Top 10 priorities for childhood cancer research revealed

A list of the top 10 research priorities for children’s cancer has been published, following a collaborative project which gathered the views of patients, families, professionals and survivors to identify gaps in research and ‘unanswered questions’.

While research over the last four decades has dramatically increased the overall five-year-survival rate for all childhood cancers to around 84%, further research is needed to not only improve outcomes for all types of children’s cancer, but to ensure all young patients go on to live long, healthy and happy lives.

Topics of healthcare research in children’s cancer are often driven by the interests of researchers and the pharmaceutical industry, meaning what is most important to children, their families and the professionals who care for them, may sometimes be overlooked.

In 2019, Children’s Cancer and Leukaemia Group (CCLG) and The Little Princess Trust (LPT) partnered with the James Lind Alliance (JLA) on a Priority Setting Partnership (PSP) to identify the research questions that are most in need of answering, according to those they matter to the most.

The JLA is a non-profit making initiative bringing together patients, carers and professionals in PSPs. The JLA PSPs identify and prioritise unanswered questions that they agree are the most important, so that researchers and research funders are aware of the issues that matter most to the people who could benefit from the research.

Ashley Ball-Gamble, Chief Executive of CCLG and member of the Children’s Cancer PSP Steering Group, said: “As a funder of childhood cancer research, our priority is to ensure that the research we support meets the needs of children and their families, and the professionals who look after them during treatment and beyond.

“The Children’s Cancer Priority Setting Partnership has provided a robust way of finding out what matters most to patients, families and professionals so that we are in a position to fund research *that is most important for them.*

“For CCLG, it’s imperative that our work is driven by those who will ultimately benefit from it, and that the money raised by those who support us is well spent.”

People who had been diagnosed with cancer while under the age of 16 - including both children and older survivors - their families and friends, and professionals involved in their treatment and care, were invited to identify the questions about childhood cancer they would like to see answered by research.

Four hundred and eighty-eight respondents, comprised of 49 patients/survivors, 291 family members and friends and 148 professionals, submitted 1299 potential research questions and topics.

Scott Crowther, dad to Ben who died in 2019, aged seven, after being diagnosed with rhabdomyosarcoma, and parent representative on the Children’s Cancer PSP Steering Group, said: “If time and money is spent on childhood cancer research, it is vital that it's focused on tackling real-world problems that affect thousands of families like mine.

“We have to stay focused on what matters to families. By getting involved as a patient representative on this project, I hope I was able to do my bit to make sure that the voices of children and their families were really heard.”

After a rigorous process which involved merging similar questions, removing ‘out of scope’ questions, and searching the published research literature for questions which were already answered or programmes of research that were ongoing, respondents were then asked to prioritise 101 questions.

The questions with the most votes were then taken to a final face-to-face workshop with childhood cancer survivors, parents, relatives and professionals to determine the final top 10 priorities.

It was essential to the project team that the views of children were heard during this process. This was done firstly through surveys asking children what is important to them, and then a workshop specifically for children. This workshop reviewed the survey responses from children and gave participants the opportunity to add additional questions.

The children's workshop came up with five top priorities from the viewpoint of the eight children involved, which contributed two new questions, and added emphasis to three others. These were then taken forward, along with 18 other questions, to the final workshop discussions.

Faith Gibson, Professor in Child Health and Cancer Care at the University of Surrey and Great Ormond Street Hospital for Children and member of the Children's Cancer Priority Setting Partnership Coordinating Team, said: "Any national research agenda-setting process should include the population who are the focus of future studies. Where children are included in this population, they must have the opportunity to contribute, as they have a unique perspective gained through experience.

"What matters most to children is our focus in this PSP, and so it was essential we found the best and most engaging way to hear directly from them – and also how their views were included in the final priority-setting process.

"We will be reporting our approach to listening to children and advocating for this in future priority setting work, which will need to be funded and informed by a process closely aligned to the JLA principles."

Following the final workshop today, we are delighted to publish the top 10 research priorities for childhood cancer. The top research priority was *"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?"*

The questions identified as high priority covered all parts of the cancer journey, including diagnosis, relapse, experience in hospital, and the long-term impact of a cancer diagnosis.

The top 10 list of priorities in full:

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.)

Dr Bob Phillips, Senior Lecturer at the University of York and Consultant in Paediatric Oncology in Leeds and member of the Children's Cancer PSP Coordinating Team, said: "While getting to the point of publishing the top 10 priorities has been a long process, this is just the beginning in terms of turning them into actual research.

"We want to encourage researchers to focus on research based on the priorities, and research funders to direct their money to work on these priority areas.

"We'll be launching a full report on the Children's Cancer PSP for the childhood cancer community of patients, families, professionals and researchers, and organising a meeting for research funders to tell them more about the priorities. We'll also be publishing in academic journals and presenting the results at medical and scientific conferences to reinforce their importance to researchers."

Mr Ball-Gamble added: "On behalf of the PSP Coordinating Team, CCLG and LPT, we'd like to thank all of the PSP Steering Group members, everyone who submitted a research question or took part in the prioritisation survey, the children and their families who took part in our children's workshops, and those who took part in the final face-to-face workshop."

You can find out more about the Children's Cancer PSP, funded by CCLG and LPT, at www.childrenscancerPSP.org.uk.