

# Cancer Clinical Research in Northern Ireland



Cancer Research UK Roundtable: February 7<sup>th</sup>, 2023

## Executive Summary

Cancer clinical research (research in which people, or data or samples of tissue from people, are studied to understand health and disease) is important in the development of new treatments for cancer, but also a critical element of patient care, particularly for those who have exhausted other treatment options.

Action 55 of the Northern Ireland Cancer Strategy (March 2022)<sup>i</sup> calls for the development of a cancer research strategy in partnership with key stakeholders. Cancer Research UK's (CRUK) roundtable event was organised to help contribute to the development of this strategy. The roundtable was attended by clinicians and other experts in cancer trials, Department of Health (DoH) officials, Members of the Legislative Assembly (MLAs), patient representatives and others from across the sector.

The event enabled a range of voices to contribute their views on this topic. **This report is a summary of discussions during the event and aims to contribute to the Department of Health's work to develop a cancer research strategy.**

Guest speakers included:

- Paula Bradshaw, MLA, Alliance Party Spokesperson on Health and Chair of the All Party Group on Cancer
- Professor Ian Young, Chief Scientific Advisor, Northern Ireland
- Dr Tomas Adell, Director of Elective Care and Cancer Policy, DoH
- Dr Melanie Morris, Operations Director, Northern Ireland Clinical Trials Network
- Margaret Grayson, former chair Northern Ireland Cancer Research Consumer Forum; Patient and Public Involvement (PPI) volunteer for CRUK Grand Challenges; member of Public Involvement Enhancing Research (PIER NI)
- Paul Givan, MLA and DUP Spokesperson on Health

The half-day event involved expert presentations followed by more in-depth group discussion. Administrative assistance and note-taking was provided by Stratagem

The event was divided into three focus areas:

### 1. Cancer clinical trials set-up and delivery

- How cancer clinical trials are set up and run in Northern Ireland.
- How Northern Ireland compares to other UK nations.
- The impact of molecular genomic testing on clinical trials.

### 2. Funding for cancer clinical trials

- How clinical trials are costed and funded.
- Funding Northern Ireland's clinical trial infrastructure.

### **3. Public involvement and participation in clinical trials**

- The Cancer Patient Experience Survey (CPES): why are Northern Ireland cancer patients not asked about research participation as frequently as in other nations?
- The role of public and patient involvement (PPI) in cancer research and trials.

There was wide-ranging and robust discussion in all sessions, with summaries provided in this report. There was good engagement from all participants, with many suggestions on how to increase and improve cancer clinical trials in Northern Ireland. Broadly, these suggestions can be distilled into three main areas for consideration.

#### **1. Cancer Clinical Research must be recognised as part of core business and not be treated as an ‘add-on’ to cancer services.**

The Department of Health should develop and lead a programme to promote clinical trials as integral to core cancer services. Clinical research must be more recognized and valued within the health service. Trusts should increase attention on clinical research and trials, including having Trust Research Directors sit on Trust Executive Boards. All Trusts across Northern Ireland should participate actively in cancer clinical research to provide equity of access to the entire population. Clinician participation in trials is currently hampered by service pressures; Trusts must acknowledge that research is part of cancer treatment and care and provide protected time for research.

#### **2. Northern Ireland cancer trials core funding from Public Health Agency Research and Development (PHA R&D) should be increased to similar levels to Scotland and Wales.**

Clinical research infrastructure funding in Northern Ireland is currently significantly lower than other UK nations on a per-capita basis. While there are budgetary pressures in the health service, it is important that research is not forgotten, and additional funding should be provided. Ideally, over time, Northern Ireland should be at the same level of funding as Wales and Scotland. This additional funding must be recurrent and be used primarily to increase staff capacity so more trial applications can be processed. A clear plan is required to ensure all core funding is spent in a way to help more patients and achieve best value. Trials staff currently on temporary contracts should be made permanent. Opportunities such as improved facilities within the Institute for Research Excellence in Advanced Clinical Healthcare (iREACH) and for cross-border trials should be proactively explored.

#### **3. Every cancer patient should be given the opportunity to discuss options in research.**

DoH, via the Public Health Agency (PHA), should publish and make widely available easily understood information about cancer clinical trials in order to promote participation. The Northern Ireland Cancer Research Consumer Forum coordinates patient and public involvement for cancer trials; this work should be more widely promoted and used to recruit new members to the Forum. All cancer patients should have the opportunity to participate in discussions about their suitability to participate in a trial.

For more information contact [margaret.carr@cancer.org.uk](mailto:margaret.carr@cancer.org.uk) or [barbara.roulston@cancer.org.uk](mailto:barbara.roulston@cancer.org.uk)

---

<sup>i</sup> <https://www.health-ni.gov.uk/sites/default/files/publications/health/doh-cancer-strategy-march-2022.pdf>