



Patient Partnership, a Key to Precision Health

Speaker: Margareta Haag

Nordic Biobank Conference 2022

Conflict of interest

No known conflicts of interest.

Patient – and person

- Pre-cancer life
- ED International Professional Federation
- Cancer patient since 1994
- Lymphoedema
- Founder of Swedish Association of Chronic Oedema 1999
- President of the Swedish Network against Cancer 2018
- Impatient patient.... Experienced in governmental, national and international organizations, reference and research groups

The Swedish Network against Cancer

- Umbrella organization for cancer-profiled patient organizations
- Advocating for all cancer patients and next of kin
- Advocating for prevention and early diagnosis, precision health, a just and equal cancer care, individually designed cancer rehabilitation and strengthened patient rights
- Patients – a resource – partners

Patient involvement in healthcare – EU Standard

Minimum requirements for person-centered care: EU Standard EN 17398-2020

Four principles of person-centered care:

- Treat people with dignity, compassion and respect
- Provide coordinated care, support and treatment
- Offer personalised care, support and treatment
- Enable service users to recognise and develop their strengths and abilities, so they can live an independent and fulfilling life

Ref. Centre for Person-centered care, GPCC, Gothenburg University. <https://www.gu.se/en/gpcc>

Obstacles for Patient partnership

- EDUCATION! Health literacy for patients and professionals: Involving patients and professionals for a mutual understanding?
- Who takes responsibility for involving patients in innovation/research?
- Governance for precision health and data sharing - Equal care in 21 autonomous regions?
- Access to precision health: Prevention, diagnostics, treatment and quality of life?
- Clinical trials – 1 patient 1 trial – health care integrated with research – National register of clinical trials?
- Quality perspectives and measuring methods – what matters to the patient?

Patient engagement - partnership

- Meet the needs of the patients focusing on what really matters to patients
- Promote shared decision-, policy making and person-centered care
- Use digital health tools – technological solutions – health data platforms
- Promote patients and carers to engage in governance: in steering, strategic, ethical committees etc.

Successful patient partnership

- National governance, assessment and quality control: equal care
- Sharing data
- Updated measuring methods to measure what matters most to the patient
- Genuine collaboration together health care, research, patients, industry and decision makers
- Patient perspective benefits patients and the health care system

Patient partnership, a key to precision health

- Patient advocates – partners for innovation, health care structure and governance – improves efficiency and quality of care
- Design/implementation of clinical trials, research, clinical and ethical guideline development
- Legislation, data linking and sharing, health technology assessment and reimbursement
- Patients – a necessary partner for successful precision health!
- **Nothing about us, without us!**

Thank you!

Margareta Haag, margareta.haag@natverketmotcancer.se