

Extract from presentation by Eibhlin Mulroe to the Joint Oireachtas Committee on Health on 13th March 2019.



Eibhlin Mulroe, CEO, Cancer Trials Ireland.

The implementation of the current National Cancer Strategy could take us significantly closer to achieving more options for patients. To date we have been enabled through funding received from the Irish Cancer Society which contributes €485,000 annually and the Health Research Board (HRB) which contributes €3 million annually; €2 million of this is distributed directly to 11 hospital based research units to enable them employ specialists. In 2006, the figure from the HRB for these hospitals was €3.8 million, almost double the amount provided today. We also receive support from the St Luke's Cancer Research Fund (€165,000 annually).

Due to our reduced funding, we have had to decline opening clinically important academic trials in Ireland.

The other half our income is generated through sponsoring our own Investigator Initiated Trials 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 research units for work on cancer trials.

Patient Involvement

Cancer Trials Ireland makes a direct impact on patient lives and it is important for this Committee to reflect on that in the context of the cancer strategy commitments. There are many stories of people who have lived longer and with improved quality of life because of their participation in a 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 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. 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 research units is highly specialised and subject to a detailed quality management system in line with best practice. 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 the NCCP for trials research.

There are people on trials today who would not be alive if they did have access to one of our trials.

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.

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.