Palliativa veckan

2–8 november 2026

Med livet i centrum



Hur har Svenska palliativregistret bidragit till utveckling av palliativ vård?

Maria Andersson
Specialistsjuksköterska onkologi
Registerhållare Svenska palliativregistret

Svenska palliativregistret

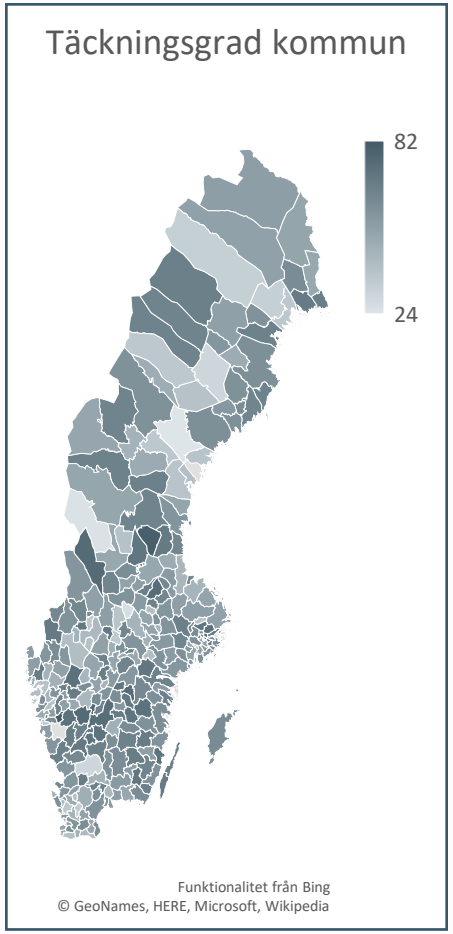
Nationellt kvalitetsregister 2005

ALLA diagnoser, åldrar, vårdformer

61 % av ALLA avlidna

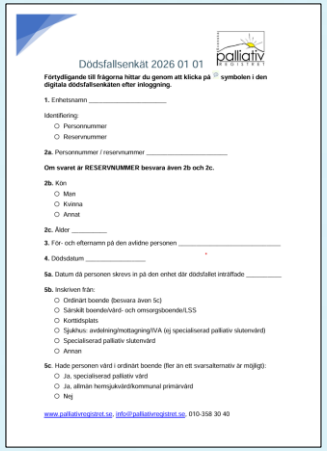
ALLA kommuner och regioner registrerar

Förbättra vården i livets slut för patienten och deras närstående



DÖDSFALLSENKÄT

- 27 frågor
- Vårdpersonal
- Efter död
- Online
- 3 månader



Dödsfallsenkät 2026 01 01

palliativ registret

Förtydligande till frågorna hittar du genom att klicka på ⓘ symbolen i den digitala dödsfallsenkäten efter inloggning.

1. Enhetsnamn _____

Identifiering:
- ○ Personnummer
- ○ Reservnummer

2a. Personnummer / reservnummer _____

Om svaret är RESERVNUMMER besvara även 2b och 2c.

2b. Kön
- ○ Man
- ○ Kvinna
- ○ Annat

2c. Ålder _____

3. För- och efternamn på den avlidne personen _____

4. Dödsdatum _____

5a. Datum då personen skrevs in på den enhet där dödsfallet inträffade _____

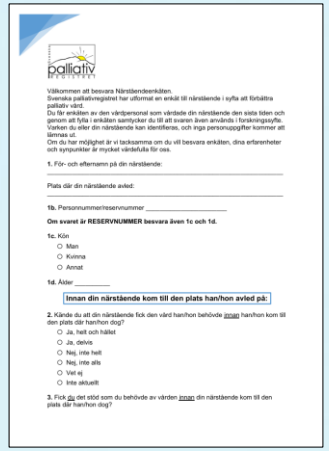
5b. Inskriven från:
- ○ Ordinärt boende (besvara även 5c)
- ○ Särskilt boende/vård- och omsorgsboende/LSS
- ○ Korttidsplats
- ○ Sjukhus: avdelning/mottagning/IVA (ej specialiserad palliativ slutenvård)
- ○ Specialiserad palliativ slutenvård
- ○ Annan

5c. Hade personen vård i ordinärt boende (fler än ett svarsalternativ är möjligt):
- ○ Ja, specialiserad palliativ vård
- ○ Ja, allmän hemsjukvård/kommunal primärvård
- ○ Nej

www.palliativregistret.se, info@palliativregistret.se, 010-358 30 40

NÄRSTÅENDEENKÄT

- 21 frågor
- Närstående
- Efter död
- Online
- Fritext
- 6 månader



palliativ registret

Välkommen att besvara Närståendeenkäten.
Svenska palliativregistret har utformat en enkät till närstående i syfte att förbättra palliativ vård.
Du får enkäten av den vårdpersonal som vårdade din närstående den sista tiden och genom att fylla i enkäten samtycker du till att svaren även används i forskningssyfte.
Varken du eller din närstående kan identifieras, och inga personuppgifter kommer att lämnas ut.
Om du har möjlighet är vi tacksamma om du vill besvara enkäten, dina erfarenheter och synpunkter är mycket värdefulla för oss.

1. För- och efternamn på din närstående:
_____

Plats där din närstående avled:
_____

1b. Personnummer/reservnummer _____

Om svaret är RESERVNUMMER besvara även 1c och 1d.

1c. Kön
- ○ Man
- ○ Kvinna
- ○ Annat

1d. Ålder _____

Innan din närstående kom till den plats han/hon avled på:

2. Kände du att din närstående fick den vård han/hon behövde innan han/hon kom till den plats där han/hon dog?
- ○ Ja, helt och hållet
- ○ Ja, delvis
- ○ Nej, inte helt
- ○ Nej, inte alls
- ○ Vet ej
- ○ Inte aktuellt

3. Fick du det stöd som du behövde av vården innan din närstående kom till den plats där han/hon dog?



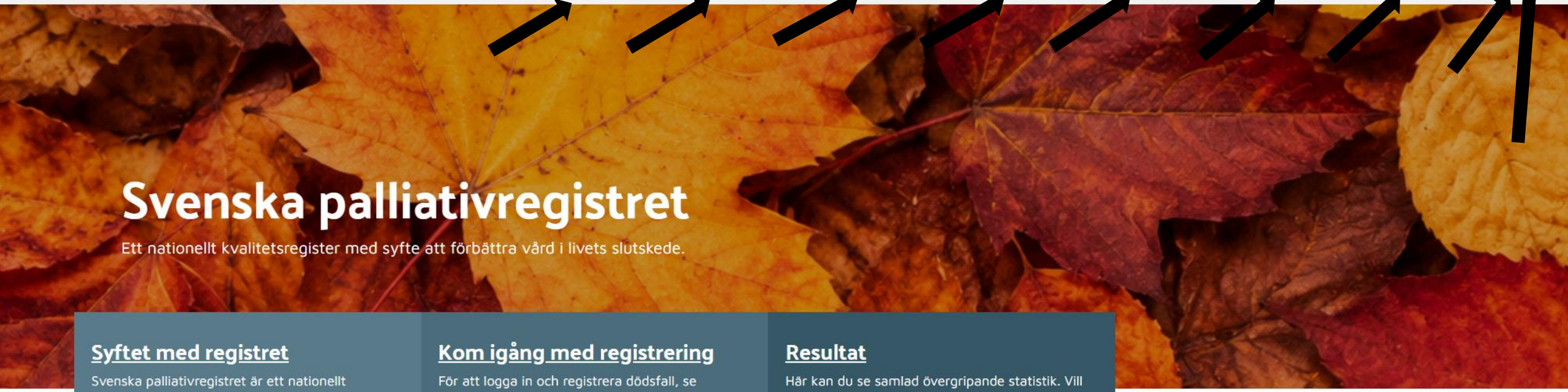







Från vård till ny kunskap





Svenska palliativregistret

Ett nationellt kvalitetsregister med syfte att förbättra vård i livets slutskede.

Syftet med registret

Svenska palliativregistret är ett nationellt kvalitetsregister. Syftet är att förbättra vården i livets slut för patienten och deras närstående. Detta inkluderar ALLA dödsfall oavsett diagnos, kön, ålder eller dödsplats. även oväntade dödsfall ska rapporteras in till oss. Vårdpersonal besvarar en enkät med cirka 25 frågor och dessa blir omedelbart till statistik som du hittar under Resultat. Där tar vi hänsyn till om dödsfallet var oväntat och du kan själv göra urval på dessa för att se vad ni eventuellt hunnit åstadkomma även för dessa personer.

Kom igång med registrering

För att logga in och registrera dödsfall, se enhetsstatistik och skapa närståendeenkäter krävs säker inloggning via SITHS kort. Första gången du loggar in i det nya systemet behöver du markera den/de enheter du önskar tillgång till. Godkänn GDPR. Ni som administrerar personal i registret kommer inte längre behöva göra detta.

Resultat

Här kan du se samlad övergripande statistik. Vill du se din enhets resultat behöver du logga in med ditt SITHS-kort. Samtliga rapporter från och med 1 januari 2022 visar de väntade dödsfallen. Vill du bara se de oväntade eller båda behöver du göra ett urval under tratten och markera ditt val under Oväntat/Väntat dödsfall. Instruktioner hittar du via länken Instruktion Resultat nedan.

BESTÄLL MATERIAL

UTBILDNINGAR

INSTRUKTION RESULTAT

Välkommen Maria Andersson!

- Meddelanden från kansliet

Kvartalets fråga

Kvartalets sista fråga för i år blir samtal vid allvarlig sjukdom. Ni får upp den som en extra fråga from 1/10 och den besvaras av alla enheter oavsett dödsplats. Den finns även för utskrift på hemsidan under Vårdpersonal och Kvartalets fråga.
(Visas fram till 2027-01-31)

Av Susanna Sjöqvist

Årsrapport 2025

Nu finns årsrapporten för 2025 på hemsidan, både under Nyheter och under Arkiv/Årsrapporter. Spännande läsning.
(Visas fram till 2026-11-30)

Av Susanna Sjöqvist

Barnfrågor

Barnfrågorna kommer fortsatt komma ,,, tom 31/1 2027
(Visas fram till 2027-01-31)

Av Susanna Sjöqvist

- Att göra

- Dödsfallsenkäter
- Närståendeenkäter

- Fritextsvar från närståendeenkäten

Här går det att hämta en PDF med de fritextsvar som närstående har lämnat i närståendeenkäten.
Välj ett intervall på minst tre månader.

Startdatum: 2026-07-28

Slutdatum: 2026-10-28

Intervallet måste vara minst 3 månader och måste ha minst 2 svar under perioden för att en PDF med svaren ska visas.

Hämta PDF

Svenska palliativ REGISTRET

Din enhet: Mönsterås OB

Maria Andersson

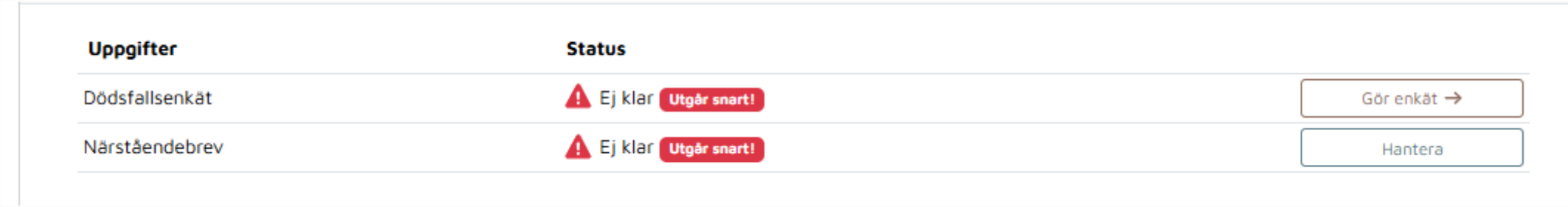
Start Dödsfall Sök Patient Enhetsenkät Utdata

NY ANMÄLAN

Sök namn/personnummer

Visa avslutade mellan datum 2026-09-04 2026-11-02

	Namn	Personnummer	När skedde dödsfallet	Uppgifter	
			Dödsfall: **9 dagar sedan**	3/3	
			Dödsfall: **16 dagar sedan**	4/4	
			Dödsfall: **20 dagar sedan**	3/3	
			Dödsfall: **39 dagar sedan**	6/6	
			Dödsfall: **47 dagar sedan**	0/2	


Uppgifter
Status
Dödsfallsenkät
Ej klar
Utgår snart!
Gör enkät →
Närståendebrev
Ej klar
Utgår snart!
Hantera

Närståendeenkät

Skapa unika brevet

Lämna inloggningsuppgifter

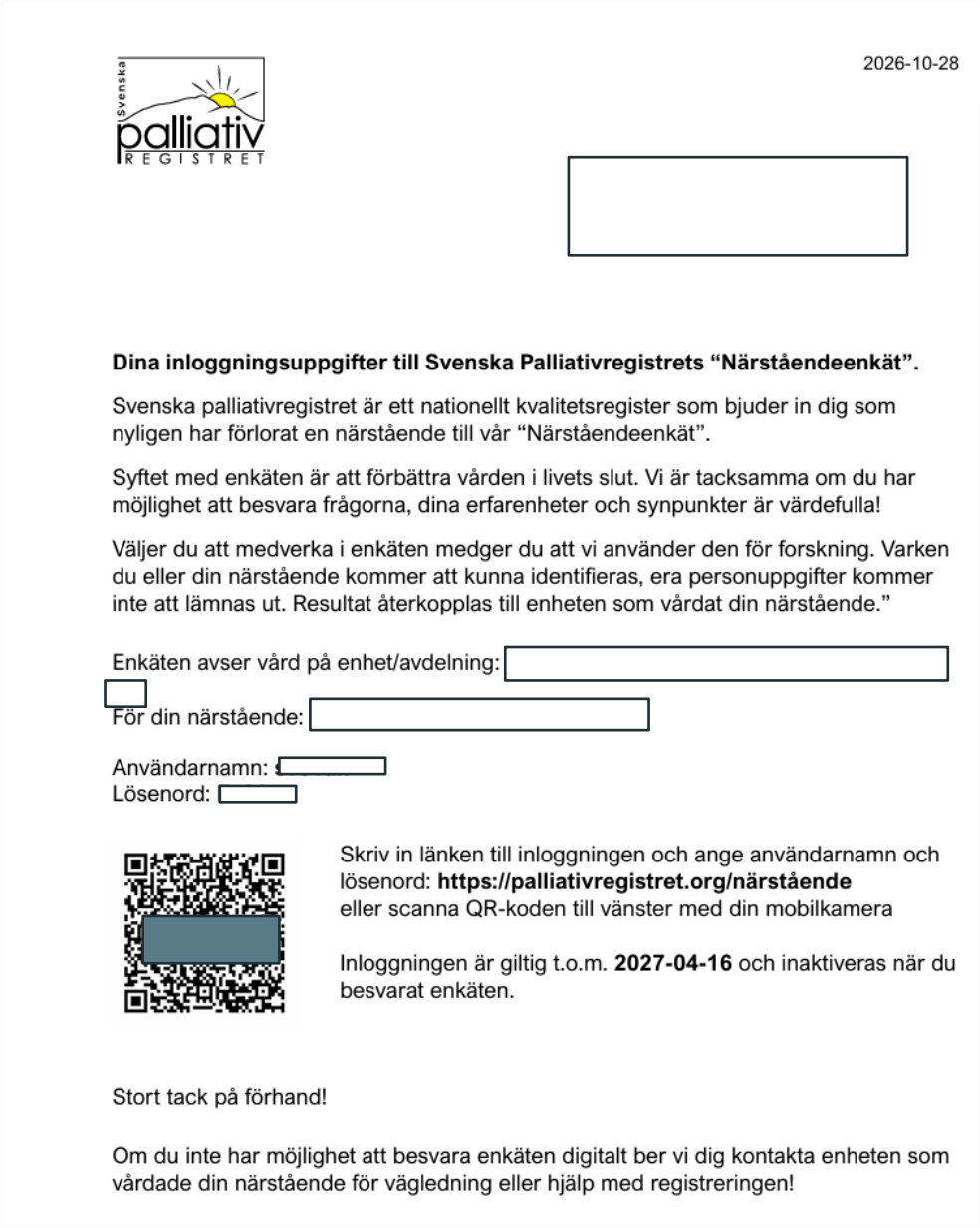
6 månader

Återkoppling till personal

Förbättringsarbete

Jämföra med er själva och hela riket

VI sammanställer resultat ☺



2026-10-28

Dina inloggningsuppgifter till Svenska Palliativregistrets "Närståendeenkät".

Svenska palliativregistret är ett nationellt kvalitetsregister som bjuder in dig som nyligen har förlorat en närstående till vår "Närståendeenkät".

Syftet med enkäten är att förbättra vården i livets slut. Vi är tacksamma om du har möjlighet att besvara frågorna, dina erfarenheter och synpunkter är värdefulla!

Väljer du att medverka i enkäten medger du att vi använder den för forskning. Varken du eller din närstående kommer att kunna identifieras, era personuppgifter kommer inte att lämnas ut. Resultat återkopplas till enheten som vårdat din närstående."

Enkäten avser vård på enhet/avdelning:

För din närstående:

Användarnamn:
Lösenord:

Skriv in länken till inloggningen och ange användarnamn och lösenord: **https://palliativregistret.org/närstående**
eller scanna QR-koden till vänster med din mobilkamera

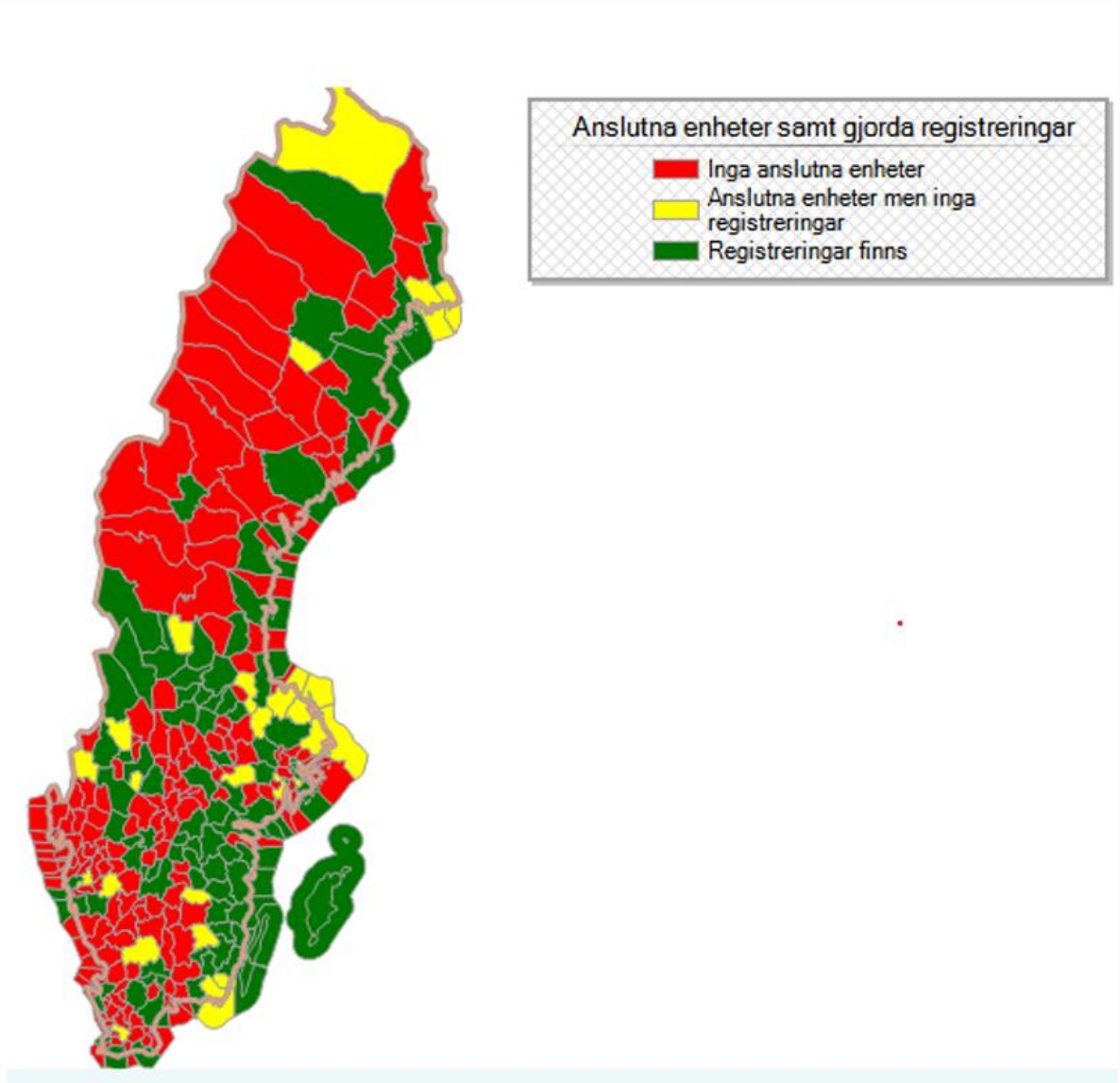
Inloggningen är giltig t.o.m. **2027-04-16** och inaktiveras när du besvarat enkäten.

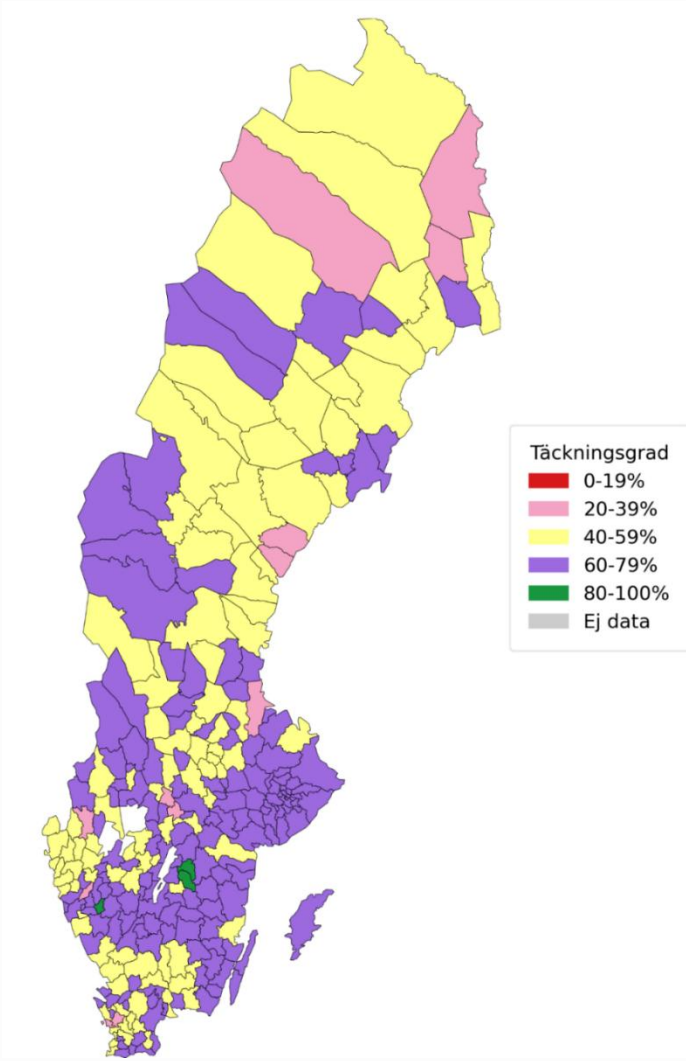
Stort tack på förhand!

Om du inte har möjlighet att besvara enkäten digitalt ber vi dig kontakta enheten som vårdade din närstående för vägledning eller hjälp med registreringen!

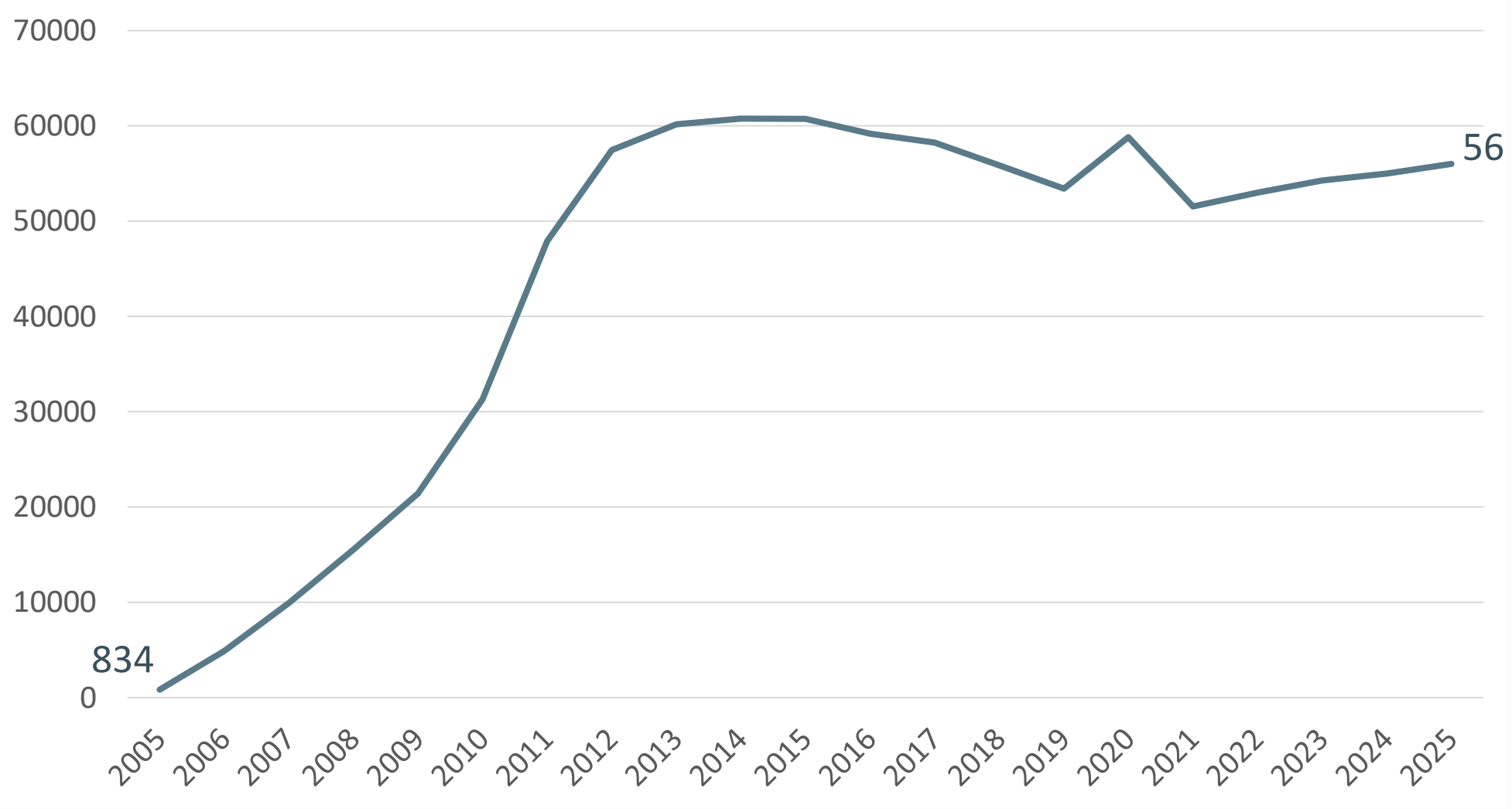
HAR Svenska palliativregistret bidragit till utveckling av palliativ vård?

Täckningsgrad per kommun 2006-2025

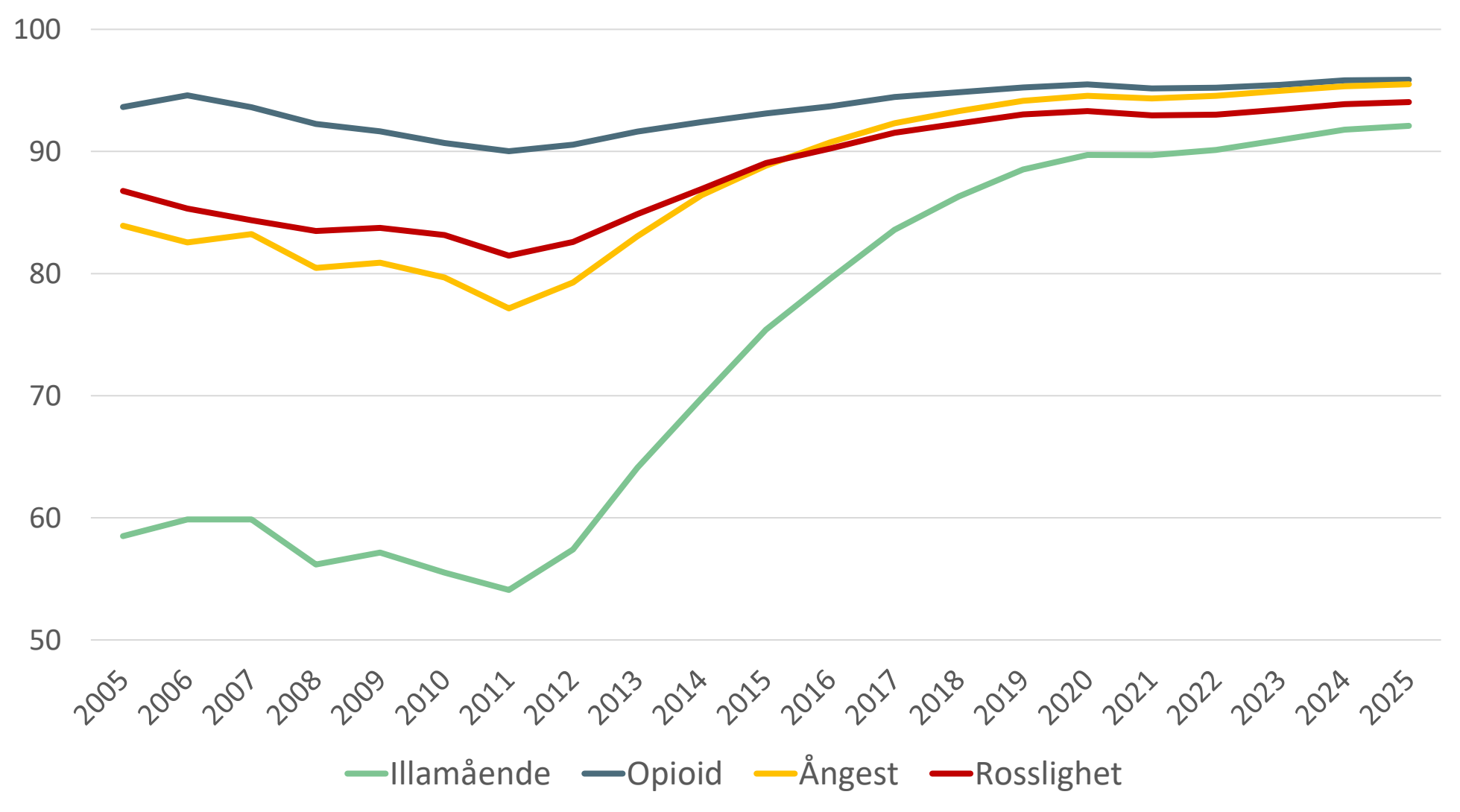




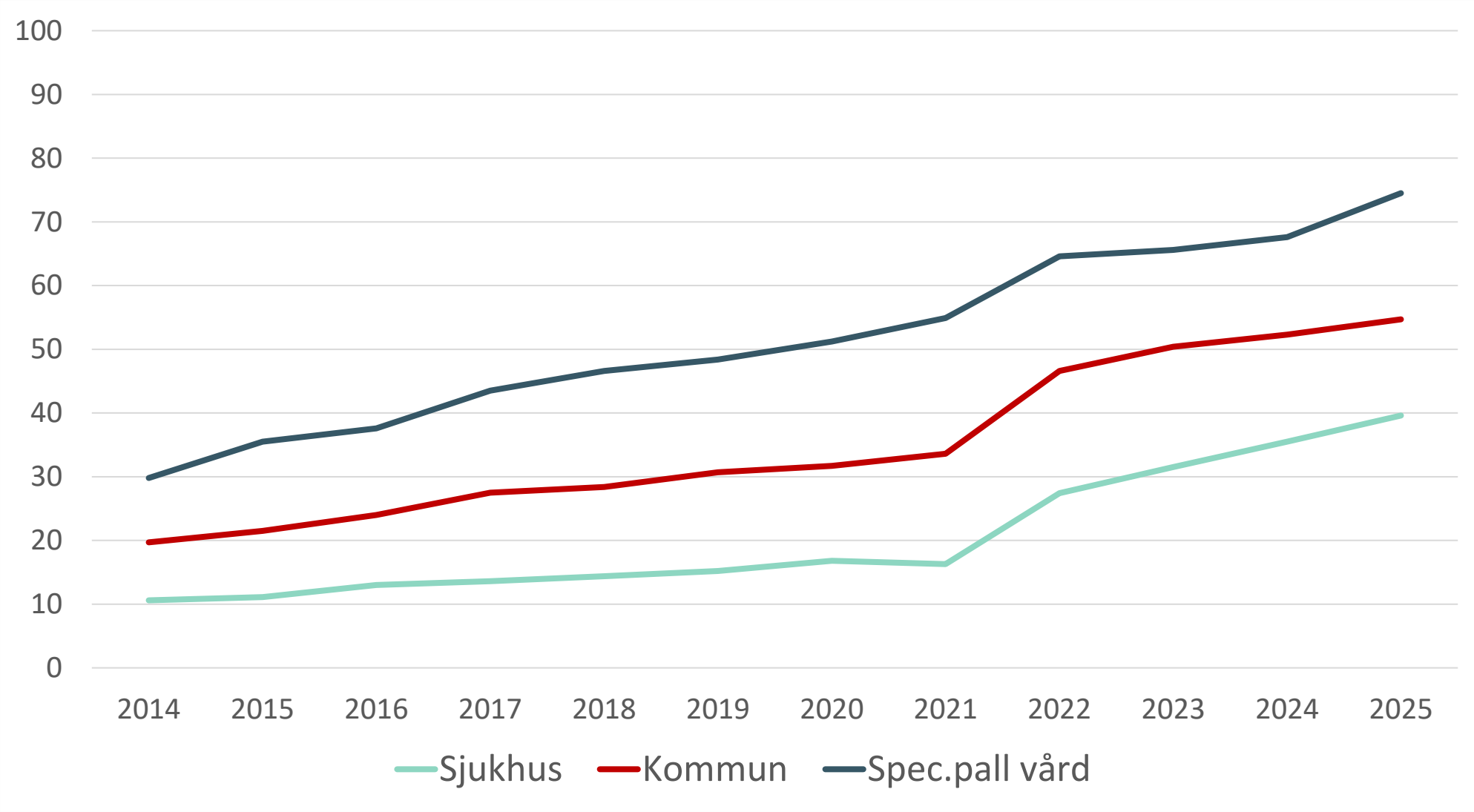
Antal Alla


70000
60000
50000
40000
30000
20000
10000
0
834
56 013
2005
2006
2007
2008
2009
2010
2011
2012
2013
2014
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2016
2017
2018
2019
2020
2021
2022
2023
2024
2025

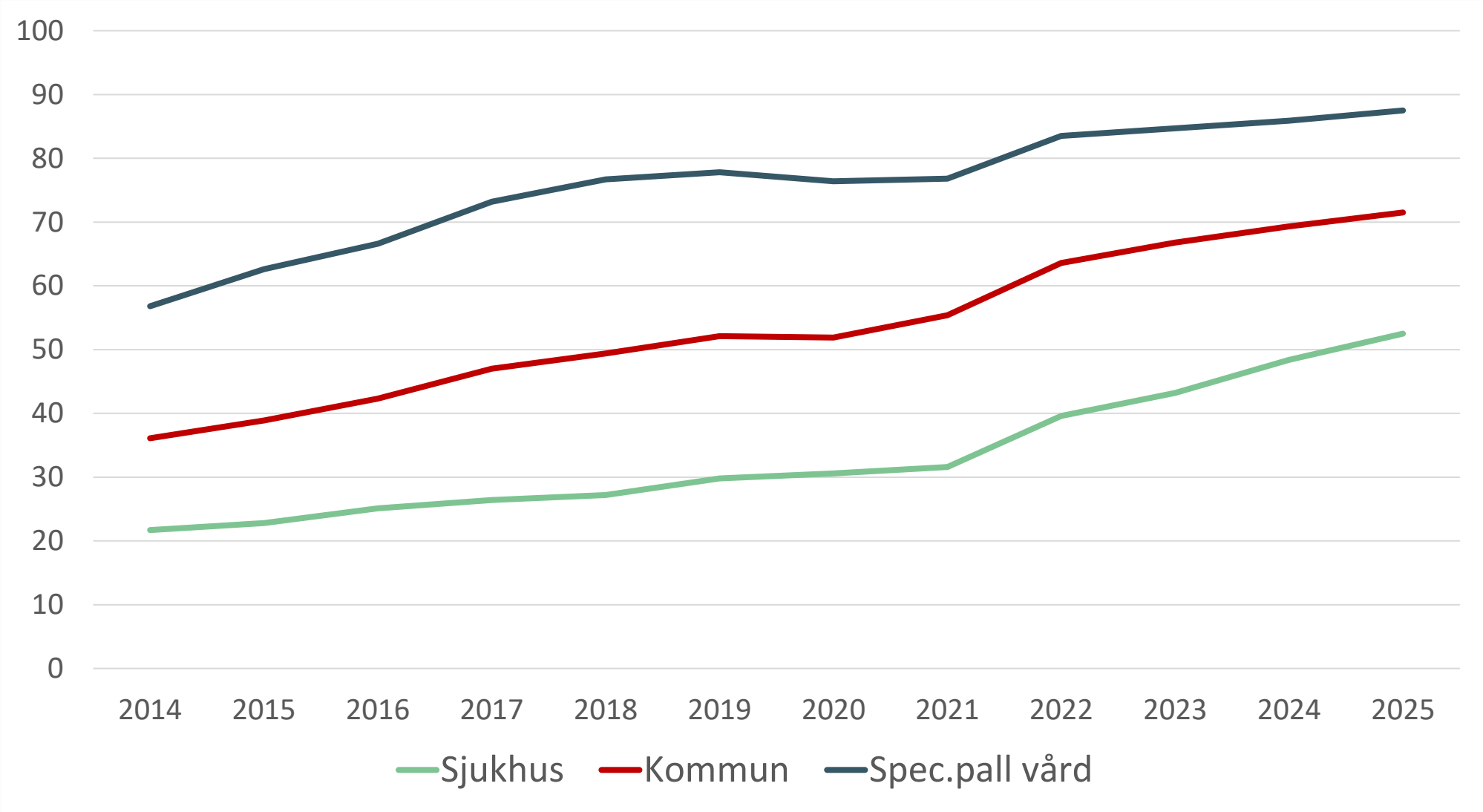
Vid behovs ordination Väntade dödsfall



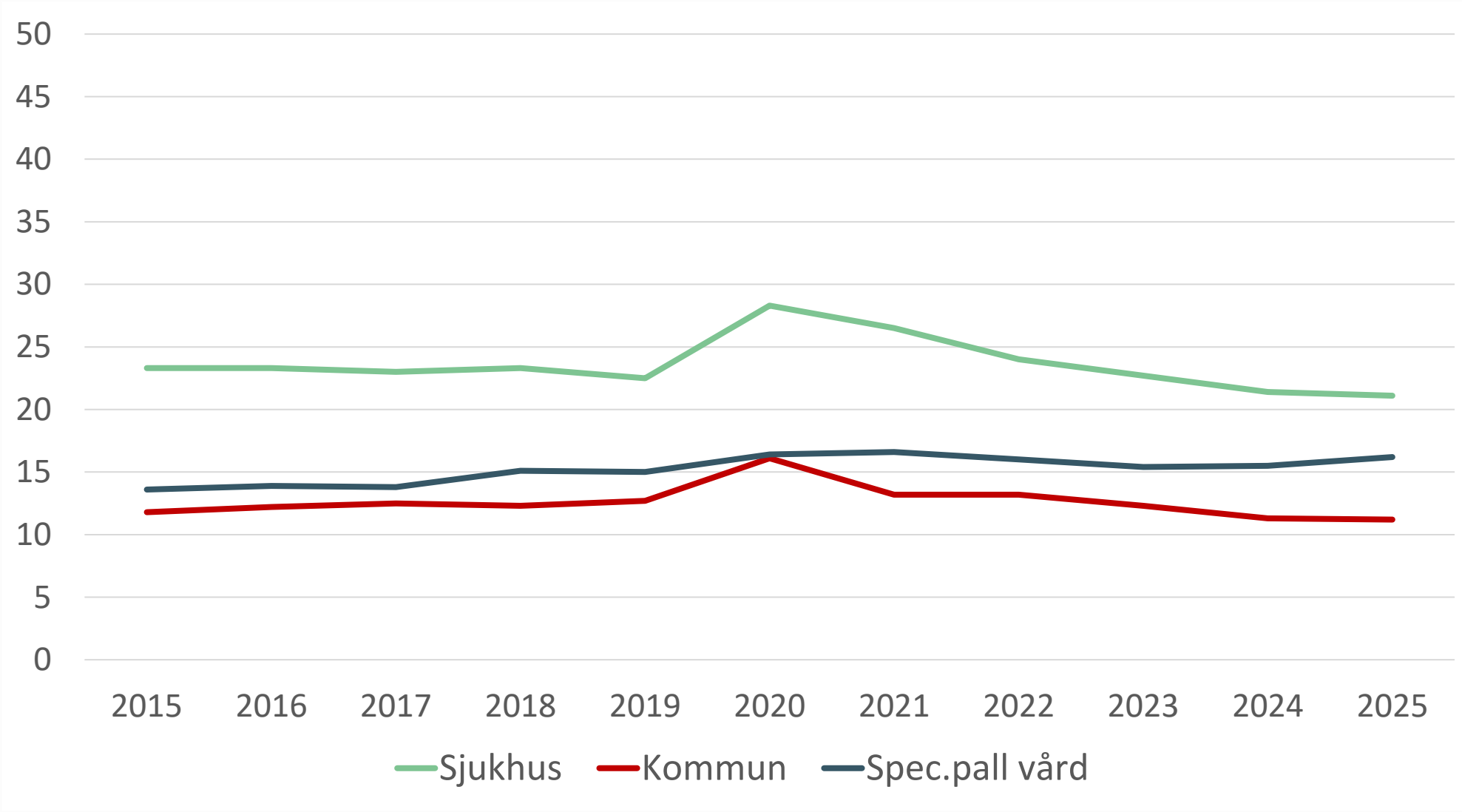
Symtomskattning Väntade dödsfall

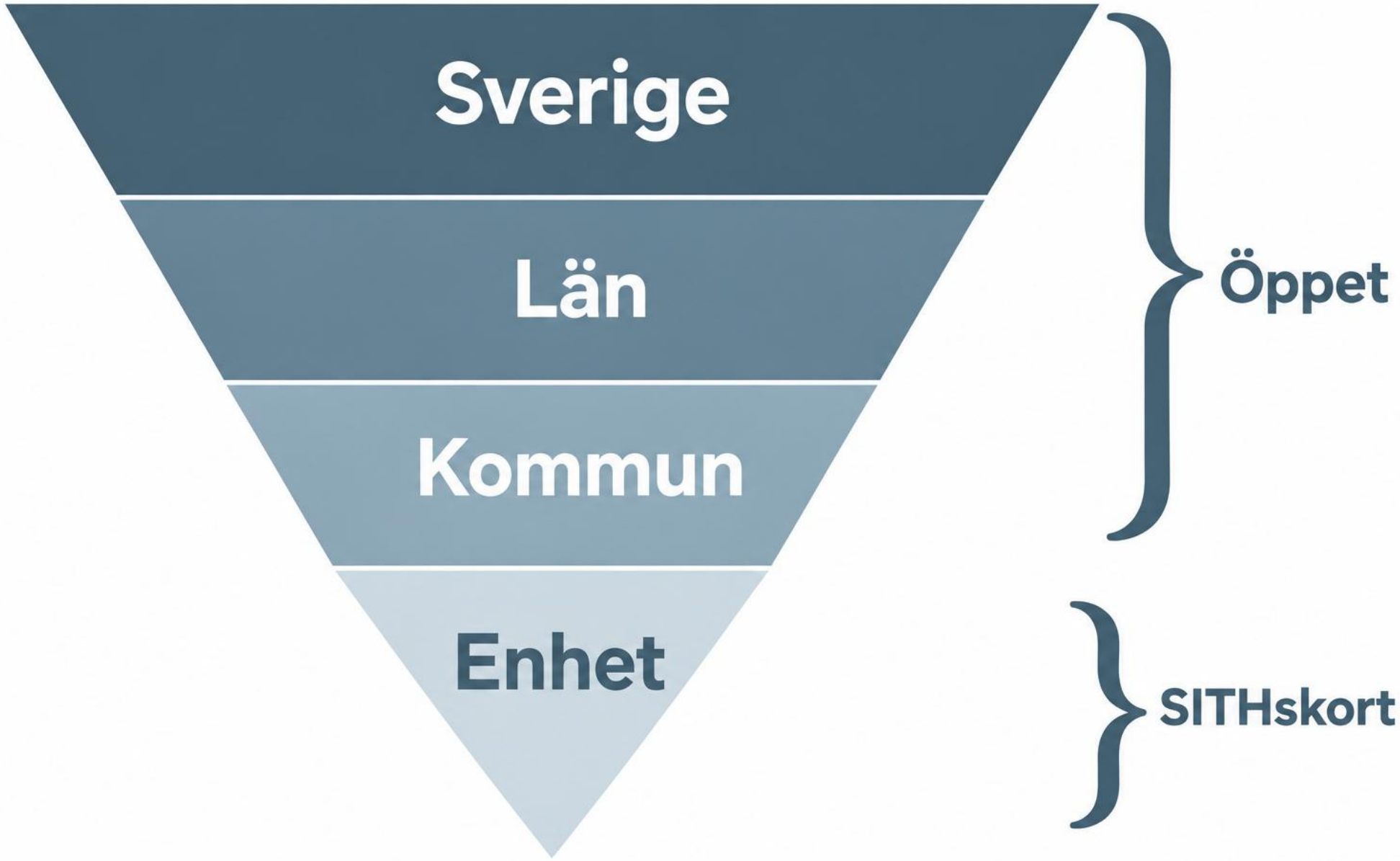


Smärtskattning Väntade dödsfall



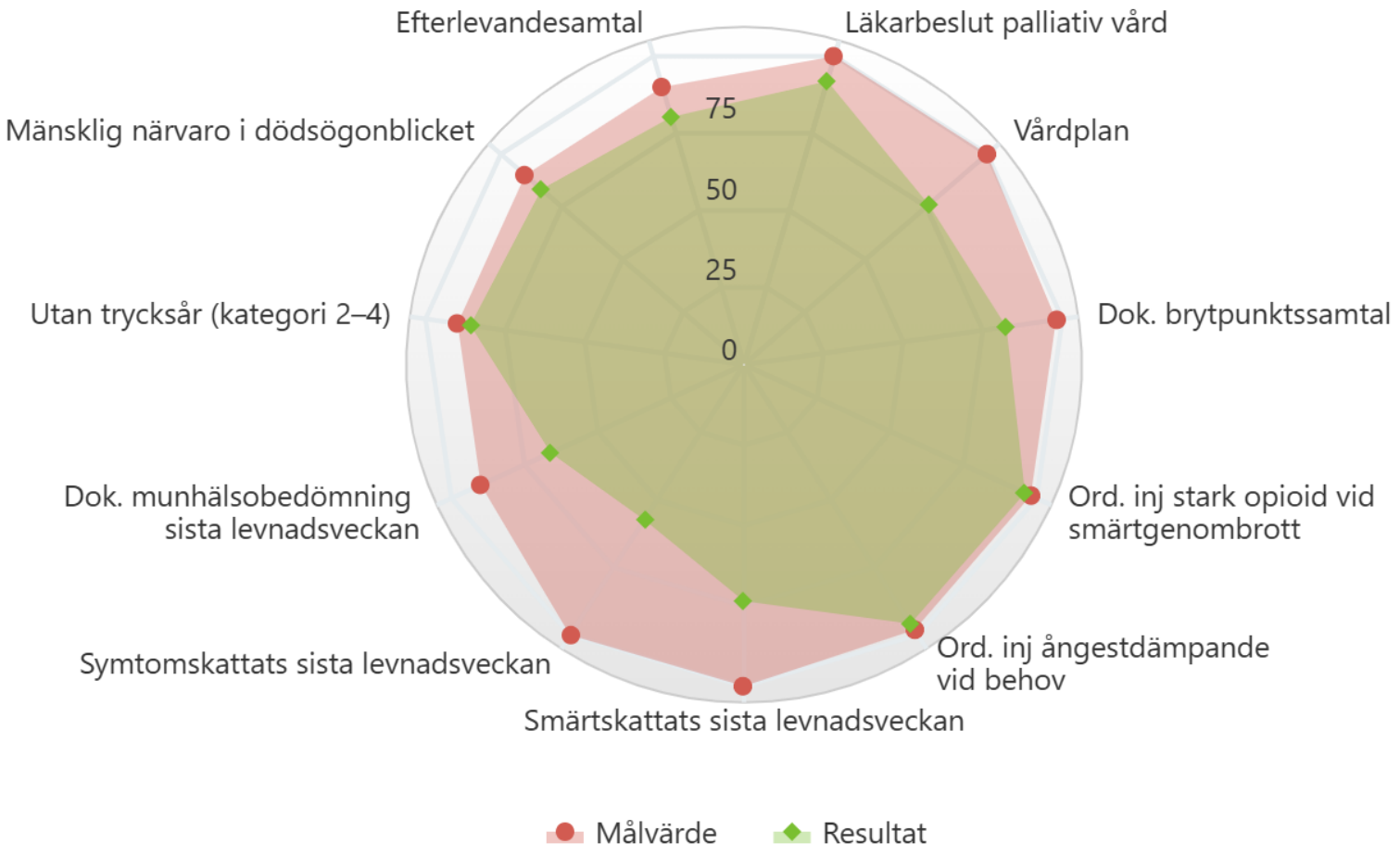
Ingen närvarande Väntade dödsfall




Sverige
Län
Kommun
Enhet
Öppet
SITHskort

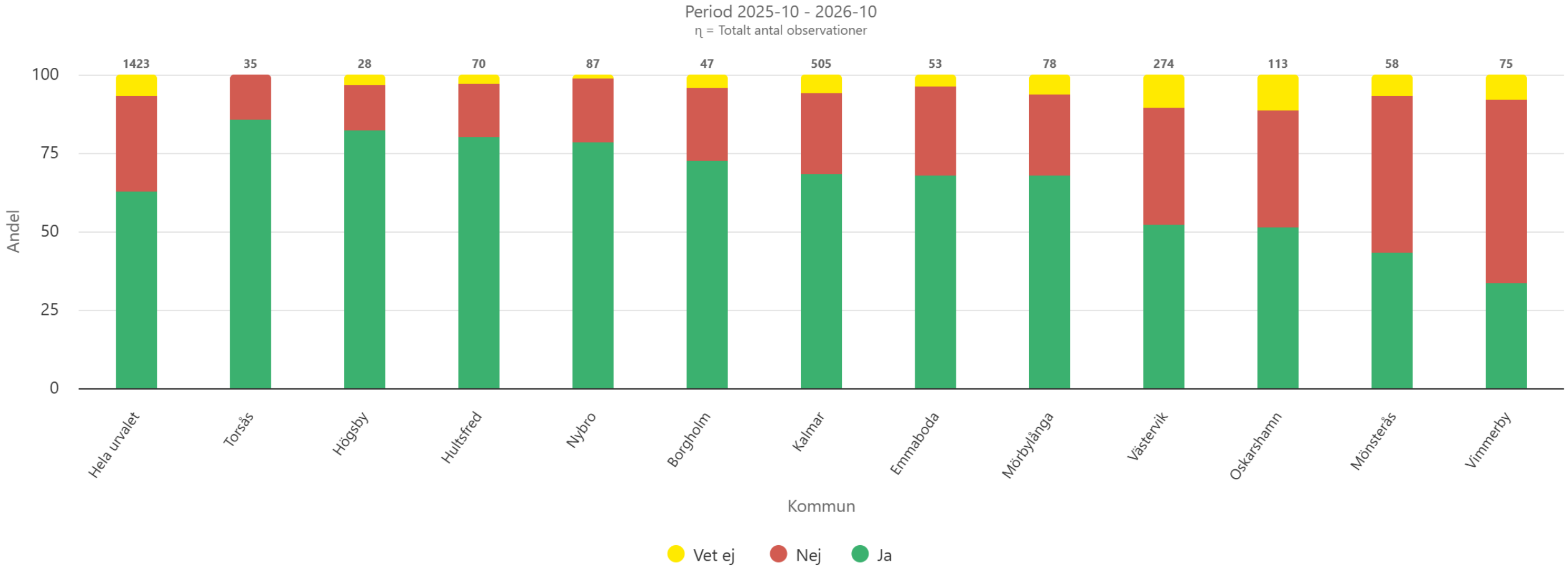
Spindeldiagram över kvalitetsindikatorer

Period 2025-11 - 2026-10



Län

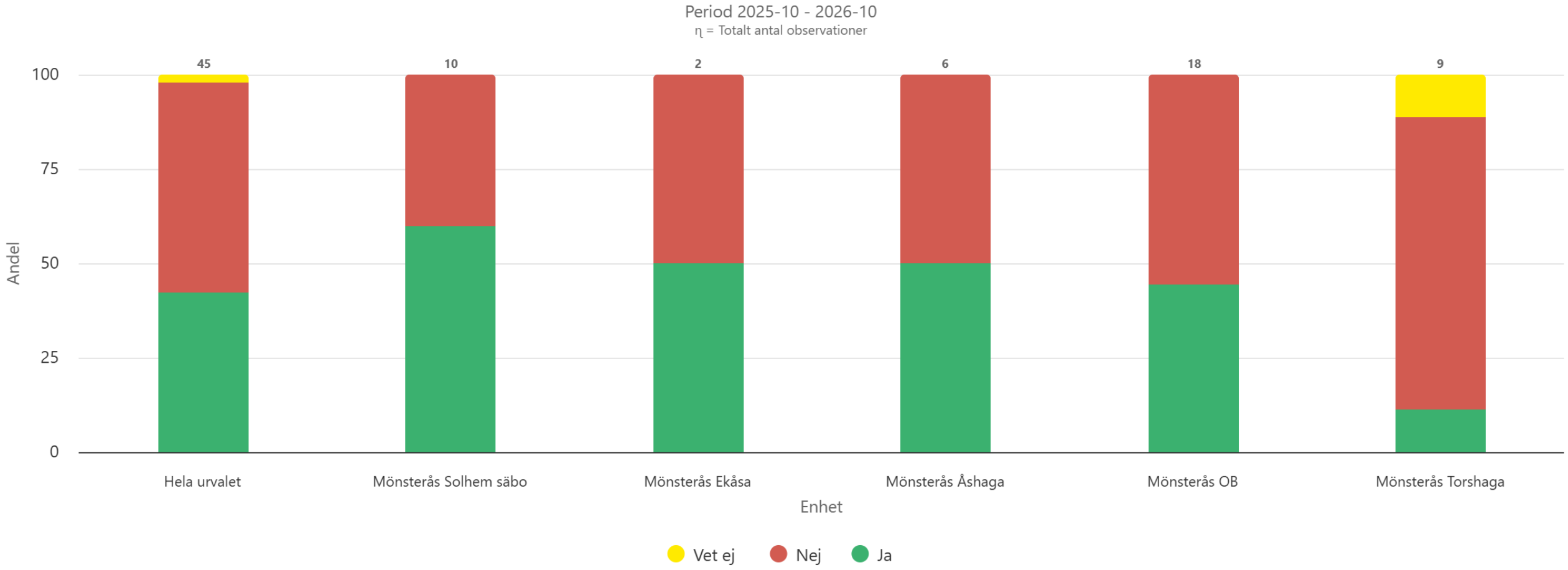
Dokumenterad munhälsobedömning sista levnadsveckan



Detta är en modifierad rapport

Kommun

Dokumenterad munhälsobedömning sista levnadsveckan



Detta är en modifierad rapport

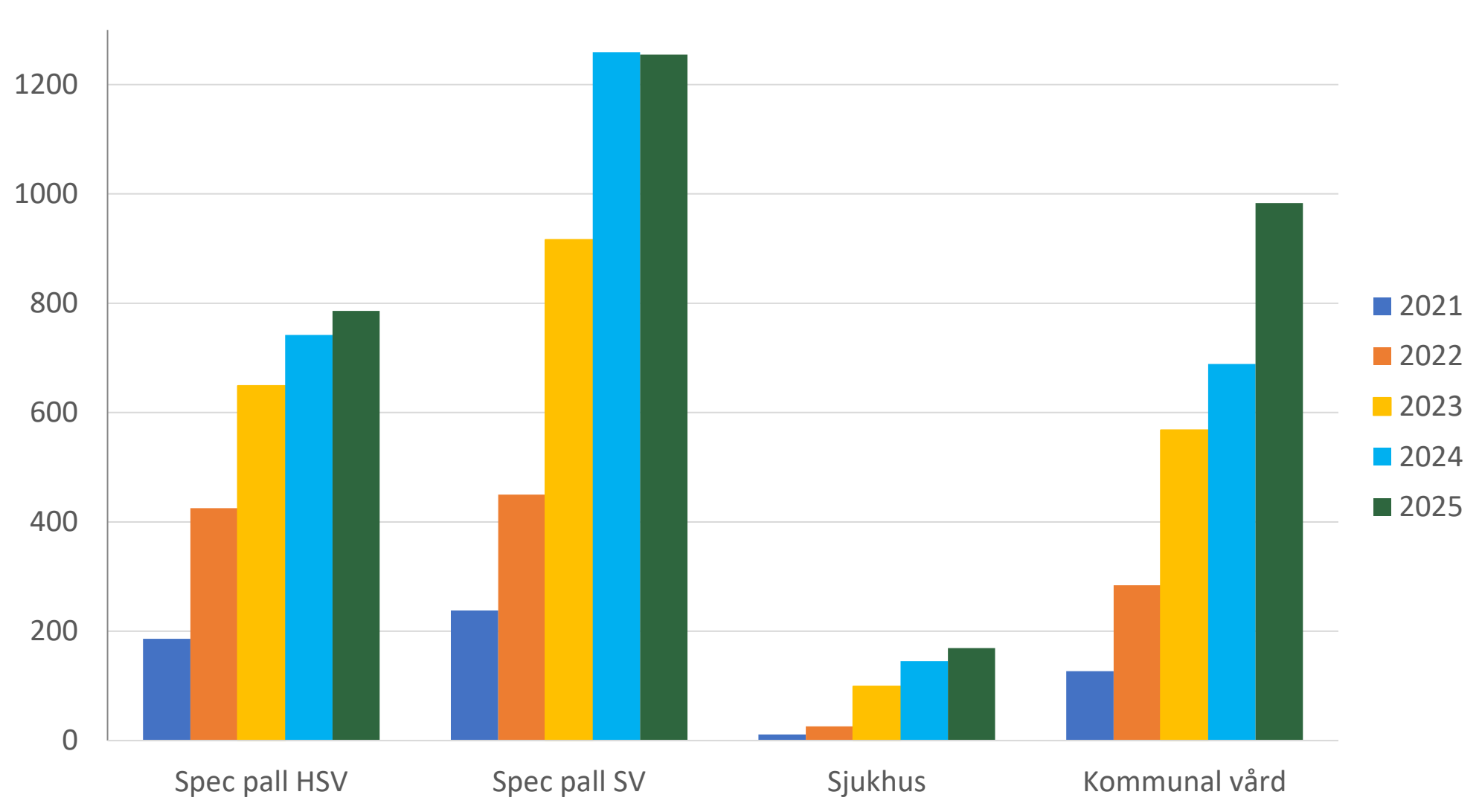
Ordinärt boende

Dokumenterad munhälsobedömning sista levnadsveckan

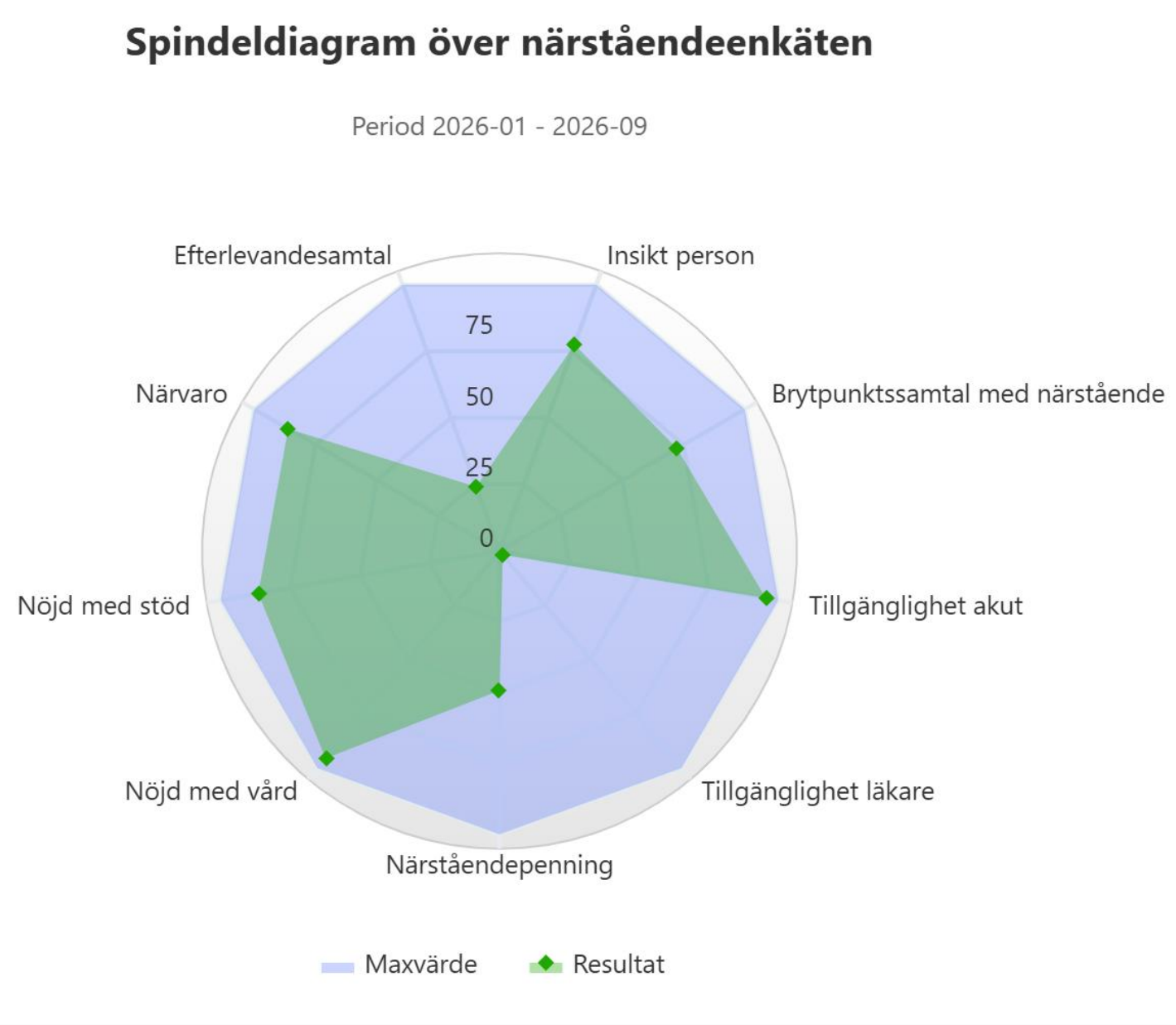


Detta är en modifierad rapport

Antal besvarade enkäter Alla



Sverige Alla



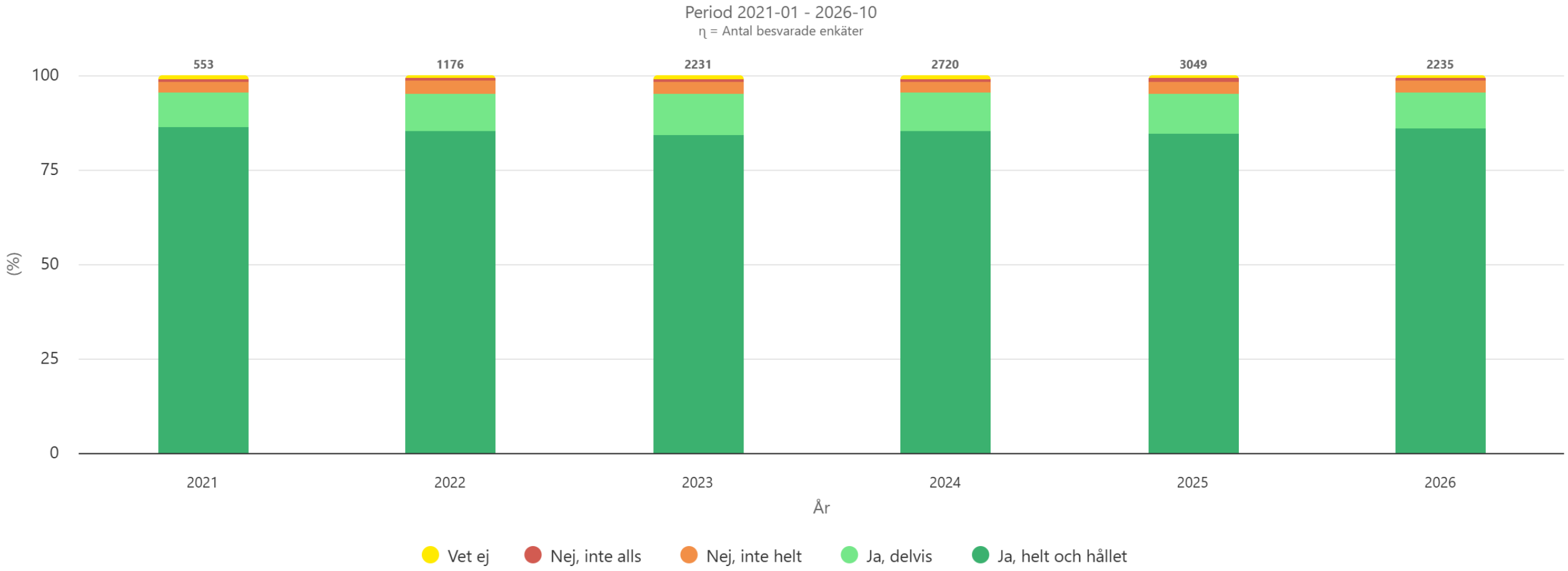
Erbjudande av eftersamtal till närstående

Period 2021-01 - 2026-10
η = Antal besvarade enkäter



Detta är en modifierad rapport

Nöjd med vård vid dödsplats



Detta är en modifierad rapport

Nöjd med stöd vid dödsplats



Detta är en modifierad rapport

”Information om vad jag som anhörig kan förvänta mig av hur döden kan te sig . Orolighet, färgskiftning rosslighet mm. Info om hur tätt man kan ge lugnan[illegible]nhörig vakar behövs det tydlighet i dett[illegible]

Information

”Bätt[illegible]re info om o[illegible]att att hantera det praktiska efter ett dödsfall, inte bara en reklamfolder från begravningsbyråerna.”



”Ett bokat samtal med anhöriga när patienten anländer och täta uppföljningssamtal så länge det behövs. Behöver inte nödvändigtvis vara en läkare.”

”Skulle önskat at[illegible]e med att prata om död[illegible] tid innan.”

Samtal

”Samtalsstöd. Hade velat haft en sjuksköterska där sista dygnen som man kunde prata med.”



”Ja, stället hon låg på är ärligt talat dödstrist. Inte en tavla, inte kabel-TV, inte TV-kanaler på flera språk, inte Netflix eller annat som kan roa en stund. Jag tycker att TV-utbudet borde maxas och att man skulle satsa lite på visuellt lugnande sa[illegible]ummen - vackra tavlor, ljusspel, blommor.”

Miljön

”Fika/Macka/Kaka/kaffe då man lätt glömmer bort att både äta och dricka när man sitter vak.”



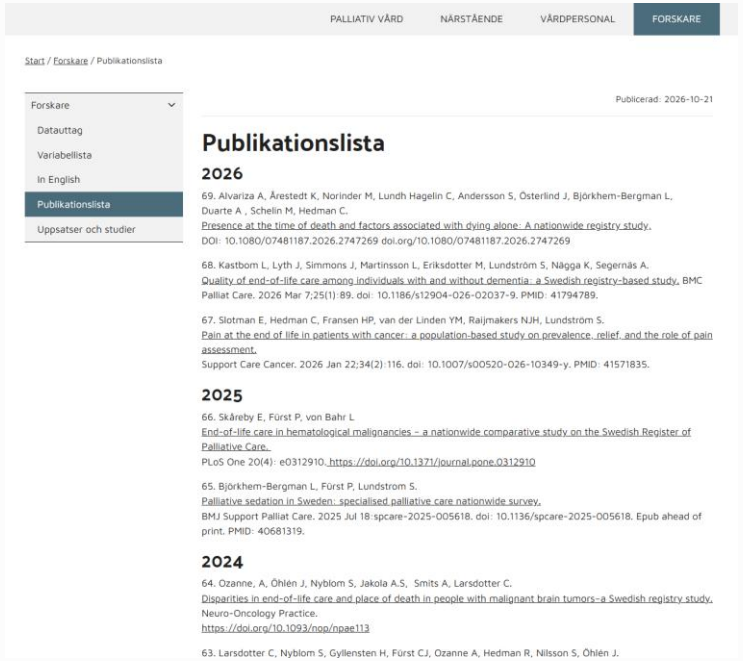
Forskning

Kostnadsfritt för forskare

69 publicerade artiklar

Hemsidan







Death Studies

ISSN: 0748-1187 (Print) 1091-7683 (Online) Journal homepage: www.tandfonline.com/journals/udst20

Presence at the time of death and factors associated with dying alone: A nationwide registry study

Anette Alvariza, Kristofer Årestedt, Maria Norinder, Carina Lundh Hagelin, Sofia Andersson, Jane Österlind, Linda Björkhem-Bergman, Anette Duarte , Maria EC. Schelin & Christel Hedman

To cite this article: Anette Alvariza, Kristofer Årestedt, Maria Norinder, Carina Lundh Hagelin, Sofia Andersson, Jane Österlind, Linda Björkhem-Bergman, Anette Duarte , Maria EC. Schelin & Christel Hedman (13 Oct 2026): Presence at the time of death and factors associated with dying alone: A nationwide registry study, Death Studies, DOI: 10.1080/07481187.2026.2747269

To link to this article: https://doi.org/10.1080/07481187.2026.2747269

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Original Research

Symptom Management and Supp
Patients with Cancer and Coron
Disease-19—A Register-Based St

Christel Hedman, MD, PhD[1,2,3], Peter Strang
Staffan Lundström, MD, PhD[2,4], and Lisa Martin

Abstract

Objective: Little is known to what extent access to specialist
disease-2019 (COVID-19) affects the occurrence of breakthroug
pital deaths. Our aim was to include patients with both COVID
dying in SPC with reference to the quality of end-of-life care.
Methods: Patients with both cancer and COVID-19 who die
from the Swedish Register of Palliative Care. The hospital and
care, including the occurrence of 6 breakthrough symptoms du
information, support, and human presence at death.
Results: Breakthrough of breathlessness was more common i
respectively; $p < .001$), while pain was less common (65% and
ratory secretions, or confusion did not differ. All 6 symptoms,
($p = .014$ to $p < .001$ in different comparisons). In SPC, a docu
tion about this were more common than in hospitals ($p < .001$
family members to be offered a follow-up talk afterward wa
Conclusion: More systematic palliative care routines may b
of end-of-life care in hospitals.

Keywords
COVID-19, palliative care, end-of-life care, cancer, sympto

Introduction

The coronavirus disease-2019 (COVID-19) pandemic has
ously affected the whole world since it started at the begi
of 2020. Patients with cancer have been affected b
COVID-19 pandemic in numerous ways. Those with
cancer or ongoing cancer treatment have an increased
getting a COVID-19 infection, an elevated risk of
disease, and, in addition, higher mortality from COVID
Furthermore, an increase in avoidable deaths due to dia
delays of cancer is to be expected.[4]

Previous pandemics have shown a profound ef
end-of-life (EOL) care due to a reduction of palliative
vices; difficulties in allowing a family to be present at
to visiting restrictions; a shortage of medications, traine
care workers with knowledge about symptom managem
protective equipment.[5] During the COVID-19 panden
ing restrictions have had a major impact on EOL
increasing loneliness, the risk of aggravated sympt
being alone during the dying phase.[6–8] Moreover,
have not had the possibility to say goodbye or to cor

Martinsson et al. BMC Palliative Care (2021) 20:102
https://doi.org/10.1186/s12904-021-00785-4

RESEARCH ARTICLE

Sym

Martinsson et al. BMC Geriatrics (2021) 21:294
https://doi.org/10.1186/s12877-021-02228-4

BMC Geriatrics

RESEARCH Open Access

Dying from COVID-19 in nursing homes-sex differences in symptom occurrence

Lisa Martinsson[1*], Peter Strang[2,3], Jonas Bergström[4] and Staffan Lundström[2,3]

Abstract

Background: Coronavirus disease 2019 (COVID-19), is a disease with diverse presentation. Several studies have shown different occurrence of symptoms for women and men, but no studies have been found examining sex differences in clinical presentation for nursing home residents dying from COVID-19.
The objective of this study was to describe sex and age differences and the impact of a dementia diagnosis on symptom occurrence during the last week in life for persons dying from COVID-19 in nursing homes.

Methods: This is a population-based retrospective study based on data from the Swedish Register of Palliative Care. A total of 1994 residents aged 65 or older who died from COVID-19 in nursing homes were identified. The impact of sex, age and a dementia diagnosis on six different symptoms was analysed using chi2-test and multivariate logistic regression.

Results: Residents dying from COVID-19 were more often men ($p < .002$). Men more often had dyspnoea and death rattles ($p < .001$). Nausea was more common in women ($p < .001$). No sex differences in the occurrence of pain, anxiety or confusion were seen. Dyspnoea and nausea were less commonly reported in residents with dementia ($p < .001$).

Conclusions: We found sex differences in symptom presentation for fatal COVID-19 in nursing home settings which remained after adjusting for age. Residents with a dementia diagnosis had fewer symptoms reported before death compared to those without dementia.
Clinical presentation of fatal COVID-19 differs between women and men in nursing homes. Residents with fatal COVID-19 present with more unspecific and less prominent symptoms when also suffering from dementia.

Keywords: COVID-19, Palliative care, End-of-life care, Nursing homes, Hospitals, Dementia

Introduction

Coronavirus disease 2019 (COVID-19), is a disease with diverse presentations. Common symptoms reported are fever, cough and dyspnoea [1]. A subset of COVID patients experience gastrointestinal symptoms [2]. Loss of taste or smell are reported among mild cases and dyspnoea is frequent among severe and fatal cases [1].

Men are more likely than women to die from COVID-19, and also more likely to be admitted to intensive care units due to COVID-19 [3]. Several studies suggest a sex difference in symptom presentation. Lechien et al. found that women with mild to moderate COVID-19 are slightly more prone to experience smell and taste dysfunction compared to men [4]. Biadsee et al. compared symptoms between women and men for a group of quarantined non-hospitalised patients and found that symptom presentation differs. Women were more likely to report a runny nose, anosmia and facial pain compared to men [5]. Pregnancy is also associated with a different clinical presentation [6].

Dementia is a known risk factor for death when infected by COVID-19 and is associated with an atypical

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BMC

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BMC Pall

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PhD,[1,2] Lisa Martins
D,[4] and Staffan Lunds

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utet, Stockholm, Sweden.
nem Foundation, Stockholm, Swed
Umeå, Sweden.
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Original Article

JOURNAL OF PALLIATIVE MEDICINE
Volume XX, Number XX, 2020
© Mary Ann Liebert, Inc.
DOI: 10.1089/jpm.2020.0249

FULL TEXT ARTICLE

Elderly

Were Clinical Routines for Good End-of-Life Care Maintained in Hospitals and Nursing Homes During the First Three Months of the Outbreak of COVID-19? A National Register Study

Lisa Martinsson, MD, PhD; Peter Strang, MD, PhD; Jonas Bergström, MD; Staffan Lundström, MD, PhD

Journal of Pain and Symptom Management, January 01, 2021, Volume 61, Issue 1, Pages e11-e19, Copyright © 2020 The Authors

Abstract

Context

Although the coronavirus disease 2019 (COVID-19) pandemic might affect important clinical routines, few studies have focused on the maintenance of good quality in end-of-life care.

Objectives

The objective was to examine whether adherence to clinical routines for good end-of-life care differed for deaths because of COVID-19 compared with a reference cohort from 2019 and whether they differed between nursing homes and hospitals.

Methods

Data about five items reflecting clinical routines for persons who died an expected death from COVID-19 during the first three months of the pandemic (March–May 2020) were collected from the Swedish Register of Palliative Care. The items were compared between the COVID-19 group and the reference cohort and between the nursing home and hospital COVID-19 deaths.

Results

About 1316 expected deaths were identified in nursing homes and 685 in hospitals. Four

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Association between paren fluids and symptoms in ho end-of-life care: an observ study of 280 patients

Anna Fritzson,[1] Björn Tavelin,[1] Bertil Axelsson[2]

[1]Department of Radiation Sciences, Umeå University, Umeå, Sweden
[2]Department of Radiation Sciences, Unit of Clinical Research Center—Östersund, Umeå University, Umeå, Sweden

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Received 28 March 2013
Revised 1 October 2013
Accepted 10 October 2013

ABSTRACT

Objectives To investigate whether dying patients receiving parenteral fluids (PF) suffer from more or less symptoms than patients who do not receive PF. Today's evidence on how PF affects palliative patients' symptoms is very scarce. Nevertheless, 40% of the patients who die expectedly in Swedish hospitals receive PF during their last 24 h of life.

Methods A historical cohort study of medical records was performed. Of the 530 patients who were reported to have died expectedly at hospital in Västerbotten county (Sweden) between 1 January 2011 and 30 June 2012, 140 cases who had received PF and 140 controls who had not received PF were identified by stratified randomisation and matched by age, sex and main disease. The groups were compared regarding documented presence of dyspnoea, respiratory secretions, anxiety, nausea and confusion during the last 24 h and the last week of life.

Results The prevalence of documented dyspnoea in the PF groups was higher than in the non-PF groups (51% vs 22% last 24 h, p<0.0001; 70% vs 45% last 7 days, p<0.001). The proportions of patients suffering from dyspnoea increased with larger administered volume. Although our main hypothesis—that the prevalence of respiratory secretions would be higher in the PF group—was not confirmed, we found a tendency in that direction (63% vs 50% last week, p=0.072). No clinically significant differences in anxiety, nausea or confusion were found.

Conclusions There is an association between PF administration and increased frequency of documented dyspnoea for terminally ill patients in their last week of life.

INTRODUCTION

When a patient's life is approaching its end due to incurable progressive disease, the oral intake mally reduc should rece hydration many year care is to reduce dis dence on patients' is scarce, make ge to give limited ging at ANH s Comm increa rattles one bene As I use use the cia tio an

To cite: Fritzson A, Tavelin B, Axelsson B. BMJ Supportive & Palliative Care Published Online First: [please include Day Month Year] doi:10.1136/bmjspcare-2013-000501

Original Article

Parenteral Hydration in Dying Patients With Cancer: A National Registry Study

Lisa Martinsson, MD, PhD, Peter Strang, MD, PhD, Staffan Lundström, MD, PhD, and Christel Hedman, MD, PhD

Department of Radiation Sciences, Oncology (L.M.), Umeå University, Umeå, Sweden; Department of Oncology-Pathology (P.S., S.L.), Karolinska Institutet, Stockholm, Sweden; R & D Department (P.S., S.L., C.H.), Stockholms Sjukhem Foundation, Stockholm, Sweden; Department of Molecular Medicine and Surgery (C.H.), Karolinska Institutet, Stockholm, Sweden; Department of Clinical Sciences Lund (C.H.), Lund University, Lund, Sweden

Abstract

Context. Clinically assisted hydration during end-of-life care among patients with cancer is controversial; practice varies between clinical settings and countries, and there is a lack of evidence.

Objectives. To examine whether breathlessness, respiratory secretion, or confusion correlates with receiving parenteral hydration during end of life, adjusted for sex, age, and place of death.

Methods. The Swedish Register of Palliative Care database was used to collect data about the usage of parenteral hydration during the last day of life, and the occurrence of three symptoms during the last week. Adults dying from cancer during 2011–2021 in hospitals, in residential care homes, and within specialized palliative care were included. Correlation between parenteral hydration and symptoms was examined using χ^2-test and logistic regression.

Results. A total of 147,488 patients were included in the study. Parenteral hydration was more often prescribed to younger persons, to men, and in acute hospitals (compared to other settings), $p < 0.001$ in all three comparisons. Patients with hematological malignancies (20%) and ovarian cancer (16%) were most likely to receive parenteral hydration, while those with brain tumors (6%) were least likely. The presence of all three analyzed symptoms during the last week (breathlessness, respiratory secretion, and confusion) were significantly correlated with having received parenteral hydration during the last day of life ($p < 0.001$). In the final logistic regression model adjusted for age, sex, and place of death, the only symptom with remaining correlation to parenteral hydration was breathlessness (OR 1.56, 95% CI 1.50–1.6).

Conclusion. There is an association between parenteral hydration and increased breathlessness in patients with cancer. Provision of parenteral hydration is more prevalent in men, younger patients, and those with hematological malignancies or ovarian cancer, and most widespread in acute hospital settings. J Pain Symptom Manage 2024;000:1–9. © *2024 The Authors. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. This is an open access article under the CC BY license (http://creativecommons.org/licenses/by/4.0/)*

Key Words

Palliative care, end-of-life care, parenteral hydration, symptoms

Key Message

This article describes a retrospective cohort study that describes the correlation between parenteral hydration and three symptoms during the last week of life for patients with cancer. A correlation between parenteral hydration and increased breathlessness was found. These data may be used as a basis for future advance care planning, as well for dialogues with relatives, who often request hydration to their immediately dying family member.

Accepted for publication: 30 January 2024.

List of abbreviations: aOR, adjusted odds ratio; CI, confidence interval; SRPC, Swedish Register of Palliative Care

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https://doi.org/10.1016/j.jpainsymman.2024.01.036

Care (2024) 23:178
04-024-01504-5

BMC Palliative Care

Open Access

y is associated with lower care higher symptom burden during fe of patients with cancer – -based register study

Mogensen[3,4], Björn Tavelin[5], Johanna Eknert[6], Staffan Lundström[7] and Peter Strang[7]

) therapy of patients in end-of-life (EOL) is controversial. The purpose of this study en PF, quality of the EOL care process and symptom burden in dying cancer patients, ch.

etrospective register study of all adult cancer deaths with documented f life as reported to the Swedish Register of Palliative Care during a three-year relief of symptoms during the last week of life as well as EOL care process quality to PF in those patients who had a documented decision to focus on EOL care s ratios were calculated, adjusting for place of death (hospital vs. non-hospital). % of immediately dying patients in hospitals compared to 6.5% outside higher likelihood for breathlessness and nausea. In patients screened for ment, PF was inversely associated with the likelihood of complete relief of anxiety, nausea and pain. Several palliative care quality indicators were inversely ersations and prescriptions of injectable drugs as needed. These associations

the last 24 h of life was associated with inferior quality of the EOL care rden in imminently dying cancer patients.

End-of-life, Cancer, Quality, Symptoms

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RESEARCH

Quality of end-of-life care among inc with and without dementia: a Swedi registry-based study

Lisa Kastbom[1,2*], Johan Lyth[1], Johanna Simmons[1,3], Lisa Martinsson[4], Maria Staffan Lundström[7,8], Katarina Nägga[1,3†] and Anna Segernäs[1,2†]

Abstract

Background Despite dementia being a leading cause of death and clinical guidelin substantial gaps in care quality for this population have previously been shown. This compare the quality of end-of-life (EOL) care provided to individuals with and witho

Methods In this registry-based study, patients registered in the Swedish Register of 2011 and 2020 were cross-referenced with patients in the Swedish registry for cognit (SweDem). For each patient with dementia registered in SveDem ($n = 39\,712$), two co matched by year of birth and gender were selected from the SRPC ($n = 79\,336$). Quali analyzed by group (dementia/controls) and by place of death, separately, using the c logistic regression analyses were conducted to examine the association between the diagnosis of dementia or not, overall and in different settings.

Results Individuals with dementia were more likely to have staff or family members documented decisions to shift to EOL care, have symptom assessments made the fir of injectables. However, they were less likely to express preferences for place of deat care transitions, especially in hospitals without specialized palliative care.

Conclusions In this study, individuals with dementia received higher quality EOL ca with those without dementia. However, they were less likely to have expressed prefe These findings highlight the need for early, proactive care planning to align care with potentially non-beneficial actions.

Keywords End-of-life care, Palliative care, Dementia, Place of death, Advance care pl Quality registry

†Katarina Nägga and Anna Segernäs contributed equally to this work.

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Lisa Kastbom
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RESEARCH ARTICLE

Quality of end-of-life care in patients with dementia compared to patients with cancer: A population-based register study

Lisa Martinsson[1]*, Staffan Lundström[2,3], Johan Sundelöf[4]

1 Department of Radiation Sciences, Umeå University, Umeå, Sweden, **2** Department of Palliative Medicine, Stockholms Sjukhem Foundation, Stockholm, Sweden, **3** Department of Oncology-Pathology, Karolinska Institutet, Stockholm, Sweden, **4** Betaniastiftelsen (non-profit organisation), Stockholm, Sweden

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Data Availability Statement: The data contain personally-identifying information, such as personal identity numbers, and potentially identifying information, such as date of death, and therefore are subject to ethical and legal restrictions on public sharing. We cannot share the data set, which is on individual level, because it is not permitted accoring to the laws that apply in Sweden. The permission we obtained for this study from the Regional Ethics Board at Umeå University, Sweden, only allowed public sharing on group level. Questions about register data availability can

Abstract

Introduction

Globally, dementia is one of the leading causes of death. Given the growing elderly population in the world, the yearly number of deaths by dementia is expected to increase. Patients dying from dementia are reported to suffer from a burden of symptoms similar to that of patients with cancer, but receive less medication against symptoms, have a lower probability of palliative care planning and seldom have access to specialised palliative care. Studies investigating the quality of palliative care in dementia are scarce. The aim of this Swedish national study was to compare the quality of end-of-life care between patients with dementia and patients with cancer regardless of place of care.

Methods

Thirteen end-of-life care quality indicators collected by the Swedish Register of Palliative Care (SRPC) were compared between patients dying from dementia and patients dying from cancer. Data were collected from deaths occurring in nursing homes, hospitals, specialised and general palliative home care, and palliative in-patient units during a three-year period (during March 2012 to February 2015). Analyses were performed using a multivariable logistic regression model, adjusted for age and gender. A subgroup of patients with Alzheimer's disease was identified and compared to patients with other and unspecified types of dementia.

Results

A total of 4624 deaths from Alzheimer's disease, 11 804deaths from other dementia diagnoses and 51 609 deaths from cancer were included. For six of the 13 quality indicators examined (prescription of PRN drugs against nausea and anxiety, information and bereavement support offered to next of kin, pain assessment and specialised palliative care consultations), poorer outcomes were shown for the dementia group in comparison to the cancer group. Two outcomes (prevalence of pressure ulcers and fluid therapy during the last 24

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f end-of-life care for persons dementia in nursing homes ospitals: a Swedish national

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röm[2,3] and Johan Sundelöf[4]

tients with advanced dementia is generally regarded as less preferable compared me. For patients with other diagnoses, young age has been associated with udies comparing the quality of palliative care for persons with advanced homes are scarce. The aim of this study was to investigate whether quality of ementia depends on age, gender and place of death.

f Palliative Care (SRPC) was used to identify patients who died from dementia in a three-year period. The likelihood of death occurring at a hospital, based on alculated. Associations between 13 end-of-life care quality indicators collected id place of care were examined in a logistic regression model.

ssociated with poorer quality of end-of-life care for 10 of the 13 measured th at a nursing home, and with better quality according to two of the outcomes. mon for men compared to women and for younger patients compared to older. ia enteral tube in the last 24 h of life was strongly associated with death at a to have their oral health assessed and less likely to have pressure ulcers at death. nes showed better results for the age group 65 to 84 years compared to those 85

as associated with poorer quality of end-of-life care compared to death in the importance of advance care planning and individual assessments in nursing ls during end of life. Despite established recommendations to avoid re strong associations between younger age, male gender and hospitalisation in needed to investigate the role of socioeconomic factors in end-of-life care for

dementia, Palliative care, End-of-life care, Hospitalisation, Gender, Age differences,

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Kvartalets fråga



Begränsad tid

Valfritt

10-15 000 svar!

Kvartalets fråga



Palliativ sedering

Antibiotikabehandling i livets slutskede

Ensam i dödsögonblicket

Infarter/utfarter

Rossel

Närstående och Smärtskattning

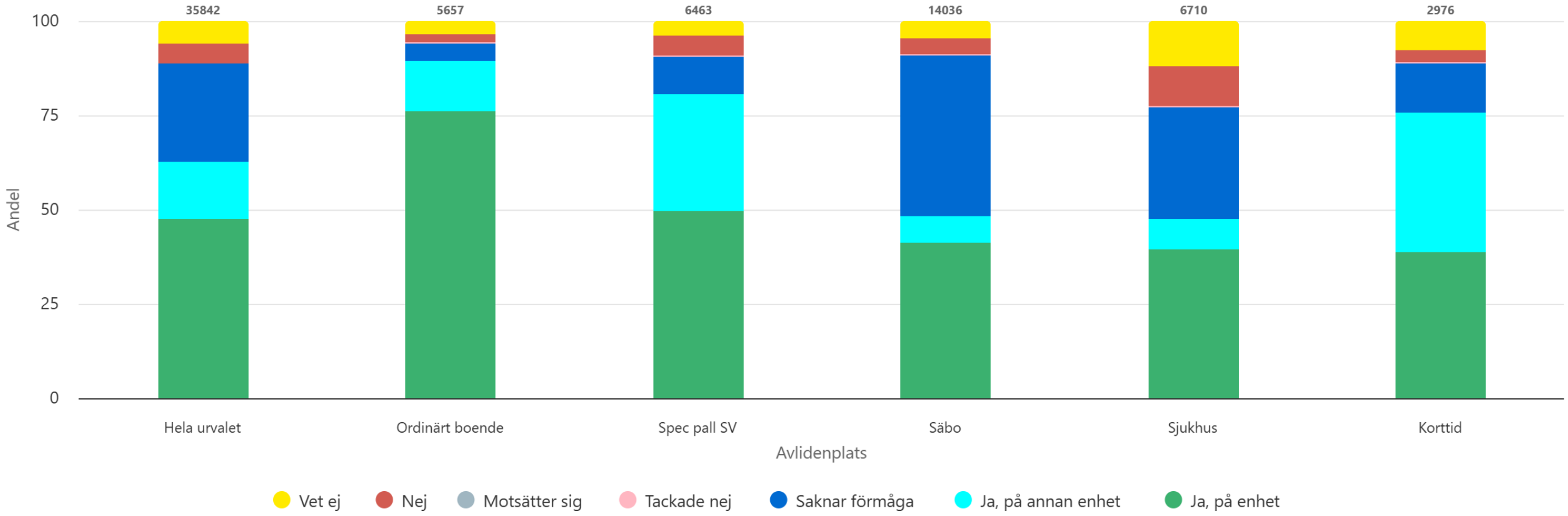
Intravenös vätska/näring

Läkemedelsordination

SVAS

Samtal vid allvarlig sjukdom till patient

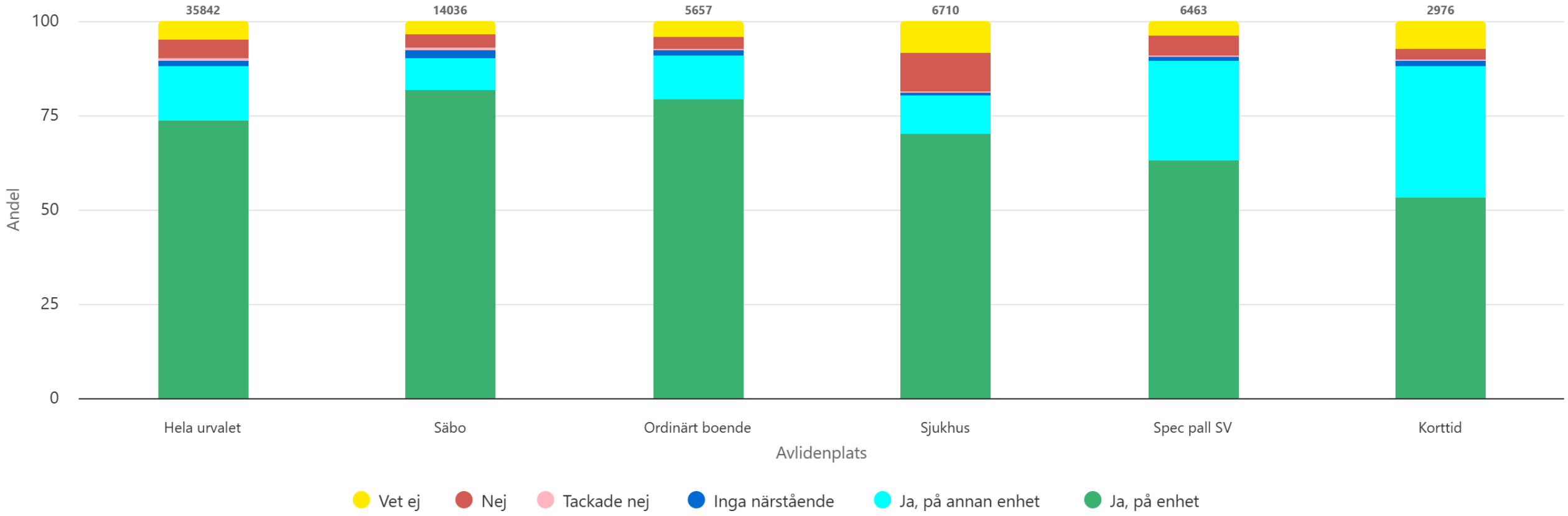
Period 2026-01 - 2026-10
η = Totalt antal observationer



Detta är en modifierad rapport

Samtal vid allvarlig sjukdom till närstående

Period 2026-01 - 2026-10
η = Totalt antal observationer



Detta är en modifierad rapport

Kunskapsstöd
- Barn
- Symtom
- Skriftliga rutiner
- Styrande dokument
- Beställ material
- Samtal vid allvarlig sjukdom

Publicerad: 2025-12-23

Samtal vid allvarlig sjukdom

Här hittar du fördjupningsfilm om samtal vid allvarlig sjukdom där du får möta patienter och personal och ta del av deras erfarenheter och reflektioner. Filmen är indelad i korta avsnitt. Ett eller flera avsnitt kan användas som utgångspunkt för reflektion, till exempel på en arbetsplatsträff eller under utbildning. Här finns även själva frågan i dödsfallsenkätem om samtal vid allvarlig sjukdom, Termer och Begrepp från Socialstyrelsen.

Filmserien som består av fyra delar:

- Samtal vid allvarlig sjukdom – En introduktion till begreppet Samtal vid allvarlig sjukdom.
- Samtal vid allvarlig sjukdom – Att komma igång med samtalen på er arbetsplats.
- Samtal vid allvarlig sjukdom – Att hålla samtal vid allvarlig sjukdom
- Samtal vid allvarlig sjukdom – Fördjupning med erfarenheter och reflektioner

Länk till filmer om samtal vid allvarlig sjukdom - Regionala cancercentrum i samverkan

Länkar till dokument gällande samtal vid allvarlig sjukdom.

Termer och begrepp från Socialstyrelsen

Frågan i dödsfallsenkäten inkl hjälptext.

Checklista vid misstanke om palliativa vårdbehov

Vid ett eller flera **ja** bör en fördjupad bedömning av patientens palliativa vårdbehov utföras.

För patienter med en eller flera livshotande sjukdomar
Successivt försämrat allmäntillstånd trots fortsatt sjukdomsinriktad behandling.
WHO performance status 3–4 (I behov av vila mer än 50 procent av vaken tid).
Upprepade oplanerade vårdtillfällen på sjukhus utan klinisk förbättring.
Ofrivillig viktnedgång.
Otillräcklig symtomlindring.
Påtaglig oro, ångest eller stress hos patienten eller närstående.
Täta infektionsepisoder som kräver behandling.
Förväntad snabb utveckling av besvärande symtom.

Fundera även tillsammans i teamet kring förvåningsfrågan:
Skulle jag bli förvånad om personen dör inom det närmaste året?

Palliativt Centrum

Samtal vid allvarlig sjukdom

Samtalsguide

Sjukdom
Nuläge
Framåt

Hur tänker du kring din sjukdom?
Vad hoppas du på/oroar du dig för?
Vill du veta hur jag tänker?
Behöver du mer information?

Behandling
Nytta
Risk

Har du några funderingar kring din behandling?
Är det någon vård du inte vill ha?

Vad är viktigt för dig?

Min person
Värdighet
Livskvalitet

Vad får dig att må bra?
Vad behöver jag veta om dig för att kunna ge dig en bra vård?

Närstående
Information
Stöd

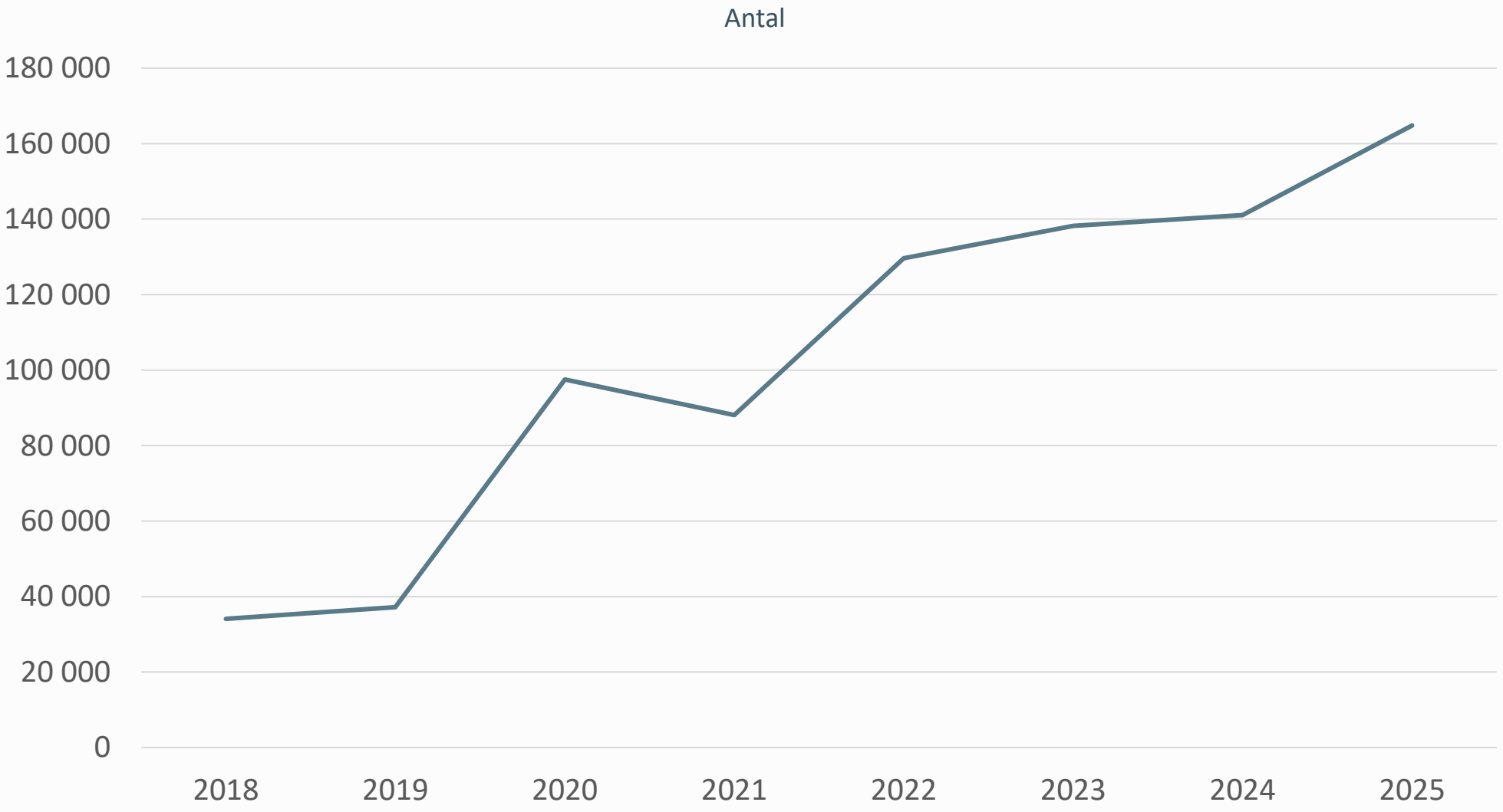
Har du pratat med din familj?
Om du blir så sjuk att du inte kan föra din egen talan
– vem kan göra det åt dig?

Framtaget av Helene Reimertz 2026

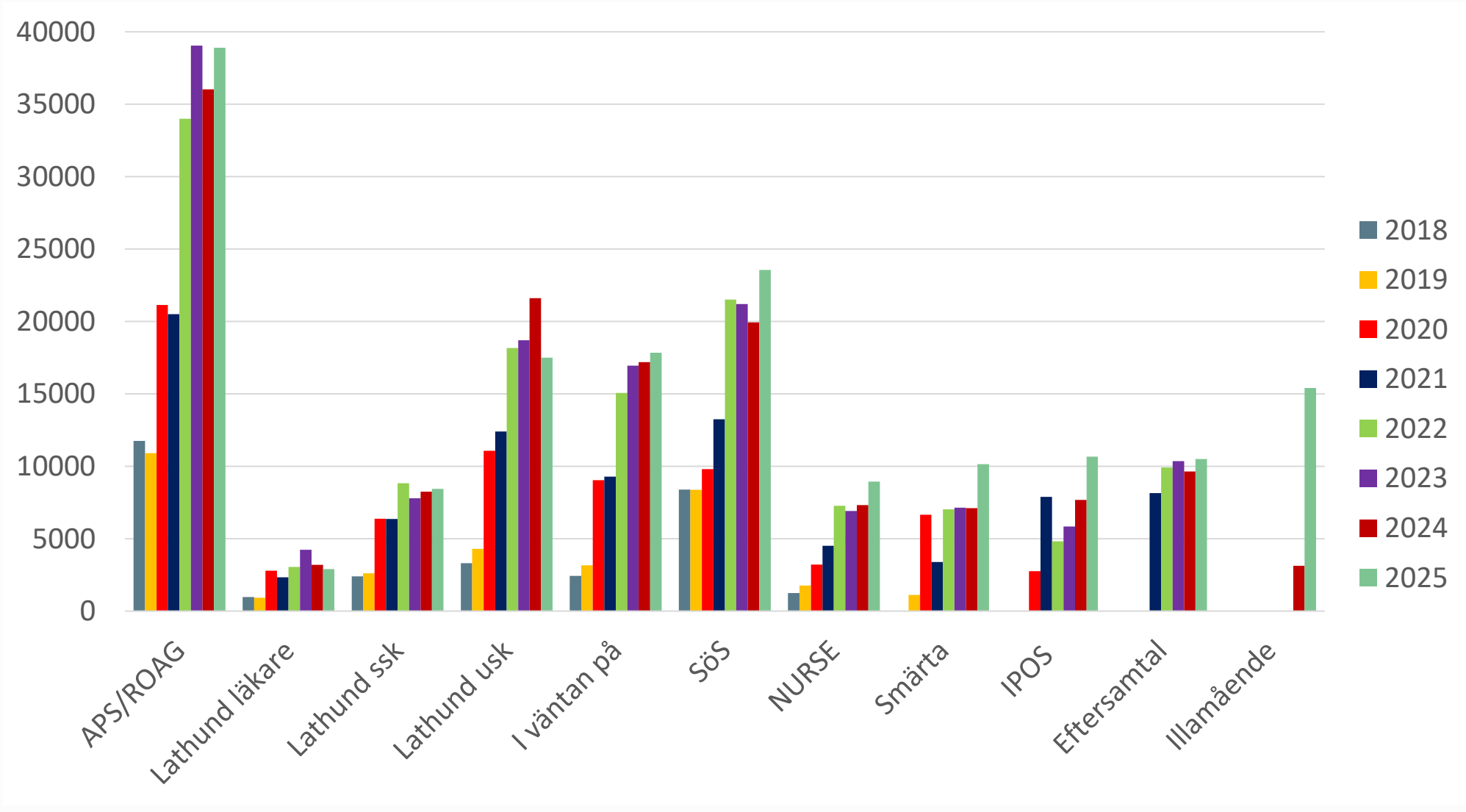
Lyssna in – Tillåt tystnad – Bemöt känslor – Dokumentera

Ovanstående fraser är exempel på frågor som kan användas för att ta reda på vad som är viktigt för patienten och dennes närstående.

Trycksaker


Antal
180 000
160 000
140 000
120 000
100 000
80 000
60 000
40 000
20 000
0
2018
2019
2020
2021
2022
2023
2024
2025

Trycksaker

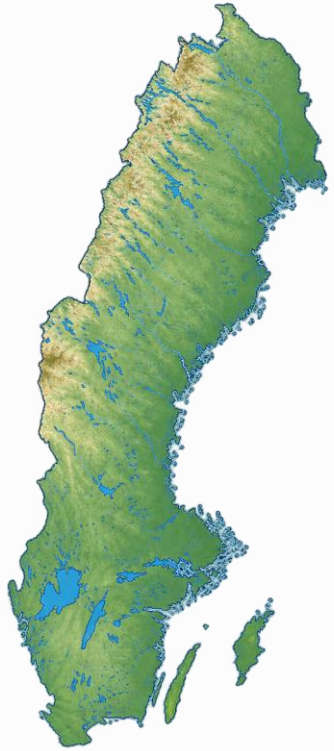

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Lathund usk
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SöS
NURSE
Smärta
IPOS
Eftersamtal
Illamående
2018
2019
2020
2021
2022
2023
2024
2025

Hur har Svenska palliativregistret bidragit till utveckling av palliativ vård?

Maria Andersson
Specialistsjuksköterska
Registerhållare Svenska palliativregistret











Förbättra vården i livets slut för patienten och deras närstående!

Tack!



WWW.PALLIATIVREGISTRET.SE

Palliativa veckan

2-8 november 2026

Med livet i centrum

Nationell enkät:

Hur förhåller du dig till allvarlig sjukdom och död?

Vill du vara med och bidra?
Scanna QR-koden