

On equal terms

Then and now

Healthwatch West Sussex Annual Report 2020-21



Contents

Message from our Chair	1
About us	2
Highlights from our year	3
Theme one: Then and now	4
Theme two: Then and now	6
Responding to COVID-19	8
Working with Healthwatch England for integrated innovation	13
Volunteers	15
Finances	17
Next steps & thank you	18
Statutory statement	19

Message from our Chair

Following the Prime Minister's national directive our face-to-face engagement ceased in March 2020, and we moved rapidly to a new and flexible plan. We refocused our immediate priority on COVID-19 and any hot topics arising from peoples' issues and experiences.

Adapting and working with others:

Previous technology and community partnerships investment made it possible for us to swiftly adapt to remote working with other community and voluntary organisations so we understood peoples' health and wellbeing needs in real time.

One example was our working with the Local Maternity Partnerships when pregnant women were struggling to get to post-natal appointments and scans. The outcome was free patient transport for those affected. Similarly, after hearing women express anxiety and confusion about when birthing partners could be with them, we were able to secure and promote clearer information.



Thank you for bringing this to our attention. We need to ensure we have the right communication going out and it looks like we need some additional communication.

Sean, Sussex Maternity System Lead

We also continued to work on priorities not related to the pandemic: An example being what we heard from people suggesting long delays in the adult neurological services. People who were referred for an Autism Assessment shared their experiences that they were unable to get access to the support they needed suggesting that autistic adults were falling through the gaps without the right support in the community.

We've since worked with community partners, and autistic people to fully understand lived experiences and this is helping shape a new Sussex Autism and Learning Disability Strategic Health Plan, which will underpin the transformation of support for West Sussex residents living with a learning disability and/or autism.

We take every opportunity to influence positive change. Martin, one of our Board Directors has spoken with senior leaders about our concern over the autism gap and from April 2021 there should be additional resources and changes to support better health and lived outcomes for those living with autism. We will continue with these and many other challenging but supportive conversations to make sure the changes are right to meet needs.



Steve Cooper, Chair from April 2021

Clue Cooper

About us

Here to make health and care better

We, Healthwatch West Sussex are the independent champion for people who use health and social care services in the county. We are here to understand what matters to local people, to help make sure their views are heard and shared with those who have the power to make change happen.

Helping you to find the information you need

We help people find the information they need about services in their area. This has been vital during the pandemic with the ever-changing environment and restrictions limiting people's access to health and social care services.

Our goals



Supporting you to have your say

We want more people to get the information they need to take control of their health and care, make informed decisions and shaping the services that support them.



Providing a high quality service

We want everyone who shares an experience or seeks advice from us to get a high quality service and to understand the difference their insight made.



Ensuring your views help improve health and social care

We want more services to use your experiences and views to shape the health and care support you need today and in the future.



"Local Healthwatch have done fantastic work throughout the country during the COVID-19 pandemic, but there is more work ahead to ensure that everyone's views are heard. COVID-19 has highlighted inequalities and to tackle these unfair health differences we will need those in power to listen, to hear the experiences of those facing inequality and understand the steps that could improve people's lives."

Sir Robert Francis QC, Chair of Healthwatch England

Highlights from our year

Find out about our resources and how we have engaged and supported people in 2020-21.

Reaching out



We heard from

17,379 people

about their experiences of health and social care.

We provided advice and information to

3,000+ people

Responding to the pandemic



We engaged with and supported

2,700+ people

during the COVID-19 pandemic

Making a difference to care



We published

130 reports

about the improvements people would like to see to health and social care services. From this, we escalated 62 concerns (some small and other effecting many) and made over 30 recommendations for improvement.

85% of recommendations

we made last year have been acted upon, at the point where we reviewed progress.

Ensuring Health and Social care that works for



90 volunteers

helped us to carry out our work. In total, they contributed over 2,400 hours. With many more people offering input and support.

9 staff

equivalent to 6 full time people with the team working voluntarily over and above their hours during the year because of the public demand.

£315,889 in funding

Received from our local authority in 2020-21

£114,275 in-kind value

From the work of our volunteers and independent board. As a not-for-profit Community Interest Company, all of the income from our social enterprise work is also reinvested in projects for West Sussex.



Theme one: Then and now **Dentistry**



Thanks to people across West Sussex sharing their experiences of dentistry we were able to help commissioners adapt to sudden changes in need and ensure patients had access to simple, clear information about their treatment.

Prior to the pandemic increasingly people told us they couldn't get an appointment within a reasonable time frame, particularly in specific parts of our county.

We found that the quality of information on dentists' websites was out of date. Nationally, Healthwatch England undertook a programme of work in partnership with local Healthwatch to get the NHS website up to date and to support dentists to keep their information up to date. In January 2020 this programme of work lead to the Department of Health and Social Care making it a mandatory part of the contract for dentists to keep the NHS website up to date and check it on a monthly basis. This will substantially improve the information available to patients trying to find a dentist.

It was also identified that some part of our society were missing out on NHS dental care. In particular, people living in care homes. Healthwatch England convinced the Care Quality Commission to investigate in 2018. As a result, they published the 'Smiling matters' report in 2019, which led to a range of immediate changes, including training for care home staff on oral care, and providing free toothbrushes and toothpaste.



Now: ongoing dentistry issues

Thanks to people sharing their experience of dental concerns during the pandemic, we pushed for a Sussex and national focus on dentistry. This has led to a campaign to ensure that the issue of dentistry is right at the top of the worry list for NHS England. Making this issue a political and policy priority has been essential to ensuring the issues continue to be addressed.

Between June – October 2020 over 140 people shared their experience of dentistry with us, over 6 x higher compared to the previous five months. Many more people shared issues on social media about dental care issues throughout this time.

The main issues included:

- Difficulties in booking emergency and routine care appointments.
- Priority being given to private patients.
- Inaccurate, out of date and confusing information about availability of treatment.

People told us that when they were unable to access a dentist, they experienced anxiety, worsening problems requiring further treatment, pain and fear and inconvenience. Some people even told us about their experiences where lack of access to care pushed them to take steps which put their own health and wellbeing at risk.

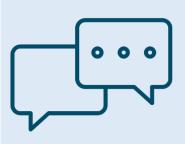


'Thank you for the advice, it's helped me to find the strength to continue to seek treatment and find a dentist (after 15 calls) that is willing to send an application for treatment, which is likely to be in August.'

West Sussex Resident (June 2020)

The lack of accurate (or in some cases any) information we found when we looked at local dentists' websites was raised with the Local Dental Committee early in the pandemic and we've worked together to get a checklist out to help local practices. This has been shared across the region to support other areas.

In the face of the ongoing pandemic we called on the local commissioners to make more resource available to the dental sector to help them clear the backlog and have had limited success (with two, reducing to one practice offering additional hours). Nationally, more availability is be championed and Healthwatch England has also asked the Government and the NHS to review the cost of NHS dental treatments, as in the current global climate the reality is a lot of people have lost their jobs and have less money, but we believe everyone should be able to access the dental treatment they need.



Share your views with us

If you have a query about a health and social care service, or need help with where you can go to access further support, get in touch. Don't struggle alone. Healthwatch is here for you.



www.healthwatchwestsussex.co.uk



0300 012 0122



helpdesk@healthwatchwestsussex.co.uk



Theme two: Then and now **Getting mental health care right**



For people, whose mental health has deteriorated so much that they need to spend time in hospital, it is vital to create a safe and comfortable space for them to recover to be able to return home.

At the end of 2014, we needed to speak up for people who were inpatients at Langley Green Hospital (one of the County's mental health hospitals) because we were concerned over what we had seen and heard from patients. We have revisited the hospital a number of times since and found much had improved.

Since then, the Care Quality Commission has reported on non-compliance with single-sex wards. We were asked to comment on a proposal document, readied for public consultation on the reconfiguring mental health beds in West Sussex and in Autumn 2018, we raised concern over the authenticity of a consultation that offered only one option as a solution and sought to create a more robust and meaningful engagement process.

After delaying the consultation to make sure people had the chance to express their views more fully, we took part in the public events and were part of the group that reviewed the findings.



Now: revised plans for mental health hospital stavs

From our involvement it is clear that both patients and staff find it beneficial to have communal space for all to come together, rather than same-sex wards only. Furthermore, the scarcity of appropriate hospital beds across England, means many people find themselves in hospitals far away from their family, friends and local community and failing to meet the travel and communication needs that are vitally important so people can stay connected.

The arrival of the pandemic delayed the publication and progress of the redesign of West Sussex mental health services, and has placed even more pressure on resources to support people living with declining mental health and those who face a mental crisis.



Understanding what patients have said as to why shared space works is important on a number of levels.'

Katrina, Locality Manager for Healthwatch West Sussex

In early 2021, Sussex Partnership NHS Foundation Trust, responsible for mental health services in Sussex, presented their proposal for changing in-patient provision across West Sussex, to the West Sussex Health and Adult Social Care Scrutiny Committee responsible for reviewing health decisions. The Trust's revised business case demonstrated how peoples' concerns had been heard and contributed to the subsequent proposal for change.

As a result, the Committee recommended that the Trust look at extra resources in and around Chichester, in the meantime the development of a centre of excellence moves forward.

Furthermore, the Senior Lead for improvement mental health in Sussex, recognised our continued challenge around the need to consider transportation and the ease with which patients' families and friends can stay in touch; we are calling for the routine 'booking in' hospital process to include travel and communication.

Access to updates on the wellbeing of patients, and limited communication with patients in hospitals has been a feature for many families during the pandemic, and evidence shows this type of disconnection hampers recovery.

Effective engagement and consultation is key to getting services right for people and for building trust and confidence in the NHS.



To find out more > > >

Visit the West Sussex Health and Scrutiny Committee page



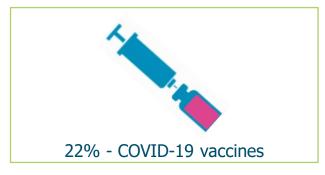
Responding to COVID-19

Healthwatch plays an important role in helping people to get the information they need about health and social care. That role has proved especially key through the pandemic. The insight we gather from people is shared nationally, with Healthwatch England, and locally with partners to ensure services are operating as effectively as possible during the pandemic. Information shared is anonymous and used to highlight themes.

This year we supported over 750,000 times by:

- Providing up to date, local advice on the COVID-19 response
- Linking people to reliable up-to-date information
- Supporting the COVID-19 vaccine programme roll-out
- Providing a safe space for people to talk though the impact of paused cancer services and separations from loved ones in care homes
- Helping people access the health and social care services they need.

Top four areas that people have contacted us about:









Improving communication on B12 deficiency treatment



Early in the pandemic, we heard repeatedly from people who were having trouble getting the vitamin B12 injections they needed. In all, 80 people shared their experience. We focused on supporting GPs to provide people with clear, consistent and appropriate advice and information. Refreshed guidance was given to GPs and we shared this information in our FAOs articles on our website to help address people's concerns.

We also supported a local GP practice to reflect on their work undertaken to review patients B12 treatment needs and who can safely be moved to oral medication during the pandemic, as this was not communicated well in their own information.



Contact us to get the information you need

If you have a guery about a health and social care service, or need help with where you can go to access further support, get in touch. Don't struggle alone. Healthwatch is here for you.



www.healthwatchwestsussex.co.uk



0300 012 0122



helpdesk@healthwatchwestsussex.co.uk

Responding to COVID-19 by enabling community voices to be heard

We have documented our communities' experiences of the pandemic. We have recorded the compassion, dedication, innovation, partnership and **strong leadership** within communities and lodged these as historical evidence with the West Sussex Records Office.

At the time of the first lockdown, we were hearing how proactively many of our community and voluntary organisations were responding to support residents. We partnered with Arun and Chichester Voluntary Action, Horsham Voluntary Sector Support, Mid Sussex Voluntary Action, and Sussex Community Foundation, captured information through a survey, undertook semi-structured phone and online conversations, which were developed into case studies and a number of reports.

Together, we looked at how voluntary organisations and community groups responded, current working, financial implications, and future planning during the first and second lockdowns of the COVID-19 pandemic.

Although organisations and groups had to stop delivering their support in their usual way, they continued to support staff, volunteers and local people. The voluntary and community organisations responded and adapted with speed and efficiency, redeploying resources and moving swiftly to remote working and support.



Poster for the International Social Prescribing Conference, March 2021



They are the unsung heroes of the COVID-19 crisis along with the many thousands of local people who have supported their communities.

Community and Voluntary Support organisation, in Mid Sussex

With health and care services emerging out of pandemic restrictions and moving to restoring services and looking at the need to level-up society by removing the barriers to health inclusion, there are significant learning points from this work. The voluntary and community sector needs to be supported to selfpromote. There is a need to be acknowledged as an asset to the wider health and care provision and be funded to continue to operate. Without the sustainability of this sector, it will be inevitable that demand will impact on statutory health and care services adversely, to a point of crisis.

Such organisations have supported many NHS and public health projects and messages. They are vital as champions of what is happening within communities. Without the sustainability of this sector, it is inevitable that there will be an adverse impact on demand for statutory services.



'Easy access to grants and investing in support through voluntary and community partners is urgently needed to meet the suppressed demands that are starting to be felt across the NHS, so that further new ways of working and technology can be realised."

Cheryl, Strategy Community Partnership Lead for Healthwatch West Sussex

Best Interest Decision Making Toolkit

Our toolkit for supporting health and care professionals working with people who have cognitive impairment, is designed to achieve better outcomes and to support professionals in secure decision-making.

Our Healthwatch West Sussex developed toolkit is now part of the NICE guidance (national Institute for Health and Care Excellence), having been quality assured for inclusion in their shared learning collection as a supporting resource.





'It will make a real difference to the lives of many vulnerable people, and to the health and care professionals supporting them.'

Irene Sobowale, CEO, The Disabilities Trust

Supporting people to have their health concerns understood during the pandemic

Over the year, complaints handling has changed with investigations and follow-up actions often having to be suspended as staff were redeployed to fight the pandemic. In the early stages of lockdown, our Independent Health Complaints Advocacy Service team proactively reviewed our service information and processes. We looked at our resources against the draft complaints framework, created by NHS England, so our documents were ready and aligned to the new way of working.

Towards the end of the year, we saw increasing demand for health complaints advocacy. If this trend continues at the current referral rate we will exceed our resources. We are looking at this closely and will be talking to commissioners early, to make sure people are not denied support to have their voice heard and complaints addressed as this often also results in valuable learning for the health and social care systems.

Both complexity and

In August, we published An Annual Reflection for the Service for 2019-2020 with Independent Health Complaints Advocacy Service case studies and learning.

help information to reflect changes to local resolution meetings which have moved to being held virtually.

Added to our self-

- number of cases has intensified. Cases often involve multiple agencies, safeguarding or serious incidents.
- Valuable Lessons: For example, our support meant a resident's mental health care complaint resulted in six recommendations to improve services.

Before the pandemic, commissioners recognised the need for a Clinical Harm Review to look into emerging concerns about an Any Qualified Provider contract for Non-Obstetric Ultrasounds, where potential harm to a number of people had taken place. We agreed to be part of the panel overseeing the review which has continued during the pandemic, to support the NHS in better understanding things from a patient's viewpoint. The learning from this work is even more relevant as the NHS starts to recover from the impact of the pandemic.

'Healthwatch's participation in this review was important, as this was looking how to identify people at risk because of issues with a provider. We were able to add value by raising non-clinical considerations, through our in depth knowledge of supporting people to have their voice heard and to help the NHS learn lessons."

Katie, Senior Independent Health Complaints Advocate for Healthwatch West Sussex



Working with Healthwatch England for integrated innovation

It is essential to determine how well specific people's health and social care needs are met. Healthwatch West Sussex are privileged to be one of five local Healthwatch nationally funded to develop a toolkit to do this.

We used set health and care experience profiles and were asked to look at the needs of:

- Children and young people with mental health support needs who are becoming adults
- Black men with a number of health needs including a recent experience of cancer.

We were able to reflect on national and local expectations, research, guidance and good practice, before approaching people to explore with them their own experiences against this context.



'This work has produced some powerful insight, and we recognise these profiles are ones that need focused attention. We can see a lot of resources are being invested in these areas, but sitting independently, it can be hard to see where progress is being felt on the ground. This work has stimulated our thinking and we are giving more thought to how we work with health and care services to show people the changes being made and how we evaluate the difference this has made.'

Katrina, Locality Manager for Healthwatch West Sussex

The Integration Index: taking a different approach to developing health and social care

The NHS in England wants to provide people with the best care possible. To do this it is important that all services, like hospitals, GP surgeries, community services and mental health services, work well together.

Often the NHS needs to think about how other public services can be included, like housing, benefits, transport, education and community organisations. All these things are vital in supporting people's wellbeing as well as their health.

For the people receiving care it should feel like they are being supported by one big joined up team which is concentrating on them.

The NHS has been thinking about this issue for some time, and important changes have been made already. But to know if this is working, they need to hear from people about their experiences. This is what the 'Integration Index' is all about. The use of health and social care experience profiles is one of the methods that have been developed to help the NHS understand why some things are not working.

Our example from working with young people

Focus Group events were advertised through social media (Instagram, Facebook and Twitter) and at Chichester College. The groups were kept small and run by a youth support organisation. The young peoples' contribution to this work was rewarded through acknowledging their voice in our report and with a £25 gift voucher.

The first event took place in February and another with College students in April.



What people told us

Professionals need to understand how low self-esteem effects people and adapt, otherwise mental health needs go unaddressed.

Recognising health literacy and offering time/information to help with understanding support. Along with the importance of support in educational settings, where many spend much of their time.

Starting over again and again, and retelling negative stories works for the 'system' but is harmful to the young people.

Young people have supported us both to understand issues and to inspire change. Our report showcases the ideas and innovations produced in these groups. These ideas work towards overcoming the issues young people have raised and now need the attention from those who can make them happen.



Volunteers

At Healthwatch West Sussex we are supported by over 40 formal volunteers but many more people volunteered their support and time (over 90 in total). All provide input to help us find out what people think is working, and what improvements people would like to make to services.

This year our volunteers:

- Helped people have their say from home, carrying out surveys over the telephone and online.
- Created engagement activities and helped shape our work and thinking.
- Carried out website reviews for local services on the information they provide, which immediately improved the information available to patients in many geographic parts of our county.
- Helped with the local volunteering efforts of shopping and collecting prescriptions for those selfisolating or shielding.

Together they added over 2,400 hours of valuable support to the work of Healthwatch in West Sussex.

Our #ConfusingComms campaign is running because people tell us the way the NHS communicates with is sometimes confusing. If you want to join Elsie and advise us on how the communication can be improved, please contact us now.



#ConfusingComms Advisor - Elsie, 18

'During lockdown, I decided I'd like to do something beyond college work. I know Healthwatch well and wanted to see if I could volunteer. As part of my role, I've been supporting the team by sense-checking what they are working on or what the NHS has produced. I can offer my view and opinions and those of my peers. I know this is valued and listened to. It has been such an interesting and rewarding experience, helping the team gather experiences of care from an age group they need to continue to hear from.'



Volunteer - Patrick

"I have been supporting Healthwatch for the last three years. A key part of my volunteering is to liaise with one of the Trusts in our county, feeding back the issues discussed at committee meetings and to raise the patient voice. With my digital skills I've also been able to audit service websites, which have led to the creation of the dental website checklist. I'm also able to share insight and my views during the regular Zoom volunteer meetings, which shape the team's priority project work. "



Volunteer with us

Are you feeling inspired? We are always on the lookout for new volunteers. If you are interested in volunteering, please get in touch at Healthwatch West Sussex.



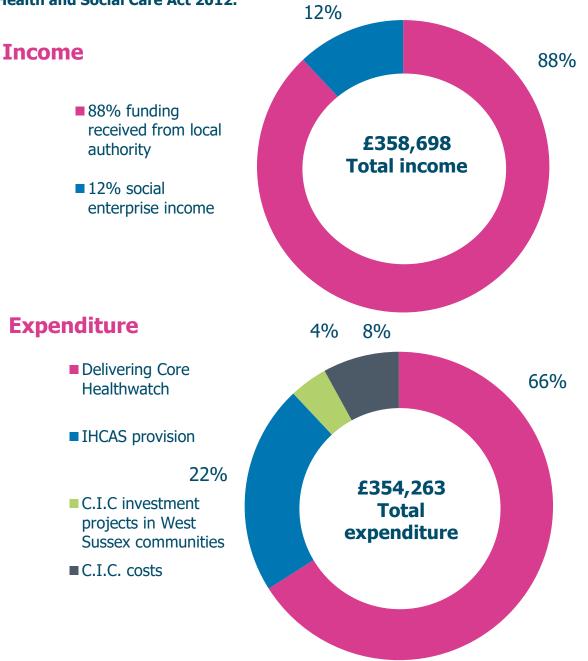
www.healthwatchwestsussex.co.uk 0300 012 0122



helpdesk@healthwatchwestsussex.co.uk

Finances

To help us carry out our work we receive funding from our local authority under the Health and Social Care Act 2012.



One of the lowest funded Healthwatch in the country per head of population.

Innovative in seeking additional funding and reinvesting Social Enterprise income

We seek to support everyone but demand exceeds our resources so we are raising concerns now.

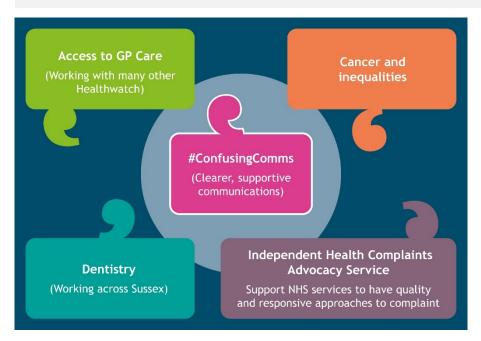
£1 of Local Authority funding: £1.48 Healthwatch West Sussex C.I.C. spending, investment and in-kind volunteering

Future priorities



Tackling unfair health differences will need those in power to listen. To hear the experiences of those facing inequality and really understand the steps that could improve people's lives, and then to act on what has been learned.

Martin Phillips, Independent Non-Executive Director for Healthwatch West Sussex



Our priorities will help commissioners and services identify the bumps and barriers in care to best support West Sussex residents to access the right support at the right time.

Alongside these priorities we need to follow up on this year's work with autistic people, those with sensory impairment, and in care homes.

We are committed to equality and diversity, and to hearing from seldom heard communities. We recognise we can do this best when we work alongside others. We will continue to work collaboratively and in partnership with others to hear from people who use services and those that cannot get access

Thanks



Our team are incredibly grateful for the support we have had over the past 12 months from local people, our community partners and health and social care leaders. One of the positives to build on from the pandemic is greater access to key stakeholders and this has helped us in our statutory role to influence decision-making. We hope people will continue to work with and truly recognise the merits of collaboration, co-production and seeing things from a patient/public viewpoint.

Sally Dartnell, Chief Officer for Healthwatch West Sussex



Statutory statements

About us

Healthwatch West Sussex CIC is a community interest company Limited by Guarantee. Registered Company Number 08557570.

Healthwatch West Sussex uses the Healthwatch Trademark when undertaking our statutory activities as covered by the licence agreement with Healthwatch England.

Healthwatch West Sussex works with Help & Care to provide its statutory activities - 19 Southbourne Grove, Bournemouth, BH6 3QS.



The way we work

Involvement of volunteers and lay people in our governance and decision-making.

Our Healthwatch board consists of eight members who work on a voluntary basis to provide direction, oversight and scrutiny to our activities, with two Executive members. Our board ensures that decisions about priority areas of work reflect the concerns and interests of our diverse local community. Through 2020/21 the board met eight times and made decisions on matters such as refocusing resources to support people through the pandemic and to raise concern for the future of day services without appropriate involvement and consideration for impact of lockdowns and changing needs to local political and health and social care system leaders.

We ensure wider public involvement in deciding our work priorities. We do this by reviewing the past insight from information and signposting enquiries, and what we have understood from attending public forums, committees and workstream meetings.

Methods and systems used across the year's work to obtain people's views and experience.

We use a wide range of approaches to ensure that as many people as possible have the opportunity to provide us with insight about their experience of health and care services. During 2020/21 we have been available by phone, by email, provided a webform on our website, attended virtual meetings of community groups and forums, provided our own virtual activities and engaged with the public through social media (with a Facebook, Twitter and Instagram presence).

We have also promoted these widely through partners and local village/town and area magazines.

We are committed to taking additional steps to ensure we obtain the views of people from diverse backgrounds who are often not heard by health and care decision makers. This year we have done this by, for example, working with community leaders and specific voluntary and community groups (who have benefited from having a *spotlight* on them.)

We ensure that this annual report is made available to as many members of the public and partner organisations as possible. We publish it widely and will be presenting this at the June 2021 Health and Wellbeing Board.

2020-21 priorities

Project / activity area	Changes made to services	
COVID-19 Response	We have raised a large amount of issues to health and care leaders, many of wish have been actioned. We have, through weekly engagement with the vaccine programme have raised issues and these have led to better communication and improvement in the delivery of vaccines.	
Young Peoples mental health	Healthwatch West Sussex represent all three local Healthwatch in Sussex on the Foundation for Our Future Oversight Board and continue to challenge the development on the independent review recommendations	

Responses to recommendations and requests

All providers respond to requests for information or recommendations.

This year, due to the COVID-19 pandemic, we were unable to make use of our *Enter and View* powers. Consequently, no recommendations or other actions resulted from this area of activity.

We escalated access to dental care to Healthwatch England who have responded reporting the crisis within dentistry and continue to call for action.

Health and Wellbeing Board and scrutiny

Healthwatch West Sussex is represented on the West Sussex Health and Wellbeing Board by Sally Dartnell, Chief Officer. Katrina Broadhill, Locality Manager sits on the Health and Adult Social Care Scrutiny Committee.

During 2020/21 our representatives have effectively carried these roles by taking part in virtual workshops and meetings and promoting the need for appropriate public information on the Board activities and a pandemic task and finish review.



Healthwatch West Sussex CIC PO Box 1360 Crawley RH10 0QS

Please note our staff and volunteers work from home and in the community, as this offers us the flexibility to cover such a large County.

www.healthwatchwestsussex.co.uk

t: 0300 012 0122

e: helpdesk@healthwatchwestsussex.co.uk

- @healthwatchws
- f @healthwatchwestsussex
- @healthwatchws
- in Healthwatch West Sussex