The Children &
Young People's
Cancer Association

A brighter future:

Our vision for children and young people's cancer research

CCLG's Research Strategy

2025–2030

Expertise.
Progress.
Community.

We are CCLG: The Children & Young People’s Cancer Association

A charity dedicated to creating a brighter future for children and young people with cancer. Powered by expertise, we unite the children and young people’s cancer community, driving collective action and progress.

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.

Foreword

At CCLG: The Children & Young People’s Cancer Association, we know research is at the heart of improving diagnosis, treatment, care, and outcomes for children and young people with cancer. It’s why four out of five children now survive their cancer, and it’s how we’ll build a brighter future.

We want to close the gap between cancers with the best and worst outcomes, discover kinder treatments that don’t leave lasting impacts, and make sure every child and young person has the right support at every step of their journey.

With that in mind, I’m excited to introduce our new research strategy. This is the result of months of work, collaboration, and input from our incredible community of researchers, healthcare professionals, and those with lived experience of cancer. It’s a true reflection of what CCLG stands for: expertise, community, and progress.

This strategy takes a fresh approach. It’s bold and ambitious, because nothing less will do for children and young people with cancer. We’ve outlined four key ambitions, painting a picture of what we want research to achieve in the long term. We know research takes time – years, sometimes decades – but it can also move fast, so we’ve built flexibility into our plans. Alongside our ambitions, you’ll find practical objectives to guide us and short-term actions to get us started. This is about action, not words.

This isn’t just a glossy brochure or a checklist that gathers dust. It’s a clear statement of what children and young people’s cancer research should look like and a roadmap to get there. But here’s the thing: we can’t do it alone. Collaboration has always been part of who we are, but now we’re stepping it up. We’re committed to bringing together the right people and organisations to make this vision a reality.

Collaboration is key to everything – building a thriving research community, embedding lived experience into research, and crucially, funding it. Research is expensive, and it demands long-term commitment. To make a real difference, we need to break down silos, worry less about who gets the credit, and focus on the priorities our community has told us matter most. By joining forces, we can fund more research, faster.

After reading this strategy, I’d love to hear from you. Are you a researcher with an innovative idea? A young person with cancer, or a parent, keen to shape future research? A charity interested in teaming up to fund work that matters? Maybe it’s 2028, and you’re checking in to see if we’ve lived up to our promises (it’s early 2025 as I write this). I hope you’ll see the evidence of progress, but we’re ready to be held to account.

A heartfelt thank you to everyone who’s contributed to this strategy and to those who’ll bring it to life in the years ahead. Together, we’re moving towards that brighter tomorrow. Let’s get started.

Ashley.

Ashley Ball-Gamble

Chief Executive

> **“We're committed to bringing together the right people and organisations to make this vision a reality.”**

> “As I take on the role of CCLG Chair, I'm excited to be bringing together the experts in children's and teenage & young adult cancer. Changes over the past year mean now is the ideal time to create alignment between CCLG, the cancer clinical research groups, and the wider children and young people's cancer community to create and deliver a truly holistic and comprehensive research strategy.
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> By creating a clear, cohesive approach to addressing what matters for children and young people, their families, communities, and the professionals supporting their care, we know we will be addressing the most important research questions.
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> The coming together of those working in both children's and teenage and young adult cancer allows the development of a research portfolio that best considers how to bridge these knowledge gaps seamlessly and is genuinely inclusive of all ages of children and young people. It will foster better equity of access to research, like clinical trials, and help consider how we improve the diversity of representation, which in turn will lead to improvements in care for more children and young people.
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> Harnessing our community's collective lived experience and combining this with our professionals' expertise allows us to curate a truly unique research portfolio, that is both visionary and world-leading, but also completely grounded in tangible and deliverable outcomes that will make a difference to every child and young person.”

Dr Sara Stoneham

Paediatric and Teenage & Young Adult Oncologist
Chair of CCLG: The Children and Young People's Cancer Association

> “I've been involved in the CCLG Patient and Parent Involvement (PPI) group since 2020 as I wanted to help with childhood cancer research following my son Sebby's treatment for leukaemia. Having worked in strategy development in my career, I was keen to get involved in thinking about CCLG's new research strategy. There was great potential to refocus CCLG's research efforts and it was exciting to be involved in this.
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> Lived experience is at the core of the strategy. PPI representatives have been involved at all stages, so our thinking is woven through all strands of the strategy. One of the four pillars of the strategy is focused on lived experience, and this shows CCLG's commitment to PPI and recognition of its importance to driving quality and meaningful research.
>
> I hope this strategy will ensure that research is making the biggest difference that it can to the treatment of children and young people with cancer and that we will see progress on this at a faster rate than in the past.”

Kate Willis, mum to Sebby diagnosed with leukaemia aged 2

CCLG PPI Research Group Member

Building on our achievements

For almost 50 years, CCLG has been at the heart of the childhood cancer community, driving progress in research, care, and collaboration.

When we were first established in 1977 as The UK Children's Cancer Study Group (UKCCSG), fewer than 3 in 10 children survived cancer, and research into childhood cancers was almost non-existent. Fourteen visionary founders united to launch clinical trials, collect vital data, and build a clinical network to advance understanding. That same year, our first clinical trial opened for children with non-Hodgkin lymphoma. Over the years, trials expanded to include almost every childhood cancer, transforming the landscape of paediatric oncology.

We laid the foundation for today's specialist network of hospitals treating children with cancer and, in 1998, launched the CCLG Tissue Bank (now VIVO Biobank), which has become an invaluable resource for scientists working to improve diagnosis and treatment. In the mid-2000s, UKCCSG merged with the UK Childhood Leukaemia Working Party to form Children's Cancer and Leukaemia Group (CCLG), bringing research into solid tumours and leukaemia together under one, united organisation.

By 2010, the delivery of clinical trials transitioned to dedicated research organisations, enabling us to focus on our role as the professional membership association for those working in children and young people's cancer, a trusted source of health information, and a leading research charity. In 2015, we published our first research strategy, committing to increasing funding for research into children's cancers. Our membership of the Association of Medical Research Charities (AMRC) demonstrates our commitment to excellence and rigorous standards in funding groundbreaking research.

Over the last decade, we've expanded our Special Named Funds programme, creating opportunities for families to honour children and young people affected by cancer while supporting pioneering research. We've grown our collaborative network, enabling more charities to fund exceptional research. In 2022, we published our first Research Impact Report, celebrating the difference made by the projects we support. The following year, alongside The Little Princess Trust, we unveiled the James Lind Alliance Children's Cancer Priority Setting Partnership report, highlighting the top 10 priorities for children's cancer research.

In 2019, we merged with Teenagers and Young Adults with Cancer (TYAC). We published the first TYAC research strategy and went on to award our inaugural grants dedicated to research for teenagers and young adults. In 2025, we proudly relaunched as CCLG: The Children & Young People's Cancer Association, bringing together our expertise to support our community and accelerate progress.

As we look ahead, our new research strategy builds on this legacy. Together, we will create a brighter future for children and young people with cancer.

Research that changes lives

At CCLG, we are proud to lead the way in shaping research that addresses the unique needs of children and young people with cancer. Effective treatment and care must be built on a deep understanding of their distinct physical, emotional, and psychological needs. Children and young people are not simply smaller versions of adults, and children, teenagers, and young adults each face their own unique challenges. That's why dedicated research is essential to improving outcomes.

To ensure we're focusing where it matters most, we partnered with The James Lind Alliance (JLA) to deliver a Priority Setting Partnership (PSP) for children's cancer research, in collaboration with The Little Princess Trust. This robust process brought together the voices of patients, parents, carers, and professionals to identify the most critical unanswered questions in children's cancer research. The final report of this work, published in 2023, highlights the top priorities and amplifies the perspectives of those who matter most: patients and their families.

Combined with the JLA PSP for Teenagers and Young Adults with Cancer, completed in 2019, we now have a comprehensive understanding of research priorities for children and young people aged 0–25. These priorities go beyond physical care, emphasising psychological and emotional support, better management of long-term effects, and a holistic approach to treatment and survivorship.

This vital work provides a clear roadmap for us and other funders, ensuring research is aligned with what families, professionals, and young people value most. As leaders in this process, we are committed to championing these priorities and ensuring they guide the future of childhood and young people's cancer research.

“The vastness of the things we could research in children and young people's (CYP) cancer is staggering and a little bit frightening. How do we pick the next question we should focus on?

Without bringing together the expertise of those who have experienced CYP cancer, those who do the research, and those who work directly in healthcare, we'll end up wasting time, money, and effort on dead ends or unimportant questions. The process we used in the PSP fairly and formally brought these groups together to come up with a shared list of priorities. This means researchers know that taking on one of those questions will benefit the CYP cancer community.

Knowing the top-rated questions lets us see which of these important areas are under-researched so we can put extra effort there and, in well-studied areas, allows us to fine-tune our research to get the answers that people are longing for.

This research strategy could help us move from a slightly disconnected group of researchers into a well-oiled team that shares the questions between ourselves to score a goal for Team CYP Cancer. It's going to help improve the way lived experience feeds into research, streamlining funding and making small pots of money melt together for greater success. This level of coordination will help reduce the repetition and overlap that reduces the efficiency of our efforts.”

Prof Bob Phillips

Professor of Paediatrics and Evidence Synthesis & Honorary Consultant in Paediatric Oncology and CCLG Member

“Through the Priority Setting Partnership process, we heard from hundreds of children with cancer, survivors, and the parents, carers and healthcare professionals who look after them. They told us about what mattered most to them and what questions or concerns they would like research to find answers for.

The PSP was a long and thorough process and the 23 questions that came out of it represent the most important questions that we need answers to. They are also really comprehensive, as they cover so many topics including diagnosis, treatment, relapse, care, support, and life after treatment.

By incorporating the PSP priorities into this research strategy, CCLG is ensuring it will fund research on what is most important to children with cancer, survivors of childhood cancer, families, carers, and healthcare teams. It will mean we start to find answers to the most pressing problems. I hope it's going to make sure CCLG continues to make a real difference to those affected by childhood cancer.”

Anna Watkins, parent to Imogen diagnosed with leukaemia aged 2

Member of the Children's Cancer Priority Setting Partnership Steering Group and CCLG Research PPI Group Member

The top 10 priorities

in children's cancer research

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?
2. Why do children develop cancer (including the role that genetics plays) and could it be prevented?
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?
4. How can we speed up the process of getting diagnosed and starting treatment in the right place?
5. Why do children relapse, how can it be prevented, and what are the best ways to identify relapse earlier?
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)
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?
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?
9. How can we make more accessible treatments that are closer to home, in shared care hospitals?
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.)

Aldiss S et al. Research priorities for children's cancer: a James Lind Alliance Priority Setting Partnership in the UK. BMJ Open. 2023 Dec 20;13(12):e077387. doi: 10.1136/bmjopen-2023-077387. PMID: 38128939; PMCID: PMC11148658.

The top 10 priorities

in teenage and young adult cancer research

1. What psychological support package improves psychological well-being, social functioning, and mental health during and after treatment?
2. What interventions, including self-care, can reduce or reverse adverse short- and long-term effects of cancer treatment?
3. What are the best strategies to improve access to clinical trials?
4. What GP or young person strategies, such as awareness campaigns and education, improve early diagnosis for young people with suspected cancer?
5. What are the best ways of supporting a young person who has incurable cancer?
6. What are the most effective strategies to ensure that young people who are treated outside of a young person's principal treatment centre receive appropriate practical and emotional support?
7. What interventions are most effective in supporting young people when returning to education or work?
8. How can parents/carers/siblings/partners be best supported following the death of a young person with cancer?
9. What is the best method of follow-up and timing which causes the least psychological and physical harm, while ensuring relapse/complications are detected early?
10. What targeted treatments are effective and have fewer short- and long-term side-effects?

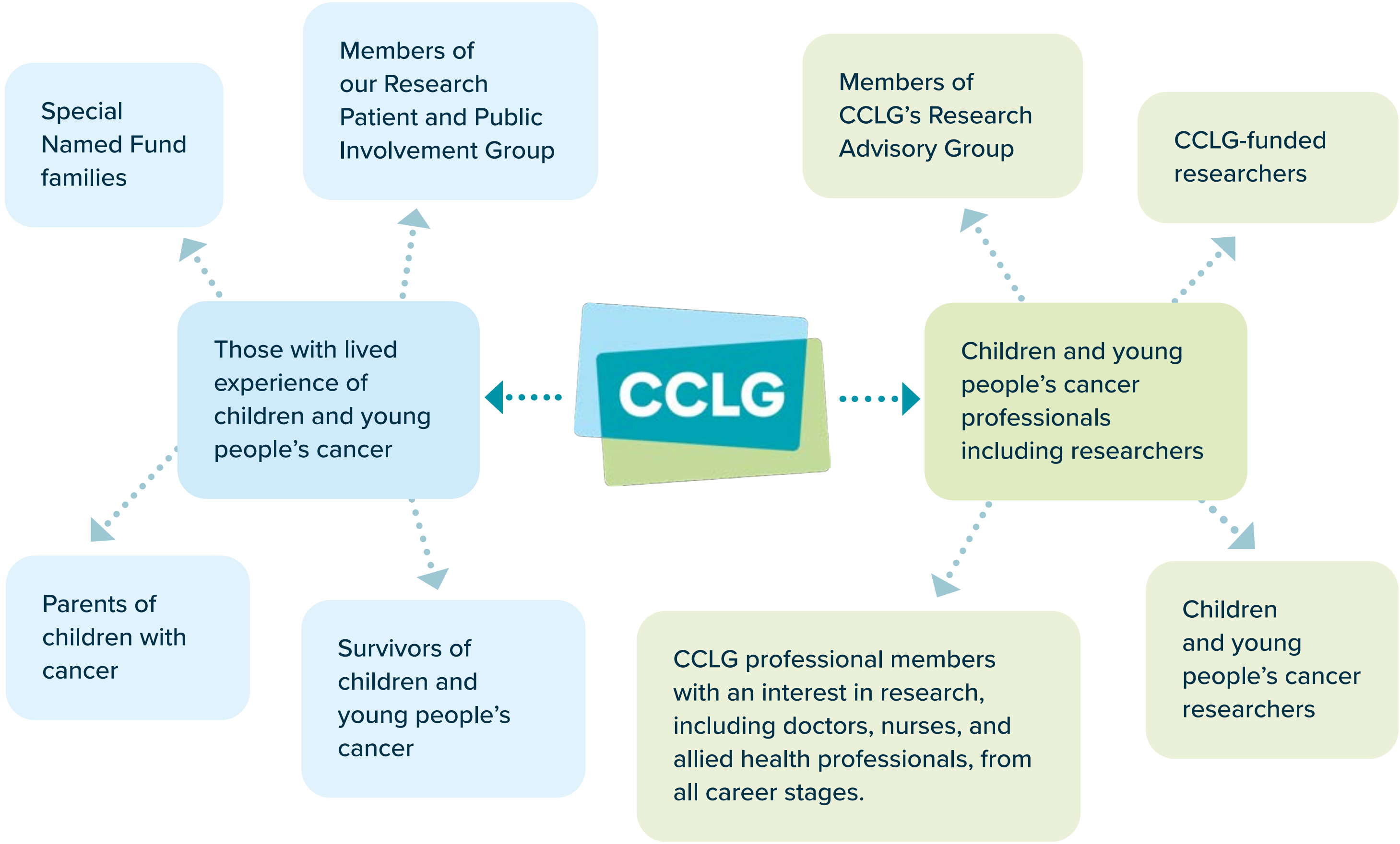
Aldiss S et al. Research priorities for young people with cancer: a UK priority setting partnership with the James Lind Alliance BMJ Open 2019;9:e028119. doi: 10.1136/bmjopen-2018-028119

Shaping the future for greater impact

In 2022, we celebrated the progress of our research with the publication of Finding a Cure for Childhood Cancer: Celebrating CCLG's Research Impact. This report showcased the exceptional researchers we've supported and the achievements of our partnerships, highlighting the significant milestones made possible by the foundations laid by our first research strategy.

Building on this success, and guided by the critical research priorities we've now identified, it's time to redefine our vision for research.

Collaboration and community engagement have always been at the heart of our approach. In shaping this strategy, we worked closely with those who have professional expertise and lived experience of cancer in children and young people. Their insights and experiences have been invaluable in helping us identify four core long-term ambitions for our research. These ambitions reflect what matters most to our community and will drive us forward in creating a brighter future for children and young people with cancer.



CCLG

- Those with lived experience of children and young people's cancer
  - Special Named Fund families
  - Members of our Research Patient and Public Involvement Group
  - Parents of children with cancer
  - Survivors of children and young people's cancer
- Children and young people's cancer professionals including researchers
  - Members of CCLG's Research Advisory Group
  - CCLG-funded researchers
  - CCLG professional members with an interest in research, including doctors, nurses, and allied health professionals, from all career stages.
  - Children and young people's cancer researchers

The process of developing our strategy

Generating ideas for our research strategy

We held 8 workshops with 44 members of our community, including 17 with lived experience. These sessions generated 444 ideas, which we grouped into 26 themes.

Focusing on what matters most

We held a workshop with 16 experts, including four with lived experience, to prioritise the themes to include in our research strategy. Following this, we created the first draft of our research strategy.

Checking we got it right

We gathered feedback from 17 experts, including four with lived experience, to make sure our final ambitions, along with our plans for achieving them, were the right ones to pursue.

Publishing our final research strategy

This strategy is the culmination of a collaborative process involving experts, including those with lived experience, from across the children and young people's cancer community.

By working hand in hand with the children and young people's cancer community, we've defined four core ambitions to shape our research efforts and drive meaningful change.

These four ambitions represent our ultimate goals, and everything we do will bring us closer to achieving them. For each, we've identified focus areas for the coming years, alongside specific actions we'll take in the first year of this strategy. This isn't a document to gather dust; it's a dynamic plan for real, lasting impact.

Research takes time. Breakthroughs often build on years of effort, and discoveries need time to translate into clinical practice. That's why we're committed to a long-term vision while staying flexible and ready to adapt. By keeping our focus on the future and embracing innovation, we'll ensure we remain at the forefront of progress.

Our four ambitions for children and young people's cancer research

- A coordinated, collaborative approach to children and young people's cancer research
- Funding the best research, led by the best minds
- Lived experience is at the heart of children and young people's cancer research
- A thriving children and young people's cancer research community

Our expert community is made up of pioneering scientists, inspiring academics, and dedicated healthcare professionals, all working tirelessly to advance the field of children's and young people's cancer research. However, this critical work is only possible because of the incredible fundraising efforts of our wider community: parents, families, and the public. As a charity, we are honoured to be entrusted with these funds and carry the responsibility to use them wisely, ensuring they support high-quality research that has a meaningful impact on the treatment, care and experience of young cancer patients.

“This new strategy is based on long-term, all-encompassing ambitions. In other words, it is not focused on specific tumour types, but rather on maximising our research community and ensuring it is inclusive. We want to harness the experiences of all professionals, patients, and families who are involved with or affected by children and young people's cancer.

Our diverse community will bring together experts from different tumour groups, training backgrounds, and career stages. Coupled with our strategy to harness lived experience, we will develop a collaborative community with a renewed focus and motivation where new ideas can foster innovation in all areas of research.”

Dr Becky Hill

Clinician Scientist & Honorary Consultant in Paediatric Oncology, CCLG member Co-Chair, CCLG Research Advisory Group

> **“It gives us hope when, for some of us, hope was taken away by cancer. I am most excited that the strategy is driving progress.”**

“Families like ours cannot live a life, under the dark cloud of childhood cancer, without knowing our child's experience was not in vain. We feel strongly that good has to come from our experiences. We want to be heard and seen, and to know that we can help make a difference. The process of building this strategy, with CCLG, is just the start of lived experiences being at the heart of children and young people's cancer research. It gives us hope when, for some of us, hope was taken away by cancer.

I am most excited that the strategy is driving progress. Childhood cancer isn't going anywhere. Without drive and coordinated, collaborative approaches, childhood cancer research could continue in isolation with little advancement. Organisations with joint goals and priorities must work together, share expertise and be committed to driving progress as one network. I am excited that CCLG is ambitious about achieving this.”

Lisa Radcliffe, mum to George diagnosed with rhabdomyosarcoma aged 3

CCLG Special Named Fund 'Just George' and CCLG PPI Research Group Member

Ambition 1: A coordinated, collaborative approach to children and young people's cancer research

We believe no single charity, hospital or research institute has all the answers. By leading genuine collaboration, we'll ensure that the right research priorities are identified, the highest quality research is funded, and no resources are wasted. Powered by our expertise, we'll be leading the charge to coordinate efforts and make a lasting impact for children and young people with cancer.

Despite the huge progress made in children and young people's cancer, there remains much more to do. Addressing the priorities we've identified is a significant challenge – one that requires collective effort.

For almost 50 years, CCLG has been at the forefront of fostering collaborations that bring together expertise across the children and young people's cancer community.

Our unique role as both a research funding charity and the professional association has enabled us to build a trusted, coordinated network that sets the direction of the children and young people's cancer field.

Objectives

How we'll achieve our ambition

➔ **Coordinating collective action**

We'll build on our established relationships with other funders and stakeholders to create a unified research strategy, taking a joined-up approach to address key research priorities for each age group and cancer type.

➔ **Promoting and driving priority research**

We'll identify and share the most pressing needs, and we'll drive research that improves outcomes and experiences for children and young people.

➔ **Understanding the research landscape**

We'll work to understand existing research activity and identify gaps, working collaboratively to fill them and addressing all priorities effectively.

➔ **Leading progress-driven research**

We'll support the Children's Cancer and Teenage and Young Adult Cancer Clinical Research Groups*, and build new strategic networks to lead key areas of research. We'll champion comprehensive research portfolios for children and young people's cancer.

*The Clinical Research Groups were previously the National Cancer Research Institute (NCRI) Research Groups. Following the closure of NCRI in 2023, CCLG has taken responsibility for hosting and supporting these groups.

Actions

What we'll do first

➔ **Establish a research steering and delivery group**

We'll bring together experts, including those with lived experience, to oversee and drive the implementation of our strategy. This new group will support us to deliver the actions outlined in this strategy and advise on future priorities to help us reach our objectives and ambitions.

➔ **Map the children and young people's cancer research landscape**

We'll use the Priority Setting Partnership priorities as a guide to understand current research activity, identify gaps, and plan for future research funding. This information will help us to plan future grant rounds to address under-funded priorities, and we'll share the gaps with other funders to help coordinate action.

➔ **Support Cancer Clinical Research Groups**

We'll assist the Children's Cancer and Teenage and Young Adult Cancer Clinical Research Groups to refine priorities and develop action plans for the next three years, ensuring they are best placed to drive clinical research priorities. These groups will play a key role in developing clinical trials and other clinical research that moves the dial on progress.

➔ **Launch a funder forum**

We'll bring together key funders to share learning, align priorities, and collaborate on funding plans for children and young people's cancer research. Working together will help us to form new collaborations for funding research, avoid wasteful duplication, and address key priorities more quickly.

> “In our mapping project, we plan to look at what research has been funded by charities and other funding bodies in the UK over the last five years. This work will help us to see where the gaps in current research are and work towards making sure that all the priorities we've identified are addressed. This is vital as these are the areas of research that children, survivors, families and professionals have identified as important.
>
> We know that some of the PSP priority areas receive more funding than others. For example, there is a lot of treatment-focused research but not as much research that focuses on the psychological and social aspects of childhood cancer. Through this work, we will be able to show where the gaps in research are. One way to fill these gaps is by funders coming together and collaborating on funding projects. Another way is for funders to share information to make sure they are not wasting funds on duplicating work, but instead are using their funds across different priority areas.”

Dr Susie Aldiss

Research Fellow in Child Health and CCLG Member
Lead on CCLG's research mapping project

“CCLG has a unique ability to coordinate and promote a truly collaborative approach to UK children and young people's cancer research.”

> “The Children's Cancer and Teenage & Young Adult Cancer Clinical Research Groups develop clinical trials for childhood and young people's cancer in the UK. Without CCLG support, they could not continue their vital work in advancing better and kinder future treatments.
>
> The new research strategy will directly lead into the work and priorities of the clinical research groups by continuously mapping research needs and gaps and building upon the Priority Setting Partnership. As well as directly funding high-quality research, the CCLG strategy critically aims to support future research and early career researchers, establishing a diverse research community that embeds those with lived experience.
>
> CCLG has a unique ability to coordinate and promote a truly collaborative approach to UK children and young people's cancer research. As the professional body representing cancer experts, with strong links to patients and carers with lived experience, CCLG will work with other major research funders to drive forward the agenda, delivering the highest quality and most important research.”

Prof Darren Hargrave

Clinical Professor in Paediatric Neuro-Oncology and
CCLG Member Chair, Children's Cancer Clinical Research Group

Ambition 2:

Funding the best research, led by the best minds

We're committed to funding research that drives meaningful progress in the treatment, care, experience, and outcomes for children and young people with cancer. By focusing on the areas where we can have the biggest impact, we'll ensure every pound we spend works harder for our community. We'll fund the best research, led by the brightest minds, and together, we can make breakthroughs happen.

At the heart of our mission is addressing gaps in knowledge, ensuring that the most pressing research questions are answered. By coordinating efforts across the funding community, we're fostering innovative approaches, and uniting experts across disciplines to spark new solutions.

With clear priorities set, our next step is ensuring these questions are tackled through appropriately diverse and inclusive research methods. We're committed to creating opportunities for nurses, allied health professionals, and others to contribute fresh perspectives, broadening the scope of research.

A longstanding priority for us at CCLG has been funding areas that are often overlooked, like supportive care, and the late effects of cancer treatment. We'll continue to champion vital research into these critical areas.

Every child and young person with cancer deserves treatment informed by the latest research. Through initiatives like our Special Named Funds programme, which enables families to direct their fundraising to specific cancer types, we're advancing research into rarer cancers and those with the poorest outcomes.

Objectives

How we'll achieve our ambition

→ Funding the right research

We'll prioritise research that meets the needs of our community, with a focus on:

- addressing unmet needs and funding gaps, supporting research in areas where it is more difficult to find funding elsewhere
- researching rarer cancers and areas that are important to families (particularly through our Special Named Funds programme)
- increasing funding specifically for teenage and young adult cancer priorities

→ Funding the best research and researchers

Through a robust, expert-driven selection process, we'll continue to fund only high-quality research that delivers real impact and share our expertise to support other funders to collectively support valuable research for children and young people with cancer.

→ Funding more research, more quickly

We'll increase funding for all types of children and young people's cancer research, by growing our income, building stronger collaborations with other funders, and expanding the CCLG Research Funding Network to support partnerships with smaller funders.

Actions

What we'll do first

→ Support underfunded areas

We'll continue offering opportunities for research in areas where it is more challenging for researchers to access funding, addressing the critical gaps that will contribute to the success of this strategy. This will include grant rounds focused on late effects, supportive care, and teenage and young adult cancer, as well as specific opportunities for nurses and allied health professionals to get involved in research.

→ Expand our research funding network

We'll recruit more charity partners to the CCLG Research Funding Network, with a focus on supporting smaller organisations to fund world-class research. We'll create impactful collaborations that can benefit from our research funding expertise and infrastructure, amplifying the impact of funding and results.

→ Enhance our research processes

We'll review and refine how we assess and monitor research projects, ensuring we fund only the best quality research, and share our experience with others to strengthen research funding across the sector. We'll work with the research community to improve our application and review process, and we'll share our learning with other funders. We'll also investigate how we can best measure and report on the impact of our research funding, so we can be more effective as a research funder.

→ Accelerate progress on unmet priorities

We'll work with the community to design innovative funding schemes that address unmet needs, with a focus on the PSP priorities, driving faster progress on the research that matters most to patients and families.

"The partnership between The Little Princess Trust and CCLG has been ongoing since 2016 and is critically important to our charity and its funding objectives.

Through CCLG, we have access to their entire community to advertise and publicise our funding opportunities. We benefit from the vast expertise of their Research Advisory Group to review our applications and make recommendations about funding, which ensures we are funding research of the best quality and greatest need.

This sharing of resources and expertise allows The Little Princess Trust to channel our funds towards research, rather than to the administration costs of funding this essential resource. In short, this means that more money can be spent on childhood cancer research."

Wendy Tarplee-Morris

Director of Services and Impact, The Little Princess Trust

"Our research is investigating the causes of genetic changes that are linked to acute lymphoblastic leukaemia. We hope that our work will ultimately identify many of the children at risk of relapse at the time of diagnosis, enabling doctors to make more informed decisions about treatments.

Our work has been funded by charities in the CCLG Research Funding Network. An initial grant from The Little Princess Trust led to a subsequent grant from Harley Staples Cancer Trust, which allowed us to immediately get to the heart of the scientific problem. It also enabled much-needed continuity in the lab by ensuring we could keep fully trained staff in post and achieve results efficiently."

Joan Boyes

Associate Professor at Leeds University

"When Ben was diagnosed with rhabdomyosarcoma, a cancer we had never heard of and couldn't even pronounce, we did a load of Google research and contacted other parents whose child had been diagnosed with the same cancer. We found that the chemotherapy drugs Ben was treated with were first developed over 40 years ago. It was hugely frustrating and upsetting that there were no better options for our son.

When Ben died a year later, Sarah and I were already doing quite a bit of fundraising through friends, family, and our community. We had to decide what to do with that money. It's a no-brainer that we need more research to understand the disease so that we can develop new treatments for it. We wanted to do what we could."

Sarah & Scott Crowther, parents to Ben, diagnosed with rhabdomyosarcoma aged 6

CCLG Special Named Fund 'Pass The Smile For Ben'

"When Jack was diagnosed with LCH, our world was turned upside down. We felt lost and powerless, searching for answers about this rare disease but finding little to help us make sense of it all. Fundraising for research has given us a sense of focus and purpose during a time when we felt completely lost.

Knowing that we've helped fund a research project into LCH has been incredibly empowering as parents on this journey. It brings us comfort and pride to know that we're not only helping Jack but also other children facing the same diagnosis. Being part of this project has given us hope. It's allowed us to focus on the future, and seeing the 'fruits of our labour' motivates us to keep going and do even more."

Lucy Comer, mum to Jack, diagnosed with Langerhans cell histiocytosis just before he was aged 1

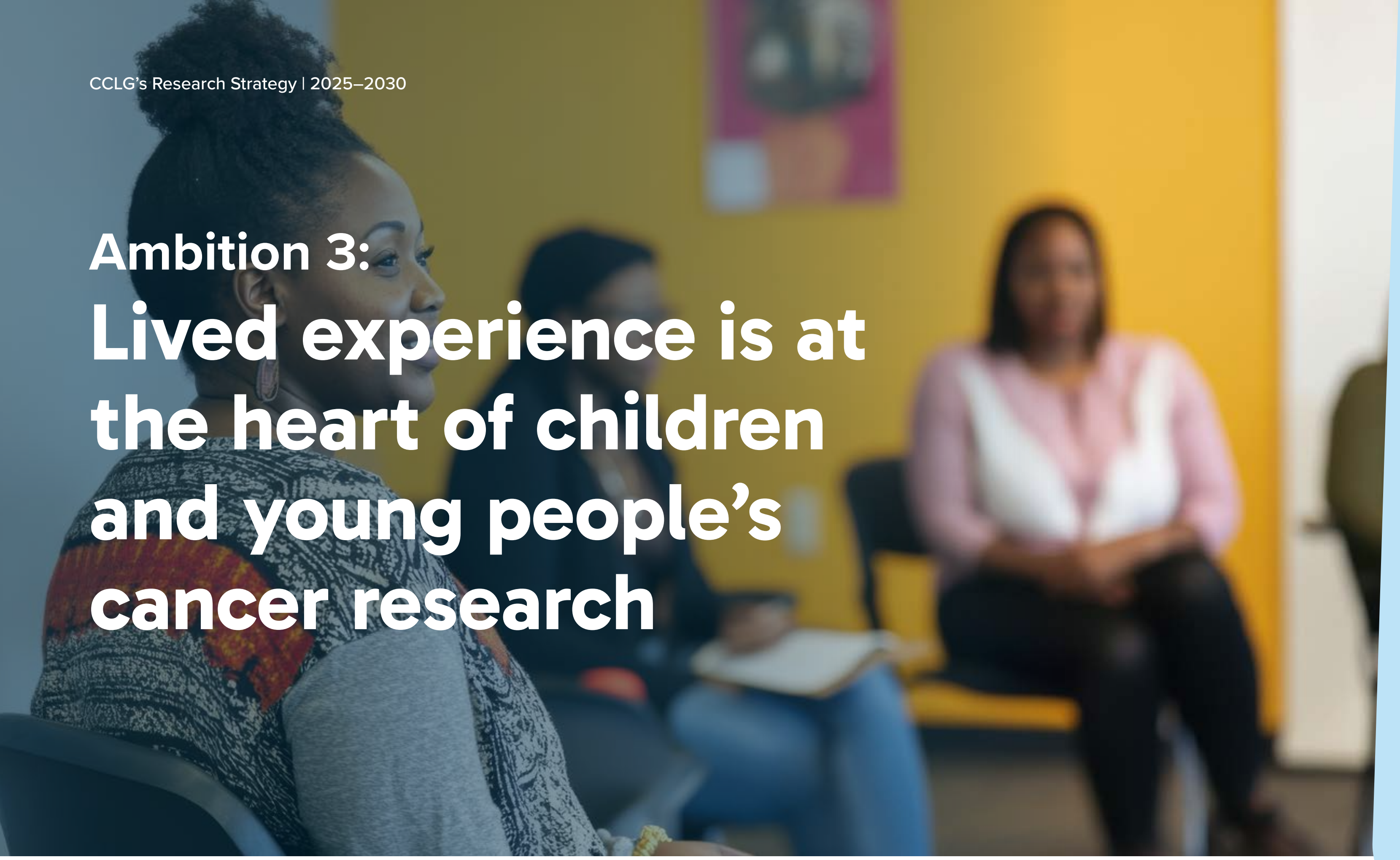
CCLG Special Named Fund 'Jack's Journey'

"CCLG's help with the research projects we are looking to fund has been incredibly useful. We couldn't have made these decisions without their expert guidance and experience. Medical research is very complicated, so having the support of CCLG to guide us through to a decision and beyond has been invaluable.

We have always looked to fund research relevant to our son's rare form of cancer, as we believe that these types of research projects generally get overlooked by larger charities. They are certainly no less important and that's why it's vital that smaller charities like ours continue to, and have the opportunity to, provide funding for these projects."

Katherine & Jamie Staples

Founders of the Harley Staples Cancer Trust



Ambition 3:

Lived experience is at the heart of children and young people's cancer research

The voices of those with lived experience are essential to driving children and young people's cancer research that truly makes a difference. By placing lived experience at the heart of everything we do, we ensure our research addresses real-world priorities, delivers meaningful outcomes, and fosters trust and empowerment for everyone involved.

This new research strategy was developed with lived experience at its core, but we know there's more to do. We believe research into children and young people's cancer must be continually shaped by those who have walked this journey. Embedding lived experience throughout the research cycle ensures our work is relevant, impactful, and of the highest quality.

There are countless ways for lived experience to enrich research, and we are focused on two key areas: ensuring our own activities are guided by these insights; championing greater involvement from patients, families, and the wider public across the research community.

Helping people understand and connect with research is just as important. Sharing high-quality, accessible information, from answering questions to communicating results, plays a vital role in building trust and engagement. Through our research blog, expert-led webinars, and research discovery days, we'll continue to create opportunities to explore, understand, and actively participate in children and young people's cancer research. Together, we can make progress that changes lives.

Objectives

How we'll achieve our ambition

➔ Turning words into action

We'll create and implement a lived experience strategy, ensuring these voices shape every aspect of our research, from designing funding schemes to sharing findings.

➔ Embedding lived experience in research

We'll support researchers to integrate lived experience into every stage of their work, demonstrating its benefits and equipping them with the tools and guidance needed to achieve meaningful involvement.

➔ Championing diversity, inclusion, and belonging

We'll ensure our lived experience efforts represent the diversity of those impacted by children and young people's cancer. By breaking down barriers to participation and offering support, we'll make involvement accessible, impactful, and rewarding for everyone.

➔ Sharing accessible research information

We'll provide engaging and easy-to-understand information about research to patients, families, and the public, and work with those with lived experience to help build understanding and trust in research about children and young people's cancers.

Actions

What we'll do first

➔ Build a lived experience network

We'll establish a dedicated network to connect and support participants, providing training and matching them with opportunities to get involved in shaping research, within CCLG and across our community of researchers and other organisations.

➔ Improve diversity in involvement

We'll investigate barriers to participation in research for those with lived experience and develop a plan to increase representation from underrepresented groups. This work will make lived experience truly inclusive and ensure that a wide range of voices are heard in planning, designing, and undertaking research.

➔ Explore innovative research design

We'll trial a 'living lab' approach to research design which brings together the insight of our community. With this approach, we'll co-create innovative approaches, focusing initially on teenage and young adult priorities to ensure their needs are met.

➔ Ensure information about research is in accessible and engaging formats

We'll make trustworthy information about research available for families and the wider public, and will liaise with those with lived experience to continue to develop our research communications activities - such as our regular webinar series - research discovery days, and research blog.

“ Developing cancer when you are just starting to make your own way in the world is very challenging. Teenagers and young adults with cancer have specific needs in cancer research, because the medical details of their cancers are usually different from young children's. Their treatment side effects can be unique, and their support needs can be very different, particularly in psychological and social areas.

This strategy directs funds specifically to cancers that begin in the teenage and young adult age group. This will support further growth in the number of researchers studying teenage and young adult cancer, both immediately and in the near future. ”

Prof Dan Stark

Consultant Medical Oncologist and Professor of Teenage and Young Adult Cancer Research and CCLG Member

Past Chair, Teenage and Young Adult Cancer Clinical Research Group

“ Lived experience brings a different level of energy and passion that I think is essential for clinical research and trial development.”

“ When you work in a lab, you become very focused on the intricacies of your experiments, but it is important to reflect on why you are doing them, and what you ultimately want to achieve in your research. Listening to the lived experience of patients and their families helps to put everything into perspective, particularly on the difficult days when things are not going to plan. ”

Prof Suzanne Turner

Professor of Childhood Cancer Biology and CCLG Member

“ Patients should always be the central focus of research – it needs to be done with patient groups and not to them. Lived experience brings a different level of energy and passion that I think is essential for clinical research and trial development. ”

Rachel Daley, mum to Jack, diagnosed with Langerhans cell histiocytosis aged 3

CCLG Research PPI Group Member

“ I joined the PPI group because I wanted to put Eli's and my family's experiences to a positive use. I have seen the progress research has made and how it influences care. Research is essential – it is the way forward for interventions and trials that hope to develop better treatments. ”

Sara Barnett, mum to Eli, diagnosed with Ewing sarcoma aged 15

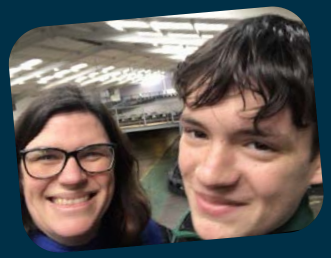
CCLG Research PPI Group Member

“ Involving young people and their experiences in our research is important – after all, it is about their journey with cancer, not ours. Co-creation approaches can help young people living with cancer navigate their journey through treatment and, after treatment has ended, manage their wellbeing and enhance their social connections. The most insightful part to me was being able to listen and immerse myself in the narrative of their experience, being able to tell their lived experience and not mine. ”

Dr Wendy McInally

Senior Lecturer & Field Lead for Children & Young People's Nursing at The Open University

“ Teenagers need to feel listened to, and that they have some control, regardless of what is happening to them.”



“Watching a teenager face cancer treatment is devastating. It would be at any age, but it is such a critical time for them when they are learning to become independent and focus on their future dreams. Their situation, physically, mentally and emotionally, feels very different to both children and adults. Through targeted research, hopefully more specific treatments can be developed which minimise the impact on their bodies, and lives, and ensure more of them survive.

Teenagers need to feel listened to, and that they have some control, regardless of what is happening to them. Prioritising lived experience in the research strategy gives them a voice and agency, making them feel that it is a true partnership. As a bereaved parent, I believe Fred's experience matters and can have meaning and purpose even though his treatment was unsuccessful. It is our hope that his legacy will be that future teenagers will not have to endure the same treatment, and their story will have a different ending. ”

Louise Bennett, mum to Fred, diagnosed with leukaemia aged 13

CCLG Special Named Fund 'Fred Bennett's Don't Look Down Fund'

Ambition 4:

A thriving children and young people's cancer research community

Research is a continuous long-term process, where incremental advancements over time lead to transformative outcomes. To sustain this journey, we need a vibrant, well-supported research community that attracts talent, nurtures growth, provides opportunities for a wide range of people to get involved, and ensures researchers can thrive.

Being a researcher in children and young people's cancer is a unique and specialised role, with its own challenges and rewards. At CCLG, we understand that researchers at every career stage need the right support to drive forward high-quality research. Within our community, there's a wealth of expertise, from brilliant scientists and professionals to insightful families, that can help researchers grow their skills and enhance their work. By facilitating knowledge-sharing and mentorship, we will build a stronger, more capable research community, and elevate the quality and impact of this vital field.

Through our professional network, CCLG has the privilege of working with exceptional experts like our Research Advisory Group, who play a key role in shaping our funding decisions. Experts from within our professional membership have provided invaluable guidance on priority areas such as research for teenagers and young adults, involving nursing and allied health professionals in research, and cross-cutting themes like late effects and supportive care. This wealth of experience is the foundation upon which we continue to develop and nurture research excellence across the field of children and young people's cancer.

We know the importance of investing in early-career researchers, so that they have the experience needed to become our future leaders. Whether their work is in the lab, clinical settings, or qualitative studies, we aim to create a supportive environment where they can thrive. Through tailored opportunities, including workshops and collaborative meetings, we'll equip the next generation of research pioneers with the tools and insights they need to shape the future of this field.

Research that drives meaningful change must be grounded in the voices and experiences of our community. It's essential that researchers are equipped to engage effectively with those who have lived experience of cancer in children and young people. We're committed to supporting researchers with the knowledge, skills, and training to work alongside experts by experience. Together, we'll make research stronger, more inclusive, and focused on the breakthroughs that matter most.

Objectives

How we'll achieve our ambition

➔ Fostering a collaborative community

We'll leverage our expertise as a professional association to create a dynamic research community where collaboration, knowledge-sharing, and mutual support flourish. Researchers will have opportunities to enhance their skills, share good practices, and access the resources they need to succeed.

➔ Supporting early-career researchers

By establishing a dedicated network, we'll provide early-career researchers with the tools and mentorship they need to grow. We'll champion high-quality funding schemes to attract and retain talent and encourage new researchers, including nurses and allied health professionals, to develop their research skills.

➔ Developing new research areas

We'll empower researchers to expand their expertise into multidisciplinary approaches, including applied health research, qualitative and mixed-methods research, reviews, and data-driven studies.

➔ Amplifying research outcomes

We'll support researchers in sharing their findings across the community, ensuring research reaches those directly affected by cancer and fuels further innovation.

Actions

What we'll do first

➔ Launch an early-career researcher network

We'll create a peer-led network tailored to early-career researchers in children and young people's cancer, offering mentorship, educational opportunities, and bespoke events. This new network will support researchers early in their careers, ensuring that talented experts continue to work in this field.

➔ Expand funding opportunities

We'll develop our funding schemes for nurses and allied health professionals, to support their development of critical research skills. This will help expand the type and focus of the research we're able to support, and begin to address a wider range of research priorities.

➔ Advocate for research impact

We'll continue to champion the importance of research in children and young people's cancer through our influencing and advocacy work. This will raise the profile of the sector, ensure that children and young people's cancer research is central to driving improvements in treatment and care, and keep it prioritised on the political agenda.

➔ Support collaboration and knowledge-sharing

We'll launch a scheme to fund research meetings and conferences, enabling collaboration, networking, and the dissemination of critical findings. This will strengthen our research community, provide opportunities for researchers to share their work, and ensure that the UK is at the forefront of children and young people's cancer.

“ Nurses and allied health professionals bring different skills, knowledge and experience to research, providing a different perspective of the patient pathway and care being received. In doing so, they may address research questions which help us increase supportive care for patients and their families, work with patients and parents to identify research questions which meet their needs, or collaborate with researchers from other professional backgrounds to provide specific research skills and expertise. ”

Dr Helen Pearson

Advanced Nurse Practitioner for Solid Tumours in Children & Young People, NIHR Clinical Doctoral Fellow and CCLG Member

“Early career researchers outlined in this strategy will be crucial for the future of children and young people's cancer research.”

“ It's so important that we support the next generation of researchers so that we can continue and grow our work in the future. While mentorship can be incredibly valuable, early career researchers can face a number of challenges, including securing the funding and opportunities needed to develop their expertise. That's one of the reasons why the support for early career researchers outlined in this strategy will be crucial for the future of children and young people's cancer research. ”

Prof Steve Clifford

Professor of Paediatric Oncology and Director, Newcastle University Centre for Cancer and CCLG Member

“ Supporting early-career researchers is critical, especially in the current funding environment, as it allows us to develop our own research interests, build a collaborative network, and develop our leadership skills. These are the necessary building blocks towards being an established, independent researcher.

Standard funding schemes rarely consider the unique position early-career researchers are in – they are simultaneously doing research, managing students, writing grants and publications, while also establishing independent networks and improving their leadership skills. It is therefore critical to have more targeted funding specifically for early-career researchers that considers their unique situation and the challenges they might face when competing with established researchers. ”

Dr Elitza Deltcheva

Early Career Researcher

“ I think researchers are missing opportunities to get family input at the birth of an idea. It would mean that their project will ultimately be relevant to families. For example, if you were going to invent a new drug to treat rhabdomyosarcoma, but you told me that the tablets were large I'd say there's no point. You're never going to get a five-year-old child to take a tablet of that size. That seems like a really small thing, but it's really important. You'd be surprised how that sort of thing isn't thought about by some scientists at the beginning. ”

Scott Crowther, dad to Ben, diagnosed with rhabdomyosarcoma aged 6, and advocate for PPI in research

CCLG Special Named Fund 'Pass The Smile for Ben' and CCLG Research PPI Group Member

“ Our project, which aims to understand the finer details of rhabdomyosarcoma genetics has only been made possible because of the unimaginable heartbreak that some families have gone through and then their tireless efforts to support scientific research. I just cannot say 'thank you' enough.

We've also been incredibly fortunate to involve Ben's father, Scott, as part of the official research team. His input and expertise from a parent perspective will make sure that our research has direction and relevance to those factors that are so important to families. This ensures that we do not become contained within a research 'bubble' where we risk losing sight of the bigger picture. ”

Dr Darrell Green

Lecturer and Group Leader CCLG-funded researcher

This is just the start:

An ongoing collaborative venture

Final reflections from Dr Sarah Evans, Head of Research at CCLG

This ambitious new research strategy for CCLG has been developed collaboratively, by and for our community. We have gathered valuable insights into what matters most to researchers, the clinical community, and, most importantly, those with lived experience of children and young people's cancer. We are deeply grateful to everyone who shared their thoughts and ideas, shaping this strategy and the focus of CCLG's future research activities.

Our success in research to date has been driven by the dedication of the members of our Research Advisory Groups. We're fortunate to benefit from their expertise and remain committed to further developing how we work with experts to guide the assessment of funding applications, as well as providing advice on building research capacity and expertise.

To achieve our ambitious vision for CCLG's research activities, we are establishing a Research Steering and Delivery Group. This group will bring together experts, including individuals with lived experience, who offer diverse perspectives and expertise across the breadth of children and young people's cancer research.

Our strategy is intentionally flexible, designed to adapt as the children and young people's cancer research field evolves. The Research Steering and Delivery Group will play a pivotal role in guiding this evolution, ensuring our plans remain relevant and impactful.

By combining the insights of those with lived experience and the expertise of leading professionals in the field, we will be able to effectively implement the exciting initiatives outlined in this strategy.

> “The CCLG research strategy is a blueprint for pioneering progress and shaping the future of children and young people's cancer research, generated by true insight as experts in children and young people's cancer. It sets out both short- and long-term relevant and achievable ambitions and crucially highlights the importance of true and real collaboration to drive ground-breaking research in this vital area.”
>
> **Prof Richard Grundy**
>
> *Professor of Paediatric Neuro-Oncology and Cancer Biology*
> *CCLG Chair 2020-2025*

We'd like to thank everyone who contributed to the development of our research strategy

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CCLG The Children & Young People's Cancer Association

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

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 children and young people's 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.

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