

PE1783/C

Cancer Research UK submission of 16 April 2020

Below are our views on the actions called for in petition PE1783, considered by The Public Petitions Committee at its meeting on 5 March 2020. Our response focuses on cancers affecting children and young people as this is what the petition relates to.

We are aware of the fact that this is just one area of work where progress needs to be made in order for Cancer Research UK to achieve our ambition of 3 in 4 people surviving a cancer diagnosis by 2034. Other, wider strategic actions that we think are vital to improving cancer outcomes in Scotland specifically are included in our response to the Scottish Government's new cancer strategy.

We recognise that more needs to be done in the UK and across the globe to raise awareness of children's and young people's cancers and to encourage more research in this area to drive and accelerate progress.

While we know that this will be difficult to do in light of the COVID-19 crisis, for our part, we are ensuring that measures are in place so that we can continue our research as best we can. We'll continue to assess the impact of this crisis on all of our work and endeavour to ensure our research, including in children's and young people's cancers, continues wherever possible.

Research into cancers affecting children and young people (aged 0-24) has always been an important area for Cancer Research UK. Over the last 40 years, we have funded research that has increased our understanding of this disparate group of diseases and supported many of the world's most successful clinical trials for children's and young people's cancers, all of which has helped bring about improvements in survival.

But we know that more needs to be done. Because today, while more than 8 in 10* under 25s diagnosed with cancer in the UK survive their disease for 5 years or more, cancer is still the leading cause of death by disease in people aged 1-24. In Scotland, this means that of the around 340** children and young people diagnosed with cancer every year, around 40*** will die from cancer.

We also know that 8 in 10 is an average survival figure across all types of cancer that affect children and young people. What it doesn't reflect is that for [some types](#), including certain types of brain and bone tumours, survival is a lot lower. On top of this, we know that survivors often experience serious long-term side effects, including infertility and hearing loss, which affect them for the rest of their lives.

To try and change this, we have developed a new research strategy for children's and young people's cancers which, through medical research, aims to bring about improvements in survival and to reduce long-term side effects for 0-24-year-olds with cancer.

Driving Progress: Our Strategy

In [this strategy](#), we highlight that cancer in children and young people is different to cancer in adults, including the types of cancer 0-24-year-olds can be diagnosed with.

This means researching these types of cancer presents different challenges to researching adult cancers, and so a different approach is needed.

Following consultation with UK and international researchers in the field, as well as patients and parents who have been affected by these types of cancer, the strategy we have developed aims to:

- Build research capacity in the UK:
 - We launched the Cancer Research UK for Children & Young People Innovation Awards. This new, national funding call aimed to create momentum for the field, to support current researchers in answering questions in children's and young people's cancers and attract researchers from other research areas. However, due to the COVID-19 crisis, we have made the difficult decision to defer all of our funding panels and committees to the second half of 2020. This means that while we still hope to provide funding through these Innovation Awards, it won't be possible until later in the year. You can find out more about our deferred funding panels and committees on our [website](#).
 - We will engage and collaborate with research communities not usually associated with children's and young people's cancers, encouraging them to apply their wide knowledge and expertise to this area of cancer research.
- Develop and support a coordinated research community:
 - We will convene a Cancer Research UK for Children & Young People's Steering Group to provide a platform to discuss ideas and set a strategic direction for research in this area
 - We will host community building workshops to support conversations and collaboration between lab scientists and clinicians, and between scientists from different research fields
- Ensure the research community has the tools and infrastructure it needs to progress
 - We will build and link together resources through our Cancer Research UK for Children & Young People Network
 - We will fund the development of vital research tools through our new funding award schemes

By addressing these aims, and working in collaboration with partners and other charities, we aim to encourage world leading scientists and doctors to consider applying their expertise to these types of cancer in order to actively grow this research community and to develop and support the environment it needs to accelerate progress.

Our ultimate aim is that through this strategy, we will develop a strong, long-lasting children's and young people's cancer research community which will bring forward the

day when every child and young person survives their cancer with a good quality of life.

Some examples of the children's and young people's cancer research we're currently supporting include:

- The [Experimental Cancer Medicine Centre Paediatric Network](#): This network runs early phase clinical trials, testing the safety of new drugs for children's cancers. Co-funded by us and the health departments of Scotland and England, it's made up of 11 paediatric centres including the [Glasgow Paediatric ECMC](#) at the Royal Hospital for Children, Glasgow which delivers phase I/II trials for children and young people in Scotland.
- The [Cancer Research UK Clinical Trials Unit](#) in Birmingham: Led by Professor Pam Kearns, this is one of the largest cancer trial units in the UK. The team there coordinates over 100 cancer trials across the country and internationally, including 15 trials for children's cancers, aiming to improve patient care and outcomes.
- The [Cancer Research UK for Children & Young People Children's Brain Tumour Centre of Excellence](#), supported by TK Maxx: The Centre is a hub of expertise for children's brain tumour research and aims to transform the way treatments for these tumours are developed. It's a collaboration between the University of Cambridge and The Institute of Cancer Research, London.
- [Paediatric tissue biobank](#): This biobank is the largest collection of tumour, DNA and other samples from children and young people with cancer in the UK. The tissue samples provided by this biobank are essential for scientists to unravel key information about children's cancers. The biobank samples are available to all researchers carrying out research into cancers affecting children and young people.

Our wider research

As well as funding and supporting these important pieces of infrastructure, we support different projects and clinical trials looking at specific types of cancer affecting children and young people including:

- In Edinburgh, Professor Katrin Ottersbach is looking at the [biology](#) of B cell acute lymphoblastic leukaemia and how it develops in infants. She hopes this work will lead to the discovery of new targets for treatment for this type of cancer.
- The [SIOP clinical trial](#): This is the largest ever carried out for ependymomas and is part of an international effort to recruit more than 500 patients from across Europe over five years, 160 of them from the UK. This much-needed trial has been set up to improve the way the disease is diagnosed and to develop more effective treatment plans by trialling different combinations of radiotherapy and chemotherapy after surgery.

- The [BIOMEDE clinical trial](#): This trial, which is now closed to recruitment, aims to find out if giving specific targeted treatments alongside standard radiotherapy works better than radiotherapy alone as a treatment for children and young people with DIPG.

Driving Awareness: Cancer Research UK for Children & Young People

We also know that more needs to be done to raise awareness of cancers affecting children and young people, and the long-term side effects they can experience as a result of their treatment.

That's why we set up [Cancer Research UK for Children & Young People](#). Through our PR, press and [social media](#) channels, as well as our shops and partnership with [TK Maxx](#) and others, this part of Cancer Research UK aims to raise awareness of children's and young people's cancers and how they differ to adult cancers – from the types of treatment to the long-term side effects survivors often experience.

When developing our communications and awareness content, we often enlist the advice, support and opinions of the Cancer Research UK for Children & Young People Advisory Panel. This panel is an online group made up of 20 people affected by children's and young people's cancers. The group is diverse and includes people affected by a range of cancer types and experiences, as well as a mix of parents and patients/survivors. Through consultations on topics from around the charity, they help to shape and influence our work - from communications about cancer to our policy, strategy and research.

We also consult them in relation to the [Cancer Research UK for Children & Young People Star Awards](#), which aim to recognise the strength and courage of children diagnosed with cancer. This scheme, run in partnership with TK Maxx is open to children in the UK who are under 18 and have been diagnosed with or treated for cancer in the last five years. Every child eligible receives a trophy, t-shirt, certificate and a £50 TK Maxx voucher, and their siblings receive a special certificate too.

I hope that the information above is useful for the Committee's work and I would be happy to discuss this further should this be of use to the committee.

Statistical references:

**National Cancer Intelligence Network. [National Registry of Childhood Tumours Progress Report, 2012](#). 2013. 5-year actuarial survival for children (aged 0-14) in Great Britain diagnosed with cancer (all cancers combined) in 2006-10. Public Health England. [Trends in five-year survival for teenagers and young adults with cancer in the UK](#), 2014. 5-year relative survival for young people (aged 15-24) in the UK diagnosed with cancer (all cancers combined) in 2002-06.*

***Average annual number of cancer cases (all cancers combined plus non-malignant brain, other central nervous system and intracranial tumours: ICD10 C00-C97, D32-D33, D35.2-D35.4, D42-D43 and D44.3-D44.5) diagnosed in children and young people aged 0-24 years in Scotland in 2015-17. <http://www.cancerresearchuk.org/health-professional/cancer-statistics/childrens-cancers#heading-Zero>*

*** Average annual number of cancer deaths (all cancers combined plus non-malignant brain, other central nervous system and intracranial tumours: ICD10 C00-C97, D32-D33, D35.2-D35.4, D42-D43 and D44.3-D44.5) diagnosed in children and young people aged 0-24 years in Scotland in 2015-17.
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