



BRIGHTLIGHT

Do specialist services for TYA with cancer add value?

Healthcare Professionals Newsletter

Summer 2015

BRIGHTLIGHT STUDY

Welcome

by Natasha Aslam

Welcome to the summer edition of our newsletter! Please read on to find out updates on our activities, important dates for your diary, updates on companion studies, and general information for you.

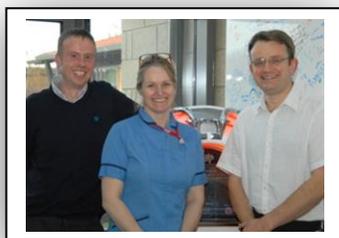
We have recruited a phenomenal **1,084** patients to date. Thank you to all healthcare professionals for allowing your patients the opportunity to share their experience of cancer services. Recruitment ended in **April 30th 2015**, with our last patient being recruited from University College London Hospitals.

Please remember our field research team Ipsos MORI will continue to contact your patients who are due an interview. Please remind your patients to complete their surveys online or on the telephone, and to fill in any Cost Records – if treatment has ended, they can return their Cost Record to us blank.

This issue features a 'frequently asked questions' focusing on **Case Report Forms** for our patients – We received questions from many of you, so we hope these answers make the process easier and can be kept for you to refer back to. We send a monthly list of patients who we require a Case Report

Form for, and are happy to answer any queries you have.

A highlight of 2015 was announcing that we passed the 1000th patient recruited mark! A big thank you to the team at **Hull and East Yorkshire Hospitals NHS Trust** (pictured below) for consenting the 1000th patient!



Thank you all for your ongoing support. Please encourage your patients to complete their surveys, and keep your eyes peeled as we begin to release emerging findings. We have a sister newsletter 'Spotlight' for young people – This is viewable on our website, and we welcome articles written by young people.

Best Wishes,

Team Brightlight



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.



Meet the Team

Professor Jeremy Whelan, Consultant Medical Oncologist; Dr Rachel Taylor, Senior Research Manager; Dr Lorna Fern, PPI Lead; Professor Faith Gibson, Workstream Lead; Anita Solanki, PPI & Cohort Manager; Sarah Lea, PhD Student; Dr Charlotte Kenten, Research Associate; and Dr Nothando Ngwenya; Research Associate

PATIENT & PUBLIC INVOLVEMENT



Forming friendships

Young Advisory Panel members have formed friendships as they work together in our workshops. They have had opportunities to represent the study at conferences and within their Units.



YAP Contributions

The YAP contribute to a range of activities including article writing for newspapers and academic journals, suggest how we can improve research, sharing what is important to them, and providing case studies.

BRIGHTLIGHT FAST FACTS : FATIGUE

1 in 5

BRIGHTLIGHTERS reported that fatigue made it difficult to get out of bed and engage in other activities

2 in 3

Young people with fatigue reported that they couldn't take part in sports activities.

1 in 3

BRIGHTLIGHTERS with fatigue reported being able to attend social events.



Patient & Public Involvement Leads Lorna and Anita are pictured engaging some YAP members with a workshop activity.

Young Advisory Panel (YAP)

by Anita Solanki

BRIGHTLIGHT has approached patient involvement slightly differently from our previous Core Consume Group model and engaged a wider group of young people. The first official BRIGHTLIGHT activity was a naming and branding workshop with nine young people. This workshop culminated in the name 'BRIGHTLIGHT', and the development of a study logo. This logo is used on all study material. The methods used in the workshop were recently published in BMC Methodology – please see the last page.

Since then, we have successfully held another three workshops which have looked at design of the website (<http://tinyurl.com/lcvr6w5>), promotional materials, and methods to improve trial recruitment, strategies to improve retention, and most recently redesign of the website www.brightlightstudy.com. This is to coincide with a revamp on our website according to our study timeline and recruitment comes to a close. As well as retaining young people and encouraging survey completion, we intend to disseminate emerging results online.

Workshops

The format of the workshop usually begins with role play from the researchers. We have found that role play is an effective way to convey a message, and engages young peoples' attention; it also shows that while we are there to work we also want to have some fun in the process. We usually base role plays on the topic we are about to cover. We then go through our activities.

We try to ensure that both the researchers and the young people know the purpose of the workshop, setting out clear objectives,

and we request feedback from the young people. We allow the participants some 'free creative space' for them to reflect, or to interpret the day as they choose. Members are invited to participate in a practical activity which we are able to use as promotional material, and they are able to keep as a memory of the day.

In September 2013 we held a workshop to explore recruitment clinical trials, and attendees produced two videos were particularly powerful for recruitment (<http://tinyurl.com/o9kxft5>), and also for user involvement (<http://tinyurl.com/n7u576o>). Another benefit of shared activities is to foster and encourage a supportive network and friendships. Many members of our YAP leave having formed solid friendships and have reported the positive effects from this.

Young people in the YAP are from a range of socio-economic backgrounds and ethnic backgrounds with a range of diagnoses. This is especially important to maintain representation, as perceptions of cancer care and ideas about research may differ. We continually approach young people to the panel and actively advertise for new members to ensure we capture a fresh voice of those recently diagnosed and receiving treatment.

If you know a patient who would like to join the YAP, or share their experience of cancer care in a written piece, or yourself as a health professional, would like to share some words, please let us know we would be happy to feature you in either this newsletter, or our sister newsletter 'Spotlight' for young people.

Case Report Forms (CRFs)

Frequently Asked Questions

We have received some queries and feedback about these Case Report Forms (CRFs) - please read on for some frequently asked questions. Please keep a copy of these to assist completion.

What are the CRFs?

The CRF is an electronic data entry system to collect clinical information from young people recruited to BRIGHTLIGHT.

Which patients need them?

All patients who have been recruited to BRIGHTLIGHT require a completed CRF. This needs to be completed 12 months after diagnosis. We will send you a list monthly containing details of patients due a CRF.

Who completes them?

Any member of the team can complete the CRF. Please note you may need access to patient medical notes or to a contact. Whoever enters the data puts their name to it so we will know who to contact if we need anything clarifying.

How do I complete them?

Data are entered into the electronic CRF (eCRF) which is accessed through a link sent every month with the list of patients we require data from. If you cannot find the link to the eCRF, please contact the BL office (Brightlight@uclh.nhs.uk) and we can send it to you.

I can't find some information about this patient

Most of the fields for entering data require a response before it can be submitted. All the information requested should be available in the Teenage and Young Adult Multidisciplinary Team proforma or on patient correspondence. If you are still unable to find information, please contact the BL team to discuss alternative options.

This patient was recruited but not treated here

Please email the study number to the BL team with details of where they were treated and if you have a contact name/email of someone at the treating hospital, we will

obtain information from them. You can also complete what you can and notify us.

Can I edit the CRF after it has been submitted?

No, you will need to send us an email of the question that needs changing and what it needs changing to.

How do I add some more information about the patient?

There is a free text box to provide information about the places of care and a comments box at the end where you can add any information about the young person's care you think it is important for us to know about, which is not covered by the existing questions.

How do I know which patients at my site need one, or have had one completed already?

We send a monthly email with the study numbers of all young people who require a CRF completed. We also send a reminder email out every month with the study number of all those who are outstanding.

How do I get a copy of the completed CRF?

When you submit the CRF you have 15 minutes to download/print a copy. After this time you will not be able to; however, the BL team will be able to download it from their central database so you can email a request – just let them know the study number.

This patient has passed away, do they need a CRF?

Yes, every patient who has been recruited to BL needs a CRF.

If you have any further questions please e-mail us. Please be aware these CRF completions are requested on a monthly basis for all patients in the study.

THE ONLINE CRF

Page 6: Section D: Multidisciplinary treatment planning and care

Details of the MDT

Is there evidence of discussion in the following MDTs? specify all that apply

Children's MDT

Yes
 No

If yes, hospital of MDT

Date discussed in the children's MDT

Dates need to be in the format "DDMM/YYYY", for example 27/03/1980.
Please make sure the date is between 01/07/2012 and 31/12/2016.

(dd/mm/yyyy)

Shared Care Patients

If the patient is shared care or received treatment elsewhere but you do not have required information to hand such as date of MDT, enter a generic date and notify us via the comments box on the last page.

Was an initial treatment plan recorded? A copy of this documentation may be requested !

Required

Yes
 No

What is the date of the document recording the initial treatment plan?

Dates need to be in the format "DDMM/YYYY", for example 27/03/1980.
Please make sure the date is between 01/07/2012 and 31/12/2014.

(dd/mm/yyyy)

Initial Treatment Plan

*Questions regarding initial treatment plan refer to documentation at **your** site, even if you are aware the patient has received treatment elsewhere.*

[Return to survey](#)

Finish later

You have not yet completed the survey. To complete it, you will need to return to the following web address **before 31 Jan 2016**. You can bookmark the web address, or request the link by email.

<https://admin.online-surveys.ac.uk/account/lsbu/preview/brightlight-case-report-form-2014-version-2/resume/680f1x5xfor9e7nua/8466378>

Link expires at 00:50 GMT on 31 Jan 2016.

Email this link to the address below:

[Send](#)

Returning at a later date

*Clicking 'Finish Later' enables you to return to the CR. Please **save or bookmark** the link provided to return to this patient – this link is unique and is required to return to the particular patient. We cannot obtain this link later for you.*

Cohort Study: Updates

by Dr Rachel Taylor

A total of 1084 young people have been recruited to Brightlight. Recruitment closed on 30th April 2015. This figure will increase as Quality Health have been recruiting directly on our behalf. An update on the total number recruited and size of the cohort will be available soon.

Wave 1 – We currently have data on 775 young people. Wave 1 data collections ends 14th July 2015 so some analysis will begin in October 2015; dissemination of emerging findings will be ongoing but results for the main outcome; whether specialist services add value, will not be released until 2017 when we have the TYA Cancer Specialism Scale data (the metric to measure the amount of specialist TYA cancer care young people have received).

Retention strategies

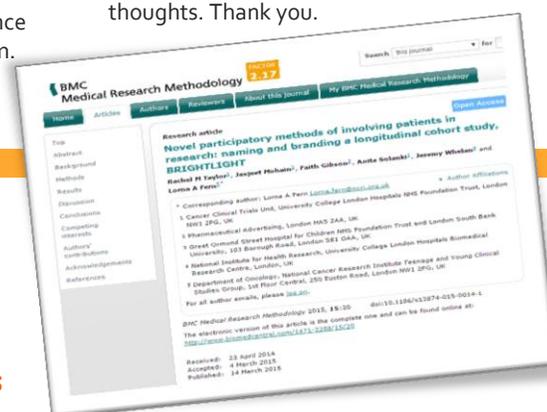
Retention in the study is currently between 55-76%. We have implemented a number of measures to encourage survey completion. Prior to wave 1, young people are sent reminder texts. At waves 2-5 we send postcard info-graphics displaying snapshot results to show what is happening with results as requested by young people.

Participants are posted personalised certificates of participation for portfolios and as a token of thank you. We also continue to give a wristband at each wave.

We have increased social media presence and will continue to utilise this platform.

We are always interested in hearing ideas or tips of how to increase retention, and our team is open to trialling novel retention methods, including use of technology, multiple modes of communication and post.

We are currently writing a paper outlining our retention measures, and the results of this. We would like to know whether your team has employed any measures successfully, or whether your patients have verbally expressed feedback or preference of team/patient contact and study retention. Please contact us with any thoughts. Thank you.



Case Study: An update

by Sarah Lea



"Data collection for the BRIGHTLIGHT Case Study is well under-way. I spent October to December 2014 travelling to various Trusts in the North Thames TYA network, speaking to young people and healthcare professionals and observing the culture of care across the network. In January, I moved on to start exploring the East Midlands TYA cancer network. I was warmly welcomed and it has been interesting to spend time at both of the Principal Treatment Centres here (Leicester and Nottingham).

In both sites I have met a large range of young people with a multitude of experiences, as well as a diverse range of health professionals who all have different roles in caring for young people with cancer. I will be using April to start analysis and draw together some of the key elements of the culture of TYA care that are coming up in the data so far. I recently visited the team at Leeds Teaching Hospitals NHS Trust and everything is now in place for me to move up in May and begin there. Watch this space for emerging findings!"

Sarah

Publications

We are delighted to announce that a branding paper authored by the team has been accepted by **BMC Medical Research Methodology**. Our paper outlines novel participatory methods to involve patients in research, and shares some of the wonderful work done by our Patient and Public Involvement team in conjunction with young people. The paper is available to download from our website, or viewable here; tinyurl.com/ltlawvu

Recruitment High

Recruitment has officially ended and we are pleased to announce the top recruiter in the last 20 days was: **Leeds Teaching Hospitals NHS Trust**. Thank you team – a £50.00 gift voucher is winging its way to your team as a token of thanks! We will continue to contact all sites when we require health checks or contact detail checks for patients. Thank you for your co-operation.

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