



Cancer Trials Ireland
Opening Statement
Joint Oireachtas Committee on Health

Prof Bryan Hennessy, Clinical Lead
Eibhlin Mulroe, CEO
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Cancer Trials Ireland, Innovation House, Old Finglas Road, Glasnevin, Dublin 11.

Tel: +353 (0)1 6677211 info@cancertrials.ie www.cancertrials.ie Twitter:
[@cancertrials_ie](https://twitter.com/cancertrials_ie)

Prof Bryan Hennessy, Clinical Lead

Thank you Chair and members of the Committee for inviting us here this morning. I am the Clinical Lead of Cancer Trials Ireland and I am joined by our CEO, Eibhlín Mulroe. We are delighted to be here to discuss the implementation of the research-related key performance indicators of the National Cancer Strategy. We also want to raise awareness of the value of clinical trials in cancer treatment.

Background

I am a Consultant Medical Oncologist working at Beaumont Hospital, Our Lady of Lourdes Hospital, Drogheda and I am a Professor of Medicine at the Royal College of Surgeons in Ireland. Like many of my colleagues I have experience of working as a clinical scientist in the US. I am an Adjunct Professor in the Division of Cancer Medicine at the University of Texas, M.D. Anderson Cancer.

Cancer Trials Ireland was established 20 years ago, is a charity set up by doctors, nurses and scientists in cancer care to work on trials across cancer disease areas. There are over 500 members and we come together regularly to develop ideas and set up cancer trials in hospitals. There are 130 cancer trials underway in Ireland and in our portfolio. These trials involve thousands of patients.

Ireland has the potential and the know-how to do more trials. By increasing investment in cancer trials infrastructure, we will be offering Irish cancer patients more options and potentially better outcomes. Cancer trials can extend lives and give people a better quality of life. When I am in the clinic with a cancer patient, there are times I want to be able to offer more than standard of care treatment and that's where a trial can help. At the moment, I know due to the resource constraints in our cancer units and at our head office, there are trials we simply cannot do at present.

Clinical Trial Landscape

Cancer is a genetic disease—that is, it is caused by changes in DNA that control the way cells function, especially how they grow and divide. These changes can be inherited, but most arise randomly during a person's lifetime. Globally, the landscape of cancer trials is changing as we move away from treatments based on tumour site of origin (for example lung, breast, pancreatic cancers) and more towards targeted studies where we look for the same mutation in a variety of tumour sites. These trials are very specific, with smaller patient numbers and are replacing the large 'one-size fits all' trials. Ireland can and does participate in these types of trials which are important for patients. We are testing whether certain targets respond to specific treatment in the context of a trial where the patient is monitored at the highest level.

Recommendations

We need to take steps to implement the National Cancer Strategy published in 2017. The previous strategy in 2006 was a game changer for cancer care. We in Cancer Trials Ireland believe this one could be a game changer for cancer research.

As many of you on the Committee are aware, we need to be ready to take on the challenge of a two-fold increase in the incidence of cancer on the island of Ireland over the next twenty years. In that context, fostering a research culture in our hospitals is important and will create more options for patients through our activity. The target (KPI 20) in the National Cancer Strategy to double the number of people with cancer who can access therapeutic cancer trials, from the estimated 3% to 6% by 2020 would not only have saved the HSE millions of euro in drug costs (€6.5 million 2016), it would provide more patients with access to promising new treatments that would otherwise not be available.

In 2018 the numbers we have collected so far suggest only **348 patients** were newly recruited to therapeutic clinical trials in 2018 and according to the last report by the NCRI there were 22,321 new cases of cancer in the same year. In 2014, the equivalent figure was **664 patients** and an incidence of 21,380 which led to calculations of **3%** baseline figure. Since 2014 we have dropped to **1.5%** on therapeutic trials, we have gone backwards.

In order to support the NCCP achieving this KPI and other research related KPIs, Cancer Trials Ireland is calling for support from this Committee to reverse the 20% funding cut to its HRB Grant which supports its Cancer Trials Research Units and General Central Office.

We need an additional €1.2 million per year to Cancer Trials Ireland Research Units and General Central Office over the next 3 years to increase activity and patient numbers up and above the 3% recruited to clinical trials.

We need protected time for clinicians and medical teams so they can do more research and foster a culture of research in our hospitals.

We recommend that the NCCP makes available a ring-fenced fund to which Cancer Trials Research Units can apply for multi-year funding for staff and capital to ensure continuity and build up human capital in each unit. While the HRB Grant covers costs it is not sufficient funding to provide a stable platform for individual research units to do more.

Thank you.

I will hand over to my colleague, Eibhlín Mulroe

Eibhlín Mulroe, CEO

Thank you, Professor Hennessy

Current Funding

The implementation of the National Cancer Strategy launched in June 2017 could take us significantly closer to achieving more options for cancer patients. To date we have been enabled through funding received from the Irish Cancer Society who contribute €485k annually and the Health Research Board (HRB) who contribute €3 million annually. €2 million of this funding is distributed among 11 hospital sites to enable employment of resource for clinical trials (in 2006, the figure for hospital sites was €3.8 million, almost

double the amount provided today). We receive support from the St Luke's Cancer Research Fund (€165k annually).

The other half our income is generated through sponsoring our own Investigator Initiated Studies funded by pharmaceutical companies and working with international not for profit research groups like ours to bring their global studies to Irish patients. Funding raised is solely used to pay staff and hospital sites for work on cancer trials.

Patient Involvement

Cancer Trials Ireland makes a direct impact on Irish patient lives and it is important for this Committee to reflect on that in the context of the cancer strategy commitments. In our submission on the 6th March, we included true life stories of patients and their experience. There are many more stories of people who have lived longer and with improved quality of life because of their participation on a clinical trial. They have been there for family, major life events and most importantly for their children and grandchildren.

There are many misconceptions concerning participation on clinical trials and we try to stimulate public conversations about trials through our "Just Ask Your Doctor" campaign. We are humbled that so many patients are willing to advocate for cancer trials on our behalf. We have established a Patient Consultant's Committee which is a subcommittee of our Board. We are accompanied today by members of that Committee. Patient involvement in the decisions we make, and the research we do is of strategic importance to our organisation.

Operational Challenges

As outlined by Prof Hennessy, we can report little movement with regard to implementation of the research KPIs outlined. Due to our reduced funding, we have had to decline opening clinically important academic trials in Ireland. These trials would benefit people with a range of cancers including lymphoma, testicular and endometrial cancer. We are unable to be proactive in exploring opportunities to open new trials in areas such as pancreatic, lung, testicular and cervical cancer. This is as a direct result of reduced funding.

The work at our office and at hospital sites is highly specialised and subject to a detailed quality management system with over 50 Standard Operating Procedures designed by us in line with best practice, and is frequently inspected by the HPRA and audits. Patients in Ireland on clinical trials can take comfort in the knowledge that their welfare is monitored at the highest level in healthcare. But it costs to do more and to maintain quality standards, therefore we need increased funding from the Department of Health through the Health Research Board and a budget commitment for NCCP for research at our hospital cancer units and Head Office.

In conclusion

The medium-term objective of Cancer Trials is to test and prove treatments that kill cancer and stop it in its tracks.

One very important difference between cancer trials and all other cancer research is that it is having a profound impact on the lives of people with cancer today. Trials deliver in the medium and immediate term.

Today our trials are providing patients with access to proven but not yet available treatments that can save their lives. There are people on trials today who would not be alive if they did have access to one of our trials.

So it is really important for decision makers to understand that when the funding for trials is reduced, life-saving treatments for patients today can be removed. Their options are reduced. Is this a wise approach. We believe not.

Thank you

We would like to take this opportunity to thank the 15,000 Irish patients who have volunteered on our trials over the last 20 years. They have made a difference for future generations of cancer patients.