

(E) Education & Train Medical schools with mandatory PC teaching	ning ∯ 5/7
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Responsible authority for PC in the Ministry of Health	<u>2</u> 00
Inclusion of PC in the basic health package at the primary care level	004
Empowerment of people and communities	
Ω	
Groups promoting the rights of PC patients	Advanced care planning-related policies

Sweden

Ind1

Existence of groups dedicated to promoting the rights of patients in need of PC, their caregivers, and disease survivors. Strong national and sub-national presence of palliative care advocacy and promoting patient rights (as a professional association of Palliative Care, i.e.) The Swedish Council for PC is an umbrella organisation set up to enhance and support the development of palliative care in Sweden. The council, created in 2004, consists of 11 national professional PC groups and networks (including physicians, nurses, nurse aids, social workers, physiotherapists, etc). The Council works with identifying neglected areas as well as suggesting improvements. It is involved in updating of the national directory for specialist units. Further networks include the National Association of Palliative Medicine Physicians, the national associations for Palliative Nursing, Occupational therapy, Physiotherapy, Dieticians, and priests in PC; and local NGOs like Betaniastiftelsen and local hospices. There are also regional PC Competence/Research Centers in Lund, Stockholm, and Växjö. The Swedish Association for Palliative Medicine, since 1997, has been a powerful organisation in collaboration with the government.

Ind 2

Is there a national policy or guideline on advance directives or advance care planning? There is a national policy on advance care planning.

There is one national policy addressing ACP of medical decisions for use of life-sustaining treatment or end-of-life care from the National Board of Health and Welfare, SOSFS 2011:7. There are no possibilities for patients or relatives to write legally binding AD or 'living wills'; the concept ACP is used in the everyday care process and is formulated in the National Programme for Palliative Care (Adult) and in the National Programme for PC for Children, the National Palliative Care Pathway (including discussion between health care staff and the person and/or relatives around the transition to palliative care, wishes and goals of care and documented in the medical record), the National guidelines and the National Board of Health and Welfare terms/concepts related to palliative care. However, these are not legally binding.

Ind 3

3.1. There is a current national PC plan, programme, policy, or strategy.

- 3.2. The national palliative care plan (or programme or strategy or legislation) is a standalone. Actualized in last 5 years, and actively evaluated or audited.

Yes, there is a standalone national palliative care plan AND there is national palliative care law/legislation/government decrees on PC. There is a governmental decree for decision makers on PC guidelines issued by the national board of health and welfare (2013, audited 2017, currently under revision, 2025). There is a national PC programme (2011, actualized in 2023, currently under revision), a national PC programme for children (2021), and PC is included in sections within most national plans, both for cancer and non-malignant diseases. In the National Board of Health's law/government policy on PC from 2013, there is a chapter on indicators (p.61 - 68), and a subsequent update in 2017 by the National Board of Health and Welfare. Indicators are continuously monitored and published by the National Board of Health and Welfare and by the Swedish Registry of Palliative care, since 2005. Several of these indicators have been implemented by the National Board of Health and Welfare in their guidelines also. The Swedish Register of Palliative Care is a national quality register that contributes to research and develSweden

3.3. There are indicators in the national plan to monitor and evaluate progress, with measurable targets. The indicators to monitor and evaluate progress are currently

implemented.

Ind 4

PC services are included in the list of priority services for Universal Health Coverage at the primary care level in the national health system.

Palliative care is included in the list of health services provided at the primary care level in the General Health Law.

Ind 5

5.1. Is there a national authority for palliative care within the government or the Ministry of Health?

5.2. The national authority has concrete functions, budget and staff.

$\bigcirc 2 \bigcirc \bigcirc$

The authority for palliative care is defined but only at the political level (without a coordinating entity defined).

200

There are concrete functions but do not have a budget or staff. opment of PC. It is built on an end-of-life questionnaire (ELQ) with 30 questions that is answered by responsible staff after the death of a patient. The questions reflect quality of care delivered during the last week in life and is based on the principles of a good death proposed by the British Geriatrics Society. Collected data is used for research, projects involving development and quality as well as local audits.

Palliative care is a priority service in the Swedish Healthcare system, which is outlined in the general Health care law. Palliative care is considered the most priority of all health care services, at the same level as acute emergency care, according to the government proposition: "Regeringens proposition 1996/97:60" page 31, which has become a law. All healthcare in Sweden is free of charge (paid by taxes) and in the diagnostic manual of the official healthcare palliative care has n° Z515. According to the government's priority investigation SOU 1995:5, palliative care must have the highest priority and is included in the list of health services provided at the primary care level.

The national authority for palliative care in Sweden is the National Board of Health and Welfare, which is a government agency under the Ministry of Health and Social Affairs. However, this agency has not a specifically assigned desk, department or person, with responsibility for palliative care development. Its main duty with regard to palliative care, is providing knowledge-based report and guidance for palliative care to the diverse regions; a role that is shared with many other disciplines.

Sweden

Ind 6

Existence of congresses or scientific meetings at the national level specifically related to PC.

At least one national conference specifically dedicated to palliative care every year.

There is a national palliative care congress every year, organised by the NRPV (National Council for Palliative Care) together the regional organisation where the congress is hosted that year. It started in 2010 and was initially organised every other year but since 2021 it is organised every year. The congress is multi professional and has scientific speakers in both swedish and english. The latest congress took place in September 2024 with more than 800 delegates.

A search for 'palliative care' and author affiliated with Sweden

yielded 794 articles in PubMed, 323 articles in Embase and 638

articles in Cinahl during the last 5 years.

Ind 7.1

Estimation of the level of peer-reviewed articles focusing on PC research published in any language in the past 5 years with at least one author from the country.

Ind 7.2

Inclusion of PC topics in national research calls.



extensive num-

published on the

ber of articles

subject.

Denotes an

They do exist national research calls that do include palliative care topics.

Ind 8

-Reported annual opioid consumption -excluding methadone-in S-DDD per million inhabitants per day.

8.204

vate Cancerfonden.



Average consumption of opioids, in defined daily doses (S-DDD) for statistical purposes 2020-2022.

Palliative care projects have received funding from national

calls from the government research fund FORTE, and the pri-

COUNTRY VS REGION AVERAGE CONSUMPTION MINIMUM CONSUMPTION IN THE REGION MAXIMUM CONSUMPTION

-9.1. Percentage of health All fully certified physicians can prescribe all of the listed essenfacilities at the primary tial medicines. All the medicines are available at the local pharcare level in Urban areas macy and patients pays a maximum of up to 2350 SEK (201 that have pain and PC euros) per 12 months for all prescribed drugs. The rest is subsimedications as defined dized by the government. There is no difference between rural in the WHO Model List and urban areas in Sweden, since all physicians can prescribe of Essential Medicines. the medicines and they are available all over the country. -9.2. Percentage of health facilities at the primary care level in rural areas that have pain and PC medications as defined in the WHO Model List of Essential Medicines. Ind 10.1 10.1.1. Percentage of health All primary care health facilities in Sweden have access to facilities at the primary immediate-release oral morphine, either in stock or through care level in urban areas requisition. that have immediaterelease oral morphine (liquid or tablet). 10.1.2. Percentage of health facilities at the primary care level in rural areas that have immediaterelease oral morphine (liquid or tablet). Ind 10.2 10.2.1. Percentage of As for immediate-release oral morphine, all primary care health facilities at the health facilities in Sweden have access to different opioids, primary care level in urban either in stock or through requisition. The rules for prescribing areas that have different opioids are the same in the whole country and the availability is opioids and in different the same in the whole country formulations. 10.2.2 Percentage of health facilities at the primary care level in rural areas that have different

opioids and in different

formulations.

Sweden

Ind 9

Sweden

Ind 11

11.1. The proportion of medical schools with COMPULSORY teaching in PC (with or without other optional teaching).

- 11.2. The proportion of medical schools with **OPTIONAL** teaching in PC.
- 11.3. The proportion of nursing schools with COMPULSORY teaching in PC (with or without other optional teaching).
- 11.4. The proportion of nursing schools with **OPTIONAL** teaching in PC.
- 11. 5. PC Full Professors.
- 11.6. Legislation/ regulations concerning PC education.



5/7

4/25

11/25





According latest compilation of training in palliative care in medical schools in Sweden for the national conference in palliative care in 2023, entitled "Palliative medicine on the medical programme - current situation and future", five medical schools teach palliative care to future physicians, while further two teach optional at the medical schools in Linköping and Stockholm (optional 4 week in addition to compulsory courses). There are today 25 nursing schools in Sweden and, as per the latest mapping of palliative care education done in 2019, four schools had a compulsory course (article, pages 5 and 6). Sweden is home for five full professors: 4 professors in palliative care (nurses), 2 in Stockholm, 1 in Östersund/Sundsvall and 1 in Göteborg; and 1 professor in palliative medicine (physician) in Stockholm.

Ind 12

Existence of an official specialisation process in palliative medicine for physicians, recognised by the competent authority in the country.



Palliative medicine is a speciality or subspeciality (another denomination equivalent) recognised by competent national authorities.

Palliative medicine was recognised as an add-on speciality in Sweden in 2015 by the National Board of Health and Welfare/ the government. Descriptive of the objectives can be found in English here. There is a specialist course in palliative medicine which is currently running its sixth round of the course (a yearly course divided into four week long modules spread across the country). Around 35 participants in each round. There are currently approximately 260 specialists in palliative medicine.

💷 Sweden

Ind 13

13.1. There is a system of specialised PC services or teams in the country that has a GEOGRAPH-IC reach and is delivered through different service delivery platforms.

13.2. Are available in HOSPITALS (public or private), such as hospital PC teams (consultation teams). and PC units (with beds), to name a few examples.

13.3. Free-standing HOSPICES (including hospices with inpatient beds).

13.4. HOME CARE teams (specialised in PC) are available in the community (or at the primary Healthcare level), as independent services or linked with hospitals or hospices.

13.5. Total number of specialised PC services or teams in the country.

Ind 14

14.1. There is a system of specialised PC services or teams for children in the country that has geographic reach and is delivered through different service delivery platforms.

14.2. Number of pediatric specialised PC services or teams in the country.

Integrated provision: Specialised palliative care services or teams are systematically provided.



In a growing number of private hospitals.



Ad hoc/in some parts of the country.

Strong presence of home care teams in all parts of the country.

 $\bigcirc 2 \bigcirc \bigcirc$

Isolated provision:

palliative care spe-

cialised services or

teams for children

some geographic

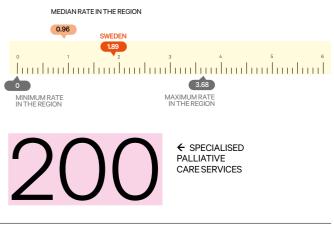
exist but only in

areas.

5

PPC TEAMS

There is only one specialised PC ward/hospice for children in Sweden, called Lilla Erstagården, localised within the private foundation Ersta clinic. There is one specialised PC home care $service, called {\it Sjukhus} ansluten {\it Avancerad Barnsjukvard i Hem-}$ met, localised at the Karolinska University Hospital. Both these services are located in Stockholm. In the rest of the country children in need of specialised PC are cared for in their homes or in a PC ward/hospice by a specialised PC service for adults in collaboration with the Department for children's diseases at the local hospital. This collaboration is growing but not established all over the country. There has recently been an establishment of a palliative multi professional consultant team for children in the south health care region (Skåne), and a similar one in the northern health care region.



The Swedish Council of Palliative Care maintains a directory of specialised palliative care services, updated using data from the Swedish Register of Palliative Care. Services are available in all counties, though not on a 24/7 basis. There are 200 services, primarily advanced home care teams and specialised palliative care wards, typically located outside hospitals at an intermediate level between primary care and hospital care. Many also provide consultation services to hospitals. Two regions lack palliative care beds in hospitals or units, and some regions have palliative care teams but no 24/7 specialised services. A few hospitals now have specialised palliative care teams, a trend that is slowly growing. Sweden's healthcare system is publicly funded through taxes, and most specialised palliative care services are financed by regional authorities. These include advanced home care teams, palliative wards, and consulting services. While the wards are not called hospices, they deliver specialised palliative care. Hospices in Sweden are private, typically offering 10-15 beds and rarely providing home care.

RATE OF SPECIALISED PC SERVICES/100.000 INH