CCLG The Children & Young People's Cancer Association

Mapping funding of UK childhood cancer research

against the James Lind Alliance Children's Cancer Priority Setting Partnership Priorities

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UNIVERSITY OF SURREY

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Expertise.
Progress.
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Contents

Foreword

Cancer in children and young people demands more than ambition. It demands alignment. It demands collaboration. And it demands action.

In 2019, children with cancer, families, survivors and professionals came together through the James Lind Alliance Children's Cancer Priority Setting Partnership to define the unanswered research questions that matter most. They set the agenda. Twenty-three priorities shaped by lived experience, expertise and hope.

This report asks a vital question: are we funding the research that answers those priorities?

What we see is encouraging – and challenging.

We see a strong and sustained commitment to developing more effective and kinder treatments. We see significant investment in understanding why children develop cancer and how relapse can be prevented. These are critical areas, and they are driving progress.

But we also see gaps.

> **"We believe progress happens when we come together around shared evidence and shared purpose."**

We see priorities identified directly by children and young people receiving no dedicated funding. We see important questions about hospital experience, transition to adult services, and long-term impact left unanswered. We see opportunities to strengthen patient and public involvement and to improve equity across geography and tumour types.

This is not about criticism. It is about clarity.

At CCLG: The Children & Young People's Cancer Association, we believe progress happens when we come together around shared evidence and shared purpose. No one organisation has all the answers. But together we can find them.

This mapping study gives us a clear picture of where we are – and where we need to go next.

It provides a foundation for smarter collaboration, more strategic investment, and collective responsibility to ensure that every priority identified by our community is addressed.

Children and young people have already told us what matters most. Now it is up to all of us – funders, researchers, policymakers, clinicians and advocates – to respond.

Ashley Ball-Gamble
Chief Executive
CCLG: The Children & Young People's Cancer Association

Executive summary

Title

Mapping funding of UK childhood cancer research against the James Lind Alliance Children's Cancer Priority Setting Partnership Priorities.

Overview

This mapping study evaluates how UK childhood cancer research funding aligns with the 23 priorities identified by the James Lind Alliance (JLA) Children's Cancer Priority Setting Partnership (PSP). These priorities were shaped by children, survivors, families, carers, and professionals to guide future research.

Purpose

To assess the alignment between funders' research strategies and actual funded studies with the JLA PSP priorities, identify gaps, and inform future funding, policy, and research directions.

Methodology

- Funders were identified: 66 potential funders; 47 eligible; data from 30 organisations included
- Timeframe: Projects funded between January 2020 and July 2025
- Mapping process: Funders' strategies and 452 funded studies were mapped to the 23 JLA priorities using a structured coding framework

Key findings

Research strategies mapping

- Three strategies explicitly aligned with the 23 JLA priorities
- Most mentioned priorities:
  - Priority 1 (effective and kinder treatments): 29 mentions
  - Priority 2 (why children develop cancer): 19 mentions
- Nine priorities – including three in the PSP Top 10 – are not referenced

Funding landscape

- Total Studies: 452 (56% completed, 44% ongoing)
- Total Funding: £112.9 million
- Most funded priority:
  - Priority 1 (effective and kinder treatments): 365 studies, £94.2 million
- Other highly addressed priorities:
  - Priority 2 (why children develop cancer): 73 studies, £16.6 million
  - Priority 5 (relapse): 44 studies, £9.6 million
- Underfunded or unaddressed priorities: five priorities received no funding, including:
  - Priority 6 (improving hospital experience) – top priority for children
  - Priority 13, 16, 20, 22 – transition to adult services, staff wellbeing, long term-effects of additional medications, Hickman line experience

Research characteristics

- Study types: 75% pre-clinical, 10% observational, 8% trials
- Cancer types: focus on leukaemia, brain/spinal tumours, neuroblastoma
- Geographic distribution: research concentrated in Greater London (37%)
- Stakeholder involvement: mentioned in only 7% of abstracts

Strategy vs. practice

- Discrepancies noted between strategic intent and funded projects
- Alignment:
  - Priorities 1 and 2 ranked highly in strategies and funded studies
  - Priorities 13, 20 and 22 have no mentions in strategies or funding
- Mismatches:
  - Priority 4 ranked high in strategies but lower in funded studies
  - Priority 5 ranked low in strategies yet higher in funded research

Limitations

- Incomplete abstracts limited mapping accuracy
- Infrastructure grants excluded
- Lack of demographic data prevented equity analysis

Recommendations and next steps

For funders

- Target underrepresented priorities, especially those identified by children.
- Promote collaborative funding to avoid duplication and maximise impact.
- Establish a shared agreement on funding responsibilities to ensure there are no gaps.

For policy makers

- Use findings to inform the implementation of the National Cancer Plan.
- Support equity of funding in terms of geography, tumour types and age.

For researchers

- Prioritise research to address concerns of children.
- Focus on gaps to develop competitive proposals aligned with unmet needs.
- Strengthen Patient and Public Involvement (PPI).
- Diversify methodologies.

For patients and families

- Raise awareness of underfunded areas to drive advocacy and influence funding decisions.

Plain English summary

What's this about?

This report examines whether UK childhood cancer research funding matches the Top 23 priorities chosen by children, families, survivors, and healthcare professionals through the James Lind Alliance (JLA) Children's Cancer Priority Setting Partnership (PSP).

The aim was to see:

- If funders are supporting research that answers the questions families and professionals care most about
- Where the gaps are
- How future research and funding can better meet real-world needs

What was done?

Researchers collected information from 30 organisations who fund childhood cancer research. They reviewed their research strategies and 452 studies funded between January 2020 and July 2025. Each strategy and study was checked to see if it addressed one or more of the 23 JLA priorities.

What was found?

- Priorities 1 (effective and kinder treatments) and 2 (why children develop cancer) were most mentioned in research strategies. Nine priorities – including three in the PSP Top 10 – are not referenced at all.
- Most research funding focused on developing better and kinder treatments (priority 1). This accounted for 81% of studies and £94 million of the £113 million total funding.
- The second most funded area was understanding why children develop cancer (priority 2), with 73 studies addressing this and attracting £16.6 million in funding.
- Reasons for relapse, prevention and earlier identification (priority 5) was addressed by 44 studies for £9.6 million.
- Some important priorities, especially those about emotional support for families, transition to adult services, and improving wellbeing of health professionals who care for children and families, received little or no funding. For example, the top priority identified by children – making hospital a better experience – was not addressed.
- Most studies were laboratory-based (pre-clinical) rather than involving patients directly.
- Cancer types included were mainly leukaemia, brain/spinal tumours and neuroblastoma.
- Research was concentrated in Greater London, with less activity in other UK regions.
- Few studies mentioned involving patients and families in their design.

Why does this matter?

The findings show that while treatment research is well supported, areas that also matter to children and families – such as emotional support and hospital experience – are being overlooked. This information can help funders, researchers, and policymakers target future funding to fill these gaps.

What happens next?

- Funders should focus on underfunded priorities and encourage collaboration
- Policymakers can use these findings to support implementation of the National Cancer Plan
- Researchers should design studies that address neglected priorities and involve patients and families.
- Patients and families can use this information to advocate for research that meets their needs.

List of tables and figures

Tables

Figures

Background and context

In 2019, CCLG: The Children and Young People's Cancer Association and The Little Princess Trust partnered with the James Lind Alliance (JLA) on the Children's Cancer Priority Setting Partnership (PSP). The aim was to identify the most important research questions in childhood cancer, as defined by children, survivors, families, carers, and professionals (Aldiss et al., 2023a).

From this lengthy but systematic process, 23 questions were taken to a final workshop to decide the Top 10 priorities. These included the Top 5 questions identified by children and young people (Aldiss et al., 2023b), alongside those most voted for by adult survivors of childhood cancer, families/carers, and professionals.

Recognising that work does not stop after the Top 10 is released (Staley et al., 2020), representatives from 16 cancer research funding organisations met to discuss if these priorities are currently being addressed and to identify gaps in funding. This mapping study was developed in response to the funders' day discussions, reflecting a shared commitment to ensuring all priorities are addressed.

Purpose of the mapping project

This mapping study is critical to highlight alignment with stakeholder priorities and to identify efficient use of resources. It will underpin recommendations from the Children and Young People Cancer Taskforce and inform the implementation of the National Cancer Plan. It will also support funders in planning future grant rounds, targeting underfunded areas, and coordinating collaborative action.

Research aim

To systematically map funders' research strategies and current funding of childhood cancer research in the UK against the 23 priorities identified by the JLA PSP.

Research objectives

To identify:

Funding landscape

- Strategic priorities: topics that funders emphasise in their research strategies
- Project distribution: number of projects planned, ongoing, or completed per priority area
- Number of funders addressing each priority area
- Funding allocation: amount of funding awarded per priority area
- Collaborative funding: proportion of projects supported through co-funding arrangements

Research characteristics

- Cancer types: types of childhood cancers included in the funded studies
- Study designs: methodologies used in the research
- Institutional distribution: UK institutions and regions conducting research aligned with PSP priorities
- Study duration: length of time each study runs or is planned to run

Stakeholder involvement

- Extent of involvement of children, young people, survivors, and families/carers in project development

Methods

Identifying funders

Organisations were identified through multiple sources, including partners in the Children's Cancer PSP, attendees of the PSP funders' meeting, members of the Association of Medical Research Charities, Principal Treatment Centres for childhood cancer, hospital charities, UKCRC Health Research Analysis appendices, online searches, and recommendations from the project team and steering group.

All potential UK funders of childhood cancer research were contacted to determine their involvement in funding relevant research. Those confirming involvement were invited to provide details of projects funded between January 2020 and July 2025. This timeframe aligns with the launch of the Children's Cancer PSP survey to collect research topics in 2020. Funders were contacted directly to ensure the most current and comprehensive dataset, including projects approved but not yet initiated. Up to two reminders were sent as needed.

Table 1 (see Appendix) presents the 23 JLA PSP priorities alongside the keywords and themes used to guide the mapping exercise. These keywords were carefully selected by the core research team, including two members who had previously led the original JLA Children's Cancer PSP. Their involvement ensured that the mapping reflected an understanding of the context and rationale behind each priority.

Research strategy mapping

Research funding strategies from participating organisations were obtained via their websites or direct contact if the strategy was being updated but was not yet published. These documents were reviewed in full, and keywords and themes from the 23 PSP priorities were mapped to identify alignment with the funders' stated research approaches. A priority was considered addressed if the strategy referenced keywords or related terms or themes.

Individual studies mapping

The mapping of individual studies was adapted from the grant mapping methodology used successfully by Marie Curie for the Palliative and End of Life Care PSP (Todd Fordham et al., 2017). Participating funders provided details of studies that focused on children with cancer or survivors diagnosed before age 16.

Data collected included:

- Project title
- Abstract
- Start and end dates
- Amount awarded
- Co-funding details
- Host institution

For organisations with open-access searchable databases, relevant data were extracted directly.

Inclusion criteria

Projects were included if they:

- Were funded between January 2020 and July 2025
- Focused on cancers with a prevalence >1% among childhood cancers
- For studies with human participants, included children, young people, or survivors (diagnosed under age 16)
- Were hosted by a UK-based institution
- For personal awards (e.g., studentships, fellowships) that these had a defined project aim and monetary value

Exclusion criteria

Organisations were excluded if they:

- Had not supported childhood cancer research in the past five years

Projects were excluded if they:

- Lacked an abstract, preventing mapping
- Were infrastructure-only grants (e.g., core funding, registry/database setup, staffing costs)

Mapping and coding process

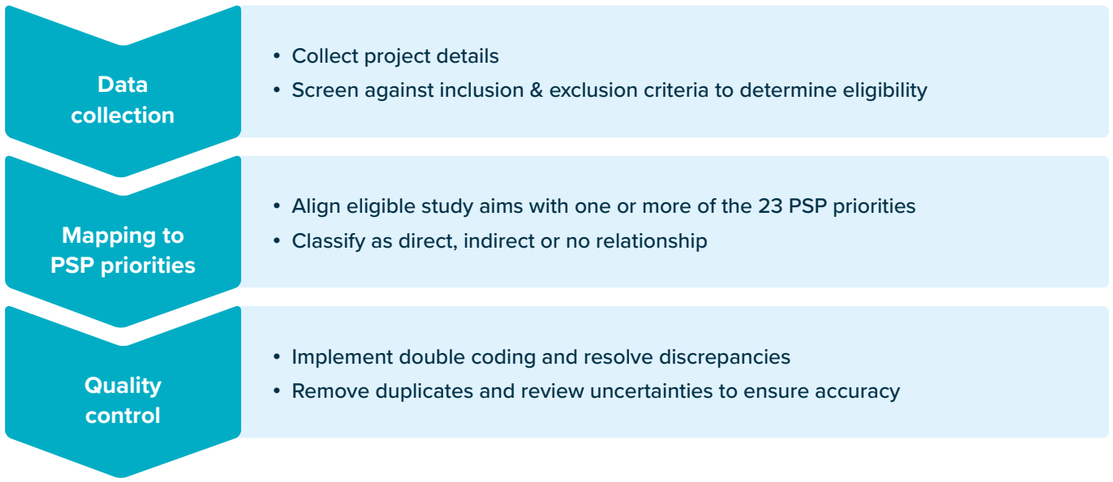
Titles and abstracts were screened against inclusion/exclusion criteria. Duplicate entries were removed from the dataset. Eligible abstracts were reviewed in detail to map study aims to one or more of the 23 PSP priorities.

The relationship between study aims and priorities was mapped as either:

- Direct: The primary aim addresses a PSP priority
- Indirect: A secondary aim aligns with a PSP priority
- No relationship

Studies could be mapped to multiple priorities. Mapping was conducted by one researcher, with a random 20% sample independently coded by a second researcher. Discrepancies were resolved through discussion to reach consensus. Any uncertainties about inclusion were reviewed by the core project team. Figure 1 shows the coding logic flowchart.

Figure 1: Coding logic flowchart



Results

Response rates and funder participation

The study achieved a high response rate and included a diversity of funders. Comprehensive coverage of the research landscape for childhood cancer within the last five years was achieved. Only two children's cancer charities were unable to take part, and one cancer charity for all ages.

A total of 97 potential funders of children's cancer research were identified. After examining their research strategies and websites it was likely that 66 of these may have funded standalone projects in the past five years. Sixty-three funders were contacted directly. Responses were received from 86% of these organisations. Twenty-seven provided data. Three organisations had searchable databases so data were extracted directly.

The figures show response rates (Fig. 2) and the breakdown of the focus of the 30 organisations who provided data (Fig. 3). Twenty-four of these organisations are members of the Association of Medical Research Charities.

Figure 2: Response rates

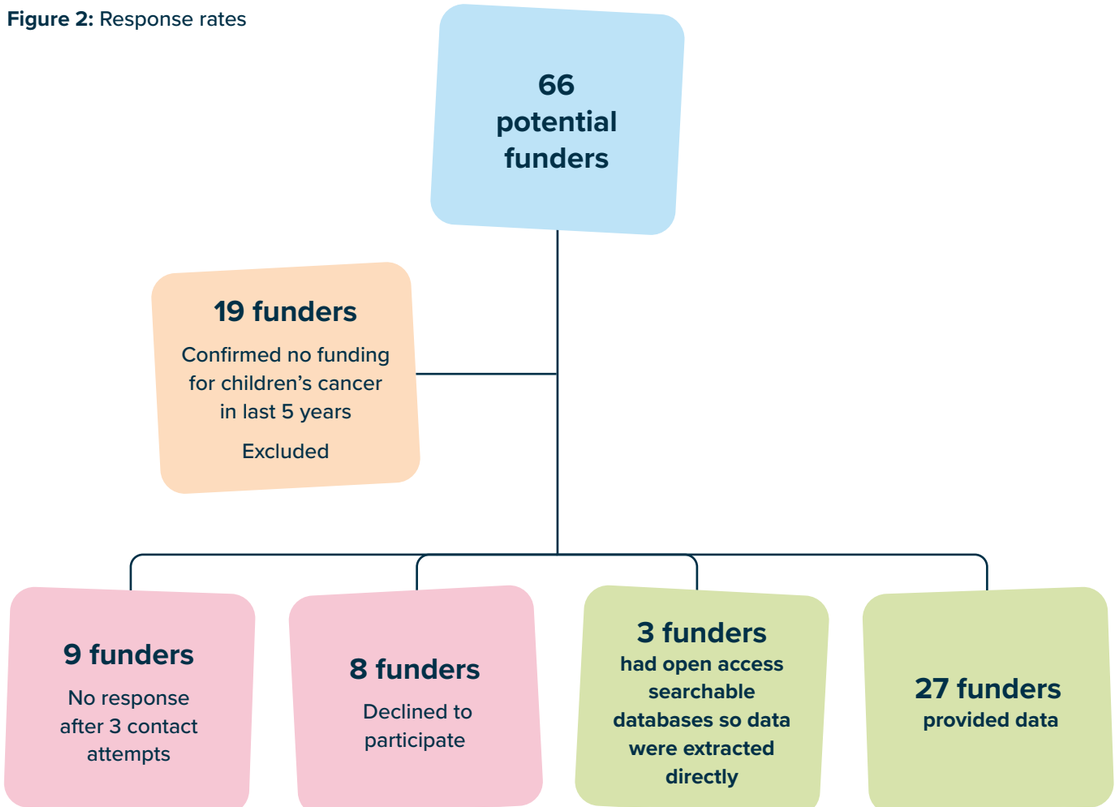
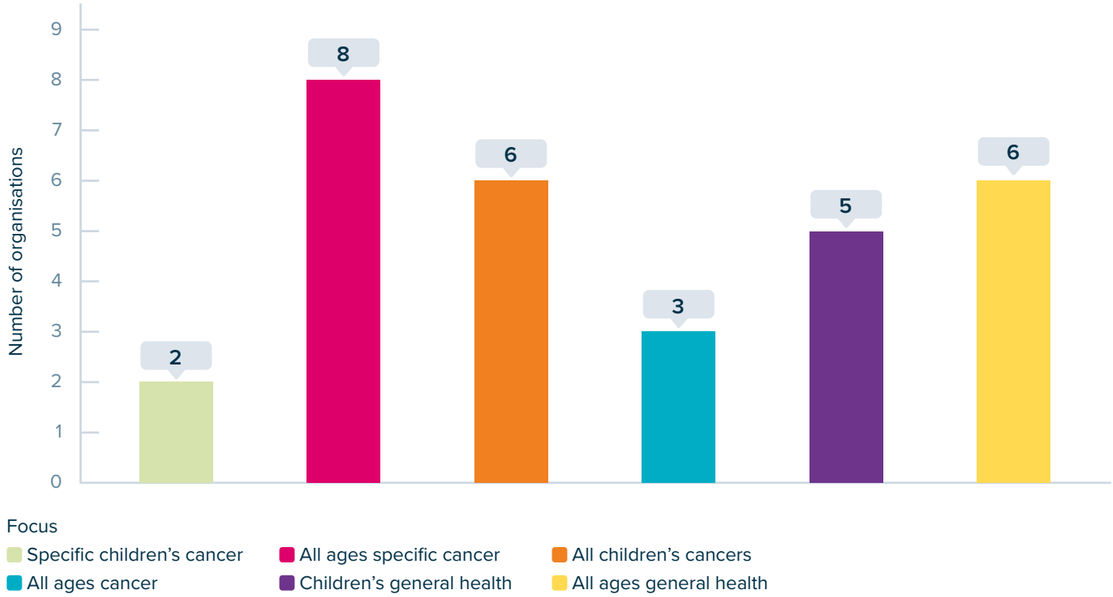


Figure 3: Focus of the 30 participating funders



Of the 19 organisations who confirmed that *they had not funded childhood cancer* research within the last five years:

1 focused on a specific cancer (all ages)

5 focused on all cancers (all ages)

4 focused on children's general health and were hospital charities

9 focused on general health (all ages)

The reasons given for *declining to participate* amongst the eight organisations, none of whom specifically focused on children's cancer, were:

3 were lacking capacity or time

2 were unable to share the data although they felt they had funded relevant work

1 did not hold the data required

1 could not provide the information

1 could not take part

No response was received from nine organisations after three attempts. Of these, two were small children's cancer charities and one was focused on cancer in all ages; whilst the remaining seven organisations were either focused on children's general health (2) or all ages general health (5).

Mapping research strategies to JLA priorities

Of the 30 participating organisations, 16 had a published research strategy and 14 provided an overview of priorities via their websites. Specific funding calls were not examined, as the focus was on mapping the overarching research strategies to JLA priorities. Additionally, historical funding calls are often difficult to identify and access.

Common themes across strategies, which do not map to any priority, included:

- Commitment to collaboration and co-funding, including international collaboration, to share expertise and accelerate progress
- Support for early career researchers and allied health professionals to extend the range of research being carried out
- Infrastructure building
- Emphasis on data-driven research
- Commitment to patient and public involvement (PPI)
- Focus on equity, diversity and inclusion (EDI) of participants and researchers
- Efforts to reduce geographical disparities

Three organisations explicitly mentioned that their strategies were aligning with the JLA PSP 23 priorities.

The most frequently referenced PSP priorities[1] were:

- Priority 1: Effective and kinder treatments (29 organisations)
- Priority 2: Understanding why children develop cancer (19 organisations)

Priority 4 (speeding up diagnosis) and priority 12 (reducing side effects) were also frequently mentioned although by a smaller number of organisations (n=12 and n=8 respectively). Four priorities were mentioned by only one organisation, and nine – including three in the PSP Top 10 – were not explicitly referenced in any strategy. These three were priority 7 (ways for children and families to get and understand information), priority 9 (accessible treatments) and priority 10 (the relationship between chronic fatigue, fibromyalgia, chronic pain and cancer). See Table 2 (see Appendix) for further details.

1. As the organisations are not all focused on children's cancer some of their research strategies will be general, so for example where a strategy maps to a priority about treatment it is not specific to children necessarily, or to cancer.

Mapping studies to JLA Priorities

Overview

Funding landscape

A total of 452 studies from 30 funders were included; 253 (56%) had been completed and 199 (44%) were still ongoing:

- Number of studies per funder ranged from 1 to 86 (median five studies)
- Total funding for these 452 studies was £112,947,386 (median: £124,999; IQR £50,008-£249,856). Individual studies received between £2,520 and £4.17 million in funding, with most falling between £10,000 and £1 million
- 39 studies were co-funded, with a total co-funder contribution of £8,663,406 (average contribution £134,424)

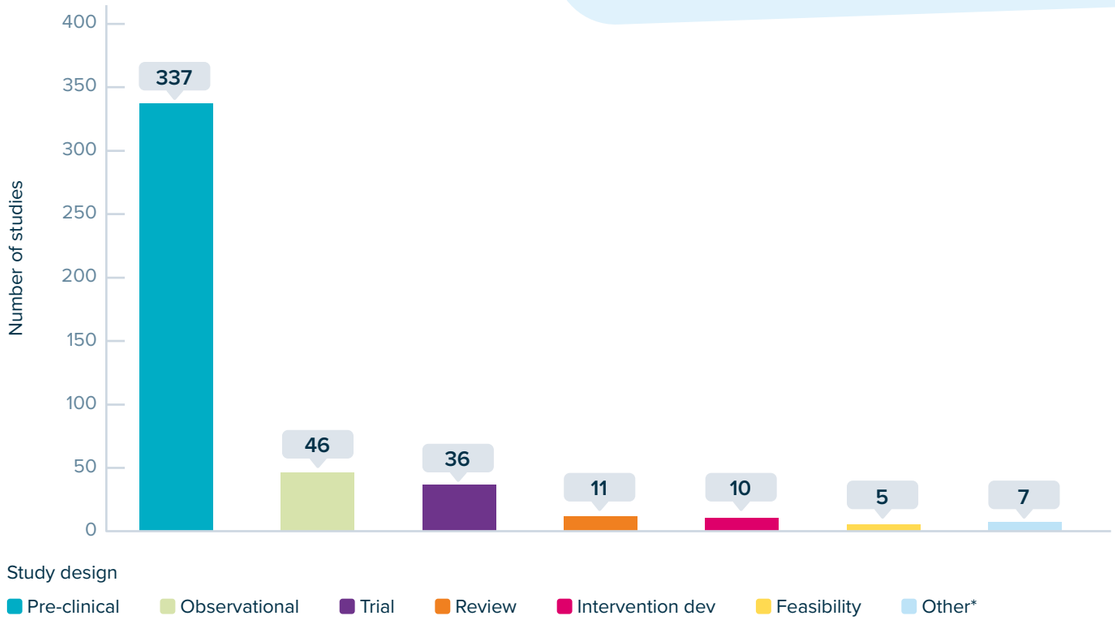
Research characteristics

The main childhood cancer types were covered by the studies, with around three quarters focused on either leukaemia (27%), brain and spinal tumours (20%), neuroblastoma (13%), bone tumours (11%), or soft tissue sarcoma (7%).+

Three quarters of the funded studies were pre-clinical (e.g., developing immunotherapy treatments; DNA profiling; examining drug resistance; repurposing existing drugs; examining tumour development; oncogenesis); 10% observational (e.g., cohort studies, cross-sectional studies, qualitative research, machine learning), 8% clinical trials, 2% reviews; 2% intervention development and 1% feasibility studies (see Fig.4).

+ **www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/childrens-cancers**

Figure 4: Types of study design used in the 452 studies



*Observational & pre-clinical (n=2); observational & review (n=2); observational & health economic (n=1); health economic (n=1); implementation (n=1)

Of the research which was not pre-clinical the populations studied included children, teenagers, families, survivors of childhood cancer and health professionals.

Studies were hosted by 81 institutions, with the highest concentration of these being in Greater London (169 studies, 37%). Figures 5 and 6 show the spread of studies across the regions of the UK.

Study length ranged from two to 60 months, with an average of 30 months.

Figure 5: Funded studies by UK region

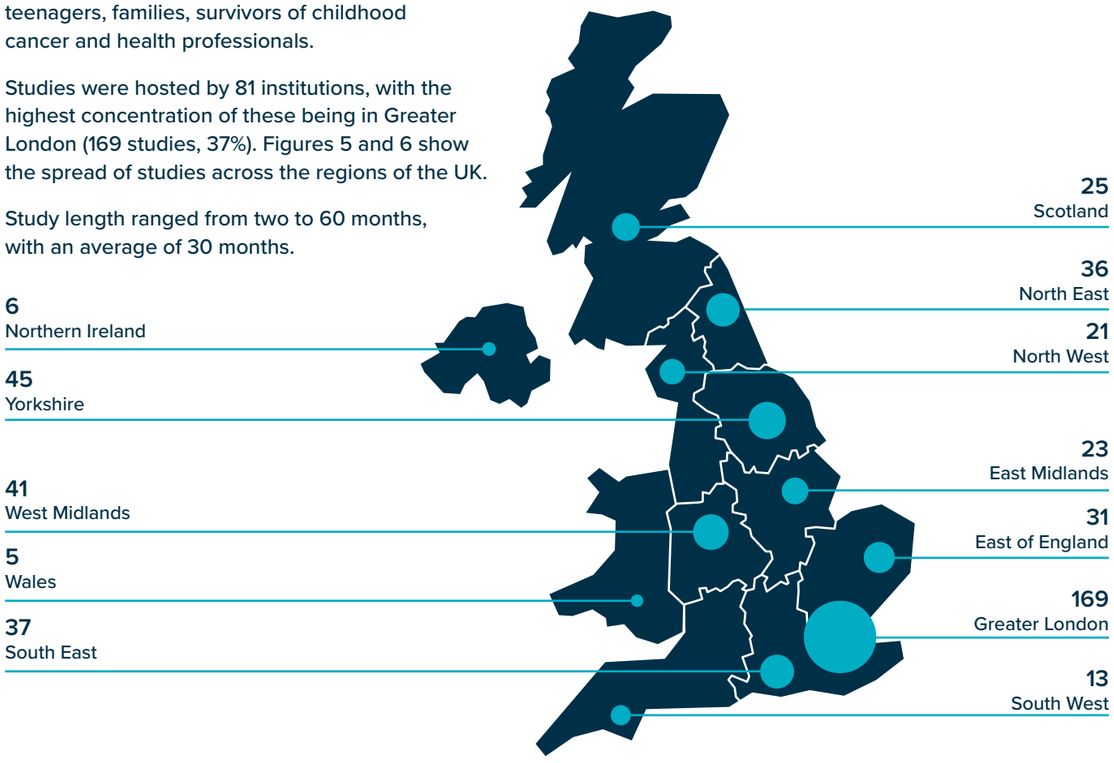
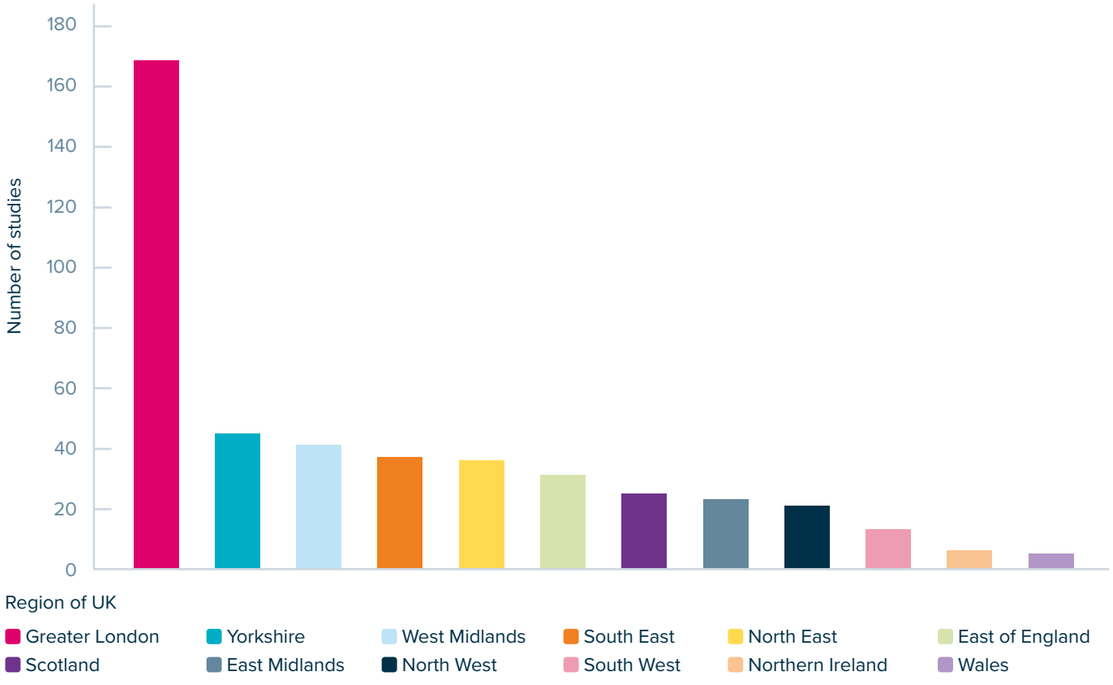


Figure 6: Number of studies in each geographical region of the UK



Stakeholder involvement

Patient and public involvement (PPI) was mentioned in only 7% of the 452 study abstracts. Among those studies involving children, teenagers, survivors, and families (excluding pre-clinical research) this increased to approximately 25%. However, this likely underrepresents actual involvement, as many abstracts lacked detailed descriptions of methodology or engagement activities.

Individual priorities

Table 3 and Figures 7-10 show the number of projects addressing the priority as a main or secondary aim and the amount of funding received.

It is clear that priority 1 (treatment) overwhelmingly receives the most research focus, being a main or secondary aim in 64% and 17% of projects. Priority 2 (cancer development) is addressed in 16% of studies. Priority 5 addressing relapse is the third most covered priority (10% of studies). These priorities combined account for approximately 80% of the total funding (see Fig. 9). Three priorities focusing on issues around short- and long-term side effects and impact of cancer and treatment are the next most covered priorities (4%, 3% and 3% of studies respectively).

Five priorities are not the focus of any of the 452 studies. One of these is in the Top 10 (priority 6, making hospital a better experience), and was in fact the top priority identified by children and young people in their workshop for the JLA PSP (Aldiss et al., 2023b). The remaining four receiving no research attention are priority 13 (transitioning to adult services), priority 16 (supporting the emotional wellbeing of health professionals), priority 20 (long term effects of additional medications) and priority 22 (improving the experience of having a Hickman line).

Figure 7: Number of studies mapping to Top 10 priorities

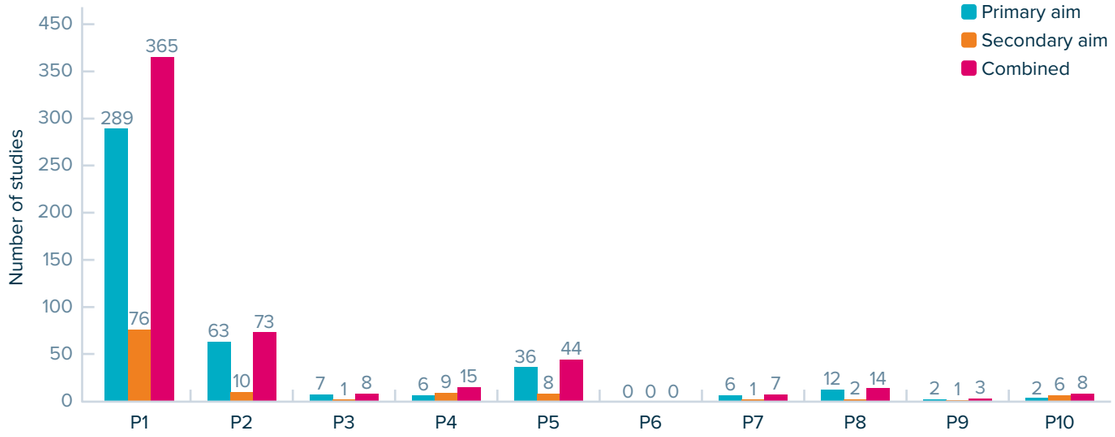
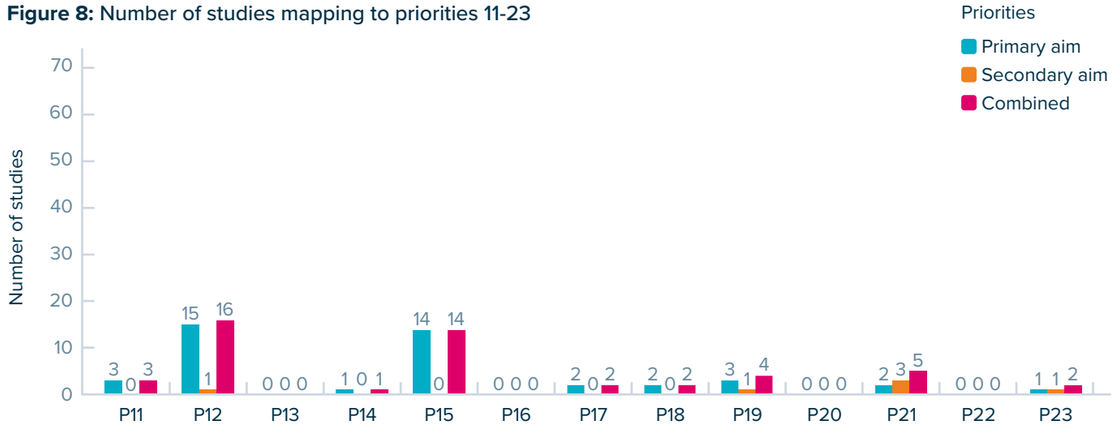


Figure 8: Number of studies mapping to priorities 11-23



Note this is on a different scale to Figure 7 so bar length should not be directly compared

Figure 9: Priorities attracting over £1million in funding

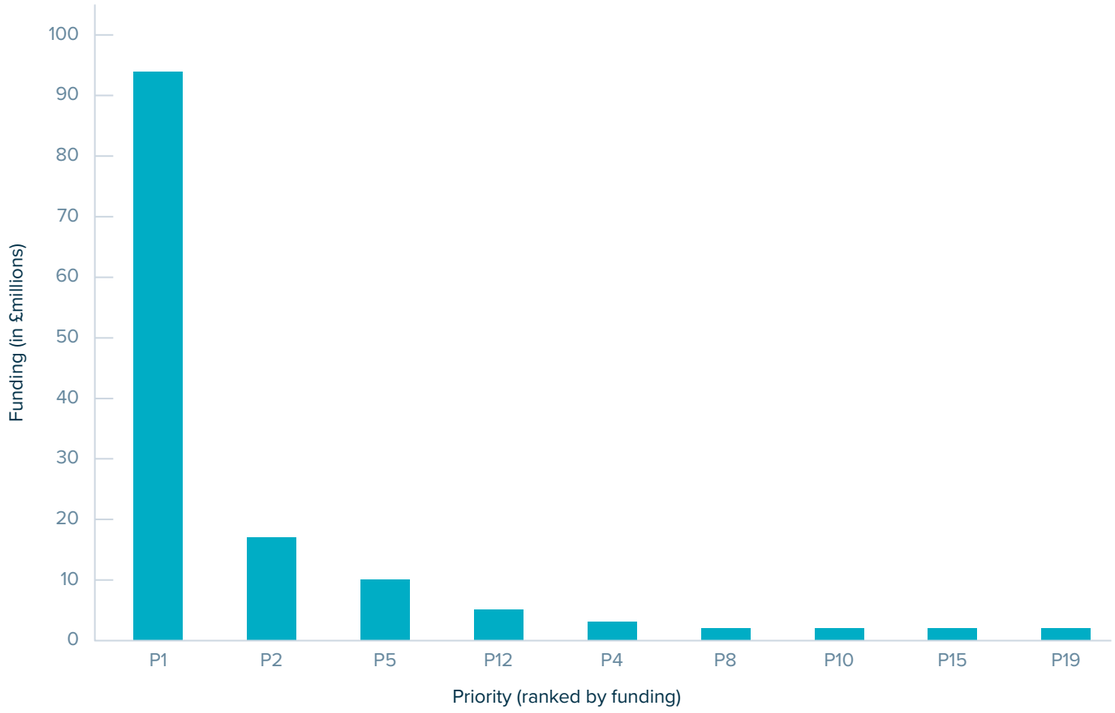
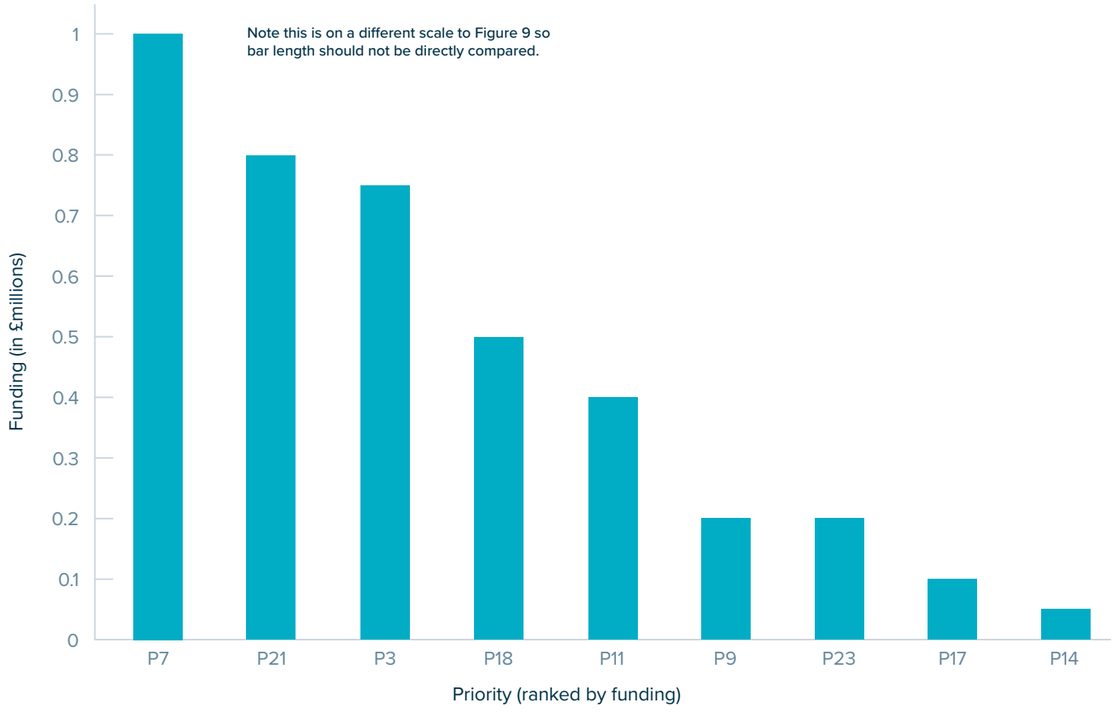


Figure 10: Priorities attracting under £1million in funding



Priorities with high levels of research focus and funding

Priority 1: Can we find effective and kinder (less burdensome, more tolerable, with fewer short and long-term effects) treatments for children with cancer, including relapsed cancer?

This priority was the most addressed by research with 365 (81%) of the studies covering it either as a main or secondary aim of the project. It received £94,197,669 in funding from 29 funders which was awarded to 57 institutions spread across all 12 regions of the UK, but with the highest proportion in Greater London (40%). Leukaemia and brain and spinal tumours were most studied and pre-clinical work dominated (see Figures 11-13).

365
studies

£94.2
million in funding

Figure 11: Priority 1 – Number of studies by UK region

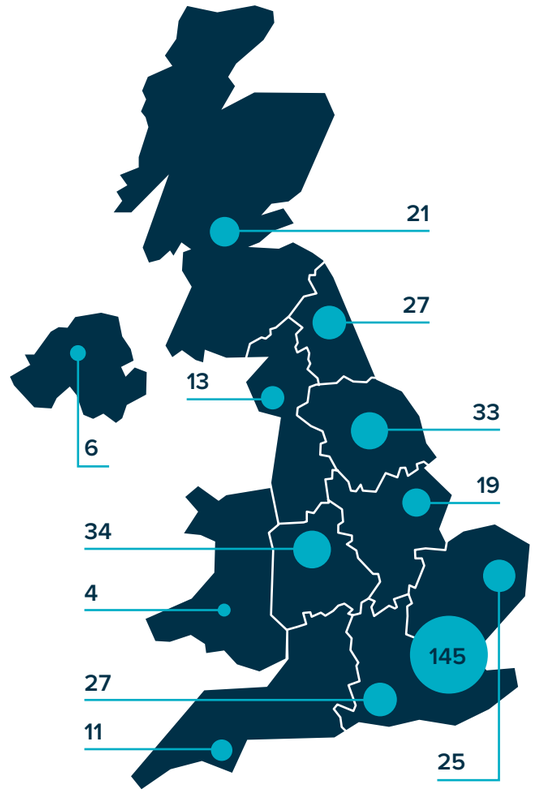
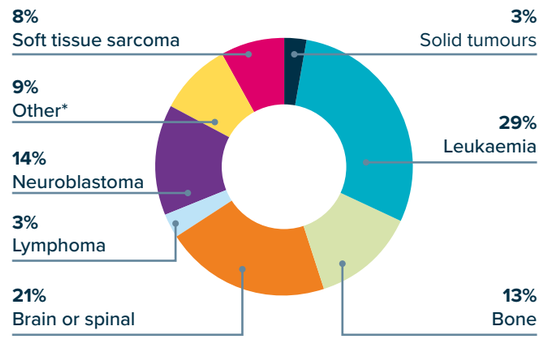
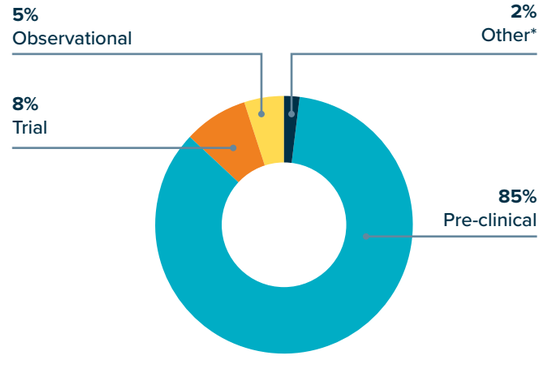


Figure 12: Priority 1 – Types of cancer covered by the research



*Other includes: studies covering all cancers (n=8); more than one cancer (n=6); germ cell (n=1); kidney (n=9), LCH (n=1); liver (n=1); melanoma (n=1); retinoblastoma (n=4)

Figure 13: Priority 1 – Study designs used in the research



*Other includes: feasibility (n=2); intervention development (n=3); review (n=2); pre-clinical & observational (1)

Priority 2: Why do children develop cancer (including the role that genetics plays) and could it be prevented?

This priority was the second most addressed by studies, with 73 (16%) covering this priority as either a primary or secondary aim. It received £16,570,910 in funding from 19 funders. 23 institutions from nine regions of the UK addressed this priority in their research (see Fig. 14) Most were in Greater London (22%), East of England (16%), Scotland (13%) and the West Midlands (13%). None were in Wales, Northern Ireland and the North-West. Figure 15 shows the types of cancers included. Almost all studies were pre-clinical research (see Fig. 16).

73 studies

£16.6 million in funding

Figure 14: Priority 2 – Number of studies by UK region

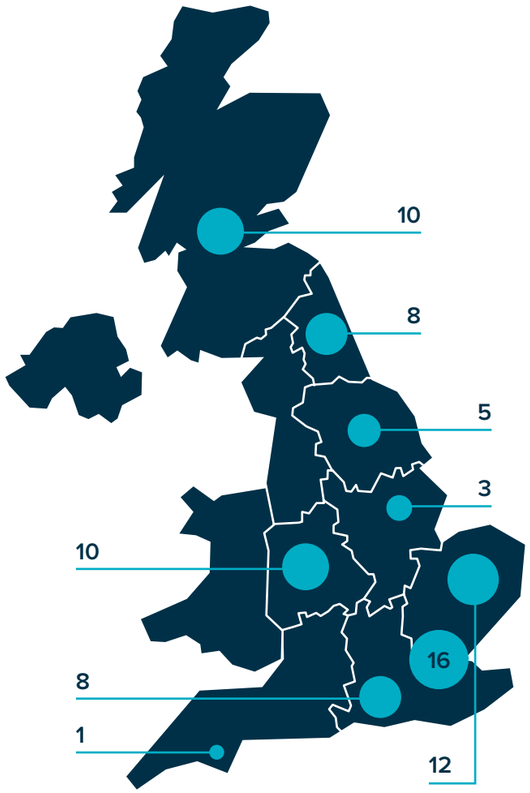
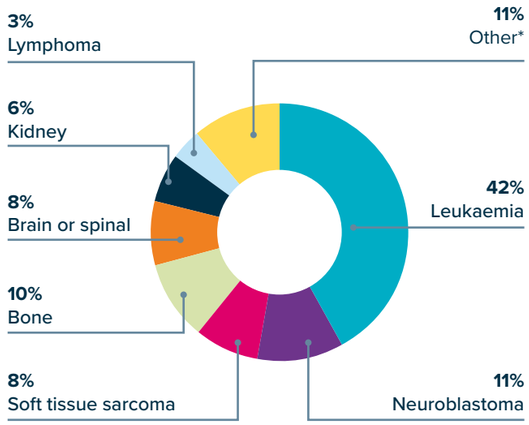
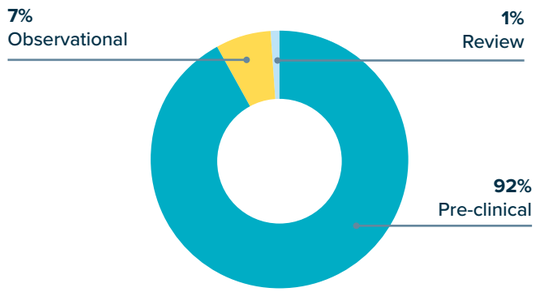


Figure 15: Priority 2 – Types of cancer covered by the research



*Other includes: studies covering all cancers (n=3); more than one cancer (n=1); melanoma (n=1), retinoblastoma (n=1), LCH (n=1), liver (n=1)

Figure 16: Priority 2 – Study designs used in the research



Priorities with moderate research focus and funding

Five priorities had moderate research interest directed towards them. They are described below in rank order based on the number of studies they attracted.

Priority 5: Why do children relapse, how can it be prevented, and what are the best ways to identify relapse earlier?

After priorities 1 and 2 this priority was the third most addressed. 44 (9.7%) studies received £9,639,086 in funding from 13 funders. 20 institutions from 10 regions in the UK (except Northern Ireland and the South-West) addressed this priority in their research, 36% of the institutions were based in Greater London. Just over half the studies were focussed on leukaemia or brain and spinal tumours, nearly three quarters were pre-clinical in design (see Figs. 17 and 18).

44 studies

£9.6 million in funding

Figure 17: Priority 5 – Types of cancer covered by the research

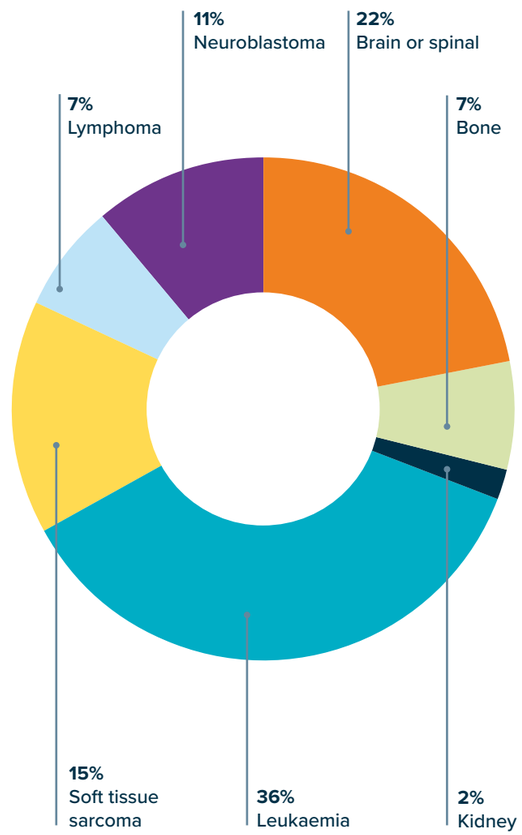
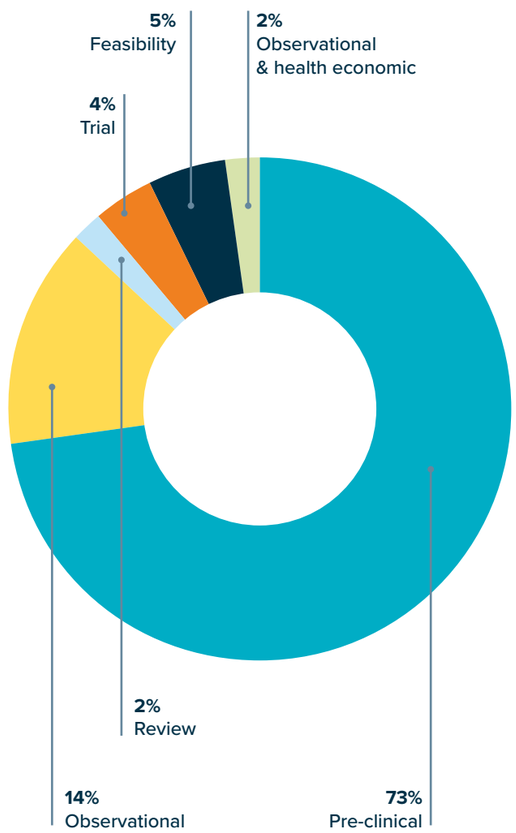


Figure 18: Priority 5 – Study designs used in the research



Priority 12: What are the best ways to reduce, predict and manage the side-effects of treatment for children (including life threatening side-effects)?

16 (3.5%) studies addressed priority 12. Seven funders awarded £5,312,657 to 11 institutions in six regions of the UK – North-West (n=4); Greater London, North-East and Yorkshire (n=3 each); West Midlands (n=2) and East of England (n=1). Most studies focussed on all cancers and were observational in design (see Figs. 19 and 20).

16 studies

£5.3 million in funding

Figure 19: Priority 12 – Types of cancer covered by the research

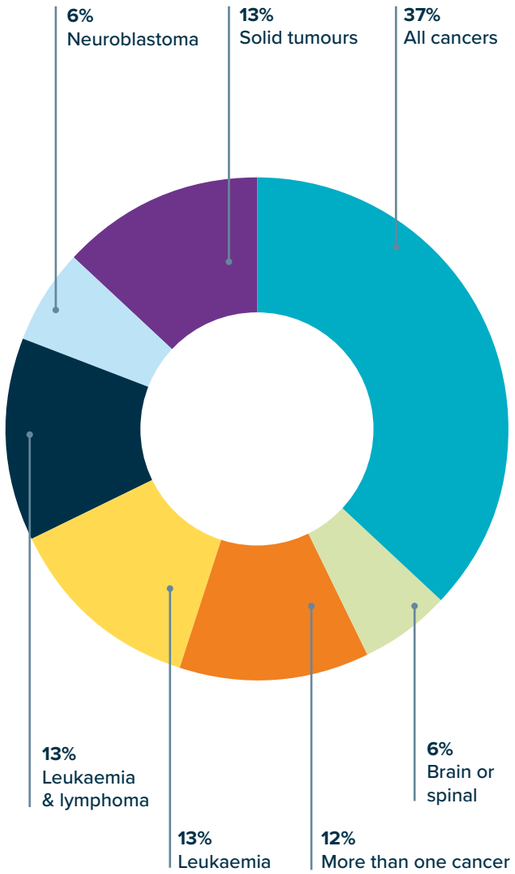
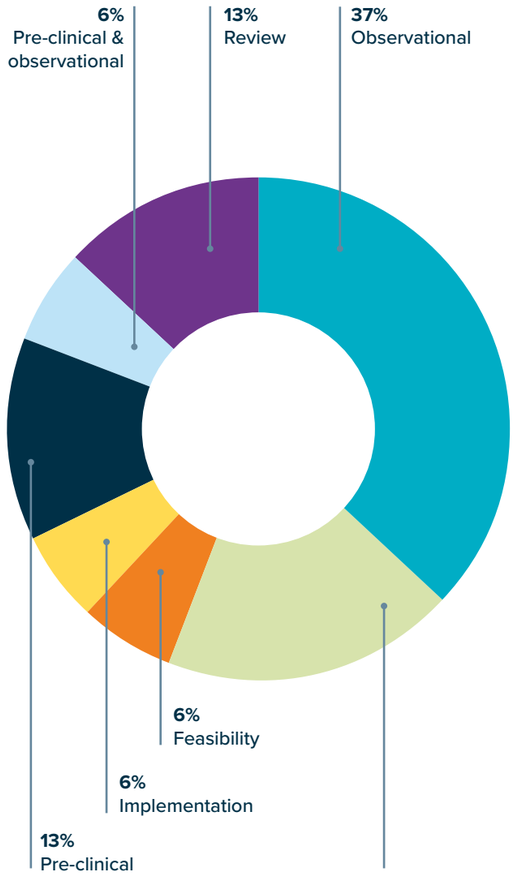


Figure 20: Priority 12 – Study designs used in the research



Priority 4: How can we speed up the process of getting diagnosed and starting treatment in the right place?

This priority was addressed by 15 (3.3%) of studies and was one of the Top 5 priorities identified by children and young people in their workshop (Aldiss et al, 2023b). However, nine of the 15 studies addressed this only as a secondary aim. These studies received £2,558,098 in funding from 11 funders. 11 institutions addressed this priority in their research. They were based in five regions of the UK – Greater London (n=5); East Midlands (n=4); West Midlands (n=3); Yorkshire (n=2) and East of England (n=1). The studies were mainly focussing on brain or spinal tumours and were pre-clinical in design (see Figs 21 and 22).

15 studies

£2.6 million in funding

Figure 21: Priority 4 – Types of cancer covered in the research

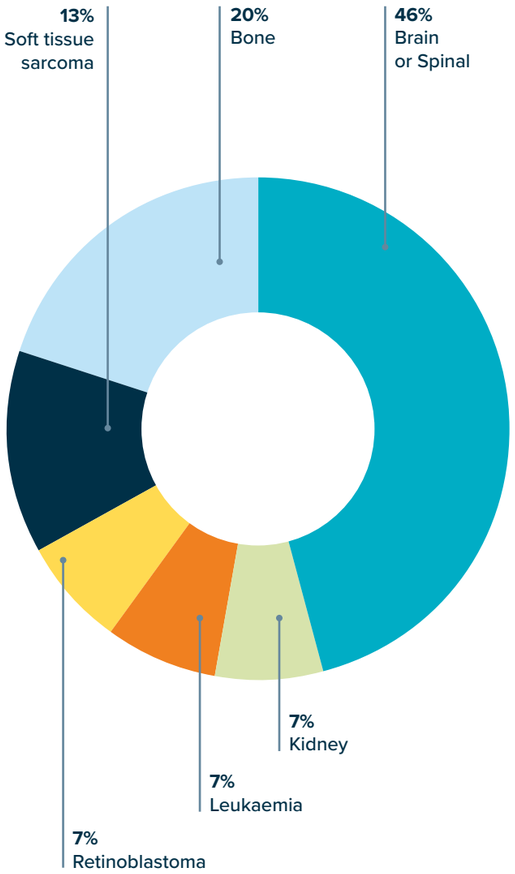
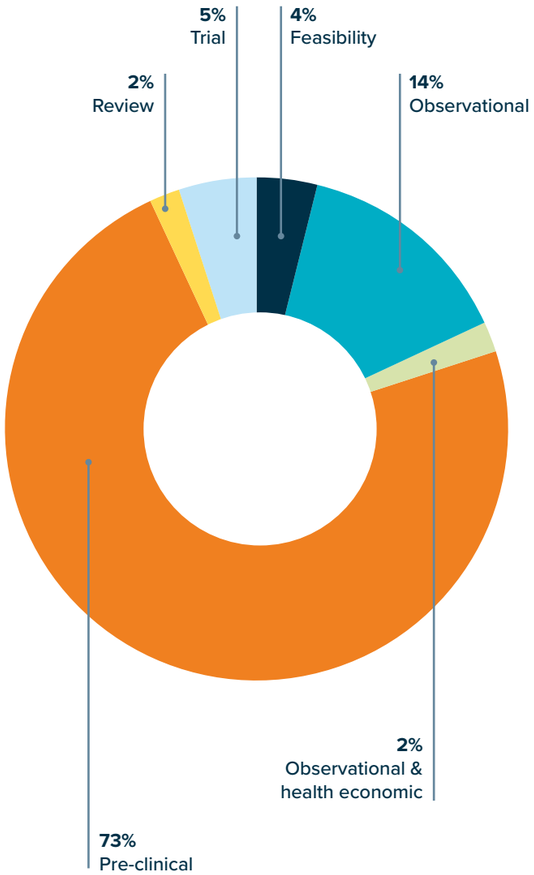


Figure 22: Priority 4 – Study designs used in the research



Priority 8: What impact does cancer and treatment have on the lives of children and families after treatment, and in the long-term; what are the best ways to help them to overcome these impacts to thrive and not just survive?

14 studies (3%) addressed priority 8 receiving £1,810,679 in funding from seven funders. 10 institutions covered this priority in their work. They were based in five regions of the UK – Greater London (n=6); South-East (n=4); North-West (n=2) and East and West Midlands (n=1 each). Most studies included all cancers, and were observational in design (see Figs. 23 and 24).

14 studies

£1.8 million in funding

Figure 23: Priority 8 – Types of cancer covered by the research

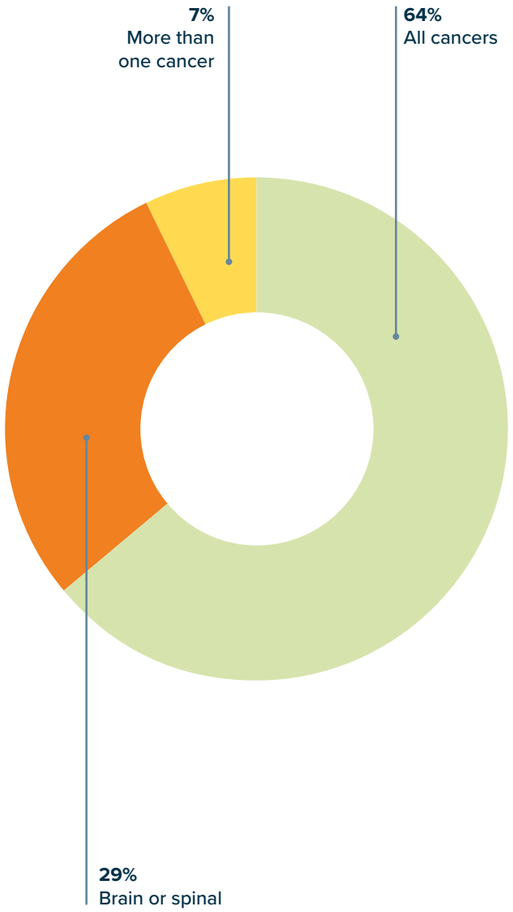
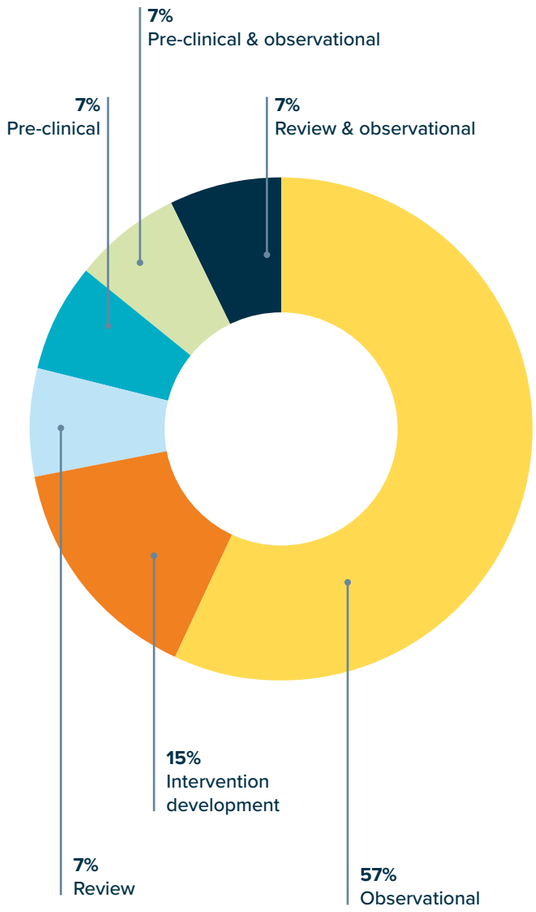


Figure 24: Priority 8 – Study designs used in the research



Priority 15: How common are the different long-term effects of childhood cancer treatment, how do they change across the lifespan, can we predict them and how can they best be prevented, detected and/or treated?

14 studies (3%) addressed this priority. £2,373,098 was awarded by six funders to 11 institutions in eight regions of the UK – Greater London (n=6); South-East (n=2); East Midlands, North-East, North-West, Scotland, South-West and West Midlands (n=1 each). Half of the studies were observational and 43% included all cancers (see Figs. 25 and 26).

14 studies

£2.4 million in funding

Figure 25: Priority 15 – Types of cancer covered by the research

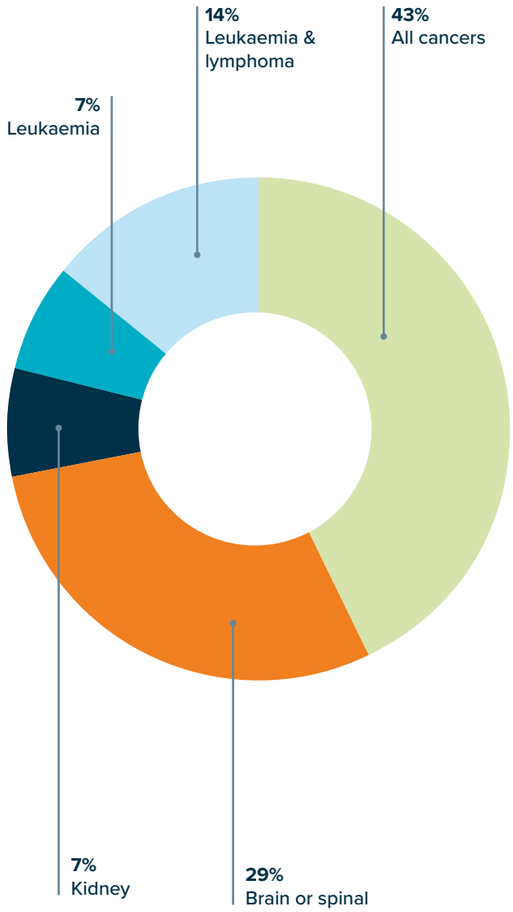
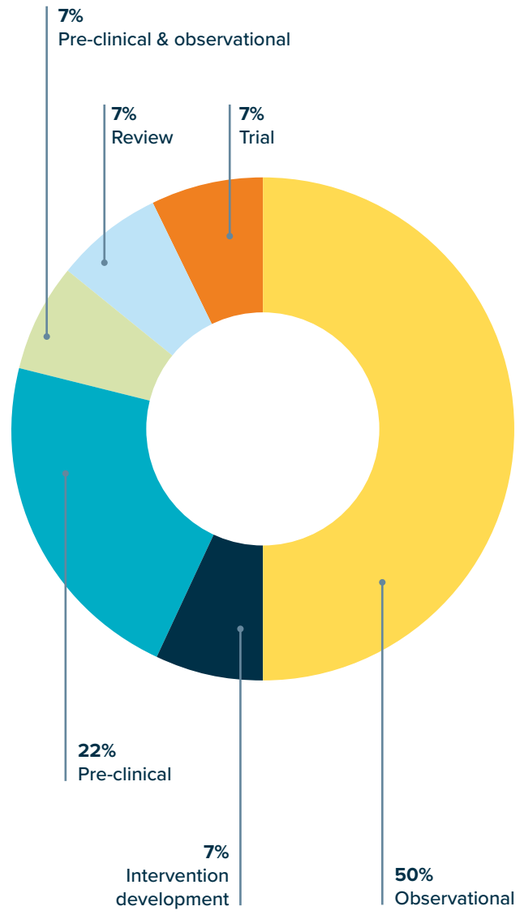


Figure 26: Priority 15 – Study designs used in the research



Priorities receiving limited attention from funders

Fewer than 10 studies addressed 11 of the priorities. These are detailed below, ranked by the number of studies focusing on each.

Priority 3: Are the psychological, practical, and financial support needs of children with cancer, survivors, and their families being met during treatment and beyond? How can access to this support be improved and what further support would they like?

8 studies

£0.7 million in funding

Despite being the third most important priority only eight (1.8%) studies examined this as a primary or secondary aim. These studies received £744,794 in funding from five funders. Seven institutions addressed this priority in their research across six regions of the UK – Greater London and the South-East (n=2 each), East of England, North-West, West Midlands and Yorkshire (n=1 each). Most of these studies were observational (n=6). Six of the studies included all cancers, one retinoblastoma and one brain or spinal tumours.

Priority 10: What is the relationship between chronic fatigue syndrome, fibromyalgia, chronic pain and treatment for childhood cancer? (Fibromyalgia is a long-term condition that causes pain all over the body.)

8 studies

£1.9 million in funding

Eight studies (1.8%) addressed priority 10. £1,968,352 of funding was provided by two funders and awarded to seven institutions across five regions of the UK – Greater London (n=3), East Midlands (n=2), South-East, South-West and West Midlands (n=1 each). Five studies focussed on all cancers, one on neuroblastoma, one on leukaemia and lymphoma and one on brain or spinal tumours. Three studies were observational, two were pre-clinical, two pre-clinical and observational and one was an intervention development study.

Priority 7: What are the best ways to ensure children and families get and understand the information they need, in order to make informed decisions, around the time of diagnosis, during treatment, at the end of treatment and after treatment has finished?

7 studies

£1.0 million in funding

Seven (1.5%) studies addressed this priority, attracting £980,363 in funding from four funders. Seven institutions addressed this priority in their research in six regions of the UK – Yorkshire (n=2), East of England, Greater London, North-West, South-West, West Midlands (n=1 each). Study designs were observational (n=3), intervention development (n=2), review (n=1) and observational and a review (n=1). Cancer categories included soft tissue sarcoma (n=2); all cancer (n=2); bone (n=1); more than one cancer (n=1); and neuroblastoma (n=1).

Priority 21: What are children's and survivors' experiences of the side-effects and long-term effects of cancer treatment?

5 studies

£0.8 million in funding

Five (1.1%) studies addressed priority 21. £775,391 was awarded by three funders to four institutions in three regions of the UK – Greater London (n=3), North-West, South-East (n=1 each). Two studies focussed on all cancers, one on leukaemia and lymphoma, one on brain or spinal tumours and one on kidney tumours. Two studies were observational, one focused on intervention development, one was pre-clinical and one was pre-clinical and observational.

Priority 19: What fertility preservation options work best for children and teenagers with cancer?

4 studies

£1.7 million in funding

Four studies (0.8%) addressed priority 19 looking at all cancers. £1,658,251 was awarded by three funders to four institutions in three regions in the UK – Scotland (n=2), the South-East and Yorkshire (n=1 each). This is one of the six priorities, together with Priorities 9, 11, 18, 23 and 14, where no research was conducted in Greater London. Two studies were pre-clinical, one observational and one a trial.

Priority 9: How can we make more accessible treatments that are closer to home, in shared care hospitals?

3 studies

£0.2 million in funding

Three (0.6%) studies addressed this priority, despite it being one of the Top 5 priorities identified by children and young people. Funding of £204,959 was provided by two funders. Three separate institutions carried out the research in Yorkshire (n=2) and the West Midlands (n=1). Two studies were reviews and one a health economic study. All three studies included all cancers, rather than focussing on a particular cancer.

Priority 11: What are the best ways to provide emotional support for children and their families 1) around the time of diagnosis, 2) during treatment and 3) after treatment (including survivors who are now adults)?

3 studies

£0.4 million in funding

Priority 11 was addressed by three (0.6%) studies, despite featuring in the Top 5 priorities for children. £366,682 was awarded by three funders to three institutions in the East Midlands, the South-East and the South-West. Two studies were observational covering all cancers and one focussed on intervention development for brain and spinal tumours.

Priority 17: During and after treatment, what issues prevent or encourage physical activity, which interventions are most effective and what should be measured to assess effectiveness?

2 studies

£0.1 million in funding

Two studies (0.4%) addressed this priority. £100,438 was awarded by two funders to two institutions to carry out an observational study on all cancers and an intervention development study on bone tumours, one in Greater London and one in the North-East.

Priority 18: What are the best ways of making sure people who had cancer as a child receive the information they need about the long-term effects of cancer and treatment?

Two observational studies (0.4%) addressed priority 18; one focussed on all cancers and the other on leukaemia and lymphoma. £505,559 was awarded by two funders to two institutions, one in the South-West and one in Yorkshire.

2 studies

£0.5 million in funding

Priority 23: What are the best ways to support children as they get older, and their needs change, to understand and take responsibility for their health, and to live with the long-term effects of cancer and treatment?

Two (0.4%) studies addressed priority 23. £169,897 was awarded by two funders to two institutions to carry out an observational study and an intervention development study both focussing on all cancers, one in the East of England and one in the South-East.

2 studies

£0.2 million in funding

Priority 14: What is the psychological and social impact of cancer and treatment on children and their families during treatment and in the long-term; what factors affect these impacts?

One (0.2%) observational study, including all cancers, addressed this priority and was awarded £56,186. The research was conducted in the West Midlands.

1 study

£0.06 million in funding

Critical gaps in research and funding coverage

Five priorities received no funding at all. Notably, priority 6 – identified as the top priority by children and young people – was among them.

Priority 6:
How can we make being in hospital a better experience for children and young people?

Priority 20:
What are the long-term effects of additional medications children with cancer may receive (such as antibiotics, pain killers, laxatives) and how can these effects be reduced?

Priority 16:
What are the best ways to support the emotional wellbeing of professionals who care for children with cancer and their families?

Priority 13:
How can transition (moving) from child into adult services be improved for young people who had cancer as a child?

Priority 22:
How can experiences of having a Hickman line be improved for children with cancer?

Alignment and gaps between research strategies and practice

Comparing the ranked orders in Table 2 (strategies referencing priorities) and Table 3 (actual funded studies and funding amounts) (see Appendix) provides an insight into possible mismatches between strategic intent and practice.

Areas of alignment

Priorities 1 (treatment) and 2 (cancer development): Ranked 1st and 2nd in both strategies and funded studies.

Priorities 13 (transition), 20 (long-term effects of additional medications), and 22 (Hickman line experience): No mentions in strategies and no funded studies.

Priorities 6 (hospital experience) and 16 (wellbeing of professionals): Mentioned once in strategies, but no funded studies.

Largest mismatches

Priority 4 (speeding up diagnosis): 3rd in strategies vs. 8th in studies → under-addressed.

Priority 5 (relapse): Low in strategies vs. 3rd in studies → researchers focus here despite limited strategic emphasis.

Conclusion and future directions

Summary

This mapping study provides the most comprehensive overview to date of childhood cancer research funding in the UK, with high engagement from the funding community. It reveals strong alignment with treatment-focused JLA priorities but also highlights critical gaps in psychosocial and patient experience research. Notably, the top priority for children – number 6 in the final list of 23 priorities – concerning improving hospital experience, is not addressed by any funded study.

The funders' strategies indicated that they would support a wide range of research, addressing many of the JLA priorities. However, the evidence is that in fact pre-clinical, treatment focused work tends to dominate.

It was encouraging to see that all major childhood cancers received some research attention, with the most common types generally attracting proportionately greater focus. Given that the majority of current research is at the pre-clinical stage, the translation of findings into tangible patient benefit is likely to follow a longer trajectory. While children's cancer research is being conducted across all regions of the UK, there is a notable concentration of activity in the Greater London area.

Patient and Public Involvement was mentioned in only a small number of studies. However, because many abstracts were brief and lacked detail, it is difficult to assess the true extent of stakeholder engagement. This therefore needs further investigation.

Limitations

We assessed how well the contributing organisations' research strategies aligned with the JLA PSP priorities, based on their most recently published documents. However, some of these strategies may not reflect current priorities or current funding directions.

Some grants had incomplete information (e.g. a limited abstract) which made mapping difficult and possibly meant that the study was mapped to fewer priorities. This may not be representative of the aims of the study. This highlights the need for researchers to supply informative abstracts and lay summaries for research awards.

By excluding infrastructure spending and focussing solely on standalone projects, this mapping may have overlooked research conducted within established research centres - for instance, fellowships or smaller studies led by senior researchers.

Because demographic data were largely unavailable from abstracts, this mapping study cannot determine whether current research is addressing health and care inequalities or supporting diverse and inclusive participation.

Whilst substantial efforts were made to include all relevant organisations it is possible that smaller charities may have been missed.

Next steps

How might this mapping project impact future funding and ultimately benefit patients?

For funders

The findings suggest a need for targeted funding initiatives to address underrepresented priorities - particularly those identified by children and young people themselves and those that receive little or no attention. It is hoped therefore that the results of this mapping study will inform future calls for funding within children's cancer by highlighting remaining gaps in terms of priorities.

Funders could diversify funding beyond pre-clinical studies to include observational, intervention development, and implementation research. In addition, they could support translational research to bridge the gap between pre-clinical work and research with clinical and real-world applications.

The Children and Young People's Cancer Coalition would be in a position to promote discussion around coordinating and collaborating on future funding and closing some of the gaps. Collaborations between funders in common areas of interest may lead to better use of limited funds and also avoid duplication. This collaboration could be both within the UK and internationally.

Funders should mandate meaningful Patient and Public Involvement (PPI) in funded projects, and support researchers to engage with stakeholders effectively, in terms of time and money.

Research strategies should be reviewed and updated regularly to reflect actual funding patterns and stakeholder priorities.

In the future it would be useful to establish shared databases to track research and how far it is aligned with JLA priorities.

For policy

The findings from this mapping project can help shape future policy decisions on children's cancer research funding. This project supported the CYP Cancer Taskforce to inform the development of the National Cancer Plan and we aim to embed the priorities into strategic planning.

Policy makers could also help to ensure equitable access to research funding and participation opportunities across the UK.

For researchers

It is important that health and social care researchers working within the field of children's cancer research are aware of the priorities that currently receive little or no funding. This will help them develop relevant, competitive funding applications and avoid duplicating efforts in areas that are already well supported.

Priorities from the Top 5 identified by children and young people that currently receive little or no funding should be addressed in future studies.

Researchers should involve children, young people, survivors, and families meaningfully in their research designs and dissemination. In addition, they should highlight PPI activities clearly in abstracts to improve visibility.

It would be useful to expand beyond pre-clinical studies to include observational, qualitative, intervention development, and implementation research and to explore mixed-methods approaches to capture the complexity of lived experiences. This would be especially useful in addressing some of the underfunded and neglected JLA PSP priorities. This type of work may benefit from collaborations across specialities to bridge the gap between the pre-clinical and applied research studies.

In order to address some of the geographical disparities, regional collaborations and multi-site studies would be useful.

For patients, survivors and families

Increasing awareness among patients and the public about underfunded research priorities could help drive advocacy efforts - encouraging charities, government bodies, and other stakeholders to direct funding towards these unmet needs.

Patients could be encouraged to participate in research studies where possible especially those involving lived experience and survivorship issues. They could also contribute to campaigns and raising awareness through social media channels.

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Acknowledgements

This project was funded by CCLG: The Children & Young People's Cancer Association.

We would like to thank the following charities and organisations for sharing their data:

Action Medical Research for Children
Alder Hey Children's Charity
Alice's Arc
Birmingham Women's and Children's Hospital Charity
Blood Cancer UK
Bone Cancer Research Trust
Brain Research UK
The Brain Tumour Charity
Brain Tumour Research
Cancer Research Wales
CCLG: The Children & Young People's Cancer Association
Childhood Eye Cancer Trust (CHECT)
Children with Cancer UK
Children's Cancer Research Fund
Grace Kelly Childhood Cancer Trust
Great Ormond Street Hospital Children's Charity
Leukaemia & Lymphoma NI
Leukaemia UK
The Little Princess Trust
Medical Research Foundation
Medical Research Scotland
Neuroblastoma UK
National Institute for Health and Care Research (NIHR)
North West Cancer Research
Sarcoma UK
Sheffield Children's Hospital Charity
Solving Kids' Cancer UK
UK Research and Innovation (UKRI)
Wellcome
Worldwide Cancer Research

We would like to thank our steering group members for their valuable contributions: Ashley Ball-Gamble; Sabine Best; Sarah Evans and Tom Lee

Appendix

Table 1: Priorities with keywords and related themes for mapping purposes

No.	Priority description	Keywords and related themes
1	Can we find effective and kinder (less burdensome, more tolerable, with fewer short and long-term effects) treatments for children with cancer, including relapsed cancer?	Treatments, effective, kinder, including relapse treatments
2	Why do children develop cancer (including the role that genetics plays) and could it be prevented?	Develop, genetics, prevention
3	Are the psychological, practical, and financial support needs of children with cancer, survivors, and their families being met during treatment and beyond? How can access to this support be improved and what further support would they like?	Psychological, practical, financial support, during treatment, beyond treatment, access, further support
4	How can we speed up the process of getting diagnosed and starting treatment in the right place?	Diagnosis, speed, right place
5	Why do children relapse, how can it be prevented, and what are the best ways to identify relapse earlier?	Reasons for relapse, early identification, prevention
6	How can we make being in hospital a better experience for children and young people? (like having better food, internet, toys, and open visiting so other family members can be more involved in the child's care)	Hospital experience
7	What are the best ways to ensure children and families get and understand the information they need, in order to make informed decisions, around the time of diagnosis, during treatment, at the end of treatment and after treatment has finished?	Information access and understanding, diagnosis, during treatment, after treatment
8	What impact does cancer and treatment have on the lives of children and families after treatment, and in the long-term; what are the best ways to help them to overcome these impacts to thrive and not just survive?	Impact after treatment and in long term. Thrive and survive
9	How can we make more accessible treatments that are closer to home, in shared care hospitals?	Accessibility of treatments, location of treatments
10	What is the relationship between chronic fatigue syndrome, fibromyalgia, chronic pain and treatment for childhood cancer? (Fibromyalgia is a long-term condition that causes pain all over the body.)	CFS, fibromyalgia, chronic pain and treatment
11	What are the best ways to provide emotional support for children and their families 1) around the time of diagnosis, 2) during treatment and 3) after treatment (including survivors who are now adults)?	Emotional support needs, diagnosis, during and after treatment
12	What are the best ways to reduce, predict and manage the side-effects of treatment for children (including life threatening side-effects)?	Side effects, reduce, predict, manage
13	How can transition (moving) from child into adult services be improved for young people who had cancer as a child?	Transition to adult services
14	What is the psychological and social impact of cancer and treatment on children and their families during treatment and in the long-term; what factors affect these impacts?	Psychological and social impact during treatment and in long term
15	How common are the different long-term effects of childhood cancer treatment, how do they change across the lifespan, can we predict them and how can they best be prevented, detected and/or treated?	Prevalence of long-term effects of treatment, predict, prevent, detect and treat
16	What are the best ways to support the emotional wellbeing of professionals who care for children with cancer and their families?	Emotional wellbeing of professionals
17	During and after treatment, what issues prevent or encourage physical activity, which interventions are most effective and what should be measured to assess effectiveness?	Physical activity, effective interventions
18	What are the best ways of making sure people who had cancer as a child receive the information they need about the long-term effects of cancer and treatment?	Information dissemination on long-term effects of cancer and treatment
19	What fertility preservation options work best for children and teenagers with cancer?	Fertility preservation
20	What are the long-term effects of additional medications children with cancer may receive (such as antibiotics, pain killers, laxatives) and how can these effects be reduced?	Long term effects of additional medications, reduction of effects
21	What are children's and survivors' experiences of the side-effects and long-term effects of cancer treatment?	Experiences of side effects and long term effects
22	How can experiences of having a Hickman line be improved for children with cancer?	Hickman line, improving experience
23	What are the best ways to support children as they get older, and their needs change, to understand and take responsibility for their health, and to live with the long-term effects of cancer and treatment?	Support for taking responsibility for health, long term effects of cancer and treatment

Appendix

Table 2: Frequency-based ranking of JLA PSP priorities referenced in funders' research strategies

No.	Priority description	Number of strategies referencing a priority (N=30)
1	Can we find effective and kinder (less burdensome, more tolerable, with fewer short and long-term effects) treatments for children with cancer, including relapsed cancer?	29
2*	Why do children develop cancer (including the role that genetics plays) and could it be prevented?	19
4*	How can we speed up the process of getting diagnosed and starting treatment in the right place?	12
12	What are the best ways to reduce, predict and manage the side-effects of treatment for children (including life threatening side-effects)?	8
3	Are the psychological, practical, and financial support needs of children with cancer, survivors, and their families being met during treatment and beyond? How can access to this support be improved and what further support would they like?	7
8	What impact does cancer and treatment have on the lives of children and families after treatment, and in the long-term; what are the best ways to help them to overcome these impacts to thrive and not just survive?	7
5	Why do children relapse, how can it be prevented, and what are the best ways to identify relapse earlier?	4
14	What is the psychological and social impact of cancer and treatment on children and their families during treatment and in the long-term; what factors affect these impacts?	3
15	How common are the different long-term effects of childhood cancer treatment, how do they change across the lifespan, can we predict them and how can they best be prevented, detected and/or treated?	3
21	What are children's and survivors' experiences of the side-effects and long-term effects of cancer treatment?	3
6*	How can we make being in hospital a better experience for children and young people? (like having better food, internet, toys, and open visiting so other family members can be more involved in the child's care)	1
11*	What are the best ways to provide emotional support for children and their families 1) around the time of diagnosis, 2) during treatment and 3) after treatment (including survivors who are now adults)?	1
16	What are the best ways to support the emotional wellbeing of professionals who care for children with cancer and their families?	1
18	What are the best ways of making sure people who had cancer as a child receive the information they need about the long-term effects of cancer and treatment?	1
7	What are the best ways to ensure children and families get and understand the information they need, in order to make informed decisions, around the time of diagnosis, during treatment, at the end of treatment and after treatment has finished?	0
9*	How can we make more accessible treatments that are closer to home, in shared care hospitals?	0
10	What is the relationship between chronic fatigue syndrome, fibromyalgia, chronic pain and treatment for childhood cancer? (Fibromyalgia is a long-term condition that causes pain all over the body.)	0
13	How can transition (moving) from child into adult services be improved for young people who had cancer as a child?	0
17	During and after treatment, what issues prevent or encourage physical activity, which interventions are most effective and what should be measured to assess effectiveness?	0
19	What fertility preservation options work best for children and teenagers with cancer?	0
20	What are the long-term effects of additional medications children with cancer may receive (such as antibiotics, pain killers, laxatives) and how can these effects be reduced?	0
22	How can experiences of having a Hickman line be improved for children with cancer? (A Hickman line is a small tube which is inserted into a vein so that treatments can be given, and blood taken without the repeated need to access veins with a needle. The Hickman line can stay in place for several months.)	0
23	What are the best ways to support children as they get older, and their needs change, to understand and take responsibility for their health, and to live with the long-term effects of cancer and treatment?	0

* These priorities are one of the Top 5 from children and young people in the JLA PSP

Appendix

Table 3: Priorities ranked in order reflecting number of studies which address this as their main or secondary aim.

No.	Priority description	Number of studies where this priority is main aim of study (direct link)	Number of studies where this priority is secondary aim of study (indirect link)	Total funding
1	Can we find effective and kinder (less burdensome, more tolerable, with fewer short and long-term effects) treatments for children with cancer, including relapsed cancer?	289	76	£94,197,669
2*	Why do children develop cancer (including the role that genetics plays) and could it be prevented?	63	10	£16,570,910
5	Why do children relapse, how can it be prevented, and what are the best ways to identify relapse earlier?	36	8	£9,639,086
12	What are the best ways to reduce, predict and manage the side-effects of treatment for children (including life threatening side-effects)?	15	1	£5,312,657
15	How common are the different long-term effects of childhood cancer treatment, how do they change across the lifespan, can we predict them and how can they best be prevented, detected and/or treated?	14	0	£2,373,098
8	What impact does cancer and treatment have on the lives of children and families after treatment, and in the long-term; what are the best ways to help them to overcome these impacts to thrive and not just survive?	12	2	£1,810,679
3	Are the psychological, practical, and financial support needs of children with cancer, survivors, and their families being met during treatment and beyond? How can access to this support be improved and what further support would they like?	7	1	£744,794
4*	How can we speed up the process of getting diagnosed and starting treatment in the right place?	6	9	£2,558,098
7	What are the best ways to ensure children and families get and understand the information they need, in order to make informed decisions, around the time of diagnosis, during treatment, at the end of treatment and after treatment has finished?	6	1	£980,363
19	What fertility preservation options work best for children and teenagers with cancer?	3	1	£1,658,251
11*	What are the best ways to provide emotional support for children and their families 1) around the time of diagnosis, 2) during treatment and 3) after treatment (including survivors who are now adults)?	3	0	£366,682
10	What is the relationship between chronic fatigue syndrome, fibromyalgia, chronic pain and treatment for childhood cancer? (Fibromyalgia is a long-term condition that causes pain all over the body.)	2	6	£1,968,352

Appendix

Continued table 3

Priority Number	Priority Description	Number of studies where this priority is main aim of study (direct link)	Number of studies where this priority is secondary aim of study (indirect link)	Total funding
21	What are children's and survivors' experiences of the side-effects and long-term effects of cancer treatment?	2	3	£775,391
9*	How can we make more accessible treatments that are closer to home, in shared care hospitals?	2	1	£204,959
17	During and after treatment, what issues prevent or encourage physical activity, which interventions are most effective and what should be measured to assess effectiveness?	2	0	£100,438
18	What are the best ways of making sure people who had cancer as a child receive the information they need about the long-term effects of cancer and treatment?	2	0	£505,559
23	What are the best ways to support children as they get older, and their needs change, to understand and take responsibility for their health, and to live with the long-term effects of cancer and treatment?	1	1	£169,897
14	What is the psychological and social impact of cancer and treatment on children and their families during treatment and in the long-term; what factors affect these impacts?	1	0	£56,186
6*	How can we make being in hospital a better experience for children and young people? (like having better food, internet, toys, and open visiting so other family members can be more involved in the child's care)	0	0	£0
13	How can transition (moving) from child into adult services be improved for young people who had cancer as a child?	0	0	£0
16	What are the best ways to support the emotional wellbeing of professionals who care for children with cancer and their families?	0	0	£0
20	What are the long-term effects of additional medications children with cancer may receive (such as antibiotics, pain killers, laxatives) and how can these effects be reduced?	0	0	£0
22	How can experiences of having a Hickman line be improved for children with cancer? (A Hickman line is a small tube which is inserted into a vein so that treatments can be given, and blood taken without the repeated need to access veins with a needle. The Hickman line can stay in place for several months.)	0	0	£0

* These priorities are one of the Top 5 from children and young people in the JLA PSP

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This report should be cited as:

Bish A., Gibson F., Brownsdon A., Chisholm J., Harris J., Hollis R., Phillips B., Aldiss S. (2026) Mapping funding of UK childhood cancer research against the James Lind Alliance Children's Cancer Priority Setting Partnership Priorities

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CCLG and The Children & Young People's Cancer Association are operating names of The Children's Cancer and Leukaemia Group, registered charity in England and Wales (1182637) and Scotland (SC049948).

Design: adeptdesign.co.uk

We are CCLG: The Children & Young People's Cancer Association. We unite the children and young people's cancer community, driving collective action and progress. Powered by expertise, we work together to create a brighter future for children and young people with cancer.

Research is the key to better treatments, improved care, and potential cures. We fund and lead world-class research, fuelling groundbreaking work led by brilliant minds. Collaboration is at the heart of our approach - bringing together the right people and organisations to drive progress and deliver real impact.

We provide trusted information and guidance for children and young people with cancer, their families, and everyone supporting them. Our expertise helps them navigate the challenges of cancer and its impact, offering reassurance and clarity when it's needed most.

Through our professional membership, we bring together the brightest minds in childhood cancer, creating a national network that drives progress. Together, we shape better treatment and care - developing guidelines, sharing knowledge, offering expert advice, leading pioneering research, and creating essential resources and education for professionals. Our collective expertise sets the standard, advocating for excellence at every level - local, national, and global.