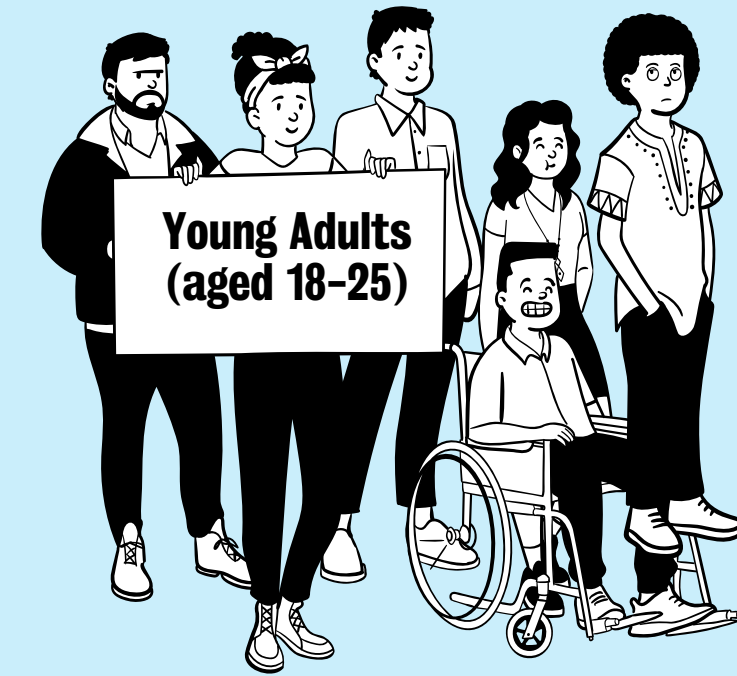


Evaluating the measurement properties of patient-reported outcome measures for young adults (aged 18–25) with life-limiting conditions – a COSMIN systematic review

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Background

- Young adults living with life-limiting conditions require age-specific care that is responsive to their needs and preferences
- Patient reported outcome measures (PROMs) are standardised questionnaires that can be used to assess patients' health status

Aims

- To identify existing PROMs developed, adapted or validated for young adults (aged 18-25) living with life-limiting conditions
- To critically appraise their measurement properties

Method

Systematic review in line with COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) guidelines¹

Data sources MEDLINE; EMBASE; CINAHL; PsycInfo; AMED via Ovid & Cochrane Library

Inclusion criteria

- Young adult (aged 18-25) living with a life-limiting condition
- Developed, adaptation or validation of a patient reported outcome measure
- Any country, any setting
- Any health outcome; evaluation of measurement properties
- Original, full-text peer-reviewed research studies of all types

Quality appraisal Studies were appraised using the COSMIN Risk of Bias checklist² and quality criteria developed by Terwee et al³

Data synthesis Patient reported outcome measure domains were mapped onto a conceptual palliative framework⁴. Measurement properties were qualitatively summarised

Results 4922 papers identified → 556 full texts → 35 papers reporting 68 PROMs
61/68 existing paediatric or adult PROMs
7/68 specifically developed for young adults (reported below)

29/35 Cancer; 2/35 Sickle Cell; 1/35 Cystic Fibrosis; 1/35 Spinal Muscular Dystrophy; 1/35 Spina Bifida
8/68 PROMs were PROMIS (Patient-Reported Outcomes Measurement Information System) measures assessing a range of symptoms and concerns including fatigue, pain, sexual function, social isolation, social interactions and social roles and activities

Table 1. Characteristics of included studies and PROMs

	Country	Disease	Age (Mean)	Number of items	Response options	Domains of PROMs mapped onto a conceptual palliative care framework ⁴				
						Physical	Psychological	Social	Spiritual	
AYA Life Impact Checklist	Australia	Cancer	22	18	Checklist		✓	✓		
Young Adult Psychosocial Assessment Strategy	USA	Cancer	Phase 1 23; Phase 2 26	41 (9 domains)	Not reported	✓	✓	✓		
Cancer Distress Scales for Adolescents and Young Adults	Canada	Cancer	Multiple studies	49 (5 domains)	4-point scale	✓	✓			
Pediatric Quality of Life Inventory - Young Adult version	Norway	Cancer	25	23 (4 domains)	6-point scale	✓	✓	✓		
The Cancer Assessment for Young Adults – Testicular	USA	Cancer	25	90 (17 domains)	3-point scale	✓	✓	✓	✓	
AYA Needs Assessment and Service Bridge	N/A	Cancer	24	57 (9 domains)	3-point scale	✓	✓	✓		
Cancer Needs Questionnaire – Young People	Australia	Cancer	Median 21	139 (8 domains)	5-point scale		✓	✓		

Table 2. COSMIN Risk of Bias assessments for each measurement property, per study

Risk of Bias Very good ● Adequate ● Doubtful ● Inadequate ●	Structural Validity		Internal consistency		Reliability		Measurement error		Construct validity		Measurement invariance		Criterion validity		Responsiveness	
	Risk of Bias	Quality criteria	Risk of Bias	Quality criteria	Risk of Bias	Quality criteria	Risk of Bias	Quality criteria	Risk of Bias	Quality criteria	Risk of Bias	Quality criteria	Risk of Bias	Quality criteria	Risk of Bias	Quality criteria
	Sufficient +	Indeterminate ?	Insufficient -													
AYA Life Impact Checklist	●	-	●	+												
Young Adult Psychosocial Assessment Strategy (YA-PAS)	●	+	●	+	●	+			●	+						
Cancer Distress Scales for Adolescents and Young Adults (CDS-AYA)	●	-	●	-	●	+			●	+	●	+			●	+
Pediatric Quality of Life Inventory (PedsQL) young adult version			●	?												
The Cancer Assessment for Young Adults – Testicular (CAYA-T)	●	+	●	+	●	+			●	+						
AYA Needs Assessment and Service Bridge			●													
Cancer Needs Questionnaire – Young People (CNQ-YP)	●	-	●	+	●	?			●	-						

None of the measures met the criteria to be recommended for use as they did not meet sufficient criteria for content validity.

Conclusions All the measures specifically developed for young adults were validated with young adults living with cancer. Of these measures, all were holistic. None of the measures met the criteria to be recommended for use as they did not meet sufficient criteria for content validity. Future studies should take existing PROMs, covering all domains of palliative care (physical, psychological, social and spiritual) and ask young adults and professionals about the relevance, comprehensiveness and comprehensibility of items in line with COSMIN guidance to assess content validity.