



THE ESTABLISHMENT OF THE ANZVASC QUALITY AND DISEASE REGISTRY: FRAMEWORK AND PROTOCOLS

JUSTIN CHUA^{1,2,3}, **PAULA BUSSA**², **JESSICA RYAN**^{2,3}, **CHRIS ASKEW**¹, **JAMES GRAY**^{1,4},
PRAVIN HISSARIA^{1,5}, **HOLLY HUTTON**^{1,6}, **CHEN AU PEH**^{1,5}, **KEVAN POLKINGHORNE**^{1,2,3}, **SUSANNA PROUDMAN**^{1,5},
VICKI QUINCEY^{1,7}, **SANJAY SWAMINATHAN**^{1,8}, **LUKE SCHAUMKELL**¹, **JOANNA TIEU**^{1,9}, **MARK LITTLE**¹⁰,
TZE GOH^{1,11}, **ANTHONY SAMMEL**^{1,12}, **A. RICHARD KITCHING**^{1,2,3}

¹ANZVASC Quality and Disease Registry Committee, ANZVASC; ²Dept Nephrology, Monash Health, Clayton; ³Monash University Dept Medicine, Clayton;
⁴Dept Rheumatology, Princess Alexandra Hospital, Woolloongabba; ⁵Dept Clin Immunology, Rheumatology & Nephrology, Royal Adelaide Hospital, Adelaide;
⁶Dept Nephrology, The Alfred Hospital, Prahran; ⁷Dept Rheumatology, Waikato Hospital, Hamilton; ⁸Dept Clin Immunology, Westmead Hospital, Westmead;
⁹Dept Rheumatology, The Queen Elizabeth Hospital, Woodville South; ¹⁰Trinity Kidney Centre, Trinity Translational Medicine Institute, Dublin, Ireland;
¹¹Dept Nephrology, Auckland Hospital, Auckland ¹²Dept Rheumatology, Prince of Wales Hospital, Randwick

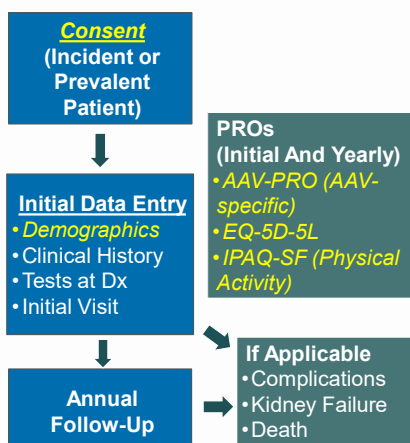
SUMMARY

- Previously, there has been no Australian and New Zealander Vasculitis Registry, despite interest and need
- Local vasculitis registry established with community involvement on the Committee and ANZVASC Board
- Modified EUVAS REDCap Data Dictionary
- EUVAS compulsory questions retained for collaboration and data linkage
- Opt-in consent
- Enrolls both incident and prevalent patients
- Core dataset: initial visit & yearly follow-up
- Capability to record additional visits
- EUVAS-aligned outcomes: acute dialysis, eGFR<15mL/min, dialysis >90d, transplant
- PROMs: AAV-PRO, EQ-5D-5L, IPAQ-SF
- Data access/publication policies adapted from ANZDATA, approved by the Board
- At 01/02/2026:**
 - Sites: **8 active sites**, ethics/governance underway at **9 other sites**
 - 264 AAV participants**, median follow-up **2 years** (range 0-9)

GOVERNANCE

- ANZVASC led
- Monash University is Data Custodian
- Monash Health is National HREC site
- NZ separate HREC approvals
- ANZVASC Registry Committee
- Clear and inclusive data access, data usage and authorship policy

CORE STRUCTURE



PARTICIPANT DASHBOARD

Record ID: Monash Health-1

Enrollment: Initial consent, Reconsent date, Initial visit date, Outcomes, Forms, Annual Visit (Y1, Y2, Y3, Y4, Y5)

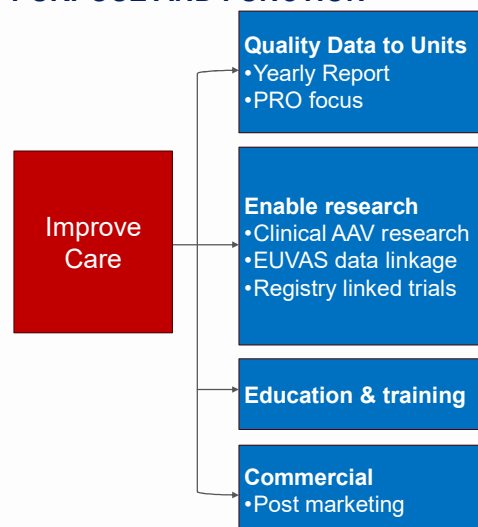
Consent (ENROL) (Y/N), Demographics (ENROL) (Y/N), Clinical History (ENROL), Tests at Diagnosis (ENROL), Initial Visit (ENROL), Annual Visit Follow-up, Additional Visit Follow-up, Complication Dashboard, Dialysis Dashboard, BVAS Dashboard (Optional), VDI Dashboard (Optional), Survey Dashboard, Patient Status, ESKD Outcome (Optional), Death Outcome (Optional), AAV-PRO (PRO) (Y/N), EQ-5D-5L (PRO) (Y/N), IPAQ-SF (PRO) (Y/N)

Repeating Instruments: ESKD Outcome (Optional), Outcomes (Y), Annual Visit (Y), Annual Visit (Y), Annual Visit (Y), Annual Visit (Y), Annual Visit (Y)

Repeating instrument results are summarised here

COMPLICATIONS (OPTIONAL) (Y/N): Annual Visit complication, Annual Visit infection, Annual Visit hypogammaglobulinaemia, Annual Visit infection, Annual Visit infection

PURPOSE AND FUNCTION



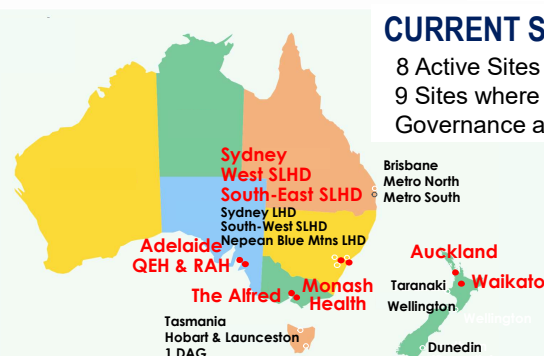
- On-line consent with single site-specific link
- Yellow** = entry by patient on-line direct to REDCap.
- Paper forms available
- Options
 - Additional Visits
 - More detailed Annual Visit
 - Semi-automated BVAS/VDI

STANDARD YEARLY QUESTIONS

- Vasculitis **status** (Active/Remission)
- Relapse**/nature of relapse (check boxes)
- Last **ANCA** IF, PR3-ANCA, MPO-ANCA
- Last **serum creatinine**
- High dose **IV PNL** (Y/N)
- Oral GC** therapy (dose range over time)
- Other IS Rx** (check boxes). For RTX/CYC cumulative dose/number doses
- IS Prophylaxis** (check boxes)
- CVS/Renoprotective Rx** (check boxes)
- Complications** (check boxes)
- ESKD**: Dialysis, Transplant, CKD 5 (Y/N)
- Death** (Y/N)
- Opted out/Lost to Follow Up** (Y/N)

CURRENT SITES

8 Active Sites
9 Sites where Ethics and Governance are underway



ACKNOWLEDGEMENTS

- Funding support for the ANZVASC-QDR provided by CSL
- Prof Stephen McDonald, ANZDATA for Data Access Policies

22nd
International
**Vasculitis
Workshop**
21 – 25 February 2026
Melbourne, Australia

