



**NEWSLETTER**  
**November 2017**

## Welcome

Welcome to our latest update. It's been a busy time since our last BRIGHTLIGHT newsletter in March, not just for BRIGHTLIGHT but for TYA cancer services across England. BRIGHTLIGHT Team member, Dan Stark has been leading the TYA workstream in the Children and Young People's Cancer Clinical Reference Group (CRG) as part of the development of the service specification for commissioning TYA cancer services. The CRG is chaired by Rachael Hough and they have done a tremendous job in getting all the evidence together (including some from BRIGHTLIGHT). This is now being reviewed by NHS England, so we look forward to the consultation period in early 2018, which will shape the way TYA cancer services are provided in the future.

We have been equally busy in the BRIGHTLIGHT Office. As we reported in the last newsletter, there has been a theatrical production of our study. Tour 1 of *There is a Light: BRIGHTLIGHT* is complete with over 600 people attending the performances, and tour 2 will shortly be coming to a close, with the final performance at FYSOT on the 25<sup>th</sup> November. We've been evaluating the impact of using drama to present research results so if you attended one of the performances and want to provide feedback, we would love to hear from you; our contact details are at the end of the newsletter and there is a survey link on page 2.

In July, we had a joint BRIGHTLIGHT-TYAC conference, which brought over 100 TYA healthcare professionals to Leeds. Supporting the afternoon BRIGHTLIGHT presentations were Dr Bob Philips running a workshop on evidence-based practice and Professor Frances Griffiths presenting the LYNC study, an evidence-based approach to communicating with young people. There were eight excellent oral presentations, so we had a lot to live up to. The feedback from the TYAC audience was good – we know some of you were a little disappointed that we didn't answer the BIG question: 'Do specialist cancer services add value?', but we were able to give you an idea of

all the great results that will be coming in 2018. We want to thank everyone for attending and all your candid discussion – we have listened and will be acting on some of your key suggestions.

In this issue of the newsletter we are showcasing a study we have just had accepted for publication, updating you on all the BRIGHTLIGHT projects and introducing you to Nishma, our health economist who will be telling us how much TYA cancer care costs!

Thank you for supporting BRIGHTLIGHT and watch this space because we will be keeping you updated more often so you don't miss anything that is going on.

*Rachel*

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### Highlights of this issue...

- Page 2: BRIGHTLIGHT 2017 – dates for your diary
- Page 3: Rachel summarises our latest completed BRIGHTLIGHT project
- Page 3: Meet Nishma Patel, our Health Economist
- Page 4: Lorna updates you on the work of our Young Advisory Panel
- Page 6: Summary of additional research, current conference activity and publications

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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
- Dr Julie Barber, Statistician, UCL
- Professor Rosalind Raine, Health Service Research, UCL
- Nishma Patel, Health Economist, 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



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.

Tour 2 dates:

7 <sup>th</sup> November	2017 NCRI Cancer Conference, Liverpool
17 <sup>th</sup> November	Chrysalis Festival, Edinburgh
18 <sup>th</sup> November	Chrysalis Festival, Edinburgh
19 <sup>th</sup> November	Chrysalis Festival, Edinburgh
25 <sup>th</sup> November	FYSOT, Birmingham

There are no more public performances. If you went to any of the shows in Tour 1 or Tour 2, we would value your feedback. If you haven't completed our evaluation you can access it here: <https://lsbu.onlinesurveys.ac.uk/brightlight-there-is-a-light-evaluation-all-performanc>

## 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 - TOUR 2

As reported in our March edition, CONTACT Young Company (CYC), in collaboration with Brian Lobel, Director Adura Onashile, Assistant Directors Mark Croasdale and Nathaniel Hall and producer Keisha Thompson, have created dramatic performance through interpreting BRIGHTLIGHT results. This toured Manchester, Brighton, Oxford and London in tour 1. The 2<sup>nd</sup> tour started at the NCRI conference in Liverpool in November with additional shows in Edinburgh and Birmingham (for invited patients only).

### 2<sup>nd</sup> Global AYA Cancer Congress



We are delighted to join our international colleagues for the 2<sup>nd</sup> Global AYA Cancer Congress in Atlanta, Georgia in December. Jeremy and Rachel have been invited to open day 3 of the conference with some never-before seen BRIGHTLIGHT results. We will also be presenting poster reporting carers

experience of AYA cancer care, defining age-appropriate care and showcasing the work of the YAP (see page 4). We are also presenting posters reporting research we are doing on other aspects of AYA care (details on page 7).

Congratulations to everyone who has had abstracts accepted, especially all those being presented from the UK.

## Completed study: Barriers to recruitment

By Dr Rachel Taylor

As you're all aware, recruitment to the BRIGHTLIGHT Cohort study was a challenge. We worked closely with patients and healthcare teams to improve recruitment and to understand the challenges as the study progressed, but we were still unable to recruit the 2,012 young people we had hoped to include.

### What were the aims?

Our aim was to understand more fully healthcare professionals' perspectives of the challenges of recruiting young people to a low-risk observational study, and to provide guidance for future recruitment processes.

### What did we do?

We conducted semi-structured telephone interviews with 23 healthcare professionals from across England. Participants included Principal Investigators/other staff recruiting into the BRIGHTLIGHT study.

### What did we find?

The emergent themes were linked to levels of research organisational management, described using the levels of social network analysis:

- Micro-level: the individual; in this case the target population to be recruited – young people with cancer
- Meso-level: the organisation; refers to place of recruitment and people responsible for recruitment
- Macro-level: the large scale or global structure; refers to the wider research function of the NHS and associated policies

Study-related issues occurred across all three levels, which were influenced by the context of the study. At the meso-level, professionals' perceptions of young people and communication between professionals generated age/cancer-type silos, resulting in recruitment of either children or adults, but not both by the same team, and only in the cancer-type the recruiting

professional was aligned to. At the macro-level the main barrier was discordant configuration of a research service with a clinical service.

### What will we do now?

This study has identified significant barriers to recruitment mainly at the meso- and macro-levels, which are more challenging for research teams to influence.

We have been publicising these challenges for some time, so it has recently been recognised by the NIHR Clinical Research Network and they have proposed several objectives to increase availability of studies for young people with cancer. How this will work in practice is not yet evident, but we are pleased that the importance of facilitating access to research for young people is now recognised and is seen as being important.

This study has recently been published on the BMJ Open website and can be accessed at:

<http://bmjopen.bmj.com/cgi/content/full/bmjopen-2017-018291?ijkey=d1iRnHmwptKCtO3&keytype=ref>

Open Access

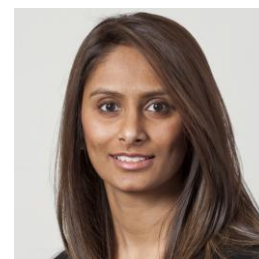
Research

### BMJ Open Qualitative study to understand the barriers to recruiting young people with cancer to BRIGHTLIGHT: a national cohort study in England

Charlotte Kenten,<sup>1</sup> Ana Martins,<sup>1</sup> Lorna A Fern,<sup>1</sup> Faith Gibson,<sup>2,3</sup> Sarah Lea,<sup>1</sup> Nothando Ngwenya,<sup>1</sup> Jeremy S Whelan,<sup>1</sup> Rachel M Taylor<sup>1</sup>

## Meet a team member

By Nishma Patel



Hi! My name is Nishma and I'm the health economist for this project. I graduated from City University, London in 2001 and completed my MSc in Economic Evaluation in Health Care. Since, I have undertaken economic evaluations alongside clinical trials, economic modelling studies, and facilitated research projects.

My first research post was at Fourth Hurdle Consulting Ltd, a health economics consultancy firm, where I completed my dissertation for MSc in Economic Evaluation in Health Care on the cost-effectiveness of heptavalent conjugate pneumococcal vaccine for use in children at high risk of pneumococcal disease. I carried out many systematic reviews looking for cost and effectiveness data to populate economic evaluation

models on the following topics: carcinoma cancer and orphan diseases, bleeding in patients with blunt trauma and drug therapy for peptic ulcers.

From September 2006-August 2008, I worked on a series of projects with the Welsh Health Economics Support Services (WHESS). My role was to liaise with trial managers, analyse data and conduct systematic reviews on childhood diabetes, dementia and domestic violence.

In September 2008, I joined the National Perinatal Epidemiology Unit (NPEU), University of Oxford as a research associate. I worked on Birthplace, a prospective cohort study. This study looked at the cost-effectiveness associated with place of birth. I was responsible for co-ordinating and conducting interviews with hospital finance directors around England, for data collection on the cost of running maternity departments. This project informed the government's policy on maternity care. I worked on an adjunct study to Birthplace called the Barkantine prospective study. This study looked at women's experiences and the costs associated with giving birth in a free-standing midwifery unit and an obstetric unit in Tower Hamlets.

In October 2010, I joined The Department of Applied Health Research (DAHR), where I have managed multiple projects. My current projects include evaluating BRIGHTLIGHT.

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## Young Advisory Panel

By Dr Lorna Fern

### Can you help us decide how best to tell people about BRIGHTLIGHT results or what we should do next?

We have worked with young people, parents, carers, siblings and healthcare professionals all through BRIGHTLIGHT to help us design the study in the best way possible and make sure we are asking the right questions. As results start come in and we think about how best to present these back to the people who need to know we will be asking you to help us. The Young Advisory Panel (YAP) meet once a year to help us with research, we also have a Facebook page which we use to keep people updated with the study and ask for advice. This year members of the YAP have been involved in showing study results either through the performance 'There is a light' or Chaining sessions at our first ever BRIGHTLIGHT conference. The photograph shows YAP members Lara and Maria with the rest of the BRIGHTLIGHT team after our July Conference.

This year has been exciting as our performance 'there is a light' toured England during spring and is about to commence the autumn tour. Here you can see YAP member Amy talking about her experience of being in the show and why you should go and see 'There is a light'.

<https://www.youtube.com/watch?v=xolsD2j7kqM>



Left to right: Rachel Taylor, Lorna Fern, Jeremy Whelan, Sarah Lea, Ana Martins, Richard Feltbower, Lara Veitch, Louise Hooker, Dan Stark, Faith Gibson, Nishma Patel

We have had three new members to the YAP this year and they recently attended a one-day workshop run by famous performer Brian Lobel. The group discussed what information and support young people with cancer needed around sex, body image and relationships. The work from this will go on to inform another research study.

If you were diagnosed with cancer between the ages of 13-24 years within the last five years and think you would like to join the YAP then please get in touch: [brightlight@uclh.nhs.uk](mailto:brightlight@uclh.nhs.uk)

Members of the YAP have the opportunity to participate in workshops. We will cover travel, food and you will be given a voucher for your participation in the day. We try to make our workshops interactive and stimulating so they are always really well evaluated:

*'Great day, enjoyable experience, brilliant day, fun, interesting'*



Photograph: YAP meeting Leeds in August 2016 to discuss online information and support needs for young people

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

FOR THOSE OF YOU GOING TO FYSOT – see you there!

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## Project updates

### The Case Study - exploring the culture of care

By Sarah Lea

I am leading the BRIGHTLIGHT case study and am coming towards the end of writing-up 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 generated rich case study findings, which will support some of the findings of the BRIGHTLIGHT cohort study. I will work with the team in the future to help to bring these qualitative findings together with the BRIGHTLIGHT quantitative data.

I presented part of my findings earlier this year at the BRIGHTLIGHT-TYAC conference: a conceptual model of age-appropriate care. This work was, to our knowledge, the first study to delve into what healthcare professionals and young people consider to be the most essential elements of 'age-appropriate care.' We have written this as a paper, which will

shortly be submitted for publication, so watch this space for that. The 'age-appropriate care' portion of the case study findings was accepted as a poster presentation at the 2nd AYA Global Congress in Atlanta, in December, so hopefully I will see some of you there and can share more with you!

### The Cohort Study - defining the experience of care

By Dr Rachel Taylor

The BRIGHTLIGHT Cohort includes 1,114 young people with valid consent and available data, including patient-reported outcomes from 830 young people. Young people have reported their experience of care and life after a cancer diagnosis by completing the BRIGHTLIGHT survey<sup>1</sup> up to 5 times over 3 years. This survey was designed specifically to reflect young people's experience and self-reported outcome after diagnosis. It is now very exciting because waves 1-4 are complete and our final wave 5 ends at the end of February 2018. If you have been contacted by Ipsos MORI to participate or know a young person who has, please take the time to complete the wave 5 survey; young people's responses are extremely important to tell us if the care they received at diagnosis has helped them continue with life and to achieve their personal milestones.

We have a few more challenges to overcome to be able to complete our analysis. We need to be able to compare severity of illness across the different places of care. As young people have been diagnosed with a wide range of cancers this is difficult as there are multiple staging criteria. We are working with Public Health England to obtain data to be able to calculate a severity scale; hopefully we will be able to share more details about this in the next newsletter.

Finally wave 1-4 surveys are freely available for use under license and can be accessed by searching for:  
[doi.org/10.5522/03/BRIGHTLIGHT\\_W1](https://doi.org/10.5522/03/BRIGHTLIGHT_W1) or  
[doi.org/10.5522/03/BRIGHTLIGHT\\_W2-4](https://doi.org/10.5522/03/BRIGHTLIGHT_W2-4)

<sup>1</sup>Taylor 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

### Carers of young people with cancer informational and support needs

By Dr Ana Martins

Carers are profoundly affected by their caregiving role yet little attention has been given to identifying and meeting their needs. In particular, the experiences of carers of young people with cancer are not described. We aimed to identify carers'

unmet information and support needs. Further, we sought to examine any differences associated with the extent of exposure to specialist care.

BRIGHTLIGHT participants nominated their main carer to complete a Carer Questionnaire addressing information needs, healthcare service experience, emotional and psychological wellbeing and support needed/received. Questionnaires were completed six months after diagnosis. Comparisons were made according to where young people's care was delivered: all in a Principal Treatment Centre (PTC), some in a PTC, or no care in a PTC. Four hundred and seventy-six questionnaires were returned (57% response rate). Mean age of carers was 45.9 (+/-10.5) years, 381 (80%) were female and 401 (85%) were parents. Data analysis is in progress.

## The Health Economics Study - calculating the cost of care

By Nishma Patel

We are one step closer to finding out what the financial burden of having cancer means young people and their family.

We have calculated the financial burden during the first 6 months since diagnosis. This includes the cost of travel, overnight stay, prescriptions, and additional out of pocket expenses. These findings will be added to the cost of care questionnaires young people have been completing for us. In addition to this, the EQ-5D questionnaires young people completed to tell us how they were feeling will be used to detect changes in their health status.

These data will be linked to where young people received care to assess association between place of treatment centre, quality of life and costs.

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## BRIGHTLIGHT at the TYAC annual conference, Leeds

BRIGHTLIGHT were honored to join TYAC for their annual conference. Rachel has already highlighted the excellent keynote presentations by Bob Philips and Frances Griffiths. It was really exciting to see all the other excellent research that is being conducted across the country. If you are a member of

TYAC then you can download the presentations from their website: <https://www.tyac.org.uk/>

The BRIGHTLIGHT presentations included work done in most of the workstreams, details are presented at the end of the newsletter. As most of this work is in progress, slides are not available yet to download from the website. There will be more results coming over the next 12 months so we were very pleased with the great reception we had from the TYA world. If you were at TYAC and want to provide additional feedback, our contact details are at the end and we always welcome suggestions on how we can do things better.

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## Other projects

### James Lind Alliance

We are super excited to be involved with the Teenage and Young Adult James Lind Alliance Research Priority Setting Exercise. This study will identify the top ten research questions for young people with cancer set by both young people, parents, carers, siblings and a range of healthcare professionals involved in their care.

#### Want to take part?

Look out for the second survey coming out in November which will ask you to rate how important 100 research questions are to you! From that, the top 20 will be taken forward to a one day workshop with young people, carers and professionals to battle it down to the TOP 10! If you fill out the survey you can also say whether you would be interested in attending the final workshop. You can keep an eye on progress here: <http://www.jla.nihr.ac.uk/priority-setting-partnerships/teenage-and-young-adult-cancer/>

And if you would like us to send you a copy of the JLA survey when it is live in November email us and we can send you the link.

### FYSOT Evaluation

Find Your Sense of Tumour (FYSOT) are two residential weekends hosted by Teenage Cancer Trust for young people (13-17/18-24 years) with cancer. The residential events bring together young people for educational presentations, motivational speakers, workshops and social events. The value of the conference has not been formally evaluated, so a one-year longitudinal evaluation was developed. A survey was developed based on observations of the conference and

interviews with professionals and young people. Young people answered the survey before, after, 3 months, 6 months and 1 year after attending the conference. Professionals and carers views were also assessed. The last stage of the evaluation will be completed in November.

## Online study

We were excited to have been funded by Teenage Cancer Trust to conduct the 'Online Study' this year. This was a study where we explored young people and healthcare professionals' perspectives of what they access online for information and support both during and after their cancer treatment. We also looked at whether they feel what information and support is currently available online meets their needs. We have written up the findings in two parts, which will be published early next year.

## Development of a sarcoma-specific patient reported outcome measure: SAM

Patient experience is central to measuring quality of care in the NHS, and Government policy encourages the use of patient-reported outcome (PRO) to facilitate patient-clinician communication. Generic PRO measures (PROMs) may not be sensitive enough to reflect the specific experience of patients with sarcoma. The aim of this project is to develop a sarcoma-specific PROM: the Sarcoma Assessment Measure (SAM) and develop the strategy to incorporate this into clinical practice.

The study will include three stages: Phase 1 is the development of the SAM questionnaire. This has included a review of the literature and in-depth exploration of patients' experience of sarcoma through semi-structured interviews/focus groups with 121 patients of all ages. SAM is being developed from this information so in Phase 2 we can test SAM as a measure of sarcoma experience and outcome. In Phase 3 we will work with patients, healthcare professionals and hospital IT experts to see how SAM can be implemented in practice.

Phase 1 is nearly complete so if you have sarcoma or work in a sarcoma service and would like to be involved, please contact us at [SarcomaResearch@uclh.nhs.uk](mailto:SarcomaResearch@uclh.nhs.uk)

# Recent publications

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

## Publications

Abrol E, Groszmann M, Pitman A, Hough R, Taylor RM, Aref-Adib G. (2017) Meeting the Digital Technology Needs of Teenagers and Young Adults (TYA) with Cancer: a cross-sectional survey. *Journal of Cancer Survivorship* DOI 10.1007/s11764-017-0618-z

Gibson F, Pearce S, Fern L, Martins A, Kelly D (2017) Improving the identification of cancer in young people: A scoping review. *Expert Review of Quality of Life in Cancer Care*. 2(2): 87-101.

Kenten C, Martins A, Fern LA, Gibson F, Lea S, Ngwenya N, Whelan JS, Taylor RM. (2017) Understanding the barriers to recruiting teenagers and young adults with cancer to BRIGHTLIGHT, a national cohort study. *BMJ Open*, 7(11): 1-12.

Ngwenya N, Kenton C, Taylor R, Whelan J. (2017) 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* 6(2): 200-21.

Pini S, Gibson F, Fern LA, Morgan S, Phillips RS, Stark DP. (2017) Multi-professional perspectives on adolescent and young adult oncology across Europe: An e-Delphi Survey. *Journal of Adolescent and Young Adult Oncology* 6(1):178-185.

Taylor RM, Aslam N, Lea S, Whelan JS, Fern LA. (2017) Optimising a strategy with young people to retain young people in a longitudinal cohort study: BRIGHTLIGHT. *Journal of Adolescent and Young Adult Oncology* 6(3): 459-469.

## Conference presentations

Martins A, Storey L, Wells M, Fern LA, Bennister L, Gerrand C, Onasanya M, Woodford J, Windsor R, Whelan JS, Taylor RM. Identifying common experiences amongst sarcoma patients. The first phase in developing a sarcoma-specific patient-reported outcome measure. BSG Conference (poster presentation) 1st – 2nd March 2017.

Taylor RM, Martins A, Lea S, Whelan JS, Fern LA. Participatory research: using board games to guide secondary analysis of big data (oral presentation) 2017 RCN International Research Society Conference Oxford, 6th April 2017

BRIGHTLIGHT-TYAC Joint Annual Conference presentations. Leeds 6-7th July 2017 (all oral presentations):

- Whelan JS. The development of BRIGHTLIGHT - study background, design and operation
- Taylor RM. The challenges & successes of conducting a complex national longitudinal cohort study of young people with cancer.

- Fern LA. Young people as partners in BRIGHTLIGHT
- Gibson F. Mapping the landscape... views of professionals from the BRIGHTLIGHT international Delphi survey and beyond
- Kenten C. When Cure is Not Likely – the delivery of end of life care for TYA with cancer
- Lea S. What is the culture of TYA care? Exploring the landscape through a multi-site case study
- Feltbower R. Developing a metric to define specialist care: the TYA Cancer Specialism Scale
- Martins A. The experience of carers
- Whelan JS. Emerging results from the BRIGHTLIGHT cohort study

National Cancer Research Institute (NCRI) Conference, Liverpool 6-8<sup>th</sup> November 2017. Jeremy led a parallel session on “Delivering high quality care for young people with cancer”. This session included three BRIGHTLIGHT oral presentations. In addition, the following were presented:

- Kenten C, Martins A, Fern L, Gibson F, Lea S, Ngwenya N, Whelan J. and Taylor RM. Understanding the barriers to recruitment of teenagers and young adults with cancer to research (poster presentation)
- Lea S, Martins A, Taylor RM, Morgan S and Fern L. The complex process of young people with cancer using online information and support (poster presentation)
- Martins A, Fern L, Whelan J and Taylor R. Carers of teenagers and young adults with cancer have unmet information and support needs (poster presentation)
- Martins A, Taylor RM, Morgan S, Bradley J, Fern L. Carer perspectives of the value of specialist residential weekends for young people with cancer (poster presentation)
- Veitch L, Morgan S, Fern L. Teenage and young adult cancer patient’s views on tissue banking (poster presentation)
- Fern L, Morgan S, Stark D, Taylor R, Darlington S, Williamson M and Veitch L. National Cancer Research Institute Teenage, Young Adult and Germ Cell Health Services Research Subgroup: Historical achievements and emerging strategy (poster presentation).

## Contact us

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