

Supplementary File 1 Detailed results of actions implemented to improve recruitment to the cohort

Table A: Possible challenges reported by healthcare professionals before recruitment began and strategies identified to overcome them

	Challenges	Strategies proposed to overcome challenges
Identifying young people	<p>Missing eligible young people if transferred to regional specialist centres</p> <p>Recruiting across a range of hospital sites</p> <p>Recruiting across multiple tumour types</p> <p>Engaging consultants: one concern was they would not think the older TYAs were eligible, a perception being that it was a ‘teenager’ study</p>	<p>Use the TYA MDT meetings to identify young people</p> <p>Co-ordination by a key person such as the Lead Nurse, cancer network head, or MDT lead to ensure details of eligible TYAs are passed to the recruiters</p> <p>Collaborative working with other centres to ensure all young people are approached, but not on multiple times</p>
Approaching/consenting young people	<p>Concerns about ‘getting past’ protective and upset parents</p> <p>Timing of consent, particularly if the patient is undergoing chemotherapy and was likely to be feeling very unwell</p> <p>Lack of experience in working with ‘children’</p> <p>Being seen or felt to ‘pressurise’ potentially ‘vulnerable and fragile’ young people to take part</p> <p>Getting treating consultant approval to approach young people</p>	<p>Encouraging the initial approach to be a conversation, and not be immediately about persuading young people to take part</p> <p>Work with paediatric nurses to help with recruiting younger TYA</p> <p>Undertake paediatric consent training</p> <p>Wait for a sufficient length of time after diagnosis – maybe two months – before introducing the study, to allow the young person to become accustomed to the emotional and practical impact of the diagnosis</p>

TYA: Teenage and young adult; MDT: multi-disciplinary team

Table B: Suggestions from healthcare professionals for keeping young people engaged throughout the study

Suggestion to keep young people engaged	Action for implementation by BRIGHTLIGHT
Get the consent process absolutely right: clear, accurate information about the survey, as buy-in from young people will increase the chances they will continue to participate	Information developed with young people, site initiation with recruiters to ensure they knew about the study and could relay information to young people in the best way
Provide TYA-friendly formats: e.g., ensure the survey could be completed on an iPad or iPhone as well as on a home computer	The survey was administered face-to-face at the first time point; subsequently it could be completed online on any platform
Use the internet: communicate via social networks like Facebook and Twitter	An open Facebook account was prohibited by the sponsor Trust but a Twitter account was opened
Ensure language used is aimed at empowering young people	All information was reviewed by the YAP ¹ and had a reading ease of >70%
Consider incentives: e.g., a medal-based reward system – for each year young people remain in the study they move up the medals from Bronze (Year 1) to Silver (Year 2) and Gold (Year 3) and get a correspondingly increasingly valuable reward each time.	The YAP suggested a reward system using wrist bands with a different colour for each wave of participation
Inform participating young people on why the study matters and why their continuing involvement is important	A website was developed to keep young people updated about the programme www.brightlightstudy.com
Maintain contact throughout	Newsletters
Disseminate progress and results so they can see the wider scale and impact of the survey, that is making a difference	Content of newsletters related to results as far as was possible
Keep parents on board perhaps with targeted communications	Newsletters sent to all the email addresses provided
Distribute posters and flyers to treatment centres	Posters and flyers provided

YAP: Young Advisory Panel; TYA: teenage and young adult

¹YAP are the BRIGHTLIGHT patient user group

Table C: Suggestions for how the BRIGHTLIGHT Team might facilitate recruitment and actions taken to address these

Suggested change	Action by the BRIGHTLIGHT Team
1. Study information for health professionals	<p>An information booklet was developed giving a brief summary of the study. This was sent electronically and as hard copies to all participating Trusts.</p> <p>Regular newsletters were developed and circulated online and as hard copies.</p> <p>Recruitment figures were circulated in a weekly Bulletin by TYAC to their members and were also Tweeted by the BRIGHTLIGHT team (@bR1GhTLiGhT)</p>
2. Make the participant information sheets as short as possible	<p>A summary booklet had been produced by Ipsos MORI¹ to send as a reminder about the study by their interviewers. An ethics amendment was made in July 2013 to allow this to be used in conjunction with the lengthy information sheet at the time of consent.</p> <p>Video versions of the information sheet were made available on the website (www.http://www.brightlightstudy.com/user-involvement/)</p>
3. Investigate any variation in recruitment rates between sites	<p>Screening logs were requested and analysed to identify reasons for suboptimal recruitment, which was fed back to each Trust with guidance on how to overcome recruitment issues.</p>
4. Reduced interval between giving information and getting consent ²	<p>An amendment was approved by the Ethics Committee to allow consent to be taken within the same 24-hour period as information was given.</p>
5. Provide BRIGHTLIGHT advertising materials	<p>Posters, flyers and postcards had been available since the beginning of the study. These were distributed not only by the BRIGHTLIGHT Team but also by CLIC Sargent and Teenage Cancer Trust.</p>
6. Keep sending the NWCIS notification ³	<p>There was a temporary pause in the CWT data being sent due to organisational change of NWCIS to Public Health England.</p>
7. Extend the window of recruitment for wave 1	<p>This was relaxed at the end of 2012 so young people could be recruited at any time in the first four months after diagnosis. We were unable to extend recruitment beyond this period because we wanted data to be collected within a specific time window. Young people were not able to enter the study at later time points because subsequent questions were informed by responses in the first survey.</p>

Table C. *cont.*

Suggested change	Action by the BRIGHTLIGHT Team
8. Reduce the number of times young people need to participate (total study participation involved 5 time points in 3 years)	The sample size calculation was based on participation at three time points (as specified in the protocol) because we were aware young people might opt in and out of participation depending on their current life commitments. We developed top tips for recruiting Trusts, including information about participation. The top tips were prominent on the website, were sent as an information leaflet, and included in the newsletter.
9. Enable information sheets to be posted to young people	An ethics amendment was approved to enable information sheets and consent forms to be posted and/or returned through the mail.
10. Make presentations at local network and Trust meetings	Members of the BRIGHTLIGHT team presented recruitment updates at every available national meeting. Trusts were also informed that the team would come to any local meetings on request. Site specific slides to present at MDTs were provided to all PTCs.
11. First survey to be online or telephone rather than face-2-face	This request could not be accommodated. A single mode of administration had been developed for the first survey. ⁴

CWT: Cancer Wait Time database; MDT: multi-disciplinary team; NWCIS: North West Cancer Intelligence Service (after the move to Public Health England became known as the North West Knowledge Intelligence Team). PTC: Principal Treatment Centre; TYAC: Teenagers and Young Adults with Cancer (the organisation representing healthcare professionals working in this area).

¹ Ipsos MORI were the commercial company administering the BRIGHTLIGHT Survey; ² Ethics guidance in the United Kingdom recommends a minimum of 24 hour between providing information and gaining consent to give participants time to process information; ³ NWCIS sent a monthly email to a dedicated person in each recruiting trust with a list of potentially eligible patients identified through the Cancer Waits dataset as newly starting treatment; ⁴Subsequent waves had a choice of online or telephone interviewer administered survey; the online option has only been selected by a minority of young people