

Patient Involvement in iCAN: A Look Back at 2024

According to its definition, patient involvement refers to patients' genuine experience of participation and being heard. It is seeing patients not as research subjects but as equal partners and active participants. iCAN is a broad initiative, and we aim at strengthening patient involvement in various ways: through the Patient and Citizen Advisory Board (POTKU) and interactive events that foster dialogue. Patient organizations also have representation in iCAN steering group. As the year draws to a close, we take a moment to reflect on the past year's activities.

POTKU's Year

The Patient and Public Advisory Council, POTKU, convenes four times a year. This year, the composition of the council underwent some changes, with four new members joining over the summer. Patient involvement in research is still a relatively new concept in Finland, but we were delighted by the high volume of excellent applications we received—and the evident understanding of what patient involvement in research entails and how POTKU can make an impact within iCAN.

This year, POTKU provided feedback on plain language summaries of new subprojects, engaged in discussions with a doctoral researcher from the iCANDOC PhD pilot program about study design and patient communication, planned patient and public events, evaluated their outcomes, and developed methods to collect input from patients and the public for researchers to use as inspiration when selecting research topics. Our meetings also touched on topics like the national program, the role of research nurses in iCAN, and other timely matters.

Collaboration with Patient Organizations and Other Stakeholders

Collaboration is key to strengthening patient involvement. We organized events in partnership with several organizations, including the Association of Cancer Patients in Finland, EuropaDonna Finland, the Finnish Gynecological Cancer Patients Association, Colores, the Finnish Cancer Center (FICAN), the Institute for Molecular Medicine Finland (FIMM), and the flagship program FCAI. Cooperation also continued with EUPATI Finland. Our sincere thanks to all these partners!

We also collaborate with patient organizations through social media to reach more cancer patients and their loved ones with updates on iCAN's research. This year, for instance, we shared short video messages via the Association of Cancer Patients in Finland's channels on World Cancer Research Day. iCAN's website, newsletter, and social media channels are also used to actively communicate about patient and public events and ongoing research.

Events

This year, we organized five patient-researcher meetings in Helsinki, Turku, and Tampere. These gatherings, which started in 2022, have now become a cornerstone of our event calendar. Programs include short presentations on research projects, guided tours of research laboratories, and informal discussions over coffee about shared interests between participants and researchers. Feedback from these events highlights their warm and welcoming atmosphere. Research groups eagerly anticipate these meetings, which we've tied to awareness events such as Ovarian Cancer Day and Lung Cancer Awareness Month.

In collaboration with FICAN and the Finnish Cancer Patients Association, the World Cancer Day event on February 4, 2024, was recognized in the global Union for International Cancer Control report. In April, a Health Data and AI event organized with FCAI reached a broader public. Additionally, together with FIMM we invited school and secondary education students for the second time to laboratory tours at Biomedicum as part of the European Researchers' Night. This year, more than 100 visitors attended. We also participated in the first-ever open house event at the University of Helsinki's Think Corner, alongside the Helsinki Biobank, Blood Service Biobank, and HUS Plastic Surgery.

Patient Involvement in iCAN's Internal Events

A crucial part of our work is raising awareness of patient involvement within the research community. This year, POTKU updates and activities were shared at iCAN's monthly internal FORUMs. We presented a poster at the iCAN retreat and showcased our efforts to enhance patient involvement at National Conference of Effectiveness Research in October, as well as during a Coffee Break session for young researchers at FIMM.

In POTKU we've been especially pleased to see that the meaningful discussions between iCAN researchers and patient communities have become key moments for all involved.

In Closing

A heartfelt thank you to the researchers for their hard work, our collaborators for their partnership, and all those who participated in our events this year. We look forward to meeting you again next year!

Matti Santalahti, Chair of POTKU
Marketta Liljeström, Project Planner