

Development of a Needs Assessment Tool (NAT) for adolescent and young adult (AYA) survivors of a brain tumour.

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Introduction

- Ongoing emotional and physical issues can cause increased dependency on family, lower levels of employment and social isolation for some survivors of a brain tumour.
- Despite initiatives to provide personalised follow-up and improve outcomes, follow-up services often fail to identify ongoing symptoms.
- Patient-reported outcome measures (ePROMs) have been shown to improve communication between healthcare professionals and patients; remote monitoring of symptoms and their management; and QoL¹.
- Despite a multitude of PROMs, there lacks the innovation and psychometric validation of NATs for use with AYA survivors of a brain tumour².

Results

Phase 1 and 2 have been conducted to improve content validity. The conceptual framework (Fig 1) constructed from synthesis of 27 qualitative studies underpins the development of the NAT. Draft items were constructed from the systematic review (207) and reduced and amended during cognitive interviews (n=8) to produce the final draft (47 items; accessed using the QR code via Qualtrics).



Aim

To develop and validate a Needs Assessment Tool for use with young adult survivors of a brain tumour aged 16-39 years.

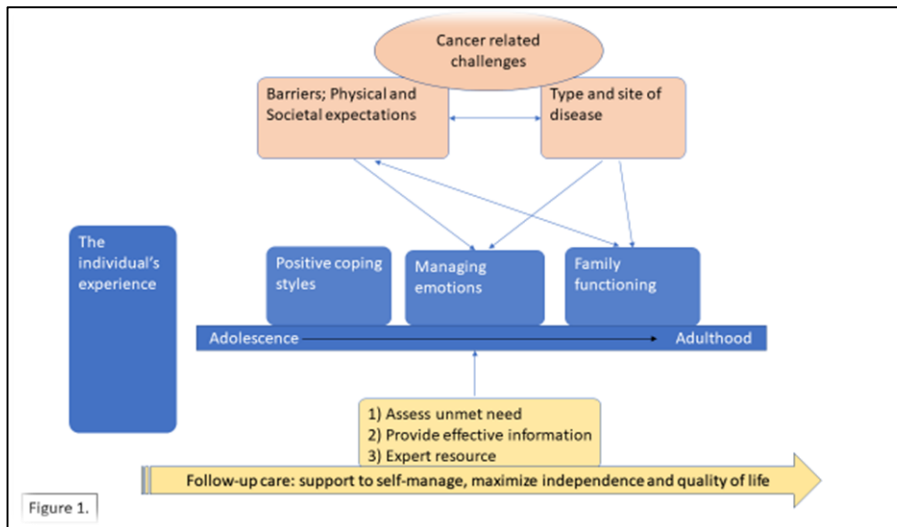
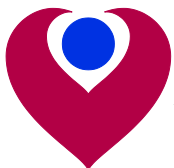


Figure 1.

Method

Application of the Consensus-based standards for the selection of health measurement instruments (COSMIN) guidance was used as a model for development. Patient representatives collaborated with the researcher throughout the study. Phase 1: systematic review and meta-ethnography to develop a conceptual framework and generate draft

items. Phase 2: cognitive interviews.
 Phase 3: evaluation of measurement properties using Rasch analysis (n=150).



Future work

Phase 3: Evaluate construct validity and reliability using Rasch analysis, concluding with a pilot study to evaluate the use of the newly validated NAT in routine follow up to innovate and improve follow-up support to survivors of a brain tumour.