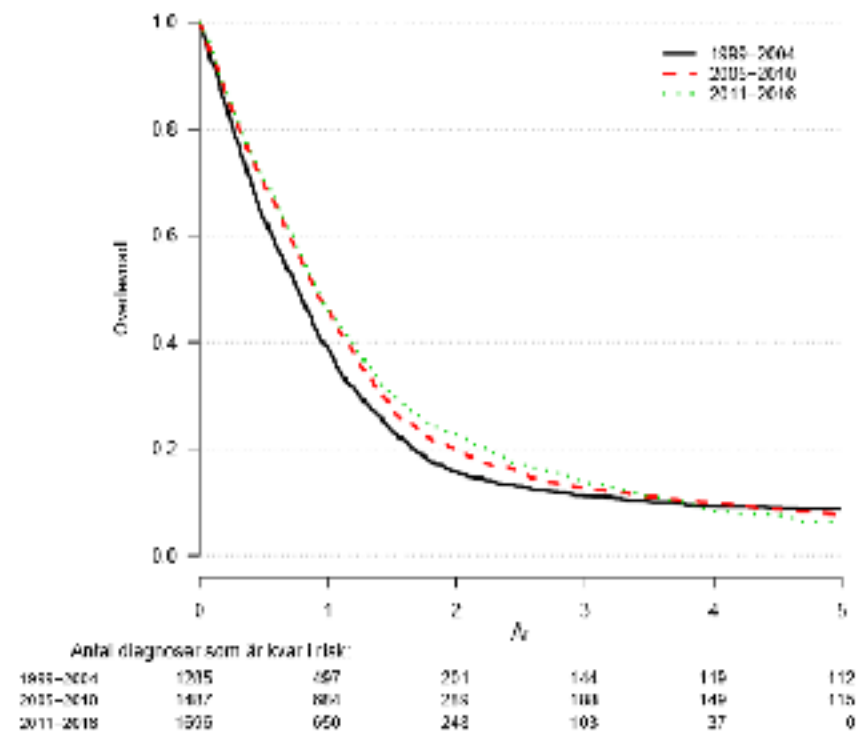


Involve the patients and caregivers in innovation and implementation

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 Vardanalyt Patient Advocacy Council

High grade brain tumor

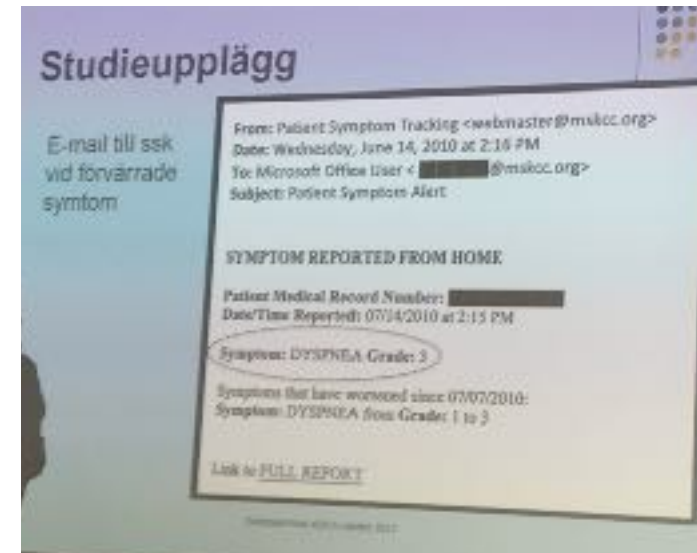
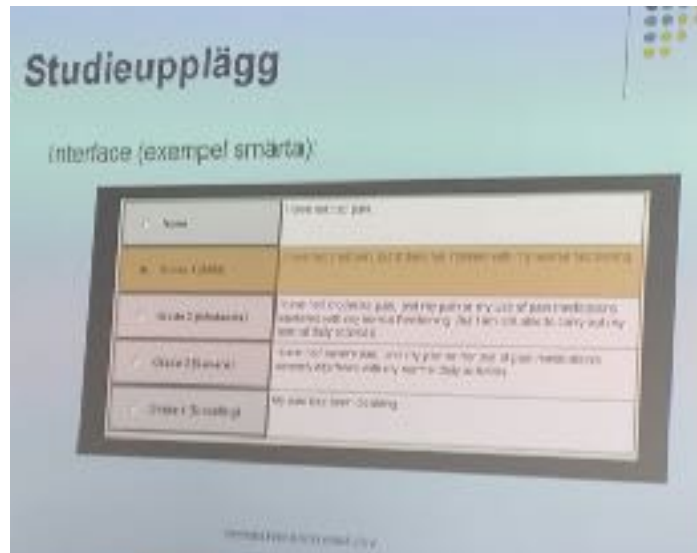


Figur 53. Överlevnad uppdelat på PAD-år. Högmaligna gliom. Endast data från Norra, Uppsala, Stockholm och Södrastra regionen.

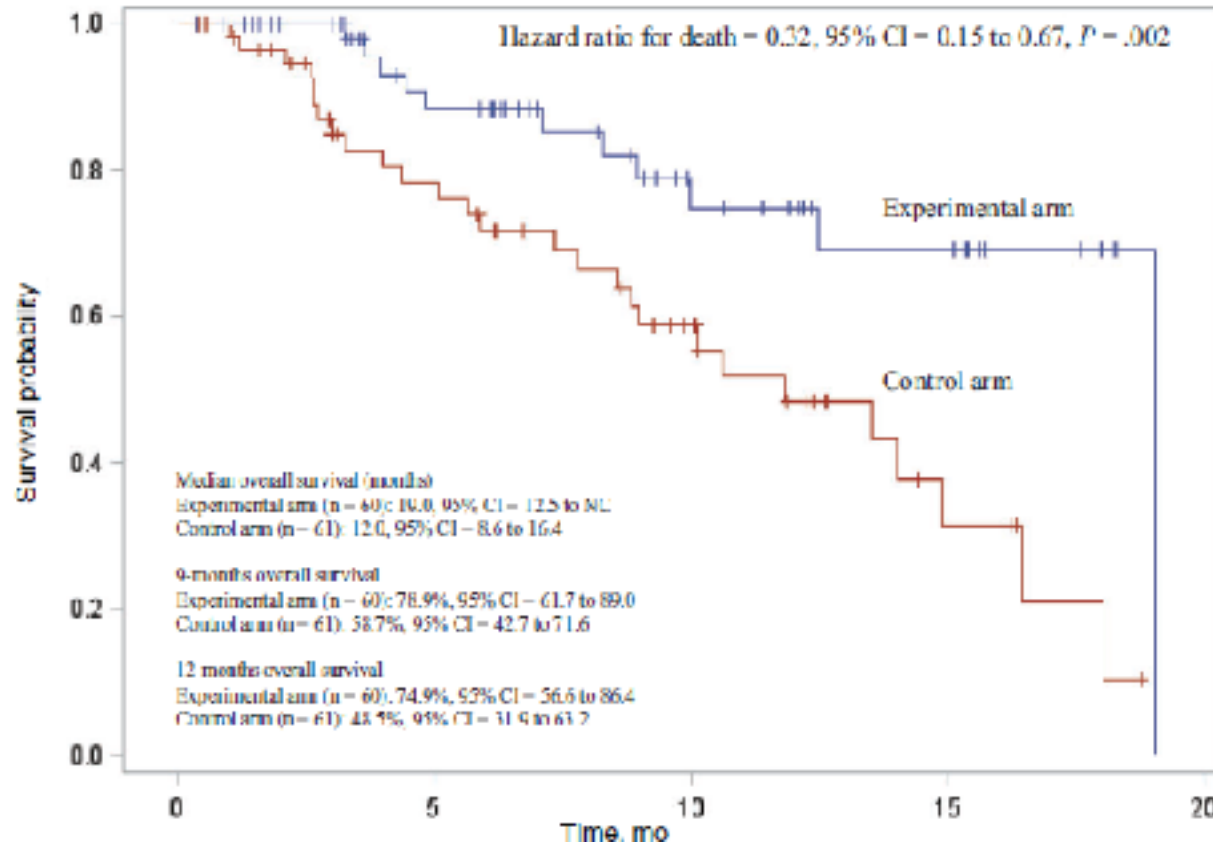
Focus on survival - but we also need to start to pay much more attention to other aspects, such as health-related quality of life.

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

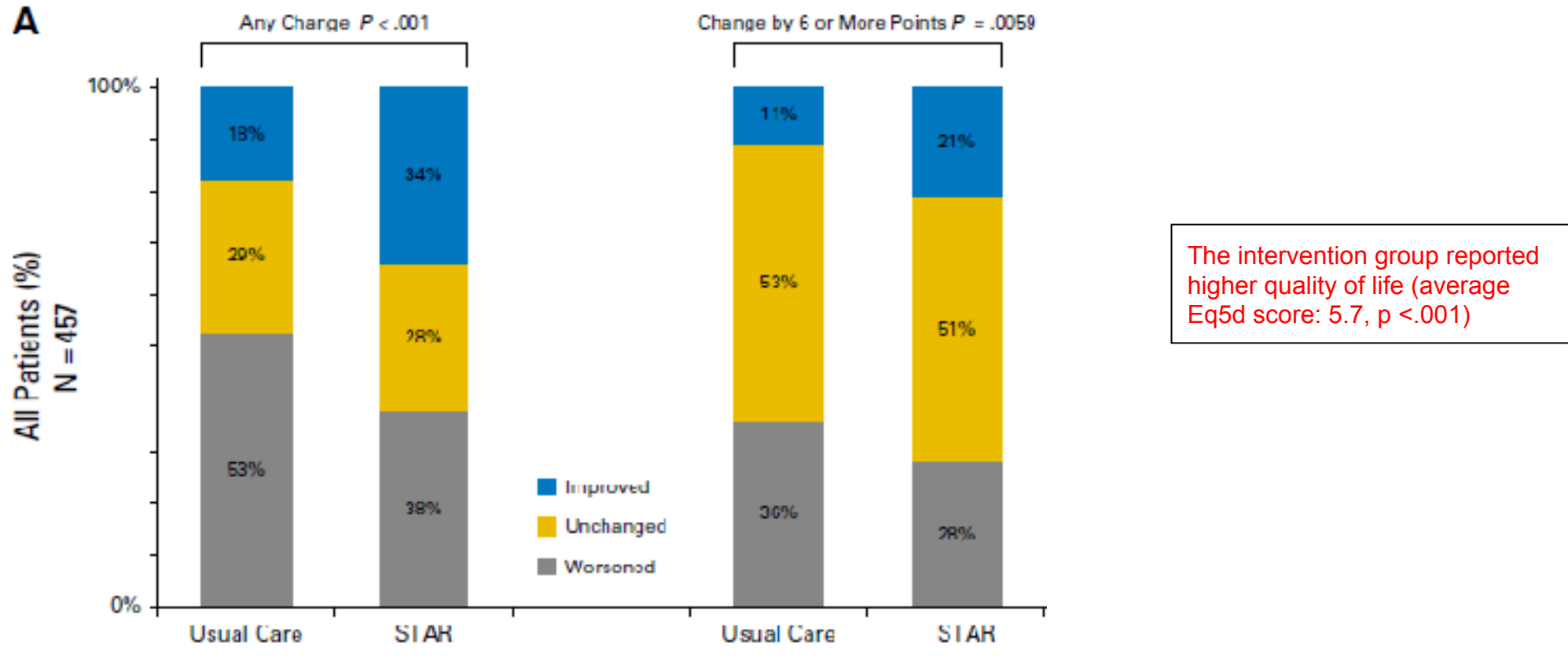


Research study presented at ASCO



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



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