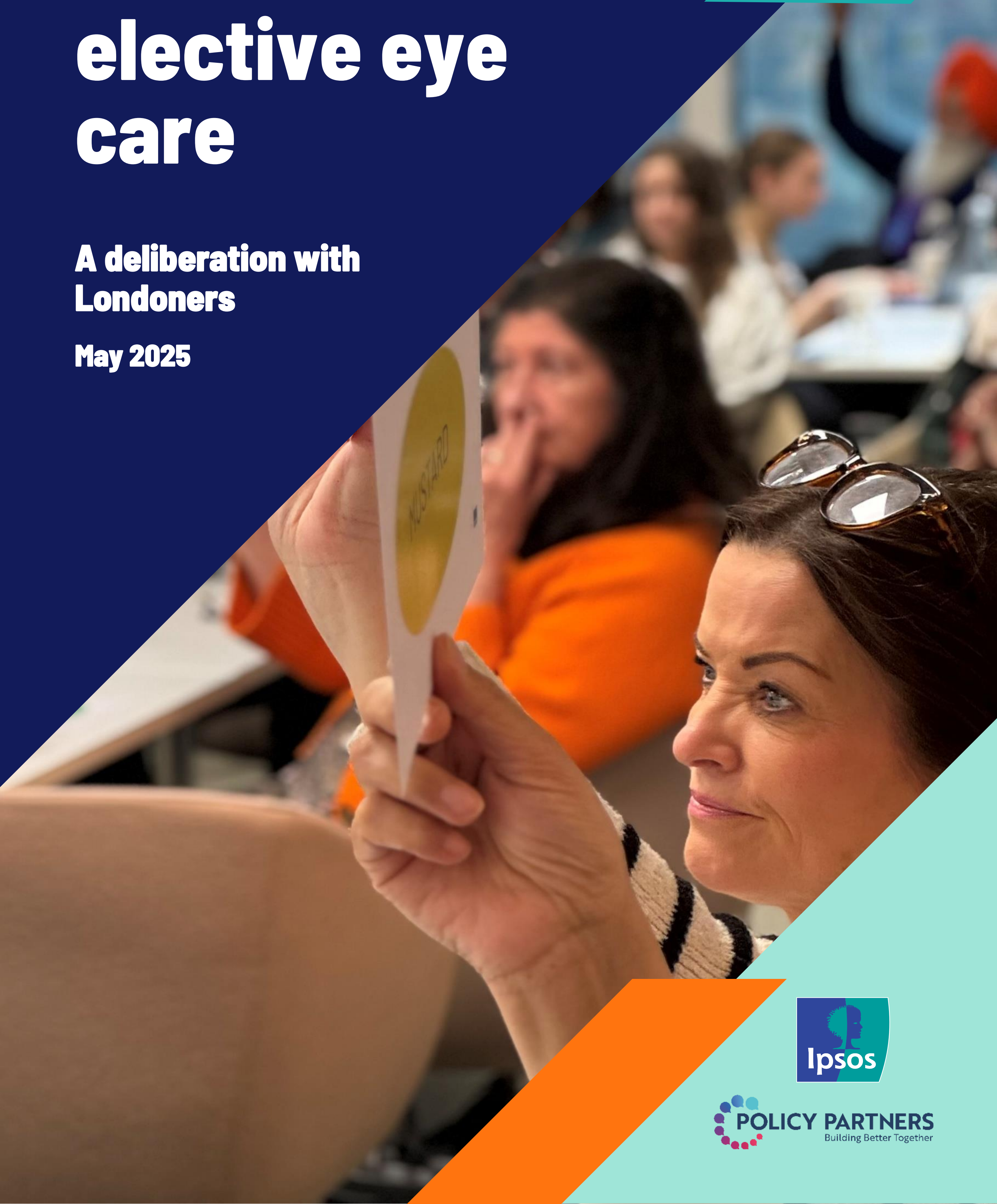
Patient choice in elective eye care

A deliberation with Londoners

May 2025



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Chapter 1: Introduction and methodology

Introduction

The NHS Constitution guarantees patient choice rights, giving patients a right to choose where their care, in this case non-emergency NHS-funded consultant-led secondary care, is provided and the information to support those choices. Informed choice conversations or processes are, however, not universally conducted. Moreover, there has been relatively little work to determine what information patients as individuals wish to have access to when making a choice. Equally, there has been little work to determine how patients wish to receive said information.

Given the complexity of the subject, and the inherent trade-offs and diversity of views, a deliberative engagement methodology was used. Ipsos, in partnership with Policy Partners were commissioned to explore the issues in more depth. In addition, they gathered empirical evidence in order to inform future design of choice offerings.

The deliberative engagement aimed to explore the following objectives:

1. Understanding public priorities and deciding factors in relation to choice. This includes:
    a. The factors most important to people when selecting a provider for onward care – Chapter 1 .
    b. Assessing the relative importance of these factors depending on the circumstances – Chapter 1.
2. Understanding both the type and amount of information the public needs to make informed decisions around where to receive onward care, as well as the preferred formats for this information - Chapter 2.
3. Public expectations in relation to the execution of choice, including:
    a. The role of different people in the decision-making process – Chapter 3.
    b. The relative advantages and disadvantages of different approaches for different types of patients – Chapter 3.
    c. The non-negotiable aspects of the process from the public's perspective (i.e. red lines) – Chapter 3.

Whilst this process will focus on secondary eyecare, we anticipate many of the findings will be applicable across other services.

Deliberative engagement

Deliberation is a progressive form of engagement used to address complex problems. It convenes 'mini publics', reflective of a larger population, over an extended period to grapple with trade-offs and dilemmas in the context of real-life constraints. This method creates an opportunity for decision-makers to understand public views that are carefully considered and rooted in real-life context. Thus, it can help build trust and relationships between official bodies and citizens and inform more trusted and supported policy in the longer term. This deliberative method was deemed to be appropriate due to the complexities of the topics covered. In addition, it provided a space to debate and discuss relevant issues and for key expectations to emerge.

Public deliberation workshops

Two full day in-person workshops were held with the same participants (see below for sample) on 22 February and 15 March 2025.

The first workshop explored the factors which drive choice in onward elective eye care:

- How these might change depending on the circumstances.
- How choice should be informed and facilitated.

Participants considered and debated several real-life dilemmas. For example, the right balance between giving people all of the information and time to make the decision, but not pressuring people. All while not leaving people to feel unsupported in the process. Participants were encouraged to think about different types of patients, including the role of health inequalities, in how the NHS should facilitate and support people to make a choice.

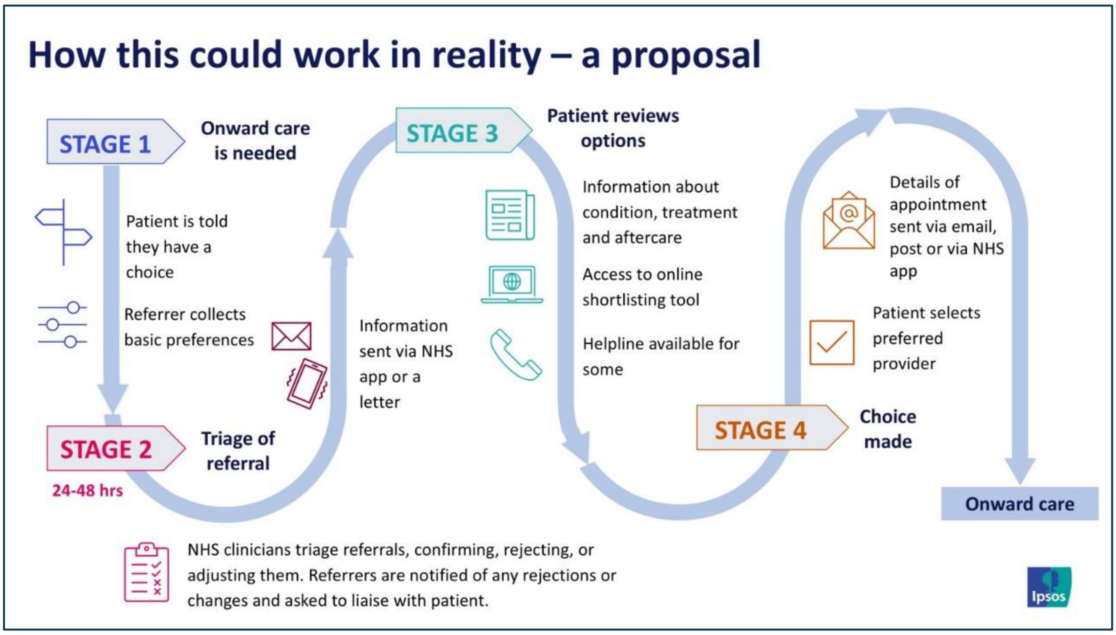
Firstly, the workshop consisted of presentations from specialists. Secondly, it consisted of smaller group discussions at tables. Participants were supported to consider different scenarios that they might find themselves in and to review a range of patient personas, purposely designed to introduce a range of eye conditions/diseases, patient circumstances and decision-making contexts.

Participants returned for the second workshop. They revisited a discussion about the drivers of choice and in the afternoon session, in four larger groups of 14-15, participants revisited how choice should be informed and facilitated. The stimulus for the afternoon discussions were a set of 15 draft expectations produced by the Ipsos team following a synthesis of discussions from across workshop 1. These were ratified, tweaked and – in some cases – changed by the four groups. This was done with support from specialists from within the NHS who challenged the group to think about feasibility, health inequalities and the role of data and AI.

The emerging expectations were also tested using a potential patient choice pathway (see Figure 1 below). This is based on a referral pathway that includes clinical triage as part of a single point of access, to assess whether they were practically feasible. In the final plenary, the emerging expectations from across the four groups were compared and A/B voting was used to collectively decide which version to take forward by the whole group.

Participants were mixed between sessions so that they were with different people. This was done to allow the participants to hear a wider range of perspectives, and to avoid ‘group think’.

Figure 1.1: Potential patient choice pathway based on the North Central London Single Point of Access



How this could work in reality – a proposal

STAGE 1 Onward care is needed

Patient is told they have a choice

Referrer collects basic preferences

STAGE 2 Triage of referral

24-48 hrs

NHS clinicians triage referrals, confirming, rejecting, or adjusting them. Referrers are notified of any rejections or changes and asked to liaise with patient.

Information sent via NHS app or a letter

STAGE 3 Patient reviews options

Information about condition, treatment and aftercare

Access to online shortlisting tool

Helpline available for some

STAGE 4 Choice made

Details of appointment sent via email, post or via NHS app

Patient selects preferred provider

Onward care

Sample composition and participants

Sixty-five participants were recruited from across the five London ICB regions and all 32 London boroughs; 58 participants completed the second workshop.

Table 1.1: Participant demographics

Category	Quota achieved
Gender	▪ x32 Female. ▪ x26 Male.
Age	▪ x3 people Aged 18-29. ▪ x7 people Aged 30-39. ▪ x12 people Aged 40-49. ▪ x16 people Aged 50-59. ▪ x9 people Aged 60-69. ▪ x11 people Aged 70+.
Self-reported ethnicity or background	▪ x1 Bangladeshi person. ▪ x3 Black African people.

Category	Quota achieved
	▪ x4 Black British people. ▪ x3 Black Caribbean people. ▪ x1 Finnish person. ▪ x10 Indian people. ▪ x2 Italian people. ▪ x1 Mixed European person. ▪ x1 Mixed French person. ▪ x1 South American person. ▪ x1 White person. ▪ x30 White British people.
Socio-economic grade[1]	▪ x16 AB (higher and intermediate managerial, administrative, and professional occupations). ▪ x22 C1 (supervisory, clerical, and junior managerial, administrative, and professional occupations). ▪ x10 C2 (skilled manual workers). ▪ x10 DE (Semi-skilled and unskilled manual occupations, those who are unemployed, and those in the lowest grade occupations).
Parental responsibility	▪ x6 parents of children 0-16 living at home. ▪ x13 people without children. ▪ x29 parents of children 17+.

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[1] Socio-economic grade is a system used for classifying individuals or households based on their social and economic status, primarily based on occupation, used frequently in social and market research. AB=

Category	Quota achieved
Caring responsibility	x13 carers
Neurodivergent condition	x8 people with neurodivergent conditions such as Autism, Dyslexia, ADHD and Dyspraxia
Visual impairment	x6 people who have a visual impairment including cataract, macular degeneration and other types of visual impairment

Oversight Group

An independent Oversight Group (OG) was established to advise on the design and delivery of the deliberative engagement. Members represented views from across the system in London and elsewhere, including senior clinicians, representatives from the independent sector and sight loss charities - see table below. The OG was invited to critique and challenge the public deliberation workshops, ensuring information provided to participants was balanced, fair and transparent.

Table 1.2: Members of the Oversight Group

Name	Organisation	Job Role
Rob Cooper	Royal National Institute of Blind People (RNIB)	Director of Strategic Engagement
Cecilia Vindrolla	UCL Research	Director of the Rapid Research Evaluation and Appraisal Lab
Ian Humphrey	College of Optometrists	Chief Executive
Peter Hampson	Association of Optometrists	Clinical and Policy Director
Ali Rivett	The Royal College of Ophthalmologists	Chief Executive
Dilani Siriwardena	Moorfields Eye Hospital and NHS England (London Region)	Clinical Director for Ophthalmology

Name	Organisation	Job Role
James Palmer	NHS England	Assistant Director of Programmes – Pathway Transformation – Eyecare
Lydia Chang	NHSE GIRFT	Joint National Clinical Lead for Ophthalmology
Elizabeth Wilkinson	NHSE GIRFT	Joint National Clinical Lead for Ophthalmology
Hilary Fanning	Moorfields Eye Hospital and NHS England	Director of Discovery, and Senior Responsible Owner for NHSE data for Research & Development Programme
David Hare	Independent Healthcare Provider Network	Chief Executive of the Independent Healthcare Providers Network
Matt Broom	Patient Representative	Chair of the Royal College of Ophthalmologists Lay Advisory Group, Council Member & Lay Examiner
Peter Thomas	Moorfields and NHS England	Executive Director of Digital Development and Chief Clinical Information Officer
Rachel Thomas	Moorfields Eye Hospital	Clinical Lead for The Single Point of Access
Irene Ctori	College of Optometrists	Vice President

How to read this report and stylistic conventions

A deliberative methodology is a qualitative approach, used to gain in-depth insights into the topic area. As it has a relatively small sample it is not intended to be generalisable to the views of the wider public. Findings are not intended to be statistically representative of the wider public. These findings are used to illustrate why people hold particular views rather than how many people hold those views.

Due to the small sample size, and the nature of deliberative engagement, findings are presented at a whole-sample level, rather than segmenting according to demographics. Where relevant, the language indicates whether views were shared by a majority or minority of participants, for example using words such as 'some', 'universally' or 'few'. Verbatim quotes are used to illustrate particular points, these are in italic text and coloured ***blue***.

Chapter 2: Drivers of choice

This chapter presents findings from participant deliberations exploring the range of factors that influence how people make decisions when selecting onward care. It examines not only which factors - such as waiting times, convenience, quality of care, or provider reputation - are considered most important, but also how participants weighed these factors against one another in different contexts and circumstances.

Quality of care as an umbrella term for important drivers of choice

Quality of care was quickly referenced as one of the most important factors that influences choice about onward care provided. However, it became apparent during the discussions that this term incorporated several different important aspects.

For some, medical expertise was important, whilst others it was the patient experience. All were important for participants to feel they can trust the provider they choose, that they will receive the best standard of treatment. However, it was also important that they will be listened to, informed, and treated with kindness during a potentially stressful time.

> ***"There is a difference between quality of care and staff expertise. You can have the most experienced surgeon who has the most awful bedside manner. If you have nice nurses who treat you well, that is quality of care."***

> ***"It is a combination of different factors. 1, the hospital itself; 2, the treatment of staff; 3, the equipment; 4, did they make me understand what I will deal with, and 5, the outcome. That is everything in a nutshell for me."***

> ***"Somewhere that is ethical and treats people as individuals, and they take a lot of effort around safeguarding so that the quality of care is there are no mistakes."***

Another aspect of quality of care was said to be continuity though the care pathway. This involved having the steps ahead explained at the beginning (when it is known), support preparing for treatment, communication throughout the journey, and continued communication through the aftercare phase. This driver of choice was most important when the suspected or confirmed diagnosis or treatment was more rare, complicated or risky, or if the condition was unknown and further tests were needed to identify the diagnosis.

> ***"I had more of an emotional response to this [case study] because it is more serious. I want to know they are there for me and I don't feel like a customer."***

Patient reviews are important for some but were cautioned by others

It was common for participants to say that they would look for patient reviews of a provider to inform their choice about onward care. They said they would be looking for information about how people were treated and communicated with during their care, rather than information on the medical treatment.

However, participants did note that patient reviews can be skewed by a tendency to report negative experiences more often than positive ones. Additionally, they cautioned the heightened emotional state that reviewers may be in. As a result, some participants said they would use patient reviews cautiously - paying attention only to clear and consistent trends. Others indicated they would not rely on reviews as a primary factor in their decision-making due to concerns about sentiment bias.

> ***"I would never look at the reviews. People who write reviews tend to be at the extremes."***

> ***"It is sort of a guide. If there are 25 reviews and 20 says something similar, you may think there is something going on there."***

There were suggestions of consistent surveying of patients, which may be more credible and balanced than unprompted reviews left on google or other review sites. Participants felt these surveys should be done regularly to have an up-to-date truthful picture of the standard of care. For some, they would want the same practitioners involved in earlier stages of their care to also oversee their aftercare, providing further familiarity and continuity.

> ***"The patient should be able to see at least one doctor that they had seen previously to show that they are following up, not just going to the same place, so that you have someone who has done your treatment and also that they know your history."***

Trusted and reliable recommendations from professionals, friends, family members or acquaintances

There were participants who would value the informed recommendation of a trusted individual as a key driver in their choice. This was often a GP (if the participant had a consistent GP that they trust) or optometrist, who they felt would have specialist knowledge of which providers are best for their suspected condition.

> ***"A GP referral is very important to me. They would normally guide my choice and I would with their recommendation."***

For other participants trusted recommendation came from a friend, family member, or neighbour who had experience with a similar issue or treatment and could offer advice on which providers to choose or avoid. This was deemed more reliable than patient reviews as they might be less emotionally charged, and they would have an idea as to whether the individual providing the feedback was rational.

The importance of provider expertise in the given speciality

Participants often said that the expertise of the provider would be a main driver of their choice. By this they typically meant whether the provider specialises in the condition or treatment they need, or are suspected to need, treating more patients with the same condition than most other providers.

> ***“That would sway my decision to see a provider. If the provider had a reputation of being a ‘specialist’, I would prefer to go there.”***

Other participants would look for individual practitioners’ expertise or specialism in the condition, or suspected condition. They said they may google for the professionals who are most well-known for the specific condition or treatment and try to choose the provider that they work at. However, they acknowledged that they may not be guaranteed to be treated by this individual even if they were to choose that provider. For some this would still be a driver of choice, as they reasoned the team working with a renowned expert would benefit from their specialist knowledge.

Information on patient outcomes provides reassurance to inform choice, but may not be accessible to all

There were participants who would want to know the success rate of treatments for a specific condition or suspected condition. They acknowledged that this information may be difficult to understand and interpret and would need to be in the context of overall success rates for that condition or treatment. However, if this was to be made available in an accessible format, participants felt this would be a clear indicator of the quality of care they could expect, and therefore a useful driver of choice.

> ***“If you see that 86% of those procedures were positive, you would go with that.”***

There was very little understanding and awareness of CQC ratings among participants, so initially few chose this as a driver of choice. When discussing it in more detail, there was some scepticism of the usefulness and validity of such a rating. Some participants compared these ratings to those generated by other regulators such as Ofsted, whom they had low trust in. Participants also worried that CQC ratings may be out of date, having just provided a snapshot of time. There was also an assumption that a CQC rating would not have assessed the individual practitioners or accounted for honest patient feedback.

For some participants, learning about CQC ratings led them to value these more as a driver of choice. They felt that they would bring together important strands of evidence that would indicate the quality of care they could expect, particularly patient experiences. They felt that the conclusions would be measured and evidenced, and valuable as long as patients understood how the rating was generated, and what is taken into account.

> ***“I trust the regulatory body more (CQC). [Patient] reviews might be influenced by heated emotions, whereas the regulator’s job is to ensure that the necessary processes are put into place. The emotional care you receive is just as important as the physical care, but I would much rather put my trust in the most competent surgical precision I can get. I tend to trust and agree with the regulator's opinion.”***

Participants wanted reassurance that CQC ratings involve unannounced visits to providers facilities, and potential ‘mystery shopper’ style evaluations of the way that staff treat patients. This is to ensure they are being inspected against the ability to be ethical and kind.

Waiting times meant both the length of wait and the certainty of an appointment

Length of wait

Participants expressed a desire to choose providers based on how long they would have to wait for treatment and how far in advance appointments could be scheduled. Waiting times became a particularly important factor when the condition was urgent, painful, impacted quality of life, or had the potential to worsen quickly. Speed of access was also prioritised when the underlying condition was unknown. Participants wanted a prompt diagnosis to gain clarity about the nature and seriousness of the issue, and to understand the appropriate treatment pathway.

> ***"I would be concerned for a long waiting time if I was not sure what I had. If I waited 6 months and was given bad news, I would be sad."***

For suspected conditions perceived to be very painful or more serious, participants said they would choose a provider based on the expected waiting time for treatment. Often this was even more so than quality of care. Urgency to be seen, in these circumstances, would be the primary driver of choice.

> ***"Pain is pain; when you are sick, you want to get rid of it – you do not care about quality."***

> ***"If it isn't as urgent, you have more choice and can make decisions around quality, facilities, reputation. If it's urgent, then you will take the first appointment."***

However, there were also participants who stated that they would de-prioritise waiting times even if the condition was particularly serious, instead placing more value on quality of care as a key driver of choice.

> ***"Glaucoma is in my family, so to me it is serious. Straight away, it is getting it done and getting it done right. Staff expertise, quality of care and information of the outcome... I had to weigh up what is more important. Getting in quicker does not necessarily mean being the best provider."***

Certainty of a scheduled appointment

In addition to the length of wait for treatment or diagnosis, participants highlighted the importance of certainty around appointment scheduling. They valued being able to plan for a specific date and time in advance. Some expressed concern that, even with a short waiting time, receiving little notice about the appointment could make it difficult to attend, potentially causing delays and added stress, emphasising the importance of reasonable notice and minimal rescheduling. Participants noted that advance notice was important not only for the patient to make arrangements, but also for friends or family members who might need to provide transport, accompany them to the appointment, or offer support afterwards.

> ***"We had to wait six months for my mother-in-law's appointment, and when the date came through, we could not make it. We then had to wait four more months, which was highly stressful."***

> ***"I would think that date is quite important. You might want to plan a holiday or something important and so you need certainty."***

Participants also said that they wanted providers to be realistic about the appointments and waiting times, explaining that it could add stress and burden if appointments are changed or cancelled. They would rather have a longer, but more realistic waiting time.

> ***"In my sons case they said a few weeks or months, and then it took a whole year. So you need to have a realistic in terms of time, I had to keep ringing them."***

Convenience and accessibility drivers

Ease and convenience were also conveyed as important drivers of choice for participants, who said this would help reduce stress at an already stressful time. If the suspected condition or treatment was not urgent, some participants would happily wait longer for a more convenient experience.

Flexibility of appointments

Participants often said that they would base their choice of provider on the flexibility offered by the provider. For example, being able to choose from a range of appointment times and days to ensure they worked alongside their schedule or job. They would like to be able to compare available appointments easily with a visual calendar or list. Aside from reducing stress, flexibility was also seen as likely to reduce indirect impacts on patients, such as loss of income or additional costs incurred for travel or parking.

Participants also stated that they would also like to be able to manage their appointment and care online. This was especially the case for those with neurodivergences, such as ADHD, who would find this far easier than managing appointments over the phone.

Location and travel

Whether or not this was a key driver of choice depended largely on participants' individual circumstances.

If they could drive or have a family member or friend who could drive them, participants said they would be willing to travel further but would want to know about the availability and cost of parking.

If they would be reliant on public transport, participants wanted to choose a provider that is reasonably close, and with good public transport links. Participants expressed that some patients may be quite anxious about getting home after treatment and would therefore want a reliable and familiar public transport route.

The location and travel options would be more important where the condition or treatment is less urgent, fairly routine, and non-invasive, for example, chalazions. Some participants said that in non-urgent cases they would be happy to wait longer for treatment from a provider that is easier to travel to.

Where the provider offered transport services to those who needed them, participants said they would want to consider the quality of those transport services, as even if those services are provided by a third party, this would be part of the patient experience, and therefore part of the quality of care offered. There were some references to poor experiences of transport providers, which undermined the quality of the care provided by an otherwise very good experience.

Ease of aftercare

While ease of aftercare was partially considered quality of care, it was largely discussed as a matter of convenience and flexibility, particularly for planned aftercare. Patients expressed a preference for attending follow-up appointments at a location close to home and easy to access, even if it differed from the original site of treatment. They also wanted to choose a provider who was flexible in aftercare communications, responsive to phone calls or emails with patients' questions and concerns. This was especially the case if the treatment typically required frequent aftercare appointments and check-ups.

When a condition or treatment was less common or carried higher risks - raising the likelihood of unplanned or emergency aftercare - patients preferred to choose a provider equipped to manage potential complications. In such cases, they often favoured providers based in or near an NHS hospital (see 'type of provider', below).

Type of provider (NHS, or non-NHS)

Participants learned that a range of providers can provide onwards care, these may be NHS or independent providers funded by the NHS.

Generally the type of provider was not a leading driver of choice for participants, although they did still express some preferences.

Participants often felt that they would trust NHS providers more than independent providers. They felt that the NHS would be able to provide the right specialists, have the right equipment, deliver higher standards of care and reassurance. Participants also considered the whole care pathway, feeling that NHS providers may be able to offer an end-to-end service compared to independent providers, with consistency from initial diagnosis, right through to aftercare.

> ***"She's [a patient persona] probably more concerned about finding a specialist for her father's specific needs and she is not as concerned about whether they are NHS or non-NHS."***

Where participants were concerned about the risk of complications during treatment, they were more likely to choose an NHS provider, specifically in or near a hospital. This was in case emergency care was needed. Some participants shared personal experiences of either themselves or family members receiving care from independent providers, only to return to NHS services after complications arose. They felt they had not fully understood the limited capabilities of the independent provider at the outset. One participant described this as going 'straight back to square one' - a situation they would want to avoid in future.

> ***"The thing with independent providers is if something happens, they wouldn't know what to do. Privately performed operations, there is no emergency services available."***

> ***"I would rather go for NHS if it was a serious situation. Emergency care is the best care."***

> ***"If I go to the NHS and they have not got space, so they put me in private practice and pay for it, how will I know how they will take care of me? I prefer the NHS for this...if I go into a coma I know I'm safe. In a private place they could do a cowboy job, they can do it, but they won't do it right."***

There were participants who felt that information sharing may be less consistent between NHS and non-NHS providers. They wanted to avoid personal responsibility as a patient for communicating medical history and details about their symptoms and suspected diagnosis. This meant that an NHS provider was more appealing.

> ***"I ended up in the emergency room of my general hospital. The doctor couldn't see the scans because they were done by a private company. I've now been referred to a different hospital, and I have printed my scans so that they may look at them."***

Some participants also expressed scepticism about the motivations of independent providers, fearing they might be more inclined to upsell services or promote more expensive products or treatments, such as glasses.

> ***"Some commercial opticians have confused me and sold me three different glasses, totalling over £1000. If there was an NHS one, I would know they are not trying to sell me anything."***

In contrast, NHS providers were valued for their clear focus on patient care rather than profit, which gave participants greater confidence in their intentions.

There were also participants who suspected that choosing an independent provider may cost the NHS more money, which is something they wanted to avoid, even if it did not affect them directly.

However, not all participants felt this way, with some suggesting that independent providers may have more capacity and be under less pressure than NHS services. This would mean they may have shorter waiting times, and the healthcare professionals would have longer to engage with each patient. They also thought that facilities may be more pleasant. These participants assumed that the same practitioners provide care at both NHS and non-NHS providers, and so there wouldn't be much difference in the staff expertise between provider types.

> ***"My personal opinion is that it wouldn't matter what setting it was as you are likely to get the same kind of doctor. In a private setting, you have the benefit of it being quick, nicer, private rooms, and equipment."***

> ***"My relative went through an independent provider and received an after-hours number to call. With the NHS, you'd go through A&E, triage, and the full system. Independent care tends to have better aftercare."***

One size does not fit all

In the second workshop, participants returned to the drivers of choice and reconsidered which would be more instrumental in driving decisions around where to receive onward eye care. These discussions concluded that there is no one size that fits all. Different drivers will take precedence in different situations even for the same patient. It depends on the urgency of the suspected condition, the level of concern or anxiety the patient is feeling, the perceived complexity of the potential procedure/risk involved and thus skilled needed to treat the patient, and the patient's personal circumstances.

Commonly chosen drivers of choice

The following drivers were, overall, most commonly chosen as important in informing choice about onward care across different scenarios and circumstances:

- Patient reviews/feedback.
- Staff expertise.

‘Quality of care’ [2]

- Waiting times (length of wait and certainty of appointment).
- Ease of aftercare (convenience and continuity).
- Convenience/flexibility of appointments.
- Location/travel.

Less commonly chosen but still drivers of choice

The following drivers were less commonly chosen as important to inform choice about onward care, however, these would still surface in certain situations. As discussed earlier in the chapter,

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[2] Given that ‘Quality of care’ was interpreted in different ways by different people, we would advise against the NHS using this framing/descriptor in shortlisting tools/communications with patients.

there was more desire for access to information on outcomes and CQC ratings once participants discussed and better understood the helpful role these could have in informing decisions.

- Information on outcomes.
- CQC ratings.
- Type of provider (e.g. NHS or independent provider).

Chapter 3: Supporting patients to make decisions

This chapter summarises participant discussions on the type, amount, and presentation of information the public needs to make informed choices about onward care. It explores what information people consider essential and how these needs vary depending on individual circumstances. The chapter also examines participants' preferences for how information should be delivered, highlighting the formats they find most accessible, trustworthy, and easy to use.

What type of information should patients have access to, to inform their choice?

Participants said that they would need information not only about the available provider options, but also about their suspected or confirmed condition. Additionally, they would need to know the nature of the condition and the associated care pathway could significantly influence their choice of provider.

With regards to information about their condition or suspected condition, the following information was deemed essential:

- A plain English explanation of the condition. Some of the eye conditions (i.e. chalazions) used as examples over the workshops were unfamiliar to the public compared to others (cataracts).
- How common the condition is, how easy it is to treat, and the typical success rate of treatment.
- The likelihood of complications or need for further treatment.
- Details about the entire care pathway, including planned aftercare and potential ongoing treatment.

This information would help patients understand the possible implication of their choices, informing their key drivers of choice. For example, when dealing with a condition perceived as urgent, decisions might be driven primarily by waiting times (length of wait). In contrast, for more complex or high-risk conditions, participants were more likely to prioritise provider expertise and the ease of accessing appropriate aftercare.

Participants expressed they would want to see the following information about each provider to inform their choice about where to go for onward care:

- The average waiting time for receiving treatment, ideally an accurate wait time but the difference between weeks or months if this was not available. It was important for this information to be up-to-date and accurate.
- Whether the same provider will manage the full care pathway, including aftercare.
- The provider's expertise, and how their success rates compare to the average success rates for that condition or treatment.

- Practical information such as location, parking and public transport links.
- A recent CQC rating and/or patient reviews (see Chapter 2 for more findings in relation to CQC ratings and patient reviews).

Participants also identified practical information they would want to know in advance of their care, even if it would not directly influence their choice of provider. This includes details such as the expected duration of the appointment or treatment, whether there is a waiting area for accompanying friends or family, and in the case of large facilities, clear guidance on where to go in the building.

In what format should patients have this information in?

Participants visualised the formats in which they would prefer to receive information about their provider options.

Many felt they would prefer to review their options online, in a comparison table or list. This felt like the most customisable approach. Participants expected that patients would be able to filter the options by the factors that mattered most to them, via a questionnaire about their priorities, or by a drop-down filter.

Participants discussed the need for information to be presented at different levels of detail. They felt that a simplified overview should be available to allow patients to easily compare and shortlist providers, with the option to access more in-depth information about each provider with a single click.

> ***"I need the location and dates at Level 1 so that I know if I can attend the appointment logistically. I need the broad stuff first so I can narrow it down... Level 1 information, to me, is "Is this possible to me?" and Level 2 information is "Is this preferable?"***

An important aspect of the different levels of information raised is that some patients may not want to know certain information. For example, some participants said they would want to avoid patient reviews or treatment success rates as it would make them anxious or confuse their decision. These participants felt that such information should be easily available but only if you choose to see it (by clicking through on a website, or asking for that information).

> ***"Reviews may dilute your outcome; they can cause a negative mindset that can influence your procedure and the aftercare process. I wouldn't want to see them up front, but I would like them available. For me, Level 1 [information] would be: waiting time, location, and specialist expertise."***

> ***"In terms of the success rate, we said this was quite scary and could put people off."***

Some gave a comparison to holiday booking websites, feeling that the options for care providers should be presented in a similar way, displaying locations, ratings, and basic information, and the ability to click on each option to find out more.

> ***"When booking a holiday, you can filter by what is most important to you. The ability to sort and filter is good."***

Participants also emphasised the importance of providing offline options to help patients compare and navigate their choices. They suggested leaflets about options, or even a printable version of the website so that someone supporting the patient can shortlist options in discussion with the patient, and then print the resulting shortlist.

For all participants, information about the condition or suspected conditions should be provided in a written format (printed or by email, as per the patient's preferences). This was important so that the patient can take the time to re-read the information and discuss it with their support network if they want to.

How might patients want to work through this information to inform their choice?

For most, at least part of this process would involve exploring the information and options alone, with the information available to them in written form (online, email or printed). Often it would use a mechanism (e.g. online portal) to filter and consider their provider options.

There were some participants who would want to involve loved ones in their decision-making process, and to do so they would also need the information available in written form (in email or printed). If a condition was quite common, participants said they would seek out people they know who have already received treatment for that condition and ask for their advice.

For some, involving loved ones is more than just emotional support, it can also be necessary from a practical standpoint, for example, if they are reliant on other people to transport them to appointment.

However, there were participants who said that they would avoid discussing the information and their options with loved ones, feeling that this would add pressure and make the process feel more 'dramatic'. They also noted that not all patients have an informal support network to navigate this process with, so this should not be an assumed part of patient's decision-making process.

For patients who do not have an informal support network, participants felt community or charity organisations, such as Age UK, may be able to help patients work through the information and feel confident in making a decision.

Speaking to professionals, such as the GP or optometrist who referred them, was considered valuable to some participants in earlier discussions. In particular if the suspected condition is rare or complicated to treat. They would want the opportunity to check they have understood the information correctly, ask questions about the condition or terminology used, and get advice on what they should consider when choosing their provider. Fellow participants pushed back on this, questioning how feasible this is in the context of busy high street opticians and GP surgeries and time pressure on professionals.

There were participants who said they would want to discuss the information with a different professional, to feel reassured by a second perspective other than the original referrer.

> ***"If it was a major issue I would want to go for a second opinion. I would want the doctor to provide me with a letter of the finding so I can work it through with my family. I don't want the doctor to say 'I am referring you straight away', I want the opportunity to discuss it with someone else."***

Participants also expressed interest in having the option to call or email potential providers directly, allowing for an initial conversation to gauge whether the provider seemed trustworthy and compassionate.

Which population groups need extra consideration when supporting patient choice?

Participants felt there were a wide range of circumstances and characteristics that could cause patients to experience health inequalities. Examples given in discussions included:

- Neurodiversity, particularly ADHD and learning difficulties, due to the potentially overwhelming information patients may have to process and consider. Participants were particularly worried about patients who may not comprehend the information about their condition, or the implications of their decision.

> ***"There is a school of thought that a lot of choice, or too much choice is overwhelming and can make things get overly complicated – so it could be said that not bamboozling people is better."***

- LGBTQ patients, who may worry about whether care providers will be accepting of them and treat them with dignity.

- Low-income patients who are paid hourly and cannot afford to miss work or have little flexibility to schedule work around appointments. Participants worried these patients may have no choice but to delay treatment, may find their options of provider much more limited by their availability, or may be disproportionately affected by transport or parking costs.

- Isolated patients who may not have a support network through the decision-making process, as well as the actual treatment and aftercare process. Participants worried that these patients could be overwhelmed, scared or fall under the radar if they stop participating in the process.

- Homeless people, who may have difficulty receiving information if they do not have a fixed address or reliable internet device.

- People with mobility issues or physical disabilities, who may need support to travel to and from their appointment, and may be worried about the accessibility of the facilities.

- Patients who do not speak English well or at all, and patients who are deaf or hard of hearing. Participants felt both of these groups may feel more anxiety and confusion if their communication needs (such as translation, braille, or sign-language) are not met, and they do not feel able to ask questions or understand the choice they are being given.

- Digitally excluded patients, who may not have access or confidence using online resources, or receiving information by email, or even text.

> ***"Accessibility may be difficult for some people in terms of online. For example, my mum is not PC literate, and as such she would miss key information if I couldn't step in for her. But online would still be the most reliable source of information."***

When considering these group participants felt strongly that the choice process must make sure the communication and information needs of patients are catered for and prioritised. Their suggestions for doing this included:

- Transport services for isolated or disabled patients.

- Collaboration with community and charity groups that support homeless people.

- Supporting patients who would prefer not to choose for themselves.

- Language support.

- Accessibility information about facilities.

Chapter 4: How to facilitate choice in decision making

This chapter explores the preferences for the decision-making process itself, who should be involved and participants' views on the risks and benefits of different approaches. It focuses on public expectations around how choices about onward care should be informed and facilitated.

Following workshop 1 deliberations, the Ipsos team synthesised discussions and the outputs from a concluding facilitated discussion in workshop 1. The discussions were focussed around what must always be true, what should always be true and what must never happen when decisions are made around where patients will receive onward eye care.

A set of 15 draft expectations were played back to participants in workshop 2 and ratified in four groups (of around 14-15 participants). During these group discussions, participants were supported and challenged by specialists from within the NHS around the feasibility of the emerging expectations.

It was made clear to participants that not all their ideas would be possible (i.e. because of practicalities, because of capacity, and/or because of finances), so much consideration was given to the implementation of the expectations. As well, the emerging expectations were tested against the patient choice pathway, and in some cases further tweaks were made to these.

Within this chapter the draft expectations are presented, as well as a summary of how these were changed (or not), forming the final expectations that were either voted in or agreed upon.

Patients should be notified that they have a choice

On learning about the NHS Constitution which states that patients should be offered a choice, participants commonly reflected that they did not know that they had a choice in where to receive elective care (eye care or otherwise) across London. This was driven mostly be personal experience, in that people had not generally experienced being told that they had a choice and/or had been offered choice. The exception to this was choice in provider for NHS blood tests.

> ***"I did not realise you had a choice when you got referred."***
>
> ***"I don't feel you get the opportunity to have a choice."***
>
> ***"From my experience, you get diagnosed, you get told to go somewhere, and you turn up."***

For some, it was hard to imagine being offered a choice driven by the assumption that waiting lists do not allow for this. Instead it would be a case of being seen by whoever and whenever there was an available appointment. It was important to participants that the NHS must inform patients that they have a choice.

> ***"Patient Choice is of no use unless you notify what the choices are."***

Recommendation forming

> Draft Expectation 1: Patients must always be informed that they have a choice and be offered a choice.

Across all groups there was unanimous agreement that the sentiment of this statement should not be changed. Participants across groups expressed that this should be communicated to participants early in the pathway and that patients should be reminded throughout that they have a choice and be offered a choice. One group added in a caveat that patients should be able to express a preference (if available) to the referrer, as well as being informed that the clinical triage step will take place, meaning that options may change after triage and this was voted in.

The choice not to choose

Participants were clear during workshop 1 discussions that there will be many patients who do not want to be burdened with choice. Thus a narrative around a 'choice not to choose' evolved across a few tables and was popular among others when shared in a plenary feedback session.

Participants emphasised that patients should be informed at point of referral that they have a choice about where to go for onward care, and asked if they want to exercise this choice. If patients state that they do not want to choose, but would rather have a professional (as 'the expert') or the NHS more broadly, decide on their behalf, this should be honoured.

> ***"Some people want to be told where to go and do not want choice."***

> ***"Some people prefer the professional to make the choice."***

Recommendation forming

> Draft expectation 2: Those patients who do not want a choice must be given the choice not to choose.

Again, across all groups there was agreement that this statement should not be changed. Participants recognised that the choice could only be properly made after the clinical triage step, given that the specialty may not be confirmed until this stage and even then, the provider choice may be limited. However, they emphasised the importance of referrers capturing a patient's preference to not be involved in the decision at the referral stage.

Similarly, in some of the groups there were also discussions about the importance of informed consent. It was felt to be important for patients to be told that they have a choice, given information to support this, but if after these steps (and only when it was clear that they had understood the information provided), they stated that they did not want to choose, this preference would be captured and observed.

Two of the four groups merged this statement with the first expectation, concerning being informed about and offered a choice and this merge was voted in by the whole group, creating a merged final expectation (below).

Final expectation 1 (which merges draft expectations 1 and 2):

Patients must always be informed that they have a choice, if available, and be able to express a preference, including the choice not to choose. Triage should be explained and options may change after triage.

Importance of removing barriers to choice

As participants discussed some of the patient personas, they restated the importance of the provision of information in different formats to support decision making. There was concern that language could become a barrier to enabling patient choice. To address this, participants suggested the use of interpreters and the provision of information in a range of spoken languages. The conversation about language then broadened to other communication requirements that some patients may have, for example, those with dementia or with visual impairments.

> ***"I think there must be some level of information provided. It must be in a format that is able to be understood. It must be clear and in a format that works for that person."***

> ***"It would be hard for anyone, let alone with a language barrier."***

Linked to the idea of information available in a format that works for the patient, participants also discussed the need for all patients to be treated fairly and equally.

> ***"It might be that commonly spoken languages are already translated, but it must be fair and equal."***

> ***"They [patients] should not be judged or discriminated against for difficulties they have."***

Recommendation forming

Draft expectation 3: Information <u>must</u> be available in a format that works for the patient: be that in different languages, in large print, dementia friendly, or braille etc.

Draft expectation 4: Patients should <u>never</u> be excluded from the choice making process because of language or other factors.

Draft expectation 5: Patients <u>should</u> always be treated fairly and equally.

While there was agreement that draft expectation 3 should be retained, one group simplified the language and removed the examples, while another added to these (visually and hearing-impaired formats). A decision was made to not vote on any changes, hence the final expectation remained unchanged.

Final expectation 2:

Information <u>must</u> be available in a format that works for the patient, be that in different languages, in large print, dementia friendly, or braille etc.

Draft expectation 4 was tweaked in very minor ways by groups. For example, one group added examples for the 'other factors': physical or intellectual disabilities. The options were not voted on as they agreed to be too similar thus the final expectation remained unchanged.

Final expectation 3:

Patients <u>should never</u> be excluded from the choice making process because of language or other factors.

Draft expectation 5 was not changed by any of the groups in sentiment. Three of the four groups changed the "should" to a "must" demonstrating they wanted this always to be the case and right from the beginning of the patient pathway, and this was voted in by all.

Final expectation 4:

Patients must always be treated fairly and equally.

Informing patients about the suspected eye condition, potential treatment and aftercare

It was important to participants to be as informed as possible about the suspected eye condition, related implications and potential treatment options to enable patients to ask the right questions to *inform their choice.*

> ***"Alongside the practicalities, he [one of the patient personas] needs to know the impact of his condition."***

There were scenarios where this felt even more important. For example, for unfamiliar eye conditions/suspected eye conditions, for patients whom are very reliant on others with regards to transport (i.e. to take them to follow-up appointments as part of the aftercare), and for those with busy lives and wanting to plan for their treatment.

> ***"Information she [one of the patient personas] may have liked would be aftercare - she may not have anticipated how much aftercare was needed. More information on the recovery period and how many follow-up appointments were done."***

Similarly, participants felt as though it would be helpful to understand the implications of their choice of provider. Specifically in terms of the pros and cons of each one and considering and comparing factors such as waiting times and distance.

> ***"Educated choice. Have information about the choices but having the option to find more choices. Pros and cons of each option."***

Recommendation forming

Draft expectation 6: Patients must always be informed about the condition itself, the treatment or procedure, and the aftercare.

Draft expectation 7: Patients must always be given the pros and cons of each option.

There were several tweaks suggested to draft expectation 6 by the different groups which were similar in sentiment. These included adding in the requirement for the patient to receive information about their known or suspected condition and related symptoms or abnormalities.

This should be provided at the point at which a choice is offered, and to be informed about the potential risks/implications of the likely procedure to treat the condition.

Participants' strong feelings about the provision of information along and across the patient pathway was emphasised in the addition of 'at every point'.

Final expectation 5:

Patients must always be informed clearly and consistently, using accessible language, about the information they have at that point in time, the condition itself, the treatment or procedure (including potential implications), and the aftercare, i.e. at every point.

Similarly, all groups revised draft expectation 7, citing concerns about the vagueness and subjective nature of the phrase 'pros and cons of each option'. Three groups tightened up the expectation to refer to the pros and cons of each provider (which was voted in by all), whereas the other group replaced pros and cons with information and data (i.e. outcome data, available appointment dates for each provider).

Final expectation 6:

Patients must always be given the pros and cons of each provider.

Support for those who need it

Throughout discussions participants were quick to point out the importance of supporting people through a decision about onward elective eye care. The point was made that many patients may not have informal networks to receive this support (see below). However, support was also considered important for people who may be struggling with overwhelm concerning too many options. A patient might be given all the information available, but no support to work through the options and this felt unsatisfactory.

> ***"As someone who struggles with anxiety, having too much information can be overwhelming."***

The need for support and advice became even more paramount in situations where the eye condition was potentially serious and/or the patient was particularly vulnerable.

Recommendation forming

Draft expectation 8: People who need it must always be given support.

While all four groups made slightly different changes to this draft expectation, three of the groups changed the sentiment to be around patients being proactively *offered* support. Participants highlighted that patient communications (i.e. emails, letters) should really emphasise that support is available for those who need it, as patients may otherwise be unaware of it and therefore unlikely to seek it out. This change was voted in by the majority, however, there were participants who did not vote for this change, making the point that it can be overwhelming to be given too much information.

There was also some prompted discussion across groups about the role of AI in providing information and support to people, given constraints on human capacity. Participants recognised that there could be a role for AI, and this would be acceptable for many patients, however, there were caveats across the groups, and new expectations emerged:

- Always having the option to speak to a human if the patient felt like they needed this.
- AI driven tools should never be used to deliver clinical guidance or without appropriate testing.
- AI not being used for advice, but rather for information provision (which felt more acceptable).

A decision was made not to vote on the new expectations, given how similar they were, so a merge of these was agreed upon to take forward (see final expectation 8 below).

Final expectation 7:

Support with decision making must be offered to all patients depending on their individual needs.

Final expectation 8:

There is a role for automated support tools (including AI driven tools) to deliver information to patients, but these should never be used to deliver clinical guidance or without appropriate testing. There should always be an option to speak to a human when using such tools.

The importance of informal networks and people not feeling lost and lonely

Participants discussed the role of others in providing advice, for example, a patient's family members or friends. They noted that many people may not have informal support networks so felt the NHS should direct people to organisations that can offer advice in the absence of these, for example charities.

> ***"Informal networks are the common denominator between these situations. Unfortunately, in elderly communities, informal networks are not as common, to have and consult with."***

Further, it was noted that the NHS should not assume that everyone is digitally confident, thus it is imperative that forms of information are accessible to patients in non-digital forms such as leaflets.

While there was a recognition that patients should not be rushed into making decisions (see below), it was also important to participants that patients are never left or forgotten about during the choice process, and thus lonely and lost in making a decision.

Recommendation forming

Draft expectation 9: Patients should always be guided to where they can get more information (written information, online and phone) – for example, groups, charities, helplines - especially if they don't have an informal network.

Draft expectation 10: Patients should never feel lonely and lost in making their decision.

There was nothing contentious about the draft expectation 9, and different groups edited it in different ways. One group merged this with an earlier expectation (about accessible information formats), while another emphasised an element of support alongside information (as for vulnerable people, information alone will not suffice), and this was voted in.

Final expectation 9:

Patients should always be guided to where they can get more support and information (written information, online and phone) – for example, groups, charities, helplines - especially if they don't have an informal network.

Draft expectation 10 was tweaked by all four groups but none of these edits changed the sentiment (i.e. words were changed, but not the meaning). The room did not vote as there were no binary choices to decide on.

Final expectation 10:

Patients should never feel lonely and lost in making their decision.

Shortlisting options based on patient preferences

Throughout discussions participants raised concerns about the detrimental impact of too much choice (occasionally referred to as 'choice fatigue'). They talked about how lots of options, and the absence of advice or guidance, could lead to feelings of overwhelm, anxiety and even disengagement in the decision-making process.

There were unanimous suggestions to offer patients a shortlist or funnelled set of provider options based on factors that matter most to patients, recognising these will be different in different circumstances and for different patients (see chapter 2). The optimum number of choices was expressed to be around 2-3 during workshop 1 discussions.

> **[When discussing a patient persona]** ***"He*** **[the GP]** ***should have said you have lots of options, what is important to you?"***
>
> ***"The filtering has not been done to avoid the overwhelm."***
>
> ***"Maybe it's just an option of 3 people to see and then making choices after. That initial choice is just a, b, and c."***
>
> ***"What's your criteria?" Point her to the website but ask the question and listen to her needs, then narrow it down together with Natalie*** **[a patient persona]** ***to keep her father's needs in mind."***

A challenge to this suggestion came from those who highlighted that there will be patients who want to see all the available options, therefore, it is important not to assume that shortlisting will be desired by everyone.

Recommendation forming

Draft expectation 11: Those patients who want it should be given a shortlist of 2-3 providers based on their preferences (prompted by a list) and what is in their best interest.

This expectation, and in particular the limited choice of 2-3 providers in the shortlist which came from discussions during workshop 1, was edited by three of the four groups to include more providers than 2-3. There was some debate around overwhelming people with too many choices. On balance, it was agreed that there will be people who will prefer more than 2-3 choices and therefore limiting choices to 2-3 might not work for all types of patients so this change was voted in.

Final expectation 11:

Those patients who want it should be given a shortlist of up to 5 providers based on their preferences (prompted by a list) and what is in their best interest.

The need for accurate and up-to-date information about waiting times

During discussions, participants stressed the importance of having up-to-date information about waiting times readily available when making decisions about onward care. They expected the system (facilitating the choice process) to keep this information current and to proactively update patients if waiting times for their chosen provider changed.

> ***"It is the granular level of the information that helps. Waiting times are one thing, but the percentage of treatments that are delayed are another level."***

Recommendation forming

Draft expectation 12: Information (i.e. about waiting times and outcomes) should be accurate and up-to date.

While incredibly important to participants, three of the four groups kept this draft expectation as a *should* rather than changing it to a *must* as the fourth group did. In groups, and also in the plenary, there was a debate around the feasibility of the NHS and its systems being able to uphold this recommendation. Those who kept the expectation as a *should* stating that this would ideally be the case but probably wasn't always going to be possible. The room was split in the vote (to keep the expectation as *should* and to change the expectation to *must*). There were slightly more votes for the latter.

Final expectation 12:

Information (i.e. about waiting times and outcomes) must be accurate and up-to date.

The importance of not rushing patients or putting them under pressure

When participants reflected on how important the choice of provider would be to many, given the implications of this decision, they stressed that people should not be pressured or rushed into making a decision. They recognised that some would want to take information away, review their options and discuss these with others, before coming to an informed choice.

> ***"Never being rushed into a decision."***

Recommendation forming

Draft expectation 13: Patients should never be put under pressure to decide, or rushed into making a decision.

All four groups made slightly different changes to draft expectation 13. One group emphasised risk and added a caveat to cover people falling through the cracks. One group added an exception for emergency situations as this felt like necessary pressure. The third group wanted to emphasise to patients the consequences of taking longer to decide, while the fourth group clarified that the decision should be made within a specified timeframe. As these changes were all so different, the room agreed not to vote across them but to harness the best bits from across all four which resulted in final expectation 13 (below).

Final expectation 13:

Patients should never be put under pressure to decide, or rushed into making a decision (except in an emergency) within a specified timeframe, and should be informed of the consequences of taking longer to decide. Patients should not be left to fall through the cracks.

Decisions being made on behalf of patients

While participants acknowledged an important role for referrers in offering guidance on appropriate options, they expressed discomfort at the idea that decisions about onward care could be made on behalf of patients without their involvement. Many felt it was morally wrong to not involve people in decisions about their care. The exception to this was those who do not have the capacity to decide for themselves.

> ***"I think for some people it will be detrimental to them [to preclude a decision being made on their behalf]. It is based on if you have the capacity and ability to choose; if not, someone will choose for you."***

> ***"There are some circumstances when they can't make those choices."***

Recommendation forming

Draft expectation 14: The decision should never be made for a patient without involving the patient, unless the patient explicitly states that they do not want to be involved, or they don't have capacity to decide.

Three of the four groups did not make any changes to this expectation, with the fourth group adding an exclusionary criterion for emergencies which was agreeable to others and was thus voted in.

Final expectation 14:

The decision should never be made for a patient without involving the patient, unless the patient explicitly states that they do not want to be involved, or they don't have capacity to decide, or it's an emergency.

Referrals driven by financial incentives for post-op care

When discussing referrals from independent providers to other independent providers (during the patient persona exercise), participants raised questions around whether financial interests might influence referral decisions. This prompted unease across several tables, with participants expressing that it felt potentially unethical. Participants emphasised that referrals should always be guided by what is in the best interests of the patient.

> ***"I wonder how financially connected the optometrists were."***

> **[Questioning financial incentives involved]** ***"Is that why they just send to the connected clinic? His needs were not put first."***

Some participants felt that referrals linked to financial incentives should be prohibited and that there should be checks and regulations in place to stop this from happening.

> ***"You shouldn't have affiliated clinics. There should be something to stop that person from getting extra money if they go to another clinic. There should be something in place."***

Recommendation forming

Draft expectation 15: Money should never be the driving factor behind the provider a patient is referred to (i.e. an optometrist referring to a specific provider because they get a fee or are affiliated). This should be regulated.

Two of the four groups made no substantive changes to this draft expectation. The other two refined the wording around monitoring, though expressed scepticism about how feasible effective regulation would be in practice. Instead, an emphasis was placed on reporting of referrals which should be monitored to identify patterns and enable appropriate follow-up where necessary and was voted in by all.

This could act as a deterrent to referrers being driven by the wrong incentives, financial or otherwise. During group discussions it was also pointed out that the need to communicate to patients that they have a choice very early on in the patient pathway (i.e. expectation number 1) would act as an additional safeguard to deter this behaviour.

Final expectation 15:

Money should never be the driving factor behind the provider a patient is referred to (i.e. an optometrist referring to a specific provider because they get a fee or are affiliated). Fees associated with referrals should be reported and monitored/regulated.

Chapter 5: Conclusions

The Patient Choice in Elective Eye Care deliberative engagement has shed light on a set of informed and considered views around how choice should be facilitated. In addition, how patients should be supported in making decisions about where to receive onward elective eye care.

The discussions of those involved were informed by real life constraints, and practical and financial feasibility. Hence the expectations voiced by the public are not a wish list, rather a set of actionable statements that emphasise what really matters to people. These take into account the hugely diverse populations across London, and summarise what must always be the case, what should (i.e. ideally) happen, and what must never happen.

The public have provided a clear set of actionable findings to support the delivery of the elective care choice pathway. The following overarching findings cut across the work and are important to note in concluding this engagement work.

One size does not fit all

It was clear from the public's deliberations that the factors that drive choice are different depending on:

- The urgency of the suspected condition.
- The perceived complexity of the abnormality or symptoms and associated risks (i.e. loss to sight).
- The level of concern or anxiety the patient is experiencing, and their personal circumstances.

The same person may value convenience over and above waiting times for a straightforward suspected eye condition yet prioritise length of wait and specialist expertise when faced with something potentially more serious, worrying and urgent.

The importance of clear communication and updates for patients

Participants' expectations point to the importance of the NHS (and independent providers it partners with) keeping patients informed through accessible communication throughout all stages of the patient choice process. For example, clearly communicating that the patient has a choice from the very beginning and updating the patient if their options change (i.e. provider waiting lists or otherwise).

The importance of fairness

The public recognised that there are patients who could otherwise be at a disadvantage in this process, for example because of language or other communication barriers. They stressed that these barriers should never be a hindrance to choice, and their expectations emphasised that everyone must be treated fairly and equally.

The public also spotted the potential financial opportunities within the independent sector. They wanted there to be measures in place, such as reporting and monitoring. This is to deter and permit non-NHS providers making automatic referrals to other independent providers on the basis of financial incentives, which were not necessarily in the patient’s best interests as this felt unfair and immoral.

Time and information to make informed choices

The public were clear that many people would need time and information before deciding on a provider. This will allow people to make an informed choice from (ideally) a shortlisted set of providers based on what is important to them, without being pressured.

At the same time, the public also stressed the importance of people not falling through the cracks. Additionally, the risks associated with this so the time for decision making should be specified and be made clear to patients.

Support should be prioritised for those in most need and information should be widely accessible

It was recognised that the NHS cannot provide personalised or human support (i.e. through manned phone lines) to all patients. Yet, it became increasingly important throughout discussions to design a system that enables this support to be available for those patients who most need it.

For example, those with dementia, elderly people, vulnerable adults or people who do not have informal support networks. This support should be offered proactively, assuming some may feel uncomfortable to ask for it. Further, it was crucial to participants that information to support patient choice is provided in formats that work for everyone. This would include (but is not limited to) people who do not speak English as a first language, people with visual impairments, and those who are not digitally confident or without internet access.

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This is the international specific standard for market, opinion and social research, including insights and data analytics. Ipsos UK was the first company in the world to gain this accreditation.

Market Research Society (MRS) Company Partnership

By being an MRS Company Partner, Ipsos UK endorse and support the core MRS brand values of professionalism, research excellence and business effectiveness, and commit to comply with the MRS Code of Conduct throughout the organisation & we were the first company to sign our organisation up to the requirements & self-regulation of the MRS Code; more than 350 companies have followed our lead.

ISO 9001

International general company standard with a focus on continual improvement through quality management systems. In 1994 we became one of the early adopters of the ISO 9001 business standard.

ISO 27001

International standard for information security designed to ensure the selection of adequate and proportionate security controls. Ipsos UK was the first research company in the UK to be awarded this in August 2008.

The UK General Data Protection Regulation (UK GDPR) and the UK Data Protection Act 2018 (DPA)

Ipsos UK is required to comply with the UK General Data Protection Regulation (GDPR) and the UK Data Protection Act (DPA). These cover the processing of personal data and the protection of privacy.

HMG Cyber Essentials

Cyber Essentials defines a set of controls which, when properly implemented, provide organisations with basic protection from the most prevalent forms of threat coming from the internet. This is a government-backed, key deliverable of the UK's National Cyber Security Programme. Ipsos UK was assessed and validated for certification in 2016.

Fair Data

Ipsos UK is signed up as a "Fair Data" company by agreeing to adhere to twelve core principles. The principles support and complement other standards such as ISOs, and the requirements of data protection legislation.

For more information

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About Ipsos Public Affairs

Ipsos Public Affairs works closely with national governments, local public services and the not-for-profit sector. Its c.200 research staff focus on public service and policy issues. Each has expertise in a particular part of the public sector, ensuring we have a detailed understanding of specific sectors and policy challenges. Combined with our methods and communications expertise, this helps ensure that our research makes a difference for decision makers and communities.