healthwatch

What people have told us about NHS administration

A Healthwatch England report - June 2020

Background

In December 2019, The King's Fund initiated a project in partnership with Healthwatch to look into the experiences of different groups of people with NHS administration. While five local Healthwatch undertook primary research, Healthwatch England analysed the data they hold nationally from local Healthwatch on NHS administrative processes to provide additional national context to the local Healthwatch data.

We analysed two sources of data - data shared via the Civi CRM system and via the reports library between April 2019 and April 2020. For the purposes of this report, we looked at the experiences of the following groups of people:

- people who used the GP or the Accident and Emergency services for issues that do not require regular follow-up,
- people seeking musculoskeletal or cancer care,
- the elderly,
- people who use mental health services or have learning disabilities,
- people who have language barriers, and
- people with sensory impairments

In total, we undertook detailed analysis of feedback from 112 people (drawn from across 34 local Healthwatch) who had shared their experiences about NHS administration problems via the CRM. We also drew on evidence from 20 reports, produced by 14 local Healthwatch, that had a specific focus on NHS admin processes.

Our findings shed light on how poor admin affected patients' experiences of care. While some admin errors were common to the different groups, they affected them in different ways. Below is the high-level summary with a few case study examples:

Findings from Healthwatch England's CRM data

Sporadic users of health services - i.e. people who generally interact with NHS services only occasionally

We analysed our CRM data for experiences of people who access health services occasionally, for example their GP or Accident and Emergency services. We have identified the following Issues:

1. Issues with GP registration- We have heard that surgery staff have either misplaced patients' registration forms or have forgotten to process them. GP surgeries have registered people who

were outside their catchment area in error and later took them off their list without informing the patients about it. Consequently, people were unable to book appointments when they needed to because their names weren't on the practice's list. People have also experienced delays in booking appointments because of complex administrative processes and staff providing incomplete information. For example, an individual had to complete both paper and online forms before they could book an appointment. Surgery staff failed to provide them with all the relevant information that they needed in order to access the online booking system.

I enquired about online registration and subsequently filled the document in- it didn't ask for ID. Later, I received a call from the practice to produce some. I then received a notification to complete the online application - I tried and it asked for my password. I hadn't set one up so returned to the surgery who were able to tell me what my password was. I logged in whilst there on my phone and that booked a telephone referral that never happened. When I queried it, I was told I had a letter for an appointment to be booked. I went to the surgery to pick up the letter as I hadn't received it and was finally able to book an appointment some 40 days later.

Patient story shared with Healthwatch Rochdale (August 2019)

2. Difficult to book appointment over the phone- While accessing GP appointments remains the main issue that most people face, many have reported that it's a bigger challenge when practices don't answer the phone. People have tried calling repeatedly but either no one has answered their calls, or they were cut off while they were still in the queue. As a result, people had to go to the practice to book an appointment and go back again at the time the appointment was due. This was particularly difficult for disabled people and for people who have work commitments or caring responsibilities.

3. The consequences of being given incorrect information- People have told us that they have been given incorrect information by the services including GP surgeries and hospitals which has left them feeling confused and frustrated. For example, GP practices have referred people to another centre for blood tests. However, when the patient got there, they were informed that the centre doesn't offer phlebotomy services. As a result, the patient had to wait for two more weeks before they could get another appointment with their GP to have their blood taken.

4. Booking errors- People have said that they have been booked for an appointment under the wrong name and then turned away by reception staff because their name didn't match with that on the surgery's system. Some people have also reported about reception staff forgetting to check them in when they arrived for their appointment, as described below:

I had a foot injury, so I visited the nearest health centre. They took a look and then recommended an x-ray. But they asked me to first check with my registered GP. I called the GP, and they insisted the only way was for me to make my way there, despite the injured foot. When I got there, they asked me to wait for an hour to see the doctor. For the next 90 minutes, my name wasn't called. When I walked over to the reception to ask what happened, they said they forgot to check me in for the appointment.

Patient story shared with Healthwatch Islington (April 2019)

5. Delayed or inaccurate referrals- We have heard that GPs have either not sent referrals on time or have missed important details about the patient's condition in the referral. As a result, patients have been unable to book subsequent appointments, e.g. for chorionic villus sampling during pregnancy, when the patient had a serious genetic problem. The GP in this case hadn't mentioned their pregnancy status in the referral letter. On another occasion, an individual had been referred to the wrong department- they were only informed about it when they arrived at the hospital and were turned away.

I was referred to the pain clinic and waited nearly 4 months for an appointment. On arrival at the Hospital Outpatients, I was informed that I could not be seen as my referral had been assessed as inappropriate! Nobody had informed me of this prior to my appointment. A waste of time and expensive parking, not to mention frustration after such a long wait since initial referral.

Patient story shared with Healthwatch Buckinghamshire (December 2019)

We have also heard that GPs don't always monitor and respond to consultants' letters following a patient's referral. People have been left to go around in circles between their GPs and the hospitals to chase-up their referrals, appointments and test results.

6. Unable to get the right medication- People have been refused medication because GPs have issued prescriptions with incorrect addresses or when the pharmacy couldn't access the system that sends through the prescriptions. Patients had to make several journeys between their surgery and the pharmacy in order to get their correct medication. We have also heard that people were issued with wrong medication or duplicates because the pharmacy staff weren't able to use the computer systems correctly. On one occasion, an individual was told by the pharmacy that their

medication had been collected by someone else but couldn't provide any details. Later, they were informed that their prescription was still at the pharmacy and they had been given the previous information in error.

7. Barriers to patient transport- Patients are required to book hospital transport a few days in advance. However, they were unable to book it as they got information about the date and time of their surgery appointment or treatment 24 hours beforehand. Some weren't aware of advance booking requirements and struggled to return home after their hospital stay. People have also been denied transport due to reasons beyond their control, as described below:

Caller has been referred by his hospital to a specialist in Cambridge and needs transport to attend. He had previously visited last year and arranged NHS Transport, however, he was unexpectedly held overnight in Cambridge and had to cancel the return transport as a result. He has now tried to book the same journey but has been told that because he cancelled previously, he will not be entitled to the same support this time.

Patient story shared with Healthwatch Birmingham (January 2020)

People who are/have been on a specific pathway of care

For the purposes of looking into the experiences of people who are or have been on a specific care pathway, we have looked at people on the musculoskeletal (MSK) and cancer care pathway. Our data found the following issues faced by these groups of people:

1. Delays in receiving appointment letters or receiving incorrect letters- People on the MSK pathway have faced delays in receiving an appointment letter because their GP practice hasn't sent the referrals on time, sometimes even a month after the initial appointment. This has led to delays in receiving treatment and has left patients with considerable pain making it difficult for them to carry out everyday tasks such as driving. Cancer patients too have faced unexplained delays in receiving appointment letters for treatments and for follow-ups. When they have tried to call the consultant's secretaries to enquire about their appointment, either no one has answered the phone or called them back when they left a message. Cancer patients can face a great deal of inconvenience when they get the wrong letter, as the case below shows. But wrong letters can also lead to delays in treatment, and serious consequences for the person's health.

Person attended Urology at [name] hospital for a prostate test. Received a letter saying everything was fine, but a month later he had another letter with worrying

results. He couldn't contact anyone for a week as all were away from the department. A week later he had a stroke due to anxiety. When he was discharged, he called the hospital, but no one knew about the letter. He made an appointment with an anaesthetist to have a biopsy but when he got to the hospital, he was told there was no appointment and that he should have had a letter cancelling the appointment.

Patient story shared with Healthwatch North Somerset (June 2019)

2. Misplaced or delayed test results- We have heard that test results of patients have gone missing or haven't been communicated to the hospital where the patient was going to receive their treatment. An individual didn't receive their test results when they were due- consequently, they couldn't arrange a meeting with the consultant to discuss their diagnosis and treatment plans which caused them a lot of stress.

3. Communication issues- Quality of care was reduced due to inadequate communication either between the services or between the patients and the care providers. People have been given contradictory information about their cancer diagnosis during separate appointments which has left them worried and confused. They haven't received any written communication following appointments over the phone. This was particularly an issue for an individual who wasn't sure about the instructions they were given about applying a medication over their suspected cancerous lesion. Cancer patients have missed follow-up appointments because their GPs haven't referred them to the hospital on time or couldn't access essential medicines because of lack of communication between the GPs and the hospitals.

Caller's husband has been undergoing cancer treatment through the hospital and has been released from care with the instruction that he will receive a regular injection of hormones from his GP. However, his GP has said that in order to proceed with the injections he will need a letter confirming transfer of care from the hospital, which the hospital have not provided. Caller has contacted the hospital to be told that the situation is 'not their problem' leaving the caller concerned that her husband's care will be left in limbo.

Patient story shared with Healthwatch Birmingham (October 2019)

People who use multiple health services, on a regular basis

We looked at experiences of three groups of people who are most likely to use multiple health services, on a regular basis. This included people with mental health conditions, people with learning disabilities and older people with one or more long term conditions. Our evidence suggests that poor NHS admin can negatively impact on their quality of care.

1. Delayed referrals- There have been delays in referrals to mental health services which in turn has led to delays in people receiving specialist appointments. Delays in receiving treatment resulted in people's mental health declining - in some cases to the point of self-harm or suicidal thoughts.

2. Inaccuracies in appointment letters- Appointment letters have been sent to the wrong address or had incorrect details such as dates and times. Services have also failed to communicate any changes to appointment times- people have found out about it only after they have arrived for their appointment.

I turned up to attend a Stress and Anxiety CBT 6-week course as per my appointment letter. Doors were locked and no answer. Eventually went to the main offices up the road only to find out that the letter that had been sent had the wrong date on it. As I work in London, I had to make arrangements to get in time for this course plus I was anxious about the course anyway. I now have to see if I can make arrangement to leave work early again to attend on the date that should have been on the letter. This course was supposed to help my stress and anxiety instead so far it has made it worse. Not a good start!

Patient story shared with Healthwatch Buckinghamshire (March 2020)

3. Services don't communicate with each other- People have reported lack of communication between services which has led to appointments being cancelled or relevant medical history being missed out. It has also caused delays in monitoring progress of treatments and access to medications. For example, the medical records of an elderly person with learning disabilities and other co-morbidities hadn’t been transferred from one hospital to another even after 18 months. This meant they couldn’t access timely care or claim benefit support.

Care providers haven’t discussed the medical interventions and associated risks or changes to medications or care plan with the patients or with the carers of people with learning disabilities. They have missed completing the mental capacity assessment form in time which has led to delays

in referrals to the mental capacity advocate services. Patients have been discharged from care without informing them about it.

Client phoned to describe experience of community mental health team. After spending a considerable amount of time as an inpatient he was told that he would be put under the recovery team (part of the CMHT). After not hearing from them he phoned up to discover that in fact he had been discharged.

Patient story shared with Healthwatch Sheffield (November 2019)

People have been unable to access necessary paper-work to certify their mental health status from their mental health care providers which has withheld them from resuming work- either no one has responded to the enquires or they have never received the communication they were promised. Parents haven't received any communication about annual health checks for their children with learning disabilities in spite of enquiring about it with their surgery multiple times.

4. Issues with prescriptions- Access to medications have been delayed due to practices forgetting to place the prescription orders in time. This has been particularly difficult for people who tend to get extremely agitated due to lack of medicines. People have also found it difficult to order repeat prescriptions using the phone because the phone lines were open for only limited hours each day. Some have had to make multiple journeys to the pharmacy because of inaccuracies in the prescriptions or they were given incorrect information.

Mother of son with autism, learning disabilities and quite severe behavioural problem. He was missing his prescription for second day running. She filled prescription 9 days before and it still hadn't been filled. Son is severely autistic and presents with significant behaviours which make the medication crucial in the day to day management of these behaviours. When she attempted to get hold of the medication, she was told an electronic prescription had been sent by GP surgery. However, she was told by the pharmacy that a prescription hadn't arrived from the surgery.

Patient story shared with Healthwatch Bedford Borough (January 2020)

5. Conflicting information- People have been unable to receive essential care because of different set of guidelines being followed by different care providers. Whilst it may not appear as a

straightforward case of poor admin, it does show that disagreements about NHS guidelines between care providers has negative consequences on people's healthcare.

Individual's daughter (52 years old) is in supported living, has learning disabilities and is partially sighted, and is due to have an operation on her cataracts. However, the individual reports that the surgeon has told her that they will not operate on the daughter without consent - and the mother does not have power of attorney. The mother went to her GP with her daughter, who the GP asked if she would be happy to have the operation. The daughter was able to say yes, and the GP wrote a letter for the surgeon with this information. But the individual says the surgeon was still not happy to proceed on this basis.

Patient story shared with Healthwatch Hillingdon (October 2019)

7. Experiences of older people- Elderly people with multiple health issues have had to chase up various care providers to ensure that their health needs are met which has left them feeling frustrated. For example, they have had to chase up a delayed home care package, the right discharge letter or a six-month feedback letter a year after the treatment. In one case, an older man faced serious consequences to his health when he didn't get the instructions on how to operate a special bed which has led to serious consequence.

Client had brain stem stroke earlier this year, was discharged from hospital and provided with a special bed which broke. He has been given a new one but there are no instructions for the carers on how to operate it. He is sliding down the bed and this is causing his toes to be infected.

Patient story shared with Healthwatch Thurrock (November 2019)

People who don't speak English as a first language or have sight and hearing impairments

Despite the Accessible Information Standard, which states that all organisations that provide health and social care are legally required to meet the information and communication support needs of people with a disability, impairment or sensory loss, our data suggests that healthcare providers have not always met their needs. While access to interpreters has been the main issue,

people who don't speak English as a first language or have hearing or sight impairments were not provided with accessible information by the care providers. As a result, they did not understand important communication about their healthcare and felt rather helpless and vulnerable. For example, a BSL user was given post-treatment instructions in written English, which they could not understand, as described in the story below:

A deaf adult post operation was given medication and a letter detailing possible side-effects or surgery complications and what to do. She was unable to read the letter, and no-one explained it to her in sign language.

Patient story shared with Healthwatch York (November 2019)

People have also told us that due to appointments running behind schedule, they were unable to access interpreter services because the interpreters were unable to wait that long. This shows that poorly run appointment schedules are not only frustrating for the patients but also impacts the quality of care they receive.

Poor admin has affected experiences of people with sight impairments as described below:

- People with sight impairments have faced difficulties in reading their medications in Braille because it was squashed and unreadable.
- An individual who was completely blind, was issued an incorrect dosage of medication from the pharmacy which they were unable to recognise and felt unwell later.

Findings from local Healthwatch reports

We reviewed local Healthwatch reports received by Healthwatch England between April 2019 and April 2020.

We identified 20 reports which contained significant evidence of people's experiences of NHS admin falling within our target patient groups. These experiences were contained in diverse sections of reports investigating the experiences of patient groups or services. We did not identify any reports whose primary purpose was to explore people's experiences of NHS admin.

Sporadic users of health services - i.e. people who generally interact with NHS services only occasionally

Many reports on GP or A&E services contained a general mention that people complained about admin issues or revealed negative ratings for quality of admin as part of a satisfaction poll on different aspects of local services. However, for the purposes of this analysis, we included only reports which went into more specific detail on the topic. Where specific issues with admin were detailed, they generally fell into the following:

1. **Not being able to get through on the phone**

Similar to people whose experiences were shared through the CRM, local Healthwatch investigating access to GP appointments regularly heard that patients have difficulty getting through to the surgery on the phone. Many people report having to call multiple times before they are able to get through to anyone.

Two separate reports by Healthwatch County Durham which reported on people's frustrations when booking appointments found that telephone triage systems introduced by some surgeries were well received by patients who had accessed them. People who were able to discuss their symptoms with a GP and be advised about whether they needed an appointment were reassured and found the system effective.

However, some people also made comments about the recorded telephone message being frustratingly long, particularly when having to ring repeatedly at 8.00am.

2. **Out of date info on websites -** A couple of reports mentioned that out of date information on websites meant that people were not aware of all appointment options available to them - for example, some GP practices offered evening appointments, but this was either not advertised or incorrectly advertised on their websites.

Another report from Healthwatch Birmingham on patient and public involvement practices in the local CCG outlined how Patient Participation Groups were primarily advertised on the website, but the details about dates and times were not accurate or up-to-date. This meant that members of the public were not able to share their views about health services in their area.

3. **Admin errors when booking appointments**

People shared experiences of arriving at appointments only to be told that the consultant is not available or arriving at appointments to be told that the appointment had been cancelled, though the patient had not been notified. Sometimes, if patients had called ahead to cancel or reschedule their appointment, this was not recorded in the system, and patients were then penalised for this or their rescheduled appointment was not able to go ahead.

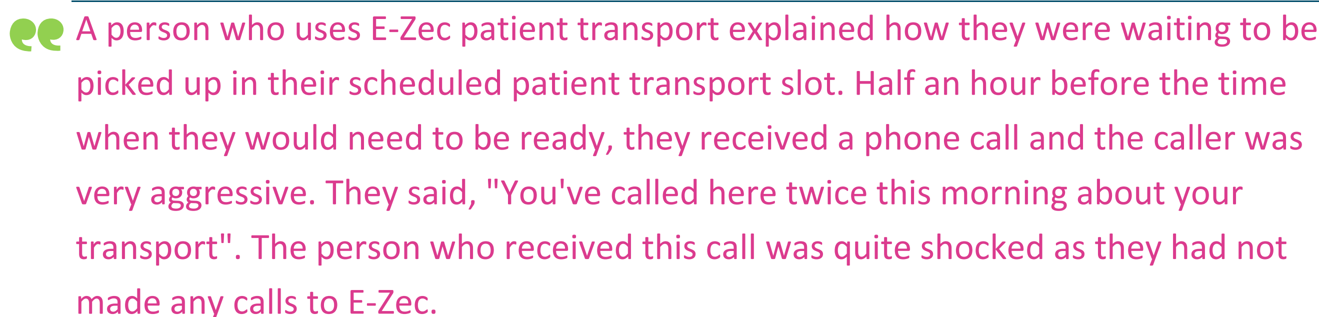
4. **Issues booking patient transport**

A report from Healthwatch East Sussex looked mainly at non-emergency patient transport

services. While respondents were broadly positive about the booking process, several said that when they had to cancel a booking there was a different number to ring and this was not clear.

One respondent said that although they needed their transport for a 07:00am pick-up, it was booked for 07:30am.

Another report from Healthwatch Staffordshire investigating the local patient transport services found that people's bookings were mixed up or contact details were inaccurately recorded, resulting in them missing their transport appointment.



A person who uses E-Zec patient transport explained how they were waiting to be picked up in their scheduled patient transport slot. Half an hour before the time when they would need to be ready, they received a phone call and the caller was very aggressive. They said, "You've called here twice this morning about your transport". The person who received this call was quite shocked as they had not made any calls to E-Zec.

Patient story shared with Healthwatch Staffordshire (July 2019)

People who are/have been on a specific pathway of care

We did not locate any reports specifically dealing with people on the musculoskeletal (MSK) or cancer care pathway which dealt with admin issues in any detail.

However, several points related to admin came up in other reports dealing with the experiences of people on a longer-term treatment pathway.

1. **Inappropriate notification of service decommissioning**

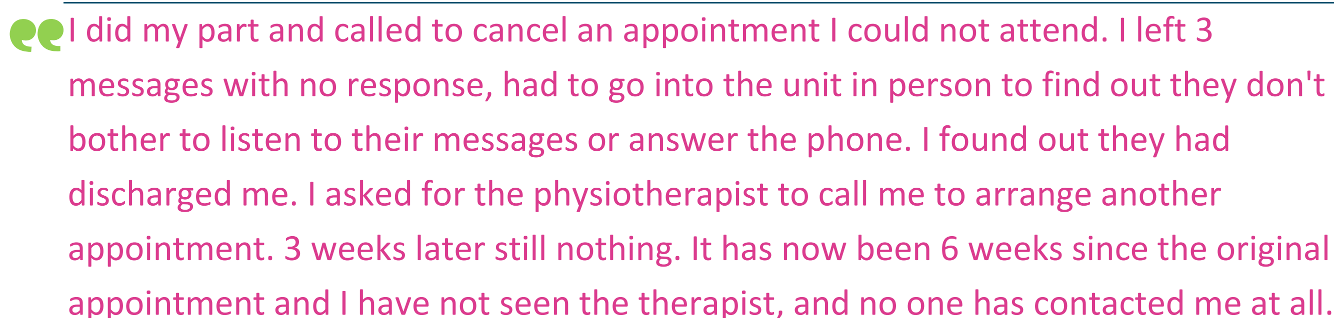
A report from Healthwatch Hillingdon collected patient experiences surrounding the decommissioning of a pain clinic. Patients shared that they received notice of the cancellation of their treatment but were not provided with any further information or alternative treatment options. Some received a letter stating that the hospital will be in touch to discuss their options, but never heard from anyone. People were unsure what to do next and anxious that they would not be able to get the treatment they had relied on for years.

2. **Lost or incorrect communications**

A report from Healthwatch Tower Hamlets on the outpatient services at the Royal London hospital outlined a number of issues related to communication of patient data.

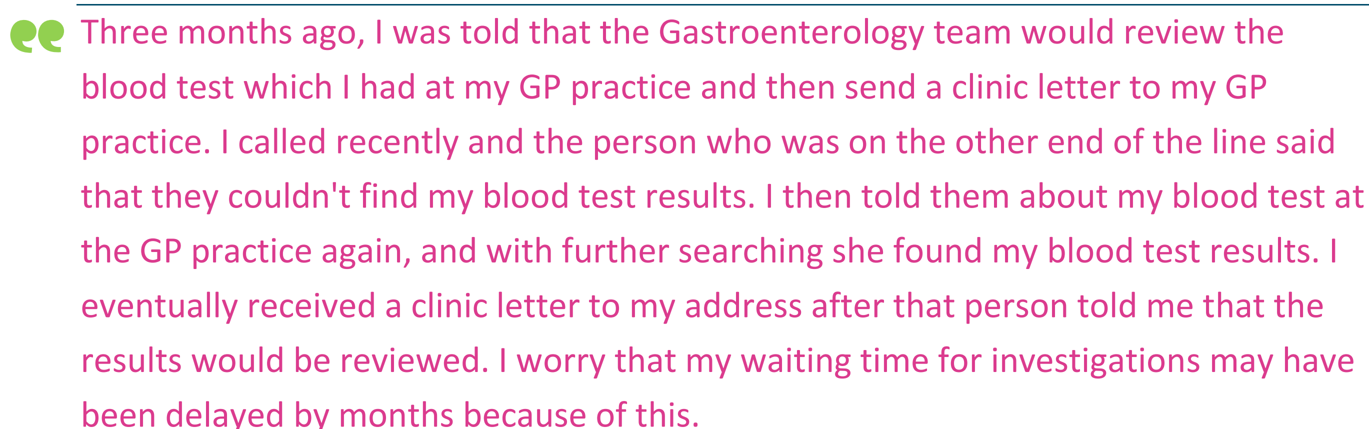
One person shared how a letter was sent to her containing notes from another patient's appointment. The letter correctly listed her NHS number and date of birth, but the contents referred to a different patient. She was extremely upset at this breach of patient confidentiality.

Others shared experiences of lost test results or no follow-up communication after discharge. One person called to cancel an appointment, and then was not able to reach the clinic again despite leaving multiple messages. When she came to the clinic in person, she found she had been discharged.



> I did my part and called to cancel an appointment I could not attend. I left 3 messages with no response, had to go into the unit in person to find out they don't bother to listen to their messages or answer the phone. I found out they had discharged me. I asked for the physiotherapist to call me to arrange another appointment. 3 weeks later still nothing. It has now been 6 weeks since the original appointment and I have not seen the therapist, and no one has contacted me at all.

Patient story shared with Healthwatch Tower Hamlets (May 2019)



> Three months ago, I was told that the Gastroenterology team would review the blood test which I had at my GP practice and then send a clinic letter to my GP practice. I called recently and the person who was on the other end of the line said that they couldn't find my blood test results. I then told them about my blood test at the GP practice again, and with further searching she found my blood test results. I eventually received a clinic letter to my address after that person told me that the results would be reviewed. I worry that my waiting time for investigations may have been delayed by months because of this.

Patient story shared with Healthwatch Tower Hamlets (May 2019)

People who use multiple health services on a regular basis

We focused on the experiences of people with mental health conditions, people with learning disabilities and older people with one or more long term conditions.

1. **Difficulties making an appointment have a greater impact when people are in crisis**

People shared that waiting on hold for a long time in order to make an appointment, or not being able to get through on the phone, can have a much greater impact on people who are in crisis and require urgent support. This can result in them giving up trying, meaning they cannot access the urgent care they need, and can be left to deal with a mental health crisis alone.

Extreme difficulty in making appointments with surgery, waiting 45 to 50 minutes when you are depressed and have no motivation is not good enough.

Patient story shared with Healthwatch Birmingham (May 2019)

During a psychotic episode, his carer phoned the crisis team 15 times in a single night, but nobody responded to the calls.

Patient story shared with Healthwatch Birmingham (April 2019)

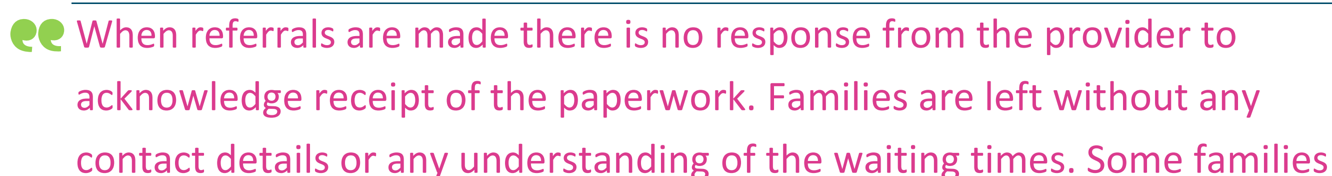
2. **Having to repeat your story**

People using mental health services over a longer period of time shared how they were frequently seen by different people, which meant that they often had to spend a large chunk of their appointment updating professionals on their recent medical and personal history. They felt that if medical notes from previous appointments could be made accessible to all relevant professionals, the therapist could read the relevant background info ahead of the appointment, and the appointment time could be used more productively.

It was also mentioned that people can find it traumatic to regularly repeat aspects of their story or past which they find distressing.

3. Lack of communication

In a report from Healthwatch Kent on the experiences of young people with autism, families shared how they felt "lost in the system" when they did not receive communication from the provider confirming their referral has been received or informing them of estimated waiting times.



When referrals are made there is no response from the provider to acknowledge receipt of the paperwork. Families are left without any contact details or any understanding of the waiting times. Some families

asked the contact person in the school, the Family Liaison Officer, who was unable to help as they were not given any acknowledgement of referrals made either. Parents described that they “felt lost in the system.

Patient story shared with Healthwatch Kent (September 2019)

People who don’t speak English as a first language or have sight and hearing impairments

1. **Issues with booking interpreters**

People who need an interpreter to access GP appointments shared experiences of having an interpreter booked for the wrong language and were thus unable to proceed with their GP appointment.

I asked twice for an interpreter but got wrong language interpreter.

The GP booked the wrong interpreter, my daughters and grandchildren help me.

Patient stories shared with Healthwatch Barnet (September 2019)

People also shared stories about being told that an interpreter had been booked for them and expecting one at their appointment, but when they arrived for their appointment, there was no interpreting provision. A report on interpreting services by Healthwatch North Yorkshire found that 10% (5/49) of people surveyed had an experience of being told to expect an interpreter but finding none when they arrived for their appointment.

One of the people who spoke to us was profoundly deaf and was taking her hearing grandson to a hospital appointment. She requested for an interpreter to be booked to assist. When they got to the hospital there was no interpreter. As they did not want to miss the appointment the family ended up FaceTiming a BSL interpreter. They were unable to use a professional interpreter.

Patient story shared with Healthwatch Stockton-on-Tees (February 2019)

2. **Not enough info given for people with sensory impairments to request support**

People with sight impairments told Healthwatch Kent about how patient letters don't contain information about how they can request support for getting to their appointment.

A report by Healthwatch Stockton-on-Tees focusing on people with sensory impairments states that "a significant number" of service users shared how it was difficult to make an appointment if they are not able to use a phone. They report trying to go to the surgery to make an appointment but are often unable to do so due to practice policy which states that patients must ring at 8am every morning should they wish to make a same-day appointment.

About us

We are the independent national champion for people who use health and social care services. We're here to find out what matters to people and help make sure their views shape the support they need.

There is a local Healthwatch in every area of England. We support local Healthwatch to find out what people like about services, and what could be improved, and we share these views with those with the power to make change happen. Healthwatch also help people find the information they need about services in their area. Nationally and locally, we have the power to make sure that those in charge of health and social care services hear people's voices. As well as seeking the public's views ourselves, we also encourage health and social care services to involve people in decisions that affect them.

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