# YORKSHIRE SPECIALIST REGISTER OF CANCER IN CHILDREN AND YOUNG PEOPLE

## PRESENTATIONS AND PUBLICATIONS (2007-2022)

#### **Publications**

Cromie, K. J., Crump, P., Hughes, N. F., Milner, S., Greenfield, D., Jenkins, A., McNally, R., Stark, D., Stiller, C. A., Glaser, A. W., & Feltbower, R. G. 2022. Data Resource Profile: Yorkshire Specialist Register of Cancer in Children and Young People (Yorkshire Register). *International Journal of Epidemiology*. https://doi.org/10.1093/ije/dyac195

Milner SH, Feltbower RG, Absolom KL, Glaser AW. Social outcomes after childhood illness: the missing measure. Arch Dis Child. 2022:. doi: 10.1136/archdischild-2021-323513.

Clements C, Cromie KJ, Smith L, Feltbower RG, Hughes N, Glaser AW. Risk stratification of young adult survivors of cancer to estimate hospital morbidity burden: applicability of a pediatric therapy-based approach. J Cancer Surviv 2021;15:452-460. doi: 10.1007/s11764-020-00939-y

Amin N, Kraft J, Fishlock A, White A, Holton C, Kinsey S, Feltbower R, James B. Surgical management of symptomatic osteonecrosis and utility of core decompression of the femoral head in young people with acute lymphoblastic leukaemia recruited into UKALL 2003. Bone Joint J 2021; 103-B(3): 589-596. doi:10.1302/0301-620X.103B3.BJJ-2020-0239.R3.

Smith L, Glaser AW, Greenwood DC, Feltbower RG. Cumulative burden of subsequent neoplasms, cardiovascular and respiratory morbidity in young people surviving cancer. Cancer Epidemiol 2020; 66: 101711.

Hughes N and Stark D. The management of adolescents and young adults with cancer. Cancer Treatment Reviews. 2018 June; 67: 45-53.

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 https://doi.org/10.1002/ijc.32066

Berrie L, Ellison GT, Norman PD, Baxter PD, Feltbower RG, Tennant PW, Gilthorpe MS. The association between childhood leukemia and population mixing: an artifact of focusing on clusters? Epidemiology 2018 doi: 10.1097/EDE.00000000000000921

Smith L, Pini S, Ferrari A, Yeomanson D, Hough R, Riis Olsen P, Gofti-Laroche L, Fleming T, Elliott M, Feltbower R, Kertesz G, Stark D. Pathways to diagnosis for Teenagers and Young Adults with cancer in European nations – a pilot study. Journal of Adolescent and Young Adult Oncology 2018; 7(5) DOI: 10.1089/jayao.2018.0045

Smith L, Glaser AW, Kinsey SE, Greenwood DC, Chilton L, Moorman AV, Feltbower RG. Long-term survival after childhood acute lymphoblastic leukaemia: population-based

trends in cure and relapse by clinical characteristics. Br J Haematol 2018; 182: 851-858 doi.org/10.1111/bjh.15424

Friend, A.J., Feltbower, R.G., Hughes, E.J., Dye, K.P. and Glaser, A.W., Mental Health of Long Term Survivors of Childhood and Young Adult Cancer: A Systematic Review. International journal of cancer 2018; Feb 22. doi: 10.1002/ijc.31337

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

Fairley L, Stark DP, Yeomanson D, Kinsey SE, Glaser AW, Picton SV, Evans L, Feltbower RG. Access to Principal Treatment Centres and survival rates for children and young people with cancer in Yorkshire, UK. BMC Cancer 2017; 17: 168

Furness CL, Smith L, Morris E, Brocklehurst C, Daly S, Hough RE. Cancer Patient Experience in the Teenage and Young Adult Population: Key issues and trends over time. An analysis of the national UK National Cancer Patient Experience Surveys 2010-2014. Journal of Adolescent and Young Adult Oncology 2017; 6: 450-458 doi: 10.1089/jayao.2016.0058

Basta NO, Halliday GC, Makin G, Birch J, Feltbower R, Bown N, Elliott M, Moreno L, Barone G, Pearson AD, James PW, Tweddle DA, McNally RJ. Factors associated with recurrence and survival length following relapse in patients with neuroblastoma. Br J Cancer 2016; 115: 1048-1057.

Imam A, Fairley LF, Parslow RC, Feltbower RG. Population mixing and incidence of cancers in adolescents and young adults between 1990 and 2013 in Yorkshire, UK. Ca Cause Control 2016; 27: 1287-1292.

Fairley L, Picton SV, McNally RJQ, Bailey S, McCabe MG, Feltbower RG. Incidence and survival of children and young people with central nervous system embryonal Tumours in the North of England, 1990-2013, Eur J Cancer 2016; 61: 36-43 <a href="doi:10.1016/j.ejca.2016.03.083">doi:10.1016/j.ejca.2016.03.083</a>

Althumairi A, Feltbower RG, van Laar M, Kinsey SE, Glaser AW, Picton SV. Patterns of hospital admissions and length of stay during 1996 to 2011 among children compared with teenagers and young adults after completing treatment following diagnosis with cancer in Yorkshire. Eur J Cancer Care 2015; 24: pp.9-9.

van Laar M, Kinsey SE, Feltbower RG. Survival of Childhood Acute Lymphoid Leukaemia in Yorkshire by Clinical Trial Era, 1990-2011. Br J Haematol 2015; 171: 116-9.

Stark DP, Bowen D, Dunwoodie E, Feltbower RG, Johnson R, Moran A, Stiller CA, O'Hara C. Survival patterns in teenagers and young adults with cancer in the United Kingdom: comparisons with younger and older age groups Eur J Cancer 2015; 51 (17): 2643-54.

O'Hara C, Moran A, Feltbower RG, Stevens MCG, Stiller CA, Whelan JS, Hough RE, Stark DP, McCabe MG. Trends in survival for teenagers and young adults with cancer in the UK 1992-2006. Eur J Cancer 2015; 51: 2039-48.

van Laar M, Stark DP, McKinney P, Parslow RC, Kinsey SE, Picton SV, Feltbower RG. Population mixing for leukaemia, lymphoma and CNS tumours in teenagers and young adults in England, 1996-2005. BMC Cancer 2014; 14: 698.

van Laar M, Feltbower RG, Gale CP, Bowen DT, Oliver SE, Glaser A. Cardiovascular sequelae in long term survivors of young people's cancer – a linked cohort study. Br J Cancer 2014; 110: 1338-1341.

Harbron RW, Glaser AW, Lillee J, Pearce MS, Feltbower RG. Secondary malignant neoplasms following radiotherapy for primary cancer in children and young adults. Ped Hem Onc 2013; 31:259-67.

van Laar M, Kinsey SE, Picton SV, Feltbower RG. Seasonality of diagnosis in cancer amongst 15-24 year olds in England, 1996-2005. BMC Cancer 2013; 13(1):365-374.

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.

Birch RJ, Morris EJ, West RM, Stark DP, Lewis I, Morgan S, Feltbower RG. A cross-sectional survey of healthcare professionals to determine what they believe constitutes 'specialist' care for teenage and young adult patients with cancer. BMJ Open 2013; 3(5).

Lethaby CD, Picton S, Kinsey SE, Phillips R, van Laar M, Feltbower RG. A systematic review of time to diagnosis in children and young adults with cancer. Archives of Diseases in Childhood 2013; 98:349-55.

Fraser LK, van Laar M, Miller M, Aldridge J, McKinney PA, Parslow RC, Feltbower RG. Does referral to specialist paediatric palliative care services reduce hospital admissions in oncology patients at the end of life? British Journal of Cancer 2013; 108:1273-9.

Nicholson BD, Picton S, Chumas P, Dixit S, van Laar M, Loughrey C, O'Reilly G, Stark D, Feltbower RG. 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. Clinical Oncology 2013. 25(3): 205-214.

McNally RJQ, James PW, Picton SV, McKinney PA, van Laar M, Feltbower RG. Space-time clustering of childhood central nervous system tumours in Yorkshire, UK. BMC Cancer 2012. 12(13) doi:10.1186/1471-2407-12-13

van Laar M, McKinney PA, Stark DP, Glaser A, Kinsey SE, Lewis IJ, Picton SV, Richards M, Norman PD, Feltbower RG. Survival trends of cancer among the south Asian and non-south Asian population under 30 years of age in Yorkshire, UK. Cancer Epidemiology 2012. 36(1); e13-e18.

Fraser LK, Miller M, McKinney PA, Parslow RC, Feltbower RG. Referral to a Specialist Paediatric Palliative Care Service in Young Oncology Patients in Yorkshire. Ped Blood Cancer 2011; 56: 677–680. doi: 10.1002/pbc.22667

Feltbower RG, Siller C, Woodward E, McKinney PA, Picton SV, Joffe JK, Stark DS. *Treatment and survival patterns for germ cell tumours among 13-24 year olds in Yorkshire, UK.* Ped Blood Cancer 2011; 56: 282-288.

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. Cancer incidence among the south Asian and non-south Asian population under 30 years of age in Yorkshire, UK. British Journal of Cancer 2010; 103: 1448–1452.

Eyre R, Feltbower RG, James PW, Blakey K, Mubwandarikwa E, Forman D, McKinney PA, Pearce MS, McNally RJQ. *The epidemiology of bone cancer in 0 – 39 year olds in northern England*, 1981 – 2002. BMC Cancer 2010;10: 357.

Manda SOM, Feltbower RG, Gilthorpe MS. *Investigating spatial-temporal similarities in the epidemiology of childhood leukaemia and diabetes*. Eur J Epidemiol 2009; 24:743-52.

Eyre R, Feltbower RG, Mubwandarikwa E, Eden TOB, McNally RJQ. *Epidemiology of bone tumours in children and young adults.* Paed Blood Cancer 2009; 53: 941-952.

Eyre R, Feltbower RG, Mubwandarikwa E, Jenkinson HC, Parkes S, Birch JM, Eden TOB, James PW, McKinney PA, Pearce MS, McNally RJQ. *Incidence and survival of childhood bone tumours in Northern England and the West Midlands, 1981-2002.* Br J Cancer 2009; 100: 188-193.

Feltbower RG, McNally RJQ, Kinsey SE, Lewis IJ, Proctor SJ, Richards M, Shenton G, Windebank K, Skinner R, Stark D, Vormoor J, McKinney PA. *Epidemiology of leukaemia and lymphoma in children and young adults from the north of England, 1990-2002.* Eur J Cancer 2009; 45: 420-427.

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.

Law GR, Feltbower RG, Parslow RC, Gilthorpe MS, Boyle P, McKinney, Roman E What do Epidemiologists mean by 'population mixing'? Paed Blood Cancer 2008; 51: 155-160

Feltbower RG, Kinsey SE, Richards M, Shenton G, Michelagnoli MP, McKinney PA. Survival following relapse in childhood haematological malignancies diagnosed in 1974-2003 in Yorkshire, UK. Br J Cancer 2007; 96: 1147-52.

## Presentations at meetings (2007-2022)

Socio-economic and ethnic inequalities in childhood cancer survival, Yorkshire, UK Cromie KJ, Hughes NF, Milner S, Crump P, Grinfeld J, Jenkins A, Norman PD, Picton SV, Stiller CA, Yeomanson D, Glaser AW, Feltbower RG.

54th Congress of the International Society of Paediatric Oncology (SIOP 2022), October 2022, Barcelona, Spain (Oral)

Understanding data for children's and young people's cancers: a participatory study. Hughes N, Feltbower R, Pritchard-Jones K, Fern L, Gamble A, Carrigan C, Connearn E, Polanco A. 54th Congress of the International Society of Paediatric Oncology (SIOP 2022), October 2022, Barcelona, Spain (poster)

The use of healthcare datasets to investigate the impact of dose intensity in the adolescent and young adult cancer population. Hughes N, Feltbower R and Stark D. International Population Data Linkage Network Conference, September 2022, Edinburgh, UK (poster).

Yorkshire Specialist Register of Cancer in Children and Young People: challenges of data linkage.

Feltbower RG

UseMyData invited seminar, June 2022 (Oral)

Yorkshire Specialist Register of Cancer in Children and Young People: epidemiological and applied health research.

Feltbower RG, Glaser AW

James Cook Hospital, Mar 2022 (Oral)

Achieving consensus on the relevant social outcomes for childhood cancer survivors: a Delphi study protocol

Milner SH, Absolom KL, Feltbower RG, Glaser AW

National Cancer Research Institute Festival, November 2021 (Poster)

Yorkshire Specialist Register of Cancer in Children and Young People: Impact and Outcomes.

Feltbower RG, Glaser AW

Candlelighters Trust Board meeting, Oct 2021 (Oral).

Survival outcomes for children and young people with cancer in Yorkshire Feltbower RG, Glaser AW

Children's Research Forum, Leeds Teaching Hospitals NHS Trust, Apr 2021 (Oral).

Survival outcomes for children and young people in Yorkshire.

Feltbower RG, Glaser AW

Candlelighters Trust Steering Group, Mar 2021 (Oral).

Childhood Cancer: Trends in Survival in Yorkshire, 1997-2016 Cromie KJ, Glaser AW, Jenkins A, Feltbower RF CCLG Winter Meeting, Virtual, February 2021 (Poster)

Yorkshire Specialist Register of Cancer in Children and Young People: Impact and Outcomes.

Feltbower RG, Glaser AW

Candlelighters Trust Board meeting, Jul 2020 (Oral).

YSRCCYP: Survival trends and long-term health in Yorkshire Feltbower RG, Glaser AW. Candlelighters staff meeting, Feb 2020 (Oral).

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)

Long-term survival and late effects for children and young people with cancer Smith L and Feltbower R

Public Health England, NCRAS Seminar Series (invited seminar), March 2019 (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 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 61<sup>st</sup> 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 60<sup>th</sup> 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 60<sup>th</sup> 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.

46<sup>th</sup> 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.

46<sup>th</sup> 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 sequalae 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 sequalae 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 sequalae 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.

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 sequalae 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 sequalae 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 sequalae 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.

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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 sequalae 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 sequalae 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. Manda SOM, Feltbower RG.

International Statistical Institute Conference, August 2009, Durban (Oral)

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

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

National Cancer Intelligence Network Annual Conference, Jun 2009, Birmingham (Oral)

Referrals to Palliative Care in Teenagers with Cancer in the Yorkshire Region Taylor L, Morgan S. Miller M, Feltbower RG.

Teenagers and Young Adults with Cancer (TYAC) Spring Education Day, May 2009 (Oral)

Treatment and survival patterns for germ cell tumours among 13-24 year olds in Yorkshire, UK.

Feltbower RG, Picton SV, Joffe JK, Stark DP.

NCRI Cancer Conference, Oct 2008, Birmingham (Poster).

Incidence and survival for bone tumours diagnosed in 0–14 year olds from Northern England and the West Midlands, 1981–2002.

McNally RJQ, Feltbower RG, Eyre R, Mubwandarikwa E, James PW, Jenkinson HC, Parkes S, Birch JM, McKinney PA, Eden TOB.

NCRI Cancer Conference, Oct 2008, Birmingham (Poster).

Incidence and survival for bone tumours diagnosed in 0–14 year olds from Northern England and the West Midlands, 1981–2002.

McNally RJQ, Feltbower RG, Eyre R, Mubwandarikwa E, James PW, Jenkinson HC, Parkes S, Birch JM, McKinney PA, Eden TOB.

International Society of Pediatric Oncology (SIOP), Sep 2008, Berlin (Poster).

Investigating spatial similarities in the epidemiology of childhood leukaemia and diabetes in Yorkshire, UK using a shared spatial-temporal component model.

Manda SOM, Feltbower RG, McKinney PA, Gilthorpe MS.

International Biometric Society Conference, July 2008, Dublin (Poster).

Treatment and survival patterns for germ cell tumours among 13-24 year olds in Yorkshire, UK.

Feltbower RG, Picton SV, Joffe JK, Stark DP.

Teenage Cancer Trust 5<sup>th</sup> International Conference, June 2008, London (Oral).

Obesity and childhood acute lymphoblastic leukaemia.

Mawdesley A, Feltbower RG, Glaser AW.

Long-term late effects of childhood cancer, Jan 2008, Niagra (Poster).

Epidemiology of haematological cancers in children and young adults aged 0-24 years in the north of England

Feltbower RG, McNally RJQ, Kinsey SE, Lewis IJ, Richards M, Shenton G, Windebank K, Skinner R, McKinney PA.

International Society of Pediatric Oncology (SIOP), Nov 2007, Mumbai (Poster).

Children and Young People's Cancer: Intelligent Commissioning – a joint PHO and Cancer Registries project

Pollock C, Fairley L, Nelson-Smith J, Feltbower R, McKinney P, Forman D, Smith K. UK Association of Cancer Registries, Sept 2007 (Poster)

Epidemiology of haematological cancers in children and young adults aged 0-24 years in the north of England

Feltbower RG, McNally RJQ, Kinsey SE, Lewis IJ, Richards M, Shenton G, Windebank K, Skinner R, McKinney PA.

14<sup>th</sup> European Cancer Conference (ECCO), Sept 2007, Barcelona (Poster).

Epidemiology of haematological cancers in children and young adults aged 0-24 years in the north of England

Feltbower RG, McNally RJQ, Kinsey SE, Lewis IJ, Richards M, Shenton G, Windebank K, Skinner R, McKinney PA.

NCRI Cancer Conference, Sept 2007, Birmingham (Poster).

## Other publications

Agency for Healthcare Quality and Research (2010). Registries for Evaluating Patient Outcomes: A User's Guide" 2<sup>nd</sup> ed Data Linkage: Linking Registry Data to Examine Long-Term Survival, The Yorkshire Specialist Register of Cancer in Children and Young People (YSRCCYP), Feltbower RG, van Laar M, McKinney PA.

Case Example 38: Linking Registry Data to Examine Long-Term Survival, The Yorkshire Specialist Register of Cancer in Children and Young People (YSRCCYP), Feltbower RG, van Laar M, McKinney PA. *Published in:* Chapter 16: Linking Registry Data with Other Data Sources to Support New Studies. Registries for Evaluating Patient Outcomes: A User's Guide, *Agency for Healthcare Research and Quality*, 3rd ed, Volume 2 (2014).

Patient And Public Views On Information, Consent And Data Sharing In The Registry Of Stored Ovarian And Testicular Tissue For Young People In The Uk (Poster). SIOP Conference 2022, Barcelona. Rebecca Mottram, Adam Glaser, Richard Feltbower, Sheila Lane, Rod Mitchell, Richard Anderson. 2022.

#### **Prizes**

Joint best poster prize. 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

"Best Poster Prize". Feltbower RG, Picton SV, Joffe JK, Stark DP. *Treatment and survival patterns for germ cell tumours among 13-24 year olds in Yorkshire, UK.* Teenage Cancer Trust 5<sup>th</sup> International Conference, London, June 2008.

#### **Research Grants**

Hughes N. The use of existing healthcare datasets to determine whether the survival of teenagers and young adults with cancer is associated with the dose and intensity of chemotherapy that they receive. NIHR, £346,583, April 2020 to December 2023

McNally RJQ, Feltbower RG (Co-I), Tweddle D. Factors associated with recurrence and length of survival following relapse in patients with neuroblastoma: a pilot study. Cancer Research UK, £32,100, Oct 2010-Sep 2011.

Birch JM, Feltbower RG (Co-I and PI for Leeds centre), Murphy MG. International Study of non-CNS Embryonal Tumours (ISET) – UK pilot. Identification of environmental and genetic risk factors for embryonal tumours occurring in children and young adults in England. CHILDREN with LEUKAEMIA, £324,539, Apr 2010 - Sep 2011

Feltbower RG (PI), West RM, McKinney PA, Forman D, Lewis IJ. Teenage and Young Adult Cancer in England and Wales: the patient journey experience. Cancer Research UK £102,499, Oct 2008 – Sep 2012, C24098/A9294.

McNally RJQ, Pearce MS, Feltbower RG (Co-I). An epidemiological study of bone tumours in children and young adults. Bone Cancer Research Trust £29,985, Jun 2007– Apr 2008.

McNally,RJQ (PI), Craft AW, Feltbower,RG (Co-I), Parslow RC. *Environmental* contributions to the aetiology of bone tumours in young people: small area analyses Bone Cancer Research Trust £30,495, Jun 2008– May 2009.

## Patient and Public Involvement Workshops

April 2022. Data linkage and data sharing workshop. Workshop two of the collaboration with DATA-CAN, CCLG and TCT exploring in more depth what the data actually looks like and how it is linked. Focused discussions on international data sharing and the use of social outcomes data.

March 2022. Proposal for the UK Register of stored testicular and ovarian tissue for 0-24 year olds (UKSTORE) led by Prof Adam Glaser and RN Rebecca Mottram. A meeting exploring the views of patients, parents and PPI representatives on the use of healthcare data for a national (UK) registry.

January 2022. Understanding data for children's and young people's cancers. A workshop co-hosted with the CCLG, TCT and DATA-CAN exploring the views of patients with young onset cancer and their carers regarding the use of healthcare data for research purposes.