



**European  
Reference  
Network**

for rare or low prevalence  
complex diseases

 **Network**  
Vascular Diseases  
(VASCERN)



# Patient-centered Quality Outcome Measures of Heritable Thoracic Aortic Disease Care

Validated by the Heritable  
Thoracic Aortic Diseases (HTAD)  
Working Group

# Introduction

Clinical Outcome Measures (COM) are essential tools for evaluating the effectiveness of healthcare interventions and tracking patient outcomes. One of the deliverables of VASCERN is to create metrics for clinical outcome measures to guide healthcare providers in providing good care for a rare disease(s) and to give others a set of measures to work towards.

The Heritable Thoracic Aortic Diseases Working Group (HTAD-WG) conducted surveys with healthcare providers, patient advocates, and patients themselves to develop a set of outcome measures. Based on the results of these surveys, they developed a set of measures called the "POM of HTAD care," which stands for **Patient-centered Quality Outcome Measures of Heritable Thoracic Aortic Disease care**.

POM can be used to monitor the availability of different aspects of healthcare within a healthcare provider (HCP). These aspects are meant to reflect what patients consider as important, what a center of expertise has to offer, and what aspects might need further development, in contrast to COM, which reflects clinical outcomes.

There are 21 measures divided into 5 categories. Of these, 14 measures are recommended and 7 are optional.

This POM can be surveyed every 2-3 years to see how the ERN and its HCPs develop over time. The next step for the HTAD Outcome Measures sub-working group is to develop patient reported outcome measures (PROM) to evaluate patients' experience with the HCP, and patients' reflection on their health status and quality of life (QoL).

DOMAIN	RECOMMENDED	OPTIONAL
<b>1. Information medical expertise</b>		
Patient access to relevant up-to-date reports	X	
Patient access to own digital clinical records/results		X
Patient friendly information	X	
<b>2. Information capacity building</b>		
Information about disease related patient organization	X	
Patient educational events		X
<b>3. Information family</b>		
Family screening advice given	X	
<b>4. Holistic approach / Interdisciplinarity</b>		
Core team present	X	
Cardiologist (ACHD/GUCH)		
Clinical Geneticist / Genetic Counsellor		
Ophthalmologist		
Surgeon		
Other specialties available upon request		X
Adult <i>and</i> Pediatric care offered		X
Periodical multidisciplinary meetings	X	
Psychosocial care available	X	
QoL questionnaire used	X	
Coordinated transition standard procedure	X	
Genetic testing available	X	
Preimplantation Genetic Testing (PGT) available		X
<b>5. Patient costs &amp; time management / Surplus / Added Value</b>		
Coordination for appointments	X	
Contact point for patients	X	
Contact point for healthcare professionals	X	
Multiple visits possible in 1 day		X
Waiting time < 4 months	X	
Feedback, "Patient Quality Management"		X



European  
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VASCERN

Gathering the best expertise in Europe  
to provide accessible cross-border healthcare  
to patients with rare vascular diseases



VASCERN, the European Reference Network on Rare Multisystemic Vascular Diseases, is dedicated to gathering the best expertise in Europe in order to provide accessible cross-border healthcare to patients with rare vascular diseases (an estimated 1.3 million concerned). These include arterial diseases (affecting aorta to small arteries), arterio-venous anomalies, vascular malformations, and lymphatic diseases.

VASCERN currently gathers 48 expert teams from 39 highly specialized multidisciplinary HCPs, plus 6 additional Affiliated Partner centers, coming from 19 EU Member States, as well as various European Patient Organisations, and is coordinated in Paris, France.

Through our 6 Rare Disease Working Groups (RDWGs) as well as several thematic WGs and the ePAG – European Patient Advocacy Group, we aim to improve care, promote best practices and guidelines, reinforce research, empower patients, provide training for healthcare professionals and realise the full potential of European cooperation for specialised healthcare by exploiting the latest innovations in medical science and health technologies.

More information available at: <https://vascern.eu>

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