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| <b>Institution:</b> University of Chichester   |   |  |
| <b>Unit of Assessment:</b> 33  |   |  |
| <b>Title of case study:</b> Creating <i>There is a Light</i> from clinical and performance-based research on experiencing cancer as a young adult  |   |  |
| <b>Period when the underpinning research was undertaken:</b> 2009-2018   |   |  |
| <b>Details of staff conducting the underpinning research from the submitting unit:</b>   |   |  |
| <b>Name(s):</b>  | <b>Role(s) (e.g. job title):</b>  | <b>Period(s) employed by submitting HEI:</b> |
| Dr Brian Lobel   | Senior Lecturer in Performing Arts: September 2012-September 2013<br><br>Senior Lecturer in Theatre (Performing Arts): September 2013-March 2017<br><br>Reader in Theatre: March 2017-December 2018 | 2012-2018                                    |
| <b>Period when the claimed impact occurred:</b> March 2017-present   |   |  |
| <b>Is this case study continued from a case study submitted in 2014?</b> N   |   |  |
| <b>1. Summary of the impact</b> (indicative maximum 100 words)   |   |  |
| <p>Drawing on a wealth of innovative research into illness, performance and spectatorship, Brian Lobel was the driving force behind <i>There is a Light</i>: the UK's first research-based theatrical performance to be created by and about young adults with cancer. Underpinned by an interdisciplinary workshop series led by Lobel and NHS experts from BRIGHTLIGHT, the project revealed the transformative potential of empowering 18-25-year-olds to disseminate clinical research in a theatrical context. Its 24-strong cast (4 of whom themselves had cancer) found powerful ways of sharing this research with diverse live public audiences, including NHS specialists and patients (amounting to 1,377 people across 6 cities), whilst also being transformed by that process themselves. <i>There is a Light</i> has since inspired NHS organisations (including BRIGHTLIGHT) to work with more creative methodologies.</p>   |   |  |
| <b>2. Underpinning research</b> (indicative maximum 500 words)   |   |  |
| <p>Teenagers and young adults (TYAs) have typically been overlooked in specialist cancer care and the research that relates to it. While potentially curable for many young people, there is evidence that outcomes for some cancers have not improved in line with those achieved for children and older adults – in spite of the clear ethical, societal and economic incentives that should make such improvements a priority. Responding to this in 2005, the National Institute for Health and Care Excellence published guidance recommending that all 15-24-year-olds with cancer receive specialist care tailored to their specific needs. BRIGHTLIGHT was created as a result, a National Institute for Health Research (NIHR)-funded programme charged with evaluating cancer services for TYAs in England.</p> <p>Since being diagnosed with cancer himself in 2001, Brian Lobel has been creating performances, academic research, interactive installations, community projects, musicals and cabaret acts about cancer and the changing body. Running throughout this work is an</p> |   |  |

exploration of how different forms of participatory and performative artistic expression can facilitate fresh, meaningful and challenging engagements with serious illness, both for wider publics and the people whose lives are personally affected by it. His work thus provides a creative meeting point between clinical research and the lived experience of what it is like to have cancer.

In *Fun with Cancer Patients* (2015, **R1**), a major collaboration between Fierce Festival and the Birmingham Teenage Cancer Trust, Lobel created an innovative installation space dedicated to raising intellectual awareness of the cancer experience. Providing 20 cancer patients with a unique context in which to develop idiosyncratic public 'interventions', **R1** provided these patient-participants with opportunities to share and explore their own unique understanding and insights. It also resulted in a 2016 essay (**R2**), which, undertaking a critical reflection on **R1**, considers how the dynamics and exchange between performance and medicine can deepen academic and popular understandings of subjectivity, patient narrative, identity, embodiment, agency, medical ethics, health and illness.

This research was further developed, in a different way, in *A Pacifist's Guide to the War on Cancer* (2016, **R3**), a National Theatre musical written collaboratively by Bryony Kimmings, Lobel and Tom Parkinson. Like **R1**, **R3** probed both wider social taboos and the generic limitations of its specific artistic setting, providing a forum for new kinds of interactive audience engagement on the subject of cancer. It also informed a further (2017) essay by Lobel exploring 'bodies with cancer and their audience', which was published in the first dedicated academic volume to address the role of theatre, drama and performance in promoting, developing and sustaining health and wellbeing in communities.

It was in 2017 that Lobel, working with BRIGHTLIGHT and the Manchester-based youth theatre Contact Young Company (CYC), turned specifically to focus on the TYA age group. *There is a Light (TIAL, R5)* was the result: a Wellcome Trust-funded (GBP26,000) project aimed at empowering 20 young CYC actors and 4 young people with cancer to explore and disseminate BRIGHTLIGHT's evaluative research on TYA cancer care. Over 5 weeks, Lobel facilitated a series of 5 interactive workshops, delivered with various medical/care professionals and a cancer patient, that explored key aspects of BRIGHTLIGHT research, alongside acting skills, voice training and choreography. Once this had concluded the cast was (atypically) given free rein to create the show *they* wanted. The resulting creative process was captured in regular video diaries and surveys, evidencing how moving from 'linear' to 'circular' strategies for knowledge dissemination can dramatically improve engagements with clinical research (**R6**).

### 3. References to the research (indicative maximum of six references)

**R1:** Lobel, Brian (2015) *Fun With Cancer Patients*. [Show/Exhibition]. ChiPrints:

<http://eprints.chi.ac.uk/id/eprint/2535/> [being submitted to REF2021].

- Funded by Wellcome Public Engagement Fellowship (GBP60,000 of GBP117,000 budget).

**R2:** Lobel, Brian (2016) *Fun with Cancer Patients: The Affect of Cancer*. In: Performance and the Medical Body. Performance/Science. Bloomsbury Methuen Drama, London. ISBN 9781472570796.

**R3:** Kimmings, Bryony, Lobel, Brian and Parkinson, Tom (2016) *A Pacifist's Guide to the War on Cancer*. Oberon Books, London. ISBN 9781786820600.

Select reviews and news articles about **R3**:

- Lyn Gardner, 'A Pacifist's Guide to the War on Cancer: a masterclass in manipulating audiences' (7 November 2016): <https://www.theguardian.com/stage/theatreblog/2016/nov/07/a-pacifists-guide-to-the-war-on-cancer>.

## Impact case study (REF3)

- Mark Shenton, 'A Pacifist's Guide to the War on Cancer' (20 October 2016): <https://www.thestage.co.uk/reviews/a-pacifists-guide-to-the-war-on-cancer-review-at-the-national-theatre--bold-bracing-healing>.
- Brian Lobel, 'Why we wrote an all-singing, all-dancing musical about cancer' (13 September 2016): <https://inews.co.uk/essentials/wrote-singing-dancing-musical-cancer-21604>.

**R4:** Lobel, Brian (2017) Proud Disclosures and Awkward Receptions: Between bodies with cancer and their audiences. In: *Applied Theatre: Performing Health and Well-Being*. Applied Theatre. Bloomsbury Methuen Drama. ISBN 9781472584595. ChiPrints: <http://eprints.chi.ac.uk/id/eprint/2534/> [being submitted to REF2021].

**R5:** Lobel, Brian, Martins, Ana, Taylor, Rachel M., McCann, Beth, Soanes, Louise, Whelan, Jeremy S. and Fern, Lorna A (2017) *There is a Light*. [Show/Exhibition].

**R6:** Martins, Ana, Taylor, Rachel M., Lobel, Brian, McCann, Beth, Soanes, Louise, Whelan, Jeremy S. and Fern, Lorna A. (2018) Sex, Body Image, and Relationships: A BRIGHTLIGHT Workshop on Information and Support Needs of Adolescents and Young Adults. *Journal of Adolescent and Young Adult Oncology*. ISSN 2156-535X. DOI: ChiPrints: <http://eprints.chi.ac.uk/id/eprint/3440/> [being submitted to REF2021].

Research funding:

- Funded by Wellcome Trust Public Engagement Fellowship (GBP26,000).

**All outputs available on request.**

#### 4. Details of the impact (indicative maximum 750 words)

Traditional 'academic' methods of communicating clinical research findings often fail to reach many of the audiences that matter the most, including the patients whose lives are directly affected by them. Successive governments have sought repeatedly to tackle this problem in the UK: in 2007 the Department of Health reported on a working group to review its role in promoting the arts and health; and in 2014 an All-Party Parliamentary Group on Arts, Health and Wellbeing was formed to 'improve awareness of the benefits that the arts can bring to health and wellbeing'. Lord Howarth's subsequent report on '[Creative health: the arts for health and wellbeing](#)' concluded that the arts had a positive impact on health, had the ability to help patients manage health challenges, and could, as a result, save the NHS money.

TIAL delivered on these objectives in a wide variety of ways, whilst also providing further insights into the underexplored potential of theatre to amplify and transform public engagements with clinical research. Its significant impacts on (1) public awareness, (2) participants and (3) NHS researchers are described below.

#### Sharing clinical research in a theatrical context

The show, which lasted just over an hour, was performed 11 times, across 6 cities, for a combined 1,377 people. 8 of these performances were delivered to general theatre audiences (including patients, their families and friends, and members of the general public), while 3 were conference performances specifically targeted at nurse researchers and patients – many of whom were adult-trained, multidisciplinary cancer specialists. Evaluation was built into the project's design. A 30-minute interactive 'talk-back' between members of the cast, the creative team, an expert healthcare professional and the audience was held after most (9) performances, and an audience survey was conducted after 3 of them (including 1 conference performance). This data was captured by the project's creative team and is publicly available in a comprehensive Open Access format (C1).

Of the survey's 88 respondents, 95% said they had learned something about what it is like to live as a young person with cancer (with 97% feeling they understood that reality better), 98% agreed that research-based drama was an effective way of educating people about cancer in young people, and 89% said that, given the opportunity, they would participate in further creative experiences related to research. One free-text respondent with 30 years' experience working with young cancer patients commented that they would remember the research insights shared by the performance 'for much longer than the hundreds of papers I've read'. Young people's evaluation of the performance at the Teenage Cancer Trust's 'Find Your Sense Of Tumour' scored it 9.48 out of 10. It was at this event (with an audience comprised entirely of young cancer patients) that *TIAL* gained its greatest traction on social media, with more than twice the level of Twitter hashtag engagements than any other performance (out of 1,192 in November 2017 as a whole). The show's substantial reach is further evidenced in 4 online review articles, 1 of them written by a young person with cancer, who described it as a 'brilliant and engaging performance' that 'accurately portrays some of the main stages and issues faced as a young adult with cancer' (C2). *TIAL* was also shortlisted for the 2018 Manchester Theatre Youth Panel Award (C3). A filmed performance is [freely available](#) on the CYC YouTube channel.

### Transforming young adult engagements with cancer

The project's 18-25-year-old creators were given video cameras and asked to record weekly reflections on the creative process. The resulting footage, which included spoken diaries, raps and visual drawings of the workshops, was independently reviewed by 2 researchers, who identified 6 key themes within it: anxieties, personal development, connections, cancer in young people, impact on the cast, and interacting with researchers.

Having reported initial feelings of bewilderment at the 'massive transition' involved in moving from conventional theatre to a researched-based project about cancer, the 20 CYC actors were able to adapt rapidly to the challenge, using the workshop series as an opportunity to develop as performers and people (having 'an all rounded view on cancer'), and finding opportunities to connect with each other in meaningful ways – especially through exploring common experiences of depression and anxiety (which TYAs often experience following cancer treatment). Their engagements with the 4 'cancer girls' were particularly transformative. They were 'shocked' by the girls' personal testimonies, the fine margins they had experienced in their illness, and their insights into TYA cancer care (e.g., the fact that TYAs often end up in children's wards). Many of the 20 CYC actors had not previously known that young people could even get cancer. For the 4 cancer patients who took part in it, *TIAL* was a uniquely moving opportunity to form meaningful connections and explore their experience of cancer. Both those with cancer and those without described the profound positive impacts of being involved. One noted that 'I feel like I am a completely different person to when I started the project' (C1).

### Influencing researchers

The project's research-generative design also extended to its creative team, who wrote diaries after each workshop attendance. These diaries reveal the power of the workshop activities that were used to relay research to the actors, helping them to grasp complex data. Those who could only attend some workshops were nonetheless made to feel included, and came to 'appreciate the enormity of what [the workshops] have done'. Dr Rachel Taylor, an NIHR Senior Nurse Research Leader, said that being involved in the project was one of the highlights of her career, adding that its success has informed the development of subsequent BRIGHTLIGHT activities (C4). These planned activities include a theatrical project exploring cancer diagnoses in prison (with Synergy Theatre Project, a prison theatre company) the dissemination of methodological advice to other NHS researchers considering using theatre, and plans for a new theatrical project conveying the BRIGHTLIGHT team's final research findings (C5). *TIAL* has also provided opportunities for young researchers,

including MA students from the University of Salford, who created a documentary about the project (C6).

TIAL thus represents an innovative and replicable model for creating highly meaningful engagements between young people, patients, research communities and the wider public.

#### 5. Sources to corroborate the impact (indicative maximum of 10 references)

**C1:** Taylor, R.M., Lobel, B., Thompson, K. et al. BRIGHTLIGHT researchers as ‘dramaturgs’: creating *There is a Light* from complex research data. *Res Involv Engagem* 6, 48 (2020). <https://doi.org/10.1186/s40900-020-00222-5>.

**C2:** Press coverage and reviews of *There is a Light*:

- Catherine Love, ‘Review: Sick! Festival in Manchester’, *Exeunt Magazine* (9 March 2017): <http://exeuntmagazine.com/reviews/review-sick-festival-manchester/>.
- Clare McVay, ‘Chrysalis Festival: *There is a Light*: Brightlight & How to Save the World...ish’, *The List* (15 December 2017): <https://www.list.co.uk/article/98012-chrysalis-festival-there-is-a-light-brightlight-and-how-to-save-the-world-ish/>.
- ‘*There is a Light*: Brightlight, issues affecting young adults with cancer’, (13 March 2017), <https://youngwildandfibroblastic.com/2017/03/13/there-is-a-light-brightlight-issues-affecting-young-adults-with-cancer/>.
- James Varney (20 March 2017), <http://www.jamesvarney.uk/review-contact-young-company-light-brightlight/>.

**C3:** ‘Celebrating The Best of 2017 at The 2018 Manchester Theatre Awards’, *North West End UK*: <https://northwestend.co.uk/index.php/homepage/news/2862-celebrating-the-best-of-2017-at-the-manchester-theatre-awards>.

**C4:** Testimonial statement from Dr Rachel Taylor, NIHR Senior Nurse Research Leader

**C5:** ‘Theatre can bring research findings to life for a wide range of audiences’, *National Institute for Health Research* (15 December 2020): <https://evidence.nihr.ac.uk/alert/brightlight-theatre-research-findings-wide-audiences/>.

**C6:** Documentary film on *There is a Light* created by MA students at the University of Salford: <https://vimeo.com/238045094>