



**Understanding patient perspectives on improving GP referrals to secondary care through the use of specialist advice and guidance**

**Patient panel workshops**

**Final report on findings and recommendations**

**September 2022**

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## Understanding patient perspectives on improving GP referrals to secondary care through the use of specialist advice and guidance

### Final report

#### Project background

NHS England is committed to transforming outpatient services for patients by “giving patients greater control and convenience in their NHS hospital or clinic appointment, [including by] working with GPs to avoid the need for an onward referral where possible”.<sup>1</sup> One of the ways in which NHS England seeks to accomplish this goal is by improving how GPs refer patients to secondary care so that patients will be able to avoid up to a third of unnecessary face-to-face outpatient appointments over the next five years.

The rationale is that improving communication and information sharing between GPs/primary care and specialists during the pre-referral process will save patients’ time, improve the patient experience, and ensure patients receive the ‘right care, in the right place and at the right time’.

**Referral optimisation** is the term used for redesigning and improving outpatient services by giving the referring clinician/GP access to expert advice from a specialist to guide and help inform the decision on whether to refer that patient to hospital.

Referral optimisation includes specialist advice, an umbrella term that covers **specialist advice and guidance**, which involves the GP sharing relevant clinical information about a patient with a specialist, so that before or instead of a referral, GPs have advice about the patient’s symptoms or condition and can decide if/where that patient needs to be referred or if the patient can be treated by the GP instead. Having access to specialist advice and guidance is believed to result in quicker diagnoses and treatment, identification of the most appropriate plan for the patient at an earlier stage, and a reduction in unnecessary referrals to hospital.<sup>2</sup>

Specialist advice and guidance could be especially helpful to GPs. In the past, GPs would routinely refer patients to hospital without receiving an opinion from a clinician who is

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<sup>1</sup> NHS England, Outpatient Recovery and Transformation Programme, Available at <https://www.england.nhs.uk/outpatient-transformation-programme/>. Last Accessed August 2022.

<sup>2</sup> NHS England, Improving the efficiency of referrals by optimising use of advice and guidance to GPs. Available at <https://transform.england.nhs.uk/key-tools-and-info/digital-playbooks/gastroenterology-digital-playbook/improving-the-efficiency-of-referrals-by-optimising-use-of-advice-and-guidance-to-GPs/>. Last Accessed August 2022.

an expert in the relevant clinical field for the patient's medical condition. Through specialist advice, GPs can access expert advice from a range of hospital specialities to discuss the most appropriate care for a patient before they refer for a hospital outpatient appointment. This is expected to help manage non-urgent (elective) patients in the most appropriate setting, helping reduce unnecessary referrals into hospital.<sup>3</sup>

In 2021, NHS England commissioned a report on clinical advice and guidance services in the NHS in England to understand the demand in primary care for specialist advice and guidance. One of the recommendations from the report focussed on patient involvement, recommending consultation with patient groups to determine what an empowering model of specialist advice and guidance would look like, how it could promote self-care, and what patient-facing educational resources should be considered.<sup>4</sup>

If the referral optimisation, specialist advice and guidance service is designed and improved with patients at the heart, it can help transform the way referrals are managed by improving communication between primary and secondary care and facilitating shared decision making with patients.

The Patients Association is an independent patient charity campaigning for improvements in health and social care for patients. We have a membership of 2,650 and 3,300 subscribers to our weekly newsletter. We are a UK-wide organisation. Our purpose is to ensure that everybody can access and benefit from the health and care they need to live well, by ensuring that services are designed and delivered through equal partnerships with patients.

NHS England engaged the Patients Association to convene three patient panel workshops to gather insights to help NHS England to gain a better understanding of how patients perceive and experience specialist advice and guidance services so that improvements can be made to strengthen outpatient referral pathways, while better engaging patients in the process.

The panel was also asked to give input on how NHS England can evaluate the impact of the referral process on patients through a patient-focused evaluation, and input on patient resources (such as leaflets and videos) about using specialist advice and guidance. A number of members of the patient panel were selected to share more about their individual experiences with the referral and/or advice and guidance processes through case study interviews.

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<sup>3</sup> NHS England, Referral optimisation. Available at <https://www.england.nhs.uk/outpatient-transformation-programme/referral-optimisation/>. Last Accessed August 2022

<sup>4</sup> NHS Commissioning Board, Clinical Advice & Guidance services in NHS England: An evaluation of demand-side factors. Developed by NECS. Available at [https://www.necsu.nhs.uk/wp-content/uploads/2021/09/NECS-AG-Evaluation-Report\\_FINAL\\_September-2021.pdf](https://www.necsu.nhs.uk/wp-content/uploads/2021/09/NECS-AG-Evaluation-Report_FINAL_September-2021.pdf). Last Accessed August 2022

This report includes an overview of the patient panel workshops, key themes and findings from the workshops, and a set of recommendations. A separate report with the individual panel member case study interviews was also prepared for NHS England.

## Overview of patient panel workshops

In 2022, three virtual workshops were held on June 30<sup>th</sup>, July 21<sup>st</sup> and July 28<sup>th</sup>. The goals of the workshops were as follows:

1. Collect insights from patients about their perspectives on and experience with specialist advice and guidance services, how referral optimisation approaches can better involve and engage patients to improve shared decision making and the patient experience, and identify opportunities for improvement to the referral process, including the specialist advice and guidance service. (June 30<sup>th</sup>)
2. Gather patient input on the design of a patient-focused evaluation of specialist advice. (July 21<sup>st</sup>)
3. Learn about the type of content that would be most useful for developing patient-facing educational resources about the specialist advice service. (July 28<sup>th</sup>)

The workshops were held on Zoom, lasted between 2-2.5 hours, and recorded. Representatives from the Patients Association chaired and facilitated the meetings. A representative from NHS England participated in the second workshop to provide an overview of the specialist advice and guidance service and answer questions.

Representatives from the Patients Association were project managers Sharrie McIntosh and Hannah Verghese. The representative from NHS England was Nana Ababio, Referral Optimisation Lead. A briefing packet with the workshop agenda, discussion questions, and background materials was sent to workshop participants before each workshop.

## Recruitment of workshop participants

### A. Recruitment of patient panel

- The goal was to recruit eight patients for the patient panel. In May 2022, an article about recruitment to the panel was published in the Patients Association weekly newsletter inviting people to find out more about the project. Those interested were asked to complete a brief vetting survey to gather information on patient demographics, experience being referred to secondary care, knowledge of specialist advice and guidance, etc. The article ran for two weeks.
- The Patients Association prioritises having patient panels that represent a diversity of backgrounds. Given that findings from this work will be used to inform an equality and health inequalities impact assessment (EHIA) to ensure that referral optimisation approaches do not contribute to or exacerbate health inequalities and disparities, our recruitment process sought to ensure that the patient panel was representative of a diversity of backgrounds. In addition to the articles in the weekly

newsletter, the project team conducted targeted outreach to key stakeholders (e.g. LGBT Foundation, Friends, Families and Travellers, Autistica, Race Equality Foundation, Asian People's Disability Alliance) to recruit participants.

- Since many patients may not be aware that specialist advice and guidance is used in their clinical pathway, the project team sought to conduct targeted outreach to patient groups who have had experience with and/or received specialist advice and guidance services. NHS England provided the project team with a list of GP practices that use specialist advice and guidance services the most. The project team contacted these GP practices to request that they post recruitment information about the patient panel. Unfortunately, our attempts to engage with the GP practices were unsuccessful and, therefore, we were unable to recruit patients directly from GP practices who had experience with specialist advice and guidance. Nevertheless, we were able to recruit some patients with experience with specialist advice and guidance from our weekly e-newsletter and stakeholder outreach activities.

## **B. Vetting and selection of patients**

- We received a robust response to the call out for participants in the e-newsletter, with more than 100 patients expressing interest in participating in the panel. We also identified candidates from our stakeholder outreach. Based on responses to the vetting survey, we identified a short list of candidates for the panel.
- One-on-one calls were conducted with the shortlist of candidates to select a target of eight participants. Our vetting process was successful in recruiting a group of patients from a broad range of demographic backgrounds including gender/gender identity (five females, three males), age (three participants were older than 65 years old, three participants were age 25-49, and two patients were age 50-69), and geographic region (two participants were from the South East, two participants were from the North West, two participants were from London, one participant was from the North East, and one participant was from Yorkshire and Humber). Panel participants also represented protected characteristics groups such as sexual orientation, transgendered, disabled, neurodiversity (autism) and ethnic background (Asian Bangladeshi, Black British, and mixed ethnicity).
- Our vetting process was also successful in recruiting a group of patients who represented clinical pathways that typically use specialist advice and guidance (gastroenterology, rheumatology, endocrinology, ENT, neurology, paediatrics, haematology, cardiology), who had extensive experiences with the referral process to secondary care, and some who had knowledge of specialist advice and guidance.
- A key barrier to recruiting patients with confirmed experience of specialist advice and guidance was being unable to recruit patients directly from GP practices identified by NHS England as routinely using specialist advice and guidance. Instead,

we relied on patient self-reporting of having experience with specialist advice and guidance. It is beyond the scope of this project to confirm and validate the use of specialist advice and guidance by contacting patients' GPs.

- The self-reported nature of the panel's experience with specialist advice and guidance is an important caveat because while during the initial vetting process for the workshop panel, two patients self-reported that their GP had requested specialist advice and guidance in at least one referral, when case study interviews were conducted with four selected members of the patient panel, all four patients reported the use of advice from a specialist during their referral process.

## Overview of Workshop #1

The Patients Association held a virtual workshop on June 30<sup>th</sup>, 2022, with a panel of eight patients from diverse backgrounds. Three topics were explored:

1. Patient experience with being referred by their GP to secondary care
2. Patient experience with the specialist advice and guidance service and recommendations for improvements
3. How the referral processes, including specialist advice and guidance, can be improved to better involve patients and improve the patient experience.

During the workshop, the group discussed the following questions:

1. What has been your experience being referred by your GP to secondary care?
  - Did shared decision making occur between you and your GP during the pre-referral process? For example, did the GP discuss with you that a referral may be needed and why?
  - Did you partner with your GP to decide whether a referral would be made?
  - Did you feel well-informed about the referral process and what would happen next?
  - Were you given written information or advice at the appointment with your GP?
2. To your knowledge, did the GP seek out advice from a specialist to help determine the next step?
3. What is your perspective on the use of specialist advice and guidance by GPs to determine whether a referral is needed or not?
4. What is your perspective on the way in which the specialist advice and guidance should be communicated to patients, e.g. during face-to-face appointment with GP, written letter/email, or remote consultation from the GP?
5. How can referral processes, including specialist advice and guidance, be improved to better involve patients and improve patient experience?

## Key themes and findings from Workshop #1

## Topic #1: What has been your experience with being referred by your GP to secondary care?

While some participants reported positive experiences during the referral process, the majority of participants reported challenges and difficulties due to delays in a referral being made, excessive wait times for a specialist appointment, lack of continuity in the GPs they saw, having to advocate for themselves to get a referral, lack of involvement in the process, and less than ideal communication with their GP.

The type of experience participants had seemed to be largely dependent on their clinician (with locum GPs offering more assistance), their geographic location, their clinical pathway, as well as the quality of information included in the referral. The seven key themes that emerged were:

1. Barriers and roadblocks to getting needed referral
2. Variation in the referral process based on the clinician, geographic location, and clinical pathway
3. Lack of continuity in the GPs patients saw during the pre-referral and referral process
4. Lack of shared decision making, partnership, and follow-up with patients during the referral process
5. Lack of patient confidence in the referral process due to existing issues in the care delivery system such as lack of access to particular services (e.g. mental health), and a complicated referral system
6. Burden on patients to self-advocate for referral and to be an expert
7. Lack of effective communication during the referral process.

**Table 1 Key themes and illustrative quotes**

<b>Topic 1: Patient experience with being referred by GP to secondary care</b>	
<b>Key themes</b>	<b>Illustrative quotes</b>
<b>Barriers and roadblocks to getting needed referral</b>	<ul style="list-style-type: none"> <li>• Participants described getting a referral as a time-consuming, complicated, and frustrating process, with participants reporting long wait times even to be referred for a diagnosis—a participant described the process as a “battle.”</li> <li>• “[Patients] don’t know where to start...even if you go to your GP for a referral, even that is a stop gap before you’ve even gone anywhere.”</li> <li>• “I go to the doctor in fear each time thinking how is this going to be, how are they going to treat me...if you say the wrong thing it can lead to you not receiving any care at all.”</li> </ul>

<b>Topic 1: Patient experience with being referred by GP to secondary care</b>	
<b>Key themes</b>	<b>Illustrative quotes</b>
	<ul style="list-style-type: none"> <li>• <i>“My engagement with my GP around transgender healthcare has been nothing but problematic...[when I tried to get a referral to an endocrine specialist] I met more roadblock from my GP...”</i></li> <li>• One participant described their experience of deciding between a rheumatology or musculoskeletal pathway. Their GP started with the rheumatology referral pathway but following blood work it was determined that a referral for the musculoskeletal pathway was more appropriate. Rather than the referral transferring over, the GP had to start a new referral which delayed treatment.</li> </ul>
<b>Experience with the referral process can vary widely based on the clinician, geographic location, and clinical pathway</b>	<ul style="list-style-type: none"> <li>• <i>“[What you experience during the referral process] depends solely on the GP or specialist you’ve gone to see and their mindset...[Getting a referral] from the GP depends on where you are, if [the GP] is up to date with your specific condition, which is down to their training, their point of view...”</i></li> <li>• <i>“The process should be easier for the patient...GPs should be looking into [the referral] and investigating further. If [the GP makes] the decision early [to do a referral], [it] can potentially save someone from having [a missed] diagnosis.”</i></li> <li>• <i>“GPs do a lot of referrals to the wrong specialists. They need to be a lot more supported on how to do a good referral.”</i></li> <li>• A participant reported their experience of presenting to their GP with recurring symptoms without receiving help from that GP. However, when they were seen by a new GP in the practice, this GP immediately investigated the issue and sought out further information from a consultant. <i>“Some GPs are reluctant to send you for further investigation, it’s about the willingness to help someone.”</i></li> <li>• Several participants described having a more positive experience when working with locum GPs to handle the referral process rather than the regular practice GP. A participant remarked,</li> </ul>

<b>Topic 1: Patient experience with being referred by GP to secondary care</b>	
<b>Key themes</b>	<b>Illustrative quotes</b>
	<p><i>"Locums seem to be more open to doing a referral to specialist services. They are more collaborative and supportive..."</i> Another participant noted <i>"I try to find a locum GP or someone who is not permanent, they tend to investigate further."</i></p>
<p><b>Lack of continuity in the GPs patients saw during the pre-referral and referral process</b> (Note: this theme emerged during a discussion at workshop #2)</p>	<ul style="list-style-type: none"> <li>• Few patients reported seeing the same GP during the referral process: <ul style="list-style-type: none"> <li>○ <i>"You don't see the same doctor...If you want to see the same doctor you have to wait a long time."</i></li> <li>○ <i>"GPs are changing on a regular basis, unless their notes are scrupulously recorded, then the next GP doesn't know what is going on."</i></li> </ul> </li> <li>• Patients reported that the lack of GP continuity negatively impact the doctor patient relationship: <ul style="list-style-type: none"> <li>○ <i>"[When you do see the same doctor] you have an understanding with that doctor when you go back, it's that progressional journey..."</i></li> </ul> </li> </ul>
<p><b>Lack of shared decision making, partnership, and follow-up with patients during the referral process</b></p>	<ul style="list-style-type: none"> <li>• <i>"There is no partnership, there is a power imbalance from the minute you step in there...My experience of partnering with the GP is that there is no partnering. I am at the mercy of whatever the GP decides. And when it comes to referral, there is never any discussion regarding making a referral. The GP often tells me that they are a referral service, so depending on what the issue is, they will decide to refer you straight away somewhere or they will decide not to refer you... you actually want the referral because without the referral, things seem to be closed down, and you don't get any help with the problem you are presenting with."</i></li> <li>• <i>"[I want the GP to say] I hear what you are saying...Let's go down this path together. You have the choice whether you want it to be video conference, you have the choice whether you want it to be face-to-face or a letter. That is going to come down to the individual person. Knowing that you are heard [is important]. The good old-fashioned bedside manner, [the GP needs to] learn how you actually talk to people."</i></li> <li>• <i>"Now with my going digital and e-consults, they are not asking for as much so it's not as inclusive. It's</i></li> </ul>

<b>Topic 1: Patient experience with being referred by GP to secondary care</b>	
<b>Key themes</b>	<b>Illustrative quotes</b>
	<p><i>very much they make the decision and you're just told about it afterwards...there seems to be much less with them getting with you and discussing anything."</i></p>
<p><b>Lack of patient confidence in the referral process due to existing issues in the care delivery system such as lack of access to particular services (e.g. mental health), and a complicated referral system</b></p>	<ul style="list-style-type: none"> <li>• A participant describing their experience seeking a referral for mental health services said their GP was hesitant to make a referral because referrals for mental health services tend not be acted upon.</li> <li>• A participant reported that even if the GP partnered with the patient during the process, that same GP can then "<i>hit a minefield</i>" because they are unclear which service to refer the patient on to.</li> <li>• A participant who works in the NHS said: "<i>Sometimes it is not always easy [for the GP] to find the correct route [to] hospital to send the right referral...[when the referral we sent was rejected] we got feedback that we have chosen the wrong department or clinic. So we need a simplified version [of the e-Referral system] for the clinician to find and choose the right hospital department and allow the patient to input [into the system]."</i></li> </ul>
<p><b>Burden on patients to self-advocate for referral and to be an expert</b></p>	<ul style="list-style-type: none"> <li>• A participant described that after many years of trying to manage their heart condition with their GP, they pushed to get a referral to a specialist. When they continued to have a negative experience with the specialist they had been referred to, they had to advocate for themselves further. "<i>I had to take charge of my own health.</i>" They described having to demand to be referred to a different specialist when not receiving adequate care from the original one. The care they received from the new specialist team that was knowledgeable about their condition "<i>made a huge difference</i>".</li> <li>• "<i>There should be a very simple pathway for primary to secondary referral and it shouldn't be for the patient to be telling the doctor what it is they need to be doing and when they need to do it..."</i></li> <li>• <i>It isn't for us to use Dr. Google when the GP is there to help us...I've done my own research. I should not</i></li> </ul>

<b>Topic 1: Patient experience with being referred by GP to secondary care</b>	
<b>Key themes</b>	<b>Illustrative quotes</b>
	<i>have to tell my GP how to take care of me. I've had to educate my GP...I went to my GP and said this is the endocrinologist I want to see and I was still met with 'I don't know how or if we can do this'. I don't understand how we end up with a situation where a GP doesn't know how to make a secondary referral. My GP does not want to engage."</i>
<b>Lack of effective communication during the referral process</b>	<ul style="list-style-type: none"> <li>• <i>"I begin to learn doctor-speak and communicate to them on their level...but that shouldn't be necessary. The doctor should be speaking at our level...the doctor is talking to you at one level, which is way above your head, and you're talking to the doctor at another level that he doesn't hear. We need to have easy language for everybody. If this system is going to work, that sort of change needs to be put in process."</i></li> </ul>

## **Topic #2: What has been your experience with specialist advice and guidance service? How can advice and guidance be improved?**

For those patients who self-reported having experience with advice and guidance, some said there was no GP follow up about the advice that was given, the GP being unwilling to engage with advice and guidance or the GP being unaware of how to properly use the service. As stated previously, because these were patients' self-reported experiences with specialist advice and guidance, we cannot confirm they did receive advice and guidance. Another important consideration is that lack of continuity in patients seeing the same GP, appears to lead to be wide variation in how (and if) the specialist advice and guidance service was used across different referral requests and different clinical pathways.

Despite some participants not having experience with or knowledge of advice and guidance, the patient panel was very knowledgeable about, and had extensive experience with, the referral process in general. After providing an overview of the advice and guidance service, the participants were able to provide insights into how the service could be improved.

Participants recommended a triage system that would work as follows:

- Sort out 'simple' versus more complicated pathways that warrant a referral
- For patients who present with a recurrent issue the GP should either automatically get advice and guidance or bypass advice and guidance and go straight to a specialist appointment
- Organise a roundtable of GPs who have treated a patient with a recurrent issue to discuss the case with a specialist to determine next steps.

- Engage patients directly in advice and guidance discussions with the specialist
- Finally, some participants recommended integrating pharmacists into the advice and guidance process.

The four key themes that emerged during the workshop were:

1. GP lack of knowledge about the referral process and reluctance to use advice and guidance and follow-up with patients
2. Establishment of a three-way dialogue between the patient, GP, and the specialist
3. Need for a triage system to streamline the advice and guidance and referral process
4. Integration of pharmacists into the advice and guidance process.

**Table 2 outlines key themes and illustrative quotes**

<b>Topic 2: Patient experience with specialist advice and guidance and recommendations for improvements</b>	
<b>Key Themes</b>	<b>Illustrative quotes</b>
<b>GP lack of knowledge about the referral process and reluctance to use advice and guidance and follow-up with patients</b>	<ul style="list-style-type: none"> <li>• <i>“It strikes me that there seems to be an unwillingness on occasion from frontline primary healthcare to go away and ask [for specialist advice]...Unwillingness to engage with specialist advice.”</i></li> <li>• <i>“Often the [GPs] don’t know what information to put [in the referral request], so therefore they end up making a wrong referral which is causing the delay and patients suffer. The e-referral booking system needs to come up with or design a platform that is more accessible and easy for everyone...It can be very frustrating for the clinician who is completing the referral because often they end up doing one referral 2-3 times.”</i></li> <li>• A participant shared their experience of a referral for diabetes care being rejected, but not being told about the specialist advice that was offered. <i>“He makes a referral to the hospital and then the hospital rejects the referral. I found out since that they offered clinical advice, but no one told me what that advice was. I was trying to track down what had happened to the referral.”</i></li> </ul>
<b>Establishment of a three-way dialogue between the patient, GP, and the specialist</b>	<ul style="list-style-type: none"> <li>• A participant expressed concern that if the patient is <i>“left out of the equation”</i> the result may be a less than ideal advice and guidance process. For example, the information</li> </ul>

**Topic 2: Patient experience with specialist advice and guidance and recommendations for improvements**

Key Themes	Illustrative quotes
	<p>provided by the GP to the specialist may be minimal and incomplete leading to a response back from the specialist that is <i>"bog standard"</i>. If there is then no attempt to follow-up with the patient directly for clarification or context, then the referral may be unnecessarily rejected. <i>"It is hard to get meaningful advice without offering the patient the opportunity to discuss."</i> The participant proposed a process whereby the patient can discuss with the specialist the advice that has been given to ask further questions or provide additional clarification. The participant felt that this would be a better process than simply passing the information along to the patient's GP, which would leave no way for the patient to ask the specialist questions.</p> <ul style="list-style-type: none"> <li>• Another participant acknowledged that this approach may not be feasible to accomplish given the logistics of joining up the patient with the specialist and GP all together. Their proposed solution was the use of digital means to allow the patient, specialist, and GP to input information directly into the advice and guidance system. <i>"[This way] everyone can see what is happening."</i></li> </ul>
<p><b>Need for a triage system to streamline the advice and guidance and referral process</b></p>	<ul style="list-style-type: none"> <li>• Some participants proposed a triage system where one route would be where the GP only needs simple advice. This would involve 'routine ailments' where the GP feels confident in their ability to manage the patient's treatment plan. In this scenario, the GP can have a simple consultation from the specialist. A second route would involve a more in-depth need and scenario where the GP does not feel they have the skill set or knowledge base to effectively manage the patient's condition. In this scenario, the GP could be routed to a specialist consultant who, based on an assessment of the patient's medical condition, would triage the patient to the most appropriate referral follow-up, such as a phone/video consultation or in-person</li> </ul>

**Topic 2: Patient experience with specialist advice and guidance and recommendations for improvements**

Key Themes	Illustrative quotes
	<p>appointment. <i>"[You would] end up with two systems, a straightforward simple advice for the GP versus a full-blown consultation with a specialist. Where you have the requirement for a secondary consultation with a specialist, there is scope for an element of triage in relation to the information that is given...[In this case] the patient is being dealt with [quickly], and not sitting around with a condition that could be dealt with nice and quickly, [or] waiting for the more complex ones to be dealt with first."</i></p> <ul style="list-style-type: none"> <li>• It was also recommended to automatically seek advice/refer patient to a specialist for patients experiencing recurrent issue/symptoms. <i>"If a patient is attending the GP surgery twice, more than three times, then [the] GP should be seeking advice to see if there is any issue...if is a recurrent issue the GP needs to take this further and seek further information from the hospital consultant."</i></li> <li>• For scenarios where a patient presents to the GP with a recurrent condition over a specific period of time, another recommendation was for those patient cases to be flagged in the system and a roundtable of the GPs who treated the patient meet to discuss the next course of action, with specialists involved in the roundtable.</li> </ul>
<p><b>Integration of pharmacists into the advice and guidance process</b></p>	<ul style="list-style-type: none"> <li>• A few participants recommended involving pharmacists as part of the specialist team to offer the GP advice and guidance. While some participants described many barriers to this (pharmacist not being knowledgeable about the full spectrum of the patient's clinical needs or having the ability to make a referral) and had reservations about this approach, it was suggested that having the pharmacist be available to also provide advice to the GP may be of value.</li> </ul>

**Topic #3: How can the referral processes, including specialist advice and guidance, be improved to better involve patients and improve patient experience?**

The overarching theme that emerged during this discussion was that shared decision making won't be possible unless patients' preferences and needs are taken into account and attended to, and patients are engaged directly in the referral process. This should entail communicating with patients in a format that aligns with their stated preference for receiving information and allowing patients to input information into the e-referral system to inform the referral making process. The participants also cautioned that while using technology to engage with patients might be the way of the future, patients have differing levels of access to and comfortability with using technology. Those differences must be considered so as not to create barriers to shared decision making.

The four key themes that emerged were as follows:

1. Take into account the individual needs of the patient, to deliver personalised care and communication that matches the patient's needs
2. Support co-production by allowing patients to input information into the e-referral system and increasing patient access to their medical records
3. What matters most to the patient and what they prioritise should guide the referral
4. Provide patient-facing educational resources to promote self-management.

**Table 3 provides illustrative quotes along the key themes**

<b>Topic 3: Improving the referral process and specialist advice and guidance to better involve patients</b>	
<b>Key Themes</b>	<b>Illustrative quotes</b>
<b>Take into account the individual needs of the patient to deliver personalised care and communication that matches the patient's needs</b>	<ul style="list-style-type: none"> <li>• A participant expressed that for shared decision making to work, patients need to be <i>"part of the process and on equal footing"</i> and that care needs to be adapted to take into account a patient's access needs and challenges. As a person with autism, when they expressed a preference for receiving communication via email rather than telephone, their wishes were disregarded. <i>"I feel totally frustrated about the lack of say and being bounced about. They will force you to use the telephone, but I struggle with the telephone and I prefer email, [but I'm told] we don't do email, this is the way we do things. Often if I get a phone call from the GP or hospital, it has me on the back foot from the beginning because I feel panicked when the phone rings and not able to formulate my thoughts and what to say, and I'm not</i></li> </ul>

**Topic 3: Improving the referral process and specialist advice and guidance to better involve patients**

Key Themes	Illustrative quotes
	<p><i>taking in what is being said. So we really do need to consider people's different communication needs and access needs."</i></p> <ul style="list-style-type: none"> <li>• A participant recommended that communications with patients could adopt some of the features used by instant messaging apps such as Facebook Messenger. <i>"Facebook messenger [has] open access [where the user can communicate by sending] a voice message or [recording a] video. [NHS can develop a similar] system where any form of communication can be accessed [by the patient] to give across the information that you need or to receive the information.</i></li> <li>• <i>Some people may want a leaflet to pick up...or [others may find it easier to get information from] a computer station [at the GP office]... It's all down to the patient and their preferred method of communication."</i></li> <li>• <i>"The patient is the customer, have we forgotten that? And if the customer is supposed to be king, then why is the customer hidden from view in the decision making process, and the engagement process and the communication process?"</i></li> <li>• <i>"We are the customer, but not to the doctor. The doctor will talk down to us. We talk to the doctor and the language we use is beneath them, so they don't hear and they talk at us in language we don't understand. They don't seem to want to interact with us at a level that works for both."</i></li> <li>• <i>"NHS system doesn't allow for a prefix, or preferred method of address. I was misgendered, my medical records show my previous name. It's not easy for the NHS</i></li> </ul>

**Topic 3: Improving the referral process and specialist advice and guidance to better involve patients**

Key Themes	Illustrative quotes
	<p><i>patient system to deal with other names. I'm just in the process of having my medical records changed into my now legal name and my gender marker, but the NHS can't simply change name, change the marker. They [instead] deleted my entire medical history and gave me a new NHS number and a completely new identify. Up until very recently meant I had no medical record for my doctor to look at."</i></p> <ul style="list-style-type: none"> <li>• A participant recommend that each GP surgery should identify which patients may need assistance with communication that involves technology. Peer leaders could also be engaged as part of this process to assist the patient so that <i>"everyone is linked into the system so that the communication flows to every patient"</i>.</li> </ul>
<p><b>Support co-production by allowing the patient to input information into the e-referral system and increasing patient access to their medical records</b></p>	<ul style="list-style-type: none"> <li>• In order for a patient's case to be accessed properly for referral, it was recommended that patients should be involved in inputting information into the system to provide context that may not be possible for the GP to provide given their time constraints. <i>"[In] the e-referral system, the patient can directly explain or give feedback on what they are going through and what their issues are. [Patients] can prepare a report for the GP. [Since] the GPs are super busy, they have 10 minutes of consultation and don't have time to write all the information the patient is saying...the GP does not have enough time to elaborate on the condition to the secondary care. So one of the possible solutions is where the patient can prepare [a report] for the GP...like a co-production and also giving power to the patient to explain their issue better."</i></li> <li>• A participant described that patients typically have limited access to their</li> </ul>

<b>Topic 3: Improving the referral process and specialist advice and guidance to better involve patients</b>	
<b>Key Themes</b>	<b>Illustrative quotes</b>
	patient records, and as a result are unable to make corrections to inaccurate information, which can impact the advice and guidance that is given.
<b>What matters most to the patient and what they prioritise should guide the referral</b>	<ul style="list-style-type: none"> <li>• A participant recommended that when a patient presents to the GP with multiple symptoms, the referral decision should take into account what matters most to the patient, i.e. the focus should be on which symptom the patient is most concerned about, which may differ from what the GP or specialist is focused on. <i>"When you go to the GP you'll often have more than one symptom. [The GP needs to know] what's the symptom you are most worried about, because what the patient is most worried about may be different from what the specialist or GP thinks. One way to get a better referral is to focus on what is worse for the patient at that time."</i></li> </ul>
<b>Provide patient-facing educational resources to promote self-management during the waiting time for the referral/outcome of the advice and guidance request</b>	<ul style="list-style-type: none"> <li>• If a patient's referral is rejected or has to wait for the referral, the patient should be provided with patient-friendly educational resources describing how they can self-manage their condition at home. These resources can help to support the patient if a secondary referral is not needed.</li> </ul>

## Overview of Workshop #2

The Patients Association held a virtual workshop on July 21<sup>st</sup>, 2022 to gather the panel's input and insights on conducting a patient-focused evaluation of the specialist advice service since an evaluation of how patients experience and use the service had not yet been conducted. Patient insights and recommendations from the July workshop will help to inform NHS England's design and implementation of a patient-focused evaluation of the specialist advice service.

Workshop participants received a briefing packet before the workshop that included a draft evaluation framework that was developed based on themes that emerged during Workshop #1, NHS England priority areas for conducting an evaluation, and a review of case studies of how specialist advice is currently used across different specialities.

## **A. Overview of draft patient-focused evaluation framework**

The goal of the evaluation is to understand and assess the impact of specialist advice, of which advice and guidance is a key component, on patients and the patient experience. Conducting a patient-focused evaluation of specialist advice will provide insights that can help to improve how the specialist advice service is implemented and ensure that patients are able to participate in the decision making process, and the results from the evaluation will also inform the NHS' wider strategy to:

- Transform patient care, support shared decision making, and streamline pathways of care
- Provide patients faster access to investigations, interventions, and treatment
- Treat patients, where possible, closer to home, reducing the need for onward referral
- Where an appointment is needed, ensure patients get to the right service and clinician the first time
- Ensure that NHS resources are used appropriately
- Support the recovery and sustainability of elective services.

The draft framework presented during Workshop #2 included the following five potential key evaluation areas with associated metrics/indicators:

1. Impact of specialist advice on patient experience and access (right person, right place, first time, every time)
2. Impact of specialist advice on supporting greater patient engagement, shared decision making, patient choice, and self-care
3. Patient awareness of the specialist advice service
4. Effective communication and information-sharing during the specialist advice/referral process
5. Impact of specialist advice on equality and health inequalities and ensuring ease and equity of access to care.

## **B. Description of draft evaluation areas**

### **1. Impact of specialist advice on patient experience (right person, right place, first time, every time)**

A primary goal of specialist advice is to ensure that patients see the right person, in the right place and every time. The patient-focused evaluation could explore the following metrics/indicators:

- Rate of referrals made to the right place, first time, every time
- Timely access to appropriate care and setting
- Duration of referral to treatment time
- Number of follow-up appointments
- Outcome of the specialist advice/referral, i.e. how well did the specialist advice meet the patient's needs and concerns (specialist advice resolved the patient's

concern and helped the patient, avoided a need for the patient to return for the same issue or need for acute care)

- Number of complaints about the specialist advice process/ medicolegal liability issues arising from specialist advice
- Streamlining of the patient journey, i.e. time duration for outcome of specialist advice to be received by patient
- Reduced transport costs (specialist advice supports patient closer to home/patient treated closer to home, reduced time off work to travel)

## **2. Impact of specialist advice on supporting greater patient engagement, shared decision making, patient choice, and self-care**

Another important goal of specialist advice is to support the engagement of patients in the decision making process. To this end, two important concepts to consider are shared decision making and patient choice. In 2021, the National Institute for Health and Care Excellence (NICE) published guidelines to make shared decision making part of everyday care in all healthcare settings. The guidelines include recommendations on embedding shared decision making at the organisational level, putting shared decision making into practice, patient decision aids, and communicating risks, benefits, and consequences.<sup>5</sup> NHS England also provides information, guidance, and resources on shared decision making.<sup>6</sup> In terms of patient choice, in 2020, the NHS updated The NHS Choice Framework that provides patients with information on what choices are available in the NHS.<sup>7</sup>

The patient-focused evaluation could explore the following metrics/indicators:

- The patient is given the opportunity to provide input and context to the specialist advice request before it is submitted
- The GP discusses the specialist advice request /outcome with the patient
- Once the specialist advice response is received, the GP and patient make a joint decision or plan in terms of treatment or care (NICE guidelines)
- Once the specialist advice response is received, the GP discusses options with the patient and the possible benefits and risks of the options (NICE guidelines)
- The information the patient receives helps them to prepare for discussing options and making shared decisions by encouraging them to ask questions, talking about what matters to them, etc. (NICE guidelines)

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<sup>5</sup> National Institute for Health and Care Excellence. Shared decision making, NICE guideline. Published June 2021. Available at <https://www.nice.org.uk/guidance/ng197>. Last Accessed August 2022.

<sup>6</sup> NHS England, Shared decision making. Available at <https://www.england.nhs.uk/shared-decision-making/>. Last Accessed September 2022.

<sup>7</sup> National Health Service. Guidance, The NHS Choice Framework: what choices are available to me in the NHS? Updated 14 January 2020. Available at <https://www.gov.uk/government/publications/the-nhs-choice-framework/the-nhs-choice-framework-what-choices-are-available-to-me-in-the-nhs>. Last Accessed August 2022.

- At the point of referral and at the point of seeking specialist advice, the GP makes the patient aware that they can choose the hospital/service/clinical care team they would like to receive care from (NHS Choice Framework)
- To help the patient to participate in the decision making, the patient is offered the opportunity to get additional support (nurse, social worker, advocate, interpreter, etc.)
- Patient receives advice on how they can be supported to self-manage (specialist advice supports self-care of patients)
- Patients expresses greater confidence to manage and monitor condition at home (specialist advice supports self-care of patients).

### **3. Patient awareness of specialist advice**

In general, patients are not aware of the specialist advice service or that their GP has used the service. Therefore, a key area to evaluate would be patient awareness and knowledge of the service. The patient-focused evaluation could explore the following metrics/indicators:

- Degree to which patients are aware of the specialist advice service and how they can engage in the process
- Patient has received information on the specialist advice service, in a communication format of their preference

### **4. Effective communication and information-sharing during the specialist advice/referral process**

An important barrier identified by the patient panel was communication breakdown that often occurred during the referral process. This was a major issue for patients and greatly impacted their experience during the referral process. The patient-focused evaluation could explore the following metrics/indicators:

- Clarity of the communication received during the specialist advice/referral process
- The patient receives information from the GP about the specialist advice response/referral, and in a communication format of their preference (e.g. in-person, phone, email, written, app)
- The information the patient receives is delivered in manageable chunks, “chunk and check” (NICE guidelines)
- The GP checks that the patient understood the information received, “teach back method” (NICE guidelines)
- Timeliness of the information communicated to the patient
- Degree to which the information is communicated to the patient in their stated preferred mode.

### **5. Impact of specialist advice on equality and health inequalities**

It is a priority that specialist advice approaches do not contribute to or exacerbate health inequalities and disparities and that they help to ensure patients have equitable access. The patient-focused evaluation could explore the following metrics/indicators:

- Access to specialist advice/referral for protected characteristic groups and other groups who experience health inequalities
- Instances of delayed response, delays in treatment/care for protected characteristic groups and other groups who experience health inequalities
- Ease and equity of access to care for protected characteristic groups and other groups who experience health inequalities
- Overall experience during the specialist advice/referral process for protected characteristic groups and other groups who experience health inequalities.

## Themes and key findings from Workshop #2

Three topics were explored during the workshop.

1. *Areas to be included in the evaluation:* Participants were asked to provide feedback on whether they agreed with the five areas being the focus of the evaluation, and what areas were missing.
2. *Type of information to collect from patients:* Participants were asked to describe the types of information (measures, metrics) that could be gathered from patients to provide data on each of the evaluation areas. Sample patient metrics were provided to patients to solicit their feedback.
3. *How to collect information for each evaluation area:* Participants were asked to provide feedback on methods for gathering information from patients, such as surveys, patient panels, etc.

### A. Overarching feedback on the evaluation framework

Participants provided overarching feedback on how specialist advice should be framed and defined, (especially as part of the patient journey), data collection and weighting of metrics, internal tools that NHS England may want to develop to track the results of the evaluation (such as a road map), and pre-evaluation activities that may be needed.

- **Framing and defining specialist advice:** A key starting point that was recommended by the patient panel was to define in detail specialist advice in evaluation materials that would be shared with patients, and how specialist advice works in practice for patients. Since most patients are not aware of the specialist advice service, it will be important to describe the service in detail and in patient-friendly language. Developing a graphic that visually depicts how the service works and that highlights points along the process where GPs and patients typically interact with the service would be helpful.
- **Specialist advice as part of the patient journey:** An overall point was made that specialist advice cannot be evaluated in isolation of the rest of a patient's journey

(i.e. what happens after the referral is made), since what the patient experiences outside of the specialist advice process can impact their referral journey. For example, not having input to the referral process or given information about the referral outcome and being referred multiple times to different specialists without a resolution can all impact the patient's experience with specialist advice. Having said that, participants stressed that the primary objective of the evaluation should be made clear that the focus is on the pre-referral and referral process and not what follows in terms of treatment and care.

- **Data collection and weighting of metrics:** While there was broad agreement with the metrics/measures outlined for each evaluation area, some participants suggested that information for some metrics would be better gathered from clinicians than patients. For example, to assess whether a patient was referred to an appropriate specialist for their condition would be more difficult for a patient to determine as opposed to their clinician or an independent entity, especially in the case of a person with a rare disease who would not necessarily be able to know whether they were referred to an appropriate specialist. Additionally, greater weight should be given to certain metrics based on the pain-point and barrier they represent for patients, such as delays in referral, timeliness of referral, communication and information sharing during the specialist advice process.
- **Creating a road map for specialist advice:** A participant recommended developing a road map of specialist advice that would visually depict the goals of specialist advice, what it is trying to achieve, and the degree to which expectations for the specialist advice service are being (or have been) met. Having a road map would allow NHS England to conduct an audit trail to validate that the process had been implemented and implemented correctly. For example, conducting an audit would help to capture whether there is consistency across specialities in the timeliness of when they followed-up and provided a response to the GP.
- **Conducting baseline data collection:** It was recommended that baseline information would need to be gathered to assess whether specialist advice had been provided and at what point. This type of baseline information would inform whether specialist advice was provided in a timely manner, was it provided too late in the process, and whether it was provided correctly, i.e. at the right time.

The next section describes specific feedback to the evaluation framework that was discussed during the workshop. **Appendix A** includes a revised evaluation framework that incorporates the feedback received during the workshop.

## **B. Feedback on evaluation areas and metrics**

Participants largely agreed with the five evaluation areas in the framework, suggesting further refinements, wordsmithing, explanation for each of the areas, and an additional evaluation area. Below summarises key points:

### **Evaluation area #1: Impact of specialist advice on patient experience (right person, right place, first time, every time)**

- There was feedback to ensure that the language used in an evaluation be patient-friendly. For example, evaluation area #1 could be re-worded and broken down to key elements of patient experience, such as, “Did the patient feel that they saw the right person or the right doctor? Did the patient feel it was at the right time? Did the patient feel that they were supported all the time?” Additionally, since delays in referrals were identified as a major barrier, metrics for this evaluation area could focus on assessing whether specialist advice was provided in a timely manner.
- It was recommended that this evaluation area be further refined and expanded to focus not only on the patient experience but also the patient journey. A focus on evaluating the patient journey would help to assess the extent to which the patient’s experience with specialist advice varied from how the service is supposed to function and operate. Participants described the patient journey as encompassing at what point the patient was made aware of specialist advice, and whether specialist advice was offered and provided in the correct way and in a timely manner.

### **Evaluation area #2: Impact of specialist advice on supporting greater patient engagement, shared decision making, patient choice, and self-care.**

- Although participants supported shared decision making and patient engagement in the specialist advice process, it will be important to guard against placing an excessive burden on patients to navigate their own referral process and care. Therefore, it was recommended that evaluation area #2 include metrics to ensure that patients aren’t having to take on an unrealistic and unreasonable amount of self-advocacy. It will be critical to ensure that the evaluation captures how well clinicians and the specialist advice process minimise the burden on patients to continually self-advocate during the pre-referral/referral/specialist advice process.

### **Evaluation area #3: Patient awareness of specialist advice**

- A point was made that this evaluation area should be prioritised first since many patients are not aware or educated about what specialist advice is and how it works.
- It was recommended that this evaluation area be further refined and expanded to also focus on patient education and knowledge about specialist advice (which is distinct from awareness). The evaluation could assess how well patients are made knowledgeable (through educational resources and other information) about the service, how it works, and how patients can engage in the process.

### **Evaluation area #4: Effective communication and information-sharing during the specialist advice/referral process**

- Participants suggested to prioritise this evaluation area given that a lack of communication and the information vacuum that many patients experience during the referral process greatly impacted the patient experience.
- It was recommended that this evaluation area be further refined to emphasise the 'feedback loop' between the GP and the patient. For example, once the referral/specialist advice is requested, the evaluation should measure whether and how information is fed back to the patient, what was the outcome from the referral/specialist advice, how it was followed up, was the referral communicated to other secondary services, and what actually happened.
- An additional metric could be included to assess the role of specialist advice more directly on facilitating improved communication – "Did the addition of specialist advice help you and your GP to have better communication and did it help in deciding whether to move onto [the referral]?"

### **Evaluation area #5: Impact of specialist advice on equality and health inequalities**

- Participants agreed that this evaluation area was an important area to be included in the evaluation since some felt that lip service is given to addressing health inequalities without tangible results being achieved or best practices being put into place. One participant shared their experience that reasonable adjustments and accommodations to their disability were not made routinely. It was also suggested to include metrics to assess the degree to which the specialist advice process met the language needs of patients whose primary language is not English, ensured that information is shared in Easy-Read formats, and that accessibility needs were taken into account for persons with visual impairments, the neurodivergent, and those with learning disabilities.
- Similar to evaluation area #2, it was recommended that this evaluation area include metrics to ensure patients aren't having to take on an unrealistic and unreasonable amount of self-advocacy. Guarding against placing an excessive burden on patients to navigate their own referral process and care is critical, especially for individuals who are from protected characteristics groups that experience health disparities.

### **Recommendation for an additional evaluation area**

- Since many participants felt that they had to engage in extensive self-advocacy during the referral process, it was recommended to add a new evaluation area that focused on the availability of mechanisms for patients to receive advocacy and assistance if they have a less than optimal experience with the specialist advice process. This mechanism would go beyond the traditional complaints process to address barriers patients experience with "not being heard", "expectations not being met", "not having input or shared decision making", and a lack of follow-up on the outcome of their referral or specialist advice request. One participant remarked that "there is no one to advocate for you" during the process. Therefore, the evaluation should measure the availability of mechanisms that advocate for and help patients to help resolve challenges if "something goes wrong" and whether the patient felt

supported during the specialist advice process while waiting for an outpatient appointment.

### **C. Feedback on methods for collecting patient information**

- Participants agreed that diverse data collection methods should be used (surveys, patient panels/roundtables) and information collected should include both qualitative and quantitative information. One participant recommended that patient panels could be organised by clinical pathway to gather feedback that pertains to specific conditions.
- To supplement patient surveys, one participant suggested also surveying GPs and specialists in order to get a 360 degree viewpoint on each of the evaluation areas. Additionally, engaging GPs and specialists as part of the evaluation might aid in getting their buy-in on the benefit of using specialist advice with their patients.
- In developing patient surveys, participants strongly recommended that appropriate due diligence and resources be invested in survey development to ensure valid, credible survey tools. Engaging patients in the survey development process would be critical. For example, submitting survey questions to patients for review would help to get a list of survey questions narrowed down to the most vital questions.

## **Overview of Workshop #3**

The Patients Association held a virtual workshop on July 28<sup>th</sup>, 2022 to gather the panel's input and insights on developing patient-facing educational resources.

Three topics were explored during the workshop.

1. What key content and topics should be included in patient educational resources?
2. Which types of educational resources would be most effective (e.g. leaflets, animated video, app)?
3. How can the resources be best disseminated to patients?
  - Stakeholders to engage to support dissemination (e.g. GPs, patient groups)
  - Opportunities and settings for dissemination (e.g. NHS website, GP offices)
  - Targeting resources to diverse and 'seldom-heard' communities

## **Themes and key findings from Workshop #3**

### **A. Content and topics**

Participants recommended that the introductory section of patient educational resources should emphasise that patients are entitled to receive specialist advice, have the right to ask their GP about specialist advice and make a shared decision with their GP about whether to request specialist advice, and that it's the GP's obligation to make the patient aware of the specialist advice service.

In terms of topics to be covered in educational resources for patients, workshop participants recommended the following:

- What is specialist advice, what is its purpose and goals?
- How does specialist advice work?
- What does the ideal/typical process look like, “patients need to know what good looks like”?
- What specialities are typically covered?
- What choices are available to patients? What can patients realistically expect in terms of choice, will there be restrictions on choice?
- What should patients expect during the specialist advice process, and if referred, what to expect during the referral process?
- How will information be shared with patients?
- What is the typical turnaround time for receiving information on the specialist advice request?
- How are patients involved in the specialist advice process? Will patients get to see the referral form and have input to it?
- How does specialist advice support shared decision making?
- How will patient choice be integrated into the process?
- How can patients make a complaint if they have an issue? Clarifying the process for making a complaint will depend on the type of service and clinical pathway.
- How can patients get advocacy or assistance services related to their specialist advice request?
- Signpost to organisations and resources to learn more.

## **B. Type and format**

Participants made the point that there should be two types of patient educational resources:

1. Resources to raise awareness and educate patients about specialist advice
2. A step-by-step guide of how patients can engage with their GP about requesting specialist advice, e.g. questions to ask the GP, what information patients should provide to the GP to ensure a high quality, complete specialist advice request, etc.

Participants felt that an educational resource is also needed for GPs to provide them with guidelines on how to engage patients in the specialist advice process, as well as guidelines on the specialist advice and referral process, since some GPs may not be fully aware of how to manage the process. This resource would emphasise shared decision making, include a list of frequently asked questions from patients and carers, provide an overview of the specialist advice and referral process, and signpost to resources for more information. This document could be used in training (and re-training) of GPs.

Participants felt the patient educational resources should be available in various formats (leaflets, animated video, etc.). For leaflets, attention should be paid to ensuring that the resource is accessible to those with visual impairments (appropriate font size

and colours, Braille version), available in different languages, and that the default version that is available is an Easy-Read version.

For digital patient resources, participants recommended the inclusion of links or a QR code to lead the reader to more detailed information. Animated videos would also be beneficial given their brevity, and they could be made available in GP practices on the TV screen in waiting rooms. However, participants emphasised that paper-based options should be available for individuals who are not comfortable accessing resources online/digitally or who do not have online access.

### **C. Dissemination strategies**

Participants discussed a variety of dissemination strategies, including:

- Targeting pharmacists to distribute the resources
- Make the resources available in A&E settings for patients who may not have access to a GP, are not registered with a GP, or who use the A&E as their primary source for healthcare. By disseminating the resources in this setting, A&E clinicians can help to educate patients about the specialist advice service for when patients do get access to a GP
- Carers should also be targeted since often times they accompany patients to GP appointments
- GPs could also be engaged to disseminate the resources either during appointments with their patients or to make them available (leaflets or animated video) in waiting rooms in GP practices. Additionally, instead of hold music while patients wait in the GP telephone queue, information about the specialist advice service could be played. Specialists can also be engaged to disseminate resources
- Patient charities and organisations advocating for patients who are impacted by health conditions for which specialist advice is typically sought can play a role, as well as charities and patient organisations who represent overlooked groups, such as ethnic minorities, individuals who experience homelessness, etc.
- A participant suggested that the Double Day Charity in Manchester could be engaged to help disseminate resources via their patient panel, as well as to train clinicians on how to engage patients in the specialist advice process
- Community centres can be targeted to ensure that local communities and overlooked groups are reached
- Patient Participation Groups (PPGs) were also recommended to help with dissemination and to educate patients. However, given that participants reported variable experiences with PPGs this was not a consensus opinion.

## **Summary of findings**

Although the patient panel was small in size (eight participants), participants were diverse in terms of demographics and protected characteristics. Insights gathered from

the workshops were illuminating, informative and in-depth, leading to a robust set of findings and themes. An important caveat is that because the findings are derived from a small patient panel size and that not all geographical regions were represented, the broad applicability of the findings may be limited. Future projects to gather additional insights and learnings from patients about the specialist advice and guidance service should ensure to involve larger patient panels and patients from all geographic regions.

While some participants reported positive experiences during the referral process, the majority of participants reported challenges and difficulties. The seven key themes that emerged were:

1. Barriers and roadblocks to getting needed referral
2. Variation in the referral process based on the clinician, geographic location, and clinical pathway
3. Lack of continuity in the GPs patients saw during the pre-referral and referral process
4. Lack of shared decision making, partnership, and follow-up with patients during the referral process
5. Lack of patient confidence in the referral process due to existing issues in the care delivery system such as lack of access to particular services (e.g. mental health), and a complicated referral system
6. Burden on patients to self-advocate for referral and to be an expert
7. Lack of effective communication during the referral process.

For those who self-reported experiencing specialist advice and guidance, they described receiving no GP follow-up about the advice given, and the GP being reluctant to engage with specialist advice and guidance. Despite some participants not having had experience with specialist advice and guidance, the patient panel's extensive experience with and knowledge of navigating the healthcare system and the referral process, enabled them to offer insights and recommendations for improving the service. The following strategies were recommended to improve specialist advice and guidance:

1. Establish a three-way dialogue between the patient, GP, and the specialist
2. Need for a triage system to streamline the advice and guidance and referral process
3. Integration of pharmacists into the advice and guidance process.

Participants strongly agreed with the need to better engage patients in the advice and guidance process. The overarching theme that emerged was that shared decision making won't be possible unless patients' preferences and needs are taken into account and attended to, and patients are engaged directly in the advice and guidance/referral process. The following were recommended to better engage patients in the process:

1. Take into account the individual needs of the patient to deliver personalised care and communication that matches the patient's needs
2. Support co-production by allowing patients to input information into the e-referral system and increasing patient access to their medical records

3. What matters most to the patient and what they prioritise should guide the referral
4. Provide patient-facing educational resources to promote self-management during the waiting time for the referral/outcome of the advice and guidance request.

In terms of conducting a patient-focused evaluation of the specialist advice service, participants recommended that, as a starting point, information packets should be prepared for patients that provide introductory information describing the service in detail, using visual graphics to depict how it works. The information packet and any associated evaluation materials should be in patient-friendly language.

Additionally, before an evaluation is conducted, baseline information should be gathered to assess the degree to which specialist advice is currently being provided to patients, at what stage during the care journey, and whether specialist advice is being provided as intended. Having this baseline information will allow NHS England to conduct an audit trail post the evaluation to validate that specialist advice is being implemented as intended.

Participants largely agreed with the proposed evaluation framework, with recommendations on wordsmithing, prioritisation, additional metrics and an additional evaluation area. For example:

- Consider prioritising evaluation areas focused on patient awareness of specialist advice and effective communication between GP and patients, since most patients do not know about the specialist advice service and communication challenges during the referral process are a significant issue for patients
- Evaluate the feedback loop between the GP and the patient, to assess whether information on the outcome of the specialist advice request is shared with patients, and what happened as a result of the specialist advice request
- To examine the impact of specialist advice on health inequalities include specific metrics to assess the degree to which the specialist advice process met the needs of a wide array of communities and patients from protected characteristics groups
- The evaluation should examine the extent to which specialist advice is striking a balance between encouraging shared decision making, self-care and empowerment while not simultaneously placing undue and unrealistic burden on patients to self-advocate
- Include an additional evaluation area to assess the availability of mechanisms for patients to receive advocacy and assistance if they have a less than optimal experience with the specialist advice process.

In conducting the evaluation, participants recommended:

- Use a wide range of data collection methods (surveys, patient panels/roundtables) and collect both qualitative and quantitative information

- Organise patient panels by clinical pathway to gather feedback that pertains to specific conditions
- Invest adequate resources to ensure the development of valid, credible evaluation tools
- Engage patients in the tool development process, e.g. use patient panels to review and narrow down survey items
- Engage GPs and specialists as part of the evaluation to get their buy-in on the benefit of using specialist advice with their patients.

Participants recommended a variety of topics and content to include in patient educational resources. Participants stressed that there should be two types of patient educational resources available, one to raise awareness about specialist advice and another to provide guidance to patients on how they can participate in the process. Participants suggested that an educational resource also be developed for GPs to provide them with guidelines on how to engage patients in the specialist advice process. Participants felt that a variety of educational resources should be made available (leaflets, animated video, etc), paying great attention to ensuring accessibility of the resources to various populations and communities. The participants identified many stakeholders who could be asked to disseminate the information, including pharmacists, charities/patient organisations, community centres, GP practices, A&E departments, and Patient Participation Groups.

## Recommendations

### Recommendations for Improving the Specialist Advice and Guidance Service

In exploring strategies to improve and better engage patients in the specialist advice and guidance service, NHS England may want to consider the following:

- **Embed shared decision making as part of the specialist advice and guidance process and infrastructure through GP training on shared decision making and modifications to the e-referral and patient health records systems that incorporate patient input.** Patients reported either a lack of skills or an unwillingness among their GPs to engage in shared decision making during the referral process, which was a cause of major frustration, leading many patients to feeling excluded. To address this barrier at the clinician level, GPs should receive enhanced training about shared decision making and tactics for incorporating shared decision making into their practice. Existing shared decision making tools, such as those available by NICE and NHS England, can be incorporated into training that is conducted with GPs about the specialist advice and guidance service, and resources can be developed for GPs that provide step-by-step guidelines and helpful tips for engaging patients during the specialist advice process.

In addition to training of GPs, we heard from patients that the referral system is not set up to involve them in the process. One suggestion would be to modify the e-

referral system (and patient health records) to allow patients to directly input information into the system. Patients could provide additional detail and context to the specialist advice and guidance request submitted by the GP to ensure a high quality and complete request that takes the patient's perspective into account and directly includes the patient as part of the process. Another suggestion, which may not be feasible, would be to establish a three-way dialogue between the GP, specialist, and the patient to discuss the specialist advice request. At a minimum, patients should be allowed to review the request with their GP and provide verbal or written input that the GP can then incorporate into the request before it is submitted.

- **Improve follow-up during the specialist advice and guidance/referral process:** A particular pain point cited by patients during the referral process was a lack of follow-up by their GP. Patients consistently reported experiencing an information vacuum where they received scant or no information about the status of their referral or what the next steps would be. Some had to take it upon themselves to search out information about their referral or to strongly advocate for themselves, which not every patient has the ability or comfort level to do. Setting expectations with GPs on the type of follow-up that should be conducted with patients during the specialist advice/referral process should be emphasised during GP training on the service. Benchmarks and protocols could be established, for example, on the standard timeline and process for following up with patients, with a system in place to monitor adherence to the standard.
- **Ensure that communication and information sharing during the specialist advice/referral process is in a format that is responsive to patient preferences:** GPs should receive training in effective communication and there should be attention paid to how information is communicated to patients. Communication approaches should take into account the individual needs of the patient and information should be shared in a format that matches the patient's communication needs and preferences. Participants expressed frustration that their GP often spoke to them in 'doctor speak' and did not heed their preferences for how they wanted to receive information. Therefore, communication skills-training should be emphasised during GP training on the specialist advice and guidance service. Additionally, communication preferences could be captured in a patient's online profile so that GPs (and the healthcare team) are made aware of patient preferences.
- **Promote greater GP consistency and continuity of care to address variation in the patient experience during the specialist advice/referral process:** The type of experience participants had during the pre-referral/referral process varied greatly and largely depended on the GPs they saw along the clinical referral pathway, with the skill level of GPs varying greatly between each other. While some variation is expected between GPs, there should be consistency in their skills across key areas that impact the patient experience, most notably skills in communication, shared

decision making, follow-up, etc. In addition to inconsistency of skill level between GPs, equally pressing for patients was the lack of continuity with the GP they saw. Few patients reported seeing the same GP during the referral process. Not seeing the same GP during the referral process led to situations where patients were having to repeat their health concerns over and over again, which can cause great anxiety and impact patients' confidence in the care they will receive. The COVID-pandemic has exacerbated existing GP workforce challenges and impacted patients being able to see the same GP; workforce shortages are also contributing to extensive frustration and variation during the referral process. NHS England should continue its efforts to address GP workforce shortages, while also continuing to invest in training to ensure consistency of skill set and standards of care provided by all GPs.

### Recommendations for conducting a patient-focused evaluation

The evaluation framework developed for this project can be used by NHS England to guide a patient-focused evaluation of specialist advice. It reflects priority areas identified by the patient panel, as well as NHS England's areas of interest. The original framework contained five evaluation areas with recommended metrics/indicators. As described in this report, participants agreed with the evaluation areas and suggested refinements to some of the evaluation areas and additional metrics/indicators and evaluation areas. The evaluation framework in **Appendix A** fully incorporates the feedback received from the workshop participants.

We want to call attention to and strongly recommend a particular recommendation from the patient panel to add a sixth evaluation area—**Availability of mechanisms for patients to receive advocacy and assistance if they experience a less than optimal experience during the specialist advice process**. The patient panel represented patients who may be more involved in their care than the most patients; nevertheless, despite being well-versed in navigating the healthcare system, some patients still experienced several challenges during the referral process, felt the need to self-advocate extensively, and were sometimes at a loss for what to do or where to seek help. For this reason, an evaluation of the specialist advice service should assess how well patients are able to locate and use resources to assist them during the referral process. This goes beyond measuring the effectiveness of and access to a complaint process, but rather access to an advocacy service that could resolve challenges and bottlenecks patients may experience.

There are many steps that will need to be taken to further refine the evaluation framework and to develop a robust evaluation design. The findings in this report should be viewed as a starting point, with the evaluation framework serving as a guide for a next phase project to design and implement the evaluation. The remainder of this section of the report describes recommended strategies for conducting a patient-focused evaluation, which includes the engagement of patients, the involvement of

regional offices and GPs, and considering a phased-approach to conducting the evaluation.

- **Engagement of patients:** Patients must continue to play a strong role in further developing the evaluation framework and providing feedback to how the evaluation is designed and what data collection tools are used. The patient panel for this project was comprised of patients from diverse backgrounds in terms of age, ethnicity, gender identification, and sexual orientation, and with extensive experience of the referral process and different clinical pathways.

Their high level of engagement in their care and knowledge about navigating the healthcare system enabled us to collect extremely productive and insightful feedback. Nevertheless, our project findings and conclusions are limited by the size of the patient panel (eight participants), geographic spread (participants represented five regions), and experience with specialist advice and guidance (two participants self-reported experience with advice and guidance). Therefore, we recommend that a next step in the evaluation design process may be to organise larger patient panels and that represent all seven regions and include patients who are confirmed to have extensive experience with specialist advice and guidance.

NHS England should think broadly and creatively about ways to involve patients and should continue to partner with patient charities (such as the Patients Association) and with local community groups to help recruit patients who can assist in further developing the evaluation design. Fostering these relationships in the early phases of the evaluation development process will aid NHS England's ability to promote the evaluation and recruit patients for the actual evaluation.

Patient organisation can collaborate with GP practices who have access to local patient panels to recruit patients with experience with advice and guidance. Participants in the patient panel workshop offered recommendations for specific organisations that could be engaged to recruit patients, such as the Double Day Charity in Manchester and PPGs. NHS England might also want to consider organising patient panels by clinical pathways to gather feedback on sections of the evaluation that would pertain to specific conditions and organising patient panels to review and design survey instruments. Gathering additional input to the evaluation framework from a larger sample size of patients will help ensure the resulting evaluation will apply to a wide range of patients.

- **Involvement of regional office leads:** Unfortunately, the patient panel did not have representation across all the regions. To ensure that the evaluation is applicable across geographical regions, it will be critical that all regional office leads play a role in developing and implementing the patient-focused evaluation of specialist advice. Regional leads could be engaged in this process by organising patient panels in their local area to gather feedback to the evaluation framework that could then be fed into developing a national evaluation framework. Since

regional offices will certainly need to be involved in the implementation of a patient-focused evaluation, securing their involvement in the evaluation design phase will ensure buy-in and that the specific needs and considerations of various localities are represented.

- **Involvement of GPs, Specialists and NHS administrative staff:** We recommend GPs should also be engaged in the evaluation design and development phase given their pivotal role in the specialist advice and guidance process. Another benefit to engaging GPs is to secure their buy-in on conducting a patient-focused evaluation, which will help to secure their assistance in helping to recruit patients for the evaluation. In addition to GPs, involving consultant/specialist teams will also be important to provide input to evaluating specific clinical pathways. Also involving administrative NHS staff who frequently are responsible for processing specialist advice requests will be helpful as they can provide insights on how to evaluate and improve the wait times for responses to requests.
- **Conduct a phased evaluation approach:** Before a full-scale evaluation can be conducted, NHS England may need to first conduct a baseline assessment of the specialist advice service. A baseline assessment is typically conducted at the start of a project or programme. Although specialist advice is not a new service, components of the service that impact the patient experience have not necessarily been fully implemented. For example, few patients appear to be aware of specialist advice, that their GP has used specialist advice, or have been engaged in the process. Therefore, it might be more practical to employ a phased approach to conducting the evaluation, starting with a **baseline assessment phase** to gather baseline data across all of the proposed evaluation areas. This would enable NHS England to assess the current state of the specialist advice service, in terms of how patients currently experience it, and to identify benchmarks and targets to be used as comparison to evaluate and measure change or improvement. Once the baseline assessment phase has been conducted, an analysis of the gaps identified (such as lack of patient awareness about specialist advice, lack of shared decision making) could then guide NHS England on which components of specialist advice need to be refined/implemented from a patient perspective before those components can be evaluated. For example, since many patients may not be aware of specialist advice, NHS England may first need to develop patient-facing educational resources and conduct a marketing/communication campaign to raise awareness about the service. Also, since it does not appear that GPs routinely engage patients in shared decision making during the specialist advice process, NHS England may need to refine the service to better address patient engagement and involvement.

This phased approach would allow the lesser developed components of the specialist advice to be further implemented so that when a full-scale evaluation is conducted, it can be comprehensive and robust. NHS England does not have to pause its evaluation plans during the baseline assessment or service refinement

phase. While these lesser developed components of the service are being refined and implemented, NHS England could proceed with a **phase one evaluation** of more established components of the specialist advice service.

In general, we believe that employing a phased approach, starting with a baseline assessment, would give a snapshot from the patient perspective of how the specialist advice service currently functions, and to identify gaps in what patient-focused components of the service need to be further refined and implemented. Following a baseline assessment, NHS England could then proceed to conduct a full-scale evaluation of all six areas. Additionally, a phased approach may be a more feasible approach given data collection limitations, budget constraints, etc.

- **Track the short and longer term impact of specialist advice:** As the evaluation is implemented, it will be critical to identify appropriate time points for data collection in order to track what are the short term and long term impacts of the specialist advice service. For some evaluation metrics, data could be collected from patients immediately following receipt of specialist advice, and then at defined intervals (e.g., three months, six months, etc.) to examine, for example, whether specialist advice resolved the patient's concern, avoided the need for the patient to return for the same issue or need for acute care, etc.

## Recommendations for developing patient-facing educational resources

Lack of patient awareness and knowledge about the specialist advice services presents a significant barrier to ensuring that specialist advice is patient-centred and that patients are engaged in the decision-making process, since patients won't feel empowered to engage in a process they are unfamiliar with. Developing patient-facing educational resources is, therefore, an important and critical first step. The patient panel strongly supported this as a necessary first step, and we agree. At a minimum, the resources that are developed should be accessible, available in Easy-Read formats, translated into different languages, and available in both paper-based and digital options. A key message that should be conveyed in patient resources is that patients are entitled to receive specialist advice, should feel empowered to discuss specialist advice with their GP, and have a right to be included in the decision making process with their GP.

Below are additional recommendations:

- **Resources for patients:** The report identifies topics to be covered in patient educational resources, the most important of which are a detailed description of specialist advice, what patients can expect during the process, and how they should expect to be involved in the process. Based on feedback from the patient panel, we strongly recommend that two types of resources be developed—an awareness raising resource that describes what specialist advice is and how it works, but equally

important would be a how-to guide for patients that includes specific instructions on how patients can engage in the process, for example, outlining specific questions that patients should ask their GP, the type of information they should provide their GP to ensure a high-quality specialist advice request, etc.

- **Resources for GPs, Specialists, and Consultants:** Since some GPs may not have the knowledge base on how to partner with patients during the specialist advice process, we recommend the development of a resource for GPs to accompany the patient resource. This resource will provide GPs with guidelines on how to engage patients in the specialist advice process and include topics such as FAQs from patients about the specialist advice process, overview of the concepts of shared decision making and patient choice and resources, where to signpost patients for further information, etc. These resources should also target Specialists and Consultants given their role in also ensuring the delivery of high, quality specialist advice services which meets the needs of patients. Specialists and Consultants may also need training to adapt their communication and patient resources to be more patient-centred and therefore meaningful to patients.
- **Dissemination:** A wide array of dissemination tactics should be employed targeting different healthcare professionals (GPs, pharmacists, specialists) and settings (GP offices, A&E) and partnering with various stakeholders who represent various patient groups and who have access to the local community and overlooked communities.

## Conclusion

As NHS England seeks to improve the specialist advice and guidance service and understand how patients experience the service, an important starting point will be to increase patient awareness about the service and to educate them about how it works and how they can partner with their GP during the process. Equally important will be to secure the buy-in of GPs and educate them about the benefits of engaging patients in the specialist advice and guidance process. Additionally, training GPs on how best to use the service and to involve patients in the process will be key to ensuring consistency in how the service is implemented so that all patients have a good and consistent experience regardless of the GP they saw, where they live, and their clinical pathway.

The patient panel provided several recommendations for how the service could be improved, including patients reviewing the request with their GP before it is submitted, patients directly inputting into the e-referral system, having a standardised mechanism in place for informing patients of the outcome of the request, and sharing information in ways that match patient preferences. Central to all of these recommendations is the importance of shared decision making, patient involvement, and effective communication.

An important insight from the patient panel that must be taken into account is the high degree of (and often times excessive) self-advocacy that patients reported having to do during the pre-referral/referral process. Although participants felt strongly about the importance of shared decision making and wanting to be involved in their care, they stressed that a balance must be struck so as not to create an undue and unrealistic burden on patients to continually have to self-advocate during the pre-referral/referral process. As NHS England makes improvements to the specialist advice and guidance service that includes ways to better involve patients in the process, care must be taken to minimise the self-advocacy burden that patients may be routinely experiencing.

Since an important first step will be to increase patient awareness of and education about the service, developing and disseminating patient-facing educational resources is vital. The resources will be key for conveying the potential benefits of the service and addressing scepticism among some patients that the specialist advice and guidance service is meant to discourage or deny referrals. Additionally, if shared decision making is a key feature of the service, these resources can also help to educate patients on how they can participate in the process.

Finally, since patients are the ultimate beneficiaries of the specialist advice and guidance service, conducting a patient-focused evaluation will be critical to provide NHS England with a snapshot of how the service is working for patients and opportunities for making improvements. Patients will need to be involved during the evaluation design process to ensure the credibility and validity of the evaluation, and GPs, Specialists, and Consultants should also be involved in helping to design the evaluation to ensure their buy-in and assistance with patient recruitment.

Addressing all of these factors will help NHS England to ensure that the specialist advice and guidance service is centred around the patient and that receiving the 'right care, in the right place, at the right time' becomes a reality for all patients.

## Appendix A:

### **A patient-focused evaluation of specialist advice**

#### **Evaluation framework**

##### **Introduction**

NHS England engaged the Patients Association to convene patient panel workshops to gather insights to help NHS England to gain a better understanding of how patients perceive and experience referral optimisation, specialist advice and guidance services so that improvements can be made to strengthen outpatient referral pathways while better engaging patients in the process. A goal of the patient panel workshops was to gather input on how NHS England can evaluate the impact of the specialist advice and guidance service on patients.

The following evaluation framework was developed based on key themes and recommendations from the patient panel workshops. The goal of the evaluation will be to understand and assess the impact of specialist advice on patients and the patient experience. Conducting a patient-focused evaluation of specialist advice will not only provide insights that can help to improve how specialist advice is implemented and ensure patients are able to participate in the decision making process, but the results from the evaluation will also inform the NHS' wider strategy to:

- Transform patient care, support shared decision making, and streamline pathways of care
- Provide patients faster access to investigations, interventions, and treatment
- Treat patients, where possible, closer to home, reducing the need for onward referral
- Where an appointment is needed, ensure patients get to the right service and clinician the first time
- Ensure that NHS resources are used appropriately
- Support the recovery and sustainability of elective services.

The framework includes the following six proposed evaluation areas with associated metrics/indicators:

1. Impact of specialist advice on patient experience, access, and patient journey (right person, right place, first time, every time)
2. Impact of specialist advice on supporting greater patient engagement, shared decision making, patient choice, and self-care
3. Patient awareness and knowledge of specialist advice
4. Effective communication and information-sharing during the specialist advice/referral process
5. Impact of specialist advice on equality and health inequalities and ensuring ease and equity of access to care

6. Availability and access to advocacy and assistance services during the specialist advice process.

### **Proposed evaluation areas**

#### **1. Impact of specialist advice on patient experience, access and patient journey (right person, right place, first time, every time)**

A primary goal of specialist advice is to ensure that patients see the right person, in the right place and every time. The patient-focused evaluation could explore the following metrics/indicators:

- Rate of referrals made to the right place, first time, every time, i.e. "Did the patient feel that they saw the right person or the right doctor? Did the patient feel it was at the right time? Did the patient feel that they were supported all the time?"
- Timely access to appropriate care and setting
- Duration of referral to treatment time
- Number of follow-up appointments
- Outcome of the specialist advice/referral, i.e. how well did the specialist advice meet the patient's needs and concerns (specialist advice resolved the patient's concern and helped the patient, avoided a need for the patient to return for the same issue or need for acute care)
- Number of complaints about the specialist advice process/ medicolegal liability issues arising from specialist advice
- Streamlining of the patient journey, i.e. time duration for outcome of specialist advice to be received by patient
- Reduced transport costs (specialist advice supports patient closer to home/patient treated closer to home, reduced time off work to travel)

#### **2. Impact of specialist advice on supporting greater patient engagement, shared decision making, patient choice, and self-care.**

Another important goal of specialist advice is to support the engagement of patients in the decision making process. To this end, two important concepts to consider are shared decision making and patient choice. In 2021, NICE published guidelines to make shared decision making part of everyday care in all healthcare settings. The guidelines include recommendations on embedding shared decision making at the organisational level, putting shared decision making into practice, patient decision aids, and communicating risks, benefits and consequences. NHS England also provides information, guidance, and resources on shared decision making. In terms of patient choice, in 2020, the NHS updated The NHS Choice Framework that provides patients with information on what choices are available in the NHS.

The patient-focused evaluation could explore the following metrics/indicators:

- The patient is given the opportunity to provide input and context to the specialist advice request before it is submitted
- The GP discusses the specialist advice request /outcome of the specialist advice request with the patient
- Once the specialist advice response is received, the GP and patient make a joint decision or plan in terms of treatment or care (NICE guidelines)
- Once the specialist advice response is received, the GP discusses options with the patient and the possible benefits and risks of the options (NICE guidelines)
- The information the patient receives helps them to prepare for discussing options and making shared decisions by encouraging them to ask questions, talking about what matters to them, etc. (NICE guidelines)
- At the point of referral and at the point of seeking advice, the GP makes the patient aware that they can choose the hospital/service/clinical care team they would like to receive care from (NHS Choice Framework)
- While promoting shared decision making, the degree to which the specialist advice process minimises the burden on patients to continually self-advocate during the pre-referral/referral/specialist advice process
- To help the patient to participate in the decision making, the patient is offered the opportunity to get additional support (nurse, social worker, advocate, interpreter, etc.)
- Patient receives advice on how they can be supported to self-manage (specialist advice supports self-care of patients)
- Patients expresses greater confidence to manage and monitor condition at home (specialist advice supports self-care of patients).

### **3. Patient awareness and knowledge of specialist advice**

In general, patients are not aware of the specialist advice service or that their GP has used the service. Therefore, a key area to evaluate would be patient awareness and knowledge of the specialist advice. The patient-focused evaluation could explore the following metrics/indicators:

- Degree to which patients are aware of the specialist advice service and how they can engage in the process
- Patient has received information on the specialist advice service, in a communication format of their preference.

### **4. Effective communication and information-sharing during the specialist advice/referral process**

An important barrier identified by the patient workshop panel was communication breakdown that often occurred during the referral process. This was a major issue for patients and greatly impacted their experience during the referral process. The patient-focused evaluation could explore the following metrics/indicators:

- Clarity of the communication received during the specialist advice/referral process

- The patient receives information from the GP about the specialist advice response/referral, and in a communication format of their preference (e.g. in-person, phone, email, written, app)
- The information the patient receives is delivered in manageable chunks, “chunk and check” (NICE guidelines)
- The GP checks that the patient understood the information received, “teach back method” (NICE guidelines)
- Timeliness of the information communicated to the patient
- Result/outcome information from the specialist advice is fed back to the patient in a timely manner and is acted upon accordingly in terms of follow-up, treatment plan, coordination with other secondary care, etc. (feedback loop)
- Degree to which the information is communicated to the patient in their stated preferred mode
- Degree to which specialist advice resulted in helping the patient and their GP to have better communication during the referral decision making process.

## **5. Impact of specialist advice on equality and health inequalities**

It is a priority that specialist advice approaches do not contribute to or exacerbate health inequalities and disparities and that specialist advice helps to ensure that patients have equitable access. The patient-focused evaluation could explore the following metrics/indicators:

- Access to specialist advice/referral for protected characteristic groups and other groups who experience health inequalities
- Instances of delayed response, delays in treatment/care for protected characteristic groups and other groups who experience health inequalities
- Ease and equity of access to care for protected characteristic groups and other groups who experience health inequalities
- Overall experience during the specialist advice/referral process for protected characteristic groups and other groups who experience health inequalities
- For protected characteristic groups and other groups who experience health inequalities, the degree to which the specialist advice process minimises the burden on patients to continually self-advocate during the pre-referral/referral/specialist advice process
- To aid participation in the decision making process, availability and access to additional supports (nurse, social worker, advocate, interpreter, etc.) for protected characteristic groups and other groups who experience health inequalities
- Degree to which the specialist advice process meets the language needs of patients whose primary language is not English
- Degree to which information shared during the specialist advice process is accessible for protected characteristic groups and other groups who experience health inequalities (e.g. persons with visual accessibility needs, individuals who are neurodivergent, individuals who experience learning disabilities, etc.)

## 6. Availability and access to advocacy and assistance services during the specialist advice process

Some patients report having to engage in extensive self-advocacy during the referral process, which represented a sizeable burden and frustration for patients, especially if they did not have access to needed support. This evaluation area focuses on ensuring that patients have access to advocacy and assistance services to help address challenges and barriers they may face during the specialist advice/referral process. The patient-focused evaluation could explore the following metrics/indicators:

- Mechanisms in place for patients to receive advocacy and assistance if they have a less than optimal experience with the specialist advice process---This mechanism is separate from the traditional complaints process and would assess, for example, patients receiving assistance on following-up on the outcome of a referral/specialist advice request and whether the patient felt supported during the specialist advice process while waiting for an outpatient appointment.
- Appropriate and adequate resolution achieved to challenges reported by patient during the specialist advice process.

### Background Resources

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