

# What people told us about health and social care

A review of our insight and evidence  
July - September 2019

This quarter we  
gathered

**1139**

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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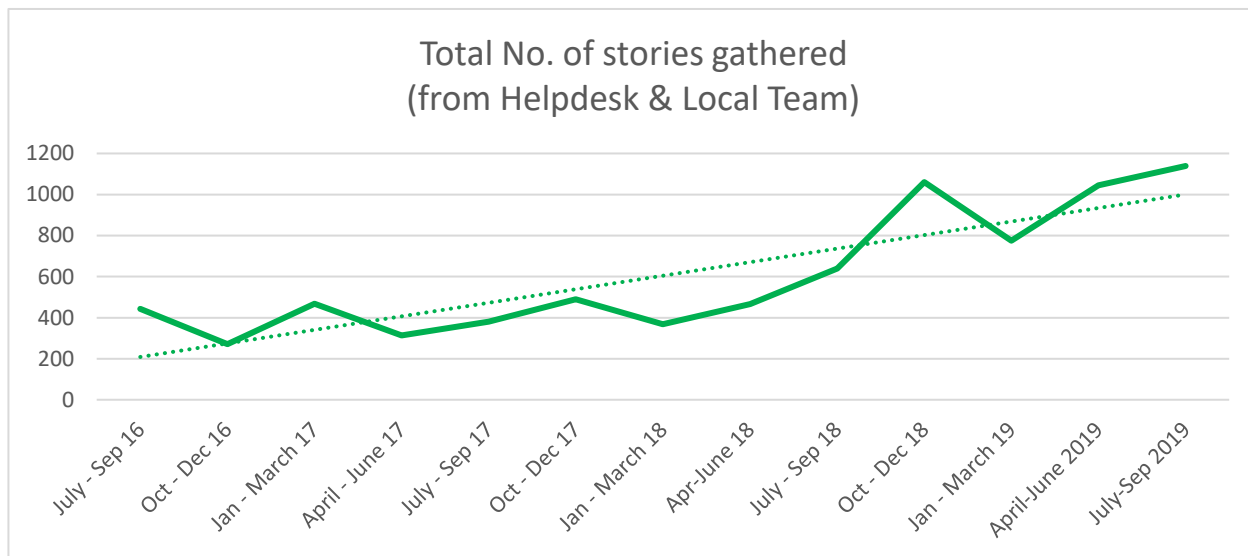
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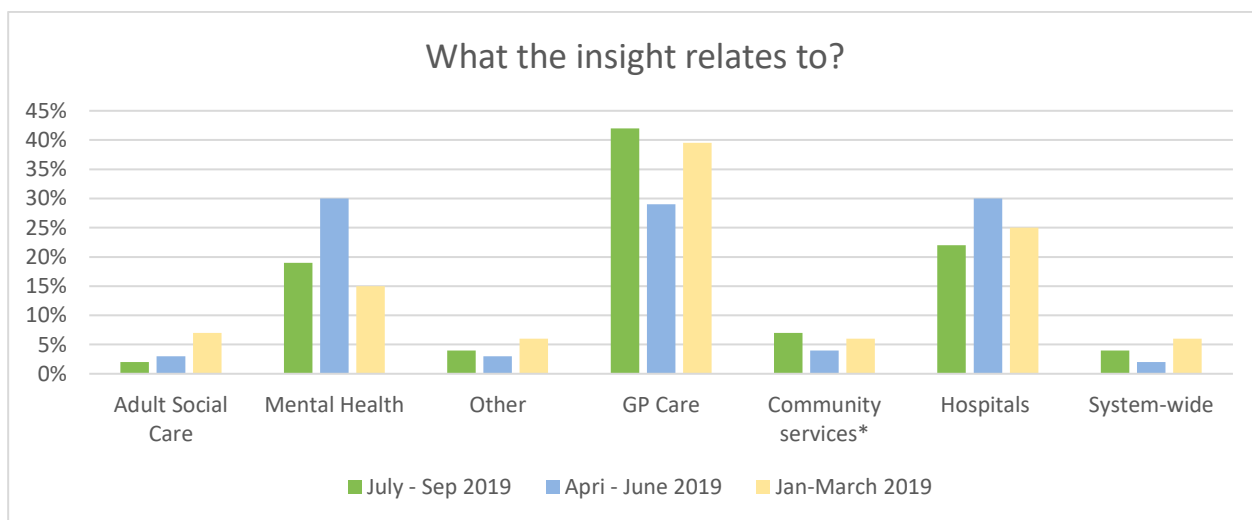
## At a glance

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.

1,139 stories and experiences were shared with us during July - September 2019.



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.



There were 8 stories about the 111 Service, which were largely positive, and a further 8 about ambulance/999 responses, which sadly more mixed in sentiment. Many of the dental and pharmacy stories were less than positive.

People spoke of transport and travel as a barrier to them getting the care and support they need.

“ Pam lives in Haywards Heath and has attended Macmillan in Brighton. *They've just spent £000's on building new premises for complimentary services, relations, hand massage etc. But do not do outreach work. You have to travel them. If I travelled to Brighton - awful journey at best of times, I wouldn't benefit from the complimentary services! So, these services are really for those who live in Brighton and not wider. As having chemo makes travelling difficult and you feel more tired.*”

On 2 October 2019, NHS Chief Executive Simon Stevens, announced at the Healthwatch England conference, a **National Review of Patient Transport** is to be undertaken. Healthwatch is calling for the scope of this to widen, to consider the links between transport and accessing health and care support which our insight has found to be a significant issue in every West Sussex community.



We know from our work in Rural North Chichester (Midhurst, Petworth and Pulborough) that where the local GPs have listened to people and understood this issue, they are working to adjust future appointment times to align with available transport. Such adjustments and working with local people on redesigning support has the potential to make a huge impact on peoples' lives and can also reduce wastage in the system.

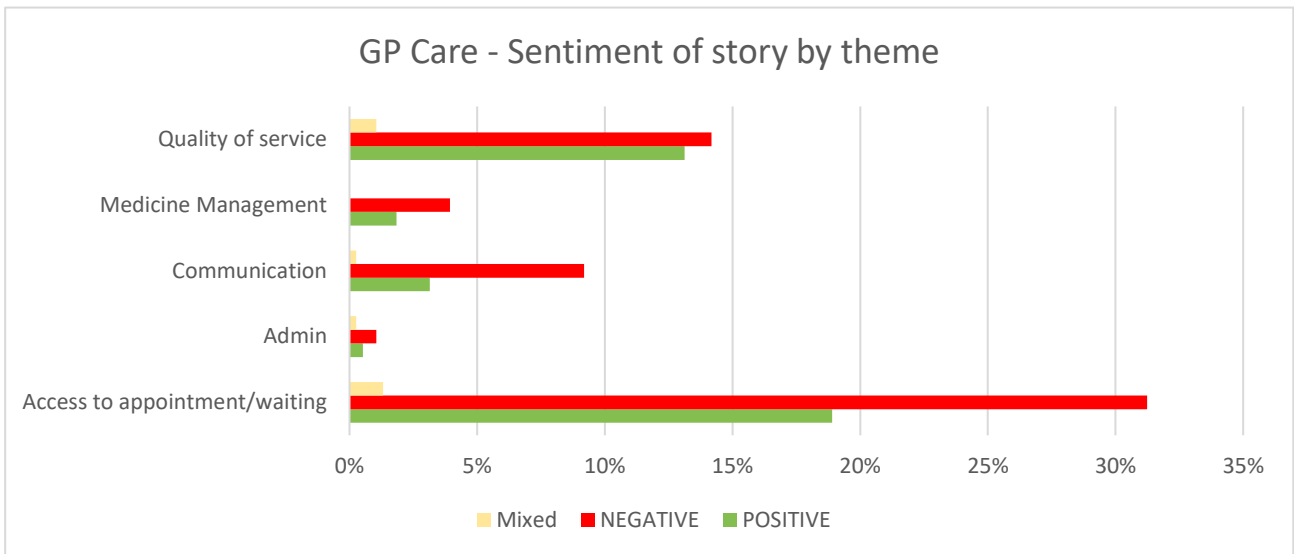
Being careful over the way transport is communicated is also important. Poor administration can cause a lot of anxiety for vulnerable patients.

“ George is a patient at Moorfields Eye Hospital in London and is registered blind. He attends this hospital as its specialists can provide the complex eye treatment he needs. He has been using non-emergency Patient Transport to get to the appointments for nearly 20 years. Recently, the transport provider changed, and George was told he would not be eligible for transport for his next appointment. He was very concerned about missing his treatment because he simply could not get to his appointment. He had tried using the hospital's PALS (Patient Advice and Liaison Service) but not managed to resolve the issue. ”

Through our enquiries, we discovered the patient letters had the wrong telephone number for the new service, and that it is the case that for the first few months of the contract, the service would still be fulfilling all transport needs. This had not been explained to patients. We were able to advice George how he could now book the transport for his October appointment and that he would have a telephone assessment at the same time.

We updated the PALs service about the admin error (as they had been unaware of this).

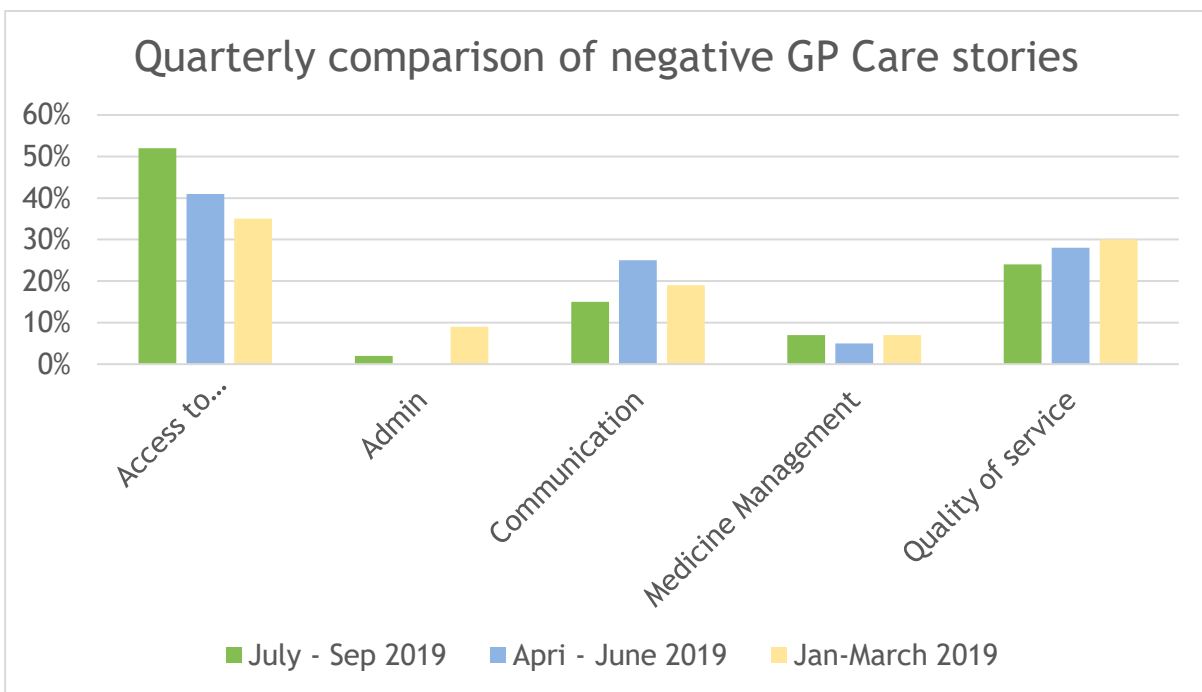
## What people are saying?



Whilst access to appointments/waiting time is the theme of half the stories we have heard this quarter, it is worth noting there has been an increase in positivity (from 8% to 18%).

We talked to commissioners last quarter, emphasising the need for frontline staff to make patients aware of appointment availability through *Extended Hours Provision*. We understand separate funding would be used to do this.

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



<b>GP care</b> <b>This is one of our Priorities for 2019/20</b>	
<b>Emerging themes</b>	<p><b>Issues with registering</b></p> <p>We received some enquiries from new Crawley residents (and surrounding areas), as they have struggled to find a GP Practice to register as a patient. In some cases, people have been trying on and off for months.</p> <p>In most cases, the practice website information for new patients wishing to register is unhelpful and this is something we would encourage practices to review.</p> <p>We would suggest this may be driving more people to A&amp;E (particularly of working-aged people).</p>
<b>Ongoing themes</b>	<p>We continue to hear that access to appointments in General Practice (GP) is an issue for many, but the rise in positive comments is encouraging.</p> <p>Others spoke of frustration at trying to register for online booking and in one case the person gave up and has reverted to phoning (which is difficult for them).</p> <p>There remains an issue around in how some GP practices and staff operate their telephones and manage call demand. We hope the Primary Care Networks will drive through improvements in this area.</p> <p>Linked to the issue of getting an appointment is a lack of personalised access for people who have communication and support need. This is despite the introduction of the Accessible Information Standard.</p>
<b>What are we doing?</b>	<p>We want to work with the Primary Care Networks and will provide briefings for the Clinical Directors, so they can benefit from understanding, from a lived experience point-of-view where discontentment is arising.</p> <p>We will also seek to use these conversations to promote the importance of involving patients / their family and friend carers and the public, in designing new ways of working, and in the development of communication about changes in GP services and how to make best use of them.</p> <p>Also, how to increase staff and patient awareness of, and willingness to use digital delivery of some services.</p>

### Difficulties in registering with a GP Practice

Caroline called for support in finding a GP, after moving to Bewbush. She said she had tried three different practices but was told they weren't taking new patients. [We gave details of NHS England, as they can require a practice to register a patient, unless their list has been officially closed \(and not just capped by the practice.\)](#)

A working-aged Worth resident couldn't get registered for 4 months. NHS England had offered a practice, but this was too far away -so she gave up. At New Year she became ill, completed the forms and was given a local surgery in Spring.

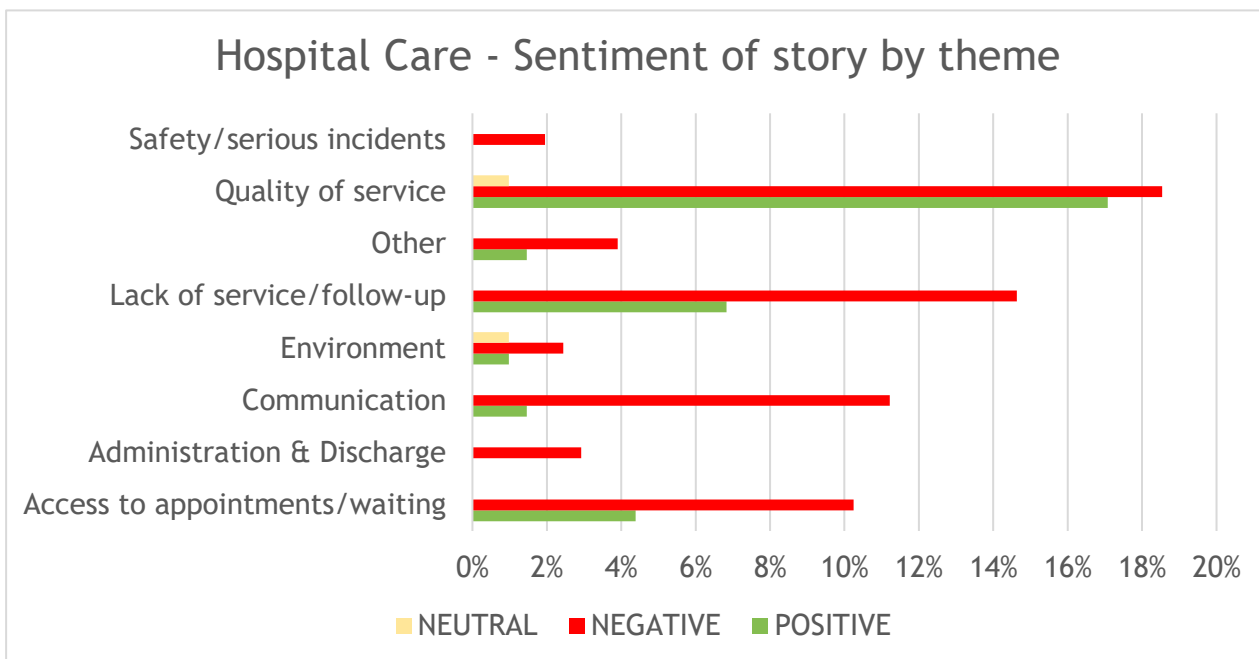
Simon (working age) told us he was not registered with a GP, saying *I just use the Crawley Urgent Treatment Centre. I was registered at Pound Hill Surgery about 17 years ago and then moved out of the area. When I returned to Crawley the population had increased and the GP had 17,000 patients registered so closed his books. I really liked my GP of 17 years ago.*

### Access to appointments

*It's really difficult to make appointments as a working person. You ring at 8am and are offered an appointment the same day, meaning you have to take time off. Practice has now started to offer evening/weekend appointments, which is so much better. I use the pharmacy a lot as sometimes it's not worth bothering the doctors. (Worthing Patient aged 25-65.)*

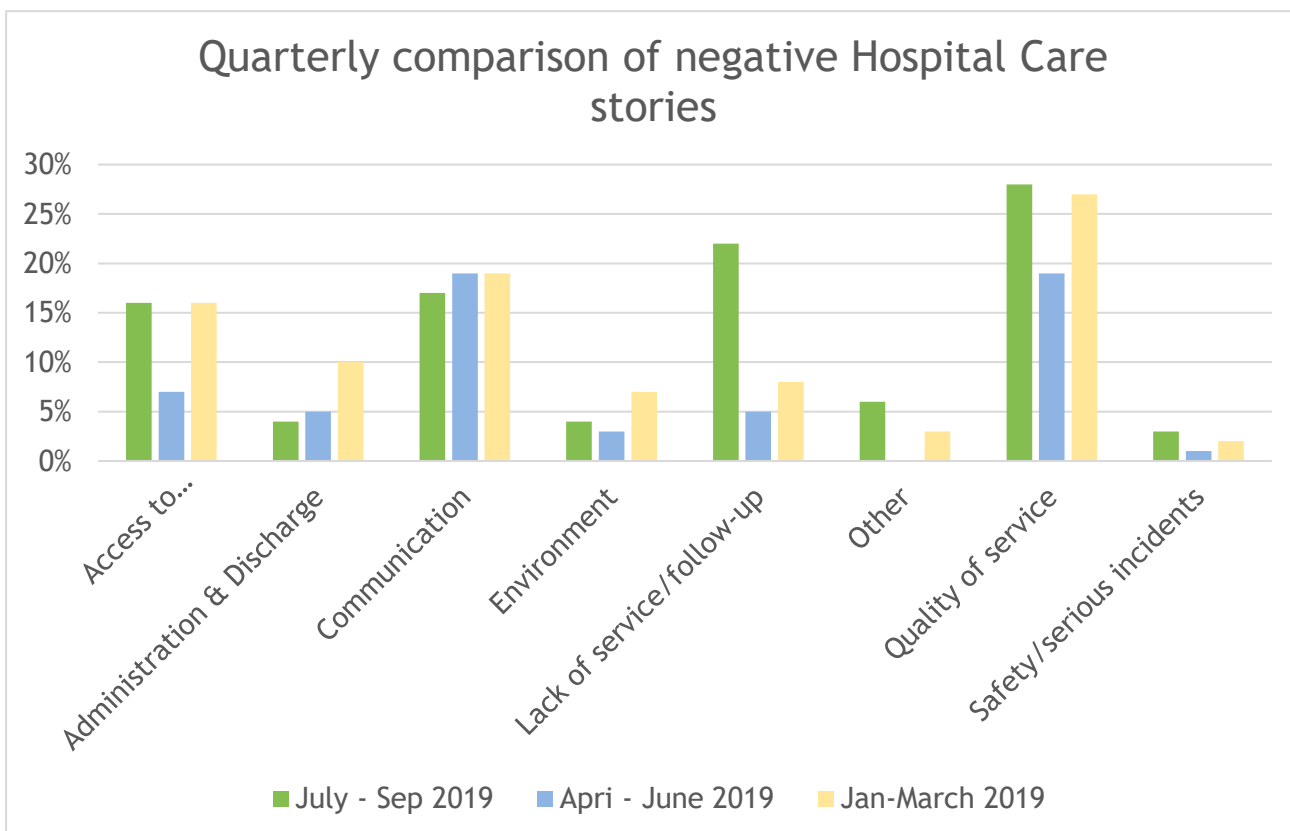
Tom told us how he'd tried to phone for an appointment (at a practice in Littlehampton): *I began the phone call at approximately 12.40, there were calls ahead of me (according to the message), but I persevered. After 24 very boring and expensive minutes the calls ahead of me were down to two. However, just after 13:00 my call was cut off. I was told the phone lines reopened at 14.00. I call this disgusting behaviour from what is supposedly a professional organisation that I rely on for my health.*

A Bognor Regis patient reported 87 attempts to call but was unable to speak to anyone, as the line was continuously engaged. They made their way to the surgery to make an appointment in person... and told us, *the first thing I said to the reception was that I tried to talk to someone on the phone The reason I explained myself, was because I was worried that they were going to ask me to carry on calling the appointments number. I got a reply, delivered in a very sarcastic way "we are very busy today as you can see". ... All she needed to say is "I am sorry you had to come in person to make an appointment, but we are very busy today"...I had to explain why I needed to see a doctor with loads of people listening. I appreciate that receptionists have to screen patients. But the way this was done felt wrong and made me feel uncomfortable..*



Whilst the quality of service theme remains similar to last quarter, the stories that relate to a lack of service/follow-up have noticeably increased in negativity. In contrast, the negative experience of staff/organisational communication has reduced by half of what it was the previous quarter.

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



<b>Hospital (secondary) care</b> Aspects of this insight may come under our Hot Topic Priority for 2019/20	
<b>Emerging themes</b>	<p>A resident reported how <i>East Surrey Hospital provides complementary services for cancer patients and families to help with emotional stress. This seems to be working very well.</i></p> <p>Given this, and travel issues others experience when trying to access services in Brighton (as shown on next page) we would suggest more is needed to help patients choose the right location for their treatment and care.</p>
<b>Ongoing themes</b>	<p>Communication and how to improve this.</p> <p>We continue to hear from people who have experienced many cancelled appointments and long waits for treatment. Unlike raw data, these stories show the negative impact this has on their lives and the frustrations they experience. For some this results in them raising a complaint but for most people, they simply continue to endure the delays.</p> <p>This quarter we heard an increased number of stories showing the human impact and the consequence for services when the right support is not forthcoming.</p> <p>We previously reported challenges patients faced because their NHS treatment was delivered in a private hospital. Sadly, people still face difficulties in getting follow-up support when their treatment is funded by NHS but done by a private provider.</p> <p>Stroke services are being reviewed and as Barbara's story suggests, the care and treatment vary across our county: Barbara had a stroke at the beginning of the year and was taken to East Surrey Hospital where she received excellent care, physio and speech therapy. She then had another stroke in the summer and was taken to Horsham Hospital. She said the care and services provided was so different, and not in a good way.</p>
<b>What are we doing?</b>	<p>We have produced a briefing of the insight in relation to cancer from the last year for the Sussex Cancer Board with a view to ensuring patient experience is at the heart of this working group.</p> <p>We will use our other influencing opportunities to continue to raise local concerns over issues relating to support and follow-up, and how this insight can make services better for patients.</p>



## Communication

When everyone works together, the experience can be so positive, as a St Richards Hospital patient shared: *I had day surgery, and this was great. I arrived by public transport and the receptionist supported me with this by finding out the times. My family collected me in the afternoon. The communication was very good.*



In contrast making small changes can have such a positive impact. Beverley said, *When I was in hospital at Brighton, I had no headboard and no name just 'gluten free'. 'What is this all about? If people do not want to have their name on the board that is their choice and we should be asked. As having our name on the board helps staff and others know who we are.*

## Follow-up Support

Some of the insight received showed even trained clinicians struggled to navigate the system and get support they urgently need. Other stories show missed opportunities and how these create further demand:

Sophie, who is not in the best of health herself, cares for her husband who was hospitalised before summer, with a bladder issue and was fitted with a leg catheter. They waited in the hospital for a long time because they were told a community nurse would be available to see them to give advice on managing the catheter. However, no one was available, and they were sent home. They called the community nurses as they didn't have the right equipment or information. This led to her husband being admitted to A&E. They thought that the responsibility fell to the GP, but the surgery informed them that it was hospital who should have provided the equipment and training. This experience was on the back of her husband's experience of a long list of errors and a missed infection.

Similarly, John (who has some significant long-term health conditions) was told to go to A&E by the local sleep clinic, after his sleep-apnoea equipment broke as he had already been discharged from their service. He needed a technician to fix the broken equipment. The service manager said he would first need to make an appointment with the GP (to make a referral) or go to A&E in an emergency. John and his wife have now been sleeping in chairs downstairs and have felt a lot of anxiety at not having the use of the machine. John had not been informed that they had been discharged from the service or who would be responsible for maintaining the equipment. Their experience has been made worse, as they have had no contact from the hospital since the GP made a referral, despite trying to contact PALS. They have tried to call on several occasions, without success.

<b>Mental health</b>	
<b>Emerging themes</b>	<p>We heard through the public consultation events and local conversations regarding proposed changes to in-patient beds in West Sussex, that patients and staff <b>are against the proposal to move to single-sex wards</b>, arguing that mixed-gender wards have fewer incidents and provide balanced interactions that reduce tension. Using this insight, we have escalated the issue of gender and ward configuration to Healthwatch England, for national clarification.</p> <p>This quarter we have heard a few stories about waits and disappointment in the <i>Time to Talk</i> service (that offers group and 1-2-1 counselling and support). We also heard a positive story about the service.</p>
<b>Ongoing themes</b>	<p>Over the summer we worked with the National Citizen Service (NCS) and 300+ students and explored with them emotional and mental wellbeing. Four of the team chose to work on health-related projects and the outputs of this work will be included in our <b>Youth Pack resource</b>.</p> <p>Lack of support in the community continues to be an issue for people and others have shared negative experiences of having physical issues which have not been addressed when they have gone to A&amp;E, because of their mental health condition.</p>
<b>What are we doing?</b>	<div style="display: flex; align-items: flex-start;"> <div style="margin-right: 20px;">  </div> <div> <p>We have analysed the stories from engaging with over 1,400 young people and their families, during the last 12 months. We will be reporting on the themes identified and this will be shared with local commissioners and the Independent Review Panel looking at Sussex-wide emotional and mental wellbeing services.</p> <p>We expect to see how the Review has reflected this insight in their recommendations and will be following up with local commissioners on how they plan to improve the local offer.</p> <p>We continue to work with the commissioners and Sussex Partnership NHS Foundation Trust to understand what local people have said in response to the public consultation on in-patient beds, which closed on 11 October. A full briefing will be given to our Chair, who is a member of the Health and Social Care Select Committee, who will discuss the proposal in November.</p> </div> <div style="margin-left: 20px; text-align: center;">  </div> </div>

### Support in the community

After a number of bereavements and stresses, Alex contact the Time to Talk service last year but experienced a 3-month delay (due to unknown admin error) and has waited 10 months to use the service due to problems accessing the different venues (there is no regular public transport to the venue in Worthing, which is where he must attend). Alex said, *I valued the service and was keen to avoid any further delay in getting the right treatment. I feel that Henfield have decided not to pay for a service which is needed and could work out of the local health centre. I've now reached a solution but am concerned about others who cannot get to different locations to access healthcare and feel this should be taken into consideration.*

*Homeless support - Time to Talk not enough. You begin to get somewhere and then the sessions stop. Not enough flexibility but where else can I go?*

*Time to Talk were really good. I had 6 sessions which helped build some tools I could use. Was offered more, but very conscious that there is a waiting list. I felt there were others more needy than me, so I turned them down.*

James (who is living with a number of diagnosis, including ADHD, Bi-polar, schizophrenia, and suffers from paranoia and suicidal thoughts) called saying his local community mental health team had discharged him from their service. *I was told that they will no longer be dealing with me and should I be in crisis, I need to attend the local walk-in. I feel dumped in the wilderness. I'm on many different medications which I don't feel are correct. I live in accommodation with addicts and am too scared to answer the door or buzzer to the property and therefore have isolated myself. I'm divorced and cannot see my children. I don't know where to turn.*

*As James had so many concerns, we gave details of Mind in Brighton and Hove, suggesting he make contact with them for some general support and advice. We invited him to contact us again if they were unable to help.*

Peter (aged 25-60) said, *I go to my GP who sends me to the Walk in Crawley, they send me back to my GP. It is like a revolving door where the patient's needs are forgotten.*

People have also shared their struggles in getting their mental health review, as David a Worthing resident (aged 25-60) explained, *I don't know why the consultant will not see me, as I would like to know if things have changed. I have been clean now for 8 years', so I have been doing my part. I do not know if I need a change in medication or not?*

<b>Social Care</b> <b>This is one of our Priorities for 2018/19</b>	
<b>Emerging themes</b>	We heard from a couple of people about how positive the <i>Falls Prevention Course</i> had been. See <a href="#">here</a> for more information on how to prevent a fall.
<b>Ongoing themes</b>	<p>Issue with people not getting access to assessments, or these being delayed, and the impact this has on their ability to live full and independent lives.</p> <p>An advocate told us about supporting a young man, who has both a learning disability and autism, who had been refused a Care Act assessment. The learning disability team in the north stated his autism had put his IQ above 70 and therefore he could not be assessed by them.</p> <p>West Sussex County Council have merged teams and the newly forming Lifelong Services Team should mean that this type of issue should not present so much going forward.</p>
<b>What are we doing?</b>	Our Board has kept Adult Social Care as a priority for 2019/20 and we will be focusing on talking to care home residents about what it means to be living in a home that is rated <i>Inadequate</i> by the Care Quality Commission. Through this project, we hope to provide guidance for local people and how homes can benefit from working with their residents and their families.

## 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.

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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