



**London South Bank
University**

Mapping teenage and young adult cancer services in England: the **BRIGHTLIGHT** Directory of Care

Final report

In 2013 we carried out a study in 11 of the 13 Teenage and Young Adult Principal Treatment Centres in the U.K.

The Mapping teenage and young adult cancer services in England study sought to provide an overview of the way care is organised across different PTCs. Each PTC and its network of care have unique clinical configurations of care, and are set within different socio-geographical contexts. Through a collaborative method involving a researcher spending from one to three days in each PTC a detailed understanding of service delivery in each PTC was obtained. The researcher interviewed healthcare professionals, young people, and their family members, carried out observations on the units, and used photography and other artistic techniques with young people to create maps of their care.

The main goal of this study was to inform the selection of five sites for a future study titled The Culture of TYA Care across Five PTCs and their Networks: BRIGHTLIGHT Case Study. This study is part of a National Institute for Health Research (NIHR) funded programme of work evaluating TYA care in England (RP-PG-1209-10013) and will commence in 2014.

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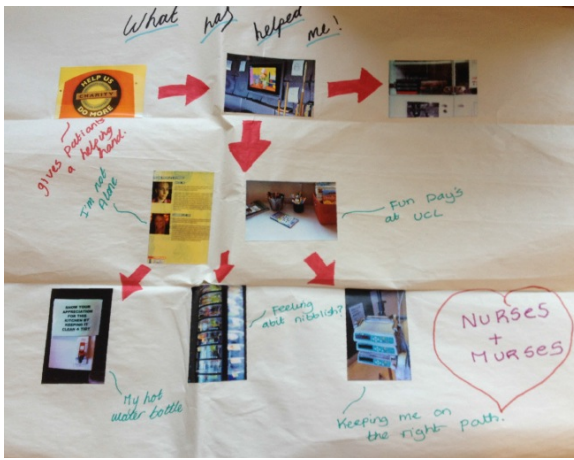
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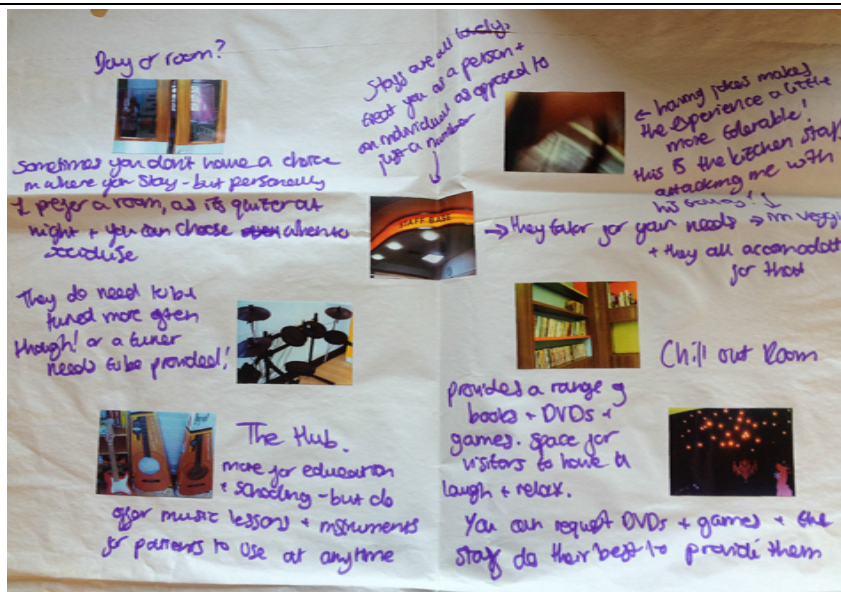


"You are treated as a person, as opposed to a patient" (young person).

Cancer accounts for 11% of deaths in teenagers and young adults (TYA) aged 15 – 24 and after accidental death is the highest cause of mortality (Birch et al. 2008; Whelan and Fern 2008). Concern has arisen that this population is currently being inadequately served by cancer services. In recent years there has been a rapid expansion in the availability of dedicated services for TYA in the United Kingdom and in 2005 the National Institute for Health and Clinical Excellence (NICE) published the *Improving Outcomes Guidance (IOG)* that acknowledged TYA as a group distinct from younger children and older adults (National Institute for Health and Clinical Excellence 2005).

Specialist care in England is centred in 13 principal treatment centres (PTC); key components should be tumour site-specific expertise delivered in conjunction with meeting the broader psychosocial needs of young people to support

successful navigation of critical life transitions. While policy directs patients towards treatment in specialist TYA cancer services there is national variation in access and delivery. Cancer registries indicate that only approximately 50% diagnosed since 2009 have been referred to a PTC for discussion by a TYA multi-disciplinary team (O'Hara, Moran, Whelan, *unpublished*). Young people are therefore receiving care in a range of environments including: designated 'shared care' centres (usually a local hospital, where acute complications of treatment are managed); and other children's and adult services.



“I have said everything they offer you, it does benefit you”
(young person).

Aim of the study

The study sought to describe where TYA care is delivered, who delivers it and how it is delivered, in each PTC.

Study objectives

- To understand the geographical layout of the TYA unit in each PTC;
- To catalogue key weekly events within each PTC as described by health professionals;
- To catalogue key weekly events within each PTC as described by young people;
- To identify other areas within each Trust that deliver care to young people;
- To identify healthcare providers external to the host Trust, within the network of the PTC who provide care for young people;
- To define the roles of external organisations providing care;
- To create a framework for the systematic selection of case study sites.

Study design

This was a mixed-methods design that combined observations, interviews, and the Mosaic method (photography and drawing) (Clark and Moss 2011).

Research methods

Semi-structured, open-ended interviews were carried out with healthcare professionals, young people, and their family members. We asked young people to photograph the helpful and unhelpful parts of the unit and draw a map of their care. The researcher also carried out observations on the wards.

Sample

A convenience sample of young people, family members and staff in each PTC were invited to participate. The researcher aimed to recruit 3 young people, 3 family members, and 3 staff members in each PTC. The total number of recruited participants was:

- 21 young people
- 15 family members
- 34 staff members

Setting

The study was carried out in the following PTCs:

- Addenbrookes Hospital, Cambridge
- Bristol Haematology and Oncology Centre, Bristol
- Clatterbridge Centre for Oncology, Merseyside
- Nottingham City Hospital, Nottingham
- Queen Elizabeth Medical Centre, Birmingham
- Southampton

General Hospital, Southampton

- St. James' University Hospital, Leeds
- The Christie Hospital, Manchester
- The Royal Marsden Hospital, Sutton
- University College Hospital, London
- Weston Park Hospital, Sheffield

Data analysis

Notes taken of the observations were typed and digital recordings transcribed verbatim. Qualitative content analysis was used initially at PTC level to describe care from young person, family and health professional perspective and at a later stage to compare these perspectives across PTCs.

This data were summarised in tables describing each site and a panel of experts used an evaluation form to select the sites that will be included in the future case study.

Findings

The young people and family members were asked to list the things that had been helpful during their care and those that had been unhelpful and needed improvement. There were some issues that were only relevant to particular PTCs, but in Table 1 we have summarised the helpful and unhelpful aspects that were shared across most sites.

"Sometimes there are people who don't really see why young people need a different approach so there are quite a lot of challenges out there to help people and convince them that this is the best thing for young people" (staff member).

Table 1. Helpful and unhelpful aspects of care identified by young people and their family members

Interviewee	Helpful aspects	Unhelpful aspects/need improvement
Young people	Caring staff Recreational activities Chill out room Internet access Television, computers, games Teachers Youth support coordinators	Shared rooms Hospital food No places outside (i.e. gardens) Long waiting times Waiting room in outpatients Noise
Family members	Caring staff Kitchen Private bedrooms Social worker Facilities to stay overnight Individual rooms Lounge/social areas	Shared rooms Shared toilets Hospital food Delays with pharmacy

The members of staff also identified helpful aspects of their daily work and challenges that still remain.

Table 2. Helpful aspects and challenges identified by staff

Helpful aspects	Challenges
Strong MDT/regular meetings	Staff shortage/burnout
Outreach model	Late effects
Team spirit/work	Keeping TYA on everyone's agenda
Combination of paediatric and adult nurses	No specific TYA facilities/working between multiple sites
TYA input	Expanding service and patient population
Family centred care	Lack of TYA staff (youth support coordinator, psychologist)
Facilities that feel like home	Lack of TYA training
Good communication with other hospitals	Non-believers of TYA services
	Extensive geographical coverage
	Transition

“The thing that I find the most useful is that you have got a space that you can bring your friends into” (young person).





"Sometimes what is on the menu when it comes, it looks totally different. [...] Like yesterday it looked miserable, so she didn't eat it" (parent).

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Conclusions and next steps

Each PTC had a unique environment, history, structure, and patient population that influenced the care delivered to young people and their families. In general, young people and family members indicated that they were satisfied with the care they had received. The staff and facilities were selected as the most helpful aspects of their care while the shared rooms and hospital food were identified as the least helpful.

The staff members pointed to particular areas of providing TYA services that they find helpful such as consistent MDT meetings and good outreach models. Even though several units have been operating for several years, many staff members still find TYA care challenging due to staff shortages, lack of recognition of the

importance of TYA services or an expanding service.

Our next step will be to create a taxonomy of TYA care which will be made available at the end of 2014. We will also start a more detailed study of 5 PTCs titled The Culture of TYA Care across Five PTCs and their Networks: BRIGHTLIGHT Case Study in January 2014.

References

- Birch, J.M., Pang, D., Alston, R.D., Rowan, S., Geraci, M., Moran, A., and Eden, T.O.B. (2008) 'Survival from cancer in teenagers and young adults in England, 1979-2003'. *British Journal of Cancer*, vol. 99 (5), pp. 830-835.
- Clark, A. & Moss, P. 2011. *Listening to Young Children: The Mosaic Approach*, Second ed. London, National Children's Bureau.
- National Institute for Health and Clinical Excellence (NICE) (2005) *Guidance on cancer services: Improving outcomes in children and young people with cancer*. London, UK: NICE, NHS.
- O'Hara, C.H., Khan, S., and Platt G. (unpublished). 'How many teenagers and young adults with cancer are being referred to specialist care in England?' Poster.
- Whelan, J. & Fern, L. 2008, "Cancer in adolescence: incidence and policy issues," *In Cancer care for adolescents and young adults*, D. Kelly & F. Gibson, eds., Oxford: Blackwell.