Involve the patients and caregivers in innovation and implementation

Eskil Degsell
- Patient (asthma)
- Caregiver (wife diagnosed with a malign brain tumor -14)
- Chairman Swedish Brain Tumor Association
- Patient and Caregiver representative at Malign Brain Tumor Pathway at Karolinska University Hospital
- Associated to Regional Cancer Center Stockholm Gotland
- Associated to Karolinska Institutet, LIME, MMC, AIM
- Member at Vardanalys Patient Advocacy Council
High grade brain tumor
Focus on survival - but we also need to start to pay much more attention to other aspects, such as health-related quality of life.

We also need to change focus from providing healthcare – to co-creating health together with citizens/patients/informal caregivers. We should focus on creating a lifelong learning system on an individual and aggregated basis.
Research study presented at ASCO
Patients in the intervention group had significant longer survival (1 year survival 75% vs 49%) (median time survival 19 vs 12 months)
Research study presented at ASCO

The intervention group reported higher quality of life (average Eq5d score: 5.7, p <.001)
So what’s the problem?

• Partly wrong focus.
• Sometimes wrong view on all stakeholders who create health and health outcomes.

• Innovation is important but we sometimes tend to forget implementation part.
• New areas don’t have a clear mandate or role to take lead.

• Partly wrong measures.
• Lack of transparency.

• Lack of incentive to do research and development work.
• Lack of knowledge.

• Sometimes lack of curiosity and an ambition of lifelong learning
Who can help us fix some of the problems?

• Patients and the caregivers.
• Share data and create lifelong learning.
• Made and implemented by patients/caregivers for patients/caregivers.
• Co-create / co-implement with patients/caregiver not for patients/caregivers.
• More action research in close collaboration with patient organizations – health care professionals – and researchers.
• Research funding based on outcomes.

• But please: See patients and caregivers as equal partners and respect our knowledge – and don’t use us for political, lobby work for pharmaceutical industry or unions etc.
Some examples:

• "What matters"? A joint collaboration between several patient organizations.

• "Get to know me tool" A joint collaboration between several diagnosis pathways at Karolinska University Hospital, Regional Cancer Center Stockholm Gotland, Karolinska Institutet and Mayo Clinic.

• "Who cares" A joint collaboration between several diagnosis pathways at Karolinska University Hospital, Regional Cancer Center Stockholm Gotland, Karolinska Institutet.

• "Patient education in a new way" A joint collaboration between several diagnosis pathways at Karolinska University Hospital.

• "Selfcare" A joint collaboration between patient organizations, Regional Cancer Center Stockholm Gotland and Karolinska Institutet.

• "React and sometimes act" A joint collaboration between several diagnosis pathways at Karolinska University Hospital, Regional Cancer Center Stockholm Gotland.

• "Lead users" A project with several partners (Sara Riggare) and funded by Vinnova.

• "BISAM" A fantastic project with former patients working side by side with health care professionals in psychiatry in Stockholm County Council.
THANKS