

## **P37 Patient-reported health outcome measures for young adults living with life-limiting conditions**

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**Objective:** To identify patient reported outcome measures (PROMs) validated for young adults (aged 18-25) living with life-limiting conditions and to critically appraise their measurement properties.

**Methods:** This systematic review (PROSPERO ID: CRD42023443273) was conducted in line with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) and Consensus-based Standards for the selection of health Measurement Instruments (COSMIN) guidelines. Six databases (MEDLINE, EMBASE, Cochrane, CINAHL, PsycINFO and AMED) were searched from inception to 03/07/2023.

**Results:** Searches identified 4922 papers. 556 full text articles were assessed for eligibility. 35 papers met our inclusion criteria, reporting 68 patient reported outcome measures. Of these, eight were PROMIS<sup>®</sup> measures assessing a range of symptoms including fatigue, pain interference, symptom management, sexual function, social isolation, social interactions and social roles and activities. Most studies recruited young adults living with cancer, non-cancerous conditions were underrepresented, particularly individuals living with complex neurodisability. Most measures used PROMs validated in children or adults, not specifically developed for young adults aged 18-25. Improving the content validity and internal reliability of tools for young adults with targeted item development based on patient and expert input, followed by rigorous pilot testing and psychometric analysis is needed to ensure relevance and consistency.

**Conclusions:** There is a lack of patient-reported outcome measures for young adults living with life-limiting conditions, especially for non-cancerous conditions. Future research may take existing measures developed for children or adults and adapt them for use with young adults. Young adults and key stakeholders should be consulted to ensure outcome measures are relevant and comprehensive for this population.