

# SHAPING THE FUTURE OF FINNISH HEALTHCARE THROUGH MPN PATIENT INVOLVEMENT IN RESEARCH



ASSOCIATION OF CANCER  
PATIENTS IN FINLAND

## CHALLENGES OF MPN CARE IN FINLAND

- Interferon is not reimbursed for MPN patients
- The National Current Care Guidelines concentrate on progressed stages of MPN diseases and take only partially into account new treatments
- Inequality in treatment – some MPN patients are not treated by hematologists
- Compared to other hematological cancers, MPN receive less attention in the Finnish cancer research

## GOALS OF MPN ADVOCACY IN RESEARCH

- Adding interest in MPN research
- Increasing the number of biobank samples
- Improving the MPN care by advocating for better infrastructure in healthcare and for personalized cancer care

## PATIENT INVOLVEMENT IN iCAN NATIONAL CANCER RESEARCH FLAGSHIP PROJECT

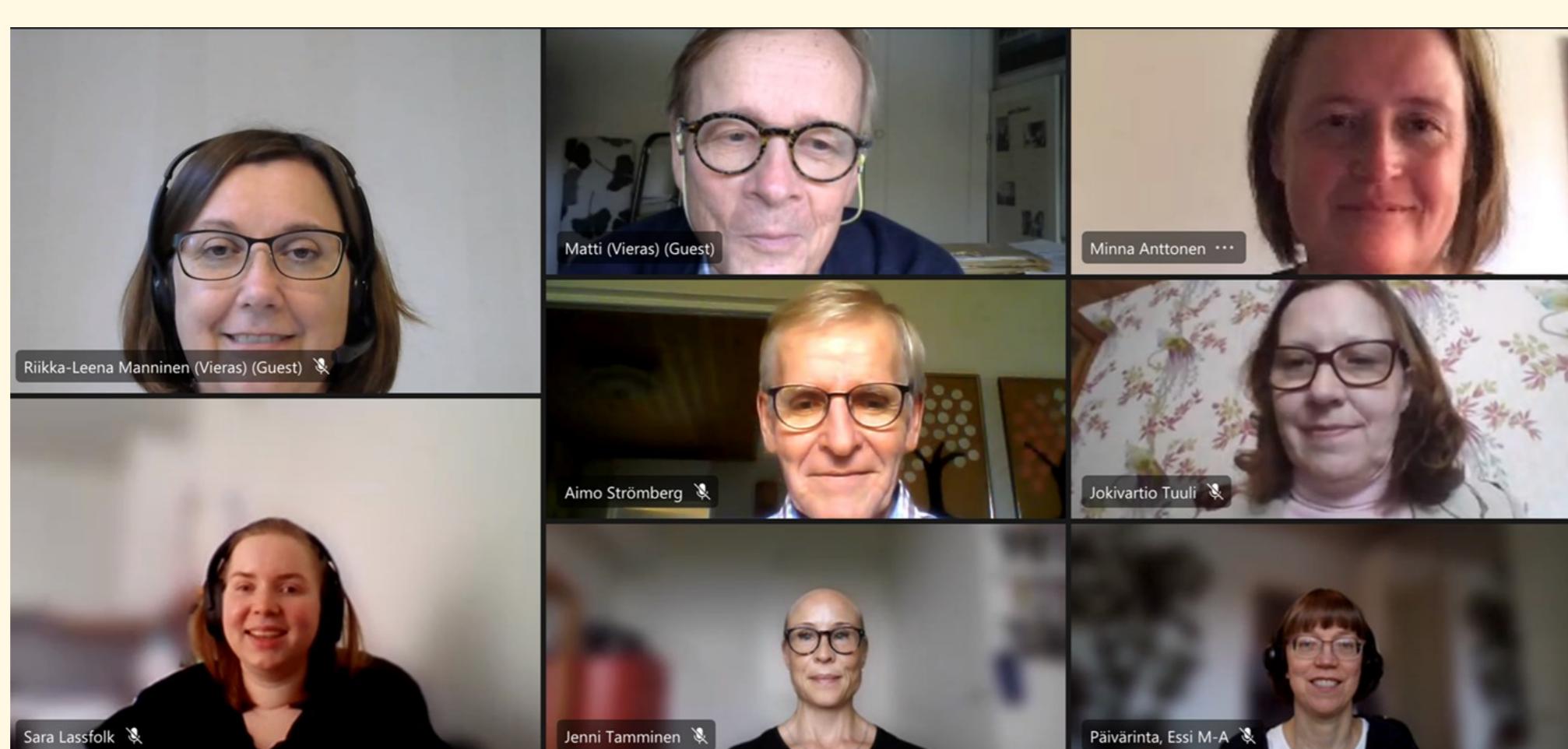
### Association of Cancer Patients in Finland's representatives in iCAN

- CEO Minna Anttonen as PO representative in the iCAN steering board
- Patient and PO representatives in the Patient and Citizen Advisory Board, MPN patient Matti Santalahti as the chair
- PCAB is coordinated by a patient involvement specialist – a coordinator working both for the patient association and iCAN

### RESULTS OF PATIENT INVOLVEMENT

- "Providing benefits for patients" as a cross-cutting objective of iCAN
- Improved collaboration and interaction between patients and researchers
- Enforcing the patient organizations' network with the professionals
- Improved communications

A snapshot of PCAB's meeting in 2021.



# iCAN

### About iCAN

iCAN leverages the unique strengths that Finland has in the areas of top-level cancer research, health registries, biobanks and digital health to provide solutions for the global cancer challenge.

iCAN is one of the Academy of Finland national research and innovation flagships for 2019-2026. The founding hosts of the iCAN flagship are the University of Helsinki and HUS Helsinki University Hospital with a goal for national reach within the National Cancer Center FICAN.

[ican.fi](http://ican.fi)

## CONCLUSIONS

Patient involvement in research is beneficial for both parties

- Ensuring relevance of research with patient perspective!
- Strengthening the networks between professionals and patient advocates

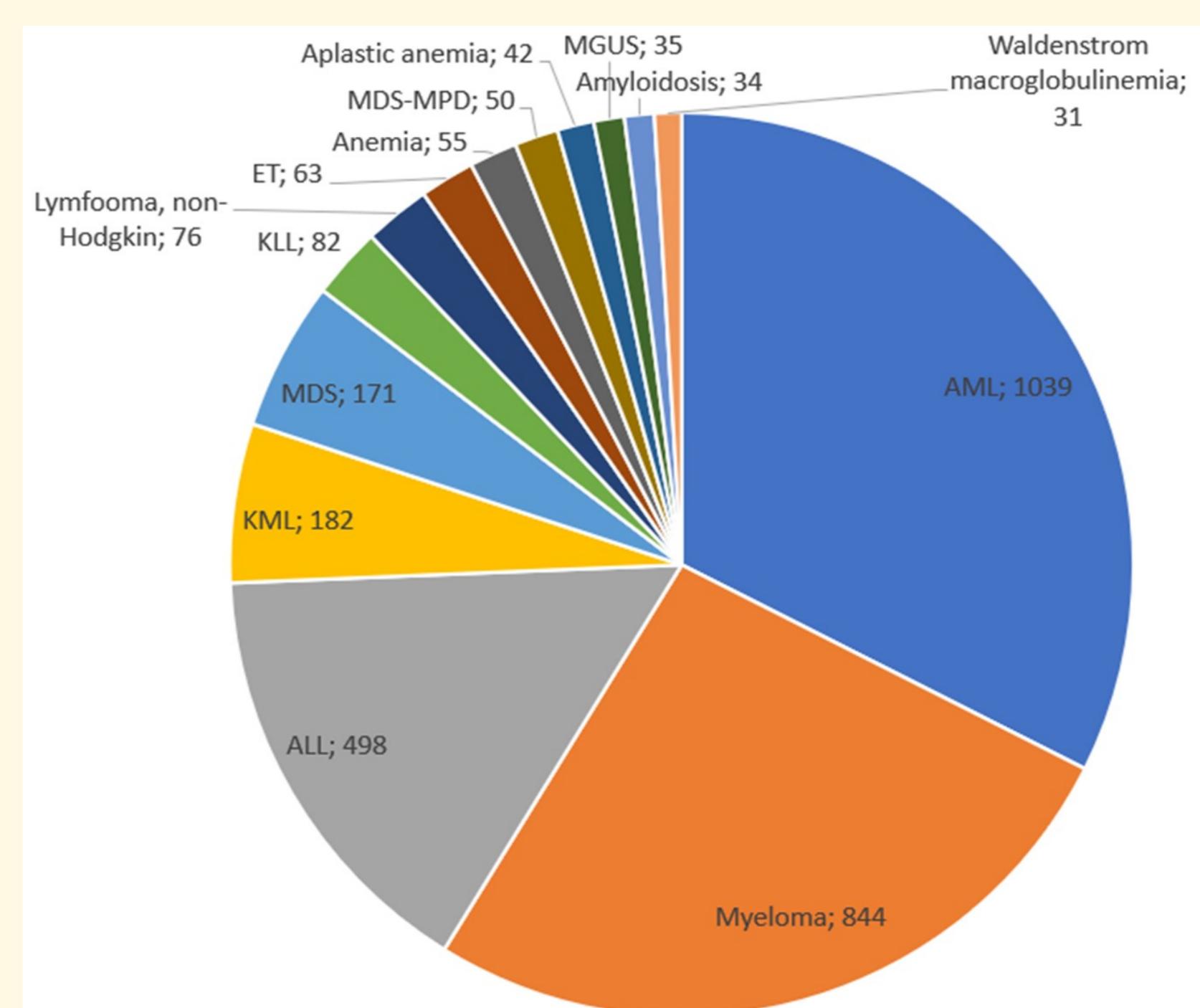
→ MPN patient advocates play a significant role in shaping the future of the Finnish healthcare by patient involvement in research and biobanks

## PATIENT INVOLVEMENT IN THE FINNISH HEMATOLOGY REGISTRY AND CLINICAL BIOBANK (FHRB)

Patients have been closely involved in the management of the FHRB since its establishment in 2014. The current chair of the Steering Group, Maria Buchert (MPN patient herself), represents the Association of Cancer Patients in Finland.

### RESULTS OF PATIENT INVOLVEMENT

- Improved communications and open data principle
- Collaboration between patient organization and biobank in lobbying



Collected samples in FHRB as of June 2022. 36% of the samples are in research use.



### About FHRB

FHRB is a national biobank that provides a representative resource of well-annotated, high quality blood and bone marrow samples coupled with wide clinical information in order to accelerate hematological research.

FHRB is owned by three partners: the Finnish Association of Haematology (FAH), the Institute for Molecular Medicine Finland (FIMM) and the Finnish Red Cross Blood Service (FRCBS).

[fhrb.fi](http://fhrb.fi)

We MPN patients do our best to help the healthcare.  
We still dream of a better future for ourselves being a  
small but noticeable group of patients.