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# What people told us about health and social care

A review of our insight and evidence  
Q1 April - June 2019

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This quarter we gathered  
**1045**  
views,  
experiences  
and stories



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



To find out more about this work visit our [what we do](#) webpage. We publish a full Community Partnership update each quarter.

Our priorities for 2019 - 2020 are:



This quarter, we carried out a Listening Tour of **Broadbridge Heath**, which we report 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](#) to complete the sign-up at the bottom right of the home page)



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0300 012 0122



@healthwatchws  
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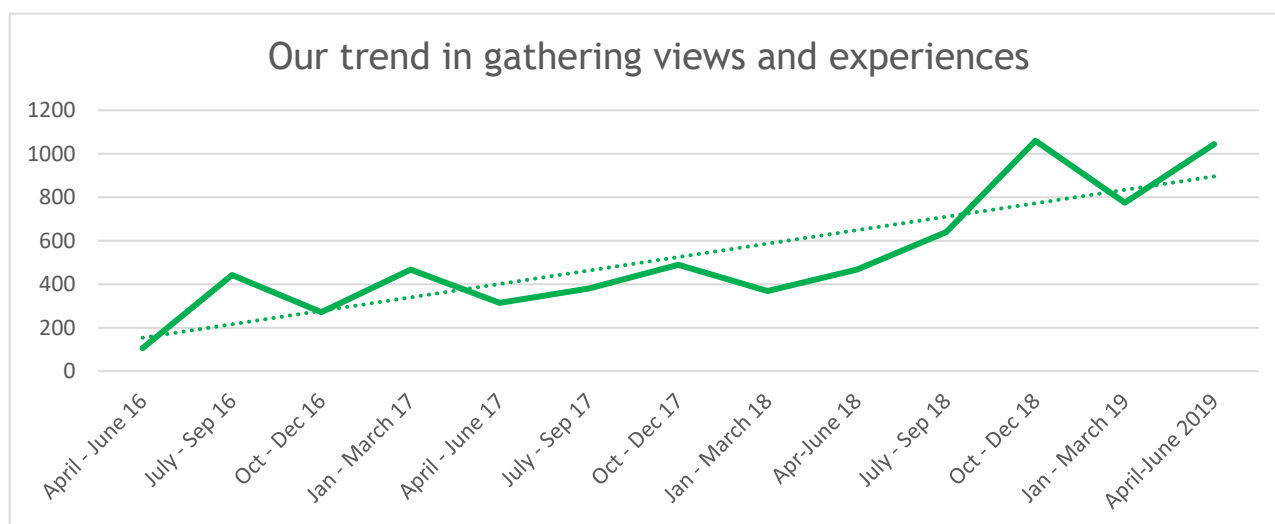
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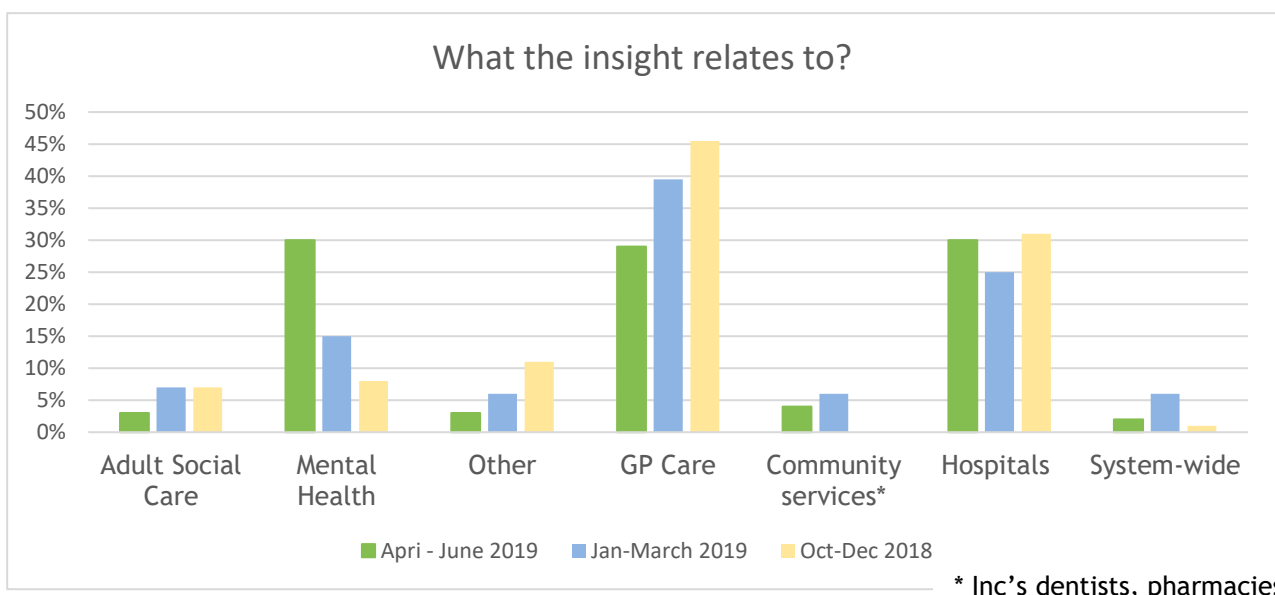
## At a glance

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 shape the support available.

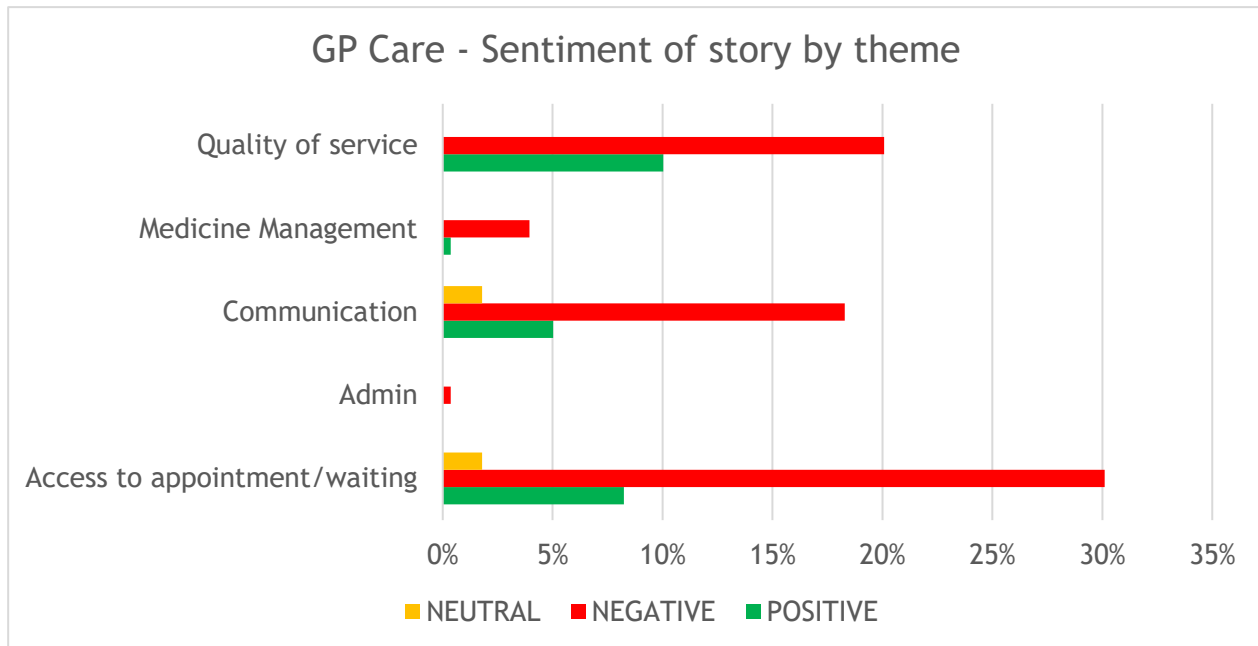
**1045** people shared experiences and views with us between April - June 19. Plus, we had over 60 survey responses.



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.



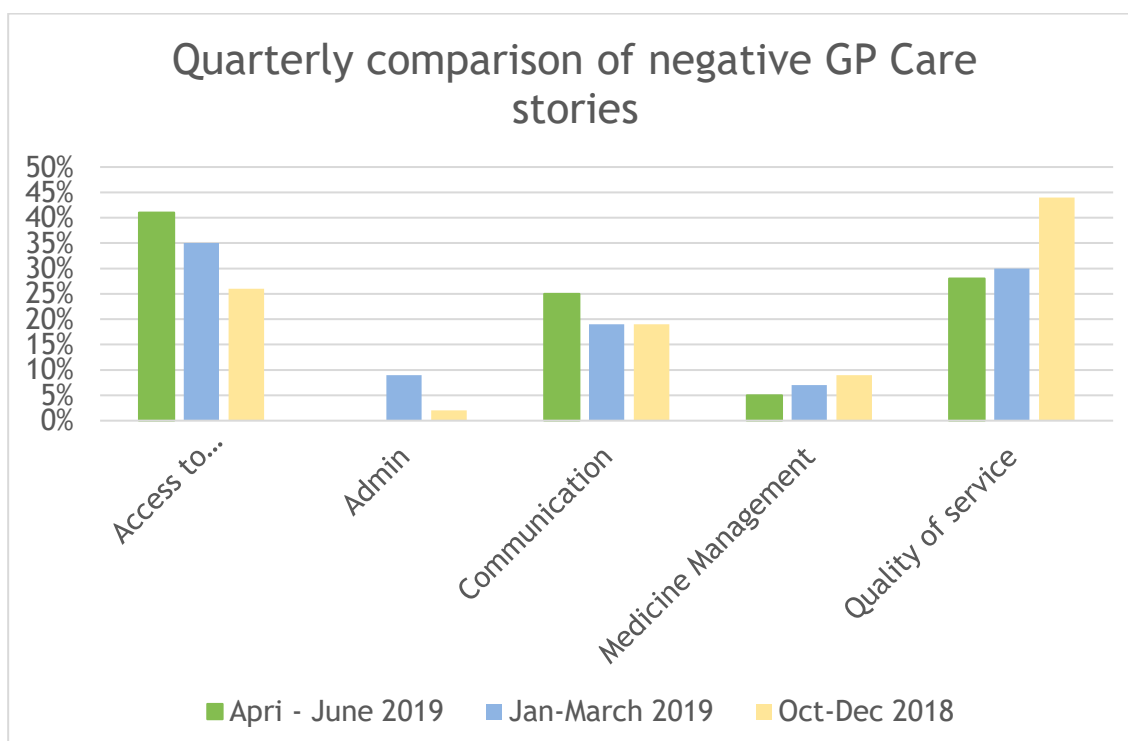
This data does not include the stories gathered through our latest Listening Tour of Broadbridge Heath. You will be able to read this insight in the report being published in quarter two.

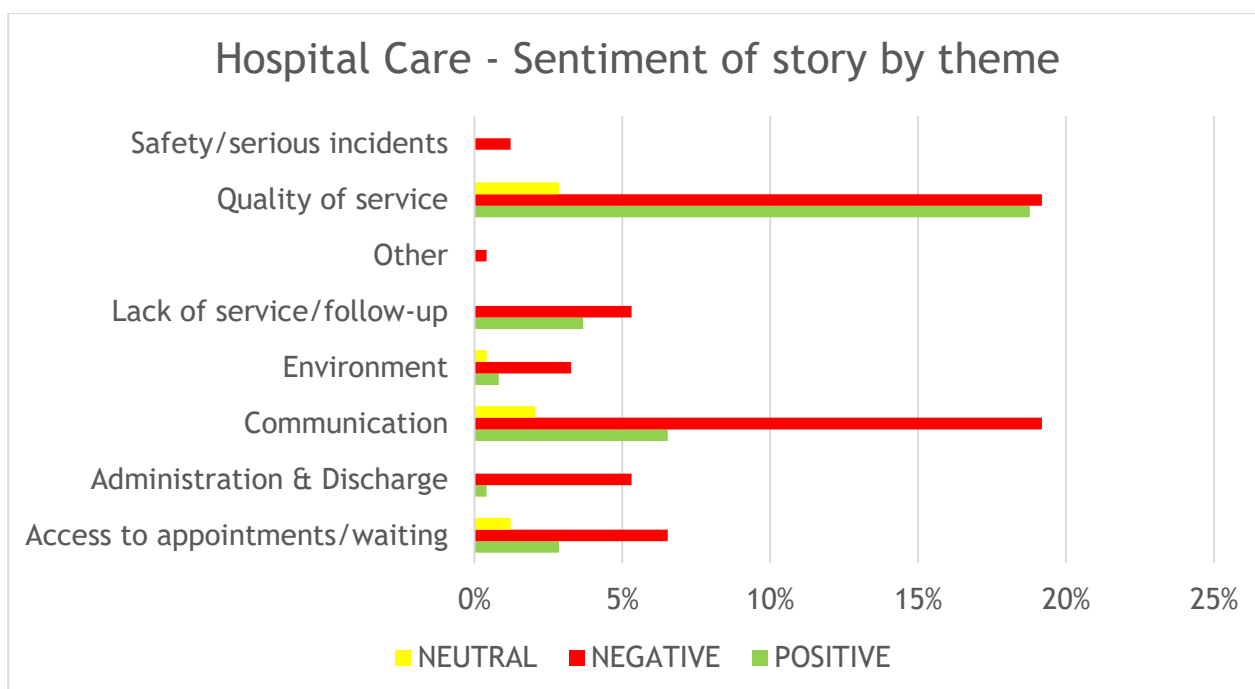


Access to appointments is still a major issue for local people, despite the introduction of improved GP access. We suggest the under-utilisation of these extended hour appointments comes down to two factors;

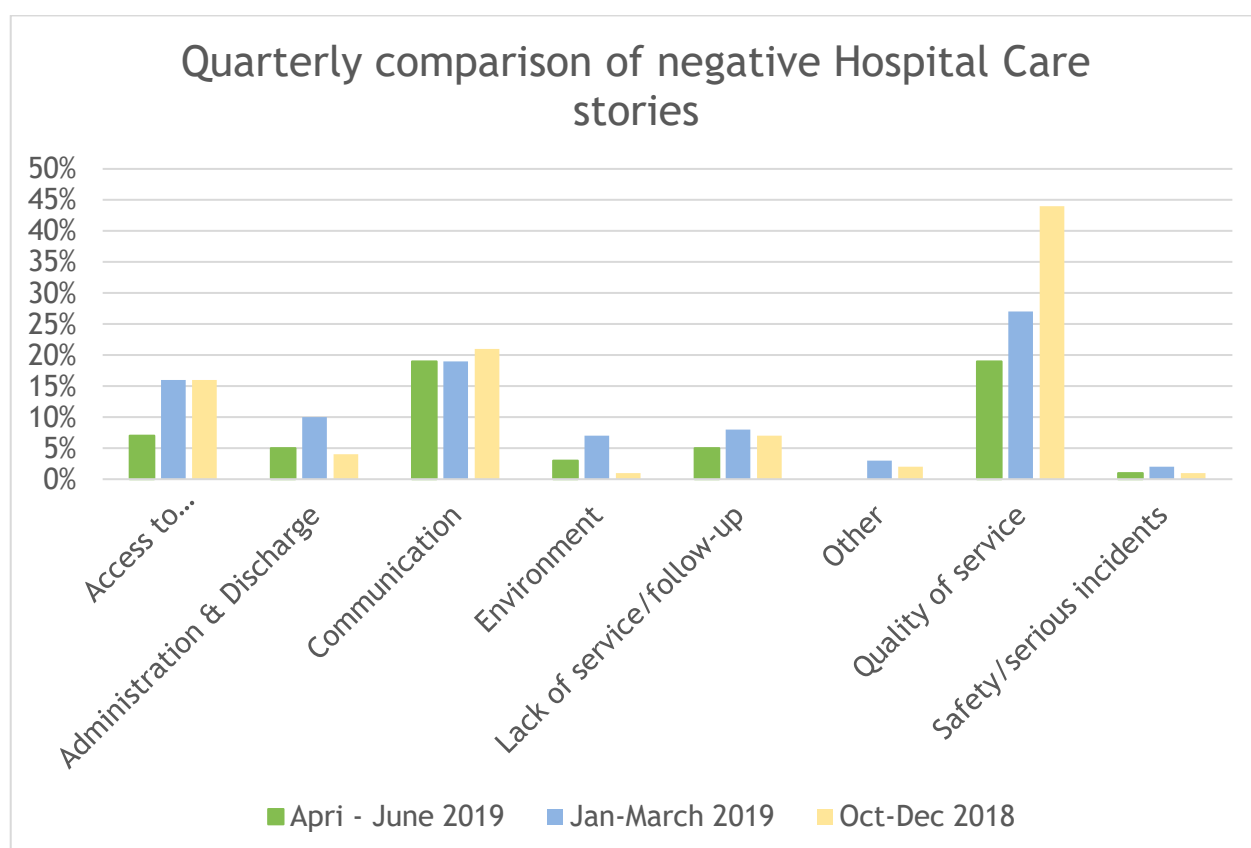
- i. extended hour appointments do not appear to be consistently offered
- ii. many patients do not know that they can book evening and weekend appointments

The chart below compares the themes to the previous quarter.





Whilst there is more of a negative picture for *quality* and *communication* there is a noticeable increase in positive sentiment in these areas, compared to the previous quarter.



## What people saying?

GP care This is one of our Priorities for 2019/20	
Emerging themes	<p>Communication whilst not an emerging issue, our focused conversations with older people how many feel they <i>are being an inconvenience when they go to the GP</i>. We explain the Bevin test, of pay now and then claim when needed.</p> <p>Patients also told us they are leaving consultations with concerns, and/or not understanding their treatment options. One of the GP online systems has been developed so that in the future patients could book appointments with community pharmacists to discuss medication. However, local services are not fully ready for this, so we would suggest, clinicians could end consultations by inviting patients to discuss medication with the community pharmacist.</p>
Ongoing themes	<p>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.</p> <ul style="list-style-type: none"> <li>• There are extreme examples of people having to wait on the phone to get through to the surgery, in particular practices. We would suggest this is an area where practice should invest time to examine and the GP Start Programme provides this opportunity with external support.</li> <li>• There remains a lack of awareness of the <a href="#">improved access</a> that offers evenings and weekend appointments.</li> </ul> <p>Communication also still comes up time and again in relation to how this impacts care or decision on where to access care.</p>
What are we doing?	<p>Our Board has kept GP Care as a priority for 2019/20.</p> <p>We hope to be able to work more closely with practices, through the newly formed Primary Care Network (PCNs) - see our website for an explanation of what a PCN is. We will aim to provide insight and to identify issues and solutions. As shown in our <a href="#">Work Plan</a>, we wish to work with a Practice or PCN, later in the financial year, to try out different ways of getting valuable feedback from patients, through creating opportunities through a <i>feedback month</i>.</p> <p>You can <a href="#">watch</a> the progress of the Midhurst practices on developing a wellbeing hub, to learn more about how the future of <a href="#">PCNs</a> may benefit patients in the future.</p>

### Access to appointments

Can never get through to the surgery on a Monday. The surgery tells you that you have to phone in the morning, but I found out from a friend that you can actually phone until 3pm and they will still give same day appointments. It would be nice if they did late night appointments as well.

Older female patient in Rural Sussex

I find it very hard to get an appointment especially as I work. The triage system is a complete waste of time.

Asian working-aged Worthing resident

Frank says his surgery is awful to get an appointment, sometimes it can take 1.5 hours to get through and then there are never any appointments. His wife has cancer, and he finds it quicker to walk to the surgery and speak to someone, however, there is always a queue out of the door at reception.

Bognor Regis Resident

My dad is 80 and has to walk down to the surgery at 8 am to try to get an appointment. If he is not ill before this he is after it.

Son met at a community event

I'm very unhappy that there is a very long message on the phone line, takes over 5 minutes to get through. You can't get an appointment even if you get through at 8am. There are no pre-bookable appointments, only on the day ones which you can't get!

Bognor Regis resident

Whilst we appreciate resourcing a telephone system to cope with local demand is a challenge, Practices can [read](#) how a Crawley GP Practice has changed its telephone messages to adjust message at peak call times.

I received a text saying I was due my annual review. So, I booked an appointment and turned up. They asked why I was there? I said I'd been told to come for an annual review. They denied this, as it wasn't due. Turns out it was for my daughter. Surely it would make sense to put a name on the text. Luckily, I hadn't had to take time off work.

Crawley Patient

There is a need for practices to be mindful of information sharing, but this must be balanced with not making assumptions. We hear from patients whose practices have more than one surgery, how there can be confusion and missed appointments because the location has not been clarified. Reviewing the issues and putting simple steps in place could bring down the rates of lost appointments.

## Hospital (secondary) care

Aspects of this insight may come under our Hot Topic Priority for 2019/20

<p><b>Emerging themes</b></p>	<p>Issue around communication with cancer patients has been noted through our recent hospital visits.</p> <p>Restricting clinicians' ability to carry out more than one aspect at a time appears to be creating issues for both the professional and the patient. Whether due to referral issues, or funding constraints, to patients it is both frustrating and illogical.</p>
<p><b>Ongoing themes</b></p>	<p>As reported last quarter, we continue to hear of issues with Coastal eye clinics and are in the process of following up on the recommendations in our published <a href="#">report</a>.</p> <p>Communication remains an issue, particularly the lack of patient involvement in treatment and testing, and the way in which things are communicated.</p> <p>There are also examples of good practice, one Princess Royal Hospital patient named their consultant, saying <i>she always comes out to call you and waits for you</i>.</p> <p>Another patient said, <i>I receive all my test results on the Patients Know Best app. It's brilliant. I've no idea how to use the app beyond viewing my London tests. Would be nice to get all my local ones on there too but I've no idea if that's possible or how I'd do it?</i></p> <p>Delays and cancelled appointments/operations remain an issue with some very negative impacts for patients.</p>
<p><b>What are we doing?</b></p>	<p>We have a seat on the newly formed Sussex Cancer Alliance and will be providing patient experience to be used at the heart of this working group.</p> <p>The hospital visiting reports contain recommendations, which are discussed with the Trusts. We ask to see evidence of improvements and then follow this up by talking to patients, when we revisit the hospital to see if this has had an impact.</p> <p>Where we have raised an environmental issue, then we check that the improvement is evident, and standards are being maintained</p>



## Processes

I was sent for a scan, but they would only scan the lower back and I needed the whole back done. I know, due to arthritis, that the pain in my neck causes me to stand and move awkwardly and put pressure on my lower back and spine. But no, I needed two visits one for lower and one for the top. This is a waste of my time and increase of my expense and theirs.

## Communication

I was recently diagnosed with aggressive (type explained) cancer. I'm seeing lots of different people and having lots of different treatments and tests, but no one tells me what or why or what the outcome may be... Looking into herbal medicines because at least I have some control.

Coastal Patient

We were left 3 months not knowing if my husband had lung cancer or not. No one seemed bothered in talking to us or had any concept that we may be worried and fearing the worst. It might be routine for them, but it's not for us.

Carer of a Coastal Patient

George has recurring cancer and earlier in the year had a biopsy. The consultant stated he should come back in 2 week times for the results and he received a letter and text confirming this. When he got to this follow up appointment, he was told the results were not back. George asked, *Why could the team not have informed him of this to save him expense and time?* He finally got the results and need two further biopsies taken. These were done at a different hospital and the consultant phoned him at 7.30pm to inform of the result. This process has been ongoing for 5 months and has been very upsetting.

Mid Sussex resident

I received a letter for a follow up appointment but was unable to attend on the date given. So, I telephoned using the number on the letter and could not get through. This was causing me a lot of stress as the clock was ticking and the letter told me what would happen if I didn't let them know I could not attend. So, on one day I telephoned before 8am and someone answered the phone ... she gave me the correct extension number. I phoned again a little later using the correct extension number and got through. So, what is needed is letters that contain the right information and correct telephone numbers.

## Delays and cancellations

I had an appointment at the hospital earlier this year, but they would not do the operation as they had not completed the investigative work. I have now lost a lot of weight and my weight is now too low to have the operation. Still waiting for the operation.



## Mental health

### Emerging themes



We have been engaging with young people and their families and there are a number of common themes emerging:

- Services are **not personalised**, as there are too many linear programmes/pathways and processes getting in the way of support.
- Young people that do **not fit into services are not being told where they do fit**, which is particularly relevant for CAMHS and transition\*.
- People feel they need to **jump through hoops** to get any chance of support, other feel they are **not being believed**.
- A general lack of awareness of what's out there by both professionals and local people.
- **Lack of support for under 11 and then under 14.**
- **\*Waiting times** (links to item 2 as well).
- **Lack of basic awareness amongst professionals whose roles impact families**, for example: benefits worker who phoned to ask the school if the child still had Downs Syndrome.

Where people had been able to access some support, we heard expressions of relief and hope, but also disappointment that it did not offer personalised programmes and people then had to go back on waiting lists for more support.

We heard very positive comments about *Allsorts* (which is commonly known about) and the *YES* (Youth Emotional Service, which is not so commonly known about, even amongst professionals).

### Ongoing themes

We continued to hear that people:

- Struggle to get support for their mental health in the community, with the Bedale Centre as once again raising concerns.
- The [public consultation](#) on the proposal to change In-patient Mental Health beds in West Sussex is now live.

<b>What are we doing?</b>	<p>We have already published and shared with the Independent Review, looking at children and young peoples' mental wellbeing support across Sussex, what local <a href="#">students</a> said about mental health and services.</p> <p>Over the summer months we will be putting together case studies and expanding on the themes being identified and this will be used to support the work of the Independent Review and to influence the commissioning of local services.</p> <p>We gave prompt and detailed feedback on the original consultation document and recommended the project team sought advice from the Consultation Institute before proceeding.</p> <p>We plan to work with the Trust and commissioners on their programme of engagement around the public consultation and have asked to see all the anonymised data collected from this consultation.</p>
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One parent we met told us that the Adult-mental Health Centre have simply failed her daughter, who was referred to the service towards the end of last year. Her daughter had to retell her story yet again which meant revisiting childhood trauma and since that first meeting, they have not heard anything. Earlier this year they chased it up and were told a letter had been sent but had been returned.

The parent is disappointed that the service did not try to get in touch again after receiving the returned letter. And that when they have spoken to them, it has all been about what they can't do, and nothing about what they can do.

When we did get an appointment, after waiting for 10 minutes they were told the doctor was off sick.

Family living in the North of the County

We have signposted a number of people to [Pathfinder](#) and other organisations to help local people in finding some support.

There are some things you can't 'recover' from, e.g. bi-polar or Autism and this needs to be recognised. Need to learn how to sustain yourself but instead everything is monetised, segregated and pathways followed/pushed that can be harmful e.g. sectioned and medicated when I needed peace and the countryside.

Person living with long-term mental health conditions

Mental health concerns effect families and we heard from Sarah, who shared her experience. *I now have to remind my husband of things as he has mental health issues. I don't know if these are due to his medications. He is suicidal and his emotions have gone. He is over medicated. I wrote a letter to his consultant and because I named the consultant, they will not now change anything without his say so. So, he is still on the same medications, because the GP cannot change anything without the consultant's permission.*

Professionals are also struggling to navigate the system. A Wellbeing Team are trying to support someone who has a complicated history involving autism, mental health and alcoholism. They are being passed back and forth between services. The GP has tried to refer to alcohol support services and a psych team, but the person still is not getting the referrals or the support they need due to the multiple diagnosis. This has been going on for more than a year. The person is only currently getting support for one element and the Wellbeing team are frustrated and not really sure what to do next. (We gave info regarding Healthwatch and Pathfinder.)

## Social Care

### This is one of our Priorities for 2018/19

<b>Emerging themes</b>	A lack of support for people living with Autism, and the roundabout of assessments and rejections for support some families are going through.
<b>Ongoing themes</b>	<p>The quality of services has come up from our conversations with people this quarter, along with lack of support.</p> <p>Not knowing where to go for support continues to be an issue for local people.</p> <p>Financial Assessments Team have informed us that some 5,000 people will be asked to go through a re-assessment process (both working aged people and pensioners). Using the insight and recommendations, the project lead has secured some fair outcomes so people can get the right information to prepare for the assessment, understand the outcome, and have time to reflect on what they may have to pay in the future, so they can make choices based on a fuller understanding.</p>
<b>What are we doing?</b>	<p>Our Board has kept Adult Social Care as a priority for 2019/20.</p> <p>We will be providing case studies to the newly formed <i>Lifelong Service</i> and asking them how the transformational work will affect such families going forward.</p>

### Quality

My carers just turn up as and when. I have a regular appointment for 10am but they arrive anytime. Today they were late, which is why I am late (to the voluntary event). She sat outside - I felt like saying 'come on in', but you just do not know if they are the carers and you do not want total strangers in your home. When she did arrive, she did not introduce herself.

Older person who receives agency care

### Lack of support

David, said his wife is having chemo for Breast Cancer and is now in a wheelchair. He is finding it difficult finding the right equipment to support her.

Young man with Cerebral Palsy, is cared for by his father. They feel that social services are not supporting them, as they've not had a review for over a year. His father feels that when everything's ok they're there to tick boxes but very hard to engage with when they actually need support.

## 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 an Independent 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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