

Measurement properties of Patient-Reported Outcome Measures (PROMs) for adolescent and young adult (AYA) survivors of a brain tumour: A systematic review

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Introduction

- Brain tumours account for 15% of all AYA cancers and are the most common childhood solid tumour.
- Survival is highest for those aged 15-39 yrs, more than half are left with life-altering, long-term disability impacting ability to reach independence.¹
- Survivorship initiatives advocate the delivery of personalised aftercare, including the use of PROMs which have been shown to improve quality of life (QoL).²
- PROMS must be valid, reliable and relevant to the population in which they are used. Therefore, the unique needs of AYAs must be acknowledged for successful clinical use.^{3,4}

Aim

To identify and evaluate the measurement properties of all PROMs developed for young adult survivors of a brain tumour. For each PROM:
 1) Identify PROM characteristics and the concept it is measuring
 2) Assess each measurement property
 3) Describe its interpretability, clinical utility and feasibility.

Method

The COSMIN ten steps to conducting a systematic review of PROMs guided this review (Fig 1).⁵ Screening was carried out by two independent researchers according to pre specified eligibility criteria. COSMIN guidance was used to assess risk of bias, criteria for good measurement properties and GRADE was applied to evaluate the quality of evidence of the included studies.

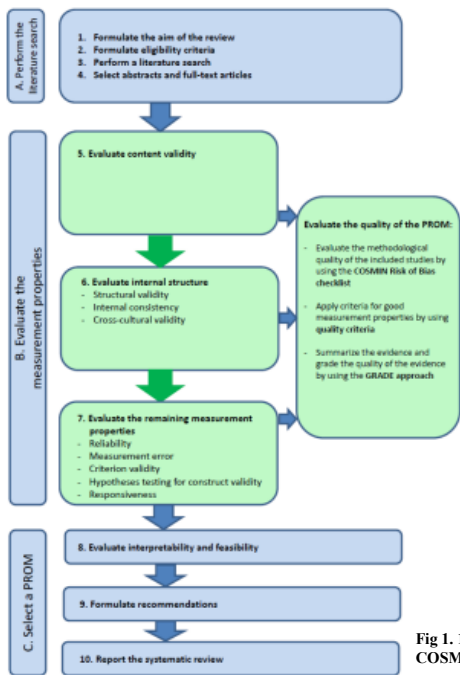


Fig 1. 10 steps by COSMIN.

Preliminary results

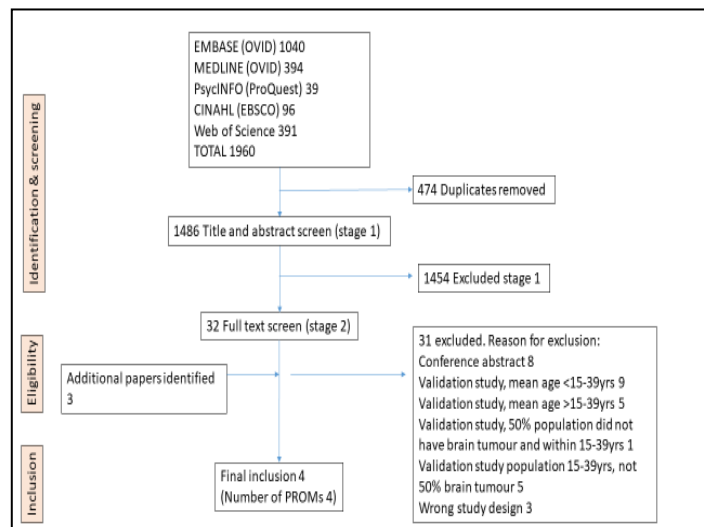


Fig 2. PRISMA flowchart of the screening process

Following the screening process (Fig 2), four studies identifying four different tools were identified: 1) single item screening tool for fatigue (Brand et al, 2016); 2) single item screening tool for pain (Chordas et al, 2013); 3) Perceived Barriers Scale to assess barriers to career development and employment (Strauser et al, 2019); 4) Quality of life measure (Yoo et al, 2010).

The single item screening tools reported insufficient results according to the COSMIN criteria for good measurement properties and therefore would not be recommended for clinical use. The most common measurement properties evaluated and reported were hypothesis testing for construct validity. Little information was presented on PROM development and the comprehensiveness of each PROM. Details on interpretability, feasibility and clinical utility were also missing.

Discussion

The review highlights attempts to evaluate fatigue, pain, QoL and employment barriers which are known to be important factors for survivors of a brain tumour. The risk of bias of all included studies must be recognised when evaluating construct validity as the new instrument was compared to another which had been validated in a different population, highlighting the paucity of AYA specific instruments and the challenge of developing AYA specific tools.

Future work

Further research should examine the use of PROMs which are both age and disease specific and focus on development of psychometrically validated tools to improve identification of unmet needs and improve the aftercare for AYA survivors of brain tumours.

