Funding of children's cancer research:

2008 data from the International Cancer Research Partnership portfolio



January 2014



Introduction

The National Cancer Research Institute (NCRI) is a UK-wide partnership, whose 22 members include the UK government health departments, charities, funding councils and industry bodies. It promotes co-operation in cancer research for the benefit of patients, the public and the scientific community.

NCRI is a member of the International Cancer Research Partnership (ICRP), which also includes organisations from Australia, Canada, France, Japan the Netherlands, and the United States. ICRP organisations share funding information in a common format (known as the Common Scientific Outline or CSO, https://www.icrpartnership.org/CSO.cfm) to facilitate data pooling and evaluation across organisations.

In response to a request from the UK children's cancer community for help in benchmarking UK activity against work elsewhere, NCRI has undertaken an analysis of the ICRP database to look at the nature and volume of childhood cancer research funded by NCRI Partners in the UK compared with other countries participating in ICRP data-sharing.

For the UK children's cancer research community, some consolidation of structures has taken place in recent years, to align more closely with trial development and delivery mechanisms in general oncology settings. The 2008 ICRP data set was the latest available at the time of analysis, and as such is effectively a measure of activity before these changes took place.

The objective of this analysis is to provide UK researchers and research funders with information that allows them to:

- reflect on research activity in the UK
- identify strengths and weaknesses compared with other countries
- identify potential areas for international partnerships.

Methods

Data set

The ICRP database includes all cancer research funded by ICRP Partner Organisations within a given calendar year. Data is submitted annually at the individual grant level to populate the database. Each award within the database is coded using two classification systems in order to analyse the data. Each award is coded to a research category using the Common Scientific Outline (CSO) and to the cancer site(s) which are relevant to the research. Awards may be coded with multiple CSO codes and cancer site codes where applicable.

The ICRP data was accessed and analysed by the NCRI Secretariat. For the database search, 2008 data was used as this represented the most recent year with a full set of data uploaded from each partner. The Canadian Cancer Research Alliance elected to supplement the Canadian data with research spend from their non-ICRP members, to provide a more representative view of research by Canadian research organisations. Organisations whose 2008 data is included in this analysis were from Canada, France, the Netherlands, the United Kingdom and the United States, and are listed in Appendix 1.

Note: These figures do not represent the entire children's cancer spend in each country, as they show only the data from organisations that contributed their information to this 2008 data set. For this reason it has been presented not as a country by country analysis, but as 'International' compared with 'UK', based on best available data.

Search methodology

Relevant entries were identified by a keyword search using the search terms below. Extracting data to Excel allowed for wildcard searches, meaning only the root form of a keyword was required to detect variant spelling.

Search terms:

- child* (includes children/childhood)
- girl* (includes girls)
- boy* (includes boys)
- infant* (includes infants/infantile)
- paediatric* (Includes paediatrics/paediatrician)
- pediatric* (includes pediatrics/pediatrician)
- youth

- young
- puberty
- adolescen* (includes (adolescence/adolescent/adolescents)
- teen* (includes teenage/teenager/teenagers)
- neuroblast* (includes neuroblastoma)
- retino* (includes retinoblastoma)
- Wilm* (includes Wilms/Wilms'/Wilm's).

Tumour site search terms were not included except where they are found exclusively in children, on the basis that where tumour types occur in both adults and children, it would be expected that an age-related term would also appear to make the distinction. The keywords 'teen', 'youth' and 'young' were also included, so this analysis includes both teenagers and younger children; as the data in abstracts did not routinely specify an age band, no specific age range can be given.

Each keyword search was done individually, then the awards identified were collated and duplicates removed. A manual review of abstracts from all the identified entries was then undertaken to exclude any 'false positive' mentions (for example where 'children' appears in the context of an exclusion criterion from a study, where 'youth' related to childhood exposures that led to adult cancers). Where manual review showed an award to be only partially relevant to paediatric research, the funding for that award was given a percentage attribution in accordance with the information in the abstract (for example, if paediatrics was one of five strands of research, a 20% attribution was made).

Notes on interpreting the data

The keyword search methodology relies on the presence of terms relating to children and teenagers being included within the title or abstracts. As such it may miss awards that could have an impact on children's cancer by extension, for example translational work within adult leukaemia research, or basic research into cancer mechanisms that may be relevant across multiple cancer types and age groups. However, the alternative to include all tumour types that appear in cancer and apportion a percentage of the totals according to incidence in children risks obscuring the focus on children's cancer and might artificially inflate the level of work with a genuinely paediatric focus.

It is important to note that the number of organisations contributing data per country varies, and that there are other research funding organisations active outside the ICRP. What we are working with is 'best available' data, and the figures should be considered as representative, not definitive, of the activity within a country.

The comparisons made in this report look at 'international spend' versus 'UK spend', to see what trends can be identified among the data we have access to. Some additional analyses of the UK portfolio are also included. Financial data was provided in the local currency for each ICRP funding organisation, but to make data comparable, all non-dollar values were converted to US dollars using the average conversion rate for calendar year 2008:

- Canadian Dollars to US Dollars: 0.99243
- Euro to US Dollars: 1.50409
- British Pounds to US Dollars: 1.97311.

Results

Data set

The 2008 ICRP data set (hereafter referred to as the international data set) contained 24,678 awards from funders in the USA, UK, Canada, the Netherlands and France. Of these, 721 awards (2.9%) had an identifiable association with children's cancer, based on the search terms above.

The UK component of the 2008 ICRP data set (hereafter referred to as the UK data set) comprised 4014 awards, of which 172 (4.3%) had an identifiable association with children's cancer.

Tables summarising the children's cancer data presented in this report can be found in Appendices 2 and 3.

Total spend on children's cancer research

The international data set captured a total of \$5.1 billion of research spend 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 (Figure 1).

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.

Figure 1. Children's cancer research spend in the 2008 international data set by funder country.

Note: These figures do not represent the entire children's cancer spend in each country, as they show only the data from organisations that contributed their information to ICRP in 2008. The contributing organisations are listed in Appendix 1.

USA Data from 10 organisations; \$119.9m of children's cancer research spend identified

UK Data from 21 organisations; \$32.0m of children's cancer research spend identified

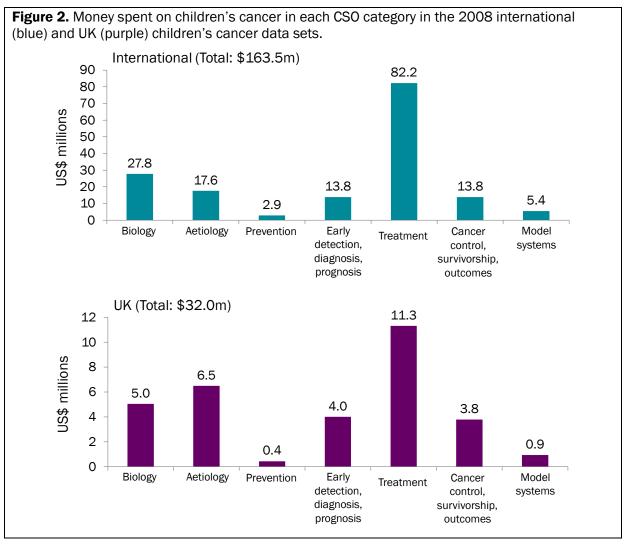
Canada Data from 40 organisations; \$10.6m of children's cancer research spend identified

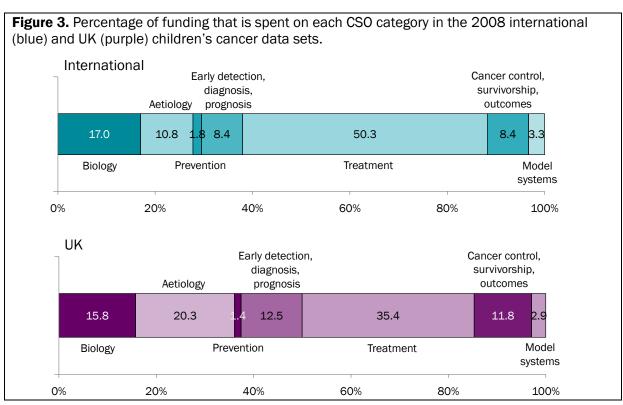
The Netherlands Data from 1 organisation; \$0.7m of children's cancer research spend identified

France Data from 1 organisation; \$0.4m of children's cancer research spend identified

Spend by research category

Figures 2 and 3 compare the way money on children's cancer research is spent internationally and in the UK. In both the international and UK children's cancer data sets, more money was spent on research into treatment than on any other type of research (Figure 2). In the international data set this was particularly striking, accounting for half of the spend on children's cancer (Figure 3). The lowest spend was seen in the CSO categories of prevention, and model systems.

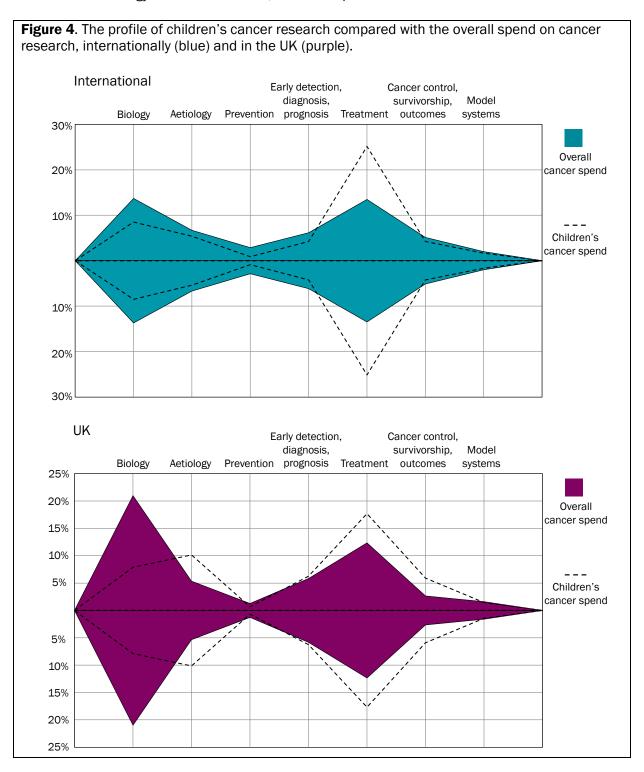




As well as comparing international and UK spending profiles against each other, it can also be helpful to look at how spend on children's cancer research compares with the way money is spent on cancer research in that data set overall (Figure 4).

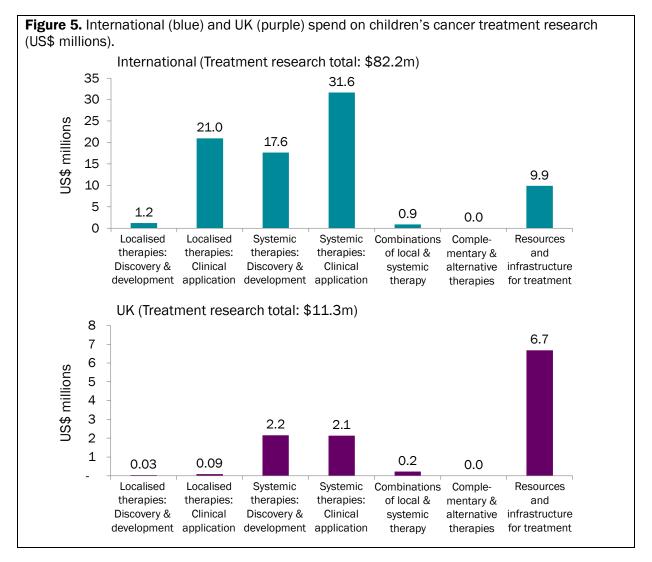
In both the UK and international data sets, there was proportionally less children's cancer research with a biology focus, compared with the profile of cancer research overall. There was proportionally more spend on children's cancer that fell into the treatment category than in the cancer research profile overall. This was particularly pronounced in the international data set.

In the UK data set, while the children's cancer data set was enriched for treatment research compared with the overall cancer spend, it also had a slightly greater proportion going towards research in aetiology and cancer control, survivorship and outcomes.



Spend on children's cancer treatment

As treatment research is the dominant area of spend for children's cancer, this has been explored in more detail, using the seven CSO subcategories of treatment research.



The UK spends very little on research into localised therapies in children, such as surgery and radiotherapy – either in terms of their discovery and development, or their clinical application (Figure 5). This is not unique to children's cancer, but reflective of a low spend on localised therapies in the UK overall (Figure 6). This contrasts with the international portfolio; while systemic therapy still dominates, research into the clinical application of both localised and systemic treatments is enriched in children's cancer, compared with the overall portfolio.

Overall, 59.0% of the UK spend on children's cancer research in the treatment category is on infrastructure, compared with 12.0% internationally. While this is a marked difference, it is not unique to children's cancer and mirrors the overall UK profile of cancer treatment spend, which is also weighted towards infrastructure (Figure 6). The differences between the UK and overseas may be partly related to coding, as infrastructure funding may be used to support direct research into treatment but this is not always detailed in the abstract. The UK children's cancer awards in this category include funding of dedicated clinical trials units for children's cancer, centre grants that include children's cancer research, the children's cancer Experimental Cancer Medicine Centres and some database/tissue banking activity. It does not include NIHR Cancer Research Network funding that may be used to support children's cancer trials, as the proportion relevant to children's cancer could not be ascertained from the data submitted.

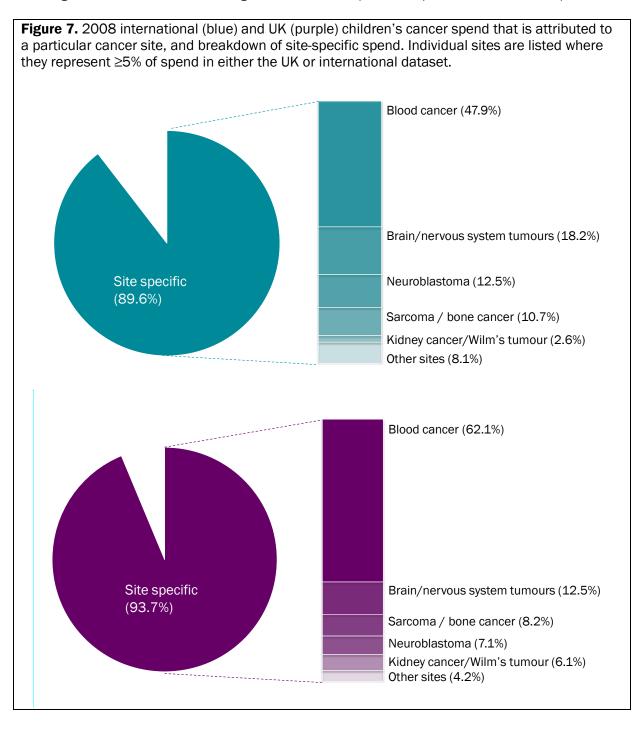
Both the UK and international portfolios lacked significant research funding on combinations of localised and systemic therapies, in children's cancer or overall. There was no spend on complementary or alternative treatment approaches in either the UK or international children's cancer data set.



Spend on different types of children's cancer

The majority of the children's cancer research in the international and UK databases was attributable to a particular disease site (89.6% and 93.7%, respectively; Figure 7).

Awards attributable to a particular disease site were further analysed to identify cancer types that made up $\geq 5\%$ of spend in the UK or international dataset. Of the children's cancer research funding that is attributed to a cancer site, blood cancer is dominant both in the UK and internationally; in the UK data set, this was more striking and accounted for almost half the site-specific spend. The blood cancer category includes leukaemia, multiple myeloma, Hodgkin's disease and non-Hodgkin's lymphoma; the vast majority of spend was on leukaemia (88.4% of international and 87.6% of UK blood cancer spend). It is worth noting that the composition of funders who submitted data in the UK may partly account for this trend (Appendix 1), with two charities whose focus was on blood cancer research included, and at least one UK charity funding brain tumour research being outside the NCRI partnership and therefore not captured.

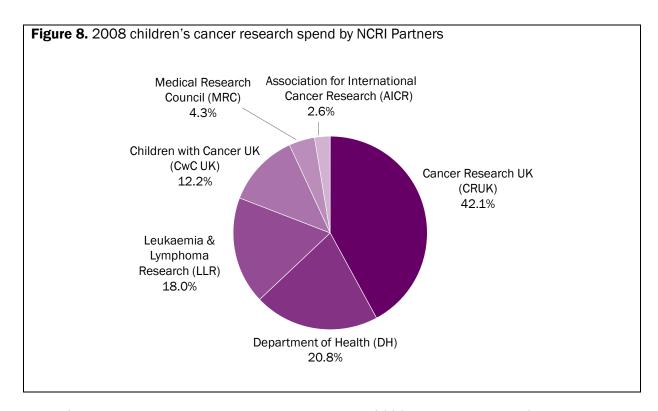


UK portfolio: Further analysis

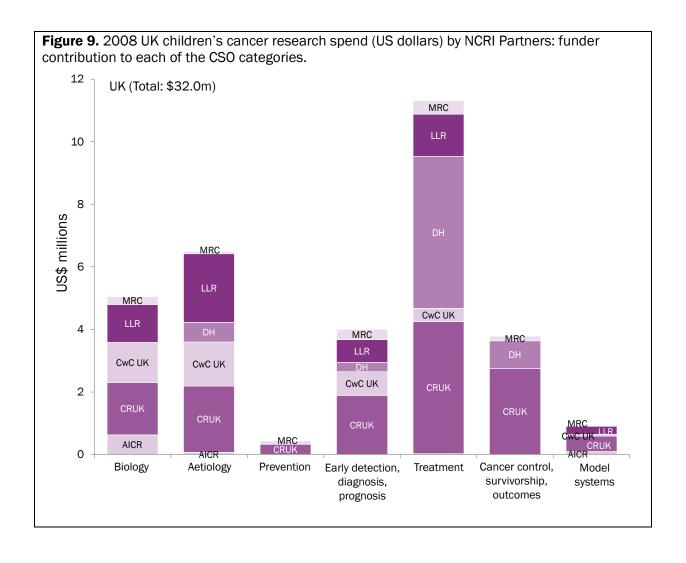
A further breakdown has been performed on the UK portfolio, to give deeper insight into children's cancer funding by NCRI Partners. Data can be found in Appendix 3.

Note: It should be expected that the figures reported directly by funders about their spend in children's cancer may vary from those cited in this report. Some of their investments, for example in policy, education, or certain types of infrastructure are not captured by the ICRP database, and reporting schedules and inclusion criteria may be different to those used here. They are also in dollar values, in keeping with the rest of this international analysis; it is the patterns of funding, not the absolute values, that are the focus.

Amongst NCRI Partners, Cancer Research UK had the greatest amount of research with an identifiable children's cancer focus in 2008, followed by the Department of Health (England) and Leukaemia and Lymphoma Research (Figure 8). Children with Cancer UK also contributed 12% of the funding for the children's cancer research portfolio.



Most funders split their investments across a number of CSO categories (Figure 9); the Department of Health portfolio was weighted towards treatment research. This is not surprising since, as seen in Figures 5 and 6 and the accompanying text (p.6-7), the treatment research category includes a significant proportion of infrastructure funding.



Summary

Key findings

This analysis of 2008 data revealed both similarities and differences between the UK and international spend on children's cancer research.

- In both the UK and internationally, most of the spending in children's cancer research was on treatment research.
- Within the category of treatment research, there was very little spend on localised treatments in the UK, either overall or in children's cancer.
- While there are challenges in identifying children's cancer spend within centre grants and large infrastructure investments, it appears that the UK spends proportionally more of its treatment research funding on infrastructure than internationally, both overall and in children's cancer.
- UK children's cancer spend amongst the NCRI Partners was more heavily weighted towards blood cancer research (the majority of which was research into leukaemia), compared with the international profile of children's cancer spend. This may partly reflect the composition of funders who contributed data.

Reflections on the analysis

It is important to note when interpreting this data set that the findings reflects only the data submitted; there are certainly other research funders in these countries who did not submit data. Even since 2008 there have been new members to the ICRP, and as the number of organisations submitting data increases, the data set will become more complete.

Within the UK component of this analysis, it is also notable that not all NCRI Partners had identifiable contributions to UK children's cancer research. For some this is to be expected, for instance in the case of the site-specific charities focusing on cancer types that only affect adults, such as breast or lung cancer. For others, it may be that children were not explicitly mentioned in the abstracts, and as such may have been missed by the search methodology used. This reinforces the need for detailed, accurate abstracting of research awards, to maximise the potential of keyword-based database analyses.

It is also notable that many organisations make contributions to the cancer arena through methods other than research funding – for example, influencing policy, providing education, or supporting cancer patients and their families. The NCRI database does not capture this activity, so the above report is only part of the picture in terms of organisational contributions to children's cancer. For this reason, and due to differences in methodology and inclusion criteria, it would be expected that the figures here cited may vary from those in funders' own analyses.

With these qualifications in mind, we hope the data will prove useful for researchers and funders involved with children's cancer research.

Acknowledgments

Data analysis and reporting was undertaken by Thomas White (NCRI) and Jenni Macdougall (NCRI).

Appendices

Appendix 1. Organisations that submitted data to the 2008 international data set in this report

Canada*

- Alberta Cancer Foundation
- Alberta Innovates Health Solutions
- Brain Tumour Foundation of Canada
- C¹⁷ Research Network
- Canada Foundation for Innovation
- Canada Research Chairs Program
- Canadian Association of Radiation Oncology
- Canadian Breast Cancer Foundation
- Canadian Breast Cancer Research Alliance
- Canadian Cancer Society
- Canadian Institutes of Health Research
- Canadian Partnership against Cancer
- Canadian Prostate Cancer Research Initiative
- Canadian Tobacco Control Research Initiative
- Canary Foundation of Canada
- CancerCare Manitoba
- Cancer Care Nova Scotia
- Cancer Care Ontario
- Cancer Research Society
- Fonds de recherche de Québec Santé
- Genome Canada
- The Kidney Foundation of Canada
- Leukemia & Lymphoma Society of Canada
- Manitoba Health Research Council
- Medical Research Fund of New Brunswick
- Michael Smith Foundation for Health Research
- National Research Council
- Natural Sciences and Engineering Research Council of Canada
- Networks of Centres of Excellence
- Newfoundland and Labrador Centre for Applied Health Research
- Nova Scotia Health Research Foundation
- Ontario Institute for Cancer Research
- Ontario Ministry of Economic Development and Innovation
- Ovarian Cancer Canada
- PROCURE
- Prostate Cancer Canada
- Saskatchewan Cancer Agency
- Saskatchewan Health Research Foundation
- Social Sciences and Humanities Research Council
- The Terry Fox Foundation

France

INCa, the French National Cancer Institute[†]

Netherlands

Dutch Cancer Society

UK

- Association for International Cancer Research
- Biotechnology & Biological Sciences Research Council
- Breakthrough Breast Cancer
- Breast Cancer Campaign
- Cancer Research UK
- Children with Cancer UK
- Chief Scientist Office (Scotland)
- Department of Health (England)
- Economic and Social Research Council
- Leukaemia & Lymphoma Research
- Ludwig Institute for Cancer Research
- Macmillan Cancer Support
- Marie Curie Cancer Care
- Medical Research Council
- HSC Public Health Agency (Northern Ireland)
- Prostate Cancer UK
- Roy Castle Lung Cancer Foundation
- Tenovus
- Welsh Government
- Wellcome Trust
- Yorkshire Cancer Research

USA

- American Cancer Society
- American Institute for Cancer Research
- Avon Foundation for Women
- California Breast Cancer Research Program
- Congressionally Directed Medical Research Programs
- National Cancer Institute
- National Pancreas Foundation
- Oncology Nursing Society
- Pancreatic Cancer Action Network
- Susan G. Komen for the Cure

^{*}The Canadian Cancer Research Alliance elected to supplement the Canadian data with research spend from non-ICRP members, to provide a more representative view of research by Canadian research organisations

[†]Part of INCa's submission to ICRP includes research which is co-funded by the French General Directorate for Healthcare Provision, Ministry of Health (DGOS) as well as DGOS-funded research administered by INCa

Appendix 2. Data on children's cancer spend in 2008, from International Cancer Research Partnership database.

	International portfolio (including UK)	UK portfolio
Research awards Total awards in portfolio (n) Childhood cancer awards (n; % of total awards)	24,678 721 2.9%	4014 172 4.3%
Research spend Total spend in portfolio (\$) Spend on childhood cancers (\$; % of total spend)	\$ 5,098,239,562 \$163,546,287 3.2%	\$912,996,212 \$32,001,032 3.5%
Relative contribution to this 2008 international data set by country* USA UK Canada Netherlands France	\$119,861,174 73.3% \$32,001,032 19.6% \$10,573,438 6.5% \$669,823 0.4% \$440,819 0.3%	N/A
Proportion of childhood cancer funding spent in each CSO category (\$; %) CSO1 (biology) CSO2 (aetiology) CSO3 (prevention) CSO4 (early detection, diagnosis, prognosis) CSO5 (treatment) CSO6 (cancer control, survivorship, outcomes) CSO7 (model systems)	\$27,793,702 17.0% \$17,605,135 10.8% \$2,870,612 1.8% \$13,807,374 8.4% \$82,212,756 50.3% \$13,816,268 8.4% \$5,440,441 3.3%	\$5,049,495 15.8% \$6,491,569 20.3% \$435,404 1.4% \$4,004,158 12.5% \$11,314,722 35.4% \$3,779,803 11.8% \$925,881 2.9%
Proportion of spend in CSO5 (treatment) on each subcategory (\$; %) CSO5.1 (localised therapies: discovery & development) CSO5.2 (localised therapies: clinical applications) CSO5.3 (systemic therapies: discovery & development) CSO5.4 (systemic therapies: clinical applications) CSO5.5 (combinations of localised & systemic therapy) CSO5.6 (complementary and alternative therapies) CSO5.7 (resources and infrastructure for treatment)	\$1,221,748	\$29,651 0.3% \$88,753 0.8% \$2,158,093 19.1% \$2,137,278 18.9% \$223,273 2.0% \$0 0% \$6,677,675 59.0%
Site specific vs non site specific children's cancer research funding (\$; %) Site specific Not site specific	\$146,484,793 89.6% \$17,061,494 10.4%	\$29,991,653 93.7% \$2,009,380 6.3%
Split of site-specific research by cancer type (sites with ≥5% of spend in either dataset) Blood cancer Brain/nervous system tumours Neuroblastoma Sarcoma/bone cancer Kidney cancer/Wilm's tumour Other cancer types	\$70,222,177 47.9% \$26,639,422 18.2% \$18,382,732 12.5% \$15,680,780 10.7% \$3,744,575 2.6% \$11,815,087 8.1%	\$18,610,215 62.1% \$3,745,951 12.5% \$2,121,803 7.1% \$2,445,739 8.2% \$1,814,937 6.1% \$1,253,007 4.2%

^{*}Note: These figures do not represent the entire children's cancer spend in each country, as they show only the data from organisations that submitted their information (Appendix 1).

Appendix 3. Further analysis of 2008 UK data from NCRI Partners, as recorded in the International Cancer Research Partnership database.

	UK portfolio	
Split of UK children's cancer research spend by NCRI Partner (\$; %) Cancer Research UK* Department of Health Leukaemia and Lymphoma Research† Children with Cancer UK [‡] Medical Research Council Association for International Cancer Research	\$6,666,812 20 \$5,744,195 18 \$3,917,035 12 \$1,369,865	2.1% 0.8% 8.0% 2.2% 4.3% 2.6%
CSO1 (biology) – split by NCRI Partner Association for International Cancer Research Cancer Research UK Children with Cancer UK Leukaemia and Lymphoma Research Medical Research Council	\$1,673,577 33 \$1,282,002 25 \$1,204,061 23	2.5% 3.1% 5.4% 3.8% 5.1%
CSO2 (aetiology) – split by NCRI Partner Association for International Cancer Research Cancer Research UK Children with Cancer UK Department of Health Leukaemia and Lymphoma Research Medical Research Council	\$2,119,783 33 \$1,405,085 23 \$630,544 9 \$2,193,084 33	1.1% 2.7% 1.6% 9.7% 3.8% 1.1%
CSO3 (prevention) – split by NCRI Partner Cancer Research UK Medical Research Council		4.9% 5.1%
CSO4 (early detection, diagnosis, prognosis) – split by NCRI Partner Cancer Research UK Children with Cancer UK Department of Health Leukaemia and Lymphoma Research Medical Research Council	\$759,787 19 \$294,198 \$733,085 18	7.2% 9.0% 7.3% 8.3% 8.2%
CSO5 (treatment) – split by NCRI Partner Association for International Cancer Research Cancer Research UK Children with Cancer UK Department of Health Leukaemia and Lymphoma Research Medical Research Council	\$4,224,849 3 \$419,091 3 \$4,857,347 42 \$1,349,760 12	0.2% 7.3% 3.7% 2.9% 1.9% 3.9%
CSO6 (cancer control, survivorship, outcomes) – split by NCRI Partner Cancer Research UK Department of Health Medical Research Council	\$884,724 23	2.8% 3.4% 3.8%
CSO7 (model systems) – split by NCRI Partner Association for International Cancer Research Cancer Research UK Children with Cancer UK Leukaemia and Lymphoma Research Medical Research Council	\$488,778 52 \$51,071 5 \$264,204 28	0.8% 2.8% 5.5% 8.5% 2.3%

^{*}Cancer Research UK's annual spend on childhood cancer has averaged £9.6m per annum over the last 7 years (ranging between £8.6m and £10m). Some of this spend is in research infrastructure and policy/education, and is therefore not included in the NCRI dataset. Figures reported by CR-UK will vary from those in this report due to differences in reporting period and inclusion criteria.

[†]Called Leukaemia Research Fund at time of data capture.

[‡]Called Children with Leukaemia at time of data capture; now called Children with Cancer UK to reflect their broader focus.

NCRI Partners













































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