

# Exploring patients and families' information needs and views of the Society for Cardiothoracic Surgery website

A report prepared by Picker for the Society for Cardiothoracic Surgery (SCTS)

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SECTION 1

Introduction



## Introduction

This report presents findings from qualitative research with cardiothoracic patients and their family/friends to explore their information needs and their views of the Society for Cardiothoracic Surgery website.

Over the past two decades, there has been a rapid growth in the amount of information available to patients, not only about specific conditions or treatments, but also on the quality of treatment and care either by institutions or regulatory bodies. In the UK, the NHS have collected information about quality of care for over a decade (e.g. as part of the NHS Patient Survey Programme<sup>1</sup>). Although this was initially for the purpose of performance management and auditing, this information has increasingly become available to patients as part of the NHS's commitment to transparency. This call for openness has coincided with the massive growth internet usage, which has allowed people to have a greater and more immediate connection to any information they could want as a consumer. Backed by multiple governments, the NHS has lead several initiatives to pursue transparency in the performance of its clinical staff and their patient outcomes to increase patient choice and, in turn, improve quality of care. The Society for Cardiothoracic Surgery have been the frontrunners in making data available to the public, and have published mortality rates for cardiothoracic surgeons on their website since 2004. In 2011, the Society for Cardiothoracic Surgery published *Maintaining Patients' Trust: Modern Medical Professionalism*<sup>2</sup> and, as part of the report, the society aligned the criteria that customers look for in a retailer, with patients criteria in the health sector. This was part of a larger strategy which went on to inform several objectives for the society going forward. This study marks a continued effort towards the society's aim that "publishing results for patients should form the backbone of new medical professionalism."<sup>2</sup>

The 'information revolution' has created an increased focus on, not just how much data is available, but how the information should be presented. As Hibbard and Peters (2003)<sup>3</sup> note, "having an abundance of information does not always translate into it being used...the usability of information about the available options can create serious barriers that undermine these intentions". Additionally, information about health and the risks and benefits of treatment or care is far more sensitive than most other consumer decisions that an individual is likely to make, making it all the more challenging to present, as "research has established that when choices are emotional, even people with high cognitive ability resort to simpler, less accurate heuristics" (Dixon et al, 2010).<sup>4</sup> Hibbard and Peters (2003) note that in the arena of health and care, it usually involves multiple and unfamiliar information including: technical terms; and comparisons of numerous unknown variables without the knowledge of how to weigh the importance of each; while still considering personal needs, values and preferences<sup>3</sup>. The challenge then is to avoid simply overloading

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<sup>1</sup> See NHS National Patient Survey Programme: <http://www.cqc.org.uk/content/surveys>

<sup>2</sup> Available at:

[http://www.scts.org/userfiles/resources/634420268996790965\\_SCTS\\_Professionalism\\_FINAL.pdf](http://www.scts.org/userfiles/resources/634420268996790965_SCTS_Professionalism_FINAL.pdf)

<sup>3</sup> Hibbard J.H. & Peters EM. (2003) Supporting informed consumer health care decisions: data presentation approaches that facilitate the use of information in choice. *Annu Rev Publ Health*; 24:413–33.

<sup>4</sup> Dixon, A., Boyce, T., Fasolo, B, & Reutskaja, E. (2010) *Choosing a high-quality hospital. The role of nudges, scorecard design and information*. Kings Fund, London.

patients with information (albeit accurate), but to ensure it is presented and targeted in a meaningful and digestible format.

One major benefit of using website content to deliver information is the ability to filter and focus information in such a way that it is not seen as overwhelming. If designed intelligently, it allows users to target those aspects of the information most important to them. Furthermore, the interactive nature of websites allows short, concise presentation of the information with the opportunity to seek further details if required.

Presently, the Society for Cardiothoracic surgery website allows users to find information by hospital and surgeon name on, for example, the range of operations undertaken by a surgeon and the overall survival rate for a three-year period compared to the national average. Information is also presented visually via graphs. Over time, the information and format has changed, but most of these changes have not been founded in an understanding of users' preferences or needs. Thus, the Society for Cardiothoracic surgery have understood the need to review the website and as such, commissioned Picker to conduct a piece of work exploring website users and potential website users' views of the website, the results of which are presented in this report.

## Research Aims and Objectives

In order to assess whether the Society for Cardiothoracic surgery website is fit for purpose, it is important to gather feedback from website visitors (previous and current), in addition to potential users. To contextualise their views, it is necessary to gain insight into patient and family members' information needs as well as their attitudes to information, including hospital level and individual clinician data. Subsequently, actionable feedback gathered about the website itself can identify whether the information is accessible and comprehensible. It can also be used to understand particular areas which may need amending to render it user-friendly and applicable as an easy and helpful tool for patients and their family/ friends to navigate to information that is most appropriate to them.

The aim of this research was to explore people's views of the Society for Cardiothoracic Surgery website content and to look at how to make it more meaningful and accessible for website visitors, particularly patients and their family members/ friends. Through a combination of qualitative methods we aimed to answer the following key questions:

- **Types of information:** What information have patients and family/friends received or looked for, and what information did they find useful or need more of?
- **Website information:** Does the website contain useful information for website visitors; and is the information presented intelligibly on the website?

SECTION 2

Methodology





## Methodology

The research employed mixed qualitative methods to gather feedback from website users' (or potential users') including patients and their family or friends

Four focus groups (n=26) as well as five short in-clinic interviews (n=9) with people likely to visit the Society for Cardiothoracic Surgery website in search for information (i.e. patients and their family or friends) were conducted, in five different locations across England to ensure geographic spread. This included Manchester, Birmingham, Sheffield and two sites in London. Participants included pre- or postoperative cardiothoracic patients and their friends or family, with no restriction on the type of procedure or when they had their diagnosis or treatment. The website is aimed at anyone who would like more information and thus the sample criteria was left fairly broad.

The interviews and focus groups explored the experiences, priorities and views of patients and their family regarding receiving information, their information needs, and their views of the Society for Cardiothoracic Surgery website. Participants were also given the opportunity to discuss what information is currently missing and to raise ideas for improvement.

### In-clinic interviews

Experienced researchers from Picker conducted 20-minute interviews with self-selecting participants following their appointment at a morning clinic at a London hospital. This included patients who were pre- or post-operative, as well as their family or friends. Participants were recruited on the day by their consultant who provided some background information and offered patients or their accompanying family members or friends the opportunity to participate. Those who were willing were introduced to the researchers who obtained informed consent before proceeding to conduct the interview.

As this was the first phase of the research, interviewers followed a short topic guide, designed to be exploratory to allow researchers flexibility to ask follow-up questions. People were asked to consider the type of information they have sought. This could have included about their condition, surgery, surgeon, or hospital among others. They were also offered the opportunity to give instant feedback on the Society for Cardiothoracic Surgery website after having the opportunity to view it on an electronic tablet device.

A total of five patients and four family members were interviewed (please see below for more detail). Consent was gained from participants before the interviews including to audio-record the discussion, and a £15 voucher was given to each participant as a thank you for their time.

### Focus groups

Focus groups are small group discussions, usually involving 6-8 participants. The discussion is led by an experienced moderator using a topic guide to maintain the focus on predetermined questions. The goal is to generate information about a carefully defined research issue. Data from focus groups help to identify and clarify underlying attitudes and beliefs about the given topic,

“teasing out what lies beneath opinion”<sup>5</sup>. Critically, unlike one to one interviews, focus groups allow participants to hear one another’s responses and to make additional comments beyond their original response as well as give the moderator and participants the opportunity to clarify their own and others’ perspectives. Furthermore, group members may influence each other by this interaction, not only between the moderator and respondent, but between group members as well. The focus group is thus not a collection of simultaneous, individual view points, but rather “a group discussion where the conversation flows because of the nurturing moderator”<sup>4</sup>.

Participants for the focus groups were recruited with assistance from Society for Cardiothoracic Surgery staff and members, as Picker do not have direct access to patients/families. Picker provided an information sheet with details about the research to volunteers, approached by Society for Cardiothoracic Surgery, to distribute the information to potential participants before/ after their clinic appointments. Those who were interested were able to ‘opt in’ to the research by contacting the staff at the respective clinics or Picker directly.

Focus groups were moderated by experienced researchers from Picker in four geographical locations across England, and each session lasted between 90 and 120 minutes. Three of the focus groups comprised between 6-12 participants; the fourth only had one participant, resulting in a one-to-one interview instead. In total, 26 patients and their family members participated in these discussions (please see below for more detail). Consent was obtained from participants before the discussion including to audio-record the discussion, and a £25 voucher was given to each participant in recognition of giving their time.

## Focus group design

The focus groups followed a semi-structured discussion guide to maintain focus on predetermined question areas and for consistency across groups, simultaneously allowing for more flexibility to ask follow-up questions based on the emerging discussions.

### 1. Stage 1 - Open discussion

Following introductions, an open discussion was initiated, whereby participants were asked about the types of information they have received, in any form, about their condition, treatment, the hospital, or surgeon. As well as any information they themselves looked for. They were also prompted to consider any information that they might have wanted or would have been useful to know prior to, or after their procedure.

### 2. Ranking Exercise

A ranking exercise was used to facilitate discussions about the type of information participants have found or would find useful. Participants were presented with six indicators for individual surgeons written on separate index cards, as well as a stack of 14 indicators about a hospital. Stacks of cards, containing the indicators in random order, were distributed to each participant. These were based on what is currently available on the Society for Cardiothoracic Surgery website as well as others that could potentially be available in the future. Participants were individually asked to rank the importance of each indicator based on what they would find useful or important

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<sup>5</sup> Patton, M.Q. Patton, M. Q., 2015. Qualitative research & evaluation methods: Integrating theory and practice : the definitive text of qualitative inquiry frameworks and options (Fourth edition.). Thousand Oaks, California: SAGE Publications, Inc

to know, followed by a discussion of their choices, facilitated by the researcher. The ranking exercise for details about the surgeon was conducted independently from the information about the hospital. The list of indicators are presented in Appendix 1.

### 3. Website information

Finally, participants were provided with content from the website. A mock consultant’s profile was presented, as well as a mock hospital profile. These included all the relevant information available on the website in the format that it is presented. The discussion aimed to elicit participants’ perceptions of the web content, particularly in light of the ranking exercise, to explore whether their opinions remained similar. This phase also addressed perceptions of the intelligibility of the information, such as the presentation of graphs.

### Ethics

All fieldwork complied with the Market Research Society Code of Conduct (2014). The proposed project was submitted to Picker’s internal ethical review and was peer reviewed. Ethical approval was not required for this project in line with the Health Research Authority guidelines, as participants were not randomised and there was not intervention which changed patient treatment or care pathways. The project has been recorded on the organisation’s research register database.

### Demographics

A total of 35 individuals participated in the focus groups and in-clinic interviews. Table 1 gives a summary of the profile of participants.

**Table 1: Interview and focus group participant demographics.**

Respondent Characteristics	Number
<b>Gender</b>	
Male	n= 19
Female	n= 16
<b>Patient or Family</b>	
Patient	n= 24
Family or Friend	n= 11
<b>Operative status of patient *</b>	
Pre-op	n= 6
Post-op	n= 29
<b>Experience of Society for Cardiothoracic Surgery Website</b>	
Yes – Previous experience	n= 5
No – No previous experience	n= 30

*\*Where a respondent is a partner or family member of the patient, the patient’s status is reported.*

## Analysis and Reporting

Audio-recorded interviews and focus groups were transcribed with personal details (such as interviewee names, or consultant and hospital names) anonymised. Researchers initially followed inductive analysis whereby they familiarised themselves with the transcripts and conferred to identify initial themes emerging from the data. Following this, a framework was developed in which data from the transcripts were coded and synthesised allowing researchers to look both across and within individual cases to explore themes. The framework was dynamic and fluid allowing for subsequent themes to emerge as researchers coded the data.

Findings from the thematic analysis were used to identify key concepts and patterns. Verbatim quotes are presented throughout the report in *purple italics* followed by their gender, their surgical status (pre- or post-op) and whether they participated in an interview (IN) or focus group (FG). This is to illustrate certain viewpoints, particularly where there was broad agreement about an issue. Although where there are differing views, these are also presented. It is important to remember that the views expressed do not always represent those of all participants.

## Limitations and Context

The research was designed to be exploratory to understand patients and their friends/family's views of the Society for Cardiothoracic Surgery website: to surface any gaps in the information provided as well as the intelligibility of the content. There are a few important contextual factors and limitations to consider when interpreting the results from this study:

- Most patients were postoperative following successful surgeries. Furthermore, almost all postoperative patients reported being healthy or recovering. Participants' self-reported positive experiences per se could have influenced their perspectives of their (or their family member's) care and treatment. This, along with the fact that the study relied on recall for parts of the discussion, is a limitation to the study. Furthermore, those who were preoperative were in the minority (only four patients).
- Only a handful of patients had come across the Society for Cardiothoracic Surgery website prior to the focus groups or interviews. Of those who did, most had only visited the website upon being invited to participate in the current research. Therefore, a lot of the discussion was hypothetical and retrospective as to whether participants may have found it useful. Furthermore, views of the website were mostly based on the mock score cards or profiles presented to participants during fieldwork.
- The website changed mid-way through the fieldwork. Although the core information was similar, some of the presentation of the information changed. Thus the report looks to reflect general views of the type of information that participants highlighted as useful or not (including those on the website or in the pipeline). As well as generalised views on the presentation of information, such as the graphs.
- Lastly, the researchers are not experts in website design or data visualisation. Thus the report draws on some literature of presenting health information, but primarily presents the views of participants, rather than making practical recommendations.

SECTION 3

Results



## Results

The interviews and focus groups with patients and their friends/family provided insight into their information needs, including views on different sources of information, on the type of information people find most important, and their perceptions of mock website content.

## Open Discussion

The first half of each focus group followed a loose structure, during which participants were invited to describe:

- The nature of the surgery they had undergone, and their associated care experiences;
- The information they had received before, during and after their surgery;
- Any information they had sought out independently;
- Any types of information they wished they'd had access to before, during or after their surgery.

The following sections of the report explores participants' background experiences and the information they had been given or sought out unprompted.

### Background experience of care

The focus groups revealed participants' initial attitudes to and preferences for information. The majority of participants had successful treatment and as such held positive views of their care and treatment. Many recalled feeling frightened and subsequently were incredibly grateful to the medical teams who 'saved their lives'. These feelings coloured initial discussions and permeated throughout the group conversations, however as is explored in subsequent sections, the focus groups allowed the moderator to tease out underlying opinions and attitudes.

Almost all participants (with the exception of six) were post-operative and reported successful surgeries. For many then, their initial general views about their care and the clinical staff, were very positive.

*"Just want to tell you that here all the doctors and the team, and the nurses were so kind and so good. So for one year I was here and it's amazing, I don't know how to appreciate them, so good... I was just happy to be here as well in the hospital." (Female, Post-op, IN)*

*"It was absolutely superb, the standard and the care, the way people treated you, because they respect you." (Male, Post-op, FG).*

When recalling the time prior to receiving the surgery, and immediately after, a number of people described feeling "very frightened" and experienced a "loss of control".

*"I was there for a week...I couldn't go out, I couldn't move, in case I blacked out. Very, very frightening." (Female, Post-op, FG)*

*“It’s only the second time in my life, I’m 65 that I’d ever been in hospital, and I was scared to death. Really, really frightened.” (Male, Post-op, FG).*

*“I think it’s the fact that you live your life as a married couple, you bring your kids up and you’re in command, you either work for somebody or you employ people and you’re in command of the situation. When you walk through that door you’re not. You’ve got to put your head round the fact that the person or the persons who are dealing with you are a team and whatever they tell you to do, do it. You’ve no control over it. If you try to control it, you’ll make yourself ill.” (Male, Post-op, FG)*

Many of those patients who had already had their surgery were thus incredibly grateful to the consultants and the medical teams, some recognising their life was saved by those who treated them.

*“Mr Z saved my life. That’s all I can say on the matter.” (Male, Post-op, FG)*

*“I owe my life to Mr W without any doubt whatsoever. He was brilliant.” (Male, Post-op, FG).*

The feelings of anxiety and vulnerability amplified participants’ reliance on those who were caring for them and many noted complete trust in consultants. Not only in their expertise and skill, but their faith that “at the end of the day” the consultants want to provide the highest quality care.

*“See the thing is no doctors come to work to do a bad job. They come to work do their best.” (Male, Post-op, FG)*

*“That’s the good thing because here they actually want to do the job that they’re paid to do. They want to be a specialist. They want to maybe do a bit of research while they’re having a poke about that’s fine. But they want you to recover... [at some hospitals] all they want to do is just do and go. Here it’s different.” (Male, Post-op, FG)*

*“This is why we rely on them because you don’t stop and say, well, do you wash your hands before you go in? Do you make sure your knives are sharp? You don’t do any of that. You just take it for granted that they’ve got all the equipment, and the training necessary, and it’s like when you take your car to the garage. It’s a leap of faith, isn’t it? You come in because you’re poorly, especially if you’re really poorly, and you don’t know what’s happening, you have no choice anyway, have you?” (Male, Post-op, FG)*

Several respondents (patients and family members) spoke of the shock at how quickly events unfolded, particularly for those whose surgery proceeded as an emergency.

*“I dialled 111 because he was sort of restless and he was sort of pacing, sitting down, lying down, up again, then pacing around, saying I can’t get, comfortable. So I thought, something is not quite right and I dialled 111 and before I could put the phone down the ambulance was outside. They had blue lights” (Female, Partner of Post-op, FG)*

*“On the Friday eleven o’clock he said well [sir] you’re going to blah, blah, blah and he was talking to the nurse, and she said right [sir] we’ve got this and something about tunes, and I thought [I’ll] go home a couple days rest ... I was in the next day, a Saturday”. (Male, Post-op, FG)*

There were a few participants who recounted less positive care pathways. Two in particular detailed that they were either not offered surgery initially, or were told it was elective. In both of these specific cases, the patients were urged by friends and family to seek second opinions and subsequently received treatment they felt was appropriate, and had positive outcomes. Their experiences too influenced their view of and need to seek out information.



*"[At first] I didn't get any information. But anyway [initially] I accepted and I asked about the prognosis and the prognosis was not very good in terms of this and I went home. And they said you are on medical treatment no operation, no stent. I went to home and I was talking to people and they said you shouldn't accept this...you should go for a second opinion." (Male, Post-op, FG)*

*"I count myself extremely fortunate, because who knows, I might still be at home now and I'm going to be deteriorating, I might have a heart attack and die, as a result of it not being done, but I know it's purely speculative, I mean, who can tell?" (Male, Post-op, FG)*

## Attitude to and preferences for information

Before describing the types of information patients and their family sought and received, it is necessary to explore participants' attitudes to and preferences for information, which emerged as a strong theme across all focus groups and interviews, even though this was not specifically sought during the research. This is an important theme to highlight as it assists with interpreting the findings from those initial discussions, as well as the reasons for them holding certain views. Furthermore, it serves as a baseline when examining if and how participants' perceptions changed over the course of the focus group.

### Did not want or need information

The positive experiences of most participants permeated throughout the discussions and as such initially shaped or coloured their perceptions on receiving and seeking information. That is, as participants were considering the types of information they wished they would have received retrospectively, having had a positive experience may result in them perceiving any additional information would have been unnecessary.

Several participants described that they did not seek additional information because of the confidence they had in their surgeon's expertise.

*"To me when I had mine, I wasn't into all this literature and all this stuff, all I wanted to do was get it over with and home. No paperwork or anything. I knew my surgeon, he introduced himself and told me what he was going to do. As far as I was concerned I said do it, that's it." (Male, Post-op, FG)*

*"I just took my surgeon's advice and I trusted him what kind of valve. I didn't research it all. I go with what he says really. He's got the experience doesn't he?" (Male, Post-op, FG)*

*"[I did not look for information] not too much because we had a lot of confidence in the doctor and all the team also. Not much." (Female, Post-op, FG)*

One participant's anxiety made it that he did not even want to know from his surgeon the specifics of what would happen during surgery, reporting that he was confident that the doctors knew what they were doing.

*"[W]hen I came in and I was terrified he came and started explaining what he was going to do...I said "with all due respect I said I really don't want to know...Give me the form and I'll sign it. Anything you find wrong put right. If I wake up it's a bonus". I said I do not want to know what and how you're going to do it."(Male, Post-op, FG)*



Furthermore, participants stated they relied on personalised information from the healthcare professional as each case would be different and that general information online or feedback from other post-operative patients would not always be specific to their situation.

*“There’s no two that are identical. Don’t judge what somebody tells you, that’s going to happen.” (Male, Post-op, FG)*

*“I don’t think we realised how big the operation was for the by-pass. Because on the internet it says that he can be driving in six weeks. And we’ve just been told it will be four to six months. On the internet it was six weeks, is that right? The internet isn’t as informative as, or makes it look as bad as what we’ve just been told, or serious as what we’ve been told.” (Female, Family of post-op patient, IN)*

In one focus group, almost all of the participants were so confident in the information they had received from staff, (including surgeons and nurses) from diagnosis onwards, they had not felt it necessary to seek out any additional information about the procedure. In this instance, a peer support initiative was in place, whereby those who had recently had heart surgery met with patients pre-operatively to talk to them about what to expect.

*“...I’ve been explained everything by the surgeon. I’ve also been to this meeting [with patient volunteers] and quite honestly, I don’t need to know anything else. Everything was more than covered.” (Male, Post-op, FG)*

### **Wanted information**

However, even when patients reported they did not want or need information, most family members stated they wanted as much information as possible, particularly in order to care for their loved one, and to understand any potential side-effects post-operation.

*“I researched everything I could find. I really wanted to know. I did look at some of it because the problems that he had afterwards it affected his heart quite badly because he’s had these two ops, he’s had problems with heart. And [he’d explain] ... how his shoulders were, how his ribs hurt, and then I’d explain to him “if you’ve got shoulder pain you’ve got to move”. I like to know everything me, a bit like that.” (Female, Partner of post-op patient, FG).*

Some family members discussed the importance of the clinical information they received, in reassuring them. For example, resources describing aftercare and what to expect following an operation were seen to be helpful, since they detailed what is a normal experience and what is a warning sign that might require further action.

*“You go... on the internet because ... you don’t know what to expect, you don’t know what’s normal and what’s not normal. People go, “oh yeah that’s normal”. But to you it isn’t. Because people say ... “oh you look really well”, and then you think, well I don’t feel it ... So you’d like to look it up to see if it’s normal”. (Female, Partner of post-op patient, FG).*

Patients who had undergone a similar surgical intervention or procedure prior to this one tended to be more confident in asking questions of their doctors and nurses, particularly questions about the care and treatment.

*“... I felt I was very well served by doctors and nurses in terms of what I needed to know. I think because it was second time around I already knew a fair bit and maybe I asked a few more pertinent questions of the nurses and doctors and surgeons.” (Male, post-op, FG)*

Some other reasons patients and family members described why they wanted access to information included:

- They wanted to know what was happening to their own body, or to understand what their partner was experiencing;
- They were given treatment options and they wanted information to make an informed choice;
- They did not necessarily agree with the treatment options they received and wanted a second opinion.

### **Hospital and Clinician-level information**

Only a few participants raised that they had purposefully or actively sought information about the hospital or clinician. When discussing information about hospitals or individual clinicians during the unprompted open discussion, participants deliberated a range of reasons for this, including an unquestioning faith in the clinician, as well as the clinicians instilling confidence in patients (which emerged as a significant factor).

*“As far as I’m concerned, you know, he obviously knew what he was talking about, we shall just go along, which I have done all my life with whatever the consultant has told me to do. I’ve had loads done and it’s never gone wrong. So, I’m quite happy at taking the consultant’s advice.” (Male, Post-op, FG)*

Reliance on referrals from other clinicians who they trusted also emerged as a reason participants did not necessarily seek out information about the healthcare professional or hospital.

*“I mean a big part of the way things work is recommendations and trusting people’s recommendation, so if you’d gone through a GP or another cardiologist.” (Male, Post-op, FG)*

*“I didn’t need to research Mr X because the girl, who does my blood because I’m on warfarin, used to work here and said he’s absolutely brilliant, you just don’t need to worry.” (Male, Post-op, FG)*

*[Did not look for information on the hospital] “I think it was my mother said, when I told her I was here, she said that’s a really good place to be, apparently. Myself I didn’t kind of check on it, but I have seen their website but I just...I didn’t not at the time.” (Male, Post-op, IN)*

Some attendees also reported that they had received treatment or surgery very quickly following an emergency admission. Under such circumstances, it was not possible to research the hospital or surgeon, even if they were so inclined.

*“I came in on a Tuesday and I didn’t go home for three weeks. They found a large tumour inside my heart, which I had no idea I’d got. No idea at all. Never spoke to him [the surgeon] never got the chance it was all a bit quick. But it was marvellous.” (Female, Post-op patient and partner of post-op patient, FG).*

Those who had not undergone emergency surgery also highlighted time pressure as a reason for not seeking out information about surgeons or hospitals. Their priority was the surgery taking place quickly, and they did not want to delay treatment by looking around for different surgeons. Similarly, the perceived delays in receiving treatment if they were to question or request alternatives based on their research was off-putting.

*“When you’re actually ill, the first thing you’re going to look for is who can fit me in quickest, and they’ll do it.” (Male, post op, FG)*

*“At the consultation they never ask what hospitals you want to go to. And when you have to go online and go to it, it becomes a much longer process. So you almost feel I might as well just stick with it because I’m in there.” (Female, Family of pre-op patient, IN).*

Relevance of the information, given the perceived or real lack of choice, was also raised as a barrier to seeking out additional information. Similarly, a few participants stated that they did not know who the consultant performing the surgery would be prior to the procedure, particularly where their surgery dates were changed a few times.

*“There was no option given. There was no option, no “would you like to come here or would you like to transfer to a heart specialist in [Hospital]”? So yeah that would have been a good point to have asked but they don’t, they never do.” (Female, Family of pre-op patient, IN).*

*“I did not know at the time [who the surgeon would be]... That changed because my appointment got cancelled. So I think it was somebody called Mr x something initially, and then in the end I think was Mr X in the end. I think but meanwhile obviously it was going to be someone different. [I was not informed each time who the consultant would be]. Not until they came around. Not until they came around and said it had been changed, yeah.” (Male, Post-op, IN)*

Others felt that such questions would not be well received by their surgeon, and one participant also feared he would be seen as causing trouble if he started asking questions or looking for information.

*“Sometimes some of the surgeons don’t like it when you ask all these things, what is your complication rate, what is your survival rate. How many patients have you operated on... they get a bit irritated by you asking too many questions. And sometimes there is no time” (Male, post-op, FG)*

*“I am just waiting to be dealt with. I don’t want to be a shop steward and cause trouble.” (Male, Pre-op, FG)*

Understanding participants’ background experiences and their initial reactions to questions about seeking information reveals the underlying perceptions that participants brought to the initial discussion. This informs interpretation of the unfolding conversation. Furthermore, while the focus groups can’t claim to be representative, these viewpoints could be present in the wider population, and as such provide some insight into how people may view and engage (or not) with certain types of information. Interestingly, some participants’ attitudes changed during the focus groups as they conversed with fellow members, particularly after being provided with the index card prompts and the mock website material. This is further discussed in the “Society for Cardiothoracic Surgery Website” section below.

## Types of information: Sources, Format and Content

During the opening discussion of the focus groups and the interviews, attendees identified a few key types of information they had received or sought themselves. These were from a range of sources, including healthcare professionals, friends and family, as well as the internet and printed material. The type of information participants received or sought, and the source of each, is described in more detail below, along with a summary of patients' views on the usefulness of each type of information. Examining the types of information and the format participants note as useful (or not), assists with understanding how information could and should be presented to ensure it is accessible to patients and their friends or family.

### Condition and Treatment

The primary type of information that participants reported receiving and actively seeking was clinical, including about their condition, symptoms, treatment and the surgery.

#### Healthcare Professionals

As to be expected, most focus group attendees mentioned receiving information about diagnosis, treatment options and the nature of proposed procedures from conversations with healthcare professionals, which they felt positive about. Some described the use of diagrams or drawings to explain the clinical procedure in more detail, which participants found very useful. Patients and family members could also attend group seminars where they received visual information and had access to nurses to ask any questions.

*“So, when she came to talk to me before this, did one of her beautiful drawings of the heart and head and feet and explained, she explained exactly the way it worked.” (Male, Post-op, FG).*

*“The seminar that we came to last week, where they showed us the valves and the heart and everything, was absolutely brilliant – first-class. If you wanted to watch, exam, after they'd spoken to you, they asked you to stay back, because some people are obviously a bit squeamish, and we did, and again we had at least another half hour of the nurse's attention.” (Female, Partner of Post-op, FG)*

In some cases, the patient had been directed towards other resources that would give a more detailed and visual explanation, such as the British Heart Foundation or NHS websites which they also found useful.

*“When I got diagnosed, my consultant also done some drawings for me, hand drawings and explained it and wrote down what it actually was, and said Google the British Heart Foundation...and it'll give all this information about [what] you've got. So that's where I got all the information from, booklets, videos, and you can actually go to YouTube and watch the procedure being done.” (Male, Post-op, FG)*

#### Online information

A widely discussed source of information was the Internet. Some patients reported that they had googled their diagnosis/ condition. The information generated by these searches came in a number of forms, including websites and videos, most commonly from the British Heart Foundation and NHS websites.

*“All my research was done on the British Heart Foundation because I found their website, especially doing searches and their information packs and you can get hard copies of them, was very, very helpful and even videos so that patients' can understand.” (Male, Post-op, FG)*

Some participants described having watched videos of the kind of surgery they were going to have (including one interview participant who had watched online videos by his surgeon, teaching students about the surgery). For those who had used these, the benefit of such videos was an in-depth knowledge of exactly what would take place, and a clearer understanding of how they might expect to feel.

*“[I]t was really good...I see (sic) everything and I could see how they open the ribs...so when I went for my operation they said is there anything you want to ask. I said no I've seen it all. And I'm actually quite happy to know what was happening to me because then afterwards you know how to look after yourself” (Female, Post-op, FG)*

However, many participants felt that they would not be able to watch such a video, whilst others felt comfortable doing so only after they had undergone the procedure.

Whilst online information was valued for being quickly and easily available, there was still a desire to access particularly relevant resources in printed form.

*“That's one of my questions, on [the Society for Cardiothoracic Surgery] website, I didn't see this anywhere. Could you press, please send me, in the paperwork, I didn't see it? - but it did say printable version, but I haven't got a printer at home so I couldn't print it out either, but it did occur to me that, if you're not on the internet, an interested individual, you could just say, I want this - please send me this section, that would be useful.” (Female, Partner of Post-op, FG)*

## **Booklets of Leaflets**

Booklets or leaflets were most commonly used to give patients information about their condition, the procedure they were going to have or their treatment options, with further detail than what was discussed in person with them. One specific document mentioned was the 'blue book', which participants described as giving them useful information about each stage of their procedure.

*“They give you the book, you know what it is, it explains from the beginning to the end, what happened, what they've done, showing you pictures.” (Female, Partner of post-op patient, FG).*

*“[The blue book] tells you what you need to expect as far as you need to see. The fact that won't sleep is perfectly normal. It gives you a lot of information about how you should or most people feel that you'll probably get depressed.” (Female, Partner of Post-op, FG)*

The British Heart Foundation's leaflets and booklets were also described as being helpful, as they were comprehensive but presented in language that was clear to those without a medical background.

*“[I]t's comprehensive. I think they're very well put together. They're usually comprehensible to a layman, which is the point” (Male, Post-op, FG)*

Some participants described being given a lot of printed information prior to their operation, which meant that they did not always pick up on every piece of information within these booklets/ leaflets

that was relevant to them. Others said that they were less likely to read printed information, particularly if there was a lot of it, than to watch a video, for example.

*“I was given these flyers and things and stuff. I haven't read half of the stuff I've been given, where the videos you just sit down and watch, it's like TV.” (Male, Pre-Op, FG)*

## **Advice & Reputation**

### **Friends and Family**

Although participants did not necessarily actively seek out information about the reputation of certain hospitals or clinicians, many noted that they received such advice from friends or family. These conversations generally covered treatment options that the patient needed to choose between (e.g. whether to have a mechanical or tissue replacement valve) as well as the reputation or previous experiences of different hospitals.

*“I don't think I'd have been happy having the operation done at [Hospital] because [Hospital] has sadly a reputation, and I have looked at that and I thought I'm not going to [Hospital], people said don't got in [Hospital], whatever you do don't go in [Hospital].” (Male, Post-op, FG)*

*“We had a choice to choose the hospital. We selected this one in here because it specialises in heart operations...Friends and other relatives had used this hospital and they were happy with that.” (Female, Post-op, IN)*

Others had spoken to friends or family members who had had similar surgery and who gave them advice about what to expect.

*“I had a friend who had a very similar operation done and he said, whatever you do when you wake up, ask for a comforter... it's a towel, a soft towel that they roll up and if you want to cough or sneeze put it across your chest, or across and that makes all the difference. And you listen to that bit...” (Male, Post-op, FG)*

In some of these cases, those friends and family were also healthcare professionals who the participant had approached for advice in a more informal context.

*“...you know, if you happen to know a cardiac surgeon... the normal thing would be to call somebody that you know and trust.” (Male, Post-op, FG)*



## Rehabilitation and aftercare

Primarily, both patients and family members expressed a desire for more information and warning about rehabilitation and aftercare. Many felt unprepared for what to expect, how they would feel, or how to care for a patient after their surgery. Box 1 provides some views from participants.

### Case Box 1: Wanted more information on Aftercare and Rehabilitation

*"I think they thought about that the operation would fix him and that would be that but as long as he's alive that's all that bothers me but then like you say the after bit the warfarin is a nightmare, the warfarin... I have to say to him, oh have you taken your pill like I do... but it is 3 times a day and, he has to take blood every week... You think it's fine you don't know there more too that, and that's what we didn't get explained. I think he should have known more about that." (Female, Partner of post-op patient, FG)*

*"The bit they don't tell you is how incapacitated you are after... It would stop stress...you've got a catheter in which you think, oh my god what do I do, and without being rude you worry about going to the loo for something else, but you can't but they tone you down, but then it's movement, moving your legs or trying to sit down. Just any form of movement hurts and they don't tell you that." (Male, Post-op, FG)*

*"[T]he information for aftermath is something we all need to know...they all say absolutely everything for what you are going to go through for surgery, but they don't give you information what to [expect] [B]ecause everybody's individual but there are some ground rules you can expect to feel this and this and this, don't panic. After the operation ... even in two months, you get strange feelings and pains coming... I never knew. And all these things was happening to my body, I was just panicking...This is something I think is very important." (Female, Post-op, FG)*

## Other information

Other patients felt that they were lacking more practical information about their time in hospital, such as what the parking and visiting arrangements would be.

*"They did show me intensive care where I would be but she didn't tell me all the visitor's information, how the restrictions would be, how long you could have was very limited... what you could or couldn't do."*

One patient described confusion about the role that different teams at two different hospitals fulfilled in providing his care; whilst he was ultimately able to get a clear explanation of this, he would have liked it to have understood how the care pathway and organisation of services worked, sooner.

*"And I couldn't understand why one test was at [Hospital 1] and another at [Hospital 2] because nobody explained anything to me. So I asked obviously, why are we duplicating? Why am having a scan and an ECG because to me it's the same? "Oh, no, no. Your surgical teams at [Hospital 1], your medical team are in [Hospital 2]. So [Hospital 1] treat you for any anomalies with your surgery but we'll treat you for your medication." (Male, Post-op, FG)*

## Information about Clinicians and Hospitals

In a smaller number of cases, respondents had sought out information about the Trust or surgeon providing their care. No-one had been given this information spontaneously. These patients described the kind of information they had looked for in the open discussion portion of the groups, as well as where they had found it.

One patient had done fairly extensive research about hospital trusts who provide the procedure he needed, having had a negative experience with his local trust. In making his decision, he took into account each surgeon's survival rate and patient outcomes, as well as infection rates at the Trust, before deciding to seek a consultation there for his procedure.

*"...I did for my research that is the best centre in Europe. I would say the best in the world, one of the best. The outcome is fantastic. I was able to go through all the surgeons...what their outcome is... the complications...the care package, with all the surgeons and what they do, the outcome, complication rate, MRSA rate, everything. So I was happy, in April [they] did some tests and June I went to see the consultant..." (Male, Post-op, FG)*

Another participant, the wife of a patient, had looked at feedback from other patients about her husband's surgeon online. Whilst she had already had a positive impression of the surgeon, the positive ratings online serviced to confirm this.

*"He was amazing really, because we didn't realise how amazing he was. He was good but until we actually sat down, even my 20 year old he was coming out and saying mum, don't worry dad's got the best surgeon here in the world. Look what they're saying about him." (Female, Partner post-op patient, FG)*

Before the ranking exercise was introduced, prompting those who had not sought out information about the hospital or surgeon to consider this information, did reveal that a few would have appreciated seeing information on the surgeon or hospital.

*I think so. If I go back...I think if my dad was to go on the internet and see this is the man that's going to be doing my operation, I think he would love to be able to read all about him. So I think yes he would. (Female, Family of pre-op patient, IN).*

When prompted to consider the types of information they might find useful, several participants who did not look up their surgeon or hospital, spontaneously expressed views retrospectively about the kind of information they might have wanted.

The majority of these participants commented that, were they to have done research about their surgeon, they would have wanted to know that they were being cared for by a specialist in the specific procedure they were having. There was a general agreement within one focus group that they would feel more confident knowing that their surgeon was a specialist, rather than a generalist. One interviewee also noted that this was the key information they sought about the clinician, that is, that they specialised in the type of procedure they required.

*"You don't want a doctor who can do everything, you want one that specialises in that rather than everything. They might be brilliant but you want someone who does exactly..." (Female, Partner of patient, FG)*

*"[B]asically he was one for the valves. Specialises in valves...So we went for that." (Female, Post-op, IN).*

*"I think it was just probably the experience of what the surgeon had had on that specific operation." (Female, Family of pre-op patient, IN).*

Others felt that information about the surgeon's training and education as well as their years of experience was important.

*"We were looking at his, more or less his education side of it. And his research, there's quite a lot of research, he's involved in that." (Female, Post-op, IN).*



*“I think frankly someone who’s got superb training and qualifications, and that’s actually where, where they’ve done their training, and has done this bloody thing a thousand, two thousand times. It’s terrible important, but because I’m very old, I naturally think that the experience is hugely important factor, and therefore I’d like to know that the surgeon that was doing me had done a huge number of these procedures, rather than being in the first year or two. I’d feel much more confident than somebody who’d been in some, who knows where they trained or whatever, and even if they’d done a lot of these operations”  
(Male, Post-op, FG)*

## Implications

There are a number of common features of the type of information that patients sought out or found valuable when going through cardiothoracic surgery. Specifically, information was most helpful when it was:

- **Clear** and presented in language that they could understand
- **Concise**; large amounts of information were found to be overwhelming, or only skim-read
- **Visual**; such as videos or diagrams aid understanding
- **Easily accessible**; e.g. easily found online or that patients were directed to by a reputable source
- **Relevant** to the patient’s individual case; conversations with healthcare professionals had the biggest impact on the choices patients ultimately made about their care
- **Practical**, including, for example, how they might expect to feel or side effects they might experience

Patients did not tend to seek out information about their individual hospital or surgeon, but when they did so, their focus was on finding a clinician and a hospital who would:

- be able to provide good care/ outcomes for their specific condition (rather than just cardiac care generally),
- keep them safe (both from complications with their procedure and infection).

## Society for Cardiothoracic Surgery Website information

Up to this point in the report, most of the discussions around information sought or not, was unprompted. That is, the preferences for and knowledge of the types of information available was based on participants’ recall prior to being presented with any specific guidance.

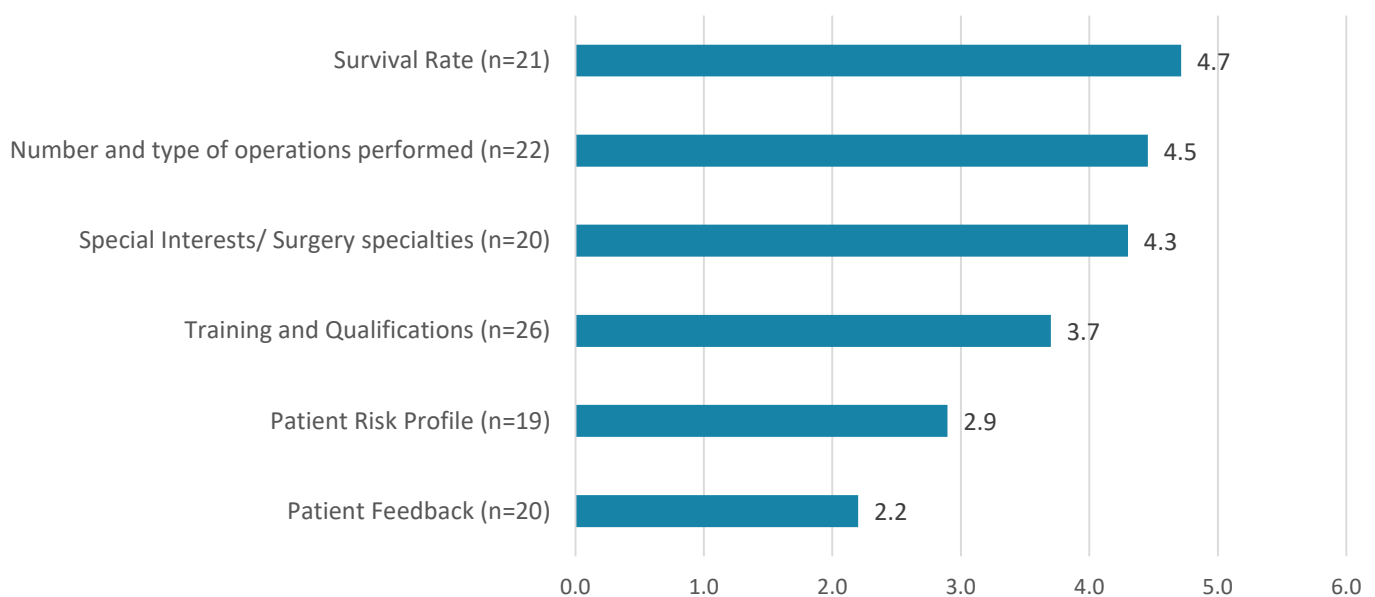
Following the open discussion, participants were presented with index cards. As described in the ‘Methodology’ section, six indicators were presented for individual surgeons written on separate index cards, as well as a stack of 14 indicators about a hospital. Stacks of cards, containing the indicators in random order, were distributed to each participant. These were based on what is currently available on the Society for Cardiothoracic Surgery website as well as others that could potentially be available in the future. Participants were individually asked to rank the importance of each indicator based on what they would find useful or important to know, followed by a discussion of their choices, facilitated by the researcher. The ranking exercise for details about the surgeon was conducted independently from the information about the hospital. The results of the two ranking exercises (surgeon and hospital) are displayed below.

Participants were also provided with content from the website. A mock consultant’s profile was presented, as well as a mock hospital profile. These included all the relevant information available on the website in the format that it is presented. The discussion aimed to elicit participants’ perceptions of the web content, particularly in light of the ranking exercise, to explore whether their opinions remained similar. This phase also addressed perceptions of the intelligibility of the information, such as the presentation of graphs which is discussed in the ‘Website Presentation’ section below.

## Ranking Exercise Results

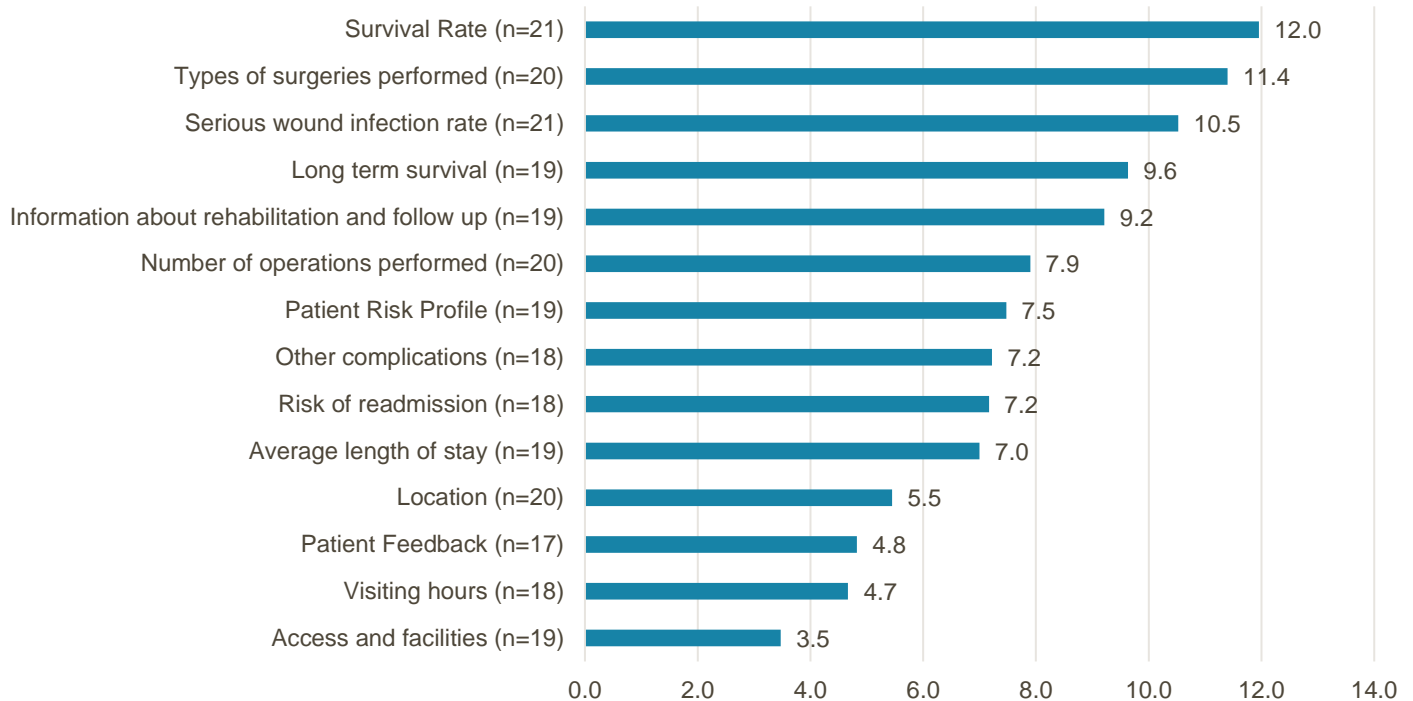
Graph 1 presents the average ranking for each “surgeon indicator” out of six, where six is the most important, and one is the least important. The graph highlights that on average, participants ranked ‘Survival rate’ as the most important indicator, followed by ‘Number and type of operations performed’, and ‘Special interests/ surgery specialities’ of the surgeon. The least important indicator was considered to be ‘Patient feedback’. The total number of participants who ranked a particular indicator are included in the graph as “(n=)”.

**Graph 1: Information about Surgeon - Average Ranking**  
(where 6 is most important, and 1 is least important)



Graph 2 presents the average ranking for each “hospital indicator” out of fourteen, where fourteen is the most important, and one is the least important. On average, participants ranked ‘Survival rate’ and ‘Types of surgeries performed’ as the most important indicators. Whereas ‘Visiting hours’ and ‘Access and facilities’ were on average ranked as the least important information during the exercise.

**Graph 2: Information about Hospital - Average Ranking**  
(where 14 is most important, and 1 is least important)



## Perceptions of information post exercise

Following the ranking exercise and viewing the mock website profiles, participants discussed at length their choices. A few key themes emerged from these discussions. Interestingly, participants' previous views to having access to this information changed somewhat from the open discussion, corroborated in the observations in the ranking exercise and the mock profiles. However, where participants found the information presented in the ranking exercise intriguing and could see the benefit of such information, many found the information difficult to understand when presented in the mock profile, and were quickly put off. Some retreated, and reverted to feeling the information, particularly about the individual clinicians, was irrelevant to them. This is further discussed below.

### Relevance of information

The follow up discussion revealed conflicting feelings about the relevance and importance of the information. After completing the ranking exercise, many people noted that it was very interesting to see and they had not thought of looking for this information before. Others felt it very important to have access to this type of information.

*"It's important to know a lot of things, it's an impact on your decision or the other. All of them are relevant and very, need to be shared with all the patients, but I think a lot of them are issues that we don't necessarily use in our decision. But I mean, it's really important that these aspects are available, should a patient wish to access them."  
(Female, Post-op, FG)*

*“At the end of the road, these are useful information and it’s good in this society having is the freedom of choice and more knowledge you have it makes it easier to choose no matter how you go about it. At least you have the knowledge. Now going to the supermarket... there are ten different types of sweetcorn so you go after the label information you go after the salt the sugar, the nuts, so I think this website and this information no matter how complicated it might be you are not used to it, for somebody very useful and for us it’s like something to give us this comfort that if we want there is a place that you can go and get information... I think this is brilliant. (Female, Post-op, FG)*

In one focus group, a few people discussed that some of the specific types information available on the website might be suited to family members rather than the patients themselves. Particularly where the patients may not want to know these details for a range of reasons.

*“Do you think, listening to us here, from us who’s actually had an operation and had it done it’s a little conciliar and let’s get it done, let’s get out of here, let’s get better. Do you not think that a lot of that information is for reassurance of your partner? As you said, you really get into detail looking at it...My wife does, as far as I’m concerned I don’t give a damn. I’m going to get done. I take it that he can do it. I’ve got to believe that because that’s what they tell me. Just looking at all this and found out the success rate was two, I’d definitely wouldn’t get it done but that would have to be something really dramatic but I think a lot of that is to console your partner. Because we’re the ones who actually have surgery whereas you don’t ask the question how good’s your surgeon until after it’s when it’s done and afterwards that you say, thank god for that.” (Male, Post-op, FG)*

Others did not see the necessity for some of, or indeed any of the categories.

*“A lot of it, I’m even not interested in the slightest.” (Male, Post-op, FG)*

*“I’ll be honest, from my point of view. A lot of the questions that we don’t even bother about.” (Female, Post-op, FG)*

*“It’s all well and good asking questions about the hospital, but if you’ve got no other choice, what can any of us do? In the end, I’d want to know, okay, well I know it’s [Hospital]. (Male, Post-op, FG)*

One couple, (where the husband had received surgery) recounted a friend’s frustrating experience of being encouraged to use the information available about individual surgeons. This friend was a private patient and it was perceived that they were required to make a choice of surgeon. However, not knowing how to use the information appropriately and being too unwell to make such decisions resulted in a negative experience.

*“In actual fact, we have a friend who had a heart problem and because she was in a private health insurance group, she asked her doctor for advice on a heart consultant in the area that she could go to, and he said, have a look on the web. Now she is into internet, and she looked on the web and got this heart consultant [in the] area, and went to see him, and within ten minutes of having this consultation, decided that he wasn’t the man for her. So, came back, went back again to her GP and said what she’d found out, could he give her any advice? - and his advice was, you’ve got to keep on looking at the stats to find who you want to go and see, at which rate she said, I can’t do that, I’m ill (which she was). Please, just send me to somebody that you can suggest, that you would under the NHS. Pretend that I’m not a private patient, pretend I’m an NHS patient, just send me. He did, and got the results, she got the results. So sometimes this isn’t as helpful as what perhaps you people think, when we are ill. We’re ill and we can’t be looking at these stats, and ignore them, it’s the same thing.” (Couple, Post-op, FG)*

## Survival Rates and Patient Risk Profile

Despite the fact that relatively few participants discussed having looked for or at surgeons' survival rates during the open discussion, this was ranked as most important by participants in the focus groups. That said, there were some disagreements about its usefulness and/or appropriateness. Those who felt this was important stated they would feel more confident about their surgery knowing that their surgeon had a 'high' survival rate.

*"You don't want to be going to somebody 50/50, you want somebody who's like 98%."  
(Male, Post-op, FG)*

Prior to reviewing the mock clinician and hospital profile, a lot of the discussion regarding survival rates hinged on participants' understanding, or misunderstanding, of the risk adjustment and the patient risk profile. Although in theory many felt they understood how it worked, there was still some debate as to how it was calculated; what should and shouldn't be factored in; and ultimately whether clinicians would change their decisions or behaviour based on the information about a patient and the publication of these statistics. Box 2 presents the conversation between two patients regarding the appropriateness of risk adjustment and illustrates the anxiety and mistrust around this topic.

### **Case Box 2: Anxiety over appropriateness of risk adjustment**

*P1: I mean he told I think he said that there's a 3% risk that you won't make it. So you got right that means that in every 100 operations he does there's a possibility that three patients could die. But if you've got a guy who won't do what he's told and you get a person who's hell-bent on smoking and drinking prior to coming here, and he's been told you're going to have to have this operation, he's not going to survive is he. It's a low chance that he's going to come outside, saying thank god, I'm wonderful now. It's not going to happen. And in the, inverted commas, failure rate, it should take into consideration and it should say people who smoke, drink prior to the operation.*

*P2: I don't think you can put that in.*

*P1: I think it should be.*

*P2: That is not how a doctor would look at it. A professional person would not look at things like that.*

*P1: But it impacts on his results don't it.*

*P2: You can't judge how those outcomes, because everyone is going to be different.*

*P1: What I'm saying if there's two patient died and they're both prolific smokers and drinkers.*

*P2: But that's a judgment against them... Other people come in that have never drank or smoked, they could be higher risk than people that you think are at higher risk that smoke and drink.*

*P1: What is the failure rate due to, and it's due to mainly cardiac failure because of... not just oh they died. That's very sad but they die for a reason. It affects the rates. If somebody's done had bad job and they've done five operations on five people who were borderline...*

In another focus group, participants also discussed their perceptions of clinicians' potential behaviour change based on the publication of survival rates. Again, there were differences of opinion with most feeling disbelief that clinicians would ever behave in such a way. A few participants acknowledged the possibility of this behaviour being a reality. Even if not employed by



individual clinicians, who some felt would be kept inline by their peers, patients suspected senior managerial staff may enforce risk-averse decision making. Case box 3 illustrates this conversation.

### **Case box 3: Discussion regarding risk averse behaviour**

*P1: I personally think that you get a hospital like this, and you get a bunch of surgeons, there's seven surgeons here, I think, heart surgeons, now I honestly believe that they talk amongst one another, and they pass information on, and I think if they're doing heart surgery, or any sort of surgery – knees, whatever, they're all interested in doing the job like doctors are, like the nurse and engineer, or whatever, except you're passing them information. If you weren't taking that on board, get out. You wouldn't be doing it. I wouldn't be in this, you wouldn't be in here.*

*P2: : I agree with you, but you're saying that if there were individuals in the surgical team, who are saying, I'm not taking him - he's really high risk, my chance of losing him is high I'm not taking him, you'd think that the group would control that or ameliorate that. So I think that's probably true as well, until you get to the very senior, people at the top of any organisation, the people at the very, very top, I'm afraid have more power. I'm not saying that's happening here or anywhere, but I think there is a possible scenario, yes, there'd be the group decision-making and people would be ousted they were underperforming, but you could have someone at the top of the tree who was more powerful, and they were controlling the group, and they could then be leaning away from the difficult cases.*

Lastly, one participant had quite strong views about clinicians who may act in a risk averse manner on the basis of survival rates being published.

*"I would find the attitude of such surgeons so completely deplorable. They would not be someone I would wish to be operated on by I mean, these are surgeons or professionals who presumably are deeply committed to doing the highest job possible and that's why I would be very, very conscientious about looking at the track records and reputation and general outlook of any surgeon who operated on either me or a member of my family."*  
(Male, Post-op, FG)

### **Training, Qualifications, Speciality and Number of operations performed**

Three indicators presented during the ranking exercise were simultaneously discussed after the exercise, namely: Training and Qualifications; Speciality; and Number of operations performed. Most agreed that these were important to know. As one participant stated:

*"Yeah, I'd like to know they're really trained in what they're doing, and on top of their job, before they get in there".* (Female, Post-op, FG)

*"Background and education and a few other things like that, which you can put your faith in that person. Yeah, background and education."* (Female, Post-op, FG)

*"No-one had told me how many operations were going on, I didn't ever ask that question, but when sort of think about it, ... I think about turnover is useful, unless you want to hear what the alternative to turnover is, it doesn't necessarily make any difference, but it would, I think, it would be useful to know how many aortic replacements per year, just because that gives you a sense of, we all want to feel positive about our surgery, we want to feel positive about our outcomes."* (Female, Post-op, FG)

Knowing a clinician's specialism was also seen as very important to patients. This information spoke to the experience of the clinician which was very important to participants. Particularly where they were performing specialised procedures.

*“I think special interest, I would make the assumption naturally that the person was an absolute specialist in this particular procedure that was being done...I think absolutely vital. I mean, it's vital that I know this person is a really seasoned bypass person, not just somebody who's doing it.” (Male, Post-op, FG)*

*“It's perfectly reasonable for a patient to want to know that the people that are interfering, with the best of all possible intentions with their bodies, are top-quality people with terrific training and a terrific track record.” (Male, Post-op, FG)*

*“[Someone might be] comparatively inexperienced, which I mean, when you're doing a routine operation that's no problem obviously, but it's the more experienced you are, when you encounter oddities, the chances are you might have seen the oddity before, I suppose.*

Similarly, participants highlighted the importance of knowing the number of operations that a clinician had performed, specifically broken down by specific procedure.

*“[They might have done a thousand operations, but actually 900 of those were something totally different]. Exactly, exactly, but I don't know what the proportion of the cardiac surgery is bypass or what is valves, and what is all the other much more exotic procedures that they do. I don't know what that is.” (Male, Post-op, FG)*

This was also true for the types of operations and number of operations performed at the hospital.

*“This information about operation is very important, how experienced the hospital has got. For example, for my liver they told me they don't have when they called me they had little experienced of liver surgeons in this hospital they had to send to me to [Hospital]. So this is something that is very important.” (Female, Post-op, FG)*

## **Patient Feedback**

During the ranking exercise, when asked to consider what information about a surgeon would be of most importance to them, there were a range of views about the importance of feedback from other patients.

However, participants did not all feel that patient feedback would always be helpful; there was a sense within one group that feedback from other post-operative patients was not necessarily accurate and, at worst, possibly misleading as they could not compare their situation to the patient giving feedback.

*“There's no two that are identical. Don't judge what somebody tells you, that's going to happen. The only thing you can be certain of here is that 99.99% you walk out. ” (Male, post-op, FG)*

Whilst some participants reiterated the value of feedback from other patients as a way to reassure themselves about the skill of their clinician, others felt that the value of this information was limited in a number of ways. Firstly, it was felt that patients were likely to be different from one another, both in clinical presentation and personality, and would therefore have different criteria for what constitutes good care, which would not necessarily be reflected in their feedback.

*“I wouldn't want patient feedback ...it's not a true reflection on that surgeon's capability ...the doctor surgeon may not come across as very sociable, [it] doesn't reflect what exactly he does...”*

*“We'd look at a few of them, the feedbacks. The feedbacks are plus and minus, any one of them. Some of them are very positive, some are negative. Maybe because they didn't*

*get, they're not happy with the hospital or something like that. Some of them. Feedback or no feedback, we decided that we are going to have operation with Mr X, so we didn't take any notice or anything." (Female, Post-op, IN)*

Others felt that the questions asked of patients did not reflect their priorities when having surgery. For example, feedback about a surgeon's personality or bedside manner did not tell them anything about their skill in performing the procedure. Indeed, one participant highlighted that good survival rate information would change their view about a surgeon who they had had a negative experience of.

*"You could...get (sic) a surgeon who appeared not to listen to you, or appears not to take your concerns seriously then you went on to the guy's website and looked at his data, the best surgeon in Northern General, what would you do?"*

### **Other information**

Although it was not ranked highly during the exercise, a few other topics that were discussed by participants included information on access and facilities to the hospital which would be useful.

*"Well, I can tell you one thing – how the hell do people get here by car? For my visitors that have come by car, they've had a total nightmare, because I think there's one road closed, and the signage to the hospital in the immediate environment, area, is apparently terrible." (Male, Post-op, FG)*

*"It was only clear from other people what the hours were. I think they were quite flexible on that though. People were coming in probably officially they weren't supposed to, but I don't think they ever threw anybody out as such." (Male, Post-op, IN)*

Participants did not see the value in knowing the average length of stay stating that this was too personal and would be different on a case by case basis. Furthermore, some recognised that they would not know how to judge or utilise this information, that is, whether a longer or shorter stay indicated good quality care.

*"I wouldn't take any notice of it personally but that's a piece of information that is in the lap of the gods. What happens to you afterwards...They told me two weeks but it was the day four I was actually singing please release me. I was actually going round the room, please release me, let me go...So length of stay, actually depends on how quickly the wound heals I think." (Female, Post-op, FG)*

One participant did note that knowing how long you might be an inpatient could assist with planning.

*"I think the average is okay. They said to me the average is for two weeks. So you think I'm in there for two weeks. After eight days he just said you're going home, you should be here you're at risk of infection. So go home. Thank you very much I'll have that." (Male, Post-op, FG)*

### **Transparency & Assurances**

One key topic that the moderators asked of participants in the focus groups was their opinion of individual clinician level data, and in particular what type of assurance would patients feel confident that the individual surgeon's survival was acceptable, that is, any specific body they would consider credible or acceptable to provide these assurances.



In some focus groups, these topics emerged naturally from the discussion. In others, the researchers posed the questions directly to the group. Most participants agreed they feel this data should be available.

*“It seems to be a backward step to take the stats away.” (Female, Post-op, FG)*

*“It’s perfectly reasonable for a patient to want to know that the people that are interfering, with the best of all possible intentions with their bodies, are top-quality people with terrific training and a terrific track record.” (Male, Post-op, FG)*

There were however, a handful of patients whose opinions were unwavering throughout the discussions: stating they did not feel the information was relevant or appropriate and that it should be kept privately for internal auditing. This was mostly due to feelings of mistrust as to the purpose of the data, that it was being used for punitive reasons rather than transparency.

Given most participants’ views that the data should still be published, as well as a lack of knowledge of the different potential monitoring bodies, there was limited discussion regarding whose assurances participants would feel were reliable. That said, one participant felt strongly that Society for Cardiothoracic Surgery is the most appropriate body as their intentions in monitoring their members came from a position of professional integrity. As opposed to being unnecessarily punitive to provide false comfort to the public as may be the case with other, politicised institutions.

*“Well, probably...people involved in the Society. It would be difficult to say for certain, but I would expect, along the assumption that the most distinguished cardiothoracic surgeons of the country are part of the leadership as trustees, as directors or whatever, the governors, I would think I would probably trust them more than anybody else because in fact, the only axe to grind that they have is the reputation of their profession, and the integrity that they have, I would make certain a lot of assumptions about it, because I think the top people are people of the highest attainment, where I think history has shown that these quango-type things, non-governmental, quasi-governmental organisation, these are the things that are set out to give comfort to the public about various societies and so forth - I don’t trust them at all, nor would I trust the management of the hospital... There is a lot of crap management in these hospitals, and if every kind of layer of management, every kind of reorganisation, every time there’s a new minister, he seems to think he needs to change everything, and then there’s all the politics and all the perception that lead to it. People’s livelihoods depend on creating the perception, an alternative.... So no, I mean I think these are the people, are probably the people best equipped with, until they can prove otherwise that they can’t be trusted, then I would have thought they would be, it would be wonderful, because they would be trustworthy”.*  
(Male, Post-op, FG)

## Website Presentation

### Overall

It is important to note that none of the participants had come across or heard of Society for Cardiothoracic Surgery or their website prior to being invited to the focus groups. A handful had looked at the website after receiving the invitation to participate in order to understand what the groups were about. In one focus group, participants presented the researcher with a brochure they had received from the hospital, in which they had subsequently noticed reference to the website. But it was felt it did not stand out enough for it to “catch their eye”, particularly when skimming through a lot of material they had received. It was also felt that the leaflet would benefit from a short explanation around the use of the website.

*“It wasn’t clear, if you see in your reference here ... I think it mentions about individual surgeons later, can be found at [www.scts.org/patients](http://www.scts.org/patients). ...that reference doesn’t sort of give the broader, it’s just sending you there to look at surgeons’ data, not to look at a patient, who mentioned, and that’s a misrepresentation...It said it was a reference, rather narrowly. That’s useful, I mean again, that means we’ve got that data, but it wasn’t giving a proper introduction to different people...It’s not eye-catching is it? No, it’s just a little tiny reference on the back page.” (Female, Post-op, FG)*

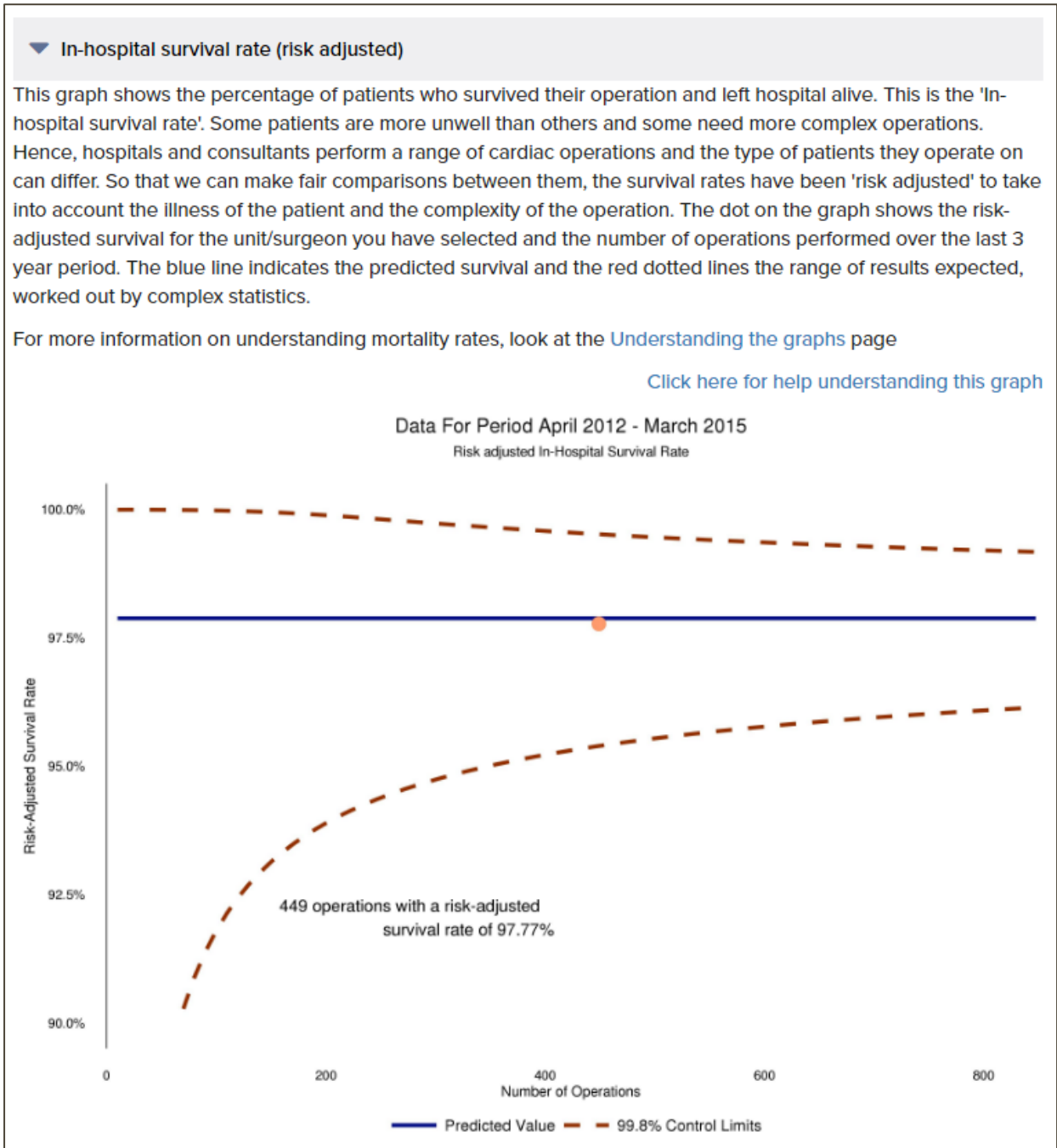
Those who had accessed the website prior to the focus group also felt that it was difficult to navigate to the “Patient” section of the website. Upon first visiting the website they got the impression that it was primarily a professional body’s website aimed at providing information for its members. Had they not known to look further, they felt they would have abandoned their efforts.

*“I didn’t find the website easy to climb into, I was probably looking for the wrong thing. Eventually I found the patient area, that didn’t help very much either.” (Male, Post-op, FG)*

### Survival rates

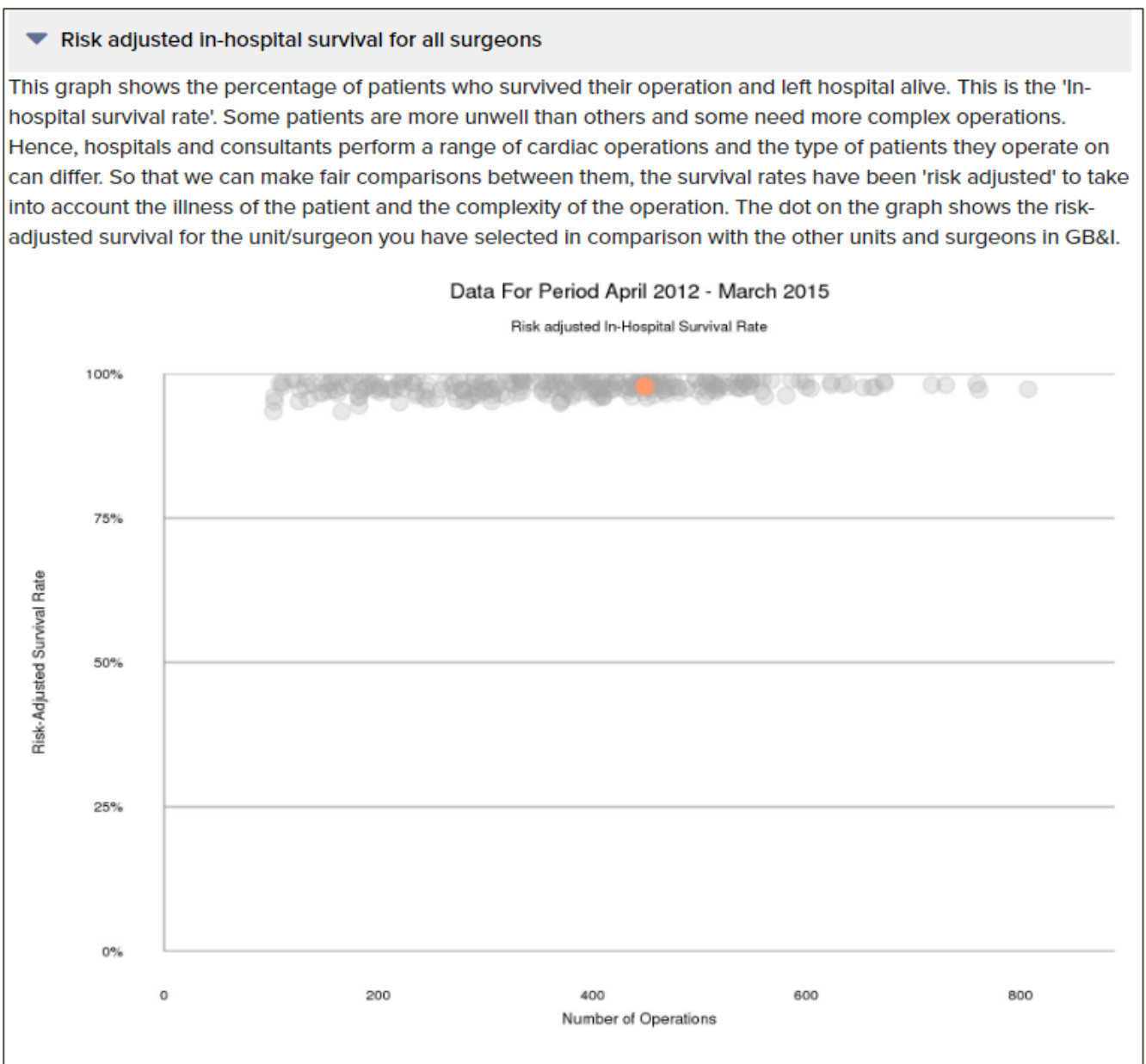
Participants were presented with two graphs from the website that detailed the individual clinician’s survival rates presented in Figure 1 and Figure 2. Many participants struggled to interpret the graph in Figure 1, highlighting that they did not immediately understand how to interpret the dotted lines. Once they read the section on “Understanding the graphs”, some felt they had a better understanding, but not all. Furthermore, participants noted that it was cumbersome to have to click to another page to get this information and they would likely skip past it. Many also commented that, as there was no basic comparative information on the graph, they could not immediately tell how the consultant in this example was performing. Not only are there no perceived comparisons other than the fact that this particular consultant fell within the expected range for the number of surgeries performed, but they felt there was no context or information on whether the number of surgeries was a lot or a little: how this compared to other surgeons. Lastly, many felt the graph lacked information about the types of surgeries performed. This echoed the sentiment described previously, that the information may be too general and not specific to their personal situation.

**Figure 1: Screenshot of Clinician Risk-adjusted Survival Rate from the Society for Cardiothoracic surgery website**



The graph in Figure 2 addressed the issue of comparability, and on the whole participants preferred this graph. However, given most consultants included in the statistics were deemed to be performing well (that is, were all clustered near the top), many felt the information was not discernible and thus not useful. Furthermore, although they did not immediately fully understand the control limits (dotted lines) from the previous graph in Figure 1, this graph lacked a baseline indicating a threshold for poor performance.

**Figure 2: Screenshot of second Clinician Risk-adjusted Survival Rate from the Society for Cardiothoracic surgery website**

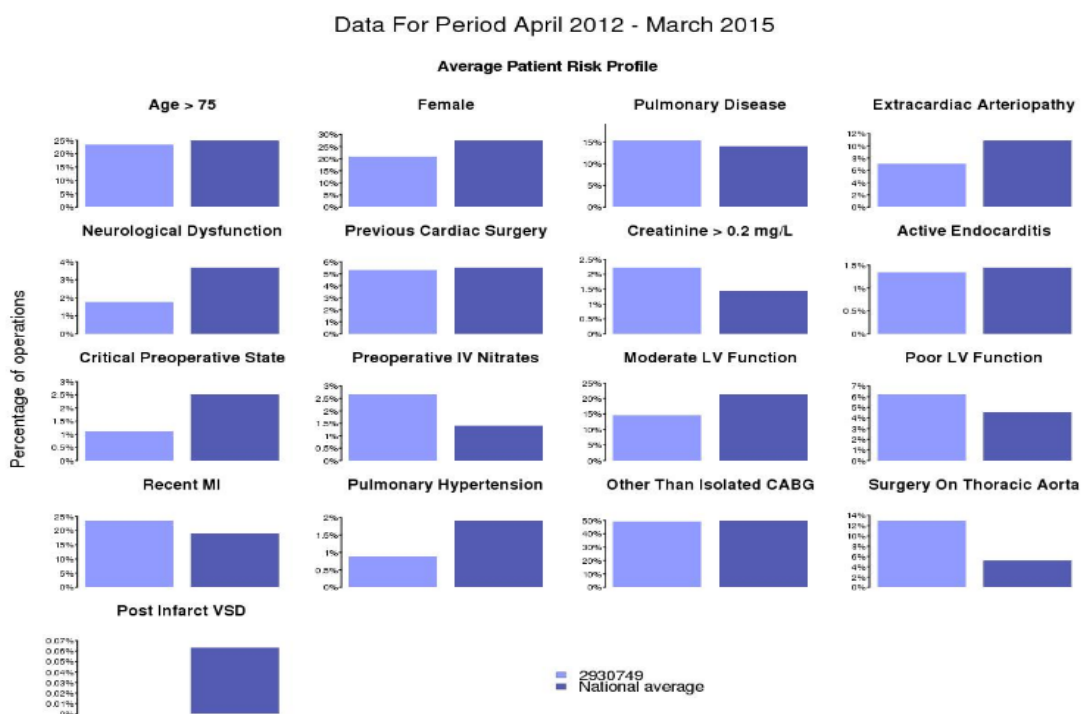
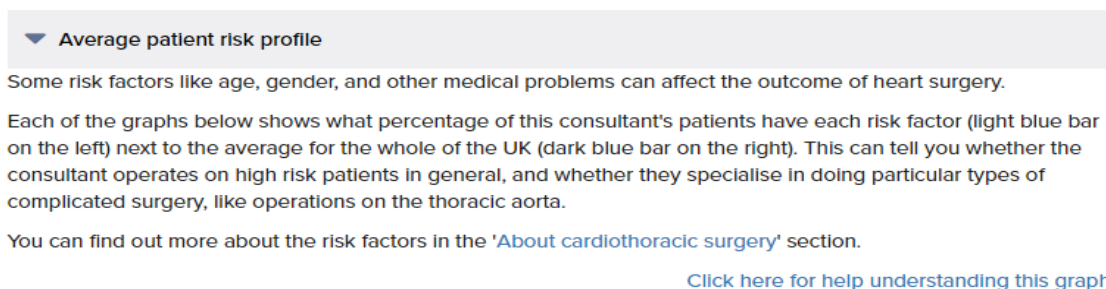


## Patient Risk Profile

Figure 3 presents the Average Patient Risk Profile that participants were presented with. As was the case after the ranking exercise, many participants did not instinctively know how to interpret the information. The overarching view was that the table contained too much information and participants quickly disengaged with the information. One participant noted that he would prefer to see the information relevant to his condition rather than an overarching summary. Others suggested that website users should be able to select criteria that are relevant to them and only view these at a single time, rather than all the information at once.

*I would obviously be very more interested in cabbage/CABG, because CABG is such a routine operation now, that in fact all the other more complex things that happen, were included in that where people, well obviously, you say it's adjusted for risk, but I mean all kinds of, what sort of all risks? I mean there's age risk, there's the other risks, but whether the actual ... The type of operation may be at variable risk. So, I don't know, but I'd love to see that in respect of my specific procedure, rather than perhaps all the cardiac work that the individual does. (Male, Post-op, FG)*

**Figure 3: Screenshot of Average Patient Risk Profile from the Society for Cardiothoracic Surgery website**



The graph presenting the number and types of surgeries performed was viewed as easy to understand and valuable information to have access to. Again participants would have liked some comparative information, for example to the national average.

**Figure 4 Screenshot of Number and Type of Operations Performed from the Society for Cardiothoracic surgery website**

**▼ Number and type of operations performed**

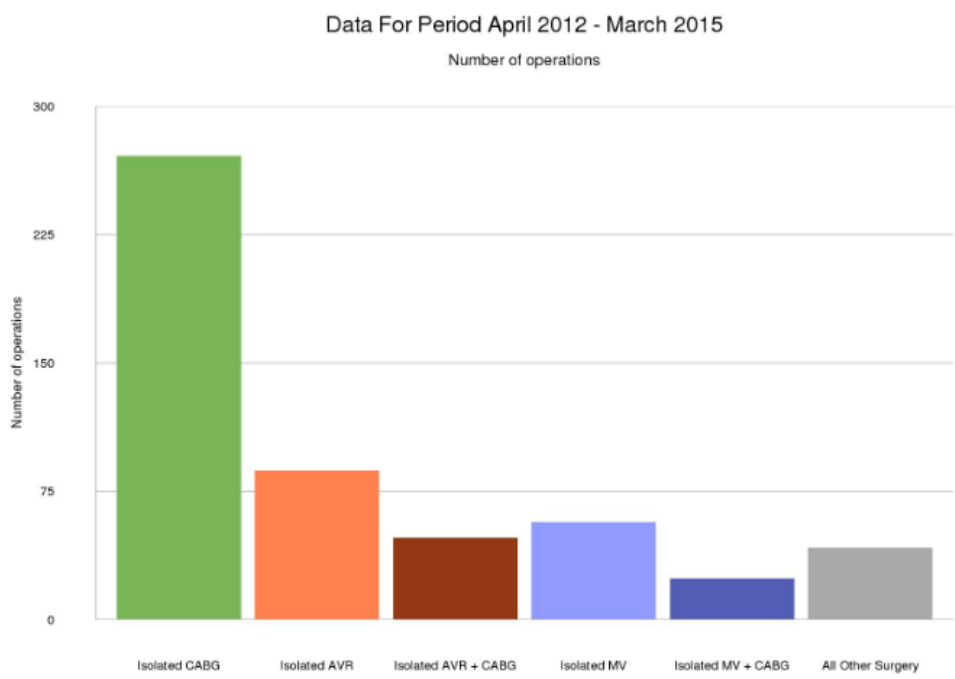
This graph shows the number and percentage of each type of heart surgery done by this consultant surgeon. The number of operations is shown in the line going up the left hand side. The percentage (%) underneath each coloured bar shows how much of this consultant's heart surgery is made up each procedure type.

The 'key' underneath the graph shows what procedure(s) each coloured bar shows. The abbreviations used are explained below:

- **Isolated:** This procedure has been carried out on its own. No other procedures were done during the same operation.
- **CABG:** Coronary artery bypass grafting
- **AVR:** Aortic valve replacement
- **MV:** Mitral valve procedure

You can find out more about these procedures in the '[About cardiothoracic surgery](#)' section. If you or someone you know is having heart surgery, it may be helpful to know whether the consultant does lots of that procedure. If you have questions or concerns about the number of procedures being done at your hospital, you should speak to your heart surgeon.

[Click here for help understanding this graph](#)





## Implications

Findings from the ranking exercise highlight that participants are interested and can be engaged in accessing and using information about individual clinicians and hospitals. However, examining findings from the mock profiles and participants' perceptions of the intelligibility of the website presentation highlights the need for some improvement to ensure the information is accessible.

- **Simple:** Participants preferred the information that was presented in a simple format, particularly graphs that did not require a lot of background reading to understand and interpret them.
- **Concise:** Large amounts of information were found to be overwhelming and difficult to interpret. For example, many disengaged from the Patient Risk Profile graph as it contained too many variables that were technical and not all relevant to them.
- **Comparable and consistent:** Participants appreciated having benchmarks to compare the information presented. For example, presenting national averages, or averages against similar types of information. The two graphs presenting Survival Rates had one comparison but not another. That is, one showed a comparison to the control limits, whereas the other showed comparisons to other surgeons. Neither had both. Similarly, although the Number and Types of Operations Performed graph (Figure 4) was easy to understand, participants felt they would like to know how this compared to other surgeons in similar positions or specialties.
- **Relevant comparability:** Many further commented that the comparisons that were provided were not useful, and more specific or relevant comparisons should be made available. For example, it would be more useful to see the Survival Rates broken down by types of operation.
- **Discernable/distinguishable:** Similarly, participants pointed out that on the second graph for Survival Rate (Figure 2), consultants all ranked really highly, which is positive, however provides no functional information as the information is not discernable (unless a specific clinician was severely underperforming).
- **Clear (no jargon):** Although participants could recognise those technical terms that were relevant to them, for example the use of CABG, many felt that the content of particularly the Patient Risk Profile graph (Figure 3), was laden with jargon. For many, the amount of detail clouded their willingness to focus on those parts that were relevant to them or that they recognised.
- **Personalised/relevant:** As noted before, participants felt the information was quite generic and they did not have the option of looking for or filtering out information specific to their situation. One person recommended creating a mechanism of clicking on those risk factors or demographic characteristics that are relevant to a specific person viewing the website, which would then provide information or statistics relevant to them.

As noted in the Introduction, one major benefit of using websites to deliver information is the ability to filter and focus information in such a way that it is not seen as overwhelming. If designed intelligently, it allows users to target those aspects of the information most important to them. Furthermore, the interactive nature of websites allows short, concise presentation of the information with the opportunity to seek (or click on more) if required.

## Conclusion

Participants had a range of experiences of care and treatment as well as attitudes and preferences to receiving and seeking information. This is an important finding to highlight for a few reasons. It reveals the viewpoints/beliefs that participants brought to the initial discussion, which firstly, informs interpretation of the unfolding conversation. While the focus groups can't claim to be representative, these viewpoints could be present in the wider population, and as such provide some insight into how people view certain types of information.

Understanding the types of information and, particularly the format participants noted as useful (or not), gave insight as to their preferences for how information could and should be presented to ensure it is accessible to patients and their friends or family. Clear, concise, and easily accessible information was fundamental, and the opportunity to have information presented visually either through drawings or videos was perceived as invaluable. Furthermore, participants wanted information that was relevant to their personal circumstances rather than generic information that could be erroneous or irrelevant.

Understanding participants' initial perceptions of receiving information provided an initial benchmark for participants' perceptions, further allowing the researchers to explore whether participants could be positively swayed or encouraged to utilise this information. This was demonstrated during the discussions as, some participants' perceptions did change during the focus groups, both through conversations with other members of the groups, and particularly after being provided with the index card prompts and the mock website material. When prompted to consider other information, such as the information available on the Society for Cardiothoracic Surgery website about individual clinicians and hospitals, people could see the benefit of it. This indicates that although participants did not intuitively consider this information, they could be encouraged to view and use this information if made readily available. It highlights the importance of making the wider population aware of the website so that people can use the information that is already available. It also highlights that, although initially people might feel they don't need the information, they can be encouraged to use it. Therefore, publicising the website and its content to both patients and their families is essential.

However, the findings from the mock profile exercise highlighted that when participants are presented with too much and/or technical information, they can shy away from it and resort to "less accurate heuristics", consistent with other research findings<sup>6</sup>. Many participants who had become engaged with the information during the ranking exercise were quickly put-off and some reverted to their initial sentiments that the information was irrelevant to them. As noted in the introduction of the report, "having an abundance of information does not always translate into it being used...the usability of information about the available options can create serious barriers that undermine these intentions"<sup>6</sup>. Furthermore, information about health and the risks and benefits of treatment or care is far more sensitive than most other consumer decisions that an individual is likely to make, making it all the more challenging to present in an engaging and non-threatening way.

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<sup>6</sup> Hibbard J.H. & Peters EM. (2003) Supporting informed consumer health care decisions: data presentation approaches that facilitate the use of information in choice. *Annu Rev Publ Health*; 24:413–33.



## Key learnings

1. People don't instinctively seek or know to look for information on clinicians and hospitals. This could be changed through **awareness raising**, and addressing those barriers that prevent patients from accessing this information or even knowing it is available. This could take the form of the Society encouraging its members to share this information with patients, rather than relying on printed advertisements as part of other brochures.
2. Secondly, when presented or prompted to look for this information, people generally find it interesting and useful, with many seeing the importance of having this information available. This strengthens the point above, that if patients are made aware of the information they may be **encouraged to utilise** it, even if initially they don't think it is valuable.
3. **Presentation is key.** Although people understood the benefit of certain types of information following the ranking exercise, many felt the information on the Society for Cardiothoracic Surgery website was difficult to interpret and thus avoided it. Presenting data poorly can inhibit people from accessing it or add to their anxieties. Key issues with the presentation included:
  - a. The **accessibility of the information**. Not only by it not being readily available when patients google it, but finding their way to the "patient" part of the website as well.
  - b. The **amount of information** presented at once is overwhelming as in the case of the Patient Risk Profile. This not only causes patients to avoid this information but it also results in misunderstanding of how this is calculated and used.
  - c. **Relevance of the information** presented is also key. Rather than presenting all the information at once, patients want to be able to select those procedures, or risk factors that are relevant to them.
  - d. Making sure the information presented has **meaningful comparisons**. In some of the graphs, such as the survival rates, patients struggled to understand whether someone was good or not.

## Appendix 1

### Ranking exercise- Key areas by surgeon and hospital.

#### Information about the Surgeon

- Patient Risk Profile: The number of patients operated on from particular risk groups, compared to the national average
- Patient Feedback
- Training and Qualifications
- Number and type of operations performed
- Survival Rate: Percentage of patients who survived operation, adjusted for the risk
- Special interests / Surgery specialties

#### Information about the Hospital

- Location e.g. proximity to home
- Information about rehabilitation and follow up
  - Who follow up or rehabilitation is with
  - How long after operation
  - Where rehabilitation to take place (home, GP, outpatient etc.)
- Access and Facilities e.g. car park, nearest bus stop
- Survival Rate: percentage of patients who survived operation, adjusted for risk
- Other complications: proportion of patients suffering stroke or kidney failure
- Long term survival rate e.g. 1 year, or 5 years
- Average length of stay
- Serious wound infection rate: proportion of patients suffering serious wound infection post-operation
- Risk of readmission (within 30 days)
- Patient Feedback
- Types of surgeries performed (at the hospital) e.g. cardiac / thoracic
- Visiting hours
- Number of operations performed: by type of operation
- Patient risk profile: the number of patients operated on from particular risk groups, compared to the national average

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