

# Briefing for the Citizen Participation and Public Petitions Committee on petition PE2193: Address Dangerous Delays in Paediatric Cancer Diagnostics, lodged by Avril Arnott

### Brief overview of issues raised by the petition

Petition <u>PE2193</u>: <u>Address Dangerous Delays in Paediatric Cancer Diagnostics</u> calls on the Scottish Parliament to urge the Scottish Government to:

- introduce mandatory clinical standards to ensure that urgent paediatric cancer referrals are subject to the same maximum wait times as adult referrals
- require clear accountability and follow-up where a paediatric cancer referral is downgraded or delayed
- fund training and update guidelines to enable GPs and clinicians to recognise and escalate signs of cancer in children as promptly as they would in adult cases
- undertake a formal review into paediatric diagnostic delays in Scotland, to identify systemic failures and implement change.

Public Health Scotland publishes children and young people with cancer in Scotland which provides information on cancer in children (ages 0 to14) and young people (ages 15 to 24). In children, the most common cancers were leukaemia and cancers of the brain and central nervous system. In young people, the most common diagnoses were carcinomas, lymphomas and central nervous system tumours (2012 to 2021). Around 130 children and 180 young people are diagnosed with cancer in Scotland each year (average over 2018, 2019, 2021).

#### Clinical guidelines

The <u>Scottish Referral Guidelines for Suspected Cancer 2025</u> are designed to be used in any primary care setting, by any member of the clinical team. They include a guideline on cancer in children and young people.

The guideline acknowledges that there is a large variation in diagnostic intervals by cancer type and that it is common for patients to see a health professional three or more times before referral. It goes on to say:

"Vague or non-specific symptoms in children may require a lower threshold for referral due to their higher risk of delayed diagnosis. Referral to secondary care should be considered for children with repeat presentations (three or more times) of any symptoms which do not appear to be resolving or following an expected pattern, taking into account parent/carer and child concerns."

The Right Decision Service has also published a <u>toolkit on teenage and young</u> <u>adult cancer services</u>.

The National Institute for Health and Care Excellence (NICE) has also published a clinical knowledge summary on <u>childhood cancers – recognition</u> and <u>referral</u> (revised August 2025). This focuses on the symptoms that are suggestive of childhood cancers and referral. It is based on the following NICE guidelines:

- NICE (2024) QS55: Cancer services for children and young people
- NICE (2025) NG12 Suspected cancer: recognition and referral. (Currently being updated – expected publication date 27 February 2026)

# Managed Service Network for Children and Young People with Cancer

The Managed Service Network for Children and Young People with Cancer was established in 2011. It is a co-ordinated network supported by all relevant clinicians operating across the NHS Scotland and aims to ensure they work collectively in accordance with national standards and guidelines. The network publishes an annual report on its structure, activities and future plans.

#### Waiting times and data

Public Health Scotland reports on <u>cancer waiting times</u> in relation to two waiting times standards (31 and 62 day) that are used to measure how long patients (aged over 16 at the date of diagnosis) have waited for their first cancer treatment. This does not include information on people aged under 16.

The Royal College of Paediatrics and Child Health (RCPCH) published a report Worried and waiting: A review of paediatric waiting times in Scotland 2024. This provided an analysis of paediatric waiting times data in Scotland from October 2012 to September 2023.

This report recommended "improvement in the collection and utilisation of child health data". Noting that improved data collection should consider:

- Enhanced data collection: Strengthen the collection of data to inform understanding of where the backlogs are building up, and where Scottish Government, the NHS Scotland and others should direct resource.
- Data for the child health workforce strategy: The bespoke child health workforce strategy we are calling for should be based on robust data and modelling of future trends, e.g. growing less than full time (LTFT)

- working. Both national and local level data will need to be utilised to enable greater insight into workforce pressures and to tackle the healthcare workforce staff shortages.
- Community Paediatrics: Implementing monthly data collection for paediatric community health services across all health boards will enable the monitoring of data, identification of service needs and staffing requirements, and will facilitate targeted efforts to address waiting lists.

The RCPCH published an update in March 2025. In this the RCPCH Scotland Officer said:

"Our recommendations to the Scottish Government are yet to be taken forward and despite the paediatric workforce's best efforts to reduce waiting times, children and young people ate still left worried and waiting".

The Managed Service Network for Children and Young People with Cancer has an ambition to have a "Once for Scotland' approach to the collection of high-quality data".

#### **Scottish Government Policy**

The Scottish Government published <u>Collaborative and Compassionate</u> <u>Cancer Care: cancer strategy for children and young people 2021–2026</u>, in September 2021. This included over 60 actions.

In response to parliamentary question <u>S6W-34294</u>, the <u>Cabinet Secretary</u> Health and Social Care said:

"The implementation of the Collaborative and Compassionate Cancer Care The Cancer Strategy for Children and Young People in Scotland 2021–2026 is managed by the Managed Service Network for Children and Young People with Cancer (MSN CYPC) into 2026. Scottish Government is working with the MSN CYPC to consider the development of any future children and young people's national cancer strategy approach required ahead of the strategy end date in 2026."

In relation to referral pathways and education, in response to <u>S6O-04815</u>, the <u>Minister for Minister for Public Health and Women's Health said</u>:

"There are specific and well-established referral guidelines for children and young people as part of the Scottish referral guidelines for suspected cancer, which have recently been clinically reviewed. The updated guidelines will be published in July. That will be supported by the provision of education resources to support primary care to make the most appropriate referral to the most appropriate pathway."

## **Key Organisations and relevant links**

- The Royal College of Paediatrics and Child Health (RCPCH)
- The Royal College of General Practitioners in Scotland (RCGP)
- Managed Service Network for Children and Young People with Cancer
- NHS Education for Scotland
- Young Lives vs Cancer has published its <u>Manifesto for Children and</u>
  Young People with Cancer in Scotland
- The Children and Young People's Cancer Association has launched an evidence based public and professional awareness campaign to improve early diagnosis of cancer in children and teenagers.
- <u>Teenage Cancer Trust</u>

#### Lizzy Burgess Senior Researcher Health and Social Care 05 November 2025

The purpose of this briefing is to provide a brief overview of issues raised by the petition. SPICe research specialists are not able to discuss the content of petition briefings with petitioners or other members of the public. However, if you have any comments on any petition briefing you can email us at <a href="mailto:spice@parliament.scot">spice@parliament.scot</a>

Every effort is made to ensure that the information contained in petition briefings is correct at the time of publication. Readers should be aware however that these briefings are not necessarily updated or otherwise amended to reflect subsequent changes.

Published by the Scottish Parliament Information Centre (SPICe), an office of the Scottish Parliamentary Corporate Body, The Scottish Parliament, Edinburgh, EH99 1SP