

# Burgess Hill Listening Tour

Throughout October and November 2018



it starts with

**YOU**

**healthwatch**  
West Sussex



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# Executive Summary

## Thank you

A huge thank you to all the people who took time out to talk to us and a special thanks to you if you shared your story.

We would like to thank the GP practices and care homes for letting us visit them. We are especially thankful for the time most of the practice managers gave us during our visits, and to the GPs we spoke to. This has given us valuable insight from a *service* point-of-view and some understanding of the challenges they face.

There are a range of activities for improving peoples' wellbeing but some are hard to contact or the details are wrong.



On the whole people value their local doctor's surgeries but there are issues which need addressing:

- Getting through to make an appointment
- Meaningful conversations



Growing concern about demand on services with the growth of houses in Burgess Hill.

See page [8](#) for commissioning response.



Local people are struggling to get the support for their own, or their children's mental wellbeing.

Along with confusion as to where to go for support.



Less than positive experiences of multiple baby pregnancy and post-natal experiences - will inform the Better Births Programme.



Local people put forward really useful suggestions and solutions which we've included in this report.



# Recommendations

Listed here are the recommendations you can find throughout this report

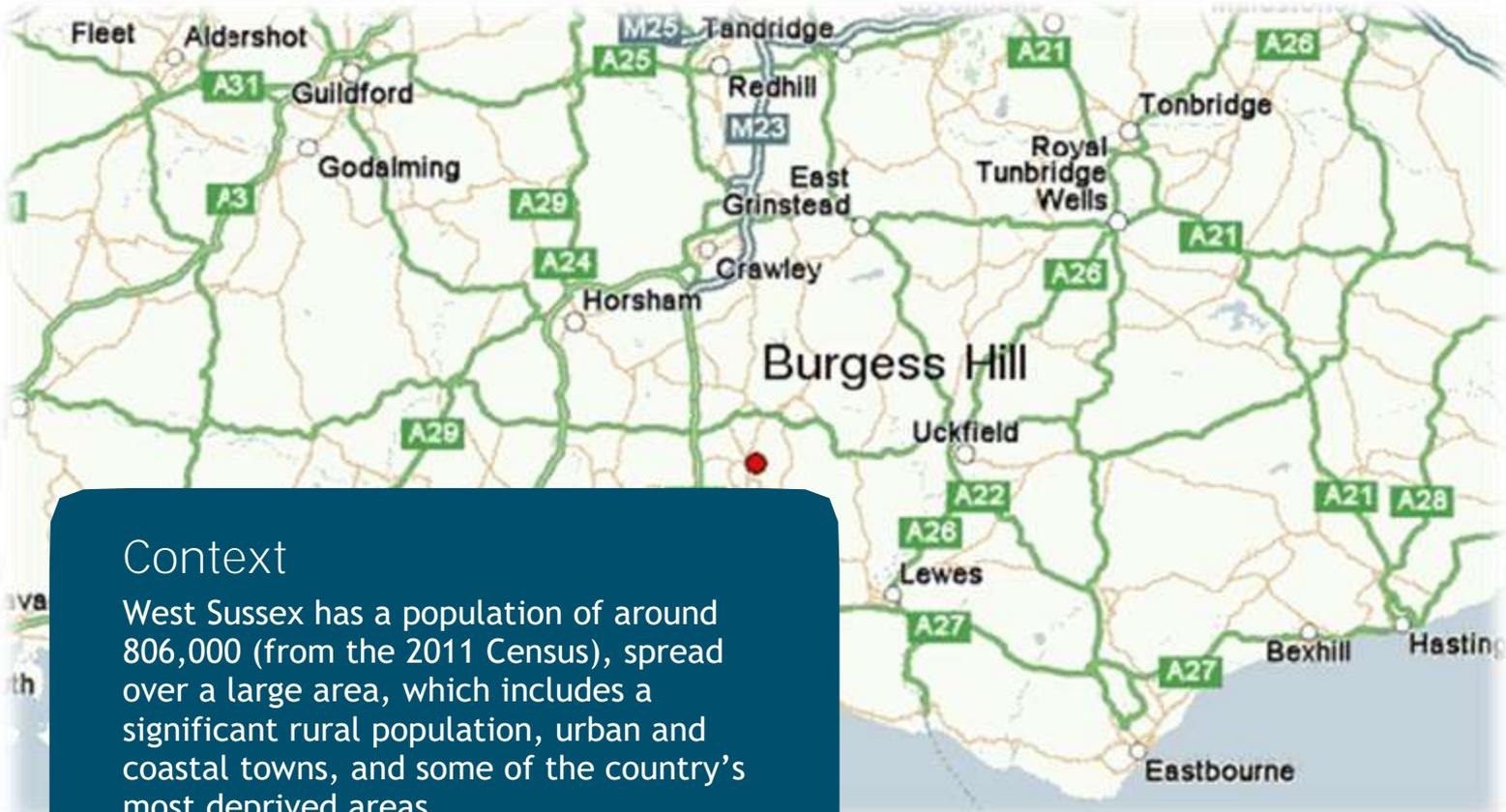
- 1 We **recommend** to all organisations they check their contact details with the following organisations, to make sure these are up to date:
  - Burgess Hill Town Council [Judy@burgesshill.gov.uk](mailto:Judy@burgesshill.gov.uk) Judy ensures there are regular updates provided to the local councillors. She also produces the *About Town* magazine, three times a year.
  - Mid-Sussex Voluntary Action - Bulletins contact is [Edita.moore@msva.org.uk](mailto:Edita.moore@msva.org.uk) and manager is [Sue.Edgson@msva.org.uk](mailto:Sue.Edgson@msva.org.uk)
  - Libraries
  - GP practices, via the Care Coordinators.
- 2 GP practice changes can be difficult for people to accept, but over time new ways of working often just get embedded and patients become accepting or adapt to a new system. A warning sign that this is not going to be the case, can be seen in the number of patients leaving a practice, and we would **recommend** this is looked at as part of any plans for changing access routes to appointment.
- 3 We **recommend** the [Referral Support Service](#), (supports GP practices and patients with hospital referrals), ask the referred patients how they plan to get to an appointment and if there are any challenges that need to be taken into account, and include this information in the electronic referral, along with any communication support needs.

We have also invited providers to consider the following.

- 4 From listening to patients, *The Brow* telephone consultation system has enabled their practice to greatly reduce the waiting time for consultations, so they deal with today's problems, today. However, there have been issues with people being able to get through on the phone, and we **invited** the partners to consider how they can review this and what can be changed to make it more satisfactory for patients. We learnt, there has been further improvements since visiting Burgess Hill and some of these are shown on page [28](#).
- 5 We invited the reception team at *The Meadows* to look at the leaflets and how best to display information (we found a leaflet on medication that was produced by the PCT, which has not existed for about 6 years). There are lots of notices asking patients to give feedback but it was not clear where feedback forms were.
- 6 We observed doctors walking along the corridor to call patients to their appointments. There is an electronic-screen but this was not being used. We invited the doctors at *The Meadows* to consider how their time, whilst waiting on the patient to reach the room they were using for the consultation, can be used to start a meaningful conversation, where this is not already being done. (How are you today Mrs X? Are you still walking the dogs regularly? etc.)

# What is a Listening Tour?

One of the ways we engage with communities and local people



## Context

West Sussex has a population of around 806,000 (from the 2011 Census), spread over a large area, which includes a significant rural population, urban and coastal towns, and some of the country's most deprived areas.

The county has multi-tiered local authorities (county council, seven district and borough councils, and many town and parish councils) and three Clinical Commissioning Groups (who are responsible for the quality the health support for our residents).

We understand we need to get close to local people

One of the ways we do this is to spend time in a town or area - so that we can get to know the people and services. We call this a Listening Tour

It is important that local people's views are gathered and shared, and that we reach a wide and diverse range of groups within our communities, so that we can understand and amplify voices to influence how health and care services evolve in West Sussex.

We also want to support local people to get the advice and information they need, to make informed decisions about their wellbeing, care and the services that support them.

# What people told us?

We recorded all the stories and comments people shared. Here are the themes:



## What's strong....

Generally

Burgess Hill appears to have a range of activities on offer, which is made possible, in some cases, through the support of dedicated volunteers.

Burgess Hill is a good place to live and there is a lot you can do here but you have to look for it.

John, a retired professional

However, people seem to need to be in a positive and proactive place to be able to find and get the most from these. This suggests, for people who are not in such a good place, having the practical support to find them and the emotional support to get settled in these activities is vital.

One source of such support can come from the **Care Coordinators** who work in the local GP Practices in Burgess Hill.

We met Helen at The Meadows, who has been in her Care Coordinator's role since spring 2018 (see page [36](#) for more details). Helen is passionate about supporting her patients and has been able to help many people to get the help they need.

Getting about

Betty told us she had to go to the Royal Sussex Hospital in Brighton, for a cataract operation and received very good care. She also attends this hospital regularly for audiology treatment and shared how the bus drivers support her.

I have to get there before 10am and if I show my pass to the bus driver, and my appointment card, they let me use the bus pass. This is very helpful.

# What people told us?

We recorded all the stories and comments people shared. Here are the themes:

## What's strong....

Starting well

We heard from Zoe who spoke very highly of Trudi one of the Town's Health Visitors.

*I have three young children and Trudi has been an angel! She is really good. Very supportive. She helped me to get a diagnosis for my son after the school's Special Educational Needs expert told me that he absolutely was not suffering from the condition I believed him to have. She really listens and understands children and parents. She deserves an award!*

Living well

Ava's story (17 years old) links to the previous comments on community support.

*I had over 5 appointments with a Community Psychiatric Nurse (CPN) a few years ago, and after six months I was sent to hospital. But they dismissed things and the more sessions I had, the less time I got. They then referred me to Sussex Oakleaf and they've been really helpful!*

We met Ava at a focus group, where others also commented on how well [Sussex Oakleaf](#) has been able to support them.

*I was referred to Sussex Oakleaf from Linwood. They've reassured me and helped me to gain perspective.*



**Mid Sussex**

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Email - [pathfinder.mid-sussex@sussexoakleaf.org.uk](mailto:pathfinder.mid-sussex@sussexoakleaf.org.uk)

One person (under 18) described the doctor at Linwood Community Mental Health Service (run by Sussex Partnership NHS Foundation Trust) as '*brilliant*' and that they even visited them in hospital.

# What people told us?

We recorded all the stories and comments people shared. Here are the themes:

## What's strong....

### GP Services

I went to get a flu jab and got a good service and a text.

I can get an appointment and the staff are nice.

People also spoke positively about having a nurse (from the Community Disability Team) go with them to appointments, and others took family members to help them to understand what the health professionals were saying.

We saw some great communication between patients and receptionists in GP surgeries across the town. This was backed up by the comments people shared.

At Silverdale Surgery you are able to speak with the receptionist who provides a really good service and is very nice with people.

The **improved GP access**, that has been available from 1<sup>st</sup> October, has made more appointments available for all West Sussex residents. New evening and weekend appointments are now offered for both urgent and routine needs but will not necessarily be with a patient's own surgery/doctor. We were able to give some assurance to employers because of this, when issues around not being able to get a GP appointment were raised.

### Hospitals

We heard a large amount of positive comments from people who had been treated at Princess Royal Hospital, in Haywards Heath (run by Brighton and Sussex Hospitals NHS Foundation Trust).

I was taken to A&E and stayed in hospital for a few days. The nurses were very kind and looked after me well. I had a drip and they made sure it was comfortable. They helped me to be calm as I was very upset. I felt safe.

Justine, who receives additional support for her learning disability

I had an accident in the 80s and still attend the Princess Royal and am supported by my sister. The staff do look after me well and make sure that I know what is happening and the next steps.

Our authorised representatives have been carrying out monthly visits to this hospital since Spring 2018, to support the Trust to recognise where improvements in cleanliness, maintenance, and food provision, are needed.

# What people told us?

We recorded all the stories and comments people shared. Here are the themes:

## What's wrong....

Generally

The difficulties we experienced getting through to clubs and organisations are likely to be the same for local people. Some of the challenges being:

- unable to leave messages because answerphones are full
- emails bounced back or not getting answered

We therefore **recommend** to all organisations they check their contact details with the following organisations, to make sure these are up to date:

- Burgess Hill Town Council [Judy@burgesshill.gov.uk](mailto:Judy@burgesshill.gov.uk) Judy ensures there are regular updates provided to the local councillors. She also produces the *About Town* magazine, three times a year.
- Mid-Sussex Voluntary Action - Bulletins contact is [Edita.moore@msva.org.uk](mailto:Edita.moore@msva.org.uk) and manager is [Sue.Edgson@msva.org.uk](mailto:Sue.Edgson@msva.org.uk)
- Libraries
- GP practices, via the Care Coordinators (see page [36](#)).

People expressed concerns over the volume of new build homes in and around Burgess Hill and how health and care services will manage with the increase in residents. Some, including people who work in health, have noted plans for new GP surgeries and are assuming this will happen.

Burgess Hill was a nice sized town and has now grown and is continuing to grow but where is the infrastructure?

It is very hard to get a GP appointment and the new housing and increasing population does not have a new GP surgery or schools, as no infrastructure is planned and this impacts on the services that are already there.

I live on an estate that was built about 10 years ago, in Hassocks. There were plans for a GP surgery and school and neither have been built.

From discussions with practice staff we understand all the local practices are currently taking on new patients, and this suggests there is still capacity locally to safely register new residents.

# What people told us?

We recorded all the stories and comments people shared. Here are the themes:

## Response from the Sustainability & Transformation Partnership Sussex and East Surrey

The local NHS is working hard with local GP and practices to ensure residents are getting the timely care and treatment they need. We know that in Burgess Hill, the number of patients who say they are satisfied with the appointment times available at their practice and the number who say they get to see or speak to their preferred GP are both above the national average.

However, we know that GP services across the whole country are increasingly experiencing growing pressure due to rising demand and issues with the recruitment and retention of GPs. This is something that is being felt locally across Mid Sussex, including Burgess Hill. NHS Horsham and Mid Sussex Clinical Commissioning Group (CCG) is working closely with local GP Practices and regional workforce planning teams to develop new ways of working to meet the growing demand and address our GP recruitment challenges.

We are working very differently across Horsham and Mid Sussex to ensure we make the most of the wider NHS workforce. For example:

- *Communities of Practice* bring together NHS and social care staff into integrated multidisciplinary teams who work closely with GPs, local hospital staff and others in the community to ensure patients with complex or long-term health conditions get the support they need and can proactively look after themselves
- The *Paramedic Practitioners* home visiting service works across a number of GP Practices to provide urgent home visits to patients with frailty and has seen a positive impact on patient experience and clinical outcomes.

Both of these projects aim to reduce demand on GP-led care. In addition, from October registered patients across Burgess Hill have been able to access both routine and urgent appointments at evenings and weekends.

While we recognise the challenges we face with GP recruitment, recent media reports of the number of patients per GP in the Mid Sussex area does not reflect the true situation. The data used does not include the additional appointments provided to nursing homes or those patients who need to be seen at home. It also does not include the additional appointments that are being provided through the *Improved Access Service* seven days a week, which covers the Burgess Hill area. So, it is important residents are reassured that the quality of our GP services across Burgess Hill remains high and that we are working to ensure local people continue to get access to services in a way that better suits them.

# What people told us?

We recorded all the stories and comments people shared. Here are the themes:

## What's wrong....

Whilst Betty has had a good experience with the buses, others have not...

The bus doesn't work for me. It takes about one and a half hours and when your appointment is only for 15 minutes it's a lot of effort. I don't know why my GP can't review my treatment instead of the hospital?

Marge (70+ years), uses buses to get to her outpatient appointments

Using the bus to get to health appointments can be particularly challenging for those living with long-term health conditions, as we heard when chatting to people at the [Sign Post](#) drop-in.

I have to go to Royal Sussex Hospital every three months. All the staff are lovely but the bus to get to appointments is very difficult. It's a rural bus, so can run late or early. If I miss the last bus I have to walk.

The bus service is awful. It makes you late for hospital appointments and other appointments.

Local people told us they think it's important for doctors to refer people to community and voluntary sector services (often referred to as the third sector).

Groups like this can and do help you much better. Doctors aren't good with the emotional parts. They tend to throw medication at the problem and with mental health it is not a straight line. We have 10-minute appointments and some people need more time.

To just give medication, which they don't explain, doesn't help me to move forward.

My husband was given Diazepam and felt great but how is this replicated in a non-medical way? He has just lost a friend and has been told to get in touch with the bereavement services, but he needs more than this as he is not someone who is able to speak up in a group setting.

Groups like [Men in Sheds](#) work well, from what people tell us, as they offer a safe environment for men to explore emotional concerns. There is a *shed* in Burgess Hill.

# What people told us?

We recorded all the stories and comments people shared. Here are the themes:

## What's wrong...

At some of the focus group discussions we heard the challenges people face when trying to get or stay in receipt of benefits.

The Department of Works and Pension (DWP) asks you if you can visit the office in Redhill - of course you say yes because you don't feel you can say no. You then feel under pressure. This then is a risk to your assessment and recovery plan, and you have to travel to Redhill even though you can't use public transport due to your (mental health) condition.

We all need help with filling the forms in, as they are complicated and then cost us in sending by recorded post and then we learn that they have not been looked at. What we need is a training session on how to fill in these forms and support through the process.

We were able to pass on Citizen Advice information for some outreach support and training for the above group members.

## Dentists

There were some examples of some good practice and how dentists have taken the time to understand peoples' needs. These, and the less than positive stories have been anonymised and shared with NHS England, along with other insight West Sussex residents have shared in the last 18 months. These will help to inform the recommissioning of dental services in West Sussex.

The themes of this are detailed in a [short report](#).

# What people told us?

We recorded all the stories and comments people shared. Here are the themes:

## What's wrong...

### GP Services

This is the first time Healthwatch has visited all the GP surgeries in Burgess Hill. It is interesting to see the disproportionate space surgeries have for their services and patient list size. Some appear too small for their medium sized list of registered patients, whilst another has lots of space for a much smaller list.

Most people are aware there is pressure on NHS services, especially to see their doctor. In many cases because they have found it difficult to get an appointment or the support they need.

It's OK here (patient sitting in a local surgery waiting room) I suppose. The only thing is they don't really treat us like people. They treat us more like a 'tablet taker' or 'patient' or 'illness/condition'. I suppose it's just a job to them and this is their workplace. But it's my life and they are here to support and care for me - it just doesn't feel like that most of the time.

This was echoed by other patients at a different GP surgery. Also, the way people deliver care can make it harder for people to care for themselves.

I feel that the doctors here don't really know me as a person, they just know me by my illness. The nurses have been visiting me at home to put ointment and a dressing on a sore. But, every nurse does it differently and gives me different instructions - one said to keep it covered and another told me to leave it open?

Most GP practices are looking at ways of managing the demand for GP appointments. One practice has introduced a system for allocating appointments which appears to be hugely unpopular with its patients.



THIS WAY

## 6 out of 11

told us they were unhappy with how they get an appointment at the GP practice

# What people told us?

We recorded all the stories and comments people shared. Here are the themes:

## What's wrong....

Getting the communication right is key. An example of how technology can confuse people, as we heard a patient say to his wife:

I used that touch-screen thing to book in. It's great isn't it? Wonderful technology. But, I'm not sure if I have actually been booked in or what I'm supposed to do next - should I just sit here and wait? Perhaps I should speak to the girl on the desk to check?

Whilst we heard much sympathy and appreciation of the NHS, we also heard and saw some of the problems people experience.

Jess told us, I feel like I'm playing *ears, nose and throat* ping pong. My child was being sent back and forth constantly between the doctor and hospital, for tonsils and adenoids. In the end we went privately due to the stress.

Amy (18-21) - It took over 9 years to get a diagnoses of Endometriosis for me. Not due to waiting times but because they did not believe me.

Megan (18-21) I go to the Princess Royal hospital for check-up for celiac and now I have been told that I need a blood test and an osteoporosis scan. These have to be arranged by my GP and not the hospital, so I am back and forth between the hospital and GP.

Margaret said there is a lack of communication between services, in her case between the GP surgery and Princess Royal's fracture clinic. This has meant I had a cast on longer than I should have, resulting in muscle wastage. Removing the cast is not something I can do myself, but I had real problems trying to get the two areas to communicate.

A support worker told us: there are still real problems with the transition between services for young people and they are falling between the cracks.

Matthew, who needs support to understand and manage his health, because of his learning difficulties, described how his own doctor helps and listens to him. But that at other times, when he's not able to see his own GP, he's come away feeling the doctor has been rude and that they believe he was wasting their time. This has led to him making another appointment to see his own GP, to get the support he needs.

Others also told us there is a real need for doctors to have meaningful conversations with their patients.

# What people told us?

We recorded all the stories and comments people shared. Here are the themes:

## What's wrong...

### Mental Health

Support for mental wellbeing, particularly for under 18s is seen locally as not satisfactory or non-existent, as shown next ...

Sadly, Burgess Hill is a town that has been rocked by several suicides this year. This seems to have had a profound effect on local people, particularly where peoples' own mental health is impacting on their wellbeing.

We heard concerns over changes to community mental health support, and a common theme around the lack of support for children's mental health, both those under and over 11-years. There were also comments that suggest there is a lack of information around what services are available.

We've lost so many mental health services in this area. Three have been closed, so now if you have a problem, the GP just ups your meds, but this doesn't help my husband.

Paula, (25-40)

It's so sad that this is the only mental health support available now. But everything is now based around Sussex Oakleaf who only cover a specific area. I could go to Lingfield, but this is outside my area.

Mark, visiting the Sussex Oakleaf drop-in  
(we were able to signpost Mark to a support worker for specific help)

The child health services are now non-existent. Children and Adolescent Mental Health Service (CAMHS) in Haywards Heath are not very good as they sent us to another service and we've been on a waiting list for 6 months now. Not getting a diagnosis early is detrimental to the child and the parents, who need help to cope.

Zoe, parent to a child over 11

I also attended the YES team (Youth Emotional Service) but many staff are leaving the service as the stress levels are too high for them. Eight years of funding cuts have really impacted. We need a simple model such as the Sparkle Group (see page [39](#)), as parents are at a very low point. These also need to be supported as its volunteer led and parents/young people do support each other in the group.

Jo (25-40), parent with older children.

# What people told us?

We recorded all the stories and comments people shared. Here are the themes:

## What's wrong....

We recently had a temporary worker who was struggling with some mental health issues and had visited their GP and had tried to find local help but were unable to find anything. The worker was unable to continue working.

Human Resource officer of a Burgess Hill business

From chatting to a small but focused group of 16 and 17-year locals, we can appreciate even more.

These young people shared their worries about: money, an unknown future, communication and how professionals make them feel judged or ignored.

Some of the doctor's care more than others. Most are only interested in giving you medication. They don't give a shit unless I'm going to kill myself. Things change when something happens, but it should not have to get to that point. **If I go to see a doctor, I'm at crisis point** and the doctors seem to want it to be worse than this before doing anything.

Tom, aged 17

I feel they don't listen. They are more interested in typing up symptoms and never hear all the things I'm saying. This means you are never able to talk about other things as you can only discuss one thing.

Poppy, aged 16

I went to my GP as I was in crisis and he ignored me. I then tried to commit suicide and now I have a note on my file that I have '*suicidal tendencies*' - really helpful! Like, I need help not labels!

George, aged 17

The support needed from their perspective is:

- A safe place where they can be themselves, if they want to talk this is supported but if they wish to be silent they can be.
- To be with people who can actively support them. Help them to learn new skills like cooking, time and money management. To explore the emotional side of things and provide tools such as discussions around worry and explaining and using tools that can support such as the worry tree, goal setting, action planning, and problem solving.

# What people told us?

We recorded all the stories and comments people shared. Here are the themes:

## What's wrong....

The group members who were seen at a Children and Adolescents Mental Health Service (CAMHS), said it was not helpful just to suggest '*read this booklet*'. All the young people we spoke to had researched their conditions and felt they understood it.

They also found it unhelpful when a CAMHS professional focused on one aspect of their mental health, without asking them what issues were most important to them.

Some of those we spoke to believe health professionals need to recognise what is available locally, and to refer people to these services promptly.



Poppy (18-21) The anti-depressants worked for about 6 months and then stopped working. We need to have other tools to support us.

For the young people who have experienced being in hospital for their mental health, the lack of support once out has been a problem.

People are being discharged and they don't know they have an appointment, so miss them and are then seen as not co-operating.

They don't have enough time to give you. It's a quick fix and there is no step down and few organisations in the community for support.

Other than the one positive comment we detailed earlier relating to Linwood Community Mental Health Centre (Haywards Heath), significantly more people spoke of referral delays, long waits or lack of appropriate support. What we heard in Burgess Hill mirrors the online reviews for this service.

One of the main complaints with this community mental health service is the telephone response. People used phrases such as getting '*sent around in a huge loop*' and told us of the difficulties they had in getting through to the right person.

It has been suggested to us, that this service is unwilling to work with other health and support professionals to offer local people the joined-up support they need to achieve as much mental wellness as possible.

# What people told us?

We recorded all the stories and comments people shared. Here are the themes:

## Response from Sussex Partnership NHS Foundation Trust

We value Healthwatch's role in providing us with important feedback on the services we provide and giving a voice to people in the local communities we serve who may not want to talk to us directly.

We understand how difficult and distressing it is for children, young people and families affected by mental health issues. We know that some families have to wait longer for certain treatments than they - or we - would like. We always try to be sensitive to their needs and to make sure they receive the right help. We are very sorry to hear about anyone who is unhappy about the care or advice they have received from us. We encourage people to talk to us where this is the case so we can do everything possible to respond.

Our Child and Adolescent Mental Health (CAMHS) teams work extremely hard to help families access the right support for the difficulties they are facing. If a child or young person doesn't meet the criteria for the specialist mental health services we are commissioned to provide, we will guide them towards appropriate wellbeing or mental health support which is available from our partners and other organisations. We will always review clinical decisions if the situation changes. Once we have assessed a child or young person and determined our specialist services are best placed to help them, we will jointly agree a plan of care and treatment to support them as soon as possible. We are also working in partnership with other local agencies, including schools and social care services, to support young people and families across all areas of their lives.

As is the case across the country, our CAMHS teams are experiencing a significant and sustained increase in demand for their services and are working with those who commission all services in the emotional wellbeing pathway across Sussex. Along with our health and care partners, we know that the way we deliver our services must change to meet the needs of our local communities. That is why - in partnership with NHS England, our local authority and Clinical Commissioning Group partners - we have commissioned an independent review of the emotional and wellbeing support in Sussex for children and young people. This review will listen to the experiences and voices of young people and their families and carers and will help us understand what is working and what is not.

Continued

# What people told us?

We recorded all the stories and comments people shared. Here are the themes:

We continue to aim to respond to demand for services by developing new and innovative ways of working. This includes the New Care Models programme, which brings together different aspects of health and social care to provide young people and their families with a complete package of care and support when they need more intensive care or support in a crisis. The aim of this way of working is to treat young people in their own homes and prevent unnecessary admission to hospital.

We are committed to working with people who use our services and their families, our commissioners and other partners in health, social care, education and the voluntary sector, to improve the care, treatment and support we provide. This includes listening to and acting on feedback.

If you have any questions or concerns about the care you receive from Sussex Partnership, please contact our Patient Advice and Liaison Service (PALS) on 0300 304 2198 or [pals@sussexpartnership.nhs.uk](mailto:pals@sussexpartnership.nhs.uk)

## Hospitals

Some people struggled during their stay in Princess Royal Hospital.

I was in hospital as I had a stroke and I pressed the button to get help to go to the toilet, but the alarm went off, but no-one came. In fact, the alarm went off all day and no-one came.

In-patient at Princess Royal Hospital, in September 2018

Princess Royal Hospital is a *shambles*. They ask you to change into a hospital gown with nowhere to do this privately. Then you have a gown with an open back and they make you wait a long time for the actual appointment. It is all really embarrassing.

People gave examples of wastage and inefficiencies in the hospital system.

The waiting times for emergency cardiac are over 4 hours at Princess Royal Hospital. This meant my husband had not got all the information he needed to make an informed decision. He had 2 or 3 scans and then had to wait about 8 weeks to see the consultant. The consultant said the scans were of no use as they were done too long ago for him to make a decision on, so the whole process has started over.



# What people told us?

We recorded all the stories and comments people shared. Here are the themes:

## What's wrong...

Sophie, who has communication needs, said: At Princess Royal Hospital the staff talk too fast. I don't understand them. When I ask them to repeat things they tell me they don't have time. This is the same in Brighton. They do not explain things to my mum as well and she lets me go in alone - I prefer this. I did, at the last appointment have Daisy, from Sign Post come in with me. She explained things to me after. This was much better.

I go to Haywards Heath and Brighton hospitals. I am not able to ask questions, but my mum goes in and they tell her. They do not know how to communicate with someone who is deaf.

Brighton and Sussex Hospitals NHS Foundation Trust also operate the Royal Sussex Hospital in Brighton and people seem less positive about their experiences with this hospital (than Princess Royal).

Have been to Brighton Ophthalmology for a cataract operation. They kept cancelling the appointment and this really got me down. They have now done the operation and I have to go back in two weeks' time.

I had my cataract removed and then went back as the eye was very sore. It turns out that the eyelashes were turned backwards. I have now had a procedure to correct this but have to have eye cream on a daily basis for the next few weeks. But the surgeon has done a good job.

I have high blood pressure and high diabetes caused by the stress of having to wait for appointments and then having them cancelled. I now need to use a machine to test my blood pressure. It's like being on a treadmill.

My husband was the patient. Everything just took so long. He was left with an open wound for 3-4 hours and then, when he was finally seen, they sent us to Brighton A&E. We don't know why because they didn't really tell us. When we got to Brighton they said we should have been fast-tracked at Princess Royal Hospital because my husband is diabetic. My husband was admitted for a couple of nights and the ward was also understaffed in our opinion. They took ages to answer the call bell, sometimes 30 minutes.

# What people told us?

We recorded all the stories and comments people shared. Here are the themes:

## What's wrong...

Communication at the Princess Royal is very limited. Staff just aren't aware of what's going on. They give you the wrong information, or directions and tell you false things or just don't know basic information. I asked about patient transport and not one member of staff in the department knew what the criteria was, so they couldn't help me.

Having 'What matters to me' conversations could help professionals in supporting people better. George told us:

I went to the Princess Royal hospital last Wednesday and my next appointment will be in three months' time. They want to reduce my Parkinson's tablets to help with the shakes and balance. I seem to have a choice ... be able to walk - with a frame, or not or be in a wheelchair. I feel that if I can walk I can draw level with my Parkinson's.

The Royal College of Physicians has published a '[Top tips for person-centred care](#)' guide recently, which was developed in partnership with their Patient and Carer Network. The guide aims to help physicians in a hospital setting to improve their communication, help patients identify priorities and concerns, involve patients in care and treatment planning, and assess patient experience.



# What people told us?

We recorded all the stories and comments people shared. Here are the themes:

## Response from Sussex Community NHS Foundation Trust

We were saddened to read the negative comments regarding individual patient experience at our hospitals. It is, however, very difficult to comment in a meaningful way as these are isolated experiences with insufficient detail to explore further. We would, however, welcome patients and their representatives to contact us directly about any instance when standards of care were not as high as they should have been.

We were disappointed to read of the poor experience of the complaints service at our hospital, particularly given the high number of complaints we successfully resolve.

We hope it is helpful and reassuring for patients and their representatives to know that our Trust has an extremely low number of complaints accepted for independent review by the Parliamentary and Health Service Ombudsman, the second stage of the NHS Complaints Process. I also hope it is helpful to know that the Trust receives very positive feedback about our complaints handling from the Healthwatch Brighton & Hove Peer Review Project, which has been running for a number of years.

In response to some of the specific issues raised:

**Call bells:** Our wards regularly review response times to call bells and, in the national Inpatient Survey 2017, our Trust was in the top 20% of hospitals for responding in a timely manner.

**Hospital gowns:** Following the introduction of a new laundry contract in 2019 the majority of hospital wards now offer patients nightgowns and pajamas, rather than gowns. We are committed to ensuring the privacy and dignity of our patients and are currently looking of ways of improving the experience of patients requiring gowns in our imaging departments.

We encourage patients to contact us directly about any problems they have experienced so that we can do our best to resolve them, learn from any mistakes and improve the way we do things in the future. We also welcome patients and their representatives to contact our Patient Advice and Liaison (PALS) for help, support and information regarding their care at our hospitals.

PALS can be contacted by telephone:

**Royal Sussex County site:** 01273 664683, 664511, 664973

**Princess Royal site:** 0144 448678. There is also a drop-in PALS office in the main reception area at the Princess Royal Hospital.

**By email:** [PALS@bsuh.nhs.uk](mailto:PALS@bsuh.nhs.uk)

# What people told us?

We recorded all the stories and comments people shared. Here are the themes:

## What's wrong...

### Starting well

We heard from Michelle who experienced great support during her previous pregnancies but her most recent one was not so positive.

Michelle was carrying more than one baby and because of this, her pregnancy care came under the consultancy team at Princess Royal Hospital, and not the midwife team.



I felt that my choices and decisions were limited and taken away from me. They told me early on that I would have to have an epidural because there was a high chance that I would need a C-section.

Not being listened to and a fear arising from this information meant Michelle felt *“unsupported throughout the pregnancy and it kind of ruined the whole experience for me.”*

Michelle told us that when it came to giving birth the midwives were able to offer her reassurance when she was absolutely terrified. They confirmed she did not have to have the epidural and that she was in control of her own decisions, unless there was a major emergency. The relief was so great, Michelle told us, that she was able to relax and deliver her babies without any intervention or difficulties.

A young mother shared her story of giving birth at Princess Royal Hospital this Summer. Her experience started well but declined after she was transferred on to the post-natal ward. During her labour and delivery, she said things were fully explained to her and she felt supported throughout the birth. In contrast, she told us she felt abandoned and unable to get the help she needed afterwards. This lack of care and support continued when she got home, to the extent that she felt she needed to complain. The mother's experience has been made worse, she told us, but the uncaring response to her complaint.

The response didn't acknowledge my grievances or answer the points I had raised. It was impersonal and there was no apology or acknowledgement of my distress. I was really upset by this and was planning to escalate it and complain further but life kind of takes over, so I left it and left it and now I think it might be too late. I am still very angry and upset and I'm putting off having more children because of the way it has made me feel.

# What people told us?

We recorded all the stories and comments people shared. Here are the themes:

## What's wrong...

We met another mother who had twins recently and appears to have had a similar experience. This mother also praised the midwife team during the delivery, as she felt *well cared for and listened to*. However, like the young mother the post-natal experience wasn't so good.

I have felt a bit dumped and quite alone and unsupported at times. I can get help if I ask for it but asking for it is difficult due to problems in getting through on the phone and they are always so busy, and I feel rather guilty when they tell me repeatedly how busy they are. I would have thought that the aftercare would be as important as the pregnancy and delivery, but it seems that it isn't.

We have shared these mothers' experiences with the [Better Births](#) Programme that is looking at how the safety and experience of giving birth can be improved across Sussex.



# What people told us?

We recorded all the stories and comments people shared. Here are the themes:

## What needs to change?

### Access to GP Services

Healthwatch acknowledges the need for GPs to try new ways of working to manage the demand for appointments, so they support the most-sick patients, whilst keeping others safe.

Speaking to GPs, we can see changes have been introduced with good intentions but where these are done without involving patients this can cause problems stemming from the unintended outcomes.

When planning any programme of change, such as looking at how calls are triaged, or appointments allocated, ideas should be tested with patients early to avoid/reduce the risk of negative consequences. As a minimum, this can be done by asking patient participation group (PPG) members for their thoughts. However, a more robust way would be to get the practice team, or PPG to survey patients, *“if we did this.... is this likely to create any issues for you”*.

When implementing changes to how patients can access appointments we suggest that good practice would be to co-produce with patients the new method but also to gather more detailed feedback from patients who have experienced the new way of working promptly. This would give valuable insight and opportunities for adjusting and improving service delivery. Despite the best planning and engagement, there can still be some unintended consequences and early feedback can alleviate these.

One of the practices in Burgess Hill undertook a significant change to how they respond to demand for GP consultations. This was done with the support of all areas of the practice, and involved patients via the PPG. This included weekly *‘change meetings’* so everyone could input into the develop of a new system.

Change can be difficult for people to accept, but over time new ways of working often just get embedded and patients become accepting or adapt to a new system. A warning sign this may not be the case, could be seen in the number of patients leaving the practice, and we would **recommend** this is looked at as part of any plans for changing access routes to appointment.

Poor mental health on the day, appears to be a common issue for why people miss health appointments. It is important to identify individual ways of supporting people to access appointments in a way that works for them. This in turn will lower the rate of *did not attend* (missed appointments).

# What people told us?

We recorded all the stories and comments people shared. Here are the themes:

## What needs to change?

### Getting to appointments

We will make sure the team looking at commissioned bus services in West Sussex (following the consultation that concluded on 18 November 2018) consider what people have shared with us in Burgess Hill before deciding on any route changes.

We **recommend** the [Referral Support Service](#), that supports GP practices and patients with hospital referrals, ask the referred patients how they plan to get to an appointment and if there are any challenges that need to be taken into account, and include this information in the electronic referral, along with any communication support needs.

### Need for meaningful conversations and identifying what matters to people

There needs to be greater appreciation/recognition amongst health professionals of the impact on young people when they are made to repeat their experiences and issues over and over. We appreciate there may be a need to 'check' a person's current thinking about their mental health at referral appointments and as people progress through their treatment/therapy. However, it is important the reasons for this checking is clearly explained to the person. Equally important, is for health professionals to show people they are listening and interested in a patient's story and that they have understood their previous history.

The General Medical Council are concluding a consultation on the draft guidance for [Decision-making and Consent - Supporting patient choice about health and care](#) (which ended 23 January 2019). This sets out a whole range of guidance for health professionals around communication, and how to have meaningful and appropriate conversations with people.

Some people told us what support would help them to understand and be involved in decisions about their health.

If when I see a doctor they used pictures, this would make it easier for us to understand and be understood.

It can be difficult to talk as the words they use are different.

When I go for blood tests they hurt my arm as the needle is sharp. It would help if they used a less sharp needle.

# What people told us?

We recorded all the stories and comments people shared. Here are the themes:

## What needs to change?

Whereas, someone else was able to explain the difference using a cream to 'numb' the area before a needle went in, kept them calm.

Doctors and nurses do not explain what they are doing to you and this is scary. At the dentist they do explain what they are doing, and this is better.

Doctors and nurses need to write it down so that we can talk about it in our 1-2-1s and support us.

Healthwatch West Sussex offer training for health professionals, around having meaningful conversations, and work with organisations to better understand from peoples' lived experiences how to improve services.

Children and Young Peoples' Mental health and wellbeing is one of the Healthwatch West Sussex priorities. Our work outside this Listening Tour, continues and we plan to talk directly to more under 18s to build a bigger picture of what works and does not work for them.

We will be sharing what young people, and their families have said with the [Independent review panel](#) looking at young peoples' emotional and wellbeing services across Sussex (which we are told is taking place over the next 18 months).

Knowing when and how to get community support for mental health and wellbeing

There is a need for greater commissioning and support for community services, which could include peer support, to make sure these are available early on and support people to sustain their recovery.

The main issue is that the NHS is too slow to get us to Sussex Oakleaf and you have to tell your story to so many people.

David, aged 17, which was then backed-up by Mark at the group

I agree. We are always having to tell our story to people and this adds to the stress as you wonder if you have missed anything. Why do they not pass on the information or read the notes? Why do I have to relive it?

# What people told us?

We recorded all the stories and comments people shared. Here are the themes:

## What needs to change?

Every service access point, whether this is a GP practice, town or district council, local support group/church etc., should be helped to know where to signpost someone with a mental health concern. Any information needs to include how a service can be accessed, e.g. if a person can refer themselves or if they need to visit their GP to be referred.

### As a starting point for children under 11:

Working to respond to feedback from children and young people; local NHS clinicians, local government children's leads and stakeholders has recently redesigned the points of access to CAMHS and emotional well-being services. This work will be finalised soon and communicated to health professionals, and will be followed with further engagement with service users.

In the meantime, if your child is at school you can speak to the school to understand what support for their mental wellbeing is available through their services/staff. Or alternatively, you can speak to you GP to help with accessing support.

### As a starting point for people aged 11-18:

For young people aged 11-18, who present with mild to moderate emotional wellbeing and mental health needs, there is:

- face-to-face counselling at various locations across the county
- a new support platform called 'e-wellbeing', offering online sessions with an experienced and qualified counsellor

To access this support you can either self-refer by contacting YMCA DownsLink Group on 07739893707 or emailing [community.counselling@ymcadlg.org](mailto:community.counselling@ymcadlg.org), or a referral can be made at the county council's Find It Out centres.

We understand there will also be group work programmes and these are due to be available at set locations from 2019. If you are interested in this type of support, please visit a Find It Out Centre. There is one at 60 Park Road, Burgess Hill RH15 8ET (01444 243922).

# What people told us?

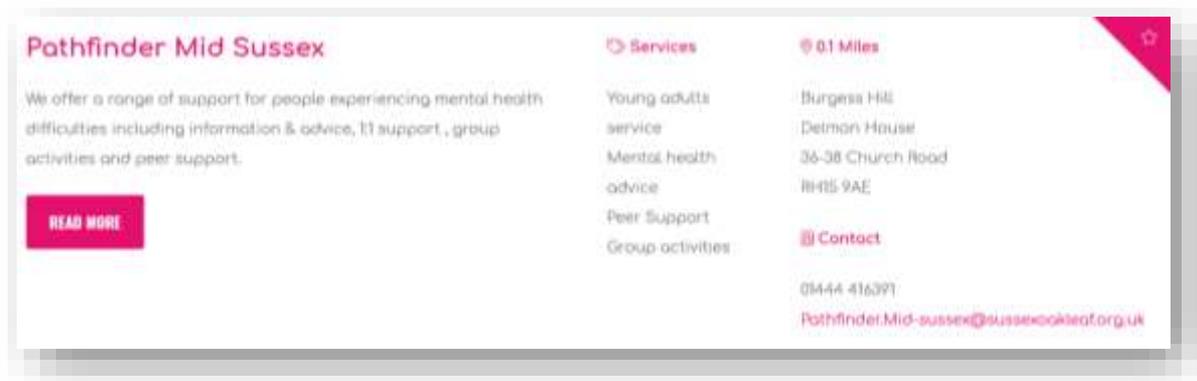
We recorded all the stories and comments people shared. Here are the themes:

Other sources of online information about mental health for young people include:

- Find, Get, Give <https://findgetgive.com/>
- Young Minds <https://youngminds.org.uk/>
- Your Space <https://www.westsussex.gov.uk/education-children-and-families/your-space/>

Young people can also access information through Find, Get, Give - a YMCA produced national website that supports young people, parents and carers and professionals around mental health. Visit the website at <https://findgetgive.com/>

As a starting point for adults:



Sussex Partnership NHS Foundations Trust has stated the Trust is planning, strategically looking at its community mental health services, and this is an important part of the Trust's proposals for reconfiguring in-patient beds in West Sussex.

Healthwatch has been invited to be part of an independent review panel. We will be using this to raise the need to provide a robust/reliable telephone service at each community centre so local people can be confident they can get the right support at the time when they need it.

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# The Brow Surgery

People spoke highly of the support and trust they have in the surgery's doctors, and staff seemed to know the patients reasonably well.



This high level of patient satisfaction in the care they receive from the Practice is also reflected in the national patient survey for 2017-8, when asked for overall experience of the practice 85% rated the practice as very good or good, which is better than the national average of 84%.

We could also see that the staff were passionate about delivering excellent quality patient care and we note that it was the only Practice within the Horsham and Mid Sussex Clinical Commissioning Group to receive an Outstanding for Care from the [Care Quality Commission](#) in 2017.

This is a practice with approximately 6,500 patients.

Having spoken to the Reception Manager and a partner at the surgery, they believe increasing their **telephone consultations**, which has been active for 2 years now, is a good way for the doctors to give advice and assurance to patients who do not appear to need a face-to-face consultation. A telephone consultation allows the GPs to listen, ask questions to shape the diagnosis, share thoughts with the patient and collaboratively agree an onward management plan with them, which may include advice, signposting to social prescribing, a prescription, arranging a follow-up with the GP or a member of the multidisciplinary team or if clinically necessary or requested a face-to-face consultation. For those who need to be seen, doctors make a same day face-to-face appointment during the telephone consultation.

From listening to patients, the issues described to us have been around their ability to get through on the telephone. We therefore invited the partners to consider how they could further review this and what can be changed to make it more satisfactory for patients.

Janice, who reacted to the slightest change in products (She has medicated shampoo and if they change something it affects the whole of her body) told us about her recent experience: I spent 45 minutes on the phone trying to get through but ended up having to leave for work in total discomfort. I don't have access to the internet or know how to use computers and therefore can't access appointments online. She had to take other steps to get the medication she needed.

Continued

# The Brow Surgery (continued)

Pat, who is over 70 and living with multiple and complex health conditions told us: I just have to take whatever appointment is offered. If this is before my daughter finishes work I have to use a taxi. This costs me £10 and it's a lot of money that I really can't afford, particularly when I need to come to the doctor's regularly.

My partner suffers from mental health problems and gets very anxious waiting for the doctor's call and this makes her symptoms worse. She refuses to go out in case she misses the phone call and will literally wait by the phone.

You have to ring and then get asked 'what for'? Then you get rung back by a doctor who may make an appointment. I find this system patronising. I'm big enough and ugly enough to know if I need a doctor or not. The people are brilliant at the surgery but the system is off-putting.

Others shared their frustrations that when a doctor states they need to have a follow-up consultation, they cannot then make a follow-up appointment in advance and must call on the day the appointment is due. The practice told us this is so the GPs can offer support through a telephone consultation and, if necessary, a face-to-face appointment. We were also told that patients should feel confident that they can call in to ask to speak to the same GP (on a day they have clinics/work) so they receive continuity of care, recognising the importance of this.

*Through feedback from our patients we acknowledge there has been problems with our patients being able to readily get through by telephone. With the help of the Patient Participation Group (PPG), the surgery has invested in a screen that shows the reception team the number of people waiting in the call queue and the length of time they have been waiting. We think this has substantially improved the call waiting times. We also have different staffing ratios for telephone answering at peak times.*

*We do try to be flexible in our offer of appointment times, including evening appointments each week to suit people's working hours and also their relatives' ability to bring them to the Practice.*

Continued

# The Brow Surgery (continued)

*From the perspective of people living with mental health issues we do tend to call them back at lunchtime/early afternoon when our system is quieter, to allow us to give them more time, we will add to our receptionists' information for patients when they call, so that it hopefully helps to allay any anxiety about the call back.*

*We plan to work with Healthwatch to survey people about their current experiences and will look at any remaining concerns or issues people are experiencing.*

## The Partners, The Brow Surgery

We met some of the PPG members on the day and could see how dedicated and supportive of the practice these patients were. Not only were they offering refreshments, the chair was asking patients about the usability of the *check-in screen*. We fed-back that this appeared to be a very accessible screen, that has also been designed to make sure personal details (such as name) were not in large print and therefore could not be seen so easily by others. There seemed to be confusion as to whether people used the checked-in screen for their appointments, or not. We understand the screen is now used for checking in for an appointment with a nurse but as the doctors have different ways of making their appointments, patients now register their arrival with the reception team.

The surgery has some significant accessibility issues, notably the parking arrangement proved challenging and the reception desk does not have a lower section, which means the reception team could not be seen easily when seated and any patients who are wheelchair users would not be able to use the counter (reception staff would stand and lean over if necessary, or come around to the waiting room side to speak to patients). We were pleased to see there is an accessible toilet, which was well equipped. However, the accessible toilet is located at the rear of the building and to get to it patients must navigate through a corridor, a fire door (which is kept closed) and a small waiting area with a number of seats. We felt this may be a challenge for some patients/carers.

*We are aware that our Practice is not as accessible as we would like it to be for our wheelchair users and have tried our best to mitigate this by our Receptionists opening doors etc for our patients whilst we await a long promised new Surgery building.*

## The Partners, The Brow Surgery

# The Meadows Surgery

This is a practice with approximately 9,600 registered patients (currently with a capacity to safely register 10,000 patients). The practice has a small number of patients leaving and registering each week, so appears to be maintaining this number.

In the main, local people seemed happy with the services at this practice and did not experience too much difficulty in getting an appointment, other than if they wanted to see a specific doctor.

I take blood thinners and see the GP every six months. I telephone and see same doctor within a week.

I do not use very often but good when needed. The head doctor asks regularly if there are any problems within the surgery.

We were able to feedback to the Practice Manager that the receptionist on duty had a fantastically warm manner about her, acknowledging people in the queue and presenting as knowledgeable. We were also able to meet and see the enthusiasm of Helen, the practice's Care Coordinator.

This practice is constrained by a lack of space. The reception area does not, we feel, offer much confidentiality. We observed the receptionist talking to someone with people standing either side of this person.



Having the repeat prescriptions at reception means people can overhear each other. There is no line to encourage people not to crowd. We noticed (but not immediately) an A4 picture frame with a 'polite notice' asking patients to keep a distance.

We raised this point with the Practice Manager, who said she normally sees people queuing to the side, away from the reception desk (where the self-check-in was located) but this had been where we were standing. She can see from her office several screens showing the reception area/waiting room and has said she will keep an eye on this.

Continued

# The Meadows Surgery (continued)

The waiting area has very limited space and only really allows chairs to be laid out in rows. There is now no space for toys. There is a TV screen (which could have important health message running) but this was not on. However, there was soft music playing.

We would invite the reception team to look at the leaflets and how best to display information (we found a leaflet on medication that was produced by the PCT, which has not existed for about 6 years). There are lots of notices asking patients to give feedback but it was not clear where the forms were.

We observed doctors walking along the corridor to call patients to their appointments. There is an electronic-screen but this was not being used. We would invite the doctors to consider how their time, whilst waiting on the patient to note the room they were using for the consultation, can be used to start a meaningful conversation, where this is not already being done. (How are you today Mrs X? Are you still walking the dogs regularly? etc.)

# Park View Partnership

We had a lot of problems locating this practice's website. In the end, we found it via the Clinical Commissioning Group's website. Even the Burgess Hill Town Council website link does not work.

This is a practice with approximately 5,500 registered patients located in a very spacious building that looks like it serves many more patients. It has reasonable parking and two large and well-lit waiting areas that over-look green space.



The Reception Manager told us that the surgery operates a buddy system, so there is normally a male and a female GP on duty at the same time. However, on the day we visited there only appeared to be one GP doing consultations.

Calls to the surgery are triaged by the reception staff who ask callers if they need an appointment with the doctor and if they could give a reason. They then make an appointment. All the patients we spoke to had not had a problem making their same day appointments.

Very happy with the surgery and I find it easy to get an appointment. I was aware there were evening appointments but not weekends, because I had an appointment for next week changed to 7pm.

However, people were less positive when it came to follow-up appointments.

I struggle to get to see my own doctor. I'm currently borderline diabetic and the doctor told me I had to see her again in two weeks. But I couldn't get an appointment for 3 weeks and this has made me anxious because of the potential diagnosis and the extra wait. If you go online it's about 6 weeks before you can get an appointment.

The Practice told us that patient involvement is through a vital Patient Participation Group (PPG), which means that patients and their family/friend carers can sign-up to receive information and to have a voice in service developments via email. Whilst this type of engagement, if used well is beneficial, we feel the partners are missing out on the valuable support an active patient group that meet in person, who are then more likely to offer support.

# Silverdale Surgery

I'm registered at Silverdale Surgery but I have to go to The Avenue Centre, which is part of the practice. I don't have my own transport and it is very difficult for me to get there. If I get a taxi it costs at least £20 from my pension.

This practice is located across two sites and has just around 12,500 registered patients. The practice employs a number of additional staff to support GP's - paramedics, phlebotomists, nurses with varying specialist skills etc.



The main branch is a converted bungalow in a residential area. The building is barely fit for purpose and has no parking. There is one single door width entrance which is heavy and on the narrow side - meaning that entry with a pushchair is challenging and entry with a wheelchair is impossible (patients who are wheelchair users have to visit the other site).

There is a ramp for those who may be unstable on their feet, but access for disabled people seems really difficult.

We were pleased to see a good amount of information in the form of posters, leaflets and factsheets, however, the noticeboard titled 'PPG' was disappointingly empty. We acknowledge it is good that the practice has this facility and the PPG representative told us they were in the process of updating the noticeboards. Perhaps a lesson from this is to add a simple "*Noticeboard under construction*", with an invitation asking patients to jot down what they would like to see here, may look better than leaving the board blank.

We observed a steady flow of patients and clinicians personally called each patient and escorted them to their respective rooms. We were told that appointments could be booked on the day, by calling at 8.30am, or pre-booked where appropriate and also online. Patients we spoke to told us they used all of these methods depending which suited their needs / met their preferences.

We spoke to staff who were aware the environment was challenging and there was an attitude of 'we are doing the best with what we've got for now - because there are plans to move into a new surgery in the near future - the team were unable to tell us any further details about this plan.

# Silverdale Surgery (continued)

The Avenue is a 'satellite' surgery to Silverdale, however, it feels like the main site as it is purpose built, spacious, has a car park and seems much more fit for purpose.

Inside the main entrance there is a large reception desk with varying heights to allow shorter people or people in wheelchairs to be able to speak to the receptionist at the same level. Although there is a potential for overhearing, the desk has a clear and polite sign, asking people to stand back and wait while someone is speaking at the desk.

There are a variety of different seats to cater for different needs. Most are wipeable material, but a few were upholstered.

Throughout the building there were posters and leaflets (on a variety of topics and information).

There was a wide corridor from the reception desk to another waiting area and consulting rooms lined both sides of the corridor. Halfway down the corridor there was a self-care station, with a hi-tech machine which could weigh patients as well as record their height, pulse (heart rate), oxygen levels, blood pressure and calculate their BMI. Signs next to the machine gave instructions and staff at reception kept an eye on it so they could support patients if needed. We observed a nurse supporting a patient to use the machine while we were there. The machine prints out the results, so they cannot be seen or heard by anyone in the vicinity. However, it did feel a little intrusive to watch someone using it and there may be an issue with privacy with this?

We observed the staff who were friendly, professional and caring. We spoke at length to the practice manager who told us they were experiencing unprecedented numbers of new registrations (we had observed 3 new patients in 3 hours) and this seems to be due to the new housing developments in Burgess Hill and patients deciding to change surgeries.

We met a couple of PPG members at this practice who told us that they felt completely involved and engaged in the management of the practice. They told us that they felt 'listened to, involved and able to influence decisions'. The PPG noticeboard at The Avenue, was also empty.

# A day in the life of a Care Coordinator

I have the opportunity to have a much more personal and indepth discussion with patients and, where patients are happy, this includes their family/friend carers, to see what information, advice and/or practical support they need.

From our discussions, together we may agree a referral to a specialist services is needed. I am able to refer to specialist care providers such as the [Responsive Services](#) or *Communities of Practice, occupational therapy (OT)* - all of which offer short term support to help people to live in their own home for longer. I call patients to follow-up after they have left hospital/respite care, to discuss their care and ensure there is sufficient care planned.

Our doctors refer people to me so I can speak to them about specific support such as mobility aids, OT assessment, carers support, etc. But I also meet with patients and their families when they come into the surgery to ask for assistance, and this can obviously cover a wide range of issues, including how to arrange home help, respite care or care homes.

Often, people will be ask how the financial side of care is assessed. I do my best to reassure them and provide as much information as I can for them to get the assistance they need.

My role also includes liaising with other NHS agencies, to make sure the best outcomes can be achieved for our patients and, with consent from a patient, I can give them more information so they can provide a more effective assessment and care plan.

As I don't have a typical day, this is not an exhaustive list but it should help local people to get a flavour of what I, and my Care Co-ordinator colleagues in other practices, do.

Helen Ring, Care Coordinator  
Meadows Surgery (Temple Grove) 01444 242 860

Tracy Egan  
Park View Surgery (Leylands Road) 01444 244 294

Tracey Marchant  
Silverdale Surgery (4 Silverdale Road) 01444 233 450

Hazel Sharrad

# Age UK Cherry Tree

The Cherry Tree Centre offers a range of activities and classes covering everything from arts and craft and painting, cross stitch and flower arranging to board games, bingo, quizzes and short mat bowls.



*I come to the Cherry Tree on a Tuesday and Thursday as it stops me feeling isolated now that I'm on my own.*

If fitness is your thing, there are classes for Tai Chi, gentle and advanced chair-based exercises, Zumba Gold, Yoga and Pilates.

The staff and volunteers provide opportunities for regular social events including monthly live music sessions, afternoon teas, theme days and parties, and monthly shopping trips to Crawley, Holmbush and Haywards Heath.

There is a lovely outdoor garden to relax in and free WiFi.

Fresh cooked lunches and a choice of healthy snacks and light bites can be purchased.

The centre also has visiting Chiropody and Hairdressing.

Door-to-door transport is provided by Bluebird Community Transport.

**Age UK also offer a range of information and advice and there is a freephone number you can call between 10am and 2pm, Monday to Friday - 0800 019 1310**

**To contact the Cherry Tree:**

**01444 236 497**

**St Alban's Hall, Fairfield Road, Burgess Hill, RH 15 8QB**

# Sign Post

Sign Post have a nurse that can go with us for appointments from the Community Disability Team.

The Old Post Office Resource Centre supports people with learning difficulties, their parents, carers and friends by giving advice, information and running courses, groups and services.

The service aims to help people to be independent and have fulfilling lives in their communities.

Signposts provides the My Network Services in Mid Sussex, offering information and advice to keep people safe and well in their homes. They may also be able to arrange support if someone needs it (as the quote above suggests.)

Activities you can find in Burgess Hill at **The Old Post Office Resource Centre**.

Mondays and Fridays 10am to 3.30pm - offering

- Computers and internet access
- Painting, and arts and crafts
- Counselling
- Mindfulness
- Pool
- Outings.

My Network drop-in Saturdays 10am to 2.00pm- Lots of social activities.



**at The Old Post Office Resource Centre**

**30 - 32 Station Road, Burgess Hill  
West Sussex, RH15 9DS**

**01444 616232**

**[info@signpostsmidsussex.org.uk](mailto:info@signpostsmidsussex.org.uk)**

**Information, advice, support and activities  
for people with learning difficulties and for their carers**

## Sparkle Group

I come to Sparkle as there's no pressure. Its open and we gain benefit.

Sparkle Groups are run by a charity called Hope that aims to reduce stress and isolation amongst families.

They are supported peer groups for mothers of any age that meet weekly with an organised termly programme of activities. The activities ensure the ladies have fun, feel connected, get out and about as well having a chance to discuss topics of conversation that strengthen their personal confidence and self worth as well as a parent and partner. They are proving to be a valuable place of friendship and support for ladies who find larger groups difficult to connect into or need longer term support in the community

For further information you can email [naomi@buildinghope.org.uk](mailto:naomi@buildinghope.org.uk)

## St Andrews Fellowship Group

The Church team run a small group called the Afternoon Fellowship at St. Andrews Church in Burgess Hill.

They meet once a month in the link building, from 2pm-4pm.

This club is for older residents and the group currently has about 24 members, all ladies up to the age of 97.





# Sussex Oakleaf

Sussex  
**OAKLEAF**  
[www.sussexoakleaf.org.uk](http://www.sussexoakleaf.org.uk)



Sussex Oakleaf have been very supportive - they've given me coping strategies, which have helped me to stop feeling ashamed.

Molly gets 1-2-1 support and said: My worker is an 'angel'. She treats me with dignity and respect and sees me as a whole person, not just seeing me for my mental health concerns.

Sussex Oakleaf

2<sup>nd</sup> Floor, Delmon House, 36-38 Church Road, Burgess Hill, RH15 9AE

01444 459517

[info@sussexoakleaf.org.uk](mailto:info@sussexoakleaf.org.uk)

<https://www.sussexoakleaf.org.uk/>



## Mental Health Support for Adults

One to one support & group activities for people experiencing mental health problems and living in West Sussex.



## Mental Health Support for Young People

Free and confidential support for people aged 16 to 25 living in Crawley, Horsham and Mid Sussex



## Lighthouse Recovery Service

Support for people with a personality disorder in Hove. Open 7 days a week providing daily groups and activities as well as individual support.



## Temporary Housing Services

Temporary accommodation in Burgess Hill and Haywards Heath for people who are homeless or at risk of becoming homeless.



## Peer Mentoring: Lived Experience

One to one & group support as well as learning for those with a lived experience of mental illness.



## 24 Hour Registered Care

Medium to long term accommodation across West Sussex with 24-hour support for individuals with enduring mental health conditions.



## Community Recovery Service

Personalised support for individuals with severe and enduring mental health conditions within their home.



## Mental Health Support to Find Work

Sussex Oakleaf can offer support and help to anyone struggling with their mental health who would like to start moving towards employment

# The Disability Trust

You see information about how we have been working in partnership with this organisation to develop useful tools for health professionals.



You can download the Best Interest resources from our website to help you record and evidence how you have worked in a patient's best interest when they cannot consent to the treatment or decision-making. These and other resources can be found on our website <http://www.healthwatchwestsussex.co.uk/our-work/resource-downloads/>

The Disabilities Trust is a leading national charity providing specialist rehabilitation, care and support for adults with acquired brain injury, autism and physical disabilities, including those with very complex needs. We also offer education services for children with autism.

The Trust says of itself: People are at the heart of everything we do and our services include purpose-built residential accommodation, community-based housing, respite care, special education and community enabling services to maximise each individual's independence.

Working in partnership with those we support, their families and friends, local authorities, health authorities, housing associations and other organisations, we have an established track record of delivering leading-edge services that meet the needs of people with complex and challenging behaviours. We are continually looking to refine our existing services and develop new ones in response to identified individual needs.

For more information about the work of The Disabilities Trust:

32 Market Place, Burgess Hill, West Sussex. RH15 9NP

Tel: 01444 239 123 Fax: 01444 244 978 Email: [info@thedtgroup.org](mailto:info@thedtgroup.org)

[www.thedtgroup.org](http://www.thedtgroup.org)



# Care Homes & Supported Housing

As part of this listening tour, our team visited residential social care settings within the town, to listen to the views and experiences of older people receiving care and support as well as hearing from the staff teams who work within these services.

We chose the following services at random:

- **Forest View Care Home, managed by Shaw Health Care**
- **Edward House Care Home, managed by Nicholas James Care Homes**
- **Prescott House Extra-Care Housing Scheme, managed by The Peabody Trust**

We spoke to approximately 60 people across the three services.

It is a challenge for us to engage and hear from people who have dementia and the insight can sometimes be difficult to interpret. However, we were able to find out very clearly and very easily if people felt comfortable and 'happy' with a service or not. Hearing from staff teams also enabled us to collect useful feedback for service providers across primary, community and acute care.

Some of the key themes can be seen in our separate reports for each of the homes.

# Preparing for the tour

By working with others, we were able to tell groups and individuals about Healthwatch West Sussex, what we do and why we are touring to listen to people in a variety of places before and during our tour. These included:

- **20 Public Noticeboards** - thanks to Burgess Hill Town Council
- Article in *About Town Magazine* - thanks to Burgess Hill Town Council and in eight local church bulletins
- **Libraries** - thanks to West Sussex County Council
- **25 large local businesses** and **three business association mailings** - thanks to Mid Sussex District Council and the local businesses
- **Information in the Job Centre**
- **Martlets Shopping Centre** stall, where we spoke to over 160 people
- **Posters/posters** in care homes, supported living homes, GP surgeries and local pharmacies - thanks for their support
- **Posters/postcards** in 50+ organisations
- **Social media posts**
- Information in the **Community Voluntary Sector's June bulletin** - thanks to Mid Sussex Voluntary Action

Across the summer, we contacted over 60 organisations and clubs, to arrange activities or piggy-back meetings as part of our tour in October and November. We also made sure we planned visits to the local GP practices, some care homes and the local hospital, in this case Princess Royal Hospital.

Despite our efforts, we struggled to get through to some, or to convince club, church and group leaders to let us come and chat to their members. This was, in some cases, due to lack of space; as speakers and guests were booked up for the year. Others simply could not accommodate us or did not respond to our multiple attempts at contacting them.

This was the fourth listening tour we've planned, and this is not something we have experienced to the level we found in Burgess Hill. We have reflected on why this may be. It is certainly something that health and care services should bear in mind when deciding how to seek the views and experiences of local people.

It's sad that this has been the case, as it has meant we cannot showcase the support provided by these missing groups. We showcase services and support through amplifying what local people tell us about the services.

# Since touring Burgess Hill

We go on tour, so we can listen to what local people say about their lived experiences of health and care services - their doctors, hospitals, dentists and mental health service.

Local people told us we needed to be closer to the people, and by spending more time in a particular city; town or cluster of villages, we have found that we can more fully understand peoples' experiences and concerns - what works well for them, and what doesn't. We have found this to be one of the most effective and cost-efficient ways of talking to local people.

Having gained this valuable insight from local people we must take action and work with those that plan, buy, provide and monitor local health and care services to make positive changes.

The insight and learning opportunities gained from this tour have been anonymised and shared with:

- **NHS Horsham and Mid-Sussex Clinical Commissioning Group (CCG)** who are responsible for planning, buying and monitoring many of the local health services
- **Local GPs**
- **Brighton and Sussex Hospital NHS Foundation Trust** who are responsible for the delivery of services at Princess Royal Hospital and Royal Sussex Hospital
- **Sussex Partnership NHS Foundation Trust** who are responsible for the delivery of local acute and community mental health services for adults and children
- **South East Coast Ambulance NHS Foundation Trust** who are responsible for the delivery of 999 and 111 services locally
- **West Sussex Health and Wellbeing Board**, which leads on improving the co-ordination of commissioning across the NHS, social care and public health services
- **West Sussex Health and Social Care Select Community**, which is the means by which proposed decisions are scrutinised, the effectiveness of existing policy is reviewed, and the budget and performance monitoring of service delivery is undertaken.

# Since touring Burgess Hill

Our work does not stop with this publication and we will continue to use influencing platforms along with our statutory powers to make positive changes for local people.

We want to continue to hear from local people about their experiences and if any of the changes have worked better for them. If you would like to comment on this report in any way, please contact us on 0300 012 0122.

Our publications are also shared with the [Care Quality Commission](#) (who regulate and inspect services, and who have the power to deregister services, which means they cannot continue to provide regulated services) and [Healthwatch England](#) (to inform a national understanding of health and care).

We recognise the pressure local services are under and are always pleased to help support practices and services by sharing best practice and using our communications channels to spread the word in communities about services available that can help patients to have a better experience (community transport, prescriptions etc.).

We continue to listen

Simply inviting people to share their experiences of health and care has enabled us to get closer to what is happening in these villages and we will continue to make sure we use every opportunity to amplify what people have told us about their experiences.

**Please contact us if you want to be part of our growing team of volunteer residents who are getting involved in making positive changes.**





The Billingshurst Community Centre  
Roman Way  
Billingshurst  
RH14 9QW

[www.healthwatchwestsussex.co.uk](http://www.healthwatchwestsussex.co.uk)

t: 0300 012 0122

e: [helpdesk@healthwatchestsussex.co.uk](mailto:helpdesk@healthwatchestsussex.co.uk)