

Yorkshire Specialist Register of Cancer in Children and Young People:

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Candlelighters

Supporting the families of children with cancer



Background to the Yorkshire Register

Background



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- The Yorkshire Register has been funded by the Candlelighters Trust for 40 years
- Candlelighters have supported a full-time Research Statistician and Data Collection Manager since 1996
- Held within the Leeds Institute for Data Analytics at the University of Leeds in a secure location
- Responsible for over 200 scientific publications and over 300 invited conference presentations
- Nationally and internationally recognised cancer intelligence and research resource

Purpose



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- To enhance the treatment and care of children and young people in Yorkshire.
- Undertake a programme of epidemiological and applied health research using data from the Yorkshire Register
- To help understand the patterns, causes of cancer, and long-term health and wellbeing of survivors
- To support the academic development of students and junior doctors in Leeds by pursuing research using data from the Yorkshire Register.
- Contribute data to other important regional, national and international studies

Unique Features



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- The only **dedicated UK information resource** holding information on children and young people diagnosed with cancer aged 0-29 years within an academic setting.
- **Fewer than 0.5%** of registrations have ever been lost to follow-up.
- More detailed information on **ethnicity, stage** of disease, **treatment, clinical features** and **relapse** than other regional and national cancer registers.
- Only UK childhood and young adult cancer register able to link records to **primary and secondary care** data, **mental health, educational outcomes, social outcomes**.

Who is involved?



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- Director/Principal Investigator – Prof Richard Feltbower
- Medical Director/Co-investigator – Prof Adam Glaser
- PhD students – Nicola Hughes, Sarah Milner, Kirsten Cromie.
- Data Manager/Database developer – Stephen Cowley.



www.ysrccyp.org.uk

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The Yorkshire Specialist Register of Cancer in Children and Young People (YSRCCYP) is a regional population based register of cancer diagnoses. It contains detailed demographic and clinical information on children and young adults aged 0-29 years diagnosed with cancer since 1974.

The YSRCCYP facilitates a [programme of research](#) investigating the epidemiology of cancer in young people and describing outcomes for long-term survivors.

The YSRCCYP collects personal data so it has very strict data protections. Our [Patients and Survivors](#) section has more information on how we use and protect your data, and the right of individuals and family members to opt-out of data collection.

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FROM
2014
TO
2018

919
patients aged 0-18 were diagnosed in Yorkshire.



184
patients aged 0-18 were diagnosed in Yorkshire per year on average.

Cancer registration in the UK



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- Ethical and regulatory approvals are not trivial
- Permission currently exists to hold and process cancer registration without explicit patient consent
- Section 251 of the NHS Health and Social Care Act 2006
- Overseen by Confidentiality Advisory Group (NHS Health Research Authority) and subject to Annual Review.
- Responsibility to ensure that cancer patients and survivors are informed about the Register so they are aware their data are being processed for research and can opt-out if they wish.



Achievements

Recent successes



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- The first comprehensive analysis of **hospital mental health episodes** following CTYA cancer treatment.
- A comprehensive evaluation of the total, combined burden of **subsequent malignant neoplasms, cardiovascular and respiratory hospitalisations** in long-term survivors.
- The only UK specialist tumour register able to link cancer registration events to **educational outcomes data**.
- The most in-depth cataloguing of cancer treatment and relapse events of any UK tumour register underpinned by new data linkages to **national (SACT) and regional (ChemoCare) electronic chemotherapy data**.

Future research work



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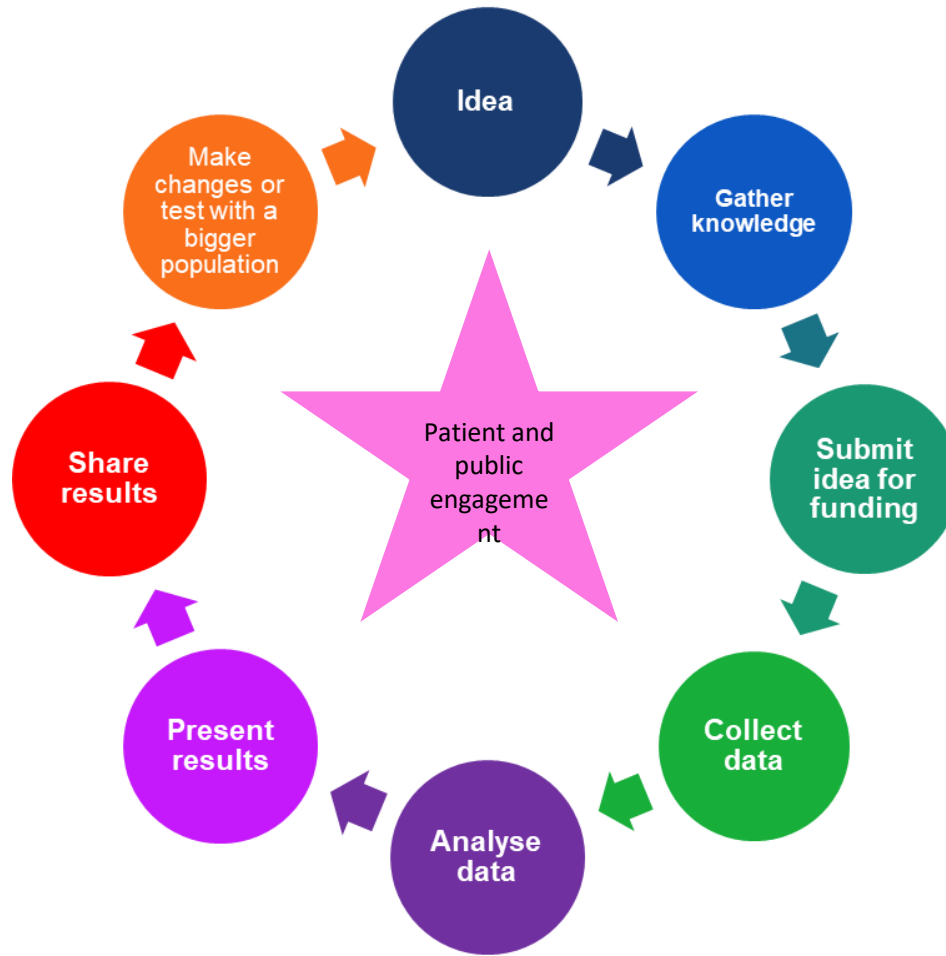
COVID-19: understand the impact on diagnosis (stage of disease), treatment and outcomes

Educational attainment: assess impact of a childhood cancer diagnosis on educational trajectory vs general population – School/College/University.

Primary care: evaluation of the burden of mental health disorders among long-term survivors

Employment status: pilot work to examine feasibility of linking to DWP dataset.







Stages of a research project





So what are the main barriers for researchers?

BMJ Open The road to hell is paved with good intentions: the experience of applying for national data for linkage and suggestions for improvement

Julie A Taylor ,¹ Sonya Crowe ,¹ Ferran Espuny Pujol ,¹ Rodney C Franklin,² Richard G Feltbower,³ Lee J Norman,³ James Doidge ,^{4,5} Doug William Gould ,⁴ Christina Pagel ¹

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ABSTRACT

Background We can improve healthcare services by better understanding current provision. One way to understand this is by linking data sets from clinical and national audits, national registries and other National Health Service (NHS) encounter data. However, getting to the point of having linked national data sets is challenging.

Objective We describe our experience of the data application and linkage process for our study 'LAUNCHES QI', and the time, processes and resource requirements involved. To help others planning similar projects, we highlight challenges encountered and advice for applications in the current system as well as suggestions for system improvements.

Findings The study set up for LAUNCHES QI began in March 2018, and the process through to data acquisition took 2.5 years. Several challenges were encountered, including the amount of information required (often duplicate information in different formats across

Strengths and limitations of this study

- Provide valuable advice and insight to those embarking on research requiring linked national data sets, reassurance to those currently negotiating the system and suggest improvements throughout the data application ecosystem for the future.
- Our experiences will overlap with those of prospective patient recruiting studies and clinical trials.
- This is a single study using linked retrospective audit data, applicability of experiences and advice may vary according to the readers requirements.
- Clinical trials and studies recruiting participants will have a greater document burden than described here, but may also have found that the system was more applicable to their research than for retrospective data analysis.
- The data sets applied for covered English centres only, as national data would have required several



So what needs to change?

A review commissioned by the Secretary
of State for Health and Social Care

Better, Broader, Safer: Using Health Data for Research and Analysis

April 2022

What needs to change?



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Goldacre Review (2022):

“invest in platforms and curation...New analysts, academics and innovators will arrive to find accessible platforms, with well curated data and accessible technical documentation. The startup time for each new project will shrink, productivity will rocket, and lives will be saved.”

What needs to change?



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Goldacre Review (2022):

“**Build a small number of secure analytics platforms** - shared
“Trusted Research Environments” - then make these the norm
for all analysis of NHS patient records data.”

What needs to change?



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Goldacre Review (2022):

“**Rationalise approvals**: create one map of all approval processes; require all relevant organisations to amend it until all agree it is accurate; de-duplicate work by creating a **single common application form** for all ethics, information governance, and other access permissions; **coordinate shared meetings when approval requires multiple organisations**; have researchers available to address misunderstandings of their project; **build institutions to help users who are blocked**; **recognise and address the risk of data controllers asserting access monopolies to obstruct competitors**; publish data on delays annually; ensure high quality Patient and Public Involvement and Engagement (PPIE) is done.”