

Yorkshire Specialist Register of Cancer in Children and Young People

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Dr RG Feltbower* Senior Lecturer in Epidemiology
University of Leeds

Prof AW Glaser Professor of Paediatric Oncology and Late Effects
University of Leeds
University of Leeds

Mr P Crump 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, a level of detail missing from the National Cancer Registration and Analysis Service (NCRAS).

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:

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- Cumulative burden of subsequent neoplasms, cardiovascular and respiratory morbidity in young people surviving cancer. (Smith et al, Cancer Epidemiol 2020)

We estimated the cumulative burden of subsequent malignant neoplasms (SMN), cardiovascular and respiratory hospitalisations in long-term survivors of childhood and young adult cancers and associated treatment risks. Ten-years post diagnosis, the cumulative incidence for a respiratory admission was 6.0% (95%CI 5.2 to 6.9), a cardiovascular admission was 2.0% (95%CI 1.5 to 2.5), and SMN was 1.0% (95% CI 0.7 to 1.4) with an average of 13 events per 100 survivors observed (95%CI 11 to 15). The risk of experiencing multiple events was higher for those treated with chemotherapy drugs with known lung toxicity (HR=1.35, 95%CI 1.09-1.68).

- Risk stratification of young adult survivors of cancer to estimate hospital morbidity burden: applicability of a pediatric therapy-based approach. (Clements et al, J Cancer Surviv 2020)

We investigated the applicability of risk-stratified levels of aftercare in predicting long-term morbidity in young adults, aged 18-29 years. Long-term survivors followed-up at a regional centre in the North of England were risk-stratified by disease and treatments received into one of three levels. These data were linked with local cancer registry and administrative health data (Hospital Episode Statistics, HES), where hospital activity was used as a marker of late morbidity burden. Similar trends in hospital activity were seen for childhood and young adult cancer survivors across National Cancer Survivorship Initiative (NCSI) risk levels. NCSI levels independently predicted long-term hospitalization risk in both childhood and young adult survivors. Risk of hospitalisation was significantly reduced for levels 1 and 2 compared with level 3. We concluded that the NCSI paediatric late-effects risk stratification system can be effectively and safely applied to cancer patients aged 18-29, independent of ethnicity or socioeconomic position.

- Respiratory morbidity in young people surviving cancer: Population-based study of hospital admissions, treatment-related risk factors and subsequent mortality (Smith et al, 2019)

Respiratory diseases are a major cause of late morbidity and mortality amongst childhood cancer survivors. This population-based study provides comprehensive analysis of hospitalisations for respiratory conditions, the associated risks of admission by earlier cancer treatment and trends in readmissions and subsequent mortality in long-term survivors of cancers diagnosed under 30 years. The risk of hospitalisation was significantly higher in cancer survivors compared to the general population. Treatment with chemotherapy with known lung toxicity was associated with an increased risk of admissions for all respiratory disease especially pneumonia. Subsequent mortality was highest in those admitted for pneumonia compared to other respiratory conditions.

- Long term survival after childhood acute lymphoblastic leukaemia: population-based trends in cure and relapse by clinical characteristics (Smith et al, 2018)

Statistical “cure models” provide additional metrics useful to identify and describe trends in survival. Additional measures include the proportion cured which is a summary of the long term survival and the median survival of the uncured which give information on those who are not long-term survivors. In this study we used a statistical cure model to explore trends in long-term survival and relapse for childhood acute lymphoblastic leukaemia (ALL) over time and by clinical characteristics. The proportion of patients cured, defined either by overall survival or relapse free survival, has increased over time while there was slight decrease in the median survival time of the uncured. We also observed a significant reduction in the risk of relapse over time.

- Comparison of ethnic group classification using naming analysis and routinely collected data (Smith et al, 2017).

In this study we compared cancer incidence trends using different methods for assigning ethnic groups to individuals: 1 – using ethnic group recorded in hospital medical records, 2 – using a naming software program to assign an ethnic group based on the ethnic origins of the individuals and 3 – using a combination of both processes. We found that using different methods of assigning ethnicity can result in different estimates of ethnic variation in cancer incidence. Combining ethnicity from multiple sources results in a more complete estimate of ethnicity than the use of one single source.

- Access to principal treatment centres and survival rates for children and young people with cancer in Yorkshire (Fairley et al, 2017)

This study described access to Principal Treatment Centres (PTC) for children (0-14 years) and teenagers and young adults (15-24 years) and the associated trends in survival. Between 1998 and 2009, 72% of all patients aged 0-24 years received all their treatment at PTC whilst 13% had no treatment at PTC. Leukaemia patients who received no treatment at PTC had an increased risk of death which was partially explained by differences in patient case-mix (Adjusted hazard ratio = 1.73 (95% Confidence interval 0.98-3.04). For leukaemia, survival outcomes for low risk patients receiving no treatment at PTC were similar to high risk patients who received all

treatment at PTC, implying a benefit of care at the PTC. Soft tissue sarcoma patients who had some or no treatment at PTC had better survival outcomes, which remained after adjustment for patient case-mix (adjusted HR = 0.48 (95%CI 0.23–0.99)), however we were unable to account for differences in stage at presentation, which may confound this finding. There were no significant differences in outcomes for other diagnostic groups (lymphoma, CNS tumours, bone tumours and germ cell tumours)

3. Data collection

The computerised Register is held within the School of Medicine, University of Leeds (<https://medicinehealth.leeds.ac.uk/leeds-institute-cardiovascular-metabolic-medicine/doc/yorkshire-specialist-register-cancer-children-young-people>). 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, we have been establishing a secure, electronic feed of information from local patient management and pathology systems (including PPM within NHS Trusts across Yorkshire), the NCRAS , 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. 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.

As a result of the Covid-19 pandemic, a patient's Covid-19 status and related data (such as date positive status was confirmed and shielding status) are also collected. This enables an analysis of the impact of Covid-19 on cancer treatments for children and young people (such as delays in treatment or non-start of treatments) and long-term health and social outcomes. Also resulting from

the changes to working practices in response to the Covid-19 pandemic, data collection is completed remotely where possible. Approval has been obtained from NHS Trusts for remote access to digitalised patient notes. All remote working procedures are subject to the same data security measures outlined in section 6 below.

Follow-up information is derived from specific contacts with:

- i. The treating consultants and the patient's GP.
- ii. NCRAS, 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.

Specific risk markers for cardiovascular disease plus metabolic factors associated with metabolic syndrome and type II diabetes will be collected, including HBAC1 levels, lipid profile (total cholesterol, serum triglycerides, high-density lipoprotein (HDL) and low-density lipoprotein (LDL), blood pressure, anthropometric measurements such as weight, height and waist circumference. We will also obtain a range of additional biomarkers of cardiovascular risk. This will include inflammatory markers, such as C-reactive protein (CRP) and past medical history of electrocardiograms (ECG). This data will facilitate a programme of research assessing the

prevalence of endocrine complications and cardiometabolic late effects in long-term childhood and young adult cancer survivors.

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, including the national Systemic Anti-Cancer Therapy (SACT) and Radiotherapy datasets, as well as ChemoCare electronic prescribing data. 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 and Analysis 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. 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.

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 v5.0; 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 13th 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. A revised HRA CAG research database application was approved in September 2020 to enable processing of linked cancer registration, primary care, secondary care, education and social welfare datasets, ref 20CAG0133.

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 a research passport with LTHT and letters of access with other NHS Trusts in order to gain access to patients' medical records. This process never involves any patient contact. 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 (<https://medicinehealth.leeds.ac.uk/leeds-institute-cardiovascular-metabolic-medicine/doc/yorkshire-specialist-register-cancer-children-young-people/>). 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 SQL server 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 (<https://medicinehealth.leeds.ac.uk/leeds-institute-cardiovascular-metabolic-medicine/doc/yorkshire-specialist-register-cancer-children-young-people/page/1>). 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 is available to download from the website.

8. Recent results from the Register

The YSRCCYP and associated research programme exist to provide a comprehensive population-based data resource to further our understanding of the causes and outcomes of cancer in young people including the burden of treatment on survivors' long-term health and social outcomes. The results provide intelligence to underpin enhanced health care delivery and patient outcomes. Whilst the data collected is from Yorkshire, the intelligence generated is of benefit to national and international health service and research partners with whom we increasingly collaborate to support improvements in health care and cancer outcomes.

The relevance of resultant research outputs to patient benefit are evidenced by a number of key publications since 2017:

Understanding of Cancer Outcomes

1) Cumulative burden of subsequent neoplasms, cardiovascular and respiratory morbidity in young people surviving cancer.

[Smith et al, Cancer Epidemiol 2020]

We estimated the cumulative burden of subsequent malignant neoplasms (SMN), cardiovascular and respiratory hospitalisations in long-term survivors of childhood and young adult cancers and associated treatment risks. Ten-years post diagnosis, the cumulative incidence for a respiratory admission was 6.0% (95%CI 5.2 to 6.9), a cardiovascular admission was 2.0% (95%CI 1.5 to 2.5), and SMN was 1.0% (95% CI 0.7 to 1.4) with an average of 13 events per 100 survivors observed (95%CI 11 to 15). The risk of experiencing multiple events was higher for those treated with chemotherapy drugs with known lung toxicity (HR=1.35, 95%CI 1.09-1.68).

2) Respiratory morbidity in young people surviving cancer: Population-based study of hospital admissions, treatment-related risk factors and subsequent mortality

[Smith et al, Int J Cancer 2019]

This population-based study documents the likelihood of hospitalisation for respiratory conditions associated with earlier cancer treatment and trends in readmissions and subsequent mortality in long-term survivors of cancers diagnosed under 30 years. We found that the risk of hospitalisation

was significantly higher in cancer survivors compared to the general population. Pulmonary toxic chemotherapy was associated with an increased risk of admissions for all respiratory disease especially pneumonia. Subsequent mortality was highest in those admitted for pneumonia compared to other respiratory conditions.

3a) Mental Health of Long Term Survivors of Childhood and Young Adult Cancer: A Systematic Review

[Friend et al, Int J Cancer 2018]

3b) Late effects of childhood cancer

[Friend et al, Lancet 2018].

This review article reported on the frequency and diversity of mental health problems found in adult survivors of childhood and young people's cancer. The review identified 67 published studies highlighting a range of issues including depression, anxiety, behavioural problems and drug misuse. Risk factors for these mental health problems included treatment with high-dose anthracyclines, cranial irradiation, diagnoses of sarcoma or central nervous system tumours and ongoing physical ill health. Weaknesses of the reviewed literature were the use of siblings of survivors as a control group, self-report methodology and lack of indications for prescriptions when prescribing data were used. Furthermore, there was little information on their frequency. We recommended further work to identify childhood cancer patients who are at risk of developing late mental health morbidity, a topic which was explored by Dr Amanda Friend as part of her successful PhD studies.

The accompanying Lancet letter also highlighted why mental health outcomes should be included in any comprehensive evaluation of late effects of childhood cancer treatment.

4) Long term survival after childhood acute lymphoblastic leukaemia: population-based trends in cure and relapse by clinical characteristics

[Smith et al, Br J Haematol 2018]

Statistical "cure models" provide additional metrics useful to identify and describe trends in survival. Additional measures include the proportion cured which is a summary of the long term survival and the median survival of the uncured which give information on those who are not long-term survivors.

In this study we used a statistical cure model to explore trends in long-term survival and relapse for childhood acute lymphoblastic leukaemia (ALL) over time and by clinical characteristics. The proportion of patients cured, defined either by overall survival or relapse free survival, has increased over time while there was slight decrease in the median survival time of the uncured. We also observed a significant reduction in the risk of relapse over time.

5) Describing the variation in hospital activity following diagnosis with cancer for childhood and adolescent cancer in Yorkshire

[A Althumairi, PhD doctoral thesis, 2017]

This study aimed to provide a comprehensive assessment of hospital utilisation among children and young people (CYP). The study included 3,151 cases of cancer aged 0-29 years diagnosed in Yorkshire during 1996-2009, and admitted to hospital during 1997-2011. The study observed a steady increase in admissions over the period. Children had higher median number of admissions (median=25, Interquartile range (IQR): 8-44) than TYAs (median=10, IQR: 3-20), and spent longer in hospital on average with median duration of three and one days per 100 person-days respectively. However, TYA with leukaemia experienced longer stays in hospital on average than children, with a median duration of eight and four days, respectively. Factors that influenced the pattern of admissions varied by cancer type, however relapse status, type of initial treatment and year of diagnosis were significantly related to hospitalisation independently. Cancer survivors had a significantly higher risk of morbidity compared with the general population after treatment completion (standardised hospitalisation rate (SHR) = 2.37, 95% CI: 2.26-2.49).

Service delivery and provision of care

6) Access to principal treatment centres and survival rates for children and young people with cancer in Yorkshire

[Fairley et al, BMC Cancer 2017]

This study described access to Principal Treatment Centres (PTC) for children (0-14 years) and teenagers and young adults (15-24 years) and the associated trends in survival. Between 1998 and 2009, 72% of all patients aged 0-24 years received all their treatment at PTC whilst 13% had no treatment at PTC. Leukaemia patients who received no treatment at PTC had an increased risk of

death which was partially explained by differences in patient case-mix (Adjusted hazard ratio = 1.73 (95% Confidence interval 0.98-3.04). For leukaemia, survival outcomes for low risk patients receiving no treatment at PTC were similar to high risk patients who received all treatment at PTC, implying a benefit of care at the PTC. Soft tissue sarcoma patients who had some or no treatment at PTC had better survival outcomes, which remained after adjustment for patient case-mix (adjusted HR = 0.48 (95%CI 0.23–0.99)), however we were unable to account for differences in stage at presentation, which may confound this finding. There were no significant differences in outcomes for other diagnostic groups (lymphoma, CNS tumours, bone tumours and germ cell tumours).

7) Risk stratification of young adult survivors of cancer to estimate hospital morbidity burden: applicability of a pediatric therapy-based approach.

[Clements et al, J Cancer Surviv 2020]

We investigated the applicability of risk-stratified levels of aftercare in predicting long-term morbidity in young adults, aged 18-29 years. Long-term survivors followed-up at a regional centre in the North of England were risk-stratified by disease and treatments received into one of three levels. These data were linked with local cancer registry and administrative health data (Hospital Episode Statistics, HES), where hospital activity was used as a marker of late morbidity burden. Similar trends in hospital activity were seen for childhood and young adult cancer survivors across National Cancer Survivorship Initiative (NCSI) risk levels. NCSI levels independently predicted long-term hospitalization risk in both childhood and young adult survivors. Risk of hospitalisation was significantly reduced for levels 1 and 2 compared with level 3. We concluded that the NCSI paediatric late-effects risk stratification system can be effectively and safely applied to cancer patients aged 18-29, independent of ethnicity or socioeconomic position.

Cancer Aetiology

We have also conducted aetiological work, for example investigating the influence of population mixing on the risk of developing childhood leukaemia:

8) The association between childhood leukemia and population mixing: an artifact of focusing on clusters?

[Berrie et al, Epidemiology 2019]

Infections have been implicated in the onset of certain childhood cancers, especially childhood leukaemia. Historically, researchers have used a proxy for exposure to infection known as population mixing which is a measure of how diverse migrants are who come into a particular geographical area. However, we showed there is a danger in using a pre-selected area based on specific characteristics such as sudden in-migration into a new town or 'clusters' of cancer, leading to risk estimates which are likely to be severely biased. Analyses instead should focus on region-wide data

National UK response to Covid-19

9) The Register (Feltbower, Glaser) has supported the CCLG and UK Paediatric Oncology Coronavirus Monitoring Project; a clinician-led project to enable tracking of childhood cancer patients who have tested positive for COVID-19 across the UK. UK data suggest that children receiving cancer treatment are not at increased risk of developing symptoms from COVID-19 infection and do well even if on very rare occasions they develop the more serious symptoms associated with COVID-19 infection. This is in keeping with the data emerging from other countries. Rapid dissemination of results to clinicians, the public and families of young people with cancer has been possible. Resultant intelligence has supported generation of evidence based care guidelines and advice to the Royal College of Paediatrics and Child Health and subsequently the Department of Health and NHS England: <https://www.cclg.org.uk/coronavirus-data>.

9. Current projects

- **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 cardio-metabolic 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 measurements and 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.

- An extension of this project is to look in more detail at the impact of cancer treatments on kidney toxicity. Routine bloods tests and measurements held will be enhanced by the collection of urinary analyses, microbiology results, radioisotope measurements and the prescription of any

anti-hypertensive medications. These additional fields will give us a greater insight into the kidney toxicity caused.

- **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.

The aim of the YSRCCYP epidemiological and applied health research programme over the next 3-5 years is to continue to provide world-leading outputs relevant to childhood and young adult cancer patients, survivors and their families, focusing on long-term health and social outcomes.

To deliver these aims, work will address the following objectives:

Objective 1. Continue to deliver classical epidemiological analyses and reports based on the collection and validation of high quality population-based cancer registration data,

working wherever possible with the other UK specialist registers and the National Cancer Registration and Analysis Service (NCRAS) currently within Public Health England (PHE).

Objective 2. Continue our internationally recognised programme of research on childhood and young adult cancer outcomes, building on analyses of physical health morbidity (e.g. metabolic syndrome, second malignancies) whilst extending into other innovative areas of social and psychological morbidity.

Objective 3. Provide added value to the Yorkshire Register by capturing additional contextual information through innovative data linkages with routinely collected administrative data such as Mental Health hospital episodes, education (DfE) and unemployment (DWP) data, and primary care data (TPP and EMIS Health).

Objective 4. Explore the development and novel application of statistical mortality models to determine to what extent the risk of death from cancer has fallen since 2000.

Objective 5. Develop public engagement work for the Yorkshire Register through improving the availability of lay information resources, working in partnership with UseMyData, the Turing Institute and Candlelighters Trust.

- **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 NRYPMMDR 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

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

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13. Recent Publications from the Register

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Smith L, Glaser AW, Peckham D, Greenwood DC, Feltbower RG. Respiratory morbidity in young people surviving cancer: population-based study of hospital admissions, treatment-related risk factors and subsequent mortality. *Int J Cancer* 2018;145:20-28. doi:10.1002/ijc.32066

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14. Presentations from the Register

Increased mental health contacts in teenage and young adult survivors treated in specialist cancer units.

Friend AJ, Smith L, Feltbower RG, Glaser AW.

CCLG Winter Meeting, Nottingham, January 2020 (Oral).

Cumulative burden of subsequent neoplasm, cardiovascular and respiratory morbidity in long-term survivors of childhood and young adult cancer

Smith L, Glaser AW, Greenwood DC, Feltbower RG

51st Annual Congress of the International Society of Paediatric Oncology (SIOP), October 2019, Lyon, France (Poster discussion)

Suitability of WHO Criteria for Quality Assessment in Teenage Boys Undergoing Sperm Banking for Fertility Preservation Prior to Potentially Gonadotoxic Treatment"

Friend, AJ, Newton, HL, Cotterill, M, Hyland, A, Hayden, C, Picton, HM, Glaser, AW.

International Society for Paediatric Oncology Annual Congress, October 2019, Lyon, France. (Poster).

Risks of Azoospermia in Teenagers Following Chemotherapy: A Comparison of Pre- and Post-Treatment Semen Analysis

Newton, HL, Friend, AJ, Cotterill, M, Hyland, A, Hayden, C, Picton, HM, Glaser, AW.

International Society for Paediatric Oncology Annual Congress, October 2019, Lyon, France. (Poster).

Radiographic outcomes of osteonecrosis in young people with acute lymphoblastic leukaemia.

Amin N, Feltbower RG.

British Society of Paediatric Radiology, September 2019, Leeds (Poster).

Long-term survival and late effects for children and young people with cancer

Smith L and Feltbower R

Public Health England, NRCAS Seminar Series (invited seminar), March 2019 (Oral)

Increased mental health contacts in long-term teenage and young adult cancer survivors treated in specialist units

Friend, AJ, Glaser, AW, Feltbower, RG, Smith, LF.

Learning from each other; Joint meeting between the Royal College of Paediatrics, Scottish Paediatric Society and Royal College of Psychiatrists, March 2019. Glasgow, UK. (Oral).

Risk and impact of respiratory hospitalisation among childhood and young adult cancer survivors

Smith L, Glaser AW, Peckham D, Greenwood DC, Feltbower RG

British Thoracic Society Winter Meeting 2018, December 2018, London (Poster)

Long-term respiratory disease among childhood and young adult cancer survivors

Smith L, Glaser AW, Peckham D, Greenwood DC, Feltbower RG
PHE NCRAS Cancer Services, Data and Outcomes Conference 2018, June 2018, Manchester (Oral)

Mental health needs of long term survivors of childhood and young adult cancer
Friend AJ, Glaser, AW, Feltbower RG. Royal College of Paediatrics and Child Health Annual Conference, March 2018, Glasgow, UK (Oral)

Mental Health of Long Term Survivors of Childhood and Young Adult Cancer: a systematic review.
Friend AJ, Glaser AW, Feltbower RG.
49th Annual Congress of the International Society of Paediatric Oncology (SIOP), October 2017, Washington DC, USA (Poster).

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).

Mental Health of Long Term Survivors of Childhood and Young Adult Cancer.
Friend, AJ, Glaser, AW, Feltbower, RG. Children's Cancer and Leukaemia Group Summer Education Meeting, June 2017, London, UK. (Poster).

Osteonecrosis results in significant long term morbidity in patients with acute lymphoblastic leukaemia.
Amin N, Feltbower RG.
International conference on children's bone health. Wuzburg, Germany. June 2017 (Poster)

Bone density and body composition in post-pubertal adolescents treated with GnRH analogues in a gender identity development service.
Amin N, Feltbower RG.
International conference on children's bone health. Wuzburg, Germany. June 2017 (Poster).

Public engagement presentations

Yorkshire Specialist Register of Cancer in Children and Young People: Survival trends and long-term health in Yorkshire
Feltbower RG, Glaser AW.
Candlelighters Trust staff meeting, Feb 2020 (Oral).

GDPR implications for research participation.
Glaser AW.
UseMyData Conference, Leeds, October 2019 (Oral).

Barriers to use of routinely collected health data in research.

Glaser AW.

UseMyData National Meeting, London, July 2019 (Oral).

Mental health contacts in long-term childhood and young adult cancer survivors

Friend, AJ, Glaser, AW, Feltbower, RG, Smith, LF.

Candlelighters Trust seminar, May 2019, Leeds, UK. (Oral).

Children's research in Leeds– using big data.

Glaser AW.

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Q&A session: "The cause & effects of diseases".

Feltbower RG.

Find Your Sense of Tumour conference, November 2017, St George's Park.