

CEO's message

There are precious few good things about the pandemic, but one of them is widespread public appreciation of clinical trials.

That is clearly reflected in the public response to two surveys about clinical trials that we undertook, one in 2020, and another in April 2022. It is unlikely that the public's awareness, understanding and appetite for clinical trials has ever been higher. Here are the headlines:

- Three in five (60%) would participate in a trial (48% in 2020)
- Nine in ten (88%) think trials are a good idea (72% in 2020)
- 85% agree trials provide access to treatments that are not otherwise available (72% in 2020)
- One in four (26%) would participate in a trial specifically to access treatments that are not otherwise available (15% in 2020)

If you want to see how else public awareness has grown in the past two years, across the board, you can see the full research details [here](#), I will make no further overtures about them. Instead, in light of the clear public support, understanding and appetite for clinical trials, I'm going to highlight the barriers to accessing them, which I'm sorry to say are numerous, and structural.

But before we even get to them, I can already tell you the what's needed to overcome them: we need people and patients to consistently demand more access to trials. If we can do that, the government will respond. We will still have to argue our case, but there at least the news is good. We have very strong arguments.

In 2016, Cancer Trials Ireland showed how every €1 invested in cancer trials generates €3 in savings in drugs for the HSE. The people of Ireland have demonstrated they understand that trials provide access to the newest treatments, and science has proved that patients on trials do better. So, where's the downside? The truth is there isn't one, but that fact does not suddenly open up new HSE budgets or policies – and it's in the area of policy that we need to see the most change.

- We need to embed health research in health planning – so that the system values health research, and what it can do for patients and patient outcomes.
- We need to resource research governance, so that hospitals, groups, and the system as a whole actually has the staff and frameworks to support embedding health research in health planning.
- We need to employ fulltime Data Protection Officers, give



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them proper training, and support them with research governance officers.

- We badly need to streamline and harmonise the data protection documents hindering clinical trials in Ireland right now.
- We need to properly resource the Office for National Research Ethics Committees, so that trials can open in a predictable, timely manner in Ireland.
- We need to offer protected time to the surgical, radiation, and medical oncologists and haematologists who want to do research.

None of these problems have an easy solution. None of them roll off the tongue in a snappy way, and none of them lend themselves to easily understandable soundbites. But they are what stand between us and enough clinical trials to reach the target of cancer patients on trials set in the National Cancer Strategy (6%). While we press government for more investment in cancer trials, it is the people of Ireland who have made new trials possible in recent years.

The spectacular fundraising success of Pat Smullen and the horse racing community has given pancreatic cancer patients in Ireland treatment options where previously there were none – and we had no prospect of opening any trials in this area. As inspiring as this is – and continues to be, with others following Pat's incredible lead to fund pancreatic and other cancer trial treatment – it highlights the shortfall in public funding. Without that, we will never overcome the barriers described above, and we will never hit our 6% target.

Eibhlín Mulroe,

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