PRIORITISED ANCA-ASSOCIATED VASCULITIS OUTCOMES FOR REPORTING FROM THE AUSTRALIA AND NEW ZEALAND VASCULITIS REGISTRY DETERMINED BY PATIENT-CLINICIAN CONSENSUS

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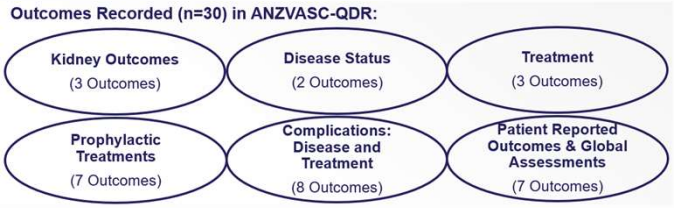
BACKGROUND

- The Australian and New Zealand Vasculitis Quality and Disease Registry (ANZVASC-QDR) has been established to study ANCA-Associated Vasculitis (AAV)
- The template of the registry is based on the EUVAS registry, modified for Australia and New Zealand
- It aims to better understand AAV and improve quality of care
- Annual reports will provide local information about AAV and its care
- Priorities for reporting outcomes in AAV registries have not been previously defined

AIMS OF THE STUDY

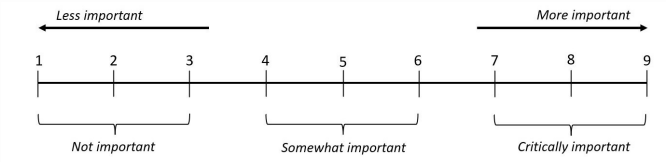
- To determine which registry outcomes are the most important for annual reporting to improve care, by asking AAV patients & clinicians



METHODS

- Three online survey rounds undertaken by AAV Patients and Clinicians (Australia, NZ, UK and Ireland) to determine the top 8 outcomes from 30 outcomes in the vasculitis registry
  - Two Delphi rounds scored outcomes with a Likert Scale and participants able to provide comments on each outcome
  - Third round ranked outcomes using pairwise comparison
- Both groups' (AAV Patients and Clinicians) scores and rankings provided equal weighting to the rankings
- After each round, several top AAV Patient and Clinician top choices and Patient Reported Outcomes / Global Assessments were protected as mandatory inclusions

First Two Delphi Rounds Used a Likert Scale:



Third Round Ranked Used Pairwise Comparison:

Participants displayed a series of randomly chosen pairs of the top 15 outcomes and asked to choose the most important of the two

Example:

Please select the outcome you consider more important to report from the registry out of the two vasculitis outcomes shown.

☐ Types of Immune Treatments Given Other Than Steroids
(Such as rituximab and cyclophosphamide)

☐ Cardiovascular Complications
(Conditions which affect the heart and blood vessels including heart attacks and strokes)

RESULTS

	Round 1	Round 2	Round 3
Number of Total Participants (% Retention from Round 1)	**233**	**202 (86.7)**	**189 (81.1)**
Number of Persons with AAV (% Retention from Round 1)	125	109 (87.2)	104 (83.2)
Number of Clinicians (% Retention from Round 1)	108	93 (86.1)	85 (78.7)

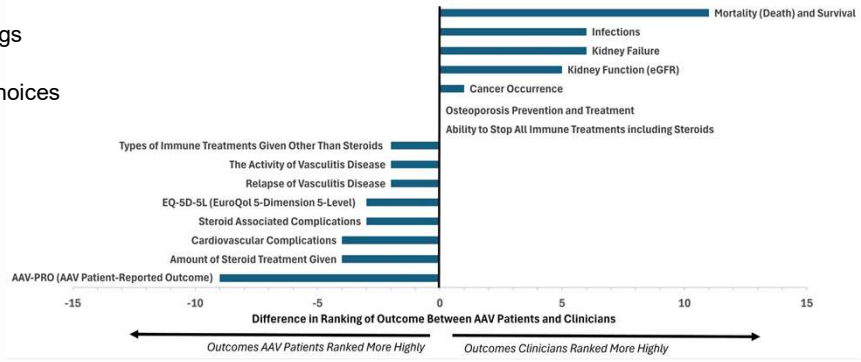
- High retention rate of participants (81.1%) through all three rounds
- Large proportion of patient participation (55% of all respondents who completed all three rounds)

Top 15 Outcomes Ranked with Final "Top 8 Determined Outcomes":

Final Consensus Rank	Vasculitis Registry Outcome	AAV Patient Ranking	Clinician Ranking
1st	Relapse of Vasculitis Disease ★	1st	3rd
2nd	The Activity of Vasculitis Disease ★	2nd	4th
3rd	Kidney Failure	8th	★ 2nd
4th	Immune Treatments Given Other Than Steroids	4th	6th
5th	Mortality (Death) and Survival	12th	★ 1st
6th	Steroid Associated Complications	5th	8th
7th	Kidney Function (eGFR)	10th	5th
8th	★ AAV-PRO (AAV Patient-Reported Outcome)	3rd	12th
9th	Amount of Steroid Treatment Given	6th	10th
10th	Ability to Stop All Immune Treatments (incl steroids)	9th	9th
11th	Cardiovascular Complications	7th	11th
12th	Infections	13th	7th
13th	EQ-5D-5L (EuroQol 5-Dimension 5-Level)	11th	14th
14th	Cancer Occurrence	14th	13th
15th	Osteoporosis Prevention and Treatment	15th	15th

★ = *Protected outcomes*

Differences Between Final Patient and Clinician Ranking of Outcomes



THEMES IDENTIFIED FROM COMMENTS

- Relevance to patient's experience of disease
- Avoiding devastating irreversible consequences of disease
- Identifying, measuring and stabilising activity of disease
- Minimising harms from immune related treatment given
- Furthering the understanding of the disease
- Uncertainties related to disease and treatment

CONCLUSIONS

- This consensus process defines the prioritised reportable AAV registry outcomes of vasculitis clinicians & consumers to improve care
- The prioritised registry outcomes comprise of:
  - AAV disease status (activity and relapses)
  - Objective clinical outcomes (mortality and kidney outcomes)
  - Treatment related outcomes (type of immunosuppression given and glucocorticoid-associated complications)
  - An AAV-specific PROM (AAV-PRO)