

Insight & Evidence



Reporting on the experiences shared by local people in West Sussex

January – March 2018

Local people have shared **368** experiences/stories



Stories more complex and detailed



Primary Care



Much lower positive comments about GP services this quarter

Hospital



Impact of bad weather

Local people help us to identify new areas to focus on



21%

Positive Experience



79%

Less than Positive

Hot Topics

Improving care for us

Sustainability & Transformation

GPs stopping routine ear wax removal



Together we speak louder
0300 012 0122

healthwatch
West Sussex

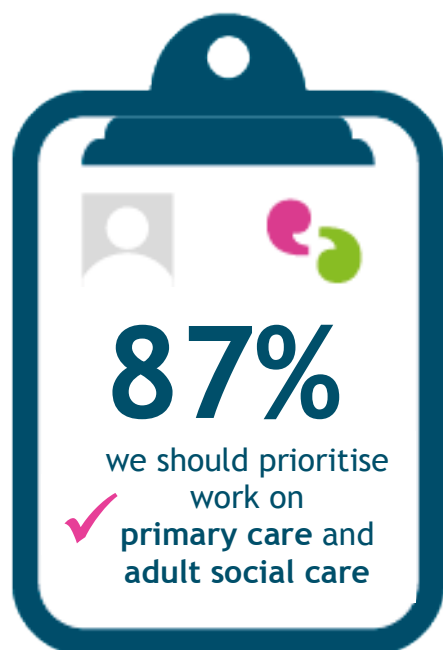
Insight & Evidence

The Healthwatch West Sussex CIC Board is set to discuss and agree new priorities for 2018-2019 on 9 May, our next public Board meeting.

Following a presentation of the last 12 months' insight given to the Board at workshop in January 2018, the operational team worked to develop some broad ideas for future work, based on the Board's suggested priorities.

We tested our thinking in a survey, which ran for a month (closing on 14 March). The survey asked local people for their views and insight on what we should be working on. It was widely promoted (including appearing in two Heads-Up newsletters, local Clinical Commissioning Group e-newsletters, personal emails, social media in three posts, reaching over 800 people.) 67 people took the survey, which has informed the proposals for the May discussion.

What local people told us we should be working on?



86% of people agreed with our proposal to show what works well for patients when it comes to accessing GP services.

I said no to GP surgeries and dentists, as I don't feel patients are happy to complain as there may be repercussions.

It is important to know what is NOT working well as that needs to be addressed!

Not sure Healthwatch should be going so softly on (GP access)... maybe a stronger two-pronged approach is needed, such as showing how patients are failed alongside what works well.

I think Primary Care should also include Pharmacists.

People agreed we need to understand what has changed for people through the innovation work West Sussex County Council has done around its provision of information and support. Similarly agreeing we should follow-up on safeguarding.

Most people agreed with prioritising under 25s mental health and wellbeing (with 10% unsure).

A few people commented on the lack of concern for adult mental health, or extending age range.

I think there is an absolute crisis in mental health services for young people and that they are our future and need to be heavily invested in, otherwise society will have to pick up the pieces later on. Current service provision, or lack of, is unacceptable.

.... Can Healthwatch be very specific in its findings about what needs to happen and who needs to do it - make them accountable?



84% ✓ should prioritise under 25s mental health & wellbeing

65% people said there were other priorities we should be working on. We asked people to describe the issues they felt we should be focusing on. Concerns with more than two related responses are summarised here:

Adult Mental Health	GPs (include access)	Social Care	NHS changes & pressures	Older people
7%	7%	5%	4%	3%

We value this feedback and will be including it in planning activities and engagement. We will continue to discuss local peoples' experiences and concerns throughout the year.

Alongside those who plan, buy, provide and monitor local health services we are involved in developing an engagement framework, which we hope will lead the way to meaningful and successful conversations with local people and communities, around health changes; opportunities and challenges.



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 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.

We have also created and continue to grow our *It Starts with You* network to give us regular two-way communication with local community groups and clubs.

Local people have shared

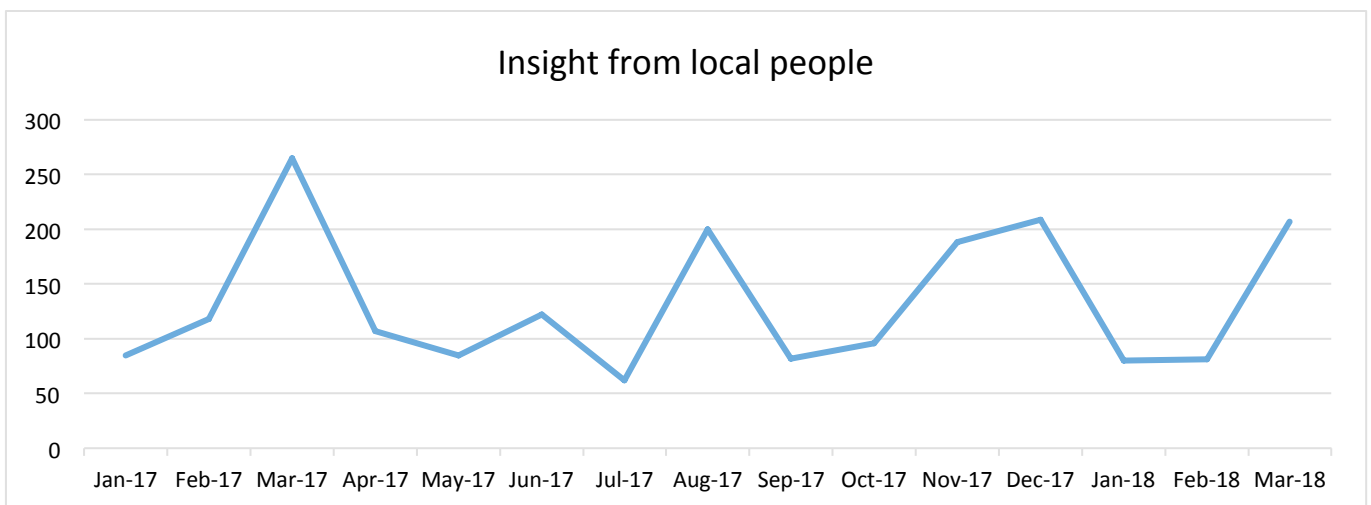
368

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



What does this tell us?

We were not surprised by the drop off stories in January and February - as like most people we struggled to get out and about, due to the adverse weather and had several event and visit engagement cancelled.

What the numbers do not reflect is the current trend of more complex and detailed accounts being shared.

What are we doing to increase our insight?

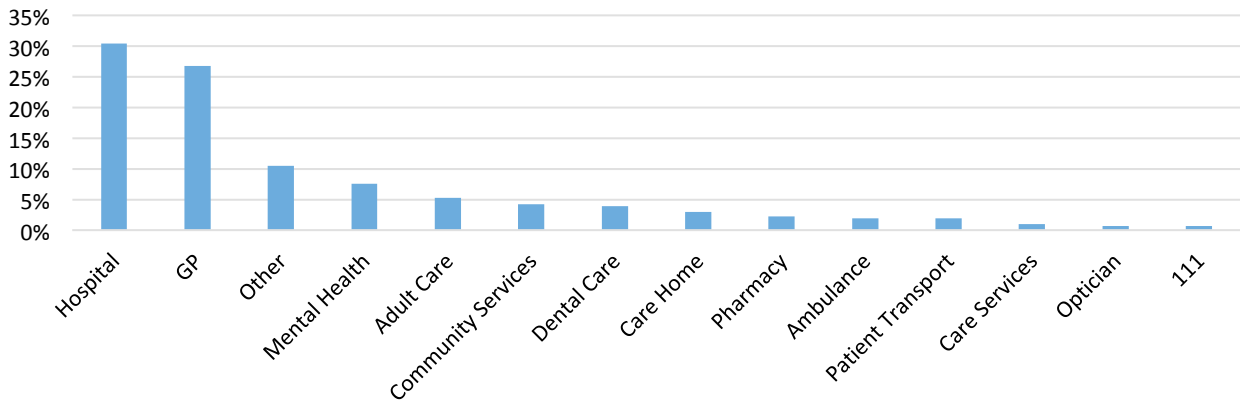
As well as investing in resources in focusing on collaborating with other voluntary organisations, we will be using 2018-19 to explore how we can increase the number of people who have a level of awareness of Healthwatch, by understanding more about how to reach out to a wider range of people including under 25s and those of working age.

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



Where stories show significant, or serious issues, these are followed up by our team and are shared with the appropriate organisations. Providers are asked to detail what action they will be taking because 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.

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

Case studies for this quarter

Fiona told us of her struggles to have her voice heard at her local GP surgery in Coastal West Sussex. "I hand delivered a letter to my surgery about my concern over Healthwatch advocates are following up on this concern and we have just completed another audit of General Practices' website complaints information to see what still needs to improve. We will be publishing our findings in the next quarter and will be following up concerns with individual practices.

response to both letters has added to the distress caused by the initial incident.



Sandra called on her mother's behalf, as English was not her first language
Her mother has been experiencing a lot of pain, since an operation over 3 years ago and her health has deteriorated, leaving long term damage to one of her organs. The consultant she was under has stated that everything was alright, and she has been told not to come back to the hospital again. Sandra has supported her mother to make a complaint, but the surgeon has refused to see her to discuss this. Our advice and information team have supported the family on the next step of their journey to getting this situation looked at.

Jonathan's wife found herself in a similar situation: Having receiving hospital treatment for a break, she was left in pain. Despite having visited both the hospital and the GP, she was told that everything was fine and it would just take time to heal. After 3 months they requested further scans, as the original x-rays they had been told were unclear. The request was denied. After 7 months she requested a referral to a specialist, which was also declined. So, they went privately, and the specialist discovered there was an underlying problem and they are now paying to have this resolved. The couple whilst able to pay for the treatment privately, feel that clinicians should have listened to their concerns. This could have prevented a lot of pain and inconvenience and avoided the risk of long-term damage.

The Healthwatch independent health complaints advocates are supporting both families to have their voice heard and to progress their individual cases.

Jason received a message from his GP surgery to make an appointment so the GP could discuss some test results

He tells us: " I went to the surgery to make an appointment and they couldn't give me one for nearly 2 weeks, I explained to the receptionist what the appointment was for and said to do you think it is good for anxiety to keep someone waiting that long when there is no indication of the results being good or bad. I was told the only thing to do is turn up in the morning and sit and wait. I went this morning at 8am and waited for the bookings to start at 8.30am. When I got to the desk after a short wait, I was told that there were no appointments left. The receptionist was the same as yesterday evening, and I am very disappointed with their manner and lack of understanding. I am self-employed and find it difficult to juggle my work schedule to make appointments.

Healthwatch appreciates the work commissioners have, and are doing, to create more in-hours appointments in primary care (so patients can see GPs, practice nurses, etc.) but this case, and others, show there are real issues with accessing appointments. One Crawley resident told us how they had spent £10 the week before just trying to get through to their GP surgery without success, saying "I'll have to spend more next week trying to get through". Another told us they'd had to make over 100 calls in the day to get an appointment.

One of our proposed priorities is to look at what works well from a patient viewpoint to help inform how services are developed in the future.





Hot Topics

What's new?

Improving care for us by simplifying and increasing where we can go when we need urgent help with our health

STP

Ear syringing

Improving care for us - by simplifying and increasing where we can go when we need help with our health

The complex landscape of where we can go if we need urgent treatment has been recognised and locally those who plan and buy services (clinical commissioning groups) have written a new service specification that will both simplify and give us more access to care.

GPs and our clinical commissioning groups have put in more general practice appointments during the week and are working on extended hours and weekend provisions. Whilst this is good news, we hear from people how they are still struggling to get an appointment.

Only last month we heard how someone tried **139 times during the day to final get to see a doctor** and another person **spent £10 on mobile phone calls without managing to get an appointment**, they are resigned to trying again and spending more money.

Our proposed work includes working with some GP surgeries to understand how people access their services, followed by time talking to their patients to find out works well for them and what could improve.

Sustainability & Transformation Plans or “STP” progress

Local Healthwatch met with the Chair, Bob Alexander to reinforce the need for greater public and patient involvement in the way services are changing both locally and across Sussex. Whilst we would like more progress to have been made by now, we are pleased to learn of planned events to take place across the county in the coming months.

Locally we are working with Coastal West Sussex Clinical Commissioning Group to support them to strengthen the involvement of local people and communities, as the [Local Community Networks](#) develop.

GPs stop routinely doing ear irrigation (ear wax removal)

Local people started to contact us for *Advice and Information* and to share their concern that general practices had ceased providing Ear Irrigation (syringing) from March 2018.

Whilst we are still looking into how local people were involved to support practices in making their decision to stop this service, we want to make you aware that if your GP believes ear wax removal is medically needed they should make a referral to an alternative NHS service. If you must visit a non-NHS organisation for this treatment it is worth shopping around - as costs can vary and not all providers are regulated in the same way.

General Practice (GPs)

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

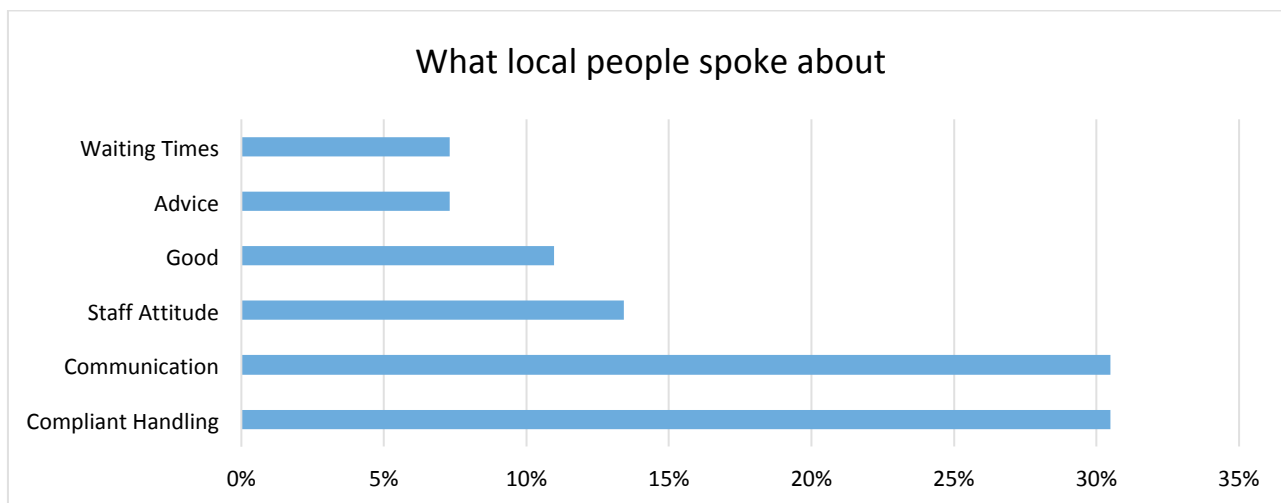
WAITING ROOM



GP Services

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?

This quarter has seen a drop in the positive comments about GPs, from 65% last quarter (and 37% the previous quarter) to under 15%.

Complaints handling remains a concern, particularly around the lack of responsiveness.

What are we doing to improve this?

As mentioned on page 5, we have revisited **GP complaints information on websites** to see what has changed, having alerted practices of when and how we will be doing this work. Our findings will be published next quarter.



Mental Health



Our *People With Lived Experience* work completed in March 2018. This project was to bring the consumer voice to the strategic 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. You can read a [concluding report](#) of this work. Pathfinder West Sussex will continue to develop and we will support them at every opportunity.



Older People with Support Needs

Progressing actions to improve hospital experiences for Horsham District residents

We are delighted with some of the follow up to December's stakeholder events. Organisations are finding new ways of working in partnership to bring about some potential solutions to some of the challenges local people shared last year.

One initiative is to support local people to have important information and items ready for hospital; bringing community transport organisations together to share ideas and potential resources. We will share more news of the "Bag Tags" later in the year.

Other older peoples' stories

Joyce called us very upset about her ulcerated legs, which had worsened due to stress

Last summer she was told she could no longer get dressings from her GP surgery (which comes under Crawley Clinical Commissioning Group [CCG]) and that the District Nurses would visit regularly. She was then told that the District Nurses would not be visiting and that she should go to planned treatment appointments. In the meantime, she has bought her own dressings and spent a lot of money on this. Joyce's mental wellbeing has been affected by the whole situation.

As Joyce was not sure where the decision was made, but it seems that it may have been one by Crawley CCG, or its members, Healthwatch helpdesk staff gave her their support unit number, to talk through the complaint/reason for the decisions (0300 200 8844). She asked about writing to her MP and Health Minister and we suggested she could do this, but they would go back to local level to investigate as well. She was happy for her phone number to be held and will provide address details etc if a referral needs to be made later down the line for advocacy support.

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 on insight we have not reported on elsewhere.

This quarter there has been an increase in the number of individual stories which detail fatalities and serious concerns. These have not been included in this report due to the sensitive nature and individuality of the accounts which make them identifiable. Some of these are being dealt with directly by the Trust or Coronor, and others are being supported by our Independent Health Complaints Advocates.

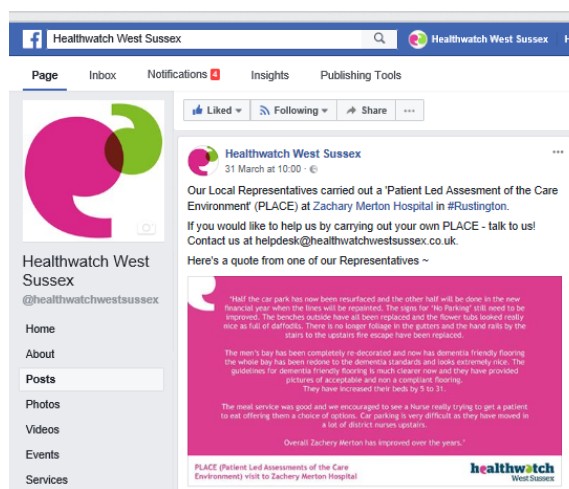
From this still relatively small but significant number of detailed stories, we have not been able to identify any trends within the stories, other than a warning sign of a local system that is under-pressure. We will continue to seek more feedback from local people about their experiences and challenge the system with integrity, through amplifying and making sure the voice of lived experience is heard.

Healthwatch has started our participation in the Patient-Led Assessment of the Care Environment (PLACE) programme, in March. Visiting local hospitals, as part of this national programme, will continue at pace, throughout the next quarter.

‘Every NHS patient should be cared for with compassion and dignity in a clean, safe environment... PLACE assessments (Patient Led Assessment of the Care Environment) will provide motivation for improvement by providing a clear message, directly from patients, about how the environment or services might be enhanced.’

<http://content.digital.nhs.uk/PLACE>

We’ve been supporting improvements at local hospitals since the introduction of PLACE because good environments matter to care and recovery. You can read about the changes resulting from our visits, through our post on Facebook.



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. 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 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' stories so decision-makers can learn from these and make improvements.

Contact Details

You can contact Healthwatch West Sussex:

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