



CANCER TRIALS IRELAND

Election Manifesto

What to put in your election manifesto:

When it comes to clinical trials, Ireland lags behind Europe.

- Denmark runs three times as many trials as Ireland despite having a similar-sized population.
- 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.

Ireland even lags behind its own targets.

- The National Cancer Strategy set a target of 6% of cancer patients participating in cancer clinical trials. We are currently at 1.5% of cancer patients participating in trials.

Meanwhile, Ireland has some of the best-trained and most highly regarded oncologists in the world, who have trained in the UK, Canada and the USA at world-class centres of excellence.

When elected, the _____ pledge to:

1. Double funding for cancer clinical trials through the HRB to €15m – if you want to double the number of trials, you have to double your support to hospitals, universities and Cancer Trials Ireland.
2. Use €5m of the Share Island Fund to support all-island cancer trials infrastructure, including the genomics testing and PET scans that doctors need to support research into new cancer treatments.
3. Cut through the red tape that delays trials opening and damages Ireland's reputation as a host country for research by immediately implementing the recommendations of the National Clinical Trials Oversight Group, and the Cancer Trials Ireland Position Paper on GDPR.

The _____ party wants Ireland to become a global leader in health research. We want to rehabilitate and improve Ireland's reputation for foreign investment in health research, and we want to enable our world-class doctors to deliver the newest, most innovative cancer treatments to patients in Ireland.

Why Are Cancer Clinical Trials Important?

Cancer Clinical Trials:

- Generate €3 of industry investment for every €1 of government funding.
- Come at no cost to the State, the patients themselves, or even health insurers.
- Empirically improve patient outcomes.
- Provide the newest, most innovative treatment options that are not otherwise available to patients.
- Provide dedicated, on-call care for participating patients.
- Enjoy huge, sustained public support (July 2024, Coyne Research):
 - 80% think trials are a good idea.
 - 79% understand trials provide access to treatments that would not otherwise be available to them.
 - 62% would participate in a trial, of whom, 32% would do so specifically to access treatments that would not otherwise be available.

Key Questions

- Why do only 1.5% of cancer patients to participate in trials when the target as per the National Cancer Strategy, is 6%?
 - Why might some of the organisations who run global clinical trials be concerned about opening trials in Ireland?
 - Why is the Irish health system unduly focused on GDPR at the expense of making people well?
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What are the issues?

GDPR and Associated Delays

The root cause of poor timelines in setting up clinical trials in Ireland is well captured in a letter from Mr Paul Egan, SC, which was printed in the Cancer Trials Ireland Position Paper:

“The objective of those addressing the interplay of GDPR and the public interest should, I submit, be more concerned with making people well than conforming to a uniquely Irish over-interpretation of the GDPR.”

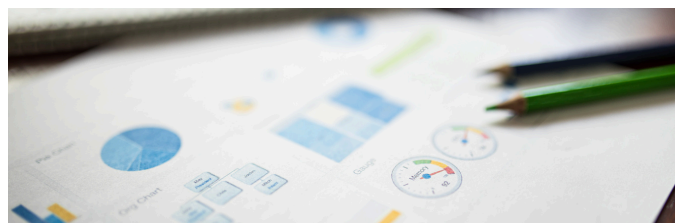
At the launch of a Cancer Trials Ireland Position Paper on how GDPR impacts clinical trials in Ireland, Patrick Kivlehan, a patient advocate, described how timely intervention and participation in a clinical trial probably saved his life. He underscored that trial opening delays could be a matter of life or death for some patients.

Consent

The current requirement to obtain successive consents and/or to re-contact for consent for secondary research is in direct conflict with the evolution of cancer research and treatment, which has shown real progress by targeting gene mutations that may have commonalities across different types of cancer.

Under Ireland’s Health Research Regulations, for example, breast cancer trial data—even with all identifiable information removed— could still not be used to support current or new research for lung cancer patients with the same mutation without seeking further consent.

Furthermore, where patients are now deceased, and while processing the personal data of deceased persons falls outside the scope of GDPR, researchers are currently required to obtain consent from the deceased person’s next of kin or legal representative under current confidentiality laws.



What are the issues?

Electronic Health Records

In most cases, national electronic health registries are not in place and are not set up to assist clinical trial organisations.

One of the most critical jobs in clinical trials is ensuring patient safety. The sponsors of clinical trials regularly visit hospitals and audit the work with patients during the trial.

In reality, when a member of Cancer Trials Ireland or a Pharmaceutical sponsor's trial monitoring team arrives at a hospital site to review patient notes and adherence to the clinical trial protocol by the clinical team, what she/he is most likely to find is a big box of paper patient notes, charts, results to leaf through, because that is how the vast majority of all data relating to patients is collected – on paper.

This is grossly inefficient, and it's another way in which Ireland lags behind comparable European countries.

National Cancer Strategy

Ireland is very far short of its target for cancer patients on trials of 6% per the National Cancer Strategy. We are currently at 1.5% of patients on interventional trials, lower than in 2019.

The Irish Cancer Society recently highlighted that Denmark has three times as many trials open to patients, while industry figures for 2024 show that Ireland is third last in Europe in the median time it takes to initiate a clinical trial in a hospital after regulators approve the clinical trial application.

The same industry figures show that of 3,500 industry-sponsored clinical trials started in the first six months of 2024, only 11 trials included Ireland – less than 1% of industry trials opened in Europe.



Who are Cancer Trials Ireland?

We are the leading cancer research trials organisation in Ireland.

We work with the foremost Medical, Surgical and Radiation Oncologists, as well as Haematologists and Research Specialists (Oncology Research Nurses, Translational Scientists, Data Managers, Pharmacists and staff) in Ireland. 98% of all cancer treating specialists in Ireland are members of Cancer Trials Ireland.

We enable, support and oversee the running of over 100 trials involving thousands of patients. In addition, our members have published many articles in peer-reviewed journals, presented abstracts, and addressed some of the most highly regarded international cancer conferences.

Since we were established in 1996, more than 25,000 patients have participated in over 420 cancer trials.

We work closely with local investigators and international collaborative groups such as ECOG, NRG, ANZUP, and global pharmaceutical companies.

While the vast majority of the trials in our portfolio are carried out in Ireland, some trials extend to Europe.

We are a not-for-profit registered charity.

We are partly funded by the Health Research Board (HRB) and the Irish Cancer Society. We also receive greatly appreciated philanthropic donations from members of the public.

In addition, we generate over half of our income from the cancer trials services we provide to pharmaceutical companies and international research groups.

Our everyday functions include planning, opening, co-coordinating, supporting, monitoring and auditing cancer trials in Ireland.

We provide training, facilitate co-operation between all professionals working in the area, and support the development of cancer trials and research units around the country.

We set policy and champion the opening of more cancer trials in Ireland through engagements with key stakeholders both in Ireland and internationally.



What are we asking for?

Cancer Trials Ireland asks that our politicians commit to improving the lives of Irish cancer patients by including supporting cancer clinical trials in their Election Manifesto. Specifically:

1. Ireland must increase Government spending on cancer clinical trials. (Why do Denmark have three times as many trials open as Ireland when we have similar-sized populations?)
2. We must use the Shared Ireland Fund to fund cancer clinical trials for the whole island of Ireland (Why should cancer patients in Ireland have fewer treatment options than their European counterparts?)
3. We have to cut through the bureaucracy that delays trials opening and discourages companies from investing here (Why is Ireland third slowest in Europe to open a trial in a hospital once the application is approved? Cancer Trials Ireland Position Paper [here](#))

Further Reading

- [Cancer Trials Ireland Annual Review for 2023](#) (published in Oct 2024)
- [Patient recruitment figures](#) for trials Jan – Sept 2024

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