

- Patient preferences for alternative surgical techniques for abdominal aortic aneurysm repair

REPORT OF A PATIENT SURVEY

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PICKER INSTITUTE EUROPE

JUNE 2008

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- build and use evidence to champion the best possible patient-centred care
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Published by and available from:

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## Executive summary

This report describes a survey of 237 patients on the abdominal aortic aneurysm (AAA) screening programmes at two English acute hospital trusts. The survey was used to assess whether patients expressed any preference between the two surgical treatment options: endovascular aneurysm repair and open aneurysm repair. The patients were all male, aged 65 years or over and with an asymptomatic aortic aneurysm of between 4.0 and 5.5cm in diameter. The objectives of the survey were to gather information to:

- identify patient preferences around the surgical treatment of AAA
- assess the factors which have influenced their preferences and the decision-making process
- examine preferences before and after patients have read an information pack containing detailed information about the two main surgical treatment options.

The findings are based on the analysis of 167 completed questionnaires. Due to the rounding of numbers, the sum of responses discussed in the report may not always equal 100%.

### About the treatment options

OSR denotes 'open surgical aneurysm repair'. This is where the abdomen is cut open and a strong plastic tube is grafted into the aorta to take the place of the failing aortic walls. EVAR denotes endovascular aneurysm repair. In this treatment, which is less invasive, the surgeon enters through the arteries in the thigh to place a 'stent' graft tube inside the patient's aorta to strengthen it. Each treatment option has its own harms and benefits, and so patient preference may play a significant role in treatment choice.

### Patients' preference for surgical treatment option

After reading the information pack, patients were more than twice as likely to prefer EVAR as OSR. Fourteen percent of patients were equally happy with either treatment and 20% were unsure which of the two methods they preferred.

### Variations in the preferences of different groups of patients

There were very few statistically significant variations in the preferences of patients at different hospital trusts, or between patients in different age groups or based on differences in health or carer status, but there were some variations that may warrant further investigation as set out below.

- Patients in all age groups preferred EVAR to OSR, but younger patients appeared marginally more likely to prefer EVAR. The likelihood of patients expressing a clear preference between either EVAR or OSR increased with age.
- Patients with a long term illness or disability were more likely to express a preference for OSR and less likely to express a preference for EVAR.
- Patients with a limiting long term illness or disability were marginally more likely to express a clear preference for the surgical treatment option, but the presence of a

limiting health condition made little impact on the extent to which patients preferred OSR as opposed to EVAR.

- Patients who provided care were markedly more likely to express a preference for EVAR than patients who did not have care responsibilities.

### **The factors influencing patient preferences for surgical treatment**

Respondents most frequently indicated that the main factor influencing their preference was 'the advice of the doctor'. Their medical history or existing condition, the invasiveness of surgery and the risk of post-operative complications were the next most frequently cited factors, though to a much lesser degree. The 'invasiveness of the surgery' and an 'existing medical condition' were important factors for many of those who preferred EVAR, but not important for those who preferred OSR. The risk of post-operative complications was a key factor for many who preferred OSR, but important to few who preferred EVAR.

Just over a third of patients preferred 'less invasive surgery, even with a possible increased risk of post operative complications' and just under a third said they preferred a lower risk of post operative complications, even with the need for more invasive surgery. The other third of patients did not know or had no preference.

Most patients who preferred OSR said that they preferred a lower risk of post-operative complications and none preferred less invasive surgery. In contrast, most of those who preferred EVAR said they preferred less invasive surgery, but a small number also said they preferred a lower risk of post-operative complications. Most of those who had no preference, or did not know whether they preferred EVAR or OSR, preferred a lower risk of post-operative complications.

In terms of other factors, patients placed most importance on a shorter recovery time, avoiding a stay in intensive care and a shorter hospital stay and least importance on the size of the scar and the risk of impotency. Responses were split almost equally between those who preferred a local anaesthetic, those who preferred a general anaesthetic and those who had no preference or did not know.

### **Variations between different groups of patients in the factors influencing their treatment preferences**

There were some small, but generally not statistically significant variations regarding the extent to which different groups of patients were influenced by different factors. The most interesting are set out below.

- Older patients were more likely to indicate that the main factor influencing their preference was the advice of the hospital doctor and more likely to say they did not know or they had no preference for less invasive surgery as opposed to a lower risk of post-operative complications.
- Scar size and impotency were more important to younger patients while a shorter hospital stay and avoiding intensive care were more important to older patients. Older patients were also more likely to prefer a local anaesthetic to a general one.
- Patients with care responsibilities were more likely to prefer less invasive surgery and slightly less likely to show concern about the risk of post-operative complications. An early theory, developed during the qualitative interviews that patients with care

responsibilities might prefer a shorter recovery time was not supported by the evidence from the survey.

### **Preferences for involvement in decision-making**

Most patients would want to be involved in the decision about their surgical treatment and few would be happy to leave the decision wholly in the hands of the surgeon. Patients who expressed a preference for either OSR or EVAR were far more likely to want to be actively involved in the decision than those who did not express a preference for treatment.

### **Initial preferences and sources of influence**

Most patients had not considered the different options for surgical repair before reading the information pack and most did not know which of the treatment options they preferred. Few patients had spoken to their hospital doctor about the available surgical treatment options or received any information at all. Only a small number said their views had been influenced, most commonly by a healthcare professional at the hospital or their GP.

In terms of the extent to which patients had considered the treatment options prior to reading the information pack, there were only small variations between patients at different hospital trusts. There was also little variation between patients in different age or health status groups. Patients who had care responsibilities were more likely to have considered the options for treatment prior to involvement in the survey and were also more likely to have spoken to their hospital doctor.

### **Patient views of the information pack as a decision aid**

Patients reported consistently positive views of the information pack as an aid to the decision about surgical treatment for AAA.

### **The impact of the information pack on patient preference for surgical treatment option**

Reading the information pack does appear to have influenced patients' preferences for surgical treatment, but only if they did not already have a preference. About two-thirds of those who preferred either EVAR or OSR after reading the information pack had not known their preference before they read the pack. Those with an initial preference for a specific treatment option appear unlikely to change their opinion after reading the information pack.

### **Conclusions and recommendations**

This analysis of 167 questionnaires completed by patients with asymptomatic AAAs provides some useful insights into the preferences, expectations and experiences of these patients. The sample represents a large proportion of all asymptomatic patients on the AAA screening programmes at the two trusts concerned. By achieving a very high response rate the survey has produced findings which can be presented with a high degree of confidence as representative of the patients at those two trusts. The lack of variation between the patients at the two different trusts allows us to tentatively suggest that the findings could be representative of those of similar patients at any English hospital trust. However, further investigation of the preferences of patients at a larger number of trusts would be necessary before generalisations can be concluded from these findings.

Patients responded extremely positively to the way in which the pack provided information to support them to make a decision about the surgical treatment options for AAA. The evidence from the questionnaire that few patients had spoken to their hospital doctor about the available surgical treatment options or received any information at all suggests that the information pack offers considerable potential for supporting informed choice for AAA patients.

Twenty percent of patients were unable to say which of the two surgical treatment methods they prefer, even after reading the information pack, and a further 14% said they were equally happy with either treatment. This suggests the need for enhanced support, in addition to the information contained in the information pack, for some AAA patients to aid their decisions around surgical treatment. On the whole, patients' preference for surgical treatment method was consistent with the sorts of things they said were important to them.

### Areas for further investigation

There were very few statistically significant variations in the preferences of patients and the factors that influenced them at different hospital trusts, or between patients in different age groups or based on differences in health or carer status. There were, however, some small scale variations that may warrant further investigation, particularly in the light of the small sample sizes which reduce the possibility of statistical significance. The following variations may be particularly interesting to explore in more depth:

#### Variations between patients in different age groups

- Patients in all age groups preferred EVAR to OSR, but younger patients appeared marginally more likely to prefer EVAR.
- Scar size and risk of impotency were more important to younger patients.
- A shorter hospital stay and avoiding intensive care were more important to older patients.
- Older patients were more likely to prefer a local anaesthetic to a general one.
- The oldest patients (aged 76 or over) were less likely to express a clear preference for a specific treatment than the youngest patients (aged 70 years or under).
- Older patients were more likely to indicate that the main factor influencing their preference was the advice of the hospital doctor.
- Older patients were more likely than younger patients to say they did not know, or had no preference for less invasive surgery as opposed to a lower risk of post-operative complications.

#### Variations between patients with different health and carer status

- Patients with a long term illness or disability were more likely to express a preference for OSR and less likely to express a preference for EVAR.
- Patients who provided care were markedly more likely to express a preference for EVAR, to prefer less invasive surgery and slightly less likely to show concern about the risk of post-operative complications than patients who did not have care responsibilities.

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# 1 Introduction

## 1.1 Context of the report

This report describes a survey conducted by Picker Institute Europe on behalf of, and in collaboration with, the Vascular Surgery Research Group at Imperial College London during January to March 2008. This work is part of a research project to explore patient views of the two main surgical treatment options for large abdominal aortic aneurysm (AAA).

The phase of the project described here consisted of a survey of 237 patients on the AAA screening programmes at two English NHS hospital trusts.

This phase of the research follows work to develop and validate a patient information pack on AAA and the two main surgical treatments, and a questionnaire to gather patients' views of the two options for treatment. The survey methodology was tested in a pilot survey of 50 patients on the AAA screening programme at Trust 1. These earlier phases are reported in three separate reports.<sup>123</sup>

A subsequent stage of the research was planned involving a series of 20 depth interviews with Charing Cross Hospital AAA patients waiting for treatment whose aneurysm was 5.5cm or larger. Problems recruiting patients for interview meant it was not possible to complete this stage.

## 1.2 Structure of the report

After this introduction, the findings are presented in five sections. Results are reported as a percentage of the entire sample (n=167) unless there are specific reasons for not doing so, as described in the text. Relationships were tested for statistical significance using Pearson Chi-Square Test unless otherwise indicated.

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<sup>1</sup> Sheldon H (2007) Surgical treatment of large abdominal aortic aneurysm – patient preference project. Report of the development of an information pack about abdominal aortic aneurysm. Oxford: Picker Institute Europe (Draft unpublished report, 30 July 2007)

<sup>2</sup> Sheldon H and Garratt E (2007) Surgical treatment of large abdominal aortic aneurysm – patient preference project. Report of the development and testing of a questionnaire to explore patient preference. Oxford: Picker Institute Europe (Draft unpublished report, November 2007)

<sup>3</sup> Sheldon H and Garratt E (2008) Patient preference project on alternative surgical techniques for abdominal aortic aneurysm repair - Report of a pilot survey. Picker Institute Europe (Draft unpublished report, 15 January 2008)

## 1.3 Aims and objectives

The aim of the survey is to gather information to assess whether patients express any preference between endovascular and open aneurysm repair.

The objectives are to gather information to:

- a) identify patient preferences around the surgical treatment of AAA
- b) assess the factors which have influenced their preferences and the decision-making process
- c) examine preferences before and after patients have read an information pack containing detailed information about the two main surgical treatment options.

## 1.4 Methods

The survey was conducted using the methodology approved by the Riverside Research Ethics Committee in September 2007 (Reference: 07/H0706/82). It consisted of a self-completion postal questionnaire, conducted in four stages during January and March 2008:

- a pre-approach letter to each patient from their AAA hospital consultant
- a copy of the questionnaire and the information sheet sent with a covering letter
- a first reminder letter
- a second reminder letter sent with a second copy of the questionnaire and information sheet.

## 1.5 Participant sampling and recruitment

All patients on the AAA screening programmes at the two trusts were eligible to take part in the survey if they met the following inclusion criteria:

- male
- aged 65 years or older
- asymptomatic aortic aneurysm of between 4.0 to 5.4cm in diameter
- not currently being considered for imminent aneurysm repair.

The screening programme co-ordinators at the two trusts identified all patients who met these criteria and excluded:

- patients who it has been decided will never undergo aneurysm repair
- patients known to have a learning disability, cognitive impairment or mental health difficulty that would be prohibitive to them completing the questionnaire.

The survey sample included all 237 remaining patients:

- 136 patients at Trust 1
- 101 patients at Trust 2.

## 1.6 Pre-approach letter and opt outs

A letter was sent from the consultant vascular surgeons at the two trusts to each patient. The letter described the research and invited them to take part. It explained clearly that they did not have to take part if they did not wish to and gave a freephone number to contact to opt out. Thirty patients, or their representatives, contacted the number indicating that they preferred not to take part in the survey, including two patients who did not meet the eligibility criteria. Their names were removed from the pilot survey database which was then passed to Picker Institute Europe.

## 1.7 Questionnaire mailings and reminders

Two weeks after the pre-approach letter was sent, 207 patients were sent an information sheet, questionnaire and covering letter - 122 from Trust 1 and 85 from Trust 2. A freephone number to contact if help was required completing the questionnaire, was given clearly on the front page of the questionnaire. A pre-paid addressed envelope for return of completed questionnaires was provided. Patients were asked to return their uncompleted questionnaire if they preferred not to take part.

Two weeks after the first questionnaire mailing, a single-sided first reminder letter was sent to 89 patients who had not responded by this point - 54 from Trust 1 and 35 from Trust 2.

Two weeks after the first reminder letter, 42 patients who had not responded were sent another reminder letter along with a copy of both the information sheet and the questionnaire (25 from Trust 1 and 17 from Trust 2).

## 1.8 Participant response rates

A flow chart illustrating the participation of patients in the survey is shown overleaf. The response rates vary according to method of calculation, from 70% to 90%.

Among the 205 patients eligible for inclusion who were sent a questionnaire, 167 returned completed questionnaires, representing a response rate of 81%.

Of the 237 patients in the initial sample who were sent a pre-approach letter:

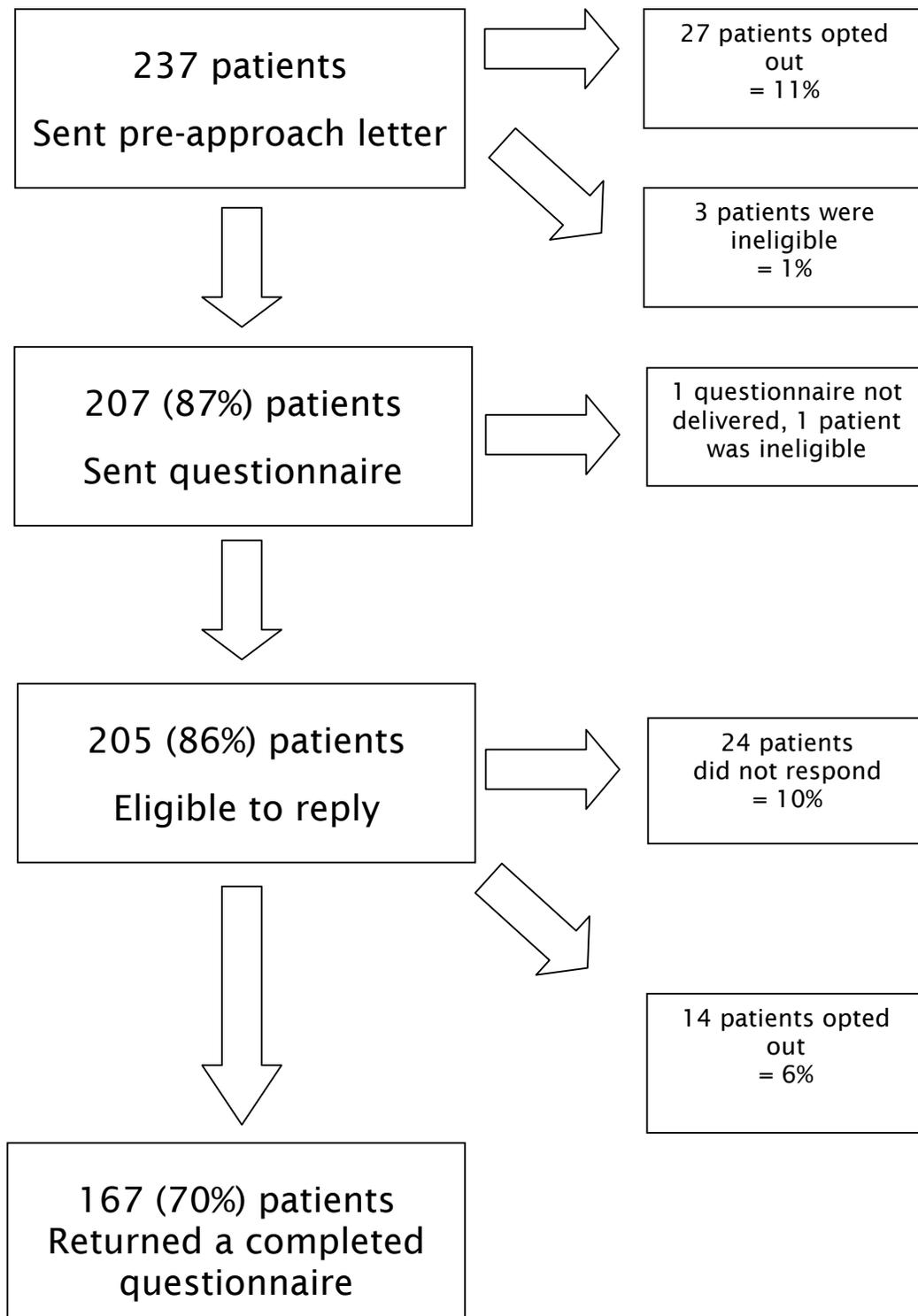
- 167 returned a completed questionnaire (a response rate of 70%)
- 46 patients explicitly withdrew (19% of the initial sample), including:
  - 27 who opted out at the pre-approach stage
  - 14 who returned a blank questionnaire

- 4 who were ineligible
- 1 who could not be contacted
- 24 patients did not respond (10%).

These figures indicate a very high level of response. Of the 27 patients who opted-out at the pre-approach stage, 13 gave reasons:

- 4 had taken part in cognitive interviews or the pilot survey and although this did not preclude their participation, they chose not to complete a questionnaire again for the full survey
- 1 patient said that he had not been diagnosed with an AAA; on further investigation it appeared that this patient does have a AAA, but had not been informed of his diagnosis
- 4 patients were not interested
- 1 was too busy
- 3 were unwell.

Reasons were not offered by the remaining patients who opted out at the pre-approach stage.



## 2 Characteristics of respondents

### Age

Respondents were born between 1924 and 1942, representing an age range of 66 to 84 years. As shown in the table below, nearly all respondents were aged 80 years or under and two-thirds fell within the ten year age range of between 66 and 75 years. This limits the extent to which any variations can be identified in the preferences of patients in different age groups.

Age Group	Frequency	Percent
66-70	55	33
71-75	61	37
76-80	40	24
81-85	7	4
Missing	4	2
	<b>167</b>	<b>100</b>

### Ethnic group

All but one respondent described their ethnic origin as 'White' and most as 'White British' (n=157; 94%).

### Education and employment

Most respondents had completed their highest educational or vocational qualification at the age of 16 years or less (n=116; 70%) and the overwhelming majority (90%) of patients described themselves as retired.

### Health status

More than half of patients said they had a long term illness, disability or condition (n=105; 63%) and nearly half of these said this caused them difficulties with the everyday activities that people of their age can usually do (n=46; 28% of all respondents and 44% of those with a long term condition). In contrast, when asked about their health over the past four weeks, nearly three quarters of respondents said their health was 'good' (n=65; 39%), 'very good' (n=48; 29%) or 'excellent' (n=9; 5%). A quarter said their health was 'fair' or 'poor' and just one respondent described his health as 'very poor'.

### Carer status

Twenty two patients (13%) declared that they provide care to a spouse, relative or friend. The majority (n=138; 83%) did not. Most patients (89%) stated that there was someone who would provide them with care at home after an operation if needed and just 12 people said there was no-one who could provide this care (7%).

### 3 Patients' preference for surgical treatment option

As the chart below shows, after reading the information pack, patients were more likely to prefer EVAR. Seventy seven patients preferred EVAR (46%) compared to 30 who favoured OSR (18%).

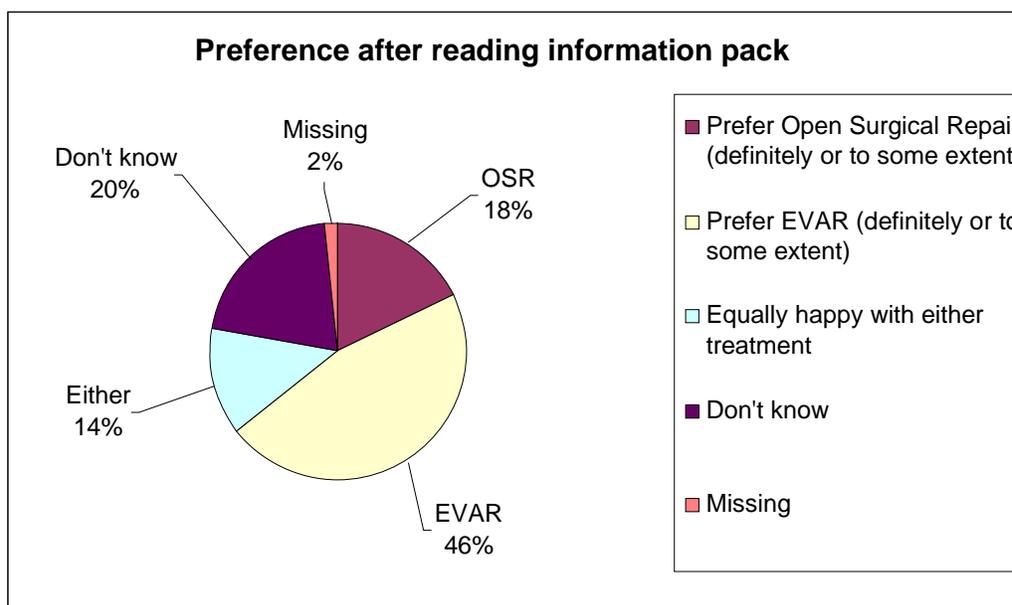
Patients who expressed a preference for EVAR were equally split in terms of the strength of their preference:

- 40 definitely preferred EVAR
- 37 preferred EVAR to some extent.

In contrast, the smaller number of patients who preferred OSR appeared more certain about their preference:

- 20 patients definitely preferred OSR
- 10 preferred OSR to some extent.

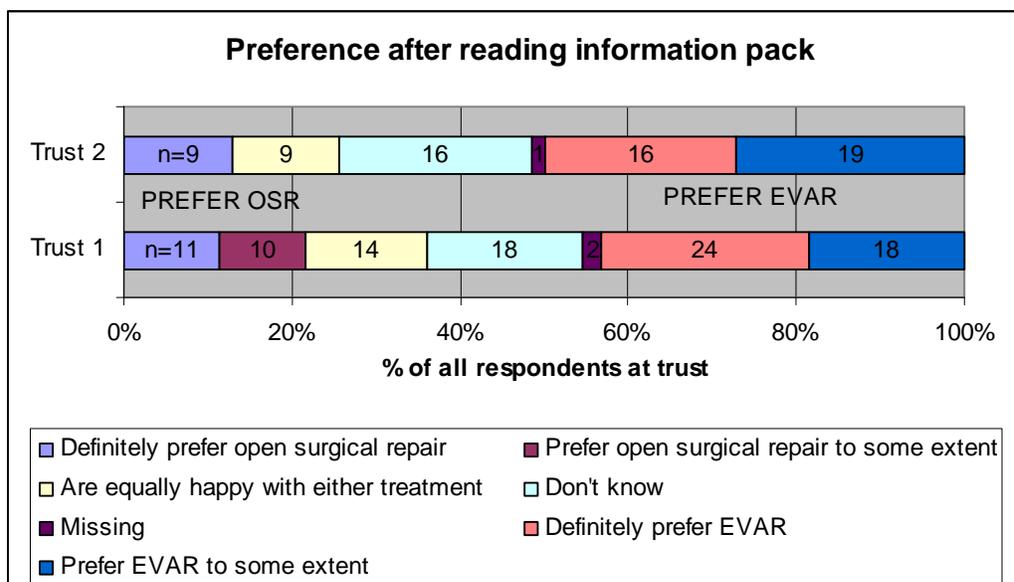
Fourteen percent of patients were equally happy with either treatment (n=23) and 20% (n=34) were unsure which of the two methods they preferred, even after reading the information pack.



### 3.1 Variations in the preferences of different groups of patients

#### Variations in the preference of patients at different hospital trusts

Patients at Trust 2 expressed a stronger preference for EVAR, over Open Surgical Repair, than patients at Trust 1, as shown in the chart below. Four times as many of all Trust 2 respondents said they preferred EVAR (n=35; 50%), as preferred OSR (n=9; 13% of all respondents from this trust). In contrast, twice as many said they preferred EVAR at Trust 1 (n=42; 43% of all respondents from Trust 2) as preferred Open Surgical Repair (n=21; 22% of respondents). Patients at Trust 2 were slightly more likely to say they did not know which of the two treatment options they preferred (n=16; 23%) compared to patients at Trust 1 (n=18; 19%). None of these variations in the preferences of patients at different trusts were statistically significant (p=.160).



#### Variations in the preferences of patients in different age groups

There was no clear relationship between patient treatment preferences and their age and no statistically significant variations. Patients in all age groups preferred EVAR to OSR.

The youngest and oldest patients appeared more likely to prefer EVAR; it was preferred by more than half of patients aged 70 years or under (n=29; 53%) and just under half of those aged 76 or older (n=23; 49%). In contrast, 36% of patients aged 71-75 (n=22) preferred EVAR. However, this variation is not statistically significant (p=.324).

The oldest and youngest patients were least likely to prefer OSR. Very few of the oldest patients, aged 76 and over, expressed a preference for OSR (n=6; 13%) and just 18% of those aged 70 or under (n=10). In contrast, nearly a quarter of those aged 71-75 preferred OSR (n=14; 23%), but as the numbers in the other age groups are very small, this relationship between age and preference for OSR requires further investigation.

The likelihood of patients expressing a clear preference between either EVAR or OSR decreased with age. Thirty eight percent of the oldest patients (aged 76 or over, n=18) expressed no preference between the two options, compared to 29% of the youngest patients (aged 70 years or under, n=16).

### Variations in the preferences of patients with a long term health condition

Nearly two thirds of respondents said they had a long term illness or disability (n=105; 63%). However, less than half of these patients said that this caused them difficulties with the everyday activities people of their age could usually do (n=46; 44% of those with a long term condition). This represents less than a third of all respondents (n=46; 28%) and correlates with patients' responses to a question about their health over the previous four weeks – 42 patients (25% of all respondents) described their current overall health as 'fair', 'poor' or 'very poor'.

Patients with a limiting long term illness or disability were marginally more likely to express a clear preference for surgical treatment option (n=31; 67%) compared to those without a limiting condition (n=76; 63%). Amongst those patients who expressed a preference, there were only very small differences between those who had a limiting condition and those who did not:

- 20% (n=9) of those with a limiting condition preferred OSR, compared to 17% (n=21) of those without a limiting condition
- 48% (n=22) of those with a limiting condition preferred EVAR, compared to 46% (n=55) of those without a limiting condition.

These variations are not statistically significant (p=.850).

### Variations in patients' preferences based on carer status

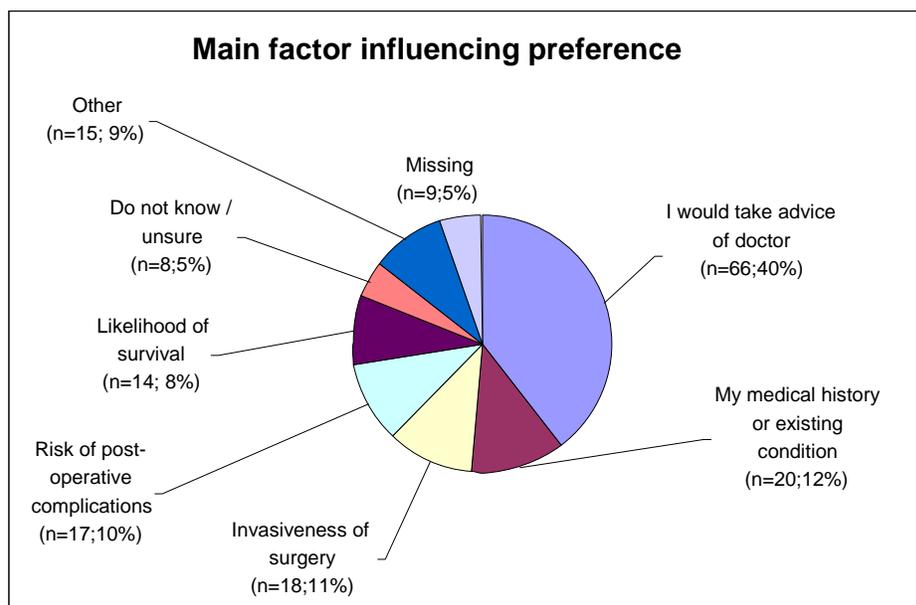
Twenty two patients said they provided care for a partner, spouse or someone else and these patients were markedly more likely to express a preference for EVAR: half said they preferred EVAR (n=11; 50%) compared to 14% who preferred OSR (n=3). The small number of patients who provided care mean that the variations revealed by these cross tabulations need to be treated with caution and whilst they are interesting, they are not statistically significant.

Just 12 patients did not have someone who could provide care for them at home after an operation. The numbers are therefore too small for analysis.

## 4 The factors influencing patient preferences for surgical treatment

### The main factor influencing patient preference

When asked to indicate the main factor influencing their preference for one of the two treatment options, respondents most frequently said they would 'take the advice of the doctor' (n=66; 40%). As shown in the chart below, the other most common factors influencing their view were the patient's medical history or existing condition (n=20; 12%), the invasiveness of surgery (n=18; 11%) or the risk of post-operative complications (n=17; 10%).



More than a third of patients who expressed a clear preference for OSR indicated that the advice of the doctor was the main factor influencing their preference (n=11; 37%). The doctor's advice was the main influence for a smaller proportion of the patients who preferred EVAR (n=25; 33%), but half of those who had no preference, or who did not know what treatment they preferred, said that this was the main factor influencing them (n=30; 50%).

Nearly a quarter of those who preferred EVAR said that the 'invasiveness of the surgery' was the single main factor influencing their preference (n=18; 23%). No patients who preferred OSR indicated this was an influence.

An existing medical condition was also mentioned by a relatively large number of those who preferred EVAR (n=12; 16%) but by just two people who preferred OSR (7%).

Those who preferred OSR frequently mentioned the risk of post-operative complications as the main factor influencing their preference (n=8; 27%). This was mentioned by just two people who preferred EVAR (3%).

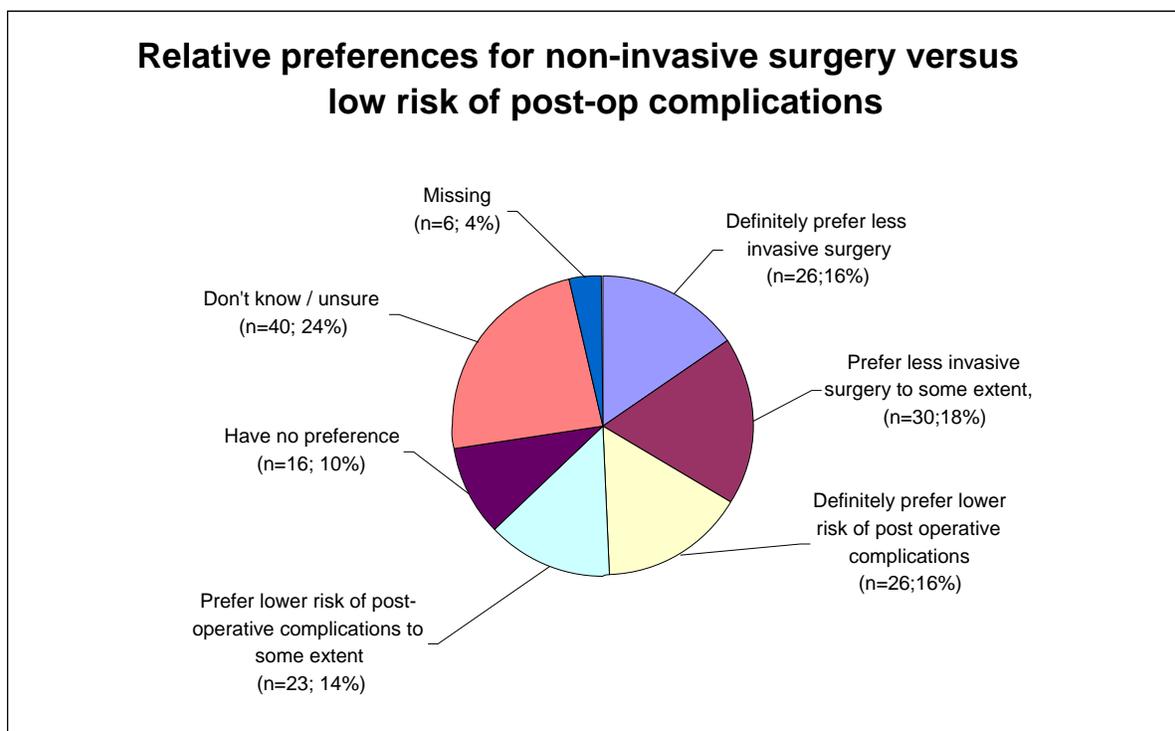
### Preference for less invasive surgery as opposed to a lower risk of post-operative complications

During interviews to develop and test the information pack and the questionnaire, we found that patients often made a trade off between:

- a) EVAR being less invasive (with an associated lower risk of death during or immediately after the operation); and,
- b) Open Surgical Repair having a lower risk of post-operative complications requiring further intervention.

One question attempted to assess which of these aspects were most important to the patient.

When balancing invasiveness of surgery versus post operative complications, a third of patients were unable to make the trade off: nearly a quarter did not know which aspect was more important to them (n=40; 24%) and 10% (n=16) said they had no preference. As shown in the chart below, just over a third (n=56; 34%) said they preferred 'less invasive surgery, even with a possible increased risk of post operative complications' and just under a third said they preferred a lower risk of post operative complications, even with the need for more invasive surgery (n=49; 29%).



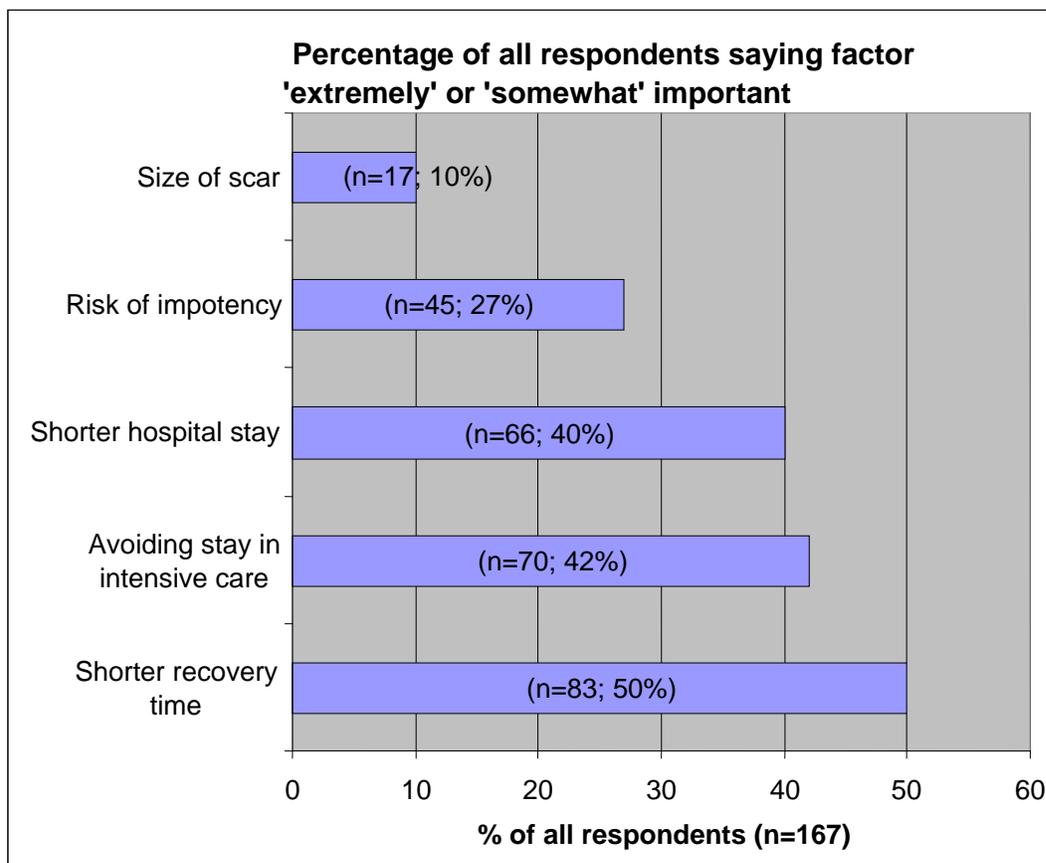
Two thirds of patients who preferred OSR, said that they preferred a lower risk of post-operative complications (n=20; 67%). None of them said they preferred less invasive surgery. In contrast, most of those who preferred EVAR said they preferred less invasive

surgery (n=51;66%). It is of some interest that 13% of patients who preferred EVAR said they preferred a lower risk of post-operative complications (n=10).

Nearly a third of the sixty patients who did not know or had no preference in terms of surgical treatment option, preferred a lower risk of post-operative complications (n=19; 32%) and most of the others did not express a preference on the issue (n=36;60%). Just five (8%) preferred favoured less invasive surgery.

### The importance of other factors in determining patient preference between EVAR and OSR

Other questions in the questionnaire explored patient views of various other differences between the two treatment options. As seen in the chart below, patients placed most importance on a shorter recovery time, avoiding a stay in intensive care and a shorter hospital stay.

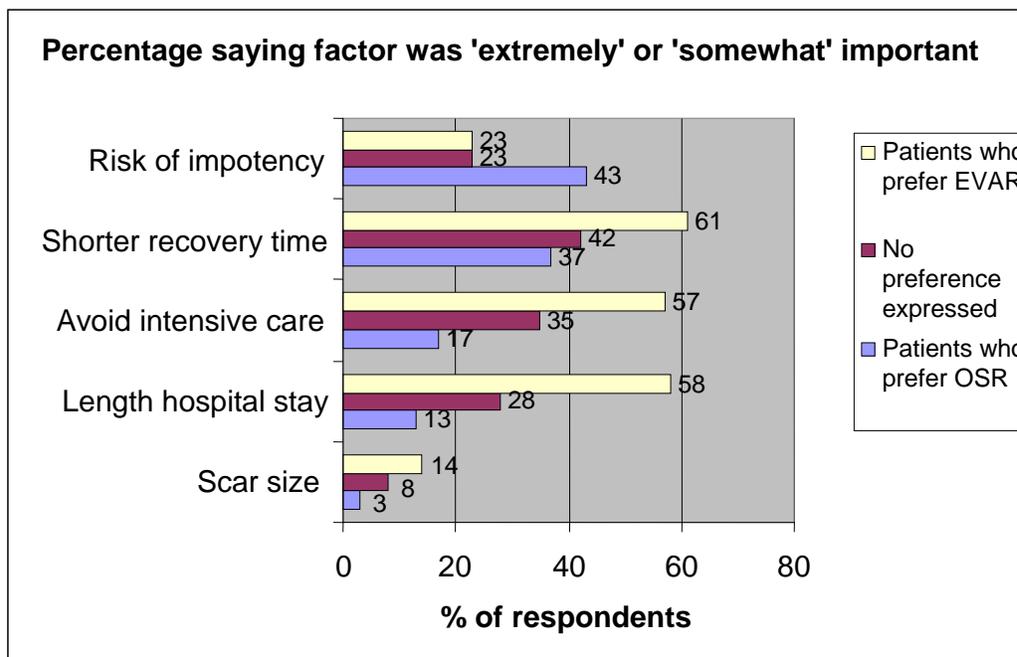


The size of the scar was the least important of these factors to respondents, with nearly three quarters saying it was unimportant (n=118; 71%) and just 10% saying this was 'extremely' or 'somewhat' important (n=17). Respondents also placed relatively low importance on the risk of impotency, with just over a quarter saying this was important (n=45; 27%) and more than half saying it was not important (n=86; 52%).

Respondents were also asked if they had a preference between a local and a general anaesthetic. Their responses were split almost equally, with a third saying they preferred

a local (n=55; 33%) and a third saying they preferred a general (n=53; 32%) and a third saying they either had no preference or did not know (n=51; 31%).

As shown in the chart and table which follow, patients tended to place importance on those factors which were characteristic of their surgical treatment option of choice. So for example, patients who preferred EVAR, placed more importance than those who preferred OSR on scar size, length of hospital stay, avoiding intensive care and a shorter recovery time.



	% of all respondents saying factor was 'extremely' or 'somewhat' important			All respondents
	Patients who prefer OSR	No preference expressed	Patients who prefer EVAR	
Scar size	3	8	14	10 (n=17)
Length hospital stay	13	28	58	40 (n=67)
Avoid intensive care	17	35	57	42 (n=70)
Shorter recovery time	37	42	61	50 (n=84)
Risk of impotency	43	23	23	27 (n=45)

Likewise, patients who preferred OSR tended to prefer general anaesthetic (n=21; 70%) and only one said he preferred a local anaesthetic. Most patients who preferred EVAR said they would prefer a local anaesthetic (n=44; 57%). A number of those who preferred

EVAR said they would prefer a general anaesthetic (n=14; 18%). EVAR is more usually performed under local anaesthetic, however as it can be done under a general anaesthetic, a preference for a general anaesthetic is not contradictory to a preference for EVAR.

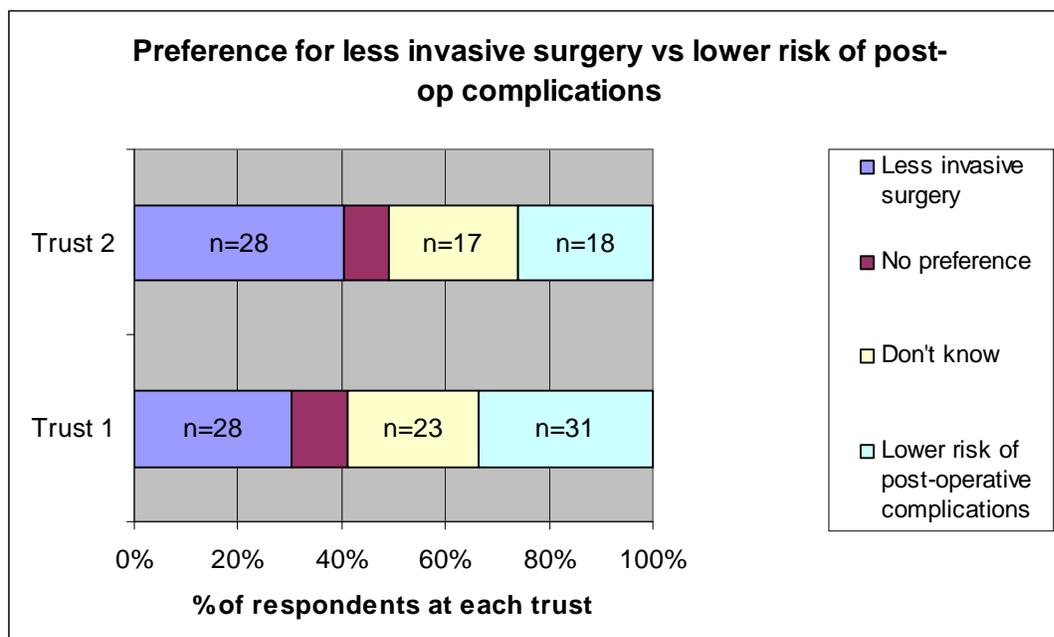
## 4.1 Variations between different groups of patients in the factors influencing their treatment preferences

### Patients at different hospital trusts

Patients at Trust 1 were more likely to say the main factor influencing their preference for surgical treatment type would be the advice of the doctor. Nearly half of patients at this trust mentioned this factor (n=43; 44%), compared to a third of Trust 2 patients (n=23; 33%). On the whole, there is little other difference between patients at the two trusts in terms of the factors that influenced them and none of the variations were statistically significant (p=.867).

Patients at Trust 2 were more likely to express a preference for less invasive surgery (n=28; 40%) than those at Trust 1 (n=28; 29%). Patients at Trust 1 were slightly more likely to express a preference for a lower risk of post-operative complications (n=31; 32%) than those at Trust 2 (n=18; 26%). Patients were as likely at both trusts to say they had no preference (10% at Trust 1 and 9% at Trust 2) or to say they did not know (24% at each).

None of these variations in the preferences of patients at different trusts were statistically significant (p=.657).



### Patients in different age groups

Older patients, aged 76 or older, were more likely to indicate that the main factor influencing their preference was the advice of the hospital doctor (n=23; 49%) compared to younger patients (n=42; 36%). The numbers of patients citing any of the other factors as 'the most important influence' are generally too small for analysis. Older patients, aged over 76, were more likely to cite the invasiveness of surgery as the 'main influence' on their preference (n=6; 13%) than younger patients (n=12; 10%). In contrast, the risk of post operative complications appeared to have more influence on patients, aged 75 or less (n=14; 12%) than on older patients (n=3; 6%).

The latter variation is supported by patients' responses when asked to directly to express a preference between less invasive surgery or a lower risk of post-operative complications: 32% (n=37) of patients aged 75 or less preferred a lower risk of post-operative complications, compared to 26% (n=12) of older patients. However, 33% (n=38) of patients aged 75 or less preferred less invasive surgery, compared to 30% (n=14) of older patients.

The evidence regarding the other factors is inconclusive and there are no statistically significant variations, except that concerning the risk of impotency. Nearly a third of the youngest patients saw this as important (n=37; 32%) compared to 15% (n=7) of older patients (p=.048).

### Health status and the factors that influence preference for surgical treatment

On the whole, there was little variation between patients with a limiting long term health condition (LTC) and those without in terms of the factors that influenced their preferences for surgical treatment. The only marked difference was that 20% (n=9) of those with a long term condition cited 'my medical history or existing condition' as the main factor influencing their preference compared to 9% (n=11) of those who said they did not have a limiting health condition.

Patients with a limiting LTC were more likely to prefer a lower risk of post-operative complications (n=17; 37%) than less invasive surgery (n=14; 30%). In contrast, patients in better health were more likely to prefer less invasive surgery (n=42; 35%) than a lower risk of post-operative complications (n=32; 26%). However, these variations are not statistically significant.

### Carer status and the factors that influence preference for surgical treatment

Patients who had care responsibilities were more likely to prefer less invasive surgery (n=9; 41%) than patients who did not have care responsibilities (n=43; 31%). They were also slightly less likely to show concern about the risk of post-operative complications. However, as explained above, because of the small number of patients who provided care, none of these variations were statistically significant.

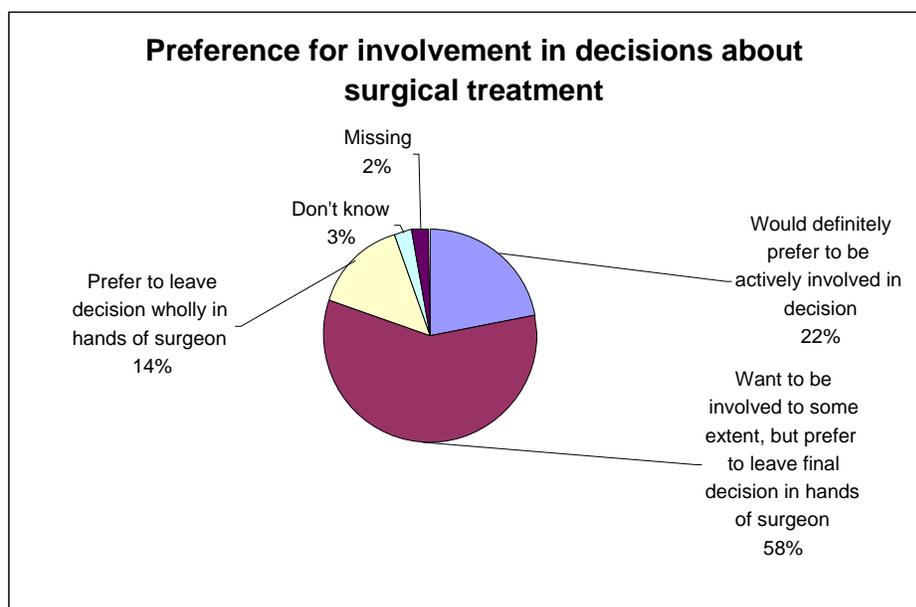
In terms of the importance placed on other aspects of the treatments there were no statically significant variations between patients with care responsibilities compared to those without. An early theory was developed during the qualitative interviews conducted to gather information to inform the information pack and to test the questionnaires that patients with care responsibilities might prefer a shorter recovery time. This was not supported by the evidence from the survey that they were no more likely to say a shorter

recovery time was important (n=11; 50%) than patients with no care responsibilities (n=68; 49%).

Patients who provided care were more likely to have discussed their treatment options with a hospital doctor (n=5; 23%) than those who were not carers (n=11; 8%). However, as explained above, because of the small number of patients who provided care, this variation was not statistically significant.

## 4.2 Preference for involvement in decision-making

Patients were asked how actively involved they wished to be in the decision about their surgical treatment. As the chart below shows, few patients would be happy to leave the decision wholly in the hands of the surgeon (n=24; 14%). Most would want to be actively involved to some degree (n=134; 80%), though a large proportion of these would prefer to leave the final decision in the hands of the surgeon (n=97; 58%).



Patients who expressed a preference for either OSR or EVAR indicated very similar preferences about involvement in decision-making around their surgical treatment. About 90% in each group said they wished to be actively involved. Those who did not express a preference between OSR and EVAR were twice as likely as those who did, to want to leave decision making wholly in the hands of the hospital doctor or surgeon (n=13; 22%; p=.050).

Younger patients were more likely to prefer active involvement (n=94; 81%) than older patients (n=36; 77%) and were less likely to prefer to leave the decision in the hands of the surgeon: 13% (n=15) compared to 19% (n=9) of older patients. However, these variations are not statistically significant (p=.562).

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## 5 The use of the information pack

### 5.1 Initial preferences and sources of influence

Patients were asked about their preference for treatment options before reading the information booklet, the nature of any advice they had already been given about treatment options and where this information had come from.

Twenty seven patients (16%) had considered the options for surgery, including nine who reported having 'definitely considered the different options for surgical repair' and 18 who had considered the options 'to a certain extent.' The majority of patients (81%) indicated that they 'had not considered the different options for surgical repair at all'.

#### Initial preference

Before reading the information pack, just under a quarter of all respondents (n=38; 23%) indicated that they had a preference for one or other of the surgical treatment options. Most patients did not know which of the treatment options they preferred (n=106; 64%). After reading the information many more patients expressed a preference (n=107; 64%) and fewer patients did not know which treatment option they preferred (n=34; 20%).

Comparing only those patients who expressed a clear preference, the ratio of those who preferred EVAR to those who preferred OSR was very similar before and after reading the information (approximately 3:1). Both groups of patients expressed a clear preference for EVAR. Additionally, a similar proportion in each group said they were 'equally happy with either treatment.'

#### Sources of advice, information and influence

Most respondents (n=147; 88%) had not talked to their hospital doctor about the available surgical treatment options. Just 16 patients (10%) said they had talked to their doctor. Of these:

- 5 felt they had talked as much as they needed to
- 11 said they still had unanswered questions.

Nearly three quarters of patients (n=110; 66%) said their views of the treatment options had not been influenced by anyone and 37 were unsure (22%). Just 20 patients (12%) said their views had been influenced, most commonly by a healthcare professional at the hospital (8%) or their GP (n=6; 4%).

The majority of patients reported having received no information about either OSR (62%) or EVAR (64%). About a third of patients indicated they had information about one or other of the procedures before they read the information pack. A hospital doctor or nurse was the most common source in both cases (n=27; 16%) and a small number of patients had received information in a hospital leaflet. A hospital leaflet was a more common source of information about EVAR (n=11; 7%) than about OSR (n=7; 4%). Very small numbers had received information from any other source.

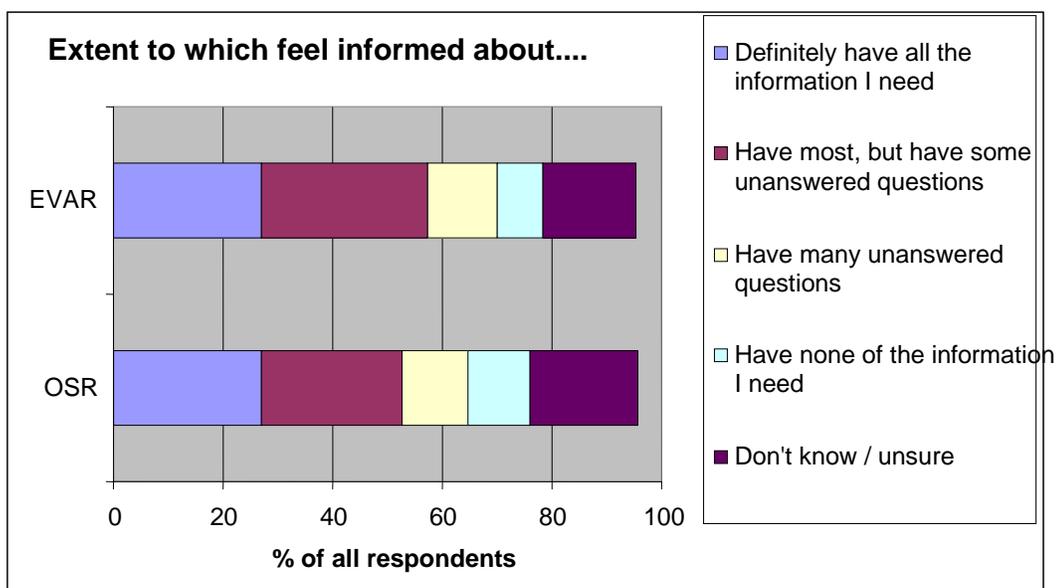
It was rare for patients to have received written information about the surgical treatment options. Just seven patients (4%) had been given information about both treatment options and four had been given information about just one of the treatments. Most patients (n=149; 89%) were given no written information and five patients (3%) did not know if they had been given any written information.

### Variations based on hospital trust and patients' age, health and carer status

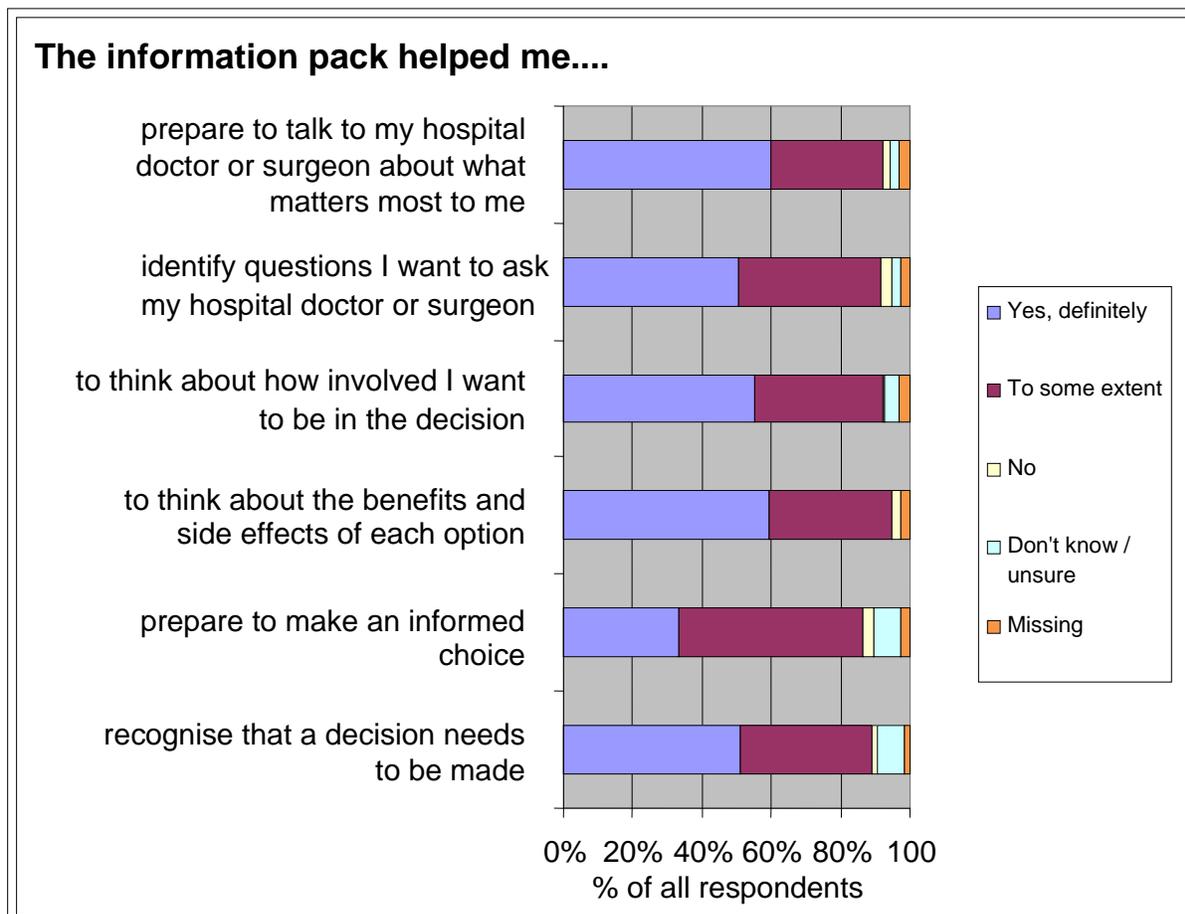
There were only small variations in the extent to which patients at different hospital trusts had considered the treatment options prior to reading the information pack. There was also little variation between patients in different age or health status groups. Patients who had care responsibilities were more likely to have considered the options for treatment prior to involvement in the survey and were also more likely to have spoken to their hospital doctor. Nearly a quarter said they had already considered the options (n=5; 23%) compared to 15% who did not have care responsibilities (n=21). The numbers involved are too small for statistical significance but support the finding that nearly a quarter of patients with care responsibilities had spoken to their doctor (n=5; 23%) compared to just 8% (n=11) of patients without care responsibilities. These variations are statistically significant (p=.04 or Fisher's Exact Test p=.052).

## 5.2 Patient views of the information pack as a decision aid

After reading the information pack more than half of patients said they had all or most of the information they needed about OSR (n=88; 53%) and EVAR (n=96; 57%). Just under a quarter said they needed considerably more information about either OSR (n=39; 23%) or EVAR (n=35; 21%). The chart below shows the extent to which patients felt informed about the two treatment options after reading the information pack.

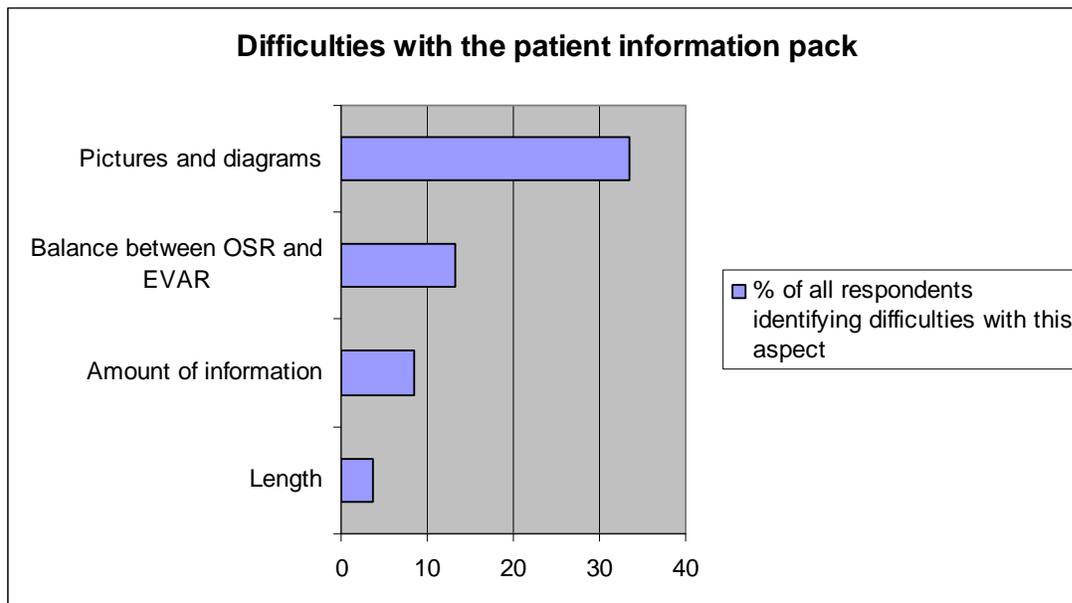


As shown in the chart below almost all patients were positive about the way that the information pack helped them in various aspects of their involvement in the decision between the two main surgical treatment options.



Just a handful of patients said the information pack was not helpful in any respect. The most negative responses about specific aspects were the six people who said the information pack did not prepare them to make an informed choice and the five people who said it did not help them to identify the questions they wanted to ask the hospital doctor or surgeon.

Overall, patients were very happy with the length of the information pack (88%), the amount of information it contained (81%) and the way that a balanced view of both OSR and EVAR was presented (76%). As the chart overleaf shows, a very small proportion had difficulties with these aspects. Nine percent thought the information was biased towards EVAR (n=15) as opposed to 4% who thought it was biased towards OSR. Although only two people thought the pictures and diagrams were 'not useful at all', nearly a third thought they were only useful 'to some extent' (n=54; 32%).



Nearly three quarters of respondents said they would not find the information more helpful in any other format (n=117; 70%). A very small number said they would find it helpful on DVD (n=18; 11%), the internet (n=11; 7%) or CD (n=2; 1%).

Patients were asked which sections of the information pack they found most helpful and just over half said they 'found all sections equally helpful' (n=86; 52%). The detailed information about EVAR was the section mentioned by the most patients as being helpful (N=29; 17%). A smaller number found the section on OSR most helpful (n=19; 11%). Other sections regarded as most helpful included the general information (n=25; 15%), risks and complications (n=25; 15%) and the comparison table (n=20; 12%). No suggestions were made for ways to improve the information pack.

## 5.3 The impact of the information pack on patient preference for surgical treatment option

### Stage of decision making

The extent to which patients had considered the options prior to reading the information pack varied little between patients who preferred EVAR and those who preferred OSR. Patients who expressed a preference for one of the two surgical options were more likely to have considered the options before reading the information pack than those who had no preference or did not know their preference after reading it.

### Initial preference before reading the information pack

Reading the information pack does appear to have influenced patients' preferences for surgical treatment, but only if they did not already have a preference. Sixty nine percent of those who preferred EVAR after reading the information pack had not known their preference before they read the pack (n=53). The same is true of 67% of those who preferred OSR (n=20).

Those with an initial preference for a specific treatment option appear unlikely to change their opinion after reading the information pack. Nearly a third of those who preferred EVAR after reading the information had already expressed a preference for it before reading the pack (n=23; 30%). A similar trend can be seen in patients who initially preferred OSR, however the numbers involved are much smaller.

### Influence of having spoken to the doctor

The number of patients who had spoken to the hospital doctor about the surgical treatment options (n=16) is too small to allow analysis of its impact on preferences for a specific surgical treatment. However, it can be observed that those who preferred OSR were more likely to have spoken to the doctor than those who preferred EVAR. This relationship between the patient's preference after reading the information pack and whether they had spoken to the doctor is interesting, but not statistically significant (p=.239).

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## 6 Conclusions and recommendations

This analysis of 167 questionnaires completed by patients with asymptomatic AAAs provides some useful insights into the preferences, expectations and experiences of these patients. The sample represents a large proportion of all asymptomatic patients on the AAA screening programmes at the two trusts concerned. By achieving a very high response rate the survey has produced findings which can be presented, with a high degree of confidence, as representative of the patients at those two trusts. The lack of variation between patients at the two different trusts allows us to tentatively suggest that the findings could be representative of similar patients at any English hospital trust. However, further investigation of the preferences of patients at a larger number of trusts would be necessary to draw any firm generalisations in conclusion from the findings.

### **Patient preferences for surgical treatment option**

Patients show a high degree of preference for EVAR as opposed to OSR, both before and after reading the information pack.

### **The impact of the information pack on patient preference for surgical treatment option**

Reading the information pack does appear to have influenced patients' preferences for surgical treatment, but only if they did not already have a preference. About two-thirds of those who preferred either EVAR or OSR after reading the information pack had not known their preference before they read the pack. Those with an initial preference for a specific treatment option appear unlikely to change their opinion after reading the information pack.

### **The potential of the information pack to support informed choice**

Patients responded extremely positively to the way in which the information pack provided information to support them make a decision about the surgical treatment options for AAA. In the context of the evidence from the questionnaire that few patients had spoken to their hospital doctor about the available surgical treatment options or received any information at all, the information pack appears to offer considerable potential for supporting informed choice for AAA patients.

### **Need for support in addition to the information pack**

20% of patients were unable to say which of the two surgical treatment methods they prefer, even after reading the information pack and a further 14% said they were equally happy with either treatment. This compares very favourably to the high numbers of patients who were unable to express a preference before reading the information pack but it also suggests the need for enhanced support, in addition to the information contained in the information pack, for some AAA patients to aid their decisions around surgical treatment.

## The influence of the hospital doctor on patient preferences for surgical treatment

The advice of the doctor was indicated to be the most important factor influencing patient views of the two surgical treatment options and this would suggest a key role for the doctor in supporting patients' decisions. Doctors helping patients navigate the evidence around AAA and providing advice about the surgical treatment options need to be aware that most patients would want to be actively involved in the decision around their surgical treatment and few would be happy to leave the decision wholly in the hands of the surgeon. Doctors need to adapt their approach to delivering information to take patient aspirations on this into account.

## The relationship between patient preferences and the things of importance to them

On the whole, patients did not demonstrate contradictory behaviour in terms of choosing the surgical treatment option which supported the factors that were important to them. Most patients who preferred OSR said that they preferred a lower risk of post-operative complications and none preferred less invasive surgery. In contrast, most of those who preferred EVAR said they preferred less invasive surgery. However, the small number of them who said they preferred a lower risk of post-operative complications perhaps warrants further investigation. Patients who preferred EVAR placed more importance on a range of other factors including a shorter recovery time, avoiding a stay in intensive care and a shorter hospital stay and a less visible scar, all of which are characteristic of this treatment option. Similarly, patients who preferred OSR tended to prefer a general anaesthetic as opposed to a local anaesthetic. This procedure cannot be performed under a local anaesthetic.

## Areas for further investigation

There were very few statistically significant variations in the preferences of patients and the factors that influenced them at different hospital trusts, or between patients in different age groups or based on differences in health or carer status. There were however, some small scale variations that may warrant further investigation, particularly in the light of the small sample sizes which reduce the possibility of statistical significance. The following variations may be particularly interesting to explore in more depth or with larger samples:

### Variations between patients in different age groups

- Patients in all age groups preferred EVAR to OSR, but younger patients appeared even more likely to prefer EVAR.
- Scar size and impotency were more important to younger patients.
- A shorter hospital stay and avoiding intensive care were more important to older patients.
- Older patients were more likely to prefer a local anaesthetic to a general one.
- The oldest patients (aged 76 or over) were less likely to express a clear preference for a specific treatment than the youngest patients (aged 70 years or under).
- Older patients were more likely to indicate that the main factor influencing their preference was the advice of the hospital doctor.

- Older patients were more likely than younger patients to say they did not know or had no preference for less invasive surgery as opposed to a lower risk of post-operative complications.

**Variations between patients with different health and carer status**

- Patients with a long term illness or disability were more likely to express a preference for OSR and less likely to express a preference for EVAR.
- Patients who provided care were markedly more likely to express a preference for EVAR, more likely to prefer less invasive surgery and slightly less likely to show concern about the risk of post-operative complications than patients who did not have care responsibilities.

Appendix One: the questionnaire

Appendix Two: frequency tables for all questions

Appendix Three: tables of all cross tabulations to explore variations between different groups of patients

Please contact Picker Institute Europe for details of how to access these documents.

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