

BRIGHTLIGHT study

By Lorna Fern, Anita Solanki and JJ Wheeler

BRIGHTLIGHT is a national study looking at cancer care received by young people aged 13-24. This research study will follow over 1,000 young people with cancer for three years to find out if they have different outcomes depending on where they are treated and the professionals involved in their care. Young people will take part in a series of surveys over the three years which asks a variety of questions about their life since diagnosis.



How and why?

We believe if our research is designed by young people with cancer, for young people with cancer, then not only will the research be more meaningful and relevant to things that really matter to young people with cancer but also more young people will want to take part in, and then stay in, our studies.

We try to involve young people in all of our research studies and have worked with young people since the beginning of BRIGHTLIGHT. Before BRIGHTLIGHT we carried out two years of what was essentially planning work where we worked with five young people as co-researchers. They carried out interviews with other young people, helped with data analysis and delivering the results back to young people and are authors on a number of publications.

The BRIGHTLIGHT YAPPERS

With BRIGHTLIGHT, we have approached involvement slightly differently and engaged a wider group of young people – our YAPPERS. The first official BRIGHTLIGHT activity was a naming and branding workshop with nine young people which is where

the name 'BRIGHTLIGHT' came from. Since then we have had another three workshops which have looked at design of the website (<http://tinyurl.com/lcvr6w5>), promotional materials, ways to improve recruitment, strategies to improve retention and redesign of the website (www.brightlightstudy.com) now that we are three years into the study.



Workshops

The format of the workshop begins with role play from us, the researchers. We have found that role play is an effective way to get the message across and is more interesting to the young people; it also conveys that while we are there to work we also want to have some fun in the process.

We then go through our activities, such as how to improve recruitment, or how we can ensure that young people continue to take part in the study over time; we normally do two but sometimes three activities. We try and ensure that the researchers and the young people know the purpose of the workshop and we always feed back the results to the young people. At the end of the day we allow the participants some 'free creative space' to interpret the day as they choose. In September 2013 we held a recruitment workshop and two videos were particularly powerful for recruitment (<http://tinyurl.com/o9kxft5>), and for user involvement (<http://tinyurl.com/n7u576o>).

We have found the environment of the workshop influences the creativity of the group. The venue we have used for the last two workshops is bright and airy and there is complete flexibility on meal and break times as costs are all-inclusive and food and drinks are available all day. It can be difficult to tell in a group when the energy might dip and a break is needed and with this arrangement we don't have to worry about activities running over, running short or the young people (or

researchers!) needing some time out.

JJ Wheeler (Young Advisory Panel (YAP) member) :

“When I was diagnosed with cancer in 2012 it was a bolt out of the blue. Suddenly I had teams of people running around arranging treatment, looking after me or just generally being there; I was the focus of a lot of attention. I wouldn’t be sat here today if it wasn’t for the fantastic support and treatment provided by NHS doctors and support staff, my family and friends, alongside charities and other organisations.

So when I was offered the chance to give something back it was a no-brainer. One of my nurses explained that the BRIGHTLIGHT study would help the government understand how cancer and treatment affect teenagers’ and young adults’ lives, the ultimate goal being to use the data to provide more effective support. Well, that’s got to be positive, right?

I’m nearly at the end of my involvement with BRIGHTLIGHT. I’ve had the chance to meet with like-minded people of a similar age group at a BRIGHTLIGHT workshop in London. Here we discussed ways to improve the service and the type of content we think is relevant with some of the key staff leading the survey.

Personally, I was given a lot of support for free from many sources. Taking part in this study has been a great way to give something back. I also feel I am being listened to and have the opportunity to create a better experience for people in the future who find themselves in the awful situation I was in three years ago.”



References

Taylor RM, Fern L, Millington H, Ashton J, Grew T, Brooman K, Starkey C, Pearce S, Whelan J, Gibson F. (2011) Priorities for a teenage and young adult specialist cancer care unit: disparity between TYA and professional perceptions. *Journal of Adolescent and Young Adult Oncology* 1(3):145-151.

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