

Debate Pack

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By Thomas Powell,

Carl Baker,

Sarah Barber,

Elizabeth Rough,

Aaron Kulakiewicz

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Childhood cancer outcomes

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Overview

Cancer in children is rare. Public Health England (PHE) analysis shows that, between 1997 and 2016, there was an annual average of 1,645 cases of cancer in the UK diagnosed in 0-14 year olds and 2,110 per year diagnosed in 15-24 year olds.¹ PHE added, however, that cancer remains the “most common cause of childhood death outside of infancy, and the most common disease-related cause of death in teenagers and young adults: only accidents and suicide are responsible for more deaths in this age group”.²

The types of cancer diagnosed in children tend to be different to those seen in adults. Some more common cancers in adults are very rarely seen in children, and there are certain cancers that almost exclusively affect children. Cancer Research UK reports that the most common types of cancer in children are acute leukaemias and cancers of the brain and spinal cord.³ Data published by PHE indicates that leukaemias account for about a third of all cancer cases in children and young people.⁴ Other, rarer, cancers that affect children include, retinoblastoma (a type of eye cancer), Wilm’s tumours (kidney cancer) and muscle or bone cancers.

Treatments for children’s cancer vary depending on the type and site of the cancer. They may include chemotherapy, radiotherapy, surgery and stem cell and bone marrow transplants.⁵

Generally, survival rates for childhood cancer are higher than adult cancers. The UK Health Security Agency reports that “more than eight out of ten young people diagnosed with cancer survive at least five years, and many of these are cured”.⁶

While survival rates are generally improving, childhood cancer and the treatments (which can sometimes last months or years) have a significant impact on a child and their family. Cancer Research UK states that survival rate statistics do not “reflect anything about quality of life after treatment”.⁷

¹ Public Health England, [Children, teenagers and young adults UK cancer statistics report 2021](#), March 2021, p4

² Public Health England, [Children, teenagers and young adults UK cancer statistics report 2021](#), March 2021, p3

³ Cancer Research UK, [What is children's cancer?](#), October 2020

⁴ Public Health England, [Children, teenagers and young adults UK cancer statistics report 2021](#), March 2021, p4, UK Health Security Agency, [Cancer in children and young people – what do the statistics tell us?](#), March 2021

⁵ Children’s Cancer and Leukaemia Group, [Treatment](#), not dated, accessed 12 April 2022

⁶ UK Health Security Agency, [Cancer in children and young people – what do the statistics tell us?](#), March 2021

⁷ Cancer Research UK, Science blog: [Different challenges, same determination: how we’re tackling children’s and young people’s cancers](#), 25 September 2020

Many children and young people will experience serious long-term side effects from the cancer treatment they have received and young people who have survived cancer may be affected by the impacts of the disease and the treatment throughout their lives.⁸

1.1 Cancer services for children

The National Institute for Health and Care Excellence (NICE) guidance on [Improving Outcomes in Children and Young People with Cancer](#) (CSG7, 2005) recognises cancer in childhood is rare and includes a wide range of cancers with small numbers of patients with each type of cancer. Hence, in order to improve treatment and survival of cancers, the national approach has been to commission these services for large populations of at least 2 million to maximise the opportunities for standardising care and evaluating outcomes. NHS England's service specification for paediatric oncology sets out that care is centralised in Principal Treatment Centres (PTCs) for Children's Cancer to ensure depth and breadth of cancer coverage.⁹

Following Sir Mike Richards' independent review of the service specification for children's cancer PTCs, the NHS England Board accepted his recommendations, including that all children's PTCs must be co-located on the same site with level 3 paediatric critical care and other specialised children's services. In November 2021 NHS England published the final PTC service specification and the linked specification for Paediatric Oncology Shared Care Units (POSCU).¹⁰ The aim of the service specifications is to improve the outcomes and experience of children and young people with cancer.

Health and Care Bill: cancer outcomes amendments

On 30 March 2022, during the Commons consideration of Lords amendments to the Bill, Lords amendments 2, 3 and 4, were accepted, which relate to cancer objectives in the NHS mandate. The amendments aim to change the focus of the cancer outcomes objectives so that they capture all cancer interventions. The Minister, Edward Argar, said these objectives will have priority over any other objectives relating to cancer, not just those relating specifically to "treatment". The Minister thanked John Barron, and the cross-party support from Members of the Commons and Lords pushing for these amendments.¹¹

⁸ CCLG, [Aftercure: for teenage and young adult survivors of childhood cancer](#), March 2015

⁹ From 2013 the children's cancer pathway has been commissioned through NHS England as a prescribed service. Clinical Commissioning Groups (CCGs) and Local Authorities may directly, or through other collaborative arrangements, commission other elements of the pathway.

¹⁰ [NHS England, Children's cancer services: Paediatric oncology shared care unit service specification \(2021\)](#)

¹¹ [Commons Hansard, 30 March 2022, c935](#)

The impact of the pandemic on cancer services

The Government has said that cancer services have continued throughout the pandemic. A PQ response on 27 January 2021 noted that the strategy for maintaining services through the second wave of Covid-19 concentrated on maintaining or stepping up hubs for cancer surgery and maximising independent sector use, along with further rolling out of Rapid Diagnostic Centres.¹² NHS England has launched the [Help Us Help You campaign](#) to urge people with potential symptoms of cancer to see their GP. NHS England announced a further [campaign to combat the fear of cancer](#) on 1 March 2022.

NHS England published a [cancer services recovery plan](#) on 14 December 2020. The plan outlines actions under the three key aims for recovering cancer services. These are to restore demand at least to pre-pandemic levels, take immediate steps to reduce the number of people waiting over 62 days from urgent referral and ensure sufficient capacity to meet demand.

The [Delivery plan for tackling the COVID-19 backlog of elective care](#), published on 8 February 2022, noted that the NHS has continued to prioritise cancer treatment throughout the pandemic and said “we have consistently seen record levels of urgent suspected cancer referrals since March 2021. To maintain this focus, our ambition is that, by March 2024, 75% of patients who have been urgently referred by their GP for suspected cancer are diagnosed or have cancer ruled out within 28 days.”

The Health and Social Care Committee undertook an inquiry on cancer services, including the impact of disruption to services during the Covid-19 pandemic. This has included oral evidence from the Department of Health and Social Care and NHS England on 20 January 2022 ([Oral evidence: Cancer Services, HC 551 2021-22](#)). Other evidence, including from NHS providers and cancer charities, can be found on the [Committee inquiry website](#). The Committee’s final report was published on 5 April 2022.¹³

A number of news stories on cancer and Covid-19 can be found on the [Cancer Research UK website](#).

1.2

Research into childhood cancers

Funding for medical research in the UK is provided by both the public and private sectors, as well as charities and non-governmental organisations. The latest data from the UK Clinical Research Collaboration (UKCRC – a partnership of the main stakeholders who influence clinical research across the business, public and charitable sectors in the UK) indicated that, in 2018, there were over 3,000 direct awards for “cancer and neoplasms” research,

¹² PQ 114231, [Health Services: Coronavirus, 27 January 2021](#)

¹³ Health and Social Care Committee, [Cancer services](#) (HC551, 5 April 2022)

amounting to a total spend of £483 million (18.9% of the total health research spend).¹⁴ The UKCRC report does not provide a breakdown of what type of cancer the research funding was directed towards, so it is not possible to state what proportion of the funding went to ‘childhood cancers’.

Public funding

National Cancer Research Institute

The [National Cancer Research Institute](#) (NCRI – a UK-wide partnership between cancer research funders) published an analysis in January 2014 of [Funding of children’s cancer research](#). The data presented in the report is from 2008 and thus is now 14 years old. The NCRI’s “international data set”, which included research awards made in the United States, UK, Canada, the Netherlands and France showed that \$5.1 billion was spent on cancer research in 2008 “of which \$163.5 million (3.2%) had an identifiable association with children’s cancer”:

Of this \$163.5 million, two-thirds was from funders in the USA, one-fifth from the UK, and the remainder from Canada, the Netherlands and France.

[...]

In the UK data set, the total spend by NCRI Partners was \$913.0 million, of which \$32.0 million (3.5%) had an identifiable association with children’s cancer.¹⁵

The NCRI also has an online tool that that allows users to search for [research spend by research and disease site](#) over the years, up to and including 2020/21.

A response to a Parliamentary Question in March 2022 provided the following figures on annual spending on cancer research (across all age groups) in the UK through NCRI partners between 2017/18 and 2019/20:

Table 1 Annual spending on cancer research in the UK through NCRI partners between 2017/18 and 2019/20

2017/18	£682 million
2018/19	£687 million
2019/20	£669 million

Source: [PQ 126876](#) [on Cancer: Research] 17 March 2022

¹⁴ UK CRC, [UK Health Research Analysis 2018](#), published 2020, p33

¹⁵ National Cancer Research Institute, [Funding of children’s cancer research: 2008 data from the International Cancer Research Partnership portfolio](#), January 2014

National Institute for Health Research

The [National Institute for Health Research](#) (NIHR) is primarily funded by the Department of Health and Social Care and is the nation's largest funder of health and care research.

A Parliamentary Question tabled in October 2021 asked how much the Department of Health and Social Care (DHSC) spent on childhood cancer research in the last three years. The Government responded that while the DHSC funded research through the NIHR, the “NIHR does not categorise research studies by age group or by type of childhood cancer”, thus making it difficult to know proportion of NIHR cancer research expenditure went towards childhood cancers.¹⁶ In its Response to a 2020 e-petition on [Fund research for childhood cancers with the worst survival rates](#), the Government stated that, overall, “NIHR cancer research expenditure has risen from £101 million in 2010/11 to £132 million in 2018/19, the largest investment in a disease area”¹⁷, rising to £138 million in 2019/20.¹⁸

Cancer Research UK

In September 2019, Cancer Research UK published a '[refreshed](#)' [research strategy](#) for children’s and young people’s cancers. It aims to “improve survival across the board and reduce long-term side effects” of children’s cancers. Some of the challenges CRUK identified in researching children’s cancers included:

- Too few researchers
- Too little discovery research
- Not enough industry support
- Poor awareness
- Fragmented expertise
- Lack of research tools

To build research capacity in the UK, CRUK has:

- launched a new, [national funding call](#) to create momentum for the field, to support current researchers in answering questions in children’s and young people’s cancers and attract researchers from other research areas

¹⁶ [PQ 60393](#) [on Cancer: Research], 27 October 2021

¹⁷ Petitions - UK Government and Parliament, [Fund research for childhood cancers with the worst survival rates](#), closed 5 September 2020

¹⁸ [PQ 93921](#) [on Breast Cancer: Research], 6 January 2022

- launched a second, parallel, [international funding call](#) to drive multidisciplinary, transatlantic collaboration and knowledge sharing.¹⁹

¹⁹ Cancer Research UK, [Statement of Intent for Children's and Young People's Cancer Research](#), September 2019

2 Parliamentary Material

2.1 Debates

[Childhood Cancers: Research](#)

07 Dec 2020 | House of Commons | Westminster Hall | 685 cc259-282WH

Motion that this House has considered e-petition 300027, relating to research into childhood cancers. Agreed to on question. Sitting suspended.

2.2 Early Day Motions

[Childhood Cancer Awareness Month and acute lymphoblastic leukaemia](#)

428 (session 2021-22)

14 Sep 2021

Kirsten Oswald

That this House acknowledges that September is Childhood Cancer Awareness Month; notes that blood cancers are the most common cancers affecting children and young people and that acute lymphoblastic leukaemia (ALL), a type of leukaemia where cancerous cells build up in the bone marrow, is the most common cancer diagnosed in children, further notes that ALL is an acute leukaemia, which means it develops quickly and needs treatment straight away; recognises there are around 790 diagnoses of ALL in the UK each year, including over 500 in people aged under 25; welcomes signs that improvements in outcomes for children and young people with ALL have been driven by improvements in treatment related to clinical trials, including the use of CAR-T therapy, which has been effective in curing some patients with advanced cancers where other treatments have failed; expresses its appreciation for the work of groups such as the Teenage Cancer Trust and Children's Cancer and Leukaemia Group who are working to provide and improve the care and treatment of young people with ALL, supporting them and their families through the aftermath of a diagnosis and the extended period of treatment, which may last for two or more years; and calls on the Government to provide additional funding and support for research into promising treatments, such as CAR-T therapy, and effective means of recognising the signs and symptoms of ALL and other childhood cancers to ensure early diagnosis, which plays such an important role in ensuring survival from these distressing diseases.

2.3

Parliamentary Questions

Cancer: Children

07 Apr 2022 | 138140

Asked by: Damien Moore

To ask the Secretary of State for Health and Social Care, what steps his Department is taking to ensure that a variety of treatments are available for children with cancer.

Answering member: Maria Caulfield | Department: Department of Health and Social Care (DHSC)

The NHS Long Term Plan commits to improve the outcomes and experience of children, teenagers and young adults with cancer. These include implementing networked care; simplifying pathways and transitions between service; ensuring that every patient has access to specialist care; and increasing participation in clinical research.

NHS England and NHS Improvement have published a service specification setting out the functions and requirements of principal treatment centres and the Children's Cancer Operational Delivery Networks. This will enable services to improve and widen access to psychological support, clinical trials and tumour banking. The National Health Service now offers all children and young people with cancer whole genome sequencing to allow more comprehensive and precise diagnosis and access to personalised treatments.

Cancer: Research

27 Oct 2021 | 60393

Asked by: Caroline Dinenge

To ask the Secretary of State for Health and Social Care, how much and what proportion of his Department's cancer research budget was spent on childhood cancer research in the last three years; and if he breakdown those figures by types of childhood cancer that received that funding.

Answering member: Edward Argar | Department: DHSC

This information is not held in the format requested. The Department funds research through the National Institute for Health Research (NIHR). The NIHR does not categorise research studies by age group or by type of childhood cancer.

In addition, not all studies research a specific condition but are aimed at prevention or to improve outcomes for multiple conditions.

Cancer: Clinical Trials

06 Sep 2021 | 38180

Asked by: Emily Thornberry

To ask the Secretary of State for Health and Social Care, what discussions he has had with his Cabinet colleagues on improving the availability of and access to clinical trials in the UK for families affected by brain and childhood cancers.

Answering member: Jo Churchill | Department: DHSC

The Secretary of State has not had any specific conversations with Cabinet colleagues on improving the availability of and access to clinical trials in the United Kingdom for families affected by brain and childhood cancers. We are determined to make it as easy as possible for the public to identify the availability of, and access to, research happening across the country, including brain and childhood cancers, and enable them to take part. We have launched the “Be Part of Research” study search application and website, which helps people to find out about health research, including clinical trials, of interest to them.

We are also working with the Tessa Jowell Brain Cancer Mission to increase high quality brain tumour research.

Cancer: Children and Young People

03 Jun 2021 | 5276

Asked by: Carla Lockhart

To ask the Secretary of State for Health and Social Care, what recent assessment his Department has made of the prevalence of cancer diagnosis among children and young people.

Answering member: Jo Churchill | Department: DHSC

In 2018, the most recent data available, there were 25,312 children and young people living with a cancer diagnosis in England. This data is available by cancer type, sex and other demographic factors and is available at the following link:

<https://www.cancerdata.nhs.uk/prevalence>

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Press Material

The following is a selection of news and media articles relevant to this debate. Please note: the Library is not responsible for either the views or the accuracy of external content.

[Blood test could shorten hospital stays for children with cancer, new study reveals](#)

University of York

17 March 2022

[Neuroblastoma: The cancer-hit families facing a funding mountain](#)

BBC

19 February 2022

[Childhood cancer survivors at greater risk of ill health](#)

Cancer Research UK

22 November 2021

[Whole-genome sequencing can improve childhood cancer outcomes – study](#)

The Guardian

8 November 2021

[Genetic discovery could guide treatment for aggressive childhood cancer](#)

Cancer Research UK

28 June 2021

[Cancer in children and young people – what do the statistics tell us?](#)

UK Health Security Agency

15 March 2021

[Different challenges, same determination: how we're tackling children's and young people's cancers](#)

Cancer Research UK

25 September 2019

4 Further reading

4.1 External reports and factsheets

World Health Organisation, [Childhood cancer](#), December 2021

Children with Cancer UK, [Childhood cancer facts and figures](#), September 2021

Public Health England, [Children, teenagers and young adults UK cancer statistics report](#), 2021

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