

Cancer Trials Ireland Hustings



On 18 November 2024, Cancer Trials Ireland hosted an important hustings event, bringing together healthcare professionals, patient advocates, political representatives, and stakeholders to discuss the future of cancer clinical trials in Ireland. The event focused on the need for increased funding, streamlined administration, and improved access to clinical trials across the country. The event was attended by 100 attendees, with 20 in-person in RCSI, Dublin and 80 joining online.

Actionable Outcomes

1. Double Clinical Trial Participation:

Achieve and surpass the National Cancer Strategy goal of 6% patient enrolment.

2. Streamline Bureaucracy:

Simplify GDPR processes, unify ethics reviews, and reduce trial start-up times.

3. Secure Sustainable Funding:

Introduce multi-annual, ring-fenced budgets for research staff and clinical trial infrastructure.

4. Expand Genomics Capabilities:

Establish a centralised genomics lab to reduce delays and improve diagnostic accuracy.



Daithí Doolan
Sinn Féin



Emer Higgins
Fine Gael



Shane Moynihan
Fianna Fáil



Denis Naughten
Independent

Eibhlin Mulroe, Cancer Trials Ireland CEO, hosting the event, set the tone with a clear and focused opening, emphasising the urgency of addressing the challenges facing cancer clinical trials in Ireland. She highlighted the critical role that trials play in improving patient outcomes, describing them as an essential part of the care pathway rather than an optional extra. Ms Mulroe framed the discussion as a call to action, encouraging collaboration between policymakers, healthcare professionals, and patient advocates to create meaningful change.



Patient Advocates: Seamus Cotter and Miriam Staunton

Seamus Cotter, a Stage IV lung cancer survivor, shared his experience with clinical trials. Diagnosed in 2016, he was given 18 months to live without access to innovative treatments. A clinical trial in Galway provided him with the treatment he needed. Mr Cotter highlighted the challenges of geographic disparities in access, explaining that patients treated in Limerick, rather than Galway, might not have the same opportunities. He also expressed concerns over administrative delays, such as the two-year suspension of trial recruitment in Galway, which he believes contributed to preventable deaths.

Miriam Staunton, diagnosed with Stage III melanoma in 2018, outlined the inequities faced by patients in accessing treatments. She initially could not receive systemic therapies as they were not reimbursed in Ireland, only becoming eligible upon progressing to Stage IV. Ms Staunton pointed out that 98.5% of Irish cancer patients do not participate in clinical trials and raised concerns over bureaucratic delays that discourage international pharmaceutical companies from conducting trials in Ireland.



"If I had been treated in Limerick instead of Galway, I wouldn't have had access to the clinical trial that saved my life. People died because trials were delayed or unavailable—and that's the reality we need to change."

Seamus Cotter

Healthcare Professionals and Advocates

Professor Seamus O'Reilly, a clinical oncologist and Clinical Lead at Cancer Trials Ireland, emphasised the vital role clinical trials play in improving cancer care. He challenged the perception of trials as supplementary, arguing that they are central to delivering effective treatments. Professor O'Reilly noted the significant progress made in cancer survival rates, attributing much of it to advancements from clinical trials. He referenced the Good Friday Agreement, which included provisions for clinical trials, as a successful example of government action that should be replicated. He also called for sustainable funding and more stable employment conditions for research staff, noting the current reliance on short-term grants.

Paul Egan, a Senior Counsel and board member of Cancer Trials Ireland, focused on the complications caused by Ireland's interpretation of GDPR regulations. He highlighted the administrative burden of repeated consent processes and multiple data protection impact assessments (DPIAs), which delay trials and deter international collaborators. Mr Egan argued that these issues could be resolved through a ministerial order and advocated for Ireland to align its processes with other EU countries to foster a more research-friendly environment.

Key Issues Raised

1. Administrative Barriers:

- Long trial start-up times, often exceeding 2.5 years.
- Ireland is the third slowest in Europe to open a trial in a hospital once the application is approved because of how we apply GDPR to health research.

2. Funding Challenges:

- Lack of multi-annual funding for trials and research staff and dependence on short-term grants for key roles.
- To double the number of trials, hospitals, universities and Cancer Trials Ireland need double the support. Increase funding for cancer clinical trials through the HRB to €15m and fund clinical trials staff through the NCCP budget.

3. Geographic Inequalities:

- Limited access to trials in rural and regional areas outside of Dublin.

4. Genomics Infrastructure:

- Delays in genetic testing due to insufficient resources.
- Need for a centralised genomics lab to support cancer diagnostics and treatment.

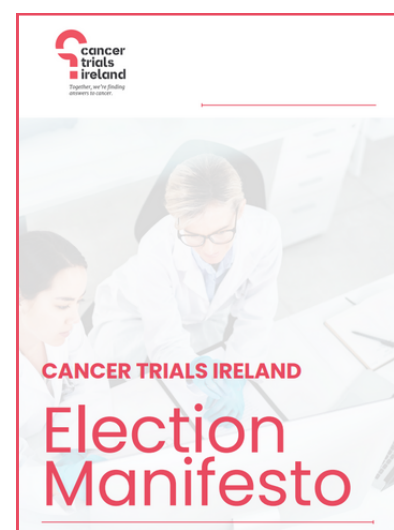
Political Representatives

Denis Naughten, former Independent TD, provided a practical perspective on healthcare policy and cancer research. He commended the progress made through the National Cancer Strategy but emphasised the need to address disparities in access to trials. Naughten pointed out that Ireland's pharmaceutical industry leadership does not translate into equivalent access for patients. He urged political representatives to deliver on commitments to expand trial participation and to use the Shared Island Fund to develop cross-border collaborations.

Dáithí Doolan of Sinn Féin underlined the importance of cross-party collaboration to prioritise cancer trials. He pledged his party's commitment to ring-fenced, multi-annual funding for trials, stressing that reliance on annual grants undermines staff morale and planning. Doolan highlighted Ireland's poor standing compared to other EU countries, calling for significant investment and systemic reform to make Ireland a leader in cancer research.

Shane Moynihan of Fianna Fail called for centralising Ireland's fragmented clinical trials infrastructure to improve efficiency and outcomes. He noted the economic potential of enhancing trials, particularly given Ireland's strong position as a pharmaceutical hub. Moynihan committed to keeping clinical trials on the political agenda through parliamentary questions and advocated for reducing administrative barriers, including Ireland's restrictive interpretation of GDPR.

Emer Higgins of Fine Gael emphasised the importance of making cancer trials a national priority. She acknowledged the country's strengths in healthcare talent and expertise but raised concerns about job insecurity for research staff. Higgins called for removing bureaucratic hurdles and ensuring Ireland adopts best practices from other countries. She also pointed to the societal and economic benefits of investing in research, describing it as essential for both patient outcomes and Ireland's competitiveness in the sector.



The event provided an opportunity for meaningful dialogue between stakeholders, highlighting the critical importance of cancer trials for patient outcomes and Ireland's healthcare system. With commitments from policymakers and calls for urgent action, there is hope that systemic changes will improve Ireland's capacity to deliver world-class cancer trials and research.

For full details of what Cancer Trials Ireland is calling for in this coming election, see our [Election Manifesto](#).



© November 2024

Cancer Trials Ireland is supported by:

