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Design of new patient-reported outcome measures to assess quality of life, symptoms and treatment satisfaction in patients with abdominal aortic aneurysm

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Category: Original Article

Competing interests

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FOR REVIEW ONLY

Abstract

Introduction: No condition-specific patient-reported outcome measures existed for patients with abdominal aortic aneurysm (AAA). The aim of this work was to develop three questionnaires to assess quality of life (QoL), symptoms and treatment satisfaction in patients with AAA.

Method: Semi-structured interview techniques were used to explore patients' experiences of having AAA in a series of focus groups and in-depth interviews. The information gathered was used to inform design and selection of items for the new tools, with the overall structure of the new questionnaires based upon tools developed previously for patients with diabetes and other conditions.

Results: 54 patients (51 men; 3 women; mean age 71.9yrs) were recruited from 4 NHS Trusts to participate in focus groups or interviews, either whilst under surveillance or following AAA repair (using open or endovascular techniques).

The Aneurysm-Dependent Quality of Life Questionnaire (AneurysmDQoL) is an individualised measure of the impact of AAA on patients' QoL. 23 domains were chosen specifically for their relevance to patients with AAA with a further 2 overview items to assess overall QoL and the impact of AAA on QoL. The Aneurysm Symptom Rating Questionnaire (AneurysmSRQ) is a 44-item measure assessing physical and psychological symptoms reported by patients with AAA. The Aneurysm Treatment Satisfaction Questionnaire (AneurysmTSQ) contains 11 items, suitable for patients pre- and post-surgical intervention.

Conclusion: The iterative development process reported here has confirmed that these three new tools have good face and content validity for patients with AAA. Psychometric analyses assessing structure and construct validity of the tools will be reported separately.

Keywords

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3 Quality of life; aortic aneurysm; patient-reported outcome measure; treatment
4 satisfaction; symptoms; AneurysmDQoL; AneurysmSRQ; AneurysmTSQ
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8 **Introduction**

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11 In the UK, abdominal aortic aneurysms (AAA) affect 5-10% of men and 1.5% of
12 women between the ages of 65 and 79 and constitute a significant cause of
13 mortality in this age group.¹ Due to the risk of rupture, patients diagnosed with
14 AAA usually undergo elective repair once the aneurysm reaches threshold size
15 (5.5cm). Techniques of AAA repair have evolved significantly in recent years
16 with large numbers now treated with endovascular repair (EVAR) rather than
17 open repair (OR). As a result of these advances and rigorous Quality
18 Improvement Programmes, surgical morbidity and mortality have fallen
19 dramatically and these parameters are therefore less useful than previously as
20 the sole markers of surgical quality.² Additionally and importantly, measures of
21 quality of life (QoL), symptoms and treatment satisfaction allow evaluation of
22 outcomes from the patients' perspectives. This allows clinicians to target those
23 issues that are most important to patients and strive for even higher quality care
24 rather than simply avoiding adverse outcomes. For this reason the last few years
25 have seen the UK Department of Health embark on a nationwide initiative to
26 encourage the use of patient-reported outcome measures (PROMs), both in the
27 surgical specialties generally and more specifically in aortic aneurysm surgery.^{3 4}
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42 In the absence of a validated aneurysm-specific QoL measure, all previous
43 studies of QoL in patients with AAA have used generic tools. **Systematic review**
44 **of these studies demonstrated that there was no clear consensus about the**
45 **overall impact of AAA (or AAA repair) on QoL.⁵ Meta-analysis of existing data**
46 **did provide some additional clarification, suggesting that QoL may be negatively**
47 **impacted after AAA repair.⁶ However, the pattern of change over time**
48 **(particularly beyond 12 months post-intervention) and any differences between**
49 **OR and EVAR may have been obscured by the use of generic tools and**
50 **heterogeneity of data in the included studies.** Many of the studies used generic
51 health status measures instead of QoL instruments and it is important to
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3 distinguish between the two if we are not to be misled: health and QoL do not
4 necessarily improve/deteriorate in tandem.⁷ Furthermore, very little is known
5 about symptoms experienced or treatment satisfaction in these patients.
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10 The aim of this work was to design three new condition-specific questionnaires
11 based on the experiences of patients with AAA to provide robust, separate
12 assessments of QoL, symptoms, and treatment satisfaction for use in clinical
13 practice, audit and research.
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16 17 18 **Methods**

19 20 21 **Recruitment of patients**

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25 Patients were recruited from 4 English NHS Trusts: St George's University
26 Hospitals NHS Foundation Trust (London), North Bristol NHS Trust, Norfolk and
27 Norwich University Hospitals NHS Trust and Worcestershire Acute Hospitals
28 NHS Trust. All participants had undergone AAA repair within the preceding 24
29 months (OR or EVAR) or were enrolled in preoperative surveillance with an
30 aneurysm that was below the threshold size for intervention. Men and women
31 were invited and there was no age constraint. Only English-speaking patients
32 were invited to take part.
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40 41 **Focus groups**

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43 Patients were identified using a purposive sampling technique (maximum
44 variation) and assigned to focus groups with similar patients (i.e. all pre-
45 intervention or OR or EVAR). This was done to prevent confusion between
46 participants who had experienced different forms of treatment. The National
47 Research Ethics Service (NRES Committee – London Chelsea – 11/LO/1416)
48 approved the process of patient recruitment prior to the start of the study and
49 patients provided written consent at each stage.
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3 The number of focus groups was determined using a 'theme-saturation' model,
4 which dictates that no further focus groups are necessary once there are no new
5 themes being presented by participants.⁸ Focus groups were moderated by a
6 trainee vascular surgeon (GP) and a health psychologist with extensive
7 experience in questionnaire design (CB). A semi-structured format was used to
8 explore patients' experiences in relation to QoL, symptoms and treatment
9 satisfaction at each stage in the treatment pathway using open-ended questions.
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11 The discussion included diagnosis, surveillance, preoperative investigations and,
12 where applicable, intervention, recovery and follow-up. More sensitive topics
13 (such as bowel or sexual function) were not broached by the facilitators during
14 focus groups to avoid causing embarrassment to participants but were discussed
15 during in-depth interviews. Written notes and audio recordings were made
16 during each session to allow subsequent transcription.
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27 Transcripts underwent content analysis to allow identification of the themes
28 raised by group participants. Individual issues were listed and grouped into
29 themes, with continual re-evaluation after each group and addition of new
30 issues/themes as they emerged. Newly identified themes were then re-explored
31 in greater depth at subsequent focus groups. This process clarified when theme-
32 saturation had been reached and resulted in a single list of all aspects of QoL,
33 symptoms and treatment satisfaction that had been raised by the participants.
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35 (Table 2 - Supplementary material).
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41 42 **Questionnaire design**

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45 The themes identified during the focus groups then determined the aspects of
46 QoL, symptoms and treatment satisfaction that were included in drafts of the
47 three new questionnaires. To minimize the need for linguistic validation, the
48 wording and structure of questions in the new tools was based upon items from
49 existing questionnaires previously developed with other patient groups and
50 validated by CB as described below. The number of items in each of the new
51 questionnaires was not predetermined, but instead resulted from selection of
52 suitable items from a pre-existing item bank to address the domains relevant to
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3 patients with AAA. If no previous bank item existed (or could be adapted) to
4 cover a QoL domain raised in the focus groups, a new item was created with
5 specialist linguistic input (to facilitate future translations into other languages)
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7 before being tested in interviews.
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10 11 12 13 AneurysmDQoL

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15 The overall format of the AneurysmDQoL and many of the individual items were
16 based upon those in the Audit of Diabetes-Dependent Quality of Life (ADDQoL)
17 and associated questionnaires designed for use by people with other conditions.
18 The ADDQoL was designed by CB and colleagues to improve on previous
19 condition-specific measures which were not individualised and often contained a
20 mixture of items measuring symptoms, functional status and treatment
21 satisfaction, with a minority including items genuinely measuring QoL. The
22 ADDQoL is the most widely used of the various -DQoL measures and is
23 linguistically validated in more than 60 languages.⁹⁻¹⁷ The design of the ADDQoL
24 was influenced by the principles underpinning the SEIQoL (Schedule for the
25 Evaluation of Individual QoL) interview methodology.¹⁸ The guiding definition of
26 QoL provided by the ADDQoL, as with the SEIQoL, is 'how good or bad you feel
27 your life to be'. The SEIQoL allows respondents to select the aspects of their life
28 of importance for their QoL before rating them for quality, thereby providing an
29 *individualised* measure of QoL. The -DQoLs differ from the SEIQoL by being
30 condition-specific and questionnaire measures rather than a generic interview
31 tool but are similarly individualised in two different ways: first, a not applicable
32 option is provided for items that may not be applicable to everyone (eg working
33 life) and, secondly, a rating of the importance of each aspect of life is elicited as
34 well as a rating of the impact of the condition on that aspect of their life (see
35 figure 1). Thus each item consists of two rating scales to measure impact and
36 importance and the two scores are multiplied to give a Weighted Impact (WI)
37 score. . The AneurysmDQoL, thereby provides a personalised assessment of the
38 impact of AAA on an individual's QoL
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3 In addition, the AneurysmDQoL also includes two broad overview items. The
4 first asks respondents to rate their present QoL and the second asks how their
5 quality of life would be if they had not had an aneurysm.
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8 9 10 AneurysmSRQ

11 Question format of the AneurysmSRQ was based on tools developed previously
12 by CB and colleagues for patients with a number of long-term conditions.^{19 20}
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16 In the first part of each question, respondents are asked to indicate whether they
17 had experienced a particular symptom at all in recent weeks (defined as 'about
18 four weeks'). For those who had experienced that symptom, the second part of
19 the question asks how much it had bothered them. Responses to the second part
20 of the question are given using a 4-point scale from 'not at all' to 'a lot'.(Fig 2).
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25 26 27 AneurysmTSQ

28 The AneurysmTSQ was based on the Diabetes Treatment Satisfaction
29 Questionnaire (DTSQ) and associated questionnaires for other conditions.²¹⁻²⁶
30 For each question in the AneurysmTSQ, patients are asked to respond using a 7-
31 point scale where a higher score indicates greater satisfaction with treatment
32 (Fig. 3).
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38 Since questionnaires were to be tested in patient interviews, all patient-
39 identified issues were included in the initial drafts even if they were considered
40 to be uncommon or unrelated to having an aneurysm, or had only been
41 mentioned by one or two participants. Several additional items were also
42 incorporated into the drafts to assess more sensitive symptoms including bowel
43 function and sexual function, which may not have been mentioned by patients in
44 a focus-group setting, but where there is evidence to suggest that AAA or its
45 repair may have a negative impact.²⁷⁻²⁹
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52 53 **Pilot interviews and questionnaire refinement**

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3 In the next stage of development, the draft questionnaires were refined through
4 in-depth interviews. In these interviews, participants were asked to work
5 through each of the questionnaires in turn, reading the questions out and
6 'thinking aloud' so that interviewers could see when they were having difficulty
7 reading or comprehending an item. This technique has been well proven over
8 many years of developing similar tools.^{9 30} Participants were also given the
9 opportunity to identify any additional issues that they felt had not been covered
10 in the new tools.
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18 **Results**

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22 Nine focus groups were held during the initial phase of development (6 EVAR; 2
23 OR; 1 surveillance). In total, these involved 41 patients with AAA, with between
24 3 and 6 participants in each group. Though the majority of groups were with
25 EVAR patients for logistic reasons, theme saturation suggested no further groups
26 were necessary for either OR or surveillance patients. Thirteen in-depth
27 interviews were then carried out during the subsequent refinement process.
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32 (Table 1)
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35 **Aneurysm-Dependent Quality of Life Questionnaire (AneurysmDQoL)**

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39 In all of the focus groups for patients who had already undergone aneurysm
40 repair (OR or EVAR), there were reports of AAA-related issues that could have
41 negatively impacted their QoL (Table 2). Preoperative anxiety was particularly
42 prevalent, with participants mentioning this spontaneously in 8 of the 9 focus
43 groups and describing feelings of having a 'ticking time-bomb inside'. Anxiety
44 about surgical intervention was also noted.
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51 Participants in 2 groups (both EVAR) reported feelings of relief once their
52 aneurysm was repaired, using phrases such as 'I felt happy to be alive', 'I had a
53 near miss' and 'it was as if the bomb had been defused'. One patient (EVAR
54 group) also said that they valued each day more since having the aneurysm
55 repaired. However, relief of anxiety following intervention was certainly not
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3 universal. With many having experienced no preoperative symptoms,
4 participants in 4 groups (3 EVAR, 1 OR) expressed concerns about the possibility
5 of other occult illnesses and how they would ever know if any 'problem' were to
6 arise with their aneurysm repair.
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11 Another commonly arising theme was the impact of restricted activity on QoL.
12 This was mentioned in 6 groups (all EVAR) and largely related to patients feeling
13 that they had to limit their physical activity (as opposed to being physically
14 incapable of doing things). In a small subset of patients (e.g. commercial drivers)
15 there were financial implications due to being prohibited from working with an
16 untreated aneurysm. Other notable QoL themes raised by participants included
17 failure to return to preoperative levels of well-being following intervention;
18 impact on relationships with family members; and the fact that some patients
19 felt unprepared for the severity of the operation or complications when they
20 arose.
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30 The initial draft of the AneurysmDQoL contained 25 items in total. Following the
31 first 2 overview items, there were 23 domain-specific items addressing the
32 impact of AAA on multiple patient-identified aspects of life of importance for QoL
33 (Table 2). The final item on the questionnaire was a free-text question, to allow
34 patients to identify any other ways in which QoL is impacted by having had AAA.
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40 In-depth interviews resulted in several minor modifications to the
41 AneurysmDQoL. To improve patients' understanding of the stem question, the
42 wording was changed from 'If I had *not* had an aneurysm, my quality of life
43 would be...' to 'If I had never had an aneurysm...'. This was because a number of
44 participants misinterpreted this to be about how their quality of life would be if
45 they had not had an aneurysm *repair*, rather than the actual condition. For
46 example, some patients commented that if they had not had an aneurysm repair
47 they would be dead. The change to the wording improved participants'
48 understanding that the item was asking them to consider their QoL at time of
49 questionnaire completion and how they feel this would be different if they had
50 never had an aneurysm (whether repaired or not). Wording of the discomfort
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3 item was also changed, with participants finding the words 'physical discomfort'
4 easier to understand than 'bodily discomfort'.
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8 In a draft version of the AneurysmDQoL, there were three items relating to
9 cognitive function, which asked about 'memory', 'ability to concentrate' and
10 'ability to think quickly and clearly'. However, a composite form of this question
11 ultimately proved to detect as much impact as the three separate items taken
12 together and the composite item was therefore retained in their place (Item 22,
13 Appendix 1).
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19 None of the participants identified any additional aneurysm-related QoL issues
20 that were not already covered by the questionnaire. The final version contained
21 23 domain-specific items plus two overview items and a single free-text question
22 about any other ways that QoL is affected. One domain specific item ('The
23 amount I value each day') was ultimately removed during validation (to be
24 reported separately), resulting in 22 domain specific items.
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31 32 **Aneurysm Symptom Rating Questionnaire (AneurysmSRQ)** 33

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35 During focus groups, patients reported a wide range of symptoms that they
36 attributed to their aneurysm or its repair (Table 2). The most common of these
37 was pain, with leg pain, lower back pain, abdominal pain and buttock pain being
38 the most common (reported in 7, 5, 4 and 4 groups respectively). Other lower
39 limb symptoms included swelling, numbness, weakness and heaviness. In
40 addition to pain and limb symptoms, there were also a number of more
41 generalized symptoms that were frequently mentioned. Participants in 7 of the 8
42 postoperative groups (all 6 EVAR groups and 1 OR group) commented on a
43 feeling of marked lethargy for many months post-intervention. Low mood and
44 weight loss were also noted in 4 groups each, with general weakness, decreased
45 activity, profuse sweating, significant bruising, and poor appetite each
46 mentioned in at least two groups.
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3 The initial draft of the AneurysmSRQ comprised 43 items asking about the
4 specific physical, mental and psychological symptoms that were identified
5 during focus groups plus 3 free-text items allowing patients to identify any
6 additional symptoms that had not been covered elsewhere. Interviews provided
7 the opportunity to discuss more sensitive topics that were not raised during
8 focus groups. The interviews confirmed that these issues were experienced by
9 patients and warranted inclusion in the AneurysmSRQ with more than 40% of
10 interviewees reporting some upset in gastrointestinal function and over 60%
11 reporting symptoms related to sexual dysfunction. The interview stage also
12 resulted in the amendment or removal of several items that participants found
13 difficult to understand or were not deemed relevant. These included those
14 relating to general muscle pains, hallucinations, lumps under the skin and wound
15 infection. A number of completely new items were also added after being
16 identified as important by interviewees. These included avoidance of sexual
17 activity (as distinct from problems with sexual function and loss of interest in sex
18 which were in the original draft), feeling faint/lightheaded, difficulty thinking
19 quickly and clearly and changes in bowel function. Furthermore, items were
20 reordered to group symptoms into themes (e.g. gastrointestinal symptoms or
21 pain etc.) so that the questionnaire followed a more logical sequence. The final
22 version contained 44 items and 2 blank items for free-text describing any
23 additional symptoms.
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40 **Aneurysm Treatment Satisfaction Questionnaire (AneurysmTSQ)**

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44 When it came to discussion of treatment satisfaction, a range of issues were
45 highlighted (Table 2), though the most frequently reported concern was that
46 patients didn't feel it had been made clear to them how serious their condition
47 was. This related to a lack of information about likely side-effects (as opposed to
48 complications covered in the preoperative consent process) and how much
49 intervention might affect them both mentally and physically. Similarly, patients
50 in six of the nine focus groups felt that that they had been given insufficient
51 information about whether they should avoid physical exertion and whether
52 certain activities, such as air travel, were safe pre- or postoperatively. Patients
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3 also frequently commented (6 of 9 groups) that they had not been given any
4 choice about the type of intervention they would have for their aneurysm (i.e. OR
5 or EVAR) and one elderly woman patient was distressed that she had had an OR
6 and would have preferred EVAR. Some appeared not to be concerned by the lack
7 of choice, however, and felt that the surgeon knew best and that they would not
8 have minded what sort of operation they had. Other reported factors reducing
9 satisfaction included insufficient time for consent, little contact with the surgeon
10 and a lack of feedback about scan results. Interestingly, however, patients
11 generally described feeling positively reassured by follow-up scans and clinic
12 visits, rather than seeing them as a burden or source of anxiety.
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21 In the AneurysmTSQ, patients are asked to evaluate their experiences of AAA
22 treatment (including any monitoring or surveillance) over the preceding few
23 weeks. The initial draft contained 15 items related to specific elements of
24 treatment and monitoring, including overall treatment, convenience, discomfort,
25 information, feedback, support, follow-up, demands of treatment and
26 monitoring, understanding and satisfaction with *type* of operation (i.e. OR or
27 EVAR). As in the AneurysmDQoL and AneurysmSRQ, there was also a final open
28 question to allow respondents to mention any particular areas of satisfaction or
29 dissatisfaction that had not already been covered.
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38 Four items were removed from the AneurysmTSQ following in-depth interviews.
39 Three of these were poorly understood by patients or unnecessarily repetitive
40 and related to demands of treatment; flexibility of treatment and how well they
41 felt the operation had worked. The fourth item to be removed asked about
42 whether patients would chose to undergo the same type of intervention again
43 should it become necessary. Unfortunately, this was found to cause concern
44 amongst participants as they felt it was suggesting that further intervention was
45 likely. It was also decided that this aspect of satisfaction was covered in a
46 separate item that asked whether patients would encourage others to have the
47 same kind of treatment for their aneurysm.
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3 Once again, despite prompting, none of the interviewees highlighted any sources
4 of satisfaction or dissatisfaction that had not already been covered by the
5 questionnaire. The final version therefore contained 11 items and a single open
6 question about any unmentioned issues.
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10 11 **Discussion**

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15 The focus groups and interviews provided significant new qualitative data
16 relating to patients' experiences of AAA and AAA repair. This has identified the
17 aspects of QoL, symptoms and treatment satisfaction that are most relevant to
18 these patients and led to the design of three comprehensive new outcome
19 measures.
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25 Over and above the health status outcomes described elsewhere in the literature,
26 patients involved in this study have identified a number of previously
27 unrecognized QoL issues associated with AAA. These included persistent
28 postoperative anxiety in both EVAR *and* OR cohorts, restrictions of activity,
29 avoidance of sexual activity, impact on family life and loss of financial
30 independence. Importantly, with the exception of anxiety, these newly identified
31 themes are not addressed at all by the generic measures of health status (such as
32 the SF36 and EQ-5D) that have commonly been used to assess patient-reported
33 outcomes in this patient group.^{31 32} This emphasizes the need for the new tools
34 - and for further study using these new tools - so that clinicians and patients can
35 together make truly informed decisions about their care.
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45 Patients described a wide range of symptoms and aspects of treatment that
46 might influence their QoL. Whilst some of these symptoms may not be directly
47 related to AAA or its repair, a conscious decision was made to retain all
48 symptoms that had been mentioned by patients in the questionnaire until a
49 much larger data collection has been undertaken. At that point it may be
50 possible to remove items if there is robust evidence that they are unrelated to
51 AAA.
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3 Whilst postoperative pain – particularly affecting the lower limbs - has been
4 described previously, what was unexpected here was that persistent pain and
5 lethargy seemed to be reported as frequently after EVAR as after OR. This differs
6 from previous evidence suggesting that OR has greater long-term physical
7 impact than EVAR.³³ Whilst the data presented here are qualitative rather than
8 quantitative, they certainly suggest that this aspect of recovery after AAA repair
9 warrants further investigation.
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16 The suggestion that AAA is a largely asymptomatic condition *prior* to
17 intervention³⁴ is supported by the fact that most of the patients in our cohort did
18 not describe overt physical symptoms preoperatively. However, that is not to say
19 that having an aneurysm had no negative impact on their QoL during this period
20 of surveillance. In the absence of major physical symptoms, the impact of AAA
21 on QoL appears to be centred around anxiety in the preoperative phase. Though
22 this may have been anticipated, what was less expected was that OR and EVAR
23 patients reported persistent anxiety *after* intervention. In the open-repair
24 group, a number of patients also expressed concerns about the relative lack of
25 follow-up and felt as though they had been left to cope alone very soon after a
26 major operation. Indeed, patients who had undergone EVAR generally reported
27 feeling reassured by follow-up scans, rather than seeing them as a burden or a
28 source of anxiety. This is contrary to previous assumptions that repetitive
29 follow-up after EVAR might cause patients to worry that they were not ‘fixed’ or
30 that CT surveillance might lead to concerns about radiation exposure.^{35 36} It also
31 highlights the need for more detailed study of this area, since awareness of such
32 patient views might influence the current trend towards more rapid hospital
33 discharge and early cessation of follow-up. At the very least it might allow
34 clinicians to guide patients’ expectations more effectively.
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50 Guiding patients’ expectations about treatment is clearly a very important part of
51 the patient-doctor interaction, and the treatment satisfaction issues described by
52 participants were often related to communication and the provision of
53 information. Patients were often unclear about the nature and severity of their
54 condition, whether they should restrict their day-to-day activity, and the
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3 likelihood of side-effects and complications. Though communication issues are
4 a common source of dissatisfaction in healthcare,³⁷ the identification of specific
5 deficiencies in this setting has highlighted clear targets for improvements in
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8 practice.
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11 Though a small number of changes were made to the newly designed
12 questionnaires during the interview phase, they were generally well understood
13 from the outset,. They were acceptable to (and welcomed by) patients and
14 proved to have good face- and content-validity. Items relating to the more
15 sensitive topics little discussed in the focus groups also proved to be highly
16 relevant and these topics therefore warrant further quantitative investigation in
17 a larger group of patients. The QoL and symptom measures are suitable for all
18 AAA patients investigated to date and psychometric validation (reported
19 elsewhere) has confirmed that the Treatment Satisfaction Questionnaire has
20 separate subscales suitable for patients pre- or post-intervention and at any of
21 the time-points studied (i.e. whilst under preoperative surveillance and
22 postoperatively from 6-weeks to well beyond 12 months).³⁸
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33 Significant efforts were made to include a representative sample of patients by
34 involving multiple centres and OR and EVAR patients, both pre- and post-
35 intervention. However, it is recognized that the ratio of male to female
36 participants was higher than might be expected based on the natural prevalence
37 of the condition. This was partly because more men than women had
38 undergone AAA repair within the preceding two years at the centres involved in
39 the study. The number of female participants was also limited by simple logistic
40 considerations such as whether they were readily contactable or available on the
41 dates of the focus groups or interviews. Nonetheless, the deliberate retention of
42 'free text' items in the final versions of each questionnaire will ensure that
43 patients have the opportunity to raise any issues that have not been covered
44 within the questionnaires to date.
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55 This paper reports the design of three new questionnaires to assess QoL
56 (AneurysmDQoL), symptoms (AneurysmSRQ) and treatment satisfaction
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3 (AneurysmTSQ) among patients with AAA. Having been developed with patient
4 involvement at every stage, these new questionnaires are believed to be highly
5 representative of the issues experienced by these patients. Psychometric
6 evaluation (to be reported separately) has confirmed their structure, reliability
7 and suitability for use in this patient group and they are now ready for wider
8 clinical use in order to improve our understanding of the impact of AAA and AAA
9 repair.³⁸
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16 Access to the questionnaires: please visit www.healthpsychologyresearch.com
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18

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35
36 Miss Jo Blundell (St George's University Hospitals NHS Foundation Trust)
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42 **References**

- 43
44
45 1. Lucarotti M, Shaw E, Poskitt K, Heather B. The Gloucestershire Aneurysm
46 Screening Programme: the first 2 years' experience. *Eur J Vasc Endovasc*
47 1993; 7 (4): 397-401.
48
49 2. Waton S, Johal A, Groene O, Cromwell D, Mitchell D, Loftus IM. Outcomes after
50 elective repair of infra-renal abdominal aortic aneurysm. London: *The*
51 *Royal College of Surgeons of England*, 2013.
52
53 3. Department of Health. Equity and Excellence: Liberating the NHS. 2010. Sep 01
54 2013 [https://www.gov.uk/government/uploads/system/uploads/attach](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213823/dh_117794.pdf)
55 [ment_data/file/213823/dh_117794.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213823/dh_117794.pdf)
56
57 4. The Vascular Society of Great Britain and Ireland. National Abdominal Aortic
58 Aneurysm Quality Improvement Programme Report. London, 2012.
59
60

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2
3 5. Peach G, Holt P, Loftus I, Thompson MM, Hinchliffe R. Questions remain about
4 quality of life after abdominal aortic aneurysm repair. *J Vasc Surg* 2012;
5 56 (2): 520-527.
- 6
7 6. Coughlin PA, Jackson D, White AD, Bailey MA, Farrow C, Scott DJA et al.
8 Meta-analysis of prospective trials determining the short- and mid-term
9 effect of elective open and endovascular repair of abdominal aortic
10 aneurysms on quality of life. *Brit J Surg* 2013; 100 (4): 448-455.
- 11 7. Bradley C. Importance of differentiating health status from quality of life.
12 *Lancet*, 2001: 7-8.
- 13 8. Rabiee F. Focus-group interview and data analysis. *P Nutr Soc* 2004; 63 (4):
14 655-660.
- 15 9. Bradley C, Todd C, Gorton T, Symonds E, Martin A, Plowright R. The
16 development of an individualized questionnaire measure of perceived
17 impact of diabetes on quality of life: the ADDQoL. *Qual Life Res* 1999: 79-
18 91.
- 19 10. Bradley C, Speight J. Patient perceptions of diabetes and diabetes therapy:
20 assessing quality of life. *Diabetes Metab Res* 2002: S64-69.
- 21 11. Bradley C. Design of a renal-dependent individualized quality of life
22 questionnaire. *Adv Perit Dial*, 1997: 116-120.
- 23 12. Mitchell J, Bradley C. Design of an individualised measure of the impact of
24 macular disease on quality of life (the MacDQoL). *Qual Life Res* 2004:
25 1163-1175.
- 26 13. Woodcock A, Bradley C, Plowright R, Ffytche T, Kennedy-Martin T, Hirsch A.
27 The influence of diabetic retinopathy on quality of life: interviews to guide
28 the design of a condition-specific, individualised questionnaire: the
29 RetDQoL. *Patient Educ Couns* 2004: 365-383.
- 30 14. McMillan CV, Bradley C, Woodcock A, Razvi S, Weaver JU. Design of new
31 questionnaires to measure quality of life and treatment satisfaction in
32 hypothyroidism. *Thyroid* 2004: 916-925.
- 33 15. McMillan CV, Bradley C, Gibney J, Russell-Jones DL, Sönksen PH. Preliminary
34 development of the new individualized HDQoL questionnaire measuring
35 quality of life in adult hypopituitarism. *J Eval Clin Pract* 2006: 501-514.
- 36 16. Speight J, Sinclair AJ, Browne JL, Woodcock A, Bradley C. Assessing the impact
37 of diabetes on the quality of life of older adults living in a care home:
38 validation of the ADDQoL Senior. *Diabetic Med* 2013; 30 (1): 74-80.
- 39 17. Wee H-L, Tan C-E, Goh S-Y, Li S-C. Usefulness of the Audit of Diabetes-
40 Dependent Quality-of-Life (ADDQoL) questionnaire in patients with
41 diabetes in a multi-ethnic Asian country. *PharmacoEconomics* 2006; 24
42 (7): 673-682.
- 43 18. Hickey AM, Bury G, O'Boyle CA, Bradley F, O'Kelly FD, Shannon W. A new
44 short form individual quality of life measure (SEIQoL-DW): application in
45 a cohort of individuals with HIV/AIDS. *Brit Med J* 1996; 313 (7048): 29-
46 33.
- 47 19. McMillan C, Bradley C, Razvi S, Weaver J. Evaluation of new measures of the
48 impact of hypothyroidism on quality of life and symptoms: the ThyDQoL
49 and ThySRQ. *Value Health* 2008: 285-294.
- 50 20. Taylor MD HT, Ward H, McBride J, Yap I, Bradley C, . Evaluation of the
51 hypoglycaemia symptom rating questionnaire ('HypoSRQ') and its
52
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3 relationship with hypoglycaemic episodes measured using continuous
4 glucose monitoring [abstract]. *Diabetes Technol The* 2013; 15: A23-A24.
- 5 21. Bradley C, Lewis KS. Measures of psychological well-being and treatment
6 satisfaction developed from the responses of people with tablet-treated
7 diabetes. *Diabetic Med* 1990: 445-451.
- 8 22. Barendse SM, Speight J, Bradley C. The Renal Treatment Satisfaction
9 Questionnaire (RTSQ): a measure of satisfaction with treatment for
10 chronic kidney failure. *Am J Kidney Dis* 2005: 572-579.
- 11 23. Brose LS, Bradley C. Psychometric development of the retinopathy treatment
12 satisfaction questionnaire (RetTSQ). *Psychol Health Med* 2009: 740-754.
- 13 24. Taback NA, Bradley C. Validation of the genital herpes treatment satisfaction
14 questionnaire (GHerpTSQ) in status and change versions. *Qual Life Res*
15 2006: 1043-1052.
- 16 25. Woodcock A, Bradley C. Validation of the HIV treatment satisfaction
17 questionnaire (HIVTSQ). *Qual Life Res* 2001: 517-531.
- 18 26. McMillan C, Bradley C, Razvi S, Weaver J. Psychometric Evaluation of a New
19 Questionnaire Measuring Treatment Satisfaction in Hypothyroidism: The
20 ThyTSQ. *Value Health* 2006; 9 (2): 132-139.
- 21 27. Letterstål A, Eldh AC, Olofsson P, Forsberg C. Patients' experience of open
22 repair of abdominal aortic aneurysm--preoperative information, hospital
23 care and recovery. *J Clin Nurs* 2010; 19 (21-22): 3112-3122.
- 24 28. Miedema BW, Schillie S, Simmons JW, Burgess SV, Liem T, Silver D. Small
25 bowel motility and transit after aortic surgery. *J Vasc Surg* 2002; 36 (1):
26 19-24.
- 27 29. Pettersson M, Mattsson E, Bergbom I. Prospective follow-up of sexual
28 function after elective repair of abdominal aortic aneurysms using open
29 and endovascular techniques. *J Vasc Surg* 2009; 50 (3): 492-499.
- 30 30. McMillan CV, Honeyford RJ, Datta J, Madge NJH, Bradley C. The development
31 of a new measure of quality of life for young people with diabetes
32 mellitus: the ADDQoL-Teen. *Health Qual Life Out* 2004; 2: 61.
- 33 31. Rabin R, de Charro F. EQ-5D: a measure of health status from the EuroQol
34 Group. *Ann Med* 2001; 33 (5): 337-343.
- 35 32. Ware JE, Sherbourne CD. The MOS 36-item short-form health survey (SF-36).
36 I. Conceptual framework and item selection. *Med Care* 1992; 30 (6): 473-
37 483.
- 38 33. Prinssen M BE, Blankensteijn J D, DREAM trial participants. Quality of life
39 endovascular and open AAA repair. Results of a randomised trial. *Eur J*
40 *Vasc Endovasc* 2004; 27 (2): 121-127.
- 41 34. Cronenwett JL, Johnston W, Rutherford RB. *Rutherford's Vascular Surgery*:
42 W.B. Saunders Company, 2010.
- 43 35. Bell PRF. Endovascular repair of abdominal aortic aneurysms. *Vasc Med*
44 2002; 7 (4): 253-255.
- 45 36. Olberg Eide TM, Romundstad P, Klepstad P, Myhre HO. Health-related quality
46 of life in long term-survivors of thoracoabdominal aortic aneurysm repair.
47 *J Vasc Nurs* 2005; 23 (3): 88-94.
- 48 37. Meryn S. Improving doctor-patient communication. Not an option, but a
49 necessity. *Brit Med J* 1998; 316 (7149): 1922.
- 50 38. Romaine J, Peach G, Thompson MM, Hinchliffe RJ, Bradley C. Psychometric
51 development of three new condition-specific questionnaires to measure
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3 quality of life (Aneurysm-DQoL), symptoms (Aneurysm-SRQ) and
4 treatment satisfaction (Aneurysm-TSQ) of individuals with abdominal
5 aortic aneurysms [abstract]. *Qual Life Res* 2015; 24 (1): 41-42.
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5 (a)	<p>If I had never had an aneurysm, physically I could do:</p> <p><input type="checkbox"/>-3 <input type="checkbox"/>-2 <input type="checkbox"/>-1 <input type="checkbox"/>0 <input type="checkbox"/>+1</p> <p>very much more much more a little more the same less</p>
(b)	<p>For me, how much I can do physically is:</p> <p><input type="checkbox"/>+3 <input type="checkbox"/>+2 <input type="checkbox"/>+1 <input type="checkbox"/>0</p> <p>very important important somewhat important not at all important</p>

Fig 1 – Example of question format and scoring for the Aneurysm-Dependent Quality of Life Questionnaire (AneurysmDQoL) (scoring shown for information only – not usually visible).
254x190mm (72 x 72 DPI)

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1 (a)	Have you felt unusually tired or lethargic in recent weeks? No <input type="checkbox"/> If <i>no</i> , go to next symptom Yes <input type="checkbox"/> If <i>yes</i> , complete (b)
(b)	If yes , how much has this bothered you? <input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> moderately <input type="checkbox"/> a lot

Fig 2 – Example item from the Aneurysm Symptom Rating Questionnaire (AneurysmSRQ).
254x190mm (72 x 72 DPI)

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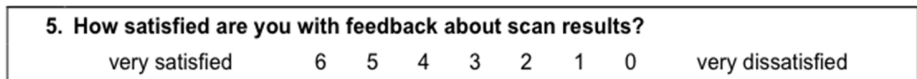


Fig. 3 - Example item from the Aneurysm Treatment Satisfaction Questionnaire (AneurysmTSQ).
254x190mm (72 x 72 DPI)

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Table 1 – Patient/group demographics

	OR	EVAR	Surveillance
Number of focus groups	2	6	1
Number of focus group participants (male/female)	8 (6/2)	29 (28/1)	4 (4/0)
Number of interviewees (male/female)	3 (3/0)	6 (6/0)	4 (4/0)
Mean age yrs (range)	74.9 (65.3-86.3)	72.9 (61.4-88.2)	73.7 (64.9-84.2)
Mean time since intervention (months) (range)	8.0 (3-20)	5.7 (2-13)	n/a

Table 2 – Aspects of QoL, symptoms and treatment satisfaction identified during focus groups

Outcome	No. of groups mentioning	Example quote
Quality of Life		
Preoperative anxiety	8	- 'what QoL could I have with a time-bomb inside of me'
- Fear of rupture	8	- I waited 18 months and it was getting bigger and bigger and I was on edge waiting for the results
- Increasing anxiety as aneurysm grew	5	
- Waiting indefinitely for intervention	2	
- Anxiety about intervention itself	2	- 'I didn't worry at first, but when it was said that action was needed I got worried'
Postoperative anxiety	4	'once you have one thing that was completely symptomless you wonder what else you might have wrong with you'
Restrictions of activity	4	'I was terrified to do anything'
Impact on work	3	'I got through all the tests to be a truck driver and they sent me for all these tests and then doc said you won't get the job, you've got an aneurysm'
Relief of anxiety postop	3	'When I had the op it felt like someone had defused the bomb'
Impact on social life	1	'I find it overwhelming in a crowded room since the operation. Prior to that you couldn't keep me out of a crowded pub.' 'I don't feel sociable'
Financial implications	1	Commercial driver: 'I'm now restricted to a 1 year [driving] licence.'
Loss of independence	1	'I don't go out so much since the operation'
Not returned to 'normal'	1	'Nothing was the same [after the operation] and nothing still is'
Not prepared for severity	1	'...it didn't feel like a serious operation'
Increased awareness of own mortality	1	'[I had a] sense of mortality...You're going to die one day'
Positive impact on relationships	1	'Quality of life, in some respects, has improved. I spend more time interacting with family and value each day more than before.'
Symptoms		
Lethargy	7	'Had no get up and go'
Leg pain	7	'Aches in legs all the time now'
Back pain	5	'I get lower back pain'
Abdominal pain	4	'Had a routine examination (scan) for stomach pains and found AAA'
Buttock pain	4	'I had some pain in my left buttock for some time'
Calf pain	4	'I get aching in the legs sometimes - claves below the knees'
Low mood	4	'I got so depressed I had to have anti-depressants afterwards'
Weight loss	4	'I lost a lot of weight...I've lost a stone'
Bruising	3	'I had a lot of bruising after - black and blue to the knees'
Leg swelling	3	'had a small amount of swelling and the nurse said it would go down'
Leg numbness	3	'I had this strange numbness'
Decreased activity	2	'Physical activity is down - perhaps because I'm thinking I shouldn't overdo it.'

General weakness	2	'I feel a lot weaker to what I used to'
Profuse sweating	2	'boiling hot, then sweating, then chills'
Poor appetite	2	'I would fantasize about food but if it was put in front of me I thought oh no'
Poor balance	1	'The legs worked but felt different – wobbly like I was drunk.'
Leg weakness	1	'The right leg is not as strong as the left. That's new since the op'
Leg heaviness	1	'...my right leg was really heavy, like a lump of lead'
Poor cognitive function	1	'I put Christmas cards there and list there and couldn't put the two together'
Panic attacks	1	'I had panic attacks for a couple of weeks – and that's not something I've ever had before.'
Hallucinations	1	'I had hallucinations I had been taken by a group and they were going to kill me.'
Changes in bowel function	1	'I went to my doctor because I had... a lot of flatulence that was causing discomfort.'
Changes in urinary function	1	'...the next day I had waterwork problems and still have'
Wound problems	1	'...wound from second op bled and bled and oozed congealed blood.'
Treatment satisfaction		
Unclear about risks (e.g. air travel)	6	'No one said what you can do and what you can't.'
No choice in type of operation	6	'...the stent option wasn't mentioned.'
Not clear how serious AAA was	5	'No mention of taking it easy until after the op...that was the first I knew how serious it was.'
Scans reassuring NOT a burden	5	'It's a pleasure coming here and being told you're OK.'
Complications sometimes confusing	3	'...was told I had a bent limb. I didn't understand..'
Insufficient time to discuss diagnosis	3	'There wasn't a lot of time to ask questions.'
Familial risks unclear	3	'[The information leaflet] didn't deal with the risks of having an aneurysm – risk factors, genetics, smoking.'
Felt unready to go home	3	'I didn't feel ready to go home...I was more knackered than I expected to be.'
Little contact with surgeon	2	'Although you get the scan you don't automatically get [to see] the consultant.'
No warning about side-effects	2	'There was a lack of information about any likely adverse outcomes of the op.' 'I had no appreciation of what I would feel like after this operation.'
Poor understanding of AAA	2	'If the AAA bursts the chances of surviving are pretty slim – but that is something I found out from the web, not from here.' 'How do they do it? Where does the blood go? I didn't really get an answer I understood.'
Little time for consent	2	'It would have been better to have had the consent form sooner.'
Insufficient feedback about scans	2	'...when they scan you they don't tell you [the results] – the operator of the scanner. You have to make an appointment.'
Hospital stay too long	1	'They kept me in for a day longer than I felt was needed'
Postop wound management unclear	1	'I wasn't sure when to take the dressings off.' 'Some hospitals don't tell you what to do but say they will write to the GP and

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		patients can talk to them.'
Insufficient follow-up / support	1	'[I] objected to being cut out of the physiotherapists list without seeing me.'
Local f/u would be preferable	1	'The only thing was can we have scans at [local hospital] because it's so much closer to home.'
Worried about radiation in theatre	1	'...worried...how much radiation I was going to get'

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Appendix 1 - Domains covered in the final development versions of the 3 new tools:

AneurysmDQoL	
1. leisure activities	
2. working life	
3. local or long distance journeys	
4. holidays	
5. physical ability	
6. family life	
7. friendships and social life	
8. personal relationships	
9. sex life	
10. getting out and about	
11. household tasks	
12. being able to do things for others	
13. enjoyment of food:	
14. feelings about the future	
15. financial situation	
16. dependence on others	
17. health	
18. the amount people fuss or worry about me	
19. energy	
20. physical discomfort	
21. anxiety	
22. ability to think clearly, concentrate and/or remember things	
23. The amount I value each day:	

List of symptoms covered in the final version of the AneurysmSRQ:	
1. tiredness	
2. headaches	
3. fevers	
4. pain/discomfort in calves	
5. pain/discomfort in thighs	
6. pain/discomfort in groin	
7. pain/discomfort in buttocks	
8. pain/discomfort in back	
9. abdominal pain/discomfort	
10. wound problems	
11. excessive bruising	
12. minor illnesses	
13. depression	
14. panic	
15. worried or nervous	
16. irritable or angry	
17. emotional or upset	
18. difficulty concentrating	
19. memory problems	

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3	20. difficulty thinking quickly and clearly
4	21. unsteady or uncoordinated
5	22. feeling dizzy, light-headed or faint
6	23. tingling or numbness in legs or feet
7	24. heaviness in legs
8	25. trembling (e.g. of limbs)
9	26. weakness in legs
10	27. swollen legs
11	28. lost interest in sex
12	29. avoided sexual activity
13	30. problems with sexual function
14	31. excessive sweating
15	32. episodes of feeling too cold or too hot
16	33. sleep problems
17	34. general weakness
18	35. poor appetite
19	36. weight loss
20	37. weight gain
21	38. indigestion or heartburn
22	39. nausea or vomiting
23	40. excessive flatulence or belching
24	41. bloating
25	42. diarrhoea
26	43. constipation
27	44. difficulty urinating
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33	Aspects of treatment covered in the final version of the AneurysmTSQ:
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36	1. aneurysm treatment (including monitoring)
37	2. convenience of treatment (including monitoring)
38	3. bothered by any discomfort or pain
39	4. information provided
40	5. ... feedback about scan results
41	6. amount of support from nurses, doctors and other clinical staff
42	7. understanding of the treatment (including any operation/monitoring)
43	8. length of stay in hospital
44	9. side effects of the treatment
45	10. post-operative follow-up
46	11. likely to encourage others to have the same kind of treatment
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AneurysmDQoL (Aneurysm-Dependent Quality of Life)

This questionnaire asks about your quality of life – in other words how good or bad you feel your life to be.

Please put an “X” in the box that best indicates your response for each item.

What we would like to know is how you feel about your life now.

I	In general, my present quality of life is:						
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	excellent	very good	good	neither good nor bad	bad	very bad	extremely bad

Now we would like to know how your quality of life is affected by having had an aortic aneurysm, its treatment (including monitoring) and/or any side effects you may have.

II	If I had never had an aneurysm, my quality of life would be:				
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	very much better	much better	a little better	the same	worse

Please respond to the more specific questions on the following pages. For each aspect of life described, you will find two parts:

For Part (a): put an "X" in one box to show how your aneurysm affects this aspect of your life;

For Part (b): put an "X" in one box to show how important this aspect of your life is to your quality of life.

1 (a)	If I had never had an aneurysm, I would enjoy my leisure activities:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		very much more	much more	a little more	the same	less
(b)	My leisure activities are:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
		very important	important	somewhat important	not at all important	

2	Are you currently working, looking for work or would you like to work?					
	Yes <input type="checkbox"/> If yes , complete (a) and (b).					
	No <input type="checkbox"/> If no , go straight to 3 (a).					
(a)	If I had never had an aneurysm, my working life would be:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		very much better	much better	a little better	the same	worse
(b)	For me, having a working life is:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
		very important	important	somewhat important	not at all important	

3 (a)	If I had never had an aneurysm, local or long distance journeys would be:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		very much easier	much easier	a little easier	the same	more difficult
(b)	For me, local or long distance journeys are:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
		very important	important	somewhat important	not at all important	

4	<p>Do you ever go on holiday or want to go on holiday?</p> <p>Yes <input type="checkbox"/> If yes, complete (a) and (b).</p> <p>No <input type="checkbox"/> If no, go straight to 5 (a).</p>
(a)	<p>If I had never had an aneurysm, my holidays would be:</p> <p style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> </p> <p style="text-align: center;"> very much better much better a little better the same worse </p>
(b)	<p>For me, holidays are:</p> <p style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> </p> <p style="text-align: center;"> very important important somewhat important not at all important </p>

5 (a)	<p>If I had never had an aneurysm, physically I could do:</p> <p style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> </p> <p style="text-align: center;"> very much more much more a little more the same less </p>
(b)	<p>For me, how much I can do physically is:</p> <p style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> </p> <p style="text-align: center;"> very important important somewhat important not at all important </p>

6	<p>Do you have any family / relatives?</p> <p>Yes <input type="checkbox"/> If yes, complete (a) and (b).</p> <p>No <input type="checkbox"/> If no, go straight to 7(a).</p>
(a)	<p>If I had never had an aneurysm, my family life would be</p> <p style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> </p> <p style="text-align: center;"> very much better much better a little better the same worse </p>
(b)	<p>My family life is:</p> <p style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> </p> <p style="text-align: center;"> very important important somewhat important not at all important </p>

7 (a)	<p>If I had never had an aneurysm, my friendships and social life would be:</p> <p style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> </p> <p style="text-align: center;"> very much better much better a little better the same worse </p>
(b)	<p>My friendships and social life are:</p> <p style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> </p> <p style="text-align: center;"> very important important somewhat important not at all important </p>

1 2 3 4 5 6	<p>8 Do you have or would you like to have a close personal relationship (e.g. husband / wife, partner)?</p> <p>Yes <input type="checkbox"/> If yes, complete (a) and (b).</p> <p>No <input type="checkbox"/> If no, go straight to 9.</p>
7 8 9 10	<p>(a) If I had never had an aneurysm, my closest personal relationship would be:</p> <p><input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>very much better much better a little better the same worse</p>
11 12 13 14 15	<p>(b) For me, having a close personal relationship is:</p> <p><input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>very important important somewhat important not at all important</p>

16 17 18 19 20 21 22	<p>9 Do you have or would you like to have a sex life?</p> <p>Yes <input type="checkbox"/> If yes, complete (a) and (b).</p> <p>No <input type="checkbox"/> If no, go straight to 10 (a).</p>
23 24 25 26 27	<p>(a) If I had never had an aneurysm, my sex life would be:</p> <p><input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>very much better much better a little better the same worse</p>
28 29 30 31 32	<p>(b) For me, having a sex life is:</p> <p><input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>very important important somewhat important not at all important</p>

33 34 35 36 37 38	<p>10 (a) If I had never had an aneurysm, getting out and about would be:</p> <p><input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>very much easier much easier a little easier the same more difficult</p>
39 40 41 42 43	<p>(b) For me, getting out and about is:</p> <p><input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>very important important somewhat important not at all important</p>

44 45 46 47 48 49 50	<p>11 (a) If I had never had an aneurysm, I could handle my household tasks:</p> <p><input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>very much better much better a little better the same worse</p>
51 52 53 54 55	<p>(b) Handling my household tasks is:</p> <p><input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>very important important somewhat important not at all important</p>

12 (a)	If I had never had an aneurysm, I could do things for others as I wish:				
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	very much better	much better	a little better	the same	worse
(b)	For me, doing things for others is:				
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	very important	important	somewhat important	not at all important	

13 (a)	If I had never had an aneurysm, I would enjoy food:				
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	very much more	much more	a little more	the same	less
(b)	My enjoyment of food is:				
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	very important	important	somewhat important	not at all important	

14 (a)	If I had never had an aneurysm, my feelings about the future (e.g. worries, hopes) would be:				
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	very much better	much better	a little better	the same	worse
(b)	My feelings about the future are:				
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	very important	important	somewhat important	not at all important	

15 (a)	If I had never had an aneurysm, my financial situation would be:				
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	very much better	much better	a little better	the same	worse
(b)	My financial situation is:				
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	very important	important	somewhat important	not at all important	

16 (a)	If I had never had an aneurysm, I would have to depend on others (when I do not want to):				
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	very much less	much less	a little less	the same	more
(b)	For me, not having to depend on others is:				
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	very important	important	somewhat important	not at all important	

17 (a)	If I had never had an aneurysm, my health would be:				
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	very much better	much better	a little better	the same	worse
(b)	For me, my health is:				
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	very important	important	somewhat important	not at all important	

18 (a)	If I had never had an aneurysm, people would fuss or worry about me (when I do not want them to):				
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	very much less	much less	a little less	the same	more
(b)	For me, not having others fussing or worrying about me is:				
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	very important	important	somewhat important	not at all important	

19 (a)	If I had never had an aneurysm, the amount of energy I have would be:				
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	very much more	much more	a little more	the same	less
(b)	How much energy I have is:				
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	very important	important	somewhat important	not at all important	

20 (a)	If I had never had an aneurysm, the amount of physical discomfort I have would be:				
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	very much less	much less	a little less	the same	more
(b)	For me, not having physical discomfort is:				
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	very important	important	somewhat important	not at all important	

21 (a)	If I had never had an aneurysm, the amount of anxiety I have would be:				
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	very much less	much less	a little less	the same	more
(b)	For me, not being anxious is:				
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	very important	important	somewhat important	not at all important	

22 (a)	<p>If I had never had an aneurysm, my ability to think clearly, concentrate and/or remember things would be:</p> <p style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> </p> <p style="text-align: center;"> very much better much better a little better the same worse </p>
(b)	<p>For me, my ability to think/concentrate/remember is:</p> <p style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> </p> <p style="text-align: center;"> very important important somewhat important not at all important </p>

If there are any other ways in which your quality of life is affected by having had an aortic aneurysm, please say what they are below:

Thank you for completing this questionnaire.

For Information Only

AneurysmSRQ

(Aneurysm Symptom Rating Questionnaire)

This questionnaire asks you about symptoms that can be associated with aortic aneurysm and its treatment (including monitoring and any operation/medication). You might have experienced some of these symptoms in recent weeks (i.e. about 4 weeks).

Each question has two parts:

for part (a) put an "X" in the box to indicate if you have had the symptom in recent weeks, **regardless of the cause**;

for part (b) put an "X" in the box to indicate how much the symptom has bothered you. **ONLY** answer part (b) if you answered "yes" to part (a).

1 (a)	Have you felt unusually tired or lethargic in recent weeks? No <input type="checkbox"/> If <i>no</i> , go to next symptom Yes <input type="checkbox"/> If <i>yes</i> , complete (b)
(b)	If yes , how much has this bothered you? <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> not at all a little moderately a lot

2 (a)	Have you had headaches in recent weeks? No <input type="checkbox"/> If <i>no</i> , go to next symptom Yes <input type="checkbox"/> If <i>yes</i> , complete (b)
(b)	If yes , how much has this bothered you? <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> not at all a little moderately a lot

3 (a)	Have you felt feverish in recent weeks? No <input type="checkbox"/> If <i>no</i> , go to next symptom Yes <input type="checkbox"/> If <i>yes</i> , complete (b)
(b)	If yes , how much has this bothered you? <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> not at all a little moderately a lot

1 2 3 4 5 6	<p>4 (a) Have you had pain/discomfort in your calves in recent weeks?</p> <p>No <input type="checkbox"/> If <i>no</i>, go to next symptom</p> <p>Yes <input type="checkbox"/> If <i>yes</i>, complete (b)</p>
7 8 9 10 11	<p>(b) If yes, how much has this bothered you?</p> <p style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> </p> <p style="text-align: center;">not at all a little moderately a lot</p>

12 13 14 15 16 17 18 19	<p>5 (a) Have you had pain/discomfort in your thighs in recent weeks?</p> <p>No <input type="checkbox"/> If <i>no</i>, go to next symptom</p> <p>Yes <input type="checkbox"/> If <i>yes</i>, complete (b)</p>
20 21 22 23 24	<p>(b) If yes, how much has this bothered you?</p> <p style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> </p> <p style="text-align: center;">not at all a little moderately a lot</p>

25 26 27 28 29 30 31	<p>6 (a) Have you had pain/discomfort in your groin in recent weeks?</p> <p>No <input type="checkbox"/> If <i>no</i>, go to next symptom</p> <p>Yes <input type="checkbox"/> If <i>yes</i>, complete (b)</p>
32 33 34 35 36 37	<p>(b) If yes, how much has this bothered you?</p> <p style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> </p> <p style="text-align: center;">not at all a little moderately a lot</p>

38 39 40 41 42 43 44	<p>7 (a) Have you had pain/discomfort in your buttocks in recent weeks?</p> <p>No <input type="checkbox"/> If <i>no</i>, go to next symptom</p> <p>Yes <input type="checkbox"/> If <i>yes</i>, complete (b)</p>
45 46 47 48 49	<p>(b) If yes, how much has this bothered you?</p> <p style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> </p> <p style="text-align: center;">not at all a little moderately a lot</p>

50 51 52 53 54 55 56 57	<p>8 (a) Have you had pain/discomfort in your back in recent weeks?</p> <p>No <input type="checkbox"/> If <i>no</i>, go to next symptom</p> <p>Yes <input type="checkbox"/> If <i>yes</i>, complete (b)</p>
58 59 60	<p>(b) If yes, how much has this bothered you?</p> <p style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> </p> <p style="text-align: center;">not at all a little moderately a lot</p>

1 2 3 4 5 6 7 8 9 10 11	<p>9 (a) Have you had abdominal pain/discomfort in recent weeks?</p> <p>No <input type="checkbox"/> If <i>no</i>, go to next symptom</p> <p>Yes <input type="checkbox"/> If <i>yes</i>, complete (b)</p>
	<p>(b) If yes, how much has this bothered you?</p> <p><input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> moderately <input type="checkbox"/> a lot</p>
12 13 14 15 16 17 18 19 20 21 22 23 24 25 26	<p>10 (a) Have you had any wound problem (e.g. infection or bleeding) in recent weeks?</p> <p>No <input type="checkbox"/> If <i>no</i>, go to next symptom</p> <p>Yes <input type="checkbox"/> If <i>yes</i>, complete (b)</p> <p>N/A <input type="checkbox"/> If <i>not applicable (N/A)</i>, go to next symptom</p>
	<p>(b) If yes, how much has this bothered you?</p> <p><input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> moderately <input type="checkbox"/> a lot</p>
27 28 29 30 31 32 33 34 35 36 37	<p>11 (a) Have you had excessive bruising in recent weeks?</p> <p>No <input type="checkbox"/> If <i>no</i>, go to next symptom</p> <p>Yes <input type="checkbox"/> If <i>yes</i>, complete (b)</p>
	<p>(b) If yes, how much has this bothered you?</p> <p><input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> moderately <input type="checkbox"/> a lot</p>
38 39 40 41 42 43 44 45 46 47 48 49 50	<p>12 (a) Have you had one or more minor illnesses (e.g. a cold, sore throat, urinary tract infection) in recent weeks?</p> <p>No <input type="checkbox"/> If <i>no</i>, go to next symptom</p> <p>Yes <input type="checkbox"/> If <i>yes</i>, complete (b)</p>
	<p>(b) If yes, how much has this bothered you?</p> <p><input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> moderately <input type="checkbox"/> a lot</p>
51 52 53 54 55 56 57 58 59 60	<p>13 (a) Have you felt depressed or low in recent weeks?</p> <p>No <input type="checkbox"/> If <i>no</i>, go to next symptom</p> <p>Yes <input type="checkbox"/> If <i>yes</i>, complete (b)</p>
	<p>(b) If yes, how much has this bothered you?</p> <p><input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> moderately <input type="checkbox"/> a lot</p>

1 2 3 4 5 6 7	<p>14 (a) Have you had feelings of panic in recent weeks?</p> <p>No <input type="checkbox"/> If <i>no</i>, go to next symptom</p> <p>Yes <input type="checkbox"/> If <i>yes</i>, complete (b)</p>
8 9 10 11	<p>(b) If yes, how much has this bothered you?</p> <p style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> not at all a little moderately a lot </p>

12 13 14 15 16 17 18 19 20 21 22 23 24 25	<p>15 (a) Have you felt worried or nervous in recent weeks?</p> <p>No <input type="checkbox"/> If <i>no</i>, go to next symptom</p> <p>Yes <input type="checkbox"/> If <i>yes</i>, complete (b)</p>
26 27 28 29 30 31 32 33 34 35 36 37 38	<p>(b) If yes, how much has this bothered you?</p> <p style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> not at all a little moderately a lot </p>

39 40 41 42 43 44 45 46 47 48 49 50 51 52 53 54 55 56 57 58 59 60	<p>16 (a) Have you felt unusually irritable or angry in recent weeks?</p> <p>No <input type="checkbox"/> If <i>no</i>, go to next symptom</p> <p>Yes <input type="checkbox"/> If <i>yes</i>, complete (b)</p>
61 62 63 64 65 66 67 68 69 70 71 72 73 74 75 76 77 78 79 80 81 82 83 84 85 86 87 88 89 90 91 92 93 94 95 96 97 98 99 100	<p>(b) If yes, how much has this bothered you?</p> <p style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> not at all a little moderately a lot </p>

101 102 103 104 105 106 107 108 109 110 111 112 113 114 115 116 117 118 119 120 121 122 123 124 125 126 127 128 129 130 131 132 133 134 135 136 137 138 139 140 141 142 143 144 145 146 147 148 149 150 151 152 153 154 155 156 157 158 159 160 161 162 163 164 165 166 167 168 169 170 171 172 173 174 175 176 177 178 179 180 181 182 183 184 185 186 187 188 189 190 191 192 193 194 195 196 197 198 199 200	<p>17 (a) Have you felt unusually emotional or easily upset in recent weeks?</p> <p>No <input type="checkbox"/> If <i>no</i>, go to next symptom</p> <p>Yes <input type="checkbox"/> If <i>yes</i>, complete (b)</p>
201 202 203 204 205 206 207 208 209 210 211 212 213 214 215 216 217 218 219 220 221 222 223 224 225 226 227 228 229 230 231 232 233 234 235 236 237 238 239 240 241 242 243 244 245 246 247 248 249 250 251 252 253 254 255 256 257 258 259 260 261 262 263 264 265 266 267 268 269 270 271 272 273 274 275 276 277 278 279 280 281 282 283 284 285 286 287 288 289 290 291 292 293 294 295 296 297 298 299 300	<p>(b) If yes, how much has this bothered you?</p> <p style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> not at all a little moderately a lot </p>

301 302 303 304 305 306 307 308 309 310 311 312 313 314 315 316 317 318 319 320 321 322 323 324 325 326 327 328 329 330 331 332 333 334 335 336 337 338 339 340 341 342 343 344 345 346 347 348 349 350 351 352 353 354 355 356 357 358 359 360 361 362 363 364 365 366 367 368 369 370 371 372 373 374 375 376 377 378 379 380 381 382 383 384 385 386 387 388 389 390 391 392 393 394 395 396 397 398 399 400	<p>18 (a) Have you had difficulty concentrating in recent weeks?</p> <p>No <input type="checkbox"/> If <i>no</i>, go to next symptom</p> <p>Yes <input type="checkbox"/> If <i>yes</i>, complete (b)</p>
401 402 403 404 405 406 407 408 409 410 411 412 413 414 415 416 417 418 419 420 421 422 423 424 425 426 427 428 429 430 431 432 433 434 435 436 437 438 439 440 441 442 443 444 445 446 447 448 449 450 451 452 453 454 455 456 457 458 459 460 461 462 463 464 465 466 467 468 469 470 471 472 473 474 475 476 477 478 479 480 481 482 483 484 485 486 487 488 489 490 491 492 493 494 495 496 497 498 499 500	<p>(b) If yes, how much has this bothered you?</p> <p style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> not at all a little moderately a lot </p>

1 2 3 4 5 6 7 8 9 10	<p>19 (a) Have you had memory problems in recent weeks?</p> <p>No <input type="checkbox"/> If <i>no</i>, go to next symptom</p> <p>Yes <input type="checkbox"/> If <i>yes</i>, complete (b)</p>
	<p>(b) If yes, how much has this bothered you?</p> <p style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> not at all a little moderately a lot </p>

11 12 13 14 15 16 17 18 19 20 21 22 23 24	<p>20 (a) Have you had difficulty thinking quickly and clearly in recent weeks?</p> <p>No <input type="checkbox"/> If <i>no</i>, go to next symptom</p> <p>Yes <input type="checkbox"/> If <i>yes</i>, complete (b)</p>
	<p>(b) If yes, how much has this bothered you?</p> <p style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> not at all a little moderately a lot </p>

25 26 27 28 29 30 31 32 33 34 35 36 37	<p>21 (a) Have you felt unsteady or uncoordinated in recent weeks?</p> <p>No <input type="checkbox"/> If <i>no</i>, go to next symptom</p> <p>Yes <input type="checkbox"/> If <i>yes</i>, complete (b)</p>
	<p>(b) If yes, how much has this bothered you?</p> <p style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> not at all a little moderately a lot </p>

38 39 40 41 42 43 44 45 46 47 48 49 50	<p>22 (a) Have you felt dizzy, light-headed or faint in recent weeks?</p> <p>No <input type="checkbox"/> If <i>no</i>, go to next symptom</p> <p>Yes <input type="checkbox"/> If <i>yes</i>, complete (b)</p>
	<p>(b) If yes, how much has this bothered you?</p> <p style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> not at all a little moderately a lot </p>

51 52 53 54 55 56 57 58 59 60	<p>23 (a) Have you had tingling or numbness in your legs or feet in recent weeks?</p> <p>No <input type="checkbox"/> If <i>no</i>, go to next symptom</p> <p>Yes <input type="checkbox"/> If <i>yes</i>, complete (b)</p>
	<p>(b) If yes, how much has this bothered you?</p> <p style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> not at all a little moderately a lot </p>

24 (a)	Have you had heaviness in your leg(s) in recent weeks? No <input type="checkbox"/> If <i>no</i> , go to next symptom Yes <input type="checkbox"/> If <i>yes</i> , complete (b)
(b)	If yes , how much has this bothered you? <input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> moderately <input type="checkbox"/> a lot

25 (a)	Have you had trembling (e.g. of limbs) in recent weeks? No <input type="checkbox"/> If <i>no</i> , go to next symptom Yes <input type="checkbox"/> If <i>yes</i> , complete (b)
(b)	If yes , how much has this bothered you? <input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> moderately <input type="checkbox"/> a lot

26 (a)	Have you had weakness in your leg(s) in recent weeks? No <input type="checkbox"/> If <i>no</i> , go to next symptom Yes <input type="checkbox"/> If <i>yes</i> , complete (b)
(b)	If yes , how much has this bothered you? <input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> moderately <input type="checkbox"/> a lot

27 (a)	Have you had swollen legs in recent weeks? No <input type="checkbox"/> If <i>no</i> , go to next symptom Yes <input type="checkbox"/> If <i>yes</i> , complete (b)
(b)	If yes , how much has this bothered you? <input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> moderately <input type="checkbox"/> a lot

28 (a)	Have you lost interest in sex in recent weeks? No <input type="checkbox"/> If <i>no</i> , go to next symptom Yes <input type="checkbox"/> If <i>yes</i> , complete (b) N/A <input type="checkbox"/> If <i>not applicable (N/A)</i> , go to next symptom
(b)	If yes , how much has this bothered you? <input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> moderately <input type="checkbox"/> a lot

1 2 3 4 5 6 7 8 9	<p>29 (a) Have you avoided sexual activity due to worry about your aneurysm / aneurysm repair?</p> <p>No <input type="checkbox"/> If <i>no</i>, go to next symptom</p> <p>Yes <input type="checkbox"/> If <i>yes</i>, complete (b)</p> <p>N/A <input type="checkbox"/> If <i>not applicable (N/A)</i>, go to next symptom</p>
10 11 12 13 14 15	<p>(b) If yes, how much has this bothered you?</p> <p style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> </p> <p style="text-align: center;"> not at all a little moderately a lot </p>

16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31	<p>30 (a) Have you had any problem with sexual function in recent weeks?</p> <p>No <input type="checkbox"/> If <i>no</i>, go to next symptom</p> <p>Yes <input type="checkbox"/> If <i>yes</i>, complete (b)</p> <p>N/A <input type="checkbox"/> If <i>not applicable (N/A)</i>, go to next symptom</p>
32 33 34 35 36 37 38 39 40 41 42 43 44	<p>(b) If yes, how much has this bothered you?</p> <p style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> </p> <p style="text-align: center;"> not at all a little moderately a lot </p>

45 46 47 48 49 50 51 52 53 54 55 56 57 58 59 60	<p>31 (a) Have you had excessive sweating in recent weeks?</p> <p>No <input type="checkbox"/> If <i>no</i>, go to next symptom</p> <p>Yes <input type="checkbox"/> If <i>yes</i>, complete (b)</p>
61 62 63 64 65 66 67 68 69 70 71 72 73 74 75	<p>(b) If yes, how much has this bothered you?</p> <p style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> </p> <p style="text-align: center;"> not at all a little moderately a lot </p>

76 77 78 79 80 81 82 83 84 85 86 87 88 89 90 91 92	<p>32 (a) Have you had episodes of feeling too cold or feeling too hot in recent weeks?</p> <p>No <input type="checkbox"/> If <i>no</i>, go to next symptom</p> <p>Yes <input type="checkbox"/> If <i>yes</i>, complete (b)</p>
93 94 95 96 97 98 99 100 101 102 103 104 105 106 107 108	<p>(b) If yes, how much has this bothered you?</p> <p style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> </p> <p style="text-align: center;"> not at all a little moderately a lot </p>

1 2 3 4 5 6 7	<p>33 (a) Have you had sleep problems (e.g. insomnia) in recent weeks?</p> <p>No <input type="checkbox"/> If <i>no</i>, go to next symptom</p> <p>Yes <input type="checkbox"/> If <i>yes</i>, complete (b)</p>
8 9 10 11 12	<p>(b) If yes, how much has this bothered you?</p> <p style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> not at all a little moderately a lot </p>

13 14 15 16 17 18 19 20 21 22 23 24 25 26	<p>34 (a) Have you felt generally weak in recent weeks?</p> <p>No <input type="checkbox"/> If <i>no</i>, go to next symptom</p> <p>Yes <input type="checkbox"/> If <i>yes</i>, complete (b)</p>
27 28 29 30 31 32 33 34 35 36 37 38 39	<p>(b) If yes, how much has this bothered you?</p> <p style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> not at all a little moderately a lot </p>

40 41 42 43 44 45 46 47 48 49 50 51 52 53 54 55 56 57 58 59 60	<p>35 (a) Have you had a poor appetite in recent weeks?</p> <p>No <input type="checkbox"/> If <i>no</i>, go to next symptom</p> <p>Yes <input type="checkbox"/> If <i>yes</i>, complete (b)</p>
61 62 63 64 65 66 67 68 69 70 71 72 73 74 75 76 77 78 79 80	<p>(b) If yes, how much has this bothered you?</p> <p style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> not at all a little moderately a lot </p>

81 82 83 84 85 86 87 88 89 90 91 92 93 94 95 96 97 98 99 100	<p>36 (a) Have you lost weight in recent weeks?</p> <p>No <input type="checkbox"/> If <i>no</i>, go to next symptom</p> <p>Yes <input type="checkbox"/> If <i>yes</i>, complete (b)</p>
101 102 103 104 105 106 107 108 109 110 111 112 113 114 115 116 117 118 119 120	<p>(b) If yes, how much has this bothered you?</p> <p style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> not at all a little moderately a lot </p>

121 122 123 124 125 126 127 128 129 130 131 132 133 134 135 136 137 138 139 140 141 142	<p>37 (a) Have you gained weight in recent weeks?</p> <p>No <input type="checkbox"/> If <i>no</i>, go to next symptom</p> <p>Yes <input type="checkbox"/> If <i>yes</i>, complete (b)</p>
143 144 145 146 147 148 149 150 151 152 153 154 155 156 157 158 159 160 161 162 163 164 165	<p>(b) If yes, how much has this bothered you?</p> <p style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> not at all a little moderately a lot </p>

1 2 3 4 5 6	38 (a) Have you had indigestion or heartburn in recent weeks? No <input type="checkbox"/> If <i>no</i> , go to next symptom Yes <input type="checkbox"/> If <i>yes</i> , complete (b)
7 8 9 10 11	(b) If yes , how much has this bothered you? <input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> moderately <input type="checkbox"/> a lot

12 13 14 15 16 17 18 19	39 (a) Have you felt nauseous or vomited in recent weeks? No <input type="checkbox"/> If <i>no</i> , go to next symptom Yes <input type="checkbox"/> If <i>yes</i> , complete (b)
20 21 22 23 24	(b) If yes , how much has this bothered you? <input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> moderately <input type="checkbox"/> a lot

25 26 27 28 29 30 31	40 (a) Have you had excessive flatulence or belching (wind) in recent weeks? No <input type="checkbox"/> If <i>no</i> , go to next symptom Yes <input type="checkbox"/> If <i>yes</i> , complete (b)
32 33 34 35 36 37	(b) If yes , how much has this bothered you? <input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> moderately <input type="checkbox"/> a lot

38 39 40 41 42 43 44	41 (a) Have you felt bloated in recent weeks? No <input type="checkbox"/> If <i>no</i> , go to next symptom Yes <input type="checkbox"/> If <i>yes</i> , complete (b)
45 46 47 48 49	(b) If yes , how much has this bothered you? <input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> moderately <input type="checkbox"/> a lot

50 51 52 53 54 55 56 57	42 (a) Have you had diarrhoea in recent weeks? No <input type="checkbox"/> If <i>no</i> , go to next symptom Yes <input type="checkbox"/> If <i>yes</i> , complete (b)
58 59 60	(b) If yes , how much has this bothered you? <input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> moderately <input type="checkbox"/> a lot

1 2 3 4 5 6	<p>43 (a) Have you had constipation in recent weeks?</p> <p>No <input type="checkbox"/> If <i>no</i>, go to next symptom</p> <p>Yes <input type="checkbox"/> If <i>yes</i>, complete (b)</p>
7 8 9 10 11	<p>(b) If yes, how much has this bothered you?</p> <p style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> </p> <p style="text-align: center;"> not at all a little moderately a lot </p>

12 13 14 15 16 17 18 19	<p>44 (a) Have you had difficulty urinating in recent weeks?</p> <p>No <input type="checkbox"/> If <i>no</i>, go to next symptom</p> <p>Yes <input type="checkbox"/> If <i>yes</i>, complete (b)</p>
20 21 22 23 24	<p>(b) If yes, how much has this bothered you?</p> <p style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> </p> <p style="text-align: center;"> not at all a little moderately a lot </p>

Have you had any symptoms in recent weeks not already mentioned above?

Yes No If 'yes', please complete one or more of the boxes below

25 26 27 28 29 30 31 32	<p>(a) Have you _____ in recent weeks?</p> <p>No <input type="checkbox"/> If <i>no</i>, go to next symptom</p> <p>Yes <input type="checkbox"/> If <i>yes</i>, complete (b)</p>
33 34 35 36 37 38	<p>(b) If yes, how much has this / have these bothered you?</p> <p style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> </p> <p style="text-align: center;"> not at all a little moderately a lot </p>

39 40 41 42 43 44	<p>(a) Have you _____ in recent weeks?</p> <p>No <input type="checkbox"/> If <i>no</i>, go to next symptom</p> <p>Yes <input type="checkbox"/> If <i>yes</i>, complete (b)</p>
45 46 47 48 49 50 51 52	<p>(b) If yes, how much has this / have these bothered you?</p> <p style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> </p> <p style="text-align: center;"> not at all a little moderately a lot </p>

Thank you for completing this questionnaire

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AneurysmTSQ

(Aneurysm Treatment Satisfaction Questionnaire)

The following questions are concerned with your experience of aortic aneurysm treatment, including any:

- monitoring
- medication
- operation

Please answer each question by circling a number on each of the scales.

1. How satisfied are you with your aneurysm treatment (including monitoring)?

very satisfied 6 5 4 3 2 1 0 very dissatisfied

2. How convenient have you found your treatment (including monitoring)?

very convenient 6 5 4 3 2 1 0 very inconvenient

3. How bothered are you by any discomfort or pain related to your aneurysm and/or its treatment recently?

not at all bothered 6 5 4 3 2 1 0 very bothered

4. Were you given any information about the following aspects of treatment for your aneurysm? Please tick one box for each aspect of treatment below.

	yes	no	don't recall
• Monitoring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Operation (stent or open-repair)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Side effects	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Follow up	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Recommended or restricted activities/movements	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4a. Were you given any of the above information in written form for you to take home?

yes no don't recall

4b. How satisfied are you with information provided about your aneurysm and its treatment?

very satisfied 6 5 4 3 2 1 0 very dissatisfied

continued on the next page ...

AneurysmTSQ continued...

5. How satisfied are you with feedback about scan results?

very satisfied 6 5 4 3 2 1 0 very dissatisfied

6. How satisfied are you with the amount of support you are getting from nurses, doctors and other clinical staff in treating your aneurysm?

very satisfied 6 5 4 3 2 1 0 very dissatisfied

7. How satisfied are you with your understanding of the treatment for your aortic aneurysm (including any operation / monitoring)?

very satisfied 6 5 4 3 2 1 0 very dissatisfied

8. Have you had an operation for your aneurysm (i.e. stent or open repair)?

yes no

If 'yes', please answer all the remaining questions.

If 'no', please go to Question 12.

8a. How satisfied were you with the length of your stay in hospital?

very satisfied 6 5 4 3 2 1 0 very dissatisfied

8b. Please consider the length of your stay in hospital for the operation. Did you feel that this was: (please tick one box)

- too short
- just right
- too long

9. How bothered are you by any side effects or after effects of the treatment for your aneurysm? [If none experienced recently, please tick here and go straight to Q.10]

not at all bothered 6 5 4 3 2 1 0 very bothered

10a. How satisfied are you with the post-operative follow-up of your condition (including any scans / clinic visits)?

very satisfied 6 5 4 3 2 1 0 very dissatisfied

10b. Please consider the number of postoperative scans / clinic visits you have had. Do you feel that this was: (please tick one box)

- not enough
- just right
- too many

continued on the next page ...

AneurysmTSQ continued ...

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11. How likely would you be to encourage someone else with an aneurysm like yours to have your kind of treatment?

very likely 6 5 4 3 2 1 0 very unlikely

Please make sure that you have circled one number on each of the scales above that are applicable to you.

12. Are there any other aspects of your aortic aneurysm treatment (including any monitoring), causing either satisfaction or dissatisfaction, that have not been covered by the questionnaire?

yes no

If **yes**, please describe below.

For Information Only

Thank you for completing this questionnaire.