

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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A message from our Chair of Healthwatch Brighton and Hove

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.





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 <u>Patient Communication Charter</u> - building on University Hospitals Sussex NHS Foundation Trust's '<u>Patient First</u>' 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
- o 57% were not notified that their referral had been sent off
- 61% were <u>not</u> notified that their referral had been received by the hospital
- Only a third of patients had chosen <u>not to</u> 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 <u>'wait well'</u>.

Our <u>7 recommendations</u> support work being done by Sussex NHS Commissioners to transform outpatient services and to embed other <u>initiatives</u> 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 <u>website</u> to read the detailed results from our work and a longer report containing the full analysis.



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.

SECTION 1

- A patient charter and our recommendations

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 unwelcome news, so that patients' expectations are not incorrectly raised.



Healthwatch reviewed <u>genuine patient letters</u> 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 <u>Community</u> <u>Diagnostic Hubs</u> (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 "Community Diagnostic Hubs - a patient centred pathway through the diagnostic journey Patients from Brighton and Hove share their experiences and views with us" (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 <u>NHS published a report in May 2021</u> 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, <u>Patient Noun Adjective: understanding the</u> <u>experience of waiting for care (October 2020) highlights patients' lived</u> <u>experiences of provider communications while waiting for care, October 2020</u> 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.

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 <u>Community Diagnostic Hubs</u> 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, "<u>Good Communication with patients waiting for care</u>".

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

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.



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

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(iil) 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.

"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 communications from my GP advising me that my referral has been sent."

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Brighton and Hove

- 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.



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 online "My Health and Care Record" and NHS App.

"The letter was misleading it implied I would hear within 2 weeks which I didn't, and it suggested the phone number was a direct number to neurology outpatient app but it was the general booking team."

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.

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.



SECTION 2

- A summary of our survey and interviews findings and

Patient communications are key to delivering system-wide change

Delivering good quality patient communications will be key to helping get the NHS back on track after COVID-19, and in delivering 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 <u>Annex</u> for further details of these initiatives)

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 and quality, timely communications with patients on waiting lists is a crucial part of this.

During the heart of the COVID-19 pandemic the NHS acknowledged that patients whose planned care had been disrupted should receive clear communication about how they will be looked after, and who to contact in the event that their clinical

circumstances change. Communications needed to be personalised, use plain English, be honest about appointments, delays and cancellations and include supporting information.

Patients have also previously told Healthwatch Brighton and Hove that communication is key to the successful delivery of health care provided via Community Diagnostic Hubs:

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





A summary of our patient survey findings

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



- A majority of people were referred by their GP for an outpatients' appointment (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. Patients are not being routinely kept informed about their referral

"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". 82% of people were <u>not told</u> by the person who was referring them how long to wait before chasing up their referral
 57% of people had not been contacted

• 57% of people <u>mad not</u> 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 specialty. **42.5% of people had been contacted.**

2. Hospital services are not routinely notifying patients

- **61% of people** <u>were not contacted</u> to notify them that their referral had been received by the hospital. **Whilst 39%** <u>had been contacted</u>.
- 3. Patients are routinely chasing up referrals
 - 48% of people had chased up their referral.
 - A further 18% did not know how to chase up their referral suggesting that they may have wanted to.
 - Just 33% of patients had not chased up their referral.
- 4. Patients are not satisfied with communications
 - 31% people were either satisfied or very satisfied.
 - 17% were neither satisfied, nor dissatisfied.
 - 52% were dissatisfied or very dissatisfied.



A summary of our patient case studies

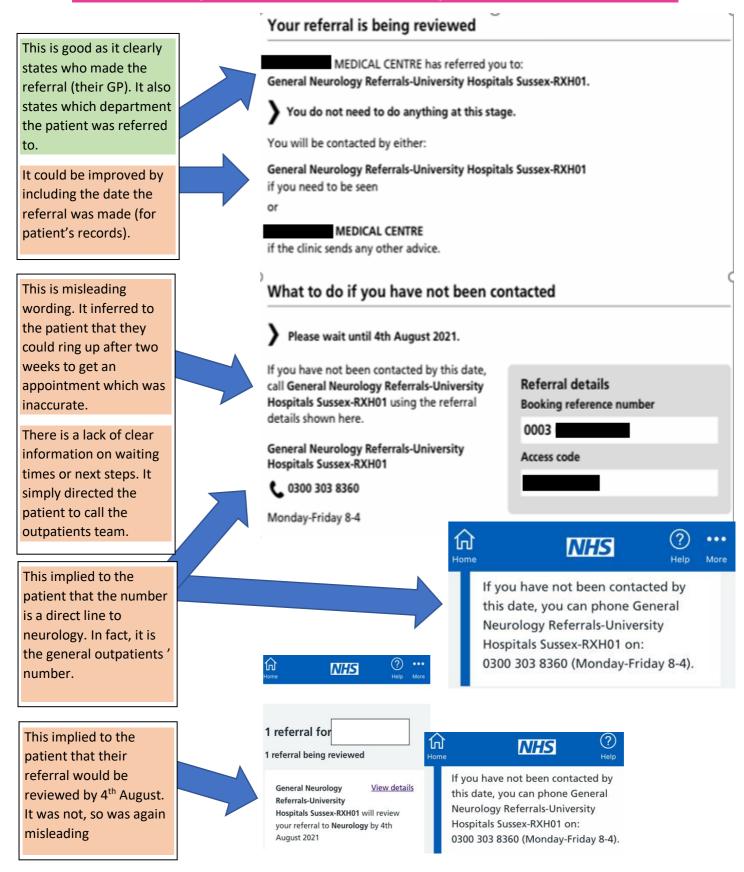
The following section summarises the key points made by the 8 people we interviewed or heard from, all of whom had been referred for an outpatient's appointment.

 Letters These 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, or including phone numbers where the implication is that these are direct lines to medical specialties 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 ' <u>My Health and Care</u> <u>Record</u> ' Amend the content of letters as soon as possible to remove misleading information and provide data around waiting lists (see below for some genuine letters, texts and online messages that were sent to patients, which Healthwatch Brighton and Hove has reviewed to determine what aspects of these are good and where they could be improved).
Text alerts	Make it automatic that patients
These are useful as they can be issued	are sent texts to confirm a
immediately and received more quickly	referral has been sent off (by the
than letters. In some cases, they provide	referrer) and also received by the
confirmation that referrals have been sent	outpatient's booking team or
off and received, as well as links that allow	specialty
patients to access their referral letter.	Texts must come from a standard
But they don't all contain consistent	number which is easily
information and often come from unknown	identifiable as being the NHS
numbers generating suspicion that they are	Texts should provide links and
spam - how many texts are then ignored?	useful numbers for patients.





Genuine examples of information sent to patients





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?"



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 <u>8am</u> or 3pm Mon - Fri to arrange this, it is not urgent Thanks,

Centre Medical



Text Message Tue 24 Aug, 16:31

This is a 7 day reminder that you have an appt booked with 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

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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

Sun 29 Aug, 16:30 This is a 2 day reminder that you have an appt booked with for a FUp Telephone on 31/08/21

NHSSMS

Text Message

16:30 at Royal Sussex County Hospital.



Two letters sent to one patient concerning the same referral

This was clear as it:	Telephone Consultation / Review
 Explained which referral it related to 	A telephone consultation / review appointment has been arranged for you to talk to: Care provider: Specialty: Date and Time: Thursday 27/05/2021 at approximately 15:00
 Provided the consultant's name 	** Please remain available for 30 minutes before and after your approximate scheduled slot**
- Gave a time, plus advised the patient to be available either side of the app time	*** 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
- Gave an estimate of how long things would take	Doctor/Health Care Professional on either your home telephone number or mobile telephone number, if this has been provided.
- Gave a number to contact	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.
But it didn't explain the purpose of the appointment which would have helped the patient to prepare and set clearer expectation.	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
This second letter is less clear:	
 It still explained which referral it related to 	
 It still provided the consultant's name 	Re: Your Gastroenterology appointment.
- It still gave a time	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
 It still gave a number to contact 	would like to offer a telephone call with your clinician on:
- The opening para was a lot clearer	Care provider: Image: Imag
 It didn't advise the patient to be available either side of the app 	*** This appointment is a TELEPHONE APPOINTMENT. Please <u>DO NOT ATTEND</u> the hospital for this appointment***
 It didn't give an estimate of how long things would take 	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.
 It didn't explain the purpose of the appointment 	BSUH thanks you for your understanding at this time Yours sincerely

Annex: 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.

<u>Shared decision making</u> 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.

<u>Getting It Right First Time</u> (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.



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