

BRIGHTLIGHT_2021 Questionnaire

Questionnaire measuring teenage and young adult cancer care experience and psychosocial outcomes at 6 months after diagnosis

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Specialist teenage and young adult (TYA) cancer services were implemented in 2005 following the publication of National Institute for Health and Care Excellence (NICE) guidance. While professionals and patients say 'specialist care' is "better" for TYA, it was unknown how specialist services affected the success of treatment and how well young people returned to normal life such as education or work after treatment. BRIGHTLIGHT was a National Institute for Health and Care Research (NIHR) funded study (RP-PG-1209-10013) evaluating whether specialist services add value, which was conducted between 2012 and 2019. A key component of the evaluation was measuring young people's experience and outcomes of care. This was measured using the BRIGHTLIGHT Survey.

The 2012 BRIGHTLIGHT survey was developed for use with young people aged 13-24 years. There were three versions to reflect changes in experience between 5 – 36 months after diagnosis. The survey was computer administered through face-to-face interview using the first survey (wave 1) and either online or telephone interview at waves 2 – 5. The Survey took 40 minutes to administer at wave 1 and waves 2-4 took approximately 30 minutes. These Surveys are available as a computer-administered scripted paper version only through XIP.

In response to changes in commissioning of services in England for TYA, a subsequent study was conducted in 2021-23 to re-evaluate the impact of service delivery on young people's outcomes. Consultation with the BRIGHTLIGHT Young Advisory Panel (YAP) concluded that the survey could be delivered online, or as a paper self-report. As the 2012 BRIGHTLIGHT Survey was developed over 10-years previously, the YAP conducted a thorough review of the content. They made suggestions on rewording questions, removing sections and reordering the questionnaire.

The BRIGHTLIGHT_2021 Survey has been redesigned to capture pre-diagnostic, diagnostic and treatment experience at 6 months post diagnosis. It also includes questions on place of care, entry into clinical trials, communication and coordination of care, education, employment and social relationships. It has been developed as a paper self-report version for young people aged 16-24 years.

References

1. Taylor RM, Fern LA, Solanki A, Hooker L, Carluccio A, Pye J, Jeans D, Frere-Smith T, Gibson F, Barber J, Raine R, Stark D, Feltbower R, Pearce S, Whelan JS(28/07/2015) , <http://hqlo.biomedcentral.com/articles/10.1186/s12955-015-0312-7>, Health and Quality of Life Outcomes, 13, 107