

Out-of-hours specialist and generalist palliative care service provision

—
An evidence review



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List of abbreviations

Abbreviation	Term
AAL	active assisted living
CaNISC	Cancer Network Information System Cymru
CASP	Critical Appraisal Skills Programme
CCP	Care Continuity Physicians
DNACPR	do not attempt cardiopulmonary resuscitation
DOH	Department of Health
EAPC	European Association for Palliative Care
ECG	electrocardiogram
EHR	electronic health record
ELNEC	End-of-Life Nursing Education Consortium
EOL	end-of-life
EPD	Electronic Patient Dossier
ESAS	Edmonton Symptom Assessment System
GP	general practitioner
GPC	generalist palliative care
HSE	Health Service Executive
HPCU	home palliative care unit
ICS	Irish Cancer Society
IH	in hours
IHF	Irish Hospice Foundation
KIS	Key Information Summary
NACPC	National Advisory Committee on Palliative Care
NHS	National Health Service
OECD	Organisation for Economic Co-operation and Development
OOH	out of hours
PEACE	Palliative Care Emphasis Program on Symptom Management and Assessment for Continuous Medical Education
PICOS	Participants, Interventions, Comparators, Outcomes and Study design
PCU	Palliative care units
SAPV	Spezialisierte Ambulante Palliativversorgung
SPC	specialist palliative care
S&GPC	specialist and generalist palliative care
UK	United Kingdom
USA	United States of America
USP	Palliative Care Units (France)
VSD	<i>Vorsorgedialog®</i>
WHO	World Health Organization

Glossary

Term	Definition
Palliative care	The World Health Organization defines palliative care as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening 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” ¹ .
Advance care planning	A process that allows individuals to document their preferences around future healthcare. These plans can provide direction to healthcare professionals and loved ones when a person is not in a position to communicate or make their own choices.
Carer	Any person, such as a family member, friend, or neighbour, who is providing assistance to another person without payment for the care given.
eHealth	A broad term describing the use of information and communications technology in healthcare. eHealth encompasses a range of services, including electronic health records (EHRs), eprescribing, telemedicine and clinical decision support system.
Ex ante	Beforehand, or prior to undertaking an activity.
Generalist palliative care	Provided by primary care professionals and specialists who have received training in or acquired basic palliative care skills and knowledge in treating patients with life-threatening diseases. Should be made available to professionals who are more frequently involved in palliative care, such as oncologists or geriatric specialists, but who do not provide palliative care as the main focus of their work. Depending on the discipline, may be taught at an undergraduate or postgraduate level or through continuing professional development.
Gold Standards Framework	A framework for optimising the service delivered to any patient nearing the end-of-life in primary care. The framework provides primary healthcare teams with tools for identifying, assessing, and recording patients’ palliative care needs.
Grey literature	Materials and research produced at all levels of government, academics, business, and industry in print and electronic formats, but which is not controlled by commercial publishers. Examples include reports, conference proceedings, and policy documents.
Life-limiting condition/illness	A condition or illness which cannot be reversed by treatment and from which a person is expected to die.
Macro level	The highest level of analysis, sometimes known as the global perspective, and which typically analyses at the societal, national, or international level.
Meso level	The intermediate level of analysis, sometimes known as the mid-range perspective, and which typically analyses at the community or organisational level.
Micro level	The smallest unit of analysis, sometimes known as the local perspective, and which typically analyses at the individual or household level.
Model of care	Describes a framework that brings together regulatory, organisational, financial, and clinical aspects of service provision to outline best practice in patient care delivery.
Narrative synthesis	Collating findings into a coherent textual narrative, and grouping and reporting the key findings across data sources in the context of their methods and validity.
Performance indicators	Metrics used by organisations to measure how well they are performing against targets or expectations. Performance indicators measure performance by showing trends to demonstrate that improvements are being made over time. Performance indicators can also measure performance by comparing results against standards or against other similar organisations.
Snowball sampling	Reviewing studies included in a systematic review for references to other potentially relevant studies.
Societal perspective	An approach to evaluation that captures data on the outcomes of interest to payers, service users, families, and unpaid carers.
Specialist palliative care	Provided in services whose main activity is the provision of palliative care. These services generally care for patients with complex and difficult needs and therefore require a higher level of education, staff, and other resources. Specialist palliative care is provided by specialised services for patients with complex problems not adequately covered by other treatment options. Specialist palliative care is usually taught at a postgraduate level and reinforced through continuing professional development.

Executive summary

Purpose: Palliative care policy in Ireland is currently under review, and out-of-hours, often referred to as “after-hours” care is a recognised gap in provision. The Department of Health (DOH) commissioned this report to systematically review and synthesise the international evidence on effectiveness and cost-effectiveness, models of care, performance measurement, and barriers to, and facilitators of, implementation of OOH specialist and generalist palliative care in Ireland.

Review questions: The evidence was reviewed to answer four related questions:

1. What is the peer-reviewed evidence for the effects of OOH specialist and generalist palliative care (S&GPC) services on patient and family/caregiver outcomes, and on cost and cost-effectiveness considering health system and societal perspectives?
2. What are the models of OOH palliative care services in high-income countries that have such programmes?
3. What are the indicators used to measure the effectiveness of OOH palliative care services in those countries?
4. What are the barriers to, and facilitators of, implementing OOH palliative care services in those countries?

Methods: The authors of this review firstly examined the peer-reviewed literature (Question 1) using a systematic review of academic (Embase, MEDLINE [Ovid], Cochrane Library, CINAHL, Allied and Complementary Medicine [Ovid], PsycINFO, Web of Science, Scopus, EconLit (Ovid)) and grey (Google Scholar, OpenGrey, ClinicalTrials.gov, World Health Organization International Clinical Trials Registry Platform, ProQuest Dissertations & Theses [United Kingdom (UK) and Ireland], RIAN.ie, Lenus, EThOS) literature published between 1 January 2000 and 1 August 2018 using specified search terms and controlled vocabulary. Studies that comparatively evaluated the effect of OOH specialist or generalist palliative care for adults on patient and caregiver outcomes, and on effectiveness and cost-effectiveness were eligible, irrespective of design. Only English-language studies were eligible, and studies in other languages with potential eligibility were recorded in order to assess potential bias. Two reviewers independently examined the returned studies at each stage (title and abstract review, full-text review, and quality assessment).

Where Question 1 examined solely peer-reviewed literature, Question 2 and 3 did not pertain to peer-reviewed literature, utilising broadly grey literature. We reviewed policy and practice documentation from 16 high-income countries which were selected due to their well-integrated palliative care services, and which are both ranked in the top 20 of the Global Atlas for Palliative Care and are members of the Organisation for Economic Co-operation and Development (Questions 2 and 3). We supplemented this with scoping searches of the peer-reviewed and grey literature. The DOH commissioning document specified 11 data points for Question 2, which included points on target population, team formation and collaboration, palliative training, and methods to enhance responsive and anticipatory palliative care, as well as four data points for Question 3, regarding performance indicators. We developed a bespoke form in Excel™ according to these data points and extracted relevant data accordingly. Narrative synthesis was employed to review identified material. Local leaders and experts in palliative care policy and practice, as well as those from academic institutions, were identified in each country and asked to review a summary of national data for accuracy and comprehensiveness.

We identified barriers to, and facilitators of, implementation (Question 4) through a secondary review of all collated material: all titles and abstracts returned by the systematic review and all reports and grey literature used in the documentary review. We employed narrative synthesis to summarise relevant material at the macro, meso, and micro levels, which categorises the material at the universal or national level, the organisational level, and the individual level respectively.

Findings: In the systematic review (Question 1), we identified one eligible peer-reviewed study, and this was judged by two independent reviewers as being of insufficient quality to include. Our search of other sources found no relevant material. The systematic review therefore included no studies.

In the documentary review of models of care in 16 high-income countries (Question 2), we identified widespread acknowledgement of the importance of integrated, 24-hour palliative care in principle.

The Australian After-hours Palliative Care Framework is the most definitive in identifying key elements for OOH models: client care planning, information systems, OOH telephone triage, OOH nursing, OOH specialist support, and follow-up quality assurance contact following a visit. Specific examples of innovation are observable in different countries, but we were unable to identify other frameworks for OOH care.

With respect to performance measurement (Question 3), the only indicators identified that were specific to OOH palliative care were those from the UK Department of Health and Social Care. These measure:

- 1) Advance care planning preparation;
- 2) Appropriate palliative specialisation competency within all OOH services;
- 3) Access to, and communication between, OOH palliative care services;
- 4) Updated and detailed patient information sharing among in-hours and OOH services; and
- 5) Access to drugs, particularly opioids.

Our review of implementation challenges (Question 4) identified more barriers than facilitators. These included insufficient resources, inadequate knowledge among practitioners and patients, a lack of advance care planning to guide non-specialists in their management of deteriorating patients, inadequate communication between, and integration of OOH services with other parts of the healthcare system, and insufficient knowledge among unpaid caregivers to provide some OOH pain and symptom management themselves. Facilitators generally mirrored these barriers, including access to information from healthcare staff and patients, effective collaboration between teams, access to medication and equipment, and effective electronic patient record systems.

Conclusions: The importance of integrated, 24-hour care for people in line with a palliative care approach, considering and ensuring patient and family preparedness, is widely acknowledged in Irish policy and practice documentation, and this is consistent with other high-income countries with well-established palliative care services. Nevertheless, international academic evidence and policy documentation lack detail on how to organise, provide, and evaluate OOH S&GPC. Since three-quarters of the week occurs outside of typical working hours, OOH palliative care provision is essential to achieving integrated, comprehensive care for this priority population. Specialist palliative care staff are not available or affordable in sufficient numbers, so meeting current and future needs requires increasing the numbers, capacity, and supports of generalist OOH providers, including general practitioners, nurses, and paramedics. Efforts to address recognised deficits in OOH palliative care in Ireland can build on examples from other countries in defining service elements and in designing specific models of OOH care, including the education of generalists and using telehealth. Specific practical steps to address known gaps and barriers are recommended. Ongoing evaluation of the feasibility and effectiveness of these new services is critical in the context of very limited evidence internationally.

1 Introduction

1.1 Background

Palliative care is the interdisciplinary specialisation that aims to improve quality of life for people with life-limiting illness and for their families through expert pain and symptom management, improved communication and goals-of-care discussions, and psychosocial and spiritual support.¹ Originating in end-of-life care (EOL), palliative care is now widely acknowledged as having potential benefits throughout the trajectory of serious and life-limiting medical disease, often provided concurrently with curative treatment, as well as in supporting families during bereavement.^{1,2}

Palliative care has a long history in Ireland, rooted in the voluntary sector.³ Since 2001, national strategic direction in palliative care has been provided by the *Report of the National Advisory Committee on Palliative Care* (NACPC), which is official Government policy.⁴ The NACPC report advocates for universal palliative care access on the basis of need, delineating three levels of specialisation among clinical staff:

- *Level one – palliative care approach*: all healthcare professionals should be aware of, and appropriately apply, palliative care principles.
- *Level two – generalist palliative care (GPC)*: healthcare professionals who are not engaged full time in palliative care but have some relevant training and experience.
- *Level three – specialist palliative care (SPC)*: healthcare professionals whose core activity is providing palliative care.

The policy states that both specialist and generalist services should be available in and integrated across all care settings, including acute general hospitals (inpatient and outpatient), hospices (inpatient and day centre), in the community (e.g. from general practitioners [GPs], in community hospitals), and in the patient's place of residence (including their own home and in residential care settings such as nursing homes).

More than 70% of Irish patients prefer to spend their palliative treatment period at home, provided that they can access appropriate services and supports.⁵ Typical general practices and palliative care day centres keep 9.00am to 5.00pm opening hours during the week,⁶ meaning that from Monday to Friday, two-thirds of a patient's day occurs out of hours (OOH), and this proportion is much higher at weekends.⁷ Meeting the policy goals of having universal palliative care that is available according to need and that is provided appropriately throughout three levels of specialisation therefore requires comprehensive OOH care provision.

Ireland performs strongly in international rankings of access to services,^{8,9} and provision has advanced significantly in Ireland during the period 1993–2018.¹⁰ Nevertheless, evaluations have identified important deficits. A minority of Irish patients who wish to die at home are able to do so;¹¹ there is documented unmet need in modifiable problems, including unmanaged pain and depression in the last year of life;¹² and there are recurring inequities in access to SPC by region and diagnosis.¹³⁻¹⁵

Poor outcomes for patients at EOL have been linked to inadequate community supports and a lack of patient confidence in OOH access.^{11,16} A recent initiative to identify research priorities for palliative care in Ireland, involving patients, carers, volunteers, and health and social care professionals, established OOH care as the number one priority.¹⁷

Lack of capacity and inequities reflect historical factors (the state's three largest cities – Dublin, Cork, and Limerick – had centres to care for the dying from around the turn of the 20th century, whereas other regions continue to lack any inpatient services)³ and contemporary ones (notably inadequate funding, particularly following the financial crisis of 2007–2008).¹⁰

Pressures on existing capacity are growing due to demographic trends. Ireland has the youngest population of any country in Western Europe, which will result in the fastest-growing rate of palliative care need over the in the period 2019–2070.¹⁸ Even if the NACPC report had been fully implemented to 2019, with universal national provision on the basis of need, current capacity would need to

increase approximately 80% by 2050. In the context of enduring gaps and under-provision, capacity must instead more than double to meet future needs.

1.2 Policy context and review purpose

Three major recent policy developments inform the context of this review.

First, in recognition of developments since 2001, the Health Service Executive (HSE) commissioned a three-year development framework to identify deficits in adult palliative care services in Ireland from 2017 to 2019.¹⁹ A key recommendation of the resultant framework was a revision of the NACPC's 2001 report, and therefore an updated national palliative care policy for Ireland, from 2020. The framework also contained a specific recommendation to consider seven-day and OOH services.

Second, in 2017, a cross-party Oireachtas committee made wide-reaching recommendations for a reconfiguration of the Irish healthcare system in the *Sláintecare Report*.²⁰ Among its key recommendations was the expansion and adoption of palliative care within a universal healthcare provision framework.

Third, the *National Cancer Strategy 2017–2026* recognised the need for coordinated and integrated palliative care on the basis of need. A key element of the palliative care recommendations was the fundamental role of GPC services in the provision of care, and the associated training needs this brings.

In summary, the Department of Health (DOH) in Ireland is engaged in a full revision of national palliative care policy in the face of insufficient capacity, unmet need, and growing demand. Policy-makers, researchers, providers, patients, and carers have all identified OOH care a key deficit in current service provision.

In order to inform efforts to address this recognised deficit, the DOH commissioned a report to synthesise the best available scientific evidence and to collate international best practice in provision of OOH palliative care for adults.

1.3 Research questions

The commissioning brief of this project, which was reviewed and finalised with researchers prior to starting the study, specified four questions:

1. What is the peer-reviewed evidence for the effects of OOH specialist and generalist palliative care (S&GPC) services on patient and family/caregiver outcomes, and on cost and cost-effectiveness considering health system and societal perspectives?
2. What are the models of OOH palliative care services in high-income countries that have such programmes?
 - a) The answer to this question should cover as many countries as is feasible.
 - b) The answer to this question should (at a minimum) address the following issues for each case country:
 - i. Definition of OOH
 - ii. Target population for OOH or after-hours S&GPC services
 - iii. Composition of specialist and generalist teams
 - iv. Roles and responsibilities of team members
 - v. Collaboration and information sharing between generalist and specialist OOH teams
 - vi. Collaboration and information sharing between OOH teams and normal-hours teams
 - vii. The S&GPC collaboration process
 - viii. Additional training requirements for OOH specialist and generalist team members
 - ix. Methods to ensure information sharing between in-hours (IH) staff and OOH staff

- x. Anticipatory actions by IH S&GPC services to support the patient, carers, and OOH generalist and specialist teams
 - xi. Methods to maximise generalist and specialist OOH teams' responsiveness to patients and their carers, including technology (telephone, electronic health record, video link), triage, decision trees, preparedness, and home visits, and
 - xii. Describe the similarities and differences between country approaches.
3. What are the indicators used to measure the effectiveness of OOH palliative care services in those countries? Include (at a minimum) the following:
 - a) List the indicators used by the selected countries.
 - b) Explain the rationale for each indicator.
 - c) Describe the usefulness of the indicator.
 - d) Assess the validity of the indicator.
 - e) Describe the similarities and differences between country approaches.
 4. What are the barriers to, and facilitators of, implementing OOH palliative care services in those countries?

At the outset of this project, we decided to address:

- Question 1 using a systematic review of databases and grey literature
- Questions 2 and 3 using a documentary review of policy and practice documents from 16 high-income countries which were selected prior to data collection due to their well-integrated palliative care service, and supplement this review with relevant material from the peer-reviewed and grey literature, and
- Question 4 using all studies and reports included in our answers to Questions 1–3.

The remainder of this report is therefore structured as follows:

- Chapter 2 presents the methods and results of our systematic review of databases and grey literature (Question 1).
- Chapter 3 presents the methods of our documentary review of policy and practice documents from 16 high-income countries (Questions 2 and 3).
- Chapter 4 presents the results of our documentary review of policy and practice documents from 16 high-income countries (Questions 2 and 3).
- Chapter 5 synthesises the barriers to, and facilitators of, implementation (Question 4) using all material collected to answer Questions 1–3.
- Chapter 6 draws together the key findings from all four questions and makes suggestions for the future of OOH palliative care for adults in Ireland, in the context of the limitations of our work.

2 Systematic review

2.1 Introduction

As detailed in the previous chapter, the first research question for this study was:

What is the peer-reviewed evidence for the effects of OOH specialist and generalist palliative care (S&GPC) services on patient and family/caregiver outcomes, and on cost and cost-effectiveness considering health system and societal perspectives??

We determined that a systematic review was the appropriate methodology to use in order to address this question.

Multiple systematic reviews have been reported in the field of palliative care. Some have examined effectiveness and/or cost-effectiveness across multiple settings and configurations,²¹⁻³¹ while others have focused on specific models and settings, including hospital inpatient^{32,33} and outpatient,³⁴ home care,³⁵ and day care settings,³⁶ as well as care provided by unpaid family carers.³⁷

In order to avoid duplication, we conducted a rapid scoping review of the MEDLINE database for a prior systematic review of OOH palliative care. None was identified.

A search of PROSPERO,³⁸ the international prospective register of systematic reviews, found no ongoing or completed review addressing our research question, but did find one ongoing review addressing a different enquiry related to OOH palliative care:³⁹

What interventions, policies, or models of care are effective in improving 'out of hours' care for palliative care patients?

We therefore decided to conduct a systematic review of peer-reviewed studies and grey literature that specifically addressed our first research question.⁴⁰

2.2 Methods

2.2.1 Eligibility criteria

Studies reporting on the following PICOS (Participants, Interventions, Comparators, Outcomes, and Study design) were eligible for this review.

2.2.1.1 Types of participants

The World Health Organization (WHO) states that palliative care may be beneficial across the trajectory of serious disease and has well-established spillover effects on families.¹ Subjects may therefore

- Be in their last year of life
- Have a terminal illness
- Have other serious/complex medical needs, or
- Be a carer for someone who falls under items.

In this context we placed no restrictions on diagnosis/need, or on patient/carer perspective. In the context of well-established differences in needs and outcomes between children and adults in palliative care, as well as the specific focus on adults from the commissioning body, we did impose an eligibility criterion by age.

Studies of adults (18 years of age and over) were eligible for inclusion. Studies of children (under 18 years of age) and studies pooling children and adults without reporting the results separately were ineligible.

2.2.1.2 Types of interventions/exposure/comparators

We interpreted OOH provision as services provided outside of typical working hours (i.e. 9.00am–5.00pm, Monday to Friday) and therefore including overnight, weekends, and public holidays. In the

event of any ambiguities with respect to intervention timing in otherwise eligible studies, we decided prior to beginning our review to resolve these through discussion and consensus among the core researchers of the review team, and, where appropriate, through contact with the author of the study in question.

The best-established models of care in Ireland and internationally are inpatient hospices, inpatient and outpatient hospitals, home care, and day care. We did not define the term 'palliative care' before starting our review, seeking studies of OOH care for people with life-limiting illnesses, resolving ambiguities through discussion and consensus among the review team, and, where appropriate, contacting the corresponding author. We did not restrict eligibility by either setting or generalist/specialist configuration of staff. We did require that studies reported on the provision and effects of OOH care separately.

Eligible interventions were therefore new models of care provided outside of typical working hours (e.g. an overnight telephone advice service), and already established models of care where the effect of OOH provision specifically was evaluated and reported on (e.g. a hospital inpatient programme that expanded services to incorporate weekends, and that measured and reported on the effect of that expansion).

We did not restrict eligibility by the variables that were being compared, but we did require that studies were generally comparative in nature. Eligible comparators therefore included traditional and alternative models of OOH palliative care.

2.2.1.3 Types of outcomes

Our primary outcomes of interest were the effectiveness (patient/carer outcomes) and cost-effectiveness (economic outcomes) of interventions.

We took a broad approach to all outcomes. Patient and/or carer outcomes could be quantitative or qualitative, and included quality of life and experience, as well as survival. Effectiveness outcomes had to be reported by the patients, carers, or a credible proxy, and not by healthcare staff or administrators. Eligible economic outcomes included any resource utilisation typically considered to fall within the societal viewpoint (e.g. cost to payers, service users, and families, as well as unpaid care). We did not require resources to represent the literal cost of provision, but also classed non-cost measures of resource utilisation as eligible – e.g. insurance programme charges and frequency use data combined with validated unit costs. Any study reporting within cost-consequence frameworks, such as cost-effectiveness analysis and cost-utility analysis, was also eligible.

Ineligible outcomes were those that related to other parties, e.g. the experience or capacity of clinical staff or the perceptions of healthcare workers of the effectiveness and cost-effectiveness of services.

2.2.1.4 Types of studies/reports

Study designs vary considerably in research on serious illness in the context of profound ethical and practical considerations.⁴¹ As such, we did not restrict our search to any one design. We planned to include the following types of studies: prospective/retrospective cohort studies, before-and-after studies, randomised controlled trials, economic evaluations, qualitative/descriptive studies, and pilot studies.

We excluded studies that did not comparatively measure the effect of interventions on our outcomes of interest.

2.2.1.5 Time period

Studies were only eligible if they finished data collection no earlier than 1 January 1996 and were published no earlier than 1 January 2000, and no later than the end of data collection in December 2018.

We based this decision both on the rapidly changing palliative care landscape in the period 1998–2018, and on the fact that Ireland's current official policy was written in 2001 (and therefore had the chance to incorporate relevant research prior to that point).

2.2.1.6 Cultural and linguistic range

Given the skills of the research team, only English-language materials were eligible for inclusion.

All returned studies in a language other than English were recorded separately in order to assess potential bias (Appendix 1).

2.2.2 Search strategy

2.2.2.1 Database search

Two information specialists (CH and DM) searched the following electronic databases:

- Embase
- MEDLINE (Ovid)
- Cochrane Library
- CINAHL
- Allied and Complementary Medicine (Ovid)
- PsycINFO
- Web of Science
- Scopus, and
- EconLit.

Searches were conducted on 1 August 2018.

Information specialists (CH and DM) and subject experts (BJ, PM, RMcQ, MR) devised searches for keywords in the titles, abstracts, subject headings, and controlled vocabulary of the databases (Table 1). We searched only for articles published from 1 January 2000 onwards, in line with our eligibility criteria.

Table 1 Database search terms (example using Embase)

#	Search terms
1	'palliative therapy'/exp OR 'terminal care'/exp OR 'terminally ill patient'/exp OR 'hospice'/exp
2	Palliat*:ti,ab
3	((terminal* OR hospice* OR 'end-of-life' OR 'end-stage' OR 'last year of life' OR LYOL OR 'life's end') NEAR/5 (care OR caring)):ab,ti
4	((advanced OR terminal*) NEAR/5 (ill* OR disease*)):ti,ab
5	('end stage' OR 'end of life' OR 'last year of life' OR LYOL or 'life's end'):ti,ab
6	#1 OR #2 OR #3 OR #4 OR #5
7	'OOH care'/exp
8	('after-hour*' OR 'OOH' OR 'outside normal hours' OR 'out of office hours' OR 'outside office hours' OR 'after office hours' OR 'outside normal working hours' OR weekend* OR holiday* OR 'off-hour*'):ti,ab
9	#7 OR #8
10	#6 AND #9

2.2.2.2 Other sources

Two information specialists (CH and DM) searched the following grey literature sources:

- Google Scholar
- OpenGrey
- ClinicalTrials.gov
- World Health Organization International Clinical Trials Registry Platform (WHO ICTRP)
- ProQuest Dissertations & Theses (United Kingdom [UK] and Ireland)
- RIAN.ie
- Lenus, and
- EThOS.

Searches were conducted on 3 August 2018. Keywords from the database search were applied (Table 2).

Table 2 Grey literature search terms (example using OpenGrey)

#	Search terms
1	(palliative OR "terminal care" OR "terminally ill" OR hospice* OR "end-of-life" OR "end-stage" OR "last year of life" OR LYOL OR "life's end") AND ("after-hours" OR "OOH" OR "outside normal hours" OR "out of office hours" OR "outside office hours" OR weekend* OR holiday* OR "off-hour*")
2	Palliative hours
3	#1 OR #2

2.2.2.3 Snowball sampling

Prior to starting the study, we decided that all studies found to be eligible and passing quality assessment would be reviewed for references to other potentially relevant studies.

We also checked other systematic reviews for citations of relevant studies: We checked all primary studies included in all systematic reviews returned by our database search, and all studies included in 17 other reviews that we knew at the outset and covered all major palliative care settings.²¹⁻³⁷

2.2.3 Study selection and quality assessment

2.2.3.1 Database search

2.2.3.1.1 Screening of titles and abstracts

Two information specialists (CH and DM) executed the searches and made the retrieved citations available in EndNote. Two team members (BJ and PM) uploaded these citations to the online reviewer tool Covidence (<http://www.covidence.org/>) and reviewed titles and abstracts independently using the eligibility criteria described in Section 2.2.1. Conflicts between the two reviewers were resolved using discussion and consensus.

2.2.3.1.2 Screening of full-text reports

Two team members (BJ and PM) independently reviewed all studies that were advanced to full-text screening on Covidence using the eligibility criteria described in Section 2.2.1. Conflicts between the two reviewers were resolved using discussion and consensus.

2.2.3.1.3 Assessment of methodological quality/bias

Following agreement on eligibility, each study was assessed for methodological quality using one of a number of standardised instruments developed by the Critical Appraisal Skills Programme (CASP, <http://www.casp-uk.net/casp-tools-checklists>), which also provides recommendations for exclusion of studies. Since multiple study designs were eligible, we decided prior to data collection to use the specific CASP tool most appropriate to each study (e.g. the CASP Case Control Study Checklist, the CASP Economic Evaluation Checklist, the CASP Qualitative Checklist, and so forth).

Two team members (BJ and PM) quality-assessed all eligible studies independently. Conflicts between the two reviewers were resolved using discussion and consensus.

2.2.3.2 Other sources

Two information specialists (CH and DM) compiled all returned grey literature in EndNote. For Google Scholar, the first 10 pages (100 items) were collated; for all other sources, all returned items were collated. One team member (RMCC) reviewed each grey literature item for potential relevance to this review. Studies published in the peer-reviewed literature were discarded if they had already been returned by the database search. Where the reviewer was uncertain of relevance, she conferred with another team member (BJ or PM).

One team member (PM) performed the review of the reference lists of other systematic reviews.

2.2.4 Data analysis

2.2.4.1 Data items

We decided prior to data collection to extract the following data items from studies that were eligible and of sufficient quality: design (e.g. randomised controlled trial, prospective cohort study, case-control study, etc.); country of origin; care setting; model of care; level(s) of provider expertise/training; sample size; patient characteristics; carer characteristics; recruitment and sampling; ethical issues, including consent; research question; outcomes; approach to confounding; statistical methods; and findings. Conflicts between the two reviewers, BM and PM, were resolved using discussion and consensus.

2.2.4.2 Data synthesis

We decided to perform meta-analyses of included studies where possible due to homogeneity of methods, participants, interventions, and reporting. Given the wide range of outcomes of interest, it was not possible to specify methods prior to data collection.

2.3 Results

2.3.1 Database search and study selection

Our search of nine databases is summarised in Figure 1

The search yielded 1,500 citations, of which 834 were duplicates. We reviewed the remaining 666 unique titles/abstracts, of which 626 did not meet the eligibility criteria. We then reviewed the remaining 40 full texts, of which one met the eligibility criteria. However, this study did not pass quality assessment due to critical omissions in reporting (Appendix 2).

The database search therefore identified zero peer-reviewed studies evaluating the impact of OOH palliative care for adults on patient/carer outcomes and/or economic outcomes.

2.3.2 Other sources

Our search of grey literature sources yielded 150 items, of which 101 were peer-reviewed articles already returned by the database search (see Section 2.3.1). The remaining 49 items were reviewed for duplicates, which were discarded (n=4). None of the remaining 45 items were found to contain evaluations relevant to this systematic review.

Our review of the citations found in other systematic reviews examined one published systematic review returned by our database search,⁴² and from 17 other reviews that we were already aware of.²¹⁻³⁷ No additional eligible papers were identified.

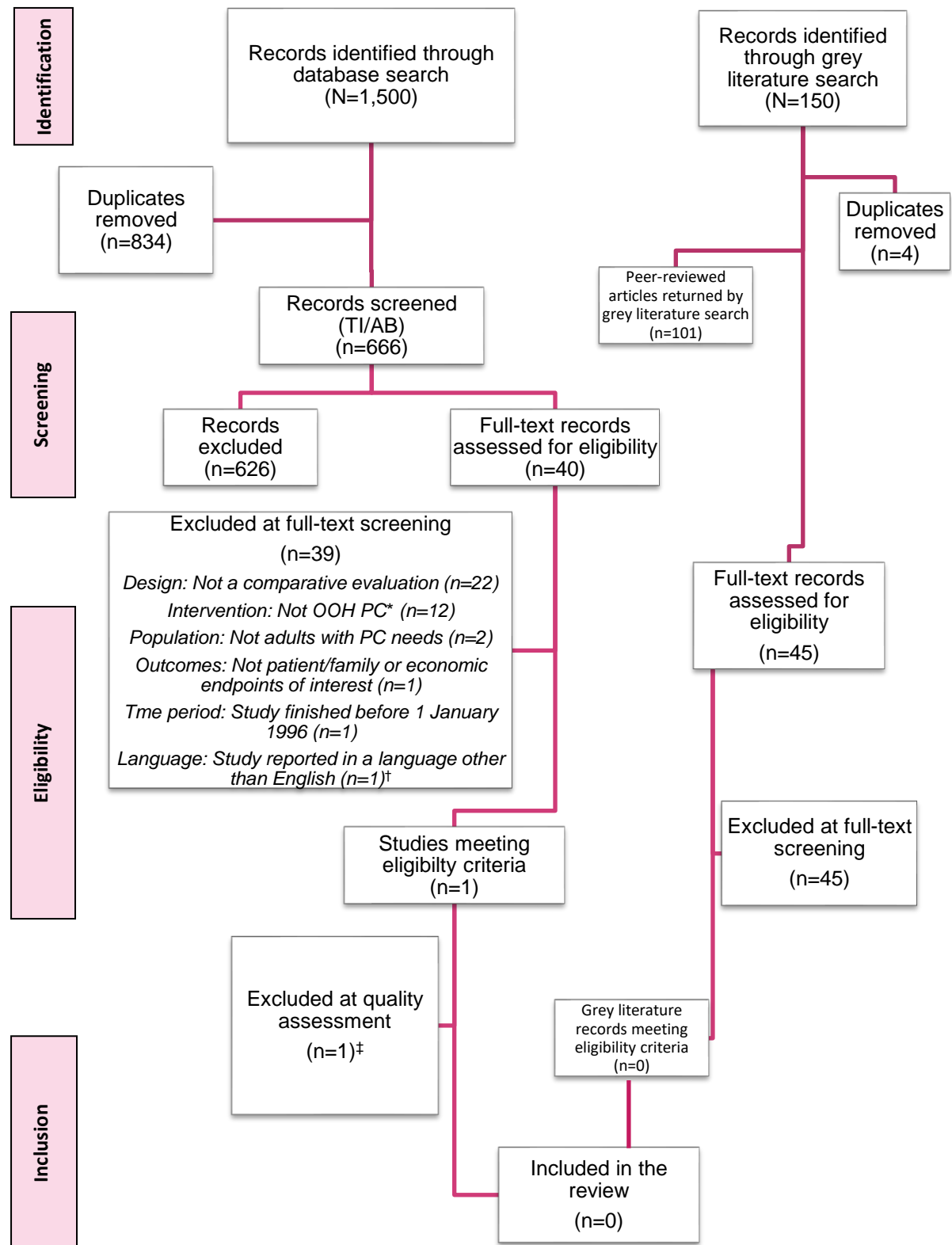


Figure 2 Database search and study selection

* PC = palliative care

† For details of paper excluded due to language, see Appendix 1.

‡ For details of paper excluded at quality assessment, see Appendix 2.

2.4 Conclusion

We conducted a systematic review of peer-reviewed and grey literature in order to identify evidence on the impact of OOH palliative care for adults on patient/carer outcomes, and on economic outcomes.

We searched nine databases using both information and subject specialists, and we searched grey literature, including doctoral theses and policy repositories. Our database search yielded only one relevant study, which two independent reviewers judged to be of insufficient quality to include in the review. Our search of other sources found no relevant material.

The review therefore includes no studies identified through our database and grey literature searches.

3 Documentary review: materials and methods

3.1 Introduction

This chapter focuses on the methods used to address the second and third research questions (see Section 1.3).

Question 2 was:

What are the models of OOH palliative care services in high-income countries that have such programmes?

- a) The answer to this question should cover as many countries as is feasible.
- b) The answer to this question should (at a minimum) address the following issues for each case country (see Section 1.3):
 - i. Definition of OOH
 - ii. Target population for OOH or after-hours S&GPC services
 - iii. Composition of specialist and generalist teams
 - iv. Roles and responsibilities of team members
 - v. Collaboration and information sharing between generalist and specialist OOH teams
 - vi. Collaboration and information sharing between OOH teams and normal-hours teams
 - vii. The S&GPC collaboration process
 - viii. Additional training requirements for OOH specialist and generalist team members
 - ix. Methods to ensure information sharing between IH staff and OOH staff
 - x. Anticipatory actions by IH S&GPC services to support the patient, carers, and OOH generalist and specialist teams, and
 - xi. Methods to maximise generalist and specialist OOH teams' responsiveness to patients and their carers, including technology (telephone, electronic health record [EHR], video link), triage, decision trees, preparedness, and home visits
 - xii. Describe the similarities and differences between country approaches.

Question 3 was What are the indicators used to measure the effectiveness of OOH palliative care services in those countries? Include (at a minimum) the following:

- a) List the indicators used by the selected countries.
- b) Explain the rationale for each indicator.
- c) Describe the usefulness of the indicator.
- d) Assess the validity of the indicator.
- e) Describe the similarities and differences between country approaches.

In order to address these questions, we decided *prior to starting the review* to examine policy and practice documents from high-income countries with well-integrated palliative care services, and to supplement this review with the peer-reviewed and grey literature, as well as with local expert input.

3.2 Countries examined

For maximum policy relevance and generalisability to Ireland, we sought high-income countries with well-established palliative care services. In order to identify such countries prior to data collection, we cross-referenced the Global Atlas of Palliative Care at the End of Life⁴³ with Organisation for Economic Co-operation and Development (OECD) member countries.⁴⁴ The Global Atlas of Palliative Care at the End of Life classifies 20 countries as having advanced integration of services, of whom 16 (including Ireland) are OECD member countries:

- Australia
- Austria
- Belgium
- Canada
- France
- Germany
- Iceland
- Ireland
- Italy
- Japan
- Norway
- Poland
- Sweden
- Switzerland
- United Kingdom (UK), and
- United States of America (USA).

These countries are the focus of our documentary review.

3.3 Data collection

Data collection combined three methods to identify policy and practice documents for the countries of interest: (1) review of governmental, academic, and health organisation websites; (2) review of results from grey literature databases identified during the systematic review (Chapter 2); and (3) Google and Google Scholar searches using relevant keywords.

3.3.1 Review of governmental, academic, and health organisation websites

For each of the 16 countries, we searched for policy and practice documentation on the websites of national and regional government bodies as well as organisations with a primary focus on palliative care.

3.3.2 Database search

Two information specialists (CH and DM) searched the following grey literature sources as part of the systematic review described in Chapter 2 of this report (see Section 2.2.2.2):

- Google Scholar
- OpenGrey
- ClinicalTrials.gov
- Health Organization International Clinical Trials Registry Platform
- ProQuest Dissertations & Theses (UK and Ireland)
- RIAN.ie
- Lenus, and
- EThOS.

These searches were conducted on 3 August 2018. Keywords from the database search were applied (Table 2). Two information specialists (CH and DM) compiled all returned grey literature in EndNote. For Google Scholar, the first 10 pages (100 items) were collated; for all other sources, all returned items were collated. One team member (RMCC) reviewed each grey literature item for potential relevance to the research questions.

3.3.3 Google and Google Scholar searches

The systematic search was supplemented with additional Google and Google Scholar searches for relevant keywords in order to identify the most relevant and highly cited materials.

3.4 Quality assessment

We targeted policy and practice documents, which are not formal research studies and are not reported according to any kind of standardised framework. Given the expected variance in format and content across countries, we decided not to use standardised quality assessment tools. We assessed each identified document on its own merits for clarity and content, and verified the accuracy and comprehensiveness of our interpretation with local experts (see Section 3.7).

3.5 Data extraction

We developed a bespoke form in Excel for extracting data for each country according to all specified data points. Documentation was examined in line with the research questions, and we extracted relevant data accordingly.

The data points to be investigated included:

- i. Definition of OOH
- ii. Target population for OOH or after-hours S&GPC services
- iii. Composition of specialist and generalist teams
- iv. Roles and responsibilities of team members
- v. Collaboration and information sharing between generalist and specialist OOH teams
- vi. Collaboration and information sharing between OOH teams and normal-hours teams
- vii. The S&GPC collaboration process
- viii. Additional training requirements for OOH specialist and generalist team members
- ix. Methods to ensure information sharing between in-hours (IH) staff and OOH staff
- x. Anticipatory actions by IH S&GPC services to support the patient, carers, and OOH generalist and specialist teams
- xi. Methods to maximise generalist and specialist OOH teams' responsiveness to patients and their carers, including technology (telephone, EHR, video link), triage, decision trees, preparedness, and home visits, and
- xii. Describe the similarities and differences between country approaches.

3.6 Data synthesis

Narrative synthesis was employed to review identified material. Narrative synthesis collates findings into a coherent textual narrative, grouping and reporting the key findings across data sources in the context of their methods and validity.

This method is well suited to this form of inquiry, whereby the data collected and processes described are predominantly text based, and in which depth of detail is important to the audience (in this case, policy-makers).

3.7 Expert review

We aimed to maximise the accuracy and completeness of our analyses through verification by experts in all included countries. Local leaders and experts in palliative care policy and practice, as well as those from academic institutions, were identified in each country through the use of the European Association for Palliative Care member association list as found on the EAPC website,⁴⁵ the All Ireland Institute of Hospice and Palliative Care,⁴⁶ and the review team's own contacts. An email was drafted which stated the aims of the investigation, explained why the individual was being contacted specifically, and requested that they give feedback with relevant evidence or pass the message on to colleagues if the recipient themselves was unable to assist in the project. Experts received reminders one week after original email contact.

Experts were asked to review a summary of national data specific to their country for accuracy and comprehensiveness. They were provided with both the Excel workbook completed during data extraction (see Section 3.5) and a country-specific narrative synthesis.

Experts represented a variety of professions from within the palliative care discipline across the 16 included countries (Appendix 3).

3.8 Non-English-language materials

Where documents were identified which required translation to English for data extraction, we used translation software. The majority of policy documents from non-English-speaking countries had English translations of the documents available. For quality assessment, the expert from each country reviewed the document closely in order to identify any lack of clarification or mistranslation present, and clarified these points. These clarifications were minimal, however, and the majority of the text was translated successfully.

3.9 Summary

The aims of Questions 2 and 3 were to document models of OOH palliative care for adults internationally, as well as the performance measures used to evaluate these models.

We identified 16 countries, including Ireland, that are both high-income (OECD members) and have advanced integration of palliative care services. We conducted an extensive documentary review of policy and practice documents to describe OOH S&GPC services in these countries, and we supplemented these analyses with grey literature searches.

Data were extracted according to pre-specified data points and collated using narrative synthesis. Country-specific findings were referred to local experts for review in order to maximise accuracy and completeness of our analyses.

Chapter 4 presents the results of this documentary review.

4 Documentary review: results

4.1 Introduction

The aims of Questions 2 and 3 were to document models of OOH palliative care for adults in countries other than Ireland, as well as the performance measures used to evaluate these models (see Section 1.3).

We presented our methods for answering these questions in Chapter 3. We identified 16 high-income countries with advanced integration of palliative care services and performed a detailed documentary review of policy and practice documents in these countries, supplemented by a grey literature review. We collected data according to pre-specified data points (see Section 1.3) and referred to local experts for review in order to maximise the accuracy and completeness of our analyses. Most experts were in concurrence with the data collected in each country, adding only small details or recently published reports in order to strengthen the body of evidence.

This chapter presents a narrative synthesis of our main results, with detailed country-by-country schema being provided in Appendix 3.

4.2 Summary of key findings

Details on findings from each of the specified data points are provided in Table 3.

Table 3 Key findings on models of care and performance indicators for OOH palliative care services in 16 high-income countries

Data point	Key findings
Models of care	
Definition of OOH	<ul style="list-style-type: none"> • <i>Weekdays</i>: 5.00pm/6.00pm to 8.00am (most countries); 7.00pm/8.00pm to 9.00am (some countries). • <i>Weekends and public holidays</i>: all times except Saturday mornings, which are IH in France and Australia.
Target population	<ul style="list-style-type: none"> • WHO definition of all people with life-limiting illness (most countries) • WHO definition of all people with life-limiting illness plus stratification by need (Australia), and • Exceptionalism for cancer over non-cancer patients (some countries, including Japan).
Composition of specialist palliative care (SPC) and generalist palliative care (GPC) teams	<ul style="list-style-type: none"> • <i>Hospital-based teams</i> <ul style="list-style-type: none"> ○ Limited OOH specialist staff; generalists with varied training, and ○ Engagement with a community palliative care unit in order to advise generalist staff on care or to supply it directly. • <i>Community-based teams</i> <ul style="list-style-type: none"> ○ Mobile palliative care teams led by nurses, both specialist and generalist, with support from specialist physicians ○ Multidisciplinary teams – including specialist and generalist doctors and nurses, rehabilitation specialists, psychologists, psychotherapists, and social workers – that can visit and assist patients both IH and OOH ○ Generalist ambulance teams and paramedics with specialised palliative care training, and ○ Voluntary organisations (e.g. Marie Curie, the Irish Cancer Society [ICS]) provide additional funding and care for certain life-limiting conditions.

Data point	Key findings
Roles and responsibilities and training of team members (Question 2(b) iv and viii)	<ul style="list-style-type: none"> ● <i>Hospital-based teams</i> <ul style="list-style-type: none"> ➤ Most likely deliver care to those with specialist needs, e.g. stabilising patients who are acutely ill at referral. ➤ Provide education to people with life-limiting conditions; recognise common trajectories and manage pain and symptoms accordingly; offer support; and ensure that care plans are respected. ➤ Nursing staff are required to assume the responsibilities of palliative care teams during OOH periods with knowledge acquired from training resources and support from palliative community services. ➤ Online training resources specifically for generalist hospital staff are available in many countries, including Ireland, where the Irish Hospice Foundation (IHF) offers training on delivering potentially upsetting news, advance care planning and implementation, final journeys, processing and coping with grief at work, and self-care at work. ● <i>Community-based teams</i> <ul style="list-style-type: none"> ➤ Home palliative care units (HPCUs) comprise both specialist and generalist doctors and nurses: <ul style="list-style-type: none"> ○ Generalist doctors and nurses deliver care during home visits or in their local clinics, and ○ Specialist staff to take care of more complex processes such as pain and symptom management. ➤ Nursing homes focus less on medicine and treatment than hospitals do, as patients are generally more stable. ➤ Some countries train generalist ambulance staff in palliative care.
Collaboration and information sharing between specialist and generalist teams and OOH and IH teams (Question 2(b) v, vi, vii, and ix)	<ul style="list-style-type: none"> ● <i>Specialist and generalist teams</i> <ul style="list-style-type: none"> ➤ Specialists function as advisory hubs when hospital specialists are unavailable. ➤ Frequent multidisciplinary meetings are held in order to share information and recommendations. ➤ Multidisciplinary meetings are held with the patient and family simultaneously in order to clarify the team members' responsibilities, roles, and functions for the patient and their care. ➤ Some countries, such as Poland, rely on a lead practitioner for each case, who gathers information from all members of the multidisciplinary team. ➤ An online shared-access record is accessible by all providers of specialist and generalist, IH, OOH, and emergency care; a portion of the record is entirely dedicated to palliative practices and the patient's care plan, e.g. the Key Information Summary (KIS) (UK). ➤ Germany offers an additional service: if an on-call pharmacy does not have appropriate medication, specialist home care services or inpatient hospices may stock and dispense opioids OOH.⁴⁷ ● <i>OOH and IH teams</i> <ul style="list-style-type: none"> ➤ It is the responsibility of individual services to collaborate with each other in order to ensure continuity of care and adherence to the patient's care plan (many countries). ➤ Referral forms: doctors give an assessment of the patient's need for home care and provide patient information and contact information in order to be available to all IH and OOH services, so that they can be updated on the patient's progress as the patient's primary physician, e.g. the general practitioner (GP) to OOH Palliative Care Handover Project (Ireland), or electronic patient records in countries such as Japan.
Anticipatory IH support for patients, carers, and OOH teams	<ul style="list-style-type: none"> ● <i>Advance care planning</i> <ul style="list-style-type: none"> ➤ A detailed plan is made with the GP or consultant outlining the patient's preferences around their palliative care plan, including a DNACPR (do not attempt cardiopulmonary resuscitation) Form, and other significant information. ● <i>Patients leaving inpatient settings</i> <ul style="list-style-type: none"> ➤ A multidisciplinary liaison contact details sheet is given to the patient and caregiver. ➤ A post-hospital telephone call is expected shortly following discharge. ➤ An appointment with the attending physician is scheduled within seven days of exit (France). ● <i>Anticipatory prescription</i> <ul style="list-style-type: none"> ➤ A supply of drugs is made available in the patient's home in case of emergency. ➤ Train both patients and family members/caregivers in clinical skills as well, empowering them to make their own informed choices in their care and medication adherence.

Data point	Key findings
	<ul style="list-style-type: none"> ➤ Specialist palliative home care teams keep stock of and dispense opioids OOH. ● <i>Telephone support</i> <ul style="list-style-type: none"> ➤ Provides emotional and practical support in order to reduce inpatient admissions ➤ Avoids unnecessary hospitalisation through tele-triage ➤ Dispatches emergency palliative services.
Maximising OOH teams' responsiveness	<ul style="list-style-type: none"> ● <i>Electronic Health Records</i> <ul style="list-style-type: none"> ➤ ePrescribing, case management, and online information sharing and record-keeping, ➤ Share users' health-related data – e.g. blood pressure, oxygen tension, or electrocardiogram (ECG) results – electronically (some countries). ● <i>Telehealth</i> <ul style="list-style-type: none"> ➤ Patients in rural areas or who have mobility difficulties only require phone consultation.
Performance indicators	
Performance indicators used and rationale	<ul style="list-style-type: none"> ● Indicators focused predominantly on capturing activity- or access-related measures related to either OOH primary care or IH palliative care. ● Few indicators specific to the quality or effectiveness of OOH palliative care have been identified or measured. ● The <i>End of Life Care Strategy</i> (UK) ⁴⁸ states that all OOH palliative care services should demonstrate and measure achievements related to five domains: 1) advance care planning preparation, 2) appropriate palliative specialisation, 3) communication between OOH palliative care services, 4) information sharing, and 5) access to palliative pain management drugs. ● The <i>End of Life Care Strategy</i> ⁴⁸ refers only to potential indicators and does not specify by which markers these indicators should be measured.
Usefulness of indicators	<ul style="list-style-type: none"> ● The systematic and documentary review did not identify any data to suggest that performance indicators have been used to inform policy or practice around OOH palliative care.
Validity and limitations of indicators	<ul style="list-style-type: none"> ● Limitations in performance indicators include: <ul style="list-style-type: none"> ➤ The lack of differentiation between IH and OOH care performance indicators, therefore making it impossible to assess OOH components of care in isolation ➤ Ignoring the OOH period of the patient's day entirely, and ➤ Coding systems used to classify each patient case prohibit the identification of cases requiring palliative care.

4.2.1 Service configuration

As noted in Section 1.1, official government policy in Ireland delineates between three levels of specialisation.^{4,49} Australia is the only other country among the 16 countries examined that takes this approach.⁵⁰ The levels are summarised in **Table 4**.

Table 4 Levels of palliative care specialisation in Ireland and Australia

Level 1

Palliative care principles should be practised by all healthcare professionals. The palliative care approach should be a core skill of every clinician at hospital and community level. Many patients with progressive disease will have their care needs met comprehensively and satisfactorily without referral to SPC services.

Level 2

A proportion of patients and families will benefit from the expertise of healthcare professionals who, although not engaged full time in palliative care, have had some additional training and experience, perhaps to diploma level. Such expertise may be available in hospital or community settings.

Level 3

SPC service providers are those whose care activity is limited to the provision of palliative care. These services are involved in complex and demanding care needs, and consequently require more training, staff, and other resources.

In all other countries examined in this review, generalist teams most frequently consist of services that may be accessed by any member of the community seeking medical advice, and include GPs, hospital doctors, nurses, and district nurses that have little to no palliative expertise or do not consider palliative care to be central to their role.⁵¹

Specialist palliative care is delivered by multidisciplinary teams which may include a combination of physiotherapists, occupational therapists, social workers, spiritual and psychological services, bereavement support, dieticians, speech and language therapists, pharmacists, and pain management specialists.⁵² Various combinations of these healthcare professionals make up a range of multidisciplinary generalist, specialist, and mixed specialisation teams within various contexts, differing from country to country. Most countries categorise their palliative healthcare teams by the locations in which they offer services, for example by describing a hospital palliative care team, a hospice palliative care team, a community palliative care team, or those practising palliative care in emergency services.

4.3 Models of OOH palliative care

Palliative care frameworks in the UK,⁵³ Australia,⁵⁴ Switzerland,⁵⁵ and Ireland⁵⁶ have all explicitly stated the need for patient-centred, 24-hour, community-based service models. These proposals are based on the understanding that this model provides more efficient and equitable care for patients; offers choice regarding place of care and of death; utilises more local services; and fulfils every patient's needs, regardless of location or preferred place of death. Other countries, such as Japan, have only just begun to develop palliative care policies, and look to well-established frameworks such as the Australian After-hours Palliative Care Framework⁵⁴, which is specific to the Australian state of Victoria but applicable in other high income countries, and the UK's Gold Standards Framework.⁵⁷

The Australian After-hours Palliative Care Framework identifies the following key elements of OOH palliative care: client care planning, information systems, OOH telephone triage, OOH nursing, OOH specialist support, and follow-up quality assurance contact following a visit.⁵⁴ These elements are mirrored by a recent systematic review investigating the key elements of 24-hour community care in Canada and the USA, which states that OOH palliative care should address patient and family preparedness; integrated teamwork; physical, emotional, and spiritual care; symptom and pain management; skilled and compassionate healthcare professionals; and efficient and responsive care.⁵⁸

4.3.1 Definition of OOH

With respect to weekdays, there are two definitions of OOH: 5.00 or 6.00pm to 8.00am, and 7.00 or 8.00pm to 9.00am. Most countries in this review define the in-hours (IH) period as being from 8.00am to 6.00pm on weekdays.^{59,60} While Australia is one of these countries, it further separates the OOH period into two categories: sociable (6.00pm to 11.00pm) and unsociable (11.00pm to 8.00am), which may come with two different pay rates for staff.⁶¹ Belgium, Switzerland, Germany, Italy, and France apply a longer IH time frame for doctors, with OOH beginning at 7.00pm in Belgium, Switzerland, and Germany,^{62,63} and 8.00pm in Italy and France.^{64,65}

The OOH period at weekends and public holidays also differs across countries. The majority of countries included in this review employ OOH services from Friday evening to Monday morning, in addition to public holidays.⁶⁶⁻⁶⁸ However, in France, it is expected that services will be available on Saturday mornings, making this an IH time frame, and OOH is defined as 12.00pm Saturday to 8.00 or 9.00am Monday, as well as public holidays.^{61,64}

4.3.2 Target population

No country has stated a specific definition for those requiring OOH palliative care services, but we interpret from the documentation that the majority of palliative care patients are a target population for these services at some point during their disease trajectory, as 75% of their week occurs OOH. Most countries in the present review adopt the WHO definition: “patients and their families who are facing problems associated with life-threatening illness, whether physical, psychosocial or spiritual.”¹ Australia breaks this definition into three distinct categories in order to allocate appropriate services:

1. “People (including families and carers) living with a life-limiting illness whose needs are straightforward and predictable.”
2. “People (including families and carers) living with a life-limiting illness whose needs range from straightforward and predictable to intermediate and fluctuating.”
3. “People (including families and carers) living with a life-limiting illness whose needs include straightforward and predictable, intermediate and fluctuating, or complex and persistent.”⁵⁰

While the majority of countries adopt the WHO definition for their target population for palliative care services, some countries prioritise certain conditions. The presence of cancer exceptionalism within palliative care service provision is observable in some countries, particularly those with lower rates of coronary heart disease per capita,⁶⁹ including France,⁷⁰ Switzerland,⁷¹ and Japan.⁷²

In Japan, for example, many palliative care units consider nurses specialised in cancer pain management to be akin to palliative care nurses, which potentially results in a lack of adequate care for those who have other chronic conditions.⁷³ Palliative care for end-stage heart failure, which is a primary target for palliative care in all other countries examined in this report, has only been treated as a palliative condition in Japan since 2018.⁷⁴

4.3.3 Composition of S&GPC teams

OOH teams are generally reliant on the services of generalist and specialist nursing and medical staff, with few other specialisations or allied health professionals working OOH. However, healthcare professionals often receive support and training from palliative care specialists, enabling them to deliver a palliative care approach to patients and caregivers.⁵¹

4.3.3.1 Hospital-based teams

While SPC units predominantly work IH, many staff members have undertaken some formal training in palliative care (with the majority of nursing and medicine courses running mandatory palliative care modules), or have undertaken a diploma in palliative care.

In addition to this, the hospital may engage the services of a community palliative care unit either for advice or support within the hospital, in order to inform generalist staff members’ palliative care practices or to supply palliative care directly.^{52,66}

4.3.3.2 Community-based teams

Community SPC refers to teams of healthcare professionals in the community, usually centred on nurses, both specialist and generalist, with support from palliative medicine specialists. These mobile multidisciplinary teams include specialist and generalist doctors and nurses, rehabilitation specialists, psychologists/psychotherapists, and social workers, who can visit and assist patients in both their family homes or in nursing and respite homes both IH and OOH.^{49,75} Requirements for mobile services differ from country to country. In Norway, at least one physician and one nurse in each municipality must have palliative care expertise and be available to guide general care providers,⁷⁶ which is similar to the community services in Italy and France, where the generalist doctors and nurses outnumber but are heavily supported by compulsory specialist staff.^{77,78}

Innovation highlight: specialist paramedic training in the UK

In the UK, Macmillan Cancer Support has introduced palliative care expertise into the ambulance service, training generalist ambulance staff with the specialist skills to support terminally ill patients. This service will also ensure that patients' care plans are uploaded into the system so their wishes can be respected throughout the emergency service process. This service allows for rapid transfer of the dying to their chosen place of death if necessary, supplying appropriate transport for the patient and carer, and ensuring that robust information systems are in place in order to ensure that the patient's end-of-life plan can be accessed by ambulance services and staff.⁷⁹

This practice of training paramedic staff also takes place in certain areas of Canada, such as Nova Scotia. These services are especially useful for rural areas and in supporting patients with mobility issues.⁸⁰

In addition to these central teams in each service setting, voluntary organisations may offer additional care for particular populations or patients with particular illnesses. In Ireland, for example, the Irish Cancer Society provides 10 nights of night nursing for individuals with cancer who are imminently dying in order to ensure that they are supported in their wish to die at home, with the IHF providing additional funding for other life-limiting conditions.⁸¹ This service is a mixed specialisation service that can be provided by a generalist and specialist staff (see **Table 4**). Applications can be made for an extension of a further four days if needed.⁸² A similar service is offered in the UK by Marie Curie, a charitable organisation that employs both generalist and specialist nurses to give night care to palliative patients,⁸³ as well as in Norway⁸⁴ and Germany.⁸⁵

4.3.4 Roles, responsibilities, and training of team members

4.3.4.1 Hospital-based teams

Across the literature, it is expected that team members within hospital palliative care units will most likely be delivering care to those with SPC needs and will therefore be required to stabilise patients and often carry out basic care due to patients being acutely ill at the point of referral to this form of care. Hospital specialist care units and teams should also provide education to people with life-limiting conditions, recognise common illness trajectories and manage pain and symptoms accordingly, offer support and advice to patients and families, and ensure that each patient's care plan is respected.^{50,86,87}

Specific responsibilities of care include clarification of the patient's care wishes, clarification of specialist and generalist care plans in order to prioritise quality of life, preparation of the patient to return home or for the dying process, assistance with difficult decision-making, psychological and spiritual support for the patient, and support of the family.

Nursing staff are often required to assume the responsibilities of palliative care teams during OOH periods using the knowledge acquired from palliative care training resources and palliative community services, which offer support and advice to generalist healthcare professionals administering care to palliative patients. Online training resources specifically intended for generalist hospital staff are available in many countries, including Ireland, in which the IHF offers training on delivering potentially upsetting news, advance care planning and implementation, final journeys, processing and coping with grief at work, and self-care at work.⁸⁸

4.3.4.2 Community-based teams

Community resources can vary widely, from volunteer home care services supported by governmental bodies to teams of specialist doctors offering guidance and treatment to patients directly within the home. Specialists within these teams, such as social workers and psychologists, offer domestic assistance and service coordination, giving carers the confidence and time to support loved ones while also reducing the likelihood of hospitalisation.⁸⁹ However, these team members generally only work IH, taking anticipatory action for OOH periods, such as stress management education, assisting in organising OOH care, and providing relaxation and coping training to caregivers.⁹⁰

The most common type of community support across the 16 countries examined in this review revolves around the generalist community or district nursing service attending to patients in their family homes and in residential care. In many countries, multidisciplinary teams offer pain management and generalist treatments such as wound inspection and dressing, in addition to providing support and guidance for patient self-management and caregivers; in Ireland, however, this service is led primarily by nursing staff.⁹¹ In the UK, these services offer hands-on nursing care to complement the statutory district nursing service and the advisory role of the palliative care clinical nurse specialist.^{52,92} Similar services are present in Italy, Belgium, and France, where HPCUs – which comprise both specialist and generalist doctors and nurses – have generalist doctors and nurses deliver basic interventions while specialist staff take care of more complex processes, such as overseeing pain and symptom management and collaborating with and advising generalist staff both IH and OOH.^{78,93}

Innovation highlight: 24-hour SPC services for complex care in Germany

Following a law introduced in 2007, specialist palliative home care in Germany has been nationally rolled out and made available to all patients with incurable, progressive diseases⁹⁴ 24 hours a day, resulting in patients being able to access the same level of service and specialisation of healthcare professionals during OOH periods as they are able to access during IH periods.⁴⁷ A home team is prescribed to a patient for an unlimited period of time and includes, as needed, medical, nursing, psychological, and other services, in addition to a coordinating service.⁹⁴ These home care teams are integrated into already existing healthcare structures, and can fill the gaps in care provided by other healthcare professionals such as GPs, oncologists, cardiologists, and nursing services. In addition to care, specialist palliative home care physicians keep stock of and may dispense opioids for patients under their care during out-of-office hours in emergency situations, as these can be difficult to acquire OOH, with many pharmacies not holding stock of these drugs. This service also assists with psychosocial support and coordination of care in cooperation with the patient's own GP if at home, or with the patient's care team if in a nursing home.⁸⁵

These services can also ameliorate the service provided by nursing homes by offering advice and support to generalist staff. Long term care facilities aim to care for the less acutely ill patients with a more holistic approach, with less focus on medicine and treatment than is provided in a hospital setting, as patients are generally more stable in this setting. In Switzerland, palliative specialists, and other specialists such as geriatricians and oncologists, can visit long term care facilities as part of mobile palliative care units, offering care within the patients' residence.⁵⁵

In the UK, palliative care specialists train generalist ambulance staff in order to ensure that the wishes of palliative patients are respected and that specialist palliative care will be available, even in the case of an emergency, whereby the patient's condition may be deteriorating but they wish to remain in the home.⁷⁹ Similarly, in Canada, palliative emergencies can be addressed by paramedic trained in palliative care, which can be accessed via the emergency services and who will arrive to the home in an ambulance without the lights and sirens on. They can administer additional pain medication or deliver physical therapy in order to make patients more comfortable.⁹⁵

4.3.5 Collaboration and information sharing

4.3.5.1 Generalist and specialist OOH teams

In all countries examined, in addition to providing specialist care during OOH periods directly, specialist teams function as information and advisory hubs for generalist care teams. Advice functions include assistance in

providing care, accepting referrals, or working in an advisory capacity during the OOH period when hospital palliative specialist staff are generally unavailable.⁹¹

In the UK, for example, in addition to responding to community cases, hospitals also have formal links with a local SPC service for the purposes of referral, consultation, and access during OOH periods.⁹⁶ All national guidelines examined recommend that generalist and specialist teams also collaborate in terms of ensuring that information is shared efficiently and exhaustively, and that the care plan is sufficiently described and disseminated among all relevant care providers in order to ensure that the individual's wishes are respected.⁸⁷ Additionally, all national policy frameworks recommend that representatives from each element of the multidisciplinary care team, both specialist and generalist, will have frequent meetings in order to share information and recommendations for the patient; however, for many countries, such as Belgium, there is no strict policy in place for these meetings.⁶⁰ Guidelines in both Australia and the UK recommend that both teams may need to meet with the patient and family simultaneously in order to clarify their responsibilities, roles, and functions for the patient and their care.⁹⁷

Some countries, such as Poland, rely on the extensive feedback and frequently updated record of a lead practitioner in the case – generally a GP if the patient is at home, or a primary consultant if in hospital⁵⁹ – giving feedback and advice in relation to the care plan which may need to be reviewed by the patient and family.⁹⁸

In Scotland, collaboration and continuity of care are made more efficient by the Key Information Summary (KIS) outlined in the Scottish Palliative Care Guidelines. This is an online record which can be accessed by members of the community care team such as GPs, district nurses, and all providers of OOH and emergency care. While the KIS is a general medical record and can be used for non-palliative patients requiring OOH care, there is a portion of the record entirely dedicated to palliative practices and the patient's care plan.⁹⁶

Germany offers an additional collaboration feature, by which if an on-call pharmacy does not have the appropriate medication available, specialist palliative home care services or inpatient hospices may stock and dispense opioids for a patient during OOH periods.⁹⁹

4.3.5.2 OOH and IH teams

Collaboration and information sharing between IH and OOH teams is not extensively described in the policy documents of many of the countries examined, which implies that it is the responsibility of individual services to collaborate with each other in order to ensure continuity of care and adherence to the patient's care plan. Organisations across the 16 countries have made efforts to bridge this gap. This can be seen in Iceland, where there are no official directives from the Directorate of Health on standards of palliative care or the structure of palliative care services in Iceland, as found by the *EAPC Atlas of Palliative Care in Europe 2013*.⁹ As such, there is no direct protocol put in place for collaboration and information sharing between IH and OOH teams in Iceland.

Icelandic home nursing organisations state that best attempts to collaborate with the patient's GP are made via an application form, in which doctors give an assessment of the patient's need for home care.¹⁰⁰ This also occurs in Belgium, where general practitioners must refer a patient to these services and collaborate with the service to provide information and be updated on the patient's progress as their primary physician.⁹³

In some countries, these written records have been effective in providing efficient continuity of care, including Ireland, which has developed the GP to OOH Palliative Care Handover Project in order to ensure patient safety and efficient transfer to another service; the project has been successfully piloted and is in the process of being rolled out across the country.¹⁰¹ The IHF has developed an information transfer form for GPs in anticipation that a patient will require OOH palliative care services. The form allows the transfer of relevant information pertaining to the patient (including current medication, prognosis and knowledge regarding the prognosis, allergies, the patient's wishes regarding the circumstances of their palliative care, and the presence of a DNACPR Form) from GPs to the OOH service in order to assist in the care of the patient.¹⁰¹

Innovation highlight: eHealth system in Iceland

eHealth policies in Iceland have been in place since 1996, resulting in well-established electronic patient health records and health information systems. Each patient has one unique record which follows them through their use of different services, reducing duplication of efforts and duplication of investigative diagnostic tests and prescriptions. These records carry information on the patient's allergies, diagnostic test results, diagnoses, previous medication, and treatment, in addition to information on DNACPR status and automatic warnings. Current developments within the Icelandic system are providing access to the National Pharmaceuticals Database in conjunction with these patient records in order to monitor the availability of the patient's medications in the local area and where to access them. These records, if well kept, may be of invaluable use to OOH services unfamiliar with the presenting patient.¹⁰²

In other countries, such as Norway, patients availing of OOH care have a 'shared access' medical record, which will be available to the patient and to any healthcare professional attending to the individual. The record will contain contacts for the patient's next of kin, GP, hospital consultant from previous visits, and home care nurse. It will also contain details of the patient's medication requirements and dosage, allergies, and palliative care treatment plan, in addition to details of their previous doctor and hospital visits and often an Edmonton Symptom Assessment System (ESAS) form, which outlines the patient's symptoms.¹⁰³ A similar service is employed in Scotland, where collaboration and continuity of care are made more efficient by the KIS outlined in the Scottish Palliative Care Guidelines.⁹⁶ This is an online record which can be accessed by members of the community care team such as GPs, district nurses, and all providers of OOH and emergency care. While the record is a general medical record and can be used for non-palliative patients requiring OOH care, there is a portion of the record entirely dedicated to palliative practices and the patient's care plan.⁹⁶

4.3.6 Anticipatory actions by IH services to support OOH care

Countries examined in this report take different modes of anticipatory palliative care action depending on potential barriers to care, including availability and access for rural patients, limited OOH resources, or over-capacity inpatient facilities. For example, in Japan, due to the high number of hospital deaths due to the lack of palliative home care teams, many hospitals have prepared a palliative care manual in collaboration with palliative care specialists, which will allow generalist staff to provide an improved standard of care in the absence of specialist support.¹⁰⁴

When preparing a patient for palliative care, most countries will take action by offering patients and families advice and resources when transferring to and from hospital or a care facility. For example, in Iceland, the transition to palliative home care services is made in consultation with clients, family members, GPs, and sponsors, ensuring that these parties are receiving education on prevention, health promotion, and control of general well-being. The ability to place patients back in their homes at their request as caregiver confidence at carrying out caregiving duties increases, not only leads to a lower symptom burden for patients,¹⁰⁵ but also allows community services to stretch their resources further to other patients.¹⁰⁰ This effort to move patients home where possible also takes place in France, where, in addition to advice and medical-related resources, a multidisciplinary liaison contact details sheet is given to the patient and caregiver, a post-hospital telephone call is expected, and a visit by the attending physician is scheduled within seven days after discharge from the hospital.¹⁰⁶

Many countries also attempt to anticipate these transfers by having patient records in place in order to 'pre-triage' new patients coming to palliative OOH services, including the Irish GP Out-of-hours Palliative Care Handover Form, which provides easy access to information regarding a patient's allergies and medications, the presence of a DNACPR Form, and the patient's wishes.¹⁰¹

Many services offer anticipatory action in the form of advice, resource sharing, and education within working hours. In both Ireland and the UK, trained cancer nurses operate a Cancer Nurseline, through which people with cancer or their families and carers can access information or advice. While it is a 9–5 weekday service, valuable information on night-time care, emergency planning, and basic aid will support patients and carers and assist them in acting independently during OOH periods.¹⁰⁷

In addition to advice and support, anticipatory action is also often taken in the form of medication provision and prescription. Ambulatory services in the UK, such as Care UK and Local Care Direct, dispense anticipatory, "just in case", medication through the National Health Service (NHS) GP and community nurse service, so that

patients can access their medications 24 hours a day, 365 days a year. Doctors have often also begun anticipatory prescribing, which is designed to ensure that there is a supply of drugs in the patient's home in case of emergency.¹⁰⁸ Staff within hospices and palliative care specialists in the community then train both caregivers and patients in clinical skills as well, empowering them to make their own informed choices regarding their care and medication adherence.¹⁰⁸ This also takes place in Germany, where specialist palliative home care teams keep stock of, and may dispense opioids, for patients during out-of-office hours, as these can be difficult to acquire OOH, with many pharmacies not holding stock of these drugs.⁹⁹

In addition to these services, many countries offer OOH patient and carer telephone support from SPC providers. Generally, an operator number is dialled and the call is diverted to a number relevant to the caller's region. Phone services and clinics should provide information for palliative care patients, carers, and health professionals; psychological support for people experiencing anxiety or fear; assistance with symptom management, including pain relief; referrals for callers to other service providers when needed; and assistance with appropriate crisis intervention. In Germany, the patient or caller can then seek advice from GPs and specialists, and can be triaged on the telephone in order to assess whether they need medical attention.⁹⁹ This is similar to a service provided in Australia, whereby a generalist nurse will triage a patient on the telephone and transfer them to a specialist nurse accordingly, depending on the condition and stage of the patient's illness trajectory.¹⁰⁹ This form of tele-triage also occurs in Ireland, where generalist OOH services such as SouthDoc, DubDoc, and CareDoc operate a generalist phone triage service provided by doctors, nurses, and home visit teams predominantly made up of both specialist and generalist nurses.¹¹⁰ These services are stated to reduce the risk of unnecessary hospitalisation and, consequentially, the risk of the patient passing away in a location other than their preferred location as stated in their palliative care plan.¹⁰⁹

4.3.7 Maximising responsiveness by OOH teams

eHealth projects, which can include components such as eprescribing, case management, and easy information sharing, are being developed in many countries following their apparent success at assisting efficient information sharing in the UK.⁵⁶ These include the *Vorsorgedialog*[®] (VSD) in Austria, which is both a record-keeper of a patient's wishes and ideas for their care plan, and an instrument of predictive planning. It allows the patient to communicate with their health services regarding their wishes and also allows their health providers to access these plans when the patient is unable to state them in emergency situations.¹¹¹ This is also used in the UK, where the Cancer Network Information System Cymru (CaNISC) in Wales is a specialist online palliative care patient record, which can be shared by all health professionals attending to the palliative patient.¹¹²

Innovation highlight: telehealth in Japan

Japan is an example of a country with well-established telehealth utilisation. eHealth systems are currently being utilised by more than 100 local government institutions, supported by significant funding since 2013. Rapid progress has been made in developing these technologies. Their primary functions are to transmit users' health-related data (such as blood pressure, oxygen tension, and ECG results) to medical institutions via the Internet. This is particularly useful for patients in remote locations, patients who have mobility issues as a result of their deteriorating condition, and patients who opt to choose home care over inpatient care due to the rurality of their home.¹¹³

In addition to online record-keeping, telehealth in the UK also allows the hospital palliative care specialist to communicate efficiently and directly with the patient, their caregivers, and the home hospice team, which allows for effective and non-disruptive continuation of care for a patient who may have mobility difficulties.¹¹⁴ France has these technologies in place as well, having recently published a ministerial decree governing the use of telemedicine for individuals with a range of mobility difficulties which inhibit access to hospitals and clinics, and therefore access to consultants and specialists. It will also be used for information and opinion exchange between health professionals, which may otherwise be impossible or inefficient in crisis situations.¹¹⁵

Canada also uses these technologies in order to attempt to access rural patients who may have access and mobility difficulties, as well as to promote efficiency and reduce hospital costs for patients who only require minor treatments or advice that can be given over the telephone. These include tele-nursing by SPC nurses who can provide expert advice which will help family caregivers determine whether their relative requires hospital care.¹¹⁶ While many countries make reference to their intentions for assisted living projects, only

Germany has begun to investigate and develop the policies regarding them, but presently no fully operational market for active assisted living (AAL) applications exists, except for simple technologies such as emergency call systems for the home and audio/video communication technologies for patients who have limited mobility.¹¹⁷

In addition to this, there is a large amount of resources available to patients online throughout all countries which can facilitate advance care planning, including webinars, a glossary of medical terminology, and aids for decision-making, including the American Association of Retired Persons in the USA.¹¹⁸ These can reduce time spent attempting to introduce patients and families to the types and modes of palliative care, and allows the patient to examine all of their options and inform themselves before meeting their doctor in order to arrange the care.¹¹⁹

4.4 Performance indicators

4.4.1 Indicators used and rationale

Indicators have focused predominantly on capturing activity- or access-related measures related to either OOH primary care or to palliative care as a whole, and therefore few indicators specific to the quality or effectiveness of OOH palliative care have been identified or measured.¹²⁰

The UK's Joint Specialist Committee for Palliative Medicine suggests that indicators which mirror daytime activity are difficult to put into place.¹²¹ Apart from medical palliative care consultants, appropriate competencies for other SPC staff providing night and weekend services have not been standardised or nationally rolled out; rather, generalists with specialist supports and resources are often put in place as surrogates in OOH periods.

Activity-related indicators used to assess the performance of specialist or generalist palliative care services capture data on factors such as the number of patients seen by community-based palliative care teams and the volume and nature of enquiries to OOH telephone triage services, while access-related indicators measure aspects such as the ratio of services to country inhabitants, palliative care beds to palliative patients, and percentage of a country serviced by mobile palliative care teams.¹²² Particular emphasis is also placed on the communication of patient data, for which electronic patient records are considered to be the gold standard in community and after-hours palliative care service provision.⁵⁴

The only instance of performance indicators for OOH specialist and generalist palliative care (S&GPC) identified in the systematic or documentary reviews were those proposed by the Department of Health in the UK (Table 5). The *End of Life Care Strategy* (2009) states that all OOH palliative care services should demonstrate and measure achievements related to five domains: 1) advance care planning preparation; 2) appropriate palliative specialisation competency within all OOH services; 3) access and communication between OOH palliative care services; 4) updated and detailed patient information sharing among IH and OOH services; and 5) access to drugs, particularly opioids.⁴⁸

These indicators of quality are assessed through examining variables such as response times, appropriateness of triage for home visits, effectiveness of information exchange, implementation of national clinical standards and guidelines, prescribing, and patient or caregiver experiences.^{120,123,124} The indicators measured were informed by the Gold Standards Framework⁵⁷ and the Liverpool Care Pathway for the Dying Patient (discontinued in 2014).¹²⁶ This approach has been adopted by OOH services throughout the UK,¹²⁷ although implementation of the quality markers proposed in the *End of Life Care Strategy*⁴⁸ is not mandatory.

Table 5 Performance indicators for OOH palliative care proposed by UK Department of Health

Domain	Application of measurement
Advance care planning	<ul style="list-style-type: none"> ● Percentage of palliative care patients who have an advanced care plan for end-of-life care ● Plan is acceptable and realistic in terms of the resources available in the locality
Appropriate palliative specialisation competency within OOH service	<ul style="list-style-type: none"> ● Medical practitioners providing OOH services are capable of providing general palliative care, comprising: <ul style="list-style-type: none"> ○ Needs assessment ○ Patient support

	<ul style="list-style-type: none"> ○ Communication skills training ○ Symptom management, and ○ Communication of knowledge relating to DNACPR and other sensitive information.
Access to, and communication between, OOH palliative care services	<ul style="list-style-type: none"> ● Each OOH service has information on how to access other OOH services, such as sourcing: <ul style="list-style-type: none"> ○ Necessary equipment for symptom management quickly ○ Symptom control drugs ○ Nursing support, and ○ SPC advice.
Updated and detailed patient information sharing among IH and OOH services	<ul style="list-style-type: none"> ● Up-to-date patient records, whether electronic or written, are shared between IH and OOH providers: <ul style="list-style-type: none"> ○ The electronic patient record is the gold standard in OOH palliative care.
Access to palliative care drugs and equipment	<ul style="list-style-type: none"> ● 24 hour access to <ul style="list-style-type: none"> ○ Pain management drugs such as opioids ○ Mobility assistive equipment ○ Catheters and syringe driver

4.4.2 Usefulness

The systematic and documentary reviews did not identify any data to suggest that performance indicators have been used to inform policy or practice around OOH palliative care. As such, it cannot be stated that any model of care is more effective than another, as insufficient attempts have been made to measure the outcomes and effectiveness of these frameworks.

4.4.3 Validity and limitations

Limitations in performance indicators include the lack of differentiation between IH and OOH care, often combining the performance indicators of both IH and OOH services, meaning that they cannot be studied separately, or ignoring the OOH period of the patient’s day entirely.

This is illustrated in the UK, where performance data on OOH services are collated under the umbrella of primary care services that undertake all patients, in which the coding system used to classify each case prohibits identification of cases requiring palliative care, revealing the need for better tools with which to capture OOH palliative care activity.¹²⁸

Data on the performance and quality of IH and OOH services are also amalgamated into one indicator in Ireland, meaning it is not possible to assess OOH components of care in isolation.¹²⁹

4.5 Summary

We performed a detailed documentary review of policy and practice documents in 16 high-income countries with advanced integration of palliative care services, supplemented by a grey literature review, in order to document models of OOH palliative care for adults and the performance measures used to evaluate these models.

Palliative care frameworks in many high-income countries with well-integrated services explicitly state the need for patient-centred, 24-hour, community-based service models in line with a palliative care approach, which should consider and ensure patient and family preparedness; integrated teamwork; physical, emotional, and spiritual care; symptom and pain management; skilled and compassionate healthcare professionals; and efficient and responsive care.

The Australian After-hours Palliative Care Framework is the most definitive in identifying key elements for OOH models, including client care planning, information systems, OOH telephone triage, OOH nursing, OOH specialist support, and follow-up quality assurance contact following a visit. Specific examples of innovative care are observable in different countries, including paramedic training in the UK, 24-hour SPC community care services in Germany, electronic patient records in Iceland, and telehealth in Japan.

The only performance indicators identified were those proposed by the UK Department of Health: 1) advance care planning preparation; 2) appropriate palliative specialisation competency within all OOH services; 3) access to, and communication between, OOH palliative care services; 4) updated and detailed patient

information sharing among IH and OOH services; and 5) access to drugs, particularly opioids. These had not been assessed for validity or usefulness.

5 Barriers and facilitators

5.1 Introduction

The purpose of this report is to inform the Department of Health in addressing known deficits in the provision of OOH palliative care for adults in Ireland (see Section 1.3). In the previous chapters, we have addressed Questions 1–3 through systematic reviews of the peer-reviewed literature and a detailed review of international policy and practice documentation which examined what is known about the models of OOH care in high-income countries, the performance measurement of these models, and the known evidence on effectiveness and cost-effectiveness.

Question 4 was:

What are the barriers to, and facilitators of, implementing OOH palliative care services in those countries?

This chapter summarises these barriers and facilitators in the context of the evidence from the systematic review (Chapter 2) and the documentary review (Chapters 3 and 4).

5.2 Methods

Consistent with the documentary review (Chapters 3 and 4), we employed narrative synthesis to summarise relevant material (see Section 3.5). It is important to note that all materials used to address Question 4 were confined to the literature identified for Questions 1–3; therefore, the present chapter is not an exhaustive review of all barriers to, and facilitators of, the provision of generalist or specialist OOH services.

We conducted a secondary review of all material used in previous chapters for discussion of the barriers to, and facilitators of, implementation:

- All titles and abstracts returned by the systematic review (n=666; **Figure 2**) were screened for references to barriers, facilitators, and implementation. Where the abstract indicated potentially relevant material, we reviewed the full manuscript for references to barriers, facilitators, and implementation, and extracted relevant data.
- All reports and grey literature used in the documentary review (**Chapters 3 and 4; Appendix 3**) were screened for references to barriers, facilitators, and implementation.

For this question, we also organised findings at the macro, meso, and micro levels:

- *Macro* is the highest level of analysis, sometimes known as the global perspective, and typically analyses at the societal, national, or international level.
- *Meso* is the intermediate level of analysis, sometimes known as the mid-range perspective, and typically analyses at the community or organisational level (service-delivery level).
- *Micro* is the smallest unit of analysis, sometimes known as the local perspective, and typically analyses at the individual or household level or at the health professional level.

Many factors identified at the macro or meso level could also be present at the micro level. For example, population-wide trends on physician attitudes or patient preferences could also be used to describe individual behaviour. We do not repeat such points in our reporting without explicit justification, assuming this to be self-explanatory. Consequently, micro-level factors reported below are predominantly divided among the perspectives of different groups of healthcare professionals.

In many cases, identified barriers and facilitators may not be specific to OOH palliative care but rather reflect challenges to OOH service provision as a whole. We report all barriers and facilitators below whether they are exclusive to OOH palliative care or not, provided they were considered relevant to OOH services in some way.

5.3 Results

5.3.1 Barriers

5.3.1.1 Macro level

At the level of health system organisation and policy development, OOH palliative care faces a number of barriers, many of which are also observed in IH palliative care processes.¹³⁰⁻¹³⁷ The macro-level barriers were mainly attributed to insufficient resources or education, issues surrounding referral to palliative services, and cultural differences (Table 6).

First, a lack of resources for both practitioners and patients to rely upon in emergency and OOH situations was highlighted throughout the literature as a barrier to care, including a lack of funding for OOH resources, in addition to issues surrounding access to opioids, specialist palliative equipment for the home, and professionals with adequate training to assist patients with palliative care needs in their own home.¹³⁰

This lack of resources may extend to the lack of education and time, which may allow practitioners to address the barriers of practitioners' self-reported lack of knowledge in relation to the services that are provided by palliative care IH and OOH and in relation to what palliative care patients are entitled to. In addition, lack of resources may have a detrimental effect on effective communication, adequate anticipatory practices, and advance care planning, which may lead to adverse effects on patient medication and treatment adherence, as well as a lack of preparedness in terms of self-management and emergency response, as reported in a UK study on GP-patient communication.¹³²

Barriers around referral have also been identified, with practitioners reluctant to make referrals and patients reluctant to be referred. Doctors fear that a referral of a patient to a palliative service will upset the patient, either by inferring that the patient is now at the EOL, by removing the familiarity of their family doctor's practice, or by the patient perceiving the doctor as abandoning them. The patient may be reluctant to be referred due to the assumption that they are "not close enough" to EOL to avail of services and due to their lack of trust in anyone but their GP during IH periods and emergency services during OOH periods.¹³⁷

In addition to these general barriers to the entire palliative population, additional barriers exist for multicultural societies, including practical issues such as a lack of translation services, a lack of female healthcare professionals for female patients whose religious beliefs specify that they must receive care from practitioners of the same gender, and potentially a lack of family caregivers in the country in which the patient is a resident. More emotive barriers also inhibit this population from accessing services due to a fear of discrimination, cultural differences in the treatment of death and discussions regarding death, a lack of representation of the patient's culture and ethnicity within palliative documentation, and a lack of cultural and religious sensitivity in relation to various aspects of care.¹³¹

Table 6 Macro-level barriers to OOH palliative care

Barrier	Key findings
Lack of resources (including time and education) for practitioners and patients	<ul style="list-style-type: none"> • Funding for OOH resources, particularly nursing and supportive care • Access to opioids • Access to equipment needed in the home • Access to professionals with adequate training outside of inpatient facilities • Lack of education regarding advance care planning at an appropriate time • Ineffective communication practices leading to adverse effects on patient medication and treatment adherence, and lack of preparedness in terms of self-management and emergency response, and • Inadequate anticipatory practices, particularly information provision to patients and carers.^{130,132}
Reluctance to refer among clinicians	<ul style="list-style-type: none"> • Fear of upsetting patients who are comforted by the familiarity of their family doctor • Not wanting to be perceived as giving up on or abandoning patients • Seeing referral as an admission of failure in looking after a patient, and • Low awareness of the potential benefits to patients and caregivers.¹³⁷
Reluctance to be referred among patients and family members	<ul style="list-style-type: none"> • Lack of trust in anyone but emergency services during OOH periods contributes to patient and carer anxiety and may increase unnecessary hospital admissions • Assumption that the patient is not close enough to EOL to avail of services • Lack of self-acknowledgement and acceptance of palliative status • Separation anxiety from a familiar care setting and team.
Incentives for hospitals	<ul style="list-style-type: none"> • Incentives to reduce hospital readmissions are causing hospitals to be reluctant to discharge a patient, resulting in more patients passing away in hospitals.¹³¹
Barriers to multicultural societies	<ul style="list-style-type: none"> • Lack of cultural and religious sensitivity in relation to various aspects of care, such as the treatment of blood transfusions and religious practices • Fear of discrimination and lack of representation of the patient's culture and ethnicity within palliative research and the documentation provided to them • Lack of translation services, which may lead to the desired end-of-life plan being misunderstood • Differences in cultural attitudes towards death and discussions regarding death • Lack of female healthcare professionals for female patients whose religious beliefs specify that they must receive medical care from practitioners of the same gender, and • Potential lack of family caregivers in the country in which the patient is a resident.¹³¹

5.3.1.2 Meso level

At the level of local system organisation and coordinated provision, palliative care again faces barriers, some specific to OOH care and some applicable more generally.^{138,139}

Organisational-level barriers include time and budgetary limitations for both healthcare staff and management, causing overlap and a lack of clarity and definition in roles and responsibilities and on referral policies. This overstretch of healthcare staff may also lead to several barriers, including lack of cohesion or collaboration in multidisciplinary teams, poor discharge planning and coordination across services, and increased burdens on IH colleagues often following the implementation of OOH care, e.g. information-sharing initiatives.¹⁴⁰

5.3.1.3 Micro level

As noted above, many micro-level factors are also observable at the macro or meso levels, and so were reported previously. For example, numerous barriers relate to patient and family knowledge and attitudes.

The remaining barriers observable at the micro level are those of different groups of healthcare professionals, including GPs, ¹⁴¹⁻¹⁴³ paramedics, ¹⁴⁴⁻¹⁴⁶ and generalist palliative care nurses (GPC) (Table 7).^{147,148 149}

Table 7 Micro-level barriers to OOH palliative care: healthcare professionals

Barrier	Key findings
GPs	
Insufficient resources to provide OOH care	<ul style="list-style-type: none"> • Lack of interest • Lack of time • Lack of remuneration, and • Live too far away for OOH care.
Inadequate integration between teams	<ul style="list-style-type: none"> • Lack of information transfer • Lack of communication • Lack of capacity of and support from specialist palliative care services to support care.
Variation in knowledge among GPs	<ul style="list-style-type: none"> • Differences in opinion on best approaches to organising end-of-life (EOL) care • Lack of interest and knowledge in palliative care for patients in a primary care setting, and • Self-reported confidence and emotional resilience in providing palliative care.¹⁴¹⁻¹⁴³
Paramedics	
Lack of protocols for moves between care settings	<ul style="list-style-type: none"> • Decision-making under time pressure of rapidly changing patient conditions • Managing specialist equipment, and • Clarifying resuscitation status of patients.
Insufficient palliative care education	<ul style="list-style-type: none"> • Palliative care services in the area • Patient entitlement to palliative care, and • Basic palliative skill set.
Poor clarity of objectives	<ul style="list-style-type: none"> • Resuscitation in the absence of advance care planning.
Inadequate support and information sharing	<ul style="list-style-type: none"> • Difficulty in accessing patient records and EOL plans.¹⁴⁴⁻¹⁴⁶
Generalist nurses	
Access difficulties	<ul style="list-style-type: none"> • Patient records, and • SPC needs assessment.
Perceived lack of formal support and acknowledgement	<ul style="list-style-type: none"> • Lack of education and emotional support for GPC nurses when carrying out palliative care, and • Perceived lack of recognition for nurses as coordinators of care.
Time constraints	<ul style="list-style-type: none"> • Unpredictable durations spent with patients with palliative care needs • Inability to spend the desired amount of time with patients with palliative care needs.¹⁴⁷⁻¹⁴⁹

While many barriers to care that GPs experience have been previously mentioned, barriers remain which are specific to individual variations in resource access, support networks, and palliative care knowledge (Table 7).¹⁴¹⁻¹⁴³

The most frequently reported barriers to OOH palliative care services by paramedics focused predominantly on issues relating to access to patient information, lack of palliative training and experience, poor clarity of objectives with regard to EOL plans, and lack of defined protocols in palliative emergencies (Table 7).¹⁴⁴⁻¹⁴⁶

Nurses who have not completed SPC training have identified many barriers, including those relating to a perceived lack of appreciation and acknowledgement on both an organisational and national level; difficulties in accessing patient information; and difficulties in organising a generalist caseload while attempting to factor in an unknown duration for palliative patients (Table 7).¹⁴⁷⁻¹⁴⁹

5.3.2 Facilitators

5.3.2.1 Macro level

Facilitators at national policy development level broadly mirrored the barriers found at macro level.^{141 151}

In concurrence with barriers identified regarding access to education and patient information, facilitators included access to electronic patient records, the ability to sufficiently organise advance care planning early in the disease trajectory, and the ability to equip patients and caregivers with the tools and knowledge needed to self-manage pain and symptoms.¹⁵⁰

In addition to these facilitators, effective communication between patients, caregivers, and healthcare providers during IH periods was also considered to be a facilitator,^{132,140,150} leading to less reliance on OOH services due to preparedness and self-management of properly educated patients and caregivers, in addition to ameliorated patient and caregiver coping skills.¹³²

5.3.2.2 Meso level

Organisational-level facilitators can be divided by setting.

In home care and primary care settings, improving cohesion among multidisciplinary teams was considered to be a valuable facilitator, which reduces both time spent investigating patient needs and information, as well as the feelings of isolation expressed by GPs working in OOH services within the system.^{140,147,151-153}

Rural residential care settings often have difficulty in securing regular visits from outside teams, and as such, a facilitator to care in this setting is ensuring that IH and OOH palliative care can be provided by on-site staff, enabled by targeted education for staff, and ensuring that IH and OOH palliative care can be provided by on-site staff, enabled by targeted education for staff and by protocols being in place for advance care planning and EOL care pathways.¹⁵²⁻¹⁵⁴

Across all settings and services, the functioning of each service relies heavily on access to medications and equipment. Services can improve access to medications through initiatives such as giving nurses the ability to prescribe independently, as well as by raising the profile of community pharmacists among multidisciplinary teams.^{147,151,152}

5.3.2.3 Micro level

Due to the individualistic nature of the facilitators categorised as micro level, findings were organised into distinct sub-categories for clarity. In order to observe how the palliative process can be enhanced for all parties involved, micro facilitators were gathered from both patient and GP and hospital palliative consultant perspective.

5.3.2.3.1 Patient perspective

Table 8 Micro-level facilitators to OOH palliative care: patient perspective

Barrier	Key findings
Patient perspective	
Familiarity with the care team	<ul style="list-style-type: none"> • GP practice is near the patient's home • GP makes regular home visits and takes the initiative to visit or phone • GP respects the patient's wishes, expectations, dignity, and autonomy, and • Patient trusts the GP and their abilities.¹²⁸
Continuity of care	<ul style="list-style-type: none"> • Detailed handovers and communication with new service providers • GP has had training in order to anticipate various scenarios in the disease trajectory • GP is accessible and available, and • GP makes appointments for follow-up visits.^{132,136}
Palliative care approach	<ul style="list-style-type: none"> • GP takes the necessary time for the patient and does not rush the patient in trying to communicate sensitive or upsetting information • GP listens carefully with empathy and commitment • GP is honest, clear, and straightforward • GP gives the patient a feeling of trust and reassurance • GP talks in accessible and everyday language, not using difficult medical terms • GP talks about the unfavourable prognosis, and • GP helps the patient to deal with unfinished business.¹³²

5.3.2.3.2 GP and hospital palliative consultant perspective

The facilitators which enable GPs and consultants to refer patients, and to feel comfortable doing so, mirror the barriers which inhibit them. Predominantly, facilitators were described as the accessibility of the patient in addition to the supports for the GP or consultant during the referral process, including access to 24-hour specialist palliative advice and knowledge of the services available in the locality (Table 9).^{132 154 155,156}

Table 9 Micro-level facilitators to OOH palliative care: GP and consultant perspective

Barrier	Key findings
GP and hospital palliative consultant perspective	
Accessibility of person and place	<ul style="list-style-type: none"> • Home is accessible and open to home visits, and • Patient's wishes and expectations are clearly defined.^{132 154}
Appropriate supports for the provider	<ul style="list-style-type: none"> • Tools available to support transfer of information and responsibility for care between the GP and the OOH service • GP has had education and training to anticipate the patient's needs and disease trajectory OOH • Access to 24-hour specialist advice and support if care needs are beyond the abilities of the GP or consultant • Good communication with SPC services, and • Dissemination of information regarding OOH services in the locality for GPs to provide to their patients should they be unavailable to provide care.^{155,156}

5.4 Summary

A secondary review of both the peer-reviewed literature (Chapter 2) and international policy and practice documentation (Chapters 3 and 4) identified a series of barriers and facilitators at the system-wide (macro), mid-range (meso), and individual (micro) levels.

Consistent with previous chapters that identified relatively few well-established OOH palliative care services with strong supporting evidence, this secondary review found more barriers than facilitators.

Prominent barriers included insufficient resources to provide OOH services, inadequate knowledge among practitioners and patients about palliative care access and entitlements, a lack of advance care planning to guide non-specialists in their management of deteriorating patients, inadequate communication between, and integration of, OOH services with other parts of the healthcare system, and insufficient knowledge among unpaid caregivers to provide some pain and symptom management themselves during OOH periods.^{132,154,155,156}

Examples of good practice for facilitating OOH care tended to address these same points.

6 Discussion

6.1 Summary of key findings

A systematic review of both the academic and grey literature identified no studies of sufficient quality that evaluated the effect of OOH palliative care on patient and caregiver outcomes, or on cost and cost-effectiveness (Question 1; Chapter 2).

A documentary review of policy and practice documents in 16 high-income countries identified widespread acknowledgement of the importance of integrated, 24-hour palliative care in principle (Question 2; Chapter 4). Detailed description of the organisation of OOH care within this ideal model was rather less common. The Australian After-hours Palliative Care Framework was most definitive in identifying model elements of OOH palliative care: client care planning, information systems, OOH telephone triage, OOH nursing, OOH specialist support, and follow-up quality assurance contact following a visit. Specific examples of innovative care models were also observable in different countries.

We identified only one set of performance measures specifically for OOH palliative care (Question 3; Chapter 4), from the UK Department of Health. These were: 1) advance care planning preparation; 2) appropriate palliative specialisation competency within all OOH services; 3) access to, and communication between, OOH palliative care services; 4) updated and detailed patient information sharing among IH and OOH services; and 5) access to drugs, particularly opioids. These indicators had not been assessed for validity or usefulness.

Reported implementation challenges identified more barriers than facilitators (Question 4; Chapter 5). Such barriers included insufficient resources, inadequate knowledge among practitioners and patients, a lack of guidance for non-specialists, inadequate communication between OOH services with other parts of the healthcare system, and insufficient knowledge among unpaid caregivers.

6.2 Policy implications

Our review of international evidence on OOH palliative care for adults suggests that Ireland's current position is typical among high-income countries with well-established services. That is, the importance of integrated, 24-hour care for people with serious and complex medical illness is widely acknowledged, but details on how to organise, provide, and evaluate OOH palliative care are much more scant.

As noted in Chapter 1, up to three-quarters of each week occurs outside of 'typical' working hours. Without OOH services, a large gap exists in sources of pain and symptom management, prescribing, advice, social support, and mobility assistance, particularly for those living at home. It is not feasible for these gaps to be substantively met by palliative care specialists, which means that increasing the numbers, capacity, and supports of generalist OOH providers (GPs, nurses, and paramedics) is likely to be required.

In order to fulfil national palliative care policies as well as recommendations of other groups, including the Irish Hospice Foundation (IHF), OOH palliative care must be embedded across the Irish healthcare system. This includes not only the creation of new services and capacity, but also improved integration of pre-existing IH and OOH services.^{157,158}

We make the following suggestions based on the research findings and in line with proposals for palliative care as part of universal healthcare in Sláintecare:

- Due to the lack of measurement using standardised indicators in OOH services, a **population-based needs assessment** for OOH S&GPC services is required in order to estimate the expansion of services required, or to support the introduction of new models of palliative care. Population-level need can be estimated using data relating to deaths and disease prevalence.¹⁵⁹ These projections can be combined with evidence about best practice and appropriate models of care in order to estimate capacity and workforce requirements. Workforce planning should include strategies for training, recruitment, and retention.¹⁶⁰ In particular, it will be important to evaluate skill gaps of current health professionals according to the requirements of the OOH model of care chosen, along with resourcing appropriate training and skill development strategies.⁴
- Detailed and realistic **planning around timing and phasing of services** is required in order to ensure adequate system capacity to provide the new services.¹³² It has been widely reported that barriers to care for nurses include lack of time to spend with patients in order to be satisfied that they have been

provided sufficient care, in addition to feelings of high stress and burnout caused by attempting to predict time needed for palliative patients in a standard day of nursing.¹⁴⁹

- **Develop, pilot, and evaluate programmes based on innovative approaches in other high-income countries.** One example is training paramedics and other generalist doctors and nurses to support a wider range of palliative care needs in the community. Training and education programmes aimed to ameliorate the confidence of general health providers while providing palliative care was also identified as a factor which could enhance continuity of care. In addition, the expansion of telehealth interventions would appear to facilitate collaboration and information sharing among healthcare professionals and to support communication with patients and families.
- **Develop, pilot, and evaluate models incorporating identified elements of OOH care,** including case management, eprescribing,¹⁵⁰ telephone triage, quality assurance assessment with patients and families following a visit,¹³² and OOH nursing.
- **Implement strategies to address identified barriers** such as inadequate guidance, skills, and confidence among generalists;¹⁴¹⁻¹⁴³ inadequate knowledge among patients, caregivers, and the general public;¹³⁷ and inadequate communication between OOH services with other parts of the healthcare system.¹⁴⁰
- It would be useful to Ireland (as well as adding to international knowledge) to **establish and resource an evaluation framework for comprehensive palliative care,** along with a government evaluation capacity, drawing on best practice from countries such as Australia⁵⁴ and the UK,⁵⁷ with regular reporting on key indicators and review of progress towards targets.

6.3 Limitations

Any systematic review is vulnerable to missing relevant material, either through mis-specification of search terms or errors in review. We minimised these risks by establishing clear PICOS and eligibility criteria prior to data collection, employing a combination of subject and information specialists in executing searches, using two reviewers independently throughout the process, and examining studies that were included in multiple other prior reviews of palliative care in different settings.

We had to restrict the number of countries in our documentary review for reasons of feasibility. Countries with relevant policy and practice documentation may have been missed. We sought to minimise bias by selecting countries according to criteria established *ex ante*.

Narrative synthesis was employed to address Questions 2–4 and may be subject to investigator bias. We sought to minimise this through the involvement of interdisciplinary experts on the research team in reviewing and discussing material, and by consulting local experts in each of the 16 countries regarding our results. Minor amendments to some countries' narrative summaries (Appendix 3) were made following the advice given by country palliative care experts; however, most experts were in agreement with all or the large majority of the information that we had identified.

6.4 Conclusion

The importance of integrated, 24-hour care for people with serious and complex medical illness is widely acknowledged in Irish policy and practice documentation, and this is consistent with other high-income countries with well-established palliative care services. Nevertheless, both academic evidence and international policy documentation lack detail on how to organise, provide, and evaluate OOH S&GPC services. Since three-quarters of the week occurs outside of typical working hours, OOH palliative care provision is essential to achieving integrated, comprehensive care for this priority population, and SPC staff will not be available or affordable in sufficient numbers. Meeting current and future needs requires increasing the numbers, capacity, and supports of generalist OOH providers, including GPs, nurses, and paramedics. Efforts to address recognised deficits in OOH palliative care in Ireland can build on the examples of other countries in defining elements of services and in designing specific models, including training generalists and using telehealth facilities. Ongoing evaluation of the feasibility and effectiveness of these new services is critical in the context of very limited evidence internationally.

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Appendices

Appendix 1 Study rejected as not English language

One study reached full-text screening on the basis of an English-language abstract that indicated potential relevance, but was rejected due to the full text not being in English:

- Giesen P, Veldhoven C, Vlaar N, Borghuis M, Koetsenruijter J, Verheggen S. Patients' opinion of weekend cover by palliative care general practitioners. *Huisarts en Wetenschap*. 2011;54(12):646-9.

The full-text language is Dutch.

Appendix 2 Study rejected at quality assessment

One study was deemed eligible but was rejected at quality assessment:

- Baird-Bower D, Roach J, Andrews M, Onslow F, Curnin E. Help is just a phone call away: after-hours support for palliative care patients wishing to die at home. *Int J Palliat Nurs*. 2016;22(6):286-91.

Eligible studies from the systematic review were assessed using the Critical Appraisal Skills Programme (CASP) suite of tools. We reviewed this study using the cohort study checklist (http://casp-uk.net/wp-content/uploads/2018/01/CASP-Cohort-Study-Checklist_2018.pdf). The first section of this checklist (Section A: Are the results of the study valid?) consists of two questions:

1. Did the study address a clearly focused issue (e.g. population studied, risk factors, outcomes)?
2. Was the cohort recruited in an acceptable way (e.g. representativeness, criteria, exhaustiveness)?

Two independent reviewers concluded that the answer to each question was 'NO'. Specifically, the reviewers recorded concerns about how the comparison group was identified. The study authors do not provide eligibility criteria (Question 1) or methods of recruitment/identification (Question 2). The study was therefore not advanced to full CASP assessment.

Appendix 3 Country Summaries

Appendix 3.1 Australia

(i) Definition of 'out of hours' (OOH)

Sociable after-hours periods: 6.00pm–11.00pm weeknights

Unsociable periods: 11.00pm–8.00am weeknights, before 8.00am and after 12.00pm Saturdays, all of Sunday, and public holidays.¹

(ii) Target population for OOH or after-hours specialist and generalist palliative care (S&GPC) services

The World Health Organization (WHO) definition has been adopted by the Australian Government with regard to palliative care,² defining this group as “patients and their families facing the problems associated with life-threatening 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.”³

This population is separated into three distinct categories:

- 1) “People living with a life-limiting illness whose needs are straightforward and predictable, including families and carers of these people
- 2) People living with a life-limiting illness whose needs range from straightforward and predictable to intermediate and fluctuating, including families and carers of these people, and
- 3) People living with a life-limiting illness whose needs include straightforward and predictable, intermediate and fluctuating, or complex and persistent, including families and carers of these people.”⁴

Australia is a country where 80% of its 22-million-person population occupies only the coastal fringes, with 20% of the population sparsely populating the central region. This results in great difficulty in ensuring that the full population has access to policing, education services, and healthcare services, specifically in this case palliative care. Each state and territory has a different approach to the organisation of palliative care in its jurisdiction.⁵ Some services (particularly those in cities and larger regional areas) have embedded specialist palliative medical staff, whereas smaller services variably use phone support as required.

(iii) Composition of specialist and generalist teams

Service teams can be categorised into areas of specialisation:

- **The home** – by home care nurses, general practitioners (GPs), and/or mobile community palliative care teams
- **Hospices** – by a multidisciplinary palliative care team including doctors, nurses, social workers, psychologists, occupational therapists, physiotherapists, and dieticians
- **Hospitals** – by the hospital’s specialist palliative care (SPC) team (as above) in cooperation with generalist staff, and
- **In nursing homes** – by palliative care specialist nurses in cooperation with generalist staff and assisted by **community care teams** if needed.⁶

Generalist palliative care services are provided within hospitals, community GPs, hospices, nursing homes, day care centres, and generalist community services.

Specialist palliative care services operate within hospitals offering consultancy services; specialist inpatient settings, such as nursing homes and hospices; and community-based specialist services.⁶

In addition to this, a palliative helpline exists for patients who cannot access these services due to rurality or access issues, particularly during the night:

- Generalist: a registered nurse with training in palliative care is will triage patient.
- Specialist: an SPC nurse with expert knowledge, skills, and recent experience in palliative care provides advice and support to callers with more complex issues.

(iv) Roles and responsibilities of team members

Both hospital and community teams should:

- Provide education to people with life-limiting conditions; recognise common trajectories and manage pain and symptoms accordingly; offer support and advice to patients and families; and ensure that the patient’s care plan is respected.⁶

Phone services and clinics should:

- Provide information for palliative care patients, carers, and health professionals
- Provide psychological support for people experiencing anxiety or fear

- Help with symptom management, including pain relief
- Refer callers to other service providers when needed, and
- Assist with appropriate crisis intervention.

Specialist services comprise specialist home nursing and support, while in other areas, these services include personal care, domestic assistance, and service coordination, giving carers the confidence and time to support loved ones while also reducing the likelihood of hospitalisation.⁵

(v) Collaboration and information sharing between generalist and specialist OOH teams

A generalist nurse will triage the patient on the telephone and transfer them to a specialist nurse accordingly, depending on the condition and stage of the patient.

(vi) Collaboration and information sharing between OOH teams and in-hours (IH) teams

- After any call to an OOH service, a summary is provided to the patient's specified palliative care provider to keep them informed of the patient's situation. The summary includes the reason for the call and the advice provided.
- In response to any change in the individual's condition, palliative staff members are required to clearly document the content of discussions and any agreed plan of care in the patient's clinical record.⁶

(vii) S&GPC collaboration process

- In addition to providing specialist care directly, specialist teams can collaborate with generalist care teams in order to assist them in providing palliative care, whether that be by accepting referrals or by being open to provide support in an advisory capacity.
- Multidisciplinary teams will meet regularly in order to reflect and review upon the patient's care plan, share information, and assess whether certain members of the team increase or decrease their involvement depending on the patient's illness trajectory.
- The Palliative Care Outcomes Collaboration is a national programme that utilises standardised clinical assessment tools to measure and benchmark patient outcomes in palliative care in order to facilitate easy understanding of a patient's condition.⁴

- There is no national collection that captures information on service provision by community nurses, some of which will be related to providing care for people living with life-limiting illnesses.⁴
- The After-hours Palliative Care Framework recommends that all those involved in community care processes should take part in working parties, regular road trips and site visits, team meetings, teleconferences, workshops, consortium meetings, emails, visual summaries through flow charts, and monthly updates, encouraging feedback/comments from all parties and celebrating achievements.⁷

(viii) Additional training requirements for OOH specialist and generalist team members

The Australian Healthcare and Hospitals Association offers free Palliative Care Online Training with modules on topics such as pain management and recognising deteriorating patients. These have Continuing Professional Development points, so they carry an incentive.⁸

Additionally, Health Pathways Melbourne is an online portal that provides evidence-based information on the assessment and management of common medical conditions, as well as referral information for local hospitals and community services.⁹

(ix) Methods to ensure information sharing between IH staff and OOH staff

While 100% of inpatient services and 97% of community services use the recommended standardised clinical assessment tools to measure patient outcomes, there is no formal palliative care network; many services are self-organised. GPs and support services contact each other of their own volition, but there is no system in place.⁴

Some regions have their own tools and forms which make this process more efficient and ensure that all information required is given, such as the Palliative Care Referral/Triage Tool within the Gippsland Region in Victoria.¹⁰

(x) Anticipatory actions by IH S&GPC services to support the patient, carers, and OOH generalist and specialist teams

In response to any change in the individual's condition, palliative staffs are required to clearly document the content of discussions and any agreed plan of care in the patient's clinical record.⁶

In some areas, patients are prioritised based on the acuteness of their condition by IH specialist services. If an individual is assigned to level 3 or 4 (increasing in acuteness), they can access a specialist service which provides a 24-hour, seven-day-per-week on-call service to primary care providers and patients.¹¹

(xi) Methods to maximise responsiveness by generalist and specialist OOH teams to patients and their carers, including technology (telephone, EHR, video link), triage, decision trees, preparedness, and home visits

Any services which require home visitation take action to train staff on such responsibilities as providing legal advice for patients and carers; active implementation of advance care planning; responsiveness to the person's wishes, including the withdrawal of life-sustaining treatment; and mediation and conflict resolution between the person, their family, and carers.⁶

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Appendix 3.2 Austria

(i) Definition of OOH

- Generally before 9.00am and after 5.00pm Monday to Thursday, before 9.00am and after 2.00pm Friday, and all day Saturday, Sunday, and public holidays.

(ii) Target population for OOH or after-hours S&GPC services

- The target group of hospice and palliative care includes palliative patients as well as their dependents and relatives, including people with an advanced stage of oncological or non-oncological disease with symptoms affecting their quality of life (e.g. pain, nausea, shortness of breath, fatigue), and/or with psychosocial problems.
- **Generalist:** between 80% and 90% of patients do not require significant specialist care.
- **Specialist:** between 10% and 20% of patients and relatives are in complex situations with difficult issues.

(iii) Composition of specialist and generalist teams

- The majority of palliative patients in Austria spend their palliative period in hospital or community settings, as a low percentage of patients can have access to a palliative care unit.¹
- **All services:** hospital palliative care, inpatient hospice, day hospice, the Palliative Consilience Service, mobile palliative team, hospice team:
 - **Generalist:** generalist services are provided by hospitals, care homes, nursing homes, hospices, GPs, mobile health services, therapists, and ambulance staff in the hospital with professional expertise in the care of palliative patients.
 - **Specialist:** specialist services are provided by hospice teams mobile hospice teams, palliative counsellors, palliative stations, and day hospices: "Specialised hospice and palliative care is aimed at patients and relatives in complex situations with difficult issues and offers beyond the primary care additional supportive and mentoring services that are tailored to the needs of patients and relatives".^{2(p#)}
 - In addition to community-based support, 300 pharmacies (out of 1,300) are rostered to be open 24 hours per day administering advice.

- Mobile palliative care, in cooperation with hospitals and non-profit organisations, provides home care from nurses and doctors, usually specialists or with specialist experience, free of charge; such care encompasses symptom management, psychosocial support, self-management education, and pain alleviation.³

(iv) Roles and responsibilities of team members

- **Generalist:** medical staff, GPs, nurses, and care assistants.
- **Specialist:** pastoral workers, social workers, nutritionists, occupational therapists, speech therapists, physiotherapists, and psychotherapists.
- Mobile palliative teams focus primarily on the supervisors of palliative patients at home or in the home, and offer advice, guidance, and presentations in pain therapy, symptom control, palliative care, and psychosocial support. The advice from the palliative team may also be used by the patients themselves.⁴

(v) Collaboration and information sharing between generalist and specialist OOH teams

- All hospice teams of 10–12 people, whether specialist or generalist, have a service coordinator who draws the multidisciplinary resources together and provides updated information to relevant parties.
- Austria has also implemented legal regulations for palliative care leave for carers, which allows a central contact for all care teams and services.⁵

(vi) Collaboration and information sharing between OOH teams and IH teams

- Collaboration is facilitated by the *Palliativkonsiliardienst*,⁶ a multiprofessional team in the hospital providing a bridge between hospital care and home/hospice care and assisting primarily the medical staff in the wards and outpatient clinics, and secondarily the patients and their relatives. The team also provides telephone counselling to doctors and social services workers, as well as patients at home.

(vii) S&GPC collaboration process

- The *Austrian Palliative Care Guidelines* state that all care teams should have a coordinator who has attended at least one basic interdisciplinary course in palliative care and has specialised training in geriatric palliative care.⁷

(viii) Additional training requirements for OOH specialist and generalist team members

- **Generalist:**
 - Training of 80% of all employees of all occupational groups (within nursing homes and hospices) according to the curriculum in Palliative Geriatrics, and the further training of employees for the *Vorsorgedialog*[®] (VSD), is required.⁸
 - Medical staff (nurses, care assistants) should have an additional qualification in palliative care (interprofessional palliative training to the extent of 160 teaching units of theory and 40 hours internship).
- **Specialist:**
 - Physiotherapists, psychologists, psychotherapists, and pastoral workers receive an additional qualification in palliative care (interprofessional palliative training consisting of 160 teaching units of theory).
 - Training of 80% of all employees of all occupational groups (within nursing homes and hospices) according to the curriculum in Palliative Geriatrics, and the further training of employees for the VSD, is required.⁸
- **Volunteers** should prove that they have the following qualifications:
 - They have completed a course designed to empower volunteer hospice attendants.
 - They have received 80 hours' training in line with the Hospice Austria curriculum.
 - They have completed an internship for at least 40 hours in the hospice and palliative area.⁹
 - They have participated in ongoing training totalling at least eight hours per year.

(ix) Methods to ensure information sharing between IH staff and OOH staff

- All inpatient facilities should have in-house report systems. Many other services use day and night coordinators to communicate information to each other and then disseminate this information to their teams.⁷

- Other teams may employ the use of district nurse report systems within the individual's home, whereby the report is updated at every visit, noting changes in the patient's illness trajectory and recommending the increase or decrease of attendance by different services.¹⁰

(x) Anticipatory actions by IH S&GPC services to support the patient, carers, and OOH generalist and specialist teams

- IH generalist health providers, such as GPs, can assist relatives in applying for palliative care leave so that they may leave work for a maximum of three months in order to care for their ill relative. If necessary, an extension to six months' leave per case is possible.¹¹
- The GP can also assist the patient in advising, planning, and uploading their care plans to the VSD in order to assist OOH and specialist services in understanding the patient's requests.¹⁰
- In addition to this, Hospice Austria recommends that GPs put in place emergency plans in the event of a crisis, particularly if the patient lives alone, as well as providing sufficiently detailed notes on the patient's preferred care plan which can be forwarded to other palliative care services in order to deliver increased efficiency in collaboration.¹²

(xi) Methods to maximise responsiveness by generalist and specialist OOH teams to patients and their carers, including technology (telephone, EHR, video link), triage, decision trees, preparedness, and home visits

- The VSD is both a record-keeper of a patient's wishes and ideas for their care plan and an anticipatory planning tool. It enables the patient to communicate with their health services regarding their wishes and it also enables the health providers to access these plans when the patient is unable to state them in emergency situations.¹⁰
- Hospice Austria recommends that the patient and their primary physician should develop preparedness plans for situations in which the patient is unable to communicate their wishes, including in the case of an epileptic seizure, sudden pain, or respiratory distress. This preparedness plan may be supplemented with a personal alarm or personal response system.¹⁰

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Appendix 3.3 Belgium

(i) Definition of OOH

Belgium defines OOH as any time between 7.00pm and 8.00am on weekdays, all weekend, and public holidays.

Doctors receive a special night-time standby rate while working within this period.¹

(ii) Target population for OOH or after-hours S&GPC services

Patients who are experiencing “the advanced or terminal stage of a serious, progressive and life-threatening illness, regardless of his or her life expectancy”.²

(iii) Composition of specialist and generalist teams

Belgium separates palliative care into a two-tier system:

1. A coordination platform which organises palliative care in the district (which is linked to second-line support teams in certain districts), targets information, raises public awareness, and coordinates the training of professionals and volunteers.
2. Second-line support teams: multidisciplinary specialist teams who are always available, 24 hours a day, seven days a week.³

Belgium has a focus on at-home palliative care – a certain amount of money is provided for nursing care, and the palliative patient at home does not have to make a personal financial contribution when treated by nurses, physiotherapists, or GPs.

Palliative services in Belgium include:

- Coordination platforms comprise coordination and administration staff, and a psychologist.
- In-hospital Belgian palliative care services, including oncological units for specific medical conditions, consist of specialists such as medical/clinical oncology doctors and nurses, as well as generalist doctors and nurses, and care assistants.
- In hospitals, palliative support teams consist of a palliative medical doctor, a palliative expert nurse, and a psychologist.
- Multidisciplinary palliative home care teams consist of palliative expert nurses, a palliative trained team doctor, and administrative and organisational staff.
- Palliative day care centre teams consist of specialist palliative nurses, a specialist palliative doctor, and administrative staff.

- Nursing homes also provide services to inpatients 24 hours a day but may require support from palliative hospital services to advise generalist staff.⁴

(iv) Roles and responsibilities of team members

- Belgian palliative care service teams within hospitals advise hospital management on the policy to be followed in the treatment of pain specific to palliative practices, specialised relief of symptoms, or the use of specialised equipment for alleviating pain, i.e. pain relief medication pumps and psychological and moral support for the palliative patient; ensure that the patient's choices of EOL location and circumstances are respected; ensure continuity of care when transferring to this location by promoting communication between the various services; and provide continuing palliative care education for physicians and general support to the patient, their family, and the healthcare team.⁵
- Palliative care residential units (hospice or nursing home palliative care units) exclusively provide palliative care within hospitals including specialised palliative medicine, high-level nursing, and support that respects the wishes of the patients, while also attempting to create a welcoming, homely atmosphere more like a home than a hospital.⁶
- Generalist community services provide basic respite and medical care, generally within daytime working hours, but will generally have limited services by way of an on-call doctor throughout the night also.⁴
- Multidisciplinary palliative home care teams provide home care with palliative care for patients. Services include symptom management, providing advisory support and help with caregiving duties, , as well as providing basic self-management and caregiving training for the patient and their family that is always available, 24 hours a day, seven days a week.⁷
- Palliative day care centres facilitate caregivers who have other commitments during the daytime.⁴

(v) Collaboration and information sharing between generalist and specialist OOH teams

- Palliative home care teams can support both the patient and the family or the other care providers. General physicians must refer a patient to these services and collaborate with the service to provide information and be updated on the patient's progress as their primary physician.⁷

- The general physicians can also request the advice or support of the palliative home care team for themselves or for other members of the care team, if they do not necessarily need a visit from the team.

(vi) Collaboration and information sharing between OOH teams and IH teams

- It is recommended that representatives from each element of the multidisciplinary care team have frequent meetings in order to share information and recommendations for the patient; however, there is no strict policy in place for these meetings.⁸
- Each organisation may have its own individualised policies in order to ensure continuity of care and efficiency of care.⁹
- Mobile palliative care teams will collaborate with a patient's GP and the GP will collaborate with the care team, due to the necessity of referral to the service.

(vii) S&GPC collaboration process

- Second-line palliative care teams supplement the work of the patient's general physicians by carrying out the more specialist care which the general physician may not be able to supply themselves. These teams work in conjunction with general physicians to not only provide specialist care but additionally to provide care outside of general physician office hours.³
- General physicians must also refer a patient to these specialist services and collaborate with the service to provide information.⁷

(viii) Additional training requirements for OOH specialist and generalist team members

- All graduates of medicine from every medical school in Belgium must complete a compulsory palliative medicine course as part of their degree.¹⁰ Belgium inserts a palliative care module in the training for many different disciplines, including nurses, paramedics, and counsellors. There is also a specialist qualification in palliative care for nurses in order to become palliative nurses.
- The Teaching and Research Centre for Environment and Health has developed a multiplatform approach to training which allows all disciplines to enhance their level of understanding and skills within the discipline of palliative care. Each care team has the option to in an interactive basic session

of one to three hours. Secondly, a course on introducing palliative culture into care can be taken, which is between 8 and 20 hours long. Lastly, a 40-hour course can be taken that focuses on knowledge and interpersonal communication skills. Other higher education courses include a diploma in palliative care for paramedics.¹¹

(ix) Methods to ensure information sharing between IH staff and OOH staff

- In and out-of-hours staff are recommended to take part in meetings in which they can adequately handover information regarding their patient's status and condition. The policy regarding these meetings generally differs from organisation to organisation.⁸
- ***For organisation***
- Mobile palliative care teams will collaborate with a patient's GP and the GP will collaborate with the care team, due to the necessity of referral to the service.⁹

(x) Anticipatory actions by IH S&GPC services to support the patient, carers, and OOH generalist and specialist teams

- Belgium's palliative care networks consolidate and coordinate many various partners in the country, such as primary care providers or their organisations, residential care centres, hospitals and palliative care units, home care organisations, and specific care organisations for families, carers, and/or volunteers working in the palliative field, allowing for a central hub of control and organisation of each patient's care.

(xi) Methods to maximise responsiveness by generalist and specialist OOH teams to patients and their carers, including technology (telephone, EHR, video link), triage, decision trees, preparedness, and home visits.

- Belgium has a system in place which loans medical equipment, including tools for 'biotélévigilance' (wireless monitoring), which will send emergency alerts in the case of a fall or a sudden illness, speeding up the process of dispatching emergency palliative care.³

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Appendix 3.4 Canada

(i) Definition of OOH

After hours in Canada is generally accepted as any period after 5.00pm and before 9.00am on weekdays, and all day on weekends and public holidays.¹

(ii) Target population for OOH or after-hours S&GPC services

Canada's palliative care system states that it is for both persons who are living with and dying from advanced illness, or who are bereaved.² Canada also provides a number of services to support family caregivers throughout the palliative process as well as when they become bereaved. Three-quarters of deaths in Canada occur in hospital or long-term care facilities, despite most Canadians wishing to spend their last stage of life at home.³ Only 20% of citizens live in the rural or remote areas that comprise 95% of this large country, with many areas sparsely populated or entirely uninhabited. Only approximately 15% of Canadian palliative care patients will require acute care that requires the use of tertiary services within a hospital palliative care unit or hospice.⁴

(iii) Composition of specialist and generalist teams

Specialist and generalist teams vary across cities and provinces in Canada:

- In some areas, home care teams from palliative care centres look after patients on referral from GPs.
- Hospital palliative care teams and units are made up of specialist and generalist doctors and nurses, as well as other specialisations such as geriatricians, occupational therapists, oncologists, and psychologists.⁵
- Many areas employ 24/7 access to palliative tele-nursing services. In addition, Canada often classes the caregivers and bereaved families as beneficiaries of palliative care, and as such has also set up free 24/7 access to:
 - Support services which will provide guidance on diet, stress reduction, emotional counselling, decision-making, exercise, and personal coaching
 - Counselling and support for families and caregivers (support groups, referral to community organisations), and
 - Grief and bereavement tele-counselling for the bereaved.⁵

- Nova Scotia offers palliative care programmes that employ the use of paramedic teams that have received specialist palliative care (SPC) training. They can treat patients once patients have been referred to the Provincial Integrated Palliative Care Program by their GP.⁶

(iv) Roles and responsibilities of team members

1. GPs are the first point of care in order to gain access to OOH services, as patients require referral to the majority of services if they no longer wish to pursue curative treatment. However, in addition to this access path to OOH services that general practitioners provide, many also offer OOH services for palliative patients or will make arrangements between doctors within a clinic so that there will always be at least one doctor available during OOH periods, although this varies from doctor to doctor.⁵
2. Palliative care paramedics can be called via emergency services (i.e. 911) but will arrive to the home in an ambulance without using the lights and sirens. They can administer additional pain medication or deliver physical therapy in order to make patients more comfortable.⁷

(v) Collaboration and information sharing between generalist and specialist OOH teams

Hospice-led programmes, whether they are inpatient or community support services, have designated coordinators who will plan and execute their organisation's services.

The hospice-led programmes also have coordinators who are responsible for coordinating services delivered by their organisation. These coordinators work in close partnership and collaboration with access centres' case managers to avoid duplication of efforts.⁷

(vi) Collaboration and information sharing between OOH teams and IH teams

IH care teams mainly consist of GPs, palliative generalist and specialist teams in day centres and outpatient facilities, specialist mobile care teams (although these teams are not strictly IH), and hospice inpatient care teams. While specialist mobile care teams and hospice inpatient care are unaffected by the disjointed care and reliance on collaboration that exclusively IH teams must consider in order to fully care for the patient, they must still endeavour to keep channels open between daytime and night-time staff.

Generally, GPs must refer patients to palliative services, which will require the anticipatory action of preparing and supplying the new service with full relevant medical details on the patient, including the early stages of the advanced care plan as provided by the patient.¹¹

Home care teams are coordinated by case managers within their organisation, who will coordinate the efforts of the multidisciplinary team and who will generally only work within normal office hours but will allow other members of the team access to a patient's schedule.

Hospice and hospital teams will coordinate care within the organisation through databases and patient reports.⁸

(vii) S&GPC collaboration process

Most SPC services in Canada require referral from a general practitioner or team. The collaboration process in Canada is quite effective overall, with specialists delivering miniature courses on certain aspects of palliative care to general practitioner, nurses, and paramedics all around the country with Pallium Canada. On a smaller scale, the collaboration process between generalists and specialists differs greatly across provinces. There are no country-wide collaboration requirements or legislation.⁹

(viii) Additional training requirements for OOH specialist and generalist team members

The majority of Canadian medicine degrees have fewer than 10 hours of palliative care teaching in their entire curriculum. It appears that most of the healthcare professionals working in palliative care professions in Canada are not actually palliative care specialists.¹⁰

Specialist:

Courses specific to palliative medicine can be obtained from the College of Family Physicians of Canada after an original certification as a family physician (GP) has been obtained. These can be undertaken as one-year programmes or as a two-year subspecialty.¹⁰

Generalist:

Individuals who are already trained as general practitioners, paramedics, or nurses can supplement their previous training with courses by a non-profit organisation called Pallium Canada, which works in conjunction with the Canadian Government. This organisation, Pallium Canada, developed new modules such as brief one-day courses for busy family medicine clinics and one-day oncology courses for non-palliative care teams in hospitals and hospices, in addition to courses for long-term care and courses specifically designed for paramedics. These courses would allow everyone that a patient may approach for assistance to have palliative care training in order to give the patient the correct form of care.¹⁰

(ix) Methods to ensure information sharing between IH staff and OOH staff

IH staff in a home care setting would include the patient's regular GP. Collaboration in this case would include the doctor's referral of the patient to a palliative care service, such as the Paramedics Providing After Hours Care at Home service, while still using the services of the GP during daytime, or would allow the patient to be taken over completely by a palliative home care service. In many situations, the case manager from the palliative home care access centre assumes the role of care coordinator, and will act as a cohesive for the IH and OOH teams by ensuring that the patient has access to care at all hours of the day and night.⁵

(x) Anticipatory actions by IH S&GPC services to support the patient, carers, and OOH generalist and specialist teams

The Canadian Hospice Palliative Care Association encourages early integration of palliative principles within other healthcare, including early DNACPR and advanced care planning being organised.

This can be done in the very early stages of chronic or life-threatening illness, when the GP is referring the patient to other services. The GP must transfer all patient details to the new service which may open up an opportunity to discuss the advanced care plan.¹¹

(xi) Methods to maximise responsiveness by generalist and specialist OOH teams to patients and their carers, including technology (telephone, EHR, video link), triage, decision trees, preparedness, and home visits

Many provinces employ the use of telephone services in order to promote efficiency and to reduce the waste of hospital costs on patients who only require small treatments or advice that can be given over the telephone. These include tele-nursing by SPC nurses, who can provide expert advice which will help family caregivers determine whether their relative requires hospital care.⁵

In addition to this, a large amount of resources are available to patients online which can facilitate advance care planning, including webinars, a glossary of medical terminology, and aids for decision-making. These can reduce time spent attempting to introduce patients and families to the types and modes of palliative care, and allow the patient to examine all of their options and inform themselves before meeting their doctor in order to arrange the care.²

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Appendix 3.5 France

(i) Definition of OOH

According to the hours of the new OOH healthcare helpline, OOH is defined as after 8.00pm each weeknight to 8.00am, after 12.00pm on Saturday, and throughout the day on public holidays.¹

(ii) Target population for OOH or after-hours S&GPC services

Palliative care is extended to people of all ages with serious, progressive, life-threatening, advanced, or terminal disease.² These people may have been diagnosed with cancer, neurodegenerative disease, AIDS, or any other medical condition related to functional difficulty (e.g. cardiac, respiratory, renal), or a combination of several diseases.³ The Société Française d'Accompagnement et de Soins Palliatifs defines those towards whom palliative care is targeted as "The patient as a person, their family and friends, at home or in institutions".⁴

(iii) Composition of specialist and generalist teams

Patients with the most difficult or complex cases will generally go to Palliative Care Units (unité de soins palliatifs; USPs), which are hospitalisation facilities that are available for a limited period of time for palliative care patients in their last stage of life. These units employ individuals who have specialised in palliative care.⁵ They are 'centres of excellence' whose mission is to treat the most complex cases, to initiate research, and to participate in training.⁶

Mobile teams are multidisciplinary palliative specialist teams visiting patients within the community, including those in nursing homes. These teams assist generalist healthcare professionals with specialist palliative information and practices⁶ and are smaller than hospital units, comprising doctors, nurses, and sometimes a psychologist.

Palliative care beds in hospitals differ from USP beds as these are for patients who continue to undergo treatments in such as chemotherapy, and having these beds in hospital allows an information-sharing network to stay open, allowing all the patient's care to take place under the same roof.⁶

Palliative services at home require the presence of team members such as an attending physician, a nurse, a physiotherapist, a speech therapist, carers, etc. in the community, as well as family or friends acting as volunteers to assist with information sharing between these parties. Home services are often assisted by mobile palliative care teams.⁶

Palliative care networks coordinate all other structures in order to maintain the link between all the professionals who take care of the patient. The network actively participates in the home care of patients who wish to remain in their own homes during their palliative period.

Volunteers offer assistance to the patient, whether this is to assist with transmission of information to the relevant professionals or simply to offer a listening ear as a therapeutic presence. Volunteers would usually fall into an OOH category, as many also have office-hours day jobs.⁴

(iv) Roles and responsibilities of team members

Mobile teams are responsible for assisting the general healthcare team with the palliative care of the patient and their family at home and in nursing homes, including the management of pain and other symptoms, providing psychological and psychosocial support, transferring the patient to and from hospital facilities, and assisting family with education regarding palliative care. These teams assist generalist healthcare teams, as they have specialist palliative training and education.⁶ They assess and assist in community-based situations by providing counselling, training, and psychological support,⁷ but do not prescribe or handle the patient at all. That is left to the general health professional on the basis of the mobile unit's advice.

(v) Collaboration and information sharing between generalist and specialist OOH teams

France takes a patient-centred approach to palliative care that puts the patients and their families at the centre of care, and it is the responsibility of the multidisciplinary team members to take detailed notes and communicate effectively with each other in order to share information. This team includes doctors, nurses, caregivers, physiotherapists, social workers, psychologists, caregivers, volunteers, occupational therapists, speech therapists, and others depending on the specific needs of the patient.⁴

Mobile units share information with generalist teams by visiting, assessing, and advising these professionals, without prescribing anything to or handling the patient themselves. They advise on a treatment plan for the patient in their palliative period, including potential drug plans, therapy plans, and psychological treatment plans.⁶

(vi) Collaboration and information sharing between OOH teams and IH teams

The system in France attempts to get individuals that will require both IH and OOH care into facilities where all of their care can be provided under one roof, thus allowing easy transmission of information. In most other cases when this is not possible, a patient and their GP will contact a mobile palliative care team which will assist both doctor and patient in organising and planning the patient's palliative care plan in line with the patient's preferences.⁴

(vii) S&GPC collaboration process

A minority of palliative care patients are in USPs, which allow easy collaboration between generalist and specialist teams, as both generalist and specialist staff make up one multidisciplinary team. These units only cater to patients with the most complex and difficult conditions, as they generally need the most specialised care.

Cross-functional teams represent more than 80% of cases requiring specialised care. These are generally specialised teams that visit and advise generalist care teams and offer advice regarding treatment plans to be carried out by the generalist teams. Cross-functional teams are the most dominant structure in the palliative care sector in France.⁶

(viii) Additional training requirements for OOH specialist and generalist team members

All graduates of medicine from every medical school in France must complete a compulsory palliative medicine course as part of their degree.⁸ Palliative care units must have both doctors and nurses that have trained in palliative care. All staff on mobile palliative care units, whether doctors, nurses, or psychologists, must have specialised training in palliative care.⁹

France has also launched a MobiQual programme, which is a palliative care training tool aimed at professionals working in the mobile teams or hospice palliative care teams, as well as nurses and physicians. This initiative aims to disseminate knowledge in palliative care and EOL support in order to support quality in institutions.¹⁰

(ix) Methods to ensure information sharing between IH staff and OOH staff

GPs must write a certificate of acceptance to palliative care in order to allow the patient access to services, and must become involved in the process of information sharing with the organisation that supports the patient.¹¹

Within the interdisciplinary teams that take over the patient's care after this step, interdisciplinary meetings to discuss patients' cases should take place at least once per week in all care units.

Clinical case review meetings should also take place frequently between the various disciplines.¹²

(x) Anticipatory actions by IH S&GPC services to support the patient, carers, and OOH generalist and specialist teams

When a patient is admitted to hospital, the attending physician, pharmacist, and other home health and healthcare professionals are contacted.

When a patient is discharged from a hospital visit, ample documentation is supplied to the patient, their caregivers, and the services which will continue their care outside of the hospital setting, which will ease the transition and allow both patient and caregivers to anticipate rehospitalisation should aggravation or emergence of new symptoms occur.

A multidisciplinary liaison contact details sheet is given to the patient and caregiver, a post-hospital telephone call is expected, and a visit by the attending physician is scheduled within seven days after exit from hospital.¹³

(xi) Methods to maximise responsiveness by generalist and specialist OOH teams to patients and their carers, including technology (telephone, EHR, video link), triage, decision trees, preparedness, and home visits

France has recently published a ministerial decree governing the use of telemedicine for individuals with a range of mobility difficulties which inhibit access to hospitals and clinics, and therefore access to consultants and specialists. It will also be used for information and opinion exchange between health professionals, which may otherwise be impossible or inefficient in crisis situations.¹⁴

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Appendix 3.6 Germany

(i) Definition of OOH

In Germany, in accordance with an agreement between doctors and the Association of Statutory Health Insurance Physicians Hesse, OOH is considered to be from 7.00pm–7.00am on weekdays, in addition to all weekend and on public holidays.¹

(ii) Target population for OOH or after-hours S&GPC services

Generally, OOH palliative care is considered part of general palliative care which cares for “patients with life-threatening illness and their families.”² However, some specialist OOH care, such as specialist palliative home care (*Spezialisierte ambulante Palliativversorgung; SAPV*), targets the “incurably ill with complex symptoms”.²

(iii) Composition of specialist and generalist teams

- Inpatient hospices:
 - These hospices are full-time care facilities with hospice nurses and a multiprofessional team but no medical presence. Specialist palliative home care teams can also come into a hospice and look after patients there. Volunteers also support the hospice staff.
- Palliative care units:
 - These units exist within hospitals and are for patients with complex physical, psychosocial, and spiritual needs. The multidisciplinary teams in these units are led by a consultant for palliative medicine. Although all facilities from the hospital can be used, most palliative care units would not provide chemotherapy (although some do). The main aim of treatment is to discharge patients either to their home, to an inpatient hospice, or to a nursing home.
 - Approximately 15% of German hospitals have a palliative care unit.
- Outpatient hospice services:
 - Volunteers support patients and relatives at home or in the hospital, spend time with them, and provide night shifts, if necessary. They can also be part of a hospice inpatient team or a palliative care unit.
 - Volunteers are specially trained and are coordinated by a central coordinator of the hospice association/group.

- Specialist palliative home care teams:
 - Specialist palliative home care teams are available 24/7.
 - Specialist palliative home care was introduced by law in Germany in 2007.
 - The teams are made up of multidisciplinary specialists – palliative care doctors, nurses, social workers, administrators, psychologists (rarely), and chaplains (occasionally).
- Inpatient palliative care services:
 - These services comprise specialists within a hospital setting, similar to hospital support teams in the UK.
 - The services assist patients while they undergo treatments requiring hospital care in addition to palliative care and which may extend life, such as chemotherapy, radiation therapy etc.³

(iv) Roles and responsibilities of team members

- Inpatient hospices:
 - Nurses, both generalist and specialist, to provide physical care
 - Doctors, both generalist and specialist, to provide consultations and discuss EOL plans
 - Trained volunteers, to assist with both physical and emotional support
- Palliative care units:
 - These units comprise multidisciplinary teams of palliative medicine doctors, palliative nurses, social workers, psychologists, physiotherapists, chaplains, and occasionally other therapists.
- Outpatient hospice services:
 - Volunteers support patients and relatives at home or in the hospital, spend time with them, and provide night shifts, if necessary. They can also be part of a hospice inpatient team or a palliative care unit.
- Specialist palliative home care teams:
 - Specialist palliative home care teams are available 24/7.
 - A multidisciplinary specialist team (palliative care doctors, nurses, and social workers) provides a 24/7 on-call service, psychosocial support, and coordination of care in cooperation with the patient's own GP if at home or with their care team if they are in a nursing home.⁴

- Inpatient palliative care services:
 - A palliative care team in hospital can provide services either in conjunction with a unit or as a mobile team throughout the other hospital areas. Where there is no palliative care unit in a hospital, the hospital support team can still provide specialist palliative care.³
- Patient or carer phones nationwide OOH number (established in 2012):
 - Due to most GPs rarely undertaking home visits, this service is organised by the regional Associations of Statutory Health Insurance Physicians. A general number is called, and an operator diverts the caller to a number relevant to their region. The patient or caller can then seek advice from GPs, as well as specialists, and be triaged on the telephone in order to assess whether they need medical attention.⁵

(v) Collaboration and information sharing between generalist and specialist OOH teams

- Specialist palliative home care services or inpatient hospices stock opioids, but only for their own patients.
- Specialist palliative home care physicians may dispense opioids OOH for a patient who is under their care, if nearby on-call pharmacies do not have the appropriate medication available.³

(vi) Collaboration and information sharing between OOH teams and IH teams

- A patient's GP and a hospital doctor can prescribe the SAPV service, from which the patient can use up to 7 days of service. The SAPV will then visit patients in their homes both IH and OOH in order to administer care.²

(vii) S&GPC collaboration process

Palliative medicine specialists provide the on-call service for palliative care units and the hospital support team. They are responsible for the patients under their care but can also assist generalists with questions regarding patients in the generalist setting.

Specialist palliative home care teams provide 24/7 on-call service for their own patients, but not for patients who are not under their care.

GPs only occasionally provide on-call services for palliative patients, and this is normally more on an individual basis than as part of a larger scale service.

(viii) Additional training requirements for OOH specialist and generalist team members

Due to legislation, all universities awarding medical degrees in Germany are required to teach palliative care.⁶ Therefore, all doctors, whether generalist or specialist, will have basic knowledge regarding palliative care if they qualified in the period 2011–2018.⁷ In some universities, mandatory palliative care teaching was introduced earlier, but it has been mandatory since 2013.

Volunteers are required to take part in volunteer preparation training in order to work with palliative patients, which includes information on the implementation of hospice work and palliative care and case-related practice support.⁸

(ix) Methods to ensure information sharing between IH staff and OOH staff

GPs and hospital consulting doctors can ‘prescribe’ a specialist home care team, which provides both specialist and OOH care, for when the patient cannot access or does not wish to access hospital care or visit their GP.

(x) Anticipatory actions by IH S&GPC services to support the patient, carers, and OOH generalist and specialist teams

In addition to IH care, specialist palliative home care physicians keep stock of and may dispense opioids for patients under their care OOH in emergency situations, as these can be difficult to acquire OOH, with many pharmacies not holding stock of these drugs.

(xi) Methods to maximise responsiveness by generalist and specialist OOH teams to patients and their carers, including technology (telephone, EHR, video link), triage, decision trees, preparedness, and home visits

Prototypes of ambient assisted living technologies are being investigated and developed, but so far no fully operational market for active assisted living (AAL) applications exists, except for simple technologies such as emergency call systems for the home and audio/video communication for patients who have limited mobility.⁹

Currently, most services which require certain information from other health professionals provide their own PDF forms on their respective websites, which provide them with the information they require in order to treat patients effectively.

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Appendix 3.7 Iceland

(i) Definition of OOH

Weekdays outside of 8.00am–4.00pm, all weekend, and all public holidays.¹

(ii) Target population for OOH or after-hours S&GPC services

Palliative care in Iceland follows the goals that the World Health Organization has outlined in its definition, aimed at alleviating the suffering of those with life-limiting illness.²

There have been no official directives from the Icelandic Department of Health on standards of palliative care or the structure of palliative care services in Iceland, as found by the European Association for Palliative Care within their Atlas of Palliative Care;³ however, there is currently work in progress by the Icelandic Department of Health, which has started work on organising and defining palliative care service in the country.⁴ In 2015, the most common causes of death in Iceland were cancer, heart disease, and chronic lung disease, all of which require some level of palliative care service.

According to the European Association for Palliative Care (EAPC), 80–100 palliative care and hospice beds are needed per 1 million inhabitants. Iceland has a population of approximately 340,000,⁵ meaning that the number of beds needed is 28–35; currently, Iceland has 16 specialised palliative care beds.

(iii) Composition of specialist and generalist teams

OOH generalist teams include home nursing (referred to as HH) support for patients in the Hafnarfjörður, Garðabær, Reykjavík, and Kópavogur areas. HH administration offices are open from 8.00am–4.00pm and dispatches staff for regular visits to patients OOH, although this service would not be appropriate for emergency circumstances. It does, however, fall under the ‘OOH’ definition, as services are provided from 8.00am–11.00pm every day, resulting in the 4.00pm–11.00pm period being accessed by patients when IH services are closed.

Specialised palliative home care teams in the capital area and in the region of Akureyri service their patients 24/7. Difficulty arises in access for patients in rural areas, who may have to access emergency services or attempt to self-manage using the advice of palliative specialists, which can be accessed by phoning the local hospital or medical service provider.⁶

Other patients visit emergency departments of hospitals, where palliative advice and medication can be administered. A palliative care physician at the palliative care unit (which also dispatches palliative home care) of the university hospital is on duty 24/7 and takes calls from the whole country in order to give advice.

The medical service provider Læknavaktin operates outside of regular working hours, offering walk-in doctor service on weekdays from 5.00pm–11.30pm, on weekends from 9.00am–11.30pm, and on all public holidays, and offering home visits on weekdays from 5.00pm–11.30pm, on weekends from 8.00am–11.30pm, and on all public holidays. Phone service is available 24 hours per day, 365 days per year.⁷

There is also a facility for home nursing in the Mosfell district, where the Reykjavík Home Service, Heimaþjónusta Reykjavíkur, carries out evening, weekend, and night services; however, these are not palliative-specific services.⁶

(iv) Roles and responsibilities of team members

Home nursing (referred to as HH) supports patients in the Hafnarfjörður, Garðabær, and Kópavogur areas at home via pre-booked appointments and assisting with drug control, bathing, surgical treatment, specialised medication, and other services specific to the patients' needs between 8.00am and 11.00pm every day.

For more immediate care, OOH ambulance drivers for Læknavaktin operate on weekdays from 5.00pm–11.30pm, on weekends from 8.00am–11.30pm, and on all public holidays. Due to the difficult terrain and inaccessibility of much of rural Iceland, ambulance drivers must drive a special-purpose vehicle and have AMF (priority driving) rights from the State Police College.⁷

(v) Collaboration and information sharing between generalist and specialist OOH teams

There are no official directives from the Icelandic Department of Health on standards of palliative care or the structure of palliative care services in Iceland.⁴ As such, there is no direct protocol put in place for collaboration and information sharing between generalist and specialist teams. The home nursing service (HH) state that best attempts to collaborate with the patients' GPs are made via electronic shared-access records, in which doctors give an assessment of each patient's need for home help.

(vi) Collaboration and information sharing between OOH teams and IH teams

Some patients receive both IH and OOH care in the same facility; therefore, collaboration is made easy due to both teams working from the same files. The EHR system, which can be updated and amended by health services, assists in this collaboration process.⁸

(vii) S&GPC collaboration process

While there are no policies in place relating to care collaboration, generalist hospital teams will always have a palliative care specialist on duty – for example in the National University Hospital of Iceland’s palliative care unit – in addition to the home care team. Palliative care nurses are also on duty 24/7 in both services.⁹

Other services can call OOH specialist facilities in order to gain palliative knowledge so that they can offer their patients some form of palliative care when specialists are not available. This may include symptom and pain management, or advice on dealing with sensitive information and situations.⁴

(viii) Additional training requirements for OOH specialist and generalist team members

It has recently been noted that due to no formal palliative care education programmes being in place in Icelandic universities, the number of doctors and nurses specialising in palliative care in Iceland is severely lacking. Icelandic physicians can undertake the Nordic Specialist Course in Palliative Medicine if they wish to become specialist palliative care doctors.¹⁰ However due to lack of educational programmes, as of 2017, there is also only one nurse who is specially trained in palliative care in Iceland, having been trained in Canada.¹¹

(ix) Methods to ensure information sharing between IH staff and OOH staff

The HER moves with the patient through all health service, ensuring the patient only has one record rather than several records which exist only in the system of the service being utilised at the time.¹²

(x) Anticipatory actions by IH S&GPC services to support the patient, carers, and OOH generalist and specialist teams

Potential caregivers have access to education and training programmes which offer information on health promotion, pain management, and medication management, which allows them to assist in weaning patients off home nursing care and on to other caregivers as caregiving edexperience increases.¹³

In addition, EHRs are updated and amended to reflect current health status and treatments, and these move with the patient throughout their lifetime and across the health services they access.¹²

(xi) Methods to maximise responsiveness by generalist and specialist OOH teams to patients and their carers, including technology (telephone, EHR, video link), triage, decision trees, preparedness, and home visits

In addition to the EHR system (which can be updated and amended by health services to assist in this collaboration process),⁸ the National Pharmaceuticals Database is currently being integrated with this system, allowing for a medication management system to be implemented so that each patient's medication needs can be compared with the current stock and availability of their medication within the health service that they are using, as well as with stock locally.¹²

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Appendix 3.8 Ireland

(i) Definition of OOH

- Monday to Friday between 6.00pm and 8.00am, and all day and night on Saturdays, Sundays, and public holidays.¹

(ii) Target population for OOH or after-hours S&GPC services

- Anyone of any age with a life-limiting illness.²

(iii) Composition of specialist and generalist teams

Extensive OOH care exists in Ireland; however, there is insufficient collaboration between IH and OOH healthcare teams for the service to run at peak efficiency.

Irish palliative care is organised into three levels:

1. Level one – palliative care approach: the principles of palliative care are applied in a generalist setting, i.e. by GPs with no extensive palliative care training, volunteers, general nurses, and general care assistants.
2. Level two – generalist palliative care: healthcare professionals who, while broadly generalists, have had some additional training in palliative care.
3. Level three – specialist palliative care (SPC): palliative care specialists who put palliative care processes and services at the core of their functionality.²

Services are provided in:

- **The home** – by home care nurses, GPs, and/or mobile community palliative care team
- **Hospices** – by a multidisciplinary palliative care team including doctors, nurses, social workers, psychologists, occupational therapists, physiotherapists, and dieticians
- **Hospitals** – by the hospital's SPC team (as above) in cooperation with generalist staff; managed by a GP or consultant-led team,³ and
- **In nursing homes** – by palliative care specialist nurses in cooperation with generalist staff, and assisted by community care teams if needed.

Community care teams consist of GPs and practice nurses, a community nursing service, a public health nurse, a community registered nurse, an occupational therapist, and a physiotherapist, in addition to home care and other support staff.²

In addition to these central teams in each location, the Irish Hospice Foundation (IHF), in partnership with the Irish Cancer Society (ICS), provides 10 nights of night nursing for individuals that are imminently dying, in order to ensure that they are supported in their wish to pass away at home. Applications can be made for an extension of a further four days if needed.⁴

OOH services such as SouthDoc, DubDoc, and Caredoc operate a phone triage service provided by doctors, nurses, and home visit teams predominantly made up of nurses.⁵

(iv) Roles and responsibilities of team members

- Both hospital and community teams should provide education to people with life-limiting conditions, recognise common trajectories and manage pain and symptoms accordingly, offer support and advice to patients and families, and ensure that the patient's care plan is respected.
- OOH services such as SouthDoc, DubDoc, and Caredoc operate a phone triage service which may suffice in terms of service; however, if the patient or carer needs further assistance, they may advise the patient to come into the treatment centre if possible, or they may dispatch home visit services or emergency services.⁵
- The IHF, in partnership with the ICS, provides 10 nights of night nursing for individuals that are imminently dying, in order to ensure that they are supported in their wish to pass away at home. Applications can be made for an extension of a further four days if needed. Despite the ICS's involvement, this service is also available for individuals with conditions such as dementia, motor neurone disease, advanced respiratory disease, heart failure, and end-stage kidney disease.⁴
- Multidisciplinary palliative care teams in the community assist in education in their locality (whether that be for medical professionals, patients, or families), telephone queries, shared assessments, and taking part in joint case conferences.⁶

(v) Collaboration and information sharing between generalist and specialist OOH teams

- In addition to providing specialist care directly, specialist teams can collaborate with generalist care teams in order to assist them in providing palliative care, whether that be by accepting referrals or by being open to consultation and support in an advisory capacity.⁶
- In addition to responding to community cases, hospitals also have formal links with a local SPC service for purposes of referral, consultation and access, or an on-site specialist should community services be insufficient.
- Generalist and specialist teams will also collaborate in terms of ensuring that the patient's care plan is sufficiently described and disseminated among all relevant care providers in order to ensure that the individual's wishes are respected.
- Both teams may need to meet with the patient and family simultaneously in order to clarify their responsibility, roles, and function for the patient and their care.³
- Depending on the type of care the individual wishes to receive, the specialist team will generally report to the lead practitioner in the case (generally a GP if the patient is living at home), giving feedback and advice in relation to the care plan, which may need to be reviewed by the patient and family.⁷

(vi) Collaboration and information sharing between OOH teams and IH teams

- The GP to OOH Palliative Care Handover Project has developed an information transfer form for GPs, in anticipation that a patient will require OOH palliative care services. The form allows the transfer of relevant information pertaining to the patient (including their current medication, prognosis and knowledge regarding the prognosis, allergies, the patient's wishes regarding the circumstances of their palliative care, and the presence of a DNACPR [do not attempt cardiopulmonary resuscitation] Form) from the GP to the OOH service in order to assist in the patient's care.⁸

(vii) S&GPC collaboration process

- Collaboration of multidisciplinary teams in the community is focused around the patient and the value of their family as carers in line with *The National Carers' Strategy*.⁹

- Within inpatient care settings, multidisciplinary meetings should take place or, failing that, reports should be made to the most responsible physician, who will then communicate this information to other relevant parties.³
- Generalists within hospital settings are assisted in palliative care endeavours by SPC staff as part of the Hospice Friendly Hospitals Programme, which ensures that expert advice and guidance is provided to the general staff, and that hospital spaces are made suitable and comfortable for people at the EOL.¹⁰

(viii) Additional training requirements for OOH specialist and generalist team members

- Some Irish universities offer postgraduate certificates in Specialist Palliative Care Practice, Loss and Bereavement, and Loss and Bereavement Counselling, delivered in partnership with the other healthcare professionals within the palliative care discipline.¹¹ The IHF also offers a number of training workshops on different aspects of palliative care, including self-care in working with grief and loss, advance care planning, EOL care and communication, familial support, and delivering sensitive information.¹²
- Doctors can also specialise in palliative care by completing four years of Higher Specialist Training in Palliative Medicine on completion of their Basic Specialty Training in Medicine.¹³

(ix) Methods to ensure information sharing between IH staff and OOH staff

- It was recently suggested that as many as 82% of GPs in Ireland do not routinely transfer patient information to the OOH service when requesting palliative care assistance; however, 96% of GPs would welcome a standardised method of information sharing,¹⁴ prompting the development of OOH handover projects. The GP → Out-of-hours Palliative Care Handover Form is a one-page form which addresses information required to ensure patient safety and efficient information sharing for both easy reference and increased response time and accuracy. Having this comprehensive patient record allows for both efficient information transfer and reference in emergency situations, which is more likely to result in the patient's wishes being respected, less risk to the patient due to knowledge regarding allergies and medications, and sensitivity being ensured regarding the patient's and their family's knowledge regarding their prognosis.⁸

- Information sharing also occurs through regular multidisciplinary meetings within all forms of care, as well as through regular reporting of information to the most responsible physician, who will disseminate an overview to all relevant parties. This is generally the patient's consultant in a hospital setting or their GP in a community setting.³

(x) Anticipatory actions by IH S&GPC services to support the patient, carers, and OOH generalist and specialist teams

- GPs, social workers, and unbiased online resources, such as Family Carers Ireland, provide advance care planning support, including explanation of the Assisted Decision-Making (Capacity) Act 2015,¹⁵ in relation to the patient's medical decisions and preferred care methods and locations.
- Family Carers Ireland operates a Careline, which offers support and advice during the day and is taken over by Samaritans Ireland to offer support at night-time. This advice, however, is not medical, but rather provides more emotional and practical support for carers.¹⁶
- Trained cancer nurses operate a Cancer Nurseline where people with cancer or their families and carers can access information or advice. It is a 9.00am–5.00pm weekday service, but can provide valuable information that will support both the patient and carer and assist them in acting independently during OOH periods.¹⁷
- IH specialists will ideally have completed the GP → Out-of-hours Palliative Care Handover Form, or a similar document, outlining important information which can be easily shared with other care teams, carers, and the patients themselves for efficient information transfer.

(xi) Methods to maximise responsiveness by generalist and specialist OOH teams to patients and their carers, including technology (telephone, EHR, video link), triage, decision trees, preparedness, and home visits

- GP → Out-of-hours Palliative Care Handover Form – easy access to information regarding patients' allergies and medications, the presence of a DNACPR Form, and the patient's wishes.⁸
- eHealth projects are currently being piloted by the Department of Health, including eprescribing, case management, and easy information sharing, which have been suggested to work efficiently in the

UK.¹⁰

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Appendix 3.9 Italy

(i) Definition of OOH

OOH counts as any time between 8.00pm and 8.00am on weekdays, from 10.00am on Saturday to 8.00am on Monday, and public holidays, as well as from 8.00am to 8.00pm on days when GPs are attending continuing education courses.¹

(ii) Target population for OOH or after-hours S&GPC services

Italy's palliative care system provides care for those who have incurable illnesses and therefore require short-term EOL care, and for those who are terminally ill but who have more extended life expectancies.²

(iii) Composition of specialist and generalist teams

Of the 60,000 doctors in Italy, 12,000 physicians work during OOH periods from 2,952 OOH service delivery points.¹

Care Continuity Physicians (CCPs) take over from general practitioners in the community by working at night-time, evenings, and weekends. Of the 60,000 doctors in Italy, 14,000 are OOH physicians.³

Home palliative care units (HPCUs) are multidisciplinary teams including specialist and generalist doctors and nurses, rehabilitation specialists, psychologists/psychotherapists, and social workers. Medical assistance from these units is available 24 hours a day.⁴

(iv) Roles and responsibilities of team members

CCPs offer basic GP services in the community during OOH periods, including basic symptom management, as well as the organisation of specialist care.

Generalist teams, whether within community clinics, GPs, or hospitals, look after aspects of palliative care that include essential services such as general symptom management, health promotion, and coordination of specialist services.

Specialist teams (which include palliative specialists, as well as oncologists, cardiologists, nutritionists, psychologists, etc.) are generally contacted by generalist care coordinators to give certain specialised aspects of care to patients.

HPCUs, which comprise both specialist and generalist doctors and nurses, have their generalist doctors and nurses deliver basic interventions and check-ups, while their specialist staff take care of more complex processes, such as overseeing pain and symptom management and collaborating with and advising generalist staff.²

(v) Collaboration and information sharing between generalist and specialist OOH teams

HPCU teams rely on collaboration between their specialist and generalist staff in order to deliver the most efficient and responsive level of care. While generalist staff can assist with basic interventions, they rely on the care plans that specialist teams have drawn up in order to administer the correct care plan, the development of which has been informed by the patient.⁵

(vi) Collaboration and information sharing between OOH teams and IH teams

While there is no national information sharing policy as of yet, recent legislation indicates the introduction of a new patient e-record which will make the process of information sharing between all teams more efficient.

This will contain details regarding:

prescriptions, reservations, medical records, health checks, previous care, location of care, diagnosis and treatment plans, semi-residential care, vaccinations, medical certificates, participation in clinical trials, prosthetic assistance, data to support the activities of telemonitoring, and data to support the activities of the integrated management of diagnostic and therapeutic treatment.⁵

(vii) S&GPC collaboration process

Italian versions of the Supportive and Palliative Care Indicators Tool and the *Necesidades Paliativas* (Palliative Needs; NECPAL) CCOMS-ICO[®] Tool are now available; these instruments can assist generalists in identifying patients who will require a palliative care approach or specialist assistance, but they are not yet rolled out nationally. Generalist caregivers can, however, use the support of palliative specialist units for advice on supporting palliative patients in the community.⁶

(viii) Additional training requirements for OOH specialist and generalist team members

Palliative Medicine is an autonomous medical discipline officially recognised by Italian law, but not yet recognised as a specialty. Several master's degrees for physicians, nurses, and psychologists are regularly

organised by Italian universities. The Italian Society of General Medicine (Società Italiana di Medicina Generale e delle Cure Primarie; SIMG) organises residential courses (50 hours) dedicated to “GPs with special interest in Palliative Care”.⁷ Between 2016 and 2018, 120 GPs participated in these courses.⁷

(ix) Methods to ensure information sharing between IH staff and OOH staff

No formal methods exist, but the introduction of the patient e-record will allow patients to give access to their health record to all IH and OOH care teams in addition to any other relevant care professionals who may need access.⁵

(x) Anticipatory actions by IH S&GPC services to support the patient, carers, and OOH generalist and specialist teams

Specialist palliative care teams offer education, skill building, cognitive behavioural therapy, environmental modifications, and stress management in anticipation of stressful periods which may inhibit caregiver abilities.⁸

(xi) Methods to maximise responsiveness by generalist and specialist OOH teams to patients and their carers, including technology (telephone, EHR, video link), triage, decision trees, preparedness, and home visits

While there is no policy relating to eHealth systems in place, if patients and caregivers wish to use an eHealth system, specialist teams will assist in claiming reimbursement for electronic health technology, including assistive technology.⁸

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Appendix 3.10 Japan

(i) Definition of OOH

Weekdays from 5.00pm to 9.00am, and 24 hours per day at weekends and national holidays.¹

(ii) Target population for OOH or after-hours S&GPC services

Japan does not have a long history of palliative care practices, but with one in three people in Japan forecasted to be over age 65 by 2030, Japan has had to begin quickly and extensively planning for the new era of long life expectancy.² Japan has a very oncology-focused palliative care service, with few palliative care units accepting non-cancer patients.³ This may be a result of 32% of Japanese deaths being attributed to cancer, which has been the leading cause of death since 1981.⁴ Many palliative care units also consider cancer pain nurses to be akin to palliative care nurses, which potentially results in a lack of adequate care for those who have other chronic conditions.⁵ Palliative care for end-stage heart failure, which is a primary target for palliative care in most other countries examined in this report, was only being investigated and treated as a palliative condition in Japan as recently as 2018.⁶

(iii) Composition of specialist and generalist teams

Palliative care units (PCUs) are standalone units with a combination of healthcare professionals, but must have at least one full-time doctor who has completed palliative care training, as well as several palliative care nurses available at all times, including OOH.

Palliative care teams exist within hospitals that do not have PCUs, and must have one full-time palliative care doctor, one or more full-time nurses, and at least one psychiatrist.³

Home care services and regional palliative care resources teams are made up of a combination of physicians, nurses, pharmacists, medical social workers, psychologists, rehabilitation therapists, nutritionists, and physiotherapists.

In order to be classed as a reimbursable palliative care service from Japan's national medical insurance, the palliative care team must include a full-time doctor, a full-time psychologist, a full-time palliative care nurse, and a pharmacist with training in palliative care.⁷ Specialised home care support clinics are expected to provide 24-hour home care by a multidisciplinary team for a wide range of patients in the community.

(iv) Roles and responsibilities of team members

- Specialists such as cancer pain nurses, palliative care nurses, and palliative care physicians work as part of PCUs, specialised home care units, and hospital palliative care consultation teams.
 - Hospital teams use these teams primarily for consultation in how to administer care for palliative patients, whereas in PCUs, these specialists administer the care themselves.
 - Full-time doctors in both services are the point of contact with the family and patient; nurses and specialist doctors will discuss any information that requires communication with the patient and their family with this primary point of contact in order to ensure clarity and ease of communication.⁷
- The Palliative Care Emphasis Program on Symptom Management and Assessment for Continuous Medical Education (PEACE) Project involves 1,298 trainers in palliative medicine and 544 trainers in psycho-oncology, and has trained 30,000 physicians.⁵

(v) Collaboration and information sharing between generalist and specialist OOH teams

- Doctors are the point of contact for all services, whether the primary doctor is the GP or the hospital consultant. Different organisations have differing policies on information sharing between teams.⁵

(vi) Collaboration and information sharing between OOH teams and IH teams

- Japan does not have traditional family GPs as Ireland or similar cultures do. Instead, local clinics exist which have many doctors serving the community. These IH doctors refer patients on to local PCUs or to hospitals with palliative care teams.⁸
- Palliative care teams in all services, however, can contact the local PCU in order to seek advice and support regarding a patient, or to request that palliative care specialists are dispatched to another location in an emergency.⁸
- Most teams will report to one primary physician who will pass any relevant information on to the OOH primary point of contact, and vice versa, in order to ensure efficiency and clarity of information transfer.⁵

(vii) S&GPC collaboration process

- Specialists in both hospitals and PCUs will report to one central physician who is responsible for sharing information with the patient and their family.⁹
- The PCU should ensure 24-hour availability to community services, hospitals, and care homes so that generalist care services can collaborate with specialists in order to either access valuable advice or to dispatch specialists for emergency consultations.⁸
- Palliative care teams support generalist doctors and nurses within hospitals, both assisting with pain and symptom management and providing active training.⁸

(viii) Additional training requirements for OOH specialist and generalist team members

- All medical schools provide palliative care lectures for all medical students.⁸
- Physicians can take part in the Palliative Care Emphasis Program on Symptom Management and Assessment for Continuous Medical Education (PEACE) Project, which is a two-day interactive course that discusses end-of-life care.¹⁰
- There is also a Japanese version of the End-of-Life Nursing Education Consortium (ELNEC) palliative nursing education programme, called ELNEC-J, which trains nurses in the specialisation of palliative care.⁸
- The Orange Balloon Project provides information about palliative care to the general public and volunteers.⁵

(ix) Methods to ensure information sharing between IH staff and OOH staff

- Many services are self-organised. GPs and support services contact each other of their own volition, but there is no official system in place. This is due to the fact that there is no GP system and that Japan provides free access to care.⁵
- Only 10% of palliative patients pass away at home, and 10% pass away in palliative care homes, with the remaining 80% passing away in hospitals. Due to each hospital having its own information sharing system, made up of electronic patient files, continuity of care is better facilitated when patients are seen by one constantly rotating and collaborating care team.⁵

(x) Anticipatory actions by IH S&GPC services to support the patient, carers, and OOH generalist and specialist teams

- Due to the high number of palliative patients passing away within hospitals, many hospitals have prepared a palliative care manual in the hospital, drawn up in collaboration with palliative care specialists, which will allow generalist staff to give an improved standard of palliative care in the absence of a palliative care specialist.¹¹

(xi) Methods to maximise responsiveness by generalist and specialist OOH teams to patients and their carers, including technology (telephone, EHR, video link), triage, decision trees, preparedness, and home visits

- eHealth systems are currently being utilised by more than 100 local government institutions in Japan. Their primary functions are to transmit users' health-related data, such as blood pressure, oxygen tension, and ECG results, to medical institutions via the Internet. This is particularly useful for patients in remote locations.¹²

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Appendix 3.11 Norway

(i) Definition of OOH

Hours outside of daytime general practice, namely Monday to Friday before 8.00am and after 3.00pm, and all day Saturday, Sunday, and public holidays.¹

(ii) Target population for OOH or after-hours S&GPC services

Any patient whose disease is not responsive to curative treatment (Norwegian Association for Palliative Medicine, 2004). Approximately 95% of the palliative patient population in Norway comprises people with incurable and terminal cancer and 5% of this population has other conditions, predominantly neurodegenerative conditions.²

(iii) Composition of specialist and generalist teams

Generalist teams may be made up of generalist nurses, doctors, physiotherapists, nutritionists, and psychologists.

Specialist groups will include surgeons, oncologists, anaesthesiologists, and palliative specialists.³

(iv) Roles and responsibilities of team members

Generalist: Generalist services include general home healthcare services including nurses, doctors and healthcare assistants, in addition to GPs, and hospital staff without palliative training.

Specialist care: Dedicated palliative care units with specialised trained staff are available to patients, which include outpatient clinics specialised in oncology, neurodegenerative, and palliative care. At least one physician and one nurse in each municipality should have palliative care expertise and be available to guide general care providers.²

(v) Collaboration and information sharing between generalist and specialist OOH teams

All patients availing of OOH care will have a shared-access medical record, which will be available to the patient and to any healthcare professional seeing to the individual. The record will contain contacts for the patient's next of kin, GP, hospital consultant from previous visits, and home care nurse. It will also contain

details of the patient's medication requirements and dosage, in addition to details of their previous doctor and hospital visits and an Edmonton Symptom Assessment System (ESAS) form, which outlines the patient's symptoms.⁴

(vi) Collaboration and information sharing between OOH teams and IH teams

Norway employs shared-access records, which will be open to all healthcare providers attending to the patient, with the patient's consent. This record will include an ESAS form (describing the patient's condition and symptoms), phone numbers for both family members and relevant healthcare professionals, and details of their medication list.⁵

(vii) S&GPC collaboration process

The Norwegian Association for Palliative Medicine states that palliative care units in hospitals and nursing homes should be available to provide advice and guidance on a 24-hour basis in order to get specialist information to generalist practitioners. Patients who will require a more coordinated treatment plan with more specialists involved in the process should have an individual and detailed report.⁵ This should be introduced by the palliative care team and kept updated by each specialist. This report should include a list of representatives from each specialised area, and details on who should be contacted during OOH periods. In addition, the plan should have details on medication, symptoms, the patient's wishes for their care, and contact details for their next of kin. This may be very useful, particularly for OOH staff that may not be able to contact the patient's primary physician outside of regular working hours.⁵

(viii) Additional training requirements for OOH specialist and generalist team members

All graduates of medicine from every medical school in Norway will have completed a compulsory palliative medicine component as part of their degree.⁶

Since 2010, GPs can take an additional course in order to gain a palliative specialty, which is run and recognised by the Norwegian Directorate of Health. Postgraduate courses are also available to those who have completed previous training as nurses, physiotherapists, and social workers.⁶

(ix) Methods to ensure information sharing between IH staff and OOH staff

Information sharing between IH and OOH staff should be eased by the organisation of a 'continuous treatment chain', which can work in two ways:

- If the patient is hospitalised as a result of an incident or diagnosis, the palliative care treatment plan should begin with joint meetings prior to discharge from hospital or nursing home, where the care team on referral to the palliative unit speaks to the new carers, whether they be home assistance or hospice carers, in order to establish the patient's history, symptoms, and needs.⁶
- If the patient wishes to stay at home, the simplest route for information sharing between IH and OOH staff would be the employment of an individual patient record which, with the patient's consent, can be shared among any healthcare professionals that will be assisting the patient through their palliative period. The palliative care team should take the initiative to establish this record in conjunction with the patient and their family.⁶

(x) Anticipatory actions by IH S&GPC services to support the patient, carers, and OOH generalist and specialist teams

Healthcare professionals are expected to assist the patient with the formation of the individualised care plan, which is available to both the patient and to other health professionals, and which can be updated with information relevant to the patient including their medication treatment plan, information on past medical history, symptoms, and details regarding their preferred care plan.⁶

(xi) Methods to maximise responsiveness by generalist and specialist OOH teams to patients and their carers, including technology (telephone, EHR, video link), triage, decision trees, preparedness, and home visits

Norway utilises e-records, which can be accessed by the patient and their relevant caregivers and health service professionals. This record will include an ESAS form (describing the patient's condition and symptoms), phone numbers for both family and relevant healthcare professionals, and details of the patient's medication list.⁶

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Appendix 3.12 Poland

(i) Definition of OOH

In Poland, according to the Polish National Health Fund, OOH care is provided after 6.00pm and before 8.00am on weekdays, and 24 hours per day on non-working days such as weekends and public holidays.¹

(ii) Target population for OOH or after-hours S&GPC services

OOH palliative care in Poland is for patients with specific incurable diseases which are progressive and life limiting. Diseases that qualify for palliative care in Poland include various cancers, as well AIDS, neurodegenerative disease, and lung and heart disease. However, between 90% and 95% of palliative care services are offered to oncological patients.² Poland's first palliative care services outside of clinical settings began in 1993 with the introduction of home care. The supports appear to be insufficient, with a recent European Association for Palliative Care (EAPC) post indicating that Poland needs four times the amount of palliative care beds it currently has, resulting in many patients dying while waiting for admission. Up to 10% of patients still have to seek palliative care on their own without any support from their doctors, and those who are referred are usually in the very advanced stages of their disease, only accessing care the very end of the palliative period.³

(iii) Composition of specialist and generalist teams

Most palliative care in Poland is delivered via 'home hospice' services, which are specialised palliative home care teams consisting of doctors, nurses, medical caregivers, psychologists, social workers, physiotherapists, chaplains, and volunteers.⁴

There are also palliative care units in hospices, or hospital units of palliative medicine, which offer around-the-clock service to patients, allowing them access to both generalist and specialist healthcare. These consist of a multidisciplinary team of people, including doctors, nurses, physiotherapists, and a psychologist.

Within outpatient clinics, however, most activity occurs within working hours, as they are only open one evening per week outside normal working hours.

(iv) Roles and responsibilities of team members

Home hospice allows patients to access healthcare services provided by a nurse or doctor 24 hours per day, seven days per week, in addition to prearranged doctor and nurse visits at least twice per week, or more often

if needed. Specialist staff appointments, both IH and OOH, are arranged by the primary physician. Doctors and nurses visit at pre-planned times within regular working hours, in addition to during OOH periods, to examine patients. The patient also has around-the-clock access to services provided by a doctor and nurse in cases of urgent need. Home hospice services will also provide patients with equipment such as oxygen apparatus, home modifications, a walking frame, crutches, or a wheelchair.⁵

Generalist healthcare staff in home hospice, stationary hospice, and palliative care hospital units offer services such as physical examinations, prescribing medicines, providing the necessary diagnostic tests, and referrals on to specialists, including those providing palliative and hospice care in a stationary or home setting, including oncologists or neurological specialists if relevant.¹

Palliative specialists have the ability to offer pharmacological treatment, pain management, psychological care for the patient and their family, rehabilitation, and the use of specialised medical equipment.⁶

(v) Collaboration and information sharing between generalist and specialist OOH teams

Home hospices have administrators and coordinators in the office, which patients can call to set up appointments or in case of emergency. These administrators will keep note of the patient's details and forthcoming appointments so that specialist and generalist teams can refer to these when needed.

Each patient in stationary hospice and hospital settings will have detailed files which can be easily referred to.⁵

(vi) Collaboration and information sharing between OOH teams and IH teams

Organisations will have differing policies on the collaboration of teams, however it is generally up to the primary physician to ensure records are robust enough to ensure adequate continuity of care.⁵

(vii) S&GPC collaboration process

Information sharing should occur within all care settings in the form of multidisciplinary meetings and regular reporting of information to the patient's GP, in addition to the patient and caregivers. No formal system of disseminating this information is in place as of yet; however, it is suggested that all services keep detailed and regularly updated files.⁵

(viii) Additional training requirements for OOH specialist and generalist team members

In order to work in palliative care units, doctors must have carried out the specialisation course in palliative medicine.⁷ Palliative postgraduate specialisation was introduced for doctors and nurses in 1999.⁸ Nurses need to have worked with palliative care patients for two years in order to work in one of these units, and in order to be specialised they must have a two-year course qualification in nursing in palliative care.⁵

(ix) Methods to ensure information sharing between IH staff and OOH staff

All palliative care hospital units and hospices must have a documentation system in place that must include patient registry, medical documentation, nursing documentation, and other documentation including complaints and applications by the patient.¹

(x) Anticipatory actions by IH S&GPC services to support the patient, carers, and OOH generalist and specialist teams

In order to prepare for emergency situations or anticipate mobility issues, home hospice services will provide patients with equipment such as oxygen apparatus, home modifications, a walking frame, crutches, or a wheelchair.⁵

(xi) Methods to maximise responsiveness by generalist and specialist OOH teams to patients and their carers, including technology (telephone, EHR, video link), triage, decision trees, preparedness, and home visits

Patients also have access to telephone consultation 24 hours per day, which provides information for palliative care patients, carers, and health professionals; provides psychological support for people experiencing anxiety or fear; assists with symptom management, including pain relief; refers callers to other service providers when needed; and assists with appropriate crisis intervention.⁶

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Appendix 3.13 Sweden

(i) Definition of OOH

Any time outside of 9.00am–5.00pm weekday office hours.¹

(ii) Target population for OOH or after-hours S&GPC services

According to the Swedish *National Care Programme for Palliative Care in the End of Life (Palliativ vård i livets slutskede: Nationellt vårdprogram)*, the target populations for OOH or after-hours S&GPC services are both patients and families suffering from problems that may occur as a result of life-threatening (non-curable) disease.²

Despite Sweden's palliative care guidelines being anchored within the regional cancer centres, they apply to the care of all affected patients regardless of their condition and are not exclusively for patients with cancerous diseases.

(iii) Composition of specialist and generalist teams

Sweden has very few palliative specialist care teams throughout a large and sparsely populated country. As such, most palliative care responsibilities are taken care of by local GPs and district nurses, with advice from specialist teams via telephone and email, or sometimes home visits. There are limited resources for community care. Patients can also take up residential care in a hospice, or a palliative care unit in a hospital if they require continued specialised care for their particular condition.³

(iv) Roles and responsibilities of team members

Once a patient is identified as having become a palliative patient, they are first evaluated by a multidisciplinary team comprising doctors, nurses, psychologists, social workers, and volunteers,⁴ who identify the patient's level of need and their cognitive ability to make EOL decisions independently, and who also inform patients of who will be looking after certain aspects of their care going forward and provide their contact details.

A patient will then be referred to a palliative care programme, depending on their wishes, which could be a home hospice facility, a stationary hospice, or a palliative care unit in a hospital if they require continued specialised care for their particular condition.

Once the patient is set up with their preferred team, the healthcare professionals will take on more applied roles.

Doctors will evaluate patient needs and ensure that the patient has access to equipment as needed, investigate the need for symptom relief and for psychological and spiritual support, investigate the relatives' needs, and investigate the patient's wishes for how they want to be cared for in their final stages of life. Nursing staff will evaluate the patient's nursing needs, including specialised dietary needs, pain management needs, mobility issues, and the introduction of mobility assistive equipment.⁴

(v) Collaboration and information sharing between generalist and specialist OOH teams

Once a patient is registered for palliative care, a doctor and nurse specialised in palliative care will draw up a care plan in close collaboration with the patient and their family. It should contain a description of what should occur throughout the palliative process as requested by the patient and advised by medical professionals.⁵

(vi) Collaboration and information sharing between OOH teams and IH teams

The Swedish National Care Programme for Palliative Care in the End of Life requires thorough information transfer when referring patients to any other form of care from the current one, be that to a different palliative care unit, home hospice mobile units, specialists, or a hospice. This report should contain a current drug list, a summary of the patient's relevant medical history, allergies, and the patient's specialised wishes regarding their religion, e.g. certain religions do not allow blood transfusion. It should also contain the patient's end-of-life wishes and their next-of-kin details. Unlike other countries' patient information reports, Sweden recommends that the report also include non-clinical details; for example, it must state what information the patient and their family have received thus far, and how they reacted to this information.⁶

(vii) S&GPC collaboration process

In densely populated areas, all home care is linked to inpatient units with 24-hour admission and advisory services for home-care patients. Due to the many sparsely populated areas of Sweden, specialists are required to have tight collaboration with local care professionals, such as GPs and district nurses, who can call in order to gain knowledge and advice on how to act in emergency situations.⁵

(viii) Additional training requirements for OOH specialist and generalist team members

While palliative care in Sweden has only become a trained profession since 1998, textbooks on palliative care and related areas have recently been published to support medical courses. Swedish nursing schools provide

specialist training courses in palliative nursing. Palliative medicine courses also began in the Linköping University in 1997 and in the Karolinska Institute in Stockholm in 2000.⁵ Volunteers can access training courses in universities and hospitals across the country.⁷

(ix) Methods to ensure information sharing between IH staff and OOH staff

Swedish hospital units generally use a structured system of documenting EOL care within the patient's regular medical records, comprised of three stages: one for the occasion when a physician documents a decision to shift treatment and care to EOL care; one for daily assessments after that decision; and one for notes regarding the death of the patient. This is regularly updated and used by both IH and OOH teams, as well as by all specialist and generalist teams attending to the patient.⁶

(x) Anticipatory actions by IH S&GPC services to support the patient, carers, and OOH generalist and specialist teams

In sparsely populated areas of Sweden, there may be no OOH services at all, with local GPs on call until 9.00pm, but otherwise with only the emergency room to offer OOH care. As such, anticipatory prescribing is a key feature of Swedish palliative care, centred around the local district nurse, who can prescribe and educate patients and caregivers on the use of opioids and other symptom management drugs.¹

(xi) Methods to maximise responsiveness by generalist and specialist OOH teams to patients and their carers, including technology (telephone, EHR, video link), triage, decision trees, preparedness, and home visits

In sparsely populated areas, Swedish specialised palliative home care teams will occasionally do home visits within a radius of 250 kilometres, but otherwise rely on communication between specialist and local generalist services in order to provide palliative care.¹

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Appendix 3.14 Switzerland

(i) Definition of OOH

OOH periods in Switzerland are generally accepted as being between 7.00pm and 7.00am on weekdays, all day on weekends, and all day on public holidays.¹

(ii) Target population for OOH or after-hours S&GPC services

Patients who are dealing with the EOL in a proactive way or who have reached the final phase of their life due to the progression of their incurable, life-threatening, and/or chronically progressive disease. Despite more than 73% of Swiss palliative patients expressing the wish to pass away at home, a recent study has indicated that nearly 80% of deaths occur in clinical inpatient settings, which suggests that the majority of patients are having their proposed care plans unfulfilled due to resource unavailability.²

(iii) Composition of specialist and generalist teams

Switzerland has a palliative care system which is predominantly focused on oncology patients. All services within the palliative care system, whether in hospitals, nursing homes, hospices, or at home, are covered by mandatory health insurance. The only factors preventing patients from accessing these services are referral from a GP, acceptance from an admission authority, or overpopulated services.³

Switzerland uses acuteness of illness to determine which service should be used. Within Switzerland, the palliative care services that exist include:

- **Hospital** palliative inpatient services for acutely ill patients for short-term palliative periods and unstable patients. Team members include general doctors, general nurses, specialist palliative nurses, specialist consultants such as oncologists, and psychologists.
- Long-term inpatient services, such as **nursing homes**, for stable patients at the beginning of slow progressing disease trajectories. Team members include general doctors, general nurses, social workers, pastoral care workers, psychologists, and rehabilitation specialists.
- **Inpatient hospice** care for relatively stable patients at varying stages of their disease trajectories. Team members include specialist doctors, specialist nurses, general nurses, social workers, pastoral care workers, psychologists, and rehabilitation specialists.

- **Outpatient clinics** for individuals who are remaining at home for their palliative period. Team members include care assistants, general doctors, general nurses, specialist nurses, specialist doctors, social workers, pastoral care workers, psychologists, and rehabilitation specialists.
- **Mobile health services** for those who are remaining at home and cannot access outpatient services. Team members include care coordinators, administrators, general doctors, general nurses, specialist nurses, specialist doctors, social workers, pastoral care workers, psychologists, and rehabilitation specialists.
- Other teams include OOH **telephone services** which function between 7.00pm and 7.00am the following day and which provide telephone triage and can dispatch emergency services if needed. In addition to this, groups of GPs will ensure that one GP will be available between 10.00pm and 7.00am, and will generally have an additional GP on standby if the demand for the service exceeds the capabilities of one doctor.¹

(iv) Roles and responsibilities of team members

- Team members within hospital palliative care units will most likely be delivering care to the most acutely ill patients on the disease trajectory. They will be required to stabilise patients and often carry out basic care due to patients being acutely ill at the point of referral to this form of care. Specific responsibilities of care include clarification of the patient's proposed care wishes, clarification of specialist and generalist care plans in order to prioritise quality of life, preparation of the patient to return home or preparation of the patient for the dying process, assistance with difficult decision-making, psychological and spiritual support for the patient, and support of the family.⁴
- Hospice care teams look after patients who are less acutely ill but who are in the advanced stages of their disease trajectory, at which point curative treatment has ceased. Therefore, treatment mainly consists of pain management and quality-of-life improving therapies; however, hospice care takes a much more holistic approach to care, with medicine and treatment being only one sector of a multidisciplinary treatment plan. Pastoral and spiritual care, in addition to psychological support for both patient and family, is a central component of hospice care.

- Nursing homes in Switzerland aim to care for the less acutely ill patients with a more holistic approach, with less focus on medicine and treatment than in a hospital setting, as patients in nursing home settings are generally more stable.⁵

(v) Collaboration and information sharing between generalist and specialist OOH teams

All care teams, no matter the context, should keep advanced and shared reports on each patient, which should be free from abbreviations and complex language that cannot be understood by everyone on a multidisciplinary team, and which should include comprehensive details on not only the patient's physical symptoms and treatments, but also on any discussions regarding treatment, any significant relatives assisting the patient, and the patient's emotional and spiritual well-being.⁶

(vi) Collaboration and information sharing between OOH teams and IH teams

- Very recently, Switzerland has begun to introduce the *Elektronisches Patientendossier* (Electronic Patient Dossier; EPD), which is an inter-institutional exchange platform for patient data containing all information necessary for efficient communication, including any data that have arisen from administration, consultation, diagnosis, prescription, referral, therapy, monitoring, and insurance.³
- It is generally advised that a full report, as mentioned above, should be passed from the current care-providing team to the future care-providing team.⁶

(vii) S&GPC collaboration process

- Generally, GPs or generalist hospital physicians will assist the patient in accessing their preferred and most appropriate mode of specialist care. Most specialist facilities and services will require a referral from a GP in order to allow the patient to access the services.
- The EPD patient register which is a form of electronic patient record.³

(viii) Additional training requirements for OOH specialist and generalist team members

- Since 2008, it has become mandatory that all medical facilities must have staff with specialised or advanced competency in palliative care, who will assist in the development of lectures and courses for other generalist staff.

- In some areas, such as Vaud and Ticino, university courses in palliative care are provided; in other areas, however, such as Lucerne, palliative care education is mainly gained through practice settings such as in hospices and clinics, or is provided by non-profit organisations.⁷

(ix) Methods to ensure information sharing between IH staff and OOH staff

- Communication portals tend to rely on the individuals strategies of the care network members. There are no policies which explicitly state what format communications should take, which can cause issues between community care organisations and hospitals.⁸
- Hospices and inpatient services will generally have a self-monitored, thorough report-based system which all staff can consult in order to treat the patient most efficiently.
- In all other systems, a reference person will need to be nominated, which will generally be the patient's GP.⁵
- The adoption of the electronic patient record – the EPD patient register.

(x) Anticipatory actions by IH S&GPC services to support the patient, carers, and OOH generalist and specialist teams

- The use of the EPD patient register allows for much more efficient information transfer in an emergency and allows for anticipatory actions to be more sufficiently planned and shared.³

(xi) Methods to maximise responsiveness by generalist and specialist OOH teams to patients and their carers, including technology (telephone, EHR, video link), triage, decision trees, preparedness, and home visits

- Many technological devices exist in Switzerland to assist and facilitate home care and to ensure the safety of the patient, including personal alarm systems and assistive technologies.³
- The EPD patient register allows any member of a multidisciplinary team to prepare for a visit with a patient, which will save time that they can use seeing to the patient rather than attempting to establish their background and disease status.³

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Appendix 3.15 United Kingdom

(i) Definition of OOH

OOH in the UK varies from beginning between 4.00pm and 6.30pm, and ending between 8.00am and 9.30am depending on the service,¹ and 24 hours on weekends and public holidays.²

(ii) Target population for OOH or after-hours S&GPC services

Many supports exist for patients with cancer; however, patients with illnesses other than cancer are restricted in terms of the organisations that provide supplemental care.³

(iii) Composition of specialist and generalist teams

Generalist teams consist of GPs, hospital doctors, nurses, and district nurses.⁴ Specialist palliative care (SPC) multidisciplinary teams include physiotherapists, occupational therapists, social workers, spiritual and psychological services, bereavement support, dieticians, speech and language therapists, pharmacists, and pain management specialists.⁵ Some facilities, for example those which are specific to certain illnesses, may have more specialised services such as lymphoedema services, complementary and comfort therapies, and creative therapies.⁵

Health professional teams within hospices consist of doctors, nurses, occupational therapists, physiotherapists, social workers, support staff, managers, psychological support staff, and volunteers.⁶

Community SPC refers to teams of palliative care clinical nurse specialists with palliative medicine specialist support. These services offer hands-on nursing care to complement the statutory district nursing service and the usual advisory role of the palliative care clinical nurse specialist.⁵

(iv) Roles and responsibilities of team members

Inpatient hospices

Inpatient hospices attempt to assist patients with pain and symptom control, psychological and social support, practical and financial advice, physical rehabilitation, and bereavement support for families.⁷

Hospital SPC teams

Hospitals with cancer units require palliative consultants plus a specialist nurse.⁷

Community SPC teams

Community SPC refers to teams of palliative care clinical nurse specialists with palliative medicine specialist support. They can visit patients in their own homes, as well as provide telephone advice.⁵

Outpatient clinics

Outpatient clinics are best suited to those patients who are still capable of travelling but require a professional or specialist intervention such as pain management, social work interventions, physiotherapy, or specialist nursing.^{7 8}

Hospice at home

In addition to district nurses, who provide care in the home, specialised palliative care nurses and a palliative care specialist support and complement this service. Each community (approximately 200,000 residents) should have a full-time consultant in palliative medicine, three specialist nurses, a social worker, a physiotherapist, and an occupational therapist available to the patients for one session per week.⁷ Community care aims to manage pain and symptoms, provide specialist rehabilitation, provide psychological and emotional support, and offer training and support with self-management.⁹

(v) Collaboration and information sharing between generalist and specialist OOH teams

Collaboration and continuity of care are made more efficient by the Key Information Summary (KIS) outlined in the Scottish Palliative Care Guidelines. This is an online record which can be accessed by members of the community care team such as GPs, district nurses, and all providers of OOH and emergency care. While the record is a general medical record and can be used for non-palliative patients requiring OOH care, there is a portion of the record entirely dedicated to palliative practices and the patient's care plan.¹⁰

(vi) Collaboration and information sharing between OOH teams and IH teams

The KIS is useful for this form of collaboration, allowing all members of IH and OOH care teams to access the information regarding the patient, such as relevant party contact details, medication, allergies, desired care plans, and detailed information entered by specialists such as cardiologists and oncologists. The patient may also consent to enter their position regarding a DNACPR (do not attempt cardiopulmonary resuscitation) form.¹⁰

(vii) S&GPC collaboration process

Generalist ambulance services, such as the North East Ambulance Service NHS Foundation Trust, have hired palliative care specialists to equip paramedics and ambulance staff with the specialist palliative training in order to ensure that the wishes of palliative patients are respected and that they receive specialist care.¹¹

(viii) Additional training requirements for OOH specialist and generalist team members

All graduates of medicine from every medical school in the UK will have completed a compulsory palliative medicine course as part of their degree.¹² In addition to the supplement to generalist training, the Royal College of Physicians has implemented specialist palliative medical training which has been regulated through the Joint Committee on Higher Medical Training. Palliative specialised nursing in the UK is a four-year programme consisting of at least two years' experience in a specialist service placement, in addition to one year of research placement and one year in a medical specialisation such as oncology or cardiology.¹³

(ix) Methods to ensure information sharing between IH staff and OOH staff

Palliative care in the home is generally coordinated by district nurses.¹⁴ A regularly updated Palliative Care Handover Form is kept with the district nursing home of any patient who is accessing community care services. All other patients not utilising home services are generally in inpatient facilities and will benefit from the internal reporting systems of the hospice, hospital, or care home.

The Cancer Network Information System Cymru (CaNISC) in Wales is an online specialist palliative care patient record which can be shared by all health professionals attending to the palliative patient.¹⁵

(x) Anticipatory actions by IH S&GPC services to support the patient, carers, and OOH generalist and specialist teams

Ambulatory services, such as Care UK and Local Care Direct, dispense anticipatory medication through the NHS, 24 hours a day, 365 days a year.

Staff within hospices and palliative care specialists in the community train both caregivers and patients in clinical skills, as well as empowering them to make their own informed choices regarding their care. Doctors have often also begun anticipatory prescribing, which is designed to ensure that there is a supply of drugs in the patient's home in case of emergency.¹⁶

(xi) Methods to maximise responsiveness by generalist and specialist OOH teams to patients and their carers, including technology (telephone, EHR, video link), triage, decision trees, preparedness, and home visits

The CaNISC in Wales is an online specialist palliative care patient record which can be shared by all health professionals attending to the palliative patient.¹⁵ Telehealth also allows the hospital palliative care specialist to communicate efficiently and directly with the patient, their caregivers, and the home hospice team within the home, which allows for effective and non-disruptive continuation of care for a patient who may have mobility difficulties.¹⁷

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Appendix 3.16 United States of America

(i) Definition of out-of-hours

Monday to Friday between 17:00 and 8:00, all day Saturday and Sunday, and public holidays. ¹

(ii) Target population for out-of-hours or after-hours specialist and generalist palliative care services

America adopts the World Health Organisation's definition of individuals with palliative care needs ², specifically "patients and their families facing the problem associated with life-threatening illness, ...with pain and other problems, physical, psychosocial and spiritual". ³

(iii) Composition of specialist and generalist teams

While teams vary in terms of specialisation depending on the needs of the patients, most teams follow the Kaiser model, which suggests that the interdisciplinary care team should consist of a physician, an advanced practice nurse, a social worker, and a chaplain. ³

Specialisation is in three tiers in the USA:

Primary palliative care is delivered by healthcare professionals who are not palliative care specialists, such as GPs or district health nurses.⁴ This includes generalist hospital teams and general community teams.

Secondary palliative care is delivered by specialised teams at specialised programs or inpatient units. These teams will provide specialist palliative care or serve as consultants to a primary team, helping GPs, district and night nurses administer as pain management, social support and advanced care planning. ⁵ These teams include palliative home care and hospice inpatient units.

Tertiary palliative care is delivered by specialised teams with expertise in advanced pain and symptom management, such as "implantable intraspinal drug-delivery systems for pain, palliative sedation, or advanced delirium management". ³ Many of these teams do not work out-of-hours, but often deliver training to primary and secondary healthcare teams in order to perform out-of-hours services.

(iv) Roles and responsibilities of team members:

In America, most palliative care is provided within hospice facilities, with limited home-based and nursing home care. Interdisciplinary teams providing specialist-level palliative care to patients with acute and life-limiting illness mainly exist within hospitals. ⁶

Multidisciplinary teams in hospices carry out medical and nursing services, social work, religious and spiritual support with chaplaincy, and bereavement support to family members. ⁴

Hospital palliative care consists of two separate teams, interdisciplinary consultation teams and inpatient units. Interdisciplinary consultation teams do not work during out-of-hours periods generally, but may offer advice and support to generalist staff in order to provide a higher quality of palliative care for particular patients during out-of-hours periods. Inpatient units are usually exclusively for patients with unmanageable symptoms or medical needs that require particular equipment or specialisms to control.⁷

Home based care consists of interdisciplinary teams providing palliative care directly or providing consultation to treating physicians. This interdisciplinary home care can be provided through hospitals, hospices and home health agencies.⁸

(v) Collaboration and information sharing between generalist and specialist out-of-hours teams

Specialist out-of-hours teams within hospitals, home health agencies and hospices support out-of-hours generalist teams by offering consultation and advice relating to symptom assessment, spiritual assessment, effective sensitive information communication, and discussion of advance care planning.⁵

Use of electronic health records are also efficiently used in some states of America but this is not rolled out nationally, and is up to the policy of the state, such as Washington, who use this record keeping system across palliative caregiving services including hospitals and hospices.⁹

(vi) Collaboration and information sharing between out-of-hours teams and normal hours teams

Primary physicians both in- and out-of-hours, generally will provide a handover relating to the patient within inpatient services to their respective counterpart physician, and transmit information relating to the patient to home-care services within home care settings.¹⁰ There is no nationwide formal policy on information sharing however some states and districts use e-health systems and other forms of handover forms in order to efficiently transmit information.

(vii) Specialist and generalist palliative care collaboration process

Within hospices and hospitals, interdisciplinary meetings frequently take place which ensures efficient information sharing between all parties of the care team.

In hospices, the team is supervised by the hospice director and the medical director, and different registered nurses, who will be the case managers for different patients, will coordinate and implement care plans. These meetings review new admissions, changes in care, deaths, and to review current patients.¹¹

Generalists rely on secondary palliative care specialists for advice on complex or difficult problems, which can be gained by calling hospice, hospitals or home-based palliative care services who will offer support out of hours. ⁵

(viii) Additional training requirements for out-of-hours specialist and generalist team members

Palliative and end-of-life care training is a component of all medical courses in most U.S. nursing and medical schools. ¹² Certain universities have entire faculties dedicated to training palliative healthcare professionals, including the California State University, who offer training from The Institute for Palliative Care. These professional development programs are designed to ensure health care professionals, whether doctors, nurses, pharmacists, physician assistants, chaplains, or social workers, can undertake extra training on advanced care planning, ethnically and culturally sensitive palliative care, communication skills, motivational interviewing, polypharmacy and self-care. ¹³

(ix) Methods to ensure information sharing between in-hours staff and after-hours staff

Most communication systems rely on a primary physician both in- and out-of-hours that can provide a handover relating to the patient within inpatient services, and transmit information relating to the patient to home-care services within home care settings. ¹⁰

Electronic health records exist within some states such as Washington, but in other states no formal system is in place. ⁹

(x) Anticipatory actions by in-hours specialist and generalist palliative care services to support the patient, carers and out-of-hours generalist and specialist teams

Healthcare professionals will regularly give anticipatory guidance relating to the final days of life to patients and caregivers, relating to pain and symptom management and information in relation to the breathing pattern that may seem unsettling to caregivers. Anticipatory prescribing for nausea and pain is also regularly provided. ¹⁴

Social workers will also assist in advising patients and caregivers on planning for their passing with advice relating to the will and end-of-life arrangements. Anxiety reducing techniques are also often taught to patients and caregivers in order to manage the last days of life and cope in emergency situations. ¹⁵

(xi) Methods to maximise responsiveness by generalist and specialist out-of-hours teams to patients and their carers including technology (telephone, EHR, videolink), triage, decision trees, preparedness, and home visits.

Patients and caregivers will be assisted by healthcare teams in order to develop and implement an end-of-life plan which can be uploaded to electronic health records should the state in which they are resident have these systems. Patients and caregivers can also be supported with the use of telephone counselling and triage and visits by multidisciplinary community services, written materials about grieving, and support groups. ¹⁶

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