

Institution: University of Leeds		
Unit of Assessment: 1		
Title of case study: Specialist cancer services improve outcomes for Teenagers and Young Adults with cancer		
Period when the underpinning research was undertaken: 2001-2014		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Adam Glaser	Professor of Paediatric Oncology and Late Effects	2015-present
Dan Stark	Professor of Teenage and Young Adult Cancer research	2003-present
Sue Morgan, MBE	Nurse consultant in Teenage and Young Adult Cancer care	Leeds Teaching Hospitals NHS Trust 1994-present
Richard Feltbower	Senior Lecturer in Epidemiology	1998-present
Ian M Lewis	Professor of Paediatric and Adolescent Oncology	NHS consultant Leeds, then University of Leeds 1986-2011
Period when the claimed impact occurred: 2013-2020		
Is this case study continued from a case study submitted in 2014? N		
1. Summary of the impact (indicative maximum 100 words) <p>Our research (2001-2020) identified poor treatment outcomes for cancer in Teenagers and Young Adults (TYA), aged 13-24, because of the non-specialised NHS system for treating patients in this group. Our research substantiated new NHS policy in 2005 that introduced specialised TYA cancer services. From 2016 onwards, our work led to gradual improvement in the health outcomes for TYA.</p> <p>Specialised treatment, designed for TYA as an age group, has significantly increased survival rates for TYA cancer patients, improved their quality of life and satisfaction with care received. Independent epidemiological data, citing our research, and national prospective cohort studies, designed using our research methodology, have demonstrated this impact. NHS specialised services now reach 1,400 TYA in the UK annually.</p>		
2. Underpinning research (indicative maximum 500 words) <p>TYA develop a specific spectrum of rare cancers. Before 2001, treatment outcomes for TYA were static or deteriorating, while contemporaneous children's and older adults' outcomes were rapidly improving. Cancer services and clinicians typically focused upon cancer by type, and TYA were expected to fit into services created for pre-pubertal children or much older adults. Therefore, in the UK, TYA patients were allocated in haphazard locations, separately from other TYA, contributing to poor outcomes. For example, if two 17-year olds presented with the same cancer while living on the same street, one could be cared for alongside 5-year olds and the other alongside 75-year olds.</p> <p>In 2001, our group undertook original research to identify and characterise the causes of poor</p>		

cancer treatment outcomes for TYA. We uncovered what should be in place to improve outcomes, and how outcomes should be evaluated. For the first time, our epidemiological research showed that high death rates were not entirely explained by traditional predictors; such as size and type of cancer [1]. The causes of poor treatment outcomes were non-specialist clinical skills, unsuitable treatment environments for TYA, and geographical dispersal of diagnostic and treatment processes. Patients treated in facilities with specialised services had 11% better cancer survival and greater receipt of standard treatments. The needs of TYA are specific to them, different to those of other age-groups in terms of drug prescription, psychological response, and the built environment for care. Therefore, the type of cancer service seemed to be an important determinant of the outcome.

We established the first dedicated population-based register for TYA to record cancer outcomes, the Yorkshire Specialist Register of Cancer in Children and Young People. Our unique Register covers all cancer diagnoses between age 0-29 years in Yorkshire, enabling in-depth assessment of trends in treatment and outcome for 10,700 children and TYA. The Register provides a platform to develop research methods, provide accurate timely data and define cancer outcomes (Principal Investigator: Dr Feltbower, Medical Director: Professor Glaser). Drs Feltbower and Stark conducted extended national cancer epidemiology studies in TYA, to map the evolving patterns of care and outcomes based on the hypothesis that change in NHS services would improve outcomes for TYA [2, 3]. Some TYA had patterns of lower survival, which originated from poorer quality of care; particularly for certain cancer types which were mainly managed in local non-specialised hospitals.

In 2005, NICE published guidance for improving patient outcomes, citing our research, with national reach [1]. The guidance defined both the requirement and nature of new specialist cancer services for TYA. Original epidemiology led in Leeds, quantified the gradual evolution in specialised care across England [4]. The odds of receiving care within a specialist service were identified at 35% for all geographical areas; varying from 22% to 72% [4]. Early trends towards increased specialisation in some cancer types were observed. Specialisation in treatment was associated with improved survival. Patients who were treated in specialised TYA centres were less likely to die than those treated in other centres [5]. From 1998-2009, care for TYA with leukaemia outside of specialised care was associated with a 1.73-fold increase in risk of death. Smaller effects were observed in patients with lymphoma and central nervous system tumours [4, 5]. The advantage gained by receiving TYA specialised care was not due to differences in the clinical measures of the severity of the leukaemia.

We developed an original method to quantify the amount of specialised cancer care received by an individual TYA patient, using NHS data [4]. We then studied the impact of this, using the methods developed in the Register, by examining relations between causes and effects. This was conducted under the BRIGHTLIGHT prospective national cohort study, during the period 2011-2019, for which Feltbower and Stark were Co-Investigators. BRIGHTLIGHT shows how NHS results changed after the application of the NICE guidance. The first results paper shows the impact of this research [6].

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

1. Wilkinson JR, **Feltbower RG**, **Lewis IJ**, Parslow RC, McKinney PA (2001). Survival from adolescent cancer in Yorkshire, UK. *Eur J Cancer*. 37(7):903-11.
DOI: [10.1016/s0959-8049\(01\)00012-0](https://doi.org/10.1016/s0959-8049(01)00012-0)
Evidence why the NHS served TYA with cancer poorly, due to place of care. Cited in the evidence review for the 2005 NICE Improving Outcomes Guidance for children and young adults with cancer (see corroboration of impact), and in the French, Portuguese, and Japanese TYA cancer care literature.
2. O'Hara, Moran, Whelan JS, Hough RE, Stiller CA, Stevens MC, **Stark DP**, **Feltbower RG**, McCabe MG (2015). Trends in survival for teenagers and young adults with cancer in the UK 1992-2006. *Eur J Cancer*, 51(14), 2039-2048. DOI: [10.1016/j.ejca.2015.06.112](https://doi.org/10.1016/j.ejca.2015.06.112)

The baseline outcomes and their change over time, until the policy change at NICE

3. **Stark DP**, Bowen D, Dunwoodie E, **Feltbower RG**, Johnson R, Moran A, O'Hara C (2015). Survival patterns in teenagers and young adults with cancer in the United Kingdom: Comparisons with younger and older age groups. *Eur J Cancer*, 51(17), 2643-2654. DOI: [10.1016/j.ejca.2015.08.010](https://doi.org/10.1016/j.ejca.2015.08.010)

The baseline outcomes and their comparators with other age-groups of cancer patients, until the policy change at NICE

4. Birch RJ., Morris EJA, **Stark DP**, **Morgan S**, **Lewis IJ**, West RM, & **Feltbower RG** (2014). Geographical factors affecting the admission of teenagers and young adults to age-specialist inpatient cancer care in England. *J Adolesc Young Adult Oncol*. 3(1):28-36. DOI: [10.1089/jayao.2013.0016](https://doi.org/10.1089/jayao.2013.0016)

The trends in patient care since the NICE improving outcomes guidance, 2005, on the pathway to our impact

5. Fairley L, **Stark DP**, Yeomanson D, Kinsey SE, **Glaser AW**, Picton SV, **Feltbower RG** (2017). Access to Principal Treatment Centres and survival rates for children and young people with cancer in Yorkshire, UK. *BMC Cancer*, 17:168. DOI: [10.1186/s12885-017-3160-5](https://doi.org/10.1186/s12885-017-3160-5)
Specialised TYA services improve leukaemia survival in Yorkshire.

6. Taylor RM, Fern LA, Barber J, Alvarez-Galvez J, **Feltbower R**, Lea S, Martins A, Morris S, Hooker L, Gibson F, Raine R, **Stark DP**, Whelan J (2020). Longitudinal cohort study of the impact of specialist cancer services for teenagers and young adults on quality of life: outcomes from the BRIGHTLIGHT study. *BMJ Open* 2020;10:e038471. DOI: [10.1136/bmjopen-2020-038471](https://doi.org/10.1136/bmjopen-2020-038471)

This has received a Research Award by the National Institute for Health Research (NIHR). Programme duration 2011-2019. Data were collected for the period 2013-2017.

Award ID: RP-PG-1209-10013 for BRIGHTLIGHT. Results to be published into 15 papers.
<https://www.fundingawards.nihr.ac.uk/award/RP-PG-1209-10013>

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

Improvements in cancer death rates and quality of life for TYA

In 2005, research from Leeds was influential in the development of NICE guidance for improving cancer outcomes [A]. There are 1,400 TYA diagnosed annually across various types of cancer in England. In 2019, NHS England published data comparing death rates for TYA between 2001 and 2013. Reductions in mortality have been revealed despite an increase in cancer incidence from 240 to 300 per million population (pmp). In 2001, the mortality for TYA was 44 pmp. In 2007, only 2 years after NICE guidance implementation, mortality was reduced to 42. Finally, in 2013, it was reduced to 32, resulting to a total of 27% reduction.

The BRIGHTLIGHT cohort study, to which the Leeds research team contributed key underpinning methods, reached over 1,200 TYA with cancer in over 100 NHS trusts in England between 2013 and 2017. Analyses indicate a significant positive impact from receiving specialised TYA cancer care [B]. We observed improved metrics of care quality:

- 78% had multi-disciplinary team involvement in specialised care compared to 50% in non-specialised care;
- 44% of the TYA in specialised care who could benefit had their cancer precisely defined by contemporary molecular techniques compared to 22% in non-specialised care;
- 60% were assessed by rehabilitation services compared to 38%;
- 73% of females received future fertility care compared to 43%.
- On a 0-100 score, where 0 is poorest quality of life, patients receiving specialist cancer care improved by 15 points over 3 years, whereas those with no specialised care improved by 10 points. The patients treated in specialised care were also more severely unwell at the outset. A similar pattern of improved psychological morbidity was observed.

Internationally, cancer survival analyses have started to indicate the impact of our work. In the Nordic countries, Rostgaard *et al* have widely cited the application of our work, and analysed Nordic cancer registers to examine cancer survival for TYA. In 1999, cancer survival was 58%. In 2013, this increased to 77% survival [C].

Impact upon clinical services and corresponding patient confidence

United Kingdom

The impacts since 2013 upon outcomes are mediated by changes within the 2005 NHS policy. Wilkinson *et al* [1] was cited within the NICE policy document (2005), mandating the creation of specialist cancer services for TYA within the NHS, and specifying the features of this specialised care [D]. These services were gradually embedded within the NHS after 2005.

In 2001, there were 5 TYA cancer services in the world; one of which was in Leeds. By 2018, these increased to 26 in the UK due to our collaborative efforts. An independent patient experience analysis of surveys by Furness *et al*, using data from all TYA with cancer in England, demonstrated that TYA have more confidence in their care in specialised units [E]. Moreover, improvement in satisfaction with care was revealed.

International Reach

There are indications that the process of specialisation in the UK is also improving cancer services internationally. Lewis was Co-Chair of Clinical Care Models within the US National Institutes of Health, National Cancer Institute and US Department of Health for Adolescent and Young Adult (AYA). This formed a Progress Review Group in 2006, which discussed the need for treating AYAs as a distinct group with special needs for clinical care and psychosocial support services. An infographic from Lewis' research entitled 'Key Elements of Patient-Centred Pathway' was used to drive the panel's discussion on the definition of a new model of care. The outcomes were published in the Report "Closing the gap: Research and care imperatives for adolescents and young adults with cancer. Report of the Adolescent and Young Adult Oncology Progress Review Group", whereby three main priorities were identified to promote a consistent standard for delivery of care to the AYA population [F]. This report led to the creation of a workshop, sponsored by the American National Cancer Institute, entitled "Next Steps in Adolescent and Young Adult Oncology" which determined key decisions around AYA specialist care [G]. These resulted in creating more AYA specialist clinical teams within US hospitals. By 2020, AYA specialist clinical teams were established within 42 US hospitals [H] compared to 2 hospitals up to 2012.

Stark and Lewis led the TYA cancer research within the EU-FP7 European Network for Cancer in Children and Adolescents, for the period 2011-2016 [I]. The network began with only 10 people working just in the UK, France and Germany, and received funds from the European Union to bring specialists together to achieve a shared understanding in treating TYA. By the end of 2016, the network consisted of approximately 350 people and had members from all but two EU nations. Since 2013, clinical networks of specialist TYA cancer wards were founded in 5 further regions of France, and entirely new networks and services were dedicated to TYA within the national Cancer Plans of Netherlands, Denmark and Eire.

Stark and Lewis were the invited international keynote speakers for the inauguration policy forum between the German adult and paediatric cancer societies in 2013. Their involvement resulted in the establishment of a new professional transition group; the Arbeitsgemeinschaft Adoleszenten junge Erwachsene. Stark was also an invited expert by the Indian Cancer Services in 2017, and his role was key for their launch of specialist TYA services [J].

Impact on international professional education

Stark is an inaugural member of the Adolescent and Young Adult education committee, jointly run by the European Society of Medical Oncology (ESMO) and Societe Internationale Oncologie Pediatrique European (SIOPE). He was a keynote speaker at the first ESMO medical training

course on TYA oncology in 2018. His lectures addressed 39 oncology specialists from 18 nations for a Europe-wide professional certification and received excellent feedback. Delegates responded that following this course, they would change the selection of treatment for TYA, include multidisciplinary team advice, provide TYA specific psychological support and introduce improved patient assessments [K].

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

A. Letter from Teenage Cancer Trust corroborating the role of the Leeds group in the impacts evidenced in the NHS England report (2019), which indicated improved TYA cancer outcomes including survival comparing before the 2005 NICE Improving Outcomes Guidance to since 2013.

B. Taylor RM, Fern LA, Barber J, Alvarez-Galvez J, **Feltbower R**, Lea S, Martins A, Morris S, Hooker L, Gibson F, Raine R, **Stark DP**, Whelan J (2020). Longitudinal cohort study of the impact of specialist cancer services for teenagers and young adults on quality of life: outcomes from the BRIGHTLIGHT study. *BMJ Open* 2020;10:e038471.

DOI: [10.1136/bmjopen-2020-038471](https://doi.org/10.1136/bmjopen-2020-038471)

C. Rostgaard K, Hjalgrim H, Madanat-Harjuoja L, Johannesen TB, Collin S, Hjalgrim LL (2019). Survival after cancer in children, adolescents and young adults in the Nordic countries from 1980 to 2013. *Br J Cancer*. 121(12):1079-1084. DOI:[10.1038/s41416-019-0632-1](https://doi.org/10.1038/s41416-019-0632-1)

D. NICE Guideline Improving outcomes in children and young people with cancer 2005

<https://www.nice.org.uk/guidance/csg7>

Second Consultation Version Feb 2005 (page 146)

E. Furness C, Smith L, Morris E, Brocklehurst C, Daly S, Hough RE (2017). Cancer patient experience in the teenage young adult population — key issues and trends over time: An analysis of the United Kingdom. National Cancer Patient Experience Surveys 2010–2014. *Journal of Adolescent and Young Adult Oncology*. 6 :450-458.

DOI: [10.1089/jayao.2016.0058](https://doi.org/10.1089/jayao.2016.0058)

F. Closing the gap: Research and care imperatives for adolescents and young adults with cancer. Report of the Adolescent and Young Adult Oncology Progress Review Group (Appendix B-23)

G. Smith AW, Seibel NL, Lewis DR, *et al* (2016). Next steps for adolescent and young adult oncology workshop: An update on progress and recommendations for the future. *Cancer*, 122(7): 988–999. DOI: [10.1002/cncr.29870](https://doi.org/10.1002/cncr.29870)

H. Testimonial letter from Executive Director from Teen Cancer America about Progress Review Group underpinning the increase in AYA specialised services in the USA.

I. European Network for Cancer research in Children and Adolescents Final Report Summary and paper: Stark D, Bielack S, Brugieres L, *et al* (2016). Teenagers and young adults with cancer in Europe: From national programmes to a European integrated coordinated project. *European Journal of Cancer Care* 25, 419– 427. DOI:[10.1111/ecc.12365](https://doi.org/10.1111/ecc.12365)

J. Testimonial letters from Head AjeT Group of German Transition Group and Organising Secretary of TYACON 2017, TYA cancer society in India.

K. Feedback from ESMO medical training course. <https://oncologypro.esmo.org/meeting-resources/esmo-preceptorship-on-aya-malignancies-lugano-may-2018>