

Statistical bulletin

Childhood cancer survival in England: children diagnosed from 1990 to 2008 and followed up to 2013

Long-term trends in the number of children (aged 0 to 14) surviving cancer 5 years after diagnosis.

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1. Main points

- For all childhood cancers combined, the general trend of increasing 5-year survival has continued for all children (aged 0 to 14 years) diagnosed in the 19 years from 1990 to 2008
- The improvements in 5-year survival for children reflect improvements for children diagnosed in each of the age groups (0 to 4 years, 5 to 9 years and 10 to 14 years)
- Interpretation should be focused on overall trends up to 2008, rather than the survival estimates for any
 particular year. This is because the number of children diagnosed each year is relatively small and the
 survival estimates for single calendar years are therefore less stable

2. Summary

This bulletin includes data on survival for all children (0 to 14 years) diagnosed with cancer (Background note 1) in England during the 19-year period from 1990 to 2008 and followed up to 31 December 2013. It presents estimates of 5-year overall survival (Background note 2) for all cancers combined. Survival estimates are reported by age group and for all ages combined, both unstandardised and age-standardised (Background note 3).

This is our second bulletin on childhood cancer survival in England. These statistics were prompted by the introduction of an indicator on 5-year cancer survival for patients under 15 years in the NHS Outcomes Framework 2013 to 2014. The NHS Outcomes Framework was established to monitor overall changes in performance of the NHS and the quality of health outcomes.

The data for our first bulletin (ONS 2013) were provided by the Childhood Cancer Research Group, University of Oxford, using data from the National Registry of Childhood Tumours (NRCT). The Childhood Cancer Research Group was disbanded in 2014, and the NRCT dataset was frozen, with 2010 the most recent complete year of incidence registrations. To allow the continued production of 5-year survival for the NHS Outcomes Framework indicator data were used from the National Cancer Registration Service to produce the estimates in this publication (Background note 6).

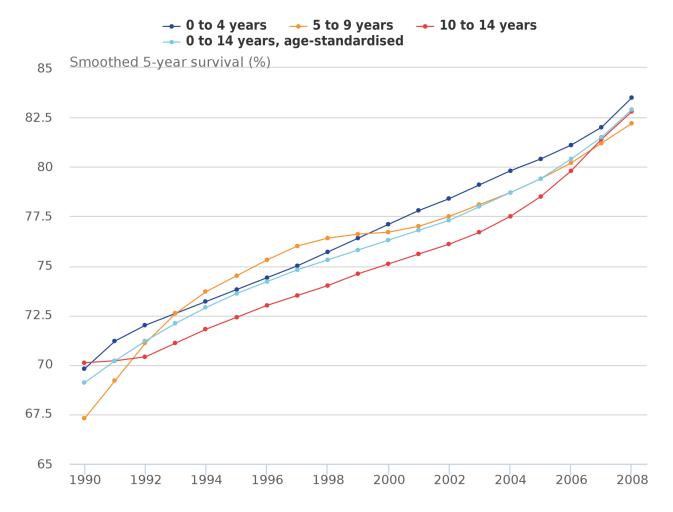
3. Collaboration

The cancer registration data in this publication have been collected by the National Cancer Registration Service in Public Health England. This publication is produced in partnership with the Cancer Research UK Cancer Survival Group, at the London School of Hygiene and Tropical Medicine.



4 . 5-year survival for children diagnosed between 1990 and 2008

Figure 1: Smoothed 5-year survival (%) for children diagnosed with cancer in England between 1990 and 2008, by age at diagnosis, and age-standardised survival for all ages combined



Source: Office for National Statistics, London School of Hygiene and Tropical Medicine

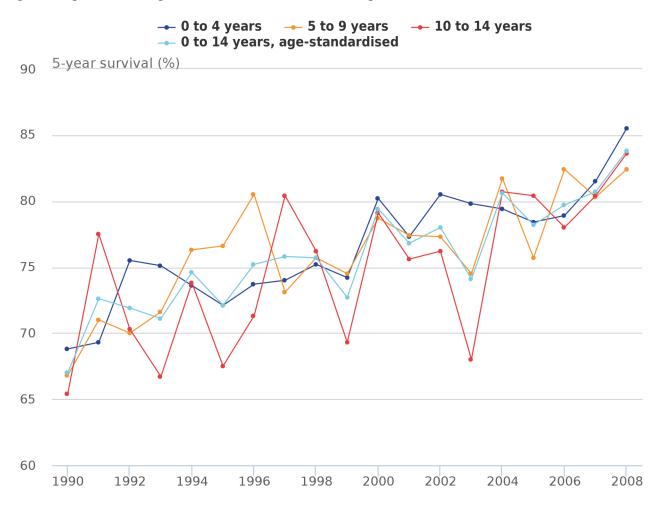
Notes:

- 1. Children aged 0 to 14 years
- 2. The time series has been smoothed to show the underlying trend (Background note 4). Care should be taken in interpreting estimates near the end of the curves, because trends are likely to change as more recent data points become available
- 3. The vertical axis of Figure 1 has been fixed between 65% and 90% to display the trends clearly for each age group
- 4. Cancer survival has improved for all 3 age groups, with a higher percentage of children surviving 5 years after diagnosis in 2008 than in 1990

The trend in 5-year cancer survival for children has shown steady improvement throughout the period 1990 to 2008. For the first 5 years (1990 to 1994), 5-year age-standardised survival was consistently below 75% (Figures 1 and 2). For the last 5 years (2004 to 2008), 5-year survival was consistently above 78%. The increases in 5-year survival for children reflect improvements in each of the age groups (0 to 4 years, 5 to 9 years and 10 to 14 years). Increases in survival could be due to improvements in treatment and supportive care.

The increases in survival for many of the principal types of childhood cancer occurred in parallel with clinical trials in the same period of time (Stiller et al, 2012). More than half of all childhood cancers diagnosed between 1990 and 2008 were either leukaemias (32%) or malignant neoplasms of the brain and central nervous system (24%; ONS, 2012).

Figure 2: 5-year survival (%) for children diagnosed with cancer in England between 1990 and 2008, by age at diagnosis, and age-standardised survival for all ages combined



Source: Office for National Statistics, London School of Hygiene and Tropical Medicine

Notes:

- 1. Children aged 0 to 14 years
- 2. Interpretation should be focused on overall trends up to 2008, rather than the survival estimates for any particular year. This is because the number of children diagnosed each year is relatively small, and the survival estimates for single calendar years are therefore less stable
- 3. The vertical axis of Figure 2 has been fixed between 65% and 90% to enable comparison between Figure 1 and Figure 2
- 4. Fluctuations in cancer survival are due to small numbers of childhood cancer diagnoses, and deaths, each year in England. Therefore focus should be on the overall trend rather than on survival estimates for any individual year

There are year-on-year fluctuations in cancer survival; however the overall trend of improvement is still evident (Figure 2). The fluctuations in cancer survival are due to the small numbers of cancer diagnoses and deaths each year among children in England. Therefore the focus should be on the overall trend rather than on the survival estimates for any individual year. For example, care should be taken when interpreting the large increase observed in cancer survival in all age groups in the year 2008. This may be due to fluctuation in the time series rather than a genuine acceleration in improving cancer survival. We cannot be certain that there has been a genuine change in this trend until 5 years of follow-up data are available for children diagnosed in more recent years.

5. Users and uses

The main users of cancer survival estimates include the Department of Health, academics and researchers, cancer charities, cancer registries, other government organisations and our own researchers, the media and the general public. The Department of Health uses cancer survival figures to brief government ministers, and as part of the evidence base to inform cancer policy and programmes, for example in drives to improve survival.

Our cancer survival estimates are also included as indicators in the NHS Outcomes Framework and the Clinical Commissioning Group Indicator Set, which are used to hold the NHS and commissioners to account. Academics and researchers use the figures to inform their research. Similarly Public Health England and other government organisations use the figures to carry out individual and collaborative projects.

Charities use the data to provide reliable and accessible information about cancer to a wide range of groups, including patients and health professionals via health awareness campaigns and cancer information leaflets and web pages. Our own researchers use the data to support further research and to publish alongside other National Statistics.

6. Policy context

In <u>Improving Outcomes: A Strategy for Cancer</u> (January 2011), the Department of Health stated that, although improvements have been made in the quality of cancer services in England, a significant gap remains in survival compared with the European average. Survival estimates for cervical, colorectal and breast cancers are some of the lowest among member states of the <u>Organisation for Economic Co-operation and Development</u> (OECD). The strategy document sets out how the Department of Health aims to improve outcomes for all cancer patients and improve cancer survival, with the aim of saving an additional 5,000 lives every year by the financial year ending 2015.

Outcomes strategies set out how the NHS, public health and social care services will contribute to the ambitions for progress agreed with the Secretary of State in each of the high-level outcomes frameworks. The indicator set for the NHS Outcomes Framework focuses on measuring health outcomes includes 1- and 5-year cancer survival indicators for all cancers combined, and for colorectal, breast and lung cancers combined.

7. Authors

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8. Acknowledgement

The National Cancer Registry at the Office for National Statistics and the London School of Hygiene and Tropical Medicine wish to acknowledge the work of the National Cancer Registration Service in Public Health England, which provides the raw data for analyses.

9. Additional Information

Further information about our cancer survival estimates can be found in the <u>Cancer Survival Quality and Methodology Information paper</u>. These are overview notes containing key qualitative information on the quality of statistics and a summary of the methods used to compile the output.

Statistics on cancer are produced:

- in Scotland by the <u>Scottish Cancer Registry</u>
- in Wales by the Welsh Cancer Intelligence and Surveillance Unit
- in Northern Ireland by the <u>Northern Ireland Cancer Registry</u>

10. References

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Office for National Statistics. Cancer Survival for Children in England, Children Diagnosed 19902006 and Followed up to 2011. Published: 10 December 2013

Stiller CA, Kroll ME, Pritchard-Jones K. Population survival from childhood cancer in Britain during 19782005 by eras of entry to clinical trials. Ann Oncol 2012; 23: 24642469

11. Background notes

- 1. All children (aged 0 to14 years) resident in England who were diagnosed between 1990 and 2008 with a malignant neoplasm of any organ, or a non-malignant neoplasm of the brain and central nervous system (CNS), as defined in the third edition of the International Classification of Childhood Cancer, were considered eligible for inclusion in the survival analyses. This is equivalent to including ICD-10 site codes C00-C43, C45-C76, C80-97, D33 and D43. Children whose tumour was only reported on a death certificate were excluded, because their duration of survival is unknown.
- 2. We report the cumulative probability of all-cause (overall) survival up to 5 years after diagnosis using the Kaplan-Meier method. This means that all deaths are included in the analysis, whatever the cause of death written on the death certificate. This is different to the procedure used in adults, for whom the net survival indicator is used, in order to compensate for mortality from other causes, which may be considerable. For children with cancer, overall survival is considered a reliable estimator of cancer survival because, unlike in adults, death within 5 years of diagnosis is almost always due to the cancer.

- 3. Survival varies with age at diagnosis, and the age profile of patients can change over time. To enable comparison of overall survival in the age range 0 to 14 years over long periods of time, age-standardised estimates are calculated as a weighted sum of the age-specific survival estimates. For children, it is conventional to use equal weights for the each of the 5-year age groups (0 to 4, 5 to 9 and 10 to 14 years), by taking the simple arithmetic mean of the age-specific survival estimates.
- 4. Figure 1 presents smoothed 5-year survival estimates to show trends over time. These data have been smoothed using the "lowess" technique (locally weighted scatterplot smoothing) because of the year-to-year variation in the survival estimates. The "lowess" technique is one of many techniques used to smooth fluctuating estimates in order to highlight patterns in the data such as temporal trends (Cleveland 1979). As Figure 1 presents smoothed trends, the values plotted in the graph are not identical to the survival estimates in the reference table.
- 5. When the data for this report were extracted for analysis on 22 May 2014, cancer registrations for children diagnosed in 2008 were believed to be at least 99% complete. Each patient's vital status at 31 December 2013 was known for over 99% of cancers registered during 2008. As in other countries, cancer registration is a dynamic process: a small number of late registrations may arrive up to 5 years after the end of a given calendar period, and other registrations may be amended or deleted. The figure of 99% completeness is based on the average number of cases for the 3 previous years (2005 to 2007), including late registrations received after publication of the data for those years.
- 6. The cancer registration data in this publication have been collected by the National Cancer Registration Service in Public Health England. The data for the first bulletin (ONS 2013) were provided by the Childhood Cancer Research Group, University of Oxford, using data from the National Registry of Childhood Tumours (NRCT). The Childhood Cancer Research Group was disbanded in 2014 and the NRCT dataset was frozen, with the most recent complete year of incidence registrations for 2010. The number of incident cases varies slightly between the 2 data sources and therefore the survival estimates differ slightly between the first and second bulletin. There is no significant difference between equivalent survival estimates in the 2 bulletins.
- 7. A list of the names of those given pre-publication access to the statistics and written commentary is available in <u>Pre-release Access List: Cancer survival for children in England: children diagnosed from 1990 to 2008 and followed up to 2013</u>. The rules and principles which govern pre-release access are featured within the <u>Pre-release Access to Official Statistics Order 2008</u>.
- 8. The Office for National Statistics (ONS) is the executive office of the UK Statistics Authority, a non-ministerial department which reports directly to Parliament. ONS is the UK government's single largest statistical producer. It compiles information about the UK's society and economy, and provides the evidence-base for policy and decision-making, the allocation of resources, and public accountability. The Director General of ONS reports directly to the National Statistician who is the Authority's Chief Executive and the Head of the Government Statistical Service.
- 9. Any enquiries regarding this document/publication should be sent to us at:

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11. Details of the policy governing the release of new data are available by visiting www.statisticsauthority.gov.uk/assessment/code-of-practice/index.html or from the Media Relations Office email: media.relations@ons.gsi.gov.uk