Crucial new study set to save young lives by better understanding childhood cancer diagnoses

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A new research study, led by experts at the University of Nottingham, which aims to understand how cancer is diagnosed in children and young people across the UK has been launched today, during Childhood Cancer Awareness Month (September).

The Childhood Cancer Diagnosis Study is funded by the National Institute for Health Research (NIHR) and leading children's cancer charity Children's Cancer and Leukaemia Group (CCLG).

The project aims to help researchers to understand the journey that children and young people experience from the start of their symptoms until they receive their diagnosis of cancer.

To do this, experts will collect information about what symptoms they experience, who they go to see with these symptoms initially, and how long it takes before the diagnosis is reached.

The research will take place at the Children's Brain Tumour Research Centre at the University of Nottingham and be led by Dr Shaarna Shanmugavadivel, a paediatrician and NIHR Doctoral Research Fellow at the University, along with Dr Shalini Ojha, and Professors David Walker and Kavita Vedhara from the School of Medicine at the University.

Childhood cancer is the most common cause of death by disease in children, teenagers and young adults in the UK, and many experience long delays to diagnosis. Delayed diagnosis can lead to worse survivial for patients, and poorer long-term health for survivors.

Every child diagnosed with cancer over a two year period will be offered the opportunity to take part in the study. This will help the research team to build a picture of the factors affecting their journey and time to diagnosis.

The study results will also inform the Child Cancer Smart project, a collaboration between CCLG and the University of Nottingham, in partnership with CLIC Sargent and the Grace Kelly Childhood Cancer Trust, which aims to develop guidance for healthcare professionals to help with symptom recognition and making appropriate referrals. Child Cancer Smart will also produce a range of awareness tools for both healthcare professionals and the general public to raise awareness of the signs and symptoms of childhood cancer.

Dr Shaarna Shanmugavadivel, NIHR Doctoral Research Fellow and lead researcher on the study, said: "Cancer symptoms in children are often non-specific, mimicking other more common childhood illnesess.

"The misperception by the public and professionals that childhood cancer is rare means it is often not considered until the child has multiple symptoms and advanced stage disease. Time is crucial; untreated, tumours grow bigger and can spread around the body causing significant damage and require more extensive surgery and more intensive therapies to offer cure.

"Delayed diagnosis is often multi-factorial due to both a lack of symptom awareness amongst the public and healthcare professionals, and the lack of paediatric specific diagnostic tools to aid healthcare professionals seeing these children and young people.

"This project will focus on investigating and addressing this problem, ultimately ensuring better survival and long-term outcomes for children."

Health Minister Jo Churchill said: "We are determined that children and young people receive the best cancer care possible and early diagnosis is a critical part of this.

"Children and young people in England were among the very first in Europe to benefit from a new generation of CAR-T cancer therapies, and we have committed to increasing participation of young people in clinical trials to 50% by 2025. This new research led by NIHR will be an important step in understanding cancer diagnosis in younger people."

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Ashley Gamble, Chief Executive of CCLG said: “We’re proud to launch the Childhood Cancer Diagnosis Study this Childhood Cancer Awareness Month.

“Many children experience long delays in getting their cancer diagnosed, and our aim is to raise awareness of the signs and symptoms, and what action to take, among both healthcare professionals and the general public.

“We know that both the time it takes to diagnose cancers in children, and survival rates, are poorer than in comparable European countries. By taking action to tnesure earlier diagnoses of thse cancers, we will decrease the risk of death, reduce treatment-related side effects and improve the quality of life for survivors.”

The Childhood Cancer Diagnosis Study will open in all Principal Treatment Centres (regional hospitals treating children with cancer) over the next few months, and run for two years. All newly diagnosed children will be asked to take part in the study, by asking their parents for permission to use routine data about diagnosis collected by the child’s oncology team.

For more information about the study, visit https://www.cclg.org.uk/CCDStudy

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Notes to editors

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About the Childhood Cancer Diagnosis Study

https://www.cclg.org.uk/CCDStudy

About Children’s Cancer and Leukaemia Group (CCLG)

CCLG is a leading national charity and expert voice for all childhood cancer. As the UK and Ireland’s professional body for those working in the field of childhood cancer, our network of dedicated professional members work together in treatment, care and research to help shape a future where all children with cancer survive and live happy, healthy and independent lives.

We fund and support innovative world-class research and collaborate, both nationally and internationally, to drive forward improvements in childhood cancer. Our award-winning information resources help lessen the anxiety, stress and loneliness commonly felt by families, giving support throughout the cancer journey.

www.cclg.org.uk

About the University of Nottingham

The University of Nottingham is a research-intensive university with a proud heritage, consistently ranked among the world's top 100. Studying at the University of Nottingham is a life-changing experience and we pride ourselves on unlocking the potential of our students. We have a pioneering spirit, expressed in the vision of our founder Sir Jesse Boot, which has seen us lead the way in establishing campuses in China and Malaysia - part of a globally connected network of education, research and industrial engagement. We are ranked eighth for research power in the UK according to REF 2014. We have six beacons of research excellence helping to transform lives and change the world; we are also a major employer and industry partner - locally and globally. Alongside Nottingham Trent University, we lead the Universities for Nottingham initiative, a pioneering collaboration which brings together the combined strength and civic missions of Nottingham’s two world-class universities and is working with local communities and partners to aid recovery and renewal following the COVID-19 pandemic.

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About the NIHR

The National Institute for Health Research (NIHR) is the nation's largest funder of health and care research. The NIHR:

- Funds, supports and delivers high quality research that benefits the NHS, public health and social care
- Engages and involves patients, carers and the public in order to improve the reach, quality and impact of research
- Attracts, trains and supports the best researchers to tackle the complex health and care challenges of the future
- Invests in world-class infrastructure and a skilled delivery workforce to translate discoveries into improved treatments and services
- Partners with other public funders, charities and industry to maximise the value of research to patients and the economy

The NIHR was established in 2006 to improve the health and wealth of the nation through research, and is funded by the Department of Health and Social Care. In addition to its national role, the NIHR supports applied health research for the direct and primary benefit of people in low- and middle-income countries, using UK aid from the UK government.

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