

Insight & Evidence



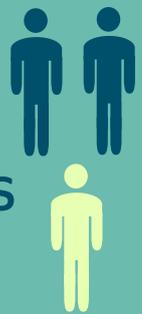
Reporting on the experiences shared by local people in West Sussex

April – June 2017

Local people have shared **314** stories



1 in 3 stories were either about hospitals or a GPs



Primary Care



Getting an appointment and poor communication are common themes

Mental Health

A lack of local services is creating really challenges for patients and their families



Less positive GP experiences reported this quarter



11%

Positive Experience



89%

Less than Positive

Hot Topics

GP Services
Significant service changes
Non-emergency patient transport
Medicines wastage

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 where and how we engage 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 we reported last quarter, all three West Sussex Clinical Commissioning Groups (CCGs) are reporting financial deficits for 2016/17, and from the [Annual CCG Assessment Process 2016-17](#), each has now been placed in special measure by NHS England.

Special measures are NHS England's response to CCGs that need to show improvement, over a short period of time, in at least one of the areas of: *leadership, financial management* and/or *quality*. These measures provide support and a higher level of monitoring to enable this improvement to happen. Whilst the West Sussex CCGs have been found to be performing below the required level, we are told this does not mean they have been failings in quality and safety. Currently, West Sussex CCG are being supported to develop an improvement plan, which will be agreed with NHS England. Delivery against the plans will be monitored regularly and each CCG will exit special measures when it has met the agreed plan.

Healthwatch is using insight and our observations to support the CCGs to understand the need to be **open, transparent and to involve local people** in shaping GP, hospital and community services, as well as any cost saving proposals.

We are all being asked to play our part in helping to improve health and social care for the County [#HelpMyNHS](#). This could be looking at what we can do to help ourselves stay well or what help we can get from a local pharmacy in the first instance. It is also important, that we all work together so that when errors occur, these are shared and taken seriously, so mistakes are not repeated. **Here is Sue's story.**

I went to our local pharmacy to collect my husband's regular repeat medication and when I got there the assistant produced a second bag of tablets and said that I had to sign for them as they were controlled high dosage pain relief drugs. I was a little confused as he hadn't said the doctor had changed or added to his regular meds, but I accepted them and signed the form. When I got home my husband was equally confused as he hadn't seen the doctor to change or add to his meds. I called our surgery and spoke to the receptionist who looked at his notes and confirmed that no additional drugs had been prescribed. She said it was a mystery and that we should return them to the pharmacy. Which is exactly what we did - on the same day. We spoke to the pharmacist who said they had definitely had a prescription sent through with his name, DOB, address and patient number - so they took it as legitimate. The error must have been made by the surgery / person prescribing. We got the pharmacist to sign to say we had returned the drugs and went home but we were so unsettled that we called the surgery again. A while later the deputy manager called us back and whilst he was very sweet, he was a bit dismissive. He said - *'well you realised the problem and you've returned them, so it's been dealt with appropriately'* - as if that was it! We are quite disturbed about this. The dosage we were given was the absolute maximum and could have given my husband seizures or a heart attack if he'd taken them unnecessarily and with his other health issues! Since the call, a doctor has called back expressing concerned, wanting to send a personal letter of apology, and blames it on patients of same/similar name. They are discussing ways of it never happening again....

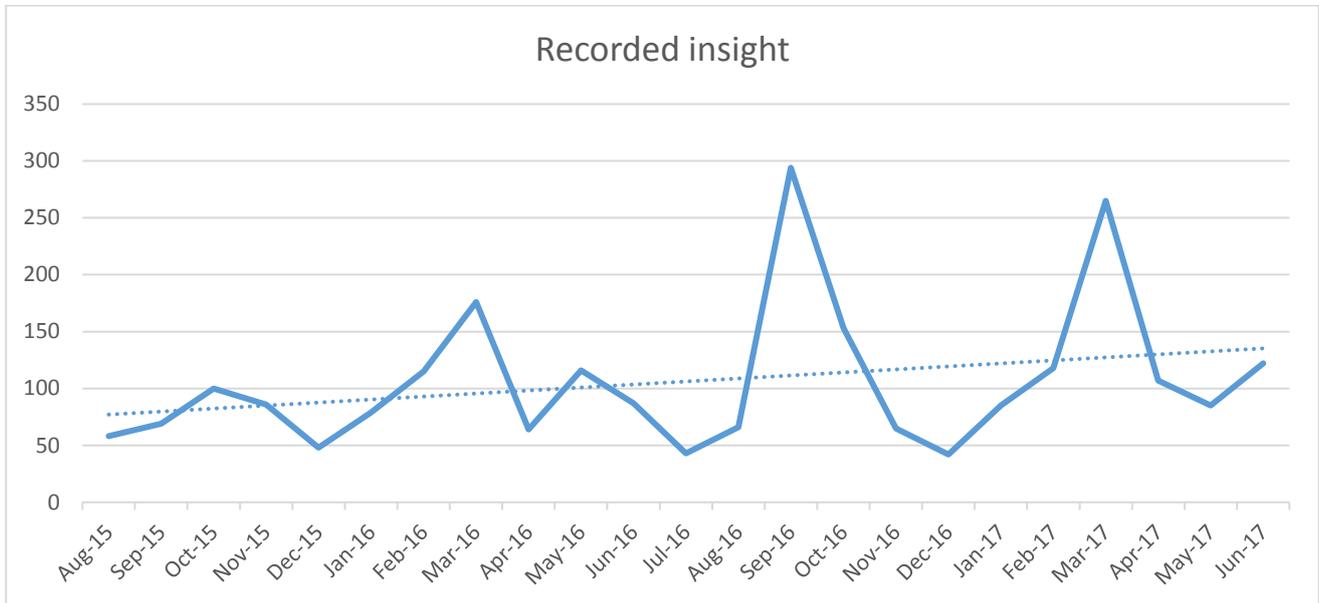
Local people
have shared

314
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?

- These figures reflect our Listening Tour in Littlehampton throughout March 2017 and into April. The insight from this is detailed in our [Listening to Littlehampton](#) report.

The particular issues around Primary Care in Littlehampton area mean that stories relating to GP services feature more prominently than

What are we doing to increase our insight?

- We have been engaging with local people with Listening Tours for a year now and have critically reflected on how we work as a team.

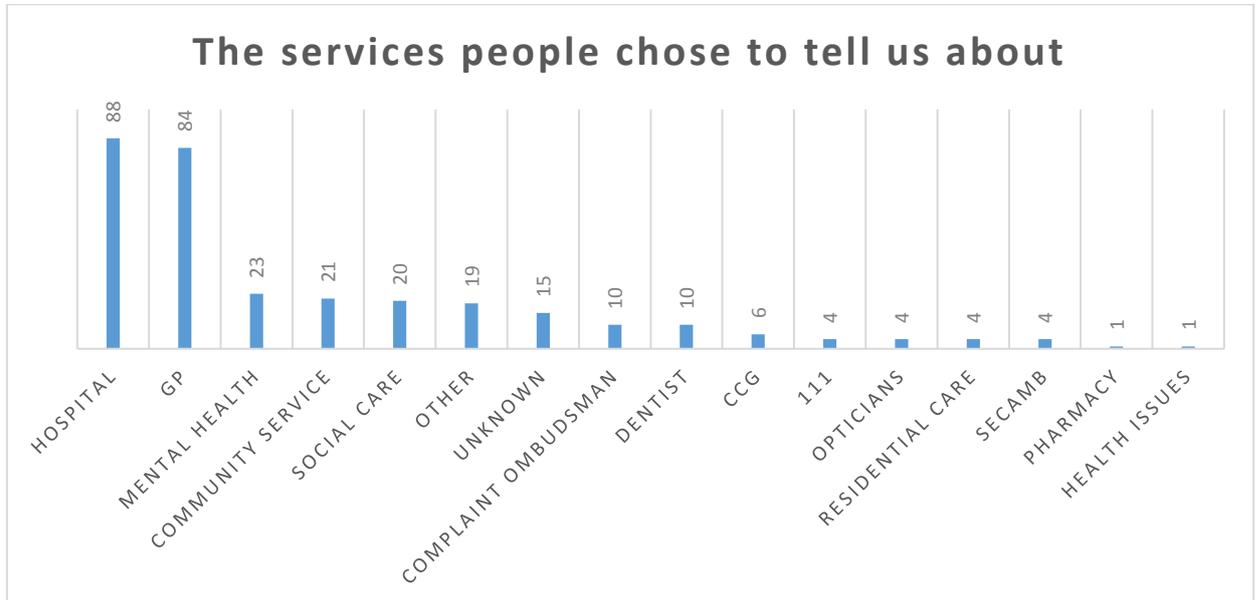
Whilst we are pleased with the growth in insight our small operational team has achieved, we are using a team opportunity to replace an existing lead role with two new community worker roles. This will enable us to reach and sustain a relationship with more local groups and clubs, to gain a regular flow of insight.

- We are now planning our next Listening Tour which will be in Petworth, Pulborough and Midhurst, in October-November 2017.

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.



Through our **Non-emergency Patient Transport Service** surveying work we visited the **Crawley Dialysis Unit**. All the patients we spoke on the day said how good the dialysis services now was, with some commenting on how the infection control had greatly improved since the service moved to the new location/provider.

Case studies for this quarter

I visited [Worthing Hospital](#) today with my daughter (who is under 10). Whilst initially being put off by the building work, we found our way to the Children's Centre and were greeted by friendly staff who welcomed us warmly. We were called in just 15 minutes late of our appointment time - quite good in our eyes! The clinical practitioner explained that she had 2 student nurses in with her and asked if we were ok with that - which we were. The team were friendly, professional and completely tuned into the children who were their patients. 'Fiona' addressed my daughter and asked her questions in a language she understood and could respond to. She also involved me in the conversation. She made us feel that - for that moment - we were her most important patients and that she would do what she could to support and advise us.

Although we have been through the system before, she was able to give us some useful and practical advice and tips to help manage and improve my daughter's situation. We left feeling positive and motivated, reassured and cared for. She will feedback her notes to the consultant paediatrician and will see us again in 3 months to monitor progress. All in all, we were impressed with the children's continence clinic team very much. We were not impressed with the loos at the North Entrance!

Betty called to ask about support with making a complaint. She had an initial operation which caused some problems, and has waited for a long time for further surgery to put things right. Her operations have been repeatedly cancelled. Betty was initially operated on in 2016 at [St Richards Hospital](#). She was left in a lot of pain and discomfort, and had a scan, which showed where the problems were. Betty saw the consultant again and was given a date in March 2017 for an operation to correct the problem. A few days before the operation she was contacted and told it was cancelled. She was given another date for a couple of weeks later. She went in for her operation and was made ready, but at the last minute it was cancelled. Betty was given a third date for her operation. Once again she went to the hospital and was made ready, only for the operation to be cancelled at the last minute.

Betty called on the day of her planned operation. She was very upset and became tearful on the phone at several points. She told us she is in agonising pain, which is becoming worse. She has lost a lot of days from work and has not been paid, leading to financial troubles and legal action. It is likely that Betty and her family will have to sell their house. She is distraught, unable to eat properly, losing a lot of weight and feeling increasingly unwell. She has low blood pressure now. Her children are anxious and upset.

Healthwatch is support Betty to make a complaint so she can get the treatment she so urgently needs.

Stop, I'm getting dizzy.....

I was referred for physiotherapy. Who referred me to pain management. Who referred me to spinal triage. Who then referred me to physiotherapy. I feel I'm just going round in circles and not getting the treatment I need.

Meanwhile - we ask what has this cost her emotionally and what has this cost our NHS.



Hot Topics

What's new?

GP Services
Significant service changes
Non-emergency patient transport follow-up
Medicines wastage

GP services

The recent announcement of the selling off of the potential site for relocating GP services in Wick, has fuelled local anger in Littlehampton. It is important now for those who plan, buy and provide GP services to involve local people in shaping the future health provision in Arun.

We are looking at how we can make sure that peoples' lived experiences inform the way health and care come together across West Sussex.

If you want to have a say about GP services please call 0300 012 0122.

Significant Service Changes (Sustainability & Transformation Planning, known as STP)

Recognising the need to be more open and transparent, local health and care leaders have agreed to publish all Programme Board papers. You can view these [papers](#) on Coastal Clinical Commissioning Group's website.

NHS England have published a [Sustainability and Transformation Partnership Progress Dashboard - Baseline View](#) (on 21 July 2017) This shows Sussex and East Surrey amongst the bottom five in the country.

Non-emergency patient transport

Local Healthwatch have been working together to look at whether the new transport service is working better for Sussex patients. Our report is being published soon. Transport is a challenge for some. **Here is Sonia's story:**

I've been told I'm no longer eligible for hospital transport because I don't need a wheelchair and am mobile. I had transport provided so I could get to specialist hand consultant at East Grinstead, which is almost 50 miles away. Since finding out I can't get the transport I contacted my GP surgery who said I'd need to pay £25 for a supporting letter. I'm unable to get the train and no other suggestions were made, so I've had to cancel appointments at East Grinstead.

The Local Healthwatch report will be published in the autumn.

Medicines Wastage

NHS England are running a national [consultation](#) looking at what should not routinely be prescribed by GPs.

Our understanding of this national consultation is that whilst this is an initial round of a list of 18 specific treatments that are up for discussion, it will set the framework for future decisions, so we feel it is vital that the NHS gets this right.

Nationally, Healthwatch England are calling on NHS England to take the consultation activities beyond merely publishing the document on its website and suggesting that CCGs can undertake local engagement activities to inform their own responses.

You can have your say on the future of local prescribing of medicines, to find out more click [here](#).



General Practice (GPs)

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

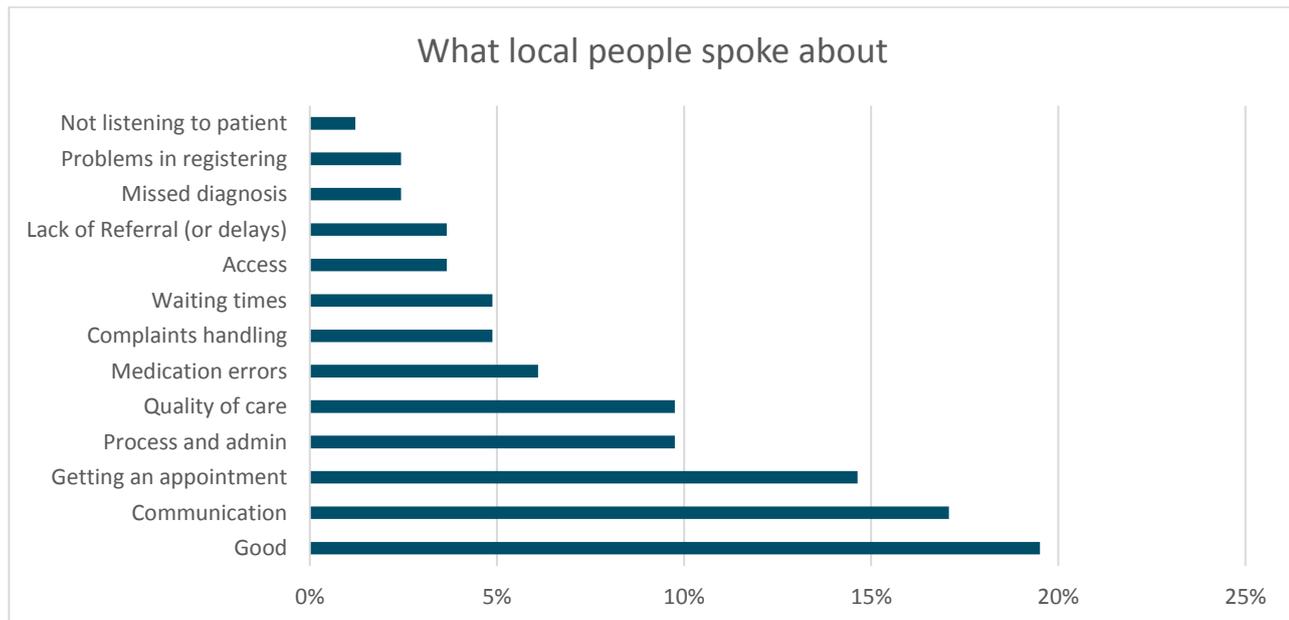
WAITING ROOM



GP Services

From April 2017 Coastal West Sussex, Horsham and Mid Sussex GPs are commissioned through the Clinical Commissioning Groups (CCG). The commissioning of Crawley GP 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 a negative shift in peoples' sentiment, from last quarter, which showed 75% of GP insight was positive, now down to 20%. We believe this reflects the Littlehampton residents' views/experience of local GP services.

Our own [audit](#) of GP website information on raising a complaint has shown this is an area where local services can make improvements.

What are we doing to improve this?

We plan to continue our discussions with local GPs in Littlehampton around how local people can be involved in shaping services and pushing for greater engagement in the *Local Community Networks*.

We have produced a resource to help GP services improve how they encourage sharing feedback and complaints.

My Mum has some health problems and I sometimes have to look after her and help her to go to the doctors because she gets anxious and panicky. The doctors at Lime Tree are always really nice to me and they help me to understand what my Mum is going through. They let me go in with my Mum. I have learnt new things and found them very interesting. I might be a nurse or a doctor when I'm older.

(12 year old Girl Guide)

Mental Health



Community
Mental Health

Sam Allen, Chief Executive for Sussex Partnership NHS Foundation Trust recently said

The need for bold, decisive action to improve the lot of people with lived experience of mental health issues is illustrated by [an analysis published by health and social care services in Sussex and east Surrey](#), the area where I work as an NHS chief executive. This shows that people using mental health services in our area are likely to live up to 20 years less than the general population; are two to four times more likely to die of cancer, circulatory or respiratory disease; and account for about 20% of all A&E attendances and emergency admissions, despite making up only 7% of the overall population.

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

My husband has a serious mental health issue and used to be seen by the senior partner at a GP surgery in Worthing. He was very well cared for and the doctor seemed to understand his needs very well. In the last few months, the doctor has left the practice and this has left my husband, and me, in a state of uncertainty and with a feeling of being forgotten. On a recent visit to the practice, my husband saw a different doctor and as a result his medication was changed. He is unsure as to why as he felt there was no clear explanation or review and he was not involved in any conversation about this change. It has caused him great anxiety.

Annie's husband is in contact with the Bedale Centre. They have been told to call the Sussex Mental Healthline on a number of occasions but reported they have NEVER been able to get through.

Annie told us she feels the Bedale centre has failed to be proactive in managing her husband's health and this has led to a crisis each time. On one occasion, last winter, she reported that her husband was showing signs of being unwell. However she felt ignored and no help was offered, so when the situation escalated a couple of days later she had to contact the police. The police instructed her to call the Bedale Centre but they only offered to email CPN (Community Psychiatric Nurse). At this point, the police took control of the call and spoke to the Bedale Centre directly. They discussed a section but the police said her husband had not done anything wrong and was in his own home but very distressed. The situation then escalated and her husband took out a knife.

More recently she spoke about a situation in which her husband's behaviour escalated and he began to show signs of being unwell and she reported it to the Bedale Centre but felt she wasn't taken seriously. She reported again his mental health wasn't managed and support wasn't offered before it reached crisis point, when he took suicidal action.



Older People
Needing Support

Insight Events

We're drafting a report from our Insight Workshop and survey into the experiences of older residents across Horsham District when they are admitted to hospital.

There will be a second insight event in September to explore issues with other stakeholders. We aim to publish the insight report in the autumn.

Older peoples' stories

Joyce shared that her husband had died at 3pm on Sunday. He had been on palliative care in Crawley. They called 111 and spoke to someone who said "I don't know what to do". The family called the Hospice Team who called the on-call doctor. They were told there was a 6 hour wait. The on-call GP arrived just before midnight (after nearly 8 hours). The GP said that he must speak to both Joyce and her son. Joyce then told us about the negative experience they had with the doctor, when he told them he needed to speak to them separately about what had happened before he had died. The explanation given, was that the doctor was required "to do this because of what goes on". He told them that he could not issue a death certificate and that they should call the GP on Monday and 3 days later they had still not got the death certificate.

Bob shared his recent experience of caring for his 81 year old mother. Over the last 5 weeks numerous professionals have disagreed with each other about the best course of action for my mother's treatment. No professionals seem willing to take responsibility and there is no co-ordination between the services. My mother's health is deteriorating and I am travelling from another county to take care of her following a (standard) operation. My mother lives in sheltered housing but has very little support. She hasn't been taking her medication and has wandering confused and has pulled her cord so often that local services will no longer come out. Errors have meant wasted journeys to hospital and they are now awaiting another assessment.



Adult Social Care

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

Mrs Smith said she had requested a needs assessment at the beginning of the year for her son (who is an adult living with Autism). She was told that someone would be in contact, that her request was with the right department and that it was being looked at by the appropriate team, when she chased this up in April. She has been given no time frame of when the assessment is likely to happen.

Mrs Smith told us this was her fourth attempt to get her son's needs assessed.



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 had a couple of stories about a lack of ambulance response.

(May 2017) Patrick called 999 I rang 999 as my partner was suffering from severe chest pains and a tingling sensation in both arms and hands. The first responder was very helpful and told us an ambulance was on its way. After 5 minutes of hanging up the phone, I received a call from a lady operator, who told me she had cancelled the ambulance as she was fully sure that her symptoms were part of her tonsillitis. I explained that I was sure it was not because of tonsillitis and that she was struggling to breathe, not responsive and in a lot of pain. I was told that if I was worried I should take her to A&E.

I drove, dangerously, 15 miles to the nearest hospital. Once we arrived at A&E we were admitted straight away. She had to spend 2 days in hospital and is now being sent for tests on her heart. The nurses were very concerned an ambulance was not sent.

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

Fiona called us unhappy about the way her brother was treated in Hospital. My brother has a mild learning disability and was homeless before being admitted to hospital with a broken ankle. He had surgery and despite having an infection on the Sunday he was discharged the following day in his pyjamas. He was dropped in an ambulance to the local council offices and has now been given temporary accommodation in a hotel. Her brother told her he didn't know what his tablets were for or what would happen next in terms of his treatment. He is now trying to manage his recovery in a hotel room without adequate support.

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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