

PE2193/C: Address Dangerous Delays in Paediatric Cancer Diagnostics

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

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