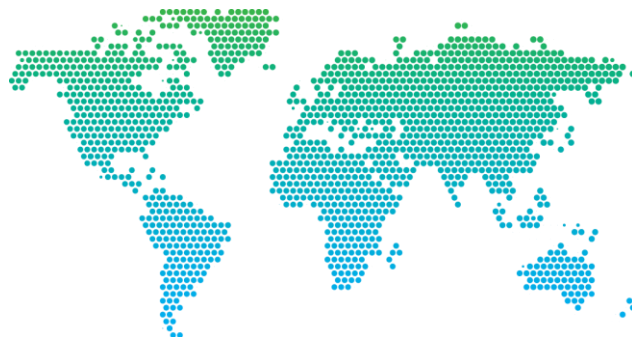


Reference Centre

Annual Report

2023/24



ORGANISATION DETAILS

Organisation name	Regional Centre of Excellence for Palliative Care, Western Norway
Number and type of centres supported	By September 2024, 480 sites around the country, in all: 24 hospitals (60 wards), 358 nursing homes (21 incl. PC beds/units) and 98 community homecare districts. A decrease in numbers of community homecare districts due to county re-organisation.

PROGRESS SINCE LAST REPORT

Progress against Reference Centre's action plan	<p>We hereby submit the report for the seventh year as International Reference Centre.</p> <p>Main function 1: Maintain and enhance the clinical documentation</p> <p>The Centre is responsible for the clinical bedside document 'The Last Days of Life', congruent with the International Collaborative 10/40 Model of Care. During autumn 2023 we started a process of minor updates related to the review by the Norwegian Directorate of Health. During this process, we decided to take a deeper look into the document, due to feedback from user sites.</p> <p>The work to integrate 'The Last Days of Life' into the most used hospital electronic patient record (EPR) system in Norway, DIPS, has been in process since January 2023. A few EPR systems in community services are being continuously followed up by the Network Coordinator. Lack of access to 'The Last Days of Life' in EPR systems is highlighted as a concern by several user sites in the annual survey.</p> <p>Main function 2: Provide support and guidance</p> <p>The Centre is facilitating the implementation and sustained use of 'The Last Days of Life'. In 2023, 6 new user sites registered, and 19 so far in 2024. We received one renewed registration in 2023, and three as part of a project so far in 2024. In 2023 we received 4 user site withdrawals, and so far in 2024 1. Reasons for withdrawals are typically other types of plans for follow up and various digital solutions, but also a few closed nursing homes. All new and renewed users have received the start kit upon registration and have been followed up by the Network Coordinator.</p> <p>Seven municipalities were approved for new or renewed funding from the Norwegian Directorate of Health for implementing, sustaining, or revitalizing the use of 'The Last Days of Life' in 2023, and for 2024 the number is 10.</p>
---	---

'The Last Days of Life' is available as a quality assurance tool on our home page and was updated in June 2024. There are long-term plans to reopen the quality assurance tool pages on the website of the Norwegian Knowledge Centre for the Health Care Services. The link to this quality assurance tool is an essential part of the start kit.

Main function 3: Provide co-ordination and support

The Centre provides coordination, mentorship and support for registered sites using 'The Last Days of Life'. We have a complete registry of all user sites, which is continuously updated. We provide new contact persons with a modified 'start-up kit' and have plans for a digital meeting for those new to the role, and for newly registered sites.

In October 2023 we hosted our first lunch webinar, open to all registered user sites. We plan for two webinars per year. In June 2024, 115 were logged on and sat together with at least 288 colleagues, participating on the second webinar. The next will be due in autumn 2024.

The Collaborative webinar series has been highlighted on our webpage.

The homepage for 'The last Days of Life' has been maintained and updated through the year.

The Network Coordinator is available for advice and support. She received 109 enquiries in 2023 and 68 so far in 2024, mostly by email.

We postponed the annual regional conference until spring 2024, hosting 100 participating nurses and physicians. Susie Wilkinson was invited online to give the participants an update on the 10/40 Model and the International Collaborative. This was very well received.

We have participated in 1 digital webinar for registered user sites, and 1 for Network nurses representing several municipalities.

Function 4: Contribute and take part in the International Collaborative

Our Network Coordinator Grethe Skorpen Iversen is member of the Executive Committee of the International Collaborative, now serving her second period. Grethe has been a co-chair and member of the Facilitator Network of the Collaborative from the start, working on the Quality Improvement Framework. The Norwegian representatives also take part in other project groups of the International Collaborative.

Function 5: Annual reporting

As part of quality control, an online survey was sent to all user sites in December 2023. The results have been analyzed and are being used as part of our further development work to improve service quality. As always, any valuable feedback will be shared with the Facilitators Network. Results from 2022 was presented at the Annual Conference in Rotterdam.

Function 6: Reference group and national developmental work

The Centre has a national reference group ('critical friends') established in 2012. This group is kept updated about the work of the Centre. The annual meeting for the group took place in Oslo in December 2023, with fruitful discussions.

The Norwegian Directorate of Health evaluated the clinical document "The Last Days of Life" and the connected support services in 2022 and made a statement to the Department of Health and Care Services. The evaluation was positive and supportive. However, a few minor changes to the document were proposed.

	<p>These recommendations have been followed up and further discussed in our reference group and with the Directorate of Health. The changes will be incorporated into the clinical document and piloted according to a project plan before national implementation.</p>
OTHER ACTIVITY	
<p>Research and Development</p>	<p>The Centre is one of the partners of the Horizon 2020 'iLIVE' project, participating in the iLIVE cohort study (including qualitative interviews) and volunteer study. We are also part of the international CO-LIVE study, investigating experiences of healthcare professionals and bereaved relatives about care of the dying during the COVID-19 pandemic.</p> <p>Palliative Medicine consultant Nina Elisabeth Hjorth completed her PhD project on advance care planning in June 2022. One of the articles in her thesis used data from the ERANet-LAC CODE project. Dr. Hjorth has been member of a workgroup in the Directorate of Health developing national recommendations on advance care planning for the health and care services. These recommendations were published, in December 2023. As part of that, an e-learning course has been developed by dr. Hjorth, Haugen et. al. Our Centre is also member of a national network on advance care planning.</p> <p>Our Centre is active in other national developmental work, such as the revision of the National Action Program for Palliative Care. Centre staff has played an active role in following up the Report on Palliative Care to the Norwegian Parliament (2019-2020), participating in the national reference group for the report and the workgroup and reference group by the Directorate of Health to develop a program for the new Speciality of Palliative Medicine.</p> <p>Our hospital has been having a strategy for palliative care since 2016. In 2022, the specialist palliative care service at our University Hospital has expanded into a comprehensive regional centre which now includes an ambulatory specialist palliative care team, a specialist palliative care inpatient unit and the Regional Centre of Excellence for Palliative Care. The inpatient unit got new facilities and expanded to eight beds in the autumn of 2023. The comprehensive regional centre has now replaced the hospital's previous Council for Palliative Care.</p> <p>In October 2023, World Hospice and Palliative Care Day with the theme Compassionate Communities was celebrated in the city centre. In December 2023 we also celebrated the WHO's Volunteer Day together with the iLIVE volunteers at the hospital. Similar plans for 2024 are in progress.</p> <p>Together with the Norwegian Palliative Care Association and the Norwegian Association for Palliative Medicine, our Centre is organizing and hosting the National Palliative Care Conference in Bergen in September 2024. We are expecting 700 participants for the three-day Conference. Our Centre is well represented, with talks on both plenary and parallel sessions, and poster sessions, presenting e.g. iLIVE results.</p>
<p>Learning and Teaching</p>	<p>Topics related to 'Best Care for the Dying Person' have been presented at hospital wards, at relevant local and regional courses, and in graduate and post-graduate education programs for healthcare professionals. In 2023, the Network Coordinator had 16 sessions for 620 attendees, mostly face to face, but also digitally. So far in 2024 she has had 3 sessions for 160 attendees, both digitally and face to face, and 10 sessions are planned for later in the autumn. In</p>

	<p>addition, our members of our staff have teaching commitments related to care of the dying.</p> <p>Since 2017, 'The Last Days of Life' has been included in the curriculum for medical students at the University of Bergen, both as part of the common teaching program and a student selective course in palliative medicine.</p>
Quality Assurance	<p>The algorithms for symptom relief in dying patients are annually updated and published on the web. The pharmacist employed at our Centre gives support on related questions.</p> <p>Our bereavement leaflet has been updated by workgroup within our centre. Leaflets are provided free of charge to hospitals and municipal health and care services across Western Norway.</p>
DOCUMENTATION OF COMPLAINTS/CONCERNS RAISED	
From within user sites	No complaints, but several user sites report a need to get the document not only available in the EPR, but also in a more user-friendly version, to avoid double reporting and to get a better overview.
From relatives, families or carers	We have not received any reports on complaints or concerns regarding the use of 'The Last Days of Life'. Neither are we aware of any such issues raised in the media during the last year.
1.	Finalize the review of our clinical document 'The Last Days of Life' and all related documents in 2024
2.	Perform the annual online survey of all registered user sites in November 2024
3.	Contribute to the International Collaborative and the Facilitator Network, and participate at the Summer School and the Symposium week
4.	Arrange two lunch webinars per year for user sites, host an online meeting for new contact persons/sites, and a regional conference day spring 2025
5.	Arrange the annual meeting of the national reference group late autumn 2024
6.	Within spring 2025, finalize the integration of 'The Last Days of Life' into the EPR system (DIPS) and support the safe implementation of the application

Functions

International Collaborative Reference Centres provide six main functions.

1. To maintain, develop, and enhance the clinical documentation for their given region/country to ensure congruence with the International Collaborative 10/40 Model.
2. To provide guidance, co-ordination, and support to the organisations across their given region or country to ensure the robust implementation and sustainability of the International Collaborative 10/40 Model.
3. To provide further education, training and support as requested by the organisations across their given region or country engaged in the International Collaborative 10/40 Model.
4. To collate implementation information from the organisations across their given region/country and submit an annual report to the International Executive Committee as described in Section 2.3 below.
5. To support organisations across their given region or country with the development of a quality assurance programme in line with health services' existing quality governance and risk framework.
6. To contribute the learning from the implementation and training of the organisations across their defined region or country back in to the International Collaborative for the furtherance of the International Collaborative 10/40 Model.

Annual reporting responsibilities

An International Collaborative Reference Centre will be expected to produce an Annual Report to the Executive Committee of the International Collaborative. The Annual Report will include:-

- Progress against the Action Plan
- The number of organisations it is supporting
- Documentation of any organisations that have received complaints/raised concerns
- Research and development activity
- Learning and teaching activity
- Quality assurance activity
- Key objectives for the year ahead.

To facilitate the collation of this report, the Reference Centre will require the organisations in its locality to provide the following information in relation to the 10/40 Model:

- The benefits and improvements in care following the implementation, including information on how this has been evaluated.
- A summary of the education and training provided to support implementation and sustainability
- An overview of research activity

- Key objectives for the following year
- Concerns or complaints from organisations regarding the International Collaborative 10/40 Model
- Concerns or complaints from relatives/families/carers regarding the use of the Care for the Dying Person documentation
- Suggestions for improvements or further development of the Care for the Dying Person documentation