

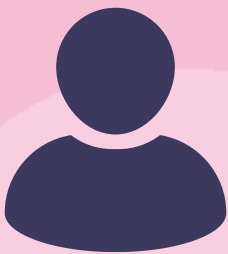
Kids Get Cancer Too

A manifesto to accelerate clinical research into children's cancers.

Cancers in children are distinctly different to those in adults. More than 4000 people younger than 25 years old are diagnosed annually in the UK. Whilst progress has been made in treating childhood cancers more effectively, still more than 80% of deaths from disease in those younger than 16 years old are caused by cancer.ⁱ For those that do survive, the high toxicity of current therapies leaves them with life-altering side effects that continue into adulthood.

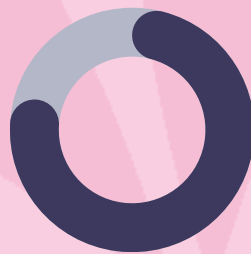
To improve this, newer, more effective treatments are needed that can only come from robust clinical research. Barriers and bottlenecks in the UK healthcare system are currently hindering progress, at the cost of children and their families.

The impact of childhood cancer



4000

People under 25 diagnosed each year in the UKⁱ



80%

Deaths by disease in people under 16 caused by cancerⁱ



57%

Childhood cancer survivors living with effects of treatmentⁱⁱ

We have identified **four key priorities** that have the potential to transform this landscape so that children and families affected by cancer are better served by the UK healthcare system. We are **calling for a focused effort by the next Government** on these priorities, in collaboration with stakeholders from across the sector, to bring the real and impactful change that is desperately needed.

ⁱ Aggarwal, Ajay et al. The Lancet. Oncology, S1470-2045(23)00511-9. 14 Nov. 2023, doi:10.1016/S1470-2045(23)00511-9

ⁱⁱ CCLG Public Survey, www.cclg.org.uk/news/cclg-survey-reveals-long-term-impact-of-childhood-cancer

Make children's cancer a priority in health policy

Despite it being the leading cause of death by disease in children, there is limited expertise and resource within government dedicated to paediatric oncology. Whilst the establishment of a Children and Young People Cancer Taskforce is a welcome step forward, this is still in its infancy and proper commitment of time and funds to make the taskforce effective are needed.

Build a sustainable funding pool for research into children's cancers

The additional burdens of running clinical trials for this patient population means that commercial investment in paediatric cancers is limited. Government spending is also low, with just £35.2 million invested in childhood cancer research in 4 years, representing 7.8% of the total spending on cancer.ⁱⁱⁱ The majority of funding comes from charitable organisations, and a more sustainable approach is needed to transform the landscape.

Efficiently deliver trials for children with cancer through the NHS

The bureaucratic set-up and approval processes outlined in the O'Shaughnessy report mean that the UK's clinical trial landscape is increasingly falling behind global competitors.^{iv} In addition, the NHS is under significant pressure due to backlogs, workforce shortages and limited investment which must be resolved in order to deliver more trials, more efficiently.^v

Ensure equitable access to novel therapies for children with cancer

These issues combined mean that there are few trials available in the UK for children's cancers, especially those that are high-risk. This puts families in the position where they feel compelled to travel abroad to participate in clinical trials that offer potentially life-saving therapies. This inequity of access must be rectified so that no family is faced with this heartbreaking reality for the sake of trying to save their child's life.

To achieve these goals, we are calling on the next Government to take action by:

- Continuing the momentum behind the newly established **Children and Young People Cancer Taskforce** and ensuring that clinical research is a key area of focus and that the Taskforce is sufficiently resourced to bring impact.
- Conducting an **independent review** of the paediatric cancer clinical trial landscape and investment profile, incorporating patient and parent voice.
- Establishing a dedicated working group to implement **robust benchmarking and metrics to record trial mobilisation and recruitment** in the paediatric population.
- Issuing specific guidance to Integrated Care Systems (ICSs) requiring that clinical trials for rare diseases, even where these trials are non-commercial, are **not de-prioritised**.
- Ensuring sufficient investment in the **NHS workforce and infrastructure** that specifically protects its capacity to sustainably deliver clinical research for children with cancer.

iii Parliamentary Questions, www.questions-statements.parliament.uk/written-questions/detail/2023-12-06/5728

iv Lord O'Shaughnessy Review, www.gov.uk/government/publications/commercial-clinical-trials-in-the-uk-the-lord-oshaghnessy-review

v Nuffield Trust Report, www.nuffieldtrust.org.uk/news-item/the-past-present-and-future-of-government-spending-on-the-nhs