



NEWSLETTER March 2017

Welcome

Welcome to our first newsletter of 2017. I realise it has been some time since we last updated you on how the study has been progressing so I wanted to give you an update and share some of the really exciting events planned for 2017.

With your help we recruited a phenomenal 1,126 young people. We have clinical, hospital admission and registry data on most of these young people and importantly patient reported experience from 830 (74%). We are now working with Public Health England to compare the Cohort to those who weren't recruited so we will know how representative they are of the total population.

The BRIGHTLIGHT Team has seen some changes over the last 18 months. *When Cure is Not Likely*, our companion study on young people's end of life care experience, was completed in December 2015 so Dr Charlotte Kenten went to lead a study on children's learning disability at Great Ormond Street Hospital and Dr Nothando Ngwenya received a fellowship to explore palliative care services in South Africa. Our Cohort Manager, Anita Solanki left BRIGHTLIGHT to join the communication team at NHS England and Research Assistant Natasha Aslam enjoyed research so much she wanted a hands on role so moved to Queen Mary's University to be a Clinical Trials Practitioner. We want to wish them all well in their new roles and are proud to have supported a great team to progress their careers.

This issue summarises one of our completed projects and updates you on the progress of the others. We are also introducing you to new members of the team: Dr Ana Martins, who is working hard to expand our portfolio of work to improve the lives of young people diagnosed and living with cancer (see page 4) and Sarah Lea, our PhD student has joined as our Research Facilitator.

Importantly, we want to update you on the exciting events planned for 2017. This is going to be an epic year for BRIGHTLIGHT and TYA cancer care because we are in the process of analysing data from studies in all three workstreams, including waves 1-3 from our Cohort. We have lots of exciting events planned to disseminate this, which are explained in detail on page 2.

Thank you for supporting BRIGHTLIGHT and watch this space because we are now beginning to reap the rewards of all your hard work so 2017 is going to be a very exciting year for TYA evidence.

BRIGHTLIGHT Team

Highlights of this issue...

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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 programme currently has six projects in three workstreams focusing on the environment of care, workforce delivering care, young people and carers experience of care, inequalities of care and cost of care (see page 5 for project updates)

Meet the Team

- Professor Jeremy Whelan, Chief Investigator, UCLH
- Dr Rachel Taylor, BRIGHTLIGHT Lead, UCLH
- Dr Lorna Fern, PPI Lead, NCRI
- Dr Ana Martins, Research Associate, UCLH
- Sarah Lea, PhD Student/Research Facilitator, UCLH
- Professor Faith Gibson, Workstream Lead, University of Surrey/Great Ormond Street Hospital
- Professor Steve Morris, Workstream Lead, UCL
- Professor Rosalind Raine, Health Service Research, UCL
- Dr Julie Barber, Statistician, UCL
- Nishma Patel, Health Economist, UCL
- Dr Javier Alvarez-Galvez, Health Service Research, UCL
- Dr Richard Feltbower, Epidemiologist, University of Leeds
- Dr Dan Stark, Medical Oncologist, University of Leeds
- Louise Hooker, Lead TYA Nurse, University of Southampton Hospitals

BRIGHTLIGHT in 2017 – dates for your diary

Aspects of data collection are now complete so we will be presenting early results later in the year in two ways: first in a way that is accessible to young people and the public; and second to healthcare professionals and the scientific community.

There is a Light: BRIGHTLIGHT



BRIGHTLIGHT are collaborating with Brian Lobel (<http://www.chi.ac.uk/staff/dr-brian-lobel>) and the Contact Theatre Youth group in Manchester to interpret and create an improvisation of our study. We have held a series of workshops with the 23 young people who are part of the Contact Young Company (CYC). Sue Morgan MBE from Leeds Teaching

Hospitals and David Wright from the Christie have joined us to help the CYC experience what it's like to have cancer as a young person and to understand the services and care they receive currently in England. Four of the CYC actually had cancer so they have been sharing their personal experiences with the CYC. One of our YAP (see page 4), Maria Onasanya has also joined the CYC to share what it has been like being part of the BRIGHTLIGHT Team.

Director Adura Onashile and Assistant Directors Mark Croasdale and Nathaniel Hall have worked with the CYC to draw on what they have learnt in the 6 weeks of workshops to create their improvised interpretation.

Each performance is being followed by a talk back by professionals leading TYA cancer care so the audience has the opportunity to ask questions about the performance, cancer in young people and about BRIGHTLIGHT.

There is a Light: BRIGHTLIGHT opened the SICK! Festival in Manchester on the 8th March and played for 3 nights, then on the spring tour they played at the ACCA in Brighton on 21st March. You still have a chance to catch the performance:

6 th April	RCN International Research Conference, Oxford
9 th April	Battersea Arts Centre, London

There will be additional performances at the end of the year in Liverpool and Birmingham. We will update you on dates when they have been confirmed.

For more details see:

https://www.bac.org.uk/content/43120/whats_on/whats_on/shows/there_is_a_light_brightlight

BRIGHTLIGHT-TYAC Collaboration



Uniting professionals. Improving practice

You have supported BRIGHTLIGHT since its inception in 2009 so we want to make sure you are the first people to see our results so we are collaborating with TYAC for their 2017 annual conference in July. The agenda will be circulated shortly but we will be presenting evidence on recruiting young people to

research, involving young people in research, unmet needs of carers, cost of specialist care and finally Professor Jeremy Whelan will address the big question: Do specialist cancer services for TYA add value? Accompanying the BRIGHTLIGHT presentations are a number of excellent speakers presenting various aspects of evidence based practice. This will also be an opportunity for you to present work you have done on implementing evidence into practice so we can learn from your experience of what has worked and what hasn't

The BRIGHTLIGHT-TYAC conference is on the 6th and 7th July in Leeds. Information about the conference will be announced by TYAC but will also be on the BRIGHTLIGHT website and circulated on social media so put the dates in your diary because this is something you're not going to want to miss!!

Completed study: Delphi survey

By Professor Faith Gibson

Delivery of care to young people with cancer aged 15-24 years in England is provided by a multi-disciplinary team (MDT). This goes beyond having a nurse and doctor but includes youth support co-ordinators, social workers and a range of allied healthcare professionals. While the membership of the MDT has been established, the competence or expertise of the MDT has not.

There are some competency guidelines available for some professional groups but these are either generic to the profession or specific to the care of children or to adults. We believe young people have unique age-appropriate needs so these guidelines may not reflect the skills needed to fulfil these. Recently a competency guideline for nurses caring for young people with cancer has been published in the UK by the Royal College of Nursing and Teenage Cancer Trust: <https://www.teenagecancertrust.org/sites/default/files/Nursing-framework.pdf>. However, to make sure delivery of care is consistent among the professional groups and equitable across geographical locations by all professionals in the MDT, having a competency guideline they can all use would be useful.

What were the aims?

The aim was to provide international consensus on the competencies required by professionals to provide specialist cancer care for teenagers and young adults with cancer.

What did we do?

A Delphi Survey is a method of getting agreement on a subject by a group of experts. It is done by sending out a number of rounds of questionnaires, each time feeding back the results of the previous round so respondents can see what everyone else thinks. The survey is administered multiple times until everyone's responses are agreed.

The BRIGHTLIGHT Delphi survey was an international e-Delphi survey (it was sent as an online questionnaire) and was conducted over 2 rounds. Experts were defined as professionals having worked in this field of teenage and young adult cancer care for more than 12 months. We identified experts through publications and invitations via professional organisations.

The initial survey was developed from work we had undertaken previously in workshops with healthcare professionals in the UK: <http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2354.2011.01322.x/full>. There were 87 closed-ended questions with responses on a 9-point Likert scale and further open-ended responses to identify other skills, knowledge and attitudes. Round 2 contained only items with no consensus in round 1 and topics suggested in the open-ended responses.

What did we find?

Of 179 professionals who registered to participate, 159 (89%) participated in round 1. The majority of participants were nurses (35%) or doctors (39%) from Europe (55%) or North America (35%). There was consensus in all 87 competencies but a number of other suggestions were made in open ended responses so a second round was sent back to participants, which were returned by 136 (86%). There were significant differences in what doctors, nurses and allied professionals felt were important skills, areas of knowledge and attitude. For example, 100% nurses vs. 79% doctors and 74% other professionals agreed providing holistic care was important, whereas 80% doctors vs. 54% nurses and 44% others agreed being able to consent to a clinical trial was important.

You can access the full report of this study:

<http://bmjopen.bmj.com/content/6/5/e011361>

Open Access

Research

BMJ Open Modified international e-Delphi survey to define healthcare professional competencies for working with teenagers and young adults with cancer

Rachel M Taylor,^{1,2} Richard G Feltbower,³ Natasha Aslam,¹ Rosalind Raine,⁴ Jeremy S Whelan,¹ Faith Gibson^{2,5}

What will we do now?

There was a high degree of consensus to the list of competencies suggesting they could influence education curriculum, professional development and inform workforce planning. As there was variation in the strength of agreement for some competencies between professional groups we need to explore this further.

To explore how the list of competencies can improve care for young people, we held a workshop earlier in March 2017. Representatives of the MDT attended this event to develop a strategy to use these in clinical practice, for workforce development and to inform education. There was a lot of very useful discussion on the day and now we have a plan in place to move this forward.

CONTACT

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Meet a team member

By Dr Ana Martins



Hi! I'm Ana and I am a social psychologist with a particular interest in how research and programme evaluation can contribute to young people and families' wellbeing.

Now for a description of what I have been doing for the last 13 years. Let me take you on a trip around three cities. Starting in Lisbon where I worked in the evaluation of a community project towards reducing/preventing child maltreatment. This was an immense learning experience on the importance of using research findings in improving intervention outcomes. It also inspired me to do my PhD thesis on "Adolescent self-representation: assessment and construction process". In my thesis I looked at how young people developed their self-concept and the influence of the quality of the relationship with their parents in this process. This part of my experience focussed on quantitative methods.

Moving now to Dublin where I worked specifically in health and patient experience. For 2 years I looked at children's experience of involvement in decisions about their care as well as parents and health professionals' views. I loved the opportunity to be able to observe the interactions between parents, healthcare professionals and young people and be

able to explore this further using in-depth interviews and focus groups. The complexity of the analysis was challenging but massively rewarding with some of the findings being used recently in the development of a leaflet for young people about how they can get involved in decisions about their care.

Now we get to London where I joined the team at London South Bank University on a 3 year project evaluating CLIC Sargent's 'More Than My illness' document. This project looked at the impact of the nurse specialist key worker role on children diagnosed with cancer and their families' experiences in 18 Principal Treatment Centres across England, Scotland and Wales. This was another complex dataset with views from families, children and professionals from questionnaires, interviews and focus groups. This informed research and practice in three aspects of how the key worker influenced family experience: knowledge, relationships and coordination.

In 2015 I joined the BRIGHTLIGHT team as a Research Associate. I started working on the carer data and I am looking forward to sharing the results of this with you later in the year. While this work has been in development I've had the opportunity to use some of my skills and interests in programme evaluation being involved in evaluating 'Find Your Sense of Tumour' organised by Teenage Cancer Trust. The mixed-methods approach to this evaluation started with the observation of the conference and interviews with professionals and young people of the steering committee. We are now at the exciting phase of hearing young people and professionals' views through surveys in a longitudinal 1 year study.

From 2017 I am now the Sarcoma UK Research Associate so I will still be working in the BRIGHTLIGHT team but I will be focusing specifically on the experiences of patients aged 13 onwards with all types of sarcoma. This is an ambitious project but I am excited to be working with professionals in the sarcoma community across the country.

Young Advisory Panel

By Dr Lorna Fern



We believe young people's involvement in research at an early stage is essential to make sure we are asking the right questions and designing studies in a way young people will

want to take part. BRIGHTLIGHT is unusual because young

people have been involved from the onset in developing the study, advising on study management and as we explained earlier, they are leading on disseminating results.

Our Young Advisory Panel (YAP) currently consists of 20 young people but is open to any young person diagnosed aged 13-24 years and currently aged 16-26, so if you have any one you think might enjoy informing future TYA research please ask them to email: brightlight@uclh.nhs.uk

Members of the YAP have the opportunity to participate in workshops. We try to make these are interactive and as fun as possible so they are always really well evaluated:

"The events get better and better each year. You guys actually take the suggestions on board and improve accordingly :)"

As we have an increasing number of research projects, members of the YAP are invited to be part of other studies. We provide mentorship so they are able to develop new skills that are transferable to other life situations.

For more information on the activity of our YAP, please see our website www.brightlightstudy.com

Project updates

The Case Study - exploring the culture of care

By Sarah Lea

I am leading the BRIGHTLIGHT case study and am currently immersed in data analysis and the write-up of some interesting findings. In total I visited 21 different NHS sites, interviewed 40 health care professionals, interviewed 30 young people and conducted approximately 120 hours of observation. This has generated masses of powerful, rich data to build the case study, which will hopefully support some of the findings of the BRIGHTLIGHT cohort study.

One of the key findings emerging from the interviews and observations is the important relationship that exists between the physical environment of care for a young person, and the social interactions and networks that they become a part of. I was honored to present this element of my work at the 1st Global AYA Cancer Congress in Edinburgh in December 2016.

I will be building on this analysis to present some new emerging results on the culture of TYA cancer care in England later in 2017.

The Cohort Study - defining the experience of care

By Dr Rachel Taylor

By September 2015 recruitment ended with 1,126 young people enrolled in the study. This was helped by an additional mechanism approaching young people directly. We want to thank Quality Health for supporting this process and while we only recruited an additional 44 young people through this method it certainly is a potential way of involving young people in low risk research in the future (see reference at the end for more details about this).

Young people are reporting their experience of care and life after a cancer diagnosis by completing the BRIGHTLIGHT survey¹ up to 5 times over 3 years. Waves 1-3 are now complete so we should have some results shortly on whether specialist cancer care adds value in the short term (18 months after diagnosis).

We have previously reported the measures we are implementing to optimise retention into the study. One challenge we found was in updating where young people were living and ensuring they are still alive. We want to thank all the clinical teams who provided updates for us every month but sadly we noted that further from diagnosis the less information secondary care teams had about young people. Quality Health are now helping us ensure we only contact young people who are alive and give us updated information about their home address and G. We are now ensuring our retention rates are above 50% at every wave of data collection.

We have also worked closely with NHS Digital to obtain Hospital Episode Statistic data so we can develop the TYA Cancer Specialism Scale, our measure of access to specialist cancer services. This will enable us to show how much specialist care a young person needs to add value.

Finally, we are collaborating with Public Health England to get population wide data so we can compare the Cohort to young people diagnosed in the same time period not recruited to BRIGHTLIGHT. This will give us an indication of the generalisability of our results. We will also be able to see who sent us the most accurate screening logs!

¹Taylor et al. Development and validation of the BRIGHTLIGHT Survey, a patient-reported outcome measure for young people with cancer. Health and Quality of Life Outcome, 2015, 13: 107

The Health Economics Study - calculating the cost of care

By Nishma Patel

As part of the BRIGHTLIGHT study, I am part of the health economics team that are calculating the cost of TYA cancer care. I am undertaking a systematic review of existing literature on the cost associated with TYA cancers. The review is including studies on the different levels of specialist care available for TYA aged 13-24 years with cancer and looking at the quality of life associated with TYA cancer. In addition to this, I will be looking at the out of pocket expenses incurred by patient, family, friends and carers.

What now?

Data from the systematic review will be used to populate the BRIGHTLIGHT economics model of TYA cancer care and provide a benchmark on costs associated with TYA cancer care. Data from out of pocket expenses will be used to describe the financial burden that falls upon young people and the additional financial support required.

BRIGHTLIGHT at the UICC World Cancer Congress, Paris

BRIGHTLIGHT were honored to be invited to join a symposium with internationally renowned researchers in TYA Cancer Care including Ashley Wilder-Smith (USA), Sumit Gupta (Canada) and Vicky White (Australia). This was chaired by our own Lorna Fern and Antoinette Anazodo (Australia).

We presented a global view of the TYA services available and gave an overview of how each country was evaluating the effectiveness of these services. This is exciting work that we are hoping to take forward to look at the global burden of cancer in young people so low and middle income countries can learn from the work we are doing but also what we can learn from them.

Presentations are available from the conference website: <http://www.worldcancercongress.org/programme/2016/session-schedule/03>

BRIGHTLIGHT at the 1st Global AYA Cancer Congress, Edinburgh

The 1st Global AYA Cancer Congress (9th Teenage Cancer Trust International Conference) was held in Edinburgh in December 2016. A lot of the BRIGHTLIGHT team attended the conference and we were honored to have a number of abstracts accepted. Sarah presented a section of her PhD on the importance of the physical and social space, and Rachel presented a poster on behalf of the team on our experience of recruiting to BRIGHTLIGHT.

The three day programme brought together a host of internationally recognised clinicians and researchers as well a number of upcoming new ones. Over 300 people attended the conference so there were many opportunities to network with our international colleagues. A highlight for the BRIGHTLIGHT Team was the launch of the second edition of the Blueprint of Care. A number of the team contributed to this and it was great seeing all the authors together.

The Blueprint of Care continues to be free and can be downloaded from Teenage Cancer Trust's website: https://www.teenagecancertrust.org/sites/default/files/BlueprintOfCare_2ndEdition.pdf

It looks like the Global AYA Cancer Congress is going to be the highlight of the TYA academic year. BRIGHTLIGHT would particularly like to thank Sam Smith for all her hard work coordinating the organisation of the conference and giving us the opportunity to present.

See you all in Atlanta in December!
<http://ayaglobalcancercongress.com/>

Recent publications

A full list of our publications and presentations is available on our website. Recent publications:

Publications

Ngwenya N, Kenton C, Taylor R, Whelan J. (in press) Experiences and preferences for end of life care for young adults with cancer and their informal carers: a narrative synthesis. *Journal of Adolescent and Young Adult Oncology*

Taylor RM, Aslam N, Lea S, Whelan JS, Fern LA. (in press) Optimising a strategy with young people to retain young people in a longitudinal cohort study: BRIGHTLIGHT. *Journal of Adolescent and Young Adult Oncology*

Taylor RM, Fern LA, Aslam N, Whelan JS. (2016) Direct access to potential research participants for a cohort study using a confidentiality waiver included in UK National Health Service legal statutes. *BMJ Open* 6:e011847 doi:10.1136/bmjopen-2016-011847

Taylor RM, Feltbower RG, Aslam N, Raine R, Whelan JS, Gibson F. (2016) A modified international e-Delphi survey to define healthcare professional competencies for working with teenagers and young adults with cancer. *BMJ Open* 6:e011361. doi:10.1136/bmjopen-2016-011361

Taylor RM, Solanki A, Aslam N, Whelan JS, Fern LA. (2016) A participatory study of teenagers and young adults' views on access and participation in cancer research. *European Journal of Oncology Nursing* 20(1):156-164

Vindrola-Padros C, Taylor RM, Lea S, Hooker L, Pearce S, Whelan J, Gibson F. (2016) How do young people, their families and staff describe specialized cancer care in England? *Cancer Nursing* 39(5): 358-366

Walker E, Martins A, Aldiss S, Gibson F, Taylor RM. (2016) Psychosocial interventions for adolescents and young adults diagnosed with cancer during adolescence: a critical review. *Journal of Adolescent and Young Adult Oncology* 5(4): 310-321.

Conference presentations

Taylor RM, Fern LA, Gibson F, Whelan JS. What are the barriers to recruiting young people with cancer to research? 1st Global AYA Cancer Congress (poster presentation) 5th – 7th December 2016

Lea S, Taylor R, Martins A, Fern L, Whelan J, Gibson F. 'It was like having a big sleepover with our chemo bags on': exploring the relationship between physical and social hospital environments. 1st Global AYA Cancer Congress (poster presentation) 5th – 7th December 2016

Anazodo A, Fern L, Gupta S, Taylor R, White V, Smith A. What can we learn from cross country comparisons of cancer care for adolescents and young adults (AYAs) to improve cancer outcomes? Symposium presentation UICC World Cancer Congress, 4th November 2016, Paris France

Ngwenya N, Kenton C, Jones L, Gibson F, Pearce S, Stirling C, Taylor R, Whelan J. "Hospice Scares the Life Out of Me": Breaking Down Barriers to Communication with Young Adults with Terminal Cancer (oral presentation) 21st International Congress on Palliative Care, 18th – 21st October 2016, Montreal Canada

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