

The Swedish Register of Palliative Care - experiences of gathering national data on quality of end-of-life care over the last 19 years

Staffan Lundström MD PhD

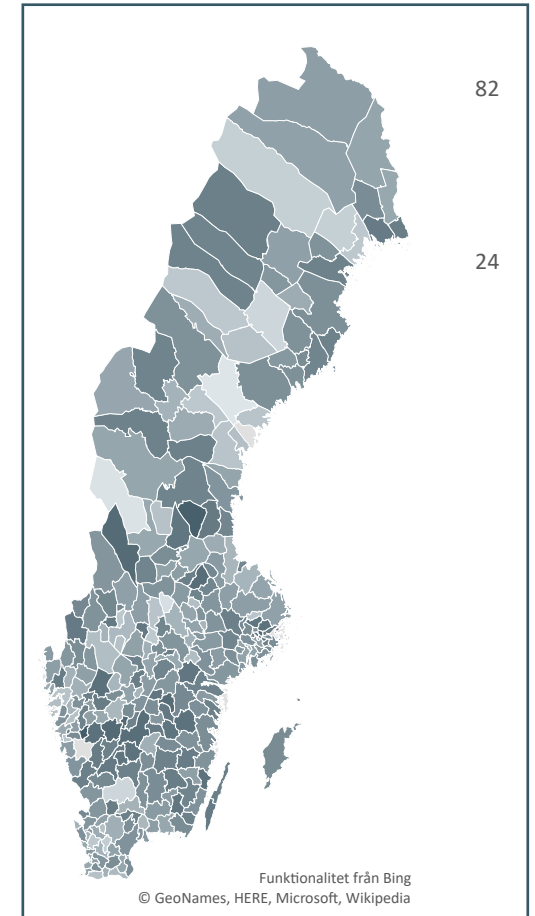
Associate Professor Karolinska Institutet
Research manager in The Swedish Register of
Palliative Care

This presentation

- About the register
- Working methods
- A selection of results
- Research

The Swedish Register of Palliative Care (SRPC)

- National quality register
- Established in 2005
- Financed by the Swedish Association of Local Authorities and Regions
- Used in all 21 regions and 290 municipalities



Aims



- To improve end-of-life care!
- All deaths (diagnosis, age, place of residence or care)
- Identify deficiencies in care
- Stimulate learning and improvement
- A basis for research
- Put pressure on decision-makers 😊

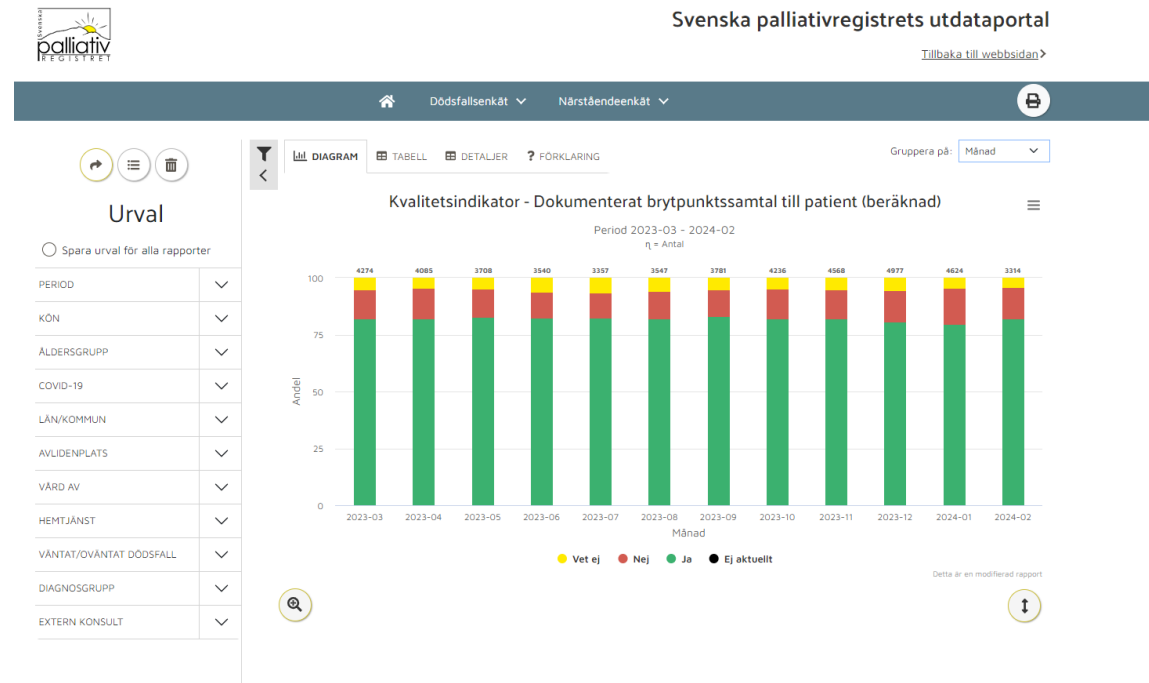
Methods

Collects data through two web-based questionnaires:

- End-of-life questionnaire
- Next of kin questionnaire

Online aggregated real time results

- Accessible to anyone
- Logged in users → data from own unit





End-of-life questionnaire



Quality of care during final week of life



27 questions completed by staff after death

Documented decision by physician
about end-of-life care?

Individual care plan?

Did the person receive information
about the transition to end-of-life
care?

Did the persons next of kin(s) receive
this information?

Pain and other symptoms assessed?

Breakthrough of any of the following symptoms at any
time during the last week of life?

- Pain
- Nausea
- Dyspnoea
- Anxiety
- Confusion
- Death rattle

Degree of symptom relief?

Was there an individual prescription
of injectable PRN drugs?

Pressure ulcers?

Assessment of oral health?

Parenteral fluids/nutrition?

Disease that caused the death?

Specialists outside the team/ward
consulted?

Preferred place of death?

Anyone present at the time of death?

Follow up for next of kin(s)?



Next of kin questionnaire

- Web based questionnaire, 21 questions
- Six languages
- Multiple choice and free text
- Compare experiences next of kin vs staff
- Tell their story
- Feedback to individual care units
- Public access online to aggregated data
- A tool for improvement

Did you feel that your loved one received good care?

Did you receive information from a physician who told you that your loved one was dying?

Do you have any suggestions for improved support?

Free comments.....

Did your loved one experience any of the symptoms?

Pain

Anxiety

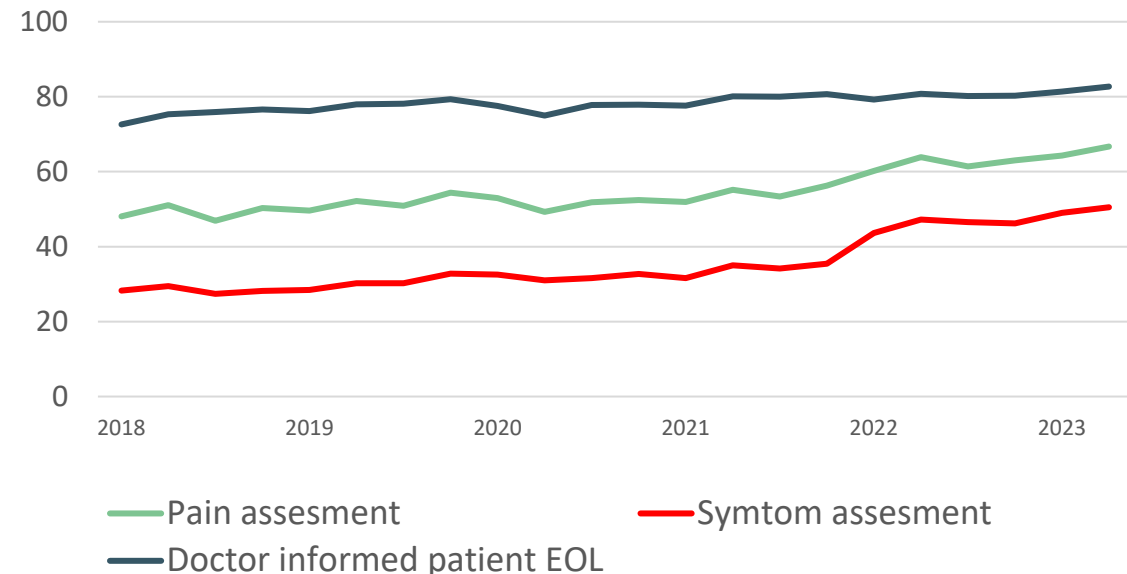
Confusion

Were you offered counselling after the death?

Anyone present at the time of death?

Results

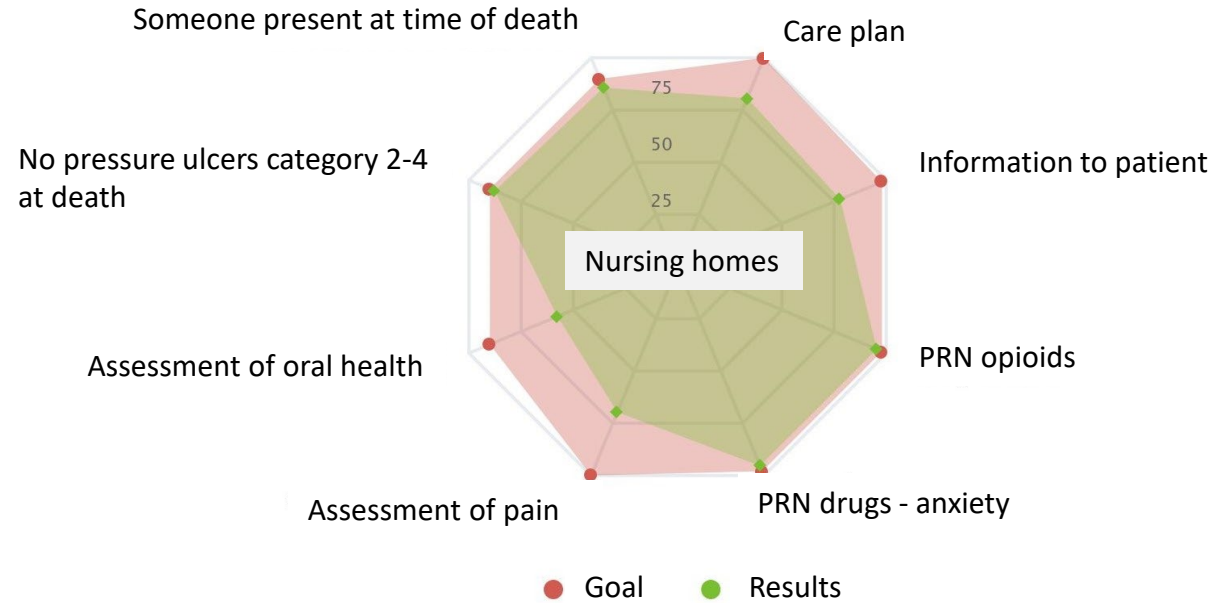
- 60 % of ALL deaths in Sweden are registered
- 36 116 physicians/nurses reporting from 5 595 care units
 - Majority reports within two weeks
- 860 000 registrations since 2005
- 60 published scientific articles since 2011
- Association with improved palliative care in Sweden



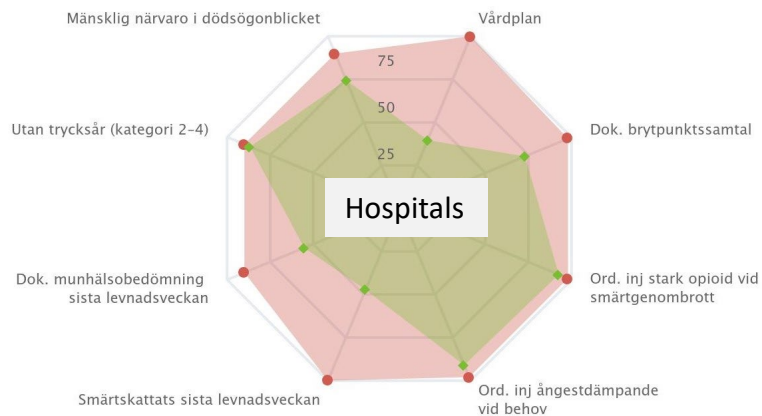
National quality indicators

Nursing home	n=22 910
Hospital	n=10 954
Spec pall.care	n=11 263

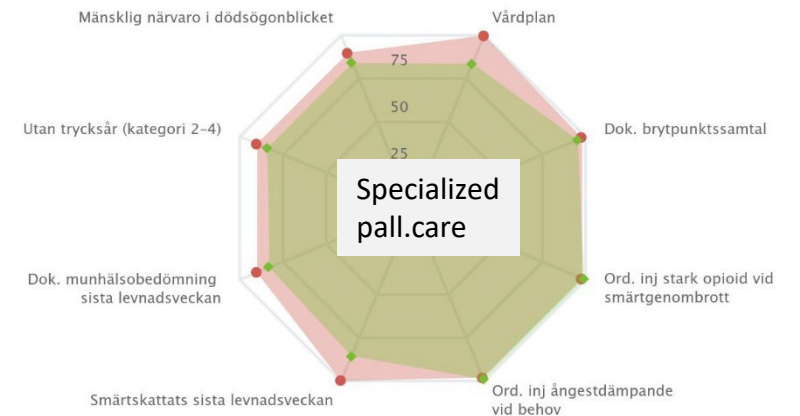
Period 2023-11 - 2024-10



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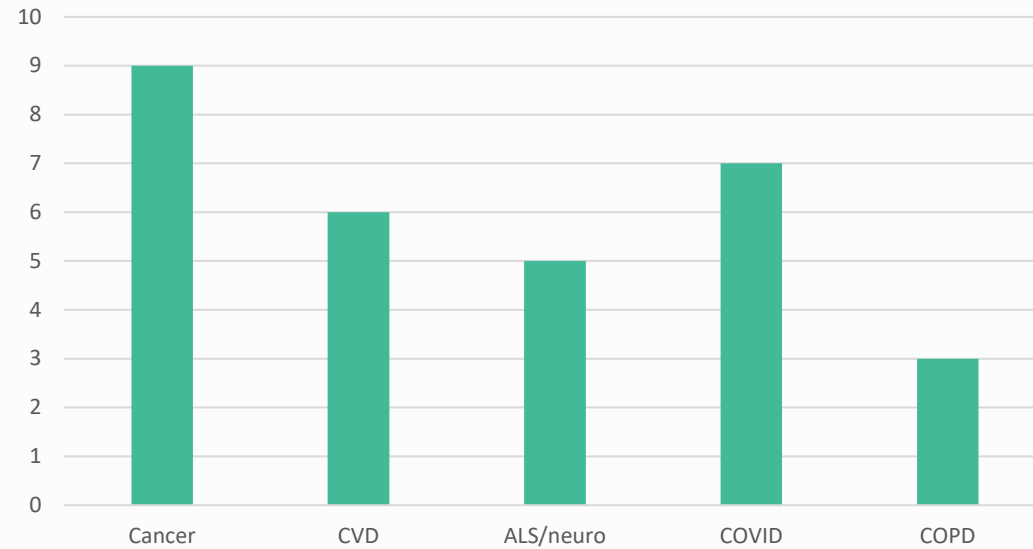


Research

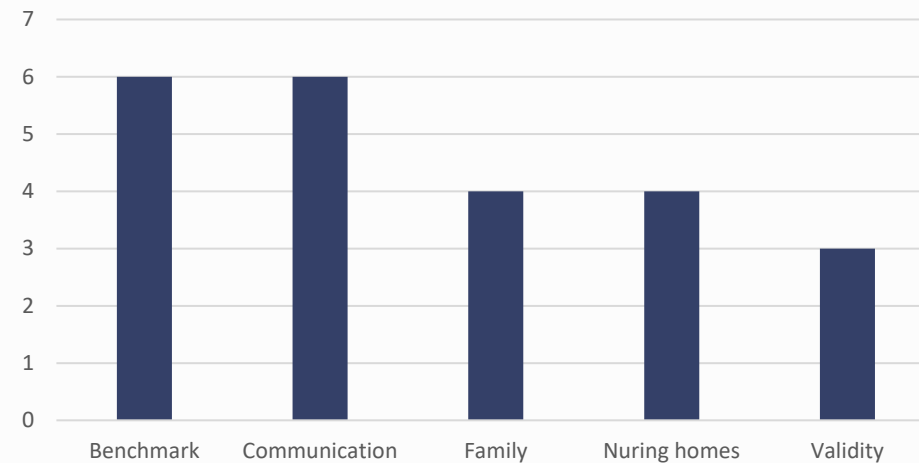
- 60 international peer-reviewed publications since 2011
- 1 doctoral thesis
- Research network
- Comparing quality of care and symptom occurrence between different diagnoses and care settings
- Research projects and quality assurance projects

Publications per diagnosis group and subject

Publications per disease group



Publications per subject



Process for data access

Available on the SRPC home page:

- Online form for applying for data access
 - Variable list
 - Description of the process for data access (inc. FAQ)
 - Publication list and list of student theses etc
 - English summary
 - Process from application to data delivery: 1 – 5 weeks
-
- www.palliativregistret.se

Upcoming...

- Add-on research questions to invited units
- Voluntary add-on questions quarterly
- Automated data retrieval from medical records
- Yearly questionnaire on structure- and process indicators to participating units
- Inspiring other countries



Conclusions

- The SRPC forms the basis for measurement of quality of end-of-life care in Sweden
- Improvements over the years
- Provides instant feedback to users
- Enormous amount of data just waiting for curious researchers... 😊



Improving end-of-life care on a national level
Is it possible?

YES!



Thank you!

www.palliativregistret.se