

Insight & Evidence



Reporting on the experiences shared by local people in West Sussex

July - September 2018

Local people have shared **639** experiences/stories



Independent Review of children, and young people's emotional and wellbeing services announced

Primary Care



Communication & complaints remain the top concerns

Spotlight



Adult Social Care Consultations



13%

Positive



83%

Less than Positive

4% Neutral

Hot Topics

Involving local people in tricky health and care decisions

Littlehampton GP in special measures

Ear syringing – update

Planning for more integrated services



Together we speak louder
0300 012 0122

healthwatch
West Sussex

Insight & Evidence

Listening to Young People

This is one of our priority areas and to support us in working with young people in schools, clubs and the community we commissioned a local production company, who have worked with young actors to produce a series of videos. You can see the first one now on our [YouTube](#) channel. Please subscribe to see more in the series.

We were therefore delighted to learn, that across Sussex a jointly commissioned independent review of children and young people's emotional and wellbeing services and their experiences will take place.

In the recent press release the commissioners stated: "We know that staff working in health, social care, education and the voluntary sector work extremely hard to try to ensure families get the help they need. However, feedback we have received from some families and local GPs has highlighted that the current system is not working as well as it should. They are telling us that it is not always clear what support is available for children and young people, from whom, or how to access it.

All partners have collectively agreed needs this needs to rapidly change as we know how difficult and distressing it is for children, young people and families affected by mental health issues.

To find out more about this review, click [here](#).

The review should mean we have a platform to amplify the voices of young people and their families; Healthwatch will endeavour to ensure these are heard clearly by the system, to make sure that changes are what people need and want.

Touring Burgess Hill

Our team are currently touring Burgess Hill (events and activities are scheduled through to mid-November). We will be reporting at the end of the year on what local people had to say about their health, wellbeing and services.

Major transformation programme announced to improve patient care

It was recently announced that South East Coast Ambulance Service NHS Foundation Trust (SECAmb) and the 22 Clinical Commissioning Groups (CCGs) that commission ambulance care across the region have welcomed plans for a major programme of work that will improve care for patients across Kent, Surrey and Sussex and North East Hampshire.

The decision follows an independent review that looked at demand for and capacity to deliver ambulance services, which was jointly commissioned by the CCGs and SECAmb.

The review, carried out by Deloitte, looked to identify the resources required by SECAmb to meet rising emergency and urgent care demand and how best to deliver the new Ambulance Response Programme standards, which have been introduced to ensure patients get the right level of care at the right time. You can find out more [here](#).

The insight contained within this report may be influenced by how and where we have engaged with local people during the quarter.

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.

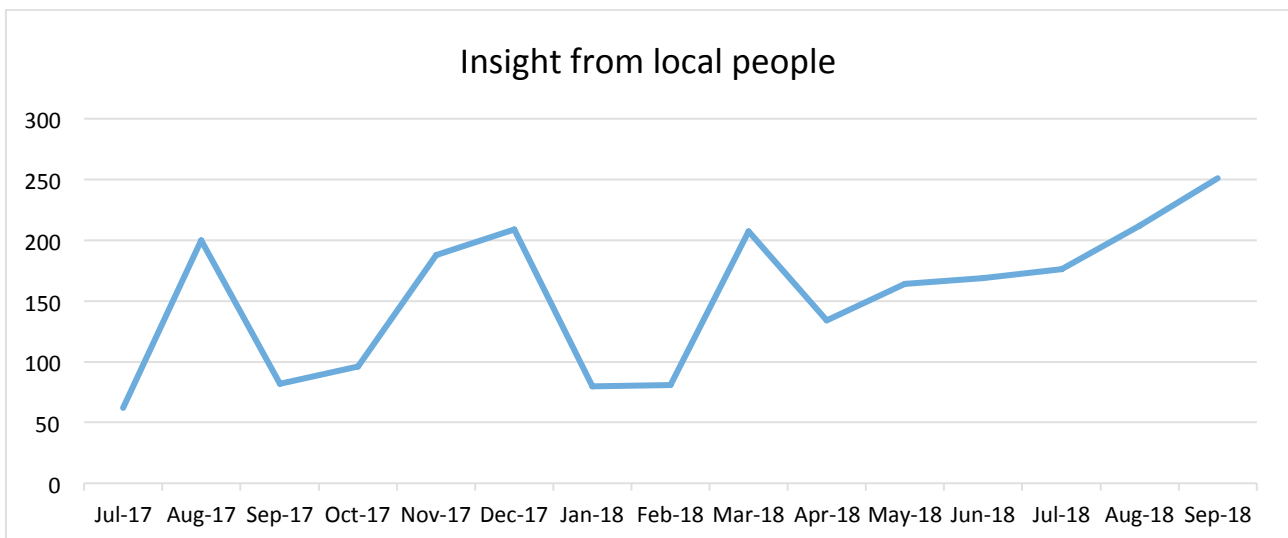
We have also created and continue to grow our *It Starts with You* network to give us regular two-way communication with local community groups and clubs.

Local people have shared
639
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 continue to hear and capture insight from more local people and this in turn means we're able to provide more evidence to support our influencing work.

The **less than positive** sentiment of peoples' experience has stayed in line with last quarter, rising from **82%** to **83%**.

How are we increasing our insight?

To ensure we provide **information and advice** and **hear from** as many people as possible, we are forming more and more community links.

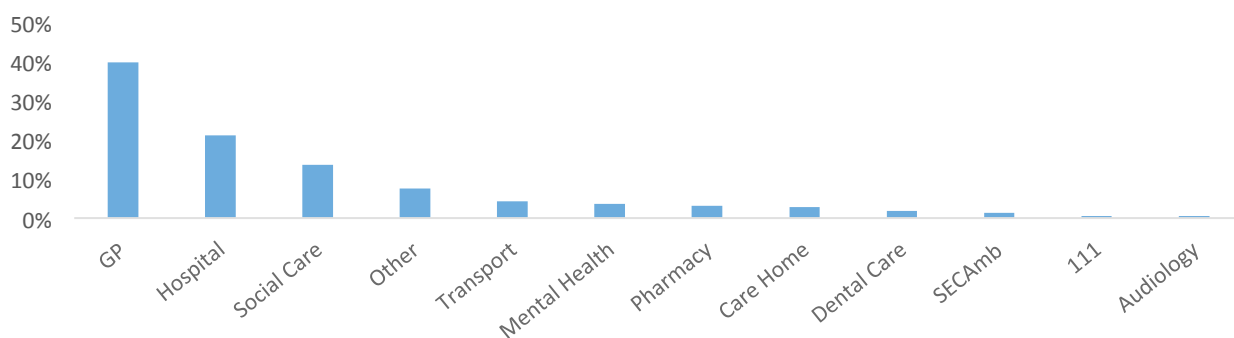
The agreed investment of our Board has meant that we are now reaching more and more working aged people, currently through promoting our services in leisure facilities, and by working directly with employers.

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. 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 picture of local peoples' insight has changed notably. Recent trends have been to hear a more even split between stories about hospitals and GPs (34% and 32% respectively, last quarter). See pages 11-12 for more details on the GP related insight.

Case studies for this quarter

Flu vaccines are available this time every year on the NHS (either through your GP practice, midwife service or pharmacy-if they offer this service) to help to protect adults and children at risk of flu and its complications. The vaccine also helps to protect frontline NHS and care staff, so services can continue to offer the support people need during the winter months.

Our pharmacy campaign; and insight from local people; reveals some issues with this year's **flu vaccine** programme. This is not surprising given the over 65 vaccine is only being produced by one manufacturer and supplies are being staggered from September to November.

If you are living with a long-term condition that leaves you vulnerable to flu and its complications; and have yet to have your vaccination, please do contact your GP **because it's still important you have this vital protection.**

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Tell us about your experience - was it easy or were there issues? Feedback on our website or call 0300 012 0122 - so we can use this to influence next year's programme.



A lesson for Hospital Trusts

Paul contacted our Independent Health Complaints Advocacy Service upset over the way he had been treated by A&E staff at Worthing Hospital. He felt he was discriminated against and ignored by staff who simply did not understand his communication needs and that they would have difficulties inserting a cannula, an issue for many people. Paul was able to explain how and why he felt the way he did to a consultant at a local resolution meeting and it was agreed that certain information would be flagged on his medical record, so in future staff would know how to treat him when he came to hospital again. Unfortunately, this didn't happen and once again Paul found himself getting very upset by the experience he had.

The team used a manual card system for alerting staff to flags on a patient record but in some cases the cards were mislaid, and staff could not see information.

Our Healthwatch Advocate was able to report the consultant apologised to Paul and through him sharing his experience, the team has been able to see their manual system was no longer appropriate. As a result, the Trust has overhauled their system and are now able to print off a record that is then clipped to the medical file. This means no more lost cards and more likelihood of staff understanding the needs of individual patients. We congratulate the Trust for learning and adapting.

We've also heard from another patient the benefit to staff, of knowing in advance that they are likely to have challenges in inserting a cannula. *"This makes our lives so much easier as we can just get the scanner to deduct the veins"*.

George is a frail elderly man. Last year he had a stroke and possibly has dementia. He is the carer for his wife who has advanced dementia. They are about to move to a care home. George has also been flagged as a vulnerable adult.

When he fell he asked his neighbour, Frank, to call an ambulance.

Frank is also elderly and a carer for his wife with dementia. So he could assist George, he had to leave his wife alone.

When the Frank called the ambulance service he found he was caught in a loop of questioning - he tried to explain the situation that he needed to get back to his wife but the operator responded with - *"just a few more questions"*. He reiterated his anxiety and the need to return to his wife but once again was told *"just a few more questions"*. After approximately 20 minutes Frank saw his wife wandering down the street. At this point, he told the operator he couldn't stay any longer, agreed to leave the house unlocked for the ambulance crew to gain access, passed the phone to George and left to help his wife.

We attend the Trust's Patient/Public Engagement Committee to discuss learning from insight and how to engage with patients and the public. This story will be discussed with them.

Commissioners are currently working with the ambulance trust and on the new specification and we will therefore make sure they are aware of this insight to make sure the new service can react more appropriately in the future.

Sepsis - life changing Stuart came into his GP surgery towards the end of last year, feeling unwell and with two large angry looking black/blue/red blisters on the sole of his foot. He explained to the clinician the blisters had increased in size considerably during the previous 12 hours and these were examined. The clinician was unsure what they were and called in a GP to get a second opinion. Neither could recognise the blisters and prescribed antibiotics, the type of antibiotic was agreed with the Lawson Unit at Brighton Hospital and should have highlighted my impaired immune system. I was sent home and told to call again if the blisters hadn't cleared up in the following two days.

Within a couple of hours of returning home from the appointment the blisters continued to get bigger and bigger, and Stuart tells us he became delirious, unable to stand and sweating profusely. The blisters eventually burst, and Stuart says *"My condition was so extreme and dramatic my partner called 999. Luckily an ambulance attended very quickly. Paramedics identified Sepsis immediately and inserted intravenous antibiotics for the infection and a liquid to stabilise the severe dehydration. The paramedics told my partner the situation was very serious and I had a 50/50 chance of survival."*

On arrival at Worthing Hospital Stuart was put into an induced Coma for a couple of days and later found out that he had spent almost a week in ICU and a few days in HDU before spending another 4 weeks in an orthopaedic ward.

During this time, he underwent 3 operations, under full anaesthetic, to try to remove the infection from his foot and was told that in the worse case scenario he could lose his foot. He went on to say, *"I was taken to the Queen Victoria Hospital in East Grinstead for a skin graft operation with skin taken from my thigh to put on my foot, under yet another anaesthetic."* Stuart left the second hospital and community nurses needed to visit him at home, twice a week to dress the graft site.

Stuart is now left with a stubborn wound on the ball of his foot within the graft area. 9 months later it is still being dressed weekly as it will not completely heal and is suffering from PTSD. The sepsis also caused other problems for Stuart including: hair loss, brittle nails, nightmares, acute kidney failure etc. Recently Stuart suffered Heart Failure and has told us: *My heart was more than likely further damaged by the Sepsis. This resulted in 8 days in hospital.*

The last 9 months have been very traumatic for me to say the least. It is not clear if a more informed reaction from the GP would have prevented the suffering. More likely a more informed and speedy reaction would have surely reduced the suffering and life changing results.

We'd like to thank Stuart for sharing his very traumatic experience.

"In the United Kingdom, there are more than 250,000 episodes of sepsis annually, with at least 44,000 people dying as a result. Sepsis claims more lives than breast, bowel and prostate cancer put together, but until recently, few had heard of it."

[Sepsis Trust, 4th edition 2018](#)

What should I do if I think someone has sepsis? Don't wait, especially if they seem to be deteriorating. If someone has one or more of the sepsis symptoms, call 999. If you're concerned about an infection, call 111. Or contact your GP and just ask: Could it be sepsis? The next page has **symptoms** and for more information on Sepsis click [here](#).

We are sharing insight and concerns with Quality Committees across West Sussex to see what can be done to reduce the risk of more people suffering like Stuart. If you have been affected by Sepsis you can find support on the [Sepsis Trust](#) website.

Don't worry, just ask if it could be sepsis

SEPSIS IS A RARE BUT SERIOUS CONDITION THAT CAN LOOK JUST LIKE FLU, GASTROENTERITIS OR A CHEST INFECTION.

SEEK MEDICAL HELP URGENTLY IF YOU DEVELOP ANY ONE OF THE FOLLOWING:

- S**LURRED SPEECH
- E**XTREME SHIVERING OR MUSCLE PAIN
- P**ASSING NO URINE (IN A DAY)
- S**EVERE BREATHLESSNESS
- "I** FEEL LIKE I MIGHT DIE"
- S**KIN MOTTLED OR DISCOLOURED

THE UK
SEPSIS
TRUST

EMAIL: INFO@SEPSISTRUST.ORG FOR MORE INFORMATION

A positive reminder for healthcare professionals:

KNOW YOUR SEPSIS SIX.

1. GIVE HIGH-FLOW OXYGEN
2. TAKE BLOOD CULTURES
3. GIVE IV ANTIBIOTICS
4. GIVE A FLUID CHALLENGE
5. MEASURE LACTATE
6. MEASURE URINE OUTPUT

BY DOING THESE SIX SIMPLE THINGS IN THE FIRST HOUR, YOU CAN DOUBLE YOUR PATIENT'S CHANCE OF SURVIVAL.

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Involving local people in tricky health and care decisions

Littlehampton GP in special measures

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Planning for more integrated services

Involving local people in tricky health and care decisions

There have been several **Big Health and Care Conversation** events across the County now and we understand local summaries from these events will be published at the end of the year and a larger report covering the events across Sussex will be published by the end of this financial year. For us, the next step is to understand how this insight will be used to inform decision-making and the need for further engagement.

We've also been working with Clinical Commissioning Groups, alongside a range of local people and organisations, to create a framework for detailing how; who and in what ways NHS commissioners will be involving local people in important conversations about health and care services. We hope to **see evidence, very soon**, of how this is being used to make sure the right patients and community groups are involved in planning for service change.

We attend various meetings to try to make sure that **decisions are not being made without involving local people and we are challenging strongly for good engagement when we become aware of planned changes** that cannot evidence how peoples' experiences and contributions have been included.

We will be expecting to see an appropriate level of public involvement evidence at the next [Health and Social Care Select Committee](#) meeting on 12 December that will consider various local authority consultations and planned service changes.

Littlehampton GP in special measures

Since we did a listening tour of [Littlehampton](#) , we've heard much feedback from local people, who want to share their experiences as patients of Fitzalan Medical Group and this has been anonymised and shared with the partners. Much of this insight reflects what the Care Quality Committee has [reported](#).

Insight

It is now critical the practice's leadership focus on improving services, and we intend to

GPs stop routinely doing ear irrigation (ear wax removal) - UPDATE

Thank you to everyone who has taken the time to share their experiences relating to this issue. Your feedback has helped us to be very clear on how, the decision by many of the GP practices in West Sussex, has impacted on peoples' lives.

We continue to push commissioners for a more appropriate system and we are told the scope of the service has been agreed and a business plan still needs to be put forward and agreed, before an appropriate service can be bought.

We remain concerned by the lack of efficiency in resolving the confusion and issues people face now, and worryingly, we are hearing how people are resorting to self-syringing, or other damaging practices.

In the meantime, we are working with the commissioners to be able to put out answers to frequently asked questions, to help people to understand how to help themselves, and how to get support when they need it.

Case Study

Planning for more integrated services

Urinary incontinence is the unintentional passing of urine. **It's a common problem** thought to affect millions of people.

Through our recent engagement we are hearing that some people are struggling to get information, advice and support, to help with their incontinence. This has led us to look at this more closely and this is what we've discovered:

- A **lack of signposting on where to buy continence products**, for people waiting to get seen by the incontinence service, which could be months of waiting
- **No easy process for arranging for the disposal of used products**
- Confusion from differing information from NHS, District and Borough and County disposal
- National information is not easy to find or follow
- The NHS and local authorities may be paying for the same service and therefore duplicating public spending
- People want to do the right thing and dispose of the products correctly, but obstacles are placed in their way

Our **case study** shows the opportunity for a more integrated approach to local issues and includes a range of recommendations to focus on.



Adult Social Care

The Care Act 2014 guidance states the core **purpose of adult care and support is to help people to achieve the outcomes that matter to them in their life**...The Care Act signified a shift for local authorities from providing particular services, to the concept of 'meeting needs'.

West Sussex residents are being asked to complete surveys on a number of services that may affect people in need of adult social care, these are:

- [Housing Support Services Consultation](#) closes on 3 December 2018.

The Council commissions a range of housing related support services through contracts with voluntary sector organisations. The services involved include specialist accommodation-based schemes for residents who are at risk of homelessness as well as 'floating support' to residents living in community settings rather than a supported housing scheme. Funding to support these services used to be provided to the County Council via a ring-fenced government grant as part of the Supporting People programme. This was removed in 2011, since when the County Council has continued to fund services from its base budget.

In view of the discretionary nature of many of the services involved it is proposed that consideration be given to whether these services are sustainable and so the Cabinet Member has approved a process which could lead to the termination of any of the current housing support contracts with providers from April 2019 onwards.

- [Minimum Income Guarantee for working aged adults](#) closes on 3 December 2018

People who receive council-funded social care support in the community are financially assessed to decide how much they need to pay towards the cost of their care. This is called their 'contribution'. The Council must ensure people have an amount of money to cover their day-to-day living costs. This amount is known as the *Minimum Income Guarantee*. People's contribution towards the cost of their care cannot reduce their income to below the guaranteed level.

Historically, the Council has applied the Minimum Income Guarantee at the Government-set minimum for older people, but has allowed a more generous level for adults of working age.

The proposal is that the Minimum Income Guarantee for working age adults in West Sussex is brought in line with the nationally set minimum amount as already applied to older people in West Sussex.

This is equivalent to income support plus 25%. For example, if income support is £100 then an additional £25 will be allowed, making a total of £125 before a contribution is charged.

We have raised concerns around the assessment process within West Sussex in a recent **report** and have still to be satisfied that the recommendations in this are being realised. It is important that this is a fair process before implementing any changes.

- [Local Assistance Network Consultation](#) closes on 3 December 2018

The Local Assistance Network (LAN) has existed since 2013 and replaced several discretionary benefits for households in crisis situations, which had previously been available through the benefits system. A ring-fenced grant to support this spending was originally provided by Department of Work and Pensions but this was removed in 2015. The LAN budget is currently £800,000 per annum.

The Cabinet Member agreed to consider the further reduction of Local Assistance Network (LAN) funding to £200,000 per annum from April 2019.

All three of these areas will be discussed by the Health and Social Care Select Committee at their public meeting on 12 December 2018. Our Chair, Frances Russell, sits on this committee to make sure that insight shared with us that relates to topics being scrutinised, is given a voice.

West Sussex County Council is currently developing a new Bus Strategy, which will consider our approach to and investment in bus services.

This follows on from a recent [Bus Strategy Consultation](#), and the County Council would now like to know more about how people use the supported bus routes across the county.

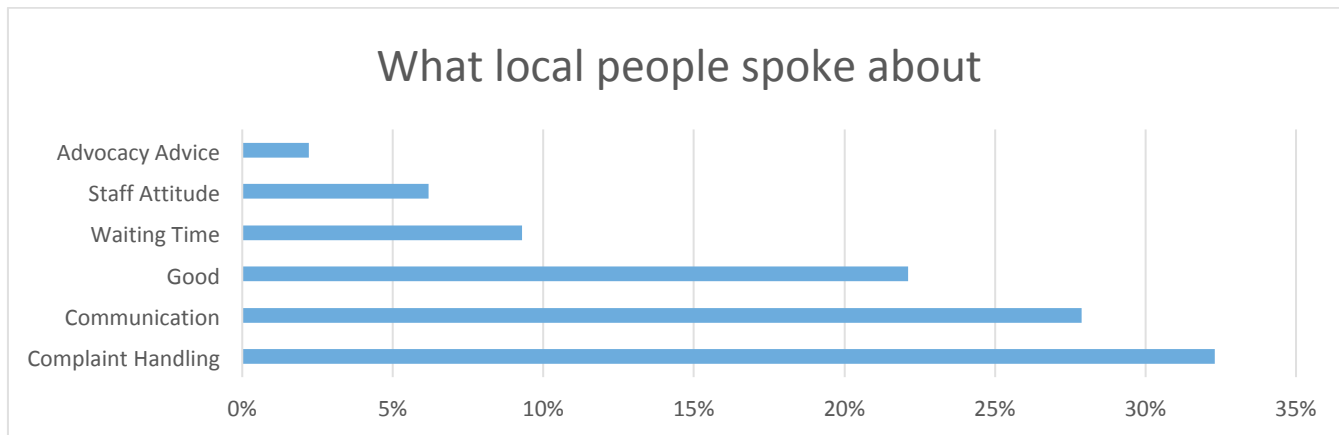
If you support someone who uses buses to get to health appointments; leisure activities, or simply the shops, then take a look at the current [bus survey](#) which closed on 18 November 2018.



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.

Here is what people have shared about their experiences this quarter (good and bad):



What does this tell us?

Good comments have increased considerably, against last quarter (which was only about 13%) but are still lower than we'd hope for, given we ask people to share good and bad experiences.

The top two issues remain at a similar level to last quarter.

What are we doing to improve this?

Our priority over the next two months' is to work with the Fitzalan Medical Group team to support them to see the opportunities and advantages of listening to peoples' lived experiences to support them to address their special measures.

We'll be drawing on some of our plans for looking at access to GP appointments and what works well for patients and their family and friend carers.

Improved GP Access to appointments has arrived - extra evening and weekend GP appointments now available

Every patient registered with a West Sussex GP practice can now access evening and weekend GP appointments through primary care hubs in local areas. These GP hubs offer both routine and urgent appointments which can be booked through the patient's own GP practice in the normal way, during normal opening hours.

Clinical Chairs at the Clinical Commissioning Group have said: "We have designed this new GP service in partnership with local people. You told us that having access to a GP in the evenings and weekends - particularly on a Saturday was important to you."

Complaints handling

Pamela called after experiencing a problem at her surgery (in Crawley). She went to an appointment (over Summer) which ran 40 minutes late. She tells us that *“As the GP was courteous and very helpful she decided not to share any negative feedback about the waiting times with the practice manager. When I needed another appointment, I thought that the GP may run late again so booked the first appointment of the day”*.

Despite this, Pamela reports she was still left waiting so went to the reception desk to find out what the problem was. The receptionist suggested the GP was in the office but he hadn't yet arrived. She spoke to the practice manager who was not sympathetic and was aggressive in tone. When Pamela said she wanted to make a complaint the practice manager allegedly said, *‘that’s fine complaints go through me anyway’*. Pamela said she recorded the conversation as she was shocked at the way in which she was spoken.

She has informed the surgery that she has a recording and they have sent correspondence back and forth, but she is unhappy with the response. She would like a meeting to discuss the incident and would like advocacy support to act as a neutral representative.

We often get email correspondents that are from people who are complaining to their GP practice about their experiences. We put this down to the fact that often our email is the only email shown on a practice website and therefore people are automatically using this.

Others like Pamela come to us because they need support to get their voice heard.

Getting information right

Zoe told us: My five children have got worms so I called the doctors to get a prescription. I was told to go and buy some stuff from the chemist, so I went to the chemist and was told that I can't buy it as 2 of my 5 children are 2 and under. The Pharmacist called the surgery and asked them to help me and that I shouldn't have to pay anyway as they are all under 16 and are entitled to free prescription. I called back the surgery to be told by the practice manager I had no idea what I was talking about and they had no interest in what I had to say where [the practice manager] turned very rude and told me that I had to buy my children's medication as the laws and guideline had changed 2 weeks ago (mid August) and that now they're not obligated to give out free prescriptions if I can buy it over the counter. I have spoken to several people in this industry and all have said that under 16 are entitled to free health care and prescription. The chemist were just as baffled as myself as to why I can't get my children the medication they need.

Zoe shared how she feels totally let down by the GP surgery and doesn't believe this is an isolated case.

Healthwatch notes there is new NHS guidance out but has raised concern with Coastal Clinical Commissioning Group (CCG) over the communication of this to this patient, and between two parts of the NHS. The CCG acknowledge that from a practice perspective, it feels like they have not realised that Over the Counter (OTC) medications have a different license to a prescribed medication. In this circumstance you could prescribe the worming treatment for a child under two but you can't buy it OTC so if it is clinically needed it should have been prescribed.

We have recommended that immediate action is taken to ensure practices are giving the right information to patients and their family/friend carers, to avoid people receiving advice from practices that contradicts that of NHS England.



Young Peoples' Mental Health and Wellbeing

For us this means working with young people and their families to understand what helps them to be mentally well, and what challenges they face when this is not the case.

Page 1 details the news of an independent review to look at emotional and wellbeing services across Sussex. Our engagement plans will help in making sure local young people contribute to this review.

Currently we are finalising the engagement resources we will use to spark conversations within classes. We are keen to work with young people to help us improve on these, so we can have meaningful conversations, so we can understand the issues; gaps and challenges from their point of view.

On Thursday 8th October, we premiered our Youth Engagement films at the *Dome Cinema in Worthing*. We've been working with young actors from Tori Productions to create a series of four episodes that celebrates 70 Years of the NHS and highlights key medical breakthroughs. The films will encourage young people to start thinking and talking about the future of the NHS.

Young actors from the films attended the launch, along with friends, family members and members of the public. VIP guests, including Councillor Hazel Thorpe, Deputy Mayor of Worthing and her Consort, Robin Rogers, Katie Waters, Youth Mayor of Worthing and Jimi Taylor, Deputy Youth Mayor of Worthing, Vicky Smart from Coastal West Sussex CCG and Miss Molly from Miss Molly's Milkshakes in Worthing also attended.



Katie Waters, Youth Mayor said

When I hear 'youth engagement' lots of things spring to mind but nothing quite like this, you have far surpassed my expectations and I am very impressed with what you have achieved.

The episodes will be available to watch online on [YouTube](#) , via Healthwatch West Sussex's channel.

Acting on your views/experience of health and social care

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 continue to make sure we use every opportunity to amplify what local people and communities tell us about their health and care experiences.

Anonymised personal accounts are used by our staff and authorised representatives to show good practice to support local leaders and health professionals to provide good and safe services, and to challenge them where necessary.

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



We here to help you on the next step of your health and social care journey - wherever it is taking you.

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.

Healthwatch West Sussex works with Help & Care to provide its statutory activities.

The logo for 'healthwatch West Sussex' features the word 'healthwatch' in white with a green comma-like symbol after 'watch', and 'West Sussex' in white below it, all on a dark teal background.

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