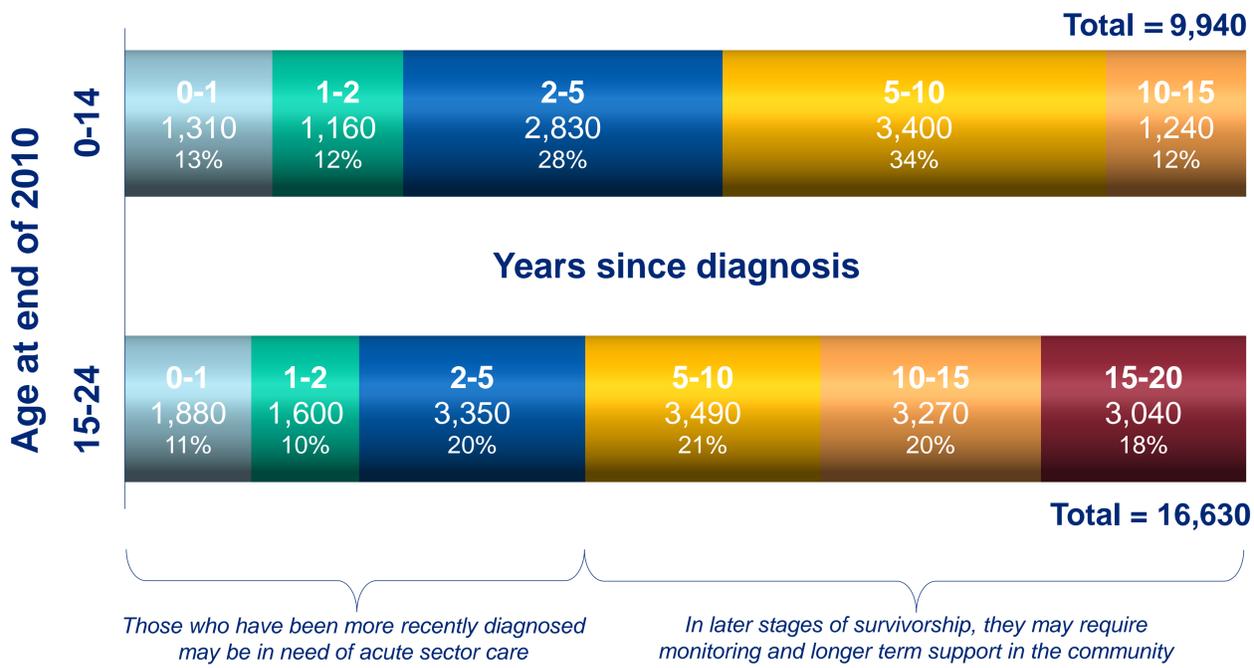


S Miller¹ H McConnell² L Hounsome³ S McPhail⁴ A Moran⁵ M McCabe⁶ L Irvine⁷

¹ Macmillan-NCIN Data Fellow; ² Macmillan Cancer Support; ³ PHE Knowledge and Intelligence Team (South West); ⁴ PHE National Cancer Intelligence Network; ⁵ PHE Knowledge and Intelligence Team (North West); ⁶ Institute of Cancer Sciences, The University of Manchester; ⁷ Macmillan-NCIN Senior Data Fellow

**More than 26,500 children, teenagers and young adults are living with and beyond cancer in the UK
accounting for just under 2% of cancer survivors alive at the end of 2010 who were diagnosed 1991-2010**

Children, teenagers and young adults living with and beyond cancer in the UK aged 0-24 at the end of 2010, diagnosed 1991-2010



Introduction and methods

Research shows that two million people are currently living in the UK with a cancer diagnosis¹. However, there is little granular information on this cancer survivorship population.

The Macmillan-NCIN Work Plan aims to identify the characteristics and needs of cancer survivors in the UK, to inform and improve service development.

The 'Segmentation of the 2 million' project involves quantifying the number of people living with and beyond cancer in the UK and 'segmenting' the data by a range of parameters including age, sex, time since diagnosis, national sub-geographies, deprivation and cancer type².

Using patient-level routine datasets from the National Cancer Data Repository³ we present here the results of analysis of **20-year** limited-duration UK cancer prevalence, for the period 1991-2010 (with the index date 31st December 2010) for children, teenagers and young adults.

Data presented here relate to children, teenagers and young adults aged 0 to 24 at the end of 2010.



Cancer prevalence

The number, or proportion, of people still alive on a given date who have been diagnosed with cancer in the past

Unique needs of children, teenagers and young adults

Children, teenagers and young adults (CTYA) have different needs to other sections of the cancer survivorship population.

Younger people may experience effects both during and after treatment on their physical growth, fertility, academic achievement, family life, emotions and social relationships; they are also at increased risk of developing secondary tumours⁴.

What can the prevalence data tell us?

Prevalence is a composite measure of incidence, mortality and survival. Knowing the **number, location** and **characteristics** of children, teenagers and young adults who are currently living with and beyond cancer in the UK is crucial in providing commensurate support and services. Outlined below are key data about the CTYA survivorship populations in England, Northern Ireland, Scotland and Wales.

NORTHERN IRELAND

Number of cancer survivors aged 0-14
316
47% ♀ 53% ♂

18% least deprived
18% most deprived

43% long-term survivors

Number of cancer survivors aged 15-24
502
46% ♀ 54% ♂

20% least deprived
20% most deprived

57% long-term survivors

WALES

Number of cancer survivors aged 0-14
508
49% ♀ 51% ♂

18% least deprived
24% most deprived

46% long-term survivors

Number of cancer survivors aged 15-24
832
43% ♀ 57% ♂

20% least deprived
21% most deprived

60% long-term survivors

Number of cancer survivors aged 0-24



SCOTLAND

Number of cancer survivors aged 0-14
774
46% ♀ 54% ♂

22% least deprived
21% most deprived

50% long-term survivors

Number of cancer survivors aged 15-24
1,404
47% ♀ 53% ♂

19% least deprived
19% most deprived

59% long-term survivors

ENGLAND

Number of cancer survivors aged 0-14
8,345
45% ♀ 55% ♂

19% least deprived
25% most deprived

47% long-term survivors

Number of cancer survivors aged 15-24
13,893
46% ♀ 54% ♂

20% least deprived
23% most deprived

59% long-term survivors

UK cancer survivors aged 0 to 14 3 most common cancers (groupings based on ICD-10 codes)

Cancer type	ICD-10 code	Number
Leukaemias	C910, C911, C920, C921, C924, C925, C930, C940, C942	3,653
Central Nervous System Including Brain	C70-C72, C751-C753, D32, D33, D352-D354, D42, D43, D443-D445	2,347
Kidney	C64, C65, C66, C68	888

Children, teenagers and young adult cancer survivors have most commonly been diagnosed with leukaemias and cancers of the central nervous system, including the brain. The tables here show the top 3 cancer groupings that have affected children versus teenagers and young adults.

The CTYA cancer survivorship population is diverse and includes patients in active treatment, longer term survivors who may later die from their disease, those who may be in the terminal phase, requiring palliative care, and others who may be cured.

Children, teenagers and young adults are a unique sub-set of the population and these data should prove useful for commissioners, public health bodies, healthcare professionals and social care and educational providers. These new figures have the potential to help us understand and improve services for, and experiences of, younger cancer survivors and their families.

The analysis presented here relates to cancer survivors who were aged 0-24 at the end of 2010. It is also useful to know that 48,600 people were alive at the end of 2010, who were aged 0-24 at the time of diagnosis - meaning some survivors would be in their 30s and 40s at the end of the period.

As this is 20-year prevalence, we would expect the number of cancer survivors **ever** diagnosed as CTYA to be higher. For the next project phase we aim to calculate 'complete prevalence', to estimate the **total** number of people living with and beyond cancer.

UK cancer survivors aged 15 to 24 3 most common cancers (groupings based on ICD-10 codes)

Cancer type	ICD-10 code	Number
Leukaemias	C910, C911, C920, C921, C924, C925, C930, C940, C942	3,899
Central Nervous System Including Brain	C70-C72, C751-C753, D32, D33, D352-D354, D42, D43, D443-D445	3,737
Lymphomas	C81-C85	3,236

References

1. J. Madsen, D. Brewster, A. Gavin, et al. *Cancer Prevalence in the United Kingdom: estimates for 2008*. Br J Cancer 2009; 101(3):541-547.
2. NCIN. 2014. Macmillan-NCIN work plan - Segmenting the cancer population. All cancers combined 20-year prevalence at the end of 2010, UK. https://www.ncin.org.uk/about_ncin/segmentation
3. Diagnosed cancers extracted from National Cancer Data Repository (NCDR); National Cancer Registration Service (NCRS) & NCIN, accessed April 2014. CLIC Sargent. The Impact of Cancer on a Child's World: The views of children aged 7-13 living with and beyond cancer, 2010. http://www.clicsargent.org.uk/sites/files/clicsargent/field_document/TheImpactofCanceronChildsWorld-FullReport.pdf
4. http://www.clicsargent.org.uk/sites/files/clicsargent/field_document/TheImpactofCanceronChildsWorld-FullReport.pdf

Prevalence data were calculated for a 20-year period, 1991-2010, for England, Scotland and Wales, and for an 18-year period (1993 to 2010) for Northern Ireland.



The 'all cancers' figures in this poster relate to all malignant neoplasms excluding non-melanoma skin cancer (ICD-10 codes C00-C97, excluding C44).

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