is going wrong.</p> <p>We'll be visiting and spending time looking at how the Clinical Commissioning Groups' referral service works and will report on this next quarter.</p> <p>We plan to work with Brighton & Sussex Hospital NHS Foundation Trust to develop a reviewing process to support in their complaints handling. We've also asked WSHFT to share their learning/improvements on serious incidents, to be able to promote good practice to another Trust where we've raised concerns over the way such incidents are investigated and reported.</p>

Case studies

Issues with appointments

Tracy had an appointment to see a Gastro specialist at a coastal hospital for an urgent matter but received a letter saying it was cancelled. She called the service to make a new appointment, only to have the staff member breakdown on the phone, as they were unable to find her an appointment for over two months. This has been going on for over half a year, with tests being carried out four months earlier. Others, she was told have been waiting 9 months for an appointment.

Bob has Parkinson's and told us: *I phone up about a month before my 6 months appointment and get to see someone as you are not now given a new appointment in advance. Last time I was told by Receptionist to 'wait my turn'.*

Accessibility and shared decision-making conversations

Monica's junior-aged son is very accident prone and autistic. He doesn't like to be touched (hypersensitivity). She describes his care and treatment as exceptional, but the healthcare professionals don't always understand his needs. This can lead to a really stressful and traumatic experience.

When I have been able to tell the nurses or doctors about his autism and his hypersensitivity before they interact with him, they have been brilliant. They have been able to take time to speak to him and create a rapport with him and then they have asked to shake his hand and then he has allowed them to listen to his chest or examine him. But, there have been other occasions when a nurse or a doctor has just barged into the room or cubicle, gone straight up to my son and said something like 'well what's up with you then young man' or 'let's see what's going on with your arm then shall we...', while moving forward to lift his clothes or touch him in some way. This has created a really difficult situation where my son will scream, thrash around, basically have a massive meltdown.

Despite his young age he quite a big boy, so this can be quite difficult for everyone and can actually put him at risk of hurting himself. I just wish ALL the doctors etc would talk to me first and that they could put some sort of sticker or message on his notes so they know to speak to me first and not just go steaming in like a bull in a china shop.

We have worked with a Trust and raised a similar issue with Adults A&E, which has led to a change in the way they alert their staff to specific issues for the patient being treated and the patient told us this has had a very positive effect on their experience.

Mental health

Children & Young Peoples' mental health is one of our priorities

Emerging themes	<p>More people are sharing feedback about:</p> <ul style="list-style-type: none"> • Healthcare professionals not understanding how to support people with mental health needs, and people not feeling able to speak to GPs or not being listened too • Lack of services/support, particularly around alternatives to medication • People not knowing how to access support for their mental health.
Ongoing themes	<p>We continued to hear that people have:</p> <ul style="list-style-type: none"> • Poor experiences, and gaps between appointments and this impacts on their recovery and wellbeing • Lack of support for children and young people who present to GPs or schools with mental health issues and support needs • Challenges in getting packages of care finalised and in place. • Inadequate quality of support when accessing the crisis or community mental health service telephone lines.
What are we doing?	<p>Much of this quarters insight around mental health has come from our Listening Tour of Burgess Hill and is detailed in the report which includes a response from Sussex Partnership NHS Foundation Trust.</p> <p>In line with the NHS Long Term Plan, we believe there is a need for greater commissioning and support for community services, include peer support, to make sure these are available early on and support people to sustain their recovery. Every service access point, whether this is a GP practice, town or district council, local support group/church etc., should be helped to know where to signpost someone with a mental health concern. Any information needs to include how a service can be accessed, e.g. if a person can refer themselves or if they need to visit their GP to be referred.</p> <p>We will be working to identify how the local implementation of the NHS long term plan reflects the above.</p>

Case study

Gentleman who lives with complex physical health challenges said of his experience of accessing a mental health telephone service, the services are stupid and a waste of money. You are asked 'on a scale of 1-10 are you depressed' and are you likely to kill yourself. *This is no good to man or beast.*

Social Care

This is one of our current priorities

Emerging themes	<p>More people are sharing feedback about:</p> <ul style="list-style-type: none"> • Adult Services - under a third of the people spoke positively and the positive comments related mainly to the voluntary sector services.
Ongoing themes	<p>We continued to hear that people:</p> <ul style="list-style-type: none"> • Have unmet needs, due to a lack of service or inability to access services • Struggle with the lack of consistency of staff providing the support and they tell us how this negatively impacts on care. • Have concerns over the assessment for adult services. • Are feeling severe impacts from a financial assessment errors/issues, as detailed in our minimum income guarantee feedback report.
What are we doing?	<p>Adult social care is one of our current priorities. We have already provided a formal response to West Sussex County Council's Draft Vision and Strategy for Adult Social Care.</p> <p>We will be meeting the project leads developing this vision and strategy to ensure that local people are involved in co-producing a new service.</p> <p>We're also working very closely with our colleagues across the voluntary sector to continue to understand peoples' lived experiences and what services need to provide in the future.</p>

Case studies

During our Burgess Hill Listening Tour we visited an assisted living complex and one of the residents shared with us that there are now more people coming to live there, who are living with dementia, even though it is assisted living accommodation. They very quickly find out they cannot cope. A vicious cycle really -can't cope at home, can't cope in assisted living. Now where to live?

Patty received rehabilitation support in hospital. My referral documents and discharge notes weren't sent to my doctor. I suffered depression due to the stroke and changes in my circumstances and had no check-up. The hospital social worker did not sign me off, so I was not allowed another social worker, so all adaptations were delayed. I had to contact all the services I needed myself. I was unable to get into my own bedroom for 3 months due to delays with the stair lift. I found the whole episode frustrating.

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 and experiences 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.

We strive for continuous improvement. You can review how we performed this quarter in our latest board [Performance Report](#).

Contact us

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

