

Insight & Evidence



Reporting on the experiences shared by local people in West Sussex

July – September 2017

Local people have shared **380** experiences/stories



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



Primary Care



Complaints handling and lack of services are common themes

Mental Health

Using peoples' experiences to raise issues in community mental health services



Issues around respite care ... will highlight concerns in a separate report



14%

Positive Experience



86%

Less than Positive

Hot Topics

Urgent Care - 111 and Out of Hours

Respite Care

Significant service changes

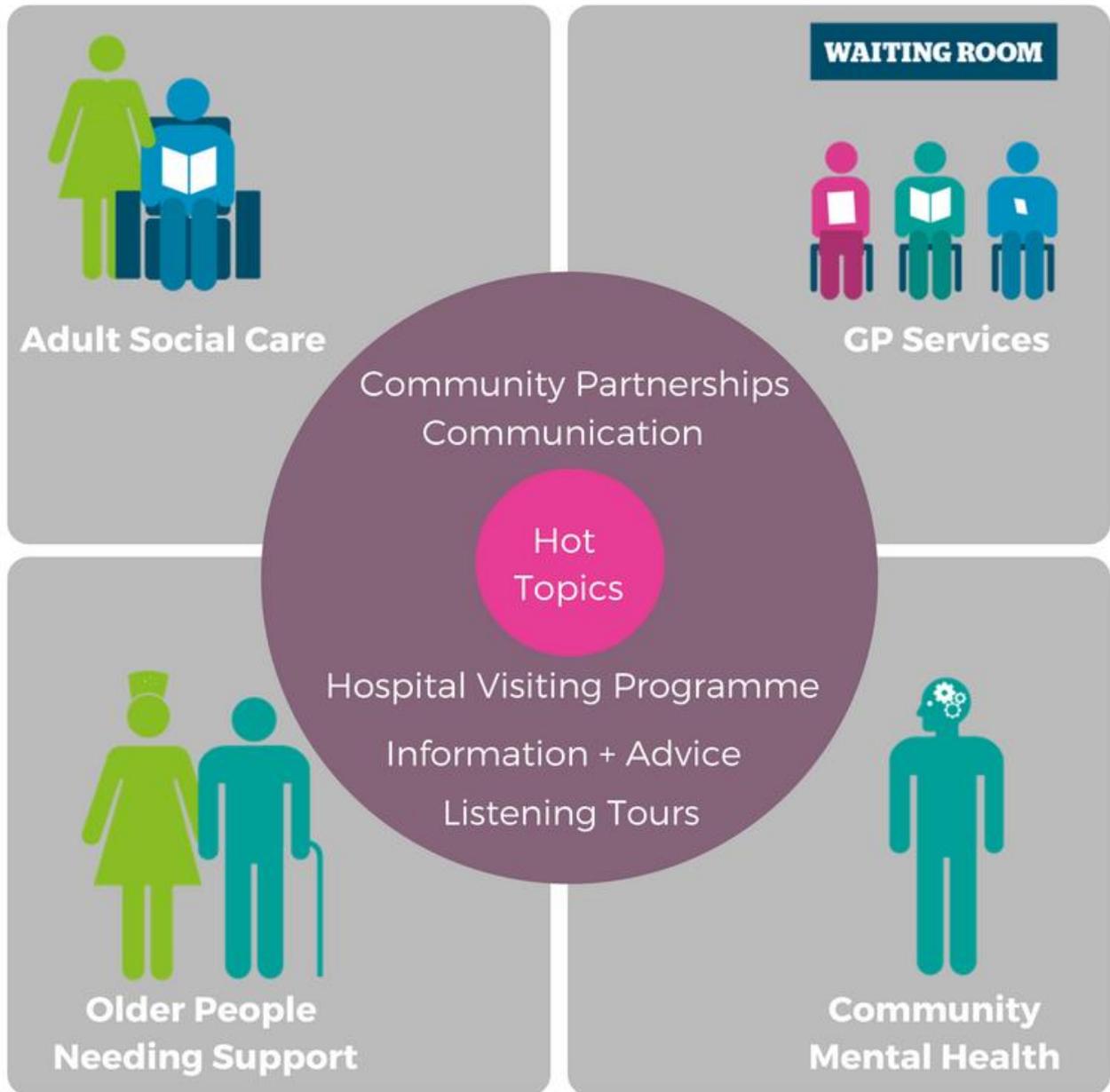


Together we speak louder
0300 012 0122

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](#).

The insight contained within this report may be influenced through 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 local people, who have chosen to share information with us.

Insight & Evidence

As the organisations that plan, buy, monitor and provide local health and care services struggle to bring their over-spending down to a sustainable level, they will be prioritising how they spend money based on clinical need and effectiveness. There are some tricky conversations to be had with people who need services now and in the future.

We **urge** all such organisations to **step-up their involvement of local people in all stages of their thinking and planning**. History shows too many examples of poorly thought-through cost-saving initiatives, which fail to take account of local needs, beliefs or behaviours resulting in more, not less spending.

Across the eight Clinical Commissioning Groups (CCGs) within the Sussex and East Surrey [Sustainability and Transformation Partnership](#) (responsible for the quality of many local services including GPs and hospital care) there are different policies on how patients get treatment. This means patients referred to the same hospital, for the same treatment, are subject to different policies and so may receive different levels of care. This is commonly seen as a health postcode lottery and is unfair.

The CCGs are looking at all treatments and procedures across Sussex and East Surrey to reduce the clinical variation, so that there is greater equality for patients and to deliver better value for money.

Future decisions to change policies around treatments will be made by the CCGs Governing Bodies.

When will we see more detail?

The first set of policies, where there are already common policies or strong national evidence, are currently going through CCGs and the STP clinical board for agreement. These are seen as uncontroversial.

The second group of policies are being reviewed where more complex or more clinical debate is needed. Involving local people in these debates must take place throughout this process and if necessary, local people will be consulted on proposed changes.

Why is it important to share your experiences and views?

Talking to local Healthwatch enables you to share your experiences, safe in the knowledge that we anonymise what you tell us and give you the satisfaction that you are informing changes to future services.

As well as inconsistency across Sussex and East Surrey, there are also inconsistencies at a very local level, and we are able, through your feedback, to highlight these and bring about changes in the quality of support others receive.

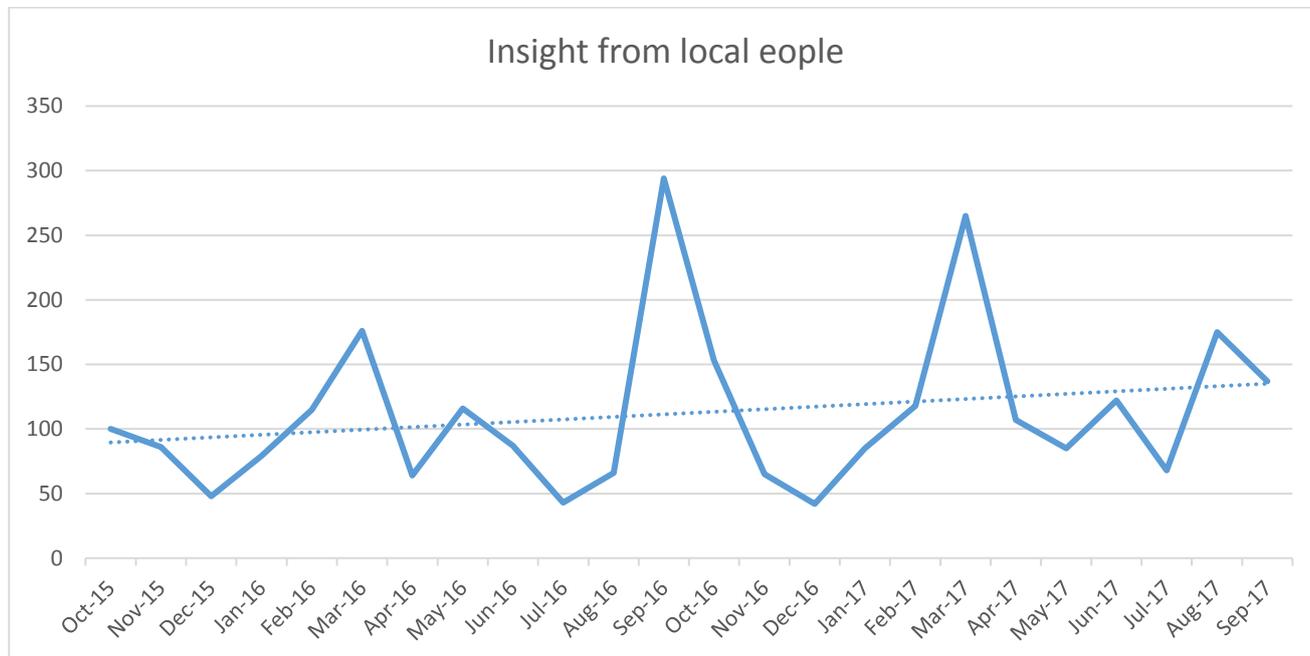
Our growing connections with communities, clubs and groups, enables us to stay connected to local people, so we hear and can then influence what needs to change.

Local people
have shared
380
experiences/
stories



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

www.healthwatchwestsussex.co.uk



What does this tell us?

- The insight has been influenced this quarter by the work of our *Engaging Local People Team*. We have focused on two project areas this month: Adult Social Care in Crawley and experiences of older Horsham District residents who have stayed in a hospital within the last 12 months.
- Our face-to-face engagement with people in the community through our *Listening Tours* yields the most useable insight (which are the spikes in numbers).

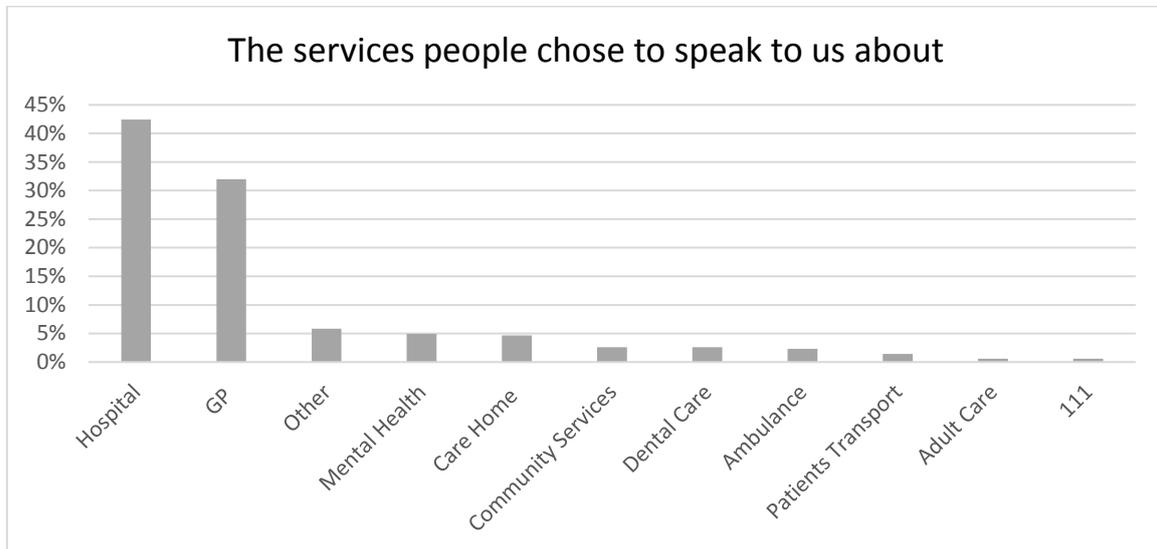
What are we doing to increase our insight?

- With our new team members we are focusing on our next Listening Tour of **Pulborough, Petworth and Midhurst** (during November 2017).
- During and after this tour our team will continue strengthening our community links in these communities to gain 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 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).

Case studies for this quarter

Barbara shared her daughter's experience of the Pain Clinic at Bognor Memorial hospital. Her daughter (who is in her twenties) has autism and she struggles with speech and has sensory needs. She was referred to the pain clinic from the hospital Maxillofacial service. Unfortunately, it appears her daughter's pain wasn't acknowledged for some time and the referral was only made following an MRI scan.

They went to the hospital for a 2 hour appointment. Barbara told us she was concerned that her daughter wouldn't cope for that long, without feeling stressed. When they arrived Barbara reported that they didn't receive a warm welcome and none of the staff were smiling. She went on to say they asked bizarre questions and did so in a patronising tone. She was later examined by a physiotherapist, which she describes as 'prodding and poking'. Barbara said she felt that the team may have made the assumption that her daughter was low-functioning, due to her Autism. However her daughter is very active and has a university degree.

The team came back with the advice to keep her head up straight to avoid pressure on her neck but Barbara feels this was unhelpful. The team came back to her a week later and advised they didn't have the 'skill set' to support her daughter. She is unhappy over the level of service offered to people with autism.

Bob had a fall in spring 2017, landing on his arm. He went to A&E at Worthing Hospital. His arm was x-rayed and put in a brace. Bob told us he also had an open wound on his finger but this wasn't cleaned although a plaster was applied. He said the doctors told him the x-ray showed this hand was fine and he was sent home. After 10 days, he saw his GP who advised him to go back to A&E because they were concerned there was a break to both arm and finger.

Bob went back to A&E. His brace was taken off and he was asked to flex his arm which he couldn't do. He was sent home again. After 2 weeks, he received a call from the consultant who told him they had made a mistake and that he needed to come back to A&E. When he went back, he was advised that he needed surgery the next day and was told not eat.

Bob went in to hospital the following morning, which was Saturday, only to be told *'there was no surgery scheduled for that day and that he should come back on Monday'*.

Bob was told the operation on his arm was realign his little finger which was broken. Instead of doing what was discussed, he told us the consultant decided to put a pin in his little finger to stabilise the arm which he did not know was broken until after the surgery. His little finger was still mispositioned after the surgery. He has since been referred for physiotherapy but he said the physiotherapist has refused to treat him due to the state of his arm. Bob has now been referred to a specialist at Chichester hospital.

hospital experiences that **'the emergency admission and treatment for his cardiac arrest** was amazing and care at Brighton was very good. Redhill emergency care was also very good but I got stuck there for a week with no communication as doctors were too busy. I feel I could have been released earlier. All in all generally good but there needs to be more communication between staff and patients. A nurse turned up with an injection into my stomach with no forewarning and explanation. I had to rely on family. I couldn't wait to escape.

Paul, who is working age and living in Crawley, started his conversation with us by saying "Don't speak to us about the NHS".

I'm in chronic pain and need both my hips replaced. My pain started 3 years ago and my GP told me to go to the gym. I paid to have some sports therapy at the gym and the person lifted my legs back and damaged them. I have been sacked from my job because the pain has meant I can't work anymore. I was put on morphine patches and I'm worried about the long term effects of this. Despite this I'm still in pain. I've had loads of MRIs and have another one booked. I won't go back to East Surrey Hospital because the consultant was so rude to me and I feel he deliberately tried to scare me (as I don't like hospitals) by saying all they could do was open me up and see what the damage was. But when I agreed to this, the consultant changed. I just want to be able to get back to work. I have lost confidence in the NHS because of this and another problem that the GP isn't referring onwards to get the treatment I need.

Our staff and volunteers are following up on this and all other insight shared.



Hot Topics

What's new?

Urgent Care - 111 and Out of Hours
Respite Care
Significant service changes

Urgent Care - 111 and Out of Hours

Local people have been asked about the future of urgent care and you can read the [feedback](#) from a survey carried out in July 2017.

Local Healthwatch across Sussex are collaboratively supporting the project team to follow-up with some specific under-represented groups of people, during November. This will help the team to get a fuller picture of local views. Local people will be further involved in the development of new joined-up services.

If you would like to be involved in discussions around how a new 111 and out-of-hours service will work in the future call us on 0300 012 0122 or email helpdesk@healthwatchwestsussex.co.uk

Respite Care

Taking a short break from caring responsibilities, or using respite care to be able to get your own treatment, is vitally important to full-time family and friend carers.

We've been hearing a rising number of concerns about the quality and safety of people in respite care or temporary care arrangements. In some cases we have needed to escalate concerns. We've included a [story](#) as an example.

We plan to do further work on this and are keen to hear from people who have experience of respite care (good or bad).

You can call our compassionate team on 0300 012 0122 or email helpdesk@healthwatchwestsussex.co.uk to share your story.

Significant Service Changes (Sustainability & Transformation Partnership/STP)

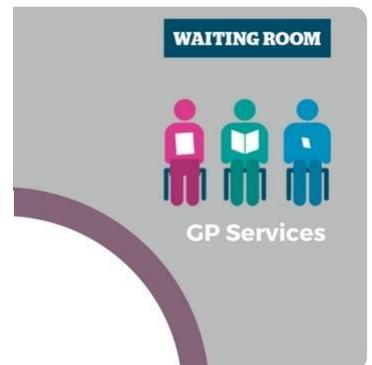
Some positive news: Bob Alexander (NHS Improvement national team) was confirmed as the new Executive Chair for our Sussex and East Surrey STP on 17 October. He has stated his priority is *"to ensure that we have the necessary leadership, governance and infrastructure in place as the STP moves from a planning phase to delivery."* He reiterated that all STP stakeholders are a partnership for delivering *"better health, better care and more sustainable services for the people we serve."*

The four Central Sussex CCGs - Crawley, Horsham and Mid Sussex, Brighton and Hove and High Weald Lewes Havens, have agreed to establish an alliance with a single leadership team in order to strengthen and streamline the commissioning functions for the four CCGs. They are currently recruiting one accountable officer and a managing director in the north and another for the south. The four CCGs will remain statutory bodies, retaining their governing bodies and accountability for commissioning for their local populations. The alliance expects to go live from April 2018 with a single operating plan for 2019/2020.



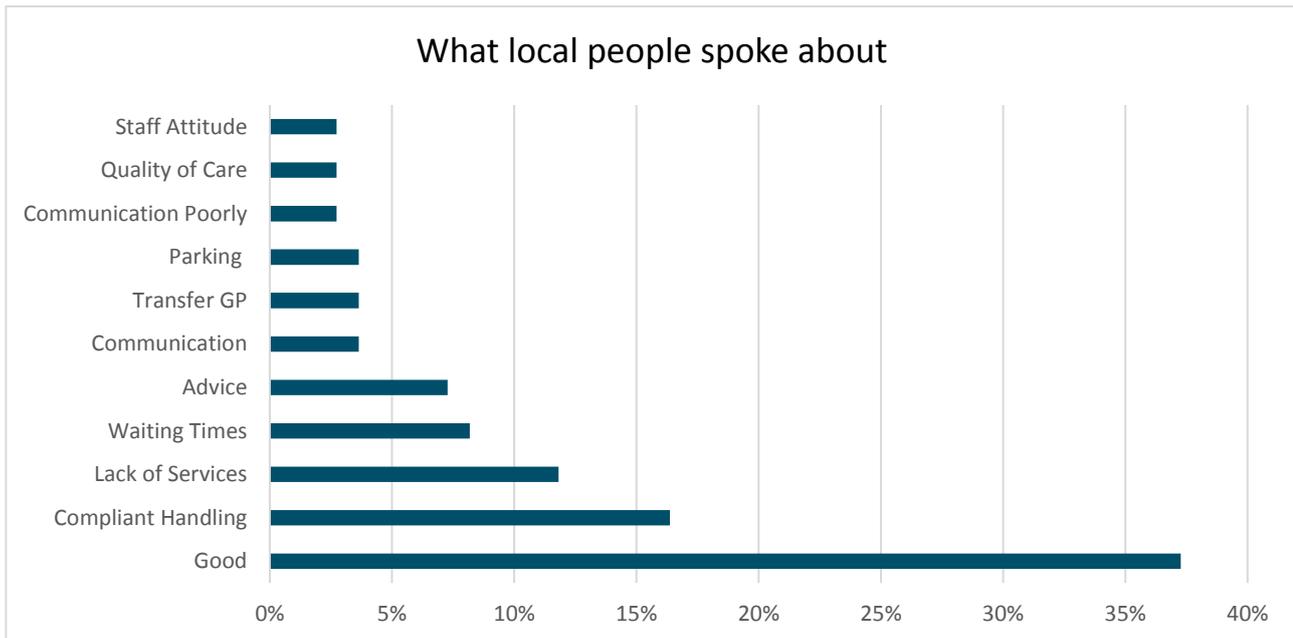
General Practice (GPs)

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



From July 2017 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?

There has been an increase in positive sentiments amongst the people who shared their GP experience, raising from only 20% to 37% this quarter.

Whilst people clearly get frustrated with waiting time the themes around complaints handling and lack of services should be of concern to those who plan, buy, monitor and provide GP services.

What are we doing to improve this?

We will be following up on our audit of GP website information on raising a complaint to see what improvements have been made.

We will be looking for examples of *What Good looks like* to local people during our listening tour of Pulborough, Petworth and Midhurst, so we can support other local practices.

Jon has been a patient at his surgery for 6 years. He told us 'getting an appointment is not too bad if not on the day. I can normally get one within a week. The staff here are helpful and the Doctors involve me in decisions. Went to Spire Gatwick Park through the NHS for injection in my back and I didn't have to wait long. I had physio at Horsham and again no long wait. Parking here is fine - if early. Everywhere else okay.'

Mental Health



Community
Mental Health

The [papers](#) (page 35 onwards) from the August 2017 STP Programme Board meeting set out the **Case for Change** for Mental Health Services across Sussex.

The Case for Change highlights both significant health inequality for local people living with mental health and the inequity in current services.

We would encourage local people, community leaders and support organisations to read this and to get involved in shaping the way forward.

Your voices make a difference: This quarter we reported insight to Sussex Partnership NHS Foundation Trust (which is responsible for delivering many mental health services in Sussex), on significant issues at their Bedale Centre. We are now working with the leadership team at the Trust to identify and implement change to make this a more accessible and responsive services.

This quarter 8% of our insight related to peoples' mental health experiences. The common theme local people spoke about was a **lack of support**.

Fiona told us she has been in touch with the community mental health team, since her parent passed away over 10 years ago. Last year, I went into the Priory during a time of crisis and since then I've had very few feelings. I manage this with the support my husband and Pepperville House. The support at Pepperville House has been inconsistent and I've had four psychiatrists in two years. I've been offered a locum psychiatrist but I feel a lot of the work requires rapport, which is based on a good relationship with them. I've been paying to see a private psychologist but it is very expensive and I can't continue paying £100 for an appointment.

Fiona also gave feedback on the Sussex Mental Healthline. You are lucky if you get through, however, I find it unhelpful as it isn't someone that knows my situation. I feel the West Sussex mental health service is under terrific strain and I've noticed many more young people are accessing mental health services.



Older People
Needing Support

Insight Events

We have published our collaborative [report](#) from our Insight Workshops and survey into the experiences of **older residents across Horsham District when they are admitted to hospital.**

This 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 will be discussing findings with the Health and Wellbeing Board in November.

Other older peoples' stories

An older gentleman came to speak to us after our Healthwatch presentation at a GP surgeries, Patient Participation Group's Annual General Meeting. He told us he has an elderly aunt (she is 93) who was in hospital in Hastings for some time. He was regularly visiting her and turned up one day and she was not there. He asked where she was so he could visit but because she is only his aunt by marriage they would not tell him. He was only able to find out where she was by contacting the care home she had originally been in and they only knew because of forwarding her clothes to the new home.

Data Protection is changing in the UK. The [General Data Protection Regulation](#) will apply from 25 May 2018. It is important all health and care services understand their responsibilities to patients and their family and friend carers and local people understand their rights.

Betty is a full time carer for her husband who has multiple sclerosis. She booked her husband's stay at [named] Care Home (for respite care) a year in advance. When they arrived, his room wasn't ready and the staff didn't seem to know what was going on. When she went to pick up her husband after 4 days she noticed that the intimate parts of his care hadn't been taken care of and so she took a picture to show the manager of the care home that her staff had not been washing her husband and taking care of him properly. She was then disgusted to find that the next time she took her husband to the care home for respite, the photo she had sent to the manager had been blown up, printed and stuck to the bathroom door. When she questioned the manager they said it was to remind staff that they needed to wash this patient properly. They were both appalled, neither of them had consented to that photo having been shown to anyone else let alone printed and put in the bathroom.



Adult Social Care

3% of our insight related to issues with Adult Social Care.

Sandra's sister is in her 50's and has Down's Syndrome. She lives in a [named] Care Home and she feels she has been neglected. There have been two safeguarding meetings, which were prompt but it took well over a year for Sandra to receive a safeguarding report. The delay in sending the report was blamed on a lack of staff and IT problems.



Insight and Evidence for 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.

We have heard a couple of stories about a lack of ambulance response:

Paula wanted to share her feedback and to find out about making a complaint about the experience she and her partner went through with South East Coast Ambulance service. I called 999 as my partner was suffering from excruciating pain in his lower abdomen. We were advised that it was not an emergency and told an out of hours Doctor would call. The doctor called within 15 minutes and told me to drive him to hospital. We were made to feel like we'd wasted the emergency services time. I was concerned about driving my partner because he was in so much pain. In the end he had to have surgery and the doctors found that his appendix was about to burst.

There were a number of stories about poor discharge arrangements relating to a number of hospitals:

Frank told us that his GP sent him to East Surrey Hospital as an emergency admission. The staff at both East Surrey and St Georges' Hospital (Tooting) were very thorough and caring but St Georges' could do with more flexible visiting hours. St Georges Hospital is very difficult and expensive to get to from Horsham. I got lots of information and a named person to contact if I had any concerns once home. I didn't get any hospital transport to help get me home and I had to pay out £100 for a taxi. When I asked about hospital transport the nurse laughed in my face and said 'get an Uber' - not very helpful when you don't have a smartphone.

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:

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



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