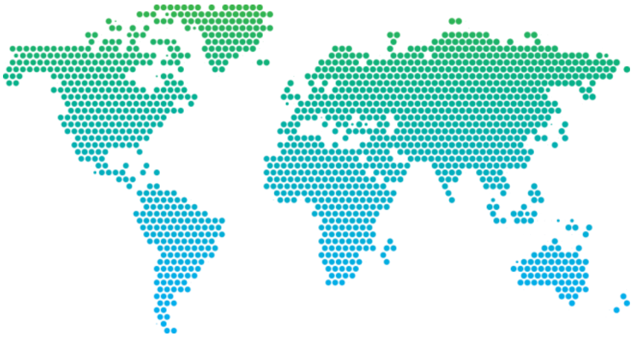
International
Collaborative
for Best Care
for the Dying Person

Reference Centre

Annual Report

2023/24



ORGANISATION DETAILS	
Organisation name	**The Institute for Palliative Care, Lund, Sweden**
Number and type of centres supported	In total: 526 units (July 2024) Municipal care: 406 Hospital care: 57 Specialised palliative care: 63. 96 new user sites were registered in 2023.
PROGRESS SINCE LAST REPORT	
Progress against Reference Centre's action plan	This is the 2nd Annual Report from Sweden. • A web-based educational programme for new user sites of the Swedish Palliative Care guide (S-PCG) was launched in December 2023. • A support for early identification of the patient – the step before assessing palliative care needs, has been developed with the working title, i-S-PCG (i stands for identification). • Revision of the S-PCG content according to new evidence and national guidelines is ongoing. • There is an ongoing national and local discussion in Sweden about which quality indicators would be relevant for early palliative care. These indicators must be congruent and measurable for units using the S-PCG. • A need for a national care guide, such as the S-PCG, for children with palliative care needs has been raised. A multidisciplinary national working group, including representatives from The Institute for Palliative Care, has been formed with the aim to develop this care guide.
OTHER ACTIVITY	
Research and Development	**Regarding research on the Swedish Palliative Care Guide (S-PCG)** The Institute for Palliative Care is working intensively on projects, funded by two larger grants, aimed to evaluate the effects of the S-PCG. In the first (2022-2024) we investigate S-PGC in different areas of the health care system, including COPD care, heart failure care, palliative care needs in the ER, as well as the implementation of the S-PGC in the nursing homes and mobile home care

teams, and in two register studies. For this project we have registered a PhD-student, who will focus three out of four of her papers on the evaluation of the S-PCG. One of the register-based studies is currently in a manuscript phase, and we have had our preliminary results accepted for an oral presentation at the national conference of palliative care in Sweden (October 2024).

In the second grant (2023-2026) we focus on the S-PGC in dementia care, which holds its own set of challenges, but also holds great promise to improve care for a previously somewhat neglected patient group. Within this project, we propose a cluster-randomized RCT with four dementia-specific nursing homes. This study is now ongoing, with one site started and several others in the start-up phase. By a slight change of design and a new ethical approval we will be able to conduct the two studies of nursing homes (patients with and without dementia) together, with two trajectories within the same design. We also aim to reach patients early after diagnosis by working together with memory clinics to implement S-PCG there. This effort will hopefully be facilitated by the recent development that a local memory clinic reached out to us at the Institute for Palliative Care to conduct a clinic-wide communication course and intervention. This indicates an awakening awareness of palliative care needs in (early) dementia care.

A research and quality improvement project in hospital settings

The overall aim of the project is to increase the availability of evidence-based and person-centred palliative care for patients and their families within Skåne University Hospital Comprehensive Cancer Centre (SUHCCC). The project will support the implementation of the National Palliative Care Programme by:

- Testing the newly developed support, i-S-PCG, which is designed to facilitate the identification of patients with potential palliative care needs.
- Assessing early palliative care needs using Part 1 of the S-PCG.
- Communication skills training.

The project adopts an innovative approach where training activities are based on the self-defined needs of the organisation. In this process, professionals and patient representatives collaborate with the project team to develop and adapt various competence-enhancing activities and interventions.

An application for funding for a scientific evaluation of the project has been submitted.

Further research regarding i-S-PCG

In relation to the project mentioned above where i-S-PCG will be tested in hospital oncology settings, a systematic review is being conducted of other validated tools aimed at identifying patients with potential palliative care needs. Additionally, the i-S-PCG will be validated through a Delphi process.

Serious illness conversations in S-PCG

A working group consisting of physicians and nurses has together with our facilitators developed a proposed structure for serious illness conversations in the S-PCG. The proposal has been sent to experts in palliative care in Sweden and to a reference group linked to the S-PCG, in total about 60 professionals. At the same time, the new structure is being tested in three specialised palliative care units in our region. Based on this, the structure of serious illness conversations in the S-PCG will be finalised and included in the next version (3.0) of the S-PCG.

Learning and Teaching	• 13 meetings have been held where information about the S-PCG has been provided to managers and physicians, among others, with a total of 257 participants. • 132 participants have completed the web-based educational programme for new users of S-PCG. • 12 face-to-face training courses were organised for a total of 327 participants. • In total **716** individuals have been reached through teaching and learning sessions.
Quality Assurance	A survey has been developed and sent out to user sites in Sweden to gather information about their experiences using the care guide. The results of the survey form the basis for this Annual Report. A total of 100 user sites responded to the survey (31% response rate). The survey included questions about positive experiences, their reflections about what works and the benefits of the use, which are important aspects for the willingness and ability to sustain the implementation. Another survey was also sent to specialised palliative care units in our region to assess the extent to which the S-PCG is being used. The survey also asked the units to report the number of patients they perceived to be at the end of life and how many of them were being cared for according to the S-PCG. Discussions are ongoing as to whether there is value in measuring this annually going forward.
DOCUMENTATION OF COMPLAINTS/CONCERNS RAISED	
From within user sites	In comparison with last year's Annual Report, several similar comments have been noticed, therefore only the new statements will be highlighted here below. • It is difficult to maintain consistent use of the care guide in units with few deaths and high turnover of healthcare staff. • Some of the care staff find it difficult to understand the importance of the care guide and how to use it, as Swedish is not their native language. • Primary care physicians often find it very difficult to make decisions about palliative care needs at an early stage and are inclined to pass the decision on, often to acute inpatient care. As a result, palliative patients are shuffled back and forth and may die either in the hospital or in community care. Sadly, too many die in hospital settings while waiting for admission to residential care, or just shortly after being placed into residential care. This could have been planned differently and, with a good care plan, many could have received dignified care in their own homes. • It is constant work to train new people and set working practices. To hold on and persevere. Being able to find arguments that S-PCG shows the quality of the care we provide. • There are many people from other countries working at the units. Some of them find it difficult to visit people who are at the end of their lives. It is not clear whether this is due to fear, cultural aspects, or other reasons. • Lack of education and readiness to care for dying patients. • It takes time to learn, you need patience with the introduction. • Reluctance from the staff to document on paper. We want the care guide in the IT system. • Too cumbersome and a lot of documentation in paper form. • Challenges arise when palliative care is defined in different ways by people. • Sometimes, too much attention is on the documents and how to fill them in, which can sometimes take the focus away from the patient and relatives.

	- Sometimes, it can be difficult to present the care plan to the patient and their relatives. - It is challenging to get everyone to use the care plan as intended. - Uncertainty arises when the care plan is not used very often
From relatives, families or carers	No complains has been raised.
OBJECTIVES FOR THE YEAR AHEAD	
1.	Continue the revision of the S-PCG and related information leaflets.
2.	Finalising a structure for serious illness conversations in S-PCG.
3.	Develop a training programme for persons assigned to support the implementation of S-PCG within their unit/organisation (train the trainers).
4.	Develop an information leaflet for patients and their families on what early palliative care entails, to aid the implementation of the S-PCG.
5.	Pilot test and start a validation process for the i-S-PCG.

EXTRACTS FROM THE REFERENCE CENTRE DEVELOPMENT DOCUMENT FOR INFORMATION/GUIDANCE

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