Citizen Participation and Public Petitions Committee
Wednesday 21 January 2026
2nd Meeting, 2026 (Session 6)

PE2193: Address Dangerous Delays in Paediatric Cancer Diagnostics

Introduction

Petitioner	Avril Arnott
Petition summary	Calling 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.
Webpage	https://petitions.parliament.scot/petitions/PE2193

1. This is a new petition that was lodged on 10 October 2025.
2. A full summary of this petition and its aims can be found at **Annexe A**.
3. A SPICe briefing has been prepared to inform the Committee's consideration of the petition and can be found at **Annexe B**.
4. Every petition collects signatures while it remains under consideration. At the time of writing, 1,110 signatures have been received on this petition.
5. The Committee seeks views from the Scottish Government on all new petitions before they are formally considered.
6. The Committee has received submissions from the Scottish Government and the Petitioner, which are set out in **Annexe C** of this paper.

Action

7. The Committee is invited to consider what action it wishes to take.

Clerks to the Committee
January 2026

Annexe A: Summary of petition

PE2193: Address Dangerous Delays in Paediatric Cancer Diagnostics

Petitioner

Avril Arnott

Date Lodged

10 October 2025

Petition summary

Calling 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.

Background information

Isla's journey began at the age of 15 when she was repeatedly referred and downgraded in her medical assessments. By the time a definitive diagnosis of cancer was made, it was too late, and her family was given the heartbreaking news that she had only months to live. Her passing has left a deep void in her family's life. If her medical condition had been treated with the same urgency as an adult's, she might still be with us today.

It is important that children and young people are assessed and treated with the same level of urgency and access to diagnostic tests as adults. No young person should be dismissed or have their symptoms underestimated simply because they appear healthy or are perceived to be too young for serious illness. This needs to be set in stone with all agencies.

Scotland continues to have one of the highest mortality rates among children under 18 in Western Europe. Strengthening early recognition, ensuring equal access to testing, and raising awareness within primary care are essential steps to prevent other families from suffering such unimaginable loss.

Annexe B: SPICe briefing on PE2193

Brief overview of issues raised by the petition

Petition PE2193: Address Dangerous Delays in Paediatric Cancer Diagnostics 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 Scottish Referral Guidelines for Suspected Cancer 2025 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 toolkit on teenage and young adult cancer services.

The National Institute for Health and Care Excellence (NICE) has also published a clinical knowledge summary on childhood cancers – recognition and referral (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 cancer waiting times 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 Collaborative and Compassionate Cancer Care: cancer strategy for children and young people 2021–2026, in September 2021. This included over 60 actions.

In response to parliamentary question S6W-34294, the Cabinet Secretary 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 S6O-04815, the Minister for Minister for Public Health and Women's Health said:

> "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."

Lizzy Burgess
Senior Researcher Health and Social Care
05 November 2025

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Annexe C: Written submissions

Scottish Government written submission, 10 November 2025

PE2193/A: Address dangerous delays in paediatric cancer diagnostics

Does the Scottish Government consider the specific ask[s] of the petition to be practical or achievable? If not, please explain why.

Every year in Scotland, approximately 180 children and up to 200 teenagers and young adults are diagnosed with cancer. Statistically, an individual GP in Scotland might see only one new cancer in a child under 15 years in a 35-year career.

If a clinician suspects cancer in children or a young person, then an urgent suspicion of cancer referral should be made to secondary care following the Scottish Referral Guidelines (SRG) for Suspected Cancer. The SRG have been updated to support GPs in referrals for children and young people, published on 6 August 2025. These guidelines have been specifically developed to support primary care clinicians to identify those with symptoms suspicious of cancer and identify those who require urgent assessment by a specialist.

The Information Services Division (Scotland) of NHS NSS (ISD) last reviewed all statistical waiting times publications in 2011 (the functions of ISD relevant to this submission are now undertaken by Public Health Scotland). This consultation process involved ISD, the Scottish Government and data providers to consider the user need and frequency of a suite of waiting times publications.

The clinically agreed decision made at that time was that the Acute Leukaemia and Paediatric Cancers statistics would no longer be published by ISD. There was clinical consensus that children with cancer symptoms should be treated as quickly as possible and it would therefore not be appropriate to subject these urgent cases to a longer 62-day target. The 62-day standard therefore applies to adults over the age of 16.

The Cancer Action Plan for Scotland 2023-2026 commits to ‘carrying out a clinically led review of latest data and evidence to determine whether there is merit in specific additional or alternative cancer waiting times standards for different types of cancer and cancer treatment’.

A project steering group is being established via the Centre for Sustainable Delivery (CfSD) which will support this review, determining if any amendments to the standards would enhance patient experience and meet the needs of the NHS for the future.

In light of the publication of the Scottish Referral Guidelines and the upcoming review of the cancer waiting times standards, the Scottish Government is of the view that acting on the specific asks of the petition would be inappropriate at this time.

What, if any, action the Scottish Government is currently taking to address the issues raised by this petition, and is any further action being considered that will achieve the ask[s] of this petition?

Whilst Scottish Ministers are responsible for determining the strategic policy of the NHS in Scotland, it is NHS Boards and healthcare professionals locally who have responsibility for service delivery and patient treatment.

The Scottish Government expects the Managed Service Network for Children and Young People to maintain a constant watch for systemic failures and to initiate local board escalation procedures it is deemed necessary to do so.

The Scottish Referral Guidelines (SRG) for Suspected Cancer support primary care clinicians to identify those with symptoms suspicious of cancer and identify those who require urgent assessment by a specialist, this includes specific guidelines for children and young people. A full clinical review of SRGs has already been completed with updated guidance published on 6 August 2025. Fourteen peer review sessions have taken place over the course of this work to ensure engagement, evidence, and input from key stakeholders such as the Scottish Primary Care Cancer Group, Healthcare Improvement Scotland, secondary care clinicians and the Scottish Cancer Coalition.

A new primary care cancer education platform – Gateway C – was launched in 2024 in NHS Scotland, funded by the Detect Cancer Earlier (DCE) Programme and supported by NHS Education for Scotland (NES).

Gateway C provides innovative and tailored information to support earlier cancer diagnosis efforts and enable effective decision-making. This free online platform is accessible to all primary care clinicians including pharmacists, dentists, and optometrists.

Further to this, the Managed Clinical Network for Children and Young People is taking action to develop further education and learning opportunities to improve referrals and ensure timely diagnosis for young people. These would support healthcare professionals who are less familiar with the unique needs of young people, as they navigate through healthcare pathways.

The Managed Clinical Network for Children and Young People is also supporting arrangements between the Principal Treatment Centres and Shared Care Centres across Scotland, to provide education and advice to assist staff on the management of patients and to identify early diagnosis.

Action 42 of the 3-year Cancer Action Plan commits to ‘carrying out a clinically led review of latest data and evidence to determine whether there is merit in specific additional or alternative cancer waiting times standards for different types of cancer and cancer treatment’. The review will require significant clinical leadership, with appropriate engagement across a range of stakeholders.

A project steering group is being established which will support the review, determining if any amendments to the standards would enhance patient experience and meet the needs of the NHS for the future. The scope of this review can include paediatric cancer.

The Scottish Government will continue to keep new clinical advice and evidence under review.

Healthcare Quality and Improvement Division, Scottish Government

Petitioner written submission, 13 November 2025

PE2193/B: Address dangerous delays in paediatric cancer diagnostics

Every year in Scotland, around 180 children and up to 200 teenagers are diagnosed with cancer.

Yet, most GPs might only see one case of childhood cancer in their entire career.

Because of this, I believe too many children’s diagnoses are slipping through the net. Symptoms in children are often not taken as seriously as they would be in adults, and vital tests are sometimes delayed or not done at all.

I believe the guidelines must change and tests should always be carried out, even if the GP doesn’t initially think cancer is likely. Early diagnosis saves lives, and every child deserves that chance.

If a clinician suspects cancer in a child or young person, an urgent suspicion of cancer referral should always be made.

In Isla’s case, this referral was made, but it was downgraded to routine, all because of the current guidelines.

This delay can mean the difference between life and death. The system needs to change so that when there’s even a small suspicion of cancer in a child or teenager, the referral remains urgent and the necessary tests are done immediately.

There was once a clear understanding that children showing symptoms of cancer should be treated as quickly as possible, and that it would not be appropriate to subject these urgent cases to the longer 62-day target.

However, as it was in Isla’s case and sadly, in many others, if the referral is downgraded to routine, these young patients are not seen urgently, which can cause devastating delays in diagnosis and treatment.

There is also a grey area for 16-year-olds, where clinicians are often uncertain whether to follow adult or child pathways.

This confusion existed in Isla’s case, and it highlights the urgent need for clearer, child-focused guidance to ensure no young person falls between the cracks.