



# Listening to Littlehampton

Listening and understanding how Littlehampton residents experience health and care - as heard in March 2017

### Who we listened to

1,500+
Residents talked to us at events

26,000+
People engaged with us on social media during our tour

### Thank you

We would like to thank everyone in Littlehampton who supported us to listen and understand both what is working well and what could improve.



Before starting our *Listening Tour*, we invited organisations and members of Patient Participation Groups to a **Lunch and Learn event**.

Some stakeholders at this meeting gave us the impression that local people were uninterested in conversations about health but we soon realised this was not the case.

When given the opportunity, we found people were open to sharing their experiences and views, and at our Market Day stall we had people queuing to talk to us.

Rather than survey people, we simply asked them to tell us about their experiences of health and care. We listened.



### Recommendation and good practice:

We anonymised peoples' experiences (and have used other names) before sharing this valuable insight with those who plan, buy and provide local services.

We **recommended** local decision-makers looked closely at the learning points (shown by the checklist symbol) and asked them to tell us what they have done or plan to do to make their services better for local people.

# Contents

Page 3 - 4
Summary of learning opportunities

Page 5 - 7
Experiencing the closure of a GP
Practice

Page 8 - 17
Needing to see a doctor

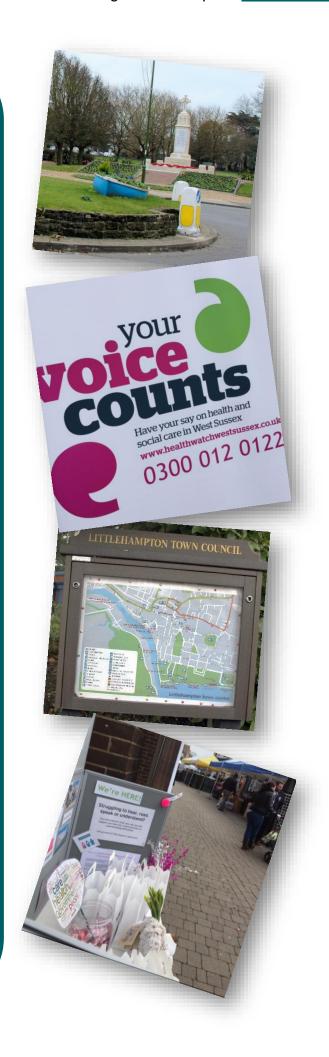
Page 22 - 25
Supporting peoples' mental health and wellbeing

Page 26 - 29
Experiencing urgent or emergency care

Page 30 - 32 Having a baby

Page 33 - 34 Other hospital care

Page 35-36
Since touring Littlehampton



# Summary of Learning Opportunities

Here are the learning opportunities gained from local peoples' lived experiences.

These are explored in detail within the report, which also shows how the Clinical Commissioning Group, Trusts and local GP practices have understood and used this feedback.

	Having more information about how a new service operates or even an opportunity to 'tour' and meet staff could help to get the relationship off to a good start.
	There should be a way for patients with very complex health and care needs to have access to a new primary care service ahead of a planned closure.
	How the phone is answered, is a good way of setting the tone for the patient/practice relationship.
	Adopting a sensitive approach and giving an explanation as to why the information helps, to make sure people receive timely assessments, to avoid negative views of the role reception staff have in triaging calls.
	When reception staff are involved in preliminary triage, or prioritising call backs, there should be clear and set processes/rules to follow. These staff should be supported to default to a safer option of speaking to a clinician if they are unsure, or if the patient is unhappy with a proposed follow-up plan.
	Recognising the call-back system can be challenging for some people is important.
	Asking people if there are any times in the day which do not work for them and assuring them they will be called back at the agreed time.

Spending time setting out information, so it is easy to read can help people learn about support in their community or how to manage their conditions.
Having staff names and photos displayed and uniforms, may help people to become more comfortable with the service.
All staff should understand the requirements of the <i>Accessible Information Standard</i> , and how they can support patients and their family and friend carers, whilst not risking breaches in data protection.
Linked to above, General Practices may find it useful to review the way patients are made aware it is their time to go to the consulting room, to avoid unnecessary delays.
All staff should be supported to understand, and have available to them, information detailing what services are available locally, when they are open and how people can access them.
Missed diagnosis reviews - as a process to let teams identify and address risks and issues, originally missed in A&E.
Trusts should work with their ward staff to look at how they can best support mothers' whose babies are in special care.
Hospital complaints teams should support maternity ward staff to ensure they work sensitively with parents who are complaining about their maternity care. This should include offering parents the opportunity to meet with them away from the hospital where they feel they had a negative experience

# Experiencing the closure of a GP Practice

Arun Medical Group (based in Littlehampton Town Centre) closed its doors on 31st October 2016 meaning 7,200 patients had to find a new doctors practice.

Once the decision had been taken to disperse the practice list, NHS Coastal Clinical Commissioning Group (CCG), who are responsible for planning and buying local health service in Littlehampton, and supporting general practices, told patients about the closure. The CCG provided information about how to register with another surgery and had people available to answer any questions.



We are aware the local practices worked closely with the CCG and each other to ensure as smooth a transfer of patients as possible. However, it is recognised that the closure of a practice of this size, has inevitably reduced the choice of practices in the area.

All of the Arun practices use the same clinical systems, so during the registration there were not, we are told, significant delays in practices accessing patient records electronically. The paper records were then manually transferred, at a later date, by Primary Care Support England (PCSE), which may have taken some time. PCSE are in the process of making significant improvements to the process for transferring patient records.

It is clear from discussions with local practices that taking large numbers of new patients is a considerable challenge and GPs and staff worked hard to ensure local people could continue to access a service.

14 people shared how this closure had directly affected them, with more commenting on how this extra demand had impacted their GP practice. Some of these people told us they'd had to return to a practice they had previously chosen to leave.

Bob and Betty (both in their early 90s) told us: We had a lot of information but it was still a bit worrying. This Surgery has taken us as patients and this is our first time here. We are surprised at how quiet it is but the reception staff have been really polite in person and on the phone and really helpful. We were impressed when we asked about a blood test and they said they would call back with my appointment. Only problem is we can't walk in and make an appointment, like we could at Arun Medical Group. We were hoping for the surgery at Morrison's to open as it is closer to where we live.

Sandra shared how she had been reluctant and uncomfortable about changing doctors. Since changing I've been very pleased with the service I've had at this Surgery and I like my new doctor very much!

### For some the change to a new surgery did not work out as they had hoped:

Clare wanted to change to a new practice in good time with the support of their GP, as her young son has severe and complex health issues. Unfortunately, this didn't happen:

I enquired about changing as soon as the first letter arrived but I was told I had to wait until the surgery actually closed. Due to my son's complex needs and conditions, there was then a problem with delays of information sharing and transferring of his notes, when we finally registered somewhere else. This was what I wanted to avoid and it caused us no end of stress, anxiety and logistical problems, in getting prescriptions and routine tests sorted.

I think (the new surgery) is awful as we never see the same doctor (or professional) twice. At Arun Medical Group we had a named doctor who knew all about my son's issues and liaised with the hospital on our behalf and there was really good communication between everyone involved. I have to manage everything myself now and it's a real struggle emotionally and practically.

Sally and George were on holiday for a few months' when the letter about the closure arrived: When we got home we tried to register at one Surgery and were told their list had only been open for one day to patients transferring. We were directed to another local one. When we got here we were told their list was also closed but when we explained that we were Arun Medical Group patients and had been away until November we were accepted. Since we registered here we've been very happy. It's a very small and friendly practice. It might look a bit shabby but the staff make up for the appearance by being fantastic!

Barbara and her terminally ill husband moved to Arun Medical Group as they were not happy with the way staff had been communicating with them at another surgery:

It was our choice and, although they weren't perfect, I was more comfortable with the staff. I heard late last year that the surgery was closing and my options were very limited. I have re-registered at (previous surgery) because that is my nearest surgery and it is difficult for us to travel. I am still not happy with the team here and I feel that I didn't have a lot of choice. So I am stuck here.

Jan told us she'd had loads of letters from The Causeway (the CCG) but wasn't sure what to do or where to go: I don't want to go to one Surgery because I've friends who say it's terrible. Thankfully I don't go to doctors very often but what am I supposed to do if I need help? I was really confused by the letters ... now I reckon it's too late! (Healthwatch offered Jan some information about what to do to register with a new GP.)



 Normally when registering with a new practice people expect to have a New Patient Check but this did not appear to have happened and people therefore only had their previous experience to shape their view of the new service.

Having more information about how a new service operates or even an opportunity to 'tour' and meet staff could help to get the relationship off to a good start.

 Whilst we recognise the task of transferring a large number of patients to new practices is huge, there should be a way for patients with very complex health and care needs to have access to a new primary care service ahead of a planned closure.

### What local practices and the CCG have learnt, said and/or done:

We have learnt from this feedback that some of the letters that were sent out to patients could have been clearer, and this is useful learning for any future similar situations.

Given the number of people re-registering, it was not possible to provide a new patient check. The doctors from Arun Medical Group worked closely with the doctors in the practices that were receiving their patients, to share information and their notes immediately on registration.

When the Arun Medical Group were aware of the need for patients to reregister in other practices, they identified over 2,000 vulnerable patients (including children under the age of 5, adults over 80, those in nursing homes, dementia patients, those with learning disabilities, mental health problems and those on certain medications, and conditions). The practice worked hard to contact these patients to offer support to register elsewhere. In spite of this, it seems that some patients with complex needs slipped through, and this is useful learning for any future similar situations.

It is worth noting that all practices in the area are accepting new patients, so should anyone wish to consider alternative GPs they are able to do so, provided they live in the boundary area of an alternative practice. To find out if you are in a practice area, you can put your postcode into <a href="MHS Choices">NHS Choices</a> which tells you the nearest practices, and you can contact them to find out if you are in their area. Alternatively, call Jacqui Hanson (jacqui.hanson@nhs.net) on 01903 708527.

Practices did provide leaflets about how the practices worked for new patients, as they were aware that they may have different approaches to the closing practice. We appreciate that more could be done to welcome new patients and we are looking into ways of explaining how the surgeries operate.

# Needing to see a doctor

The loss of Arun Medical Group, as a key provider in Littlehampton, was very noticeable in the stories we collected.

Although there were obvious negative impacts, we also heard the closure has led to local practices (which are individual businesses), being more willing to come together to find better ways of meeting the health needs of local residents, within the available resources.



There are now 6 GP practices with 7 surgeries in Littlehampton. We spent time talking to people in each practice.

As we should expect, some residents were full of praise for local NHS services.

**Emily called her Surgery** as she was very dizzy: I got an appointment immediately and saw a new female doctor. She gave my head a twist and massaged my neck and the dizziness ceased straight away! Very impressed with the service.

**John told us:** I was recently sent to a surgery that wasn't my own to be seen by a doctor, which wasn't ideal but I was seen promptly and felt cared about. When I put in a recent prescription it was ready for me when I needed it. This made me feel as though I could trust this service.

**Justine said about her Surgery:** the Paramedic service here is brilliant! The nurses are good too and do a lot of the work because the doctor's don't seem to have many clinics. When you see the paramedic they are very thorough and can do prescriptions too. I would say it's a very efficient service.

Others have seen and experienced the pressures and demands on the NHS and here we explore the learning from what local people have shared.

Through our discussions with local people, it is clear some are disappointed that there is still not a GP surgery on the Morrison's site. This space has been empty for 10 years now and we are told has been vandalised internally.

Others spoke about the old Littlehampton Hospital and their desire to see health services delivered here again. With a few people saying these empty spaces create a sense that the health of Littlehampton residents is not worth investing in.

### What local practices and the CCG have learnt, said and/or done:

Fitzalan Medical Practice and Westcourt Medical Practice are working with the CCG, Arun District Council and NHS England, to see whether a new GP surgery can be developed on the Morrison's site in Wick. Currently, the GP practices are working up the internal design and costs of a new build practice. Once this work is done, the CCG's responsibility is to determine whether what is being proposed provides value for money, over the proposed length of the lease, which is likely to be 25 years. This will be an important decision about how the CCG uses local NHS money, given both the cost and maintenance required, for a new build health facility.

The old hospital site is bordered by land owned by West Sussex County Council, Arun District Council and Sussex Police, as well as the NHS for the nearby health centre. All these organisations have agreed to work together to look at how the whole site In Maltravers Road/East Street can be used in the future. This makes more economic sense and will help to regenerate the whole area. Feasibility work is being undertaken now to determine how the land can best be used, which will include new health provision. As with all new developments, this is a long-term project and dependent on capital (initial) and revenue (ongoing) funding being available.

### Registering as a new patient

We heard about, and saw, people struggle to register as new patients.

Jo was shocked to discover she couldn't register her new born baby at her own practice. After I had my baby I went to my surgery to register her. My partner and I had been patients there a long time. We had never had a totally fantastic service but equally we weren't unhappy with them, so we were more than happy to have our new baby registered there too. But when I went in they said that their list was closed and that they couldn't take on new patients.

I thought this was awful - my baby was 3 days old! I tried negotiating with them and asked to speak to someone senior but was told that the policy was no new patients and that there was no room for negotiation. I decided to move my whole family to another surgery, who were happy to have all five of us!

We saw an elderly couple trying to register at a surgery. The couple told the reception staff the name of their road and were asked which side of the Fuel Station they lived on. Clearly this was the boundary line, and as they said lived on what was the 'wrong' side of the station, they were told they could not register. They were not offered any further information or advice.

Some Fitzalan Medical Group patients shared their disappointment, at having registered at Wick Surgery, they were only able to get an appointment at the other surgery. We were told how difficult it was to get to this surgery, when you have to walk across town with a sick child or had to get childcare in place to cover the extra time it takes to get to the surgery.

However, we also heard having access to the Wick Surgery, instead of the Fitzalan Road Surgery, was better for one patient as they worked closer to the surgery.

### What local practices and the CCG have learnt, said and/or done:

It is the GP policy that any newborn babies are able to register with their parents, even if the practice is not taking on new patients, and staff are aware of this. We apologise for any inconvenience, and acknowledge that this was a busy, confusing time with the lists opening and closing at each surgery. We will continue to update staff about this.

We will make sure our practice staff, including receptionists are kept up to date with local practice boundaries so they can divert patients appropriately when needed.

Fitzalan Medical Practice has recently recruited more staff and have more appointments available at Wick Surgery.

We have now completed recruiting all the extra staff needed to look after the patients we have registered. This includes: 2 full time doctors, 2 nurses, 1 paramedic practitioner and 4 reception staff.

# Working to manage demand

Most of the GP practices have introduced a **telephone triage system**. This type of system aims to make sure each patient is referred to an appropriate clinician (a pharmacist, practice nurse, paramedic practitioner or GP) to get an appropriate level of care within an appropriate time period.

Patients at The Lawns told us they can call and book an appointment to see the doctor. All the patients we spoke to at this practice told us they have had good experiences. Patients are seen by the same doctor (this is a single-handed practice).

Triage systems usually start with patients themselves, with most people having already reflected on their condition and considered who they feel they need to see and in what timeframe. Others will have spoken with friends, neighbours, relatives or work colleagues. The usual starting point for a GP practice's triage is for reception staff to establish with a patient their assessment of their degree of urgency. Patients we spoke to, were largely not very positive about this part of the process, particularly at Fitzalan Medical Group.

Louise who is in her mid-twenties and is a patient at Fitzalan Medical Group, explained how she feels about the triage system: The receptionist asks what is wrong and I don't feel comfortable telling them. If you call for an on the day appointment you have a phone consultation. It is difficult to relay what is wrong over the phone, so it feels like it's a test. If the doctor deems you ill enough you end up with an appointment.

This was a view shared by other Fitzalan patients

I don't like telling the receptionist about my health issues, I think they're just nosey half the time and you end up saying it all again to the doctor or nurse when they call you back anyway.

**About a year ago**, my 3 year old daughter was suffering with breathing problems. I was quite anxious and called the surgery for an urgent appointment but was told there were no appointments available for 3 weeks. I stressed the urgency to the receptionist but she just said a firm no. I was so upset and worried that, in the end, I called 999 and my daughter was taken to hospital and put on a nebuliser for an hour or two. I just don't like the receptionist making these sort of decisions. I don't like the call back system to decide if you need an appointment surely you know if you need to see someone or not, in most cases?

I called Fitzalan Surgery last week because I was worried and anxious about my own mental health. I'd been struggling for a few days and felt like I needed a bit of support. The telephone person asked me a lot of questions that I thought were quite intrusive and made me feel uncomfortable. Then they said that one of the doctors would call me back to assess me and see if I needed an appointment there or with the Mental Health Team or just a prescription. That was last week and I'm still waiting for the call back!

Most practices have experienced nurse or paramedic practitioners doing the triage call backs. These qualified people assess patients' symptoms and concerns, and should then be agreeing with each person how these needs might be best met, either by giving telephone advice or a face-to-face appointment, along with a suggestion of the appropriate urgency. This works for a few patients we saw.

Julia likes the triage, call back system at Fitzalan Medical Group. It suits me. They assess you to see if you need to see a doctor or one of the paramedics or one of the nurses. We never have to wait too long - 20 minutes on average, which I feel is quite reasonable.

We saw the Paramedic Practitioners expertise in practice during a visit to Park Surgery. A patient had called in the morning for an appointment as she was not feeling well. The Paramedic Practitioner immediately recognised the lady was seriously ill. We witnessed how this emergency was handled in a calm and efficient way and that the staff took the time to let other patients know there would be a delay. Two nurses and a GP were involved in caring for the patient until the ambulance arrived, which ended up taking 25 minutes.

Some patients told us they felt confident enough to challenge the triage professional or had experience to know when a clinical suggestion was not right. Others appeared more accepting of initial advice but later needed more support.

David had a badly infected finger from gardening. We went through the normal triage system at the GP surgery but the symptoms were difficult to describe. My husband is not the best at articulating issues! The receptionist or nurse or whoever it was, didn't think it was a problem and said we should go to the chemist to get some antiseptic and it would get better in time. They would not see him. After 24 hours it was much worse, so we took ourselves off to the MIAMI\* clinic at The Park Surgery to seek help. They had a quick look at him but told us we'd have to see our own doctor, as it needed antibiotics and probably lancing or a minor procedure to drain the pus. They said they couldn't do it and they wouldn't prescribe the antibiotics.

Eventually, after I kicked up a stink on the phone - we were seen by a doctor at our Surgery and he cleaned the finger and lanced the infection. He dressed the wound and prescribed antibiotic cream and tablets. He said that had the infection been left, it could have been quite serious. He mentioned sepsis.

It did seem a bit silly we had to go through such a long-winded process. Nobody listened and nobody took us seriously. Surely patients know their own bodies and can tell if something is wrong. When we ask for help it's because we need help, not because we're doing it for fun!

\*MIAMI - Minor Injury Assessment and Minor Illness

Where people said they insisted on having an appointment with a particular doctor, they told us the wait for the appointment, was too long. One person was 'disgusted' that his 75 year old mother has had to wait two months to see her own doctor at her Surgery.

Others also spoke about long waits to see a doctor at this surgery.

The Royal College of General Practitioners acknowledge that "while (triage) systems work very well in some areas, they shouldn't be considered a blanket solution to ensuring that patients have good access to general practice services whilst resources are so scarce. As such, every GP surgery is responsible for implementing its own appointment booking system, taking into account local needs.'

(November 2016)

http://www.rcgp.org.uk/news/2016/november/telephone-triage-systems-are-designed-to-help-patients.aspx



How the phone is answered, is a good way of setting the tone for the patient/ practice relationship.

Westcourt Medical Centre's phone system has a clear and friendly message recorded by a doctor, stating they are 'trying a new triage system' and promotes quiet times for calling. We called during a quiet time and the call was answered promptly, in a very friendly manner - with the person giving their name.

This seems a positive way of letting patients know they don't have to call first thing in the morning. However this will only work, if people are still able to get a prompt appointment when they call later in the day.

Continued over



 The questions reception staff ask can come across as intrusive and local people do not understand why such questions are necessary or how these staff have the clinical knowledge to use this information. This was particularly an issue mentioned by Fitzalan Medical Group patients.

This is something that can be resolved through adopting a sensitive approach and giving an explanation as to why the information helps to make sure people receive timely assessments. Having such a discussion can also help establish a person's preference, communication needs and any choices available in the triage process, e.g. a phone call back at a particular time.

Patients also need to feel confident that reception staff are not making clinical judgments about their needs. Where they are involved in preliminary triage, or prioritising call backs, there should be clear and set processes/rules to follow. These staff should be supported to default to a safer option of speaking to a clinician if they are unsure, or if the patient is unhappy with a proposed follow-up plan.

For example we were told Park Surgery staff have prompt access to the doctors so they can provide appropriate support to patients.

 Recognising the call-back system can be challenging for some people is important.

Asking people if there are any times in the day which do not work for them and assuring them they will be called back at the agreed time, could help people to have access to early clinical advice to reduce the use of hospital services.

### What local practices and the CCG have learnt, said and/or done:

At Fitzalan Medical Practice, the telephone triage system has been in place for several years. By telling the receptionist what your problem is, it enables doctors and nurses to sort out the queue and make sure that patients get what they need by the right person at the right time. Many problems can easily be sorted out over the telephone and it means that patients that need a face to face appointment will get it promptly.

Receptionists are trained to treat this information sensitively and confidentially but if this is too off-putting for a patient they can record that the problem is 'personal', and the doctor will call them back. Patients are given the opportunity to say when they can be called. Receptionists are not expected to make clinical decisions and they do have access to clinical staff if they are uncertain about the urgency of a call.

In order to organise the surgery efficiently it is preferred if most calls come in the morning and we tend to receive only urgent calls in the afternoon. However, we recognise that this will not work for some of our patients and so if the problem is explained to the Receptionist we can usually make alternative arrangements.

Local Practices now have funding to develop a new online provision through our practice websites, which will also make gaining access more convenient for some patients.

The feedback from this report suggest that people are not clear about some of the more flexible aspects of this system. We will address this by reviewing the information on the website and the initial phone message, to make it clearer why receptionists might be asking questions Fitzalan Medical Group would be keen to get help from Healthwatch to do some 'video with patients and clinicians explaining how it works, and this can be shown on the website and on TV screens in the waiting rooms.

The locality director, for the area, has listened to all the GP practice phone messages and they are being reviewed to respond to the suggestions here.

# Creating a caring environment

We saw very contrasting waiting areas.

Westcourt Medical Centre's photo board is visible to patients and its staff wear clear name badges. Other surgeries have staff in uniforms.

The Park Surgery has a fresh waiting area with large information wall frames, organised by topics. To develop these, the reception staff spoke to people sitting in the waiting room about what information they would like to see displayed. There is a TV, displaying information and patient name and consulting location when a patient needs to go to their appointment room. This was funded through the Patient Participation Group's fund-raising and patient donations.

In contrast, the walls and surfaces at the Fitzalan Road and Wick Surgeries were awash with posters and leaflets, and it was hard to see anything through the volume of information. One couple told us there was not a way they could share their views with the surgery. We pointed out the 'Friends & Family Test Feedback' surveys and box, as these were not in a visible place. These surgeries do not have any electronic displays and clinicians come into the waiting area to call out patients' names. We saw that not all patients heard their names being called.



- Spending time setting out information, so it is easy to read can help people learn about support in their community or how to manage their conditions.
- Having staff names and photos displayed and uniforms, may help people to become more comfortable with the service.

### What local practices and the CCG have learnt, said and/or done:

Fitzalan Surgery has just been redecorated and the *Friends* and Family Test feedback surveys and box are very visible now. Their staff photographs are on the website, and the practice will consider putting up photograph displays of medical staff as part of the redecoration.

Fitzalan and Healthwatch are exploring opportunities to review how information is displayed at Wicks Surgery.



### Communication

The introduction of the *Accessible Information Standard* in July 2016 should now mean all patients, and their family and friend carers are asked about their communication needs. Their communication needs should then be recorded, shared appropriately and individuals should receive support so they can access and communicate with services, which should help them in making decisions about their care and treatment.



Despite this, some people told us they struggle to have meaningful conversations with NHS staff.

We met Georgina at a Carers Support event and she told us about the frustrations she has when speaking to NHS staff. I have had several times where I have been speaking to professionals, both in a hospital and at our GP surgery, and they have cut me off or told me that they can't discuss my husband's care or treatment because of the Data Act. I think they hide behind this. They don't understand what the Act is or what it does. I am the main carer for my husband and although he doesn't lack capacity, he does have serious memory issues and I have his written permission to act on his behalf, to support him to make and keep appointments, etc. But some of these jobsworths won't even let me make an appointment for him because of this fantasy of data protection.

We witnessed good communication and heard about areas where communication with patients could be improved.

Linda was visiting her Surgery with her husband, who is still working but was at the surgery to have a follow-up check after a heart attack.

I came into the surgery after my husband had been discharged from Worthing Hospital following a heart attack, as he hadn't been given the right paperwork to get the medication he needed. The receptionist made me feel I was to blame, when it was a system error.

I then had to come in again, as we were making a claim against our holiday insurance, having not been able to go away because of his heart attack. We needed the doctor to complete a short form. When I enquired about this, the same receptionist just said 'No'. I went on to explain that it was only a short form and we would not be able to make a claim without it. She reluctantly then said 'No without having a payment upfront'. The cost was £35 and we were told this would take 3-4 weeks to complete.

Paula shared an experience she had last year that left her feeling very unhappy.

My 6 year old had a bad ear and was screaming in pain. I was convinced she had an infection and called the doctors. I was told there were no appointments available but we could see the triage nurse. The nurse was also concerned, so she sought a second opinion from one of the GPs. He was curt and dismissive, saying she had a virus and told us to just give her Calpol.

We went home and she was screaming in agony, so after a few hours I called 111 and we got an out-of-hours appointment. The doctor confirmed a deep and rampant infection.

We spoke to Janice who was back for another appointment for a blood test.

This is my second visit this week, as no one told me I had to 'fast' for the test and my blood sugar readings were borderline but I had eaten toast and marmalade before the appointment.

Tia (who is in her 20s) told us she has tried to make a formal complaint to the Surgery but was not successful.

I was told the paperwork wasn't filed properly, and now the member of staff I was complaining about treats me very differently. Their tone of voice changes when I am on the phone and sometimes they say they have booked an appointment for me, I turn up and the appointment has never been made. I have started to get my mum to listen in on the phone calls and I call 10 minutes later to double check the appointment has been made. Now I don't go to a GP appointment without my mum. I don't trust them at all. Not only are the reception staff rude and ignorant but I don't feel like the GPs take any of my symptoms seriously and I feel like they just ignore them and see me as a problem.

This was not an isolated experience. Other patients told us about errors in appointments they had made and the frustration this caused. Others described their experiences in terms such as:

I feel fobbed off by the doctors here.

Don't talk to be about doctors.... I feel they have 'written me off'.

I would never take my children to see Doctor (name given) as I always feel belittled and told off for being ill.

A patient shared their confusion about how they can use the MIAMI (Minor Injury Assessment and Minor Illnesses) clinics in town.

My friend said she went with her child and they just turned up and walked in. When I went with my son, we were told we have to make an appointment through our GP or through 111. I don't know what the system is and I don't know how to find out. I asked the receptionist at my surgery but they didn't seem to know.



- All staff should understand the requirements of the Accessible Information Standard, and how they can support patients and their family and friend carers, whilst not risking breaches in data protection.
- Linked to above, Practices may find it useful to review the way patients are made aware that it is their time to go to the consulting room to avoid unnecessary delays.
- All staff should be supported to understand, and have available to them, information detailing what services are available locally, when they are open and how people can access them.

### What local practices and the CCG have learnt, said and/or done:

As local practices, we are improving awareness of the Accessible Information Standard. We are currently undertaking a programme of education for reception staff, focusing on signposting to services.

The MIAMI clinic was introduced in winter 2016/17 and we recognise there were some early teething problems, which have been put right.

The MIAMI Clinic is not a drop-in service. In order to get an appointment with MIAMI, patients need to contact their GP surgery, who will organise this if it is appropriate.

# Areas where peoples' GP Practice experience could be improved

We recognise the pressure on local GP practices and that some patients are more than happy with the support they get from the surgery, but we heard experiences which suggest more support could have been offered.

A patient told us this was the third time they had been in to the surgery to check on the status of a referral. They had been told their paperwork was still not actioned, as it was sitting in the secretary's tray. The patient was very distressed but was sent away again.

Joyce's mother is living with dementia in a local residential home. My mother's GP recently decreased her medication by half, without any explanation. The notes go directly to the home and the staff are usually very good at communicating with us but this time it took them over a week to get in contact about this change. Mum had begun feeling bad before the GP visit and a community psychiatric nurse (CPN) decided to put her on some antipsychotics. The GP was unaware of this change and the CPN was also unaware of the changes in pain medication. It has been a cycle of poor communication and mum is suffering more because of it.

Charles had a routine blood test in last year and went back to his GP for another matter 4 months later: It was only then that I was told I had type 2 diabetes. I hadn't been aware my blood was going to be tested for this, as no had told me. I've since been back and asked what the symptoms of diabetes are, other than blood sugars. My GP went through the list and I've none of these.

Harry went to his GP last autumn for a problem and he asked for a blood pressure check but the GP said no as they were out of time. He was directed to the pod in the waiting room: I went straight to it and the reading was very high. I went home and looked it up online and realised it was very, very high and I was at risk. I made an emergency appointment the next day and saw another doctor, who told me I needed to start blood pressure medication immediately as I was at risk of a heart attack!

Sarah is living with fibromyalgia and feels the doctors at her Surgery aren't interested as soon as she says she has this condition. I'm under the pain clinic at Bognor War Memorial Hospital, which is very good. My consultant has had to phone the surgery directly, to get them to respond.

**Veronica called her Surgery** to make an appointment for her 90 year old mother but was told she would get a call back in 10 days'. She told us 'when the doctor called, it was only for a chat and not an appointment'.

Wendy who is in her late 60s went to her doctors as her toe was really hurting: I was told there was nothing the doctor could do. When a nurse came to visit me to check on my catheter I mentioned it and she said that I needed to go to the hospital, as my toe was blue and there was something seriously wrong. Someone had a look at it in the hospital and it turns out I had a piece of glass inside my toe.

### What local practices and the CCG have learnt, said and/or done:

Local Practices recognise that they do not always get it right, and when things go wrong we review them at regular monthly meetings and try to improve our services as a result. All the responses have been fed back to the individual practices.

It is important that people should feel able to give feedback, and make complaints, directly to the surgeries so that we can review what happened. Fitzalan Medical Group would welcome Healthwatch to review our complaints information and process to ensure it is clear and accessible.

We do regularly monitor feedback on NHS choices, and have recently received many lovely comments. The Practice managers always responds to these as they acknowledge how kind it is of patients to take the time to post. The Practice Managers are always happy to speak to a patient if there is a complaint, or to call them back when available.

# Supporting peoples' mental health and wellbeing

Local people told us about some of the good ways local services are supporting peoples' mental wellbeing.

Jonathan's daughter is now 18 and has had long term mental health issues, including depression, anxiety and suicidal thoughts.

We've been through the mill with CAMHS (Child and Adolescents Mental Health Services) over the years and endured the transition to adult services, which was a challenge in itself. She has been quite well for a while but in the last few months she has been very withdrawn and we've sought help once again.

Thankfully our GP at The Coppice Surgery suggested we made a self-referral to the young peoples' services run by Coastal MIND in Littlehampton. We saw a lovely lady who talked us through all the options and support networks and my daughter has opted to attend a community group session. She is a bit anxious about attending for the first time, on her own. So I will go with her and the group leader has said that I am allowed to do this for the first few sessions. We both felt the support and reassurance from MIND was excellent.

**Another person** described local MIND as 'brilliant'.

Sadly, we heard from many more people who struggled to get the support they need to recover or stay mentally well.

Barbara shared that her husband has a long term mental health condition and how she has found local service:

A few weeks ago my husband had a psychotic episode and a mental health crisis. I called Pepperville House (which has a psychiatric support team run by Sussex Partnership Foundation Trust) as we'd been instructed to do in his care plan.

I spoke to the person on duty and they gave us some immediate advice and support and said they'd speak to their team and get a more senior psychiatric person to call me back, to offer more in-depth support and perhaps arrange a home visit or an appointment for us to go in for a meeting. That was nearly 2 weeks ago and we're still waiting for this call back.

I've got so frustrated that I took my husband to our GP, who has admitted he is not a mental health expert and has limited knowledge in this field. He is going to chase Pepperville House and hopefully get things moving for us.

#### Julia told us about the challenges her son and family have faced:

My son has had mental health issues since he was very young and was prescribed Prozac when he was in Junior School. This was later suddenly stopped by another doctor and the consequences were awful. He is now in his late twenties. The struggles he has had have put a tremendous strain on our family.

He still lives with me and is dependent on me for everything. He has serious mental health issues and I've sought help from my GP so many times but I feel they just aren't interested or they don't know what to do with us.

One GP thought he could be autistic - which I believe is the case, having done my own homework. So a mental health worker was sent to our house to assess and diagnose him a few months ago.

My son rarely leaves his room. He doesn't communicate very well and when she came to our house, he wouldn't come out of his room to see her. She wouldn't go in, even though I said she could. So she concluded after chatting to me for a few hours that he wasn't autistic and that he was disengaging with services. Therefore no help was offered and he was discharged from the Mental Health Team.

I feel this is utterly wrong. My son needs help and I can't get it for him. I don't think the worker/assessor really knew about mental health issues to be honest.

I have lost all faith in the services.

Lucinda's heart is breaking for her grown up daughter, who has learning disabilities, she said, as she's not getting the support she needs in a mental health unit:

I'm an elderly lady now and I'm still the main carer for my daughter. She has developed serious mental health issues and has attempted suicide. She was sectioned last year because her behaviour was unmanageable and she'd become dangerous. The mental health unit can't support her learning disability needs. There isn't the provision for her to join in with the activities or group therapy sessions because they can't cater for her needs or support her to take part.

Paula's son, who is now in his early twenties, has mental health problems and has been in various mental health hospitals:

There are no activities in Meadowfield and my impression is that they just sit around drinking coffee and singing Kumbaya and then he gets discharged back to me. Last time he was discharged with no support at home and no care plan. The Chichester unit seems to have much more going on.

A Physiatrist advised that my son should live independently. So this was organised but whenever he goes into crisis, he has to come home as there's no support.

For those who support vulnerable people who are not only living with mental ill health but also have drug or alcohol issues, getting professional support for someone who is in crisis is really challenging: We had a chap living in our home who was threatening to self-harm and hurt others. We called the crisis line and had to lock the chap in his room. We ended up waiting 8 hours. Eventually a psychiatrist and worker turned up, which was 2.5 hours past our going home time. We were told he needed to go into an acute mental health hospital bed but then they had none available locally. He ended up 100s of miles away.

Parents shared their frustration over the limitations of local support for children and young people living with mental health issues.

Paul has two step-sons who have both struggled with their mental health: I attended CAMHS sessions with the boys when they were under 16. I was surprised when they took the boys off for a consultation and didn't let us in or know what was going on. This caused problems when the boys would come out saying their medication had changed and we'd have no ideas why or what to expect. I can't understand why when the law says they are still a child, as parents we were excluded?

Louise has two daughters who have had mental health problems and she told us about their experiences:

My eldest daughter has multiple mental health problems, including Asperger's. The Worthing CAMHS are only interested in treating young people who have ADHD etc. She was put on 8 different medications and we had to push for her to see a specialist.

Things got so bad that our family went into crisis and she had to go into care. She is now at University (out of the area) and is getting lots of support, including CBT (cognitive behavioural therapy) and is drug free. She's the happiest she has ever been.

My younger daughter has anxiety and it took 5 months to get an appointment and then she was just put on medication.

### What the Trust has learnt, said and/or done:

It's always difficult to read people's poor experiences of mental health services because we are committed to providing the very best care for everyone we serve. That, said, sometimes we don't always get it right and we are just as committed to learning from our patients and their families to make things better in the future.

We recognise the hard work of Healthwatch in producing this document and their on-going support in efforts to improve outcomes for patients.

It is important to stress that the vast majority of Sussex Partnership patients benefit from timely and appropriate mental health care from dedicated staff, either at home, in a community setting or, sometimes, in hospital. However, every patient deserves the best possible service and we recognise that currently some people are not experiencing this.

Continued

### What the Trust has learnt, said and/or done:

We are doing a lot as a Trust to improve our services:

Our services are working more closely together so that our Trust specialists in Autism spectrum condition can advise and support our mental health services wherever possible. We are also working with local commissioners to try and ensure people with Autism, Aspergers and other developmental disorders are better understood and supported by our mental health services as we are very aware how they often fall between gaps in services and are left very vulnerable as a result.

We are also reviewing and changing how we work to more closely involve young people and their families, specifically by ensuring our care planning is done in partnership with young people and families. And work with our commissioners and health partners continues to develop an assessment process for neurodevelopmental assessments and post diagnosis support.

We accept there is always more that we can do.

# Experiencing urgent or emergency care

From what people told us, we can determine local people remain confused as to when, where and how to get the help they need when they are unwell. The introduction of the new *Our NHS* campaign and posters should help to reduce some of this confusion.

People who shared with us that they had called NHS 111, provided locally by South East Coast Ambulance Service (SECAmb), appeared to have had very different experiences.

Patsy told us how her husband had cut his finger really badly doing some DIY: We didn't want to trek to A&E and wait for hours for something that was quite minor but we were worried that it might need some more in-depth treatment or dressing, than just a plaster! So I called 111 and explained everything. We had to examine and describe the wound - size, shape, what had caused the injury and other health issues/medication etc. Then the person on the phone, I think they were a nurse, talked me through how to clean and dress the wound. He didn't need to go to A&E and it healed beautifully.

Despite being on her own and being physically sick, Caroline feels she had to endure a really long and drawn out assessment process when she called 111: Although I appreciate the need for the assessment, they could hear I was being sick and crying. They couldn't fast track or skip the process. Eventually the 111 person told me that I really needed an ambulance and should be seen at A&E. They told me they couldn't arrange it and I had to hang up and call 999 myself. I later discovered I had a kidney stone.

Sue called 111 for information about whether she needed to seek further medical help with her son: My 3 year old son was unwell and I'd given him some Calpol but then my husband also gave him a maximum dose as he didn't know I'd already given it to him. We didn't panic but wanted to check to see if it was dangerous and if there was any need to seek medical help. I called 111 and they answered quite quickly but after a really lengthy verbal assessment, most of which seemed irrelevant to me, we were told that our situation wasn't a high priority and that a doctor would call us back within 12 hours. We were told that if he deteriorated or we were at all worried, we should take him to A&E. I was actually appalled at the response and was quite worried but not to the point that I wanted to put him or us through the trauma of going to A&E if it wasn't necessary.

Henry wasn't impressed when he called 111 as he thought his wife was having a stroke: It took 20 minutes to get the information across and the person on the phone asked to speak to my wife.

In contrast, Frank recently called 111 for his wife: We got an excellent response even at 11pm and the doctor was very helpful and understanding.

Some people shared their experience of the local 999 service, also provided by South East Coast Ambulance Service (SECAmb).

Keith lost his father last year and his lasting image is seeing 5 paramedics working on his Dad.

Bob had a minor heart attack at home recently and his wife called 111 (not 999) because she didn't know what to do. The ambulance arrived 10 minutes later and they were very good. They took him straight to Royal Sussex Hospital, where they sorted everything out.

We spoke to someone who supports residents who are homeless, have mental health or drug problems. We call for an ambulance and they turn up and are unable to deal with the person as they are under the influence and we're left with the situation.

### What local practices and the CCG have learnt, said and/or done:

The seven CCGs across Sussex have recently extended the 111 contract, until March 2019, with South East Coast Ambulance Service (SECAmb). The information provided in this report is very helpful and we will be feeding these issues, along with other patient feedback into the contract extension work, to improve patient experience as well as feeding into the design of the new 111 model.

Together, we see the value of local people continuing to share their experiences in the meantime to help shape the future of this service.

# Worthing Hospital A&E

16 people told us about their experiences of visiting Worthing Hospital's A&E, with just over half giving a positive account. We heard statements like 'Worthing A&E staff are fantastic'.

Bruce came to Fitzalan Surgery earlier this year for a health check but ended up being bluelighted to Worthing Hospital: I found the care at Worthing Hospital to be very good. I don't sleep well and didn't like the environment but as I was awake at 2am the staff would give me a cup of tea and some food - I was hungry because the portion sizes of the meals weren't enough.

Emily's grandmother, who is in her late 80s and has dementia, had a fall and broke her hip in the care home where she lives: She was taken to Worthing Hospital and is now on an orthopaedic ward. They have been marvellous. They can cope with her dementia as well as her physical problems and post-op care.

Karen went to Worthing Hospital A&E back in December with her father who had pneumonia: All the staff seemed stretched beyond capacity. There were no beds. However, everybody we met was polite, happy and reassuring.

Others said they were grateful for the care they had received but there were areas which had caused issues for them.

#### Betty's elderly father was admitted to Worthing Hospitals A&E:

The paramedics were great and I think the A&E staff were brilliant. But there were some fundamental tests and actions which weren't done. He was discharged and had another heart attack a week later, resulting in him having a stent operation and spending a couple of weeks in hospital. His abilities were not the same but when they asked him if he could make a cup of tea and do his shopping he said yes and therefore no care was put in place. He was discharged with no formal support and I ended up having to give up my voluntary work to care for him. I wasn't made aware of any support available through Carer's Support, which I found out about today from you (Healthwatch event).

When Dad went into hospital he was on 3 tablets and he came out with two carrier bags of loose medication. A total of 22 separate drugs. It took me a couple of hours just to sort out this medication. I was so worried about overdosing him!

Douglas described himself as a season ticket holder for Worthing Hospital because he has a number of long-term conditions: I'm full of praise as they saved my life! My consultant has told me that if I get certain symptoms I must come straight to hospital for treatment, which I've done on a number of occasions. Each time I've struggled to get the A&E consultants to take me seriously and get me to the specialist. Finally the consultant wrote and sent me a letter that I can take with me, so that the A&E staff know what to do. This worked the last time I had to go in.

For a few people their experiences were not good ones.

Debbie is in her 30s and very recently attended A&E as she was suffering from severe stomach pain, so much so, that she could hardly breathe or move:

I arrived at Worthing Hospitals A&E at 2am. I laid in a cubicle for several hours and had basic blood and urine tests. I was discharged at 6am, after being told I was probably constipated and to take Paracetamol. I was in such a state that I accepted the advice and left.

As I was in so much pain, my partner took me back to Worthing A&E that evening. They discharged me at 1am with the same diagnosis - constipation. I hadn't had a scan, x-ray or other tests. A doctor hadn't even examined me - they had simply asked questions.

I was so bad when I got home that my family ended up calling 999. The paramedics came quickly and did a thorough assessment. We told them about the two visits to Worthing A&E, so they offered to take me to St. Richards Hospital in Chichester. At St. Richards they did lots of tests and examinations/scans and found that I had a twisted ovary, and it was at risk of rupturing, which in turn could cause sepsis. I was admitted, had surgery and am now having follow-up treatment.



Missed diagnosis reviews - a process to enable teams to identify and address risks and issues, originally missed in A&E, is a valuable learning opportunity to improve patient care and reduce financial costs.

### What local practices and the CCG have learnt, said and/or done:

I am very pleased and encouraged to see that even when patients have attended when the department has been incredibly busy, they have acknowledged that our staff remained caring, polite and cheerful.

All patients receive a thorough assessment by both nursing and medical staff and we have introduced a new approach called EDIT, in January 2017, senior nurse practitioners request investigations, in order that the results are available to Doctors as soon as possible to determine a possible diagnosis. A&E Consultants work in the department seven days a week until after 20:00pm and then on-call, so there is always a Senior Clinical Decision Maker available for advice and support for our junior medical team.

Our service is constantly adapting in line with patient feedback, which we are happy to receive from any of our patients. All patient feedback is discussed with the team to ensure that we learn from our mistakes and agree what corrective actions can be put in place to ensure that patients have a positive experience when they receive care in A&E.

Trust response provided by Catherine Keegan, Matron Worthing A&E

# Having a baby

All the parents we met whose babies had been born in St Richard's Hospital said they had a good experience.

We met Lucy and her 3 month old daughter, who was full of praise of the maternity unit at St Richards Hospital: My partner was running between me in the maternity ward as I had to stay in for a few days after giving birth, and to intensive care, as his father had been admitted. The hospital staff were very good and gave him access to a private room so he could rest and visit when he needed too. My baby has since had some health issues and been back to the hospital and again they have been very good.

Simon's wife went into labour at 38 weeks, and having done research and attended antenatal classes (as it was their first baby) they had anticipated a long labour so stayed at home. After about 3 or 4 hours my wife wanted to push and the pain was so intense she couldn't walk or get into the car. I called the maternity ward at St Richards Hospital and they arranged an ambulance to come. It arrived within 20 minutes and the crew were great. At hospital it all happened really quickly and our son was born within an hour of us arriving. It took us by surprise but was a positive experience. Our son is almost four now and my wife is due to deliver our second child in a few weeks, again at St Richards.

Karen has a 2 year old son and spoke very highly of her birthing experience at St Richards Hospital. However, she went back into hospital 10 days later, as she was haemorrhaging and had to have an operation. She got her mother to call 111 because she thought the bleeding after giving birth was normal (as this is her first child). 111 got an ambulance to her.

Mandy feels the maternity services at St Richards Hospital were absolutely great:

I had my daughter there 2 years ago and she was born with a collapsed lung. The care was fantastic and they picked up the problem really quickly and she was treated and transferred to special care unit. I was moved to a post-natal ward with new mums and their babies, which was quite upsetting for me. One of the midwives was so lovely and could see I was very upset. So she closed the curtains around my bed and reassured me. She gave me her time. I felt lost and alone and she made me feel calm and hopeful. My daughter was back with me in 2 days.

Mandy's account of how upsetting it was to be on a ward with mothers and their babies, when your baby is in special care, was experienced by a mother at Worthing Hospital but this was not picked up and she told us 'I feel the maternity unit failed me by putting me into a ward with new mums and their babies when my son was so seriously ill'.

The parents whose babies were born in Worthing Hospital told us of very mixed experiences.

Justine, whose daughter is now 6 months old said she had a good experience in Worthing Hospital and staff picked up that her baby had clicky hips when she was just two days old: We were referred to Southampton Hospital for her treatment and this went really well. She has made good progress and was transferred to St Richards Hospital after 4 months of harness treatment. The specialist is meant to see her every 6 weeks and we've received a letter acknowledging the transfer but haven't got an appointment as yet and it's overdue. I haven't been in contact as there is no telephone number or email on the letter and it makes it clear that they will be in contact with us.

Nina had twins towards the end of 2016 and said she had a really bad experience at Worthing Hospital. I was induced at 38 weeks and my labour progressed well. I already have a toddler, and had him at the same hospital, so I kind of knew what to expect and had received good care with him. There weren't any complications or issues. I had an epidural for pain relief the first time and it worked well for me, so I asked for one this time. Unfortunately, the anaesthetist was junior or inexperienced and this is where things started going wrong.

He tried 3 times to get the needle into my back unsuccessfully. It was really painful and very uncomfortable for me. He then punctured something in my back and I was leaking spinal fluid. The process made me feel very unwell, I was headachy, and had nausea and disturbed vision. There was a bit of panic in the room and the midwives appeared to be getting distressed and angry with him. Finally, he got it right or so he thought. Within 30 minutes of him leaving the delivery room I was in agony and it was apparent it hadn't worked. They went to find him but it took 50 minutes to seek him out! I was told there were no other anaesthetists available but it was a weekday (but early morning) so I was quite miffed about this.

When the anaesthetist returned, he topped me up with epidural and at this point there was a discussion between him and the midwives about whether he had given me a spinal block or an epidural. I didn't know there was a difference! He didn't seem to remember. I was in too much pain to really know what was going on and still very unwell due to the earlier error.

I delivered my babies naturally but I have no real memories of their birth as I was totally consumed with the trauma, anxiety and pain of the situation.

I had to stay in hospital for a week, mainly due to the effects of the damage to my spine, the wound in my back - which became infected and the symptoms it caused. I had a heavy, debilitating and constant headache which lasted several weeks and affected my ability to do simple tasks. I had to return to hospital/GP many times following my discharge, for follow-up treatment and wound care. I also suffered a significant bleed after the births and had to have a blood transfusion.

My husband made a formal complaint to the hospital but all we got was a weak explanation from the hospital. Not even an apology. We got this after 3 months.

We have since met with Worthing Hospital's complaints manager to discuss a number of complainant concerns and an action plan has been agreed to create a sustainable improvement on their complaints process.



- Trusts should work with their ward staff to look at how they can best support mothers' whose babies are in special care.
- Hospital complaints teams should support maternity ward staff to ensure they work sensitively with parents who are complaining about her maternity care. This should include offering parents the opportunity to meet with them away from the hospital where they feel they had a negative experience.

### What local practices and the CCG have learnt, said and/or done:

Unfortunately, we know the facilities for women whose babies are on the Neonatal Unit at Worthing Hospital are not as good as what we are able to provide at St Richard's Hospital. Whilst there is a "Bonding Room" where parents can stay with their baby prior to discharge home from the Neo Natal Unit, we regret that there are no separate facilities for mothers to stay, apart from the post-natal ward in the early days following birth. We do aim to offer a side room, but this is not always available as there is only one room.

We do realise that this area requires improvement and we are exploring options to see what could be done to provide a better experience for mothers in this situation.

We are always striving to improve our service to our mothers and their families. We have recently reviewed our process around complaints and we now contact the complainant within 48 hrs to discuss the issues that they have experienced. If required, a meeting is arranged in their preferred location, with a Senior Midwife, usually Head of Midwifery or Matron.

If the complaint is as a result of an incident that requires investigation/review then we meet with the family prior to the review so that their questions can be asked to the panel.

Trust response provided by Gail Addison, Midwifery Matron

# Other hospital care

A few years ago we reported on peoples' poor experiences of Worthing Hospital's eye clinic. It was disappointing to find that for some people their experiences have not improved.

Brenda told us she has been back and forth to Worthing Hospital's Eye Clinic for months. I had cataract surgery there and it was brilliant but the outpatients is awful! There is always a long wait and you are lucky if you are seen within a couple of hours of your appointment time. I have always had to wait for unreasonably long periods and then I'm only in the room with the doctor for 5 minutes. It's very frustrating!

Frances is living with a long term eye problem and has been going to the eye clinic for more than 8 years: It is utter chaos and always has been! If you have an afternoon appointment you're alright but if you go at 10am you can be there all day. We've heard its moving to Shoreham. Travelling to there will be difficult for me - it's not easy for my husband and I as we both have multiple health issues and no transport. It's hard enough getting to Worthing.

A patient has been told there is a 26 week wait for an appointment at the eye clinic, so is now considering whether to have non-NHS treatment.

### What local practices and the CCG have learnt, said and/or done:

We have redesigned treatment pathways for Cataract, Age related Macular Degeneration and Glaucoma. The changes have been designed to reduce the time a patient spends in clinic as well as reducing the number of visits a patient has to make from 3 or 4 currently down to a single visit in many cases. For some conditions, this is not possible but the team continue to work together to further improve these processes and other pathways for Ophthalmic patients. In some cases, we will offer treatment (injection, laser or minor operations) where the patient is suitable and would like to proceed.

Another area we have looked at is the length of time that patients spend in clinic at their appointment - we have revised the appointment times with the support of the booking teams and expect patients to be in the department for no longer than two hours. This will include any tests including dilation of pupils, consultation and a treatment plan for patients.

The Worthing Eye Department has now relocated to Southlands Hospital (Shoreham). Work has commenced to increase the number of car parking spaces available for both staff and patients. This move provides much needed clinical space to undertake the newly developed pathways and will accommodate outpatients, diagnostics testing and outpatient treatments as well day case surgical treatment.

Current waiting times for Ophthalmology Appointments at both sites are approximately 18 weeks. We expect appointment waiting times to reduce following the launch of the new Eye Unit.

Trust response provided by Donna Steeles, Assistant Director Performance and Improvement in relation to Eye Clinic

One of the areas which seems to be working well for the people we spoke to is the Cancer Care at Worthing and St Richards Hospitals. There was one exception, this person told us how they had waited over 5 months for the scan result and this was only after chasing the consultant's secretary. The patient was told that her 'case was at the bottom of the basket' and had been overlooked. She has since been back for another scan this year and they did send her a report promptly.

Waiting times for referral appointments and treatment were raised by a few people. One person has been waiting 14 months now to sort out a neurological problem which is causing multiple seizures each month.

Sally told us she had a hip replacement operation 3 years ago at St Richards Hospital, and then her other hip was replaced 2 years ago at Worthing Hospital:

I had expected to have physiotherapy, as this is what they told her me the time of the surgery. I now go back to Southlands Hospital every 3 months for painkillers. Earlier this year I asked again about physiotherapy and was told that the staff will need to send a letter to my GP (which is Fitzalan Surgery) to explain what the diagnosis is and the reason I need therapy. The GP, I'm told can then refer me to the physiotherapist. I don't really know what is wrong with me and can pronounce it, and I never seen it written down.

I understand the process but it's very frustrating that it has been going on for 2 years. I've called my GP to ask about the letter, as it's been over a month, and the surgery has told me they have not received it yet.

# Since Touring Littlehampton

We go on 'tour' so we can listen to what local people say about their lived experiences of health and care services - your doctor, your hospital, your mental health service.

You told us we needed to be closer to local 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.

Having gained this understanding, 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 was shared with:

- NHS Coastal West Sussex Clinical Commissioning Group (CCG) who are responsible for planning, buying and monitoring many of the local health services
- Local GPs and through the Local Community Network
- Western Sussex Hospitals NHS Foundation Trust who are responsible for the delivery of services at Worthing, St Richards and Southlands **Hospitals**
- 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.

These organisations were invited to consider the Littlehampton insight and learning opportunities, and to tell us how they intend to respond to what has been said. Some of these responses have been included.

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 and Healthwatch England.

#### We are always listening

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

We spent time talking to people at the Wickbourne Centre, which is a vibrant and dynamic open-to-all resource, that has a sense of great community spirit. It is well used and appears to be led by the community. We met Sophie here and she has kindly volunteered to hold monthly *Listening Sessions* at the Centre and will be an ongoing Healthwatch presence in Littlehampton.

We will also look at ways of engaging local people and working with community partners to continue to listen and learn from peoples' lived experiences.

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

