Victorian Integrated Cancer Services

Palliative Care and Advance Care Planning: Current Practices in Victorian Cancer Services project

A summary report

VICS January 2023





Victorian Integrated Cancer Services

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Authorship

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This report was developed by Geraldine Largey, Southern Melbourne Integrated Cancer Service (SMICS).

Acknowledgement

Barwon South-West Regional Integrated Cancer Service (BSWRICS), who led the Palliative Care and Advance Care Planning Study.

Key messages

This summary report presents the findings from the Palliative Care and Advance Care Planning: Current Practices of the Victorian Health Services project undertaken by the Victorian Integrated Cancer Services in 2020–21. It includes recommendations to improve the access and timeliness of palliative care for cancer patients and recommendations to improve participation in and documentation of advance care planning (ACP).

- 95.8% (n = 9813) of cancer patients (N = 10,245) required one or more admitted episodes of care in the last 12 months of life.
- 65.7% (n = 6727) of cancer patients (N = 10,245) received an inpatient palliative care consultation or a palliative care approach to care during admission.
- 84.6% (n = 5692) of patients (N = 6728) did not receive their first inpatient palliative care within the recommended timeframe (longer than three months before death).
- 11.7% (n = 742) of patients (N = 6325) had documented evidence of an advance care directive (ACD).
- 10.1% (n = 639) had evidence (N = 6325) of a medical treatment decision-maker (MTDM) alert.
- 62% (n = 45) of Victorian health services surveyed (N = 73) did not have a dedicated ACP workforce.
- Referral to palliative care occurred late, either following disease progression or cessation of active treatment.
- The introduction of specialist palliative care was not always consistent with the optimal care pathways (OCP) guidance.
- There was a significant variation in the timeliness of palliative care referrals.
- Limited access to specialist palliative care in rural areas led to delays in access to symptom relief and more prolonged intervals between optimal interventions.
- The preferred place of death was not achieved for many patients.

Summary

The Palliative Care and Advance Care Planning: Current Practices in Victorian Cancer Services project aimed to understand current practices relating to palliative care referral and advance care planning (ACP) in Victoria. Timely completion of ACP and receipt of palliative care both deliver proven benefits to people with metastatic/advanced cancer. Accordingly, they are priorities of the *Victorian Cancer Plan 2020–2024*. The project was funded by the Victorian Integrated Cancer Services (VICS).

The project consisted of four components:

- a palliative care literature review and an ACP literature review
- a study of patterns of end-of-life care (N = 10,245) to comprehensively understand the care for those who died from cancer across public and private hospitals and outpatient community-based care in Victoria between 1 July 2018 and 30 June 2019
- a qualitative review of medical records (N = 34) to examine the end-of-life care of patients with cancer who died in hospital
- analysis of ACP in 73 health services operating 132 public and private hospitals to identify data-based gaps.

Program of work outcomes

Literature review

An extensive review of the palliative care and ACP literature was completed.

Study of patterns of end-of-life care

This study aimed to understand access to palliative care and the factors associated with providing timely palliative care to people (N = 10,245) who died from cancer in Victoria between 1 July 2018 and 30 June 2019. The study also aimed to identify and describe the proportion of patients receiving care in a hospital who had an advance care directive (ACD) or medical treatment decision-maker (MTDM) documented and to describe the factors associated with the completion of one or both documents. Information relating to the existence of an ACD and/or MTDM was available only for those patients receiving care while admitted to a public hospital.

Most of the patient cohort (N = 10,145) were male (55.1%, n = 5640) and born in an English-speaking country (73.5%, n = 7528). A total of 38.7% (n = 3891) lived outside a metropolitan area. The following findings relate to the use of health services, the provision/timing of palliative care and documentation of ACD in the last 12 months of life.

Use of health services in the last 12 months of life

- 95.8% (n = 9813) of patients (N = 10,245) required at least one hospital admission
- Patients received a median of six admitted episodes (interquartile range [IQR], 3–13)
- 66.7% (n = 6827) of patients died in an acute or palliative care bed in a hospital

Receipt of palliative care in the last 12 months of life

• 65.7% (n = 6727) of patients (N = 10,245) received an inpatient palliative care consultation or a palliative care approach to care during admission

- 38.4% (n = 3935) required specialist palliative care or a hospice bed during their illness
- 8.2% (n = 825) received direct contact from a community palliative care service

Timing of access to palliative care

- The median time from the first inpatient palliative care episode to death was 20 days (IQR 7–55)
- 15.4% (n = 1036) of patients (N = 6728) received timely inpatient care (defined as longer than three months before death)
- 45.2% (n = 3142) of those who died in a hospital (N = 6952) first accessed inpatient palliative care in the admission during which they died
- 29.9% (n = 979) of those who died in a palliative care bed (N = 3274) had a length of stay of three days or fewer

Documentation of ACD/MTDM alert

- 11.7% (n = 742) of patients (N = 6325) had documented evidence of an ACD
- 10.1% (n = 639) had evidence of an MTDM alert
- The median time from the date of the first documented ACD to death was 88.5 days (IQR 30–234)

Qualitative review of medical records

This study sample ⁱ (N=34) aimed to explore the end-of-life care of patients with cancer who died in one of four hospitals (one large metropolitan hospital, one small rural hospital and two regional hospitals) in Victoria, focusing on factors relating to referral to palliative care.

Twenty-four percent (n = 8) of the records audited had evidence of an ACP discussion, while 21% (n = 7) had evidence of a patient completed ACD. There was significant variation in the time from the first episode of palliative care to death, ranging from 25 to 231 mean days. Thematic analysis revealed referral to palliative care often occurred late, either following disease progression or after active treatment ended. The limited access to specialist palliative care evident in rural areas led, at times, to delays in accessing symptom relief and more prolonged intervals than desired between optimal patient interventions. The rural community palliative care clinical nurse consultant (CPC-CNC) supported the care of the palliative care patients by providing advice/education on symptom management to hospital medical officers (HMOs) and nursing staff as required.

Analysis of gaps in ACP

This study aimed to analyse ACP systems, processes and documentation in health services (N = 73) across Victoria and identify ACP implementation gaps so appropriate recommendations could be constructed to address the problems identified. It found that 29% (n = 21) of health services had an ACP medical lead. A total of 38% (n = 28) of health services had a dedicated ACP workforce. Of these, 46% (n = 13) reported that ACP

A lack of access to paper-based medical records during COVID-19 resulted in limited access to ACP data and the inability to conduct the planned statewide audit of medical records.

responsibilities formed part of a broader role, while verbatim comments indicated it was not a routine part of optimal care. Most (66-90%, n = 44-66) health services reported their ACP policy, procedures or guidelines contained the appropriate content, while 85% (n = 62) reported their ACD template was consistent with the Victorian ACD template.

Introduction

There are opportunities to address variations in the timing of access to palliative care and ACP practices. Local variation among cancer services (e.g. limited access to specialist palliative care in rural areas) and within the Integrated Cancer Service (ICS) regions, such as days between palliative care referral and death, will prioritise recommendations and the work of the VICS. VICS will work with cancer services and other stakeholders to identify which of the following recommendations will be prioritised for implementation, locally or statewide.

Recommendations

Study of	patterns of end-of-life care
Timing o	f access to palliative care and ACP
Rec 1	Patients of metastatic/advanced cancer receive a timely referral to specialist palliative care (defined as at least three months before death) alongside or in addition to the usual care
Rec 2	Patients with metastatic/advanced cancer have access to and are given the opportunity to undertake ACP early in their pathway of care
Rec 3	Patients with metastatic/advanced cancer are given the opportunity to document their preferences for care in an ACD and/or to appoint an MTDM
Collectio	n and storage of data
Rec 4	Include data items specific to hospital-based consultancy palliative care in the population-wide Victorian Admitted Episodes Dataset (VAED)
Rec 5	Strengthen the data collection around community and ambulant/outpatient palliative care recorded in the Victorian Integrated Non-Admitted Health (VINAH) dataset to enable future capture of all settings of palliative care provision and allow for more complete benchmarking over time in and across sectors
Rec 6	Advocate to expand outpatient palliative care services to improve access to early palliative care and ensure this activity is recorded reliably
Qualitat	ve review of medical records
Promotic	n of palliative care services
Rec 7	(a) Promote to health services/professionals delivering cancer care that palliative care services are as essential in treating metastatic/advanced cancer as other disciplines and should be provided concurrently with other cancer treatments
	(b) Encourage more palliative care teams to participate in multidisciplinary meetings (MDMs) to represent a ready and reliable way of highlighting the need for palliative care referral
Rec 8	(a) Disseminate information about palliative care education programs within the cancer sector to heighten awareness of and access to palliative care education
	(b) Promote early palliative intervention so clinicians may consider timely referral of all patients with advanced/metastatic cancer to specialist palliative care

ACP proc	esses, models of care and research and quality improvement activities
Rec 9	Health services develop rigorous processes (to meet the statutory record-keeping requirements of the Medical Treatment Planning and Decisions Act 2016 that will enable them to identify if a person has an ACD on admission and ensure the documentation is uploaded into the medical record
Rec 10	Review existing palliative care models in rural and regional areas to identify ways to improve patient access to specialist palliative care support (e.g. expanding access using telemedicine)
Rec 11	Explore community and outpatient palliative care models and undertake quality improvement activities to reduce hospital admissions for end-of-life care and achieve more proactive and anticipated palliative care in the home
Analysis	of gaps in ACP
Rec 12	Health services that treat patients over the age of 65 and look after patients with cancer and chronic illnesses have dedicated EFT to offer them Advance Care Planning
Rec 13	The cancer workforce of each health service includes ACP leaders, champions and/or trained staff in their allocated EFT
Rec 14	(a) Health services implement specific processes to record the details of a patient's MTDM in the medical records and make it easy for clinicians to access those details(b) Health services have processes to ensure the MTDM field is captured on admission
Rec 15	Clinicians receive regular and routine ACP education using the readily available resources such as Advance Care Planning Australia's Learning Hub, face-to-face training and train the trainer for health professionals and ACP webinars available from Cancer Council Victoria
Rec 16	All Victorian health services have policies, procedures and guidelines that include the necessary ACP information content and standardised consumer information, and ensure their ACD consumer information aligns with the Victorian template
Rec 17	All Victorian ACD forms follow the Victorian ACD template
Rec 18	Hospital patient administration systems (PAS) include a field for MTDM

Recommended targets

The project's steering committee recommended the following palliative care and ACP targets (along with current levels for each indicator) for achievement within three years (Table 1).

Table 1: Recommended targets

Indicator	Current		Target
	N	%	
Specialist palliative care accessedii	10,245	65.7%	≥ 80%
Specialist palliative care accessed ≥ 3 months before death	6728	15.4%	≥ 80%
Access to an ACP intervention (e.g. conversation and information)			100%
Timing of ACP intervention ≥ 12 months before death			100%
ACD documentation (current data – public hospitals only)	6325	11.7%	≥ 40%
Identification of the MTDM	6325	10.1%	100%

Conclusion

The Palliative Care and Advance Care Planning: Current Practices in Victorian Cancer Services project identified variation in ACP and palliative care from optimal care for those who died from cancer in Victoria. The review of ACP practices (via medical record audit) showed a lack of planning for future medical treatment decisions and a low prevalence of ACDs in health records. Palliative care was often provided late in the trajectory of care. Few patients received timely inpatient palliative care, and patients received a median of six inpatient episodes of care in the last 12 months of life.

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Specialist palliative care was deemed to have been provided if one of the following occurred: (1) use of the palliative care or hospice bed, where the patient was principally under the care of a specialist inpatient palliative care service, (2) the patient received an inpatient consultation or a palliative care approach to care from an alternative hospital care team with consultation from the specialist hospital-based palliative care service as appropriate, and (3) use of the community palliative care service was also noted (where available) for services that reported patient access into the VINAH dataset.

Section 1: Project overview

Background

Palliative care and advance care planning are important elements of optimal end-of-life care.

Traditionally, access to palliative care was only enabled once cancer therapies had ceased. Current evidence, however, suggests that concurrent and integrated palliative care with routine oncology care significantly enhances people's quality of life and mood. It also lessens the need for aggressive end-of-life care and extends survival time.^{1–3} Research shows that those who die from cancer have higher healthcare costs than those who die from any other cause. Also, 40% of those costs are expended in the last month of life.⁴ Hui and colleagues found that palliative care referral that occurred earlier than three months before death was linked to fewer emergency department (ED) visits, fewer hospitalisations and fewer hospital deaths.⁵ Moreover, starting palliative care early is linked to improved quality of life and reduced symptom intensity in cancer patients.⁶

Advance care planning (ACP) is the process of planning for future health and personal care whereby a person's values, beliefs and preferences are communicated early. This guides clinical decision making at a future time when that person cannot communicate their treatment decisions.⁷ The goal of ACP is to align the care a person receives with their care preferences. In 2017, a national study reported that only 27% of people with a cancer diagnosis had documented their ACP preferences in an Advance Care Directive (ACD).⁸ The role of ACP as an essential component of optimal care in the oncology population is increasingly acknowledged in Australian policy documents.^{9–11} ACP has several improved outcomes at end of life including:

- reduced hospitalisation
- increased likelihood that the person will die in their preferred setting
- reduced stress, anxiety and depression for surviving loved ones. 12-16

The Palliative Care and Advance Care Planning: Current Practices in Victorian Cancer Services project began in March 2020, aiming to:

- understand current practices relating to palliative care referral and ACP in Victoria
- identify ways to reduce unwarranted variation in care
- improve the quality of services provided to all Victorians with metastatic/advanced cancer.

The overarching aims and objectives of the project are described below.

Aims

- To document the current patterns, timing and circumstances of palliative care accessed by patients with advanced/metastatic cancer and to recommend appropriate responses to any identified gaps in care
- To document the current ACP practices and consider appropriate responses to gaps identified

Objectives

- To define, collect, collate, analyse and report on data required to achieve the project's aims
- To explore and summarise relevant work already undertaken in this area by reviewing available literature on projects
- To clarify definitions for key terminology in the OCP and promote these to the cancer sector (palliative care, specialist palliative care, timely referral and appropriate referral)
- To determine and report the proportion of cancer patients who have:
 - o discussions (documented and non-documented) about ACP
 - o an advance care directive (ACD) in place
 - accessed palliative care
- To determine and articulate to the palliative care and ACP planning sectors the role of Victorian Integrated Cancer Services (VICS) in supporting improvements to palliative care and ACP
- To increase the understanding of palliative care and ACP among VICS
- To determine whether a stage 2 (implementation stage) is necessary and within the scope of VICS and to provide advice on potential projects and all the steps required to identify these

The project had four distinct components. The specific aim and objectives of each of the four study components are described in Table 2.

Table 2: Study component aims and objectives

Aim	Objectives		
1. Palliative care literature review a	nd ACP literature review		
Examine and report the evidence relating to PCACP in the cancer setting.	 Describe the literature relating to palliative care focusing on current international best practice, evidence about the timing of palliative care referral, and barriers to timely and appropriate palliative care intervention. 		
	 Examine Australian primary studies reporting on ACP in people with cancer to better understand the efficacy of ACP in this population, including any barriers and facilitators to uptake. 		
2. Study of patterns of end-of-life ca	ire		
Document patterns of palliative care and ACP to provide a comprehensive understanding of care for all people who died from	 Identify and describe the proportion of patients who accessed palliative care and the timing of this access and identify and describe the factors associated with providing timely palliative care. 		
metastatic/advanced cancer in Victoria between 1 July 2018 and 30 June 2019.	Identify and describe the proportion of patients receiving care in the public hospital system who had an ACD and/or Medical Treatment Decision Maker (MTDM) documented, and describe the factors associated with completing one or both documents.		
3. Qualitative review of medical records			

Aim	Objectives
Explore the end-of-life care of patients with cancer who died in hospital, focusing on the care processes and decision making for referral to palliative care.	 Describe the experiences of patients considered 'palliative care concerns' and how they were addressed. Identify the date of the first palliative care consultation in relation to the patient's date of death Map the patterns of care for the last three months of life, including contextual factors surrounding: engagement (or lack of engagement) in palliative care services and critical decision making related to treatment and care. Compare patterns of care related to palliative care referral and intervention to those specified in the Optimal Care Pathway (OCP).¹⁰
4. Analysis of gaps in ACP	
Analyse ACP systems, processes and documentation (e.g. policy, forms) in cancer services across Victoria.	 Identify ACP implementation needs and gaps in cancer services across Victoria. Provide data to inform project recommendations.

Governance

The governing bodies and roles involved in the project's governance and the reporting lines are outlined in Figure 1.

Department of Health (DH) Cancer Support Treatment and Research (funder and policy direction) VICS Network Group (budget allocation, risk escalation, executive) Project Steering Group (expertise, leadership, promotion and solution) Lead ICS Barwon South West Region Integrated Cancer Service (project sponsor) Project Manager ICS Project Officers x 8 (local communication, resources, stakeholder engagement, reporting and facilitating local collaboration) (project management, communication, stakeholder engagement, reporting and consultation)

Figure 1: Governing bodies, roles and reporting lines

Scope

Inclusions

Adult cancer patients receiving care in public and private Victorian health services.
 Notably, the scope varied slightly for each component of this project.

Example: Study of patterns of end-of-life care

- Information relating to the existence of ACD/MTDM was available only for patients receiving care while admitted to a public hospital.
- Information about the community palliative care service was noted (where available) only for services that reported patient access to the VINAH dataset.

Exclusions

- Non-cancer patients referred for palliative care or ACP intervention.
- Processes (e.g. procedures, methods, routes) for the providing palliative care.
- Patients under 18 years of age and services provided to this population.

Methodology

A mixed methods approach to this project was adopted. Each study component had a distinct methodological approach.

Literature reviews

Two separate literature reviews were conducted. A review of the literature relating to palliative care was conducted as part of this project **(Appendix 1)**.

A review of the literature relating to ACP for people with cancer was conducted by <u>Advance Care Planning Australia</u>. A copy of the literature review report can be obtained from the senior author <u>Linda.Nolte@austin.org.au</u> or first author <u>Helena.Rodi@austin.org.au</u>.

Study of patterns of end-of-life care

This study used a retrospective, population-based, cohort design study to examine statewide patterns of end-of-life care for Victorians who died from cancer between 1 July 2018 and 30 June 2019. The study team included clinicians and researchers from the palliative care and cancer fields. The project's steering committee included sector representation and provided expert opinion and guidance to the project as a whole. Institutional ethics approval was provided by the St Vincent's Hospital Human Resource Ethics Committee (LRR 221/20).

The study population (n = 10,245) was identified from the Victorian Cancer Registry (VCR). It included all unique adult cases (18+ years) with a cancer-related cause of death and a death occurring within the specified study timeframe. It used existing hospital health service databases containing information routinely collected: specifically, the identified cohort's linked data relating to inpatient health service and ED use in the 12 months before death. Information collected included:

- the nature of the patient's illness
- procedures coded after each admitted episode
- the use of health services across all public and private hospitals and outpatient/community-based care in Victoria.

Using linked data, the study aimed to understand the access to and timing of palliative care and the prevalence of ACD documentation. Notably, information about the existence of ACP and MTDM was collected only for those patients receiving care while admitted to a public hospital. Consequently, the proportion of patients with these variables was corrected to reflect this sample subset only. Information about a community palliative care service was noted (where available) only for services that reported patient care to the VINAH dataset.

The linked data was provided by the Centre for Victorian Data Linkage, Department of Health, Victoria. Information was captured with inherent quality control methods and strict criteria outlined in data dictionaries provided by the data custodians. This ensured high data completeness and minimised missing data. Data sources included the VCR, the Victorian Death Index, VAED, the Victorian Emergency Minimum Dataset and VINAH data. Data reporting was consistent with the REporting of studies Conducted using Observational Routinely collected health Data (RECORD) statement. A range of socio-demographic, clinical characteristics and health service characteristics data was collected and coded from the information in the VCR and VAED data sources.

Data analyses were performed using Stata version 15.1 (Stata Corp, College Station, Texas, United States of America). Descriptive statistics were used to describe the study population

and summarise the outcome variables of interest. The postcode of the patient's primary residence was used to classify the Index of Relative Socioeconomic Disadvantage (IRSD), remoteness as defined by the Australian Statistical Geographical Standard¹⁸ and to identify the ICS region the patient lived in.

Qualitative review of medical records

The records of a subset of all adults who died from cancer between 1 July 2018 and 30 June 2019 were randomly selected (every third medical record) from four hospitals in Victoria (one large metropolitan hospital, one small rural hospital and two regional hospitals). Specifically, patients who were 18 years or older at the time of their death and who met the inclusion criteria below were selected. A total of 35 medical records were chosen. One patient with myelodysplasia was excluded. The remaining 34 records were included in the audit.

Inclusion criteria for case selection was:

- had a primary cancer diagnosis
- received care for cancer at a participating hospital site
- died from cancer within the specified study timeframe
- had been an inpatient when they died
- had their primary residence in Victoria.

Data was extracted to examine the factors determining the palliative care provided to patients who died from metastatic/advanced cancer and any ACP event that occurred in the three months before death. Data was sourced from the patient's hospital electronic medical records and community-based records such as domiciliary palliative care (where available). Relevant information about the referral to palliative care was collected. All extracted data was entered into a customised case report form (**Appendix 2**) that collected health information for the three months preceding the patient's death and health information at the time of referral to palliative care if referral occurred more than three months before death. All information was collected, stored and used in accordance with the *Privacy and Data Protection Act 2014* and the *Health Records Act 2001*.

Management of patient data was in line with the *National Statement on Ethical Conduct in Human Research* 2007 (updated 2018) and the *Australian Code for Responsible Conduct of Research* 2018.

Analysis of gaps in ACP

The analysis of gaps in ACP aimed to analyse ACP systems, processes and documentation in cancer services across Victoria. A gap analysis survey (**Appendix 3**) specific to this study (based on a framework obtained from Advance Care Planning Australia) was developed. Only health services that had a memorandum of understanding with an ICS and provided cancer care and/or end-of-life care were included. Eighty-six health services were invited to take part. Seventy-three health services operating 132 public and private hospitals were included in the survey. Health services with more than one hospital campus were listed as one participant and completed one survey. Each ICS assigned a project manager to conduct face-to-face interviews with the appropriate clinician in each health service between November 2020 and January 2021. Clinicians who could not take part in a face-to-face interview completed a written survey. Respondents were asked to provide:

- general information about the health service
- information about the health service's ACP staffing

 information about the content of the health service's ACP policies, procedures and guidelines.

Data collected was entered into the survey in REDcap. Most questions allowed for respondent comments to be collected.

Section 2: Key findings

Literature review

Palliative care literature review

Several studies, including expert consensus, observational and randomised control trials, suggested that palliative care referral should occur **at least three months before death** to deliver the reported benefits of palliative care.^{5,19–22} An assessment of the literature reviewed is presented in **Appendix 1**.

ACP literature review

A review of the literature relating to ACP for people with cancer was conducted by Advance Care Planning Australia. A copy of the literature review report can be obtained from the senior author Linda.Nolte@austin.org.au or first author Helena.Rodi@austin.org.au.

Thematic synthesis was undertaken to identify recurring concepts from multiple studies and develop a thematic framework to convey the main themes in the relevant Australian literature. Five main themes were identified: prevalence of ACP in people with cancer, people with cancer and their support people's views of ACP, concordance between people with cancer and their support person's views, oncology healthcare professional views of ACP, and barriers and facilitators of ACP.

Study of patterns of end-of-life care

This study aimed to understand access to, and timing of palliative care and the factors associated with providing timely palliative care to the 10,245 patients who died from cancer between 1 July 2018 and 30 June 2019. Information about the use of health services across all public and private hospitals and outpatient community-based care in Victoria was collected. Information related to receiving direct contact from a community palliative care service was noted (where available) only for services that reported patient access to the VINAH dataset.

The median age of death was 75 years (IQR, 66–84). Most (97.6%, n = 10,000) of the cohort were non-Indigenous, male (55.1%, n = 5640) and married/partnered (55%, n = 5631). The majority (73.5%, n = 7528) were born in an English-speaking country, with only 7.1% (n = 729) of patients requiring an interpreter. Notably, 38.7% (n = 3891) lived outside a metropolitan area. A total of 38.7% (n = 3967) of the cohort recorded a low IRSD score of between eight and 10. Approximately one-third of patients (34.7%, n = 3553) reported private hospital use. Thoracic (20.7%, n = 2119), genitourinary (15.7%, n = 1609) and colorectal (11.9%, n = 1220) malignancies were the most common cause of cancer death. More than 50% of the cohort (55.3%, n = 5464) had at least one comorbidity. A detailed description of these findings is presented in Table 3.

Table 3: Description of the cohort and health service at end of life

Characteristic	N = 10,245 patients	% of patients
Age at death		
< 50	495	4.8%
50–59	920	9%

Characteristic	N = 10,245 patients	% of patients
60–69	2065	20.2%
70+	6765	66.0%
Gender		
Male	5640	55.1%
Female	4605	44.9%
Any private hospital use		
No	6692	65.3%
Yes	3553	34.7%
Marital status		
Single	4008	39.1%
Married/partnered	5631	55.0%
Not stated/missing	606	5.9%
Interpreter required		
Not stated/missing	685	6.7%
No	8831	86.2%
Yes	729	7.1%
Born in an English-speaking country		
No	2717	26.5%
Yes	7528	73.5%
Indigenous		
Not asked or did not answer	164	1.6%
Not Indigenous	10,000	97.6%
Indigenous	81	0.8%
IRSD (expressed as a decile)		
1 (least disadvantaged)	1026	10.0%
2	739	7.2%
3	744	7.3%
4	1030	10.1%
5	836	8.2%
6	997	9.7%
7	891	8.7%
8	1288	12.6%
9	1568	15.3%
10 (most disadvantaged	1111	10.8%

Characteristic	N = 10,245 patients	% of patients		
Not known	15	0.1%		
ICS region of patient residence				
Southern Melbourne ICS	2606	25.4%		
North Eastern Melbourne ICS	2181	21.3%		
Western and Central Melbourne ICS	1761	17.2%		
Barwon South Western Regional ICS	781	7.6%		
Loddon Mallee Regional ICS	764	7.5%		
Gippsland Regional ICS	721	7.0%		
Hume Regional ICS	561	5.5%		
Grampians ICS	524	5.1%		
Unknown (due to unknown address)	346	3.4%		
Remoteness (of patient residence)				
Major city of Australia	6264	61.1%		
Inner regional Australia	2924	28.5%		
Outer regional Australia	1028	10.0%		
Remote / very remote Australia	18	0.2%		
Not known	11	0.1%		
Cancer listed as the cause of death				
Bone & cartilage	15	0.1%		
Brain and CNS	362	3.5%		
Breast	613	6.0%		
Colorectal	1220	11.9%		
Endocrine	43	0.4%		
Gastrointestinal	769	7.5%		
Genitourinary	1609	15.7%		
Haematological	956	9.3%		
Head & neck	252	2.5%		
Liver & gallbladder	595	5.8%		
Melanoma and skin	295	2.9%		
Mesothelial and soft tissue	242	2.4%		
Pancreas	767	7.5%		
Thoracic	2119	20.7%		
Unknown primary	388	3.8%		
Comorbidities (excluding cancer)				

Characteristic	N = 10,245 patients	% of patients
At least one comorbidity	5464	53.3%
No comorbidity	4349	42.4%
Not known	432	4.2%

Use of health services

In the last 12 months of life, 95.8% (n = 9813) of the patient cohort (N = 10,245) required at least one hospital admission (Table 4). Three-quarters (75.3%, n = 7711) had at least one ED presentation, while 19.2% (n = 1965) had one or more admissions to an ICU.

Table 4: Use of health services in the last 12 months of life

Use of health service	N = 10,245	N of patients	% of patients	Median	IQR		
At least one hospital admission ³	At least one hospital admission ³						
No		432	4.2%				
Yes		9813	95.8%				
Number of admitted episodes	9813			6	3–13		
Bed days	9813			33	17–56		
At least one acute admission ³							
No		554	5.4%				
Yes		9691	94.6%				
Number of acute admissions	9691			6	3–13		
Acute bed days	9691			25	13–42		
At least one ED presentation							
No		2534	24.7%				

Acute hospital admission: anything that occurred in the acute hospital that was not a palliative care bed or an 'other'.

³ Palliative care hospitalisation: the primary clinical purpose of care was palliative care and care was provided in a palliative care unit or by a palliative care specialist (hospitalisations with a care type of palliative care). Other end-of-life care hospitalisation: a diagnosis of palliative care was recorded, but the primary purpose of clinical care was not recorded as palliative care. Source: <a href="https://www.aihw.gov.au/reports/palliative-care-services-in-australia/contents/admitted-patient-p

Use of health service	N = 10,245	N of patients	% of patients	Median	IQR
Yes		7711	75.3%		
Number of ED presentations	7711			2	1–4
At least one ICU admission					
No		8280	80.8%		
Yes		1965	19.2%		
Total ICU hours	1965			52	24–113
Site of death					
Hospital, acute bed		3553	34.7%		
Hospital, palliative care bed		3274	32.0%		
Hospital, other		125	1.2%		
Outside hospital		3293	32.1%		

Note: a) continuous variables are presented as median and IQR, b) categorical variables are presented as n and %.

A total of 66.7% (n = 6827) of patients died in a hospital's acute or palliative care bed. The median number of admitted episodes (N = 9813) was six (IQR, 3–13), while the median number of ED presentations was two (IQR 1–4). The median number of bed days was 33 (IQR, 17–56).

Palliative care and ACP

The provision of palliative care, the timing of palliative care, the existence of ACD and the quality of end-of-life care were measured.

Palliative care was considered provided if one of the following occurred:

- use of a palliative care or hospice bed, where the patient was principally under the care of a specialist inpatient palliative care service
- the patient received an inpatient consultation or a palliative care approach to care from an alternative hospital care team with consultation from the specialist hospitalbased palliative care service as appropriate
- use of a community palliative care service was also noted (where available) for services that reported patient access into the VINAH dataset.

Care outcomes

In the last 12 months of life, 65.7% (n = 6727) of the patient cohort (N = 10,245) received an inpatient palliative care consultation or adoption of a palliative care approach to care during admission. Almost 40% (38.4%, n = 3935) of patients needed a specialist palliative care or hospice bed during their illness. Only 8.2% (n = 835) received direct contact from a community palliative care service. Of these, 219 did not receive inpatient palliative care.

In the last 30 days of life, 62.2% (n = 6370) of patients (N = 10,245) needed two or more acute hospital admissions, and 10.2% (n = 1047) presented to ED on two or more occasions, while 6.5% (n = 663) were admitted to an ICU. Moreover, 11.4% of patients (n = 1173) received chemotherapy treatment in the last 30 days of life. VICS Summary Report Palliative Care and Advance Care Planning Practices

The time (N = 6728) from the first inpatient palliative care episode to death was 20 median days (IQR 7–55). Notably, only a small proportion (15.4%, n = 1036) of the patient cohort received timely inpatient palliative care (defined as \geq 3 months before death). Of the patients (N = 6952) who died in a hospital, 45.2% (n = 3142) first accessed inpatient palliative care in the hospital during their admission. Of the cohort of patients (n = 3274) who died in a palliative care bed, 29.9% (n = 979) had a length of stay of three days or fewer.

The median time from first ACD to death (N = 6325) was 88.5 days (IQR, 32–234). A total of 11.7% (n = 742) of the patient cohort had a documented ACD, while 10.1% (n = 639) had an MTDM alert. The palliative care and ACP outcomes are presented in Table 5.

Table 5: Description of palliative care and ACP outcomes

Care outcome	Cohort size	N	%	Median	IQR
Provision of palliative care	10,245				
No inpatient palliative care accessed		3517	34.3%		
No palliative care accessed*		3298	32.2%		
Inpatient palliative care consultation / adoption of a palliative care approach to care		6727	65.7%		
Use of specialist palliative care or hospice bed		3935	38.4%		
Community palliative care direct contact*	835	8.2%			
Timing access to palliative care	6728				
Time from first inpatient palliative care to death				20	7–55
Receipt of 'timely' inpatient palliative care ≥ 3 months before death		1036	15.4%		
First palliative care in death admission, if died in hospital	6952	3142	45.2%		
LOS \leq 3 days, if died in palliative care bed	3274	979	29.9%		
Documentation of ACD +	6325				
Any ACD documentation (ACD or MTDM)		1070	16.9%		
ACD present		742	11.7%		
MTDM alert		639	10.1%		
Both ACD & MTDM alert		295	4.7%		
Time from first ACD to death				88.5	30–234
Quality end-of-life care indices	10,245				
≥ 2 ED presentations in the last 30 days of life		1047	10.2%		
≥ 2 acute hospital admissions in last 30 days of life		6370	62.2%		
LOS ≥ 14 days in last 30 days of life		3189	31.1%		

ICU admission in the last 30 days of life	663	6.5%	
Chemotherapy in the last 14 days of life	429	4.2%	
Chemotherapy in the last 30 days of life	1173	11.4%	

Continuous variables are presented as median and IQR. Categorical variables are presented as numbers and %. + ACP reporting from VAED has been restricted to patients receiving care at public hospitals only due to a lack of reporting on ACP in private hospitals.

Factors associated with care outcomes

The factors associated with care outcomes were assessed using univariate regression, reporting odds ratios, 95% confidence levels, and p-values.

The predictors of inpatient palliative care provision, timely inpatient palliative care provision and the existence of ACD in the inpatient medical record are presented in Tables 6, 7 and 8, respectively.

Predictors of inpatient palliative care

Patients most likely to access inpatient palliative care (Table 6) were: between the ages of 70 and 79; male; married/partnered; English-speaking; non-Indigenous or unknown status; had one or more comorbidities; and did not use a private hospital service. Relative socioeconomic disadvantage was not a strong predictor of receiving inpatient palliative care.

Table 6: Predictors of inpatient palliative care provision

	Did not access PC	Accessed inpatient PC	Odds	95% CI		<i>p</i> -value
Number of patients	3517	6728	ratio			
Age at death						
< 60	333 (9.5%)	1082(16.1%)	1.00	ref		_
60–69	542 (15.4%)	1523 (22.6%)	0.86	0.74	1.01	0.07
70–79	946 (26.9%)	1928 (28.7%)	0.63	0.54	0.73	< 0.01
80–89	1130 (32.1%)	1763 (26.2%)	0.48	0.42	0.55	< 0.01
> 90	566 (16.1%)	432(6.4%)	0.23	0.20	0.28	< 0.01
Gender						
Female	1544 (43.9%)	3061 (45.5%)	1.07	0.98	1.16	0.12
Male	1973 (56.1%)	3667 (54.5%)	1.00	ref		_
Marital status						
Married/partnered	1747 (49.7%)	3885 (57.7%)	1.38	1.28	1.50	< 0.01
Single or unknown	1770 (50.3%)	2843 (42.3%)	1.00	ref	_	
Country of birth						
Non-English speaking	811 (23.1%)	1906 (28.3%)	1.32	1.20	1.45	< 0.01
English speaking	2706 (76.9%)	4822 (71.7%)	1.00	ref	_	

^{*} Sourced from VINAH: reporting varies across organisations, so data may be incomplete.

Remoteness area	Remoteness area						
Major city	2065 (58.7%)	4199 (62.5%)	1.00	ref	_		
Inner regional	1061 (30.2%)	1863 (27.7%)	0.86	0.79	0.95	< 0.01	
Outer regional	379 (10.8%)	649 (9.7%)	0.84	0.73	0.97	0.01	
Remote / very remote	10 (0.3%)	8 (0.1%)	0.39	0.16	1.00	0.05	
Indigenous							
Not Indigenous/unknown	3495 (99.4%)	6669 (99.1%)	1.00	ref	_		
Indigenous	22 (0.6%)	59 (0.9%)	1.41	0.86	2.30	0.18	
Comorbidity							
No comorbidity	1405 (45.5%)	2944 (43.8%)	1.00	ref	_		
≥ 1 comorbidity	1680 (54.5%)	3784 (56.2%)	1.07	0.99	1.17	0.098	
Any private hospital	Any private hospital						
No	2120 (60.3%)	4572 (68.0%)	1.40	1.28	1.52	< 0.01	
Yes	1397 (39.7%)	2156 (32.0%)	1.00	ref			
IRSD (expressed as a de	cile)						
1 (most disadvantaged)	315 (9.0%)	711 (10.6%)	1.00	ref	_		
2	277 (7.9%)	462 (6.9%)	0.74	0.61	0.90	< 0.01	
3	247 (7.0%)	497 (7.4%)	0.89	0.73	1.09	0.27	
4	338 (9.6%)	692 (10.3%)	0.91	0.75	1.09	0.30	
5	303 (8.6%)	533 (7.9%)	0.78	0.64	0.95	0.01	
6	301 (8.6%)	696 (10.4%)	1.02	0.85	1.24	0.80	
7	315 (9.0%)	576 (8.6%)	0.81	0.67	0.98	0.03	
8	467 (13.3%)	821 (12.2%)	0.78	0.65	0.93	< 0.01	
9	523 (14.9%)	1045 (15.6%)	0.89	0.75	1.05	0.16	
10 (least disadvantaged)	429 (12.2%)	682 (10.2%)	0.70	0.59	0.84	< 0.01	

Predictors of timely inpatient palliative care

Patients most likely to receive timely inpatient palliative care (Table 7) were aged between 80 and 89; married/partnered; English-speaking; lived in a major city; not Indigenous / not stated; used a private hospital service; and had one or more comorbidities. Relative socioeconomic disadvantage was not a strong predictor of timely inpatient palliative care.

Table 7: Predictors of timely inpatient palliative care

	Late PC	Timely inpatient PC	Odds ratio	95% CI	<i>p</i> -valu	e
Number of patients	5692	1036	ratio			
Age of death						
< 60	875 (15.4%)	207 (20.0%)	1	ref	_	
60–69	1270 (22.3%)	253 (24.4%)	0.84	0.69	1.03	0.10
70–79	1677 (29.5%)	251(24.2%)	0.63	0.52	0.77	< 0.01
80–89	1503 (26.4%)	260 (25.1%)	0.73	0.60	0.89	< 0.01
90+	367 (6.4%)	65 (6.3%)	0.75	0.55	1.01	0.06
Gender						
Male	3122 (54.8%)	545 (52.6%)	1	ref	_	
Female	2570 (45.2%)	491 (47.4%)	1.09	0.96	1.25	0.18
Marital status						
Single or unknown	2371 (41.7%)	472 (45.6%)	1	ref	_	
Married/partnered	3321 (58.3%)	564 (54.4%)	0.85	0.75	0.97	0.02
Country of birth						
Non-English speaking	1575 (27.7%)	331 (31.9%)	1.23	1.06	1.42	< 0.01
English speaking	4117 (72.3%)	705 (68.1%)	1	ref	_	
Remoteness area						
Major city	3500 (61.6%)	702 (67.8%)	1	ref	_	
Inner regional	1610 (28.3%)	250 (24.1%)	0.77	0.66	0.90	< 0.01
Outer regional	566 (10.0%)	83 (8.0%)	0.73	0.57	0.93	0.01
Remote / very remote	7 (0.1%)	1 (0.1%)	0.71	0.09	5.80	0.75
Indigenous						
Not Indigenous / not stated	5643 (99.1%)	1026 (99.0%)	1	ref	_	
Indigenous	49 (0.9%)	10 (1.0%)	1.12	0.57	2.22	0.74
Any private hospital use						
No	3818 (67.1%)	754 (75.8%)	1	ref	_	
Yes	1874 (32.9%	282 (27.2%)	0.76	0.66	0.88	< 0.01
Comorbidity						
No comorbidity	2519 (44.3%)	425 (41.0%)	1.00	ref	_	
≥ 1 comorbidity	3173 (55.7%)	611 (59.0%)	1.14	1.00	1.31	0.05
IRSD (expressed as a de	cile)					
(Most disadvantaged) 1	622 (10.9%)	89 (8.6%)	1.00	ref	_	

All 2	383 (6.7%)	79 (7.6%)	1.44	1.04		0.03
3	432 (7.6%)	65 (6.3%)	1.05	0.75	1.48	0.77
4	595 (10.5%)	97 (9.4%)	1.14	0.84	1.55	0.41
5	435 (7.7%)	98 (9.5%)	1.57	1.15	2.15	0.00
6	590 (10.4%)	106 (10.3%)	1.26	0.93	1.70	0.14
7	495 (8.7%)	81 (7.8%)	1.14	0.83	1.58	0.42
8	694 (12.2%)	127 (12.3%)	1.28	0.96	1.71	0.10
9	876 (15.4%)	169 (16.3%)	1.35	1.02	1.78	0.03
(Least disadvantaged) 10	559 (9.8%)	123 (11.9%)	1.54	1.14	2.07	< 0.01

Note: a) continuous variables are presented as median and IQR, b) categorical variables are presented as n and %.

Predictors of ACD on inpatient records

Patients most likely to have an ACD in their inpatient records (Table 8) were between the ages of 70 and 79; male; married/partnered; English-speaking; not Indigenous / not stated; lived in a major city; and had one or more comorbidities. Relative socioeconomic disadvantage was not a strong predictor of the existence of an ACD in the inpatient record.

Table 8: Predictors of ACP in inpatient records

	No ACD	ACD exists	Odds ratio	dds	n valu	
Number of patients	5583	742		95% CI	<i>p</i> -value	
Age at death						
< 60	906 (16.2%)	97 (13.1%)	1.00	ref	_	
60–69	1200 (21.5%)	172 (23.2%)	1.34	1.03	1.74	0.03
70–79	1538 (27.5%)	201 (27.1%)	1.22	0.95	1.58	0.127
80–89	1536 (27.5%)	190 (25.6%)	1.16	0.89	1.50	0.273
90+	403 (7.2%)	82 (11.1%)	1.90	1.38	2.61	< 0.01
Gender						
Male	3169 (56.8%)	380(51.2%)	1.00	ref	_	
Female	2414 (43.2%)	362 (48.8%)	1.25	1.07	1.46	< 0.01
Marital status						
Single or unknown	2475 (45.6%)	358 (49.3%)	1.00	ref	_	
Married/partnered	2947 (54.4%)	368 (50.7%)	0.86	0.74	1.01	0.06
Non-English speaking	1750 (31.3%)	137 (18.5%)	0.50	0.41	0.60	< 0.01
English speaking	3833 (68.7%)	605 (81.5%)	1.00	ref	_	
Country of birth						

	No ACD	ACD exists	Odds		n valu	
Number of patients	5583	742	ratio	95% CI	CI p-value	
Non-English speaking	1750 (31.3%	137 (18.5%	0.50	0.41	0.60	< 0.01
English speaking	3833 (68.7%)	605 (81.5%)	1.00	ref	_	
Indigenous						
Indigenous	54 (1.0%)	9 (1.2%)	1.26	0.62	2.56	0.53
Not Indigenous / not stated	5529 (99.0%)	733 (98.8%)	1.00	ref	_	
Remoteness area						
Major city	3182 (57.1%)	364 (49.1%)	1.00	ref	_	
Inner regional	1722 (30.9%)	272 (36.7%)	1.38	1.17	1.63	< 0.01
Outer regional	658 (11.8%)	105 (14.2%)	1.39	1.11	1.76	< 0.01
Remote / very remote	11 (0.2%)	1 (0.1%)	0.79	0.10	6.17	0.83
Comorbidity						
No comorbidity	2340 (42.4%)	284 (38.5%)	1.00	ref	_	
≥ 1 comorbidity	3182 (57.6%)	454 (61.5%)	1.18	1.00	1.38	0.04
IRSD (expressed as a de	cile)					
(Most disadvantaged) 1	727 (13.0%)	68 (9.2%)	1.00	ref	_	
2	448 (8.0%)	80 (10.8%)	1.91	1.35	2.69	< 0.01
3	486 (8.7%)	71 (9.6%)	1.56	1.10	2.22	0.01
4	608 (10.9%)	133 (17.9%)	2.34	1.71	3.19	< 0.01
5	515 (9.2%)	59 (8.0%)	1.22	0.85	1.77	0.28
6	614 (11.0%)	63 (8.5%)	1.10	0.77	1.57	0.61
7	502 (9.0%)	55 (7.4%)	1.17	0.81	1.70	0.41
8	643 (11.5%)	68 (9.2%)	1.13	0.79	1.61	0.50
9	682 (12.2%)	90 (12.1%)	1.41	1.01	1.97	0.04
Least disadvantaged 10	347 (6.2%)	55 (7.4%)	1.69	1.16	2.47	< 0.01

Note: a) continuous variables are presented as median and IQR, b) categorical variables are presented as n and %, c) ACD documentation was sourced from VAED records of public hospital patients.

Qualitative review of medical records

This study aimed to explore the end-of-life care of patients with cancer who died in hospital, focusing on the factors relating to referral to palliative care. The medical records of 35 patients who died from cancer between 1 July 2018 and 30 June 2019 were randomly selected from four Victorian hospitals (one large metropolitan, two regional and one rural). One patient with myelodysplasia was excluded. The remaining 34 records were included in the audit.

The mean age of patients was 75 years. Fifty-three percent (n = 18) were male. Lung malignancy (n = 6) was the most common cancer encountered, followed by haematological (n = 5) and pancreatic (n = 4) cancer. An analysis of cancer type by number is presented in Table 9.

Table 9: Cancer type

Cancer type	Number
Bowel	2
Breast	1
Gastric	1
Liver	1
Lung	6
Melanoma	3
Mesothelioma	3
Oesophageal/gastric	3
Ovarian	2
Pancreatic	4
Unknown primary	3
Haematological	5
Total	34

Timing of specialist palliative care referral

The time from specialist palliative care referral to death varied from 25 to 231 mean days within and across different health services (Table 10).

Table 10: Days between palliative care referrals in death

Type of health service	Days between palliative care referra		
Large metropolitan hospital, mean days (IQR)	25	1–88	
Small rural hospital, mean days (IQR)	231	48–752	
Regional Hospital A, mean days (IQR)	40	11–71	
Regional Hospital B, mean days (IQR)	109	2–474	
All mean days (IQR)	80	1–752	

Palliative care/ACP themes

Several palliative care themes emerged from the medical records' qualitative review (Table 11). They included:

- Palliative care and cancer treatment did not always occur concurrently
- The introduction of specialist palliative care was not always consistent with OCPs

- The CPC-CNC in rural areas played a critical role in enabling palliative care
- There was variation in the timeliness of palliative care referrals.

Table 11: Palliative care themes

Themes	Supporting evidence
Palliative care and cancer treatment did not always	For most patients who received a palliative care referral, the referral occurred after cancer treatments ceased.
occur concurrently	 Palliative care was only considered relevant for some patients when the disease had progressed or when active treatment was futile. This occurred despite some patients seemingly having substantial palliative care needs before treatment was stopped.
	 Patients treated in regional and rural centres appeared more likely to receive palliative care and cancer treatment simultaneously and/or receive early referrals to palliative care. In this sample, a few rural doctors practised early integration of palliative care, resulting in a high likelihood of concurrent treatment.
The introduction of specialist palliative care was not always consistent with OCPs	The OCP recommends initiating specialist palliative care for patients diagnosed with cancer of unknown primary ²³ during the diagnostic phase. Of the cohort of 34 patients, three had a diagnosis of cancer of unknown primary, but referrals were late or non-existent:
	 one was referred 219 days after diagnosis one was referred 34 days after diagnosis, despite having no
	cancer-directed therapy
The CPC-CNC played a critical role in rural areas (see examples in Appendix 4)	In rural areas (where access to specialist palliative care is limited), the CPC-CNC was a central point of contact for patients across the end-of-life care continuum/care settings and a resource for staff training and education. The CPC-CNC:
	 was the consult link to the community palliative care (CPC) service and the general practitioner (GP) (especially outside the allocated visiting consult time at the hospital)
	 provided expert advice on symptom management to HMOs and nursing staff and provided education on symptom management as required
	visited patients while inpatients at the local hospital
	 offered continuity of care between home and acute settings (worked clinical shifts in the acute environment)
	 were sometimes identified by patients as the care coordinator or 'problem solver'.
Variation in the timeliness of palliative care referrals	In the large metropolitan hospital, patients were referred less than two weeks before death, and none received cancer treatment and palliative care concurrently.
	Comparatively, palliative care referrals and access were earlier in the regional hospitals.
	Notably, in the small rural hospital, all patients were referred to palliative care, reflecting the practice of the community palliative

Themes	Supporting evidence
	care team, who actively sought out referrals from the oncologist, hospital, and community nursing staff.

In addition, several ACP themes emerged from the qualitative review of the medical records (Table 12).

Table 12: ACP themes

ACP themes	Thematic evidence
Lack of ACP at end-of-life	 There was a lack of ACP for medical treatment decisions at end of life, including limited evidence of ACP, goals of care (GoC) and/or ACDs: 68% (n = 23) had a GoC and/or an ACD. 21% (n = 7) had a patient-completed ACD. 24% (n = 8) had evidence of an ACP discussion. Several patients were referred to their GP to complete an ACD, but it did not eventuate. Two patients with neither an ACD/GoC were admitted to an ICU shortly before death. Notably, GoC forms were more likely to be completed by the patient's medical practitioner in the final months of life than an ACD.
No ACP documentation in the medical record	9% (n = 3) of the patient cohort (n = 34) stated they had an ACD, but it was either not found or was incorrectly filed.
The preferred place of death was not achieved for many patients	The preferred place of death was often not documented in the patient's medical record nor identified and valued as a GoC by the attending team.
	Some patients who had documented their wish to die at home but required admission for symptom management did not achieve their preferred place of death. This was more apparent in rural areas, where patients did not have ready access to specialist palliative care and cancer care. Consequently, the patient deteriorated, and their family resolved that a hospital or hospice was a more appropriate place for end of life.

Analysis of gaps in ACP

This study aimed to analyse ACP systems, processes and documentation in cancer services across Victoria, identify ACP implementation gaps and provide data to inform project recommendations. A total of 73 of 86 health services (RR = 85%) operating 132 public and private hospitals were included in the survey. Seventy percent (n = 56) of participant health services provided comments to one or more questions. The inpatient bed capacity of the participant health services is presented in Table 13.

Table 13: Inpatient bed capacity by the number of participant health services

Inpatient beds	Number of health services
< 50	28
50–100	18
101–500	17
> 500	10
Total	73

Roles of respondents

The roles of respondents who completed the survey are presented in Table 14.

Table 14: Roles of respondents

Role	Number of respondents
ACP clinician or manager	11
ANUM/NUM / nurse consultant / nurse practitioner	12
Clinical coordinator	16
Director clinical services / clinical services manager / DON/ADON / executive clinical lead	22
Palliative care clinician or manager	7
Quality coordinator	2
Social work	3
Total	73

Findings

ACP workforce characteristics and EFT

Notably, 99% (n = 72) of health services reported (or left response blank) having no medical EFT for ACP, while 73% (n = 53) reported having no nursing or allied health EFT (Table 15). Only 29% (n = 21) of health services reported having designated medical leadership in ACP. Some respondents reported ACP was incorporated into most roles in the health service and managed by available clinical staff. Of the 30% (n = 28) of health services with dedicated ACP staff, 46% (n = 13) indicated this to be part of a broader role, while verbatim comments suggested it was not embedded into routine care.

^{iv} Respondents were asked how many medical EFT were dedicated to ACP in their health service. If the answer was left blank, then it was assumed they had no dedicated EFT for ACP.

Table 15: ACP workforce characteristics and EFT

Health service responses (N = 73)	% (n) responses
ACP workforce characteristics	
Designated medical leadership ^v in ACP	29% (21)
Dedicated ACP staff	30% (28)
Of these 28 dedicated ACP staff; the ACP role was a dedicated role	54% (15)
Of these 28 dedicated ACP staff; the ACP responsibilities formed part of a broader role	46% (13)
Number of ACP medical EFT in each health service	
No medical EFT (or no response)	99% (72)
0.2 EFT	1% (1)
Number of ACP nursing or allied health EFT	
No EFT (or no response)	73% (53)
EFT 0.1 ≤ 0.8	18% (13)
EFT 1.5	3% (2)
EFT 1.6	1% (1)
EFT 2.1	1% (1)
EFT 2.4	3% (2)
EFT 4.0	1% (1)

ACP staff's primary function

Respondents were asked to select the statement (Table 16) that best described the function of the dedicated/nondedicated roles. Most (94%, n = 68) indicated their function included discussing ACP with patients, developing ACP policies/procedures and supporting/educating clinical staff about ACP.

Table 16: ACP respondents' primary function

Function	% (n) responses
Educate staff, develop processes, policies and procedures for ACP to occur as part of general clinical practice	33% (24)
Responsible for seeing patients and discussing ACP with them	32% (23)
Support clinical staff to work through the ACP process with patients	29% (21)
Generally, do not see patients, rather facilitate the process occurring as part of standard care by other staff	6% (4)

^v Medical leadership was defined as 'the person holds organisation responsibilities for ACP, would be involved in policy and form endorsement, may provide training and or support the ethical end-of-life decision making'.

Several respondents commented that there were no dedicated ACP staff in their health service. Instead, ACP was conducted chiefly by multiskilled inpatient staff, the patient's GP or as part of a community home visit.

ACP as part of best practice

Seventy-seven percent of health services (n = 56) responded that ACP was offered as part of best practice. However, the additional comments indicated that the process was ad hoc, and patients were, in some instances, required to make further appointments outside the health service to complete an ACD.

Several respondents indicated that ACP was part of the referral, intake and discharge processes. In some cases, it was identified on admission if ACP exists. If not, the option was offered and a referral was made to the public health team. In other cases, respondents indicated ACP was not embedded into routine care, and staff did not have the training or time to facilitate conversations with patients. While ACP was meant to be offered and metrics were in place, there was no leadership to enforce and ensure it happened across the health service.

Availability of ACP policies, procedures and guidelines within health services

Ninety-six percent (n = 70) of respondents indicated that they had an ACP policy guideline or procedure, but only 63% provided a copy of the relevant documents. The remaining 4% (n = 3) (one community health service, one private hospital and one rural hospital that provided acute and palliative care services) reported not having the relevant documents. The number of health services indicating whether their ACP policy, procedures or guidelines contained the specified content is presented in Table 17.

Table 17: Content of ACP policies procedures and guidelinesvi

Does the content include	Yes, % (n)	No, % (n)
Medical Treatment, Planning and Decisions Act	89% (65)	11% (8)
Advance care directive	90% (66)	10% (7)
Advance care plan	86% (63)	14% (10)
Consent	81% (59)	19% (14)
Capacity	84% (61)	16% (12)
MTDM or substitute decision-maker	92% (67)	8% (6)
Support person	82% (60)	18% (13)
Storage of ACP documents	84% (61)	16% (12)
Health practitioner obligations (e.g. to access them)	73% (53)	27% (20)
Enactment of the preferences within documentation	66% (48)	34% (25)

vi Advance Care Planning Australia did an analysis of policy sourced nationally and created a <u>preferred list of items for an ACP policy</u> https://www.advancecareplanning.org.au/docs/default-source/acpa-resource-library/acpa-publications/content-and-quality-assessment-of-advance-care-planning-policies-030820.

Consumer access to ACD forms and information

Respondents were asked if they had an ACD form for consumers and if it was consistent with the recommended Victorian template (Table 18).

A total of 85% (n = 62) reported their local ACD form was consistent with the template recommended by the Department of Health, Victoria.

Table 18: Use of and consistency with Victoria's ACD template

Use of and consistency with Victoria's ACD template	% (n)
Yes, ACD form was used, and it is consistent with the recommended Victorian ACD template (but may have a local logo)	85% (62)
Yes, ACD form was used, but not consistent with the recommended Victorian ACD template	5% (4)
No, ACD form was not used	5% (4)
Not applicable; health service is in New South Wales	1% (1)
Not known	3% (2)

Patient administration system

The MTDM is a statutory role recognised in the Medical Treatment Planning and Decisions Act, legally authorising the recognised decision-maker to act on behalf of a non-competent person to make medical decisions and provide consent to treatment or non-treatment. Next of kin is **not** a role recognised in this legislation. Therefore, a person's next of kin should not make medical decisions and provide consent for a non-competent person because they are not legally authorised.

Respondents were asked whether the health service PAS had fields for next of kin and/or an MTDM. This review found that 92% (n = 67) of health services have a PAS that includes a field for next of kin, while 27% (n = 20) did not contain a field to record the person's MTDM. The number of health services with none, one or both fields is presented in Table 19.

Table 19: Fields in PAS

Fields in PAS recording the MTDM and/or next of kin	% (N)
PAS includes a field for next of kin	92% (67)
PAS includes a field for MTDM	73% (53)
PAS includes a field for next of kin and MTDM	67% (49)
PAS includes a field for next of kin but not MTDM	22% (16)
PAS does not include a field for next of kin but does include MTDM	5% (4)
PAS does not include a field for next of kin nor MTDM*	3% (2)

^{*} One of these health services was a large public hospital whose PAS Integrated People Management includes a field for Enduring Power of Attorney – Medical. They are working towards having the field changed to MTDM. They do not use next of kin. The other health service is a private hospital.

Discussion

The Palliative Care and Advance Care Planning: Current Practices in Victorian Cancer Services project provides a comprehensive understanding of palliative care and ACP outcomes for inpatients who died from cancer in Victoria between 1 July 2018 and 30 June 2019. It revealed patients did not always receive early and appropriate referral to palliative care services and ACP, described in the OCPs as the national standard of high-quality cancer care that all Australians should expect. Moreover, the Victorian cancer plan 2020–20249 sets a target measure that 90% of cancer patients receive specialist palliative care within 12 months prior to death by 2030 and seeks a 50% increase in the number of people with metastatic cancer with an ACD by 2024.

Study of patterns of end-of-life care

Current evidence shows a referral to palliative care greater than three months before death results in fewer ED presentations, fewer hospitalisations and fewer hospital deaths.⁵ In this study, only 15.4% (n = 1036) of patients (N = 6728) received their first inpatient palliative care episode three months or more before death. This finding suggests more needs to be done to achieve referral to specialist palliative care early in the pathway of care. MDMs represent a ready and reliable way of highlighting the need for palliative care referral. Healthcare workers need to emphasise further the value of early palliative care in improving symptom management and quality of life for people affected by cancer. Additionally, VICS have a role in including palliative care team members in MDMs by making a case for specific tumour streams with low survival (e.g., lung, pancreatic) to include consideration of referral to palliative care. Moreover, VICS can advocate with the MDM chair to raise palliative care referral as part of the MDM discussion. VICS also has a role in supporting health services in implementing more flexible and responsive outpatient models of care (e.g. virtual palliative care clinics) to support early referral to palliative care. The current evidence suggests that telehealth support results in shorter wait times for patients to see a palliative care specialist, more same/next day appointments for urgent referrals and more frequent contact with patients and their family/caregivers overall.²⁴

The finding that 95.8% (n = 9813) of patients (N = 10,245) required at least one hospital admission in the last 12 months of life supports the evidence that cancer patients have significantly higher rates of health service use and 27% higher total healthcare costs than their non-cancer counterparts in the last six months of life. 25 This project showed that of those who died in hospital (N = 6952), 45.2% (n = 3142) first accessed inpatient palliative care in the hospital admission during which they died. In the last 30 days of life, 62.2% (n = 6370) of patients (N = 10,245) needed two or more acute hospital admissions, while 31.1% (N = 3189) had a length of stay of 14 days or more. These findings further amplify the need for early and appropriate (tailored to provide the right level of intervention for the right patient in the right setting at the right time) referral to palliative care services. Similarly, more targeted education of clinicians to promote the evidence-based benefits of concurrent and integrated palliative care with cancer-modifying therapies should be considered to improve symptom control, quality of life, decrease aggressive treatments at end-of-life and decrease hospital costs.^{26–30} Further exploration of community/outpatient models of care to reduce admissions to hospitals for end-of-life care and achieve more proactive and anticipatory palliative care in the home is also recommended.

In the 12 months before death, only 8.2% (n = 835) of patients received direct contact from a community palliative care service. The recording of out-of-hospital care in the VINAH dataset varied across organisations and was considered likely to be limited. Strengthening the data collection around community and ambulant/outpatient palliative care will enable all settings

that provide palliative care to be captured in datasets and allow for more complete benchmarking over time. Notably, only 11.7 % (n = 742) of patients (N = 6325) who died within the study period had evidence of a documented ACD compared with the 26.8% (n = 168) who had at least one ACD recorded.⁸ Similarly, very few patients (10.1%, n = 639) had an MTDM alert.

Qualitative review of medical records

In this review, 24% (n = 8) of patient records (N = 34) had evidence of an ACP discussion, while only 21% (n = 7) had a patient-completed ACD. Additionally, 9% (n = 3) of patients reported having an ACD, but it was either not located in the health record or incorrectly filed. This suggests that improvements need to be made to relevant processes to ensure ACD is available at the point of care.

The thematic analysis further indicated that palliative care did not always occur concurrently with cancer treatment and was more likely to be considered following disease progression or cessation of cancer treatment. These findings identify variation with the standard described in the OCPs and the expectations outlined in the national *Palliative care service development guidelines*. The American Society of Clinical Oncology further suggests that patients with advanced cancer receive dedicated palliative care services early in the disease trajectory and concurrent with active treatment. 32

The study was limited by a lack of access to paper-based medical records during the COVID-19 pandemic. This resulted in restricted access to statewide ACP data. The limited access to specialist palliative care evident in rural areas led, at times, to delays in accessing symptom relief and more extended intervals between optimal patient interventions. This points to a need to consider alternative models of care.

Analysis of gaps in ACP

Seventy-three health services (public and private) participated in the analysis of the gaps in ACP. Two-thirds (62%, n = 45) of health services did not have a dedicated ACP workforce. Only 29% (n = 21) of respondents reported having designated medical leadership in ACP. Of the 30% (n = 28) that reported having ACP staff, 46% (n = 13) indicated this to be part of a broader role, while verbatim comments indicated it is not a routine part of optimal care delivery. Notably, another Australian study²² found that following a discussion about ACDs led by the patient's clinician, ACD completion increased to more than 70%. This supports the recommendation that health services have a dedicated workforce to help patients complete an ACP.

Conclusion

This project revealed that patients with advanced/metastatic cancer in Victoria received a median of six inpatient episodes of care in the last 12 months of life. Very few patients received their first inpatient episode of palliative care within or more than three months before death. It further showed a lack of planning for future medical treatment decisions and a low prevalence of ACDs in the health record. VICS can play a key role in working with and across sectors to address the variations identified to better align care with the OCP. Additionally, they can collaborate with the member health services to help achieve target improvements in palliative care and to prioritise ACP in the *Victorian Cancer Plan 2020–2024*.

Abbreviations

Abbreviation	Title
ACD	advance care directive
ACP	advance care planning
CPC	community palliative care
CPC-CNC	community palliative care – clinical nurse consultant
ED	emergency department
GoC	goals of care
GP	general practitioner
НМО	hospital medical officer
IRSD	Index of Relative Socio-economic Disadvantage
IQR	interquartile range
ICS	Integrated Cancer Service (one part of VICS)
ICU	intensive care unit
MDM	multidisciplinary meeting
MTDM	medical treatment decision-maker
OCP	optimal care pathway
PAS	patient administration system
RR	response rate
VAED	Victorian Admitted Episodes Dataset
VCR	Victorian Cancer Registry
VICS	Victorian Integrated Cancer Services (all 9 ICS)
VINAH	Victorian Integrated Non-Admitted Health data

Appendices

Appendix 1: Palliative Care and Advance Care Planning Project literature review



Palliative Care and Advance Care Planning Project Literature Review

Introduction

This literature review describes literature related to timely and appropriate referrals to palliative care. Palliative care is defined by the World Health Organisation as an approach that improves the quality of life of patients [adults and children] and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through early identification, correct assessment and treatment of pain and other problems - whether physical, psychosocial, or spiritual. ¹ The literature review focuses on current international best practice, evidence relating to timing of palliative care referral, and barriers to timely and appropriate palliative care intervention.

Background

In Victoria, palliative care is delivered through community, inpatient and consultancy services, administered by public, private and non-government providers.² Public and non-government community palliative care services link with other services to provide palliative care in the patient's home such as the Bolton Clarke Nursing Service, Home and Community Services (generalist nursing support). Volunteers are an essential part of the palliative care sector.² Currently the Victorian Government funds 31 health services to provide 264 designated palliative care beds and 39 community palliative care services to support patients and families at their usual place of residence.³ There are five day hospices providing day programs offering clinical care, respite and therapeutic activities.³ In 2018, 138,300 people were diagnosed with cancer in Australia and a high mortality rate of 133 people dying from their disease per day.⁴

The Victorian Integrated Cancer Service (VICS) is conducting a state-wide project that aims to provide, definitions and measures for 'timely' and 'appropriate' referral to palliative care. The literature review forms part of this broader project.

Benefits of early palliative care

Early intervention of palliative care services has been demonstrated to improve patients' symptoms and quality of life, improve family outcomes and reduce hospitalisation and cost at

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the end of life while ensuring care matches patients' preferences.⁵ Evidence demonstrates incremental advantages according to timing of palliative care.⁶ Ziegler and associates found that there is an association between longer interval from first contact with palliative care to death and important quality indicators of end-of-life care. Palliative care initiated greater than two weeks before death was associated with avoiding a hospital death; and initiated more than four weeks before death was associated with a reduction in emergency hospital admissions and an increased likelihood of receiving an opioid analgesic. Palliative care initiated more than 32 weeks before death was associated with a reduction in chemotherapy in the last four weeks of life.⁶

Even though palliative care referral frequently occurs at a time of crisis (eg, end of life), palliative care is most effective when introduced early. Appropriate and timely symptom interventions, patient education, and side-effect management may help to minimize emergency department visits and admissions to hospital, whilst extending the person's function. 13,7 Evidence from randomized controlled trials has demonstrated benefits in quality of life outcomes from early palliative care concurrent with standard oncology care in patients with advanced cancer.

A study by Temel et al, showed that early outpatient palliative care for patients with advanced cancer can alter the use of health care services, including care at the end of life. Significantly, more patients in the early palliative care arm of the study than in the standard care arm had resuscitation preferences documented in the outpatient electronic medical record. Early introduction of palliative care also led to less aggressive end-of-life care, including reduced chemotherapy and longer hospice care.⁹

Palliative care not only improves quality of life for the patient, but it also has an economic benefit with cost savings up to 25% of the total health care expenditure when compared with usual care.¹⁰

Best practice

Many national and international organisations including the World Health Organisation, the American Society for Clinical Oncology (ASCO), European Society for Medical Oncology (ESMO)

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and the Australian and New Zealand Society of Palliative Medicine (ANZPM) recognise the importance of early palliative care alongside standard cancer care. ^{11,12,13} The appropriate question is not whether palliative care should be offered, but what is the optimal model of delivery, when is the ideal time to refer, who is in greatest need of a referral, and how much palliative care should oncologists be providing, particularly given the shortage of palliative care resources internationally. ¹³

Despite increasing evidence of the importance of early referral to palliative care leading to improved quality indicators in end-of-life-care in the literature, many people with end stage cancer do not receive timely or appropriate palliative care in Victoria. Collins et al¹⁴ identified that 59% of cancer inpatients in Victoria accessed palliative care in their last year of life. For those that do access palliative care, it often occurs very late; with a median of only 27 days before death. For many (61%), the first palliative care consultation was in the final hospital admission which concluded with death.

Optimal timing

How timely and appropriate palliative care is achieved at a person-centred level is an area of current research. Some patients with advanced disease may have few symptoms and their support care needs well met, thus instead of early palliative care for every cancer patient, palliative care needs to be timely. ⁷

In a large study, using the Delphi consensus methodology, 60 international experts were asked about the appropriate time to refer patients with advanced cancer to outpatient palliative care.

A consensus was a minimum of 70% of experts agreeing. The panellists surveyed identified two major time-based criteria:

- Within three months of advanced cancer diagnosis for patients with life expectancy of one year or less.
- 2. Progressive disease despite two lines of palliative systemic (disease-modifying) therapy.

The two criteria were identified as the most appropriate timing criteria for outpatient palliative-care referral. Both criteria involve patients with limited prognosis. One perspective is referrals which are late may deprive patients of the full benefits associated with early

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palliative care, such as timely symptom management to minimise crises and end-of-life discussions to reduce the likelihood of aggressive interventions at end-of-life. On the other hand, very early referrals might result in patients being assessed by palliative-care specialists when they have few concerns and thus deriving little benefit. Additionally, the health systems would be overwhelmed and unable to provide services due to the limited infrastructure of palliative-care programmes available.¹⁵

In relation to cancer trajectory, the World Health Organization describes palliative care as applicable early in the course of illness, in conjunction with other therapies intended to prolong life¹. The term early is generally not defined. It can lead to differences in interpretation about when palliative care referral is reasonable. In the literature, there is considerable variation of the term "early", ranging from time of diagnosis of advanced disease, to shortly after or upon failure or discontinuation of curative treatments, to the period just before expected death (in months)^{7,16}. These variations may contribute to delays in the timely integration of palliative care ¹⁶

Watanabe et al in their study looking at frequency, timing, and predictors of palliative care consultation demonstrated that cancer type is an independent predictor of access to specialist palliative care. There was higher frequency of palliative care consultation among patients with gastrointestinal cancers in the study, which they thought may be attributable to referral of patients with recognized poor-prognosis cancers (e.g., pancreatic).¹⁷ They also found patients with younger age, higher income, and interval from advanced cancer diagnosis to death >2.5 months had a significantly higher likelihood of receiving palliative care consultation. Younger age has been demonstrated in other studies to be a predictor to receiving palliative care.^{18,19} Patients with older age and gynaecological, head and neck, haematological, and nervous system cancers had a significantly lower likelihood of receiving palliative care consultation. ¹⁷

Late referral leaves little time to establish confidence in community-based care, or to complete complex communication tasks, such as exploring the person's values, future preferences for medical treatment, and/or establishing goals of care.

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Ensuring patients receive timely and appropriate access to palliative care can be achieved using a number different tools. One such method is to use a trigger tool such as the Supportive and Palliative Care Indicators Tool (SPICT).²⁰ Such tools support clinicians with their clinical judgement and assisting them to identify unmet needs of the patient.

In a retrospective study, using seven palliative care referral tools, applying them to the medical records retrospectively. Gemmell et al found that if trigger tools had been utilised, 91% of patients would have received a palliative care referral 6 months before their final admission. This is compared to 46% of patients who received a palliative care referral prior to their final admission as a component of their actual care.²¹

Another tool to assist with referrals is to utilise standardised referral. This is achieved by defining transition points along a cancer illness course. These transition points are generally associated with poor prognosis. Transition points are used to trigger integration of palliative care as a standard part of quality oncological care and enhance clinician-based referral in routine clinical practice.²⁵

Barriers

Clinician reluctance to engage in conversations about expected prognosis with patients can add to delays in palliative care referrals. Other barriers identified are different palliative care models and lack of consistency of models across geographical areas. ²²

Obstacles to timely engagement with palliative care include limitations in workforce and service models, availability of services, failure to recognise poor prognosis or patient needs, and fear of destroying hope or upsetting patients.^{23,24,25} Specific patient-flow obstacles have been described as barriers to palliative care referral. Those obstacles include lack of referral criteria and clearly defined timing for palliative care referrals.²⁶

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Conclusion

The consensus in the literature is early referral to palliative care is best practice, however there is no clear established definition of what defines early. The evidence suggests there are incremental improvements the longer the time from referral to death of the person.

Timely and appropriate referral is person centred, and therefore based on individual needs rather than prognosis. There are many clinical trials looking at various person-centred methods to ensure timely and appropriate referral; studies aimed at defining transition points and other studies looking at the use of validated assessment tools.

There is well-documented evidence that palliative care can and should be available to people whilst still undergoing disease modifying treatment, embedding the palliative care in the multidisciplinary team.

Further research is required to more accurately define the interventions required will effectively result in timely and appropriate referrals, however at present there is sufficient evidence to encourage earlier referrals to palliative care with a view to decreasing the gaps between current practice and consistent, integrated, timely and appropriate palliative care

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Appendix 2: Case record form used in the qualitative medical record review



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Medical Record Review Case Record Form

	Demographi	ic information
Unique identifier		
Date of birth	//	
Date of death	//	(note information will be collected for 3 months prior to this date)
Initials		
Sex	☐ Male	
	☐ Female	
	☐ Other	
5	□ Unknown	
Postcode		
Country of birth	☐ Australia	
	☐ Other (please specify)	
	☐ Unknown – informatio	on not available in record
Relationship status	☐ Married/de facto	
	☐ Divorced/separated	
	□ Widowed	
	☐ Single	
,	☐ Unknown – informatio	on not available in record
Language status	☐ Speaks English	
	☐ Interpreter required.	(specify in free text)
	☐ Unknown – informatio	on not available in record

	Cano	er History	
Cancer type	☐ Skin and melanoma ☐ Basal and squamous cell ☐ Bowel ☐ Brain ☐ Breast ☐ Endometrial	☐ Hearnatological (document type) ☐ Head and Neck ☐ Liver ☐ Lung ☐ Melanoma ☐ Oesophogastric	□ Ovarian □ Pancreatic □ Mesothelioma □ Prostate □ Sarcoma □ unknown primary □ other
Date of metastatic disease	// (confir	med by biopsy or imaging)	
Date of palliative care referral	//		
Preferred place of death	☐ Hospital ☐ Home ☐ Hospice ☐ other ☐ Unknown – information	not available in record	
Location of death	☐ Hospital ☐ Home ☐ Hospice ☐ other ☐ Unknown – information	not available in record	

Social and Medical History

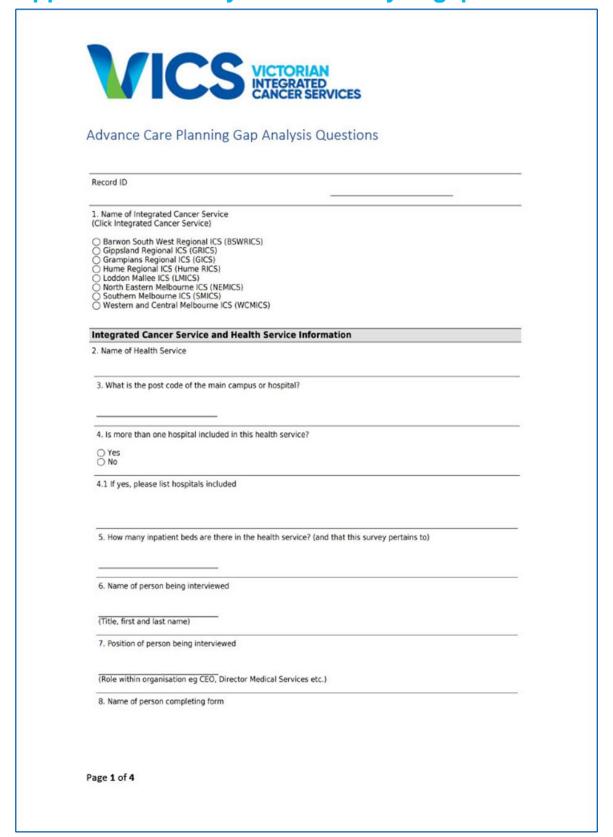
Note- try and identify any bits of information that you perceive might:

Be issues for care eg. complex symptoms, psychological distress etc.

		where care is delive	red
- Influence i	f PC needed	/avoided etc	
		ns being made/ena	
- Record chi	ronologically	, starting 3 months	prior to death
Date(s)	Summary	or Narrative from r	medical records for 3 months preceding death
//			
//			
//			
//			
//			
//			
//			
//			
Encounters with	health se	ervices last 3 mo	onths of life
Date	Length	Department/	Narrative
	of stay	admission type	
	(days)		
//			
//			
//			
//			
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Date Summary or Narrative from medical records Cancer treatment	Data/a\	Data	Commence of Name time from modified and or
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Appendix 3: Survey used to analyse gaps in ACP





Advance Care Planning Gap Analysis Questions

Advance Care Plannin	ig Starring and Er i
9. Does this health service	have medical leadership in advance care planning?
	ns that the person holds organisational responsibilities for ACP, would be involved in policy ay provide training and/or support ethical end-of-life decision-making.))
Yes No Not known	
9.1 Please provide name o	of ACP medical leader
. Does the health service	have advance care planning staff?
Yes No Not known	
.1 The advance care plan	ning role is best described as
Dedicated role ACP responsibilities form	part of a broader role
.2 How best would you de ck all that apply)	escribe the ACP staff's primary function?
Be responsible for seeing Support clinical staff to v	rocesses, policies and procedures for ACP to occur as part of general clinical practice g individual patients and discuss ACP with them work through the ACP process with individual patients. fual patients, rather facilitate the process occurring as part of standard care by other

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Advance Care Planning Gap Analysis Questions

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10.3 How much medical EFT is dedicated to advance care planning	
(number to 2 decimal places)	
10.4 How much nursing or allied health EFT is dedicated to advance care planning?	
(number to 2 decimal places)	
11. Please add any further information to add relating to staffing or EFT.	
12. Is advance care planning offered as part of standard care to patients with cancer within this health service?	
YesNoNot known	
13. Please add any further comments relating to advance care planning for cancer patients.	
Policies Procedures and Guidelines	
4. Does the health service have an advance care planning policy, procedure or guideline?	
O Yes O No	
Not known	
4.1 If yes, please can you upload a copy of the policy, procedure or guideline	
14.2 Does the policy, procedure or guideline cover the following? tick all that apply)	
☐ Medical Treatment Planning and Decisions Act ☐ Advance Care Directive	
☐ Advance Care Plan☐ Consent	
☐ Capacity ☐ Medical treatment decision maker / Substitute decision maker	
Support Person Storage of ACP documents	
Health practitioner obligations eg. To access them Enactment of the preferences within documentation	
age 3 of 4	



Advance Care Planning Gap Analysis Questions

Does your service have an Advance Care Directive form available to consumers? e instructions for details of Victorian template)	
Yes and is consistent with the recommended Victorian template (but may have local logo) Yes but not consistent with the recommended Victorian template No Not known Not applicable. Health Service is in NSW	
1 For NSW Health Service, does your service have an Advance Care Directive form available for consumers	?
Yes and is consistent with the recommended NSW template (but may have local logo) Yes but not consistent with the recommended NSW template No Not known	
Does the Patient Administration System include a field for next of kin? eck with admissions)	
Yes No	
Does the Patient Administration System include a field for Medical Treatment Decision Maker? eck with Admissions)	
Yes No	
Please add any further comments. ease add any further information you think might be useful)	

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Appendix 4: CPC-CNC involvement in rural care

Examples

Example 1

The CPC-CNC visited a patient who had high anxiety and pain episodes while an inpatient in hospital. They assessed that there was a psychological component to the patient's pain and that treating anxiety was an appropriate first step (in conjunction with analgesia).

She followed up with the oncologist, who agreed and prescribed anti-anxiolytic treatment and analgesia. The CPC-CNC subsequently communicated the clinical decision-making outcomes to the CPC and the GP (thus becoming the link between the oncologist and the CPC and GP).

Example 2

The oncologist and CPC-CNC assessed the patient's pain as not being managed well. The CPC-CNC advised the nurse caring for the patient that a 2.5 mg breakthrough dose of morphine was insufficient and to give 5 mg as per the medication order form.

On another occasion, the same patient's wife rang the CPC-CNC when he was an inpatient because she was concerned about inadequate pain management. The CPC-CNC visited the patient in hospital amid further recommendations to improve his pain. There was no documentation of the wife discussing these issues with the nurse on the ward, the nurse in charge or the HMO.

Example 3

The patient was taking fentanyl lozenges, which were not controlling their pain. The patient was reviewed by an oncologist who recommended that fentanyl lozenges were too short-acting and that the patient switch to something more suitable.

When the patient's pain continued to be poorly controlled, the CPC-CNC advised the HMO about the patient's pain management and consulted with the CPC GP about pain management via telephone.

Glossary

Advance care directive

An advance care directive is a legal document made under the *Medical Treatment Planning* and *Decisions Act 2016* that contains one or more of the following:

- an instructional directive containing legally binding instructions about future medical treatment the person consents to or refuses
- a values directive that documents the person's values and preferences for their medical treatment decision-maker to consider when making decisions for them
- the name of the person they appoint as a medical treatment decision-maker who can make decisions on the person's behalf about their health and/or personal care.

To make an advance care directive, the person must have decision-making capacity.⁷ For an advance care directive to take effect, the person must have lost their decision-making capacity.

Advance care planning

Advance care planning is the planning of a person's future health care. It specifies the health care the person would or would not like to receive if they become seriously ill or injured and cannot communicate their preferences or make decisions. This often includes the care the person would prefer to receive towards or at the end of life.³³

Appropriate palliative care

Care that is tailored to provide the *right* level of intervention for the *right* patient in the *right* setting at the *right* time.³⁴

Goals of care

Goals of care describe what a patient wants to achieve during a specific episode of care, within the context of their clinical situation. Goals of care are *the clinical and personal goals for a patient's episode of care* that are determined during a shared decision-making process. They are updated with each hospital admission or change in the patient, or when the patient, substitute decision-maker or family requests a change.³⁵ⁱ

Instructional directive

A document containing legally binding instructions about future medical treatment that the person completing the form consents to or refuses. It has the same effect as the person consenting to, or refusing, the medical treatment in person.

Because health practitioners are bound to follow the directive, a person should only complete an instructional directive if they know the medical treatment that they want, or do not want, in the future.³⁶ⁱⁱ

Medical treatment decision-maker

A person authorised under the *Medical Treatment Planning and Decisions Act 2016* to make medical treatment decisions on behalf of another person who does not have decision-making capacity to make that decision.

A person's medical treatment decision-maker is the highest ranked person from the list below, who is 18 years of age or older, reasonably available, and willing and able to make the relevant decisions.

- 1. The person's appointed medical treatment decision-maker
- 2. A guardian appointed by the Victorian Civil and Administrative Tribunal to make decisions about the person's medical treatment
- 3. The highest ranked available person from the list below who is in a close and continuing relationship with the person. If there are two or more possible candidates, the oldest person must be selected:
 - a. the person's spouse or domestic partner
 - b. the person's primary carer
 - c. an adult child of the person
 - d. a parent of the person
 - e. an adult sibling of the person.

Valid appointments made in other Australian states and territories are also recognised.³⁷

Palliative care

Palliative care is defined by the World Health Organization as an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through early identification, impeccable assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.³⁷

Palliative approach

A palliative approach aims to improve the quality of life for people with a life-limiting illness and their families by reducing their suffering through early identification, assessment and treatment of pain, and consideration of their physical, cultural, psychological, social and spiritual needs.³⁸

Person-completed plan

A person-completed plan is an advance care directive completed by a person (with capacity) that specifies their current and future health care. It can also include their beliefs, values and preferences.

Primary palliative care

Primary palliative care is palliative care provided to a patient and their family that is delivered by primary carers (e.g. GPs and general nurses) and non-specialist palliative care clinicians (e.g. medical oncologists).

Specialist palliative care

Specialist palliative care is the active, total care of a person with a life-limiting illness, and their family members. It is provided by medical, nursing or allied health professionals (individually or as part of an interdisciplinary team) who have recognised specialist palliative care qualifications and accreditation and who work mainly, if not exclusively, in an expert interdisciplinary team of palliative care health professionals.

Specialist palliative care clinicians look after and provide complex care to clients and families VICS Summary Report_ Palliative Care and Advance Care Planning Practices I 59

who have complex symptoms and/or complex spiritual, psychological, cultural or bereavement needs. Examples of complex care include negotiating a difficult family meeting, addressing veiled existential distress, and managing refractory symptoms.³⁹

Specialist palliative care clinicians also provide education and support to other clinicians and usually undertake or collaborate in research.⁴¹

Timely referral to palliative care

Timely referral to palliative care is achieved when a patient receives the benefits of palliative care, as described in Figure 2. Previous studies (including expert consensus, observational and randomised controlled data) suggest that palliative care referral is timely when it occurs at least 3 months before death.^{5.19,20.21.22}

During personalised cancer care, an optimal approach would involve identifying patients who have the greatest palliative care needs, and their automatic referral to specialist palliative care.

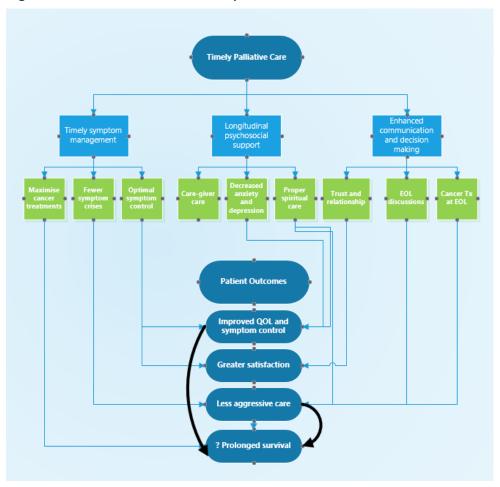


Figure 2: Outcomes and benefits of palliative care

Adapted from *Improving patient and caregiver outcomes in oncology: team based, timely and targeted palliative care: a Cancer Journal for Clinicians.* Adapted with permission.

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