

# Scale Structure and Measurement Properties of a Disease Specific Patient-Reported Outcome for Anti-Neutrophil Cytoplasmic Antibody-Associated Vasculitis

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## SESSION INFORMATION

**Date:** Wednesday, November 16, 2016

**Session Title:** Vasculitis IV: Diagnosis and Assessment of Disease Activity

**Session Type:** ACR Concurrent Abstract Session

**Session Time:** 9:00AM-10:30AM

**Background/Purpose:** ANCA-associated vasculitis (AAV) is an organ- and life-threatening disease. Patients present with active disease, followed by periods of remission and flare, and have impairments in mental and physical wellbeing due to disease and treatment. An international team has developed a disease- specific patient- reported outcome measure: the AAV-PRO, supported by a steering group, including four patient partners, in collaboration with the Outcome Measures in Rheumatology (OMERACT) Vasculitis Working group. Candidate questionnaire items were produced following in-depth qualitative research in the UK, US, and Canada plus cognitive interviews, extensive piloting and independent linguistic and translatability assessment.

**Methods:** Patients with AAV were recruited from Vasculitis UK, and the Vasculitis Patient-Powered Research Network, US. Patients completed the 35 candidate questionnaire items, plus information about their disease, at baseline and three months (included transition item charting change). Paper

copies were used in the UK and an electronic online version in the US. UK patients also completed the Euro-QoL-5D (EQ-5D-5L). In the US, a test-retest exercise was completed 3-5 days following baseline. Exploratory factor analysis (EFA) and Rasch analysis defined the underlying scale (domain) structure. The following properties were determined for each domain: convergent validity, using Pearson correlations between domain scores and the EQ-5D-5L; known groups validity, using t-tests to compare mean scores for different disease states; test-retest reliability, analysing intraclass correlation coefficients (ICC), with respondents reporting “no change”; and longitudinal construct validity, analysing mean change scores and effect sizes in relation to transition item responses at three months.

**Results:** The survey included 626 patients with AAV, mean age 59.9 years (standard deviation (SD) 13.9), 29% reported current “active disease” and 43% a flare within the last 2 years. EFA and Rasch analysis supported a 29-item profile measure comprising 6 domains: “Organ-Specific Symptoms”, “Systemic Symptoms”, “Treatment Side Effects”, “Social and Emotional Impact”, “Concerns about the Future”, and “Physical Function”. Domains individually fitted the Rasch model (no significant item-trait interaction at the 1% level) and had good internal consistency (Cronbach’s alphas 0.73 to 0.93). Mean AAV-PRO domain scores were all higher for patients reporting “active disease” versus “remission” (all  $p < 0.001$ ). Correlations between domain scores and the EQ-5D-5L index ranged from  $r = 0.55$  to  $r = 0.78$ . In respondents reporting “no change” ( $n = 97$ ), ICC values were high (range 0.89 to 0.96) for comparisons of each domain’s 3-5 day test re-test scores. Comparison of mean score changes and effect sizes (ES) for each domain demonstrated stable scores in those reporting “no change” and appropriate positive and negative changes in “much better” or “much worse” disease.

**Conclusion:** The AAV-PRO, a new disease-specific PRO measure for use in ANCA-associated vasculitis, has good face, content, and construct validity, is reliable, feasible, and discriminates among disease states of importance.

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