Participants in the patient panel had a range of different experiences of refractive surgery. The patients present had received treatment at different times over a long time period, from 15 years to 9 months ago, and one participant had not yet been treated.

The discussion covered a broad spectrum of the issues affecting patients throughout the course of their treatment. Participants expressed their views based on their own experiences of surgery and following their expectations of what best practice should be.

The points made can be divided into the following broad categories:

**Clinical teams**

The participants said that all clinicians should be qualified according to the relevant professional standards and that they should have up to date training based on the latest research.

**Choice**

The participants felt that all patients should be provided with the information they need to make an informed choice about their care. This could include information about surgical teams’ experience, the equipment used, the surgical environment and technology.

The patient participants thought that all clinicians should demonstrate their past experience to patients. It should be possible for patients to make a choice about their surgeon based on the surgeon’s experience, but this shouldn’t prevent junior surgeons from gaining experience.

They said that at the moment people find out about their surgeon’s ability and experience through word of mouth, but there should be a national scoreboard of experience which independently verifies the outcomes achieved would be of value.

Not all patients felt they would use this data but all the participants recognised the value of such a dataset as long as it was independent, consistent and objective.

The biographies and professional backgrounds of the whole team, not just the surgeons, should be made available to patients so that they can make an informed choice.

**Patient Suitability**

One patient had been told they should wait for a year, to make sure their prescription was stable, before having surgery. While she had been disappointed she recognised that this was important in making sure she was suitable for surgery and would benefit most from it.
One patient commented that it can be difficult to know what is likely to be important to you later in life when you’re making a decision about surgery, so it’s important that all the risks are clearly explained and patients don’t have false expectations.

One patient said she had a demonstration using contact lenses of how her monovision treatment was likely to affect her eyesight and that such demonstrations could be useful for patients.

**Informed Consent**

Patients believe it is important that everything is explained to them clearly, in plain English without any jargon.

Information should be as simple as possible to make sure patients understand what they’re being told.

They wanted to be able to take away an information pack so that they could read it in their own time and discuss it with friends and family.

It was noted that if a patient is keen to have treatment then they are unlikely to read small print and important information should be presented clearly.

Some patients commented that they had been shown videos as part of their informed consent and they found this helpful.

Patients agreed that they need to have the opportunity to ask questions. They want to be able to speak to someone who knows what they’re talking about and is sufficiently qualified but who is also capable of explaining things clearly in a straightforward and down-to-earth manner.

The patients discussed whether they would like to meet the surgeon prior to the day of surgery.

One patient commented that they had felt that everything had been really clearly explained to them and so less of an issue for her. It was noted that this could be a generational issue. The younger patients were more comfortable with technology and didn’t feel that alternative methods of communication have a negative impact on how relationships are formed or information is transferred.

Another participant said that if you’re just going to get relayed the same information there was no need to see the surgeon as well, and it may even be confusing.

They agreed however that all patients should be given the choice to see the surgeon if they wished to, as some would find it reassuring, and that it was important to let patients decide.

The patients agreed that they wanted choice about how they see clinicians.

Some patients said that they would always want to meet their clinicians to ask them questions. Other patients said they would prefer to ask questions by telephone or Skype, and would be happy to have the consent conversation in this way. Some patients thought that a telephone or Skype consultation could be more convenient for some patients and is a more modern form of practice. Patients agreed that they felt it should be their choice.
Endorsements

Many of the patients said they were uneasy about endorsements of surgery by celebrities, and that if people were being paid to endorse something then it brought into question their authenticity.

They agreed that it would be unacceptable for a celebrity or well-known figure to endorse surgery if they hadn’t actually had it themselves.

However, the patients also noted that it’s really useful to make up your mind about surgery if you hear from someone who has had it.

Some patients said that it endorsements were fair enough. If someone has had surgery and it has changed their life, then it’s understandable that they would want to let people know about it and potentially benefit too.

Patients said they would want to know why someone has had surgery and what it’s done to their life. Any endorsements should be transparent.

The group also discussed surgery being offered as prizes. It was agreed that this isn’t a problem. Price can be an issue for many patients and if they’re lucky enough to win surgery that shouldn’t be prevented.

As long as patients are suitable for surgery and have been properly informed and given their consent, then participants thought there was no problem in them being offered surgery as a prize.

Redress & Mediation

The patients all agreed that if something was to go wrong, they would want to know that they could go back to the provider and that help would be available.

Access to follow up care was viewed as the most important factor after surgery. Some patients said they felt reassured knowing that there was a 24hr phone number for them to call if they had any concerns.

Patients should be given all the information about the follow up care they can expect prior to surgery. There should be clarity about the aftercare available, and patients need to know what service they’ll be receiving in advance.

Patients thought that they should be able to have corrective surgery done if necessary, and this should be included in the original cost of surgery if it was needed within a certain amount of time from when the first procedure was carried out. One patient suggested that one year was very generous, while others thought it could be extended for certain patients depending on their personal circumstances.

The patients discussed what should happen when things go wrong.

They said that the first port of call for redress should be the providers’ complaints process, as the team that performed the surgery would also be best placed to alleviate concerns. Providers and surgical teams should take responsibility for the patients they treat.

But patients also said that there should be an independent body that patients could go to when
necessary—this was mentioned at a number of points in the discussion.
Refractive Surgery Patient Interview
Tuesday 9th May

The interviewee had refractive surgery in November 2016 and has been very pleased with the outcome. He had originally intended to have LASIK surgery, but was recommended by the surgeon to have LASEK instead.

The points made can be divided into the following broad categories:

Choice

When he first looked into having surgery, the patient found all the information available quite confusing which made his decision more difficult.

He researched different providers but wasn’t sure who to use as it is a big potentially dangerous decision, and the sector can be intimidating.

If he hadn’t had recommendations from people he knew and he trusted he wasn’t sure if he would have considered or gone ahead with surgery.

He thought it would be useful to have a single independent resource published online which would make doing research and making choices about care less intimidating. All this information should be as transparent as possible and should give realistic guidance about providers, procedures and the risks involved.

Patient Suitability

The patient said he had only been offered the latest surgery option in all his preliminary consultations. It was only when he met the surgeon, a week before surgery, that he was told another procedure would actually be more appropriate for him.

He was a lot more confident about going ahead with the procedure after meeting the surgeon a week before surgery. He then felt, on the day of surgery, like he was seeing a familiar face – someone he already knew and trusted.

If he hadn’t had contact with the surgeon beforehand he wouldn’t have been so confident about the procedure.

He said he wouldn’t like to have had this consultation with the surgeon by Skype as he found it very reassuring to be physically examined by the surgeon prior to surgery. He noted, though that this was probably more important in his case as the surgeon had made an alternative procedure recommendation to him when this face-to-face consultation happened.

Informed Consent

The patient was given the consent documents on one of his first appointments with the provider. He thought this was very helpful.

He felt he had the consent documents well in advance of when he would actually need to sign them and had plenty of time to examine and consider the documents.
He had the opportunity to talk through the consent documents during appointments with the provider.

Endorsements

The patient noted that he had had personal recommendations from people he knew and trusted, and that these were the most effective form of endorsement.

He said that the genuine experiences of ‘normal’ people would mean much more to him than endorsements by celebrities.

He did think that endorsements were an important aspect of explaining the benefits of surgery though. He noted that a lot of the stories online come from people who have had negative experiences and these do not represent the general experience of refractive surgery patients.

He said there needed to be a balanced approach, reflecting the fact that surgery generally goes very well and it changes people’s lives.

Redress & Mediation

The patient thought an independent mediator would help people who have fears prior to surgery.

Knowing that there is an official, reputable and independent body to go to if there is a problem would help people feel more confident. The prospect of taking on a company on your own could be forbidding.
Refractive Surgery Patient Interview
Thursday 11th May

The interviewee had refractive surgery in 2008. She was short-sighted and was motivated to have surgery because she felt her eyesight was deteriorating and didn’t want to need multiple sets of glasses or varifocals.

The points she made during the discussion can be divided into the following broad categories:

**Choice**

When the patient chose her provider, she thought it may have been marginally cheaper than rivals, but she went with them because she had a sense of assurance.

The patient didn’t do any research into the surgeon who treated her.

She said that she really wanted it done, but there was always a nagging doubt as she’s used to medical procedures being provided by the NHS and she has trust in the NHS.

She felt that as it was more of a commercial transaction, she had greater nervousness when considering refractive surgery.

She thought standards which all providers – regardless of size or type – could be measured against were a good idea.

**Patient Suitability**

When deciding to have surgery the patient felt the decision was her own. She only saw an optometrist before surgery and didn’t see the surgeon until the day of surgery.

When the patient did see the surgeon on the day of surgery, it gave her much more confidence in the procedure.

She felt if she had seen the surgeon prior to the day of surgery it would have given her more confidence prior to the procedure. The patient thought a Skype call with the surgeon prior to surgery would have also given her increased confidence but she didn’t feel that a telephone call would have had the same effect.

The patient believes all information provided to patients should be well-presented with clarity and transparency. Jargon should be avoided as much as possible.

**Informed Consent**

The patient noted that usually when you go into a medical procedure it is not so much your choice. As refractive surgery is your own choice you want to be sure you’re making the right decision.

She said she would want someone with a clinical background and suitable experience taking her through the consent process. She didn’t think this needed to be the surgeon, but felt it shouldn’t be someone, such as a manager or sales assistant, who didn’t have a medical/clinical background.
She said that patients want to be clinically supported, they shouldn’t feel as if they are buying something.

**Endorsements**

The patient thought endorsements from high-profile people were helpful as they give you confidence in the procedure. They let you know that it’s an established procedure, it’s safe, and what its benefits could be.

She thought endorsements from clinical professionals would also help, but not necessarily from ordinary, non-high-profile people without a medical background.

**Redress & Mediation**

The patient thought an independent system of redress in the event that things go wrong would be a good idea.
Refractive Surgery Patient Interview
Thursday 11th May

The interviewee has not had refractive surgery, but wears glasses and is a prospective patient. She recently had another form of surgery and this experience shaped her responses.

The points she made during the discussion can be divided into the following broad categories:

**Choice**

She felt it was important to know how experienced the team that was treating you was, and specifically that they have experience relevant to the eye condition that they have.

The success rate of the individual surgeon who will operate, not just the provider, is good to know. This would include the number of procedures they’ve carried out, and would specify the type of procedure that you’re having yourself.

She thought that it is good to have a choice of surgeon. When she recently had another form of surgery, she met two consultants and chose the one who she wanted to operate on her. This was partly instinctive but could also be informed by evidence of their experience.

**Patient Suitability**

The importance of the patient understanding the procedure and having realistic expectations was raised.

She noted that she had presbyopia and felt it was important to know how any surgery would affect her, what the limitations were, and how likely further deterioration was.

The patient needs to have individual personalisation according to their needs and based on changes that could happen in the future.

**Informed Consent**

She noted that while logically it probably isn’t important to meet the surgeon prior to surgery, doing so can provide patients with added peace of mind. Patients should at least be offered the option of meeting a surgeon in advance of the surgery day.

She said she’d rather this meeting happened in person than by Skype, but suggested this may be a generational difference and that younger patients may prefer Skype.

She felt consent needed to be part of a consultation directly with a clinician. She felt there were wider legal implications to consent, so it couldn’t just be taken by any member of office or sales staff, but also didn’t necessarily need to be taken by the surgeon. She thought the optometrist was probably the right person with the correct level of experience to take consent.

Consent was seen as more than just paperwork, and there should be a clear opportunity to ask questions, but also to be guided through the process as patients may not know what questions they should be asking in the first place.
**Endorsements**

She felt celebrity endorsements make no difference to her decision making process.

Endorsements from genuine patients who you’ve spoken to and can speak from their own experience help prospective patients make decisions.

She also noted though that with so many differing views online, at some point patients need to make up their own mind. It can be hard to get a balanced view and patients know that in the end it’s their own choice.

**Redress & Mediation**

The patient felt that the more open and accessible redress and mediation services are the better. All providers should be held to the same account and judged on the same criteria.

She thought that pure mediation is helpful where it can achieve results, perhaps in cases where a patient had unrealistic expectations.

She also thought that an additional level of independent redress, such as an ombudsman, may be helpful. This would give a patient an option when mediation hadn’t been successful, but before they feel the need to involve the regulator.

She also felt that such an independent body would be useful to help prospective patients choose between providers if it monitored and recorded the complaints it received and could publish the outcomes of them.
Refractive Surgery Patient Interview
Friday 12th May

The interviewee had cataracts in his 40s and had cataract surgery on both of his eyes. The first eye was treated by a private provider, outsourced from the NHS, the second was treated by NHS services themselves. The patient found that there was a significant difference between the treatments he received at each. His experience with the private provider was very straightforward and smooth, however the NHS treatment caused him distress and the care he received was of an unacceptable standards.

The patient said however that his vision in both eyes was now perfect and he was pleased with the results. Despite this he felt that the quality of care he had had with the NHS needed improving. An essential part of this improvement needed to include better communication and integration of services provided by different providers and clinicians.

Choice

He said that when making a decision his first port of call was invariably the internet, where he’d research the options available and read reviews of other patients. He noted though that, like most people, he was fairly cynical about all the information he reads online, and looks for reference material to support any conclusions he makes.

The patient said that an independent reference point where prospective patients could find this unbiased, verifiable information would be of use.

Patient Suitability

The patient thought that it is important people have realistic expectations of what could be achieved and how long any benefits to their vision would last. He said this was something of particular interest to him because, as a relatively young cataract patient, there was very little information about how long it would take before deteriorating.

From his own experience, the patient said he had not had any information about how his eyesight might change over time, or informing him about potential complications down the line. He noted that his surgery was to treat cataracts and therefore he didn’t feel as if he had any choice.

Informed Consent

It was explained to the patient that there was no guarantee that he would he’d have perfect vision after surgery. He said he had understood this, but was aware that not everyone would completely understand this, even after having all the risks fully explained to them.

He was asked whether he wanted to have his eyesight corrected to perfect vision or if he would like to still need contacts. At the time, the patient felt this was an odd question as of course he would want perfect vision. He felt this was an example of how things might not be accurately explained to patients so that the choices they need to make aren’t clear. Clear, tailored communication from treatment teams is essential.

Endorsements

The patient wondered if it would be possible to have some form of rating system to make
endorsements more transparent, and to ensure that there is balance and negative views don’t overwhelm others’ feedback.

He used the example of Air BnB reviews and suggested that for such a system to work for the refractive surgery industry it would need to be reciprocal and independently monitored. This wouldn’t neutralise the voices of disaffected patients, but would provide balance by also airing the views of patients for whom surgery has been a success.

**Redress & Mediation**

He noted that redress and mediation systems are helpful and work well in other industries.