

PHASE 1: Face Validity

- a) Qualitative interviews mapping expressed needs to tool items

Patients n=90

Families n=38

- b) Cognitive interviews to investigate comprehension

Patients n=73

Families n=29

PHASE 2: Construct Validity

Cross sectional POS & MVQoL correlation

Patients n=285

Families n=199

PHASE 3:

- a) Internal consistency
- b) Test-retest reliability
- c) Time to complete

Patients n=307

Families n=200