

Engaging Patients and Caregivers in Establishing Research Priorities for Aortic Dissection

Acosta et al. (2019)

<https://doi.org/10.1177/2050312118822632>

For which topic were research priorities identified?

aortic dissection

In which location was the research priority setting conducted?

Europe - Sweden

Why was it conducted at all?

Although guidelines on the management of AD express several uncertainties that merit to be studied, research priorities of AD survivors have never been identified.

What was the objective?

to establish the top 10 research uncertainties in aortic dissection together with the patient organization Aortic Dissection Association Scandinavia

What was the outcome?

a ranking list of 10 research areas

How long did the research prioritization take?

October 2017 - May 2018

Which methods were used to identify research priorities?

survey; workshop

How were the priorities for research identified exactly?

Step 1: collecting research uncertainties: pilot survey and literature review: review of guidelines on management of AD. Step 2: survey: participants were asked to rate 94 uncertainties and free text option to add any additional uncertainties. Step 3: data processing: processing, cleaning and collating data. Step 4: workshop: prior to workshop steering committee ranked uncertainties, based on their rankings list of 24 research uncertainties was compiled, this list was brought to workshop, participants were asked to rank 24 uncertainties in round table discussions with facilitated group technique

Which stakeholders took part?

Survey: 30 patients from the subgroups AD type A (n=18), AD type B (n=6), unspecified AD (n=3) and aortic aneurysm (n=3), 45 caregivers, 28 physicians and 17 nurses managing patients with AD. Workshop: 3 patients, 3 caregivers, 1 nurse

How were stakeholders recruited?

Participants 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.

Were stakeholders actively involved or did they just participate?

Stakeholders not only participated but were also actively involved in the research prioritization process: They were part of a steering group. The steering group consisted of 3 patients and 3 caregivers. The members met by telephone every 2 weeks.