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Extract from Rigsrevisionen's report  
submitted to the Public Accounts Committee

# **Waiting times for specialist palliative care for patients with life-threatening illnesses**

# 1. Introduction

## 1.1. Purpose and conclusion

1. This report addresses how long patients with life-threatening diseases wait to access specialist palliative care.

In 2023, approximately 7,600 Danes commenced specialist palliative care. The majority of patients referred for this type of care are terminally ill. Most patients receive specialist palliative care in a hospital or hospice setting, while some receive care in their own homes.

2. Patients referred for specialist palliative care are in challenging circumstances and often experience severe pain or have other complex palliative needs. Therefore, it's crucial that the waiting time for access to specialist palliative care is short. Lengthy delays can prevent patients from receiving the best possible care.

The Public Accounts Committee previously criticised the regions' administration in their 2020 report on access to specialist palliative care. The committee found it unsatisfactory that the regions had not ensured that patients with life-threatening illnesses had access to specialist palliative care when needed. This criticism was partly due to the regions not adequately guaranteeing referrals regardless of diagnosis and the lack of clear improvements in access to specialist palliative care between 2016 and 2019.

Following the report, the then Minister for Health and Elder Affairs stated that the regions had prepared a joint memorandum in August 2020 on the development of palliative care (Position Paper on the Development of Palliative Care). This paper outlined four key guidelines and 15 recommendations aimed at strengthening palliative care and ensuring that all patients and patient groups with needs are offered specialist palliative care. Two of these guidelines specified that the regions would *"address the inequality in who receives palliative treatment"* and *"initiate palliative treatment early and support more terminally ill patients in actively making decisions about their treatment process"*.

In our follow-up to the 2020 report, we found in June 2023 that the regions still hadn't ensured shorter and more uniform times to access specialist palliative care. Furthermore, we received information suggesting that some units providing specialist palliative care were not reporting accurately how long patients waited.

3. The purpose of this study is to determine whether the regions have ensured prompt and uniform times to access specialist palliative care for patients with life-threatening diseases.

There are no legally mandated maximum times to access specialist palliative care, but item 7 of section 2 of the Health Act states that the time to access treatment should be short. To assess whether the times to access are indeed short, we use the professional targets for time to access that the regions themselves employ in managing and developing this area. These targets are:

- **Treatment target:** 80% of referred patients must start specialist palliative care before they become too ill or die.
- **Maximum 10-day time to access target:** 90% of patients starting specialist palliative care must begin treatment within 10 days of referral.

#### **Danish Palliative Database**

The Danish Palliative Database is part of the Regions' Clinical Quality Program and focuses on specialist palliative care. Its purpose is to provide a basis for enhancing the quality of this care.

A patient is considered to have started specialist palliative care upon having an initial in-person meeting at the treatment site. According to the Danish Palliative Database, while the ideal treatment target would be 100%, a standard of 80% has been set due to the nature of the diseases and the necessary time for allocation.

Four of the regions argue that Rigsrevisionen cannot examine trends in the time to access specialist palliative care based on these targets. They contend that the targets haven't been politically adopted within the regions but were developed by experts within the Danish Palliative Database based on clinical evidence, standard clinical practice, or expert opinion. These four regions also point out that the data supporting the targets were not collected to specifically monitor time to access specialist palliative care.

In contrast, the Capital Region of Denmark agrees with Rigsrevisionen that the progress against these targets can be used to assess how long patients wait, because the regions use these professional targets as benchmarks in their quality improvement efforts and have committed to working towards them.

Rigsrevisionen notes that all regions use these targets in their ongoing work to improve the quality of specialist palliative care, including ensuring that patients start treatment quickly after referral and before their condition deteriorates significantly. The regions also use this data for management and development within the field, as well as for research and to build general knowledge in this area.

Based on this, Rigsrevisionen considers these targets relevant for evaluating whether the regions have ensured short and uniform times to access specialist palliative care. Therefore, Rigsrevisionen uses these targets and the underlying data – as we did in the 2020 report – to track trends in the time to access specialist palliative care.

In 2023, the regions spent approximately DKK 300 million on operating specialised units in hospitals, including outreach teams, and around DKK 485 million on the operation of hospices.

Rigsrevisionen initiated this study in October 2024.



## Conclusion

**The regions have not ensured prompt and uniform times to access specialist palliative care for patients with life-threatening diseases. Rigsrevisionen notes that almost five years after the Public Accounts Committee last criticised how long patients wait, no significant improvement has been made. Rigsrevisionen finds this unsatisfactory. The consequence may be that patients do not receive adequate palliative care, potentially reducing the quality of their final days.**

The study reveals that patients receiving specialist palliative care in 2023 typically received it for 20 days – 4 days less than in 2019. This suggests that the regions are starting specialist palliative care later. Over the same period, the number of patients starting this care decreased by 15%. Consequently, fewer patients are beginning palliative care, and those who do are receiving it for a shorter duration.

Overall, the regions are close to meeting the target of treating 80% of referred patients before they become too ill or die. However, there are regional differences. In 2023, the North Denmark Region treated 91% of referred patients, while Region Zealand did not meet the target, treating only 73%.

Not all regions are meeting the goal of having 90% of patients start treatment within 10 days. Nationally, 79% of patients began treatment within this timeframe in 2023. There are significant regional differences – for instance, Region Central Jutland exceeded the target, treating 92% of patients within 10 days, while the Capital Region of Denmark only treated 65% within 10 days.

The study shows systematic differences in the time to access specialist palliative care depending on the underlying disease. In 2023, 81% of referred cancer patients received specialist palliative care before becoming too ill or dying. For patients with other life-threatening diseases, the corresponding figure was 70%. More cancer patients than other patients also start treatment within the 10-day target. The Public Accounts Committee criticised this difference in 2020, and Rigsrevisionen finds its continued existence unsatisfactory.

The study shows that the regions have generally ensured correct reporting of data on the time to access specialist palliative care. Typically, errors are few and unsystematic, with the exception of two units in the Capital Region of Denmark, where systematic reporting errors were identified.