

# Children in the UK and Ireland still diagnosed later with larger kidney cancers than in rest of Europe

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Children with kidney cancers continue to be diagnosed with larger and more advanced tumours in the UK and Ireland than in other Western European countries, according to research presented at the NCRI Festival.

As a result, a leading childhood cancer expert has called for all staff providing primary healthcare for children in the UK's National Health Service (NHS) to be trained in paediatric medicine so that diseases such as kidney cancer can be detected earlier.

Mrs Reem Al-Saadi, a senior translational research manager at UCL Great Ormond Street Institute of Child Health, University College London, UK, presented findings from the first study to look systematically at how children are diagnosed with kidney cancer in the UK.

Reporting on 603 out of 712 children registered with kidney cancer between 2012 and 2018 from 20 treatment centres in the UK and Ireland (about 90% of all children diagnosed with kidney cancer in these countries), she said that 86% had Wilms tumour (the most common type of kidney cancer in children) and 14% had non-Wilms kidney tumours. Computerised tomography (CT) and magnetic resonance imaging (MRI) scans that create detailed images of the inside of the body were reviewed centrally as part of the investigations to ensure consistency of diagnosis.

"We found that spread of the kidney cancer to the lungs was detected in 24% of children; this was definite in 18% and detected only by the CT scan in 6%, which means the nodules were so small that there is uncertainty about whether they are cancerous or not," she said.

"The majority of children were only diagnosed once they had started to show symptoms: 77% had symptoms specific to tumours at diagnosis, such as abdominal mass, abdominal pain or blood in urine; 16% had non-specific symptoms; 5% were diagnosed as a result of genetic screening and 2% as a result of a child health check. This means that only a few cancers are being picked up incidentally before symptoms start to show."

The average (median) size of tumours was 547ml in volume, with one quarter being larger than 901ml.

"The tumour volumes we saw are not significantly different to those from an analysis of children diagnosed in 2002-2011 when tumour volumes were shown to be larger than those found at diagnosis in Germany. The median volume then was 572ml in the UK compared to 382ml in Germany," said Mrs Al-Saadi.

The findings come from the IMPORT study (Improving Populations Outcome of Renal Tumours of childhood), which has since been expanded to include international research groups and has become the UMBRELLA study. With the exception of work in Germany, it is the only initiative in the world to collect standardised data on the route to diagnosis for a child with kidney cancer.

Kathy Pritchard-Jones, Professor of Paediatric Oncology at Great Ormond Street Institute of Child Health, is chief investigator of the IMPORT and UMBRELLA studies. Speaking before the NCRI Festival, she said: "We only have very early comparative data for about 1,000 cases diagnosed from 2019 onwards, but this early analysis from the

UMBRELLA study found that 75% of children in the UK and Ireland are diagnosed with tumour-related symptoms, which is higher than in most other European countries. This confirms similar findings from an international trial conducted between 2001 and 2011."

She continued: "We know that in European countries where children have smaller tumours at diagnosis, the primary care provision is done by trained paediatricians working in the community. They may be more likely to examine a child all over when they come in with vague symptoms and, therefore, are more likely to pick up that something isn't quite right in the abdomen.

"Efforts are required to achieve earlier diagnosis of kidney cancers in children in order to improve survival rates in the UK and Ireland. We believe that frontline primary healthcare for children should be provided by staff trained in children's medicine. The problem of late diagnosis for [kidney](#) cancer is part of a wider problem of late diagnosis of serious diseases in childhood in the UK that has been highlighted by the Royal College of Paediatrics and Child Health."

The findings reported today include two years of follow-up of the children after 2018. During this time 78 (13%) relapsed and 44 (7%) died.

Prof Pritchard-Jones said: "Treatments haven't changed in the past decade, and we expect the UMBRELLA study to show overall survival rates to remain similar at just over 90%. The study will enable us to make international comparisons to see how the UK is performing in terms of early diagnosis and treatment for children with abdominal tumours, and it will help us to monitor improvements."

Childhood [kidney cancer](#) is a rare disease. Wilms tumour is diagnosed in about 87 children each year in the UK. Treatment is one of the success

stories in childhood cancer in recent years, with more than 90% of children surviving. However, there are some sub-groups that have a poor outcome, suffering recurrences of their cancer and, in some cases, dying. Early diagnosis before cancer has started to spread, combined with improved treatments, could help improve outcomes in these children.

Prof Pritchard-Jones and colleagues are investigating ways to personalise treatment to each child based on biological signals that could be used to identify the intensity of treatment needed. They are also testing the use of artificial intelligence to assess the nodules seen in CT scans for their likelihood of being [cancer](#) that has spread (metastasised) from the primary tumour.

Richard Neal, member of the NCRI Screening, Prevention and Early Diagnosis (SPED) Group and Professor of Primary Care at the University of Exeter, UK, who was not involved with the research, said: "It's disappointing to see that there has been very little progress in the past 20 years in diagnosing this disease at an earlier stage, when the tumours are smaller and easier to treat successfully. This works also demonstrates the difficulty in picking up these tumours at an early stage. There may be additional challenges in [diagnosis](#) as a result of the COVID-19 pandemic, with fewer patients, including [children](#), being seen face to face and having physical examinations. We urgently need work to explore what interventions might work to improve the situation."

**More information:** 'Efforts to achieve earlier diagnosis of renal tumours in childhood are required to improve survival rates in the UK and Ireland', by Mrs Reem Al-Saadi et al. Short talks – Prevention and early detection session, 18.30-19.00 hrs, Thursday 11 November: [conference.ncri.org.uk/program ... and-early-detection/](https://conference.ncri.org.uk/program...and-early-detection/)

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