

Setting a Research Agenda for Vascular Ehlers-Danlos Syndrome using a Patient and Stakeholder Engagement Model

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For which topic were research priorities identified?

vascular Ehlers-Danlos syndrome

In which location was the research priority setting conducted?

North America - USA

Why was it conducted at all?

Vascular Ehlers-Danlos syndrome (vEDS) is a rare, syndromic, heritable condition with life-threatening complications that include aortic and arterial aneurysms, dissection, and rupture.

What was the objective?

to develop infrastructure and research priorities with engagement from vascular Ehlers-Danlos syndrome stakeholders

What was the outcome?

a ranking list of 5 research questions

How long did the research prioritization take?

October 2017 - September 2018

Which methods were used to identify research priorities?

Delphi

How were the priorities for research identified exactly?

Step 1: Delphi round 1: development of broad research topics by teleconference and survey, participants were asked about relevance of each topic based on their experience and perceived importance of the topic. Step 2: data processing: refinement of research questions, group discussion on questions. Step 3: Delphi round 2: participants were asked to rank 12 patient-centered research questions

Which stakeholders took part?

Patients, family members and caregivers, clinicians, and researchers. Delphi round 2: 169 participants. Participants: patients (n=107 [54.3%]), family members and caregivers (n=80 [40.6%]), and clinicians and researchers (n=10 [5.1%]).

How were stakeholders recruited?

The survey disseminated via social media. The second survey was distributed to the entirety of the vEDS Research Collaborative mailing list and shared on an individual basis through social media by vEDS Research Collaborative members.

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 an advisory board. The advisory board consisted of 5 members: 2 patient partners, 1 family member, 1 researcher, 1 clinician. The members met monthly via teleconference and were responsible for strategic planning, event planning, and preparing funding applications on behalf. Additionally, a stakeholder group was composed. The group consisted of 25+ people (including patients, families, clinicians, and researchers). Members met monthly via teleconference and were responsible for giving feedback on survey materials, outreach plans, and contributing meaningfully to major decisions.