

# Insight & Evidence



Reporting on the experiences shared by local people in West Sussex

October - December 2017

Local people have shared **439** experiences/stories



4 in 10 stories were about hospitals, and 1 in 3 were about GPs



## Primary Care



A large increase in positive sentiments to peoples' experiences

## Hospital



Leading up to winter

Reflection on last 12 months insight to inform new work



**21%**

Positive Experience



**79%**

Less than Positive

## Hot Topics

Significant service changes  
Urgent Care - 111 and Out of Hours  
Urgent Care - in the community  
Sustainability & Transformation



Together we speak louder  
0300 012 0122

**healthwatch**  
West Sussex

# Healthwatch West Sussex Priority Areas 2017-2018

Healthwatch West Sussex is prioritising work in the following areas:



To find out about the activities we are including please download our [plan](#).

Please note, in January, the Healthwatch West Sussex Board will be considering our future priorities based on what we have heard and seen in the last year. We will then work test our ideas for work plans with members of the public before implementing them from April 2018 to March 2019.

The insight contained within this report may be influenced by how and where we have engaged with local people during the quarter (for example if we are carrying out a *Listening Tour* in a particular part of the county).

However, through enhancing our profile throughout West Sussex and nationally, we continue to receive insight from a wide range of local people, who have chosen to share information with us.

# Insight & Evidence

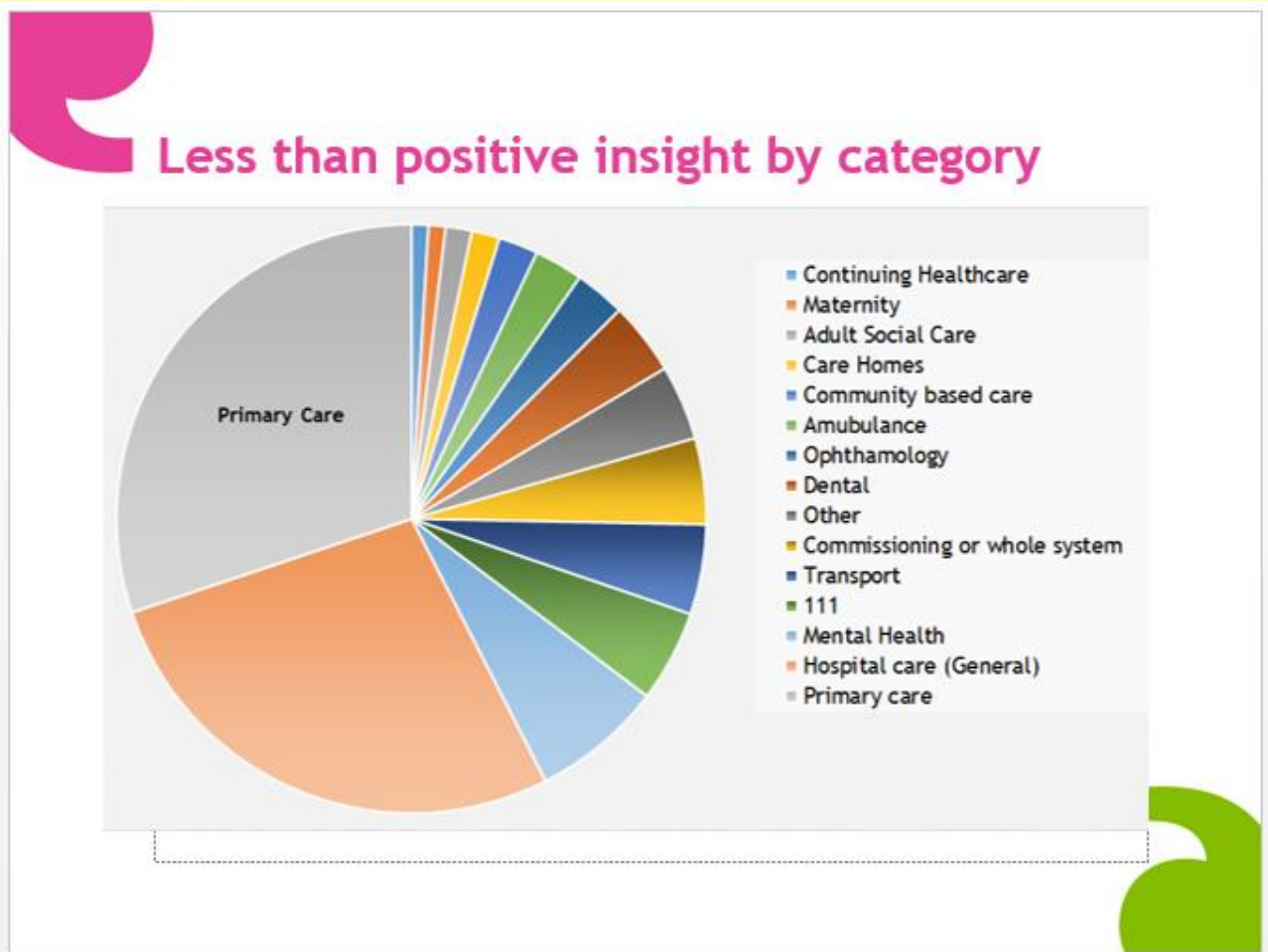
We are reflecting on the insight we have gathered from local people during the last year to inform our planning for what we should be prioritising in 2018/2019.

It is important to put our valuable insight into context, as the 1,600 + items of feedback we have received are a small representation against the overall usage of health and social care services in West Sussex.

The NHS usage nationally:

- 340 million GP appointments in England last year
- Transport 4.7 million patients to A&E by ambulance
- manage 21 million A&E attendances
- and over 113 million outpatient appointments
- provide 100 million contacts in community services
- provide specialist mental health and learning disabilities services for over 1.8 million people
- deliver over 648,000 babies.

The chart below shows the top categories for negative insight we received in West Sussex.

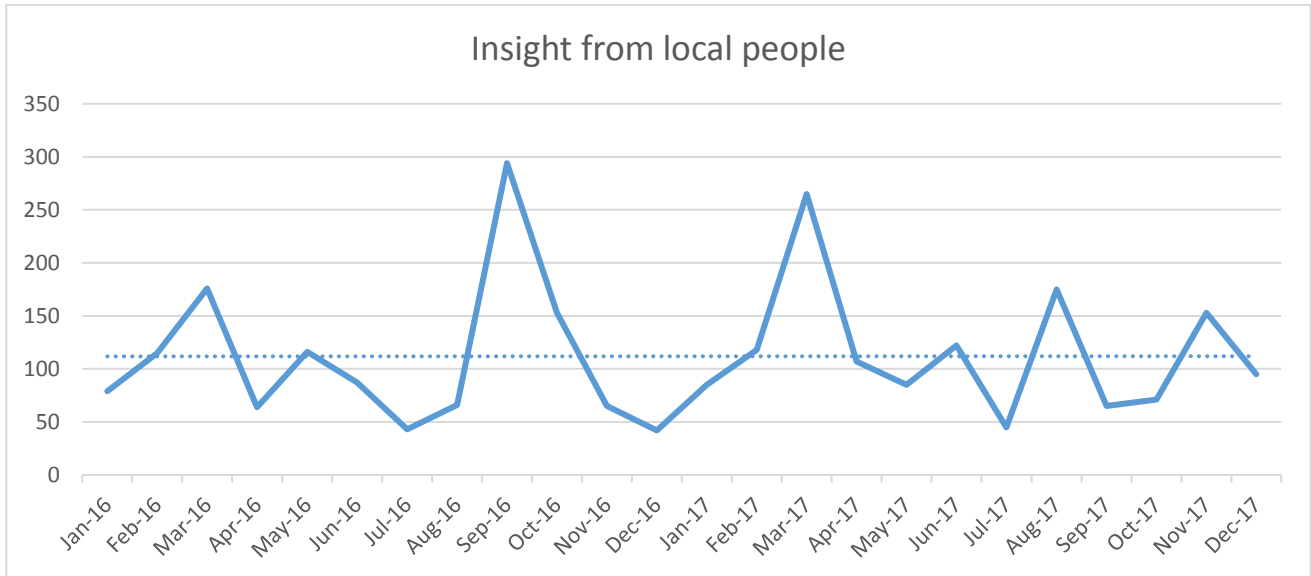


Local people  
have shared  
**439**  
experiences/  
stories this  
quarter



To find out how we engage with local people or to *Get Involved* with our work please visit our website

[www.healthwatchwestsussex.co.uk](http://www.healthwatchwestsussex.co.uk)



### What does this tell us?

The peak this quarter was generated by a *Listening Tour* in Rural West Sussex resulting in strong numbers of stories. With a considerable rural population across the county, whilst these totals are lower than we would collect from a tour in a town, they give a valuable view of common experiences.

- Our helpdesk team continue to take calls directly from local people, which are generated through our promotional materials and health and social care organisations and community partners raising awareness of Healthwatch.
- The highest volume of direct contact insight relates to Western Sussex Hospitals NHS Foundation Trust.

### What are we doing to increase our insight?

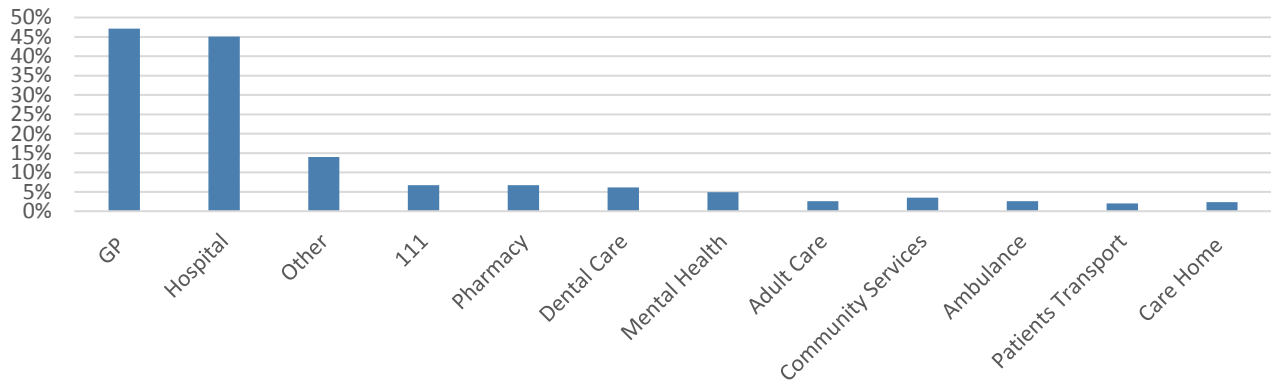
- We are in the process of looking at priorities for an 18 month period to start in the new financial year. We will create new opportunities for face-to face engagement as well as other ways of gathering insight.
- As Listening Tours represent a good return on investment for high quality insight, we plan to continue these through the next year. We have shared our Listening Tour model and toolkit with Healthwatch England so that it can be used nationally.
- Our Community Engagement team will be strengthening our community links across the county to gather regular quarterly feedback through a network of clubs and groups.

## Every Voice Matters



When local people share their experiences of using health and care services with us, their comments are captured on our secure database and anonymised before we share any information.

The services people chose to speak to us about



The above graph **does not** include the numbers or insight from our surveying during this quarter, which was project specific and elicited by us (therefore not what people have chosen to tell us about).

Where stories shows significant, or serious issues, these are followed up by our team and are shared with the appropriate organisations. Providers are asked to what action they will be taking as a result of having this insight. This is followed up to see what has or has not changed as a result. Other insight is shared by our staff and volunteer team at various influencing opportunities, such as informing our work on Equality Impact Assessments, enter and view and future work planning.

*Donald called for advice as he has put in a complaint about the care home (in Bognor Regis) where his partner, Betty, now lives. Donald told us he had several concerns over Betty's welfare in the home, including some that were around her safety. Donald visits regularly but is only allowed to see Betty in the lounge. He feels this is because he has put in a complaint about the home. He is concerned he had not been allowed to look at Betty's room to make sure she has all her personal belongings. He managed to sneak up to her room to check that all was well but is now concerned as she didn't appear to have any clothes in any of the cupboards or wardrobe. Betty has said that she is unhappy on many occasions and Donald thinks she does not look well. Donald said reported he reported a particular allegation to the police and to Betty's social worker. He feels his concerns were brushed aside and not taken seriously. He was invited to a meeting but when he attended he found he was supposed to have had a letter to read before the meeting; which he never received. The outcome of the meeting has been far from satisfactory and he feels no-one is listening to him.*

Healthwatch advised speaking to the [Care Quality Commission](#) and Donald said he was going to contact them to see if he can get this investigated further. Our Helpdesk team escalated the matter and we carried out an *Enter and View* visit to see what other insight we could gather. What we heard and saw did not reveal any similar concerns.

**Mrs S called for advice as her daughter Jodie's eye operation had been cancelled at the last minute.** It should have been carried out at Queen Victoria Hospital (East Grinstead). Mrs S told us her daughter has special needs and went on to say: *I am desperate for her to have the operation as she has (condition details given) and is struggling to see. This is affecting her school work badly and I am worried about how this will affect her in High School. It is very difficult to explain to my daughter that she is not having the operation tomorrow after all. Someone from PALS is going to talk to the admissions team and see if the operation can be carried out tomorrow. I was upset that it has been cancelled at such short notice, when we have made special arrangements to be off work, etc.*

The admissions team has asked for more information, which seems odd as the information should already be on Jodie's record.

Mrs S was happy for Healthwatch to record her feedback and was advised we can help if she decides to raise a complaint. In the meantime, we suggested she continue to speak to the hospital's PALS as they may be able to find out what information is needed quickly.

**Midhurst resident spoken to during our Listening Tour (November 2017).**

*I am a patient at our local Surgery and they have generally been very good. However, the other day I called with an issue and was offered a call back by a doctor. When the doctor called me back they were very short with me - to the point of being quite rude actually. The doctor concluded that I should actually visit the surgery later that day and set up an appointment for me. I was a bit miffed by their attitude and lack of positive communication, but I went along as requested. When the doctor came to call me for my appointment the first thing they said to me was 'sorry'. The doctor gave a full and heartfelt apology for the way they had spoken to me on the phone - although they didn't offer me an explanation. I felt that it was a really positive thing for them to do and was quite pleased to receive the apology. It gave me my faith back!*

**Anonymous from the November Listening Tour.** My baby was only weeks old and was my first child. She had seemed a bit unwell for a few hours but as the day went on, I became increasingly concerned, although there were no definitive symptoms. She wasn't as alert as usual and hadn't been so enthusiastic with her feeding. I was quite worried, so I called 111 and talked through my concerns and my feelings with them. They went through the standard questions. *I totally appreciate and understand that they need to do that - but as there was no temperature and she had fed etc., they dismissed me and advised me to simply monitor and watch and wait. I just had a gut instinct that something was wrong and I felt strongly that she needed to be seen by someone, so I had a bit of a meltdown with them and told them that I would call an ambulance, they then said that they would arrange a paramedic to visit and check her over. When the paramedic arrived, her condition had further deteriorated and they were very concerned, so she was admitted to St Richards Hospital quickly. She needed to be in intensive care (ITC) for a while and was even transferred to another hospital's ITC unit for a few days because her condition was so serious. The ward staff at (both hospitals) were outstanding and couldn't be more caring and supportive. Parents are encouraged to stay with their children and help with their care. Everything was explained well and we were fully informed and involved in all decisions. It's just a shame the 111 services do not respect or recognise parental 'gut instinct'!*



## Hot Topics

## What's new?

Significant service changes

Getting involved in the planning for 111 and Out of Hours

Urgent care changes

### Urgent Care - 111 and Out of Hours

Following on from the [feedback](#) from an NHS survey carried out in July 2017, Local Healthwatch in Sussex were asked to gather views from under-represented groups where numbers of responses in the NHS survey were low.

We spoke to and surveyed people in November and December and have produced a report that will be published in February 2018.

Whilst much of the findings were similar to the previous survey, one of the big differences appears to be peoples' views on having 111 as a central number for same day appointment needs. We put much of this positive swing (compared to the initial NHS survey) down to framing this question in the context of the demand for GP appointments.

#### [Urgent Care](#) - In the community

NHS England recognise the complex landscape of urgent treatment provisions, from A&E to locally commissioned GP run hubs. Clinical Commissioning Groups locally must roll-out standardised **Urgent Treatment Centres** which will open 12 hours a day, seven days a week, integrated with local urgent care services and these must be established for April 2019. You can read more on this [in the papers for 10 January 2018](#).

### Sustainability & Transformation Plans or "STP" progress

- Executive Chair, Bob Alexander is to have a meeting with the Secretary of State for Health on Monday 29 Jan - a Deep Dive into our STP which will help in the next phase of planning and implementation.
- Procurement for Urgent Care provision has now started and culminates in March.
- Initial *Digital* workstreams are making progress – an example is the pilot of the use of digital communications as an alternative to paper letters.
- The STP is also starting to see the benefits from being able to make comparisons across the footprint which has flagged issues with wide variations in supplier pricing which can then be addressed.
- Ambulance demand and capacity review underway in relation to conveyances. Focus will be on getting the right size and location of operation with the finances to support it.
- Local Community Networks in the Coastal Clinical Commissioning Group geography are progressing with their Place Based Plans for 8 communities. Similar Place Based Planning is taking place in the north of the county across Central Sussex and East Surrey Alliance.

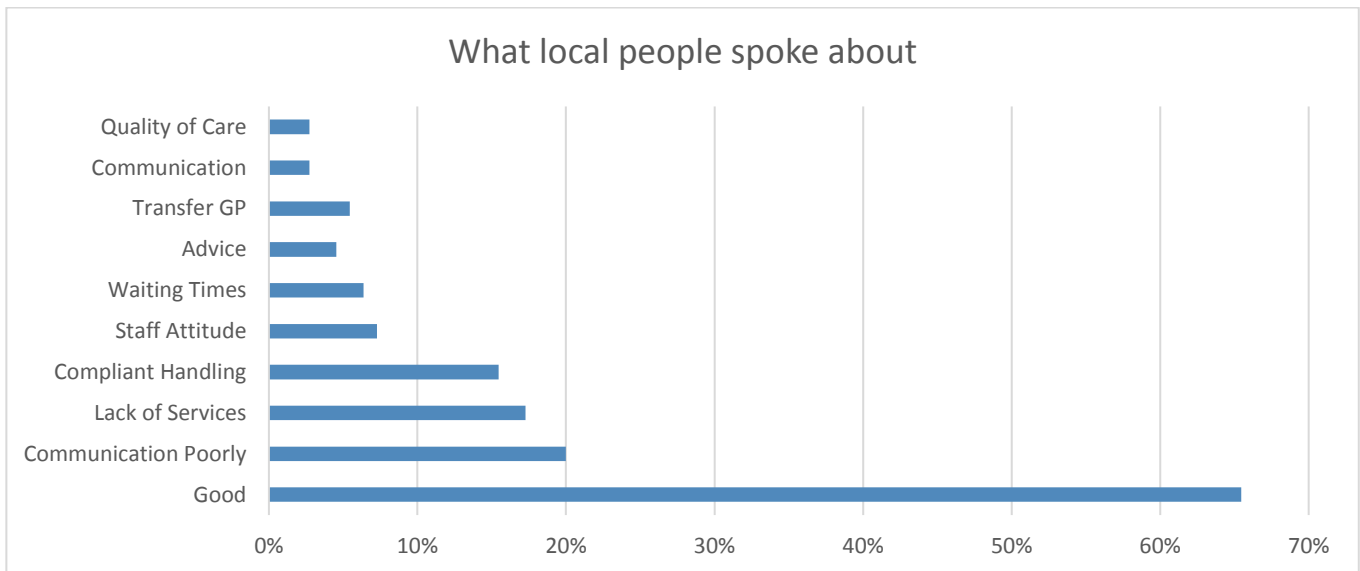
# General Practice (GPs)

GPs are private businesses that receive public funding through various contracts.



Coastal West Sussex, Horsham and Mid Sussex GPs are commissioned through the Clinical Commissioning Groups (CCG). The commissioning of Crawley GPs remains with NHS England.

The graph below shows what people have shared about their experiences this quarter (good and bad):



## What does this tell us?

It is encouraging to see, that despite the demand for GP appointments, 65% of the stories shared this quarter gave a positive sentiment. This is a large rise against the 37% last quarter and reflects the positive insight shared by local people in rural West Sussex (as heard on our tour of Pulborough, Petworth and Midhurst.)

**We are looking at potential activities for 2018/2019 and will use this insight to inform these plans. We will run a survey in, spring 2018, so local people can help us to make sure we are working on the right priorities.**

## What are we doing to improve this?

One of the negative areas from this insight is around complaints handling. In March 2018 we will be following up on our audit of GP complaints information on websites to see what has changed.

We will share, in advance, our audit criteria with local practices and then produce a summary table showing the audit outcome by practice. We plan to offer support to any practices not evidenced as making it easy for people to find out how to raise a complaint.



# Mental Health




We were pleased to have been part of one of the Care Quality Commission's inspections of Sussex Partnership NHS Foundation Trust this quarter. This gave us an opportunity to see first hand what takes place in an inspection and to give feedback.

We were further delighted to see the outcome of this round of inspections. The Trust has been able to demonstrate through these inspections a positive shift in the way they support local people, to gain an overall rating of *Good*.

Our [People With Lived Experience](#) continue to support the development of Pathfinder West Sussex, a collaboration of local organisations seeking to achieve a more joined up approach to how they support peoples' mental wellbeing and health. The team's focus is on communications and co-production in the next quarter.

Our insight during the last 12 months is informing our early thoughts on new priorities and for mental health:

**Key Themes - Mental Health**



- Adult community:**
  - Half is about lack of local support when in crisis
  - Waiting times
- Hospital care:**
  - Poor care and treatment
  - Discharge and lack of care plans
- Young people:**
  - Waiting time and lack of support



## Insight Events

We published our collaborative [report](#) detailing the Insight from earlier workshops and a survey into the experiences of **older residents across Horsham District when they were admitted to hospital**. The report offers some very helpful tips to local people when facing hospital treatment or appointments. It also offers some important learning opportunities for local leaders.

We discussed potential solutions with a cross-sector of organisation in December 2017 and actions are being taken forward.

## Other older peoples' stories

### Patricia shares a very important message for care homes, commissioners and inspectors

After caring for my husband for several years, he now lives in a Care Home. He has dementia and some other medical needs too. Since he's been at the home I've been impressed by the quality of care and the staff are all lovely. But there is a lack of activities, exercises and social interaction for him and this concerns me. He has become frustrated, short tempered and has lost weight and appears weaker physically. There is a programme of group activities available but he has refused or hasn't been interested in what's on offer and so they have stopped asking him now and he has no encouragement or 1-1 support to do anything really. When I spoke to one of the nice carers about this and mentioned that he used to love walking round our garden at home, she suggested I pop in at 3pm the next Wednesday as she said there would be a wheelchair available for me to take him round the garden. I was a bit worried about doing this myself, but I agreed and thought it would be nice for him. I talked to him about it and he seemed to be pleased with the idea. My husband and I were very disappointed when the wheelchair wasn't then available. I just feel that no-one is caring for his emotional or social wellbeing although they are very good at his physical and medical needs. It is so sad. **It seems to me that his character and personality are becoming invisible - I know this could be the dementia but it is also because he is left unstimulated in his room 24/7.**

**Healthwatch comment: Like so many of your stories, Patricia's really shows the importance of seeing people as a whole not just looking at caring for physical needs.**

**Anonymous from the feedback form:** I was visiting a relative who has lived at (care home name given) for a few years. Overall, I would consider the staff as very caring but there are some management issues that were noticeable during my visit. There was a man who wanted to walk around the unit but he was being managed as a falls risk, he had an alarm on his chair. Two staff decided to walk him and they lifted him out of the chair by dragging from under the armpits. I have reflected on my visit yesterday. We were offered drinks but at no time did I see our relative or other residents being offered or have access to fluids, these were not obviously available. I did however, visit after lunch and assume drinks would have been offered then. The home has tried to be dementia friendly but does not meet this.

**We gained further information from the person and have anonymised and shared insight with West Sussex County Council and Care Quality Commission to inform their monitoring and inspection work.**

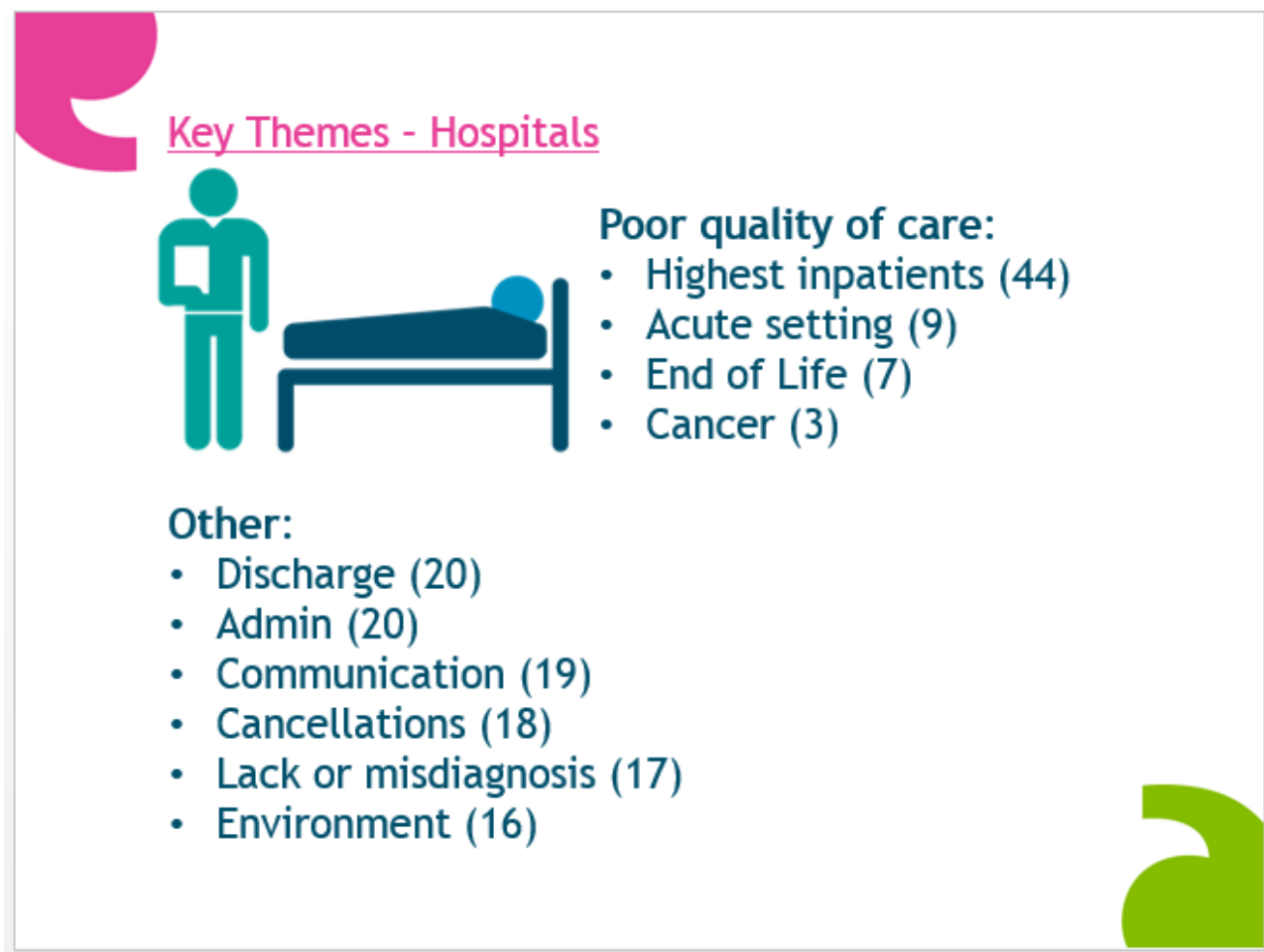


# Insight and Evidence for Local Hospital and Ambulance Trusts


We have a team of skilled and trained **Liaison Representatives** - one for every Trust as shown on our [Influencing and Liaison Map](#). These Representatives attend meetings and engagement committees with Trusts to highlight relevant insight to support the development of their services.

Our Liaison Representatives explore the main comments/concerns shared with us using an anonymised but detailed insight, reported separately. We are reporting by exception or insight we have not reported on elsewhere.

The themes from the last 12 months of less than positive insight for local hospitals as:



## Key Themes - Hospitals



**Poor quality of care:**

- Highest inpatients (44)
- Acute setting (9)
- End of Life (7)
- Cancer (3)

**Other:**

- Discharge (20)
- Admin (20)
- Communication (19)
- Cancellations (18)
- Lack or misdiagnosis (17)
- Environment (16)

**Sarah spoke to us during our Listening Tour:** We had a friend staying and he had hot/cold shaking symptoms, after calling 111 they went through a checklist for sepsis. They contacted the ambulance and this arrived within 15 minutes with one paramedic and another ambulance and they took our friend to A&E (St Richards Hospital). They had to react very quickly and were superb. The friend stayed in hospital for some weeks. I arrived to visit him one day and when I got to the ward I was told he had gone - been discharged! He was in his dressing gown waiting for drugs in a public waiting area. I took him home still in his dressing gown. I feel this is where the service falls down.



**Fiona shared her maternity experience.** I live in a small hamlet just outside of Midhurst. My pregnancy was smooth, with no complications, as I am generally in good health. So, even though this was my first pregnancy, I chose a home birth and was fully supported by my GP and midwife.

When I went into labour everything was going well and things were calm and comfortable. But, a few hours into the labour, my midwife was concerned that there were potentially issues with my baby, so I became quite anxious and distressed. The midwife, me and my partner agreed that I should go to hospital, so she called 999 for an ambulance to transfer me there. She said that was the safest way to get there. We waited for over an hour for the ambulance to arrive and I became very upset and frightened about what was happening. My midwife was amazing and she stayed with me the whole time. The paramedics were great and the team at St Richard's were also very good. But the situation was very distressing and I just can't understand why we had so long to wait - there was no explanation.

I am lucky that my son was born with no problems and we both recovered from our ordeal - but it has put me off having more children and has put me off a home birth! I am now also worried that if I had cause to call an ambulance at home for myself or a family member, it would take a long time. This has caused me to consider moving into town to be in a more accessible location.

**Healthwatch comment:** this case study shows the lasting effect a situation that was mostly likely due to demand, has on a person which can go beyond the immediate health needs.

**Jane spoke to us during our Listening Tour:** My toddler climbed and fell over the stair gate a few weeks ago and bumped his head. I wasn't too worried until a few hours later, as he was sleepy and then he was sick. I called 111 and they were great. They asked a lot of questions to assess the injury and then told me to take him straight to A&E at Worthing Hospital. When we got to A&E they said that they were expecting us, but said they were busy so we'd have to wait in the general waiting area. We sat there for 4 ½ hours without seeing anyone! We were eventually called in after midnight and he was asleep by then. What felt like a 30 second consultation repeated all the questions we had been asked by the 111 team and they then said to not worry and discharged us with advice to monitor him for 24 hours. We feel that we had conflicting advice from the 111 team - who felt it could be a serious issue - and the A&E team, who dismissed us as anxious parents. Thankfully he was ok and there were no lasting effects.

## We are always listening

Simply inviting people to share their experiences of health and care has enabled us to get closer to what is happening across the County and we will continue to make sure we use every opportunity to amplify what people have told us about their experiences.

**Please contact us to share your experience of health and care, good or bad. You can be part of our growing team of local residents who are getting involved in making positive changes.**

Before sharing any insight with those who plan, buy, provider or monitoring services, we anonymise the information, so that it cannot be traced back to individuals. We share local peoples' story so decision-makers can learn from these and make improvements.

## Contact Details

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.

### You can contact Healthwatch West Sussex:

Healthwatch West Sussex  
Billingshurst Community Centre  
Roman Way  
Billingshurst  
West Sussex  
RH14 9QW  
Phone number: 0300 012 0122

Email: [helpdesk@healthwatchwestsussex.co.uk](mailto:helpdesk@healthwatchwestsussex.co.uk)

Website: [www.healthwatchwestsussex.co.uk](http://www.healthwatchwestsussex.co.uk)

Healthwatch West Sussex sub-contracts to Help & Care to provide its statutory activities. The contact details are:



The Pokesdown Centre  
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