

Time to change

Putting good communications with patients at the heart of service change

“

There is nothing worse than not knowing especially when you have something that you are anxious about and that is causing discomfort. It leaves you in a state of anxiety and tension and you feel you are not being heard. As a patient you feel you have no control. If you feel you are not being listened to followed by no communication, it makes you feel you do not matter.

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Published: November 2021

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1. What Healthwatch Brighton and Hove did ... at a glance

This Healthwatch report is a summary of a substantial review of patients' experiences of being referred for an outpatients' appointment. It showcases the core standards that patients themselves recommend should be applied to all the communications they receive.

We urge our local NHS Trust and Sussex NHS Commissioners to sign up to these standards and to create a [Patient Communication Charter](#) - building on University Hospitals Sussex NHS Foundation Trust's '[Patient First](#)' approach to transforming hospital services for the better.

Healthwatch heard from 53 patients with contemporary experience about the communications they had received after being referred for an outpatients' appointment. This is what they told us:

"The big problem is that you do not get any confirmation that your referral has been accepted and where you are in the system. I just assumed the basics had been done."

- 52% were dissatisfied or very dissatisfied with communications, or lack of them
- Most were referred by their GP, but GPs did not consistently provide them with information about their referrals
- 57% were not notified that their referral had been sent off
- 61% were not notified that their referral had been received by the hospital
- Only a third of patients had chosen not to chase up their referrals to find out what was going on.

We spoke in detail to 8 people to gather in-depth feedback. These case studies highlighted both good and poor examples of communications and led us to [review some genuine letters](#), texts and online messages that had been sent to patients. These showed that some parts of the referral system deliver good communications, but other examples highlighted that urgent improvement is needed.

Our key finding is a lack of consistency in patient communications that must be addressed if every patient is to have a 'good' experience and 'wait well'.

Our [7 recommendations](#) support work being done by Sussex NHS Commissioners to transform outpatient services and to embed other initiatives (see [Annex D](#)) that are intended to support patients such as 'waiting well' and 'patient initiated follow ups'. NHS Commissioners have already agreed that they can help improve patient communications.

You can visit our [website](#) to read a 15 page summary report.

2. A message from our Chair of Healthwatch Brighton and Hove

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Sadly, there is nothing new about patients' stories in our latest report - many are waiting in limbo for appointments to NHS outpatients' departments (OPD), feeling somewhere, someone must know what is happening to them. They go back to their GP for help. They grapple with the dark arts of finding the right phone number to check at the hospital or clinic. When they do get their letter about an appointment, they spend hours trying to decipher it.

However, some patients do get a good experience - few all the way through their referral - but good enough to feel they have had a positive experience. So, there are examples of excellent practice all over the place, in GP surgeries and in booking clinics such as text reminders about appointments, and clear and concise letters received in sufficient time to get to the appointment.

If all referral pathways were to adopt the practices of the best, Sussex Services could be an exemplar. It could alleviate the undoubted and explicit frustration of patients and deliver a better and more satisfying situation for staff who take the brunt of the dysfunctional elements within our referral systems.

In the aftermath of COVID-19, waits for appointments and tests will be with us for the foreseeable future. This is recognised in the NHS initiative to assist patients to 'wait well'. Notwithstanding this contradiction - as waiting is in itself, often a poor experience - the improvements summarised in this report would assist waiting for an appointment to be better. If people know what is happening to them, where else to go for help and when, it helps them to not only manage their condition, but their life. People put plans on hold thinking the letter will come. They struggle with their pain thinking the letter will come. The least that can be done to help people 'wait well' is to communicate with them about what is happening to their referral.

“Essentially, the biggest issue which has affected my outpatient referral, and which has caused uncertainty and confusion, are the poor communications, particularly at the start of the process. Surely, it should be simple to create a uniform way of communicating with patients.”

By moving towards the best practice exemplified in this report not only would it be a better experience for patients, but it would help the NHS achieve some of their aspirations to transform services and better manage limited resources that are in high demand.

”

3. Response to our report from Sussex NHS Commissioners



We absolutely value the engagement expertise and insight that Healthwatch brings to our work, ensuring that the voice of patients and our local communities are heard and at the heart of all we do. This report is very much welcomed as we work to further improve the communication with patients as they are referred for treatment and as they wait for that treatment. It is vital that this insight continues to shape the initiatives being developed to improve that support and put patients in control of their own healthcare wherever possible.

This report will be used to further develop initiatives such as shared decision making and patient initiated follow up, as well as specific work to consider patient letters, communication when people are waiting, and how people are contacted by services at the time of their appointment.



4. Methodology used to produce this report

Healthwatch Brighton and Hove designed a short survey to capture people's high-level views and experiences of being referred for an outpatient's appointment and in particular the communications they had received regarding this. We wanted to understand what was good, poor, and how things could be improved. The survey questions were based on patient feedback we had received from three patients over the summer of 2021, and a longer outpatients' survey that Healthwatch Brighton and Hove conducted in 2019.

We launched the survey in August 2021 and kept it open for a month, promoting it via our newsletter, social media platforms and website. On Facebook, we reached over 8,000 people across Brighton and Hove and engaged with nearly 400, and eight people shared their comments online. 50 people completed the full survey which contained 13 questions, plus a shortened set of demographic questions, and took on average 8 minutes to complete. The questions asked:

- Whether people had been told by the person who had made their referral how long they should wait before chasing it up
- Whether people had received an acknowledgement to confirm that their referral had been sent off, and/or received by the hospital
- Whether people had chased up their referral, and how many times they had done this
- Overall satisfaction with the communications received about their referral.
- We also provided people with the opportunity to share more details about their referral.

We invited people to take part in a short telephone interview with a member of the Healthwatch Brighton and Hove staff team so that they could share more details about their experience and 16 people provided their contact details. Seven people subsequently responded to a request to set up a call and we spoke to five. The calls took place in October and lasted on average 20 minutes. We have recorded these anonymised conversations as case studies shown in [Annex C](#). We have also included the three case studies that we received over the summer. We have used comments received from these interviews, those provided by survey respondents and on Facebook to support the analysis of the survey data.

“... the biggest issue which has affected my outpatient referral, and which has caused uncertainty and confusion, are the poor communications, particularly at the start of the process. Surely, it should be simple to create a uniform way of communicating with patients. Delivering this will undoubtedly save thousands of staffing hours and therefore costs to the hospital. Delivering communications has to sit at the heart of how outpatients’ referrals are improved.”



5. Recommendations for improving patient communications

Our recommendations for Sussex NHS Commissioners and our local NHS Trust, not only incorporate findings from our patient survey and eight case studies (see below), they also build upon our earlier work looking at how good communications can support the development of [Community Diagnostic Hubs](#) and our substantial involvement in stakeholder engagement work in the transformation of planned care services¹. They align to guidance published by the NHS in May 2021, “[Good Communication with patients waiting for care](#)”. In addition to our recommendations, Healthwatch supports a Sussex NHS Commissioners initiative to incentivise GPs to make consistent, high quality outpatient referrals which follow a standardized format.

Healthwatch recognises that the recovery of planned care services and their redesign for the future is not a quick fix. The crisis in waiting times for treatment does however give an opportunity to do things differently, more effectively and efficiently. The changes we recommend will give greater satisfaction to staff as well as patients and improve the reputation of some services where complaints about waiting and communications have escalated.

There are quicker wins, and bigger solutions to work towards.

¹ Planned care is the provision of routine services with planned appointments or interventions in a hospital (outpatients, day cases, planned surgery) or community settings e.g. in your GP surgery.

Quicker wins (3-6months)

1. **Sussex NHS Commissioners and University Hospitals Sussex NHS Foundation Trust (UHS)** should commit to working with Healthwatch (and patients) to create and sign up to a Patient Communication Charter and then publish this. The Charter, consisting of a series of core standards, should be underpin the production of all future patient communications.
- 2(i) **Sussex NHS Commissioners** should commit to implementing a system which ensures that standardised alerts by text or email are always sent out from all GP practices to patients confirming that a referral has been sent off (within 3 working days of the GP appointment).
- 2(ii) Similarly, standardised patient notifications must always be sent from the booking hub (or medical specialties) at **UHS Trust** to confirm that a referral has arrived within 3 days of it being received.
- 2(iii) A commitment should be made to ensure that all texts and emails will come from a standard or recognisable number / address which is in itself easily identifiable.
3. **Sussex NHS Commissioners** should commit to working with providers of services to publish honest, accurate and easily accessible data on waiting times for every specialty; and these must be routinely updated each month. All data should be produced using a consistent methodology and reflect urgent and routine waiting times.
- 4(i) **Sussex NHS Commissioners** should establish a Board or Working Group that includes local Healthwatch, which has a Sussex specific brief to improve all patient communications, covering all pathways. The Board/Group can also be tasked with actioning the recommendations contained in this report.
- 4(ii) The Board/Group should be tasked with mapping a standard outpatient journey to identify the key points at which patient communications are needed. A common and agreed set of principles about how, when and in what format patient communications need to be delivered should then be agreed.

"The same-day notification that my referral had been sent off, together with immediate access to my referral letter was excellent."

Medium term fixes (within 12 months)

- 5(i) **Sussex NHS Commissioners** should commit to working with providers of services and Healthwatch to review patient letters to improve and standardise their content.
- 5(ii) A commitment should be made to ensure that all letters will be written with the patient in mind and always explain the **"what, why, when, where, who, how, and how long the process will take"**. This is particularly important where patients have multiple referrals.

- 5(iii) A commitment to issue letters within a set time is needed. Letters are essential for those without phone or email but often arrive within a day or two of an appointment, providing patients with little advance notice.
 - 5(iv) All patient letters should be scrutinised by patients - the people they are intended for - to sense and language check. A Healthwatch volunteer group can deliver this to help ensure that they are fit for purpose.
 - 5(v) A commitment should be made to ensure that all letters connected with a referral will appear on the patient's "My Health and Care Record" and NHS App.
6. **Sussex NHS Commissioners and UHS Trust** should commit to doing more to better promote the NHS App and 'My Health Care Record' and to support patients to use these so that they receive timely information about their referrals which can be accessed this at their convenience.

Longer term fixes

- 7. **Sussex NHS Commissioners** should establish a quality referrals mechanism to measure the success of any system changes that are implemented as a result of our recommendations. This data should be used to identify where changes are not happening so that targeted support and guidance can be provided e.g. those specialties or GP practices who are not routinely updating patients.

6. Background to our report

National context

An average of over 100 million outpatients appointments take place every year, but the NHS Long Term Plan has stated that the current model of outpatients is outdated and unsustainable. In response the NHS is rolling out an Outpatient Transformation Programme aimed at giving patients greater control and convenience in their hospital or clinic appointments. Recently, it was announced that 5.7 million people are waiting for hospital care and in response, the Government is spending an extra £5.9 billion to tackle the problem. But this ambition to reduce waiting times will not be easily met if patients are not communicated with about their referrals and understand what to expect. Healthwatch England has described waiting lists as being inevitable, and stated that it's how we manage them that matters - patients need to make partners in their own care which is achieved in part through effective communication.

The Royal College of Physicians in their report Outpatients: the future - adding value through sustainability (November 2018) stated very clearly the importance of communication in helping to deliver a good outpatients' function:



Organising principle

Patients should be fully informed of what to expect from the service prior to appointments. That includes the aim of the appointment and expected waiting times.

“ The traditional one-model-fits-all approach to outpatient care is not able to keep up with growing demand and fails to minimise disruption to patient lives. Clinicians are increasingly frustrated with, and fatigued by, growing pressures from waiting lists and overbooked clinics. **Patients are frustrated by poor communication** and long waiting times. (page 2)

Patients have eloquently described how the doctor-patient interaction in the traditional outpatient model only represents ‘the tip of the tedious iceberg’ which stands between a patient and what we consider to be a quality interaction. **Their insights highlight system failures that prevent effective communication** and patient flow, hindering efficiency and patient experience. (page 10)

”

The report also highlights the impact which poor communication can have on abandoned or cancelled appointments, and getting communications right can significantly help to avoid valuable appointments going to waste:

“ Commonly reported reasons for DNAs Administration factors

- Clerical errors or **communication failures**
- No longer needing to attend
- Difficulty in cancelling appointments
- Poor appointment notification design
- Lack of notification or short notification
- The appointment booking process. (page 18)

”

In May 2021, the [NHS published a report](#) setting out core principles for providers to deliver personalised, patient centred communications to patients. The guide was produced by NHS England and NHS Improvement with support from Healthwatch, National Voices, the Patient’s Association, The Richmond Group of Charities and Versus Arthritis. The report stated very clearly:

“ .. every patient whose planned care has been disrupted by COVID-19 receives clear communication about how they will be looked after, and who to contact in the event that their clinical circumstances change.

... that systems should maintain effective communication with patients including proactively reaching out...

... it is now more important than ever to maintain frequent and honest contact with patients who are waiting for care.

”

Unfortunately, this has not always been the reality, with one patient telling Healthwatch Brighton and Hove as part of our recent work:

“ the referral was made before the full impacts of COVID-19 were felt, and it would have been nice to have been contacted to advise me how COVID-19 would affect my referral, but I heard nothing. ”

The NHS guide highlights the following core principles of good patient communications:

- **Ensure they are personalised** and give clarity on the next steps of a patient's care pathway including likely and honest timescales, and what they can expect. This will enable the patient to participate in an informed discussion about their treatment.
- **Use plain language** - they should be clear, accessible and easy to understand.
- **Ensure that are honest** - about appointments, delays and cancellations and provide a clear and honest message with a compassionate tone.
- **Include supporting information** - this should be provided to the patient to help them manage their condition whilst waiting for care.

The NHS guide provides a list of resources to aid Trusts and Commissioning Groups deliver good patient communications during COVID-19. We have included these are [Annex E](#) as they contain template letters which could be used to improve patient communications, although Healthwatch Brighton and Hove does not consider that some of these template letters are fully fit for purpose.

A National Voices report [Patient Noun Adjective: understanding the experience of waiting for care \(October 2020\) highlights patients' lived experiences of provider communications while waiting for care](#) revealed that a range of communication barriers may exist for some, and states:

“ To improve communications with patients, you should seek to:

- 1) Understand the importance of improving the experience of waiting.
- 2) Invest in developing patient-centred information and communication.
- 3) Support people while they wait, by:
 - a. providing and supporting self-management and shared decision-making
 - b. monitoring routinely and providing clear pathways to specialist advice
 - c. exploring potential for carefully delivered virtual healthcare
 - d. partnering with and signposting to voluntary, community and peer support.

To build on the National Voices report, this document lays out the core principles to support the standardisation of clear, person-centred communication with patients across the health service.

This is essential to improve patient experience and understanding when waiting for treatment in these uncertain times.

Communication strategies must be focused on two areas:

- the individual patient
- engaging with the local population



Local context

In 2019-20, the Brighton and Sussex University Hospitals Trust (BSUH) had over 950,000 appointments, seeing over 50,000 people across their outpatient departments a month and receiving on average 600-650 new referrals a day. The average time waited for a first appointments attendance from GP referral was 73 days. BSUH merged with Western Sussex Hospitals NHS Foundation Trust to form University Hospitals Sussex NHS Foundation Trust (UHS) in April 2021 and the number of outpatient referrals across the new, larger Trust will be substantially higher.

Prior to COVID-19, BSUH was unable to consistently offer non-emergency outpatient appointments and operations within 18 weeks of a GP referral to all patients all the time. Since COVID-19, this situation has worsened. Historically, some specialties have been particularly affected, for example urology, whilst other services face less pressure.

At the same time, UHS Trust (like all Trusts) experiences high levels of patients who do not attend their booked appointments, and it has previously been estimated that a considerable proportion of people who call up with queries regarding their appointment did not need to.

But the high rate of non-attendances also suggest that patients may not be receiving the information they need at the right time, and/or face difficulties when trying to arrange or amend their appointments.

In this context, small changes or improvements to existing systems and patient communications could have sizeable positive impacts for thousands of patients. University Hospitals Sussex NHS Foundation Trust operates a '[Patient First](#)' approach to transforming hospital services for the better. And one of their key values is delivering good communications.

NHS Sussex Commissioners are currently developing, enhancing or expanding a number of initiatives that are designed to give patients more control over their care. **Delivering good quality patient communications will be key to helping get the NHS back on track after COVID-19, and in [delivering these patient-focused changes](#):**

- ‘Getting It right first time’ i.e. getting the patient to the right service first time’ (*GIRFT*)
- ‘Patient initiated Follow-up’ (*PIFU*). Supporting patients to access a follow up appointment, or support
- ‘Shared decision making’, where the clinician and the patient decide together what is the best course of treatment/support or action
- ‘Single point of access’ and ‘one stop services’ to streamline access for patients and make best use of workforce
- ‘Did not attends’: efforts are needed to stop the 1 in 5 people who fail to attend their appointment which means that the patient did not receive care and the appointment was wasted.

(See the [Annex D](#) for further details of these initiatives)

Why Healthwatch Brighton and Hove believes that good communications sit at the heart of a better outpatient’s system

Patients have previously told Healthwatch Brighton and Hove that communication is key to the successful delivery of health care. In our report “[Community Diagnostic Hubs - a patient centred pathway through the diagnostic journey](#) Patients from Brighton and Hove share their experiences and views with us” which we shared with Sussex NHS Commissioners in June 2021, patients said they want to receive quality, clear, and accurate communications throughout all stages of their journey:

“Communication is key. I want to be told why I am having tests, when they are, what they entail, how long they’ll take, how long before my results, what could they mean, what can you rule out, what can’t you rule out.”

“I want to receive accurate and timely information which is written in a clear way with simple explanations.”

“I want to be able to track my journey online (to see its progress).”

Patients want to understand what will happen to them and when. They also want better access to their medical records to be able to monitor their progress. Effective communication can empower patients:

“If the patient is made to feel important with a role to play in dealing with their own condition they are empowered and much more likely to take the necessary steps alongside medical treatment to achieve the best outcomes.”

Whilst poor communications can have adverse impacts:

“The time left waiting without hearing anything generates worry, anxiety and can have a negative impact on health.”
“I want better communication to happen between the different healthcare systems, so that I do not have repeat my symptoms and personal story with different people. This can make the entire process quite overwhelming and brings an added stress to the process.”

The above comments were received from patients in April/May 2021 as part of our work exploring what patients wanted to see from the newly created Community Diagnostic Hubs (CDHs). One of the key ambitions for CDHs is to improve the patient experience in diagnosis. Our report concluded that communications were pivotal to the success of Community Diagnostic Hubs, but our findings apply equally to all patient pathways. Our report stated:

- “
- Having good communications in place will ensure Community Diagnostic Hubs are successful. There are two parts to this:
 - Defining very clearly what they can and cannot do; what services they will and will not offer. Explaining any limitations will help achieve clearer patient expectations.
 - Ensuring that timely, clear, and simply worded communications are provided at each stage of the diagnostic journey. These need to be made fully accessible and the only way to ensure that this happens is for the referring clinician to ask the patient what their needs are at the very start of their diagnostic journey.
 - Providing patients with clear communications can reduce unnecessary anxiety, prevent uncertainty, reduce unnecessary chase-ups and free up valuable NHS staff time.
 - Digital technology can help to deliver good communications. It speeds up the delivery of appointments and diagnostic test results. People told us that they want to have online access to monitor, track, and check the progress of their referral, and to see their appointments and test results. Online options must be easy and simple to access and use. At the same time Healthwatch has previously identified how online systems must provide for those who are digitally excluded.
 - Everyone who is involved in a patient's diagnostic journey must play their part in delivering good communications. This starts with the referring clinician explaining to a patient what tests they are being referred for and checking they understand. This continues with back office staff booking appointments which respect reasonable adjustments and specific patient requirements. Next, technicians must take time to clearly explain what tests are being done. The process ends with a clear explanation of all test results (avoiding medical terminology and jargon) and offering the chance to discuss these.
- ”



7. A Summary of our findings

50 patients told us about their outpatient referrals and the communications they had received

1. GPs are not consistently notifying patients about their referral

- A majority of people were referred by their GP to outpatients: 38 people or 76%.
- 15 patients had been notified by their GP practice that their referral had been sent off, whilst 22 had not.
- Only 6 of 38 GPs who had made an outpatients' referral had provided information to patients explaining how long to wait before chasing up their referral.

"I chased it and was told it was a 40 week wait! GP had originally said 2-3 months."

2. Not all patients are kept informed about their referral. Those patients who were told us that they had received notifications quickly in most cases.

- The overwhelming majority of people were not told by the person who was referring them how long to wait before chasing up their referral: 41 or 82%.
- A majority of people had not been contacted by the person who referred them to confirm that their referral had been sent off to the hospital's outpatients' booking team or speciality. 27/47 people had not (57%), whilst 20/47 had (42.5%).

"The same day notification that my referral had been sent off, together with immediate access to my referral letter was excellent."

- 15 of the 20 (75%) people who had been contacted to advise them that their referral had been sent off, said they had received notification of this within one week.

"The big problem is that you do not get any confirmation that your referral has been accepted and where you are in the system. I just assumed the basics had been done."

3. Hospital services are not routinely notifying patients they have received a referral but where this does happen then notification happens quickly in half of cases

- There is inconsistent practice across specialties and/or the outpatients' booking team at our local NHS Trust when it comes to notifying patients that their referral has been received. A majority of people (61%) were not contacted (n28/46), whilst 39% had been contacted (n18/46).
- The results from our survey showed that **the following services only sometimes notified patients that they had received their referral:** ENT, MSK, Gynaecology, Digestive Diseases, Neurology, Podiatry, Eye/Ophthalmic, Urology, Endocrinology and Orthopaedics.
- 9 of the 17 (53%) people who **had** been contacted to advise them that their **referral had been received** said they were notified of this within one week of their referral having been sent off.

"The letter was misleading ...it implied I would hear within two weeks which I didn't ..."

4. Patients are routinely chasing up referrals

"I didn't hear anything and had to call up several times just to find out there was a huge waiting list. It took ages to get through and the person on the other line sounded very stressed."

- 22 people felt the need to chase up their referral. 24.5% did this just once (n11/46), 15.5% did this 2-3 times (n7), 9% did this 4 or more times (n4).
- 8 people did not know how to chase up their referral suggesting that they may have wanted to.
- One third of patients said that they hadn't felt the need to chase up their referral (n15/46, or 33%).

5. Patients are not satisfied with communications they receive about their referrals

In terms of satisfaction with the communications people had received about their outpatients' referral (texts, calls, emails, letters, etc):

- 31% people were either satisfied or very satisfied (n13).
- 17% were neither satisfied, nor dissatisfied (n7).
- 52% were dissatisfied or very dissatisfied (n22).



8. A summary of our case studies

The following section summarises the key points made by the 8 people we interviewed or heard from, all of whom had been referred for an outpatient's appointment. Where discussions took place, these focussed on any communications that had happened immediately after a referral had been made, and those which took place later on. Patients were also asked for their views about improving communications. ([Annex C](#) has more details).

This highlighted 10 common things that patients want from their communications:

1. To be given a choice about how they are communicated with
2. For communications to be consistent and provide accurate information
3. To receive regular updates and to be kept informed
4. To receive information in a timely way
5. To receive information about waiting times to be seen
6. To be given a contact number for queries
7. To be provided with (or signposted to) information about how to manage possible conditions whilst waiting, or places to go for further support
8. An option to keep track of their referral online
9. To be provided with a record of phone calls
10. For staff/any communications to be honest even if it's bad news so that patients' expectations are not incorrectly raised.

Letters



They are useful for people to keep track of things and to provide a record of what has happened.

They can take too long to be posted out. Some patients received letters after an unexpected phone call from medical staff, causing unnecessary anxiety.

They often contain misleading or inaccurate information e.g. implying patients can call up after two weeks if they haven't heard to arrange an appointment, and including phone numbers where the implication is that these are direct lines to medical specialities when in fact, they are for the general Outpatients Booking team.

They are not routinely uploaded to patient's 'My Health and Care Record'.

Ensure letters are posted out far sooner or use email

Ensure all letters are automatically entered on to a patient's '[My Health and Care Record](#)'

Amend the content of letters as soon as possible to remove misleading information and provide data around waiting lists (see [Annex B](#) for some real-life letters, texts and online messages that were sent to patients, where Healthwatch Brighton and Hove has considered what aspects of these are good and where they could be improved).

Text alerts



These are useful as they can be issued immediately and received more quickly than letters. In some cases, they provide confirmation that referrals have been sent off and received, as well as links that allow patients to access their referral letter.

But they don't all contain consistent information and often come from unknown numbers generating suspicion that they are spam - how many texts are then ignored?

Make it automatic that patients are sent texts to confirm a referral has been sent off (by the referrer) and also received by the outpatient's booking team or speciality

Texts must come from a standard number which is easily identifiable as the NHS

Texts should provide links and useful numbers for patients.

Online systems



Patients welcome the idea of an online system which enables them to track their referral. Systems ideally need to show that a referral has been made and received, show waiting lists and where the patient is on that list: people want to know even if it's bad news as this empowers them.

Promote the 'My Health and Care Record' more, and provide support for patients to use this

Ensure this system is automatically updated with any letters pertaining to a referral and make sure that any patient alerts to access new letters etc., are clear and issued quickly.

Outpatients Booking Team



The team were described as friendly, polite, succinct and 'stressed sounding'. The team were able to confirm that referrals had been received and an idea of waiting lists but often offered no additional information beyond this.

It was quite often difficult to get through, and the repetitive answer message provided no indication of where people were in the queue.

Better communications that confirm referrals have been sent off and received, as well as better quality letters that contain transparent information about waiting times, will undoubtedly reduce call volumes to the team

Improve the answer message to give an indication of where people are in the queue. And consider offering a call back

Staff should offer an apology for any delay in answering a call.

Make it a free phone number.

Phone calls



Patients like to speak with another person, but phone calls should never happen unexpectedly as this can cause anxiety.

Phone calls need to be booked in with patients.

GPs



Patients described GPs as the ‘gatekeepers’ of outpatient referrals, sometimes having to convince them to make a referral. The information provided by GPs to patients varies considerably and some information is inaccurate.

GPs must be supported to enable them to make excellent quality referrals. They need access to information around waiting times and referral processes so that they can share this with patients.

9. A patient charter for good patient communications

The following standards have been identified by Healthwatch from our survey of patients, interviews and research. We believe that these can be adapted by NHS Sussex Commissioners and our local NHS Trust to create a Patient Communication Charter which could underpin all communications.

Interviews conducted by Healthwatch in October 2021 highlighted 10 common things that patients want from their communications:

1. To be given a choice about how they are communicated with
2. For communications to be consistent and provide accurate information
3. To receive regular updates and to be kept informed
4. To receive information in a timely way
5. To receive information about waiting times to be seen
6. To be given a contact number for queries
7. To be provided with (or signposted to) information about how to manage possible conditions whilst waiting, or places to go for further support
8. An option to keep track of their referral online
9. To be provided with a record of phone calls
10. For staff and any communications to be honest even if it's bad news, so that patients' expectations are not incorrectly raised.

Healthwatch reviewed genuine patient letters and concluded that these need to include the “what, why, when, where, who, how, and how long”.

- **What:** referral does the letter relate to? E.g. “*This letter relates to the referral to [service] made by [referrer] on [date]*”. Being this specific is useful for patients who have more than one referral ongoing
- **Why** is the letter being sent? Is it to confirm that a referral has been sent or received, to share information, to describe what will happen next, a call to action? And what choices (if any) does the patient have?
- **When** will the patient hear next, and/or when is their appointment or when might it be (patients must be given information on average waiting times)
- **Where** is (or might be) the location(s) of their appointment(s), or choices of locations. This information links to the development of Community Diagnostic Hubs (see below)

- **Who** will the patient be seeing, and who will contact them (their GP, the specialty, Outpatients' Booking team)? Also, who can the patient contact in the meantime if they need to with any questions
- **How** will the appointment proceed i.e is it a face to face or telephone or video appointment?
- **How long** will the appointment take: this is essential information that the patient needs to plan for time away from work, to arrange care, etc.

In our report on ["Community Diagnostic Hubs"](#) (June 2021) patients told Healthwatch that **good communications encompass all of the following:**

1. Define very clearly what can and cannot be done and explain any limitations which then help to set clearer patient expectations
2. Are timely, clear, and simply worded communications and are provided at each stage of the diagnostic journey
3. Are fully accessible to the patient (referring clinicians must ask patients what their communication needs are at the very start of the diagnostic journey)
4. Make full use of digital technologies. These speeds up the delivery of appointments and diagnostic test results. People want to have online access to monitor, track, and check the progress of their referral, and to see their appointments and test results. Online options must be easy and simple to access and use. At the same time online systems must provide for those who are digitally excluded.
5. Are delivered by everyone who is involved in a patient's diagnostic journey.

An [NHS published a report in May 2021](#) set out the core principles for providers to help deliver personalised, patient centred communications

1. **Ensure they are personalised** and give clarity on the next steps of a patient's care pathway including likely and honest timescales, and what they can expect. This will enable the patient to participate in an informed discussion about their treatment.
2. **Use plain language** - they should be clear, accessible and easy to understand.
3. **Ensure that are honest** - about appointments, delays and cancellations and provide a clear and honest message with a compassionate tone.
4. **Include supporting information** - this should be provided to the patient to help them manage their condition whilst waiting for care.

A National Voices report, [Patient Noun Adjective](#), October 2020 concluded that to improve communications with patients, providers should:

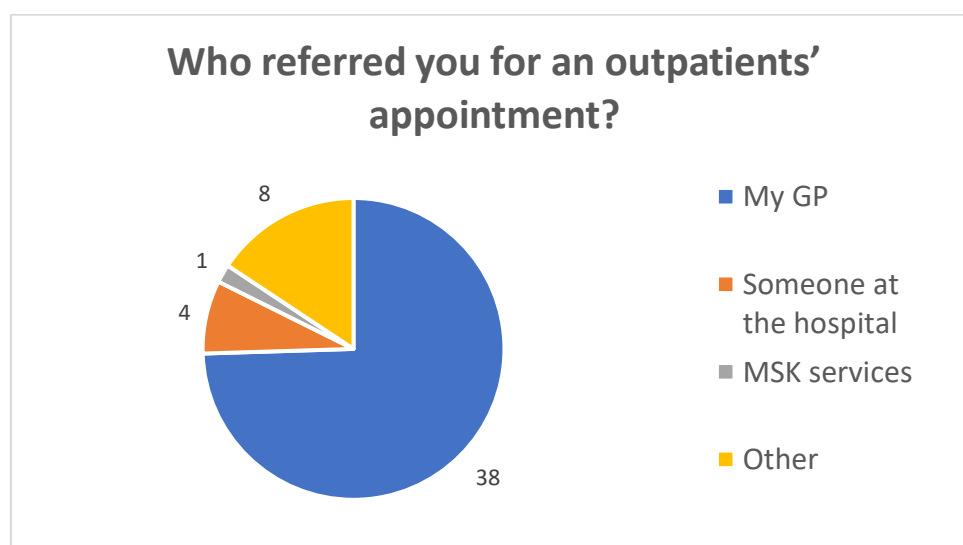
1. Understand the importance of improving the experience of waiting
2. Invest in developing patient-centred information and communication
3. Support people while they wait, by:
 - a. providing and supporting self-management and shared decision-making
 - b. monitoring routinely and providing clear pathways to specialist advice
 - c. exploring the potential for carefully delivered virtual healthcare
 - d. partnering with and signposting to voluntary, community and peer support.

10. Analysis of the survey responses (in full)

The full data from the Healthwatch survey and the questions we asked is available at [Annex A](#).

Q1. Who referred you for an outpatients' appointment?

The majority of the people who responded to our survey had been referred for an outpatients' appointment by their GP.



50 patients answered this question about their referral and the full breakdown is as follows (people could select more than one answer):

- 38 people (76%) people were referred by their GP
- 4 people (8%) were referred by someone at the hospital
- 2 people (4%) were referred by an optician
- 1 person each were referred from MSK services, a dental practice, a diabetic nurse, by the Out of Hours service, podiatry, and a unit the patient called 'L9'. One person did not provide a clear answer to this question. One person indicated that they had been referred by both their GP and someone at the hospital.

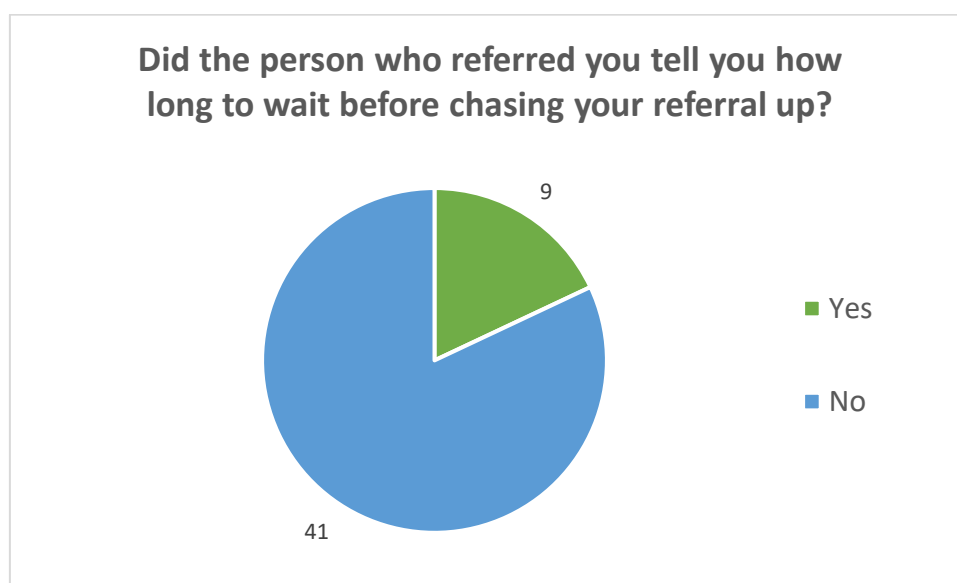
“If you feel you are not being listened to [at the outset] followed by no communication, it makes you feel you do not matter here either.”



Q2. Did the person who referred you tell you how long to wait before chasing your referral up?

50 people answered this question. The overwhelming majority of people had not been told by the person who had referred them how long to wait before they should start to chase up their referral: 41 people, or 82%.

When we examined the data in more detail, only 6 of the 38 GPs who had made a referral had provided advice to patients about how long they should wait.



“ I chased it and was told it was a 40 week wait! GP had originally said 2-3 months. ”



✓ “ My GP referred me to neurology and a day later I was sent a text from my practice advising me it had been sent off together with a link to download a referral letter. This was the first time my GP had done this. ”

✓ “ I received a text three days later advising me that my referral had been received and a link to access ‘My Health and Care Record’. ”

Q3. Were you contacted to advise you that your referral had been sent off to the hospital's outpatients' booking team?

47 people answered this question. A majority of people had not been notified by the person who had initially referred them to confirm that their referral had been sent off to the hospital's outpatients' booking team or speciality:

- 27 people had not (55%)
- 20 had (43%).

When we examined the data in more detail, we identified inconsistent practice across GP practices when it comes to notifying patients that they had sent the referral off. 15 practices had done this, whilst 22 had not. We did not identify any obvious pattern in terms of whether GPs were better at notifying patients about referrals to some services, but not others.

“The big problem is that you do not get any confirmation that your referral has been accepted and where you are in the system. I just assumed the basics had been done. My condition is not life threatening - I hope - but needs treatment, but someone else's might be.”



”



“The same day notification that my referral had been sent off, together with immediate access to my referral letter was excellent. This is the first time that I've ever received any kind of communications from my GP advising me that my referral has been sent off.”

”

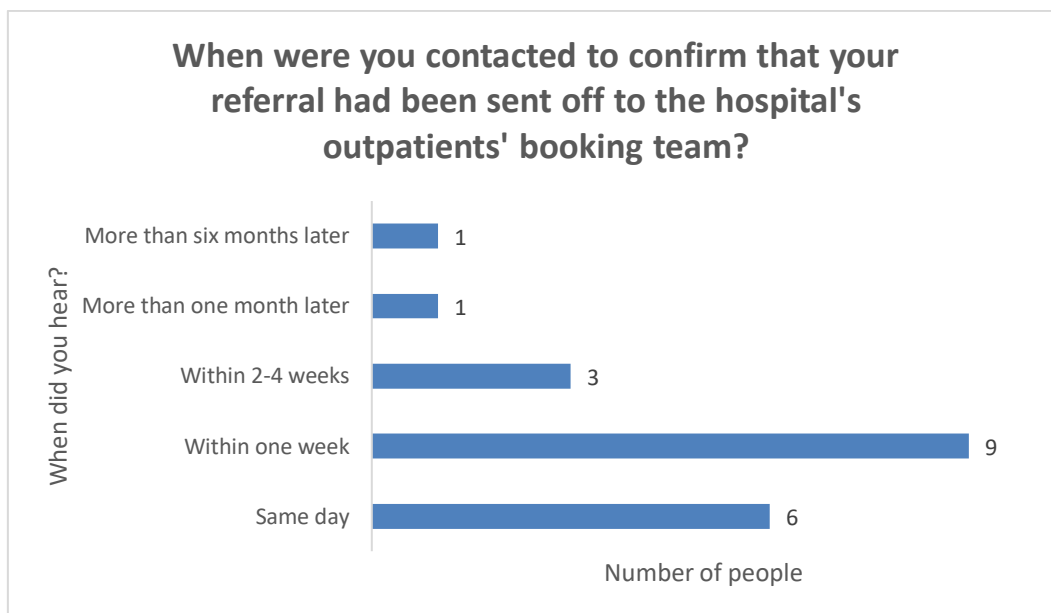
Q4. When were you contacted to confirm that your referral had been sent off to the hospital's outpatients' booking team?

20 people were eligible to answer this question.

15 of the 20 (75%) people who had been contacted to advise them that their referral had been sent off said they had received notification within one week. The full breakdown of data is as follows:

- 6 people (30%) had been notified the same day (where known these people had been referred to: Dietetics, Neurology, Eye, MSK and Gynaecology)
- 9 people (45%) had been notified within one week (where known these people had been referred to: ENT, MSK, Gynaecology and Dermatology)
- 3 people (15%) had been notified within 2-4 weeks (where known these people had been referred to: ENT and MSK)

- 1 person heard back more than a month later (this person had been referred to Neurodevelopmental services)
- 1 person heard back more than six months later (this person had been referred to ENT).



When we also examined the data for the 27 people who **had not** been notified that their referral had been sent off, this revealed that they had been referred to the following services (where known):

- Digestive Diseases (8 people, or 29.5%)
- Eye/Ophthalmic (4 people, or 15%)
- Gynaecology (4 people, or 15%)
- ENT (3 people, or 11%)
- MSK (2 people, or 7%)
- Urology (2 people, or 7%)
- Rheumatology, Respiratory Clinic, Dietetics, Neurodevelopmental services (1 person, or 4% each)

As can be seen, there does not seem to be a standardised approach when it comes to notifying patients that their referral had been sent off.

“

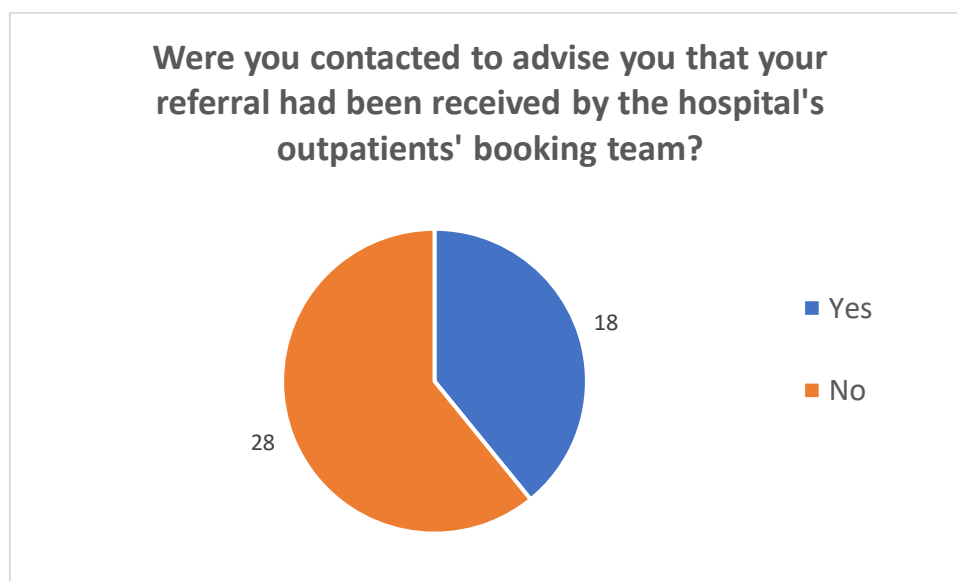
The main thing is consistency.

”

Q5. Were you contacted to advise you that your referral had been received by the hospital's outpatients' booking team?

46 people answered this question. A majority of people had not been contacted to advise them that their referral had been received by the hospital's outpatients' booking team or the speciality:

- 28 people had not (61%)
- 18 people had (39%)



When we examined the data further, we identified that there is inconsistent practice across services and/or the outpatients booking hub when it comes to notifying patients that their referral had been received.

Digestive Diseases and Gynaecology are the services most mentioned for not notifying patients.

The results from our survey showed that the following services only sometimes notified patients that they had received their referral: ENT, MSK, Gynaecology, Digestive Diseases, Neurology, Podiatry, Eye/Ophthalmic, Urology, Endocrinology and Orthopaedics.

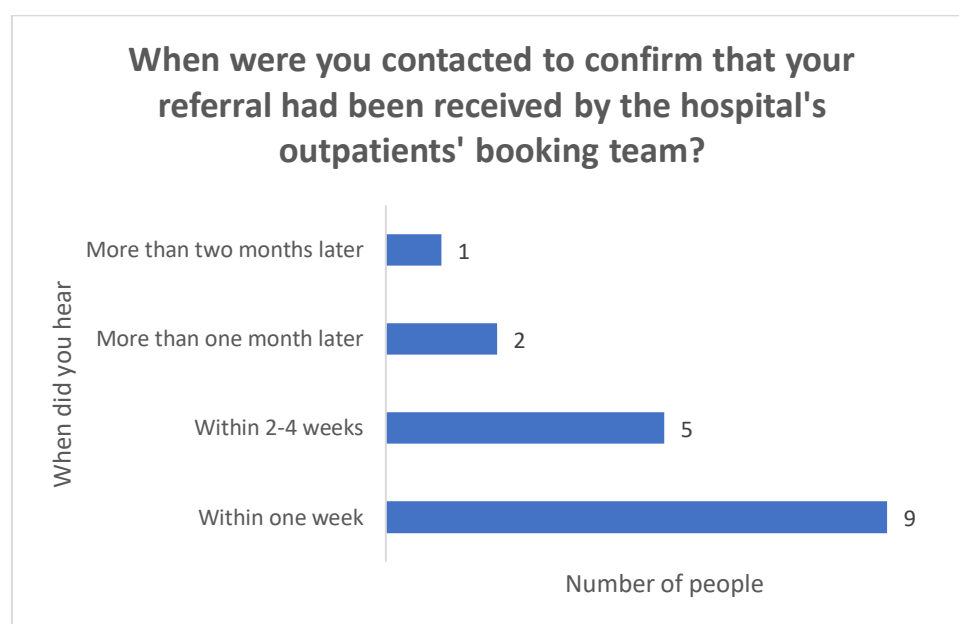
“I am disgusted actually as the appointment I am waiting for is serious, I have received one letter from outpatients advising that due to COVID-19 there is a back log for the treatment I am in need of.”



Q6. When were you contacted to confirm that your referral had been received by the hospital's outpatients' booking team?

17 people were eligible to answer this question.

9 of the 17 (53%) people who had been contacted to advise them that their referral had been received said they had received notification within one week.



“ The letter was misleading as it implied I would hear within two weeks which I didn’t, and it suggested the phone number was a direct number to neurology outpatient app but it was just the general booking team ”



The full breakdown is as follows:

- No one had been notified the same day that their referral had been sent off
- 9 people (53%) had been notified within one week of their referral being sent off (where known these people had been referred to: ENT, Gynaecology, Digestive diseases, Neurology, Podiatry and Eye/Ophthalmic)
- 5 people (29%) had been notified within 2-4 weeks of their referral being sent off (where known these people had been referred to: ENT, MSK, Eye/Ophthalmic, Urology, Endocrinology and Orthopaedics)
- 2 people (12%) had been notified more than a month after their referral being sent off (where known these people had been referred to Digestive Diseases and Neurodevelopmental services)
- 1 person had been notified more than two months after their referral being sent off (they had been referred to the Respiratory clinic).

When we examined the data for the 29 people who had not been notified that their referral had been received by the hospital outpatients' booking team or

speciality, this revealed that they had been referred to the following services (where known). Several people were referred into more than one service so %s add up to more than 100):

- Digestive Diseases (6, or 21%)
- Gynaecology (6, or 21%)
- ENT (5, or 17%)
- MSK (4, or 14%)
- Eye/Ophthalmic, Dermatology, Dietetics, (2, or 7% each)
- Orthodontics/Maxillofacial, Urology, Rheumatology, Podiatry, Infectious Diseases and Cardiology (1, or 3.5% each).

Q7. How many times have you chased up the progress of your outpatients' referral?

45 people answered this question.

22 people felt the need to chase up their referral.

11 people (24.5%) did this just once
7 people (15.5%) did this 2-3 times
4 people (9%) did this 4 or more times.

In addition, 8 people did not know how to chase up their referral suggesting that they may have wanted to (which would make a total of 30 patients who wished to chase up their referral, which is 65% of the 46 people who provided this information).

Just one third of patients said that they had not felt the need to chase up their referral (n15/46, or 33%).

“Essentially, the biggest issue which has affected my outpatient referral, and which has caused uncertainty and confusion, are the poor communications, particularly at the start of the process. Surely, it should be simple to create a uniform way of communicating with patients. Delivering this will undoubtedly save thousands of staffing hours and therefore costs to the hospital. Delivering communications has to sit at the heart of how outpatients' referrals are improved.”



”



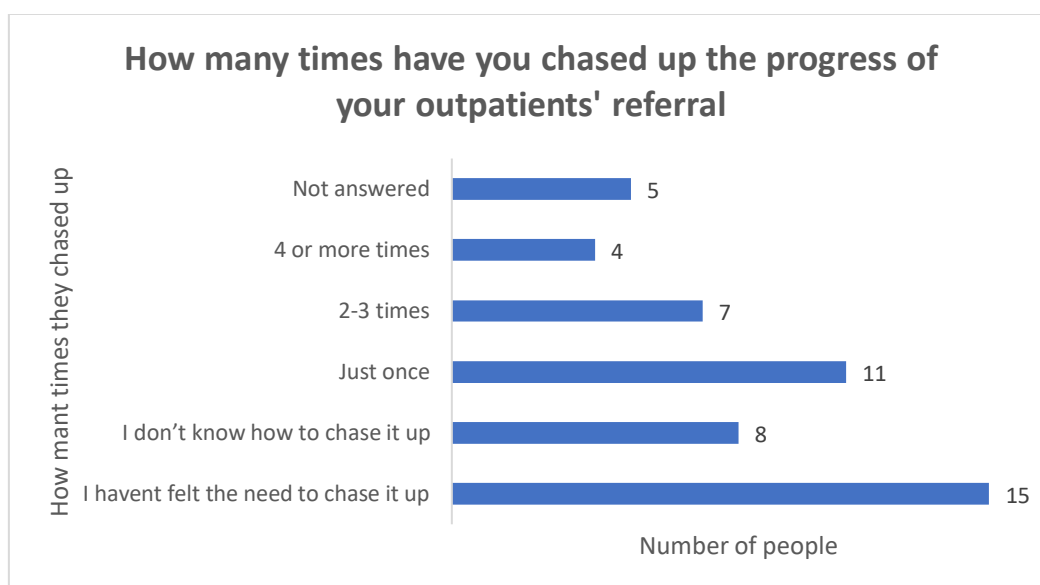
“The outpatient booking team have been great on the phone, very kind and understanding.”

”

“ The Consultant who ordered more blood tests and bowel tests, but 3 weeks later I am still waiting for these to arrive. I don't have a number to call or the name of the person I spoke to. ”



“ I didn't hear anything and had to call up several times just to find out there was a huge waiting list. It took ages to get through and the person on the other line sounded very stressed. ”



We examined the details of the 30 people who chased up their referral or who said they did not know how to do this:

- 29 **had not** been told by the person who was referring them how long to wait before chasing up their referral
- 17 **had not** been notified that their referral had been sent off
- 23 **had not** been notified that their referral had been received
- 7 people who had been notified that their referral had been received nevertheless chased up their referral.

This highlights the importance of sharing basic information with patients about their referral to avoid them making unnecessarily enquiries.

“ I was told I am on the waiting list then transferred to few different people until I reached a dead end of the voicemail. My issue was not urgent but I still don't know how long I will have to wait. ”



“ I didn’t hear anything and had to call up several times just to find out there was a huge waiting list. It took ages to get through and the person on the other line sounded very stressed. ”



Q8. How did you chase up your outpatients' referral?

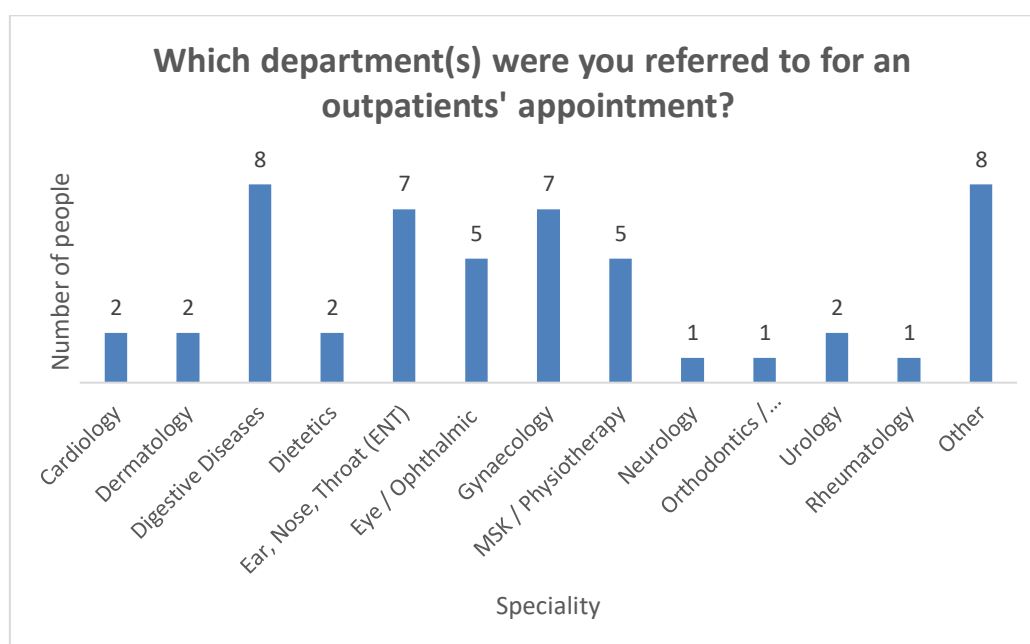
22 people were eligible to answer this question. People could select more than one answer providing 27 responses overall.

Of the 22 people who had chased their appointment:

- 12 (54.5%) only contacted the outpatients' booking hub
- 4 (18%) only contacted their GP
- 4 (18%) contacted both the outpatients' booking hub and their GP
- 1 person contacted their dentist and also the outpatients' booking hub
- 1 person called up the speciality they had been referred to directly.

Q9. Which department(s) were you referred to for an outpatients' appointment

The data showed that five specialities received 5 or more referrals: Digestive Diseases, ENT, Eye/Ophthalmic, Gynaecology, MSK. Given the low overall number of survey respondents (50) we have not performed detailed analysis of the results for each of these five services as the sample size would not provide results which could be tested for statistical significance.

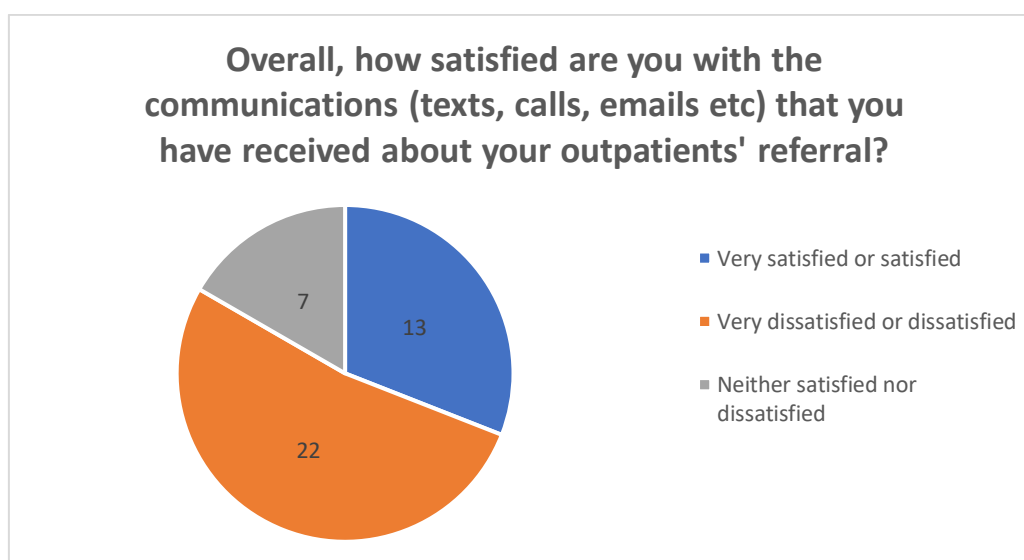


Q10. Overall, how satisfied are you with the communications (texts, calls, emails etc) that you have received about your outpatients' referral(s)?

42 people answered this question, and the majority of people were dissatisfied or very dissatisfied with the communications they had received about their outpatients' referral:

- 13 people (31%) people were either satisfied or very satisfied
- 7 people (17%) were neither satisfied, nor dissatisfied
- 22 people (52%) were dissatisfied or very dissatisfied.

Three specialities received 100% dissatisfied ratings from patients as regards the communications received about outpatient referrals: Gynaecology, MSK, and Digestive Diseases.



We examined the characteristics of the people according to their satisfaction ratings to see if there were any common features.

Those who were dissatisfied shared several similar traits:

- None of the people who said they were dissatisfied with communications had been advised how long to wait before chasing up their referral
- Half had not been notified that their referral had been sent off
- Less than a third had been notified that their referral had been received
- Over thirds had chased up their referral up.

Conversely, of those who were satisfied with communications:

- A third had been advised how long to wait before chasing up their referral
- Just under half had been notified that their referral had been sent off
- Two thirds had been notified that their referral had been received
- Over three quarters hadn't felt the need to chase their referral up.

These findings highlight the direct correlation between patient satisfaction with outpatient communications and being provided with basic information about:

- a. How long they should wait before needing to chase up their referral
- b. Being notified that their referral has been sent off
- c. Being notified that their referral has been received.
- d.

The provision of such information may reduce the number of patient enquiries by two thirds.

The full analysis revealed:

Characteristics of the 22 people who were dissatisfied or very dissatisfied:

- 5 people each had been referred to Gynaecology, MSK, or Digestive Diseases
- 3 people had been referred to ENT
- 2 people each had been referred to Eye/Ophthalmic
- 1 person each had been referred to Dermatology, Cardiology, Rheumatology, Endocrinology, Orthodontics/Maxillofacial, Podiatry, Neurodevelopmental services and Urology
- 19 (86%) had been referred by their GP, 3 (14%) by other health professionals
- No one had been told how long to wait before chasing up their referral
- 11 (50%) had been notified that their referral had been sent off, 8 (36%) of those within one week
- 11 (50%) had not been notified that their referral had been sent off
- 6 (27%) had been notified that their referral had been received, 2 (9%) within one week, 2 (9%) within 2-4 weeks, and 2 (9%) more than one month later
- 16 people (73%) had not been notified that their referral had been received
- 15 (68%) had chased up their referral up, 6 (27%) didn't know how to chase it up. Just one person said that they didn't feel the need to chase their referral up.

Characteristics of the 13 people who were satisfied or very satisfied:

- 3 people had been referred to Eye/Ophthalmic
- 3 people had been referred to ENT
- 1 person each had been referred to Respiratory Clinic, Orthopaedics, Infectious Diseases, Podiatry, Urology, Cardiology, Dermatology, Dietetics and Neurology
- 9 (69%) had been referred by their GP, 3 (31%) by other health professionals
- 4 (31%) had been told how long to wait before chasing up their referral, 9 (69%) had not been told

- 6 (46%) had been notified that their referral had been sent off, 5 (38%) within one week
- 7 (54%) had not been notified that their referral had been sent off
- 8 (67%) had been notified that their referral had been received, 4 (50%) within one week, 7 (54%) within 2-4 weeks
- 5 people (38%) had not been notified that their referral had been received
- 10 people (77%) hadn't felt the need to chase their referral up, whilst 3 (23%) people had.

Annex A - survey questions and responses

Who referred you for an outpatients' appointment (select all that apply)?

(51 responses received from 50 people as multiple choices could be selected)

My GP	A community nurse	Someone at the hospital	Someone from Musculoskeletal services (MSK), or physiotherapist	Other (please specify)
38	0	4	1	Optician - 2 Dentist - 1 Diabetic nurse - 1 Out of Hours - 1 L9 - 1 Podiatry - 1 Not answered 1

Q2. Did the person who referred you tell you how long to wait before chasing your referral up?

(50 responses received)

Yes	9
No	41

Q3. Were you contacted to advise you that your referral had been sent off to the hospital's outpatients' booking team?

(47 responses received. 50 people were eligible to answer)

Yes	20
No	27
Not answered	3

Q4. When were you contacted to confirm that your referral had been sent off to the hospital's outpatients' booking team? (select one answer)

(20 responses received, 20 people were eligible to answer this question)

Same day	Within one week	Within 2-4 weeks	More than one month later	More than two months later	More than three months later	More than six months later	I haven't heard yet	Not answered
6	9	3	1	0	0	1	0	1

Q5. Were you contacted to advise you that your referral had been received by the hospital's outpatients' booking team?

(46 responses received. 50 people were eligible to answer)

Yes	17
No	29
Not answered	4

Q6. When were you contacted to confirm that your referral had been received by the hospital's outpatients' booking team? (select one answer)

(17 responses received, 17 people were eligible to answer this question)

Same day	Within one week	Within 2-4 weeks	More than one month later	More than two months later	More than three months later	More than six months later	I haven't heard yet
0	9	5	2	1	0	0	0

Q7. How many times have you chased up the progress of your outpatients' referral (select one answer)?

(45 responses received. 50 people were eligible to answer)

I haven't felt the need to chase it up	I don't know how to chase it up	Just once	2-3 times	4 or more times	Not answered
15	8	11	7	4	5

Q8. How did you chase up your outpatients' referral? (select all that apply)

(37 responses received from 22 people as multiple choices could be selected. All 22 people who were eligible to, answered this question)

I called or emailed the outpatients' booking team	I called or emailed my GP	Other
17	8	2 Called dentist Called the speciality directly

Q9. Which department(s) were you referred to for an outpatients' appointment (select all that apply)?

(responses received from 42 people as multiple choices could be selected. 50 people were eligible to answer)

Cardiology	2
Dermatology	2
Digestive Diseases	8
Dietetics	2
Ear, Nose, Throat (ENT)	7
Eye / Ophthalmic	5
Gynaecology	7
Haematology	0

MSK / Physiotherapy	5
Neurology	1
Orthodontics / Maxillofacial	1
Urology	2
Renal	0
Rheumatology	1
Radiology - X-ray	0
Other	8: Colonoscopy Endocrinology Podiatry (2) Respiratory Clinic Orthopaedics Infectious diseases Neurodevelopmental services

Q10 Overall, how satisfied are you with the communications (texts, calls, emails etc) that you have received about your outpatients' referral(s) so far (select one answer)?

(42 responses received. 50 people were eligible to answer)

Very satisfied	Satisfied	Neither satisfied nor dissatisfied	Dissatisfied	Very dissatisfied	Not answered
7	6	7	12	10	8

Q11 Please add any final comments about your outpatients' referral (Positive comments are highlighted)

1. Just given up now all I get is a telephone appointments which are useless
2. I've not heard anything from anyone
3. Referral 'got lost' - neither dentist nor hospital could tell me how or 'where'. I waited 2 years for the appointment then was given an initial date at very short notice - I had to ask for a new date so I had time to make arrangements for being looked after following general anaesthetic. Communication was very poor until right before the appointment.
4. I am disgusted actually as the appointment I am waiting for is serious, I have received one letter from outpatients advising that due to covid there is a back log for the treatment i am in need of. I have been waiting since last September 2020.
5. Very good and friendly
6. I did eventually see a specialist exactly 1 year after urgent referral.

7. On ringing told by outpatients they were not even booking in non-urgent referrals at moment. No communication of this by them to me until I chased up. Unclear if my referral will ever be acted upon.
8. I recently received a hospital appointment, not connected to my latest recent referral, which I didn't know about by the audiology dept to ENT in 2020.
9. GP forgot to send referral- I had to chase this up after 4 weeks. I had a prompt telephone consultation with the Consultant who ordered more blood tests and bowel tests, but 3 weeks later I am still waiting for these to arrive. I don't have a number to call or the name of the person I spoke to
10. For autism and adhd the wait for an assessment is 18 months or could be more now due to covid. I've not heard anything since I got the first letter and I think the waiting time is totally unacceptable for the assessment and to start getting treatment for my adhd. I had to pay to go private for the assessment but for me to be prescribed meds for my adhd I still have to wait 18 months to someone through the NHS before I can have any help and/or treatment
11. I was expecting an appointment in 6 months time, instead I saw the consultant within 5 weeks! Pleasantly surprised.
12. I chased it was told it was a 40 week wait! GP had originally said 2-3 months. Have had to go to a private appointment as cannot wait until January earliest.
13. Would like to know how to chase
14. I was given an unnecessary referral to gynaecology for HRT as the out of hours GP appt my surgery made due to their staffing issues was not knowledgeable about menopause to make the very simple treatment decision I was asking to go on continuous HRT 17 months after my last period. I followed up with the GP surgery who said they'd cancel, what I was told was an urgent referral and ask the gynae team in writing to agree prescription. Due to this and other bad experience I moved GP surgery. I followed up and was told to call outpatients the referral was triaged as non-urgent with a 44 week waiting list. If I hadn't changed GP I'd have been left in early menopause with disabling symptoms without treatment for almost 2.5 years. I got the referral cancelled and my new GP prescribed continuous HRT.
15. Three days before my appointment I was telephoned unexpectedly by someone from the Diabetic Eye Screening team. I was totally confused but think they were trying to arrange an appointment. I said I had a hospital appointment and then there was no response so I left it. Later in the morning, while my partner was present, a man called back from the Eye Screening Team. Again I was confused and as I was trying to leave for work I was becoming more agitated and ended up saying I was getting annoyed and closed my phone case. However, I hadn't hung up and the call was on speakerphone and both of us heard him laughing at my statement. My partner said "Is he laughing? Is he laughing at you?" I said yes. She

immediately called them back and asked to speak to a manager and wasn't called Sara.
16. I have been referred two times. One as urgent
17. They don't give you any results
18. The outpatient booking team have been great on the phone, very kind and understanding, but all they are able to tell me is that the referral hasn't yet been triaged. The wait for Infectious Diseases is supposedly 5 weeks for urgent cases and 6 weeks for routine appointments, I'm 5.5 weeks since referral and haven't been triaged to then be able to make an appointment (so expecting potentially a further 6 week wait once this has finally happened).
19. The appointment has been done. Less than 12 weeks wait.
20. I have been waiting for this appointment for 3 years, it has finally come through as a phone consultation, at this stage I can eat very little, process very little and am in a huge amount of pain. The service has been reprehensible.
21. I was told I am on the waiting list then transferred to few different people until I reached a dead end of the voicemail. My issue was not urgent but I still don't know how long will I have to wait.
22. I didn't hear anything and had to call up several times just to find out there was a huge waiting list. It took ages to get through and the person on the other line sounded very stressed
23. I was referred by my GP to Digestive Diseases on 11 Jan, and as I hadn't heard anything I called up my GP at the end of April to chase. They gave me two numbers to call and wished me good luck! By coincidence, on this day I also received a call from a standard unknown mobile number (27 April) which I chose to ignore assumed it to be "cold caller". I answered the second time and it turned out to be the NHS calling me. After this phone call things moved quickly and I was called up to book a phone consultation a few weeks later. I was texted with details of the appointment although it didn't come from an NHS sender. Apart from the first 3 months when I heard nothing at all, everything else has been very good. But patients shouldn't be left in the dark and having to chase
24. My GP referred me to neurology and a day later I was sent a text from my practice advising me it had been sent off together with a link to download a referral letter. This was the first time my GP had done this. Sadly, the letter was misleading as it implied I would hear within two weeks which I didn't, and it suggested the phone number was a direct number to neurology outpatient app but it was just the general booking team. I also received a text three days later advising me that my referral had been received and a link to access My Health and Care Record. It wasn't obvious the text was from the NHS as it simply came from a sender called 'Message' so at first I thought it was a scam. No info on waiting times so I still had to call up and wait 7 mins to speak to a very stressed sounding operator who told me I would be waiting 40-45 weeks! Not the 2 weeks suggested by the

letter i had received from my GP. In the end I paid to go private as i couldn't wait a year just to speak to a consultant

25. I was happy with original appointment which was on a 2 week referral pathway. I am very dissatisfied with what happened then when my condition was seen as routine. My referral appears to have disappeared into a black hole.

Questions 12 and 13 allowed respondents to provide their contact information to take part in future surveys and/or telephone interviews

Demographic data question

Q14. What is your gender identity?

(42 responses received. 50 people were eligible to answer)

Female	32
Male	5
Not answered	13

Q15. Is your gender identity the same as the gender assigned to you at birth?

(37 responses received. 50 people were eligible to answer)

Yes	33
No	0
Prefer not to say	4
Not answered	13

Q16. How old are you?

(36 responses received. 50 people were eligible to answer)

80 and over	0
70-79	6
60-69	9
50-59	7
40-49	4
30-39	7
18-29	1
Under 18	0
Prefer not to answer	2
Not answered	14

Q17. What is your sexual orientation?

(37 responses received. 50 people were eligible to answer)

Bisexual	2
Gay man	4
Lesbian / gay woman	0
Heterosexual / straight	25
Don't know	0

Prefer not to say	4
Asexual	1
Other	1
Not answered	13

Q18. What is your ethnic background?

(35 responses received. 50 people were eligible to answer)

White/ English/Welsh/Northern Irish/British	30
White Irish	1
White Gypsy or traveller	0
Any other white background	2
Black or Black British, African	1
Black or Black British , Caribbean	0
Any other Black background	1
Asian or Asian British, Bangladeshi	0
Asian or Asian British, Indian	0
Asian or Asian British, Pakistani	0
Chinese	0
Any other Asian background	0
Mixed Asian and White	0
Mixed Black African and White	0
Mixed Black Caribbean and White	0
Any other Black background	0
Arab	0
Prefer not to say	0
Other	0
Not answered	15

Annex B - Genuine examples of information sent to patients

This is good as it clearly states who made the referral (their GP). It also states which department the patient was referred to.

It could be improved by including the date the referral was made (for patient's records).

This is misleading wording. It inferred to the patient that they could ring up after two weeks to get an appointment which was inaccurate.

There is a lack of clear information on waiting times or next steps. It simply directed the patient to call the outpatients team.

This implied to the patient that the number is a direct line to neurology. In fact, it is the general outpatients' number.

This implied to the patient that their referral would be reviewed by 4th August. It was not, so was again misleading

Your referral is being reviewed

██████████ MEDICAL CENTRE has referred you to:
General Neurology Referrals-University Hospitals Sussex-RXH01.

➤ You do not need to do anything at this stage.

You will be contacted by either:

General Neurology Referrals-University Hospitals Sussex-RXH01
if you need to be seen
or

██████████ MEDICAL CENTRE
if the clinic sends any other advice.

What to do if you have not been contacted

➤ Please wait until 4th August 2021.

If you have not been contacted by this date, call General Neurology Referrals-University Hospitals Sussex-RXH01 using the referral details shown here.

General Neurology Referrals-University
Hospitals Sussex-RXH01

☎ 0300 303 8360

Monday-Friday 8-4

Referral details

Booking reference number

0003 ██████████

Access code

██████████



NHS Home Help More

If you have not been contacted by this date, you can phone General Neurology Referrals-University Hospitals Sussex-RXH01 on: 0300 303 8360 (Monday-Friday 8-4).

1 referral for ██████████

1 referral being reviewed

General Neurology Referrals-University Hospitals Sussex-RXH01 will review your referral to Neurology by 4th August 2021 [View details](#)

NHS Home Help

If you have not been contacted by this date, you can phone General Neurology Referrals-University Hospitals Sussex-RXH01 on: 0300 303 8360 (Monday-Friday 8-4).

Texts sent to one patient

This was an excellent text sent to the patient one day after their GP had referred them. It provided confirmation that the referral had been made and allowed the patient to see their actual referral letter.

This text was also excellent. It was sent from the patient's GP to the patient to arrange a follow-up appointment. It was sent a few weeks after the patient had been signed off by their consultant. The consultant had written to the GP with a recommendation to arrange a consultation with the patient to speak about further options to manage their symptoms. The patient was not left wondering "what next?"

GPSurgery >
You have today been referred to Neurology and attached you will find details on what to do if you have not been contacted by the 4th August.
Best wishes - Secretary
Please view your document here (link will expire in 28 days):
florey.accurx.com/d/8qs57yhqfn

We have had a recent hospital letter and the Gp has asked if you could book a tel/cons to discuss this. Please call at 8am or 3pm Mon - Fri to arrange this, it is not urgent
Thanks,
[Redacted] Medical Centre

< [Profile Icon]
+44 77 [Redacted]
Text Message
Tue 24 Aug, 16:31

This is a 7 day reminder that you have an appt booked with [Redacted] for a FUp Telephone on 31/08/21 16:30 at Royal Sussex County Hospital. If you are able to make this appt, no reply is needed. If you must reschedule this appt please reply with REBOOK 2711. If

MESSAGE >
BSUH Digestive Diseases Department: We have made your appointment for 31/08/2021 @ 16:30 approx. This will take place as a telephone consultation - please DO NOT attend the hospital. If you no

< [Profile Icon]
NHSSMS >
Text Message
Sun 29 Aug, 16:30

This is a 2 day reminder that you have an appt booked with [Redacted] for a FUp Telephone on 31/08/21 16:30 at Royal Sussex County Hospital.

These three texts were useful as they provided the patient with reminders.

Where they need to be improved: they were sent from unrecognisable numbers: one random number, one called NHSSMS, and another recalled 'Message'. All three could easily be mistaken as spam

Two letters sent to one patient concerning the same referral

This was clear as it:

- Explained which referral it related to
- Provided the consultant's name
- Gave a time, plus advised the patient to be available either side of the app time
- Gave an estimate of how long things would take
- Gave a number to contact

But it didn't explain the purpose of the appointment which would have helped the patient to prepare and set clearer expectation.

This second letter is less clear:

- It still explained which referral it related to
- It still provided the consultant's name
- It still gave a time
- It still gave a number to contact
- The opening para was a lot clearer
- It didn't advise the patient to be available either side of the app
- It didn't give an estimate of how long things would take
- It didn't explain the purpose of the appointment

Telephone Consultation / Review

A telephone consultation / review appointment has been arranged for you to talk to:

Care provider: [REDACTED] or a member of the clinical team.

Specialty: Gastroenterology

Date and Time: Thursday 27/05/2021 at approximately 15:00

**** Please remain available for 30 minutes before and after your approximate scheduled slot****

***** This appointment is a TELEPHONE ASSESSMENT*****

***** DO NOT ATTEND the hospital for this appointment*****

We will ring you at home around the time stated, on the number you have previously provided.

This telephone appointment will last approximately 15 minutes and you will be contacted by your hospital Doctor/Health Care Professional on either your home telephone number or mobile telephone number, if this has been provided.

If either of these numbers are not suitable then please contact the Appointment line above to advise of a telephone number that you would prefer us to use.

If the above date or time is not convenient, please contact the Appointment line number to reschedule the appointment. These appointments are in great demand and if you are not available then it is important that you contact us so that we can offer the appointment to another patient.

Yours sincerely

Outpatient Booking Team

Re: Your Gastroenterology appointment.

BSUH is following Public Health England guidance and encouraging patients to stay at home. The Trust has taken the decision to reduce face to face consultations where possible. Your clinician has decided that your appointment is suitable for a telephone consultation. Therefore you should **NOT** attend. **Instead we would like to offer a telephone call with your clinician on:**

Care provider: [REDACTED] member of the clinical team.

Specialty: Gastroenterology

Date and Time: Tuesday 31/08/2021 16:30

***** This appointment is a TELEPHONE APPOINTMENT. Please DO NOT ATTEND the hospital for this appointment*****

If the above date or time is not convenient, please contact the Appointment line number or email to reschedule the virtual appointment. These appointments are in great demand and if you are not available then it is important that you contact us so that we can offer the appointment to another patient.

BSUH thanks you for your understanding at this time

Yours sincerely

Annex C - Case studies

CASE STUDY ONE: A GP referral (April 2020)

“ The main thing is consistency. ”

Summary

The patient was referred by their GP to neuro developmental service. They were not contacted to confirm that their referral had been sent off but did receive confirmation relatively quickly to confirm their referral had been received by the hospital. The patient has chased up their referral four times by emailing the specific hospital department and their GP asking them to expediate the referral. The patient decided to go private to avoid an 18 month wait to see a consultant, paying £800 to receive a diagnosis. They are still waiting to see a NHS specialist. The patient is very dissatisfied with the communications received about their referral.

What worked well

- They received a letter within a month direct from the service to confirm them that their referral had been received.
- Some details of their referral appeared on their 'My Health and Care Record'.

What needs to be improved?

- The patient was not notified by her GP that her referral had been sent off.
- The patient has had to chase up their referral at least 4 times due to a lack of information:
 - by calling the service directly to enquire how long they would wait to be seen, only to be told that they couldn't say but that it could be up to 18 months
 - chasing up their referral with their GP
 - chasing their GP again asking them to expedite the referral, but the GP didn't include any information about how their condition was affecting them so it was refused
 - contacting their GP again to expedite.
- Since the referral, the patient has not been sent any updates, and not been provided with any information to help manage their condition.
- The referral was made before the full impacts of COVID were felt, and the patient feels it would have been nice to have been contacted to advise them how COVID would affect their referral, but they heard nothing.
- The patient uses 'My Health and Care Record' but noticed that only some appointments and letters were showing, whilst some were missing.

In terms of preferences for being communicated with:

- **Letters** are useful particularly for an individual with autism or ADHD as it helps them to keep track of things, but managing hard copies can be difficult, which is why these important documents all need to be available in one place such as the My Healthcare App.
- **Texts** can be confusing and overwhelming for someone with ADHD, especially when they do not always indicate which referral it relates to. It is counterproductive to fail to provide enough information as this forces the individual to call their GP practice to enquire.
- **Phone calls** need to be booked in for someone with autism or ADHD as unexpected calls can cause panic.

What needs to be improved?

- All correspondence relating to a referral needs to be amalgamated onto the 'My Health and Care Record'.
- Patients need to be automatically sent regular updates.
- Patients should be provided with information to help manage their condition whilst they wait to be seen.
- Texts need to contain clearer information about the referral.
- Phone calls must always be booked in.

CASE STUDY TWO: A GP referral (January 2021)

“Essentially, the biggest issue which has affected my outpatient referral, and which has caused uncertainty and confusion, are the poor communications, particularly at the start of the process. Surely, it should be simple to create a uniform way of communicating with patients. Delivering this will undoubtedly save thousands of staffing hours and therefore costs to the hospital. Delivering communications has to sit at the heart of how outpatients' referrals are improved.

”

In summary

The patient was referred by their GP to digestive diseases. They were not contacted to confirm that their referral had been sent off, or to confirm it had been received by the hospital, and after 3 months they chased this up with their GP. They were eventually contacted by the hospital 3.5 months later from an unidentified number. Some letters and appointments appeared on their 'My Health and Care Record' and they also received some alerts notifying them that new letters were available to download. They had a telephone appointment with an NHS specialist after 4.5 months and procedures took place 5 months later. They received notification of a follow up appointment with the consultant to discuss their results 7.5 months after the referral was first made, and once their results had been shared with them were contacted directly by their GP to arrange a consultation to discuss the outcomes. The patient is neither satisfied nor dissatisfied with the communications received about their referral mostly because there has been no consistency, but the patient did feel that communications improved as time went by.

What worked well

- Staff spoken to were always helpful and friendly, and they didn't overcommit which helped set their expectations.
- Some letters appeared on their 'My Health and Care Record' and emails alerted them when a new letter was available to download.
- The NHS App provided them with accessible information, but not always in the most patient friendly way.
- Once in the system then things seem to happen relatively quickly and efficiently.
- Appointments happened as planned and ran like clockwork.
- Reminder text messages were sent regarding appointments.
- Procedures happened as planned and on time
- Follow up appointments were arranged and took place as planned
- Follow ups by their GP were arranged and happened as planned.

What needs to be improved?

- The current ‘black hole of communication’ to confirm that a referral has been sent off or received is unacceptable. This lack of information creates uncertainty, confusion, and anxiety: *“Has my referral been sent or received?” “Should I chase it up?” “Who do I contact?”*.
- The patient needs to know easily and quickly that a call or text is from the NHS so that these do not go unanswered or unactioned. An unknown number could easily be considered a cold caller or scam. All messages from the NHS should be readily identifiable as such.
- All letters - not just some of them- connected with a referral should appear in one place online.
- The content of all the letters need to follow a more consistent template and be helpful for patients. A lack of clarity meant that the patient had to call their GP and the Outpatients’ Booking team which wasted everyone’s time.
- Public information on waiting times is non-existent which again resulted in the patient having to call up the NHS - another waste of time.
- Support, advice, and information whilst the patient is waiting is needed. For 3.5 months they heard nothing and had no information about who they could call to get advice from other than their GP.

This patient provided a timeline of their outpatient journey which includes some of the letters and texts they received:

First step: from GP referral to first contact by the hospital (3.5 months later)

1. **11 January.** Patient was referred to gastroenterology in January 2021 by their GP.
2. **27 April.** Patient called their GP on 27 April (3.5 months later) to check that their referral had gone through. The receptionist gave them two numbers to call for the Brighton referral unit 0800 0316639 or 020 3824 2001 and wished them “good luck!”. On the same day they received a call from a standard unknown mobile number which they initially chose to ignore assuming it to be a “cold caller”. They answered the second time and it turned out to be the NHS calling them. This was the first communication the patient had received. The patient had not found information anywhere else, although they have subsequently downloaded the NHS App and use this to check referrals, test results, etc. The person the patient spoke to asked if they still had the same symptoms as when they were referred, or whether anything had changed. This seemed very sensible, but the patient felt that it they said there had been a change that this would have cancelled their referral or pushed them down the list. They were then informed that a consultant would be looking at a batch of referrals on 28 April and the patient would receive a letter explaining the next steps in 7-14 days. They were also told what the outcomes could be and an indicative waiting list of 60 months were mentioned but it wasn’t clear if this was the actual waiting time. She also explained to the patient that as their referral would be

passed to the consultant that this would probably generate an automated appointment text or email for tomorrow afternoon (i.e. when the consultant would be assessing referrals). She said to ignore this as it was a fault with the system which they were working to correct. After the call the patient looked, but couldn't find any up-to-date information about waiting times.

Second step: An appointment for an initial consultation (4 months later)

3. **19th May**, the patient received a follow up call asking them to have a telephone consultation and was offered dates. They also managed to get logged into their My Health and Care Record.
4. They got an email that day alerting them to a letter which was available online confirming the appointment date they had selected. They did not find the My Health and Care Record very user friendly.
5. The letter explained they would be having a telephone consultation, who with, when and roughly how long it would last. It advised them to be available 30 minutes before and after their allocated time slot. This allowed them to plan their time, and work.

Telephone Consultation / Review

A telephone consultation / review appointment has been arranged for you to talk to:

Care provider: [REDACTED] or a member of the clinical team.

Specialty: Gastroenterology

Date and Time: Thursday 27/05/2021 at approximately 15:00

**** Please remain available for 30 minutes before and after your approximate scheduled slot****

***** This appointment is a TELEPHONE ASSESSMENT*****

***** DO NOT ATTEND the hospital for this appointment*****

We will ring you at home around the time stated, on the number you have previously provided.

This telephone appointment will last approximately 15 minutes and you will be contacted by your hospital Doctor/Health Care Professional on either your home telephone number or mobile telephone number, if this has been provided.

If either of these numbers are not suitable then please contact the Appointment line above to advise of a telephone number that you would prefer us to use.

If the above date or time is not convenient, please contact the Appointment line number to reschedule the appointment. These appointments are in great demand and if you are not available then it is important that you contact us so that we can offer the appointment to another patient.

Yours sincerely

Outpatient Booking Team

Step three: speaking with a consultant (4.5 months)

6. **27th May**. Their telephone consultation took place, which was excellent. They were given ample time to explain their condition and had all their queries answered. A follow up call happened the same day (as the consultant had wanted to run the case past his senior) and they were advised of their choices for next steps.
7. They were told that they would be contacted by Endoscopy within 14 days.

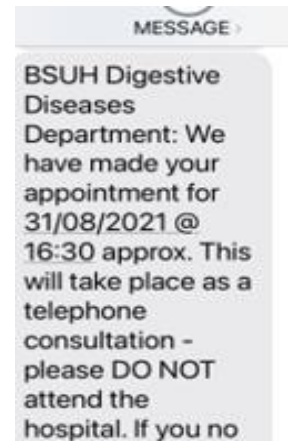
8. They were advised that a letter would be sent to their GP, copied to them. The letter took quite a while to arrive and was received after a call from their GP (see step four). This letter didn't appear on their 'My Health and Care record'.

Step four. Investigative procedures (5 months later)

9. **7 June.** They received a text from BUSH on 7 June (i.e. within the 14 days) asking them to call up to make an appointment which they did. The text sender wasn't identified as being from the NHS, it simply said "Message" which wasn't helpful. They called up immediately and it was answered quickly, and they were subsequently offered a date for 19 June to have their procedure.
10. **11 June.** They received a call from their GP confirming what the consultant had advised and dates were arranged for these with their GP.
11. **19 June.** Their procedure went ahead and worked like clockwork. They were seen on time, the ward was calm, and staff were very friendly and explained things really well. They were given an 'outcomes' letter within 30 mins of the procedure ending which advised them what the surgeon had detected.

Step five: post procedure follow-up notification (6 months later)

12. **20 July.** They received a text from "Message". It transpired this had been sent from Digestive Diseases. The text advised them that an outpatients' appointment had been booked for the 31 August, 4:40pm.
13. They also received an email advising them that a new appointment letter was available to review on their 'My Health



Re: Your Gastroenterology appointment.

BSUH is following Public Health England guidance and encouraging patients to stay at home. The Trust has taken the decision to reduce face to face consultations where possible. Your clinician has decided that your appointment is suitable for a telephone consultation. Therefore you should **NOT** attend. **Instead we would like to offer a telephone call with your clinician on:**

Care provider: [REDACTED] a member of the clinical team.
Specialty: Gastroenterology
Date and Time: Tuesday 31/08/2021 16:30

***** This appointment is a TELEPHONE APPOINTMENT. Please DO NOT ATTEND the hospital for this appointment*****

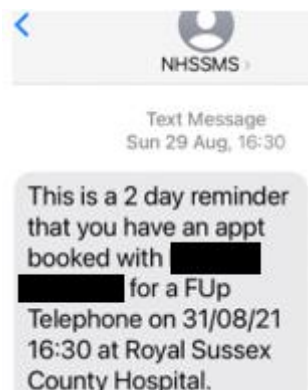
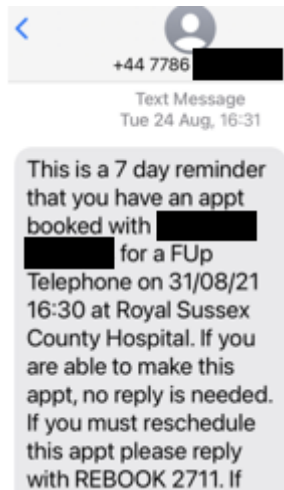
If the above date or time is not convenient, please contact the Appointment line number or email to reschedule the virtual appointment. These appointments are in great demand and if you are not available then it is important that you contact us so that we can offer the appointment to another patient.

BSUH thanks you for your understanding at this time

Yours sincerely

and Care Record'. Unlike the first letter this one was unhelpful as it failed to tell them what it related to, or how long the appointment might last. The letter appeared on their 'My Health and Care Record' the same day.

14. They received two texts a few days apart reminding them of their appointment. The first came from a random unidentified number, whilst the second came from the NHSSMS. Whilst it was great to get these reminders but why couldn't they both come the same phone number?



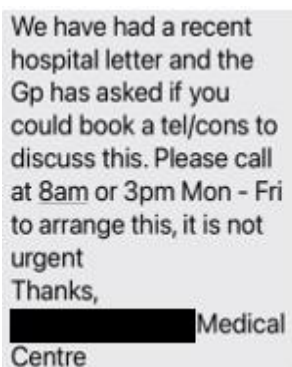
If you must reschedule this appt please reply with REBOOK 2711. If you no longer need to be seen and can be discharged back to your GP please reply with CANCEL 2711

Step six: consultant follow up appointment (7.5 months later)

15. **31 August.** Their telephone consultation took place on the phone and went very well. They were provided with ample chance to ask questions and seek clarification; there was no sense of it being rushed.

Step seven: GP follow-up (8 months later)

16. **On 3rd September** - 4 days after their consultation follow-up they received a text from their GP asking to discuss the letter they had received from the consultant, and to book an appointment. On 6th September they rang and booked them in for a telephone appointment on 9th.



CASE STUDY THREE: A GP referral (November 2020)

“The big problem is that you do not get any confirmation that your referral has been accepted and where you are in the system. I just assumed the basics had been done. My condition is not life threatening - I hope- but needs treatment, but someone else's might be.”

In summary

The patient was referred by their GP. They were not contacted to confirm that their referral had been sent off but did receive an appointment to see a consultant within a month. The consultant explained that they would need to see someone else, but the patient never received any confirmation about this onward referral and after 4 months rang their GP who told them to ring the hospital. It took them many weeks to get to speak with someone but they could not explain why their onward referral had been delayed. The patient has chased up their referral by calling the hospital and their GP. After 6.5 months they still had not heard anything and remain unclear whether to chase it up again or not. They are very dissatisfied with the communications received about their referral.

What worked well

- The initial referral from their GP was very quick, just one month.
- The first consultant they spoke to provided clear advice about why they were being referred on.
- The call handler on the Outpatients' Booking hub was helpful and informative.

What needs to be improved?

- They received no information about their referral for almost four months. They had no idea whether to chase things up, or not.

This patient provided a timeline of their outpatient journey.

First step: from GP referral to first contact by the hospital (one months)

1. **November 2020.** They saw their GP who referred them on.
2. **7 December 2020.** They saw a specialist who referred them to another department (the letter to my GP was dated 7/12/20).

Step two: onward referral (4 months, no outcome to date)

3. **April 2021.** Having heard nothing, in April they contacted their GP and got a date to speak to them in a months' time. When they eventually spoke with their GP, they told them to talk to hospital.
4. It took weeks to get through to the Outpatients Booking Team as the line was always engaged, or they rang off.
5. **12 July.** The booking clerk told them that the referral had been received on 30/4/21 about 20 weeks after the referral letter. She could see the letter but could not explain why they only received it in April. She advised the waiting time was 36 weeks or into next January (2022), over a year since the patient first went to their GP.

CASE STUDY FOUR: A GP referral (July 2021)

“

The same day notification that my referral had been sent off, together with immediate access to my referral letter was excellent. This is the first time that I've ever received any kind of communications from my GP advising me that my referral has been sent off.

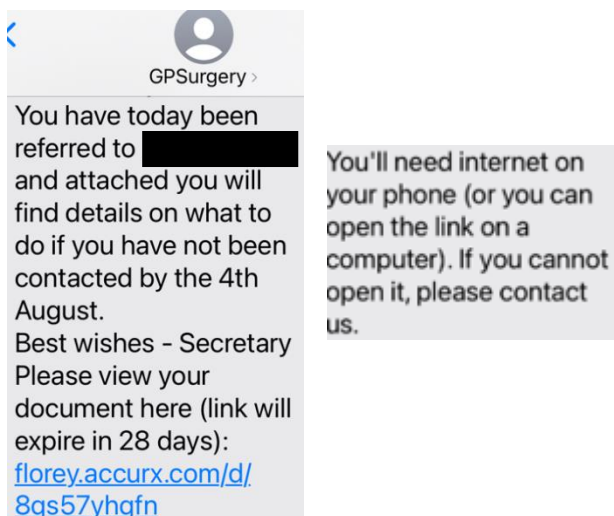
”

In summary

The patient was referred by their GP to neurology. They were sent a text from their GP the same day to confirm that their referral had been sent off together with a link to the referral letter. This letter contained incorrect and misleading information, as did information on their NHS App - both incorrectly suggested they would be contacted within 2 weeks or that they could chase things up after that time. They were notified by text (an unknown number) that their referral had been received by the hospital. The patient is dissatisfied with the communications received which are inaccurate, misleading and lacking.

What worked well

- 21 July - their GP referred them into neurology and on the same day they were sent a text notification from their GP practice informing them that the referral had been made. The GP text include a link to the referral letter.



- The online letter however contained misleading information:
 - It gave a telephone number for enquiries which implied that it was for neurology, but in fact it was for the general outpatient booking team
 - It gave incorrect opening times for the outpatients booking hub
 - It suggested that after 2 weeks be contacted but if not, then they could call up to chase their referral. When they rang up the outpatients' booking line they were told there was an 8-45 week wait.
 - The referral letter did not appear on their 'My Health and Care Record'.

Your referral is being reviewed

██████ MEDICAL CENTRE has referred you to:
General Neurology Referrals-University Hospitals Sussex-RXH01.

➤ You do not need to do anything at this stage.

You will be contacted by either:

General Neurology Referrals-University Hospitals Sussex-RXH01
if you need to be seen
or

██████ MEDICAL CENTRE
if the clinic sends any other advice.

What to do if you have not been contacted

➤ Please wait until 4th August 2021.

If you have not been contacted by this date,
call General Neurology Referrals-University
Hospitals Sussex-RXH01 using the referral
details shown here.

General Neurology Referrals-University
Hospitals Sussex-RXH01

☎ 0300 303 8360

Monday-Friday 8-4

Referral details

Booking reference number


0003 ██████

Access code

██████

- 23 July - they received a text to advise that their referral had been received by the hospital. This did not identify as being sent from the NHS, simply coming from sender 'Message'. It also failed to indicate which referral it related to.

<

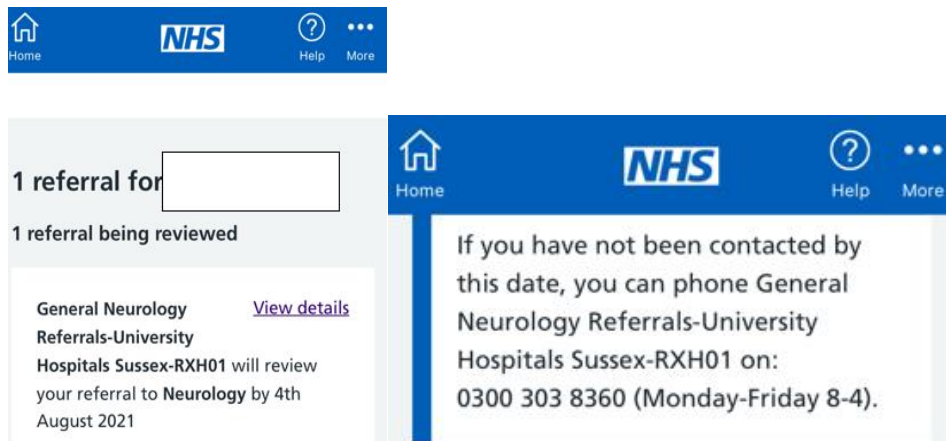
 MESSAGE >

Fri 23 Jul, 18:02

We have received a referral from your GP or Healthcare provider for you to be seen. During this time of post-COVID recovery we ask that you bear with us and we aim to have an appt. booked with you as soon as possible.

You now have the option of receiving test results, appointment information and correspondence with us via our patient portal (which you can link to NHS App also). Please follow the link to <https://bit.ly/3we5LOp> and use NHS Login to register. If you have already registered you do not need to do so again.

- The patient checked their NHS APP account and saw their referral was showing and that it was being reviewed. The information was explicit that the hospital would review their referral by 4th August - but they did not hear anything, so clearly this information is wholly inaccurate. The number quoted to call was not for General Neurology Referrals, but simply the outpatients' referral team, so again, this information is inaccurate.



- They called the number, and it was the Outpatient Booking Centre. They waited 7 minutes before getting through to someone. Whilst waiting the answer message which was on a loop said *"All of our staff are taking calls at the minute. We are currently receiving a high number of calls atm and will answer asap"*. There was no indication of where they were in the queue. The chap who answered simply said "Outpatients booking", no 'hello' or 'how can I help?'. He sounded thoroughly miserable.
- They were told that waiting times to see a consultant were 8-10 weeks for urgent referrals, and 40-45 for non-urgent.
- Three months on from their initial referral they had received no further updates, information, advice or support.

What worked well

- The same day notification that the referral had been sent off, together with immediate access to their referral letter was excellent. Good points about the letter were that
 - It confirmed which speciality they'd been referred to
 - That the patient didn't need to do anything
 - That they should wait 2 weeks to hear, otherwise to call the number given.
- The text confirmation from the hospital that the referral had been received.

What needs to be improved?

- **Text messages** - the text message from the NHS needs to be easily identifiable as such.
- **Letters**
 - letters contents need to be changed and amended to ensure they contain accurate information about the opening times of the Outpatients' Booking Hub; make it clear what the telephone number relates to i.e. whether it is for a speciality or the general Outpatients' Booking Hub; remove the 'call up after 2 week's instructions altogether or make it explicit what might happen after 2 weeks, and contain much clearer information about waiting times so that patients do not call up to ask this.
- **Outpatients telephone line** - the answer message needs updating to provide callers with an indication of where they are in the queue or what the waiting time is, or an option to be leave a number to be called back on (similar to what many utility companies do). There needs to extra staff on the outpatients' line to alleviate obvious stress and excessive workloads. Staff should be able to answer the phone politely and with courtesy and offer an apology for any delay in answering the call.
- **Support whilst waiting** - patients should receive information straight away about what to do to manage their possible condition whilst waiting, or guidance or places to go for further support and a number to call to ask questions.
- **'My Health and Care Record'** - this should be automatically updated with any information or progress otherwise what is the point of it?

CASE STUDY FIVE: A referral made by an optician (May 2021)

“Be clear about the referral pathway in patient communication so that the patient understands what is going to happen and approximately when. Be clear about who is going to do what. Don't make promises that can't be kept.”

In summary

The patient was referred by their optician to Ophthalmic services. The referral did not go through their GP but they were given a form to show their GP that the referral had been made. The patient was not contacted to confirm that their referral had been sent off, or to advise them that their referral had been received by the hospital. The patient has not chased up their referral. The patient was very satisfied with how the initial referral proceeded. Their first operation took place in September, and they are waiting for a second referral for a second operation.

What worked well

- The time between the first referral (in July), their first appointment (July) and their appointment (September) were all relatively quick.
- Communications to do with the first operation were all good.

What needs to be improved?

- Nothing was sent to the patient to confirm that a referral had definitely been set off or that it had been received. This should be mandatory for all types of referral.
- There was a great deal of wasted time and chasing up of the second operation. The hospital referred this back to the optician, but the optician knew nothing about it. The patient had to chase this up and wondered why the hospital - who knew they needed a further operation - couldn't simply have put the referral through themselves.
- Patients should automatically be given details about waiting times.
- Communications need to be sent out in a consistent way, provide accurate information and to keep patients well informed.
- Staff should be honest with patients in their communication with them even if it is bad news. Making promises that can't be kept causes unnecessary anxiety. For example, saying “6 - 8 weeks for the second op” as they said to this patient, led to them looking at their phone / waiting for the letter within that time, and when it didn't come, this caused stress. Patients' expectations must not be incorrectly raised.

Ideas for improving communications

- All forms of communication should be utilised (phone call, email, letter), but text is the quickest method.
- Better promotion of the NHS App is needed so that patients can access test results, their GP health record and prescriptions.
- An online system to track referrals would be a positive step.

CASE STUDY SIX: A GP referral (July 2021)

“Your told it's been done, and have to believe that, or expect it to, but then you don't hear anything. No updates. It's a bit worrying as cancer was mentioned. But you don't want to pester them.”

In summary

The patient was referred by their GP to dermatology. They were contacted to confirm their referral had been sent off within a week but were not contacted to advise that referral had been received by the hospital. They eventually chased their referral up. The patient was dissatisfied with the communications received about their referral.

What worked well

- They received a text within a week of their GP referral asking them to call the outpatient booking hub with any queries. They didn't call immediately but when they rang up in late August/early September they were verbally told that their referral had been received.
- They asked about waiting lists and were given clear information that November would be the earliest time that they would be offered an appointment.
- When they phoned the outpatients' booking hub the person who answered was polite and answered all their questions.

What needs to be improved?

- All patients must be sent confirmation about their referral.
- Communications need to be sent out in a consistent way, provide accurate information and keep patients informed.
- It needs to be made clearer who patients can contact to chase up their referral or make enquiries, and when to do this to avoid doubt.

Ideas for improving communications

- To receive a call or text from your GP that your referral has been sent off within 3 working days
- To receive a call or text from the hospital confirming that your referral has been received by them within 1 -2 weeks
- To receive regular updates to keep you informed
- To receive information about waiting times to be seen
- To be given a contact number for queries
- Prefer written confirmation (email, text, letter) so you have this to check back against. Calls provide no record.
- Would use 'My Health and Care Record' and NHS App if they were easier to use.

CASE STUDY SEVEN: A GP referral (June 2021)

“There is nothing worse than not knowing especially when have something that you are anxious about and that is causing discomfort. It leaves you in a state of anxiety and tension and you feel you are not being heard. As a patient you feel you have no control.”

In summary

The patient was referred by their GP to Digestive Diseases. They experienced difficulties getting their GP to refer them. After being referred, they were not contacted to confirm that their referral had been sent off by their GP practice. They were contacted within a month to advise that their referral had been received by the hospital. They chased up their referral 2 or 3 times due to a lack of communication. The patient received conflicting communications regarding test results and received letters regarding test results after phone calls from nurses.

What worked well

- Very little. They have received various calls from various departments (although this was not always been helpful).

What needs to be improved?

- Getting GPs to make a referral
- Being given information about waiting times for test results. The patient waited a long time to receive CT scan results which caused anxiety especially as there were no communications received whilst waiting and no indication provided as to how long it would take.
- Communications need to be sent out in a consistent way, provide accurate information and keep patients informed. The patient had to resort to contacting PALS for information as no one else is communicating with them.
- Providing people who have been referred urgently with a point of contact.
- Improve the turnaround of letters being posted out. The patient received a letter dated 4th October on 14th meant that they received the phone call from a nurse in between, which came as a complete surprise.
- Providing a record of phone calls made would be helpful. The patient spoke to a number of people who clearly knew little about their condition meaning that they had to repeat information.

Ideas for improving communications

- To receive regular updates to keep patient up to date.
- To receive information about waiting times to be seen.
- To be given a contact number for queries.
- Being able to keep track of a referral online would offer reassurance, especially if this allowed patient to check that their name was on a waiting. This would give some comfort even if the patient was far down the list. It would also be a cheaper way of checking than phoning someone.
- Letters are slow to arrive, so it would be preferable to receive a text or email.

CASE STUDY EIGHT: A GP referral (spring 2021)

In summary

The patient was referred by their GP to ophthalmology. They were not contacted to confirm that their referral had been sent off but were contacted within a week to advise that their referral had been received by the hospital. They did not chase their referral up. The patient was satisfied with the early communications they received about their referral.

What worked well

- They were impressed that everything happened quickly.
- The patient uses 'My Health and Care Record' and received an email notification advising them that a new letter was available to view.
- The patient also received a text message to confirm their referral had been received.
- Reminder texts were received about appointments.

What needs to be improved?

- Communications need to be sent out in a consistent way, provide accurate information and keep patients informed.
- Better prompts are needed to help patients use the 'My Health and Care Record'. The patient received an email and only then discovered that they should call up to book an appointment. A duplicate letter was never received.
- Letters can be slow to arrive and emails are quicker but the patient was told that information about her pre assessment could only be sent out by letter.
- The appointment letter didn't explain what would happen or help the patient to prepare.
- At the outpatient appointment itself they were seen quickly but the health professional didn't introduce themselves or explain what they were going to do, and the tests turned out to be unnecessary. The patient was there for two hours (as expected) but they were moved to different parts of the department but no one told them where they were going or why - knowing this would have eased any anxiety.

Ideas for improving communications

- To receive a call or text from a GP that a referral has been sent off within 3 working days.
- To receive a call or text from the hospital confirming that a referral has been received by them.
- To receive regular updates to keep patients up to date.
- To receive information about waiting times to be seen.
- To be given a contact number for queries.

Annex D - initiatives designed to transform patient services

NHS Sussex Commissioners are currently developing, enhancing or expanding a number of initiatives that are designed to give patients more control over their care, and communications:

Patient Initiated Follow Up (PIFU): Giving patients greater control over their hospital follow-up care. Following a hospital appointment, it is often necessary to arrange follow-up appointments for ongoing care. Traditionally, these appointments are offered at routine intervals but to give patients and their carers the flexibility to arrange their follow-up appointments as and when they need them, NHS England and NHS Improvement is supporting providers to roll out patient-initiated follow-up (PIFU). Delivering PIFU is part of the transformation of outpatients taking place locally and is a key part of the NHS's response to the COVID-19 pandemic, helping providers and systems manage waiting lists and to see patients most in need more quickly.

Waiting Well. There is a huge effort and focus on bringing waiting lists down. There is growing concern both nationally and locally about the adverse impact on the health and well-being of those patients continuing to wait, their potential physical or mental deterioration, whether they will be well enough for their surgical procedure and the widening of health inequalities. Waiting Well has been established to engage with as many clinicians as possible to better understand the risk, needs and health inequalities of patients on these waiting lists, by developing a single oversight of patient need through shared data and intelligence, and identify how best to provide support. Good communications also rests at the heart of this.

Shared decision making ensures that individuals are supported to make decisions that are right for them. It is a collaborative process through which a clinician supports a patient to reach a decision about their treatment. The conversation brings together the clinician's expertise and what the patient knows best: their preferences, personal circumstances, goals, values and beliefs. Providing the patient with communications is pivotal to the success of this initiative.

Getting It Right First Time (GIRFT) is a national programme designed to improve the treatment and care of patients through in-depth review of services, benchmarking, and presenting a data-driven evidence base to support change. The principle that a patient should expect to receive equally timely and effective investigations, treatment and outcomes wherever care is delivered, irrespective of who delivers that care, GIRFT aims to identify approaches from across the NHS that improve outcomes and patient experience, without the need for radical change or additional investment. Good communications must clearly rest at the heart of this.

Annex E - Resources

Good communication with patients waiting for care and letter templates
<https://www.england.nhs.uk/coronavirus/publication/good-communication-with-patients/>

Personalised and shared decision-making
Guidance and resources (NHS England and NHS Improvement):
<https://www.england.nhs.uk/shared-decision-making/guidance-and-resources/>

Shared decision making infographic (NHS England and NHS Improvement):
<https://www.england.nhs.uk/publication/shared-decision-making-summary-guide/>

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