september 2026

RETHINKING PALLIATIVE CARE

International perspectives

GUPTA STRATEGISTS

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Inhoudsopgave

About this report

This report examines how five countries – Australia, Canada, England, Italy and Sweden – have organized palliative care, and what the Netherlands can learn from their experiences. The report combines insights from literature research, policy research and group interviews. This research was commissioned by the Nationaal Programma Palliatieve Zorg II (NPPZ II) and produced by Gupta Strategists.

The **Nationaal Programma Palliative Zorg II** (2022-2027) is the successor to NPPZ I (2014-2020) and focuses on the organization and implementation of palliative care in the Netherlands. The programme is coordinated by Stichting PZNL, which was commissioned by the Ministry of Health, Welfare and Sports (VWS) to design and manage the programme. Between 2022 and 2027, €150 million has been allocated to improve the quality and accessibility of palliative care, and to increase awareness of it among patients, professionals and the general public. For more information on this programme, visit our website: www.nppz.org.

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INTRODUCTION

What can the Netherlands learn from palliative care in other countries?

The Netherlands has built a strong foundation for palliative care

Every year, around 170,000 people die in the Netherlands, of whom approximately 120,000 die from a condition for which death was foreseeable. Care provided in the final year of life accounts for around 8% of total healthcare spending. Despite these numbers, half of those who would prefer to die at home do not manage to do so, and a third of patients with cancer receive potentially inappropriate care in the last thirty days of their lives, such as emergency department visits, hospital admissions and ICU stays. For patients and their loved ones, these statistics also reflect uncertainty about care because of unclear responsibilities, and dying in a way that does not fit the care they need or would have wanted.

In 2014, the Dutch Ministry of Health, Welfare and Sports (VWS) invested EUR 50 million into its first National Programme Palliative Care (NPPZ). Since then, professionals, researchers, care organizations, government and insurance companies have completed two national palliative care programmes. The first programme (NPPZ I, 2014–2020) focused primarily on research and awareness, while the second programme (NPPZ II, 2022–2026) focuses on organization and implementation of palliative care.

With the two palliative care programmes, the Netherlands has taken important steps in the organisation of palliative care. There is a national quality framework (the *Kwaliteitskader palliatieve zorg,* known in English as *the Netherlands Quality Framework for Palliative Care*), awareness among patients and care professionals has increased, more training is available, and – most importantly – conversations about the end of life happen earlier and more often than they did a decade ago. And there are reasons to be optimistic about palliative care in the Netherlands. If you compare statistics on place of death between countries, we see that the Netherlands has the lowest number of hospital deaths by a large margin. And there is reason to believe that the delivery of hospital treatment (including ED, ICU and expensive oncological care) is low in the Netherlands compared to similar countries[1],[2].

[1] Oosterveld-Vlug et al. (2022). Evaluating quality of care at the end of life and setting best practice performance standards.
[2] Mitchell et al. (2024). Potentially burdensome care at the end-of-life for cancer decedents.

Place of death – Country comparison
[Distribution of place of death in total adult population, latest available year1]

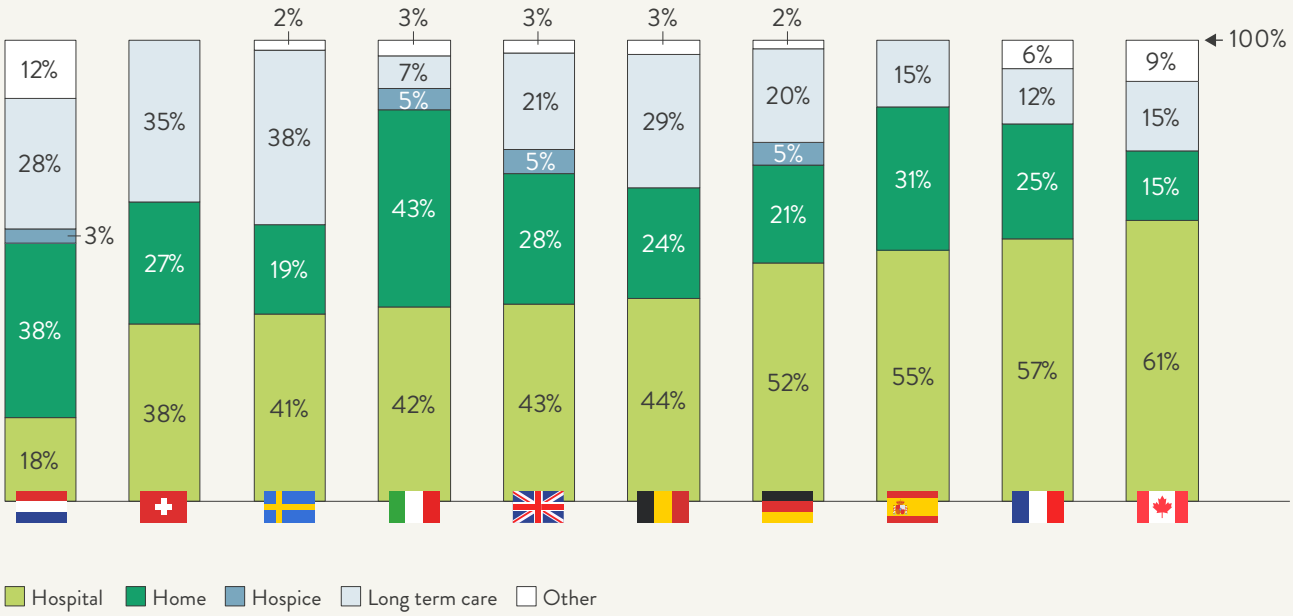

Figure 1 – Comparison of the place of death between the Netherlands and 9 other OECD countries. We use data from the latest available year, but data availability varies between countries. Netherlands = 2023 (source: Palliaweb.nl); Switzerland = 2011 (Reich et al., 2013); Sweden = 2019 (Larsdotter et al., 2024); Italy = 2015 (Neodemos); UK = 2022 (Department of Health & Social Care); Belgium = 2022 (StatBel); Germany = 2017 (Dasch & Zahn, 2021); Spain = 2015 (Cabañero-Martinez et al., 2020); France = 2013 (Poulalhon et al., 2018); Canada = 2015 (CIHI, 2018)

The aim of this report is to learn from palliative care in five countries

The achievements of the Dutch National Care Programmes have been built through sustained effort from many different people and organizations to make palliative care a "self-evident part of regular care". But there is also an unfinished agenda. Not everyone who needs palliative care receives it: in particular people with diagnoses other than cancer and people in vulnerable circumstances. An ageing population and workforce shortages make it more important than ever to organize palliative care well.

This report asks: What can the Netherlands learn from countries that have organized palliative care differently? We compare the Dutch approach to palliative care in Australia, Canada, England, Italy and Sweden. We chose these countries because they represent different models of organizing, financing and measuring care, and because they offer concrete lessons for the Dutch context. The research draws on scientific literature, policy documents, and interviews with patients, relatives and care professionals.

At the outset of this research, one of our initial interests was whether formally recognizing palliative care as a medical specialism improves patient outcomes. As the study broadened, the evidence we gathered does not settle this question definitively: we found no hard evidence that formal recognition improves outcomes, nor that it does not. Policy documents in the countries we studied regularly mention that every care provider should be able to deliver basic palliative care, regardless of specialism. At the same time, we observe international differences between care providers and organizations in how they structure training for specialist palliative care and the priority they give it. They connect to a theme we return to in the next section: embedding palliative care within integrated care.

We make three recommendations to improve palliative care in the Netherlands: (1) Make ACP a normal part of adult life by decoupling it from explicit 'identification' of the palliative phase; (2) Build a national data system to see if palliative care reaches patients and if quality meets national standards, and (3) Be careful not to over-formalise the role of social work in palliative care. On this last point, we instead recommend a number of small steps that we could take to improve the relation between healthcare and social care and that do not require a large bureaucracy.

Two patterns that run through all recommendations

Stop treating palliative care as non-regular care

Our experiences with the national programmes have taught us that, despite the ambition to embed palliative care into regular care, we have a tendency in the Netherlands to respond to gaps in care by building separate solutions. If care workers are insufficiently equipped to have difficult conversations, we design separate training modules. If there is inadequate financial incentive to transition patients to palliative care, we design complicated financing structures. We are developing separate digital environments for palliative care, and we make separate, often elaborate working agreements for palliative care between professionals who should already be collaborating on many other topics.

We believe that palliative care is not something to be carved out from the rest of healthcare. Most of what people need at the end of life, like a professional who knows them well and continuity of care across settings, should not be made into a separate system. The examples from other countries in this report work well because they are integrated into the wider healthcare system. For example, Canada's approach to advance care planning reaches more people because it is framed as a normal part of adult life, not a separate medical procedure. And the Swedish quality register is effective because it is part of national healthcare data infrastructure, not a separate entity.

Good palliative care puts the patient at the center of decisions

The second pattern is subtler but equally important. The past decade has produced real achievements in frameworks, standards and coordination structures for palliative care. These matter, but they can also lead to care that is organized around what professionals and institutions find manageable, rather than around what the person who is dying and their loved ones actually want and need. This shows up in various ways. Patients who have carefully documented their wishes may find that their Advance Care Plan is unknown to care workers or not always taken seriously. Quality registers are built around medical outcomes, but data

on what patients and families actually experience is rarely collected. Nor is a clear distinction made between data that guides an individual patient's own care and data meant for regional and national steering. And policy discussions about palliative care can become elaborate conversations between organizations about frameworks and governance, in which the person who is dying is represented in the footnotes.

We believe that good palliative care means involving patients in decisions that concern them, from first conversations about what lies ahead to where they spend their final days. Countries that do this well do not treat patient involvement as an add-on, but build it into how care is planned, delivered and evaluated. We try to take that seriously in this report, not only because it shows respect for patients and relatives, but also because we believe that it leads to solutions that are genuinely better. We try to ask, for each topic, not only what works in the system, but also what works for the person at the center of it.

Lessons from abroad for Dutch palliative care

Five countries show what works and where to be careful

Recommendation 1
Make early ACP a regular part of care

- **1.1** Broaden triggers to make Advance Care Planning a normal part of adult life
- **1.2** Broaden who can lead the conversation and clarify accountability
- **1.3** Invest in patient-held records, not dedicated infrastructure

Recommendation 2
Build a national data system for quality

- **2.1** Agree on a minimal data set and collect data through three existing moments
- **2.2** Return data to care teams, make it public, and use it to improve care
- **2.3** Don't wait on a national registry to make capacity data available

Recommendation 3
Be careful formalizing the role of social care

- **3.1** Be careful about formal structures to connect healthcare and social care
- **3.2** Ensure access to social expertise through existing care structures
- **3.3** Improve practical and emotional support for informal caregivers

TWO PRINCIPLES RUN THROUGH EVERY RECOMMENDATION

Don't treat palliative care as separate...	... by making ACP independent of explicit 'identification' of the palliative phase	... by embedding quality and capacity data in national care data infrastructure	... by using existing care structures to connect palliative care and social care
Keep the patient at the centre ...	... by centering conversations on patients' wishes, not their diagnoses	... by measuring what patients experience and by making data available to patients	... by centering care on a patient's social situation, not only the medical one

Figure 2 – We see three ways for the Netherlands to learn from other countries: (1) normalizing ACP as part of adult life, decoupled from 'identification'; (2) building a national data system to monitor reach and quality; and (3) avoiding over-formalization of social work in palliative care. Two principles run through every recommendation: integrating palliative care into regular healthcare rather than treating it as a separate system, and keeping the patient at the center.

RECOMMENDATION 1

Make ACP a regular part of care by decoupling it from explicit identification

Where do we stand? Advance care planning (ACP) conversations happen too late, for too narrow a group of patients, and depend on a clinical 'identification' moment that care professionals find difficult and often defer. As a result, patients arrive at crucial decisions without them or their carers having had the chance to prepare.

What this recommendation changes: By decoupling ACP from the 'identification' moment, patients no longer have to wait until a professional judges that the end of life is near to start discussing their values, wishes and needs for future care.

Why this fits the broader pattern: ACP should not be a separate clinical act tied to a diagnosis. Following Canada's example, it becomes a normal part of adult life, no separate module, no separate moment, just good care from the start. Conversations can start from what matters to patients, not from a prognosis. The result is care that reflects what matters most to a person.

Palliative care planning starts too late and does not reach enough people

Advance Care Planning (ACP) is one of the most powerful tools in palliative care. ACP means that patients and relatives discuss and prepare their values, wishes and needs for future care while they still have the capacity to do so. When done well, ACP can mean the difference between receiving care that actually reflects what a person wants, and care that reflects decisions made by others under pressure. For patients and relatives, this is a difference between stress and comfort. For care workers, this means last-minute coordination and uncertainty can be prevented. And for the healthcare system, early ACP has a potential to significantly reduce unnecessary healthcare costs at the end of life. In the Netherlands, this could save between EUR 30 and 180 million a year in ED, hospital and ICU costs[3].

All of the countries in this study, including the Netherlands, acknowledge the value of early ACP. However, experience in the Netherlands shows that ACP does not yet reach all intended patients. Conversations happen too late, too infrequently, and for too narrow a group of patients[4].

One problem is that ACP is dependent on a clinical judgment that a patient is entering the palliative phase. Physicians find this 'identification' (in Dutch: '*markeren*') of patients difficult. It means having a conversation about dying that can be uncomfortable, and for medical professionals it can feel like giving up on a patient[5]. Additionally, many patients have non-linear illness trajectories, especially outside of oncology, that make identifying the palliative phase difficult. For patients with dementia, heart failure, COPD or frailty, there is often not a clear moment at which identification feels natural. As a result, identification and consequently ACP are sometimes avoided.

[3] PZNL, Gupta Strategists (2022). De olifant de kamer uit.
[4] Knottnerus, Francke (2020). Advance care planning in de huisartspraktijk: wat wordt er besproken en wat kan er beter?
[5] Nederlandse Internisten Vereniging (2024). Leidraad Proactieve Zorgplanning in Nederlandse Ziekenhuizen. NHG (2023). Richtlijn Proactieve Zorgplanning

Canada reframes ACP as a normal part of adult life

The ambition to encourage early ACP and the difficulties surrounding this goal are not unique to the Netherlands. All countries included in this study have an ambition to start ACP early and to increase coverage. But whereas most countries rely on awareness campaigns, education and clinical guidelines, Canada has taken a different approach.

Canada's solution is remarkably simple. Instead of pushing for earlier identification of the palliative phase, Canada has simply removed identification as a precondition for ACP. The Canadian Hospice Palliative Care Association (CHPCA) suggests structuring ACP around 5 D's. These are five life events that can provide a reason to have an ACP conversation, independent of medical status[6]:

- **Decade** - reaching a new life decade (turning 50, 60, 70, etc.).
- **Death** - the death of a loved one, prompting reflection on one's own wishes.
- **Divorce** - a change in relationship status, with implications for who acts as decision-maker.
- **Diagnosis** - a new serious or chronic condition.
- **Decline** - a noticeable deterioration in health or independence.

Probably the most distinctive element is the 'Decade'-trigger. By encouraging patients and care professionals to have conversations about future care at every new decade of life (50, 60, 70), ACP is reframed from a clinical act to something closer to writing a will. It is a normal process that any adult might take, independent of a medical prognosis or physician's judgment. In fact, three of the five triggers require no medical context at all (Decade, Death, Divorce).

But Canada goes one step further. If initiating ACP does not require a medical trigger, then ACP may also not require a medical professional to lead it. In Canada, the process of exploring and recording values, wishes and needs related to care can be led by any trained professional, including social workers and case managers. Only translation of those wishes into a formal clinical order requires a physician[7]. Some provinces provide trained ACP facilitators who can lead conversations without clinical referral. This opens the door to having ACP conversations in different settings such as a community center.

The simplicity of this model is what makes it powerful. Most innovations in palliative care (and care in general) add something new: an extra coordination role, a new training module or a new financing structure. Canada's approach to ACP actually removes something, namely the assumption that a medical diagnosis is needed before conversations about care and dying can take place. This shift has the potential to significantly increase the uptake of ACP. For care workers, it removes the uncomfortable requirement to explicitly 'identify' someone as palliative before having ACP conversations. It makes it possible to reach people who would not have been easily identified through a clinical channel, for example because their illness

[6] Canadian Hospice Palliative Care Association. *Advance Care Planning Canada: A CHPCA Initiative*.
[7] Alberta Health Services. *Goals of Care Designation Policy*.

trajectories do not offer a clear moment to act. Advance Care Planning becomes a normal process for anyone willing to proactively think about what matters to them[8].

It is important to note that the Canadian model is still in an early stage of implementation. Participants in our group interview in Canada were largely unfamiliar with it, which suggests that the distance between policy design and day-to-day practice remains substantial. Canada offers a promising blueprint, not a proven track record. The underlying reasons for the unfamiliarity of care workers with the model remain unclear; we have not found systematic evidence on the barriers to implementation in Canada. What we can say is that the gap between policy design and day-to-day practice is a well-documented pattern in healthcare more broadly, and repeatedly confirmed in our group interviews. Canada's experience is a reminder that a well-designed model is not the same as a working one. That said, pockets of strong uptake do exist, for example in Alberta and Oshawa (Ontario), where frontline clinicians have embraced broader ACP triggers as regular practice even without an explicit national mandate.

England's lesson: ACP infrastructure requires good implementation, complemented by a patient-held minimum dataset

An international comparison of the ACP process shows another important factor to make ACP effective: making the care plan accessible across medical settings. Even if patients and professionals do have conversations about care wishes, if the resulting care plan is not accessible to the GP who covers at night, the ambulance crew that arrives in a crisis, or the hospital that admits a patient three months later, these recorded wishes are unlikely to be followed.

England's experience with ACP documentation shows the promise and the difficulty of such digital infrastructure. Since 2008, England has been working on EPaCCS: a system of electronic registers designed to record and share end-of-life care preferences across care settings. Uptake has been slow and uneven across regions[9]. Research points to a number of explanations: limited consultation with users during commissioning, poor interoperability between systems, and unclear added value for professionals who already have access to comprehensive electronic records[10]. However, where EPaCCS has been well-implemented, outcomes are positive. Patients are significantly more likely to die in their preferred place, and hospital admissions in the final months of life are substantially reduced.

England's ReSPECT form offers a complementary lesson. The ReSPECT form is a patient-carried document that summarizes urgent care preferences and treatment limits. It is effective precisely because it is immediately available to any care provider, including ambulance crews and out-of-hours services, without requiring access to specific digital systems.

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[8] There are some signs that a similar move is being considered in the Netherlands. The Netherlands Society for Internal Medicine (Nederlandse Internisten Vereniging) in 2024 published a new guidelines on advance care planning in hospitals, in which they acknowledge the discomfort that doctors may have with explicit identification of the palliative phase. They recommend in the guidelines that advance care planning be made part of the regular care process, and suggest that advance care planning should be used "at least for every patient with a non-curable illness, and ideally with every patient".

[9] Pocock et al. (2021). Underutilisation of EPaCCS in end-of-life care.

[10] Pocock et al. (2026). Challenges in implementing an Electronic Palliative Care Coordination System (EPaCCS).

Insights from literature on early and broad Advance Care Planning

The evidence on Advance Care Planning in the Netherlands shows a consistent pattern: ACP happens, but too late, too narrowly, and without follow-through. Bekker et al. (2022) analysed GP records for patients with cancer, organ failure, and multimorbidity. While in 65% of records at least one ACP-related item had been documented (most often preferences around euthanasia, preferred place of death, and concerns about the future), documentation was often incomplete and rarely covered non-oncological disease trajectories in any depth.[a] Azizi et al. (2022) examined ACP specifically for dementia patients in Dutch general practice and found that ACP conversations occurred in only a minority of cases, and often not until the final weeks of life, which is precisely the moment when many patients can no longer fully participate.[b]

Melin-Johansson et al. (2021) shows that this is not unique to the Netherlands: a third of patients in Sweden had no documented end-of-life discussion, with the groups least likely to have had one being patients with dementia, older patients, women, and those dying in nursing homes or hospitals.[c] The consequences of late or absent planning are measurable. Earp et al. (2021), in a study of over 50.000 decedents across eight chronic disease groups in Alberta, found that early specialist palliative care (defined as starting 90 or more days before death) was associated with a 32% reduction in the risk of hospital-based acute care in the final 30 days of life, compared with no palliative care.[d] Scott et al. (2024) show that the same logic applies to ACP: patients whose care plan was digitally available six or more months before death had fewer emergency presentations, fewer hospital admissions, and lower in-hospital death rates than matched controls.[e]

Where ACP outcomes are accessible to all care providers, the data are encouraging. Pocock et al. (2021) found that in England, patients who had an EPaCCS record were significantly more likely to die in their preferred setting, even though only 18% of patients who died had such a record.[e] The gap between what is possible and what happens is the clearest argument for both broadening who can lead ACP conversations and ensuring that their outcomes are accessible when it matters.

References:

[a] Bekker et al. (2022). Advance care planning in primary care: a retrospective medical record study.
[b] Azizi et al. (2022). Occurrence and timing of ACP in persons with dementia in general practice.
[c] Melin-Johansson et al. (2021). A third of dying patients do not have end-of-life discussions with a physician.
[d] Earp et al. (20₂1). Hospital-based acute care in the last 30 days of life among patients with chronic disease that received early, late or no specialist palliative care.
[e] Scott et al. (2024). Association of advance care planning with hospital use and costs at the end of life.

Recommendation | Make Advance Care Planning a regular part of care

Lessons from abroad for Dutch palliative care

Five countries show what works and where to be careful

Recommendation 1
Make early ACP a regular part of care

- **1.1** Broaden triggers to make Advance Care Planning a normal part of adult life
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TWO PRINCIPLES RUN THROUGH EVERY RECOMMENDATION

Don't treat palliative care as separate...	... by making ACP independent of explicit 'identification' of the palliative phase
Keep the patient at the centre	... by centering conversations on patients' wishes, not their diagnoses

Figure 3 – The example of Advance Care Planning in Canada and England points to three building blocks that would increase ACP uptake in the Netherlands and make it more effective: adopting broader triggers for ACP, broadening who can lead the conversation, and making the care plan accessible across settings, including to patients.

Building block 1 | Adopt broader triggers that make ACP a normal part of adult life

Following the example from Canada, we recommend that the Netherlands move from a single, medical trigger for ACP ('identification') to a broader set of life events that can prompt ACP conversations. An easy start would be to make ACP a standard element of periodic consultations for patients with chronic illness (heart failure, COPD, dementia or frailty), not only after 'identification'. But the broader ambition should be to make ACP a normal part of life, for example by adopting the Canadian 5D-model. It may be worth examining how the Dutch donor register achieved broad public uptake, or whether information on ACP could be coupled with reaching retirement age, without formalising the conversation itself.

Adopting broader triggers for ACP not only make ACP more broadly available for patients, but it is also likely to change what the conversation is about. Instead of starting from a clinical prognosis, early ACP conversations can start from what matters to a person: their values, wishes and needs. This puts the patient at the center from the first moment, and produces richer, more useful information. Once a framework like the 5 D's is in place, structured updating is quite natural. All countries in this report emphasise that ACP is a process, not a single event, because what a person wants and needs can shift as illness progresses. Broader triggers makes it easier to put this in practice, because it creates recurring, natural moments to return to the conversation. This differs from how some Dutch care workers now approach ACP as a one-time conversation; revisiting it periodically, for example whenever a new trigger occurs, has real added value precisely because values, wishes and needs can change over time.

Building block 2 | Broaden who can lead the conversation and clarify accountability

Following Canada, the Netherlands may also consider extending who can lead ACP conversations. Two distinct questions are at stake: who can lead an ACP conversation, and who remains responsible for the ACP process over time. This building block addresses the first, while the second is addressed below and in Building block 3. We already see in some parts of the Netherlands that conversations are being had by practice nurses (POH), district nurses or hospital nurse specialists, instead of only by the GP or medical specialist. Assessment tools such as interRAI, already used in Dutch home care and long-term care, offer a complementary way to flag patients who may benefit from an ACP conversation without requiring a physician. In the longer term, it is worth considering extending this role to professionals in social care (see recommendation 3).

Making ACP a regular life event means shifting primary responsibility away from healthcare, at least in the early stages. For people without a clinical diagnosis, ACP is first and foremost a civic act, comparable to writing a will. The role of carers is not to initiate the conversation, but to receive and record its outcomes. The GP or practice nurse (POH) seems best positioned for recording medically relevant outcomes like treatment limitations and advance care directions in patient files.

The picture changes when ACP becomes clinically relevant, when a patient has been diagnosed with a chronic disease or has been identified as palliative. At that point, accountability becomes more formal. Following the Dutch Quality Framework, the care team should explicitly appoint a central care provider (centrale zorgverlener), who acts as the first point of contact for patients, and is responsible for keeping ACP plans current and coordinating care across settings. Whether this role is consistently accepted across all lines of care, including whether medical specialists and general practitioners are willing to collaborate as equals with practice and district nurses, is not yet known and should be monitored as this model is rolled out. Broader adoption will also depend on the barriers and facilitators to acceptance and on supporting the behaviour change itself.

Building block 3 | Pursue digital infrastructure and patient-held records in parallel

ACP conversations only guide care when their outcomes are available at the moment it matters: at night, in a crisis and across settings. England's experience points to two complementary strategies. The first is continued investment in digital infrastructure. The lesson from EPaCCS is not that such infrastructure fails, but that it requires genuine end-user involvement, interoperability between systems, and clear added value to medical professionals. Australia's My Health Record (MyHR) offers a working example of a patient-controlled national ACP register operating at scale.

The second strategy is ensuring that a minimum dataset travels with the patient independently of system availability, as a complement to digital infrastructure. We believe that investing in tools that strengthen patient agency over health information should not be a fallback strategy, but a structural complement to digital interoperability. The USD-4D, a validated Dutch instrument in which patients monitor their own symptoms and bring the record to consultations, provides an example.. Experience with USD-4D shows that, when patients actively carry and contribute to their health information, the patient can become a reliable node in the information network. Moreover, marking this data appropriately could support future research into the prognostic significance of specific symptoms for remaining survival[11].

[11] Lormans (2025). When you get what you want, but not what you need: Understanding, validating and facilitating the use of the Utrecht Symptom Diary - 4 Dimensional in palliative care. More than 20 diagnosis- and treatment-specific USD variants are already in use in the early palliative phase, and the OPTIMISM study is building on this evidence base for further implementation. For more information, see Kolendhof et al. (2024). Validation of 11 added items of the outpatient version of the Utrecht Symptom Diary in patients receiving chemotherapy or targeted therapy, and IKNL (2024). Ontwikkeling en implementatie van structurele symptoom monitoring voor patiënten met ongeneeslijke kanker.

RECOMMENDATION 2

Build a national data system for quality registration

Where do we stand? The Netherlands has no structural system to monitor whether palliative care reaches the right patients, meets quality standards, or matches what patients actually experience. Regions, hospices, and insurers do not always have access to valuable benchmark information, and patients are at risk of falling through gaps in the system.

What this recommendation changes: A national data system makes visible what is now invisible: whether care reaches the people who need it, whether this care is of the desired quality, meaning it meets the process, outcome and patient-reported measures defined below, whether wishes are followed, and whether the experience of patients and relatives actually improves.

Why this fits the broader pattern: Sweden's quality register works because it is part of national healthcare data infrastructure, not a separate palliative care project. We recommend embedding measurement in existing systems, and letting the data serve every patient, regardless of diagnosis. Adding experiences of patients and relatives gives patients a foundation for accountability and gives care teams the information to do better.

The Netherlands lacks the data to know if palliative care is good enough

The Dutch Quality Framework contains an ambition for continuous quality improvement in palliative care. But the Netherlands currently has limited data to steer on. IKNL and PZNL publish aggregated figures on Earle-type indicators (including hospital deaths and emergency visits in the final thirty days of life)[12]. But we do not systematically monitor whether patients are identified early enough, whether they have an (up-to-date) ACP, or if they are discussed in multidisciplinary meetings. And experiences of patients and relatives are structurally absent from national data: if someone dying at home considered the care to be good, if families felt sufficiently involved or if recorded wishes were actually followed.

Care organizations face a similar blind spot. A nursing home or hospice that wants to improve the quality of its palliative care has no national benchmark to orient itself, though some regional dashboards such as the *Kerncijfers palliatieve zorg* exist. Regional differences in care quality almost certainly exist and without systematic data they remain difficult to correct. At a system level, there is no reliable picture of how many people receive palliative care, from whom, and whether that care matches actual needs.

[12] Palliaweb. Kerncijfers palliatieve zorg in Nederland. https://palliaweb.nl/kennis-en-onderzoek/kerncijfers.

Hospice care provides another clear illustration of where data is lacking. Based on a one-time study, we know that the Netherlands had 246 hospice locations with 1,370 beds in 2024 (8 beds per 1,000 deaths)[13]. But there is no structural monitoring to keep this information up to date. Capacity varies widely between regions (from 4 to 12 beds per 1,000 deaths), but there are no norms for regional availability, there is no waiting list registry, and no party is formally responsible for ensuring sufficient capacity[14]. Insurance companies have a duty of care, but they do not have the data to objectively establish whether they have met this duty. Patients who cannot find a hospice in their region have no one to turn to, because no one is responsible for the gap. And although demand is expected to grow (15%-33% by 2040, or 200 to 450 extra beds), it is anyone's guess whether capacity will keep pace.

Sweden's national register: Structured data collection and sharing creates a learning system

In contrast, Sweden has operated a national quality register for palliative care since 2005: the *Swedish Register for Palliative Care* (SRPC). The register covers all care settings: hospitals, hospices, home care and nursing homes. It works via a questionnaire completed by care professionals after every death. The form (around 25 questions) asks what happened in the final weeks of life: was a conversation held about the prognosis, was a pain assessment conducted, was an opioid prescription available, and did relatives receive bereavement support? Results are fed back via an online portal, where teams can compare their scores against regional and national averages. In 2025, national coverage was 61% of deaths[15].

Alongside the questionnaire for care workers, the SRPC sends a separate survey to relatives via a digital link with a unique password within three months of the death. The survey asks both how the patient experienced the final period of life and how the family members experienced the situation[16]. Data from SRPC show that bereavement support was offered after 57% of hospital deaths, compared with 87–97% in specialist palliative care units[17]. Without a register, that gap would have remained invisible.

Participation is not mandatory, but strongly incentivized: institutions that do not register lose access to the benchmark reports that make the register valuable. Data on the SRPC website are publicly accessible at municipal and regional level. Individual care units can retrieve their unit-specific results; the public can compare aggregated municipal and regional averages and follow developments over time. Aggregate outcomes are also reported to *Vården i siffror* (Healthcare in Figures), a platform managed by Sweden's Association of Local Authorities and Regions, and to the Open Comparisons published by the National Board of Health and Welfare[18].

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[13] Berenschot (2024). Versterken *Hospicezorg: Onderzoek naar huidige en toekomstig benodigde capaciteit.*

[14] Gupta Strategists (2025). Hospices in Nederland: Adviezen richting toekomstbestendige inrichting en bekostiging.

[15] Svenska Registret för Palliativ Vård (SRPC). National Quality Register. https://palliativregistret.se/

[16] Lövgren et al. (2019). *Cancer patients hospitalised in the last week of life risk insufficient care quality*

[17] Elmstedt. Et al. (2019). *Cancer patients hospitalised in the last week of life risk insufficient care quality: a population-based study from the Swedish Register of Palliative Care.*

[18] Sveriges Kommuner och Regioner (SKR). Vården i siffror. https://vardenisiffror.se

The SRPC sits within Sweden's broader framework of national quality registers covering major

disease areas and care processes, jointly funded by the national government and the 21 regions. This is an example of how to avoid the first pattern from our introduction: the SRPC is not a separate palliative care register developed alongside the healthcare system, but part of the infrastructure through which Sweden holds its entire care system publicly accountable. That is the model we recommend the Netherlands should follow: palliative care data embedded in the national data infrastructure that already exists, through IKNL's systems and the broader network of national quality registers.

The register's value extends beyond individual care teams. Because the SRPC covers all diagnoses and all settings, it has become an important source for scientific research on palliative care. Studies using SRPC data have documented large regional differences in access to specialist palliative care for cardiovascular patients[19] and stark disparities in care quality between cancer and COPD patients[20]. These patterns can inform policy, but they require data infrastructure to be made visible.

Our interviews add an important caveat. Professionals working with the SRPC noted that the register has not solved the measurement problem on its own. A participant observed that many units, including specialist units, treat registration of deaths as sufficient, without monitoring what actually happened during the care process: "If you run a specialised palliative care unit, you have to monitor other things to be able to know what you actually do." In other words, a register is only as good as the culture of learning it sits within. Data collection without feedback, reflection and improvement support changes little.

Australia adds patient outcomes measurements and a needs estimate

Australia's Palliative Care Outcomes Collaboration (PCOC) adds two elements. First, it measures patient-level clinical outcomes. Whereas Sweden asks after death whether certain steps were taken, Australia measures during the care process how the patient is actually doing. For example: how severe is the pain and how much has it improved after an intervention? These outcomes are fed back to care teams every six months as benchmark reports. Second, Australia links its clinical data with population-level datasets to estimate unmet need. For example, Australia has recently mapped that of the 109,000 people estimated to require palliative care annually, only 41% receive specialist care. The linkage appears to be a one-off exercise rather than an ongoing process[21]. But if done regularly, it provides important information for policy makers and care planners.

Between 2015 and 2024, the number of palliative care services participating in PCOC

[19] Nyblom et al. (2024). *Registry study of cardiovascular death in Sweden 2013–2019.*

[20] Strang et al. (2021). *Chronic obstructive pulmonary disease and lung cancer*. This report primarily uses the VAL-registry, which is a data registry used in the Stockholm area, which shows many similarities to the national SRPC.

[21] Palliative Care Outcomes Collaboration (PCOC) (2023). Data Quality Statement 2023. University of Wollongong.

doubled from 104 to 202 services, with a similar rate of growth for patients (from 36,300 to 72,400) and episodes of care (48,300 to 95,500)[22]. PCOC is federally funded, participating services must submit data to receive this funding, and the Aged Care Act 2024 anchors palliative care as a legally enforceable right, shifting it from optional add-on to mandatory care responsibility[23].

Canada's palliative care atlases are a first step in making capacity visible

Canada has no national register for palliative care, but it does have an exemplary capacity system. Pallium Canada has developed provincial atlases mapping the availability of palliative care services, hospice bed capacity, and organizational bottlenecks by region. Editions for British Columbia, Ontario and Alberta were published in 2025[24]. These atlases were developed partly because Canada faces a structural shortage (4 hospice beds per 100,000 inhabitants against a guideline of 7–10) and there was no systematic picture of regional shortfalls.

Although the atlases cannot be used to track patient access or available capacity in real time, they do offer something actionable: a regional inventory of palliative care capacity (hospice beds, specialist teams, home care availability) that can be developed without waiting for new legislation or IT systems. Any such system should from the outset be designed as a living document, updated regularly and, once the underlying data infrastructure is in place, embedded in a structural register. A valuable addition could be an estimate of where palliative care services are needed based on demographic statistics.

Measure what patients experience, not just what professionals observe

The examples above focus primarily on data collected by professionals. But the most useful data on quality of care come from patients themselves. Internationally, a number of instruments have become the standard for patient-reported outcome measurements (PROMs) in palliative care. In Canada, the Edmonton Symptom Assessment System (ESAS) is widely used. This system asks patients to rate nine symptoms, including pain, fatigue, nausea and anxiety, on a 0–10 scale. It takes around 1-2 minutes to complete, and the assessment is used as important clinical input. ESAS is also collected routinely at cancer clinics across most of Canada for regular oncology visits, not only in palliative care. Yet ESAS focuses mainly on physical and psychological symptoms and does not explicitly distinguish the four dimensions (physical, psychological, social and spiritual) that a fully holistic instrument would cover[25].

In England, the Integrated Palliative care Outcome Scale (IPOS) by the Cicely Saunders

[22] AIHW (2026). *Palliative care services in Australia: Trends in palliative care services, patients, episodes, phases, and outcome results in PCOC-participating services, 2015–2024.*

[23] Australian Government Department of Health and *Aged Care (2024). Aged Care Act 2024 - Statement of Rights.*

[24] Pallium Canada (2025). *Canadian Atlas of Palliative Care*. https://www.pallium.ca/canadian-palliative-care-atlas/

[25] Watanabe et al. (2009). *The Edmonton Symptom Assessment System* ; Hui et al. (2020). *Time requirement of the Edmonton Symptom Assessment System*.

Institute offers a broader instrument with specific variants for neurological conditions, renal failure and paediatric care[26]. Both instruments share the same logic: a short questionnaire completed by the patient, with scores feeding directly into the conversation with the care team, and aggregated into national benchmarks. Because both instruments use structured, validated questions rather than open-ended ratings, they are less prone to the extremes seen in public rating platforms such as Zorgkaart Nederland, where mostly very good or very bad experiences get recorded.

Insights on the value of data collection and monitoring from literature

The case for investing in palliative care is well-supported in the literature. Across multiple countries and diagnosis groups, access to (early) palliative care is consistently associated with fewer emergency department visits, fewer hospital admissions, and fewer ICU admissions, and a higher likelihood of dying in the preferred setting. In a Dutch study of over 43,000 patients with cancer, exposure to palliative care (whether early or late) was associated with substantially lower rates of potentially inappropriate care in the final month of life: 16% versus 45%, measured as hospital admissions, ED visits and ICU stays in the final month of life[a]. Patients receiving palliative care had lower rates of hospital admissions, emergency department visits and ICU admissions, and were more likely to die at home or in a nursing home.[b] One study in Italy found that palliative care "reduced hospitalizations by over 70%, long hospital stay by 75%, ED visit by 65%, and use of chemotherapy by 35% during the last month". Further, in-hospital death was extremely limited in patients with cancer who were admitted to PC (2.8%) compared to those who were not admitted (58%; OR= 0.01)".[c]

A data register by itself does not produce better care outcomes. But it does make improvement possible. Without systematic measurement, care teams have limited means of knowing how their patients are faring comparable to teams elsewhere, and policymakers have no way to identify where investment is most needed. The studies cited above were only possible because data infrastructure exists to generate them. Despite the large study mentioned, in the Netherlands a structured system to collect, monitor and publish data on palliative care is largely absent.

[26] Murtagh et al. (2019). Validity, reliability and responsiveness of IPOS. *Palliative Medicine.*

What the evidence from Sweden and Australia shows is that registers, when combined with feedback loops and improvement support, drive measurable change over time. Participation in Australia's PCOC has been associated with statistically significant improvements across all patient outcome measures since benchmarking was introduced in 2009[d]. That is the chain this recommendation seeks to build: better data, better visibility, and through that, better care.

Two examples from Sweden show what becomes visible once such data infrastructure exists. The first is variation between diagnosis groups. In Sweden, registry data showed that access to specialist palliative care in the final three months of life was 76.7% for patients with lung cancer and 17.7% for patients with COPD, with the consequence that among COPD patients without specialist access 45.2% died in acute hospitals, compared to 11.8% among those who did have access.[e]

The second example shows variation between regions. Nyblom et al. (2024) found that the proportion of cardiovascular patients who accessed specialist palliative care at the time of death ranged from 0.9% to 5.1% across Swedish healthcare regions; a fivefold difference that only became visible because of the register, and only becomes correctable once visible.[f]

References:

[a] Boddaert et al. (2022). Inappropriate end-of-life cancer care in a generalist and specialist palliative care model.
[b] Quinn et al. (2020). Association between palliative care and healthcare outcomes among adults with terminal non-cancer illness.
[c] Chiaruttini et al. (2022). Palliative medicine favourably influences end-of-life cancer care intensity.
[d] COC National Report Jan–Jun 2024. University of Wollongong / Palliative Care Australia
[e] Strang et al. (2021). Chronic obstructive pulmonary disease and lung cancer: access to palliative care.
[f] Nyblom et al. (2024). Registry study of cardiovascular death in Sweden 2013–2019.

Recommendation | Stop measuring in silos: build one national quality system for palliative care

Lessons from abroad for Dutch palliative care

Five countries show what works and where to be careful

Recommendation 2
Build a national data system for quality

2.1 Agree on a minimal data set and collect data through three existing moments

2.2 Return data to care teams, make it public, and use it to improve care

2.3 Don't wait on a national registry to make capacity data available

TWO PRINCIPLES RUN THROUGH EVERY RECOMMENDATION

Don't treat palliative care as separate...	... by embedding quality and capacity data in national care data infrastructure
Keep the patient at the centre	... by measuring what patients experience and by making data available to patients

Figure 4 – Three building blocks make up the recommended national data system: 1) a minimal dataset, 2) public data used to improve care and 3) regional atlas of palliative care capacity before national registry. Together they connect to the two patterns that run through all recommendations.

Building a national data system for palliative care in the Netherlands does not require starting from scratch. Most of the necessary pieces already exists, just not yet connected to each other. IKNL already collects and publishes indicators of potentially inappropriate end-of-life cancer care, adapted from Earle *et al.*. The Netherlands also has a quality framework that defines what good palliative care should look like[27], and the IZA transformation regions have built a shared set of process and outcome indicators to track their progress against it. On the patient-experience side, the Consumer Quality Index (CQ-index) and Patient Reported Experience Measures (PREMs) are already embedded across Dutch healthcare and offer a natural connection point.

Separately, in 2023 the NPPZ II steering group adopted its own set of 17 quality indicators for palliative care, developed with PZNL, IKNL and Nivel together with the medical scientific societies, V&VN, Palliactief and Patiëntenfederatie Nederland. Each indicator is classified as structure, process or outcome, and grouped under one of five categories: right care, right place, right moment, right provider, and right information. Right information stands in for the program's actual fifth goal, right financing, set aside because financing does not itself indicate quality.

[27] Palliaweb. *Kwaliteitskader Palliatieve Zorg Nederland*. See also: ZonMw. *Op weg naar een systeem om kwaliteit van palliatieve zorg inzichtelijk te maken.*

What is missing is not a framework but structural data collection against one: moving from a set of indicators on paper to a living measurement system. The process and outcome layers described below build directly on the NPPZ II set; the patient-reported layer is the genuinely new addition. The task is therefore to extend what exists into a system that covers all settings, all diagnosis groups, and returns data to the people and organizations that can act on it.

Building block 1 | Agree on a minimum dataset and collect through existing moments

The starting point is agreement on what to measure. Based on the international examples, we propose a minimum dataset that consists of three layers:

- **Process indicators** track whether the basic building blocks of palliative care are in place: the percentage of palliative patients with a recorded identification, the percentage with an (up-to-date) advance care plan, and the percentage discussed in multidisciplinary meetings, in general practice as well as in specialist palliative care, so that the picture is not limited to patients already reached by specialist teams. These are the indicators the Dutch transformation regions already use, and they connect directly to the ambitions of the Quality Framework.
- **Outcome indicators** track what actually happens at the end of life: hospital deaths, emergency department visits and ICU admissions (the existing Earle indicators) supplemented by the percentage of patients who die in their preferred setting. A second set of outcome indicators can come from the bereavement surveys: whether a pain assessment was conducted, whether medication was available, whether conversations were had about what is coming, and whether relatives received bereavement support. Dutch hospices already collect comparable data through the *Sympal* database. However this data is rarely shared beyond the individual organization while they are the ones that matter most to patients and families.
- **Patient-reported outcomes** capture what only patients can report: symptom burden, quality of life, and the experience of care. What a patient wants and needs can shift as the illness progresses, so the measurement interval should stay flexible rather than fixed. ESAS or IPOS are good examples for a starting point. The Dutch USD-4D follows a similar logic across four dimensions (physical, psychological, social and spiritual) and has recently been validated in doctoral research[28]. These outcomes should be embedded within the broader set of quality indicators defined in the Netherlands Quality Framework for Palliative Care, rather than treated as standalone measures.

We recommend that the dataset should stay small. Sweden's SRPC works with around 25 questions per death; Australia's PCOC uses five validated instruments. Complexity is the enemy of coverage. A short, stable dataset that nearly everyone completes is more valuable than a comprehensive one that most organizations skip. The dataset should also cover all diagnosis groups from the start: not just cancer, but dementia, heart failure, COPD and frailty. Building a register around the patients who already have the best access would entrench exactly the inequalities this system is meant to address.

[28] Lormans (2025). *When you get what you want, but not what you need: Understanding, validating and facilitating the use of the Utrecht Symptom Diary - 4 Dimensional in palliative care.*

The minimum dataset can be created by collecting data from three sources, each tied to a moment that already exists in good palliative care. Together, these three streams produce a complete picture: what the care system did, what the patient experienced, and what the family witnessed.

- **The care professional:** Process indicators (whether a patient has been identified, has an advance care plan, and has been discussed in a multidisciplinary meeting) should be registered by the care team as part of normal care delivery. This already happens in some regions in the Netherlands. The task is to extend consistent registration to the rest of the country and aggregate it nationally. IKNL already calculates the Earle outcome indicators (hospital deaths, emergency department visits and ICU admissions in the final 30 days) from linked administrative data, without requiring additional registration by care professionals. This data can currently lag and requires manual work; automating these extractions and updating them more frequently would strengthen the system. Connecting those existing calculations to the broader register should be a small step, but one that adds a nationally comparable outcome layer to whatever process data is collected locally.
- **The patient:** A validated patient-reported outcome instrument, ESAS or IPOS , is completed by the patient at regular intervals during the palliative phase. The scores feed into the conversation with the care professional and aggregate into the national system as patient-reported outcomes.
- **The bereavement survey:** after a death of a patient with a diagnosed life-limiting illness, a short professional questionnaire captures the care the patient received while dying (was pain assessed, was opioid medication available, did relatives receive bereavement support). Within three months of the death, a brief anonymous survey goes to the family directly, asking both how the patient experienced this period and how the family experienced the situation themselves. This is the model Sweden has used successfully since 2005.

Building block 2 | Return data to care teams, make it public, and use it to improve

Data that is collected but not used or returned changes nothing, and a benchmark report nobody reads or discusses changes just as little. Abroad, what makes the system worth participating in is not the register itself but the feedback loop built around it: teams receive their own results, compare them with similar organizations, and use that comparison to ask why they differ and what to change. Every care organization that submits data should receive a benchmark report showing how its scores on identification rates, advance care plan coverage, place of death and patient-reported outcomes compare with similar organizations nationally and regionally, and that report should feed into a recurring cycle of local review rather than arrive as a one-off document. This active use, not the reporting requirement itself, is what drives participation in Sweden without mandating it.

Ideally, participation would be based on such an intrinsic incentive: organizations that submit data receive benchmark reports that allow them to compare their own performance against peers. Alternatively, participation and data submission could be coupled with a financial incentive. This is what happens in Australia, where hospitals activity-based funding depends on submitting relevant data.

National and regional results should be publicly accessible, as they are on the SRPC website in Sweden. Aggregate outcomes by region and care setting give patients, families, policymakers, scientists and journalists something to work with. Individual provider performance stays confidential, to maintain a learning culture rather than a blame culture. The feedback loop only closes if organizations act on the data. IKNL consultants and the Expertise Centers for Palliative Care (EPZs) might help care teams interpret their benchmark results and translate them into improvement plans; the role that Australia calls improvement facilitators.

Building block 3 | Don't wait on a national register to make capacity data available

A quality register measures outcomes for people already receiving palliative care. It does not answer the question of who is not being reached, and whether or not there is sufficient capacity. For that, a separate instrument is needed, which can be developed without waiting for a national register to be operational.

A regional atlas of palliative care capacity should start where most people want to die: at home. The primary focus should be on home care availability, including intensive home care, and nursing home capacity, with hospice beds and dedicated facilities as a secondary layer. This ordering matters: hospice pressure is largely a symptom of insufficient home care capacity, not a problem in itself. In 2024, estimated required hospice capacity already exceeded available beds by at least 150, but without data on home care availability by region, that figure tells only part of the story. A Dutch Palliative Care Atlas would make the full picture visible: by region, by diagnosis group, and relative to projected need. It should be designed as a living document from the start, updated annually and, once the register is operational, embedded in the national data system so that capacity figures and quality outcomes can be read alongside each other.

RECOMMENDATION 3

Be careful using formal structures to connect health and social care

Where do we stand? In the final phase of life, patients are often burdened not so much by medical problems as by psychological, social or spiritual ones: loneliness, questions of meaning, or the exhaustion of family care givers. The medical system often fills a lack of attention to these matters with more interventions rather than the relational care that patients actually need.

What this recommendation changes: Adding formal structures between health and social care has not solved this problem in other countries. Rather than building new coordination structures, this recommendation invests in what is already present, like the professionals, informal care givers and volunteers who are close to the patient, and removes the barriers that prevent them from working. The goal is care built around relationships, not bureaucracy.

Why this fits the broader pattern: The reflex to solve every gap with a new formal structure creates more coordination roles, more bureaucracy, and not better care. England's experience shows this clearly. Small steps that strengthen what already exists work better for patients than new systems layered on top.

Care for the social dimension of dying is underdeveloped

What people need at the end of life is often not reducible to medical care alone. In line with the WHO definition of palliative care, the Dutch Quality Framework states that good palliative care addresses the physical, psychological, social, and existential dimensions of palliative care. In practice, the physical (medical) dimension receives the most attention, the most training, and the most funding. Whether the other three dimensions receive attention often depends more on the interests and training of the individual care workers involved than on any structural guarantee.

This matters for a number of reasons. First, it reflects what most patients want: to die at home, cared for by someone who knows and is trusted by them. This requires a care infrastructure built around relationships, not interventions. Second, neglecting the social dimensions of palliative care risks over-medicalization. Much of what weighs most heavily on people at the end of life (loneliness, questions of meaning, practical disorder, an exhausted family carer) is not a medical problem. When these dimensions go unaddressed, the medical system may fill the gap with more consultations, interventions and hospital admissions. Third, demographic pressure makes attention to social care unavoidable. The number of people needing palliative care in the Netherlands is expected to grow by 30% by 2040, and a system already struggling with personnel shortages cannot absorb that alone. The growing number of volunteers active in Dutch palliative care today will only become more essential.

An increased awareness of the relation of healthcare and social care (used here broadly, encompassing informal care, social work and municipal welfare support) is not unique to

palliative care. Across domains ranging from mental health and chronic disease to preventive care there is a growing recognition that medical problems may have non-medical causes, and that durable solutions require more than clinical interventions. There are examples where the relation between health and social care is developed with good results, e.g. helping people with financial stress to reduce mental health issues. But for many aspects of healthcare there is a looming sense that 'social care' is required for effective solutions, but the connection between health and social care has not yet been effectively established.

All five countries try to connect healthcare and social care

All countries in this study face a version of the same tension: Ageing populations mean that more people will need palliative care in the coming decades; care worker shortages make it impossible to absorb that growth through formal care expansion alone, and the needs of people at the end of life overlap with social and practical needs that formal care is not designed to meet. All five countries try to connect healthcare and social care more explicitly and arguably, all five are ahead of the Netherlands in doing so. But being ahead does not mean that these countries have found the answer. The five countries show a spectrum of interventions that differ considerably in scale, cost, and in evidence of effect.

Italy has gone furthest in legislation. Law 38/2010 mandates that palliative care teams in hospices and specialized home care must include a psychologist as a core team member, and recommends including a social worker.[29] The role of these team members is concretely defined: psychosocial assessment of the patient and family, practical navigation of financial support and housing, coordination in complex discharge situations, and bereavement support. The law is national, but execution is developed regionally, and uptake varies between regions. Two further laws are relevant here: Law 219/2017, which formalises advance directives and advance care planning and requires physicians to refrain from therapeutic obstinacy in the final phase of life, and gives palliative sedation a legal basis; and DM 77/2022, which sets out the framework for territorial care of chronic, frail and palliative patients.

England has taken the most ambitious system-level approach. Palliative care is formally defined as a joint responsibility of health and social care, not only in aspirational policy documents but also in law. The Health and Care Act 2022 requires Integrated Care Boards (ICB's) to commission palliative care in partnership with local government. The Ambitions for Palliative and End of Life Care state that health and social care are equal partners.[30] NICE guidance is also explicit: care must be coordinated between health and social care practitioners across organizations. Social workers are recognized contributors in specialist services, though their presence is not mandated by name in every team. Despite all these laws and ambitions, the May 2025 Commission on Palliative and End-of-Life Care found that the separation of social services from health care continues to cause gaps, with patients frequently unsure who is responsible and facing repeated assessments that leave them exhausted, while the two systems operate with separate financial and organizational structures that have not been bridged.[31]

[29] Legge 38/2010; Piccione T. (2024). L'assistente sociale nelle cure palliative.
[30] Health and Care Act 2022; Ambitions Partnership (2021). *Ambitions for Palliative and End of Life Care 2021–2026.*
[31] Commission on Palliative and End-of-Life Care (May 2025). *Volume 1 Report, p. 46.*

Sweden has created a statutory coordination instrument: the *Samordnad Individuell Plan* (SIP). This is similar in content to the Dutch palliative care plan (PZP), covering all four dimensions of palliative care. But in the Netherlands this plan is made by the healthcare system (GP, district nurse and specialist), and municipalities, welfare organizations and social care providers often do not participate in its making or execution. The Swedish SIP is legally different. Whenever a person needs both healthcare and social care services, the patient and family have the right to request a SIP and to take part in its development, and both healthcare providers and municipalities are legally obligated to help create it.[32]

Canada offers two examples from different provinces. In Alberta, palliative care coordinators are assigned to help patients and relatives navigate the healthcare system by coordinating care transitions, supporting advance care planning, and acting as a fixed point of contact across settings. In practice, this function is usually filled by a home care coordinator rather than a distinct 'palliative care coordinator' role. Dedicated palliative care coordinators mainly exist in large cities, once a patient has been identified and referred as palliative, and capacity there is limited. Nurse navigators fill a related but separate role in some provinces. This role is comparable to the Dutch *centrale zorgverlener*, but in contrast to the Netherlands, this role is usually fulfilled by someone from a nursing, social work, or community care background.[33] The idea is that these professionals are better positioned to address the non-medical dimensions of palliative care, and that making them responsible for coordination might prevent unnecessary medicalization of care. Quebec has taken a different approach through its *Centers Locaux de Services Communautaires* (CLSCs). A CLSC is a publicly funded community health and welfare center that serves as the primary access point for home-based care (not just palliative care, but all home care). The CLSC performs a needs assessment, and CLSC staff provide nursing, rehabilitation, social services and support from a single organization. There is no coordinator who must bridge separate systems, because those systems are not separate: healthcare and social care are delivered by the organization in the same visit.[34]

Australia has approached the connection between healthcare and social care primarily through quality standards rather than legislation or coordination instruments. The National Palliative Care Standards (edition 5.1, 2024) require specialist palliative care teams to include social workers as members, with their role explicitly defined under Standard 2 on psychosocial and spiritual needs.[35] Since 2024, aged care institutions are also required to demonstrate access to psychosocial expertise, including social work, as a condition of accreditation. Australia is also the most explicit about the role of volunteers. Volunteers are not treated as an informal supplement to the care team but as a named discipline, with their own national competency framework. Care organizations must demonstrate structured processes for recruiting, training, and supporting volunteers. Trained volunteers provide companionship, respite for family carers and presence during the final hours of life for patients who would otherwise die alone.[36]

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[32] *Hälso- och sjukvårdslagen* (HSL 2017:30); *Socialtjänstlagen* (SoL 2001:453).
[33] Alberta Health Services. Home Care and Palliative Care. https://www.albertahealthservices.ca.
[34] Gouvernement du Québec. *Act Respecting End-of-Life Care* (2014, gewijzigd 2023).
[35] Palliative Care Australia, *National Palliative Care Standards* (Edition 5.1, 2024), Standard 2.
[36] Palliative Care Australia, *National Competency Framework for Palliative Care Volunteers* (2024).

Insights from literature on integrating social work in palliative care

The case for investing in the social and relational dimensions of palliative care rests on two distinct bodies of evidence.

The first concerns what determines quality of care. Van Roij et al. (2022) followed over 1,100 patients with advanced cancer and 831 relatives in the Netherlands. While patients themselves rated clinical care reasonably well, their relatives rated it markedly lower. Their responses reflect experiences of exclusion, inadequate information-sharing, and insufficient support for the caregiver. Among both groups, satisfaction was most strongly associated with continuity of care, clarity about who the key care provider was, and feeling heard.[a] ElMokhallalati et al. (2023) confirmed the same pattern at population level in England, analysing five years of bereaved-carer survey data: the relational and coordinating dimension of care was the strongest predictor of whether relatives rated end-of-life care as good.[b] What makes this relevant for this recommendation is that it identifies the domain where palliative care most often falls short (the relational aspect), and the importance of this aspect for patients' and relatives' experienced quality of palliative care.

The second body of evidence concerns who is left out. Torensma et al. (2020) found that patients in the Netherlands with a non-Western migration background were admitted to hospital in the last month of life at a rate of 51.6%, compared to 33.9% for Dutch or Western patients. Specialist palliative care involvement was lower, and end-of-life care decisions were made less often.[c] ElMokhallalati et al. found the same in England: deprivation and ethnicity were among the strongest predictors of worse carer-rated care quality.[b] Moreover, the research suggests that the equity gap in palliative care is not primarily a medical problem, but is rooted in social, cultural, and communicative barriers (the terrain where formal medical roles have limited reach and where relational continuity, language, and trust determine whether care reaches the person at all). Adding a named role to a specialist team does not automatically reach the people most at risk of falling outside it. But reaching them requires being present where they are, in trusted relationships, and in involving languages other than the language of the clinic.

What the literature does not show is whether any specific formal structure reliably improves these outcomes. We have not found studies that compare outcomes in palliative care teams with and without social workers in a way that generates generalizable evidence. What the literature does consistently show is that integrated, community-based palliative care produces better outcomes than fragmented, hospital-centered care — through the work of teams that typically include social and psychosocial roles alongside clinical ones, without isolating their specific contribution.[d] The candid conclusion is that the problem is well-evidenced; the solution is not.

References:

[a] Van Roij J et al. (2022). Quality of life and quality of care as experienced by patients with advanced cancer and their relatives: the eQuiPe study;
[b] ElMokhallalati Y et al. (2023). Characteristics of good home-based end-of-life care: analysis of 5-year data from a nationwide mortality follow-back survey in England;
[c] Torensma M et al. (2020). Care and decision-making at the end of life for patients with a non-Western migration background living in the Netherlands;
[d] Bergqvist J et al. (2020). The impact of integrated home palliative care services on resource use and place of death.

Recommendation 3 | Be careful of formal structures; rather, invest in small steps

Lessons from abroad for Dutch palliative care

Five countries show what works and where to be careful

Recommendation 3
Be careful formalizing the role of social care

3.1 Be careful about formal structures to connect healthcare and social care

3.2 Ensure access to social expertise through existing care structures

3.3 Improve practical and emotional support for informal caregivers

TWO PRINCIPLES RUN THROUGH EVERY RECOMMENDATION

Don't treat palliative care as separate...	... by using existing care structures to connect palliative care and social care
Keep the patient at the centre	... by centering care on a patient's social situation, not only the medical one

Figure 5 – Three building blocks for connecting palliative and social care: be careful about formalizing the role of the social domain. Instead, ensure access to social expertise through existing care structures and improve support for informal caregivers. All building blocks connect to the two patterns that run through all recommendations.

Building block 1 | Be careful about formalizing the role of the social domain

Across the five countries, we notice a pattern similar to the Netherlands. When (palliative) care runs into problems that healthcare alone cannot solve, the reflex is to say that the solution should be found 'in the social domain' (the Dutch policy domain of municipal welfare, informal care and community support, distinct from formal healthcare). But proposed solutions that build formal structures between healthcare and the social domain are a different thing, and one that evidence does not support.

The international examples show an array of possible ways to approach the relation between healthcare and social care. But our conclusion is that, in the countries that have gone furthest in formalizing this relation, solutions have not proven to provide better care outcomes. England has legally anchored palliative care as a joint responsibility of health and social care, and yet the 2025 Commission found that the two systems still operate separately. Italy has mandated psychologists in specialist care networks, and yet to the extent that it works this may at least partly be because social capital still exists in a way that it no longer does in Northern Europe. In each case, the instrument addresses a real problem, but the gap between the instrument and the supposed outcome remains substantial.

For the Netherlands, the warning is sharpened by domestic experience. The decentralization of youth care and social support to municipalities provides a visible example of what happens when complex care problems are transferred to formal social care structures without sufficient clarity about who is responsible, what the task entails, and how it will be resourced. With the restructuring of these laws, municipalities received new responsibilities without the knowledge, scale, or capacity to fulfil them. Families find themselves surrounded by an increasing number of workers whose primary activity is coordination rather than care. Bureaucracy has grown, and yet care outcomes have not visibly improved. The same warning was raised for palliative care in 2022: the reflex to build new structures is not a substitute for clarity about ownership and resources.[37]

The same risk applies to palliative care. We see a strong impulse to call for increased collaboration between healthcare and social care. But if this connection is formalized without a clear answer to what that means in practice (who does what, for whom, funded how) the result is more likely to be a bureaucratic infrastructure than a meaningful improvement in how patients and relatives are supported. This does not mean that the social dimension of palliative care should be left to chance. It means that we do not think that the right response is to build large new coordination structures, but rather to invest in what is already present and to remove the barriers that prevent it from working.

[37] PZNL, Gupta Strategists (2022). *De olifant de kamer uit.*

Building block 2 | Ensure access to social expertise through existing care structures

The most important setting for palliative care is the home. It is where most people want to spend their final phase of life, and where the social dimensions of dying are most directly present. It is also the setting where access to non-medical support is most uneven. Whether a patient and their family have someone to turn to with practical questions, financial concerns, or the weight of an exhausted carer depends largely on which GP practice they are registered with, which district nursing organization is involved, and whether that organization happens to employ someone with relevant expertise.

The step we recommend does not require building new structures. Care professionals involved in palliative home care, GPs, practice nurses, and district nurses, should have easy access to a professional with psychosocial and social expertise. Not as a separate role assigned to every individual patient, but as a structural presence in multidisciplinary meetings (MDO) and as a known, accessible point of contact for the care professionals who are closest to the patient.

The RESV structure[38], set to become the organizational backbone of primary care in the Netherlands, offers a natural vehicle for this. RESVs have an explicit mandate to organize primary care and to connect it with the social domain. Ensuring that professionals with psychosocial expertise are structurally part of palliative care MDOs could be a natural extension of what RESVs do, and is a concrete step that requires no new legislation and fits the direction the Dutch healthcare system is already moving in. Where the RESV structure is not yet organized well enough to take this on, regions should be free to use the structure that fits them best, such as an existing palliative care network.

Building block 3 | Provide structural support for informal caregivers

Across the EU, informal carers, mostly family and friends, provide an estimated 80% of long-term care. The same holds at the end of life, when informal caregivers carry out most day-to-day care for people dying at home. A Dutch study of working family caregivers found that combining a job with end-of-life care often leads to burnout and sick leave when work or care arrangements cannot be adjusted in time. Financially, caregivers report lost income and out-of-pocket costs, sometimes debt.

Some countries treat this as a policy responsibility, not a private one. Sweden's närståendepenning offers paid leave, via national insurance, to care for a seriously ill relative. Canada's compassionate care benefit gives up to 26 weeks at 55% of income for the same purpose. Both go further in treating the cost of informal care as a legitimate policy target.

[38] Regional Primary Care Collaboration Networks (RESVs) are regional networks of care and welfare organizations that jointly take responsibility for organizing primary care in their area. They are a core element of the Visie eerstelijnszorg 2030, signed in early 2024. Formation is underway across the Netherlands, with structural funding from 2027 onwards. Their explicit mandate includes connecting primary care with the social domain.

Some initiatives exist in the Netherlands to support informal caregivers: *mantelzorgondersteuning* under the Wmo, respite care, and in some municipalities a *mantelzorgcompliment*. But structural solutions to support informal caregivers remain limited. For example, care workers making time for practical, emotional and spiritual support of families often struggle to get their efforts reimbursed, even if investing in such support reduces the chance that the family will turn to intensive home care later. And local or regional initiatives to support informal care givers may be available, but are often difficult to find for people who are not already intimately familiar with social care structures.

Recommendation 3 mostly serves as a word of caution: Be careful to invest lots of time and money into formal structures to connect healthcare and social care, that have not proven themselves internationally and run a large risk of increasing bureaucracy. Instead, ensuring points of contact for healthcare professionals and expanding efforts to support informal care givers and volunteers seems to us a much less risky, and more rewarding, strategy to ensure all dimensions of palliative care are addressed.

CLOSING REMARKS

Build on the momentum and make ownership explicit

Capitalize on the momentum from the national palliative care programs

Thanks to the national palliative care programs, the Netherlands has taken an important step in strengthening palliative care. Rather than marking an endpoint, the completion of these programs signals a new start. Whereas our 2022 report made the case for a transformation, this report asks what the Netherlands can learn from countries that are further along. The current blend of public interest, political support, and international perspectives presents an ideal opportunity to move forward. What this international comparison adds is three concrete recommendations. The recommendations are grounded in what works elsewhere and specific about what the Netherlands needs to change.

Besides the concrete recommendations, this report also adds a set of questions to ask more openly. Are we reaching the people who need palliative care with the culturally sensitive approach an increasingly diverse society demands, or only the ones who fit the system we have built? And are we thinking with patients, giving them real autonomy over their own care, or for them? Throughout the report, we have aimed to embed palliative care within existing care structures instead of recommending something separate, and we have tried to put the patient and their loved ones at the center of decisions, not only out of respect but from a genuine belief that it leads to better decisions and better care. The three recommendations reinforce each other: normalizing ACP, building shared data, and connecting health and social care all serve the same goal of care that fits within a person's life, informed by what matters to them across every dimension: physical, psychological, social and existential.

Making it happen: Who can take responsibility?

Recommendations do not implement themselves. The international comparison shows this clearly: the distance between good policy and working practice is where ambitions most often stall or fail. With all three recommendations, we find that when accountability is spread across too many parties, ultimately no one feels responsible. The following paragraphs provide an overview of who we think are best-placed to take action on the three recommendations in this report.

Recommendation 1 | Make ACP a regular part of care by decoupling it from explicit identification

Normalise ACP as part of adult life. Conversations about values, wishes and needs before a clinical diagnosis belong outside the healthcare system. We believe that the Dutch Patients' Federation (*Patiëntenfederatie Nederland*) is best placed to build public awareness of ACP as a normal part of adult life, comparable to making a will or assigning a legal proxy. This could mean investing in public campaigns and working with municipalities and community organisations to reach people outside the healthcare system. If responsibility for ACP awareness broadens beyond medicine, public health bodies such as the RIVM or GGDs could play an important role, comparable to population screening programmes. We think that the *Patiëntenfederatie* can also play a role in positioning patients as active holders of their own care documentation, advocating for ACP documentation to become a standard part of patient health records, and ensuring that the design of those records reflects what patients actually need in a crisis.

Embed broader ACP triggers and roles in clinical guidelines. Once ACP intersects with medical decisions such as treatment limitations, documented wishes and clinical handover, it requires clinical ownership. We believe that the *Nederlands Huisartsen Genootschap* (NHG), together with *Palliatieve Zorg Adviesgroep Huisartsgeneeskunde* (PalHAG), are the key actors. If they update clinical guidelines to reflect broader ACP triggers and broader roles (practice nurses, district nurses and case managers as legitimate conversation leaders), it would shape the behaviour of the majority of Dutch GPs.[39] The *Federatie Medisch Specialisten* (FMS) has a parallel role for the medical specialist context, as does *Verpleegkundigen & Verzorgenden Nederland* (V&VN) for the *Verpleegkundig Specialist*, whose independent clinical authority increasingly extends to the treatment decisions and documented wishes. Together, NHG, PalHAG, FMS and V&VN define what ACP looks like when it enters the healthcare system, and their guidelines are the most powerful lever available for changing practice at scale.

Recommendation 2 | Build a national data system for quality registration

Build the national data system. *Integraal kankercentrum Nederland* (IKNL), together with DICA, already collects and publishes the Earle indicators nationally and has the infrastructure to extend this into a broader quality measurement system. The concrete steps are: structurally collecting data against the 17 quality indicators adopted by the NPPZ II steering group in 2023, setting up a bereavement survey following Sweden's model, and connecting capacity data to quality outcomes in a Dutch Palliative Care Atlas that starts with home care and nursing home availability. One way to organize this is through a dedicated taskforce, with follow-up funding from the Ministry of Health, Welfare and Sport (VWS). We believe that IKNL could also take the lead in deciding, together with the expertise centers palliative care (EPZs), which validated patient-reported outcome instrument becomes the Dutch standard.

[39] Additionally, the Landelijke Huisartsen Vereniging (LHV) can play a role in ensuring that General Practitioners have room to act on a new guideline, by advocating sufficient time in consultations and adequate reimbursement.

Recommendation 3 | Be careful using formal structures to connect health and social care

Guard the coherence and hold the line. We believe that the formation of a *Regieorgaan* for palliative care, as recommended in the report '*Samen leven tot het laatst*'[40], creates a natural owner to guard the coherence between the recommendations, monitor whether ownership is actually being taken, and to hold the line against the institutional reflex to respond to every gap with new formal structures. The precise division of roles between the Regieorgaan, the Nederlandse Zorgautoriteit (NZa), Zorginstituut Nederland (ZiN) and health insurers still needs to be worked out. The *Regieorgaan's* mandate explicitly covers stimulating palliative care as an integral part of the broader care, welfare and social domain. This is what recommendation 3 requires: not new formal structures connecting health and social care, but better use of what already exists, through RESV networks, *wijkteams*, and existing social care infrastructure. The *Regieorgaan* is also best placed to connect the two layers of ACP ownership, societal and medical, and to monitor whether they are actually reaching each other in practice.

Provide the system conditions. Finally, we believe that the Ministry of Health, Welfare and Sports (VWS) can provide a number of important conditions to make these recommendations work. Most importantly, the RESV development underway across the Netherlands should explicitly include palliative care in its scope. We believe that the RESV's are the most logical place to organize the connection between healthcare and social care, and that embedding palliative care within these provides a safeguard against developing separate structures for palliative care. In regions where RESVs are not organized at sufficient scale, several RESVs may need to collaborate, or another existing structure may work better, in line with the principle that regions choose their own most logical approach. Additionally, we think that VWS could help with all recommendations by speeding up the development and implementation of the preconditions for digital interoperability, by providing a structural budget for a national quality register, and by providing PZNL/Agora with a clear mandate after 2027 to continue to coordinate and assist the implementation of better palliative care in the Netherlands.

[40] AEF (2026), *Samen leven tot het laatst*. Visie en strategische agenda voor palliatieve zorg en ondersteuning. Mei 2026.

APPENDIX A

Methodology: we combined literature research, policy research, and group interviews

This appendix describes the research approach behind this report. To understand what the Netherlands can learn from palliative care abroad, we combined three methods: a literature review of what drives palliative care outcomes, policy research into how care is organised in five countries, and group interviews with patients, relatives and care providers. We began with an exploratory scan of ten countries and selected five for in-depth study. Figure 6 summarises the approach; the sections below describe each step in more detail.

Figure 6 – Overview of the four-step research approach, with the guiding research questions and method for each step.

We performed exploratory research on palliative care in 10 countries

As a first step in the research, we conducted an exploratory study on palliative care in ten countries: Australia, Belgium, Canada, France, Germany, Italy, Spain, Sweden, Switzerland, the UK. These countries were selected on the basis of a number of criteria:

1. **Maturity of palliative care** – Palliative care organization in these countries is developed to such an extent that we expect to be able to learn from these countries.
2. **Comparability of the healthcare system** – The organization of healthcare is sufficiently similar to the organization of care in the Netherlands, to ensure that good practices can be adopted;
3. **Data availability** – There is sufficient access to information on the organization of palliative care, either through policy documents or through the network of the Dutch Institute of Palliative Care (Stichting PZNL) and Expertise Centers for Palliative Care;

Among other things, we researched the history of palliative care organization per country, the existence of palliative care strategies and policy, the organization of palliative care pathways, and progress on palliative care outcomes. We used a combination of policy research, existing comparative studies and interviews with representatives in seven countries where access to relevant stakeholders was available.

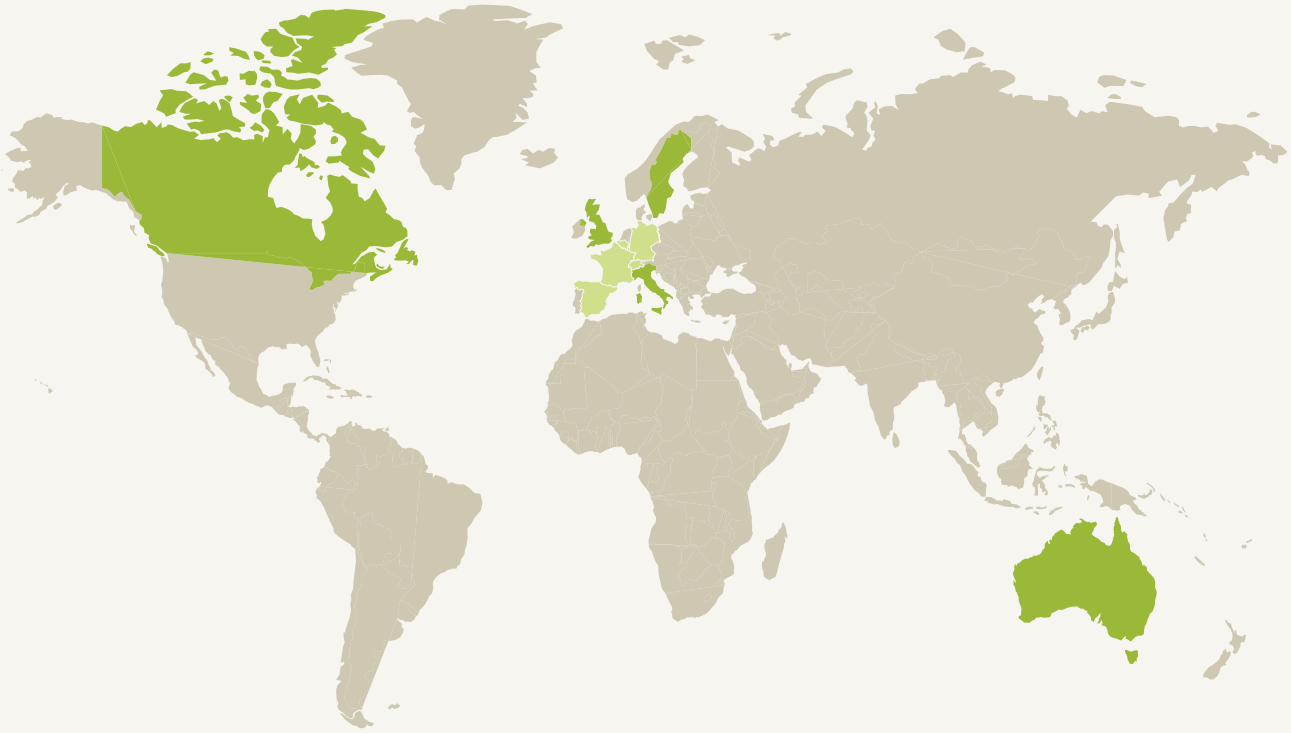

Figure 7 – Countries included in the exploratory research ( ), and selected for further research ( ).

From this, we selected five countries for further study: Australia, Canada, England, Italy and Sweden. These countries were chosen for different reasons. Together they cover the main policy areas relevant to the Netherlands, with sufficient variation in the organization of palliative care in these countries to have broad coverage. Also, in the exploratory research two examples already stood out to us as potentially interesting for the Netherlands, namely the data infrastructure and quality monitoring in Sweden and Australia.

Literature review | We performed a rapid review to understand what drives palliative care outcomes

To understand which factors drive outcomes in palliative care, we conducted a rapid scoping review of scientific literature, designed to identify patterns across countries and outcome domains that could inform recommendations. We searched PubMed and Embase for studies between 2020 and 2025. The population of interest was adults aged 18 and older with any advanced, incurable, life-limiting condition. Studies were included if they reported measurable outcomes of palliative care in Australia, Canada (Alberta or Ontario), England, Italy, the Netherlands or Sweden. The search identified 4,198 records across both databases; after deduplication, 3,591 records were screened on title and abstract, 242 reports were assessed for full-text eligibility, and 80 were used for data extraction.

Outcomes were structured around five domains aligned with the NPPZ outcome framework: quality of life and symptom burden, patient and carer satisfaction, quality indicators of end-of-life care (including place of death, hospital admissions, emergency department visits, ICU admissions, chemotherapy use and involvement of palliative care services in the last month of life), process indicators (ACP discussions, GP involvement, information transfer), and healthcare expenditure at the end of life.

Policy research | We analysed policy to understand how care is organized in the five countries

For each of the five selected countries, we collected and analysed national policy documents, quality frameworks, clinical guidelines and government strategies relating to palliative care. Rather than applying formal selection criteria, we prioritized the most recent available documents per country, supplemented by existing comparative studies and country reports where national sources were incomplete or unavailable.

Documents were analysed thematically, structured around the hypotheses and research questions that emerged from the exploratory study. For each theme, we asked whether the evidence from a given country confirmed, challenged or nuanced the patterns observed elsewhere. This approach allowed us to move beyond description and use the policy analysis to test assumptions rather than simply catalogue differences. The thematic structure of the analysis follows the five themes that organize Appendix A2: definitions of palliative care, care pathways and settings, roles and responsibilities of care providers, data and quality monitoring, and funding.

Group interviews | We interviewed patients, relatives and care workers to learn from their experiences

To test whether the findings from the literature review and policy analysis reflected lived experience, we conducted a generic qualitative study using group interviews. We distinguished between interviews with patients and their relatives, and with care professionals working in palliative care settings. Separating the groups allowed participants to speak freely without having to adjust their perspective. In one country we did not manage to organize a group interview, so we conducted separate interviews.

The group interviews took place online and lasted a maximum of 90 minutes. Each session was moderated by a single moderator supported by one observer who had substantive knowledge of the overall research. Sessions were recorded with participants' prior consent. Participants received background information on the five topics before the session.

Both types of group interviews were structured around the same five predefined topics: the definition of palliative care, the organization of care, care worker capabilities, data collection and monitoring, and funding. For each country, findings from the exploratory research and policy analysis informed specific questions for validation or further exploration within these topics. This allowed the group interviews to do more than confirm existing findings: where participants' experiences diverged from the policy and literature evidence, those divergences are noted explicitly in the relevant sections of this report.

APPENDIX B

Overview of research findings: organization of palliative care differs between countries, but challenges are similar

In the service of readability, we focused the main body of the report on three specific recommendations. However, the research covered a number of other aspects of palliative care. In this appendix, we provide a thematic overview of how palliative care is organized in the countries under investigation: Australia, Canada, England, Italy and Sweden. We researched where palliative care organization is similar and where countries differ. Rather than describing each country separately, the chapter is structured around a set of themes: (1) Definition of palliative care; (2) Care pathways and settings; (3) Roles and responsibilities of care providers; (4) Data and quality monitoring, and (5) Funding for palliative care.

Definitions | All countries start from the WHO definition, but differ in how they operationalize palliative care

All countries use the WHO definition as the primary reference point

Many policy documents on palliative care start with a definition of important terms, such as palliative care, end-of-life, and advance care planning. Australia, Canada, England and Sweden all use the WHO definition of palliative care as the primary reference point:

> *Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening or life-limiting illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.*[41]

Australia, Canada, England and Sweden explicitly cite the WHO definition in policy documents[42], emphasizing quality of life, relief of suffering, and attention to physical, psychosocial, and spiritual needs. The use of a shared definition shows international alignment and a widespread belief that palliative care is more than healthcare in the final days of life, but concerns quality of life more broadly.

Differences in definitions can disadvantage groups and make cooperation difficult

At the same time, countries differ substantially in how they operationalize palliative care in practice. England, for example, makes a clear temporal distinction between palliative care and "end-of-life care", the latter being defined as the last year of life[43]. Sweden, by contrast, defines end-of-life rather narrowly as the last days of life, with access and care transitions structured around a "breakpoint conversation"[44].

[41] World Health Organization (WHO) – Factsheet palliative care, as cited in NHS England (2022). *Palliative and End of Life Care: Statutory Guidance for Integrated Care Boards* (ICBs).
[42] Australian Government Department of Health and Aged Care (2018). National Palliative Care Strategy; Health Canada (2018). Framework on Palliative Care in Canada; NHS (2022). Palliative and end of life care: Statutory guidance for integrated care boards; Socialstyrelsen (2025). Termbank Palliativ Vård
[43] National Institute for Health and Care Excellence (NICE, 2021). Quality Standards. End of Life Care for Adults.
[44] Socialstyrelsen (2025). Termbank Palliativ Vård.

In all countries, there is a gap between broad strategic definitions and narrower operational criteria. National definitions typically describe palliative care as needs-based and applicable across diagnoses. However, access to palliative care and specialist services is often determined by narrower criteria such as prognosis, disease stage, or referral. This can create a gap between who is eligible for palliative care and who actually receives it[45]. This gap tends to disadvantage patients with unpredictable or prolonged disease trajectories, such as dementia, frailty, or chronic organ failure. The Netherlands faces the same tension: the Quality Framework describes palliative care in broad, needs-based terms, but in practice access is most consistently organized around oncological diagnosis and proximity to death.

Care pathways and setting | Organization of palliative care services and the roles of care providers differ between countries

Across Australia, Canada, England, Italy and Sweden, palliative care trajectories follow a broadly similar logic. While countries use different terms, and sometimes organize steps in slightly different ways, the overall approach is comparable. In all five countries, care pathways include some form of **identification** when a palliative approach to care is appropriate, **assessment** of needs and **planning** of care, **coordination** of care between professionals, and **delivery** of care. The Netherlands organizes its care pathways along the same lines, which makes the international comparison particularly instructive: the differences lie not in the structure, but in how each step is executed, by whom, and for which patients.

Identification | Countries are transitioning from a prognosis-based to a needs-based approach to palliative care

All five countries explicitly endorse early and prospective identification of palliative care needs. Whereas historically in most countries identification of palliative care used to be primarily prognosis-based (or time-based), policy documents in especially Australia and Canada mention a desire to shift to a needs-based approach to palliative care[46,47]. Instead of tying palliative care to a specific moment in the disease trajectory (e.g. when curative options are exhausted), the needs-based framing starts from the patient's experienced problems: symptom burden, functional decline, psychosocial distress or care complexity. This transition reflects increased attention in palliative care to diseases outside of oncology, such as dementia and chronic organ failure, where disease trajectories are usually less predictable. The Netherlands endorses the same shift in its Quality Framework, but in practice identification remains most consistently triggered by oncological diagnosis or proximity to death. This gap between needs-based ambition and diagnosis-triggered practice is a challenge all five countries share.

[45] Australian Institute of Health and Welfare (2025). *Palliative Care Services in Australia*.
[46] Palliative Care Australia (2005). *A Guide to Palliative Care Service Development: A population based approach*.
[47] Canadian Hospice Palliative Care Association (2015). *The Way Forward: National Framework*.

Responsibility for identifying palliative care needs is deliberately kept broad and dependent on professional judgement

Across countries, responsibility for identifying palliative care needs is deliberately distributed across the clinical workforce. Rather than assigning identification to a single specialist group, policies[48] emphasize that any clinician with patient contact should be able to recognize emerging palliative care needs. Policy documents especially highlight the role of clinicians who have ongoing, longitudinal contact with patients, which includes general practitioners, primary care physicians, community nurses, and hospital clinicians. The logic is that these professionals are best placed to notice gradual changes, declining functions, or shifts in patient priorities. For this reason, Australian guidelines recommend that a General Practitioner has an active responsibility to identify the appropriate moment to discuss palliative care with patients[49], while England suggests that expertise should be provided in hospitals, care homes, hospices and at home[50]. When specialist palliative care teams are mentioned, they are typically described as consultative rather than initiatory in the identification process.

Policy documents recommend a range of tools that can help clinicians identify which patients are in need of palliative care, such as the Surprise Question, SPICT, AMBER and the Gold Standards Framework. These tools are not presented as instruments that 'decide' whether someone is in need of palliative care, but rather as reminders for clinicians to pause and consider things from a wider perspective. The call about whether a patient has palliative care needs is deliberately left to professional judgment.

[48] Australian Government Department of Health (2018). *National Palliative Care Strategy*; National Institute for Health and Care Excellence (2018). *Decision-making and Mental Capacity*.
[49] Royal Australian College of General Practitioners (2022). *RACGP Aged Care Clinical Guide (Silver Book)*.
[50] Cicely Saunders International (2021). *You Matter Because You Are: An Action Plan for Better Palliative Care*.

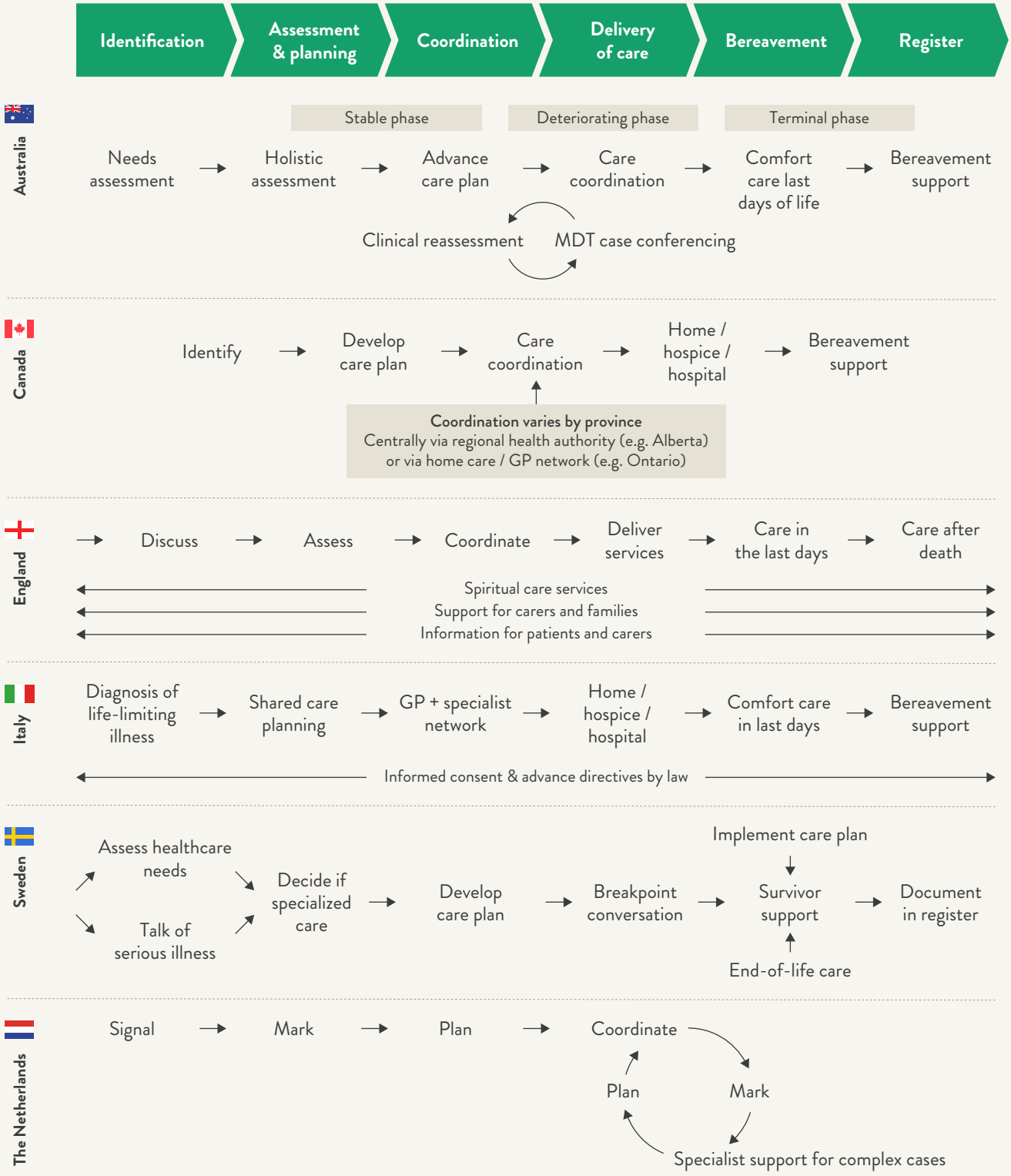

Figure 8 – Care pathways across the five countries follow a similar sequence of identification, planning, coordination and delivery, but differ in how steps are structured, who coordinates, and how formally bereavement and registration are embedded.

Assessment and planning | All countries recognize Advance Care Planning as an important element of the palliative approach to care

Across all countries studies, Advance Care Planning (ACP) is recognized as a core element of palliative care. Policy documents consistently describe ACP as essential for aligning care with patients preferences and values, improving coordination between healthcare providers, and avoiding unwanted or non-beneficial interventions. Across all countries, ACP is presented as an ongoing, iterative process of reflection and dialogue, rather than a one-off conversation or a single documented decision.

Countries do differ in when ACP is expected to take place. In Canada and Australia, ACP is increasingly framed as a process that can begin early, including for people with chronic illnesses or even healthy adults. Policy documents in Canada suggest revisiting ACP at key moments such as the "5 D's": a new Decade of life, Death of a loved one, Divorce, a new Diagnosis, or functional Decline[51]. In England and Sweden, ACP is operationalized as taking place later, triggered by identification of the last phase of life or clinical deterioration.

Responsibility for Advance Care Planning is intentionally shared between actors, which may lead to uneven uptake

As with identification, in most countries responsibility for Advance Care Planning is intentionally shared between actors. Patients are generally expected to reflect on their values and preferences, clinicians and care organizations to initiate or facilitate conversations and ensure documentation, and governments to provide legal frameworks, guidelines and supporting infrastructure.

While this division of labour reflects the relational nature of ACP, it also creates a risk that responsibility becomes diffuse. For example, NICE-guidelines in the UK recommend that all practitioners who come into contact with a person should enable ACP if the person wishes to engage[52]. At the same time, UK policy documents and evaluations acknowledge that this diffusion leads to uneven uptake, depending on individual clinicians' confidence, time, and training. When ACP is "everyone's responsibility", there is a risk that no single professional or organization is clearly accountable for initiating conversations, ensuring follow-up, or keeping plans up to date.

Countries differ in how they manage this shared responsibility in practice. Sweden assigns primary accountability to the physician, particularly the district physician, while the broader care team plays a supporting role. Italy takes the most formal approach: Law 219/2017 explicitly designates the physician as responsible for initiating Pianificazione Condivisa delle Cure (shared care planning) with patients who have a serious illness, and defines this communication as "time of care" - a legally recognized professional duty. England and Australia occupy a middle ground: responsibility is broadly shared across all practitioners in contact with the patient, with the GP typically assuming a coordinating role in practice. Canada goes

[51] Covenant Health Palliative Institute / Alberta Health Services (2025). *Advance care Planning & Personal Directives: Recommendations for Legal Practice in Alberta.* Covenanthealth.ca

[52] National Institute for Health and Care Excellence (NICE, 2018). *Decision-making and mental capacity.*

furthest in decoupling ACP from clinical responsibility: in addition to health professionals, trained ACP facilitators without a clinical background can lead conversations, and in some provinces, this has extended into community settings.

Documentation and sharing of outcomes is consistently the weakest link in ACP

Across the five countries, documentation and data-sharing of ACP outcomes consistently emerge as the weakest part of the system[53]. ACP outcomes are often recorded inconsistently, stored in siloed systems, or not accessible across care settings. As a result, care preferences may not be available at critical moments, limiting the ability of ACP to guide clinical decision-making across providers and settings. This is recognized by all researched countries, and many are investigating (digital) solutions for ACP documentation. What appears to work is simplest: the ReSPECT form used in England, a document that patient carries themselves, largely sidesteps the interoperability problem because the patients hold the record. Implementation of more comprehensive digital solutions remains uneven across all countries.

Coordination | Coordination of care across services is universally recognized as important, but rarely structurally anchored

Palliative care patients typically receive care from multiple providers, across settings, and over time. Across all countries, coordination of palliative care is universally recognized as essential. At the same time, coordination is rarely structurally anchored, because of the highly variable care paths of palliative patients, the decentralized organization of care systems, and the preference for flexibility over formal role delineation. In Canada, for example, national frameworks emphasize the importance of coordination, but responsibility for organizing palliative care rests largely with provinces, resulting in substantial variation in how coordination is arranged[54]. In England, coordination is deliberately framed as a shared task across services and care settings, reflecting a policy preference for locally adapted collaboration rather than formally defined roles[55].

Coordination of palliative care is often deliberately organized close to patients. In the absence of formally designated coordination roles, this means that coordinating functions typically default to professionals who are already longitudinally involved with patients, such as general practitioners, nurse practitioners and home nurses. For example, in England, a patient's GP typically serves as the lead clinician for community-based palliative care[56]. They identify when a patient is approaching end of life, place them on a palliative care register, initiate advance care planning, and convene multidisciplinary reviews with district nurses and other professionals,

[53] NHS England (2024). EPaCCS Implementation Guidance; ACP Canada / Canada Health Infoway (2025). Interoperability report; Advance Care Planning Australia (2024). ACPA report; Svenska Palliativregistret (2025). Annual Report (coverage rate 61%).

[54] Framework on Palliative Care in Canada Act, S.C. 2017, c. 28; Constitution Act, 1867, s.92 (health jurisdiction – provincial powers); Canadian Institute for Health Information (CIHI). Access to Palliative Care in Canada. 2023.

[55] NHS England (2019). NICE guideline: End of life care for adults: service delivery; Ambitions for Palliative and End of Life Care (2nd edition), p. 4; NHS England (2022). Palliative and End of Life Care: Statutory Guidance for Integrated Care Boards, p. 2

[56] Gold Standards Framework. Proactive Identification Guidance (PIG). goldstandardsframework.org.uk; Royal College of General Practitioners & Marie Curie. Daffodil Standards for Primary Care (2019).

and coordinate medication, referrals, and out-of-hours plans. Specialist palliative care teams in hospitals, hospices or community services do not usually take over primary responsibility, but act as consultants who assess complex symptoms, advise on treatment, and support decision-making across settings. This approach supports adaptability, but it also makes coordination highly dependent on local organization and individual professional capacity.

In Australia and Sweden, coordination of palliative care is primarily organized through multidisciplinary teams. For example, in Sweden, palliative care is structured so that most patients receive palliative care from their regular healthcare providers such as primary care teams, hospital departments, and nursing-home staff[57]. These professionals are expected to have basic palliative care competencies. When needs become more complex, specialist palliative care teams may operate as mobile consultation services. Palliative care delivery relies on coordinated collaboration among physicians and (assistant) nurses, social workers, therapists and spiritual care providers, and team meetings and shared care plans are commonly used to align goals, distribute responsibilities, and maintain continuity of care across settings.

Italy relies on dedicated multidisciplinary palliative care teams that function as part of a coordinated network across a province or sub-region, sometimes complemented by charitable providers; palliative care is free of charge by law. In regions such as Lombardy, a regional palliative care department coordinates the various local networks, which in turn combine into a single regional network.

Canada is the only example among the studied countries that has moved toward formally designed palliative case coordinators. These are professionals whose primary role is to manage transitions and continuity across different care settings. In the Netherlands, coordination is similarly organized close to the patient, with GPs and community nurses typically taking on coordinating functions in the absence of formally designated roles. The Quality Framework describes coordination and continuity as a core element of palliative care, and transmural palliative care teams have developed through NPPZ I and II to support this. Uptake and organization vary by region.

Care delivery | Countries differ in how palliative care is delivered across hospital, hospice, long-term care and home care settings

Across the five countries, home is both the most preferred and, in policy, the most promoted setting for end-of-life care. In practice, a substantial proportion of people still die in hospital, with considerable variation between and within countries. In Sweden, data from the national palliative care register show a gradual shift toward home deaths over the past decade, though hospital and nursing home deaths remain common, particularly for older patients and those without a cancer diagnosis. In Canada, place of death varies markedly by province, with studies from Ontario showing that over half of decedents do not receive a home visit from any provider in the last 90 days of life. In England, around half of people now die in their usual place of residence, but geographic access to inpatient hospice facilities remains unequal, with drive time to the nearest hospice a significant predictor of where people die.

[57] Nationellt vårdprogram för palliativ vård (National Care Programme for Palliative Care), 2023, pp. 21–22; Socialstyrelsen. Nationella riktlinjer för palliativ vård (National Guidelines for Palliative Care), 2025, p. 14.

The role of hospices differs substantially between countries. England has a well-developed hospice sector, though it relies heavily on charitable funding, creating structural variation in capacity. In Canada, residential hospices are scarce in many provinces, and patients waiting for an appropriate care setting frequently occupy acute care beds. In Sweden, specialist palliative home care teams provide hospital-level care in patients' homes, reducing the need for inpatient admission. Italy's model relies more heavily on family-based informal care, supplemented by home care services, with evidence that palliative care admission is associated with substantially lower rates of hospital death and acute care use. Availability of hospice beds is considered another benchmark for palliative care coverage in Italy.

The Netherlands shares the policy ambition of home-centred care, but regional variation in home care capacity and hospice availability mirrors some of the challenges seen in Canada and England.

Roles and responsibilities of care providers | Palliative care education is increasingly being specialized, but countries are still exploring the relation between generalist and specialist care

Across all five countries, policy documents share a common starting point: every care provider should have the basic skills to deliver palliative care. This generalist foundation is seen as essential to reaching the broad population of patients who need palliative care, many of whom will never be referred to a specialist team. Integration does not reduce the need for specialist expertise; if anything, expecting every care professional to recognise and initiate palliative conversations increases the need for consultation, training infrastructure and implementation support from specialist networks, consortia and expertise centres. At the same time, all countries have seen a growth in specialized palliative care education programs, certification pathways, and dedicated specialist roles over the past decade.

The boundary between generalist and specialist care is drawn differently across countries, and the right balance remains an open question. In Sweden and Australia, specialist palliative care teams function primarily as consultative services that support generalists in managing complex cases, rather than taking over primary responsibility. In Canada, the distinction is operationalized through billing codes and referral pathways, with generalists providing the majority of care and specialists reserved for complexity. In England, the NHS model emphasizes that palliative care expertise should be available across all settings, hospitals, care homes, hospices and at home, with specialist teams accessible but not routinely required.

The role of social workers varies considerably. Italy has embedded social workers in specialist palliative care teams through national legislation. Sweden uses a statutory coordination instrument that brings health and social care professionals together around individual patients. In England and Canada, social work involvement is recognized but not uniformly required. Volunteers play a notable role in hospice settings across all countries, particularly in England, where the voluntary sector is structurally integrated into hospice care delivery.

The Netherlands follows the generalist-first model, with specialist consultation available through regional and hospital palliative care teams. Social work is described in the Quality Framework but not required, leaving availability dependent on setting and local initiative.

Data and quality monitoring | Sweden and Australia provide inspiring examples of structural data collection and monitoring on palliative care outcomes

There is no single, shared set of quality indicators for palliative care across the five countries. Countries monitor a number of similar outcome domains: where people die, how much hospital care they receive near the end of life, whether people have access to palliative care services and whether certain conversations take place. Yet these outcomes are defined and measured in different ways. Even when outcomes appear comparable, they are often calculated over different timeframes or limited to different diagnoses. For instance, 'place of death' is tracked by all five countries, but Sweden measures it via the national palliative register across all diagnoses, while Italy's monitoring is largely limited to oncological patients. In addition, each country applies a number of indicators that reflect its own policy priorities, such as national quality registers, diagnosis-specific coverage measures, or regionally monitored implementation targets.

Australia and Sweden both offer noteworthy examples of how structural data collection can drive quality improvement in palliative care, although they do so through different models[58]. Australia combines mandatory datasets with a voluntary clinical outcomes program (Palliative Care Outcomes Collaboration (PCOC))[59,60]. This combination captures both patient level outcomes and system level information. Around 85% of specialist palliative care services participate in PCOC, with an important motivation that they receive valuable benchmark reports allowing to compare their performance with national averages.[61] Sweden anchors its palliative care-specific monitoring primarily in a single national quality registry: the Swedish Register for Palliative Care (SRPC)[62]. This registry gathers standardized data on care processes and quality indicators during the last week of life across all settings, supplemented by surveys of relatives. Data are immediately fed back through real time dashboards, publicly accessible regional overviews, and quarterly service reports.

[58] Saurman et al. (2022). *Preferred place of death: a study of 2 specialist community palliative care services in Australia*; Melin-Johansson et al. (2021); Böling et al. (2024); Szilcz et al. (2022). NB: quality indicators must be selected carefully given the limitations of the underlying data source.

[59] Admitted patient care national minimum data set: national health data dictionary version 12, Summary - Australian Institute of Health and Welfare.

[60] Palliative care services in Australia, Palliative care outcomes - Australian Institute of Health and Welfare.

[61] PCOC, University of Wollongong (2023). Data Quality Statement. In 2023, 137 specialist palliative care services participated, representing approximately 85% of services nationally.

[62] Nationellt vårdprogram för palliativ vård (National Care Programme for Palliative Care), 2023; Socialstyrelsen, Nationella riktlinjer för palliativ vård, 2025. The SRPC is the primary clinical quality registry for palliative care; broader health system monitoring also draws on Socialstyrelsen's national registers and the Healthcare in Figures platform.

Elements				
Formal framework	• National standards (PCA) • AIHW palliative measures • PCOC registry	• No national mandate, provincial variation	• NICE Quality Standards QS13	• National guidelines 2025 (non-binding) • Palliative register (SRPC)
Indicator type	• Structure, process & outcome • Patient-reported (PROM)	• Provincial & local data	• Process & experience • Place-of-death, emergency-care review	• Outcomes & process (SPR) • Recorded per care phase
Key indicators	• Physical & psycho-social distress • ACP • Preferred place • Avoidable admissions	• Timely access • ACP • Symptom monitoring (ESAS) • Home care <48 h	• Early identification • ACP • Coordination	• Last week of life: pain assessment, symptom care, care plan, relative survey
Care phases covered	• All phases • Stable > terminal (PCOC)	• Provincial variation	• Mainly end-of-life • Identification, planning, dying, aftercare	• Broad scope • Whole illness journey
Target groups	• All diagnosis • Separate sets: aged & pediatric	• All diagnose • Vulnerable groups • 14 cultural Safety indicators	• All adults (18+) • Separate specs for children	• All diagnosis, ages and settings
Mandatory / voluntary	• Voluntary	• Voluntary • Wide provincial variation	• QS13 & NACEL voluntary	• Non-binding guidelines • Strong normative expectation

Table 1 – An overview of quality indicators in Australia, Canada, England and Sweden. Coverage reflects information from included policy documents and expert interviews; not all elements are comparably documented across countries[63].

[63] Unlike the other four countries, Italy does not have a national quality register for palliative care. Quality monitoring is primarily structured through Decree 43/2007 and the National Guarantee System (NSG), with indicators focused mainly on hospice capacity and cancer care. This limits comparability with the data infrastructures of the other countries studied.

Both countries illustrate how systematic feedback loops are designed to foster a continuous learning culture. Australia's PCOC provides care providers with biannual benchmarking reports and on site support from "Improvement Facilitators" to translate data into practice improvement. Sweden's SRPC offers real time dashboards, spider diagrams for national quality indicators, and quarterly service reports that allow units to compare themselves with regional and national averages. Whereas Australia excels in linking datasets for the purposes of capacity planning and identifying unmet need (e.g. estimating the "population in need" and comparing this to actual service reach), Sweden excels in accessible, routine, high coverage reporting that is deeply integrated into frontline quality work. Both models offer transparency at the system level, while protecting individual provider performance from public ranking to maintain a blame free culture. For the Netherlands, these examples underscore the importance of broad coverage across settings, better linkage between existing data sources, and timely, actionable feedback for care providers. They also highlight that data infrastructures are most effective when combined with training, benchmarking and improvement support.

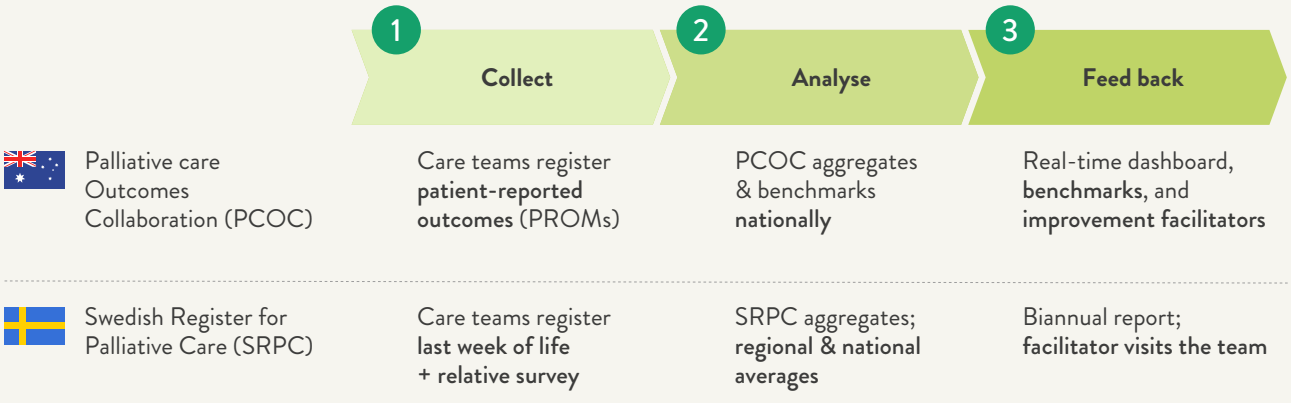

Figure 9 – Two models for structural data collection and quality improvement in palliative care. Australia's PCOC and Sweden's SRPC both operate continuous collect–analyze–feedback cycles, but differ in how improvement support reaches the care team: PCOC uses externally deployed improvement facilitators, while SRPC relies on self-directed access to real-time dashboards and benchmarks.

Funding for palliative care | Funding systems differ between countries, which sometimes leads to unintended financial incentives

Funding models for palliative care differ markedly across countries, and each system offers useful insights into how financial structures can shape access and timing of palliative support. Australia illustrates the clearest example, because acute care is reimbursed at higher rates than palliative care, especially for short admissions, hospitals face an incentive to classify terminal patients under acute diagnosis rather than palliative classifications[64,65]. Canada shows a more indirect version of this dynamic: curative care is fully publicly funded, while homebased and hospice palliative care rely on mixed financing, resulting in cost shifting to families. Economic analyses estimate that 20-26% of end-of-life costs are paid out-of-pocket by patients and families[66]. Sweden, by contrast, uses a tax funded system with regulated patient fees and protection against financial hardship, meaning incentives across care settings are more balanced[67]. England combines NHS funding with significant charitable financing for hospices; although palliative care is free at the point of use, the reliance on philanthropy creates structural variation in availability and capacity.

Across these countries, three cross cutting themes emerge. First, the balance between curative and palliative incentives may shape clinical behaviour. When acute care generates higher revenue, early referral becomes financially unattractive. Second, funding for home based palliative care varies. Sweden and England support home care relatively consistently through public funding, while Australia and Canada are still transitioning toward more flexible, needs based models. Third, regional equity is a recurring challenge. Canada displays pronounced "postcode lotteries"[68] in access to community care and hospices. Australia's mix of federal-state responsibilities produces similar geographical variation. Sweden stands out for minimizing out-of-pocket payments, while England and Canada show greater dependence on private or charitable contributions, especially in non hospital settings.

The Dutch financing landscape shares structural tensions with the countries studied. Like Australia, the current fee-for-service system creates production incentives for care providers that work against the goals of palliative care: time-intensive conversations, early identification, and avoiding non-beneficial treatment are poorly rewarded under activity-based reimbursement.[69] Like Canada, financing is fragmented across legal frameworks, like the Zvw,

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[64] Independent Hospital and Aged Care Pricing Authority (IHACPA). *National Efficient Price Determination 2024–2025.*

[65] IHACPA. *National Efficient Price and National Efficient Cost Determinations 2024–2025.*

[66] Canada Health Act, R.S.C. 1985, c. C-6; CIHI (2023). *Access to Palliative Care in Canada*; CIHI (2025). *National Health Expenditure Trends*, 1975–2025; Pesut et al. (2010). *Tracking the evolution of hospice palliative care in Canada*. BMC Health Services Research.

[67] Hälso- och sjukvårdslagen (HSL, 2017:30), §§ on patient fees and high-cost protection (högkostnadsskydd). See also: 1177.se. Patient fees and high-cost protection. The law requires that fee arrangements do not create unequal access, with particular protections for children, older adults, and people with long-term care needs.

[68] Canadian Institute for Health Information (CIHI). Access to Palliative Care in Canada. 2023 (documents significant provincial variation in access to palliative care services); Canadian Cancer Society. Hospice palliative care bed benchmarks and provincial data (national average of 3.97 hospice beds per 100,000 inhabitants, with only British Columbia and Yukon meeting the recommended benchmark of 7 per 100,000

[69] Nederlandse Zorgautoriteit (2025). *Stand van de Zorg 2025: Palliatieve Zorg*.

Wlz and Wmo, and access to home-based and hospice care depends partly on insurer agreements rather than statutory entitlement, creating regional variation in what patients can actually access.[70]

At the same time, the Netherlands is more actively in transition than most of the countries studied. The introduction of a payment title for advance care planning in hospitals in 2025 marks a concrete step toward aligning financial incentives with palliative care goals.[71] Experiments with alternative financing models, including bundled payments for transmural palliative care, have been tried and are currently being evaluated.[72] The ambition to extend proactive care planning reimbursement to general practice from 2027 signals a direction of travel, though the gap between hospital and primary care financing remains a risk in the interim.[73]

The case for structural reimbursement of time-intensive end-of-life conversations, i.e. conversations that the current system has long rewarded less than the treatments they can prevent, has been made consistently over the past decade.[74] That the argument has now translated into a payment title reflects a shift in what the system is prepared to recognize as care. The structural tension between curative incentives and palliative goals has not been resolved, but the direction of travel is no longer in doubt.

The international comparison suggests two strategic implications. The balance between curative and palliative incentives will not shift through payment titles alone: as Sweden illustrates, consistent incentives across settings require system-level commitment rather than piecemeal additions to an activity-based structure. More fundamentally, the question for the Netherlands is not whether to build a separate palliative financing track, but how to embed palliative care as a full and measurable component of broader quality-driven financing reform, including for dementia, heart failure and COPD, which remain structurally underrepresented in current payment structures.[75]

[70] Stichting PZNL (2025). *Handreiking financiering palliatieve zorg 2025.*
[71] Nederlandse Zorgautoriteit / Federatie Medisch Specialisten (2025). *OZP Proactieve Zorgplanning MSZ (zorgactiviteit 190099).*
[72] Nederlandse Zorgautoriteit (2024). *Experimenten met alternatieve bekostiging in de palliatieve zorg.*
[73] Palliaweb / NZa (2025). *Verkenning bekostiging proactieve zorgplanning Segment 1.*
[74] PZNL, Gupta Strategists (2022). *De Olifant de Kamer Uit. Over de potentie van de implementatie van proactieve transmurale palliatieve zorg.*
[75] Nederlandse Zorgautoriteit (2025). Stand van de Zorg 2025: *Palliatieve Zorg.*

APPENDIX C

Overview of included studies literature research

Table 2 – An overview of the 74 studies included in the rapid review, covering palliative care outcomes across the Netherlands, Australia, Canada, England, Italy and Sweden, published between 2020 and 2025.

Author (year)	Country	Study design	Key topic / outcome
Azizi (2022)	Netherlands	Electronic health record study	ACP timing and frequency in dementia in Dutch general practice (n=15,493)
Barbera (2023)	Canada – Ontario	Retrospective matched cohort	Routine symptom assessment (ESAS) and uptake of palliative care (n=204,688)
Bekker (2022)	Netherlands	Retrospective record study	ACP documentation in GP records across cancer, organ failure, and multimorbidity
Bergman (2022)	Netherlands	Retrospective cross-sectional	Trends in GP palliative care in the Netherlands 2009–2019 (n=3,121)
Bergqvist (2020)	Sweden	Population-based observational	Specialist home PC: reduction in hospital admissions and ED visits (n=2,780)
Bergström (2025)	Sweden	Prospective cohort	Symptom trajectory in palliative home care cancer patients (n=240)
Boddaert (2020)	Netherlands	Nationwide observational	Inappropriate EOL care and palliative care exposure in cancer (n=43,067)
Boddaert (2024)	Netherlands	Retrospective observational	Specialist PC timing and inappropriate EOL care in two hospitals (n=2,603)
Böling (2024)	Sweden	Cross-sectional, registry	Palliative care consultation in last week of life (n=265,129)
Bosetti (2021)	Italy	Retrospective cohort	Preventive drug prescribing in last year of life: cancer and chronic disease
Brinkman-Stoppelenburg (2020)	Netherlands	Observational	Palliative care team consultation and QoL in Dutch hospitals (n=164)
Brown (2021)	Canada – Ontario	Retrospective cohort	Physician PC delivery models: generalist, consultation, specialist (n=231,047)
Cai (2020)	Canada – Ontario	Longitudinal cohort	Preferred vs actual place of death in home-based PC: congruence (n=290)
Cai (2021)	Canada – Ontario	Longitudinal cohort	Predictors of achieving preferred home death in palliative home care
Cheung (2020)	Canada – Ontario	Retrospective cohort	Days at home in last 6 months in haematological malignancies (n=11,127)
Chiaruttini (2022)	Italy	Retrospective database	Palliative care admission and end-of-life care intensity in cancer (Lombardy, n=26,539)
Chu (2021)	Canada – Ontario	Retrospective cohort	Immigrant vs long-term resident end-of-life care; aggressive care rates

Author (year)	Country	Study design	Key topic / outcome
Chukwusa (2020)	England	Population-based observational	Geographic access to inpatient hospice and place of death (n=123,088)
Earp (2021)	Canada – Alberta	Retrospective cohort	Specialist PC timing and acute care use across eight chronic diseases
ElMokhallalati (2023)	England	Observational, 5-year survey	Determinants of good-quality home EOL care (VOICES bereaved-carer data)
Fremont (2025)	Canada – Ontario	Retrospective cohort	EOL symptom management prescribing and community death (n=55,903)
Furst (2023)	Sweden	Retrospective registry	Specialist PC and place of death in chronic heart failure (n=4,322)
Grant (2024)	Australia	Observational cohort	Primary care home visits and anticipatory prescribing: hospital use
Grant (2025)	Australia	Retrospective cohort	GP role at EOL: contacts, home visits, anticipatory prescribing (n=7,025)
Hafid (2025)	Canada – Ontario	Retrospective cohort	Outpatient care patterns (primary/palliative/specialty) in heart failure (n=65,625)
Henoch (2021)	Sweden	Nationwide registry	Specialist PC vs hospital for late-stage COPD: symptoms and ACP
Hsu (2020)	Canada	Retrospective cohort	Inpatient PC and acute care outcomes in Ontario and Alberta (n=363,970)
Iqbal (2025)	Canada – Ontario	Retrospective cohort	Systemic anticancer treatment at EOL and high healthcare use (n=68,963)
Isenberg (2020)	Canada – Ontario	Cost-effectiveness study	Home-based EOL care: cost-effectiveness and community death
Jia (2024)	Canada – Ontario	Retrospective cohort	PC delivery differences: ethnically Chinese vs non-Chinese Canadians
Kenny (2024)	Australia	Retrospective cohort	Specialist PC duration and costs in last year: cancer and non-cancer
Khan (2021)	Canada – Ontario	Retrospective analysis	EOL quality indicators across three Canadian provinces over 12 years (n=376,108)
Maclagan (2022)	Canada – Ontario	Retrospective cohort	Palliative care and place of death in COPD (n=35,492)
Mah (2022)	Canada – Ontario	Retrospective cohort	Quality indicators for gynaecologic cancer EOL care over 13 years
Malhotra (2023)	Netherlands	Cross-sectional	QoL, treatments, and symptom burden in advanced cancer (n=1,088)
McKenzie (2022)	Canada – Alberta	Retrospective cohort	Healthcare use in neurodegenerative disorders; specialist PC access (n=1,439)

Author (year)	Country	Study design	Key topic / outcome
Melin-Johansson (2021)	Sweden	Nationwide registry	End-of-life discussions: frequency and associated factors (SRPC 2015–2017)
Mitchell (2024)	Australia	Population-based cohort	Potentially burdensome EOL care in cancer deaths in NSW (n=80,005)
Monnery (2023)	England	Prospective observational	Enhanced supportive care teams: symptom burden, place of death, costs (n=4,594)
Mracek (2021)	Canada – Alberta	Retrospective cohort	Palliative vs generalist home care and ED visits in cancer (n=6,976)
Murmann (2024)	Canada – Ontario	Retrospective cohort	PC use by mortality risk profile in home care clients (n=247,377)
Nilsson (2020)	Sweden	Nationwide register	Rural vs urban home death likelihood in palliative cancer (n=8,990)
Nilsson (2024)	Sweden	Prospective cohort	Preferred and actual place of death in palliative cancer patients (n=242)
Nyblom (2024)	Sweden	Nationwide registry	Place of death and specialist PC in cardiovascular disease (n=209,671)
Ohlen (2025)	Sweden	Nationwide longitudinal	National palliative care policy impact on place of death (n=152,462 cancer)
Oosterveld (2022)	Netherlands	Nationwide observational	Quality indicators: place of death and hospital care in 31 Dutch regions (n=109,707)
Oosterveld-Vlug (2022)	Netherlands	Nationwide observational	Regional variation in quality indicators and best-practice standards (n=109,707)
Pereira (2024)	Netherlands	Observational, claims data	Integrated PC: inappropriate EOL care and costs (n=210 vs 420 controls)
Pitson (2020)	Australia	Population-based analysis	Radiotherapy/chemotherapy in last 30 days of life (n=12,760)
Pocock (2021)	England	Cross-sectional	EPaCCS digital care records and association with community death (n=1,723)
Quinn (2020)	Canada – Ontario	Population-based cohort	PC and place of death in heart failure (n=74,986)
Quinn (2020)	Canada – Ontario	Population-based matched cohort	PC and healthcare use in non-cancer illness (n=113,540)
Quinn (2021)	Canada – Ontario	Population-based cohort	PC delivery differences across cancer, dementia, and organ failure
Quinn (2022)	Canada – Ontario	Matched cohort	Collaborative home-based PC for heart failure: generalist/specialist roles
Romano (2022)	Italy	Retrospective cohort	PC for non-oncological diseases: place of death and referral timing

Author (year)	Country	Study design	Key topic / outcome
Saurman (2022)	Australia	Cross-sectional	Preferred vs actual place of death in community PC services (n=2,353)
Scott (2023)	Canada – Ontario	Retrospective cohort	NP and physician home visits and community death (n=103,664)
Scott (2024)	Australia	Retrospective cohort	ACP document timing and hospital use/costs (n=5,586 vs matched controls)
Seow (2021)	Canada – Ontario	Population-based cohort	Early PC and end-of-life outcomes: hospital use and place of death
Seow (2021)	Canada – Ontario	Population-based cohort	Early PC and health system costs in last month of life (n=79,648 pairs)
Seow (2021)	Canada – Ontario	Observational cohort	Symptom trajectories in home care cancer patients (n=27,295)
Singh (2023)	Australia	Retrospective linked data	Hospital use in last year for heart failure/ cardiomyopathy deaths
Snoswell (2025)	Australia	Cost-consequence analysis	Telepalliative care (SPaRTa) for rural patients: place of death and costs
Strang (2021)	Sweden	Retrospective registry	Specialist PC access: COPD vs lung cancer; ED visits, hospital death
Strang (2024)	Sweden	Registry-based study	Direct medical costs in last year of life by cancer type (n=20,431)
Szilcz (2022)	Sweden	Retrospective cohort	Overtreatment quality indicators in cancer deaths 65+ in Sweden (n=54,177)
Torensma (2020)	Netherlands	Nationwide mortality follow-back	EOL care differences by migration background in the Netherlands
Triandafilidis (2024)	Australia	Retrospective audit	EOL care for dementia: PC consultation, ACP documentation, place of death
Van Roij (2022)	Netherlands	Prospective multi-center cohort	QoL and care satisfaction in advanced cancer: patients and relatives (n=1,103)
Van Sopall (2021)	Canada – Ontario	Retrospective cohort	Sex differences in EOL care intensity in heart failure (n=396,024)
Von Bahr (2025)	Sweden	Retrospective registry	Specialist PC and ED visits/hospital death in haematological malignancies
Webber (2021)	Canada	Retrospective cohort	Active in-home physician PC model: community death and ED visits (n=354)
Wiltshire (2024)	England	Retrospective cohort	Healthcare use in all expected deaths in England 2021/22 (n=400,000)
Yi (2020)	England	Mortality follow-back survey	Care costs in last 3 months: hospital vs community vs palliative (3 countries)

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