

Background & Aim: Von Willebrand Disease (vWD) is a rare bleeding disorder with broad physical, emotional and social impacts on quality of life, yet there is limited understanding of how different generic health related quality of life (HRQoL) tools perform in this condition. We compared the EQ-5D-5L and AQoL-4D to evaluate their sensitivity to HRQoL differences across vWD types in the UK PIVOT-vWD study.

Methods: Data were utilised from the UK cohort of the PIVOT-vWD study (Oct 24 – Jan 25); a direct-to-community, cross-sectional study capturing outcomes of vWD, patient and clinical characteristics across 116 individuals.

Specific HRQoL measures collected:

Participants were grouped as follows:



PROs: Patient Reported Outcome Measures.

Those for whom vWD type was 'unreported' or 'acquired' were excluded.

Distribution of responses across domains of each HRQoL instrument were assessed using frequency and percentage. Spearman's rank coefficients were calculated to analyse associations between instrument domains.

Results: The included sample totalled 104 individuals:

N=86 Self-complete

N=18 Proxy-complete

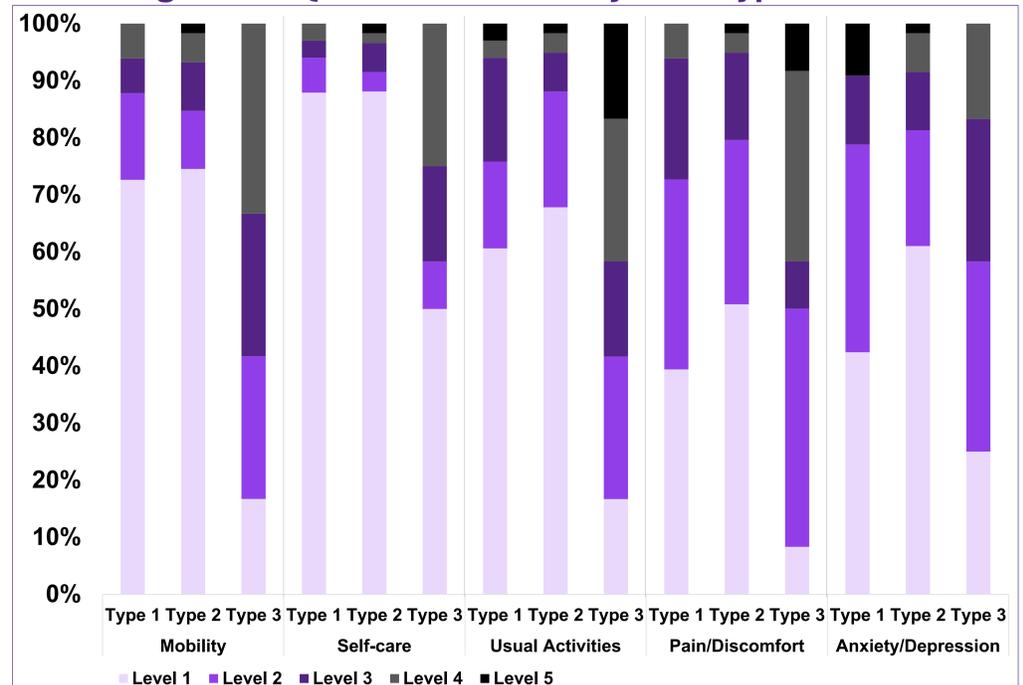
N=33 Type 1

N=59 Type 2

N=12 Type 3

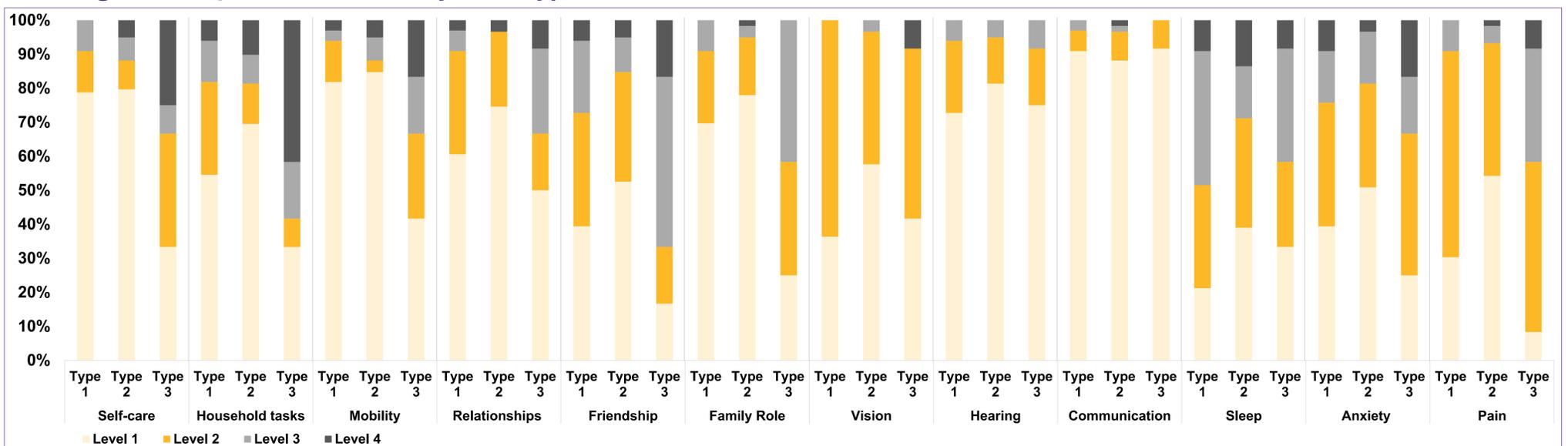
EQ-5D-5L results were similar for Type 1 and 2, with 27% vs. 25% reporting moderate to extreme problems in mobility, 12% vs. 12% in self-care, and 30% vs. 32% in usual activities. These rose in Type 3 to 83%, 50%, and 67% respectively; pain/discomfort (27–29% vs. 43%) and anxiety/depression (18–20% vs. 43%) also increased (Figure 1).

Figure 1: EQ-5D-5L Domains by vWD Type



AQoL-4D captures a broader and deeper quality-of-life burden in von Willebrand Disease than EQ-5D-5L.

Figure 2: AQoL-4D Domains by vWD Type



Across 12 AQoL-4D items, responses were similar for Types 1 and 2. Type 3 patients reported more problems with self-care, mobility, household tasks, family role, and pain. Sleep, anxiety, and friendships showed moderate burden across types; hearing and communication were rarely affected (Figure 2).

The strongest convergent correlations were seen between the AQoL-4D and EQ-5D-5L for anxiety ($rs = 0.87$) and pain ($rs = 0.82$), confirming overlap in core physical and emotional domains. In contrast, sensory and communication domains were weakly correlated ($rs \leq 0.33$), demonstrating the AQoL-4D's added sensitivity to aspects of HRQoL not captured by the EQ-5D-5L (Table 1).

Table 1: Correlation between EQ-5D-5L and AQoL-4D Domains

AQoL-4D	EQ-5D-5L				
	Mobility	Self Care	Activity	Pain	Anxiety
Self-care	0.543	0.682	0.433	0.471	0.299
Household tasks	0.55	0.628	0.541	0.532	0.274
Mobility	0.587	0.658	0.587	0.473	0.318
Relationships	0.342	0.422	0.431	0.479	0.469
Friendship	0.413	0.458	0.533	0.6	0.578
Family Role	0.55	0.62	0.549	0.521	0.472
Vision	0.282	0.256	0.303	0.317	0.239
Hearing	0.293	0.33	0.271	0.309	0.2
Communication	0.296	0.385	0.209	0.258	0.225
Sleep	0.41	0.302	0.456	0.558	0.501
Anxiety	0.297	0.38	0.404	0.483	0.873
Pain	0.601	0.465	0.659	0.821	0.459

Conclusion: Type 3 vWD patients reported markedly higher problems across domains of the EQ-5D-5L and AQoL-4D compared with Types 1 and 2. While both EQ-5D-5L and AQoL-4D reflected these differences, the AQoL-4D uniquely identified wider social and sensory impacts, underscoring its added value in assessing the true quality-of-life burden of vWD.

