

# What people told us about health and social care

A review of our insight and evidence  
October - December 2019

This quarter we  
gathered

**1112**

lived 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 also  
popped-up in libraries  
throughout the County  
and worked with young  
people.

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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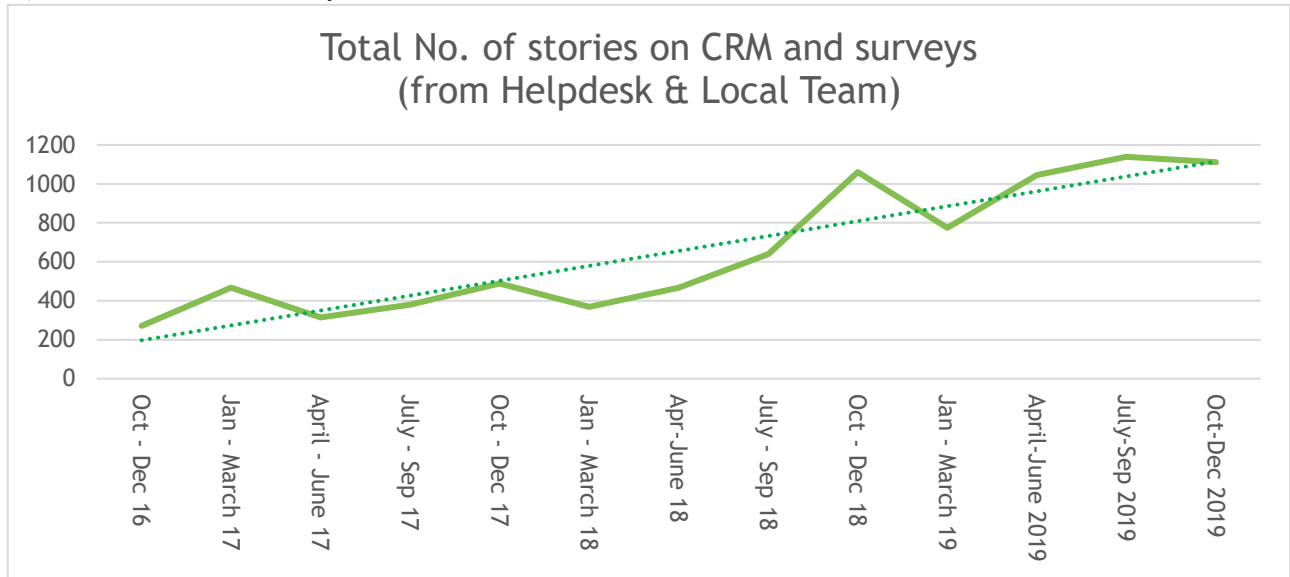
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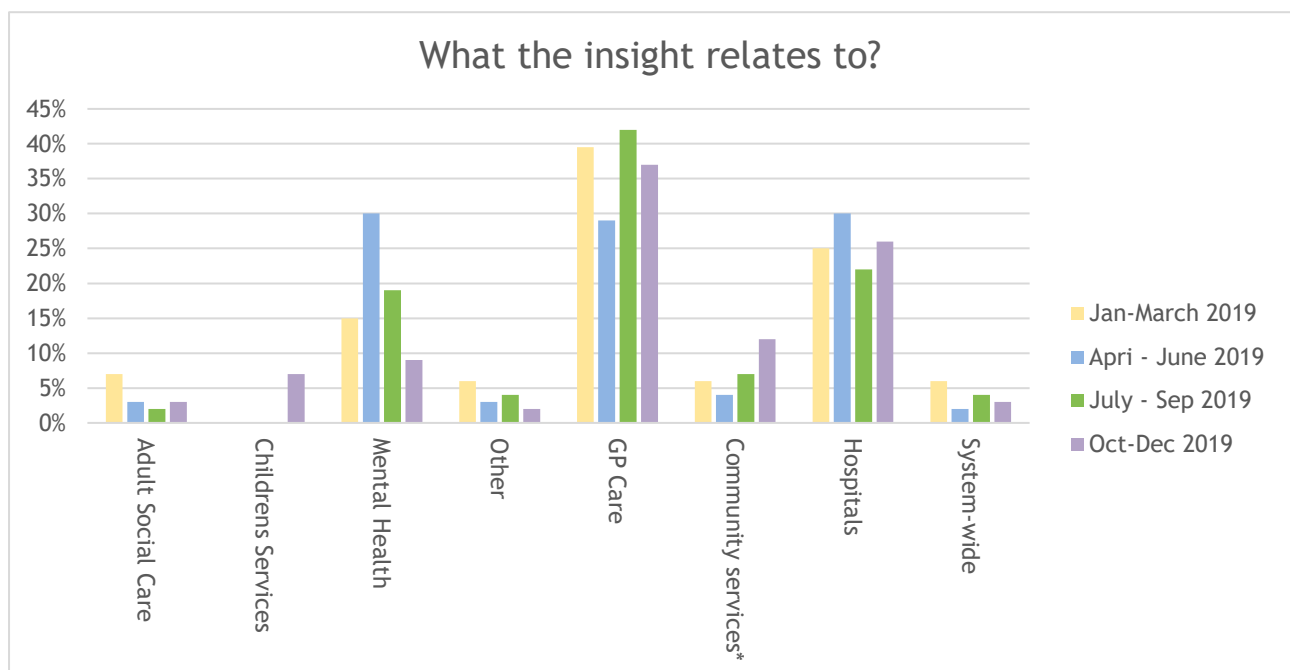
## At a glance

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.

1,112 stories and experiences were shared with us between October - December 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.



Matt's comment below stuck a cord and we believe is key to helping people to help themselves and services. It echoed what young people have been saying to us.

“If you have not experienced good service, you don't know what it looks like. You're provided with a certain level of care - good or bad. It's your frame of reference that say if it is good or bad.”

Matt (aged 18-25) resident of West Sussex



Sitting alongside our case studies and use of this *Good Practice icon*, we will be working with Young Reporters (aged 12 - 16), commissioners and services to create awareness videos. The work aims to show what to expect and also where things may be changing. We're planning to work with a group of young people to examine their health rights and to create information on this.

This is important. Where people can proactively participate in managing their health and understand what to expect, then they can alert staff if they are starting to stray away from this. Early alerting of issues can reduce the impact on them and services.

The logistics of getting to and from health appointments or hospitals came up often in our conversations with local people and is something that appears to rarely be taken into account. As this example demonstrates, a failure to consider this leads to additional work for the NHS.

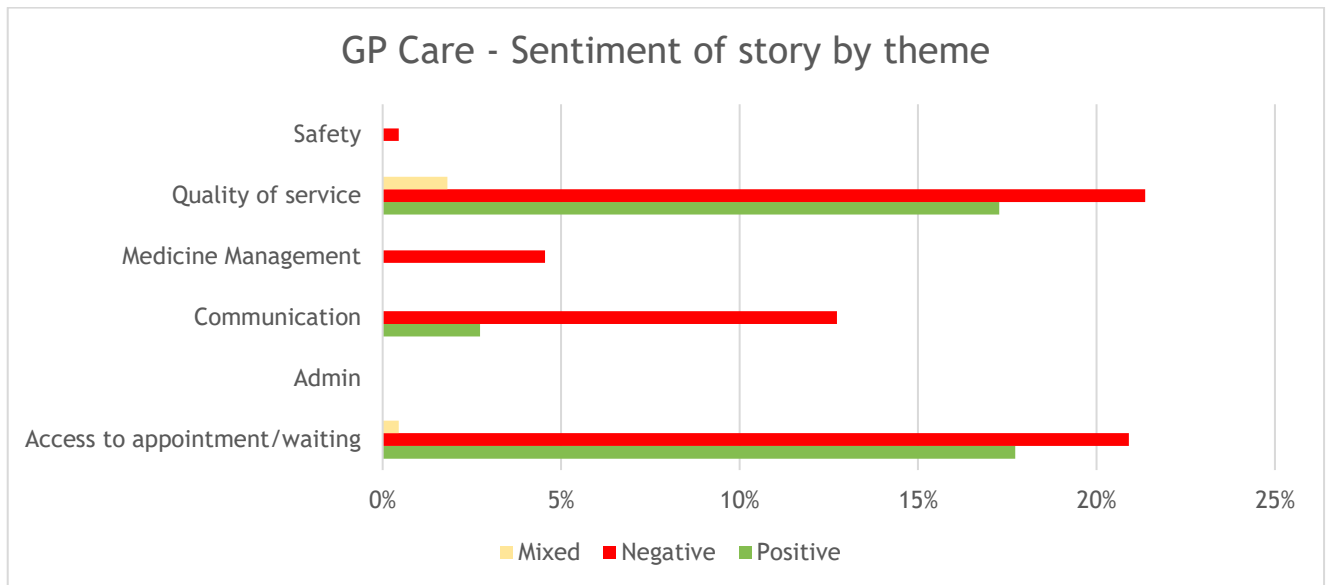
“David told us: I went for blood tests and because of the wait for an appointment at the surgery, it took 6 weeks to get the results reviewed and in that time, I had lost 5kg. The Doctor made an urgent referral to the specialist (Coastal area).

I have gastro problems anyway and usually see a gastro specialist at the Royal Surrey Hospital (Guildford). As I don't drive it is easier to get to, as its only one bus ride. When I've been to East Grinstead to see the specialist it's a three bus journey ride. Who knows how long it would be to Worthing or Chichester on the bus from Horsham.

I wrote to my specialist and asked for help and the specialist liaised with the service I had been referred to and arranged an appointment at the Royal Surrey.

It can take all day to go to one appointment and between myself and my wife we have an appointment every week. My wife has physio in Horsham, which is 2 buses. One bus didn't arrive at 4:45pm so we ended up taking a taxi. I will need treatment for my cataracts soon, but I don't know where to go because of the waiting times, but more importantly the travelling times.

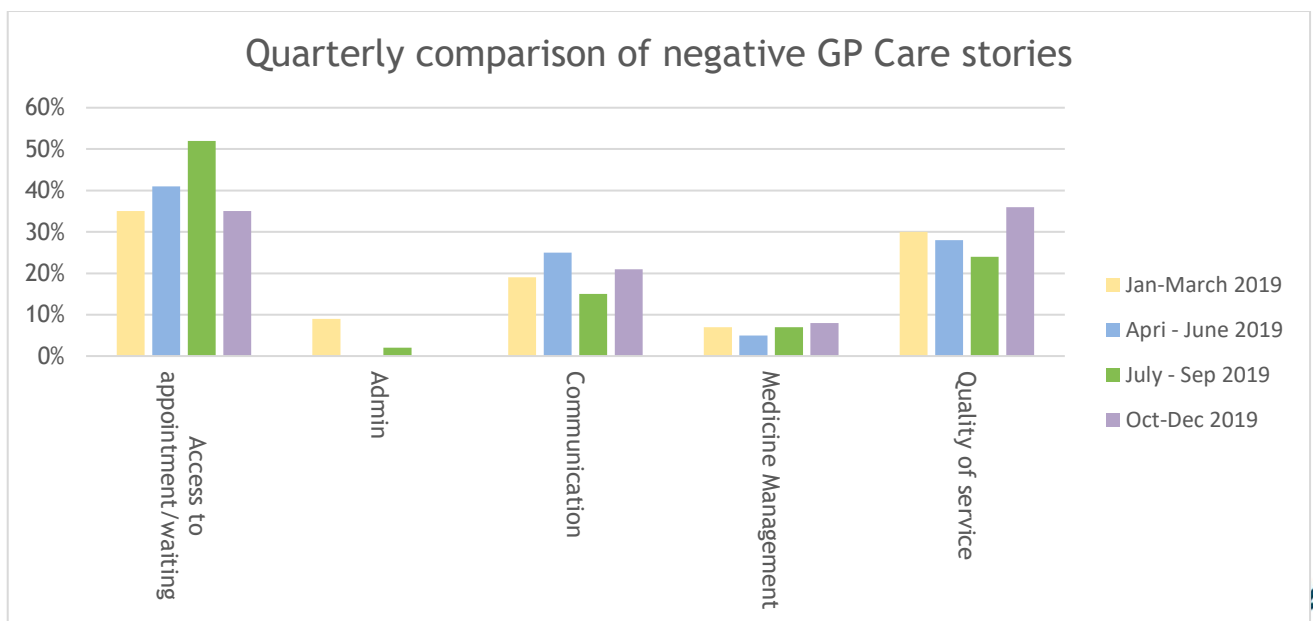
## What people are saying?



Quality of service was the number one topic this quarter. We heard several examples where individual GPs, and other clinicians, **have supported patients through very challenging times**. Sadly, we can't showcase these here as the stories may be too identifiable.

Whilst access to appointments/waiting time is in the top two themes for GP care we have heard this quarter, it is worth noting there is now more of an even balance of sentiment (with the negative comments previously being 32%). Talking to patients, more are aware of the **Extended Hours Access to appointment service** than we have previously come across.

Below compares the negative sentiment by themes to the previous three quarters.



<b>GP care</b> This is one of our Priorities for 2019/20	
<b>Emerging themes</b>	<p><b>Access to support for transgender patients</b></p> <p>We have had a flurry of stories from the transgender community, with people contacting us directly (rather than through us engaging with them at support groups etc). Access to medication has been at the core of their concerns and we have written a paper to the Clinical Commissioning Group (CCGs), with some recommendations around improving support.</p> <p>There is also an issue over how data is captured, and thereby how health inequalities for this community are identified.</p> <p>People are expecting a long wait under the NHS to access gender reassignment clinics but there are specific unmet needs that can be addressed locally. Work is being done in Sussex to review how best to meet the need of transgender patients.</p> <p>Sussex has also done work on the use of pronouns and this is something that we would encourage all GP providers to take onboard.</p>
<b>Ongoing themes</b>	<p>We continue to hear that access to appointments in General Practice (GP) in some areas is poor and generally, people express a feeling that demand is high, and that face-to-face appointments are a scarce thing. <a href="#">Video consultations</a> have been introduced in some parts of West Sussex (through an online/smartphone app). The service can give medical advice, deal with prescriptions and referrals on the same day (including weekends). This service may be especially helpful to people who may struggle to get to a surgery, either due to work or mobility concerns.</p> <p>Communication is part of the quality of service perception and onward issues for patients and services. Our example on the next page shows how understanding patient communication needs and support can make such a huge difference.</p>



## Supporting the Transgender community



Emma told us: The GP assessed and believed that a 3 month injection to prevent periods was in my son's best interests with regards to his health and wellbeing. A referral was also made to GIDS (Gender Identity Development Service at the Tavistock clinic). My son was able to articulate his needs himself without me, so had the capacity and understanding. We're still waiting for the first appointment at the Tavistock (GIDS website says this can be 22 - 24 months), but in the meantime, the GP has helped as best they can.

In contrast, Kelly's daughter hasn't been able to get support to delay puberty and is in very poor mental health, with suicidal thoughts. The family are struggling to know where to turn and feel totally unsupported.

**There is a test case going through the High Court at the moment that may have a very significant outcome in this area**

## Personal communication needs



Margaret's adult son has learning disabilities and she described how one of nurses at the surgery has made friends with him and he feels confident. She told us: when we last visited, he had his flu jab and the nurse was around to support him and this made a huge difference.

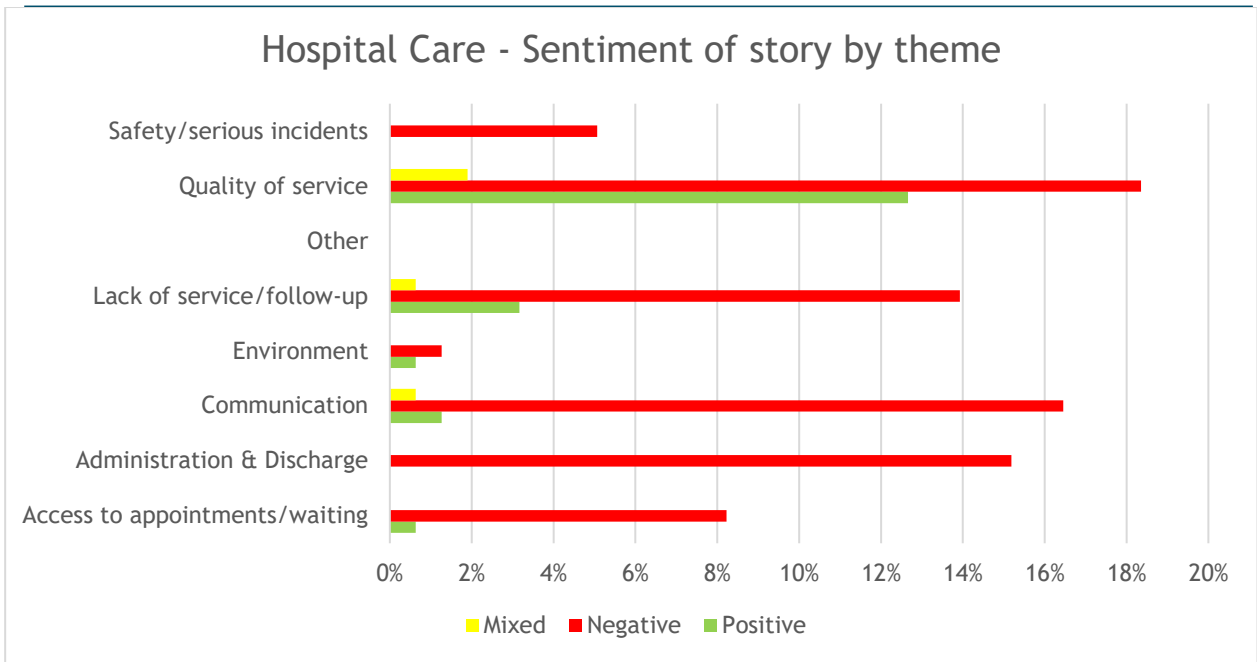
In contrast, Maxine's son has autism and told us: he can be very dramatic when he is in pain. We went to the MIAMI clinic (Littlehampton) because he thought he had broken his finger. I didn't think he had but wanted to get it checked. The doctor that saw him didn't seem to have any experience of autistic kids or empathy towards him. It ended up with my son screaming and having a complete meltdown in the room.

As well as asking people about their communication and support needs and then working to meet these, services may find it useful to download and use our [Best Interest Decision Making Toolkit](#), co-produced with the Disabilities Trust. The toolkit is now being shared with NICE and we hope to see this endorsed and used by more clinicians. It works - don't just take our word for it.

“ We were approach by a professional at the Partnerships First Steps to Adulthood Worthing event this quarter, who said: You came to speak at the WSPiC last week about the Toolkit. I went back and used the tools with a someone who had a dental issue and the tools worked really well. Then a couple of days later someone call into the centre and I used the toolkit and followed the questions, again worked really well. The toolkit is now part of our information pack and all staff are using it. Thank you for coming along to talk about the pack and for helping our practice. We now have a record of the decisions we make and are also able to support better by telephone as well as face to face.

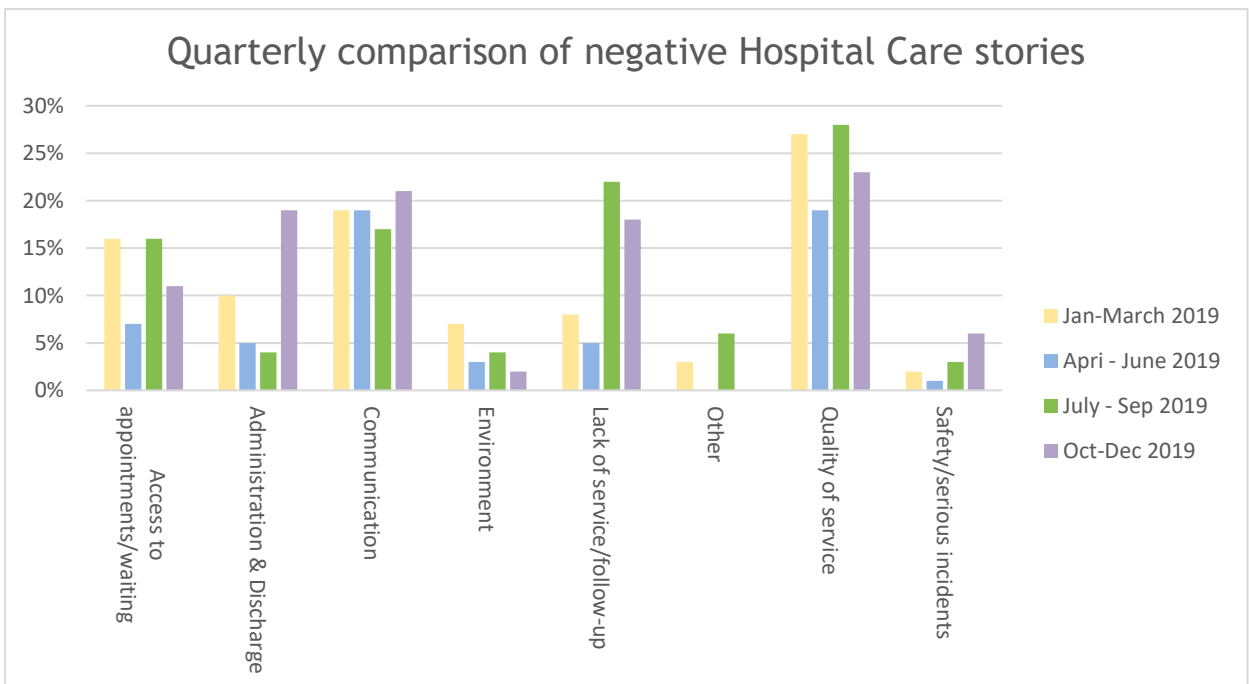






The negativity around the quality of hospital services follows the pattern of the last quarter, but with fewer positive comments this time. What these percentages fail to show is some of the extremes in people’s experiences, with some stories suggesting considerable harm to individuals.

The chart below compares the negative sentiment by themes to the previous three quarters.



<b>Hospital (secondary) care</b> <b>Aspects of this insight are included in our Hot Topics for 2019/20</b>	
<b>Emerging themes</b>	<p>There has been a worrying upward trend of negativity in the <b>discharge processes</b>, with people reporting concerns around being sent home late at night and in some case alone. Others have told us that they did not have a package of support in place and so struggled or have lost some independence as a result.</p> <p>Some stories suggest people experienced harmful outcomes and in most cases are coming to us for support to get answers and solutions.</p>
<b>Ongoing themes</b>	<p><b>Maternity experiences</b> do and will naturally vary. We found during our Bewbush Listening Tour that local parents spoke, on the whole, very positively about their hospital experiences. As a contrast to this, we have included a Coastal area experience on the next page, as this suggests a possible learning opportunity.</p> <p>We appreciate hospitals remain busy throughout the year, rather than being limited to winter-time when additional factors add to demand. Some of the negative stories around the quality of the service are clearly as a result of this pressure and we would like the system to seek ways of understanding what needs to happen to avoid poor outcomes.</p>
<b>What are we doing?</b>	<p>Our insight will be shared with the appropriate Trusts where there is concern over the discharge process, and we will be raising this in the Winter Plan's discussion at the Health &amp; Social Care Select Committee meeting on 15 January.</p> <p>As well as supporting individuals through our Independent Health Complaints Advocacy Service (IHCAS), we share quality and safety concerns with the system in some cases at the highest level.</p> <p>Having complaints heard and understood can make a huge difference. In one recent IHCAS case we supported a grieving family. The outcome of the complaint has been that national pathways have been changed to make sure the right questions are asked at the right time to identify the possibility of Sepsis.</p> <p>We plan to carry out a 24 hours <i>Enter &amp; View</i> in February to understand from current patients what is working and not working for them.</p>



## Maternity

Annabel said: I was meant to have a homebirth, but there were no midwives available. This meant I had to transfer from home to hospital in the final stage of labour. I understand the reason why, but it was very difficult. I had to leave my home birthing pool and travel to Worthing Hospital. When we got to the hospital, it was the middle of the night and hard to get in with all our stuff. There were no wheelchairs available, and no one to ask for help or directions. Luckily, we did manage to find a wheelchair, which I had to lean-on to be able to walk. We eventually found the delivery suite, but my husband confessed that he'd been frightened as he had no idea where to go and we were just wandering the corridors. I found the transfer very stressful. And didn't feel like the midwife listened to me. She kept telling me not to push as I wasn't ready (based on the examination when we first arrived when I was very tense), however I'd been needing to push since before we got to the hospital, and when she finally re-examined me she was surprised that I was fully dilated. The midwife was nice, but I felt she was disinterested and that what I was saying didn't matter. I felt very out of control because what I was telling her was dismissed and ignored. I'm so sorry that what had been a beautiful labour at home, ended up being panicky and stressful and what I experienced ignored.

*Healthwatch comment:* this suggests a need for community midwives to encourage expectant parents to take a pre-birth tour of the maternity service, even if they plan to give birth at home, just in case plans have to change.

## A system under pressure

A working-aged patient told us: I went for a procedure and was in the recovery room area and they took me off a bed and put me onto a small plastic chair - as they needed the bed. No-one came over to check on me. I would like to be in a position to say '*no thanks to the NHS*' but we cannot.

Sandra said her elderly mother-in-law had a stroke. When she was discharged from hospital, she didn't have a care plan or any medication or information. She was "dumped" at home and left to be looked after by her neighbours until my husband could step in (as they were not in the country).

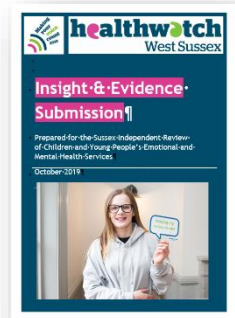
## Follow-up Support



My GP referred me to Physio (at Horsham Hospital), who have been amazing. They gave me exercises to do which are helping but I am most impressed by the help they gave me to access outside exercise classes.

My physio found me a Qi gong class, which I did for 6 weeks but I decided it wasn't for me. So, they then found me a [Paracise](#) class which I attend every Monday and it has been amazing. It is really helping me with my balance and coordination.

<b>Mental health</b>	
<b>Emerging themes</b>	
<b>Ongoing themes</b>	<p>We continued to hear stories of people waiting a long time to access 1-2-1 counselling from <i>Time to Talk</i> services (see next page as an example).</p> <p>We are still hearing personal accounts from young people and seek their views on services and their health in general.</p>
<b>What are we doing?</b>	<p>We'll be speaking to commissioners about waiting times and how they monitor this.</p> <p>We've been following up on our formal submission to local commissioners and the <b>Independent Review Panel looking at Sussex-wide emotional and mental wellbeing services</b>. This submission was the result of engaging with over 1,400 young people and their families.</p> <p>The draft recommendations from the Review and the Chair's Report should be made available in Mid-February. We've been told work has already begun to address some of the early recommendations.</p> <p>Healthwatch West Sussex is a Community Interest Company and so any income we generate through our social enterprise work can be invested in our Communities. One example is our new <b>Youth Pack</b> which we have developed and successfully piloted. This fantastic resource has been co-produced with young people and stakeholders and is designed to facilitate engagement with young people in ways that are meaningful to them. The pack offers a <i>pick and mix</i> style of activities that we plan to make freely available so professionals (e.g. in commissioning, schools, health and care services, youth groups) can test new ideas and evaluation services.</p> <p><b>This will be presented at the next Health &amp; Wellbeing Board meeting on <a href="#">30 January</a>.</b></p>



### Support in the community

Sarah told us: I was referred to *Time to Talk* by my GP but had to wait a year for 1-2-1 sessions. I also want to do a Mindfulness course but was told I had to do the Time to Talk sessions first, so it has been nearly two years waiting for that. I'm also waiting for a self-management course to come up in Horsham, rather than in Burgess Hill or Haywards Heath.

Julia said she was referred to *Time to Talk* by her GP and once they did the initial assessment, she was given a telephone counsellor. She told us: the sessions started ok but then the woman just started asking questions and then repeating the answers back to me. I couldn't get her to understand me and so I asked to make a complaint and talk to her superior. Her colleague then suggested that maybe 1-2-1 sessions would be better and so referred me to that rather than group sessions. They have been great, but I would like to see more trained Mental Health staff in the service.

### Supporting children and young people (from different events)

A local mother suggested: **Child Development Centre (CDC)** (this was in Worthing) need to be more realistic with information about waiting times, what is available and outcomes. The processes are never simple. We wouldn't get so frustrated if we knew the truth. Don't make promises you can't keep!

Another mother shared their family's experience telling us: I haven't heard from the CDC in over a year regarding my daughter. So, I phoned them and queried. They said they didn't know what had happened but two days later two appointments arrived for check-ups. They are so disorganised, have lost records and notes on numerous occasions. There are not enough staff and it feels like you are just a number.

**Healthwatch comment:** families have shared ways of improving the CDC service and we believe this demonstrates the need for greater engagement with families to develop services. Here is an example.

A comment on working with poor and deprived families, means acknowledging many of the parents will have poor literacy skills (*this isn't just about reading it's about understanding how systems work*). Signposting needs to be appropriate for the person. Giving a list of organisations can be daunting. Many people respond better to being signposted to a named person as they can find approaching the unknown intimidating. A name immediately makes it more human and approachable. It's less scary, there's more trust and it's likely to feel less like being talked down to.

<b>Social Care</b> This is one of our Priorities for 2019/20	
<b>Emerging themes</b>	<p>Concerns over the quality of care being provided in two care homes in Coastal West Sussex.</p> <p>Waiting times for Occupational Therapy (OT) assessment and the impact this is having on families.</p> <p>We are starting to get personal stories about families' experience of Children's Social Services. Amongst mainly negative accounts, we heard a very positive story of the support a family had received from the <b>Intensive Planning Team</b> at West Sussex County Council and the positive outcome for the young person.</p>
<b>Ongoing themes</b>	<p>West Sussex County Council's Adult Services Improvement - Next Step is being discussed at the Health and Social Care Select Committee (HASC) on 15 January. You can read the supporting <a href="#">documents</a></p>
<b>What are we doing?</b>	<p>The Care Home concerns have been shared with the Care Quality Commission and the West Sussex County Council's Contract Team.</p> <p>Our Healthwatch Manager attends the HASC meetings to ensure insight from local people informs the discussion and decision-making.</p>

**Support in the community**

My mum has been unable to sleep in a bed for more than a month now. She cannot get in or out without considerable effort and pain. She stays in the same chair downstairs, day and night. I contacted West Sussex Adult Carepoint and explained the situation. Fourteen days later, they phoned back for more details, effectively a repeat of what I had said previously. The staff were friendly and understanding and agreed that mum needed advice and/or help.

Yesterday mum received a letter from them explaining that she will be added to a waiting list and the time she should expect to wait for someone to be in contact is six months. I'm lost for words! The whole thing is stressful, frustrating and exhausting for us all.



## 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 are here to help you on the next step of your health and social care journey.

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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