National Guidelines –
Performance Assessment 2016

End of life palliative care

Adherence to National Guidelines

Socialstyrelsen
THE NATIONAL BOARD OF HEALTH AND WELFARE

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Foreword

The Swedish National Board of Health and Welfare has carried out a national performance assessment of palliative care at the end of life. The basis for this assessment has been adherence to the National Board of Health and Welfare's national knowledge support base for good palliative care at the end of life from 2013.

The results of the assessment are presented in two reports. One is this document: *National Guidelines – Performance Assessment 2016 – End of life palliative care.* The other is entitled *Indikatorer och underlag för bedömningar* [Indicators and material for assessments], which contains a description of the method employed and all the results. This latter report, which is a summary of the former report, also contains the areas for improvement which the National Board of Health and Welfare has identified.

The assessment is mainly targeted at decision-makers and administration managers at different levels within county councils, regions and municipal authorities. But it may also be useful to other operators, such as patient associations, relevant professional groups and the media.

The project leader for the assessment was Christina Broman. Other project team members who have contributed to the report are Mikael Nyman, Robert Linder and Riitta Sorsa. The external experts involved have been Greger Fransson, Carl Johan Fürst, Inger Landgren, Susanne Lind and Ulla Olsson.

A special word of thanks must be expressed to the Swedish Register of Palliative Care for providing material for the assessment. The project was headed up by temporary head of unit, Inger Lundkvist.

Olivia Wigzell,
Director General

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Summary

The National Board of Health and Welfare has adopted a national approach in evaluating the provision of palliative care at the end of life, using the National Board of Health and Welfare's national knowledge support base from 2013 as a starting point.

It is important that county councils, regions and municipalities have a general overview of the process which contributes to good palliative treatment and care as this will facilitate planning for this provision and the allocation of responsibility and create conditions conducive to good cooperation among the various operators.

The aim of palliative care is to meet the needs of the individual (the patient) and their next of kin when illness or age means that their life is drawing to its close.

The assessment highlights that some of the recommendations in the knowledge support base yield positive results and the trends indicate a steady improvement.

But the assessment also shows that there are a number of areas for improvement in county councils, regions and municipalities where further impetus is required in ensuring that the treatment and care comply to an even greater extent with the knowledge support base, supplemented by the national care programme, which will provide a common basis for good palliative care at the end of life.

Areas for improvement for county councils, regions and municipalities

The knowledge support base showed that the provision of palliative care was not uniform and the results from the assessment show that improvements need to be made in several areas.

The results in the report highlight the significant differences in terms of palliative care provided in county councils, regions and municipalities. There are major disparities when it comes to ongoing training and instruction, for example. If staff do not receive ongoing training in palliative care or any other instruction, this indicates that palliative care is still neglected in terms of skills development and

staff support, which can make it difficult to meet the patient's need for palliative measures, such as symptom relief and interaction with both patients and their next of kin.

The National Board of Health and Welfare has identified in the assessment the following areas for improvement for country councils, regions and municipalities:

- Offering staff ongoing training to enable them to provide good palliative care.
- Offering instruction to staff.
- More people requiring palliative care at the end of life must be given an oral health assessment.
- Increasing the proportion of people requiring palliative care at the end of life who undergo a pain assessment.
- More people requiring palliative care at the end of life need to have an end of life care conversation.
- Cooperating in order to obtain a general overview of the process for ensuring the provision of good palliative care.
- More patients require care planning, involving all the operators in order to ensure that the care will guarantee patient safety.
- More organisations require access to palliative counselling teams.
- More organisations need to offer support to the next of kin.
- More organisations need to have procedures for post-bereavement meetings.
- Providing palliative care to children and adolescents by ensuring that there are procedures about how palliative care should be provided.

Palliative care goes by different names

With regard to palliative care, there is a lack of clarity regarding definitions, care content and the name used, which can adversely affect all the care providers and prevent the development of palliative care.

More patient groups require palliative care

Cancer conditions still represent the largest diagnosis group receiving palliative care, but there are also other patient groups which are in great need of the palliative care approach and expertise.

Patients with other chronic diseases may enter a stage where palliative care and a palliative approach are required in order to provide them with the best conceivable care. Examples of such diseases are COPD, heart failure and dementia.

Introduction of a knowledge support base by county councils, regions and municipalities

The National Board of Health and Welfare has used a survey conducted in February 2016 to record how county councils, regions and municipalities have received knowledge support promoting good palliative care at the end of life and what actions have been carried out based on this. The results show that more than half of city council and regional management teams have had initiatives for introducing the national knowledge support base. At municipal healthcare service level, only a quarter of municipalities have had similar initiatives. Palliative care accounts for a large part of municipal healthcare services and all the recommendations largely concern municipal healthcare.

New assessment in several years

The National Board of Health and Welfare will carry out again in several years an assessment of palliative care at the end of life and then follow up the results from this report. The authorities will mainly focus on the areas for improvement which have been identified, but other indicators will be followed up as well. The objective is for county councils, regions and municipalities to be able to use the reports as a starting point for their efforts in making further improvements to palliative care.

Introduction

The Swedish National Board of Health and Welfare monitors, evaluates and reports on the situation and development with regard to healthcare and social services. The Swedish Health and Medical Services Act (HSL) (1982:763) stipulates that the objective of providing healthcare is to ensure a good state of health and good care under uniform conditions for the whole population. To fulfil this objective, according to this law, healthcare services must meet the requirements for good care. The authorities use the term "good health, treatment and care". This means that the treatment and care provided must be knowledge-based, safe, personalised, effective, uniform and accessible.

Part of the task carried out by the National Board of Health and Welfare is to support knowledge management in relation to the provision of healthcare and social services. This task also includes devising national guidelines, a knowledge support base, indicators, target levels, open comparisons and assessments of treatment and care for specific disease groups.

This report evaluates the provision of care based on the National Board of Health and Welfare's national knowledge support base for good palliative care at the end of life from 2013 [1].

Spotlight on palliative care

Just over 90,000 people die in Sweden every year. It is reckoned that between 70,000 and 75,000 of these require palliative care. Among the number of people who die, less than one per cent of them are children and adolescents under the age of 18. This means that around 480 children and adolescents died in 2015. People receiving end of life care receive it in different forms. This includes as inpatients and outpatients, as well as community care provided by the municipality. Most people receive different forms of care during the final period of their illness.

Palliative care can be split into general and specialised palliative care. General palliative care is provided to patients whose needs can be met by staff with a basic level of knowledge and expertise in palliative care. It is provided in hospitals and in municipal residential care homes in cooperation with primary care. Specialist palliative care is provided to patients with complex symptoms or whose life situation entails special requirements and is administered by a multi-professional team with specific knowledge and expertise in the area of palliative care. This care is administered in a specialist palliative organisation or within a unit providing general palliative care with the support of a palliative care team.

The transition to palliative care at the end of life is a process which varies in duration for different individuals. It may mean that the time left to live is short, but is still felt as being meaningful and sometimes fairly active. In other situations, it means that there is a very short time left and that the patient is expected to die within a period of a few days to a week. Determining this transition involves a medical conclusion being reached on the basis of an assessment of the prognosis. The medical decision can be regarded as an important transition point. In the majority of cases, it means that the patient has reached a situation when the treatment given specifically for the relevant disease no longer has any life-prolonging effect of any benefit to the patient and when death is expected to take place in the foreseeable future. Identifying the transition point to palliative care at the end of life creates conditions for enabling the needs, wishes and concerns of the patient and the next of kin to be addressed.

Purpose and boundaries

Purpose of the assessment

This report is an assessment of the structures, processes and results of the county councils, regions and municipalities. The purpose is to present an open comparison and assessment of the state of palliative care in Sweden based on the following questions:

- Is the care provided in accordance with the recommendations made by the National Board of Health and Welfare in the knowledge support base?
- Is the care provided according to the six criteria stipulated for good care, i.e. that the care is knowledge-based, safe, personalised, effective uniform and accessible?

Assessment's boundaries

The assessment must include patients requiring palliative care, irrespective of their diagnosis. However, access to register data will affect the report's focus as the extent of reporting can vary between diagnoses.

It has not been part of the assessment's remit to set national target levels for the indicators.

Results in two reports

The assessment of palliative care at the end of life is published in two reports.

This report *National Guidelines – Performance Assessment 2016 – End of life palliative care – Adherence to National Guidelines* contains the assessments made by the National Board of Health and Welfare.

The other report *National Guidelines – Performance Assessment 2016 – End of life palliative care – Indikatorer och underlag för bedömningar* [Indicators and material for assessments] contains a description of the methods deployed and an account of the results for all the indicators and surveys included in the assessment.

Both reports can be ordered or downloaded from the National Board of Health and Welfare's website at www.socialstyrelsen.se.

Stakeholders

The assessment is mainly targeted at decision-makers at different levels: politicians, civil servants and hospital administrators within county councils, regions and municipalities. It may also be useful to other stakeholders, such as patient associations, the care professions and media. The other intention behind the report is to provide a source for openly presenting quality management results and support for the public debate about palliative care.

National palliative care programme

The national care programme, which has been devised as part of the care programme activity in the regional cancer centre (RCC) [2], is intended to provide a description of palliative care, regardless of diagnosis, age, ethnicity, background or other factors. This focuses on general palliative care at the end of life. An updated version of the care programme is planned for January 2017. The care programme will subsequently be supplemented by online material, such as a section on palliative care for children and adolescents.

The care programme, together with the National Board of Health and Welfare's national knowledge support base for good palliative care at the end of life [1] and the Swedish Register of Palliative Care [3], form a common basis for providing patients with good treatment at the end of their life and offer conditions for improved palliative care.

Cooperation and communication

The work has been carried out by a working group comprising programme officers from the National Board of Health and Welfare and external experts. The working group has been working in collaboration with the Swedish Register of Palliative Care.

The assessment's structure and implementation have been presented to the NSK (national collaboration group for knowledge management) and a group comprising representatives of administration managers and authorities.

The NVRP, the national council for palliative care, was also informed. This is a non-profit association whose tasks and objectives are to work for the provision of coordinated care throughout the country. Several professional and patient associations have also been informed.

A large number of people have contributed in different ways to the work involved in compiling the report, both inside and outside the National Board of Health and Welfare.

The project organisation is presented in Appendix 1.

Structure of the report

After the introduction comes the chapter entitled *Areas for improvement*. This chapter contains the assessments made by the National Board of Health and Welfare, based on the results of the assessment.

This is followed by the chapter entitled *Method*, which features a description of the conditions for monitoring palliative care at the end of life, as well as a concise description of the data sources which have been used in the assessment.

The chapter entitled *Detailed description of areas for improvement* outlines a selection of the results used a basis for the conclusions made by the National Board of Health and Welfare.

The report is concluded with an appendix containing a list of the members of the project organisation. For access to the complete material used for the assessment, including indicator descriptions, refer to the report *National Guidelines – Performance Assessment 2016– End of life palliative care – Indikatorer och underlag för bedömningar* [Indicators and material for assessments], which can be ordered or downloaded from the National Board of Health and Welfare's website at www.socialstyrelsen.se.

Areas for improvement

This chapter describes the areas for improvement earmarked by the National Board of Health and Welfare for the county councils, regions and municipalities. The areas for improvement are the areas where the assessment has highlighted that there are major regional differences, and the National Board of Health and Welfare believes that the treatment and care provided fail to reach the desired level of quality. In these cases, the results should be improved.

The idea is that the assessments made by the National Board of Health and Welfare will be able to support administration managers and the organisations in their quality assurance and improvement work.

Areas for improvement for county councils, regions and municipalities

Offering staff ongoing training to enable them to provide good palliative care

One prerequisite for enabling staff to provide good palliative care is offering them ongoing training. It is vital that staff have good knowledge of palliative care so that they can fulfil the patients' various requirements for support and symptom relief and also enhance their quality of life. The results indicate that there are major disparities among county councils, regions and municipalities. The provision of ongoing training in the country is inequitable. It is of paramount importance that staff are offered ongoing training as their knowledge of palliative care is vital to ensuring that patients at the end of their life receive the support and symptom relief they need.

The National Board of Health and Welfare believes that the county councils, regions and municipalities can improve the provision of palliative care at the end of life by

- doing more to offer staff ongoing training in palliative care.

Offering instruction to staff

Providing instruction is an area which should be made a top priority. It is alarming that a large proportion of the staff looking after patients requiring palliative care at the end of life are not provided with any instruction on how to do this. Everyone looking after patients receiving palliative care should basically be offered instruction on how to do this. The care provided to palliative patients cannot be provided over again or be rectified. Providing instruction ensures that staff will feel confident in interacting with patients receiving palliative care. Having an effective set of instructions will increase the chance of patients being provided with the best possible care at the end of life. The provision of instruction seems to be neglected in most areas of healthcare and especially in municipalities, but this is also the case in hospital clinics and primary care. Staff are often working in emotionally difficult situations and instruction should be provided on a regular basis.

The National Board of Health and Welfare believes that the county councils, regions and municipalities can improve the provision of palliative care at the end of life by

- ensuring that staff receive instruction on a regular basis.

More people requiring palliative care at the end of life must be given an oral health assessment

Patients receiving palliative care are in great need of care and problems with oral health can have a significant impact on their quality of life. Many patients are given medication which affects their oral health. Therefore, they ought to be given an oral health assessment, especially those in the over 80s age group. These patients are often given several medicines which can cause dryness in their mouth and they are in the patient group which finds it the most difficult to take care of their oral health themselves. The mouth is obviously a part of the body and the care provided must be based on a holistic approach. These results are worth highlighting since only less than half of patients have received an oral health assessment which has been documented.

The National Board of Health and Welfare believes that more patients require an oral health assessment and that the disparities in this regard are too great. County councils, regions and municipalities should review their procedures so that more patients receiving palliative care can have an oral health assessment carried out.

The National Board of Health and Welfare believes that the county councils, regions and municipalities can improve the provision of palliative care at the end of life by

- ensuring more patients undergo an oral health assessment.

Increasing the proportion of people requiring palliative care at the end of life who undergo a pain assessment

Pain is a symptom which commonly occurs at the end of life. When pain goes untreated, it diminishes the quality of life and increases the risk of medical complications. The National Board of Health and Welfare gives a high priority to analysing and assessing pain regularly as part of the national knowledge support base for good palliative care at the end of life. Pain assessment needs to be carried out in a systematic way to be able to identify pain symptoms and reduce the pain experienced by the patient receiving palliative care. In spite of this, the results show that only 38% of patients have undergone a pain assessment, with major variations between counties (county councils and municipalities). The National Board of Health and Welfare believes that a significantly higher proportion of patients should be given the opportunity to have their pain assessed, thereby providing a better basis for providing sufficient pain relief during their final days of life.

The National Board of Health and Welfare believes that the county councils, regions and municipalities can improve the provision of palliative care at the end of life by

- assessing the patients’ pain at the end of life.

More people requiring palliative care at the end of life need to have an end of life care conversation

Good palliative care during the end stage of life means that patients and their next of kin are informed that the patient's illness and condition have reached a point where treatment to both slow down and cure it will be stopped, and there will be a transition to palliative care at the end of life.

A key aspect of the support and care provided at the end of life is that individuals are well informed about their situation. Being informed is of intrinsic value as it provides patients receiving palliative care with the opportunity to reach a decision independently about what kind of care they want to receive during the final period. The results indicate that only half of patients have had an end of life care conversation. There are also differences among counties (county councils and municipalities) and among age groups.

The National Board of Health and Welfare believes that the county councils and regions can improve the provision of palliative care at the end of life by

- offering patients an end of life care conversation.

Cooperating in order to obtain a general overview of the process for ensuring the provision of good palliative care

It is important that county councils, regions and municipalities have a general overview of the process which contributes to good palliative treatment and care as this will facilitate planning for this provision, the allocation of responsibility and good cooperation among the various operators. One way of doing this is to have procedures in place. To ensure that palliative care is provided in an equitable manner and safeguard patient safety for the individual, all organisations should have procedures in place determining how they cooperate with each other. In spite of this, the results show that too large a proportion of organisations do not have any cooperation procedures.

The National Board of Health and Welfare believes that the county councils, regions and municipalities can improve the provision of palliative care at the end of life by

- all organisations having procedures determining how they cooperate with each other.

More patients require care planning, involving all the operators so that the care will guarantee patient safety

When a patient receiving palliative care needs to be transferred to another form of care or another unit, it is vitally important that information about the patient's previous and current medical history, medical prescriptions and future plans are passed on and that plans are made along with the operators who will be involved in the continued care of the patient. Care plans should be produced for all patients as the care provided must ensure the patient's safety. Otherwise, there is a risk of patients not receiving the input which they require. It is paramount that everyone who provides the patient's care is involved in the care-planning process. The patient, relatives and care providers must be aware of the purpose and focus of the care being provided.

The National Board of Health and Welfare believes that the county councils, regions and municipalities can improve the provision of palliative care at the end of life by

- increasing cooperation through jointly planning care.

More organisations require access to palliative counselling teams

The task of palliative counselling teams is to improve the palliative care being provided by acting as a resource to support care staff and offer advice in direct patient cases. The results highlight disparities in terms of access to palliative counselling teams in primary care and in the municipalities. This means that further efforts need to be made to ensure the provision of palliative care.

The National Board of Health and Welfare believes that the county councils, regions and municipalities can improve the provision of palliative care at the end of life by

- ensuring that more organisations - in both primary care and the municipalities - are given access to palliative counselling teams.

More organisations need to offer support to the next of kin

Support for the next of kin is a fundamental aspect of palliative care. The objective is for everyone to be offered support. The results show that more than half of municipalities offer support to the patient’s next of kin, but there are very large variations between the counties. There is also a similar outcome for the primary care sector. With regard to procedures for focusing on the next of kin’s needs when they are children and adolescents, the results indicate that a number of primary care institutions and hospital clinics do not have any procedures in place.

The National Board of Health and Welfare believes that the county councils, regions and municipalities can improve the provision of palliative care at the end of life by

- ensuring that both municipalities and the primary care sector review their efforts in terms of providing support to next of kin
- ensuring that the primary care sector and certain hospital clinics should strive to draw up and put procedures in place for looking after the needs of the next of kin of patients requiring palliative care when they are children and adolescents.

More organisations need to have procedures for holding a post-bereavement meeting

Responsibility for care does not end when death occurs. The next of kin often have various outstanding issues on which they have not had an opportunity for closure. When death has occurred and the care staff, sometimes along with the next of kin, have looked after the deceased, the next of kin must be offered a post-bereavement meeting. This should take place a suitable period of time after the patient has died.

The National Board of Health and Welfare believes that it is important to have procedures on how to hold post-bereavement meetings in all organisations caring for patients at the end of life so that a uniform level of care is provided.

The National Board of Health and Welfare believes that the county councils, regions and municipalities can improve the provision of palliative care at the end of life by

- putting procedures in place on how to hold post-bereavement meetings
- all organisations offering next of kin a post-bereavement meeting.

Providing palliative care to children and adolescents by ensuring that there are procedures on how the palliative care should be provided

Children and adolescents receiving palliative care must have this care tailored to their individual needs. Palliative care can be initiated as early as at the time of the child's birth or when a diagnosis has been established, and may be required for a short or lengthy period of time. The needs of children and adolescents for palliative care can vary greatly, depending on their age, illness and expected course of events. One way of ensuring that good palliative care is provided is by using procedures. The National Board of Health and Welfare believes that it is important that procedures are in place at all children's and adolescents' clinics to ensure the provision of palliative care for children and adolescents.

The National Board of Health and Welfare believes that the county councils and regions can improve the provision of palliative care at the end of life by

- having procedures in place on how to provide palliative care to children and adolescents
- having procedures in place on how municipal care services, primary care and specialist palliative care organisations will cooperate with each other
- having procedures in place on how post-bereavement meetings are to be held.

Assessment based on good treatment and care

The National Board of Health and Welfare's assessment is mainly based on the indicator-based results and is intended to analyse whether palliative care at the end of life is knowledge-based, personalised, safe, effective, uniform and accessible.

However, the indicators used in the report are not sufficient to make a complete assessment of palliative care at the end of life. Therefore, this report describes only the indicators based on the aspects of personalised and uniform care.

Personalised care

Healthcare must be provided with respect for the specific needs, expectations and integrity of the individual. Individuals must have an opportunity to be involved in their own care. One way to achieve this objective is by offering an end of life care conversation, which is carried out with respect for and sensitivity towards every patient's needs.

Uniform care

Uniform care means that healthcare must be supplied and allocated under uniform conditions. All citizens must have the same opportunities to receive healthcare and be treated equitably, irrespective of such factors as where they live, their gender, age, education and country of birth. Equality is highly relevant to the way in which we present and comment on the indicators and their results in this report. The National Board of Health and Welfare has taken into account gender and age, as well as geographical differences when assessing each indicator. The results highlight differences which exist between men and women, for instance, in terms of oral health assessment. Another example is the end of life care conversation, where there are differences among age groups. In the oldest age group of patients over 80, these patients do not have end of life care conversations to the same extent as in other age groups.

Method

This report presents an assessment of adherence to the National Board of Health and Welfare's national knowledge support base for good palliative care at the end of life from 2013 [1]. The report provides a basis for continuing quality assurance work in this area. The assessment is based on information from the national quality register and from the National Board of Health and Welfare's register, as well as from surveys conducted among county council and regional managers, all municipalities and districts, primary care organisations, specialist palliative care organisations, a selection of hospital clinics or similar institutions, and from children's and adolescents' clinics.

Indicators

The indicators used in the assessment are taken from the national knowledge support base. Appendix 2 contains a technical description of the indicators. The appendix can be obtained from the National Board of Health and Welfare's website www.socialstyrelsen.se.

List of indicators

Each indicator has been assigned a letter. These terms are consistently used in headings for the body text, in diagrams and in references.

Table 1.1 lists the indicators featuring in the assessment.

Table 1.1 List of indicators for palliative care at the end of life

	Indicators for palliative care at the end of life
Indicator A	Oral health assessment during the last week of life
Indicator B1	Pain assessment during the last week of life
Indicator B2	Symptom assessment during the last week of life
Indicator C	Pro re nata (PRN) opioid analgesics
Indicator D	PRN tranquillisers
Indicator E	No occurrence of pressure sores
Indicator F	End of life care conversation
Indicator G	Two or more inpatient admissions during the last 30 days of life
Indicator H	Report to the Swedish Register of Palliative Care

The results for all the indicators are described in detail in the report *National Guidelines – Performance Assessment 2016 – End of life palliative care. Indikatorer och underlag för bedömningar* [Indicators and material for assessments].

This report only describes the results for the areas for improvement identified by the National Board of Health and Welfare. See the chapter entitled *Areas for improvement.*

Using data sources

The assessment is primarily based on data obtained from the Swedish Register of Palliative Care and a number of surveys, as well as from the National Board of Health and Welfare's health data registers.

Data has been taken from the following of the National Board of Health and Welfare's individual-based registers:

- Patient Register
- Cause of Death Register.

Six surveys have been conducted:

- survey among county council and regional managers
- survey among municipalities and districts
- survey among primary care organisations
- survey among specialist palliative care organisations
- survey among a selection of hospital clinics or similar institutions
- survey among children's and adolescents' clinics.

Comparison of data

The results are presented and compared in the report at an organisational level for the country and for county councils (regions) and municipalities. In terms of the indicators, the results are organised at county level and contain both county council and municipal data. The indicators also describe the data broken down according to gender, age groups, diagnosis and form of care. In the case of the indicators, the term "county council" will continue to be used to include the regions as well.

First and foremost, the results for each county council, region and municipality in terms of quality assurance work over time should take precedence rather than comparisons with other county councils, regions and municipalities. The quality assurance work must also focus on the whole care process and not only on the indicators measured at a national level. Each organisation should also use its own prerequisites to identify strengths and weaknesses and look at how to continue with the quality-improvement efforts.

All the diagrams rank the county councils or counties in order, with the best result being at the top and the worst result being at the bottom of the diagram. Where it is not possible to rate the results, county councils and counties are ranked instead from the highest to the lowest value. The main purpose of ranking the various county councils, regions and municipalities is not to play them off against each other, but to highlight the variations there are throughout the country.

Detailed description of areas for improvement

This chapter describes a selection of results used as the basis for the assessments made by the National Board of Health and Welfare. A complete description of all the indicators and results featuring in the assessment, along with relevant diagrams is contained in the background report *National Guidelines – Performance Assessment 2016 – End of life palliative care. Indikatorer och underlag för bedömningar* [Indicators and material for assessments].
The following areas for improvement are included in the chapter:

- Offering staff ongoing training to enable them to provide good palliative care.
- Offering instruction to staff.
- More people requiring palliative care at the end of life must be given an oral health assessment.
- Increasing the proportion of people requiring palliative care at the end of life who undergo a pain assessment.
- More people requiring palliative care at the end of life need to have an end of life care conversation.
- Cooperating in order to obtain a general overview of the process for ensuring the provision of good palliative care.
- More patients require care planning, involving all the operators in order to ensure that the care will guarantee patient safety.
- More organisations require access to palliative counselling teams.
- More organisations need to offer support to the next of kin.
- More organisations need to have procedures for post-bereavement meetings.
- Providing palliative care to children and adolescents by ensuring that there are procedures about how palliative care should be provided.

Ongoing training

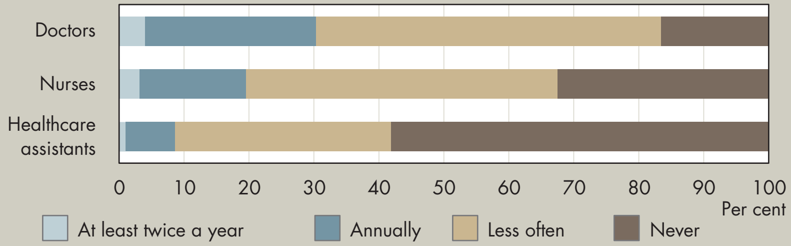
Ongoing training is a prerequisite for enabling staff to provide good palliative care. It is very important that staff have good knowledge of palliative care so that they can fulfil the patients' various needs for support and symptom relief and also enhance their quality of life. Ongoing training in palliative care is often based on a holistic approach where symptom relief, teamwork, communication and support for next of kin are key components.

Primary care staff are offered ongoing training to a small extent

In the primary care sector, around 30% of primary care institutions state that doctors are offered ongoing training in palliative care every year. The level of ongoing training varies among county councils between 10 and 55%. Twenty per cent of institutions state that they offer ongoing training annually to nurses and ten per cent to healthcare assistants. More than half of primary care institutions say that they never offer healthcare assistants ongoing training. A possible explanation for this is that the main responsibility for providing nursing care in the home has shifted from primary care to municipal healthcare services.

Diagram 4.1 Ongoing training for staff – primary care

Proportion of primary care staff involved in providing palliative care at the end of life who have been offered ongoing training (2013–2015).



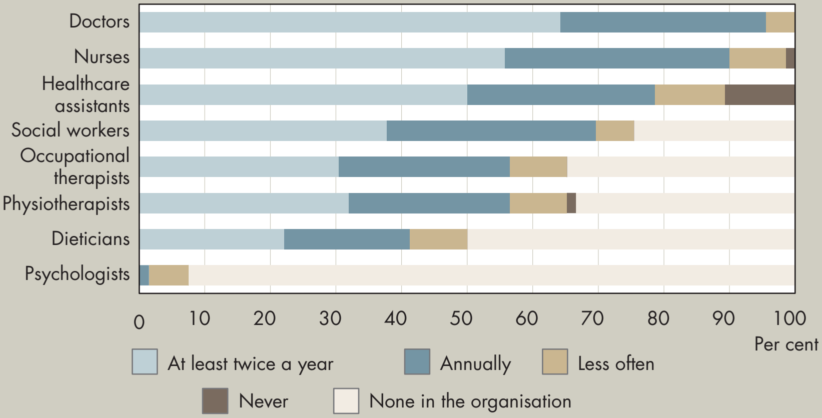
Source: National Board of Health and Welfare's survey, February 2016.

Almost all staff working in specialist palliative care organisations are offered ongoing training.

In the majority of specialist palliative care organisations, staff are offered ongoing training in palliative care every year. More than half of the organisations offer ongoing training to doctors and nurses at least twice every year (Diagram 4.3). Health care assistants and paramedical staff are not offered ongoing training to a similar degree. A possible explanation for this is that these categories of staff do not always belong to the specialist palliative care unit in terms of organisational structure.

Diagram 4.3 Ongoing training for staff – specialist palliative care

Proportion of staff involved in specialist palliative care who have been offered ongoing training (2013–2015).



Source: National Board of Health and Welfare's survey, February 2016.

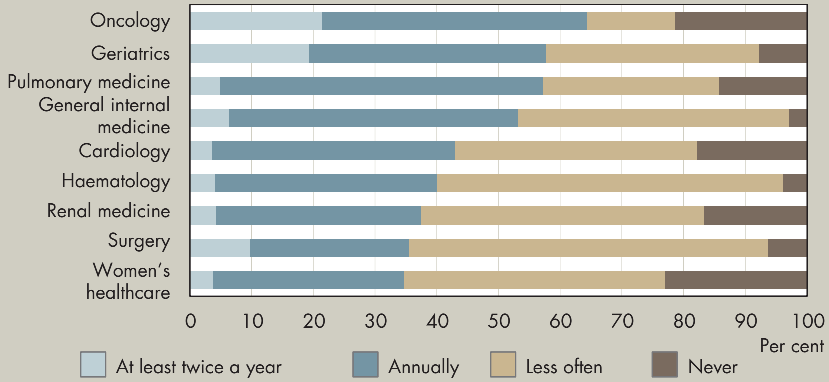
Ongoing training in palliative care is offered to a varying degree in hospital clinics

Of the hospital clinics or similar institutions which answered the question, around 70% of hospital clinics in the field of oncology stated that ongoing training was offered at least once a year to staff involved in providing palliative care at the end of life.

In all the hospital clinics the provision of ongoing training for doctors and nurses is roughly the same (Diagram 4.4 and 4.5). Other categories of staff are offered ongoing training to a somewhat less extent.

Diagram 4.5 Ongoing training for staff – hospital clinics

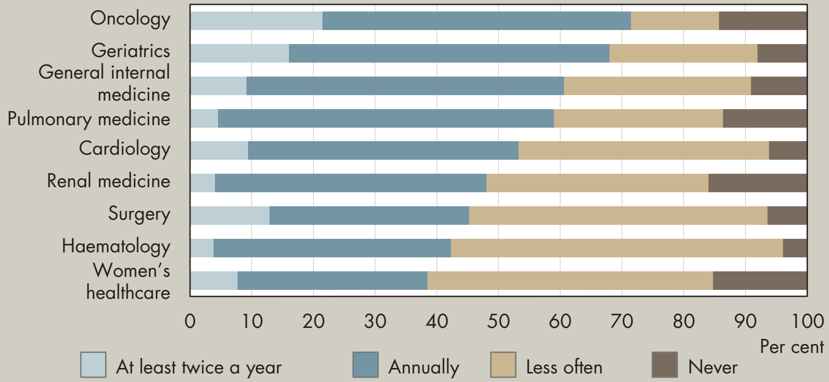
Proportion of doctors in hospital clinics or similar institutions involved in providing palliative care at the end of life who have been offered ongoing training (2013–2015).



Source: National Board of Health and Welfare's survey, February 2016.

Diagram 4.6 Ongoing training for staff – hospital clinics

Proportion of nurses in hospital clinics or similar institutions involved in providing palliative care at the end of life who have been offered ongoing training (2013–2015).



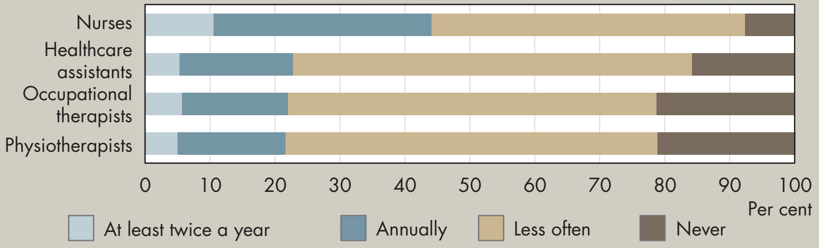
Source: National Board of Health and Welfare's survey, February 2016.

Ongoing training in palliative care – but not in all municipalities

Ongoing training in the municipalities involves the provision of ongoing training to staff who care for patients at the end of life in residential care homes, short-term care homes or the patients' own homes. It is mainly nurses within these organisations who are offered ongoing training in palliative care. A little 40% of municipalities offer nurses ongoing training once a year or more often. The proportion of municipalities which offer ongoing training to healthcare assistants, physiotherapists and occupational therapists is between 20 and 24%. Diagram 4.8 shows how often ongoing training is offered to care staff working in residential care homes. This pattern is similar for care staff working in short-term care homes and providing care in the patient's home.

Diagram 4.8 Ongoing training for staff – municipalities

Proportion of care staff in residential care homes in the municipality/district who have been offered ongoing training in palliative care at the end of life (2013–2015).



Source: National Board of Health and Welfare's survey, February 2016.

Assessment of the results

According to the recommendations made in the National Board of Health and Welfare's national knowledge support base for good palliative care at the end of life [1], county councils, regions and municipalities should offer ongoing training to staff who are involved in the provision of palliative care at the end of life.

In spite of this, the results from the National Board of Health and Welfare's assessment indicate that there are major disparities among county councils, regions and municipalities. Ongoing training is the responsibility of the medical healthcare service and should be offered to staff who are involved in providing palliative care.

The results indicate that, within specialist palliative care organisations, all staff are generally offered ongoing training, whereas for those in primary care, which mainly includes doctors who provide palliative care to patients, only 30% of primary care institutions state that ongoing training is offered.

There are hospital clinics within, for instance, oncology, pulmonary medicine and geriatric departments which do not offer any ongoing training at all. This is surprising as patients are cared for in these departments who are seriously ill or at the end of life.

There are noticeable differences in the municipalities. As a large proportion of palliative care is provided in the patient's own home or in residential care homes, staff who lack expertise in palliative care can create uncertainty in both patients and their next of kin. It is normal for a team to be formed to provide palliative care to the patient. For this reason, it is important that all staff receive ongoing training.

The National Board of Health and Welfare believes that the provision of ongoing training in the country is inequitable and that it is of paramount importance that staff are offered ongoing training as their knowledge of palliative care is vital to ensuring that patients at the end of life receive the support and symptom relief which they need.

Instruction

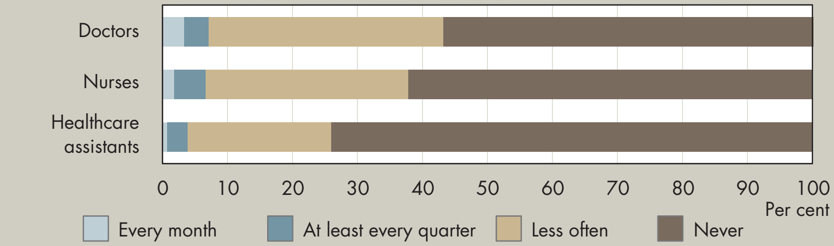
Instruction forms an important part of the provision of palliative care and gives staff an opportunity to reflect on experiences and events during their work. Instruction provides an opportunity to express feelings, receive support and guidance, and also to learn from experiences. Instruction can also be an important method for developing the skills of individual staff and of the organisation as a whole. Group instruction provides staff with a chance to learn from each other and to develop common methods for supporting patients and their next of kin. According to the National Board of Health and Welfare's recommendation in the national knowledge support base for good palliative care at the end of life, county councils, regions and municipalities should offer staff instruction on how to provide palliative care [1].

Almost no instruction is offered in primary care

Staff involved in providing palliative care at the end of life in primary care are offered instruction to a small extent. Seven per cent of primary care institutions offer instruction at least once a quarter to doctors and nurses, and four per cent to healthcare assistants (Diagram 5.1). A possible explanation for this is that the main responsibility for providing nursing care in the home has shifted from primary care to municipal healthcare services.

Diagram 5.1 Provision of instruction to staff – primary care

Proportion of primary care staff involved in providing palliative care at the end of life who have been offered instruction (2015).



Source: National Board of Health and Welfare's survey, February 2016.

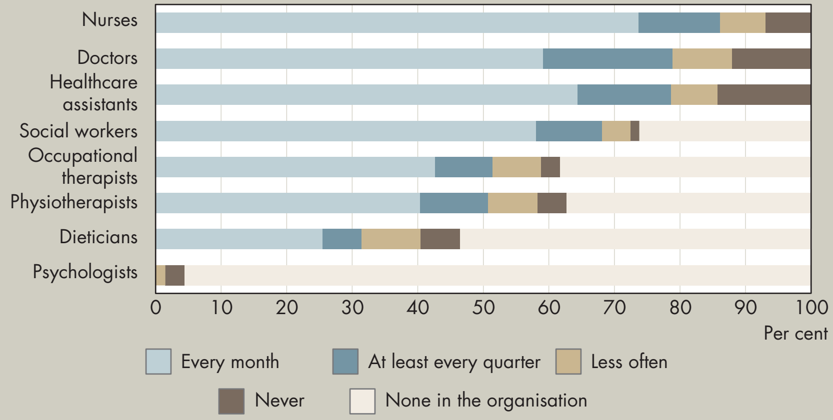
Instruction is offered to the vast majority of staff in specialist palliative care organisations

Most specialist palliative care organisations offer staff instruction on providing palliative care at least every quarter. More than half of the organisations offer it every month (Diagram 5.2).

According to comments from several organisations, paramedical staff do not belong to the specialist organisation, but, in terms of organisational structure, they belong to other organisations. Some specialist palliative care organisations do not include healthcare assistance either as part of their organisations.

Diagram 5.2 Provision of instruction for staff – specialist palliative care

Proportion of staff involved in specialist palliative care who have been offered instruction (2015).



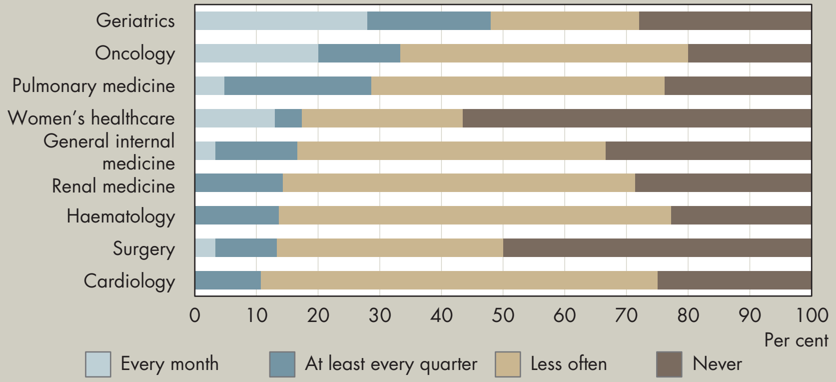
Source: National Board of Health and Welfare's survey, February 2016.

There is a varying provision of instruction in hospital clinics

From the selection of hospital clinics or similar institutions which answered the question, around half of the geriatric hospital clinics offer instruction to doctors and nurses at least every quarter. Instruction is offered to the other categories of staff, to a lesser extent. Diagrams 5.4 and 5.5 show the extent of provision of instruction to doctors and nurses.

Diagram 5.4 Instruction for staff – hospital clinics

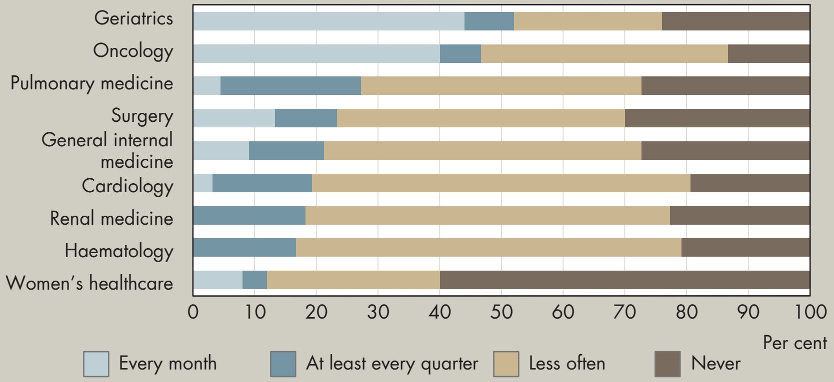
Proportion of doctors in hospital clinics or similar institutions involved in providing palliative care at the end of life who have been offered instruction (2015).



Source: National Board of Health and Welfare's survey, February 2016.

Diagram 5.5 Instruction for staff – hospital clinics

Proportion of nurses in hospital clinics or similar institutions involved in providing palliative care at the end of life who have been offered instruction (2015).



Source: National Board of Health and Welfare's survey, February 2016.

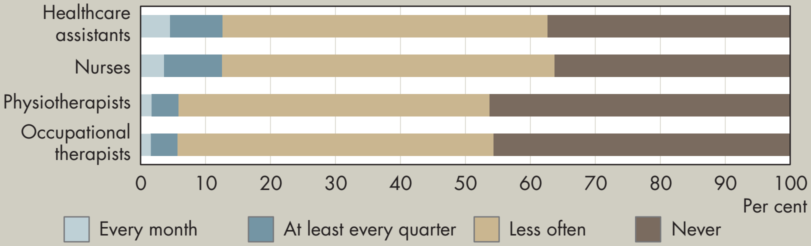
Instruction provided – but not in all municipalities

Instruction is offered in the municipalities to care staff looking after people at the end of life who live in residential care homes, short-term care homes or their own homes. Roughly one in eight nurses and healthcare assistants receive instruction at least every quarter.

In the case of physiotherapists and occupational therapists, roughly one in twenty receive instruction. Diagram 5.7 shows how often instruction is offered to care staff working in residential care homes. The picture is generally similar for staff providing care in short-term care homes and in patients' own homes. The provision of instruction to nurses and healthcare assistants varies among counties from no municipality to a third of municipalities offering instruction.

Diagram 5.7 Provision of instruction to staff – municipalities

Proportion of care staff in residential care homes in the municipality/district who have been offered instruction in palliative care at the end of life (2015).



Source: National Board of Health and Welfare's survey, February 2016.

Assessment of the results

In the national knowledge support base, the National Board of Health and Welfare recommends that county councils, regions and municipal healthcare services should offer healthcare staff instruction in providing palliative care [1]. The provision of instruction is also a priority area in the national care programme [2]. which must supplement the knowledge support base.

Several county councils and regions have responded that they have carried out initiatives to provide instruction on specialist palliative care after the knowledge support base was published and the national care programme introduced. At municipal healthcare level, only a third of the municipalities have carried out initiatives to provide instruction in this area.

The results indicate that the recommendation about offering instruction to staff involved in providing palliative care to patients at the end of life has not extended to all organisations, as intended by the knowledge support base. The National Board of Health and Welfare believes that the provision of instruction seems to be fairly neglected in most areas of healthcare and especially in municipalities, but this is also the case in hospital clinics and primary care.

Staff are often working in emotionally difficult situations and instruction should be provided on a regular basis. The largest shortcomings seem to be among staff involved in providing palliative care to patients. If staff do not receive ongoing training in palliative care or any instruction, this indicates that palliative care is still neglected in terms of skills development and staff support, which can make it difficult to meet the patient's need for palliative measures, such as symptom relief and interaction with both patients and their next of kin.

In the National Board of Health and Welfare's view, county councils, regions and municipalities should review the structure for providing instruction to staff looking after patients who require palliative care at the end of life. Providing instruction is an area which should be made a top priority. Everyone looking after patients receiving palliative care should basically be offered instruction on how to do this. The care provided to palliative patients cannot be provided over again or be rectified. Providing instruction ensures that staff will feel confident in interacting with patients receiving palliative care. Having an effective set of instructions will increase the chance of patients being provided with the best possible care at the end of life.

Oral health assessment during the last week of life (indicator A)

It is important for patients to have control over their oral health at the end of their life. Oral problems can, in some cases, be due to a fungal infection which, in turn, can affect a number of functions, such as the ability to swallow, speak and sleep, thereby having a powerful impact on patients' quality of life.

Results and variation

During the period 2011-2015, there was an increase in the proportion of patients who were documented as having had an oral health assessment during the last week of life (Diagram A1). The proportion is largest in the 18-29 age group (Diagram A4). In the country as a whole, 47% of patients had undergone this kind of assessment. There are disparities between the sexes. Variations between counties (county councils and regions) range from 35 to 60% (Diagram A2). A breakdown of diagnoses indicates that cancer is the diagnosis for which most oral health assessments have been carried out (Diagram A5).

Assessment of the results

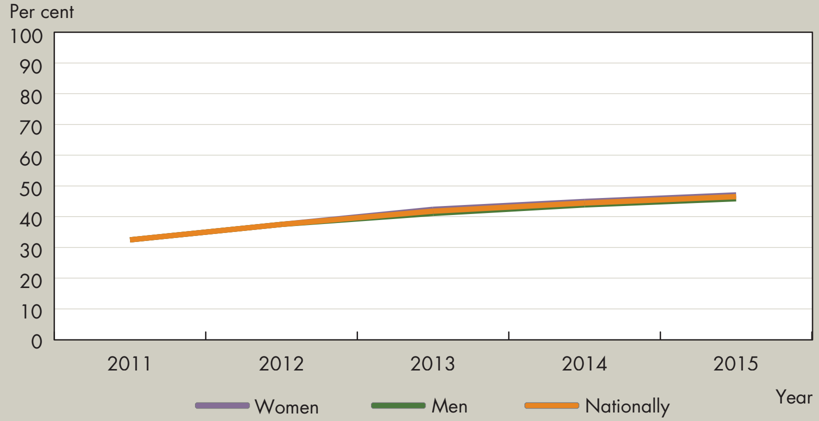
Patients receiving palliative care are in great need of care and oral health problems can have a significant impact on their quality of life. An oral health assessment is required to be able to identify problems and illnesses affecting the mucous membrane, teeth and gums. According to the Swedish Register of Palliative Care, an assessment is carried out most on patients in specialist palliative care units. The lowest proportion of oral health assessments has been carried out in hospital clinics where only around 40% of patients have undergone this type of assessment.

Many patients are given medication which affects their oral health. Therefore, they ought to be given an oral health assessment, especially those in the over 80s age group. These patients are often given several medicines which can cause dryness in their mouth and are the patient group which finds it the most difficult to take care of their oral health themselves. The mouth is obviously a part of the body and the care provided must be based on a holistic approach.

These results are worth highlighting when only less than half of patients have received an oral health assessment which has been documented. The National Board of Health and Welfare believes that more patients should be given an oral health assessment and that the disparities in this regard are too great. County councils, regions and municipalities should review their procedures so that more patients receiving palliative care can have an oral health assessment carried out. A possible explanation as to why so few patients have undergone this assessment is the lack of procedures for and expertise in carrying out oral health assessments. In such cases, the care staff need to receive training.

Diagram A1 Oral health assessment during last week of life

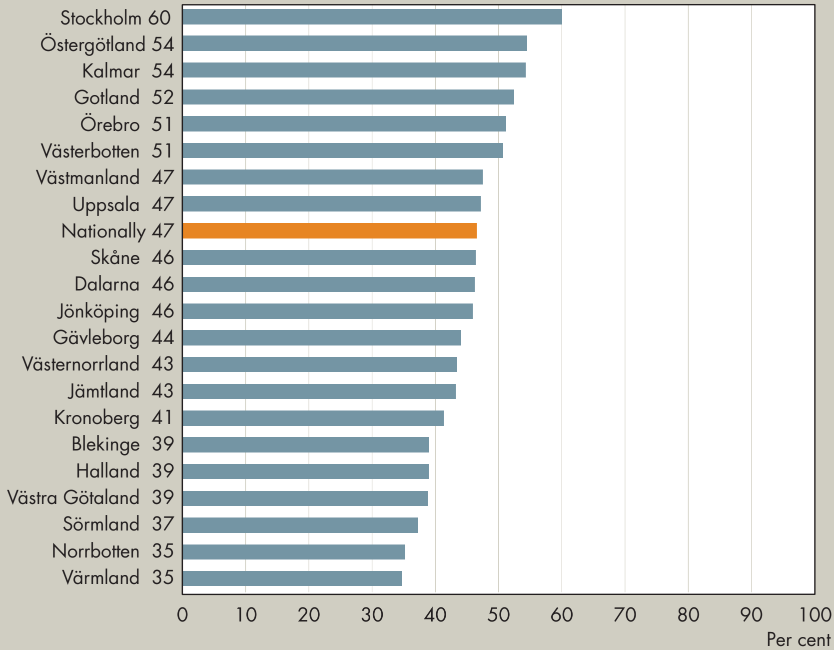
Proportion of patients who have undergone a documented oral health assessment during the last week of life.



Source: Swedish Register of Palliative Care.

Diagram A2 Oral health assessment during last week of life

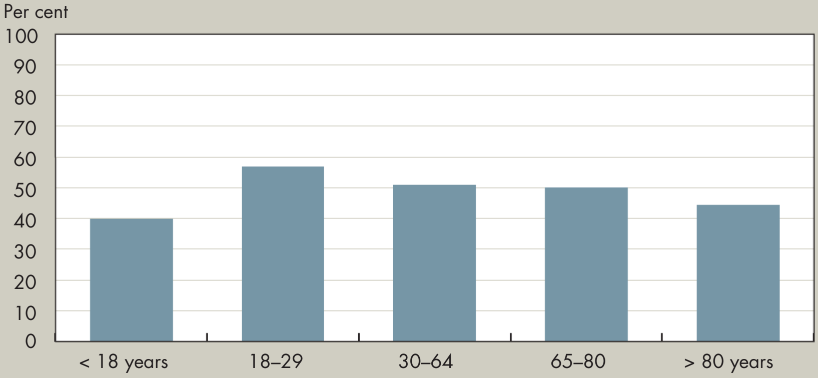
Proportion of patients who have undergone a documented oral health assessment during the last week of life (2015).



Source: Swedish Register of Palliative Care.

Diagram A4 Oral health assessment during last week of life

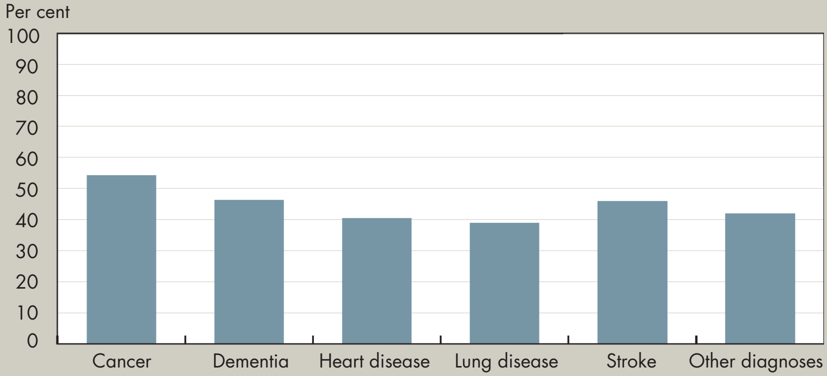
Proportion of patients who have undergone a documented oral health assessment during the last week of life, broken down by age group (2015).



Source: Swedish Register of Palliative Care.

Diagram A5 Oral health assessment during last week of life

Proportion of patients who have undergone a documented oral health assessment during the last week of life, broken down by diagnosis (2015).



Source: Swedish Register of Palliative Care.

Pain assessment during the last week of life (indicator B1)

Untreated pain diminishes the quality of life and also increases the risk of medical complications. The National Board of Health and Welfare gives a high priority to analysing and assessing pain regularly as part of the national knowledge support base for good palliative care at the end of life [1]. Pain assessment needs to be carried out in a systematic way to be able to identify pain symptoms and reduce the pain experienced by the patient receiving palliative care. Where possible, a structured assessment instrument should be used, but the patient is not usually able to reply at the end of life stage. Therefore, it is important to constantly make a clinical assessment to minimise the risk of untreated pain.

Results and variation

The period 2011–2015 saw an increase in the proportion of patients whose pain had been estimated using an approved pain assessment instrument during the last week of life (Diagram B1.1). The proportion is highest in the age groups under 18 and 30-64 (Diagram B1.4). In the country as a whole, 38% of patients have undergone pain assessment. There are disparities between the sexes. Variations between counties (county councils and regions) range from 21 to 57% (Diagram B1.2). A breakdown of diagnoses indicates that cancer is the diagnosis for which most pain assessments have been carried out (Diagram B1.5).

Assessment of the results

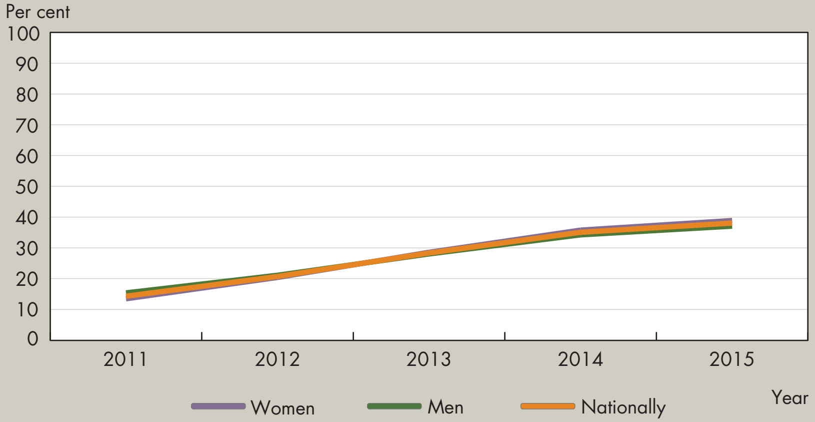
All patients should undergo pain assessment at the end of life stage, even during the last week of their life. This means that a procedure must be in place for regularly assessing pain (and other symptoms) to achieve a patient-reported basis for improving pain and symptom relief.

In spite of this, the results show that only 38% of patients have undergone a pain assessment, with major variations between counties (county councils and municipalities). There is a gap of more than 35 percentage points between the best and worst scores.

The National Board of Health and Welfare believes that a significantly higher proportion of patients should be given the opportunity to have their pain assessed, thereby providing a better basis for providing sufficient pain relief during their final days of life. The counties (county councils and municipalities) which are the worst in the comparison should review their pain assessment procedures and ensure that the pain assessment instruments which are available and recommended will benefit patients to a considerably greater extent.

Diagram B1.1 Pain assessment during last week of life

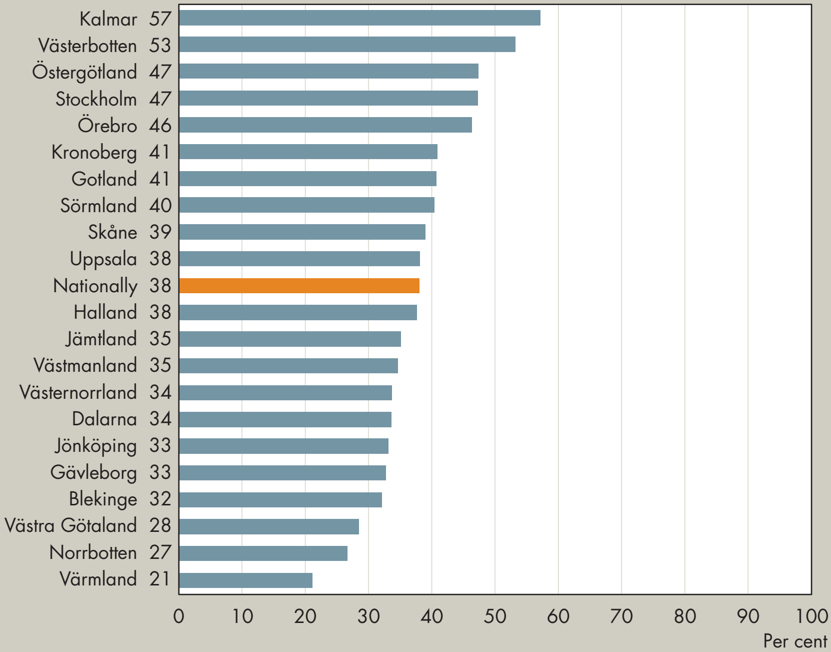
Proportion of patients whose pain has been assessed using an approved pain assessment instrument during the last week of life.



Source: Swedish Register of Palliative Care.

Diagram B1.2 Pain assessment during last week of life

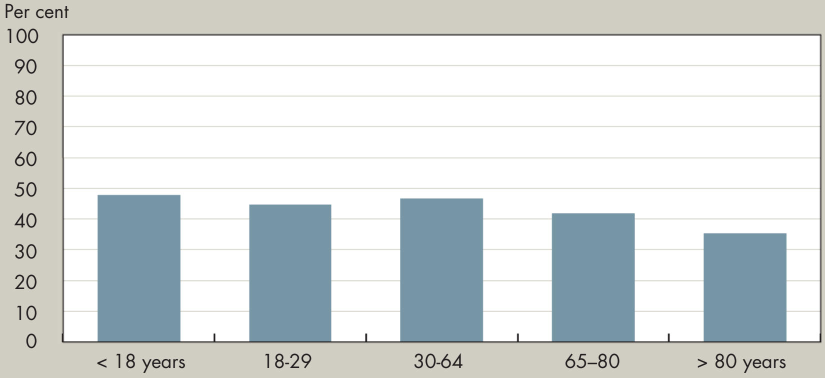
Proportion of patients whose pain has been assessed using an approved pain assessment instrument during the last week of life (2015).



Source: Swedish Register of Palliative Care.

Diagram B1.4 Pain assessment during last week of life

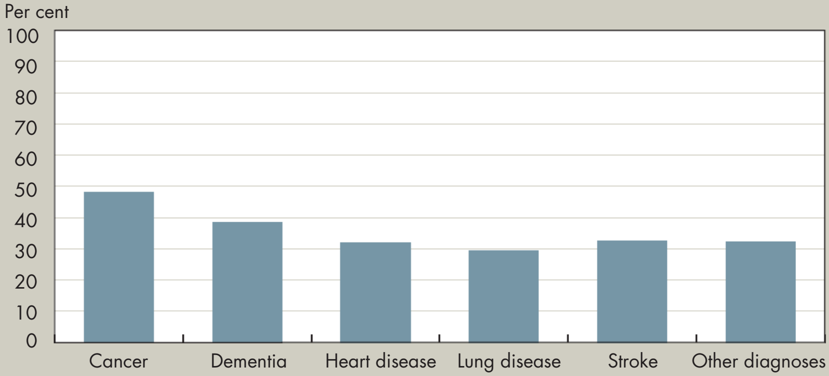
Proportion of patients whose pain has been assessed using an approved pain assessment instrument during the last week of life, broken down by age group (2015).



Source: Swedish Register of Palliative Care.

Diagram B1.5 Pain assessment during last week of life

Proportion of patients whose pain has been assessed using an approved pain assessment instrument during the last week of life, broken down by diagnosis (2015).



Source: Swedish Register of Palliative Care.

End of life care conversations (indicator F)

A key aspect of the support and care provided at the end of life is that individuals are well informed about their situation. Being informed is of intrinsic value as it provides patients receiving palliative care with the opportunity to reach a decision independently about what kind of care they want to receive during the final period. It may be about deciding where they are going to die and having time to see and say goodbye to their next of kin. Not all patients want to know everything, at least not during the first discussion. Some patients who are dying have lost the ability to actively participate in discussions about their continued care. In this case, it is just as important that the dialogue is held with the patient's next of kin.

Results and variation

During the period 2011–2015, there was an increase in the proportion of patients whose death was expected by the care staff and an end of life care conversation was held with them (Diagram F1). The proportion is largest in the 30-64 age group (Diagram F4). In the country as a whole, 55% of patients held this kind of discussion. Variations between counties (county councils and regions) range from 44% to 65% (Diagram F2). A breakdown of diagnoses indicates that cancer is the diagnosis for which most end of life care conversations have been held (Diagram F5).

Assessment of the results

The end of life care conversation can be challenging for patients, their next of kin and the care staff. But ensuring good-quality communication about the prognosis and care to be provided at the end of life can avoid any anxiety and misunderstanding, as well as improve the patient's quality of life. For this reason, it is important that the care staff carry out what is known as a transition point assessment and make plans for an end of life care conversation. All patients should be offered an end of life care conversation. But there may be some patients who do not want to know everything, at least not during the first discussion. The care pathway can vary depending on the diagnosis, which means that an end of life care conversation can be held on several occasions.

The skill required in holding an end of life care conversation does not differ in any crucial way from the skill required to hold any other “difficult” discussions about care. Basic training in how to hold discussions should be given as part of all basic healthcare training courses. In this instance, holding an end of life care conversation should mainly be part of doctor training courses. Subsequently, this ability should be honed through ongoing training and internal skills training.

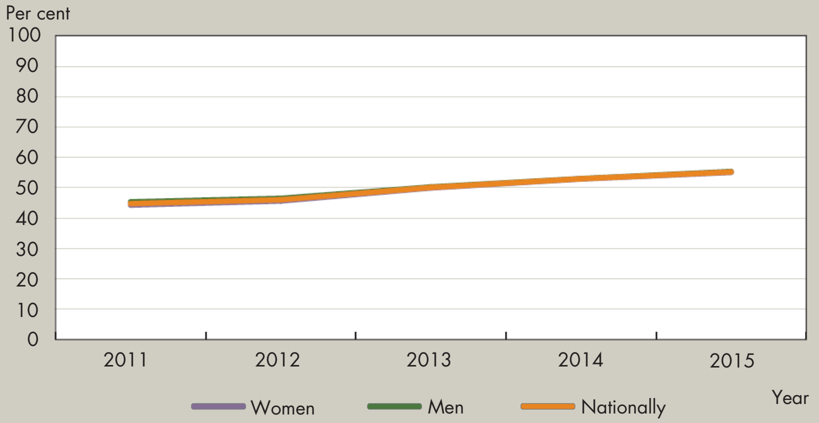
For patients with chronically progressive diseases and for elderly patients in general, it is a natural step to hold discussions about the patient’s assessments and wishes when there is a deterioration in the illness or functional status, thereby making it possible to set common goals in terms of the care to be provided. In this case, an end of life care conversation dealing with the transition to care at the end of life will become part of ensuring continuity.

The results indicate that only half of patients have had an end of life care conversation. There are also differences among counties (county councils and municipalities) and among age groups. In the over 80s age group, these patients do not have end of life care conversations as often as patients in other age groups.

The National Board of Health and Welfare believes that the city councils and municipalities should have gone further in this important task of having an end of life care conversation in order to discuss the care based on the patient’s condition, requirements and wishes.

Diagram F1 End of life care conversation

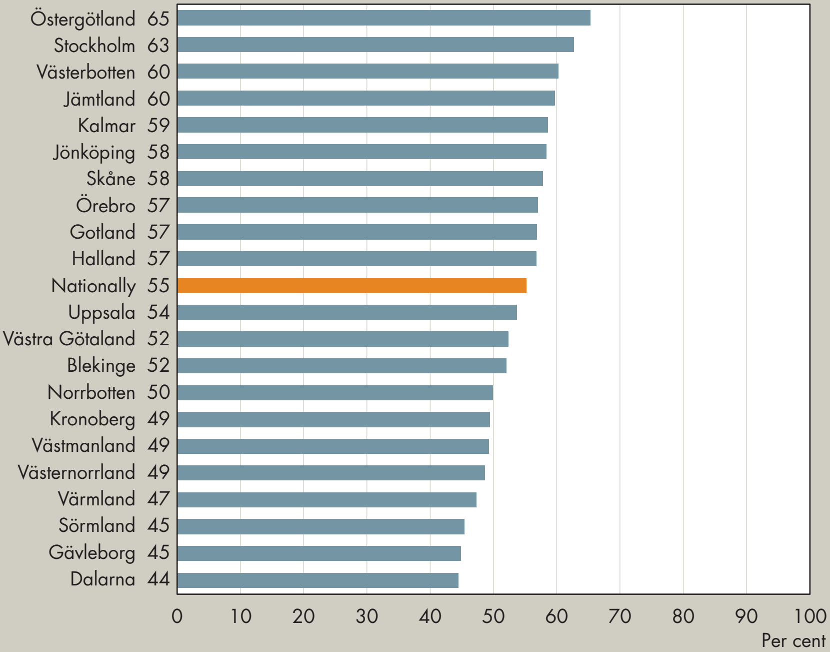
Proportion of patients at the end of life stage who had an end of life care conversation.



Source: Swedish Register of Palliative Care.

Diagram F2 End of life care conversation

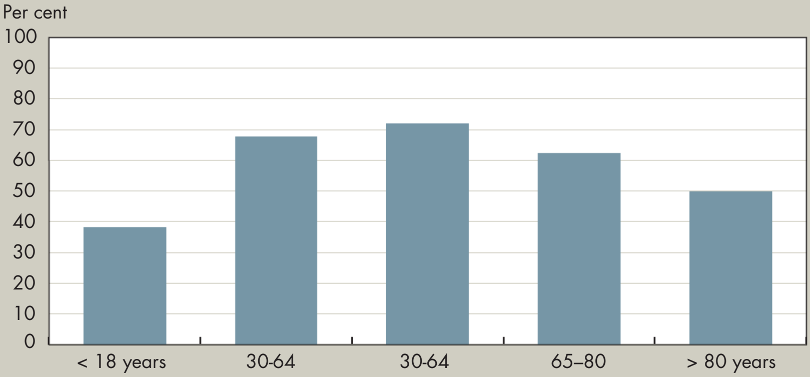
Proportion of patients at the end of life stage who had an end of life care conversation (2015).



Source: Swedish Register of Palliative Care.

Diagram F4 End of life care conversation

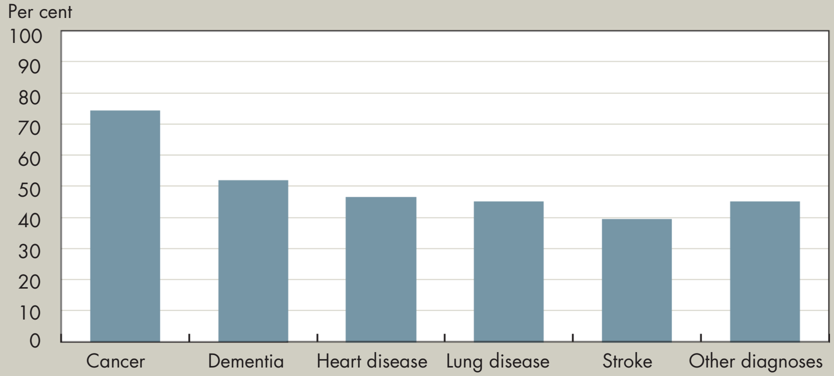
Proportion of patients at the end of life stage who had an end of life care conversation, broken down by age (2015).



Source: Swedish Register of Palliative Care.

Diagram F5 End of life care conversation

Proportion of patients at the end of life stage who had an end of life care conversation, broken down by diagnosis (2015).



Source: Swedish Register of Palliative Care.

Cooperation and coordination

Efficient cooperation and coordination between the county councils' and regions' organisations and the municipalities is vital for ensuring that the care provided will work for every individual. Palliative care includes input from several disciplines and often from several administration managers. This is why cooperation and coordination are key to good palliative care.

Cooperation procedures

One way of ensuring cooperation is by using procedures. Procedures mean, in this case, a certain approach which is used with regard to how cooperation is to operate. The procedure must be familiar to staff in the organisations and used by them. Procedures can be both verbal and in writing.

Ensuring cooperation in county councils and regions

Primary care

Close to 90% of the country's primary care institutions indicated that they have procedures in place for establishing cooperation with municipal healthcare services for patients requiring palliative care at the end of life (Table 6.1). The proportion for specialist palliative care units and inpatient facilities was more than 60%. The reply to this question shows that primary care has different tasks to carry out throughout the country. According to the description from some primary care institutions, they seldom have or do not have responsibility at all for patients requiring palliative care. Several institutions comment that palliative care is included primarily as part of the doctors' remit.

Table 6.1 Cooperation procedures – primary care

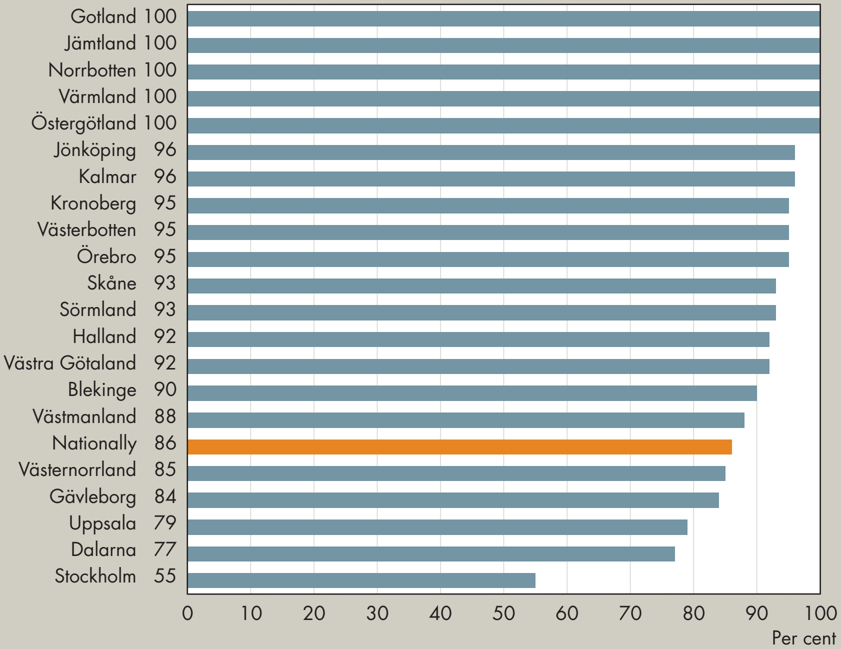
Proportion of primary care institutions which have procedures about how cooperation is to operate for patients receiving palliative care.

	Procedures for cooperation with municipal healthcare services	Procedures for cooperation with inpatient facilities	Procedures for cooperation with specialist palliative care units
Primary care institutions	86	64	68

Source: National Board of Health and Welfare survey for specialist palliative care, February 2016.

Diagram 6.1 Cooperation procedures – primary care

Proportion of primary care institutions which have procedures about how cooperation is to operate with the municipal healthcare services for patients requiring palliative care at the end of life.



Source: National Board of Health and Welfare's survey, February 2016.

Specialist palliative care

More than 90% of the specialist palliative care organisations have indicated that they have procedures in place for cooperating with inpatient facilities and municipal healthcare services. Almost 75% have stated that they have procedures for cooperation with primary care.

Table 6.2 Cooperation procedures – specialist palliative care

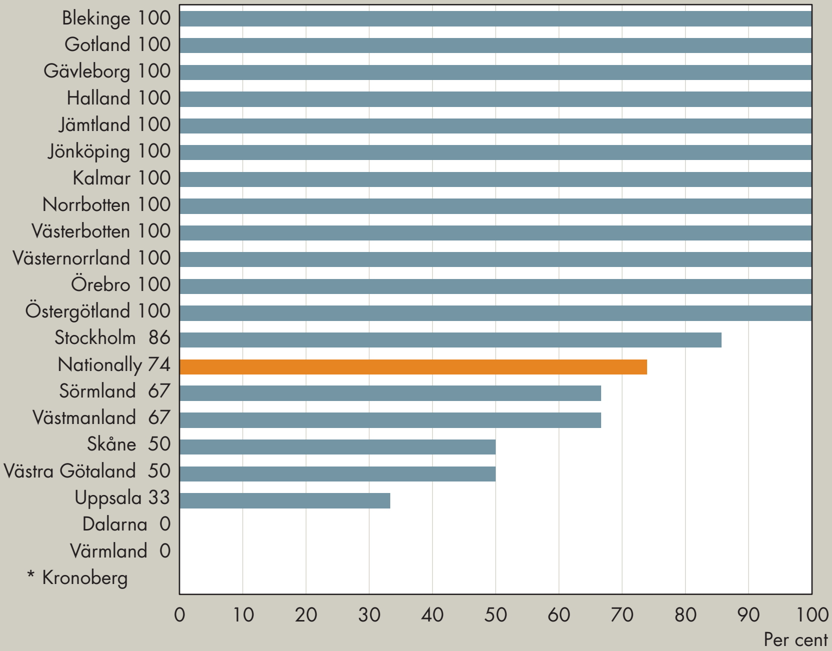
Proportion of specialist palliative care organisations which have cooperation procedures.

	Procedures for cooperation with primary	Procedures for cooperation with inpatient facilities	Procedures for cooperation with municipal healthcare
Specialist palliative care	74	93	94

Source: National Board of Health and Welfare survey for specialist palliative care, February 2016.

Table 6.4 Cooperation procedures – specialist palliative care

Proportion of specialist palliative care organisations which have procedures about how cooperation is to operate with primary care for patients requiring palliative care at the end of life.



* No information available

Source: National Board of Health and Welfare’s survey, February 2016.

Hospital clinics

The majority of hospital clinics or similar institutions which were asked this question said that they had procedures describing how cooperation is to operate. The availability of procedures for cooperation with the specialist palliative care units varies between 75 and 96%, whereas the availability of these procedures with primary care and municipal organisations is slightly less.

Table 6.3 Cooperation procedures – hospital clinics

Proportion of hospital clinics or similar institutions which have procedures about how cooperation is to operate for patients receiving palliative care.

Selection of hospitals or equivalent	Procedures for cooperation with municipalities	Procedures for cooperation with specialist palliative care	Procedures for cooperation with primary care
Geriatrics	84	96	84
Women's healthcare	77	92	76
General internal	67	80	61
Haematology	87	88	68
Cardiology	61	75	53
Pulmonary medicine	86	91	73
Renal medicine	73	78	65
Surgery	70	91	78
Oncology	75	94	68

Source: National Board of Health and Welfare's survey for a selection of hospital clinics or similar institutions, February 2016.

Ensuring cooperation in the municipalities

More than 80% of municipalities have stated that they have procedures for cooperation with primary care (Table 6.4). Procedures for cooperation with specialist palliative care units are most common where patients are treated in their own home. In the case of inpatient facilities, more than 60% of the municipalities have procedures in place. The answers show that responsibility for palliative care varies throughout the country.

Table 6.4 Cooperation procedures – municipalities

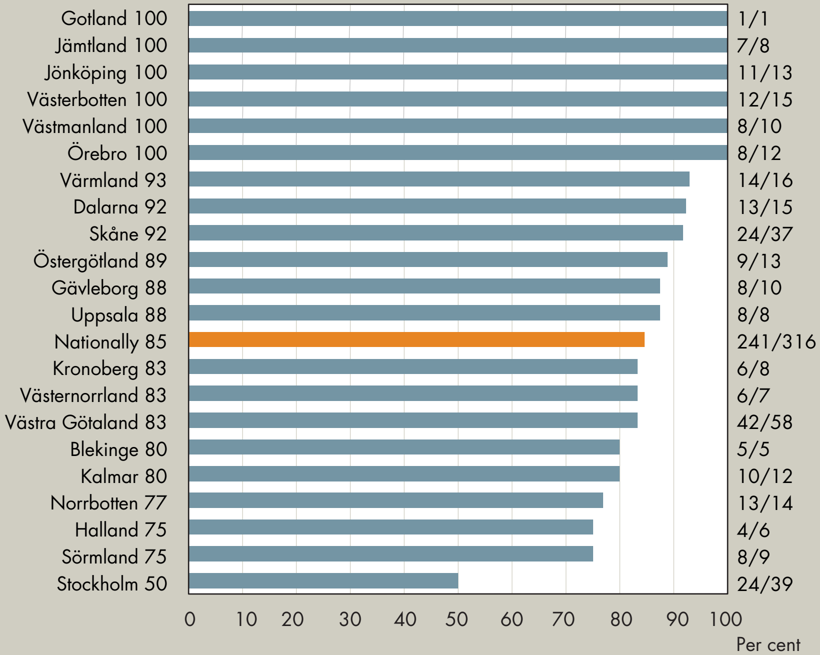
Proportion of municipalities and districts which have procedures about how cooperation is to operate for patients receiving palliative care.

Form of care in municipality	Procedures for cooperation with primary care	Procedures for cooperation with specialist palliative care	Procedures for cooperation with inpatient facilities
Residential care home	85	71	66
Short-term care home	83	76	64
Provision in patients' own	84	82	69

Source: National Board of Health and Welfare's survey for municipalities and districts, February 2016.

Table 6.5 Cooperation procedures – municipalities

Proportion of municipalities and districts which have procedures in residential care homes about how cooperation is to operate with primary care for patients requiring palliative care at the end of life.



* Number of municipalities responding to the survey/total number of municipalities in the county.

Source: National Board of Health and Welfare's survey, February 2016.

Assessment of the results

It is important that county councils, regions and municipalities have a general overview of the process which contributes to good palliative treatment and care as this will facilitate planning for this provision, the allocation of responsibility and good cooperation among the various operators. One way of doing this is to have procedures in place. The National Board of Health and Welfare believes that there should be procedures in place in all organisations in order to ensure that palliative care is provided in an equitable manner and to safeguard patient safety for the individual

Care planning

When a patient receiving palliative care needs to be transferred to another form of care or another unit, it is important that information about the patient's previous and current medical history, medical prescriptions and future plans is passed on and that plans are made along with the operators who will be involved in the continued care of the patient. Patients should be included in the planning process and their next of kin can be involved, if the patient wishes.

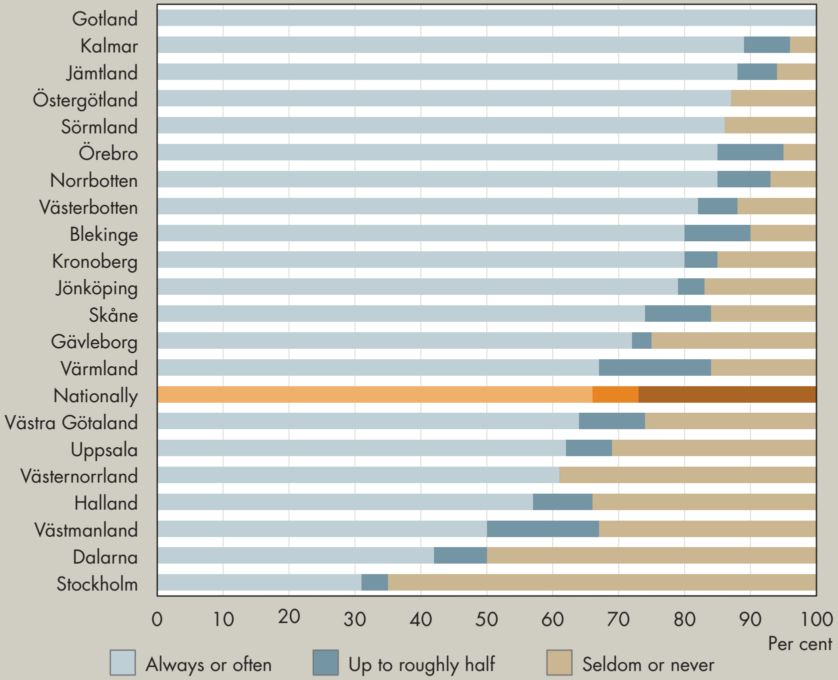
County councils' and regions' care planning activities

Primary care

As part of the survey from the National Board of Health and Welfare, primary care institutions were asked to what extent care planning was carried out with the municipal healthcare services for patients receiving palliative care at the end of life. Almost two thirds of primary care institutions replied that care planning was always or often carried out. The replies indicated that there were differences in primary care's provision of palliative care or that primary care institutions rarely had patients requiring palliative care.

Diagram 6.8 Care planning – primary care

Proportion of primary care institutions which have carried out care planning with municipal healthcare services for patients requiring palliative care at the end of life (2015).



Source: National Board of Health and Welfare's survey, February 2016.

Specialist palliative care

The National Board of Health and Welfare asked the specialist palliative care organisations to what extent municipal healthcare services and primary care were involved in planning care when patients receiving palliative care were discharged.

The overwhelming majority of specialist palliative care organisations have stated that municipal healthcare services are always or mostly involved in planning care when patients are discharged (Table 6.5). A number of organisations replied that they generally never had any patients receiving palliative care who were discharged to primary care.

Table 6.5 Care planning – specialist palliative care

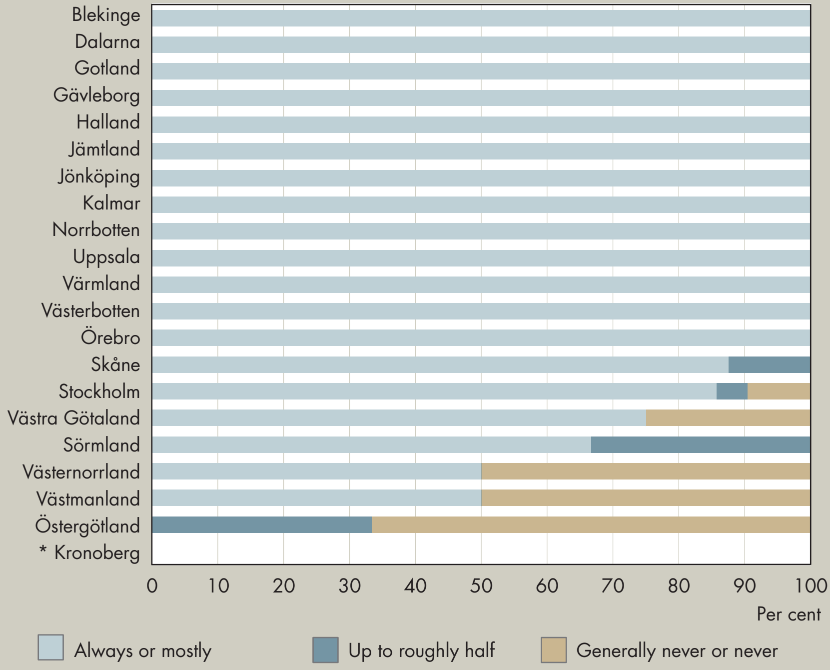
Proportion of specialist palliative care organisations who replied that municipalities, districts and primary care institutions are involved in planning care when patients requiring palliative care at the end of life are discharged (2015).

	Municipal healthcare services involved in care planning on discharge	Primary care involved in care planning on discharge
Always	47	21
Mostly	36	13
Up to roughly half	6	4
Generally never	11	35
Never	0	28

Source: National Board of Health and Welfare survey for specialist palliative care, February 2016.

Diagram 6.10 Care planning – specialist palliative care

Proportion of specialist palliative care organisations which have carried out care planning with municipal healthcare service when patients requiring palliative care at the end of life are discharged (2015).



* No information available

Source: National Board of Health and Welfare's survey, February 2016.

Hospital clinics

When a selection of hospital clinics or similar institutions were asked to what extent municipal healthcare services were involved in planning care when patients requiring palliative care at the end of life were discharged, most of the clinics replied that this always or very often happened. A similar question was asked regarding the involvement of primary care in this process, with between 20 and 45% of the hospital clinics responding that this always or often happened.

Table 6.7 Care planning – hospital clinics

Proportion of hospital clinics or similar institutions which replied that municipalities, districts and primary care institutions are involved in planning care when patients requiring palliative care at the end of life are discharged (2015).

	Municipality is always or often involved in care	Primary care is always or often involved in care
Geriatrics	76	24
Women's healthcare	68	20
General internal medicine	74	33
Haematology	77	36
Cardiology	61	29
Pulmonary medicine	70	39
Renal medicine	70	45
Surgery	73	24
Oncology	75	37

Source: National Board of Health and Welfare's survey for a selection of hospital clinics or similar institutions, February 2016.

Municipalities' care planning activities

The majority of municipalities replied that care planning is always or often carried out along with primary care, specialist palliative care organisations and hospital clinics.

Table 6.10 Care planning – municipalities

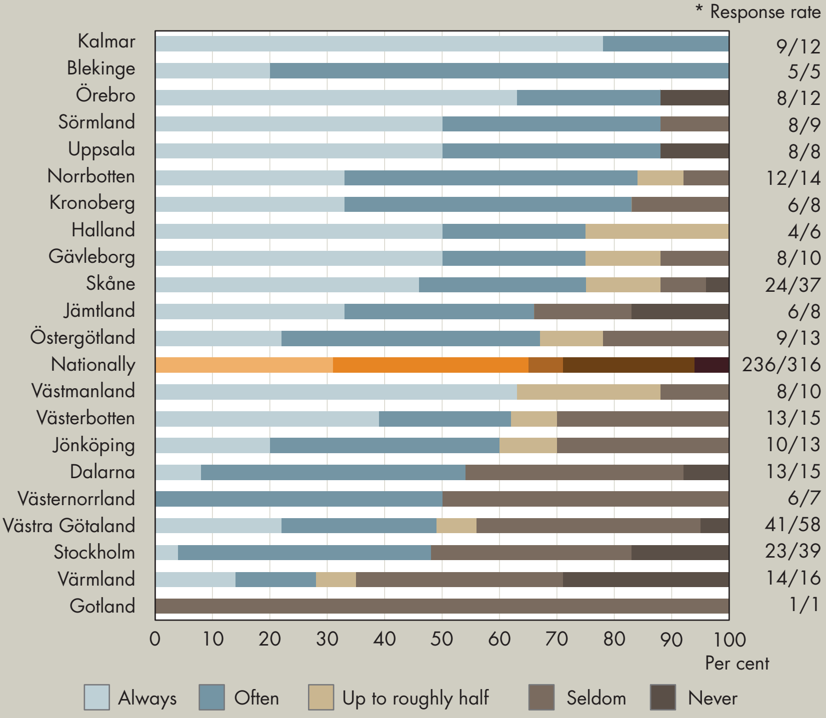
Proportion of municipalities and districts where care planning has been carried out for patients requiring palliative care at the end of life (2015).

	Care planning with primary care	Care planning with specialist palliative care	Care planning with inpatient facilities
Always	31	40	38
Often	33	29	33
Up to roughly half	6	6	7
Seldom	23	20	19
Never	6	5	3

Source: National Board of Health and Welfare's survey for municipalities and districts, February 2016.

Diagram 6.12 Care planning – municipalities

Proportion of municipalities and districts where care planning has been carried out with primary care when discharging patients requiring palliative care at the end of life (2015).



* Number of municipalities responding to the survey/total number of municipalities in the county.

Source: National Board of Health and Welfare's survey, February 2016.

Assessment of the results

All patients requiring palliative care, who are planned to be discharged from inpatient care to primary care and municipal healthcare services, need to have their care planned. The task of planning care means that it is clearly defined how responsibility is allocated and who does what, and where the various areas of responsibility are when the patient is discharged from inpatient care. Therefore, it is paramount that everyone who provides the patient's care is involved in the care planning process. The patient, relatives and care providers must be aware of the purpose and focus of the care being provided. The outcome should be that care planning is carried out for all patients as the care provided must ensure the patient's safety. Otherwise, there is a risk of patients not receiving the input they require if there is no care planned for them.

Access to palliative counselling teams

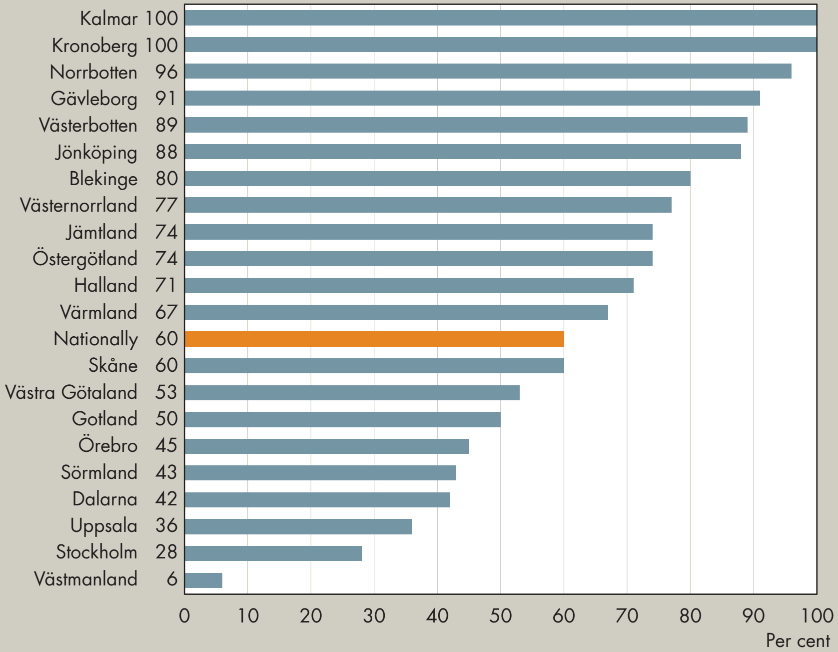
The task of a palliative counselling team is to improve the palliative care provided. The team is a resource for supporting care staff and offering advice in direct patient cases. This can relate to matters concerning medication, ethical issues or matters about support for next of kin. The team does not have any responsibility for patients.

Primary care's access to palliative counselling teams

Sixty per cent of primary care institutions state that they have access to palliative counselling teams (Diagram 6.13). The figures vary among county councils between 6 and 100%. The responses from several primary care institutions indicate that they have a facility for contacting palliative teams or specialist palliative care organisations.

Diagram 6.13 Palliative counselling teams – primary care

Proportion of primary care institutions which have access to palliative counselling teams.



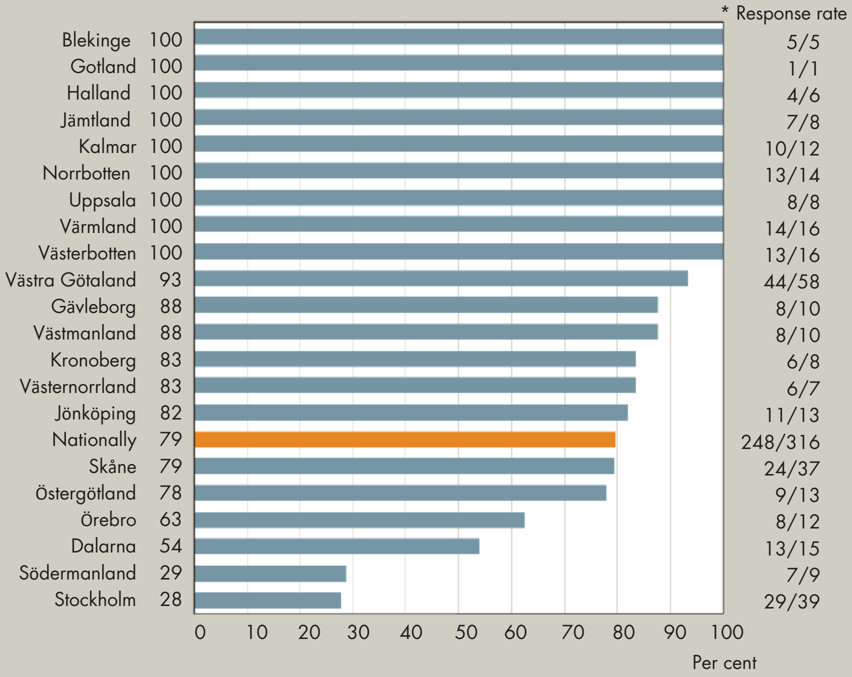
Source: National Board of Health and Welfare's survey, February 2016.

Municipalities' access to palliative counselling teams

Eighty per cent of the municipalities indicate that they have access to palliative counselling teams (Diagram 6.14). Several municipalities mention that they work closely with specialist palliative care organisations, but there are also municipalities which do not know whether they have access to palliative counselling teams.

Diagram 6.14 Palliative counselling teams – municipalities

Proportion of municipalities and districts which have access to palliative counselling teams.



* Number of municipalities responding to the survey/total number of municipalities in the county.

Source: National Board of Health and Welfare's survey, February 2016.

Assessment of the results

In the case of primary care institutions which stated that they seldom have responsibility for palliative patients, there should be a considerable need for a palliative counselling team. The fact that there are municipalities which do not know whether they have access to a palliative counselling time highlights the lack of communication during care transitions.

There are some primary care institutions and municipalities which answered that they have close contacts with specialist palliative care organisations for obtaining advice and support on matters relating to palliative care. The results show that there are major variations in terms of access to palliative counselling teams. This means that additional efforts need to be made to ensure that palliative care is available.

Support for next of kin

Support for next of kin is a basic part of palliative care and it can be provided in many different ways. Support often means that the healthcare service offers the next of kin the chance to participate in providing care, but it also means emotional and practical support. The need for support may vary during the period of the patient's illness, depending on its course.

County councils' and regions' activities involving support for next of kin

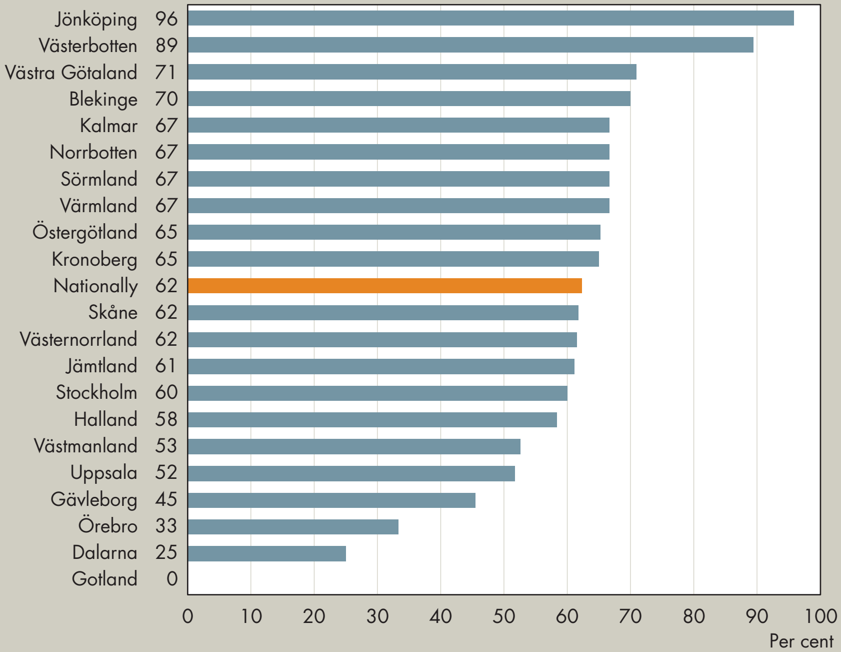
Primary care's support for next of kin

Around six out of ten primary care institutions replied that they offer some form of support to the next of kin of patients requiring palliative care at the end of life. The level of support offered to next of kin varies among the county councils and regions, ranging from no primary care institutions offering support to generally all primary care institutions offering support (Diagram 8.1). A number of primary care institutions mention that they are not responsible for patients receiving palliative care or only have a few patients like this.

One in three primary care institutions have procedures in place for focusing on children and adolescents who are the patient's next of kin. There are variations among county councils and regions on this issue. The proportion of primary care institutions which have these procedures varies from 5% to 63%.

Diagram 8.1 Support for next of kin – primary care

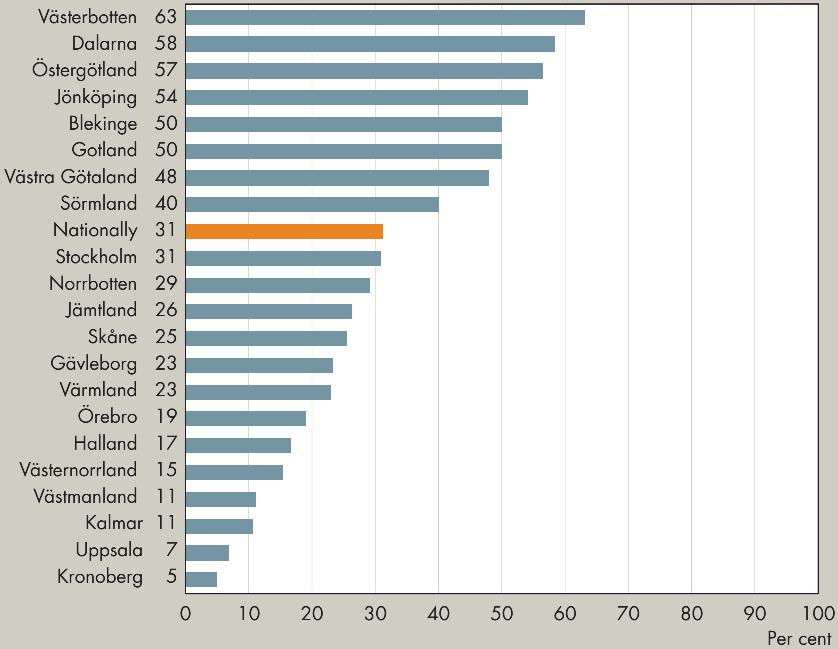
Proportion of primary care institutions offering support to the next of kin of patients requiring palliative care at the end of life.



Source: National Board of Health and Welfare’s survey, February 2016.

Diagram 8.2 Procedures for supporting next of kin – primary care

Proportion of primary care institutions which have procedures for taking care of children and adolescents who are the next of kin of patients requiring palliative care at the end of life.



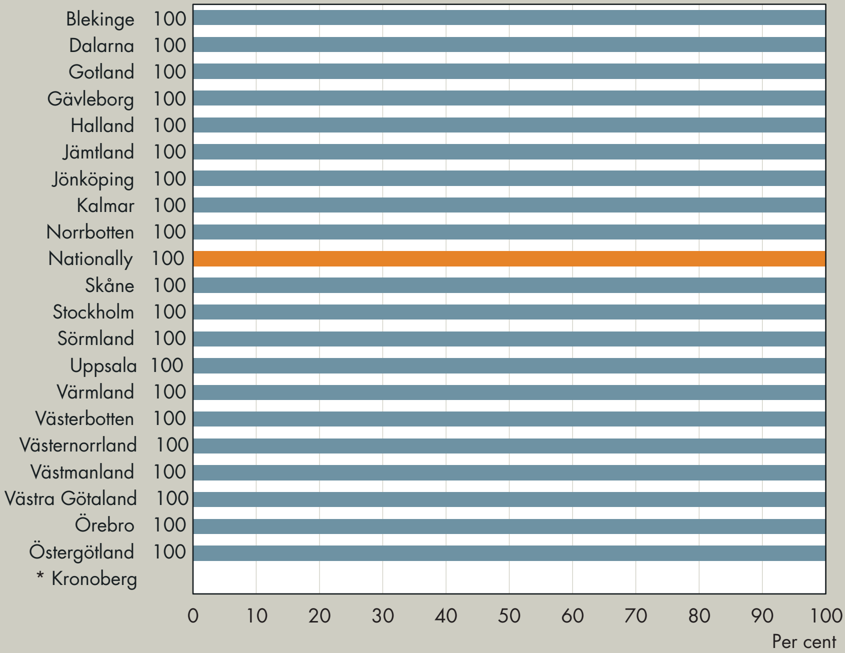
Source: National Board of Health and Welfare's survey, February 2016.

Support for next of kin from specialist palliative care organisations

In general, all specialist palliative care organisations offer some form of support to the next of kin of patients requiring palliative care at the end of life (Diagram 8.3). Seventy-seven per cent of specialist palliative care organisations have procedures focusing on children and adolescents who are the patient's next of kin (Diagram 8.4).

Diagram 8.3 Support for next of kin – specialist palliative care

Proportion of specialist palliative care organisations offering support to the next of kin of patients requiring palliative care at the end of life.

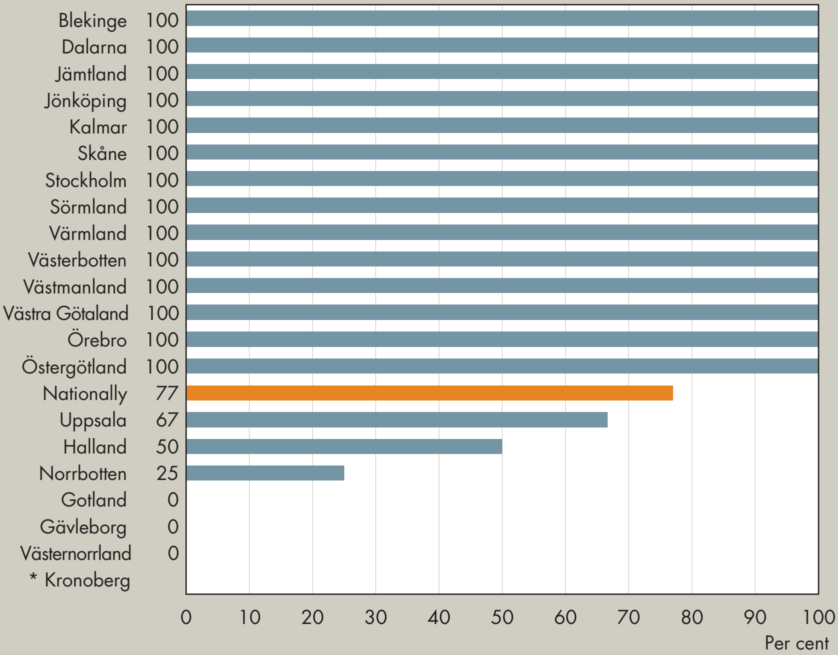


* No information available.

Source: National Board of Health and Welfare’s survey, February 2016.

Diagram 8.4 Procedures for support for next of kin – specialist palliative care

Proportion of specialist palliative care organisations which have procedures for focusing on children and adolescents who are the next of kin of patients requiring palliative care at the end of life.



* No information available.

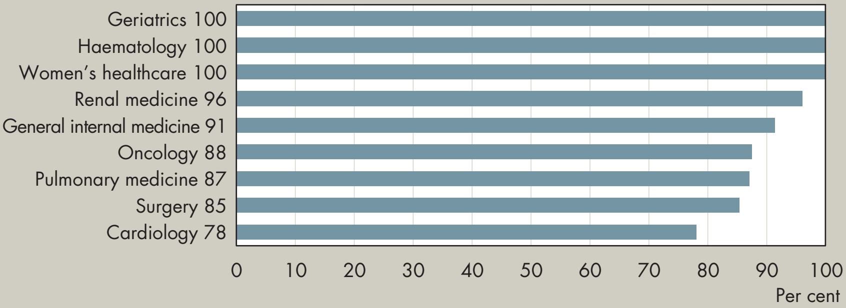
Source: National Board of Health and Welfare's survey, February 2016.

Hospital clinics' support for next of kin

All hospital clinics or similar institutions specialising in geriatrics, haematology and women's healthcare state that they offer support to the next of kin of patients requiring palliative care at the end of life (Diagram 8.5). In terms of procedures for focusing on children and adolescents who are the patient's next of kin, there is a variation among hospital clinics of between 52% and 93% (Diagram 8.6).

Diagram 8.5 Support for next of kin – hospital clinics

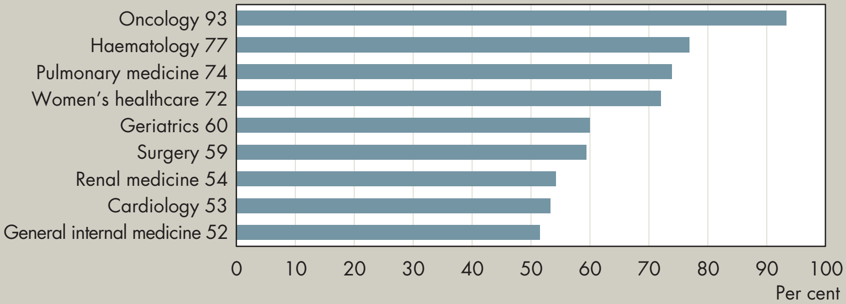
Proportion of hospital clinics or similar institutions offering support to the next of kin of patients requiring palliative care at the end of life.



Source: National Board of Health and Welfare's survey, February 2016.

Diagram 8.6 Procedures for supporting next of kin – hospital clinics

Proportion of hospital clinics or similar institutions which have procedures for focusing on children and adolescents who are the next of kin of patients requiring palliative care at the end of life.



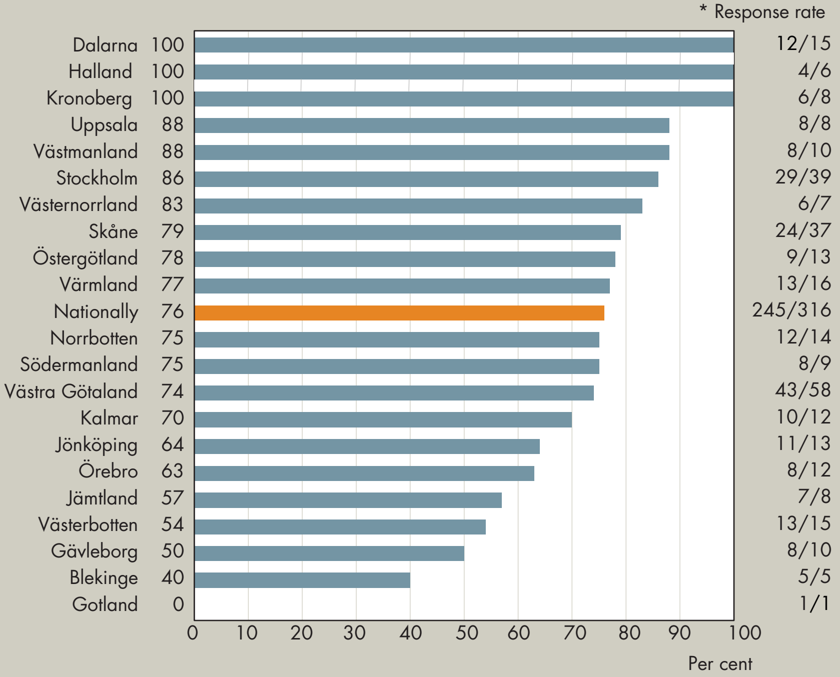
Source: National Board of Health and Welfare's survey, February 2016.

Municipalities' activities providing support for next of kin

Around three quarters of municipalities state that they offer some form of support to the next of kin of patients requiring palliative care at the end of life. Whether or not the municipalities offer support to next of kin varies depending on the county. In three counties – Dalarna, Halland and Kronoberg – they responded that all municipalities offer support to next of kin, whereas there are some counties where the proportion offering this kind of support is less than half (Diagram 8.7).

Diagram 8.7 Support for next of kin – municipalities

Proportion of municipalities and districts offering support to the next of kin of patients requiring palliative care at the end of life.



* Number of municipalities responding to the survey/total number of municipalities in the county.

Source: National Board of Health and Welfare's survey, February 2016.

Assessment of the results

Support for the next of kin is a fundamental aspect of palliative care. The objective is for everyone to be offered support.

The results indicate that 60% of primary care institutions offer support to next of kin in some form, with huge variations among county councils. This also applies to procedures for focusing on the needs of children and adolescents who are the patient's next of kin. In this instance, two thirds of primary care institutions do not have any such procedures at all. A number of primary care institutions have mentioned that they are not responsible for patients receiving palliative care or only have a few patients like this. Regardless of this, primary care has a responsibility for children and adolescents after the patient's death.

It is a positive outcome that all organisations involved in specialist palliative care offer support to next of kin, with four out of five specialist palliative care organisations having procedures for focusing on the needs of children and adolescents who are the patient's next of kin.

Hospital clinics largely offer support to next of kin. However, the results indicate that a number of hospital clinics do not have any procedures in place for focusing on the needs of children and adolescents who are the patient's next of kin.

The results for municipal healthcare services show that more than 70% of the municipalities offer support to next of kin, but with large variations. This shows that many, but not all municipalities understand the importance of offering this support.

The National Board of Health and Welfare believes that the municipalities in particular, but also primary care institutions, should review their work in terms of support for next of kin and that primary care institutions, as well as certain hospital clinics should ensure that there are procedures in place for focusing on the needs of children and adolescents who are the patient's next of kin.

Post-bereavement meetings

Responsibility for care does not end when death occurs. The next of kin often have various issues outstanding on which they have not had the opportunity to have closure. When death has occurred and the care staff, sometimes along with the next of kin, have looked after the deceased, the next of kin must be offered the opportunity for a meeting after their bereavement. This should take place a suitable period of time after the patient has died.

Post-bereavement meetings offered by county councils and regions

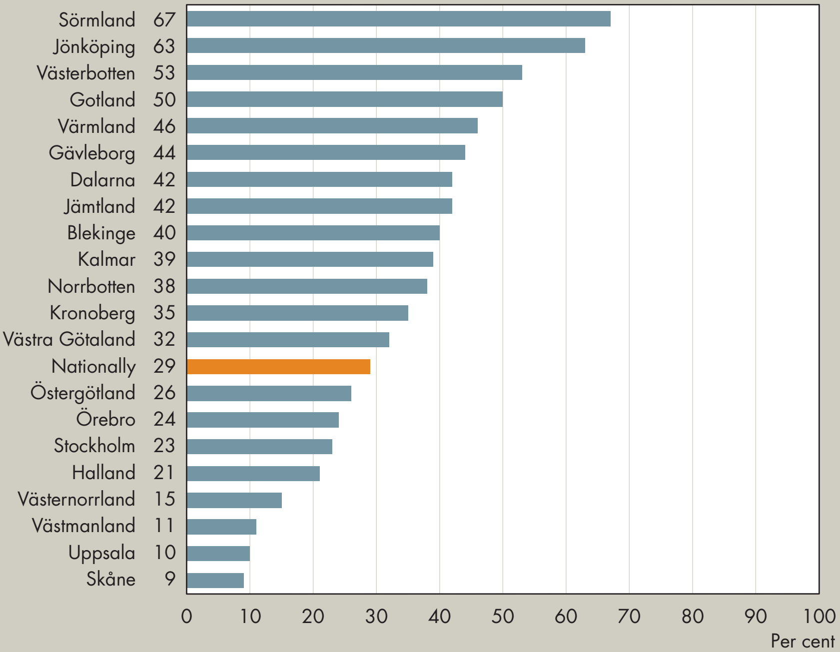
A post-bereavement meeting should be held as part of the city councils' and regions' activities by the member of care staff in the unit who is responsible for this and familiar with the deceased person and his or her course of treatment.

Post-bereavement meetings in the primary care sector

According to the primary care sector, around a third of primary care institutions have procedures on how to hold post-bereavement meetings and more than half of these institutions always or often offer a post-bereavement meeting. Most primary care institutions mention that they only have a few patients requiring palliative care or that this is not one of primary care's tasks.

Diagram 9.1 Post-bereavement meetings – primary care

Proportion of primary care institutions which have procedures on how to hold post-bereavement meetings.



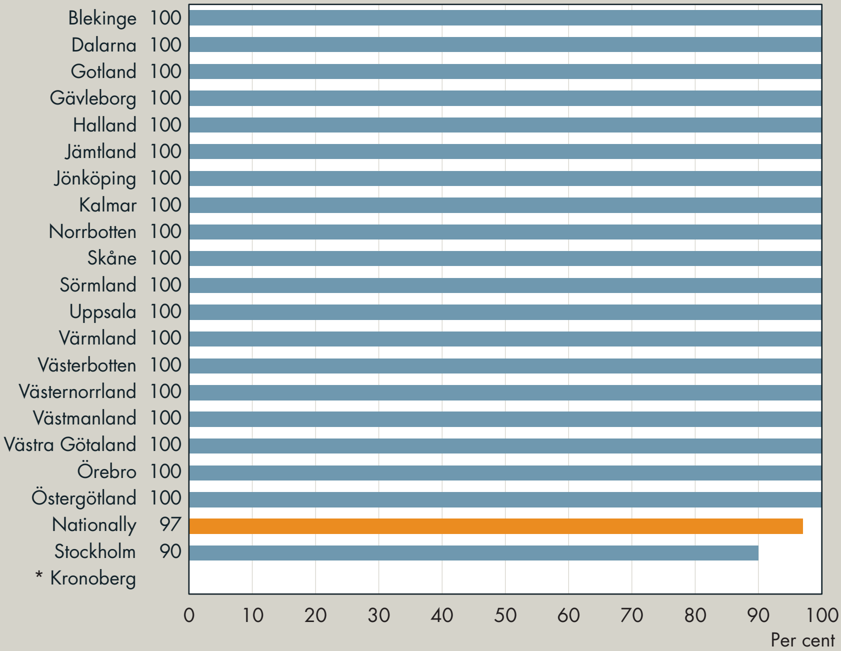
Source: National Board of Health and Welfare's survey, February 2016.

Post-bereavement meetings in specialist palliative care organisations

In general, all specialist palliative care organisations have procedures in place on how to hold post-bereavement meetings and, generally speaking, all organisations always offer a post-bereavement meeting.

Diagram 9.3 Post-bereavement meetings – specialist palliative care organisations

Proportion of specialist palliative care organisations which have procedures on how to hold post-bereavement meetings.



* No information available.

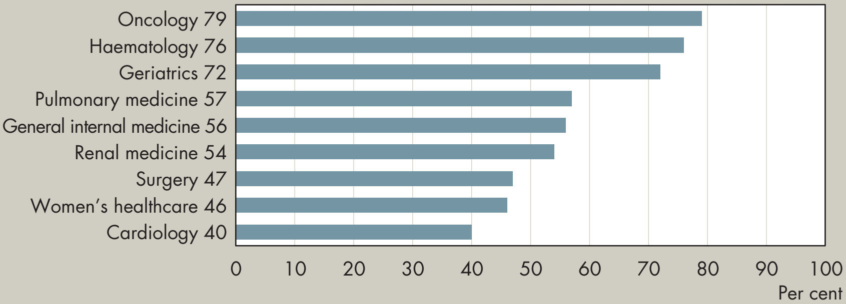
Source: National Board of Health and Welfare's survey, February 2016.

Post-bereavement meetings in hospital clinics

Among the selection of hospital clinics and similar institutions which responded to this question, more than 70% of hospital clinics in the fields of oncology, geriatrics and haematology replied that they had procedures for holding post-bereavement meetings. Between 40% and over 50% of hospital clinics in the field of cardiology, women's healthcare, surgery, renal medicine, general internal medicine and pulmonary medicine had similar procedures. The majority of hospital clinics answered that they always or often offered a post-bereavement meeting.

Diagram 9.5 Post-bereavement meetings – hospital clinics

Proportion of hospital clinics or similar institutions which have procedures on how to hold post-bereavement meetings.



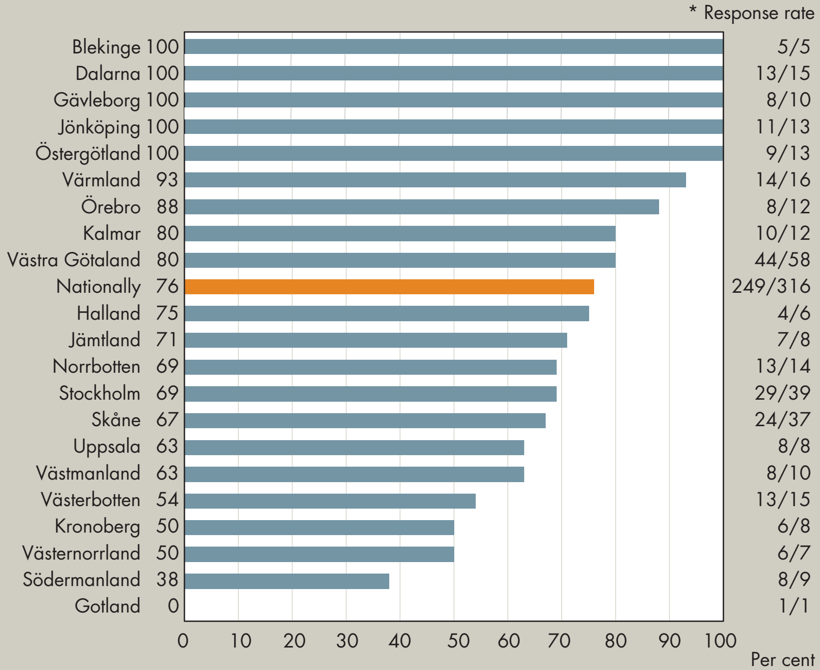
Source: National Board of Health and Welfare's survey, February 2016.

Post-bereavement meetings in the municipalities

Seventy-six per cent of municipalities stated that they have procedures on how to hold post-bereavement meetings. More than 80% of municipalities offer a post-bereavement meeting.

Diagram 9.7 Post-bereavement meetings – municipalities

Proportion of municipalities and districts which have procedures on how to hold post-bereavement meetings.



* Number of municipalities responding to the survey/total number of municipalities in the county.

Source: National Board of Health and Welfare's survey, February 2016.

Assessment of the results

It is important that county councils, regions and municipalities have procedures in place for monitoring when the next of kin are contacted after the patient's death. The results indicate that specialist palliative care organisations have clear procedures on how to hold post-bereavement meetings and that they always or very often offer such meetings to the next of kin. Primary care does not, to a large extent, have such procedures. Only 30% of primary care institutions have any procedures and just over half of them offer a post-bereavement meeting. The results for hospital clinics show that they have procedures in place to a varying degree, from 40% to over 70%. The majority of hospital clinics always or often offer a post-bereavement meeting. Seventy-six per cent of municipalities have procedures in place, with most of them offering a post-bereavement meeting.

The National Board of Health and Welfare believes that it is important to have procedures on how to hold post-bereavement meetings in all organisations caring for patients at the end of life so that a uniform level of care is provided. A number of primary care institutions have mentioned that they only have a few patients requiring palliative care. The National Board of Health and Welfare believes that it is precisely for this reason that it is even more important to have procedures for this in place.

Palliative care for children and adolescents

Children and adolescents receiving palliative care must have this care tailored to their individual needs. Palliative care can be initiated as early as at the time of the child's birth or when a diagnosis has been established, and it may be required for a short or lengthy period.

Ensuring good palliative care for children and adolescents

One way of ensuring the provision of good palliative care is by using procedures. In this situation, procedures provide a particular approach to how palliative care should be provided to children and adolescents. The procedure must be familiar to staff in the children's and adolescents' clinics and used by them. Procedures can be both verbal and in writing

More than half of children's and adolescents' clinics (17 out of 25) state that they have procedures on how palliative care should be administered to children and adolescents requiring palliative care at the end of life.

Table 10.2 Palliative care procedures

Does your children's and adolescents' clinic have procedures on how palliative care should be administered to children and adolescents requiring palliative care at the end of life?

County council/region/clinic	Yes	No
Uppsala (Akademiska)	Yes[1)]	
Sörmland	Yes[2)]	
Östergötland (Linköping)	Yes	
Östergötland (Norrköping)	Yes	
Jönköping (Ryhov)	Yes	
Kronoberg	Yes	
Kalmar (Kalmar)	Yes	
Kalmar (Västervik)		No
Gotland		No
Blekinge	Yes	
Skåne (Skåne University Hospital)	Yes	
Skåne (Helsingborg)		No
Skåne (Kristianstad)	Yes	
Halland	Yes	
Västra Götaland (SÄS, Borås)	Yes	
Västra Götaland (NU/NÄL)	Yes[3)]	
Värmland		No
Örebro	Yes	
Västmanland		No
Dalarna	Yes	
Gävleborg		No
Västernorrland		No
Västerbotten (University Hospital of Umeå)	Yes	
Norrbotten (Sunderby)	Yes	
Norrbotten (Gällivare)		No

Source: National Board of Health and Welfare's survey, February 2016.

No response was received from Stockholm (Astrid Lindgren Children's Hospital and Sachs' Children and Youth Hospital), Västra Götaland (Queen Silvia Children's Hospital and Skövde) and Jämtland (Östersund).

1) Not in all departments.
2) Not for the whole county.
3) For oncology.

Cooperation

Effective cooperation is instrumental in ensuring that the care provided works for the patient. Palliative care includes input from several disciplines and often from several administration managers. This is why cooperation and coordination are key to good palliative care. The needs of children and adolescents for palliative care can vary greatly, depending on their age, illness and expected course of events. In this case, procedures supporting cooperation mean, in this case, a certain approach which is used with regard to how cooperation is to operate. The procedure used must be familiar to staff in children's and adolescents' clinics and used by them. Procedures can be both verbal and in writing.

When asked about procedures for cooperating with municipal healthcare services, primary care and specialist palliative care organisations, more than half of the children's and adolescents' clinics (13 out of 25) replied that they cooperated with the specialist palliative care organisations. However, the level of cooperation varies among the country councils.

Table 10.3 Cooperation

Does your children's and adolescents' clinic have procedures on how cooperation is to operate with municipal healthcare services, primary care and the specialist palliative care organisations in the case of children and adolescents requiring palliative care at the end of life?

County council/region/clinic	Cooperation with municipal health care services	Cooperation with primary care	Cooperation with specialist palliative care
Uppsala (Akademiska)	Yes[1]	Yes[1]	Yes[1]
Sörmland	Yes	Yes	Yes
Östergötland (Linköping)	No	No	Yes
Östergötland (Norrköping)	–	–	–
Jönköping (Ryhov)	Yes	Yes	Yes
Kronoberg	Yes	No	Yes
Kalmar (Kalmar)	–	–	Yes[2]
Kalmar (Västervik)	No	No	No
Gotland	No	No	No
Blekinge	No	No	No
Skåne (Skåne University Hospital)	No	No	Yes
Skåne (Helsingborg)	No	No	No
Skåne (Kristianstad)	No	No	Yes
Halland	Yes	No	Yes
Västra Götaland (SÄS, Borås)	Yes	No	Yes
Västra Götaland (NU/NÄL)	Yes	Yes	Yes
Värmland	No	No	No
Örebro	Yes	No	No
Västmanland	No	No	No
Dalarna	No	No	Yes
Gävleborg	No[3]	No[3]	No[3]
Västernorrland	No	No	No
Västerbotten (University Hospital of Umeå)	Yes	Yes	Yes
Norrbotten (Sunderby)	No	No	No
Norrbotten (Gällivare)	No	No	No

Source: National Board of Health and Welfare's survey, February 2016.

No response was received from Stockholm (Astrid Lindgren Children's Hospital and Sachs' Children and Youth Hospital), Västra Götaland (Queen Silvia Children's Hospital and Skövde) and Jämtland (Östersund).

[1] Not in all departments.

[2] Not for the whole county.

[3] Work in progress. No formalised cooperation.

Post-bereavement meetings

Responsibility for care does not end when death occurs. The next of kin often have various issues outstanding on which they have not had the opportunity to have closure. In this case, procedures on how to hold post-bereavement meetings mean a certain approach which is used for holding post-bereavement meetings. The procedure must be familiar to staff in the children's and adolescents' clinic and used by them. Procedures can be both verbal and in writing.

Most children's and adolescents' clinics (19 out of 25) stated that they have procedures on how to hold post-bereavement meetings.

Table 10.4 Procedures for post-bereavement meetings

Does your children's and adolescents' clinic have procedures on how to hold post-bereavement meetings?

County council/region/clinic	Yes	No
Uppsala (Akademiska)		No
Sörmland	Yes	
Östergötland (Linköping)	Yes	
Östergötland (Norrköping)	Yes	
Jönköping (Ryhov)	Yes	
Kronoberg	Yes	
Kalmar (Kalmar)	Yes	
Kalmar (Västervik)	Yes	
Gotland	Yes	
Blekinge	Yes	
Skåne (Skåne University Hospital)	Yes	
Skåne (Helsingborg)		No
Skåne (Kristianstad)	Yes	
Halland	Yes	
Västra Götaland (SÄS, Borås)	Yes	
Västra Götaland (NU/NÄL)	Yes	
Värmland		No
Örebro	Yes	
Västmanland		No
Dalarna	Yes	
Gävleborg	Yes	
Västernorrland		No
Västerbotten (University Hospital of Umeå)	Yes	
Norrbotten (Sunderby)	Yes	
Norrbotten (Gällivare)		No

Source: National Board of Health and Welfare's survey, February 2016.

No response was received from Stockholm (Astrid Lindgren Children's Hospital and Sachs' Children and Youth Hospital), Västra Götaland (Queen Silvia Children's Hospital and Skövde) and Jämtland (Östersund).

Assessment of the results

The provision of palliative care to children and adolescents differs in several aspects from the palliative care provided to adults. Staff with paediatric expertise should be involved, directly or indirectly, in providing palliative care to children and adolescents, which may take place both at home and in hospital. There is a long tradition in the medical treatment of children and adolescents of viewing the child and family as a team, even at the end of life stage, based on considerable experience in the areas of paediatric oncology, neurology and neonatal care.

Several children's and adolescents' clinics describe palliative care for children and adolescents as an important area for development, including through providing procedures and training, as well as by means of cooperation. The National Board of Health and Welfare believes that it is important for procedures to be in place at all children's and adolescents' clinics to ensure the provision of palliative care for children and adolescents.

The knowledge support base for good palliative care at the end of life has not given any particular consideration to children and adolescents. It is important to produce scientific evidence to be able to assess the effects and make recommendations. The National Board of Health and Welfare considers it paramount to take the needs of children and adolescents into account when updating the national knowledge support base in the future. Children are children and not small adults.

References

1. National knowledge support base 2013. Palliative care at the end of life. Stockholm: Swedish National Board of Health and Welfare; 2013.
2. The Confederation of Regional Cancer Centres in Sweden. National palliative care programme 2012-2014. Principal regional cancer centre: Stockholm Gotland; 2012.
3. Swedish Register of Palliative Care, www.palliativ.se

Appendix 1. Project organisation

Project management team

Christina Broman	Project leader
Mikael Nyman	Programme officer
Riitta Sorsa	Programme officer

Group of experts

Greger Fransson	Consultant, Unit for Palliative Medicine, Kalmar County Hospital. Registry manager at the Swedish Register of Palliative Care.
Carl Johan Fürst	Professor, consultant, Palliative Care Institute at Lund University and Region Skåne
Inger Landgren	Specialist in general medicine, lead clinician, Slottsgatans health centre, Oskarshamn
Susanne Lind	State-registered nurse, masters in healthcare sciences, PhD studies, Institute of Health and Care Sciences, Palliative Research Centre, Ersta Sköndal Bräcke University College and Department of Neurobiology, Care Sciences and Society, Nursing Division, Karolinska Institutet
Ulla Olsson	Local Authority Senior Medicine Adviser, Luleå municipality, President of the National Association of Local Authority Senior Medicine Advisers

Other project members

Lina Boberg	Statistician
Grethe Fochsen	Programme officer
Jesper Hörnblad	Statistician
Caroline Kjulin	Administrator
Robert Linder	Statistician
Kajsa Mulder	Production manager
Tsega Muzollo	Statistician
Harriet Wennberg	Communication support