

# Cancer Patient Advocates from Northern Ireland and the Republic of Ireland Unite for Collaboration at RCSI Dublin

On September 25th and 26th, patient advocates from the Cancer Trials Ireland Patient Consultants Committee and the Northern Ireland Cancer Trials Network NI Cancer Research Consumer Forum (NI CRCF) gathered at the Royal College of Surgeons in Ireland (RCSI) in Dublin. The two-day event was a unique opportunity for both groups to share insights, collaborate on projects, and strengthen cross-border relationships in the fight to open cancer clinical trials on the island of Ireland.



## Day 1: Setting the Stage for Collaboration

The first day started with a warm welcome as attendees met in the Royal College of Surgeons, Dublin, for lunch and networking. This initial meet-and-greet set a positive tone, fostering a sense of community among advocates from both sides of the border. Some attendees had met in previous forums such as AIRCI or, like Siobhan Gaynor and Ann McBrien, had worked together on joint projects, while many were meeting each other for the first time.

The afternoon's sessions began with a focus on patient-led research. Siobhan Gaynor and Ann McBrien presented their experiences collaborating on a patient-led survey focusing on metastatic breast cancer. Siobhan worked with Cancer Trials Ireland to bring the study, concentrating on patient needs, to life and worked with Ann to ensure that patient voices from both sides of the border were represented. They shared some of the results from the survey and highlighted changes to policy and practice that they hope to see implemented as a result. The session highlighted the importance of involving patients in research initiatives, the power of the patient voice, and the benefits of working together across the North and South.

Emer Mulvaney spoke next, providing insights from Cancer Trials Ireland's perspective and emphasising the organisation's commitment to incorporating patient voices in clinical trials. She reflected on the importance and success of the Metastatic Breast Cancer Survey, noting that data from the study featured at ASCO and ESMO in 2024 – the foremost oncology conferences in the USA and Europe, respectively. Emer was also able to share that fellow patient advocate Martin Sweeney, also in attendance, will soon launch his patient-led research study on prostate cancer. This is the second patient-led survey that CTI has supported, and the process is becoming more refined as more studies are conducted.

Emer emphasised that starting point is always the idea, which comes from the patient. The patient has the initial idea for the research and essentially designs the study, but with help and support from CTI at every step along the way. For example, with Martin's study, he began with a goal and a set of objectives, and the team worked backwards to draft the survey questions, involving other specialists, medical professionals, and patients along the way. The key takeaway for the patient advocates was 'You are the Experts!'. The feeling in the room was that more patient-led studies would be both welcomed and needed in the future.

Next, the group heard from Dr Paul Kelly about the upcoming all-island investigator-initiated trial, INSPIRE. The study seeks to explore the use of stereotactic radiation, a new technology, in the treatment of prostate cancer. By avoiding delivering radiation to nearby organs, including urinary, bowel and sexual organs, this treatment protects these organs and lowers the risk of side effects. Dr Kelly believes that the new treatment could provide more convenience to patients, reducing their radiation treatment time to just five days whilst offering excellent cure rates.

This forum, and others like it, are valuable opportunities for doctors and researchers to get genuine patient input on their ideas. In this instance, Dr Kelly is seeking two patient representatives, one from the North and one from the South, to join the trial steering committee and give their feedback to help refine the concept and improve the trial. This presentation underscored the critical role of patient advocacy in shaping research agendas and driving impactful outcomes.



The day concluded with a community consultation about a patient advocacy course, Voice (Vision On Information, Confidence and Engagement), which some of this group had completed. The course, delivered by Barts Cancer Institute, provides a week-long intensive training in basic cancer biology, introduction to research terminology and study design, and critical evaluation of research proposals and scientific papers. Sessions include information on what cancer is, how it is caused, how it develops and how it is detected and treated. Course participants spend time in a research laboratory to help build their understanding. The members of this group who had previously attended shared that the course had expanded their knowledge of the science around cancer and increased their confidence to become more effectively involved in cancer research as patient advocates. It was noted that many other patient advocacy courses exist, and there may be a cross-over between them.



## **Day 2: Expanding Knowledge and Future Directions**

The second day began with an excellent session from the Irish Cancer Society's Claire Kilty and Nikki Warner. They shared examples of how the Irish Cancer Society supports and empowers patients and emphasised the importance of public and patient involvement (PPI) in cancer research and advocacy. The ICS works with cancer patients and their loved ones to make sure their voices are heard, lobbying the government for increased funding and for changes to legislation such as the 'Leave Our Leave' campaign, which urged the government to amend legislation so that women going through a cancer diagnosis during pregnancy or postpartum can defer their maternity leave.

The presentation highlighted the need for a centralised PPI network across Ireland to improve cancer research and patient outcomes. This proposed network would serve as a hub for best practices, training, and resources, bringing together various stakeholders across the island. It would focus on inclusivity, ensuring the representation of diverse communities affected by cancer, and advocate for sustained investment in cancer research infrastructure. Recommendations include establishing a salaried leadership team and a rotating executive to ensure proper governance and a long-term commitment to PPI in cancer research.

Next, Cancer Trials CEO Eibhlin Mulroe spoke about the organisation's vision and mission. The vision is to enhance access to cancer trials, aiming to extend patient lives while growing cancer research. The mission is to serve as a globally recognised hub for cancer trials, known for excellence in governance, collaboration, and innovation. Eibhlin shared that critical areas of focus for 2024 include reducing trial delays, improving clinician engagement, and streamlining operations. The presentation emphasised the importance of collaboration across the island of Ireland and discussed how patients and researchers alike benefit from partnerships with key institutions and global organisations.

Following these presentations, the group engaged in key discussions about improving the distribution and reach of the PROACT Survey, a patient-led project from Martin Sweeny. The survey focuses on the relationship between prostate cancer therapy and a patient's sexual function and mental health. It aims to assess the efficacy and sufficiency of the information provided versus the actual impact to discover if patients are adequately prepared. There is also a version of the survey that partners can complete to gain their perspectives.

Suggestions for disseminating the survey included sharing via sports and community groups such as GAA and golf, targeting specific prostate cancer support groups and linking with partner organisations such as the Marie Keating Foundation. Those in the room with relationships with relevant groups in NI offered advice and expressed willingness to share the survey on Martin's behalf. This will help to ensure that responses are collected from patients on both sides of the border, which is crucial for this study to be truly representative of prostate cancer experiences on the island of Ireland.

### **A Step Forward in Cross-Border Collaboration**

This two-day meeting at RCSI was more than just a gathering; it was a testament to the power of collaboration and the shared commitment to growing patient involvement in cancer research and clinical trials across Ireland. The knowledge shared, relationships built, and projects discussed will undoubtedly enhance the impact of cancer trials and patient advocacy on both sides of the border.

As the event concluded, participants expressed a strong sense of optimism and determination. Together, the Cancer Trials Ireland Patient Consultants Committee and the NI CRCF are paving the way for a more united approach to cancer research, with patients at the heart.