

# Yorkshire Specialist Register of Cancer in Children and Young People

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<b>Dr RG Feltbower*</b>	Senior Lecturer in Epidemiology University of Leeds
<b>Dr RC Parslow</b>	Senior Lecturer University of Leeds
<b>Mr D Batty</b>	Data Manager

University of Leeds  
**\*Address** School of Medicine/Leeds Institute for Data Analytics, Room 8.49,  
Worsley Building, Clarendon Way, Leeds LS2 9JT.  
**Tel/Email** 0113 343 4842, r.g.feltbower@leeds.ac.uk

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APPENDIX I\*: DATA COLLECTION FORM

APPENDIX II\*: INFORMATION LEAFLET FOR PATIENTS

\*Attached as separate pdf documents

## **Abstract**

Cancer is a rare disease in children and young people and one that places a considerable burden not only upon the patients themselves but also on their families and the health care system. Little is known about the causes of malignant conditions in this young age group. The Yorkshire Specialist Register of Cancer in Children and Young People is an established population-based register of tumours diagnosed in the childhood, adolescent and young adult age ranges. The Register currently contains information on 10,500 young people diagnosed with cancer while living within the former Yorkshire Regional Health Authority. Data on children under 15 years has been collected since 1974, whilst data accrual for 15-29 year olds began in 1990.

The primary aim of the Register is to investigate the causes of cancer through the application of epidemiological analyses. This includes monitoring time trends and investigating geographical patterns of disease across the region. Secondly, our aim is to investigate the delivery of care to young people with cancer in Yorkshire to ensure the best treatment is available and to minimise long-term health and social effects; for example by looking at pathways of care, factors that influence survival and minimise long-term complications. The Register data are also available to ensure optimum planning of cancer services for children and young people in the region and to provide clinicians with an information service on their patients. To undertake this, the Register will continue to collect complete and accurate information on a prospective basis.

Funding for the project has been provided by the Leeds Candlelighters' Trust since 1984 and most recently by the Laura Crane Youth Cancer Trust since 2017.

## 1. Aims of the Register

The work of the Register falls into three main areas, the aims of which are

- To investigate the causes of cancers in children and young people through comprehensive epidemiological and molecular analyses describing patterns of cancer incidence. This includes investigations of the effects of environmental factors and population characteristics such as deprivation, ethnicity and other socio-demographic variables that might explain any differences in incidence rates. The timing of exposure to these potential risk factors, which may influence the onset of disease, is considered from the time of conception up to diagnosis.
- To investigate the delivery of care to young people with cancer in Yorkshire to ensure the best treatment is available; for example by looking at pathways of care and factors that might influence survival and minimise long-term complications.
- To help inform the planning of cancer services for young people in the Yorkshire Region and to provide clinicians with relevant and timely information about their patients.

In order to achieve the above aims the Register needs

- To continue to collect complete, accurate and timely population-based data on children and young people diagnosed with malignant disease whilst resident in the Yorkshire and the Humber Strategic Health Authority.
- To continue to monitor the cohort through follow-up of all patients, ascertained through notifications from Public Health England via data held on the National Cancer Registration and Analysis Service (NCRAS). This enables us to carry out relevant survival analyses.
- To make use of other routine health related databases such as Hospital Episode Statistics, primary care data and hospital data from long term follow-up clinics to facilitate research into health care pathways pre and post cancer diagnosis and describe the prevalence of late health effects of treatment.
- To make use of other non-health related datasets to examine social outcomes following childhood and young adult cancer. Examples of social outcomes will include a) educational performance derived from the National Pupil Database, Individual Learner Record and Higher Education Statistics Authority; b) employment and welfare support information through the Department for Work and Pensions.

- To provide an information service for local clinicians and to advocate the use of the Register in health services research projects across Yorkshire in collaboration with regional consultants.

## **2. Background**

Cancer in children and young people is extremely rare and different to that found in adults (1). Despite wide-ranging research over recent decades, surprisingly few risk factors have been consistently identified in association with paediatric cancers. Moreover, little attention has been focused on large-scale epidemiological studies of cancer in older adolescents and young adults. This study therefore aims to extend an established database collecting information on patients' demographics, together with their type of cancer, treatment and survival stretching back over 40 years.

The Yorkshire Register remains one of only four specialist databases covering the paediatric age range, and the only one of its kind in England covering all patients diagnosed under the age of 30 (2). Uniquely, the Register includes information on treatment, relapse and follow-up details missing from the National Cancer Registration and Analysis Service (NCRAS). The Yorkshire Register continues to work with colleagues in NCRAS to minimise the burden on local providers to provide comprehensive data on the patient pathway in support of lifecourse epidemiology.

Although the descriptive epidemiology of paediatric cancer is well documented (1,3), malignant disease is similarly rare in adolescence but remains poorly described, despite accounting for a sizeable morbidity and mortality in the older age range. It is recognised that teenagers and adolescents with cancer are a particularly challenging group for the health care services and only recently have the needs of this group been addressed in a systematic manner. Cancer patients in this age group have differing requirements, with children and older adults both needing specific psychological, educational and social support. The Expert Advisory Group in Cancer to the Chief Medical Officers of England and Wales has recognised these needs and recommends the formation of specialist units for adolescents with cancer (4). Underpinning this requirement is the need for good information on this group of young people in order to document incidence and survival and clearly identify the special support necessary for delivery of comprehensive care (5-6). The Yorkshire Register is therefore in an excellent position to evaluate the delivery of care in this older age group.

The value of the Yorkshire Register accumulates with time providing a database of increasing numbers for analyses of this rare condition. Epidemiological analyses require large numbers of cases in order to ensure high statistical power and that the results are applicable to the general population. Because the epidemiology of paediatric and young adult cancers is still poorly understood, data is usually presented in biologically distinct diagnostic subgroups. It is therefore imperative that the Register continues to collect accurate information on the diagnosis of young people with cancer in Yorkshire.

The technical aspects of inputting, validating and securing the computerised database have been extensively refined over recent years. Standardised procedures are in place for data collection, validation, ascertainment cross-checks with other data sources, extraction and follow-up. Not only is the information used to identify incidence and survival trends across the Region but also to underpin health services research projects including the delivery of care in important areas such as adolescent cancer and to act as a clinical resource used by local oncologists and research staff.

Recent research data from the Register have shown that:

- Assigning ethnicity derived from multiple sources, e.g. hospital admissions, name recognition software, results in a more robust classification of ethnicity than the use of a single source [I].
- Almost three-quarters of patients received all their treatment at a dedicated hospital for children and young people, whereas 1 in 8 had no treatment at a specialist unit. Those with leukaemia who received no treatment at a dedicated hospital were more likely to die than those who did visit a specialist unit. Survival outcomes for those with leukaemia were similar for low risk patients receiving no treatment at a dedicated hospital and those who were high risk patients who received all their treatment at a specialist unit [II].
- We did not find any evidence for an association between population mixing and the risk of developing leukaemia, lymphoma, central nervous system or germ cell tumours among TYAs [V].
- Survival rates among children and young people in Yorkshire and the north east of England clearly differed between 2 aggressive forms of CNS tumour, medulloblastoma and primitive neuroectodermal tumour (PNET), with the former having a better overall prognosis. These survival differences became apparent one year after diagnosis. We also identified a significant improvement in survival rates over time. Importantly, we saw no differences in survival between teenagers and young adults and younger children [VI].

### 3. Data collection

The computerised Register is held within the School of Medicine, University of Leeds ([http://medhealth.leeds.ac.uk/info/545/yorkshire\\_specialist\\_cancer\\_register](http://medhealth.leeds.ac.uk/info/545/yorkshire_specialist_cancer_register)). The security of the data are described in detail in section 6.

The geographical area covered by the Register aligns with the Yorkshire and the Humber Strategic Health Authority (SHA). The Region covers a population of 5.1million, 1.9 million of whom are aged under 30 years. Subjects diagnosed with a malignancy aged 0-29 years whilst living in the Yorkshire and the Humber SHA are be eligible for inclusion on the Register.

Historically, cancer registration records have been identified primarily through hospital records involving manual abstraction of information from hospital notes. More recently and in the future we have been establishing a secure, electronic feed of information from local patient management and pathology systems, the NCRAS within Public Health England), as well as primary care datasets, in order to improve the efficiency of the Yorkshire Register data collection. Where essential data on cancer diagnosis and treatment are missing or incomplete from the electronic data sources, we manually abstract information from local hospital notes and patient management systems. Registry data will on occasion and for the purposes of quality assurance be crosschecked and validated against other datasets held by the NCRAS and Northern and Yorkshire Cancer Teams (Public Health England). The data comprises personal and demographic information (e.g. name, date of birth, address, postcode) along with diagnostic and clinical data on treatment (chemotherapy drugs and doses, radiotherapy site and dose, surgery). A field also identifies whether patients were treated on a Teenage Cancer Trust (TCT) unit or within a Principal Treatment Centre to evaluate the impact on survival compared to those receiving care in non-specialist centres. Copies of diagnostic pathology reports, cytogenetic and molecular genetic diagnostics are retained to provide comprehensive information on diagnosis and facilitate future research should diagnostic classifications change.

**Follow-up information** is derived from specific contacts with:

- i. The treating consultants and the patient's GP.
- ii. NCRAS (Public Health England), who provide an annual notification of deaths occurring among the Register cohort including cause, place and date of death.

Patients for whom we are unable to obtain follow-up information are traced using their local Health Authority; otherwise we trace the patient's whereabouts and current GP through the NHS Central

Register (NHSCR)/Office for National Statistics (ONS) and the NHS Clinical Spine Application (CSA) to ascertain the status of those lost to follow-up. Information is provided on whether the patients are dead, embarked or untraceable; death certificates are also sent to us listing cause of death and place of death.

As part of our ongoing research into the long term health outcomes of children and young people diagnosed with cancer we collect additional information for patients on the register attending the long term follow-up clinics at Leeds Teaching Hospitals Trust. Patients attending these clinics complete a holistic needs assessment which includes the completion of the distress thermometer and a problems check list. These data items are used as a measure of psychological health to assess the prevalence of distress in long term cancer survivors and the associations between patient characteristics and levels of distress.

Over recent years, we have successfully completed an exercise linking individual patients on the Register with their NHS numbers for more accurate matching to other registry databases and the CSA, enabling us to track the current health status of the patient more effectively. We also plan to obtain data from primary care records which will then be linked with the Register, allowing us to explore and evaluate the use of primary care services by survivors of children's and young people's cancers. This will be facilitated through a data flow process which will be adapted from the Comprehensive Patient Records for Cancer Outcomes study (<https://lida.leeds.ac.uk/research-projects/cpr-for-cancer-outcomes/>). The proposed Yorkshire-wide data flow describing the linkage of pseudonymised Yorkshire registry and HES data with primary care data is outlined within Figure 1. In essence, the Yorkshire Register will act as a data provider of pseudonymised registry and HES datasets for research so that pseudonymised cancer registration and linked hospital admissions data can be shared and processed to facilitate linkage to primary care information in a secure environment.

Additional, enhanced treatment information on chemotherapy and radiotherapy will be obtained through NCRAS, exploiting the availability of national Systemic Anti-Cancer Therapy (SACT) and Radiotherapy datasets. Further details are provided in section 9 in relation to a specific project although these extracts will also be used as part of continual data validation exercises.

Information on any subsequent primary tumours for patients in the register are obtained through cross checks with the National Cancer Registration Service to obtain information on all tumours diagnosed throughout the patient's lifetime. This will enable us to examine the incidence and risk of



developing a subsequent primary tumour in long term survivors of cancer in children and young adults.

**Diagnostic classification** - the epidemiological investigation of childhood and adolescent cancers are generally based on groupings by histological type of tumour and not the site of the cancer as is common in adult cancer epidemiology. All diagnoses on the Register are coded according to ICD-O versions 2 and 3 (based on ICD10/ICD11) using morphology and site. As part of the process for checking data accuracy, a computer program from the International Agency for Research on Cancer (IARC) called 'child check' is used to validate the diagnostic coding and permit the allocation of diagnostic groupings for ICD-O-2/ICD-O-3 with the International Classification of Childhood Cancer (ICCC) (9) which updates the previous Birch and Marsden (10) categories. Teenagers and Young Adults (TYA) are classified separately using an algorithm designed by Birch and colleagues (11) and sub-divided into 10 main diagnostic groups.

**Internal validation** exercises are carried out annually to ensure the diagnostic codes are compatible with different morphological and topographical combinations, and checks on dates of birth/diagnosis performed with data from the Northern and Yorkshire Cancer Teams (Public Health England). The data are also routinely validated for elimination of duplicates, consistency, accuracy and diagnostic coding, the latter using the ICCC program.

All addresses and postcodes at diagnosis are verified using Quick Address. Each postcode is then mapped to a small area Census code (sascodes) using the National Statistics Postcode Directory and assigned to a census enumeration district (ED) or Output Area (OA). ED/OAs are then aggregated up into electoral wards (EW) or lower super output areas, county districts, counties or Clinical Commissioning Groups (CCGs) within the Yorkshire Region, dependent on the geographical level of analysis. This permits the characterisation of geographical areas by social class, ethnic group and other variables such as population mixing, at different scales using census data.

#### **4. Ethical approval**

The work of the register is only undertaken with the approval of a Multi Centre Research Ethics Committee. Approval was originally obtained from the Northern and Yorkshire MREC (Ref MREC/0/1/3) in May 2000 and amendments submitted for approval thereafter. Current approval was provided in March 2014 reflecting a change to the study protocol, notably around changes to data security, the study team (addition of a Data Manager), the research work programme, plans to exploit primary care data and taking advantage of electronic data flows in relation to registration information..

#### **5. Statistical Analysis**

Incidence rates are calculated using mid-year population estimates and are usually age-sex standardised in any regional analysis. Rates are then broken down into 12 main ICCC and TYA diagnostic groups (leukaemia, lymphoma, CNS, etc.) to facilitate comparison with other regional, national and international data.

Ecological analyses are usually performed at EW or lower super output area level and Poisson regression used to model the heterogeneity across these small areas. The effects from areal-based measures such as socioeconomic status, population density and proportion of non-white individuals are then calculated and summarised using incidence rate ratios. Survival analyses are carried out based on the date the patient was last seen (or date of death) and modelled in relation to socioeconomic status and ethnicity. Allowance is usually made for the diagnostic staging of the disease and the period of diagnosis. Multiple imputation techniques are implemented in cases where stage at diagnosis or other prognostic variables are missing.

## 6. Data security and patient consent

**Data security** - Extreme care and attention is paid to maintaining the security and confidentiality of the Register data. The Register has its own Scientific Advisory Group which includes representation from the following areas – university research, public health, clinical medicine, health care professionals, patients and lay persons. The Advisory Group is responsible for ensuring that appropriate procedures are in place to ensure the physical security of the data and its release. Data security is managed through adherence to the Secure Electronic Environment for Data (SEED) Information Governance Policy v3.0; this infrastructure will shortly evolve into the new University of Leeds Integrated Research Campus having attained accredited certification to the international standard for information security management, ISO/IEC 27001:2013. This will ensure that the IRC meets the requirements to store health data shared by NHS Digital, Public Health England and other NHS or social care organisations.

In summary the following physical precautions are in place to protect the database

- Only those essential members of staff who work on the Register and require direct access to the database are granted authorisation.
- All users of the SEED/IRC system must sign a confidentiality agreement, which includes stipulating that security and confidentiality must be maintained. Certain breaches of security could lead to disciplinary and legal action being taken.
- The database is held on an encrypted firewall-protected area of the University of Leeds IRC.
- Daily back ups are taken to ensure the integrity of the data and held off-site.

Personally identifiable information is also held subject to the following conditions

- No information is ever published in which individuals can be identified.
- No individuals on the Register are ever approached directly.
- Data are only released according to the requirements of the Information Governance Policy which specifies the circumstances for data release.

Data will be held indefinitely enabling the accrual of an ever-increasing dataset relating to cancer in young people and allowing more powerful statistical comparisons to be performed and the effects of risk factors estimated more precisely.

**Patient consent** - Consent for the transfer of personal information is a requirement of the General Data Protection Regulation 2016, the Human Rights Act 1998 and the common law. However, the National Information and Governance Board for Health and Social Care (NIGB) exempted the UK Association of Cancer Registries (UKACR), of which the Yorkshire Specialist Register is a member, from gaining informed patient consent for the holding of personal information through Section 251 of the NHS Act 2006 (originally enacted under Section 60 of the Health and Social Care Act 2001). We have subsequently submitted a bespoke application for the Yorkshire Register to the Health Research Authority Confidentiality Advisory Group (CAG); this application was successfully approved on 13<sup>th</sup> August 2014 (Reference Number: CAG 1-07(b)/2014). The Yorkshire Registry can therefore continue to be used to process cancer registry and related linked data for the purposes of epidemiological and health services research.

Our legal basis for processing such data under Article 6 of the GDPR is condition (e) "Public Task", i.e. the processing is necessary for us to perform a task in the public interest, which also satisfies conditions (g) and (i) in Article 9(2). Patient information leaflets are available which explain what data are collected and processed, and how patients may discuss their right to erasure. However, when considering any request for erasure, we would remind the participant or their parent/guardian that we are not automatically obliged to remove their personal data as our legal basis is Public Task. A fair processing and privacy policy is also available on the Yorkshire Register website.

**Access to medical records** - Clinical governance has now imposed conditions on the conduct of research within the NHS. This has resulted in our data collection manager requiring individual honorary contracts with each of the 11 different NHS Trusts in order to gain access to patients' medical records. This process never involves any patient contact. Contracts were agreed with every NHS Trust in the Yorkshire and Humber SHA and are currently being renewed to run until 2020. Other members of staff working on specific Registry research projects will seek separate R&D approval and honorary contracts/access letters with relevant NHS Trusts to scrutinise medical records.

## 7. Dissemination of information

Information about the implementation and findings from the Register include

- **Procedure Manual and Documentation** - A procedure manual covering all aspects of data collection and computerisation for the Register, ranging from data abstraction (using a standard data collection form – Appendix I) to inputting, follow-up, maintenance and validation has been produced and is available online ([http://medhealth.leeds.ac.uk/downloads/545/yorkshire\\_specialist\\_cancer\\_register/](http://medhealth.leeds.ac.uk/downloads/545/yorkshire_specialist_cancer_register/)). This will facilitate the operation of the database and ensure the continued collection of high quality data. An automated system for identifying and chasing patient follow-up has been established. Technical documentation has also been included and made available on the website describing each data field stored in the Access database.
- **The DocDat website** (<http://www.icapp.nhs.uk/docdat/>) is a national database providing details of active clinical databases in the field of health in the UK. Over 150 databases are currently registered and its aim is to provide information about them and to give some idea of their range of data and its quality. The Yorkshire Register is one of the entries on this site and has been involved in the development of generic data security policies for clinical databases.
- **Informing patients and health care professionals** about the Register and its research involves regular updates to the Register website ([http://medhealth.leeds.ac.uk/info/545/yorkshire\\_specialist\\_cancer\\_register](http://medhealth.leeds.ac.uk/info/545/yorkshire_specialist_cancer_register)). Furthermore, patient and parental information leaflets are distributed to patients and families via the core information pack given out by Macmillan nurses and TYA nurse specialists at diagnosis (Appendix II). A poster summarising the work of the Yorkshire Register has been designed and will be displayed in the main paediatric and adolescent cancer wards in Leeds and Sheffield where the majority of children and young people in Yorkshire are treated. Additional copies will be displayed in the Teenage and Young Adult cancer wards in Leeds and Sheffield as well as the long-term follow-up clinics in Leeds and Sheffield. A copy will be made available to download from our website.

## 8. Recent results from the Register

- Assigning ethnicity derived from multiple sources, e.g. hospital admissions, name recognition software, results in a more robust classification of ethnicity than the use of a single source [I].
- Almost three-quarters of patients received all their treatment at a dedicated hospital for children and young people, whereas 1 in 8 had no treatment at a specialist unit. Those with leukaemia who received no treatment at a dedicated hospital were more likely to die than those who did visit a specialist unit. Survival outcomes for those with leukaemia were similar for low risk patients receiving no treatment at a dedicated hospital and those who were high risk patients who received all their treatment at a specialist unit [II].
- We did not find any evidence for an association between population mixing and the risk of developing leukaemia, lymphoma, central nervous system or germ cell tumours among TYAs [V].
- Survival rates among children and young people in Yorkshire and the north east of England clearly differed between 2 aggressive forms of CNS tumour, medulloblastoma and primitive neuroectodermal tumour (PNET), with the former having a better overall prognosis. These survival differences became apparent one year after diagnosis. We also identified a significant improvement in survival rates over time. Importantly, we saw no differences in survival between teenagers and young adults and younger children [VI].

## 9. Current projects

- **Gender differences in outcomes** – Through links with Prof Alan White (collaborator), a leading researcher in men's health, we aim to explore reasons for generally poorer outcomes for males. We plan to determine whether the lack of improvement in survival for females with ALL can be explained by adverse cytogenetics or an interaction with ethnicity, since south Asian children in Yorkshire have poorer survival rates than their non-south Asian counterparts
- **Risk of late effects of cancer treatment** – The aims of this work programme are to produce a comprehensive picture of the health profile of children and young people diagnosed with cancer by linking information on patient outcomes from primary care records (currently those using the system1 system, but in future all other primary care data management systems in the UK will be included so that we are able to identify all NHS consultation episodes for the Yorkshire register cohort), secondary care (which will be obtained from Hospital Episode Statistics (HES) data including inpatient, outpatient, A&E and mental health admissions) and other routine datasets. We will endeavour to compare the health of patients on the Register with the background population. Previous work has thoroughly investigated cardiovascular disease [XXXV] and we now wish to focus on other areas, including but not limited to mental health, fertility problems and respiratory illnesses. We hope to identify how these vary by demographic factors as well as type of malignancy and treatment received. Additionally, we hope to establish whether the risks of developing these problems have changed over time as treatment protocols have altered. We will look further at the impact of relapse or poor response to initial treatment on developing these problems.
- **The effect of chemotherapy on patient outcomes** - in this project we will enhance the treatment data held in the register through linkage with the national Systemic Anti-Cancer Therapy (SACT) dataset and hospital electronic prescribing systems such as ChemoCare. This will enable us to compare the chemotherapy doses and intensities given to patients with the same tumour types and see if this has any effect on outcomes including survival and relapse. We will also be able to look at the toxicities experienced by patients by reviewing routine blood tests collected prior to chemotherapy. From this we will be able to see if any dose modifications were made as a result and again look at whether this had any effect on patient outcome. By comparing patients treated at different hospitals we will, for some tumour types, be able to see whether, and if so how, practices differ between Principal Treatment Centres and peripheral hospitals.



- **Educational outcomes** – Through data linkage to the National Pupil Database, Individual Learner Record and Higher Education Statistics Authority we will look at how the educational trajectory of patients is affected by a cancer diagnosis in the childhood and young adult years. We will examine the association between patient and diagnosis characteristics and their effect on educational trajectories. Using the enhanced treatment data as described above we will investigate whether there is any association between chemotherapy received and educational outcomes. We will also obtain information on pupil absences and exclusions as well as data on those with Special Educational Needs, to see whether this can be used as a predictor of poor adherence to treatment, which we will obtain from outpatient HES data. This will help to identify patients at high risk for non-compliance and enable extra support measures to be put in place.
- **Social outcomes** – these will be investigated for the Yorkshire Register cohort through linkage to information on employment and welfare support data held by the Department for Work and Pensions. Employment rates among the cancer population will be compared to the general population and predictors of lower employment levels identified. Levels of welfare support (e.g. receipt of benefits) will also be examined in the cancer cohort in contrast to the general population; we aim to identify specific clinical and socio-demographic factors which are associated with higher level of welfare support.

**Patient pathways** –One of the key areas of concern depicted in the cancer reform strategy of 2007 is that of delays in diagnosis of cancer, and how this may impact upon survival and other outcomes amongst children and young adults. As well as considering pathways to diagnosis, it has become increasingly important to consider the critical post-diagnosis time window. Over 75% of children diagnosed with cancer become long term survivors, and this is a cohort which is at risk of developing a range of co-morbidities as a result of treatments received during their childhood. These research questions can be answered using the Register’s detailed data on treatment in combination with linked HES and primary care data to examine medical data both pre and post cancer diagnosis.

Other specific objectives include:

- • To understand the risk of mental health illness and how this compares to young people unaffected by cancer, by looking at data from primary and secondary care records.

- To calculate future cancer incidence rates and prevalence statistics in Yorkshire between 2017-2030, firstly to enable healthcare managers to plan future services and secondly to supply the Candlelighters Trust with the latest cancer statistics for dissemination to families.
- To investigate unusual family patterns of cancers which occur within siblings.
- To identify factors which influence length of survival for low grade brain tumours, especially among adolescents and young adults, results which will contribute to a major European analysis of these tumours.
- To describe long-term outcomes for a rare form of brain tumours occurring in the optic nerve.
- To determine whether changes in the way radiotherapy treatment has been delivered over the last 25 years for brain tumours has led to any significant improvements in survival rates and a reduction in the time spent in hospital.
- To describe survival rates of leukaemia and lymphoma and the effect of place of care using a unique tumour classification scheme tailored for young people and developed by colleagues at the University of York.
- To assess evidence of any inequalities in survival rates according to ethnic group.
- To determine the impact on survival outcomes and risk of hospitalisation following the introduction of dedicated professional meetings of cancer specialists to agree the best way to manage the care of young people (groups known as multidisciplinary team meetings).
- To identify the proportion of NHS activity which takes place in primary care vs. secondary care following cancer diagnosis for long-term survivors in order to help plan better services.
- To assess the feasibility of using anonymised linked consumer and household spending data to determine whether there are differences in buying habits between the cancer population and background population of Yorkshire.
- To assess the feasibility of using anonymised linked educational data to determine whether there are differences in attainment levels between the cancer population and background population of Yorkshire, especially for those with brain tumours.

To identify factors which affect whether young people who experience end of life care go on to die at their preferred place of death.

One other national project is ongoing which ties in closely with the ongoing epidemiological and health services research using data from the Yorkshire Register focusing on teenagers and young adults (TYA) with cancer.

- **External liaison** - Maintaining links with other registries and outside bodies is seen as a key function of the Register. Particular links have been established and combined with research projects developed with the NRYPMR at Newcastle (Dr Richard McNally) and the West Midlands Children's Cancer Registry (Professor Helen Jenkinson)
- **Hypothesis testing** – the Register is available for testing hypotheses generated by other independent studies and other *ad hoc* data requests.

## 10. Funding

The Leeds Candlelighters' Trust has financially supported the data collection for the Register since 1984 and has also included funding for a research statistician since 1996. It has also supported a data manager since 2014. The Laura Crane Youth Cancer Trust has also supported the running of the Register since 2017.

## 11. Glossary

<b>CCLG</b>	Children's Cancer and Leukaemia Group
<b>ED</b>	Enumeration District: the smallest areal denominator available from the 1981 and 1991 Census
<b>EW</b>	Electoral Ward: areas defined by the amalgamation of EDs, more suited to epidemiological studies, usually containing approximately 5500 people.
<b>HMDS</b>	Haematological Malignancy Diagnostic Service
<b>IARC</b>	International Agency for Research on Cancer
<b>ICCC</b>	International Classification of Childhood Cancer
<b>NCRAS</b>	<b>National Cancer Registration and Analysis Service</b>
<b>NIGB</b>	National Governance Information Board for Health and Social Care
<b>NRCT</b>	National Registry of Childhood Tumours
<b>NRYPMDR</b>	Northern Region Young Person's Malignant Disease Register
<b>PHE</b>	Public Health England
<b>UKACR</b>	UK Association of Cancer Registries

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### 13. Recent Publications from the Register (2007-2018)

- I. Smith L, Norman P, Kapetanstrataki M, Fleming S, Fraser LK, Parslow RC, Feltbower RG. Comparison of ethnic group classification using naming analysis and routinely collected data: application to cancer incidence trends in children and young people. *BMJ Open* 2017; 7 (9) e016332; DOI: 10.1136/bmjopen-2017-016332
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- XV. van Laar M, Glaser A, Phillips RS, Feltbower RG, Stark DP. The impact of a managed transition of care upon psychosocial characteristics and patient satisfaction in a cohort of adult survivors of childhood cancer. *Psycho-Oncology* 2013; 22(9):2039-2045.
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- XXXI. Taylor JC, Law GR, Boyle PJ, Feng Z, Gilthorpe MS, Parslow RC, Rudge G, Feltbower RG. Does population mixing measure infectious exposure in children at the community level? *Eur J Epid* 2008; 23: 593-600.
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## 14. Presentations from the Register

Trends in cure and relapse by clinical characteristics for children diagnosed with leukaemia aged 0-17 years in Yorkshire 1990-2009: a population-based study

Smith L, Glaser AW, Kinsey SE, Greenwood DC, Feltbower RG

Society for Social Medicine 61st Annual Scientific Meeting, September 2017, Manchester (Oral presentation)

Access to principal treatment centres and survival rates for teenagers and young adults with cancer in Yorkshire, UK

Smith L, Stark DP, Yeomanson D, Kinsey SE, Glaser AW, Picton SV, Evans L, Feltbower RG

Teenagers and Young Adults with Cancer/BRIGHTLIGHT Conference, July 2017, Leeds (Oral)

Trends in cure and relapse by clinical characteristics for children diagnosed with leukaemia aged 0-17 years in Yorkshire 1990-2009: a population-based study

Smith L, Glaser AW, Kinsey SE, Greenwood DC, Feltbower RG

PHE NCRAS Cancer Data and Outcomes Conference 2017, June 2017, Manchester (Oral)

Pathways to diagnosis in teenage and young adult cancers in Europe: Results from a pilot study.

Fairley L, Pini S, Feltbower RG, Stark DP.

Teenage Cancer Trust 9th International Conference and 1st Global AYA Cancer Congress December 2016, Edinburgh (Oral).

Recruitment to clinical trials is associated with superior survival in teenage and young adult patients with acute lymphoblastic leukaemia.

Hough R, Moran A, Khan M, Sandhu S, Feltbower RG, Stiller C, Stevens M, McCabe M.

Teenage Cancer Trust 9th International Conference and 1st Global AYA Cancer Congress December 2016, Edinburgh (Oral).

Epidemiology of Ewing sarcoma in the north of England 1990-2011.

Feltbower RG, Roberts P, McNally RJQ, Bown N, Brownhill S, Burchill S.

48th Congress of the International Society of Paediatric Oncology October 2016, Dublin (e-Poster)

Access to principal treatment centres for children and young people in Yorkshire and the effect on survival

L Fairley, D Stark, D Yeomanson, S Kinsey, A Glaser, S Picton, L Evans, R Feltbower

48th Congress of the International Society of Paediatric Oncology October 2016, Dublin (e-Poster)

Healthcare burden among young people with cancer and related comorbidity: a population based linked cohort.

AA Althumairi, SE Kinsey, SV Picton, AW Glaser, M Hall, RG Feltbower.

48th Congress of the International Society of Paediatric Oncology October 2016, Dublin (e-Poster).

Comparison of ethnic group classification using naming analysis and routinely collected data: application to cancer incidence trends in children and young people

L Fairley, P Norman, S Fleming, R Feltbower, R Parslow

Society for Social Medicine 60th Annual Scientific Meeting, York, September 2016 (Oral presentation)

Different analytical strategies yield contradictory findings when investigating the association between childhood leukaemia and population mixing.

Berrie L, Baxter PD, Ellison GTH, Norman PD, Law GR, Feltbower RG, Gilthorpe MS.

Society for Social Medicine 60th Annual Scientific Meeting, York, September 2016 (poster)

Healthcare burden among young people with cancer and related comorbidity: a population based linked cohort.

AA Althumairi, SE Kinsey, SV Picton, AW Glaser, M Hall, RG Feltbower.

Cancer Data and Outcomes Conference 2016: Using data to drive services

June 2016, Manchester (poster).

Is specialist childhood and adolescent cancer care good or bad for your health?

R Feltbower

Department of Health Sciences, University of York (invited lecture), June 2016.

Access to principal treatment centres for children and young people in Yorkshire and the effect on survival

L Fairley, D Stark, D Yeomanson, S Kinsey, A Glaser, S Picton, L Evans, R Feltbower

PHE NCRAS Cancer Data and Outcomes Conference 2016, Manchester, June 2016 (Poster)



Cancer Patient Experience in the Teenage/Young Adult (TYA) Population: Key issues and trends over time. An analysis of national cancer patient experience surveys  
CL Furness, L Fairley, S Daly, R Hough  
PHE NCRAS Cancer Data and Outcomes Conference 2016, Manchester, June 2016 (Poster)

Access to principal treatment centres for children and young people in Yorkshire and the effect on survival  
L Fairley, D Stark, D Yeomanson, S Kinsey, A Glaser, S Picton, L Evans, R Feltbower  
LICAMM Early Career Group Science Day, May 2016, Leeds (Oral presentation)

Healthcare burden among young people with cancer and related comorbidity: a population based linked cohort.  
AA Althumairi, SE Kinsey, SV Picton, AW Glaser, M Hall, RG Feltbower LICAMM Early Career Group Science Day, May 2016, Leeds (Oral presentation)

The Yorkshire Specialist Register of Cancer in Children and Young People: patterns and causes of cancer.  
R Feltbower  
Families information event, February 2016, Candlelighters Trust, Leeds (Oral presentation).

Analysis of Long-Term Outcomes, Management and Prevalence of Osteonecrosis in UKALL 2003: 3.6% of Adolescents and Young Adults Over 10 Years of Age with Acute Lymphoblastic Leukaemia Required Hip Replacement.  
N. Amin, S. Kinsey, R. Feltbower, A. Vora, R. Wade, R. Hough, C Rowntree, N. Goulden, C. Mitchell, B. James  
American Society of Hematology, Dec 2015, Florida (Poster).

Prevalence, Management and Long Term Outcomes of Osteonecrosis in Young People with Acute Lymphoblastic Leukaemia.  
N. Amin, S. Kinsey, R. Feltbower, T Mushtaq, B. James  
British Society for Paediatric Endocrinology, Sheffield, Nov 2015 (Oral).

Hospital admissions patterns among children, teenagers and young adults after cancer treatment in Yorkshire between 1996-2001.  
AA Althumairi, SE Kinsey, SV Picton, AW Glaser, M van Laar, RG Feltbower.  
Leeds Children's Hospital Conference 2015, October 2015, Leeds (poster presentation).

The pattern of hospital admissions and length of stay during 1996 to 2011 among children in compared with teenagers and young adults after diagnosed with cancer in Yorkshire  
AA Althumairi, SE Kinsey, SV Picton, AW Glaser, M van Laar, RG Feltbower.  
NCIN Cancer Outcomes Conference 2015: United Against Cancer, June 2015, Belfast (Oral)

Hospital admissions patterns among children, teenagers and young adults after cancer treatment in Yorkshire between: 1996-2011.  
AA Althumairi, SE Kinsey, SV Picton, AW Glaser, M Hall, RG Feltbower LICAMM Early Career Group Science Day, May 2015, Leeds (Oral presentation)

The Yorkshire Specialist Cancer Register of Children and Young People.  
RG Feltbower.  
Sheffield and Leeds working together meeting, April 2015, Sheffield (Oral)

The role of the specialist childhood cancer registries.  
RG Feltbower.  
CCRG celebration meeting, April 2015, Oxford (Oral)

Yorkshire Specialist Register of Cancer in Children and Young People: Epidemiology and Applied Health Research  
RG Feltbower, AW Glaser, on behalf of the Yorkshire register research team.  
46th Congress of the International Society of Paediatric Oncology, October 2014, Toronto (Oral)

Are we looking in the right place? A study of time to diagnosis of cancer in children and young adults within Yorkshire secondary care services.  
C Lethaby, SE Kinsey, SV Picton, M van Laar, R Phillips, RG Feltbower.  
46th Congress of the International Society of Paediatric Oncology, October 2014, Toronto (Poster)

Missing data and survival analysis of central nervous system tumours amongst children and adolescents in Yorkshire,

UK, 1990-2009.

M van Laar, DC Greenwood, DP Stark, RG Feltbower.

46th Congress of the International Society of Paediatric Oncology, October 2014, Toronto (Poster)

When and Why do Teenage and Young Adult Oncology Patients Die Early in the Cancer Pathway?

E. Dunwoodie, V. Watkins, M. Lane, M. van Laar, R. Phillips, G. Hall, D. Stark. ESMO Congress, September 2014, Madrid, Spain (Poster).

Missing data and survival analysis of central nervous system tumours amongst children and young people in Yorkshire, 1990-2009.

M. van Laar, D. Greenwood, D. Stark, R.G. Feltbower.

Medical Research Council Conference on Biostatistics, March 2014, Cambridge (Poster).

Cardiovascular late effects in survivors of childhood and young adult cancer in Yorkshire.

van Laar M, Gale CP, Glaser AW, Bowen DT, Oliver SE, Feltbower RG.

Paediatric Grand Rounds, Leeds Teaching Hospitals NHS Trust, December 2013, Leeds (Oral).

Missing data and survival analysis of central nervous system tumours amongst children and young people in Yorkshire, 1990-2009.

M. van Laar, D. Greenwood, D. Stark, R.G. Feltbower.

NCRI Cancer Conference, November 2013, Liverpool (Poster).

Cardiovascular Late Effects in Survivors of Childhood and Young Adult Cancer. M.van Laar. Paediatric Oncology Breakfast Seminar, October 2013 (Oral).

Missing data and survival analysis of central nervous system tumours amongst children and young people in Yorkshire, 1990-2009.

M. van Laar, D. Greenwood, D. Stark, R.G. Feltbower. The European Cancer Congress, September 2013, Amsterdam (Poster).

Smart use of existing data - Cardiotoxicity in long term survivors of childhood cancer.

M. van Laar.

West Yorkshire Patient and Public Involvement Group, Leeds, June 2013 (Oral).

Seasonality of diagnosis in cancer amongst 15-24 year olds in England, 1996-2005

M. van Laar, S.E. Kinsey, S.V. Picton, R.G. Feltbower

44<sup>th</sup> Congress of the International Society of Paediatric Oncology, October 2012, London (Poster)

Changes in the patterns of care of central nervous system tumours among 16-24 year olds and the impact on survival in Yorkshire between 1990-2009.

RG Feltbower, SV Picton, C Loughrey, S Dixit, G O'Reilley, DP Stark, M van Laar, P Chumas, BD Nicholson. 44<sup>th</sup> Congress of the International Society of Paediatric Oncology, October 2012, London (Poster)

Changes in the patterns of care of central nervous system tumours among 16-24 year olds and the impact on survival in Yorkshire between 1990-2009.

B.D. Nicholson, S.V. Picton, C. Loughrey, S. Dixit, G. O'Reilley, D.P. Stark, R.G. Feltbower. Teenage Cancer Trust Conference, June 2012, London (Poster).

Seasonality of diagnosis in cancer amongst 15-24 year olds in England, 1996-2005

M. van Laar, S.E. Kinsey, S.V. Picton, R.G. Feltbower

Teenage Cancer Trust Conference, June 2012, London (Poster).

Seasonality of diagnosis in cancer amongst 15-24 year olds in England, 1996-2005

M. van Laar, S.E. Kinsey, S.V. Picton, R.G. Feltbower

Childhood Cancer Conference, April 2012, London (Poster).

UK Case Control Study of Brain Tumours in Children, Teenagers and Young Adults: a Pilot Study.

RG Feltbower, PA McKinney, RD Alston, SJ Fleming, JM Birch

NCRI Cancer Conference, November 2011, Liverpool (Poster)

Seasonality of birth in cancer amongst 15-24 year olds in England, 1996-2005

M. van Laar, S.E. Kinsey, S.V. Picton, Catherine O'Hara, R.G. Feltbower  
NCRI Cancer Conference, November 2011, Liverpool (Poster)

Seasonality of birth in cancer amongst 15-24 year olds in England, 1996-2005

M. van Laar, S.E. Kinsey, S.V. Picton, Catherine O'Hara, R.G. Feltbower  
43<sup>rd</sup> Congress of the International Society of Paediatric Oncology, October 2011, Auckland, NZ (Oral)

Transition of care for survivors of childhood cancer to adult cancer care

M. van Laar, A. Glaser, R.S. Phillips, R.G. Feltbower, D.P. Stark  
43<sup>rd</sup> Congress of the International Society of Paediatric Oncology, October 2011, Auckland, NZ (Oral)

Cardiovascular sequelae in long term survivors of childhood and young adult cancer

Simms AD, van Laar M, Birch RJ, Gale CP, Glaser AW, Bowen DT, Oliver SE, Feltbower RG. European Society of Cardiology Congress, August 2011, Paris (Poster)

Multiple Imputation and Survival Analysis: - an example using cancer registry data

M. van Laar, D.P. Stark, R.G. Feltbower. IEA World Congress of Epidemiology, August 2011, Edinburgh (Abstract to be published in *Journal of Epidemiology and Community Health*)

Seasonality of birth in cancer amongst 15-24 year olds in England, 1996-2005

M. van Laar, S.E. Kinsey, S.V. Picton, Catherine O'Hara, R.G. Feltbower  
NCIN & UKACR Conference, June 2011, London (Poster)

Transition of care for survivors of childhood cancer to adult cancer care

M. van Laar, A. Glaser, R.S. Phillips, R.G. Feltbower, D.P. Stark  
NCIN & UKACR Conference, June 2011, London (Poster)

Cardiovascular sequelae in long term survivors of childhood and young adult cancer

van Laar M, Birch RJ, Gale CP, Glaser AW, Bowen DT, Oliver SE, Feltbower RG.  
TYAC Spring Education Day, May 2011, London (Oral)

Multiple Imputation and Survival Analysis using cancer registry data

M. van Laar, D.P. Stark, R.G. Feltbower. Young Statisticians Meeting, April 2011 (Poster)

Cardiovascular sequelae in long term survivors of childhood and young adult cancer

van Laar M, Birch RJ, Gale CP, Glaser AW, Bowen DT, Oliver SE, Feltbower RG.  
TYAC Winter Education Day, December 2010, Bristol (Oral) :- cancelled due to weather

Differences in hospital inpatient patterns between attendees and non-attendees at a paediatric and adolescent long-term follow-up clinic in Yorkshire, UK.

Birch RJ, van Laar M, Glaser AW, Stark DP, Lewis IJ, Feltbower RG.  
Protocol – April 2018, Version 10

TYAC Winter Education Day, December 2010, Bristol (Oral) :- cancelled due to weather

Incidence rates and survival trends of cancer in 0-29 year olds by ethnic group in Yorkshire, UK

van Laar M, McKinney PA, Parslow RC, Glaser AW, Kinsey SE, Lewis IJ, Picton SV, Richards M, Shenton G, Stark DP, Norman P, Feltbower RG.

TYAC Winter Education Day, December 2010, Bristol (Oral) :- cancelled due to weather

International teenage and young adult cancer care – a survey of professional opinions

Birch RJ, Stark DP, Lewis IJ, West RM, Forman D, Feltbower RG.

TYAC Winter Education Day, December 2010, Bristol (Oral) :- cancelled due to weather

Epidemiology and patterns of care among primary central nervous system tumours diagnosed in 16-24 year olds, between 1990-2009 in Yorkshire, UK.

Nicholson BD, Picton SV, Loughrey C, Dixit S, O'Reilley G, Stark DS, Feltbower RG.

NCRI cancer conference, November 2010, Liverpool (Poster)

Evidence of an infectious aetiology for teenage and adult cancers – an analysis of seasonality of birth

Feltbower RG, Van Laar M, Kinsey SE, Picton SP, Moran A.

NCRI cancer conference, November 2010, Liverpool (Poster)

Cardiovascular sequelae in long term survivors of childhood and young adult cancer

van Laar M, Birch RJ, Gale CP, Glaser SW, Bowen DT, Pearson IR, Oliver SE, Hall AS, Feltbower RG.

American Heart Association, Scientific Sessions November 2010, Chicago (Poster)

Cardiovascular sequelae in long term survivors of childhood and young adult cancer

van Laar M, Birch RJ, Gale CP, Glaser SW, Bowen DT, Oliver SE, Feltbower RG.

NCRI cancer conference, November 2010, Liverpool (Poster)

Differences in hospital inpatient patterns between attendees and non-attendees at a paediatric and adolescent long-term follow-up clinic in Yorkshire, UK.

Birch RJ, van Laar M, Glaser AW, Stark DP, Lewis IJ, Feltbower RG.

NCRI cancer conference, November 2010, Liverpool (Poster)

Incidence rates and survival trends of cancer in 0-29 year olds by ethnic group in Yorkshire, UK

van Laar M, McKinney PA, Parslow RC, Glaser AW, Kinsey SE, Lewis IJ, Picton SV, Richards M, Shenton G, Stark DP, Norman P, Feltbower RG.

NCRI cancer conference, November 2010, Liverpool (Poster)

International teenage and young adult cancer care – a survey of professional opinions

Birch RJ, Stark DP, Lewis IJ, West RM, Forman D, Feltbower RG.

NCRI cancer conference, November 2010, Liverpool (Poster)

Cardiovascular sequelae in long term survivors of childhood cancer

van Laar M, Birch RJ, Gale CP, Glaser SW, Bowen DT, Oliver SE, Feltbower RG.

42nd Congress of the International Society of Paediatric Oncology, October 2010, Boston, US (Oral)

Differences in hospital inpatient patterns between attendees and non-attendees at a paediatric and adolescent long-term follow-up clinic in Yorkshire, UK.

Birch RJ, van Laar M, Glaser AW, Stark DP, Lewis IJ, Feltbower RG.

42nd Congress of the International Society of Paediatric Oncology, October 2010, Boston, US (Oral)

Incidence rates and survival trends of cancer in 0-29 year olds by ethnic group in Yorkshire, UK

van Laar M, McKinney PA, Parslow RC, Glaser AW, Kinsey SE, Lewis IJ, Picton SV, Richards M, Shenton G, Stark DP, Norman P, Feltbower RG.

42nd Congress of the International Society of Paediatric Oncology, October 2010, Boston, US (Poster)

International teenage and young adult cancer care – a survey of professional opinions

Birch RJ, Stark DP, Lewis IJ, West RM, Forman D, Feltbower RG.

42nd Congress of the International Society of Paediatric Oncology, October 2010, Boston, US (Poster)

Space-time clustering of childhood central nervous system tumours in Yorkshire, UK

McNally RJQ, James PW, Picton S, McKinney PA, van Laar M, Feltbower RG

42nd Congress of the International Society of Paediatric Oncology, October 2010, Boston, US (Poster)

Incidence rates and survival trends of cancer in 0-29 year olds by ethnic group in Yorkshire, UK

van Laar M, McKinney PA, Parslow RC, Glaser AW, Kinsey SE, Lewis IJ, Picton SV, Richards M, Shenton G, Stark DP, Norman P, Feltbower RG.

Society for Social Medicine 54th Annual Scientific Meeting, September 2010, Belfast (Oral)

Cardiovascular sequelae in long term survivors of childhood and young adult cancer

van Laar M, Birch RJ, Gale CP, Glaser SW, Bowen DT, Oliver SE, Feltbower RG.

Paediatric Oncology Breakfast Seminar, July 2010, Leeds (Oral)

Epidemiology and patterns of care among central nervous system tumours diagnosed in 16-24 year olds between 1990-2009 in Yorkshire.

Nicholson B, Picton SP, Stark DP, Feltbower RG.

Yorkshire and the Humber Deanery Academic Foundation Presentation Day, July 2010, Wakefield (Oral).

Referral to a Specialist Paediatric Palliative Care Service in Young Oncology Patients in Yorkshire.

Fraser LK, Miller M, McKinney PA, Parslow RC, Feltbower RG.

5<sup>th</sup> International Paediatric Palliative Care Conference, July 2010, Cardiff (Poster).

Cardiovascular sequelae in long term survivors of childhood cancer

van Laar M, Birch RJ, Gale CP, Glaser SW, Bowen DT, Oliver SE, Feltbower RG.

UKACR & NCIN Conference, June 2010, Birmingham (Oral)

Incidence rates and survival trends of cancer in 0-29 year olds by ethnic group in Yorkshire, UK

van Laar M, McKinney PA, Parslow RC, Glaser AW, Kinsey SE, Lewis IJ, Picton SV, Richards M, Shenton G, Stark DP, Norman P, Feltbower RG.

UKACR & NCIN Conference, June 2010, Birmingham (Poster)

Differences in hospital inpatient patterns between attendees and non-attendees at a paediatric and adolescent long-term follow-up clinic in Yorkshire, UK.

Birch RJ, van Laar M, Glaser AW, Stark DP, Lewis IJ, Feltbower RG.

6<sup>th</sup> International conference on teenage and young adult cancer medicine, June 2010, London (Poster)

International teenage and young adult cancer care – a survey of professional opinions

Birch RJ, Stark DP, Lewis IJ, West RM, Forman D, Feltbower RG.

6<sup>th</sup> International conference on teenage and young adult cancer medicine, June 2010, London (Poster)

Referral to a Specialist Paediatric Palliative Care Service in Young Oncology Patients in Yorkshire.

Fraser LK, Miller M, McKinney PA, Parslow RC, Feltbower RG.

Yorkshire Cancer Network End of Life Research Day, May 2010, Harrogate (Poster).

Incidence rates and survival trends of cancer in 0-29 year olds by ethnic group in Yorkshire, UK

Van Laar M, McKinney PA, Stark DP, Parslow RC, Picton SV, Kinsey SE, Lewis IJ, Norman P, Feltbower RG.

Young Statistician's Meeting, Mar 2010, Liverpool (Oral & Poster)

Space-time clustering of childhood CNS tumours in Yorkshire between 1974-2006.

Feltbower RG, Picton SV, James PW, McNally RJQ

NCRI Cancer Conference, Oct 2009, Birmingham (Poster).

Differences in hospital admission patterns between attenders and non-attenders at a paediatric long-term follow-up clinic in Yorkshire, UK.

Feltbower RG, Birch R, Stark DP, Lewis IJ, Kwok-Williams M, Murray R, Glaser AW.

NCRI Cancer Conference, Oct 2009, Birmingham (Poster).

No improvement in survival for osteosarcoma diagnosed in 0 - 39 year olds in northern England, 1981 – 2002.

Eyre R, Feltbower RG, James PW, Blakey K, Mubwandarikwa E, Forman D, McKinney PA, Pearce MS, McNally RJQ.

Society for Social Medicine, Sep 2009, Newcastle (Oral)

Modelling multivariate spatially correlated frailty effects using Bayesian survival methods.

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