

# Engaging patients and caregivers in establishing research priorities for aortic dissection

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## Abstract

**Objectives:** The aim of this study was to establish the top 10 research uncertainties in aortic dissection together with the patient organization Aortic Dissection Association Scandinavia using the James Lind Alliance concept.

**Methods:** A pilot survey aiming to identify uncertainties sent to 12 patients was found to have high content validity (scale content validity index = 0.91). An online version of the survey was thereafter sent to 30 patients in Aortic Dissection Association Scandinavia and 45 caregivers in the field of aortic dissection. Research uncertainties of aortic dissection were gathered, collated and processed.

**Results:** Together with research priorities retrieved from five different current guidelines, 94 uncertainties were expressed. A shortlist of 24 uncertainties remained after processing for the final workshop. After the priority-setting process, using facilitated group format technique, the ranked final top 10 research uncertainties included diagnostic tests for aortic dissection; patient information and care continuity; quality of life; endovascular and medical treatment; surgical complications; rehabilitation; psychological consequences; self-care; and how to improve prognosis.

**Conclusion:** These ranked top 10 important research priorities may be used to justify specific research in aortic dissection and to inform healthcare research funding decisions.

## Keywords

Aortic dissection, patient involvement, James Lind Alliance, research priorities

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## Introduction

The incidence of type A and type B aortic dissection (AD) was 5.5/100,000 person-years in the population of Malmö, Sweden, between 2000 and 2004.<sup>1</sup> In this epidemiological study, 62% of patients had type A AD and 38% type B AD, and 77.8% and 21.4% of individuals, respectively, died outside hospital.<sup>1</sup> The overall incidence rate for AD is highly likely underestimated, however, especially for type A AD due to the declining autopsy rate in the population.<sup>2</sup> The most important risk factors for AD are previous aortic disease such as aortic aneurysm,<sup>1</sup> hypertension,<sup>3</sup> age, smoking and hereditary connective tissue disorders<sup>4</sup> such as Ehlers–Danlos syndrome and Marfan’s syndrome. Although guidelines on the management of AD express several uncertainties that merit to be studied, research priorities of AD survivors have never been identified.

The Aortic Dissection Association Scandinavia (ADAS) was founded in 2014 as the world’s first patient organization for AD carriers and has members from Denmark, Norway and Sweden (<http://aortadissektion.com>). Lately, researchers have gained insight on the importance of involving patients, family members and the public in the design and conduction

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**Table 1.** Validation of pilot questionnaire on research priorities for patients with aortic dissection (AD).

Uncertainty	Item content validity index (I-CVI) Items rated 3 or 4 on a four-point Likert-type scale
1. How the diagnosis AD affects quality of life	0.89
2. How the diagnosis AD affects activity in daily life	0.89
3. How the diagnosis AD affects social activities	0.78
4. How the diagnosis AD affects functional ability	1.0
5. How the diagnosis AD affects sexual life	0.67
6. How the diagnosis AD affects the possibility of getting pregnant	0.44
7. The importance of living habits for disease progress	0.89
8. Importance of self-care in relation to AD	1.0
9. Heredity in relation to AD	1.0
10. Diagnostic possibilities to detect and treat AD	1.0
11. Surgical treatment of AD	1.0
12. Endovascular treatment of AD	1.0
13. Medical treatment of AD	1.0
14. Surgical complications in AD	1.0
15. Pharmacological side-effects of medical treatment for AD	1.0
16. Prognosis of AD	1.0

of health-related studies.<sup>5</sup> By their own experiences from disease, conditions or situations, patients can contribute unique perspectives to research and propose research questions which more effectively can be applied in patient care.<sup>6</sup> The James Lind Alliance (JLA) concept has developed a structured method for engaging patients and clinicians for priority-setting partnership of research uncertainties for a more effective research agenda.<sup>7</sup> This process is based on principles of justice and transparency and brings patients and clinicians more closely together for joint decisions on research priorities. Patient and caregiver research priorities of uncertainties have never been determined for AD. The Department of Cardio-Thoracic and Vascular Surgery, Skåne University Hospital, has academic representatives within thoracic surgery, vascular surgery, vascular medicine and nursing and has therefore unique prerequisites for a priority-setting partnership with ADAS in determination of research priorities of uncertainties in AD. The aim of this study was to establish the top 10 research uncertainties in AD using the JLA concept.<sup>7</sup>

## Methods

### Settings

A priority-setting partnership and a steering committee were both established according to the JLA process.<sup>7</sup> This research was performed as a collaboration between ADAS members and caregivers from the Department of Cardio-Thoracic and Vascular Surgery, Skåne University Hospital. The steering committee consisted of three patients and three caregivers (one vascular surgeon, one vascular physician and one vascular nurse specialist). The project manager was S.A. and the facilitator was C.K. The chairman of ADAS was contacted

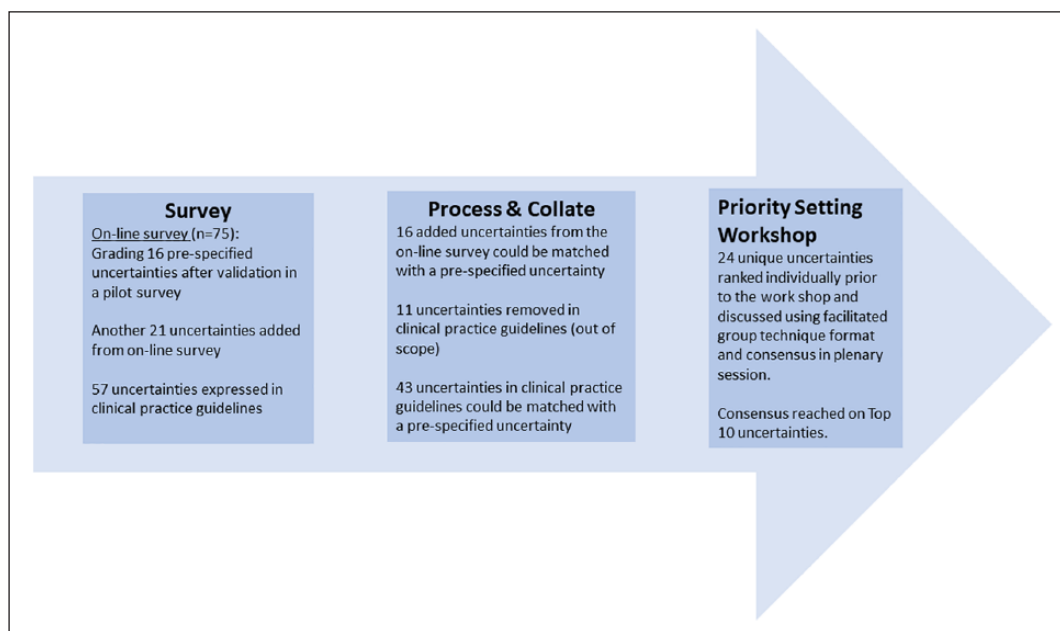
on 27 October 2017 and the final workshop was conducted on 9 May 2018. The steering committee was formed at the start of the project, followed by telephone meetings every 2 weeks for the duration of the process. The scientific secretary of the regional ethical review board in Lund was consulted, providing an advisory written statement that this project does not fall under the intentions of the ethical review law.

### Content and face validity in pilot survey

A questionnaire with 16 uncertainties (Table 1) developed by the steering committee was sent by regular mail to 12 patients selected by ADAS for evaluation of content (comprehension of all facets of the question) and face (subjective relevance of the question) validity. Besides six demographic questions, each of 16 proposed uncertainties was evaluated with regard to item content validity index (I-CVI) and face validity on a four-point Likert-type scale. High item rating score was defined as items rated 3 or 4 on a four-point scale. The item is recommended if I-CVI is greater than 0.78. The scale is recommended if average I-CVI or scale CVI (S-CVI) is greater than 0.9.<sup>8</sup> None of the respondents expressed another research uncertainty at this stage.

### Online survey questionnaire

Either membership of ADAS or being a physician or nurse managing patients with AD was the inclusion criteria for participating in this study. After the validation process of the questionnaire and revision of one question, the questionnaire with 16 uncertainties was sent online to 30 patients via ADAS and via a research nurse to 45 caregivers (members of the Swedish Societies of Vascular Surgery, Vascular Medicine and



**Figure 1.** Summary of the priority-setting process for determination of the top 10 research priorities of uncertainties for AD.

Vascular Nursing), that is, physicians and nurses managing patients with AD. No a priori sample size calculation was justified in this exploratory study. There was a possibility to add uncertainties in free text in the questionnaire. The free online tool SurveyMonkey (SurveyMonkey Europe UC, Dublin, Ireland; <https://www.surveymonkey.com>), recommended by Lund University, was used for distribution of questionnaires, collection of anonymized answers and results were exported to Statistical Package for the Social Sciences (SPSS) for Windows version 24.0 (IBM SPSS Inc., Chicago, IL, USA).

### Guidelines on management of AD

The following societies were identified to have published recent (from 2013) guidelines on the management of AD: European Society of Vascular Surgery,<sup>9</sup> American College of Emergency Physicians,<sup>10</sup> European Society of Cardiology,<sup>11</sup> Canadian Cardiovascular Society/Canadian Society of Cardiac Surgeons/Canadian Society for Vascular Surgery<sup>12</sup> and Japan Circulation Society.<sup>13</sup> Any stated research uncertainty expressed in these guidelines was collated.

### Processing the research uncertainties

All collated uncertainties from survey respondents and clinical guidelines were processed. Unclear uncertainties, duplicates or uncertainties considered clearly out of scope were removed, and expression of similar uncertainties were merged and expressed as just one uncertainty. A shortlist of uncertainties with rankings of uncertainties by patients and personnel from the online survey was distributed to the steering committee for their individual rankings prior to the final prioritizing workshop.

### Final workshop

The 1-day workshop included the steering committee (three patients and three caregivers) and a research nurse. The workshop used a facilitated group technique format (a process where an individual who is agreed upon and acceptable to all of a group's members intervenes to assist in making decisions to improve productivity and efficiency but who has no authority to make decisions).<sup>7</sup> All uncertainties were written down on separate paper cards. After round table discussion, the uncertainties were categorized as high, intermediate or low research priorities and placed in three different stacks of papers. The stack with high research priority uncertainties was adjusted by either removing or adding uncertainties from the intermediate stack, resulting in 10 remaining uncertainties. A consensus approach was used to rank the top 10 uncertainties. Figure 1 summarizes the priority-setting process for determination of the top 10 research priorities of uncertainties for AD.

## Results

### Validation

Nine patients (75%), six men and three women, answered the pilot survey questionnaire. Median age of these respondents was 63 (range: 53 – 69) years. Eight of them were married and one was living alone. The overall S-CVI was 0.91. I-CVI scored satisfactorily in 14 questions, whereas 2 questions did not reach sufficient I-CVI score: the questions 'How the diagnose AD affects sexual life' and 'How the diagnosis AD affects the possibility of getting pregnant'. It was therefore decided to adjust the latter question to 'How the diagnosis AD affects the possibility to have children';

**Table 2.** Top 10 research uncertainties for aortic dissection (AD) identified by patients and caregivers from the online survey.

Respondent type	Percentage of highest ranking Items rated 5 on a five-point Likert-type scale	Rank	Uncertainty
Patients (n = 30)	80.0	1	Diagnostic possibilities to detect and treat AD
	80.0	1	How the diagnosis AD affects activity in daily life
	73.3	3	How the diagnosis AD affects functional ability
	66.7	4	How the diagnosis AD affects quality of life
	66.7	4	Prognosis of AD
	63.3	6	Endovascular treatment of AD
	63.3	6	Surgical treatment of AD
	60.0	8	Heredity in relation to AD
	60.0	8	The importance of living habits for disease progress
	53.3	10	Surgical complications in AD
Caregivers (n = 45)	53.3	10	Pharmacological side-effects of medical treatment for AD
	75.6	1	Diagnostic possibilities to detect and treat AD
	68.9	2	Endovascular treatment of AD
	66.7	3	Medical treatment of AD
	60.0	4	Surgical treatment of AD
	57.8	5	Heredity in relation to AD
	57.8	5	Prognosis of AD
	53.3	7	Surgical complications
	51.1	8	How the diagnose AD affects quality of life
	48.9	9	The importance of living habits for disease progress
44.4	10	How the diagnosis AD affects functional ability	

otherwise, the questionnaire was left unchanged. The questionnaire has face validity.

### Profile of online survey respondents

A total of 30 patients, 16 men and 14 women, responded. Median age was 62 (range: 45 – 75) years. The following subgroups of diagnoses were represented among the patients: AD type A (n = 18), AD type B (n = 6), unspecified AD (n = 3) and aortic aneurysm (n = 3). Patients' civil status was as follows: married (n = 19), unmarried (n = 1), co-habiting (n = 4) and living alone (n = 6). The patients had been treated by open surgery (n = 20), endovascular surgery (n = 3) or medical therapy only (n = 7). In total, 18 (60%) patients reported having suffered a treatment complication.

Overall, 45 caregivers, 28 physicians and 17 nurses, responded. Their median age was 49 (range: 24–65) years, 28 were men and 17 women.

### Ranking of specified uncertainties from the online survey

The ranking of research uncertainties among patients and caregivers is shown in Table 2. Both groups ranked 'Diagnostic possibilities to detect and treat AD' highest. The two lowest rankings among patients were 'How the diagnosis AD affects the possibility to have children' (26.7% of highest ranking) and 'How the diagnosis AD affects sexual life' (30.0% of

highest ranking). The lowest rankings among caregivers were 'How the diagnosis AD affects social activities' (20.0% of highest ranking), 'How the diagnosis AD affects the possibility to have children' (24.4% of highest ranking) and 'Pharmacological side-effects of medical treatment for AD' (24.4% of highest ranking).

### Additional uncertainties retrieved from patients from the online survey

The following additional uncertainties were retrieved: 'Relation between AD and other diseases', 'Psychological consequences of AD', 'How the diagnose AD affects social relations', 'Rehabilitation after AD' and 'Patient information and care continuity'.

### Uncertainties from the guidelines on management of AD

The following additional uncertainties were retrieved from guidelines only: 'Prevalence of aortic dissection in men and women in the population', 'Quality assurance of treatment methods' and 'Disease progression in AD'.

### Establishing top 10 research priorities for AD

A list of the 24 research uncertainties identified was used for the final prioritizing workshop. The final top 10 research

**Table 3.** Final top 10 research uncertainties for aortic dissection (AD).

Rank	Uncertainty
1	Diagnostic possibilities to detect and treat AD
2	Patient information and care continuity
3	How the diagnosis AD affects quality of life
4	Endovascular treatment
5	Medical treatment of AD
6	Surgical complications in AD
7	Rehabilitation after AD
8	Psychological consequences of AD
9	Importance of self-care in relation to AD
10	Prognosis of AD

priorities of uncertainties in AD are listed in Table 3. Highest ranking was assigned to ‘Diagnostic possibilities to detect and treat AD’. ‘Patient information and care continuity’ and ‘Psychological consequences’ were identified as uncertainties by patients exclusively and were ranked as number 2 and 8, respectively. ‘Rehabilitation after AD’ was identified both by patients and in guidelines and was ranked as number 7.

## Discussion

Patient involvement in the present JLA-based study probably resulted in a more effective research agenda regarding AD for better healthcare than if research uncertainties would have been prioritized by physicians and other caregivers alone. However, both patients and caregivers ranked uncertainties regarding diagnostic issues as the most prioritized. In view of this important finding, the guidelines of the American College of Emergency Physicians on the evaluation and management of suspected AD<sup>10</sup> must be judged as the most timely, appropriate and effective of the five guideline publications. This guideline is almost exclusively devoted to diagnostic issues, raising research uncertainties on patient history, physical examination, diagnostic testing combinations, laboratory and imaging issues.<sup>10</sup> Even though computed tomography angiography of the thorax is highly accurate for diagnosing this potentially fatal disease, overtesting for this rare entity might cause a considerable clinical and financial burden. A better approach for clinical decision-making at the emergency department level is highly warranted,<sup>10</sup> a concern which was also clearly mediated by the patient representatives of the steering committee at the final workshop.

Patient information and care continuity was ranked as having second highest priority due to strong influence from the ADAS members. ADAS has indeed requested written patient information, featuring information on AD and aftercare, from healthcare providers.<sup>14</sup> Patients often have questions regarding appropriate life style, work activities and exercise after having survived an AD. Despite some counterproductive fear of physical activity in an old guideline,<sup>15</sup> exercise is probably doing more good than harm.<sup>16</sup> Maintaining physical activity could have beneficial effect on achieving normal blood

pressure, heart rate and body weight.<sup>16</sup> The Swedish Society of Vascular Surgery is currently performing an inventory, requesting written material on patient information from vascular surgery units, in order to develop preoperative and post-operative information after different operative procedures. ADAS has also strongly argued for better care continuity and follow up at tertiary vascular centres for better and safer management of AD instead of follow up by the family physician.

Quality of life was ranked third. It therefore seems worthwhile, as for the evaluation of revascularization procedures in peripheral arterial disease,<sup>17,18</sup> to develop and implement AD-specific patient-reported outcome measures in registries to learn more about quality of life in AD.

The ranked research priorities with regard to endovascular treatment and surgical complications to operation indicate a wish for improvement in minimal invasive surgical therapy, and ultimately safe and effective treatment of type A AD. There are, however, two major obstacles for successful thoracic endovascular therapy, stroke and neurocognitive decline<sup>19</sup> and spinal cord ischemia.<sup>20</sup> Hence, it is highly likely that continued research efforts are needed for a long time to overcome these challenging issues.

Research of uncertainties regarding medical treatment of AD was also highly prioritized. There are many unanswered questions such as optimal blood pressure level in the chronic phase and best medical treatment. A recent Cochrane review has concluded that there is no high-quality evidence and very little data to support guidelines<sup>9</sup> recommending the use of betablockers over other antihypertensive medications as first-line treatment of chronic type B AD.<sup>21</sup>

Patient involvement in this study also led to prioritization of research uncertainties concerning rehabilitation and psychological consequences of AD, suggesting a need for improvement in follow-up strategies and protocols. Virtually, all survivors of type A AD have undergone a dramatic experience, and these patients may benefit from support by a specialist nurse. In addition, recent research suggests that neurologists and rehabilitation physicians seem to be needed in the rehabilitation plan protocol for possible better outcome in patients with complicated AD.<sup>22</sup>

Research uncertainties regarding possibility to have children were ranked lowest among patients. This seems logic in view of the relatively low survival rate of AD leading to issues on reproductivity being of secondary interest. As the respondents from ADAS were also in their upper middle ages, this question was probably considered as irrelevant for them personally. I-CVI for this uncertainty was found very low in the validity evaluation and the study investigators considered to remove this uncertainty from the online survey. However, the exact proportion of patients with hereditary AD such as Ehlers–Danlos syndrome and Marfan’s syndrome,<sup>23</sup> a considerable younger age group than those without hereditary AD, in ADAS was unknown for the steering committee members, why we chose to just revise this uncertainty. Data on family history of AD were not requested in the patient questionnaire.



The low I-CVI for sexual life merits further investigation. It was reported that AD patients reduce their sexual activity, mostly due to fear of adverse aortic events such as rupture,<sup>24</sup> even if most patients had not been exerting themselves at onset of AD. In addition, physicians might, without any evidence, have recommended them to adhere to a more safe and quiet life style. Resuming sexual activity after a period of abstinence after AD may therefore be a complex transition. Whether or not the respondents would have prioritized this uncertainty differently after implementation of written post-operative information encouraging sexual activity remains to be evaluated.

The findings of this study are strengthened by the transparent joint JLA process involving both patients and caregivers. Nation-wide responses from the online survey were recruited through ADAS and caregivers through members of the Swedish Societies of Vascular Surgery, Vascular Medicine and Vascular Nursing and not from a particular geographic region only. The proportion of respondents with type A and type B AD is representative for the epidemiology of AD in the population, and the equal gender distribution among the online survey respondents was considered good to be able to capture a variety of perspectives. However, management of type A AD is operative, whereas type B AD is most often treated conservatively, which may influence the ranking of research uncertainties among patients and caregivers. Further studies on these respective subgroups seems to be warranted. One limitation of the study was the possibility of subjective opinions and experiences expressed by the steering committee members, which might have affected processing and prioritization. Many of the submitted uncertainties were not worded as research questions but rather as comments, which made the steering committee member impelled to use judgement when turning these comments into research uncertainties. Nevertheless, the priority-setting process employed provided a robust list of questions for researchers to address over the coming years.

In conclusion, via a comprehensive and transparent process involving ADAS, we have identified a list of 10 ranked research priorities for AD. Patients' important priorities highlighted questions particularly related to patient information, quality of life and psychosocial aspects of having AD. The top 10 list may be used to guide clinical research, to justify the importance of research questions and to inform healthcare research funding decisions.

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This joint project between the patient organization Aortic Dissection Association Scandinavia (ADAS) and healthcare representatives is dedicated to Anders Jansson (5 July 1955 to 3 July 2018), former chairman of ADAS and founder in 2014. He participated actively initially in this important collaboration project, but was due to illness unable to participate to the end. The authors honour his dedication to the project by completing this task.

### Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Ethical approval

The scientific secretary of the regional ethical review board in Lund was consulted, providing an advisory written statement that this project does not fall under the intentions of the ethical review law.

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### Informed consent

Written informed consent from all subjects or their legally authorized representatives prior to study initiation was waived by the regional ethical review board in Lund (written correspondence with Rolf Ljung, 2017-09-04). Verbal informed consent was obtained from all subjects before the study.

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