

Healthwatch in Sussex “Ask Us - Tell Us” Campaign Feedback from Brighton and Hove residents.



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Introduction

Since the beginning of the first lockdown in March 2020, Healthwatch Brighton and Hove has been working more closely with colleagues across Sussex, in Healthwatch East Sussex and Healthwatch West Sussex under the title of Healthwatch in Sussex. Healthwatch in Sussex was approached by the NHS and Social Care to understand what is and what isn't working during Lockdown 2 and we responded by launching the Ask Us – Tell Us Campaign across Sussex. This encouraged people to either tell us their experience of Health and Social care services, for example if they were more worried or affected by changes to care or support services. Also, to ask us about how services are running during lockdown for example GPs, outpatients and dental. We encouraged people to respond via our online feedback form already on respective websites. This report is about the 34 people who responded to Healthwatch about Brighton & Hove services.

Findings are presented according to the services that people responded about:

- GP
- Outpatient appointment - not an overnight stay in hospital
- Accident & Emergency services
- Dental services
- Other services

Findings

We had 34 responses to this campaign from Brighton and Hove residents about services in their city. 12 people responded on GP services; seven comments were about outpatient appointments (not involving an overnight stay); two people provided a response on Accident & Emergency services and another two people commented about dental services. We had six enquiries regarding the COVID-19 vaccine. The balance was made up of one comment on each of the following: care homes; emotional and mental health NHS wellbeing support; test & screening results; pharmacies and direct payments to provide a lived-in carer.

F1: GPs

We received feedback from 12 people about GP services. Five of these were **positive comments** and included **good customer service, safe care and efficient medical care**. Two people talked about their concerns about possible cancer growths which either became worse or occurred during lockdown or just after. In both cases, they were dealt with quickly by their surgeries who offered face-to-face appointments and carried out the appropriate tests. In one case, the person needed and was offered surgery within a month of the initial enquiry and included an “excellent” receptionist service as part of the experience. In the other case, “as soon as the tests were back” they were offered another face-to-face appointment which included a further examination, as a result of which they were “given the ‘all clear’”.

Positive comments about General Practice

“I have had very good service from receptionists, and have been transferred by the GP practice to having prescriptions delivered [and] had a personal call from GP about my prescriptions.” Emma

“I really must commend a faultless, clear and very customer friendly service during these difficult times from Trinity Surgery, Hove.” Philip

“I changed surgeries in February this year so I knew no one at my new surgery when lockdown started in March. I would like to thank everyone at Mile Oak surgery for their kindness, patience and medical care.” Laura

“Such an excellent service.” Nigel

“I have had a telephone consultation with my GP which was very effective and I was sent for tests at the hospital and a face to face consultation with a GP. I was the only patient in the GP surgery and he was in full PPE so I felt safe.” Felicity

From the 12 comments received about GP services, half of these (six) were **negative**. All of the negative comments were about the **difficulty in getting an appointment**. Each person advised that they had found it “impossible” to get through on the phone. One person commented they had called 176 times over the course of two days, but when they visited the surgery they were told to make an appointment on line but “the online appointments didn't work either so I gave up and persevered

with the symptoms". The second time they had new symptoms, they called 49 times before getting through and making an appointment. A second person called "100 times" before getting through to find there were "no appointments available".

One person had **mixed comments** saying "on the three occasions I have needed medical advice this year, I have been sympathetically and well treated". However, they warned that the reliance on online and mobile phone contact, may result in **face-to-face appointments being only "reserved for the seriously ill"**.

Negative comments about General Practice

"The service in its current form is not meeting the health needs of its community, putting peoples health at risk and is not fit for purpose." Jack

"Extreme difficulties in getting through by phone. No appointments if walk in. Complicated on-line form should phone back next working day. Not satisfactory if no access to or computer skills." Tom

"You have to use the on-line option which takes a week or more to get a response." Tina

"While I'm working on the frontlines with them I am told I can't book an appointment in advance. [...]after calling over 100 times usually, there are never any appointments. If they don't have the resources to give out appointments why are they even open?"
Mandy

"After 20 minutes [...] I was eventually talking to a person. This must be dreadful for anyone on a telephone package with a limited number of minutes a month." Nigel

"I do find it [...] daunting to find everything done online or by mobile phone. It has been slightly embarrassing receiving a phone call when masked up and in a supermarket! The upside is that I am spoken to either on the same day or the following day. The worry is that this will become the norm and face to face consultation will be a rare thing reserved for the seriously ill." Jane

F2: Outpatient appointments – not involving an overnight stay in hospital

We received feedback from seven people about outpatient appointments. Three respondents fed back on **waiting times**. Two of these comments showed long waiting times, while one person was seen earlier. The big issue for two of these people was around **miscommunication** for example, being told a time to wait for a call which comes much later than advised or not hearing anything at all for months, despite the urgency of the referral.

Another comment about **miscommunication** was regarding the fracture clinic. The person was offered an appointment to fit a support boot due to a stress fracture. On arrival they were misdirected upstairs and left waiting for 45 minutes, until they asked someone who advised the person to come back downstairs. This meant a choice between walking downstairs which was understandably difficult or waiting for “someone to push the lift button downstairs in order to send it up to me” as it was not possible to call for the lift from upstairs. Further miscommunication was around the information they were sent home with. This was described to them as “information on how and how long to use the boot” but turned out to be “just a manufacturer’s receipt”.

This same person has had a very **good experience** “since getting home of the falls prevention service has been brilliant. I’ve been checked for blood pressure and diabetes, had a physio visit to give me exercises and an equipment visit, even a pharmacist one day.”

Outpatient services – waiting times and miscommunication

“I was referred to gynaecology in March but still have not heard from them despite being marked urgent, and phone calls from me requesting an appointment. I have had to go privately and had an appointment within two weeks.” Nina

“Awaiting cardiologist but in a very long queue, so far it’s been 6 months. [I’m] not surprised under the circumstances.” Tina

“After GP telephone triage & two separate calls with the team, I was referred to ENT and told that the wait could be up to 42 weeks. I was advised by text within a week to expect a call from an ENT consultant but not offered any option to change it and told to be available 30 mins either side of the expected call. Two hours later than the appointment, the specialist called and within ten minutes, he was convinced that nothing urgent was required but I should stay on the list for a face to face consultation....some time in the future.” Adam

“Of the fracture clinic appointment to fit a support boot: The whole experience felt like a farce with staff not seeming to know what to do.” Sarah

Two comments were about various levels of **social distancing**. One person advised that levels of social distancing and safety differed in her experience between two hospitals (Princess Royal Hospital (PRH) and the Royal Sussex County Hospital (RSCH)). Another person described her experience at Hove Polyclinic as being “unsafe”. She was asked on two occasions to remove her snood, despite this being allowed¹ - she had health reasons (arthritis and fibromyalgia) for not wearing a mask. She also noticed that despite a notice to the contrary, more chairs were available than the maximum number of people allowed in the waiting room and a staff member stood too close to allow for social distancing.

One comment was about being sent to an **unnecessary appointment** after detection of a Basal cell carcinoma rather than being sent straight to the consultant.

Outpatient services

Social distancing

“Two appointments: At the Royal Sussex County Hospital, there were a small number of patients but not everyone was social distancing. In the Princess Royal Hospital, it felt much safer with fewer patients. In all appointments I was seen quickly and courteously and had good feedback from staff.” Felicity

“Only two people to queue [but] there were five chairs and they were all occupied” [in the waiting room]. A staff member stood in the doorway so three of us were within centimetres of each other. [...] I have been isolating as much as I can because my son is a transplant patient and I can honestly say that this [visit to Hove Polyclinic] was the most unsafe I have felt.” Lucy

Mistaken referral

“My visit went well but a biopsy has already shown a Basal cell carcinoma so why was the appointment with Clinical Photography (which I believe is something of a triage tool) rather than directly with a Consultant?” Margaret

¹ See Age UK’s advice on suitable face coverings: <https://www.ageuk.org.uk/information-advice/coronavirus/coronavirus-guidance/face-covering-guidance/>

F3: Accident & Emergency (A&E)

Two of the comments we received were about A&E. One person was very impressed with both experiences they had, including the **kindness of all staff** they encountered and the way they were **“kept informed at all points”**. They were also impressed with the efficient way their situation was dealt with, from the ambulance arriving within eight minutes, being seen by a doctor within ten minutes and all tests being arranged and **carried out efficiently and resulting in a quick diagnosis**.

Another person was not so fortunate and had a particularly bad experience with one member of staff who was “very rude” showing **“great levels of unprofessionalism and no patient care”**.

Mixed comments on Accident & Emergency Services

“The [Worthing] hospital staff were amazing. From consultants to porters, patient; compassionate; kind; professional and efficient but also exhausted and very, very busy. I'm exceptionally glad we still have an NHS to turn to.” Maria

“I appreciate the work of all NHS staff now more than ever, but have been really distraught by the poor care I received recently. I was taken into A&E by two of my carers...as I developed some worrying symptoms including being unable to stand & speak. [...] My carer and I arrived ...with formal documents to prove my PA looks after me and a list of my chronic health conditions. ...a very rude member of staff...refused entry to my PA ...and said ‘there is nothing clinically wrong with you’ [before taking any tests]. [...] He also pushed me onto the wheelchair without wiping it down...COVID-19? I was taken into hospital by an ambulance a day later ...I have now been left with a severe delay and am seeking neurological support.” Anon

F4: Dental Services

We received two comments concerning dental services. The first comment was a simple confirmation of an “excellent” service. The second comment concurs with the concerns we have heard recently from several service users, who have found it difficult to find NHS dental services.

Dental services

“The dentist has been excellent.” Tina

“Finding an NHS dentist ...None are taking on new patients, the best I've got is being put on a waiting list that may take over a year to get round to me. Is my only option to go private?”
Charles

F5: Other services

We had five isolated comments about the following services:

Care homes – over-reliance on two visitors, means that when one is ill, there may be **no one available to visit**; when visits are carried out on either side of a perspex screen, and PPE, the respondent asks why grandchildren are not able to visit, denying the care home resident that part of their life that makes it “worth living”.

Emotional and mental health NHS wellbeing support - one respondent felt ‘left out in the cold’ by these services.

Pharmacies – one respondent advised us of an **“offensive and totally unnecessary” phone call** from a pharmacist asking about her diet and exercise in connection with new medication she was taking. The pharmacist did not communicate with her the reasons for the call, where the information was going or why the information was necessary.

Other services

Care Homes

“Pleased that two people are now allowed [to visit but she] doesn't get a visit with grandchildren seen behind screen and other things that make her life worth living ...More is asked of us to make it safe...wear masks, [sit] behind perspex screen two metres apart. If this isn't safe then logically we shouldn't visit at all/ it needs to be made safe, and if it is safe then visitors should not be excluded within the resources that homes have. This needs to be fed back to those in power regionally and nationally so that guidelines can become more helpful so there is more ability to individualize, including how to risk assess as well. ...More encouragement of money for Pods to be built to facilitate visits.” Julia

Emotional and mental health NHS wellbeing support

“Mental health have left me to get on with self care which is dreadful.” Tina

Pharmacy services

“A phone call from the pharmacist... Instead of wanting to know how I was getting on, she proceeded to ask about my diet, exercise and water intake. ... She said she “ had to” fill in the form, and these questions would help me lead a healthier life style. There is no information given as to where this form is going, nor whether my personal details are added to the form. I find a lecture from a pharmacist ... very offensive and totally unnecessary.” Penny

Test & screening results – One respondent advised us of a mix of **miscommunication and poor service** regarding an urgent endoscopy. Waiting over two months for the initial test, then having to chase the results, being booked for an operation but not informed about this and then waiting three months for the operation, needing a last-minute blood transfusion as no one had tracked her low blood count despite this being “the initial reason I was referred”.

Direct payments to provide a lived-in carer – following her own experience, one respondent brought to our attention her concern about the difficulty that informal carers might **have accessing COVID-19 testing and PPE provision**.

Other services

Test or screening results

“I was told by both my GP & consultant that I would be fast tracked for endoscopy at RSCH as part of rapid access guidelines. ...Was not able to get appointment earlier than [two months] despite pointing out this was meant to be fast tracked within 2-4 weeks. Pandemic was given as reason for delay. Then had to really push to get results of this test. Meanwhile I was evidently booked in for an operation but had no idea of what this was or when it would be!

Had to wait over 3 months for operation & needed a blood transfusion at the last minute as no one was tracking my low blood count even this was the initial reason I was referred.

Worsening symptoms meant I have had to take a break from my volunteer role.”
Melanie

Direct payments to provide a lived-in carer

“I manage a Council Direct Payment pot of money to manage my mother’s care in her own home. We use a variety of live-in (mostly agency) carers and I also have unpaid carer status as I do some of the hands on care myself. Our circumstances while not exceptional did not fit into the initial set ups for getting testing and PPE provided. It therefore took me a long time to establish clear pathways to access what we needed to keep us safe and prepared during the first lockdown. I have had difficulty in the Autumn in accessing tests although resolved more recently. I am concerned that with changing responsibilities for testing and provision of PPE those that need to know how to access these things may not get informed of new access routes etc.” Vivienne

F6: Enquiries about COVID-19 vaccine

In addition to comments about experience of services, we received six enquires about the COVID-19 vaccine. People wanted to know who was qualified to receive it and what priority list there was in distributing it. People also asked how they would be contacted (via email, phone or other means) to inform them that they were going to receive it and when that was likely to be.

Enquiries about COVID-19 vaccine

“Do you know how paid care workers access the vaccine in further phases? For instance those who work with sick children. A GP wouldn’t know where you work so I assume it’s the responsibility of bosses? John

I expect I will be in the 'quite urgent' list but all I want to know is HOW will I be contacted as I am not very reliable with e-mail.” Amy

“My mother is higher than I am on the priority list told us by the media, but if I care for her, how does that affect my priority?” Donald

Conclusion

Within the 34 comments received about a range of Brighton and Hove services, there were common themes running throughout.

Challenges with getting the care needed for example, finding the right NHS dental service, difficulty in getting through to the GP surgery to make an appointment and waiting times for an appointment once booked, as with the cardiology and gynaecology outpatient appointments.

Another theme running throughout was about **communication received about the care**. One person was kept informed throughout their experience in the A&E department. However, the patient in the fracture clinic was misdirected upstairs, ignored for 45 minutes, and sent home with the incorrect aftercare information. One person was not told by a pharmacist as to why personal information was needed and an endoscopy patient was not informed that an operation was booked for them.

A further theme was one specifically related to these times around **access to COVID-19 testing and safety rules** as with the examples in the care home; of the unpaid carer helping her Mum; and the comment around the limits of face-to-face GP appointments. Six people also had questions around the **COVID-19 vaccine** and eligibility status.

A fourth theme is around **the care itself** – in some cases efficient and safe as with five of the comments about GP services; in the case of one of the patients who attended the A&E department; and thorough care by the falls prevention service for another patient. There were also cases of very poor care, for example the person who felt they had been left by the mental health services; for the person who received a last-minute blood transfusion and one unprofessional member of staff in the A&E department.

While the services experienced are unconnected, the themes reflected are similar throughout – the ability to get an appointment, to be informed throughout the process, and to receive good quality of care is important to all people accessing any health and social care service.