



BMJ Open Young people's opinions of cancer care in England: the BRIGHTLIGHT cohort

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To cite: Hughes L, Fern LA, Whelan JS, *et al*. Young people's opinions of cancer care in England: the BRIGHTLIGHT cohort. *BMJ Open* 2023;**13**:e069910. doi:10.1136/bmjopen-2022-069910

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2022-069910>).

Received 06 November 2022

Accepted 31 July 2023



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ABSTRACT

Objectives The BRIGHTLIGHT cohort study was the national evaluation of cancer services for teenager and young adults (TYA). This was analysis of free-text survey data to better understand their experiences of cancer care.

Design Cohort study

Setting National Health Service hospitals delivering cancer care in England

Participants 830 young people newly diagnosed with cancer.

Interventions Exposure to specialist care in the first 6 months after diagnosis defined as care in a TYA Principal Treatment Centre (PTC). This was categorised as follows: all care in a TYA-PTC (ALL-TYA-PTC), no care in a TYA-PTC (NO-TYA-PTC) so care delivered in a children/adult unit only and some care in a TYA-PTC with additional care in a children's/adult unit (SOME-TYA-PTC).

Primary outcome Data were collected through the BRIGHTLIGHT survey included free-text questions which asked patients 'what was the best aspects of their experiences of care' and 'what aspects could be improved'. These comments were analysed using content analysis. Themes were compared between categories of care, then ranked in order of frequency, ranging from the most endorsed to the least.

Results Overall, young people were most positive about their healthcare team, while the area highlighted for improvement was diagnostic experience. Differences between the three groups suggested those who had some or all treatment in a TYA-PTC valued the place of care. Regardless of where TYA were treated their healthcare teams were favourably viewed. Age appropriate place of care was highlighted to be of value for those in PTCs.

Conclusions These data show the value young people placed on the care they received in TYA specific wards. Young people who accessed some or all of their care in a TYA-PTC highly endorsed their place of care as one of the best elements of their care, and it is further emphasised by those who had shared care who experienced difficulty with lack of age-appropriate care when treated outside the TYA-PTC.

INTRODUCTION

The landscape of cancer care for young people has developed significantly within England over the past three decades.¹ It is recognised that a cancer diagnosis at a key developmental time-point causes disruption for young people, including long-term and

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The BRIGHTLIGHT study was the first nationwide evaluation of cancer care for young people in England.
- ⇒ Young people were recruited from oncology, haematology, adult, child and specialist teenage and young adult cancer units therefore representing the complete range of environments where young people are treated in the National Health Service.
- ⇒ Data were collected from young people in their own homes to reduce reporting bias of completing the evaluation of care in the environment where care was delivered.
- ⇒ Not all young people could be assigned to a category of specialist care, which may limit comparisons between the three groups of none, some or all specialist care.
- ⇒ The BRIGHTLIGHT cohort represents 20% of the incident cases at that time and may limit generalisability.

short-term impacts on their physical and mental well-being.²⁻⁴ Studies show a cancer diagnosis can cause prevalent biographical disruption to areas such as education, employment and the development of social and romantic relationships for this population.⁵ Alongside this, young people are likely to experience complications to fertility, sexuality and body image.^{6,7} Multiple periods of hospitalisation impacts important social milestones, potentially hindering young people's ability to move towards independence and integrating with peers.^{5,6}

Recognising that young people could be affected by cancer in way that were not experienced by children or older adults, the National Institute for Health and Clinical Excellence (NICE) issued the Improving Outcomes Guidance for Children and Young People with Cancer in 2005.⁸ This guidance proposed a system of care in England which centred around creating Teenage and Young Adult (TYA) specialist services provided by a Principal Treatment Centre (PTC). The guidance stated that all young people aged 15–18 years must receive cancer care within

a PTC, while those aged 19–24 should be given a choice on whether to have their care in a PTC or more locally to home in an in adult hospital but must have ‘unhindered access’ to TYA specialist care.⁸

To accommodate these recommendations, 13 PTCs were created across England facilitating equitable access across the country. The PTCs were housed within existing National Health Service (NHS) hospitals. The TYA-PTCs aimed to provide specialist age-appropriate environments, with access to a specialist TYA multidisciplinary team including Clinical Nurse Specialists and Youth Support Coordinators, alongside advanced clinical treatment regimens and access to clinical trials.^{8,9} However, despite these recommendations, there was little evidence to support improved outcomes associated with care in the TYA-PTC and by 2010 when the recommendations were aimed to be implemented, half of the young people receiving care for a cancer diagnosis continued to be treated in children or adult wards, with limited access to the age-appropriate facilities.¹⁰ Further key questions which remained unanswered from the NICE Improving Outcome Guidance included: What was age-appropriate care? What were the most important elements of a TYA service? And how much did it cost the young people, their families and the NHS? To address these questions and better understand the experiences of young people receiving cancer care, the National Institute for Health and Care Research funded the BRIGHTLIGHT study. BRIGHTLIGHT was the first prospectively recruited cohort study focused on TYA in England, which aimed to determine whether care in the TYA-PTC was associated with improved outcomes, and to define age-appropriate care, its delivery and associated costs.¹¹

Central to BRIGHTLIGHT was a cohort of newly diagnosed young people who were followed longitudinally for 3 years.¹⁰ The cohort was divided into three distinct groups based on where they had received their admitted care within the first 12 months of their diagnosis. The NO-TYA-PTC group received no care in a TYA-PTC during this period (care was delivered in a children or adult cancer unit only), while the ALL-TYA-PTC received all of their care in the TYA-PTC. The SOME-TYA-PTC group received a mixture of care, receiving some care in the TYA-PTC and additional care in a local child or adult cancer unit.¹² The primary outcome measure for BRIGHTLIGHT was quality of life, which was highest in those who received no treatment in a TYA-PTC (NO-TYA-PTC) at 6 months following diagnosis, followed by those who received all their treatment in a TYA-PTC (ALL-TYA-PTC).¹² Rates of improvement in quality of life were faster in the ALL-TYA-PTC group and at the end of 3 years, average quality of life was similar to those in the NO-TYA-PTC group. However, the SOME-TYA-PTC group had the lowest quality of life throughout the 3 year study period. Survival, anxiety, depression and social support was the same among all three groups.^{12,13}

These findings were counterintuitive, as it had been presumed by professionals and young people that access

to a TYA-PTC would lead to more positive outcomes.^{14–17}

Additionally, recent findings suggest that TYA patients miss out on important opportunities when not treated in a specialist age-appropriate environment, such as access to peer support.¹⁸ Some sociodemographic factors were seen to vary between groups, such as the NO-TYA-PTC group including slightly older patients in either full or part time employment who were less likely to have as severe a prognosis, and the ALL-TYA-PTC group being more likely to come from less deprived areas. However, when these differences were taken into consideration during statistical analysis, they were found to have no impact on the outcome of BRIGHTLIGHT’s findings.^{1,13} Several factors were proposed as potential explanations, such as young people who did not have access to specialist care would potentially compare themselves to older cancer patients in adult wards and therefore, may have perceived themselves to be more well in comparison. Receiving care locally may have resulted in less travel, which could have positively impacted their quality of life. Those in the SOME-TYA-PTC group were shown to have the lowest level of quality of life, which in part may have been caused by the complexities of intrahospital communication, and inconsistencies in care between services.¹⁹ Approximately a third of this group consisted of young people with bone and soft tissue sarcomas,¹⁰ who are known to have a poorer prognosis despite intensive treatment.^{20,21} However, this did not impact the results when taken into consideration during analysis. The results of those receiving SOME-TYA-PTC care are of concern as current commissioning of services within the NHS in England advocate for a system of joint care between PTCs and local hospitals.²² Nevertheless, it is now a decade since BRIGHTLIGHT data were collected and may reflect a culture of TYA care which was still in active development.²³ Consequently, BRIGHTLIGHT_2021 is collecting data to understand how the current configuration of TYA-PTC services impacts outcomes and experiences.²⁴

BRIGHTLIGHT findings suggested much is yet to be learnt about the experiences of young cancer patients navigating care.¹¹ To better understand the differences in experiences of places of care, we examined the free-text comments inputted by young people during their first survey approximately 6 months after diagnosis.

METHODS

Patient and public involvement

Young people have been involved in this study from the feasibility stage onward. They were involved in study development, acted as co-researchers and were instrumental in the design and methods of the study. A representative of the Young Advisory Panel (YAP) was a coapplicant on the grant and the YAP has been part of the management of the study since the grant was awarded in 2011. Details of the extent of young people’s involvement in BRIGHTLIGHT is provided in reference 11.

Participants and setting

The BRIGHTLIGHT cohort and recruitment methods have been described in detail.¹⁰ In summary, young people were eligible for inclusion in the BRIGHTLIGHT cohort if they were aged 13–24 years, newly diagnosed with any cancer and resident in England at the time of diagnosis. Exclusion criteria included young people who were not capable of completing the survey, if death was anticipated within 6 months and those receiving a custodial sentence. The study was open to recruitment in 109 NHS hospitals of which 97 recruited patients. BRIGHTLIGHT was approved by London Bloomsbury Research Ethics Committee (11/LO/1718) and the Confidentiality Advisory Group (ECC 8-05(d)/2011). Young people gave written consent, while parental consent was obtained for those under 16 years.

Data collection

Young people completed five surveys over 3 years at 6, 12, 18, 24 and 36 months after diagnosis. The first survey was administered by an independent research company through face-to-face interviews in the young person's home using a computer-assisted device. Subsequent surveys were delivered through telephone interview or online. The BRIGHTLIGHT survey consisted of validated questionnaires, and bespoke experience questions designed by young people.^{15–25} The first survey at 6 months after diagnosis contained questions specifically about the place of care. These were included in this survey only because the majority of young people would have complete treatment at this time and we wanted to capture the experiences of the initial acute phase of treatment. This analysis used the two open-ended free-text questions in this first survey which asked:

- ▶ What has been the best thing about your experience of care?
- ▶ And what, if anything, could have been done to improve your experience of cancer care at any stage of your treatment?

Analysis

Free-text comments were analysed using content analysis by two researchers (LAF/RMT), which were checked by a third (LH). Comments were inserted into an Excel file; each comment was assigned a code. These were deductively developed based on the judgement and expert knowledge of TYA services of the researchers. The comment was assigned a second code where the researcher felt the comment encompassed multiple concepts. As a team the codes were grouped into overarching themes, and the codes were renamed as the subthemes.²⁶ Themes were first compared for the whole sample using a pivot table to calculate the frequency of their endorsement. This was done for the themes relating to what participants felt was 'best' about their care, and 'what could be improved'. Themes were then compared between the categories of care. Themes and subthemes were then ranked in order of frequency, ranging from the most endorsed to the

least. Finally, the results were descriptively presented as a narrative comparison.

RESULTS

Of the 830 responses to the survey, free-text comments were provided by 820 (99%; [table 1](#)). The best aspects of care and what could be improved are summarised in [table 2](#). Examining the cohort as a whole, six themes were identified for the best aspects of care: healthcare team, place of care, delivery of care, communication, end of treatment and 'nothing'. This last theme denoted that either there were no best aspects of care or nothing was required to improve care. For areas where improvements could be made, 10 themes were found: diagnostic experience, delivery of care, communication, place of care, healthcare team, food, end of treatment, cost of care, other and 'nothing'. As with the best aspects of care, this last theme denoted that no changes were required to improve care.

Overall, participants felt the best thing about their experiences with cancer care was the healthcare professionals who cared for them. In particular, they highlighted the many ways in which the professionals supported them through a difficult time, and felt they were essential to their experiences. Place of care, delivery of care and communication were subsequently highlighted as important parts of the experience. A small number of patients (n=54) were unable to be assigned to one of the three categories of care. Their comments have been included in the overall rankings of care ([table 2](#)), but they are not included once the sample is divided into NO, SOME or ALL-TYA-PTC.

When asked what improvements could be made, the majority of participants felt that nothing could be improved on, reflecting a positive experience of TYA undergoing cancer care in England. Where improvements could be made, particular emphasis was put on improving the diagnostic experience for young people. Other elements such as improvements to food and cost were mentioned by a minority of participants.

Comparisons between the categories of care

The comparison of experiences according to categories of care is summarised in [table 3](#) and [table 4](#). The subthemes and supporting responses are presented in the online supplemental file 1.

NO-TYA-PTC group

What was best? The NO-TYA-PTC group rated the healthcare team as the best aspect of their care. This reflects relationships with staff which showed kind attitudes and feeling supported and secure in their care.

They were relaxed and jokey/but good at their job and didn't make me feel nervous, so down to earth. Talk to you like they have known you all your lives you aren't just another person coming through the door. Like family. (Female, 19–24)

Table 1 Participant characteristics

Characteristic		Category of TYA care at 12 months from diagnosis				
		All patients n=820	NO-TYA-PTC n=273	SOME-TYA-PTC n=309	ALL-TYA-PTC n=188	
Age at diagnosis (years)	Mean (SD)	20.17 (3.25)	21.08 (2.95)	19.4 (3.4)	20.05 (3.13)	
Gender	Male	452 (55%)	148 (54%)	163 (53%)	108 (57%)	
	Female	368 (45%)	125 (46%)	146 (47%)	80 (43%)	
Ethnicity*	White	723 (88%)	249 (91%)	271 (88%)	160 (85%)	
	Mixed	14 (2%)	4 (2%)	5 (2%)	4 (2%)	
	Asian	60 (7%)	15 (6%)	23 (7%)	19 (10%)	
	Black	14 (2%)	3 (1%)	7 (2%)	2 (1%)	
	Other	9 (1%)	2 (<1%)	3 (1%)	3 (2%)	
Marital status		n=720	n=248	n=260	n=169	
	Married/civil partnership	26 (4%)	9 (4%)	8 (3%)	6 (4%)	
	Cohabiting	93 (13%)	43 (17%)	27 (10%)	18 (11%)	
	Single/divorced	601 (83%)	196 (79%)	225 (87%)	145 (86%)	
Current status	Working full/part time	255 (31%)	125 (46%)	72 (23%)	41 (22%)	
	In education	268 (33%)	58 (21%)	111 (36%)	79 (42%)	
	Other work (apprentice/intern/voluntary)	17 (2%)	6 (2%)	5 (2%)	6 (3%)	
	Unemployed	31 (4%)	10 (4%)	10 (3%)	7 (4%)	
	Long-term sick	126 (15%)	39 (14%)	51 (17%)	31 (16%)	
	Not seeking work	123 (15%)	35 (13%)	60 (19%)	24 (13%)	
	Leukaemia	103 (13%)	18 (7%)	48 (16%)	32 (17%)	
	Lymphoma	266 (32%)	110 (40%)	74 (24%)	70 (37%)	
Type of cancer	CNS	30 (4%)	8 (3%)	8 (3%)	11 (6%)	
	Bone	78 (10%)	7 (3%)	67 (22%)	3 (2%)	
	Sarcomas	49 (6%)	8 (3%)	23 (7%)	13 (7%)	
	Germ cell	153 (19%)	53 (19%)	56 (18%)	30 (16%)	
	Skin	31 (4%)	22 (8%)	1 (<1%)	4 (2%)	
	Carcinomas (not skin)	100 (12%)	41 (15%)	30 (10%)	23 (12%)	
	Miscellaneous specified†	5 (1%)	3 (<1%)	1 (<1%)	1 (<1%)	
	Unspecified malignant	5 (<1%)	3 (<1%)	1 (<1%)	1 (<1%)	
	Location*‡	Birmingham	120 (15%)	41 (15%)	59 (19%)	12 (6%)
		Bristol	89 (11%)	51 (19%)	31 (10%)	4 (2%)
		Cambridge	21 (3%)	12 (4%)	8 (3%)	1 (<1%)
Manchester		72 (9%)	22 (8%)	35 (11%)	9 (5%)	
Merseyside		33 (4%)	13 (5%)	11 (4%)	6 (3%)	
East Midlands		105 (13%)	15 (6%)	24 (8%)	58 (31%)	
Leeds		71 (9%)	19 (7%)	25 (8%)	25 (13%)	
London		163 (20%)	60 (22%)	81 (26%)	10 (5%)	
Newcastle		42 (5%)	12 (4%)	6 (2%)	23 (12%)	
Oxford		16 (2%)	4 (2%)	4 (1%)	7 (4%)	
Sheffield		27 (3%)	6 (2%)	9 (3%)	9 (5%)	
Southampton		61 (7%)	18 (7%)	16 (5%)	24 (13%)	

*Wave 1 data were used with missing values completed using available PHE data.

†Four 'unclassified'—treated in cancer unit but did not have cancer.

‡The TYA-PTC and hospitals linked to the multidisciplinary team at the TYA-PTC; where available based on hospital of diagnosis, for 77 cases based on recruiting hospital.

§

ALL-TYA-PTC, all care in a TYA-PTC; CNS, central nervous system; NO-TYA-PTC, no care in a TYA-PTC; PHE, Public Health England; PTC, Principal Treatment Centre; SOME-TYA-PTC, some care in a TYA-PTC; TYA, teenager and young adults.

Table 2 Ranking of the overall ‘best aspects of care’ and ‘what could be improved’

Aspects of care that could be improved (n)*	Best aspects of care (n)*	Rank
Nothing (216)	Healthcare team (274)	First
Diagnostic experience (121)	Place of care (177)	Second
Delivery of care (116)	Delivery of care (149)	Third
Communication (110)	Communication (139)	Fourth
Place of care (99)	End of treatment (18)	Fifth
Healthcare team (50)	Other (17)	Sixth
Food (27)	Nothing (14)	Seventh
End of treatment (15)		Eighth
Cost of care (8)		Ninth
Other (7)		Tenth

*Number of responses included the theme.

Delivery of care was highlighted as positive, with emphasis on the speed in which it was delivered. In terms of communication, respondents felt they were generally well informed about their treatment by their healthcare team but that it could be improved, and that the healthcare team would generally be available when needed.

They listen to me and have always helped with side effects from reaction to chemo, prescribed drugs. (Female, 19–24)

Despite being ranked second overall (table 2), place of care was mentioned by a much smaller number of participants in this group as their best experience of care to those who had experienced some or all of their care in a TYA. This possibly reflects the prevalence of more age-appropriate care and resources that were made available in TYA-PTCs compared with non-TYA-PTCs, resulting in this group having fewer positive experiences of their place of care in comparison to their peers in the all or some TYA-PTC groups.

They didn't treat me like a child even though I was surrounded by younger children. (Female, 13–18)

What could be improved? The majority of the NO-TYA-PTC group felt that nothing could improve their experiences of cancer care. Where improvement could be made, it was felt there were some incidences of being poorly informed of

their treatment plans by their clinical teams or not feeling as involved as they would have liked, as well as some issues with intrahospital and interhospital communication. Some reported feeling that treatment could be slow but again this was only reported by a few participants.

When I am given my appointments, I would like more information of what the appointment involves. (Male, 19–24)

Improvements in diagnostic experiences were also mentioned as an area of improvement. Two areas highlighted for improvement were the speed of the diagnostic process and communication around the delivery of the diagnosis.

From the beginning it could have been improved that is, my doctors and A&E (accident and emergency) could have done more to get me in hospital quicker and get a quicker diagnosis (Male, 19–24)

Similar to its ranking on what was best about treatment, place of care was ranked low on what could be improved. Again, we theorise that this may reflect the fact the NO group were not as aware of what resources their peers in the other groups had available to them and subsequently had no comparisons.

SOME-TYA-PTC group

What was best? The SOME-TYA-PTC group highlighted the healthcare team that delivered their care as the best part of their care.

The ward is designed for younger people and the nurses they provide are really friendly/they also provide the youth worker who are also good all staff excellent. (Female, 19–25)

Place of care was ranked second, when they experienced age-appropriate care, this was a positive experience, as were the resources which were made available to them in the TYA-PTC. This group generally felt that the delivery of their treatment was to a good standard, communication largely kept them feeling informed and that healthcare teams would be available if they needed them.

Everyone explained everything clearly, they have been understanding and their response has been very effect [sic] and speedy. (Male, 13–18)

Table 3 Comparison of the top themes in the best aspects of care

ALL-TYA-PTC (n)	SOME-TYA-PTC (n)	NO-TYA-PTC (n)	Rank
Healthcare team (61)	Healthcare team (96)	Healthcare team (98)	First
Place of care (51)	Place of care (94)	Delivery of care (66)	Second
Communication (33)	Delivery of care (43)	Communication (54)	Third
Delivery of care (28)	Communication (42)	Place of care (27)	Fourth

ALL-TYA-PTC, all care in a TYA-PTC; NO-TYA-PTC, no care in a TYA-PTC; PTC, Principal Treatment Centre; SOME-TYA-PTC, some care in a TYA-PTC; TYA, teenager and young adults.

Table 4 Comparison of top themes in aspects of care that could be improved

ALL-TYA-PTC (n)	SOME-TYA-PTC (n)	NO-TYA-PTC (n)	Rank
Nothing (53)	Nothing (67)	Nothing (60)	First
Diagnostic experience (40)	Place of care (44)	Communication (44)	Second
Delivery of care (27)	Communication (44)	Delivery of care (41)	Third
Place of care (21)	Diagnostic experience (41)	Diagnostic experience (33)	Fourth
Communication (16)	Delivery of care (37)	Place of care (26)	Fifth
Healthcare team (10)	Healthcare team (19)	Healthcare team (18)	Sixth
Food (3)		End of treatment (10)	Seventh

ALL-TYA-PTC, all care in a TYA-PTC; NO-TYA-PTC, no care in a TYA-PTC; PTC, Principal Treatment Centre ; SOME-TYA-PTC, some care in a TYA-PTC; TYA, teenager and young adults.

What could be improved? Again, quite positively, this group felt there was little that could be done to improve their experiences of care. However, interestingly where improvements could be made, place of care was highlighted with a particular emphasis on age-appropriate care. This likely reflects this group's experience of receiving care between a TYA-PTC and a children's or adult cancer unit. This meant that sometimes they received care which was age-appropriate and at other times, they may not and knowing that more age-appropriate care was available made their experience less positive.

Not being treated with younger children because they are loud and scream a lot. (Female, 13–18)

Communication was also highlighted, which may reflect a lack of coordination in care when delivered across multiple hospitals. Some respondents mentioned that they felt they did not always feel informed about their plan of care and others also highlighted some issues with intrahospital and interhospital communication, which may be as a result of being treated in different hospitals.

Lack of communication between the two hospitals which meant I didn't have any blood tests for some time so they failed to pick up on some changes which were quite important (Female, 19–24)

Similar to the NO-TYA-PTC group, diagnostic experience was highlighted as an area which could be improved but this was not a highly endorsed for the SOME-TYA-PTC group.

...having more knowledge about cancer and young people/ I was told that young people don't get cancer. I had to fight for 5 months for a biopsy. (Female, 19–24)

ALL-TYA-PTC group

What was best? As with the other categories of care, the ALL-TYA-PTC group endorsed the healthcare team who supported them throughout treatment as the best part of their experiences of TYA cancer care. Consistent with the NO-TYA-PTC and SOME-TYA-PTC groups, the healthcare team was felt to be an impregnable element of their care.

Having a clinical nurse specialist to talk to at any time, by phoning mobile on a private number also the staff on the teenage cancer ward were great fun and very welcoming. (Male, 19–24)

Place of care was also highly endorsed by this group reflecting on their experiences of receiving all of their treatment in a PTC. This group highlighted the important elements of age-appropriate care and how much of a positive impact it had on them. Further to this, this group showed that communication with their healthcare team was good for the most part, and the speed at which their care was delivered was likewise good.

The WARD NAME made you feel more comfortable and at home when you attended for treatment (ie, sofas, televisions, activities etc.). The ward staff were very friendly and were there whenever you needed to talk or ask a question. I had bad anxiety about coming to the hospital at any time and the nurses and doctors understood my situation and adapted well to how I wished to be seen/treated. (Female, 19–24)

What could be improved? Again, consistent with the other groups, the ALL-TYA-PTC group overall did not report that much could be done to improve their experiences. Interestingly, improvements in diagnostic experiences were mentioned most frequently by this group. However, difficulties around diagnosis were not just confined to primary care and examples in secondary care were also cited.

Diagnosis could have been given much quicker... the consultant I saw was too laid back and didn't act quickly enough to get me a MRI scan, and I had to wait 2 weeks for a scan. (Male, 19–24)

The speed of the delivery of care was mentioned by a small number of participants which could be improved on, as well as improvements to interhospital communication. Place of care was mentioned as an area for slight improvement, suggesting that even more age-appropriate care should be made available.

During chemo you can sometimes be there all day so perhaps provide things to do for older children. (Female, 13–18)

DISCUSSION

These results go some way to providing a more in-depth understanding of the experiences of young people who have experienced no, some or all TYA-PTC care. The BRIGHTLIGHT cohort were recruited over a decade ago and so provides a snapshot of TYA care in its developing stages. Encouragingly at the time, there was a high level of positivity for cancer services, regardless of whether it was in a TYA-PTC or not. This does not indicate that one is superior to the other, rather it reflects that the majority of young people expressed feelings of satisfaction and gratitude towards the centres in which they received their treatment. This also substantiates quantitative data collected from the cohort at the same time where the majority rated their satisfaction with care as being excellent/good ($n=777$; 94%).¹⁰ Core to these experiences were the healthcare professionals working to support these young people. Previous research has found that young people and their caregivers put great value on having staff who are kind and supportive, with an emphasis on staff who take the time to get to know patients and their families beyond the elements of routine care.²⁷

A primary aim of TYA cancer care is offering services above and beyond cancer treatment, with a particular emphasis on the holistic needs of young patients. Healthcare workers play a pivotal role in this.¹⁹ The environment of care influences the facilitation of healthcare worker holistic competencies.¹⁹ Less frequent exposure to young patients was linked with lower levels of holistic competencies which can be acutely felt by TYA patients.¹⁹ This is particularly salient as evidence suggests that healthcare worker behaviour can have a detrimental impact on young people, particularly when it is perceived as patronising, dismissive, disconnected or apathetic, that is, not age-appropriate.²⁸ Young people did not observe a high incidence of negative experiences with healthcare workers across the three categories of care with improvements in the healthcare team being ranked low among all three categories. This likely indicates that while discrepancies may exist between the level of holistic care young people receive, healthcare worker conduct is a central prevailing impact factor on their experiences of treatment. Our results suggest that at the time of BRIGHTLIGHT recruitment, cancer services in England already exhibited a solid basis on which TYA care could be expanded on.

Interesting differences did emerge between the groups regarding their environments. Place of care was signalled out as an element valued by young people who had access to the TYA-PTC (SOME and ALL groups), with a particular emphasis on age-appropriate care and resources made available to them. This seemed to reflect the value of receiving care in specialist TYA units which were

equipped with a variety of resources for the age group, such as entertainment and socialising areas, specialist staff to interact with such as Youth Support Coordinators and being treated with people their own age. Young people who had some access to the TYA-PTC also reflected a higher need for improvement in terms of place of care, which may highlight the paradox of shared care arrangements, where young people received some care in wards not specifically set up for their age group. It is possible that knowing what was available in the TYA wards made this experience more frustrating for them as there was a lack of consistency in their care, and they advocated for the non-TYA-PTC areas to be improved in terms of age-appropriate facilities and resources. While 85% of participants who had no access to the TYA-PTC made no reference to place of care in either a positive or negative light, this may reflect their lack of awareness of what resource the TYA-PTC centres offer. This is an important outcome to understand further, as the current guidelines advocate for more joint care for TYA cancer patients.²² Nonetheless, the SOME group who experienced this suggested that improvements in age-appropriate care needed to be made in the non-TYA specific wards and have been previously shown to have the lowest quality of life across the three categories of care.¹²

Communication emerged as an area for improvement, more often for young people who had no or some access to the TYA-PTC. Communication has been previously identified in the BRIGHTLIGHT study as an area of core competence for TYA cancer care.⁹ Young people who had no TYA-PTC care felt they were not always well informed about their treatment, compared with those who had all their care in a TYA-PTC who reflected feeling very well informed. The comments from this group also reflected the benefit of having staff available and accessible to them, which echoes the ethos of the TYA-PTC multidisciplinary team being assembled with a variety of TYA specialist staff, which has been widely documented.^{19 29} Young people who had no or some access to the TYA-PTC made mention of the complications which could arise from interhospital and intrahospital communication. Recent findings have advocated for improvements in the links between different services caring for young people with cancer.³⁰ This reflects the complexities of both interdepartmental communication between wards, and the reality of the more complicated levels of communication between hospitals.

For young people who were receiving SOME-TYA-PTC care again, this showed some of the difficulties which might be associated with navigating care between hospitals. As a core competency, the importance of communication has been clearly demonstrated in other studies.^{29 19 28} Much in the way that age-appropriate care is fostered by environment, this may also suggest that communication is influenced by place of care.¹⁹ Less exposure to young people and their needs can hinder healthcare workers' abilities to communicate with them appropriately, which may be reflected in the need for improvements advocated

by young people who had no or some TYA-PTC care. Staff working in a TYA-PTC were therefore likely to have more access to support continued education around communication and supporting young people than those where services follow more adult and paediatric models of care.³¹ Again, this suggests that even in the early stages of service development, communication was likely influenced by placement in a specialist service. Given that communication is a core competency for TYA care we can also theorise that this has continued to benefit young people who had all their care in the TYA-PTC as culture has developed. Understanding the development and improvement in communication in other places of care will therefore be pertinent to measure to ensure equitable access of care for young people.

Finally, diagnostic experiences were highlighted as an overall area in need of improvement across the three categories of care, particularly those who received all their care in a TYA-PTC. The timeliness of diagnosis was an area that many participants felt needed improvement as well as communication of the diagnosis. Participants expressed that they felt the route to diagnosis had been long and difficult, and often found fault in the ways that healthcare workers interacted and communicated with them at the start of this process. Similar to other studies, many felt that their General Practitioner had not recognised the severity of their symptoms, not listened and time had been lost on referring them for further testing. Comparable to other studies, negative diagnostic experiences were also encountered in secondary care.³² Improving the diagnostic experience is particularly challenging and multifactorial, which includes public and professional lack of awareness of the types of cancer common in TYA and potential signs and symptoms of cancer in this particular age group. Many studies now have identified the timeliness of cancer diagnosis as a particular problem for TYA.³²⁻³⁴ We have also identified that TYA with longer routes to diagnosis were more likely to report lower quality of life and be clinically anxious or depressed at 6 months following diagnosis,^{33 35} and therefore, identifying and testing interventions that expedite the time to diagnosis and optimise communication around the time of diagnosis is a research priority. When looking at the cohort as a whole, improving diagnostic experiences was cited as area which needs most improvement, although this differs by category of care. Improving the diagnostic experience is frequently highlighted as a research priority nationally and internationally, although the solutions and interventions are not easily identified as yet.³⁶

An important consideration of these findings is the time which has elapsed since the BRIGHTLIGHT data were collected. During 2012–2014, TYA services were still in development. A study into the TYA culture of care alongside BRIGHTLIGHT has shown that it takes time and resources for TYA services to actualise.²³ Though it takes time for this culture to evolve, once in place, it was shown to have significant impacts on young people's experiences of care.²³ This mirrors the importance of

holistic competencies of healthcare workers being underpinned by the right environment.¹⁹ Important too for the development of services is TYA clinician leadership and high volume of young people, both of which may be lacking in hospitals where young people are treated less frequently across child and adult wards, as seen with the NO-TYA-PTC and SOME-TYA-PTC groups.²³

Funding for specialised TYA services is necessary for their continuation, but to support this, it is important to show the value of these services and the care provided over and above standard cancer care. The BRIGHTLIGHT study was the first attempt to evaluate TYA services and outcomes in England.¹¹ The implications from the culture of care study within BRIGHTLIGHT suggest that time is an important ingredient for the benefits of specialist services to become apparent. Given the high value assigned to place of care by young people who had access to the TYA-PTC (ALL and SOME groups) in these early stages of service development, one could theorise that advancements in TYA care will have continued to improve their experiences since BRIGHTLIGHT first began. While treatment in a TYA-PTC did not initially appear to improve quality of life at 6 months after diagnosis, faster rates of improvement were observed in TYA receiving all their care in the TYA-PTC, with those in the SOME-TYA-PTC group having lower quality of life throughout the study trajectory. One explanation for this could be due to the embryonic status of some TYA services in England at the time of data collection. It is possible that the culture of care had not had time to evolve, and subsequent studies have repeatedly shown the worth of being treated in specialist age-appropriate care.^{31 37} New cohort data are being collected through BRIGHTLIGHT and comparisons on the value of place of care will therefore have important implications for the future of specialist TYA care.

This study has several limitations. As previously mentioned, BRIGHTLIGHT data reflect a service configuration almost a decade ago and does not reflect the evolution of TYA care observed in England over the past decade. The study also recruited approximately 20% of the diagnosed population during that time. Additionally, there has been some debate around the classification of specialist care which was first used to define the three groups in the BRIGHTLIGHT study. This has been extensively discussed.^{12 13} Second, some of the themes were only expressed by a minority of young people, though these have not been included in the overall rhetoric of this paper (ie, cost of care, n=8). We could not assign category of care to 54 young people and could this have altered the final rankings when comparing between groups. Finally, some of the free-text comments lacked context from which we could gain full insights into the young person's perspective. Despite these limitations, a key strength of the study is the free-text comments were spontaneous responses from young people, which gave us unbiased glimpses into their circumstances. This is particularly interesting as it captures a timepoint in which

they were actively dealing with diagnosis and treatment and provides unfiltered real-time thoughts, providing an insight into these important early experiences of care. Another important strength of this paper is that its findings resonate with multiple other papers within the BRIGHTLIGHT continuum, drawing a more substantial link between these different aspects of the programme of evaluation.¹¹

CONCLUSIONS

The analysis of the free-text comments from the first collection of BRIGHTLIGHT data paints an interesting but ultimately positive view of cancer services for this age group in these early stages, which may act as an indicator of the direction services were heading at this time. This study also has interesting implications for the implementation of the proposed 'joint care' and adds to the suggestion that creating environments infused with further elements of age-appropriate care for the TYA cohort, regardless of status as a TYA-PTC or not, would be highly beneficial.^{18–29} Access to a multidisciplinary team highly trained in working with this age group was another area which shows the benefit of receiving care in a TYA environment. Furthermore, this has the potential to improve the psychosocial development of these young people, being treated with others closer to their own age and in similar circumstances, as this is an area of concern which continues to go unmet.⁴ Improving the diagnostic experience of TYA remains challenging and research identifying effective interventions are needed across the diagnostic pathways. Healthcare professionals working in cancer care, regardless of TYA-PTC status, should be commended and celebrated for the amazing work they do. BRIGHTLIGHT is currently gathering new prospective data to compare with these previous findings, which hopes to further shed some light on the development and growth of TYA services over the last 10 years.

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Acknowledgements We would like to thank the 1114 young people who consented to participate in BRIGHTLIGHT and the healthcare professionals who recruited them. We would also like to thank our Young Advisory Panel (YAP) for their ongoing input to study design and interpretations. The BRIGHTLIGHT study group comprises: Javier Alvarez-Galvez, Julie Barber, Richard Feltbower, Faith Gibson, Louise Hooker, Sarah Lea, Nishma Patel, Rosalind Raine and Dan Stark.

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Contributors JW, RMT and LAF were involved in developing the protocol; RT coordinated the running of the study and was responsible for data acquisition; RMT, LAF and LH contributed to the analysis; RMT, LAF and LH drafted the manuscript. All authors have read and agreed to the published version of the manuscript. The BRIGHTLIGHT study group was part of the conceptualisation of the BRIGHTLIGHT programme grant, where these data were generated. JSW, RMT and LAF are responsible for the overall content as the guarantor.

Funding This paper presents independent research funded by the National Institute for Health and Care Research (NIHR) under its Programme Grants for Applied Research award (Grant Reference Number RP-PG-1209-10013). RMT is partially funded through UCLH Charity and LAF is funded by Teenage Cancer Trust. The views expressed are those of the author(s) and not necessarily those of the

NIHR, the Department of Health and Social Care, UCLH Charity or Teenage Cancer Trust.

Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not required.

Ethics approval This study involves human participants and was approved by London Bloomsbury Research Ethics Committee (11/LO/1718) and the Confidentiality Advisory Group (ECC 8-05(d)/2011). Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement All data relevant to the study are included in the article or uploaded as supplementary information.

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