Citizen Participation and Public Petitions Committee
Wednesday 25 February 2026
5th 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. The Committee last considered this petition at its meeting on 21 January 2026. At that meeting, the Committee agreed to write to the Scottish Government and the Royal College of Paediatrics and Child Health.

2. The petition summary is included in **Annexe A** and the Official Report of the Committee's last consideration of this petition is at **Annexe B**.

3. The Committee has received new written submissions from the Cabinet Secretary for Health and Social Care and the Royal College of Paediatrics and Child Health Scotland, which are set out in **Annexe C**.

4. Written submissions received prior to the Committee's last consideration can be found on the petition's webpage.

5. Further background information about this petition can be found in the SPICe briefing for this petition.

6. The Scottish Government gave its initial response to the petition on 10 November 2025.

7. Every petition collects signatures while it remains under consideration. At the time of writing, 1,527 signatures have been received on this petition.

Action

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

Clerks to the Committee
February 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: Extract from Official Report of last consideration of PE2193 on 21 January 2026

The Convener: For the next new petition, I note that we have some guests in the public gallery, and we are also joined by Jackie Baillie.

PE2193, lodged by Avril Arnott, 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 when a paediatric cancer referral is downgraded or delayed; fund training and update guidelines to enable general practitioners and clinicians to recognise, and escalate action on, signs of cancer in children as promptly as they would in adult cases; and undertake a formal review of paediatric diagnostic delays in Scotland, to identify systemic failures and implement change.

The petition was motivated—as petitions too often are—by the tragic passing of a young girl after she was repeatedly referred and downgraded in her medical assessments. The petitioner argues that no young person should have their symptoms underestimated simply because they appear to be healthy or are perceived to be too young for serious illness.

The Scottish Government points to a number of projects, either completed or in progress, that directly address the points raised by the petition. The Scottish referral guidelines were updated last summer to support GPs in referrals for children and young people. The cancer action plan for Scotland for 2023 to 2026 includes carrying out a clinically-led review of the latest evidence to determine

“whether there is merit in specific additional or alternative cancer waiting times standards for different types of cancer and cancer treatment”.

In 2024, NHS Scotland launched a primary care cancer education platform, which provides primary care clinicians with information to support earlier cancer diagnosis efforts and enable effective decision making. The Scottish Government expects the managed service network for children and young people with cancer to be alert to systemic failures and to initiate local board escalation procedures if necessary. Additionally, the Scottish Government previously stated that the managed service network handles the implementation of “Collaborative and Compassionate Cancer Care: cancer strategy for children and young people 2021-2026”. That work started in 2021 and is due to be completed in 2026.

Before the committee decides what action to take, I invite Jackie Baillie to contribute to our thinking.

Jackie Baillie (Dumbarton) (Lab): I know that the committee is no longer routinely inviting MSPs to speak, so I appreciate the opportunity. I join you in welcoming Isla’s mum, dad, aunt, uncle and grandmother to the visitor gallery today.

We all agree that there have been significant advances in cancer care. Our clinicians do an exceptional job, but that is what makes Isla’s experience all the more disappointing. She first went to her GP in July 2022, and she received a diagnosis some two years later. By that time, her cancer had spread and was too advanced to treat.

The family raise three main issues. First, GPs who are diagnosing such conditions see only about 180 children and 200 teenagers every year, so the reality is that a GP will not come across a child with cancer very often. The family want improvements in diagnosis by and guidelines for GPs. In fairness, the Scottish Government is addressing that, which is particularly welcome. Secondly, there is no longer data collection on the number of children and teenagers who get cancer. Again, the Government says that it is addressing that, which is also welcome, but there is work to do before it becomes a reality.

I would like to concentrate on the third issue. Isla’s GP made an urgent referral for a biopsy—it was at that stage that the clinic downgraded the referral from urgent to routine, and we lost even more time. It decided to do that on the basis that she was young—that was it. The sole clinical judgment was that she was young, so the referral was just made routine. It is inappropriate to downgrade on the basis of somebody’s age.

I risk being on the wrong side of the committee, but I think that we should take our chances and keep the petition open. I invite the committee, if there is time remaining, to write to the Scottish Government specifically on the referral point, which the Government has not addressed in its submission to any great degree, and to ensure that children and young people in Scotland will be treated in exactly the same way and as urgently as adults with cancer.

10:00

The Convener: In the face of your eloquence and in view of the tragic circumstances that underpinned the petition—which might otherwise have been avoided, for all we know—that is a very focused additional inquiry, so I am minded, if the committee is willing, to hold the petition open by exception and to make that specific request of the Scottish Government. I do not think that we can go any wider, given that we want to see what action we can get. We have certainly been able to highlight the issue through the evidence of the petition’s having been raised and the contribution that you have made.

If colleagues are content, we will hold the petition open, by exception, and we will seek to clarify the specific point that Jackie Baillie has raised with the Scottish Government.

Davy Russell (Hamilton, Larkhall and Stonehouse) (Lab): I totally agree. So far, allowing local escalation has meant that there are no hard and fast guidelines. Failure occurs where there is no structured guideline.

The Convener: Any of us who is a parent, even if that was perhaps some time ago—well, we are always parents, but even if our children are no longer children—thinks, “There but for the grace of God.” To think that something might have been avoided if the issue had not been dismissed simply because of a prejudice against the idea that young people might have cancer is deeply disturbing.

Fergus Ewing: I was struck by the background information to the petition, which pointed out that Scotland continues to have one of the highest cancer mortality rates in western Europe among children under 18. That is a shocking statistic.

I was not aware of many of the issues that Jackie Baillie has eloquently set out. Although it is heartening that some progress has been made on points 1 and 2, she is absolutely right to focus on point 3 and seek a specific answer from the Scottish Government. However, I see no reason why we should not at the same time write to the Royal College of Paediatrics and Child Health to see what it says about the issue. Plainly, the Scottish Government refers regularly to advice, National Institute for Health and Care Excellence guidelines and everything else from the royal colleges, so it might be worth while to do that—there would be no harm in it.

The Convener: I am content to do that in relation to the focused issue. The Scottish Government will appreciate the urgency with which the committee would appreciate its considering the point that we are raising, but we should certainly make it clear to any third party that, given the limited time for the Parliament to consider the issue further, we would appreciate it if they were able to come back to us promptly.

Are colleagues content with the proposal?

Members indicated agreement.

The Convener: We will therefore hold the petition open and act on that basis. I thank Jackie Baillie for her contribution and the people in the gallery for being with us this morning.

Annexe C: Written submissions

Cabinet Secretary for Health and Social Care written submission, 6 February 2026

PE2193/C: Address Dangerous Delays in Paediatric Cancer Diagnostics

I am writing to you in response to your recent ask of Scottish Government to provide a specific response to the second ask of petition **PE2193,** urging Scottish Government to *require clear accountability and follow-up where a paediatric cancer referral is downgraded or delayed*.

The Scottish Government believes that age should not be a discriminating factor in diagnosing cancer, and we very much understand the importance of a timely and accurate cancer diagnosis, regardless of the individual's age. I met today with the parents of Isla Sneddon who so tragically lost her life to cancer at such a young age. Isla was clearly let down by the system, and I gave my assurances to Isla's family that the Government will do all we can to make the changes we need to see.

In answer to the specific ask relating to clear accountability and follow-up where a paediatric cancer referral is downgraded or delayed; the Centre for Sustainable Delivery is currently reviewing supporting guidance for the Scottish Referral Guidelines (SRG) for Suspected Cancer. This Urgent Suspicion of Cancer national regrading guidance makes clear that if a referral is regraded, then a communication should be sent to the referring clinician with explicit reasons for this and considerations for next steps in care.

Separately, the SRG for Children and Young People was updated in August 2025 with significant revisions to support primary care in detecting cancer earlier, including for non-specific symptoms of cancer.

The specific changes to the SRG which relate to supporting a timely diagnosis of cancer in children and young people, include:

- Additional information on incidence, routes to diagnosis and possible delays added.
- Expanded section on cancer types found in this age group e.g. additional description of the features of the more frequent cancers diagnosed.
- New section added on assessment to aid recognition of cancers in children e.g. added features that should raise suspicion of cancer including attendance patterns, persistent symptoms or parent/carer concerns.
- New section added on assessment to aid recognition of cancers in young people e.g. added possible reasons for symptoms of cancer to be misattributed.

These SRG revisions give particular emphasis to the frequency of presentations of children and young people to primary care. This was with a view to supporting primary care clinicians in liaising with secondary care colleagues working with children and young people with cancer if they had ongoing concerns.

Clinicians are being supported to use these new guidelines through educational resources to ensure that they make the most appropriate referral to the most appropriate pathway. These include bespoke assets focusing on children and young people to support early identification of possible symptoms of cancer and prompt referral.

It may interest you to know that we work collaboratively with the Managed Clinical Network for Children and Young People with Cancer (MCN CYPC), who are a dedicated network of cancer specialists with the core function of supporting NHS Boards to deliver gold standards of care for children and young people with cancer. This includes supporting the timely and accurate diagnosis of cancer in children and young people. They have worked with the Centre for Sustainable Delivery to develop these guidelines and are actively supporting colleagues across the country to use them

Understanding the significance of a timely and accurate cancer diagnosis in children and young people, the Scottish Government has also committed to explore the referral process for a cancer diagnosis in children and young people, when an individual presents to a primary care clinician with persistent symptoms. This would be similar to Jess' Rule in NHS England which encourages primary care clinicians to rethink a diagnosis if an individual presents three times with the same symptoms or concerns. Any review of the referral process will be clinically-led, however I confirmed to Mr and Mrs Sneddon today that I have instructed my officials to liaise with the UK Department for Health and Social Care on Jess' Rule to understand how it is being implemented and to establish how we can do similar in Scotland.

With regards to wider accountability, NHS Boards hold GP practices to account for service delivery. An individual doctor's professional conduct is regulated by the General Medical Council.

To update the Committee on the other asks raised by the petition, the Centre for Sustainable Delivery are leading the clinically-led review of the current cancer waiting time standards. I can confirm this review will specifically include paediatric and teenage and young adult cancers.

The establishment of six Rapid Cancer Diagnostic Services across Scotland are helping us find cancer faster in adults. The services are providing primary care clinicians with access to a fast-track diagnostic pathway for people with non-specific symptoms suspicious of cancer and I am keen to understand whether the expansion of these services to children and young people could also be beneficial. Again, I am ensuring advice is clinically-led however I will of course keep Parliament updated on any developments.

I hope the information provided is helpful and I again restate that the Scottish Government is committed to improving the experiences of children and young people with cancer.

Yours sincerely,

NEIL GRAY

Royal College of Paediatrics and Child Health Scotland written submission, 12 February 2026

PE2193/D: Address Dangerous Delays in Paediatric Cancer Diagnostics

Thank you for the opportunity to provide a response to the Citizen Participation and Public Petitions Committee's petition *PE2193: Address Dangerous Delays in Paediatric Cancer Diagnostics*, and in particular the Committee's request for RCPCH's view on greater accountability when an urgent paediatric cancer referral by a GP to be downgraded or delayed by a specialist, solely based on the patient's age.

The NHS is currently facing immense pressures, particularly within paediatric services, where unacceptably long waiting times can have serious and lasting consequences for children and young people. While delays in care are concerning for all patients, the impact on children is especially critical. Many essential treatments and interventions are time-sensitive for children, with effectiveness often dependent on being delivered within specific developmental windows. Missed opportunities for early intervention can lead to irreversible harm, compounding health inequalities and placing greater strain on services in the long term.

These delays are not only a service challenge but a clear children's rights issue. Under the UNCRC, every child has the right to the highest attainable standard of health, as set out in Article 24. This means that timely, appropriate and accessible healthcare is not optional but is an obligation. When children face long waits for assessments, treatment or referral, their rights are not being upheld. We must ensure that children's health needs are prioritised across every hospital, clinic, school and community, recognising that protecting their right to health requires investment, coordinated action and a system designed around what children need to thrive.

The Royal College of Paediatrics and Child Health's *Facing the Future: Standards for children with ongoing health needs* set out what safe, timely and well-coordinated care should look like for all children. While the standards do not address cancer pathways specifically, they cover the whole system and include cancer services within their scope.

In relation to accountability when referrals are modified, several standards are relevant. Standard one requires referrals to be assessed and responded to within five working days, with paediatric involvement in the child's care from the point of referral. Standards two and four highlight the importance of rapid access to specialist advice for healthcare professionals, including urgent advice available at any time of day or night. Other standards highlight the need for robust communication systems, timely sharing of information and clear processes for monitoring, reviewing and improving services (standards five, seven and eleven).

The standards also emphasise the importance of involving children, families and all relevant professionals in the design and evaluation of services (standards ten and eleven), alongside strong leadership for children's services at executive or board level (standard nine). These principles reinforce the need for an accountable system in which decisions are transparent, evidence based and responsive to the needs of children and their families.

For further information the full Facing the Future report is attached and available here: https://www.rcpch.ac.uk/resources/facing-future-standards-ongoing-health-needs

We trust this response assists the Committee’s deliberations and remain available to provide any further clarification if required.