

Patient advocates in cancer research

Matti Santalahti

Association of Cancer Patients in Finland Chair of the Patient and Citizen Advisory Board, iCAN









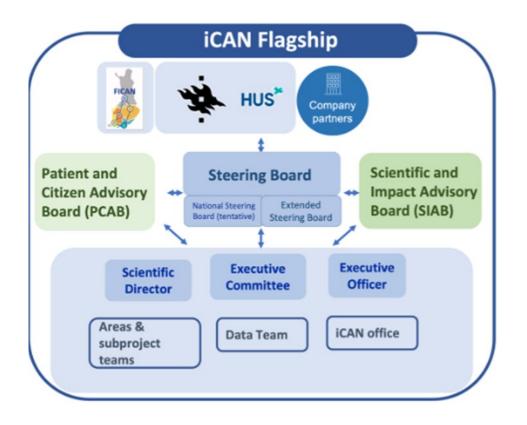
Problem statement and background

- The need for **cancer research** is not widely recognized by decision-makers and general public
 - Patients' lived experience and voice are needed to ensure that research is relevant





Patient involvement at Cancer Research Flagship iCAN



Patient representatives in the flagship governance

- in the Steering Board
- via Patient and Citizen Advisory Board





Patient and Citizen Advisory Board members are committed to

1. Proactively enhance patient involvement

2. Propose concrete actions



- 3. Build bridges between patients, patient organizations, researchers, and the project's Steering Board
- 4. Provide comments as needed on documents and other materials, for example project plans





Strengthening dialogue between researchers, patients and citizens with

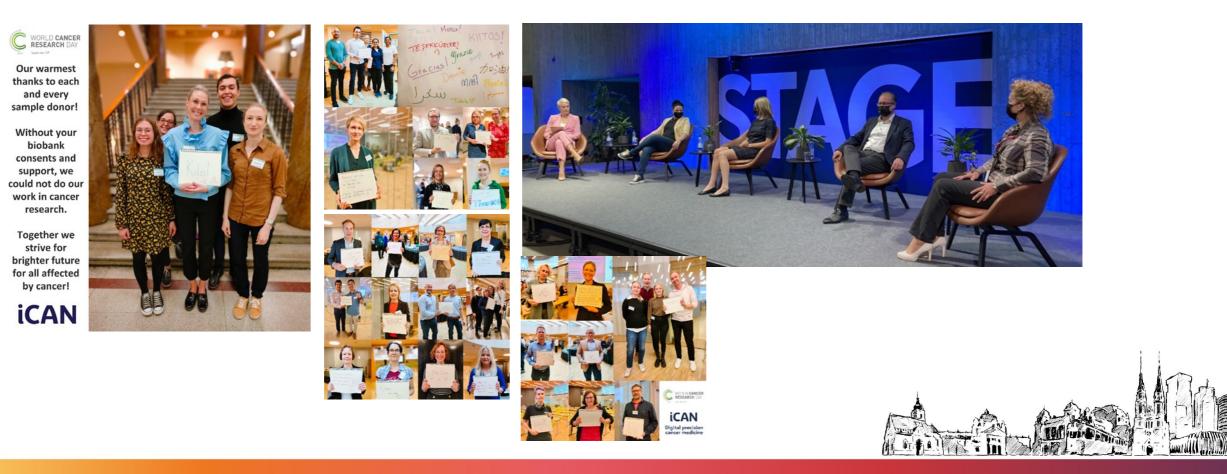
Patient-researcher meetup series: discussions and lab-tours







Raising awareness with events and campaigns





Result and Impact:

Patients are warmly welcomed to the iCAN community and together with the researchers we are cocreating new culture of patient involvement.

Conclusion and recommendations:

- Patient and public involvement is motivating and effective at its best for the researchers and patients.
- Be brave to contact researchers and try to get involved when new projects are planned.
- Remember that it takes time and effort both from the patient advocates and professionals.





THANK YOU!

Matti Santalahti

mattikalervo.santalahti@elisanet.fi

For more information you can also contact Marketta Liljeström, marketta.liljestrom@syopapotilaat.fi

