



# BRIGHTLIGHT Newsletter

## Winter 2014

BRIGHTLIGHT STUDY

ISSUE 2

## Healthcare Professionals

By Team Brightlight

Welcome to the Winter issue of the BRIGHTLIGHT newsletter. We hope you enjoy this issue. Thank you for your ongoing support of the study.

We have been busy in 2014, raising the profile of our study and liaising with your teams who have recruited a massive 972 patients – thank you for involving your patients in research. We have extended recruitment to patients up until April 2015 (who have a diagnosis date until 31<sup>st</sup> December 2014) so please continue to approach young people.

We have recently introduced a supplementary measure to support recruitment. QualityHealth has contacted all sites to access records aiming to identify patients who may not have been recruited. Mechanisms are in place to exclude contacting patients who have already been approached.

159 health professionals in the field of teenage and young adult cancer care around the world completed our web-based Delphi Survey. The survey aimed to explore the skills, knowledge and attitudes of health professionals caring for young people with cancer. Consensus on core competences was obtained. The results are currently under write-up and will be available for dissemination.

We have outlined the Companion Study: 'When Cure Is Not Likely', and a Case Study on page 3, so please have a look and consider whether any of your patients are eligible to participate.

If you have any comments, or would like to be featured in future editions, please drop us a line – contact details are on the last page.

**We wish you a Merry Christmas and a Happy New Year!**



### The Study

BRIGHTLIGHT is a National Institute for Health Research (NIHR) funded programme grant evaluating cancer services for 13-24 year olds in England. The study evaluates cancer services using a bespoke survey, and health economic measures. The cohort will be followed for three years after diagnosis.



### The Team

Professor Jeremy Whelan; Consultant Medical Oncologist, Dr Rachel Taylor; Senior Research Manager, Dr Lorna Fern; R&D Coordinator, Professor Faith Gibson; Workstream Lead, Anita Solanki; PPI and Cohort Manager, Natasha Aslam; Research Assistant, Sarah Lea; PhD Researcher, Dr Charlotte Kenten; Researcher, and Dr Nothando Ngwenya; Researcher.

# BRIGHTLIGHT Cohort Study

By Dr Rachel Taylor

## STUDY BRIEF

The BRIGHTLIGHT Cohort study is central to the NIHR programme grant. The information collected directly from young people, who are newly diagnosed with cancer will show us whether specialist cancer care has an impact on outcome; the outcomes that are important to young people.

Following young people for three years will allow us to determine whether the care young people receive at diagnosis has a long term impact. Young people are being recruited across 107 Trusts in England, which has been coordinated by researchers within the NIHR Clinical Research Network in collaboration with cancer teams



## CURRENT SITUATION

Despite substantial support for BRIGHTLIGHT at study onset, recruitment has proven difficult. An impressive 972 young people have been recruited to date and we would like to extend our thanks to those who have helped make this happen. However, this is some way short of the anticipated 2,012 by April 2014. Following discussion with our statisticians and the NIHR, a lower sample size (minimum 1,000 young people) has been approved and a no cost extension for recruitment until April 2015, with young people having a diagnosis date to December 2014. Despite the less than optimal recruitment, data collection is currently progressing well. Currently 602 (79%) young people have participated in wave 1, with retention at waves 2 and 3 81% and 74% respectively. Wave 4 (two year after diagnosis) started in the summer and early indicators suggest young people are continuing to stay with the study.

### Update on Data Collection

BRIGHTLIGHT will be open to recruitment until April 2015 and patients are eligible up to four months from diagnosis. Please help us optimise recruitment in our final phase. If you think you have an eligible patient then contact us on [brightlight@uclh.nhs.uk](mailto:brightlight@uclh.nhs.uk). Please also remember we have approval to conduct refusal interviews – to contact young people who don't want to participate. This is a really important opportunity to learn about the drivers and barriers to research participation, so if you have a young person who declines to consent to the study, please fill out a refusal form (available on our website) and ask them to tell us why.

We are also keen to hear your views about recruitment strategies, or any perceived challenges you have encountered.

Please visit our website for all patient and healthcare professional documents, including our protocol:

[www.brightlightstudy.com](http://www.brightlightstudy.com)

# Patient and Public Involvement

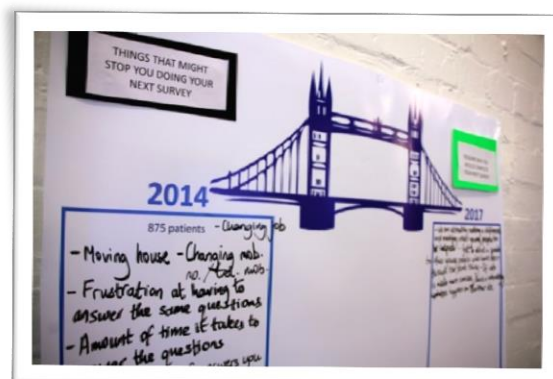
By Dr Lorna Fern & Anita Solanki

Involving young people in research has been a pivotal part of BRIGHTLIGHT. BRIGHTLIGHT was preceded by a feasibility study where we worked with young people as co-researchers. We have continued with this philosophy ensuring the voices of young people are at the core of the study. In September 2014 we held our fourth annual workshop, bringing together our Young Advisory Panel (YAP) to offer their thoughts on retention to the study.

Retention rates for young people between first interview and third are considerably higher than we anticipated, with approximately 7/10 young people continuing to take part up to 18 months after diagnosis. As a research team we were nervous about retention at wave 4 which is two years post diagnosis, recognising that many young people will be fully integrated back to their routines.

We asked our YAP for some insight as to what may prevent young people from taking part in further waves of the study, what would incentivise them, and subsequently what we could do to encourage continued participation. Varied reasons for non-completion were cited; personal issues, conflicting commitments, health, time, or reluctance to re-visit their cancer diagnosis.

Reasons for continued participation included; being heard, contributing back to the community, and obtaining a sense of pride and commitment. We have contacted our YAP providing an outline of strategies we have begun implementing to improve retention.

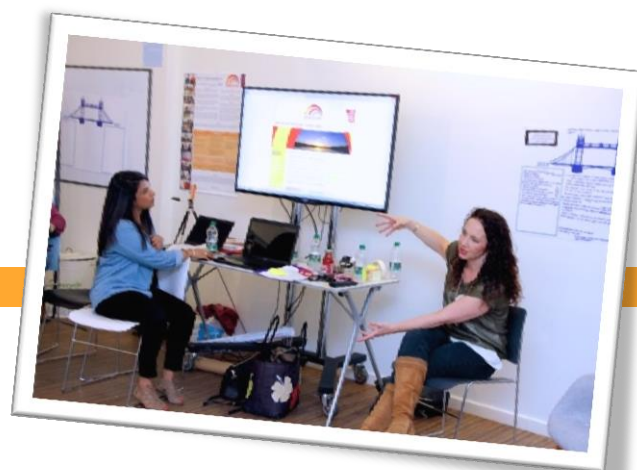


## FOLLOW US

Healthcare Professionals and Patients are welcome to follow us on Twitter for updates on the study.



@bR1GhTLiGhT



# Meet the Team

By Anita Solanki

**Each issue we will introduce a member of the BRIGHTLIGHT Team. This issue presents Anita, Cohort and Patient & Public Involvement Manager who has been with the team since July 2012.**

"I first became interested in working with young people shortly after completing my Psychology degree. Working for mental health services in Manchester and Bristol gave me the opportunity to work both clinically and in research roles with this population, and led to pursuing a role which combined elements of both.

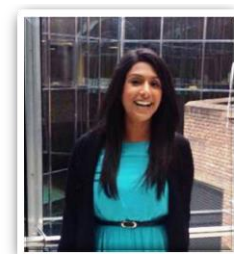
Working within the BRIGHTLIGHT team allows me to do just that! I engage with young people at various stages of their cancer journey as communication with

study participants is key to keeping them engaged – especially teenagers and young adults. This may also benefit retention rates from recruitment through to subsequent stages of data collection. The majority of communication is online through dedicated website or social media platforms.

As a study about young people it is imperative to involve young people in the research design and in any developments we make. Working collaboratively with our Young Advisory Panel is therefore crucial to ensuring any changes made to the study are those suggested by young people – they are very vocal and we take all their feedback on board.

User involvement is continuous so when I'm not planning a workshop, or writing the next newsletter for young people, I am making follow up communication to patients who have recently taken part in one of their five BRIGHTLIGHT interviews to see how they got on. This serves as a good opportunity to continuously gather any feedback.

If any of your patients would like to join our Young Advisory Panel, please visit our [YAP](#) page."



# Case Study

by Sarah Lea

Sarah is part of the BRIGHTLIGHT Study team, endorsed by London South Bank University. Her qualitative study, seeks to explore three main research questions:

1. How does clinical context of each Principal Treatment Centre and its network shape teenagers and young adults individual experience of care?
2. What is different and what is common across the culture of teenage and young adult cancer care in the four Principal Treatment Centres and networks of care?
3. What are the perceptions of care of teenagers and young adults and professionals in each Principal Treatment Centre and its network?

The "culture of care" refers to the continuum of patient care, through time and in different spaces, aiming to generate a greater understanding of young people's cancer journey.



If you know a young person at the sites below who may want to participate, please contact Sarah on [leas2@lsbu.ac.uk](mailto:leas2@lsbu.ac.uk)

## Study design

A multi-site case study design will explore the "culture of care" across TYA cancer networks.

## Sample

In each of the four networks, a sample of ten 13 to 24 year olds who are receiving/have received treatment, and up to ten HCPs involved in their care, will be invited to participate.

## Methods

Sarah will conduct site tours of the units and interviews with both TYA and Healthcare Professionals at each network

## Analysis

Data will be analysed for each network case and a process of cross-comparison will explore the collective "culture of care" of TYA cancer.

## Selected Sites:

- North Thames Children and Young People's Cancer Network (PTC: University College Hospital, London)
- East Midlands Children and Young People's Cancer Network (PTC: Nottingham City Hospital, Nottingham & Leicester)
- Central South Coast and Dorset Children and Young People's Cancer Network (PTC: Southampton General Hospital, Southampton)



# When Cure is Not Likely

By Dr Charlotte Kenten and Dr Nothando Nqwenya

**What do young adults with cancer and their families need and how can it best be delivered?**

'When Cure Is Not Likely' (WCINL) is a companion study to BRIGHTLIGHT funded by *Marie Curie Cancer Care* and led by Prof. Jeremy Whelan. It aims to examine and understand the important parts of care in the last year of life for young people with any cancer aged 16-40 years old and identify how patients and family members can be supported to achieve preferences for care; and the challenges that exist for health and social care professionals.

The study involves two cohorts: *Cohort 1 - BRIGHTLIGHT*: The BRIGHTLIGHT Cohort identifies participants aged 16-24 years, and *Cohort 2 - Hospitals and Hospices*:

*Cohort 1 - BRIGHTLIGHT*: Young people self-nominate through questions in the main BRIGHTLIGHT survey. The BRIGHTLIGHT cohort manager checks the patient's palliative status and subsequently contacts the patient. Following this, Charlotte or Nothando, the researchers will contact the patient with further information and invite them to participate in an hour long interview with the option of a further interview 2 months later.

*Cohort 2 - Hospitals and Hospices*: We are working with Palliative Care and tumour teams in London, Leeds and Southampton to identify 16-40 year olds receiving palliative treatment. Patients are invited to take part in one interview and nominate a family member and HCP to be interviewed.

Data will be analysed and used to inform scenario workshops involving patient representatives, family members and HCP's. All results will be further refined by an Expert Panel leading to the development of recommendations for practice.

If you are asked by BRIGHTLIGHT about a patient's palliative status we would be grateful for a prompt response so we can give eligible young people the opportunity to share their experiences and contribute to improving care for future patients..

If you think you would be in a position to assist us with any aspect of the research please get in touch; [Charlotte.Kenten@uclh.nhs.uk](mailto:Charlotte.Kenten@uclh.nhs.uk) or [Nothando.Nqwenya@uclh.nhs.uk](mailto:Nothando.Nqwenya@uclh.nhs.uk)



# Updates

## FAST FACTS

# 80%

Of teenagers and young adults felt that healthcare professionals involved them in treatment decisions

# 90%

Of teenager and young adults said that the explanation given about treatment was 'very helpful'

# 80%

Of teenager and young adults rated healthcare teams as 'excellent' in helping them prepare for treatment side effects

## BRIGHTLIGHT Case Report Forms

We have e-mailed all sites to inform you that the CRF is now complete and we need to begin collecting data from young people recruited to BRIGHTLIGHT when they are **12 months** after diagnosis. This one-year clinical data is vital for evaluating clinical processes and outcomes of care.

This information has been requested from your team. Initially, we have sent a list of participants who were diagnosed between July 2012 and September 2013, which we would like you complete by **31/01/15**.

From here on in we will be sending an email at the beginning of the month with just the patients diagnosed a year previously which we would like completed that month.

The CRF can be saved and returned to complete later, but you are unable to go back and forwards between pages. Our e-mail contains all the information you need to know, outlining the content of the CRF so you will know the order of information being requested. We also need information about high cost drugs, which can be entered either into the CRF or can be submitted as a separate form.

Please start completing the CRF for your patients using the link we have emailed. If you have any questions or queries, please don't hesitate to ask.

FAQ: My patient is shared care/transferred for care elsewhere – do I still fill out the CRF? Yes please do, we presently require the recruiting Trust

# Before you go

## CONTACT US

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W: [www.brightlightstudy.com](http://www.brightlightstudy.com)  
T: @bR1GhTLiGhT

## Did you hear?

We were honoured to be awarded a poster prize at the National Cancer Intelligent Network Outcomes Conferences 2014 – the winning poster is featured on our website, and explored barriers to recruiting young people to research trials.

In Summer 2014, University College London Hospital held a Research Open Day. Researchers presented interactive stands engaging with patients, the public and local schools. We were delighted to have been voted 'Best Stand – people's choice' out of 25 stands by members of the public, and were pleased to promote our research study and the importance of accessing clinical trials.

## Thank you!

A big thank you all healthcare professionals for consenting patients to the BRIGHTLIGHT Study. We are very grateful to you for involving young people in research.

We feature weekly recruitment updates for each site on our website, and also tweet our weekly 'top' recruiters so keep an eye on our social media. The TYAC weekly bulletin, also reports our weekly recruiters too!

If you would like to share your experience of consenting to the BRIGHTLIGHT Study, or have any feedback from your patients regarding their involvement, please let us know.

