MANNING VALLEY *PUSH 4 PALLIATIVE*

NSW Legislative Council Portfolio Committee NO 2
INQUIRY INTO HEALTH OUTCOMES AND ACCESS TO HEALTH AND HOSPITAL SERVICES IN RURAL, REGIONAL AND REMOTE NEW SOUTH WALES

TAREE HEARING – Wednesday 16 June 2021

SUPPLEMENTARY QUESTIONS for
Ms Judy Hollingworth, Founder and Deputy Chair, Manning Valley Push for Palliative, submitted 28 July 2021

1. In addition to what is contained in your submission and evidence provided at the public hearing, do you have any further comments regarding the current provision of palliative medicine, nursing and care in Taree and the region?

The importance of retaining a Palliative care specialist permanently for the area, increasing from 0.5FTE to 1.0 FTE; together with palliative care trained Clinical Nurse Consultants and Nurse Practitioners.

The current appointee at 0.5 FTE is proving the correctness of these core contentions in our submission for a pall care specialist (PCS) - see our December 2020 submission to you - namely that:

a. The specialist's presence and experience significantly lifts the quality of care for patients, both directly and via better informed medical practitioners, such as other-medical specialists, who now *do* address questions of palliative care with their patients (rather than avoid them) and also refer them to the PC specialist team

b. The same effect has been seen in the awareness and readiness of local GPs, hospital and community nurses, and allied health providers.

c. This means more effective community palliative care - and hence more patients able to be treated as they wish, and to die at home where that is their preference.

d. We expect that the PC specialist's costs are significantly offset by enhanced efficiency and reduced patient costs. We understand that he additional analysis required to prove this is being undertaken in the local hospital

   i. Dr Yvonne McMaster – a retired palliative care specialist and long-standing lobbyist for increased funding and provision of palliative care services in NSW, including regional areas - has submitted arguments and estimates of cost-savings to the NSW Treasurer and Minister for Health repeatedly in the past 8 or so years. *Two that we have are attached to the covering email*, though they are dated.

   ii. KPMG has also done a study on the economics of palliative care for the national peak body *Palliative Care Australia* "Investing to Save" (also attached to covering email)

e. The level of 'community readiness' and welcome for the palliative care specialist enhances his impact and effectiveness. We hear that, individuals, a range of local health practitioners and other community bodies are already demonstrating this interest by attending or referring to the clinics he has set up.

We urge the NSW Government to focus on and provide even greater support to these endeavours, including the enhanced palliative care support team towards which Dr Veltre and his current palliative care team are working.

Manning Valley Push For Palliative has developed a close relationship with all in this hospital-based specialist palliative care team as well as the community Health [palliative care team and will continue to facilitate and support their advocacy and educational work in this community.

The new Out of Hospital Program

This commenced here on 1 July and takes in under its umbrella what we knew of as the HammondCare and SilverChain End of Life care 'packages' that have been available in metropolitan Sydney (mainly Western Sydney) and in the lower Hunter for some years. This is most welcome, but so far, is not capable of being a fast-response program owing to steps required for approvals process and commissioning of services, and time-lags involved. A transcript of a discussion on 16 July between Community health and the two local charities is inserted below. about its effectiveness so far.

The bottom line for GLPCS and MVP4P is: our gap-funding is still required as the new program is slow and uncertain in response. We hope that can change

2. In addition to what is contained in your submission and evidence provided at the public hearing, do you have any further comments regarding ways to improve both the access and availability of palliative medicine, nursing and care in Taree and the region?

a. *The importance and value of retaining palliative-care-trained/aware social worker (a first priority, put to us repeated by the community health team for our advocacy), occupational therapist and physiotherapist (as their second priority),* given the particular practical needs and vulnerabilities palliative care raises in the home environment.

b. At an anecdotal level, we have heard from patients, their personal supporters and other health practitioners that these kinds of care have been as needed, effective and appreciated as clinical care - sometimes more so.

a. Attracting recruiting and retaining personnel with these skills

i. We note that attracting then recruiting personnel with these skills requires its own approach, as there is more demand for such personnel overall than supply, in our area and in many parts of the state. For example, a palliative care specialist position was approved for Tamworth area (our own LHD) some years ago but – we understand - has not yet been filled.

ii. Incentives for medical, nursing and allied health trainees to undertake the necessary studies and then take up positions in our district and others like it, are needed. One possibility is to recruit trainees in the are – for example 'bonded' schemes as mentioned by Dr Holliday at the hearings; or otherwise help local talent to undertake training in essential services with a view to staying home to train and practice or coming back home to practice. The new Taree Universities Campus has this as one of its aims.

iii. We understand that the Committee has put a series of questions to the LHD, hospital and other medical practitioners who gave evidence on 16 June. While we as a voluntary group do not have the data or resources to affirm our points above, we believe that if needed, much of it can be obtained from the HNEH LHD administration.

<table>
<tr><td>**Meeting**</td><td>**One Off meeting to discuss introduction of End of Life Care Packages**</td></tr>
<tr><td>**Date**</td><td>**16/7/2021**</td></tr>
<tr><td>**Completed by**</td><td>**Trish Lowe**</td></tr>
<tr><td colspan="2">Deidre Stokes, Elizabeth Fisher [Great Lakes Palliative Care Support] and Judy Hollingworth [MVP4P} attended in person and via telephone.
Zoom unsuccessful</td></tr>
<tr><td colspan="2">Overview of Out of Hospital Program provided – this service provides non-clinical support for patients and carers, ie Personal Care, respite, Domestic assistance, transport, meals and social support</td></tr>
<tr><td colspan="2">Discussed teething issues with our initial referrals not being seen prior to dying. Guidelines for providers require patient contact within 48 hours</td></tr>
<tr><td colspan="2">Where practical patients should be referred to government funded services, Out of Hospital Packages, carer Gateway.</td></tr>
<tr><td colspan="2">If patient has suddenly deteriorated and requires personal care immediately at End of Life MVP4P and GLPCS are still agreeable to fund a Local service provider to attend personal care.
This is in the hope/expectation that state-government funding *will* become a fast-response service in reasonable time, with less reliance on these community-organisations for meeting urgent, shorter term care needs.
If patient require minimal assistance early in trajectory of illness, ie domestic assistance, MVP4P and GLPCS agreeable to fund until government funded resources available. ie CHSP</td></tr>
</table>

COST OF ENHANCING PALLIATIVE CARE IN NSW 2018

		FTE positions				
PALLIATIVE PHYSICIANS						
Metropolitan LHDs						
- Western Sydney LHD		1				
- Northern Sydney LHD		1				
- South East Sydney LHD		2				
- South West Sydney LHD		2				
- Sydney LHD		1				
- Illawarra Shoalhaven LHD	*(for Shoalhaven end)*	0				
- Nepean Blue Mountains LHD	*(for Lithgow end)*	1				
- Central Coast LHD		0				
		8	x	$350,000	=	$2,800,000
Regional and Rural LHDs						
All these positions funded in 2017 Budget		0				$0
SPECIALIST PALLIATIVE CARE NURSES (Statewide)						
Average of 3 extra per LHD x 15 LHDs for aged care consultations		45	x	$100,000	=	$4,500,000
ALLIED HEALTH (Statewide)						
Average 3 extra per Metro LHD (8 LHDs)		24	x	$116,800	=	$2,803,200
Average 4 extra per Rural LHD (7 LHDs)		28	x	$116,800	=	$3,270,400
						$13,373,600

NOTE
Allied health includes a range of Clinicians; including Social Workers, Occupational Health, Physiotherapists, Psychologists and Dietitians.

Dr Yvonne McMaster
2 April 2018

Palliative Care in New South Wales
Business Case

Submission by Dr Yvonne McMaster FRACGP
& Dr Anthony Ireland FRACP Dip PH FAChPM

Submission enquiries:
Dr Yvonne McMaster
Retired Palliative Care Specialist

15 February 2013

FOUR POTENTIAL COST BENEFITS FROM ENHANCED PALLIATIVE CARE

BENEFIT 1:

Reduced terminal hospital admissions through increased community-based palliative care services. Will address unmet need and increase proportion of deaths at home. Estimate **3,860** fewer terminal admissions to hospital. Current PC service provides estimated 16,000 registrations with 24% home deaths. Enhanced PC service would provide 22,000 registrations with minimum of 35% home deaths.

Saving: 3,860 admissions @ average cost of $14,700 = **$56.7M**

BENEFIT 2:

Provision of palliative nursing and medical support to residential aged care facilities (RACF) to optimise terminal care in place. Currently between 16% and 32% (2,680 to 5,360) deaths of RACF residents occur in hospitals. Optimised PC service can achieve a two-thirds reduction. Estimate two-thirds reduction in transfers to hospitals being **1,790** fewer terminal admissions. [12]

Saving: 1,790 admissions @ average cost $14,700 = **$26.3M**

BENEFIT 3:

Optimised palliative care service can reduce pre-terminal hospital usage, currently estimated at 224,000 bed-days in last 90 days of life.[13] With enhanced PC, the 22,000 PC patients average 2 days, & the 25,400 non-PC patients average 5.6 days [13 (Box 1, derived)], totalling 186,240 bed-days. Thus Palliative Care support could reduce pre-terminal hospitalisations by **37,760** bed-days (i.e. 224,000 - 186,240), rounded here to 37,500.

Saving: 37,500 bed-days @ average cost $1,040 = **$39.0M**

BENEFIT 4:

Enhanced palliative care in acute hospital units will result in reduced acute care episodes and increased palliative care episodes. We estimate **2,570** transfers of cancer and non-cancer patients from acute care to lower cost palliative care units. (PC for cancer deaths in acute care would increase from the current 33% to 50% and PC for non-cancer deaths from the current 8% to 20%.)

Saving: 2,570 episodes @ average cost differential $6,300 = **$16.2M**

TOTAL POTENTIAL SAVINGS per annum (in 2010 dollars) = **$138.2M**

PLACE OF DEATH IN NSW: COMPARATIVE 2009-10

In NSW a higher proportion of people die in hospitals and a lower proportion potentially die "at home" (i.e. in neither hospital nor aged care) than in other parts of Australia. This difference (14.4 per cent vs 20.6 per cent is highly significant, $P<0.0001$)

Table I: PLACE OF DEATH 2009-10

DEATHS	NSW	%	Rest of Australia	%	AUST	%
TOTAL [1]	47,400	-	94,720	-	147,000	-
HOSPITAL [2,3]	26,140	55.1	46,890	49.5	74,000	51.4
AGED CARE [4,5 #]	14,470	30.5	28,320	29.9	54,000	30.1
ELSEWHERE	6,790	14.4*	19,510	20.6*	19,000	20.0

* Difference is highly significant $P< 0.0001$

\# Reported numbers for aged care adjusted for double counting (13% of hospital deaths aged 65+ have also been counted in aged care [5]).

The relatively low "ceiling" of 14.4 per cent for deaths which may occur at home, is presumptive evidence for less-than-optimal resources to support end-of-life care in community settings.

SUPPORTING CALCULATIONS

BENEFIT 1:
Terminal hospital admissions reduced by enhancing community-based palliative care services

a. Calculation of *Optimal* palliative care *caseload*

- Current estimate of annual PC registrations is 16,000 [7]
- Approximately 78 per cent of which have cancer (n = 12,000).
- Total annual cancer deaths = 14,100 [1] ; not all will accept or need palliative care, hence only limited unmet need for cancer patient *registrations.* However the low home death rate for cancer patients in NSW will be improved by enhancing community palliative care services.
- Non-cancer registrations currently < 3,500- 4,000 per year
- Deaths from *non-cancer, non-acute* disease in NSW = 25,000 [10]
- Palliative care can benefit 35-40 % (8,750-10,000) of these [14]
- Calculated unmet need in range of 5,250 to 7,000 *(say 6,000) registrations per year*, raising the potential PC service registrations to 22,000 , as shown in the penultimate paragraph of the next item (b).

b. Calculation of *Potential* number of *home deaths*

- Some Palliative Care services within NSW currently achieve 24 per cent home deaths [6,9]
- Metropolitan Adelaide describes 30 per cent home deaths in 2012 with planned increase to 50 per cent in 2016 [8]
- Palliative Care Outcomes Collaborative reports Australian home death rates of up to 53 per cent for 2011-12 [9]
- Target value of 35 per cent applied in calculation.

Thus, whilst the *current* position is 16,000 palliative care registrations with 24 per cent home deaths (i.e. 3,840 home deaths), the proposed *enhanced* position would be 22,000 PC registrations with 35 per cent home deaths (i.e. 7,700 home deaths).

Thus there would be 3,860 *additional* home deaths (i.e. 7,700 less 3,840) and the same number fewer hospital deaths. This figure of 3,860 fewer hospital deaths has been used in the calculations for Benefit 1 on page 2.

c. Calculation of costs for terminal hospital admissions 2009-10

(i)	Length of stay (LOS) for terminal episode, acute care	= 10 days [3]
(ii)	LOS for terminal episode, palliative care	= 12 days [3]
(iii)	Additional LOS continuous with terminal episode	= 5 days [16]
(iv)	Cost per bed-day, acute care	= $1,260 [12]
(v)	Cost per bed-day, palliative	= $ 840 [12]

Thus,

(vi)	Mean cost for end-of-life hospital admission, acute - calculated by multiplying (iv) by [(i) + (iii)]	= $18,900
(vii)	Mean cost for end-of-life hospital admission, palliative - calculated by multiplying (v) by 15 days	= $12,600
(viii)	Average cost with 25% palliative admissions [6]	= $17,300
(ix)	Potential cost savings to reflect 85% occupancy rate	= $14,700

Explanatory Notes:

- Value of $14,700 (item ix) used in Benefit 1 and Benefit 2
- Value of $18,900 (item vi) - $12,600 (item vii) = $6,300 used in Benefit 4

BENEFIT 2:
Terminal hospital admissions reduced by providing palliative nursing and medical 'in-reach' to residential aged care facilities (RACF)

a. Current estimate is that 13 per cent of hospital deaths for patients aged 65 years and over are from RACF [5] (i.e. 13% x 20,400) = 2,680

b. Enhanced palliative care reduces this by two-thirds [14] i.e it prevents 1790 such admissions (see calculations for Benefit 2 on page 2).

BENEFIT 3:
Optimising Palliative Care service can reduce pre-terminal hospital usage

Study of hospital and health costs in NSW in 2004 identified average 13.0 days in hospital in *last 90 days of life* for each deceased person. [11]

Extrapolating this 13.0-day figure to 47,400 deaths in 2009-10 gives 616,000 bed-days in the *last 90 days of life* (i.e.13.0 x 47,400).

The 'Place of Death' table on page 3 identifies 26,140 deaths in hospital with an average hospital stay of 15 days (see previous entry under Benefit 1 c, i.e 10 + 5 = 15 days) = 392,000 bed-days *for the terminal episode*.

Thus the “pre-terminal” bed-days in the last 90 days of life total **224,000** bed days (calculated as the difference between 616,000 and 392,000).

Currently, 16,000 *palliative* patients are known to have reduced pre-terminal hospital use. Data from Western Australia suggests the average pre-terminal stay (in the last 90 days of life) for patients receiving optimal palliative care is < 3 days. [15]

If the current 16,000 *palliative* patients each use an average of 3 pre-terminal days in hospital, together they spend a total of **48,000** such days in hospital. By subtracting this figure from the 224,000 derived above we arrive at a total of **176,000** pre-terminal bed days for the 31,400 *non-palliative* patients (47,400 total deaths minus the 16,000 palliative deaths). Thus the average pre-terminal admission for *non-palliative* patients is **5.6 days** (176,000 divided by 31,400).

In the enhanced palliative care model, the 22,000 *palliative* patients will use an average of 2 days in hospital with their total pre-terminal usage being **44,000** bed-days.

Use by the 25,400 *non-palliative* patients (i.e. 47,400 total deaths minus the 22,000 deaths in patients receiving palliative care) is 25,400 x 5.6 days = **142,240** bed-days.

Thus, under the enhanced palliative care model, the total pre-terminal hospital bed-days will be 44,000 (palliative) + 142,240 (non-palliative) = **186,240** bed-days.

Thus, enhancing palliative care will save **37,760** bed-days of pre-terminal hospitalisations, calculated as follows: 224,000 (currently, see above) minus 186,240 (after enhancing palliative care).

This 37,760 figure has been rounded down to 37,500 in the calculation on the summary page for Benefit 3 (see page 2).

We have calculated the actual figure saved under Benefit 3 is $45,696,000 which translates into $1,218.56 per bed-day saved. However, since the service description of the non-palliative bed-days saved is unknown, we have used 85% of the latter figure, namely $1,040 per bed-day saved (see page 2).

BENEFIT 4:
Changes in care type by enhancing palliative care access to terminal patients in acute hospital units reduces terminal episode costs through reduced use of intensive care, diagnostics, medical and surgical procedures and pharmaceuticals. [13]

a. Current:
Palliative care for cancer deaths = 1,589 / 4,754 (= 33.4%)
Palliative care for non-cancer deaths = 1,064 / 14,189 (= 7.5%)
Total palliative care episodes = **2,653**.[3]

b. Estimated from enhanced palliative care:
Cancer deaths = 50 per cent x 4,754 = 2,377
Non-cancer = 20 per cent x 14,189 = 2,838
Total palliative care episodes = **5,215**

c. Additional palliative care
Episodes with enhanced palliative care = 5,215
Less, Episodes with current Palliative care = 2,653
Thus, Additional palliative care episodes = **2,562**

d. Palliative episodes have a $6,300 cost reduction
(as shown in calculations for Benefit 1).

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Out of Hospital Care
End of Life Packages
Information for Local Health Districts

NSW GOVERNMENT | Health

What are End of Life (EoL) Packages?

- End of Life (EoL) packages are **non clinical** packages of case management and home care services delivered through the NSW Health Out of Hospital Care (OHC) Program.
- Packages provide **low to medium** levels of home care services for patients who are in the deteriorating or terminal phase of a life limiting illness or condition.
- Packages are available for **up to six weeks** at a time. Repeat packages may be available to patients who require further support.

What is provided?

Case Management
Each patient is allocated a Case Manager who will be their main contact throughout the EoL package. The Case Manager will either visit the person in hospital, at home or if urgent speak with the family/carer via the phone to assess their needs.

The following services **may** be provided depending on the client's assessed needs:

Personal Care
Assistance with bathing, oral care, hygiene, dressing and grooming
Domestic Assistance
Cleaning, vacuuming, mopping, laundry and shopping
Meals
Meals delivered to the home or meal preparation
Transport
For medical and other appointments
Social Support
Accompaniment to appointments, shopping, paying bills
In Home Respite
Support for carers

Who can refer?

Referrals can be made from NSW public hospitals or LHD community teams including: Specialist Palliative Care, Community Nursing, Chronic Care and Aged Care.

LHDs have identified key referrers or teams that can screen patients for eligibility.

How do I refer?

Once a patient has been identified and screened by staff, referrals within HNELHD are to be forwarded to the OHC Centralised Intake Service as follows:

Email Referral to:
HNELHD-OutofHospitalCare@health.nsw.gov.au

Fax Referral to:
(02) 4924 6098

Phone:
1300 730 622

When do I refer?

Referrals should be made as soon as possible once it has been determined the patient is experiencing functional decline and is in the deteriorating or terminal phase of Palliative Care.

This will enable patients, their families and carers to commence services earlier and build trust and rapport with their key workers.

Who is eligible?

A person who:

- is experiencing functional decline and is in the deteriorating or terminal phase of a progressive life limiting illness or condition (this could be 3 months or less before death),
- is of any age**
- requires non-clinical home care services to manage at home for as long as possible,
- has a carer/family members that require non-clinical home care services to support the patient to die or remain at home for as long as possible,

**While the EoL packages are available to people of all ages these do not generally cater for the specific needs of children. Instead the packages are there to support parents in their caring role.

Who is not eligible?

- A person who resides in a residential aged care facility and is requiring home care services to be provided in that facility.

Funding

OHC is a State funded initiative and is managed in conjunction with LHDs by the **NSW Ministry of Health Out of Hospital Care (OHC) Team.**

For further information, please contact **HNELHD Out of Hospital Care Coordinator** by email HNELHD-OutOfHospitalCare@health.nsw.gov.au or phone 1300 730 622.

Version 1, May 2021

NSW Health

Out of Hospital Care

Interim Guidelines

NSW
GOVERNMENT

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Produced by: NSW Ministry of Health

The NSW Ministry for Health acknowledges the traditional custodians of the lands across NSW. We acknowledge that we live and work on Aboriginal lands. We pay our respects to Elders past and present and to all Aboriginal people.

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Contents

> NSW Health will “Continue to support and develop hospital avoidance and post discharge care to reduce acute demand by developing service models that deliver the right care, in the right place, at the right time”.
>
> The NSW State Health Plan: Towards 2021

SECTION 1

Background

1.1 What is the Out of Hospital Care Program?

The NSW Health Out of Hospital Care (OHC) Program offers improved opportunities to care for people at home after hospitalisation and to prevent avoidable hospital admissions. This is a major priority for NSW Health and part of our commitment to deliver the right care, in the right place, at the right time.

Caring for people at home is well regarded by patients, their families and carers. This enables continuity of care and reduces the risk of hospitalisation, especially for people who are at risk of falls or infections. Care at home helps to take the pressure off public hospitals by freeing up beds, reducing demands on emergency departments, and containing treatment staffing costs.

The NSW Health OHC Program (formerly known as the ComPacks Program) began in 2003. The program expanded in 2018 with the introduction of the Safe and Supported at Home (SASH) packages and in 2021 with the End of Life (EoL) packages (see Diagram 1). The role of the OHC Program is to support patients who are discharged from NSW public hospitals and to minimise preventable admissions for people living in the community. This is achieved by delivering **short and medium-term** packages of non-clinical care to eligible patients across the state.

It is anticipated that up to 35,000 OHC packages will be delivered to patients across NSW each year. These services are critical as research shows that patients and their families/carers can face major barriers to accessing care in the community including long waiting times for services.

1.2 OHC Packages

OHC packages deliver low to medium levels of care which include non-clinical case management and home care services such as personal care, domestic assistance, meals, transport, respite and social support. Patients can seamlessly transition between the three package types if their care needs change without any disruption to their services.

ComPacks

ComPacks are available to in-patients of participating NSW public hospitals who require short-term coordinated home care services, to return home safely. ComPacks are available for up to six weeks post discharge from hospital and do not provide ongoing or intensive levels of care in the home.

Healthy at Home (HaH) – ComPacks

ComPacks is also used in some LHDs as an early intervention hospital avoidance strategy. This is known as Healthy at Home (HaH) ComPacks. These packages are delivered in partnership with LHD clinical services to prevent hospital admissions.

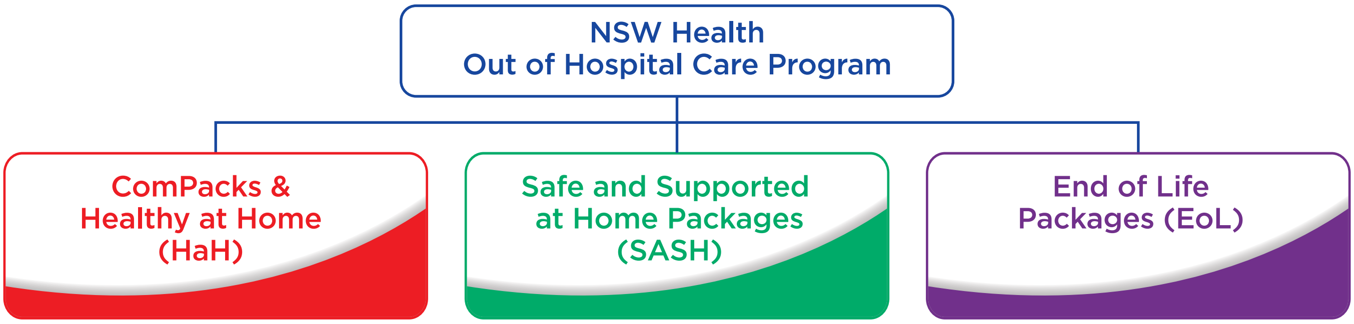
Safe and Supported at Home (SASH)

These packages are available for people who are accessing LHD community health or out-patient services. They are also available for patients being discharged from hospital who may be at risk of an avoidable admission. The role of the SASH package is to support patients with functional impairment/s who are in the process of applying for the National Disability Insurance Scheme (NDIS) or have been deemed ineligible for this scheme.

End of Life (EoL)

EoL packages support patients with a progressive life limiting illness or condition. The packages are designed for patients who are in the deteriorating or terminal phase of their illness or condition, require assistance with daily living tasks and wish to die in their own home or to remain at home for as long as possible. The package can also support family members or carers. Referrals can be made from the in-patient or out-patient settings and from LHD community-based teams, including (but not limited to) Specialist Palliative Care, Community Nursing, Chronic Disease and Aged Care Assessment Teams.

Diagram 1. NSW Health Out of Hospital Care



1.3 About this Document

The NSW Health OHC Guidelines have been developed in consultation with representatives from key stakeholder groups and are designed as a resource for frontline Health staff, LHD Relationship Managers and Service Providers. They outline the key components of the programs including eligibility, referrals, service delivery, assessment, stakeholder responsibilities, co-ordination, and performance management (see Diagram 2).

1.4 Key Definitions

Note that throughout this document:

- NSW Health Out of Hospital Care is referred to as OHC.
- An Out of Hospital Care recipient is referred to as a ‘patient’.
- LHDs and St Vincent’s Health Network are referred to collectively as LHDs.
- Home Care Services is used to describe services delivered through the NSW Health OHC program. This does not include Australian Government funded aged care programs or other services provided as part of the National Disability Insurance Scheme (NDIS).

SECTION 2

NSW Health Out of Hospital Care Program

2.1 Aim

The aim of NSW Health OHC is to:

- reduce unnecessary hospital time for patients being discharged home from public hospitals in NSW and
- prevent avoidable hospital admissions.

2.2 When to Choose Out of Hospital Care

NSW Health clinicians making referrals need to be aware of the various programs that offer home care at the point of discharge from hospital and those that offer support accessible from the community. Being aware of what is available will help clinicians refer people to the right program.

NSW Health OHC is appropriate to use when:

- a patient requires immediate access to case management and home care for a safe discharge home and/ or to prevent an admission or readmission to hospital,
- services are not in place or cannot be immediately accessed through other programs and
- no informal support options such as family or friends are available for the patient.

The Australian Government also provides community support programs. These include: Home Care Packages (HCP) Program, Commonwealth Home Support Program (CHSP), Department of Veterans' Affairs (DVA), Transitional Aged Care Program (TACP) and the Short-Term Restorative Care Program (STRC). See Appendix 1 for more information about these programs.

2.3 Who is Eligible for Out of Hospital Care?

The target groups for the OHC Program are people of all ages who are either inpatients in a NSW Health Public Hospital or have been referred by a NSW Health Community Health Service or Out-patient Team. Eligible people may be suffering from acute or chronic health conditions, functional impairment/s or a life limiting illness that impacts on their ability to manage their activities of daily living and therefore puts them at risk of unnecessary hospitalisation.

Eligibility

To be eligible for the OHC Program:

- the patient or carer consents to participating in the program,
- the patient requires non-clinical case management and home care services to enable that person to be discharged home safely and to prevent avoidable admission,
- the patient has no other programs or services in place that provide the level of care that is required. For example, if the patient is currently receiving the Commonwealth Home Support Program (CHSP), their Service Provider may be asked to temporarily increase their services. If this is not possible OHC may be provided,[1]
- the patient does not require a package of care that is long term or an intensive level of community supports beyond the scope of the program and
- the patient is not living in Residential Care.

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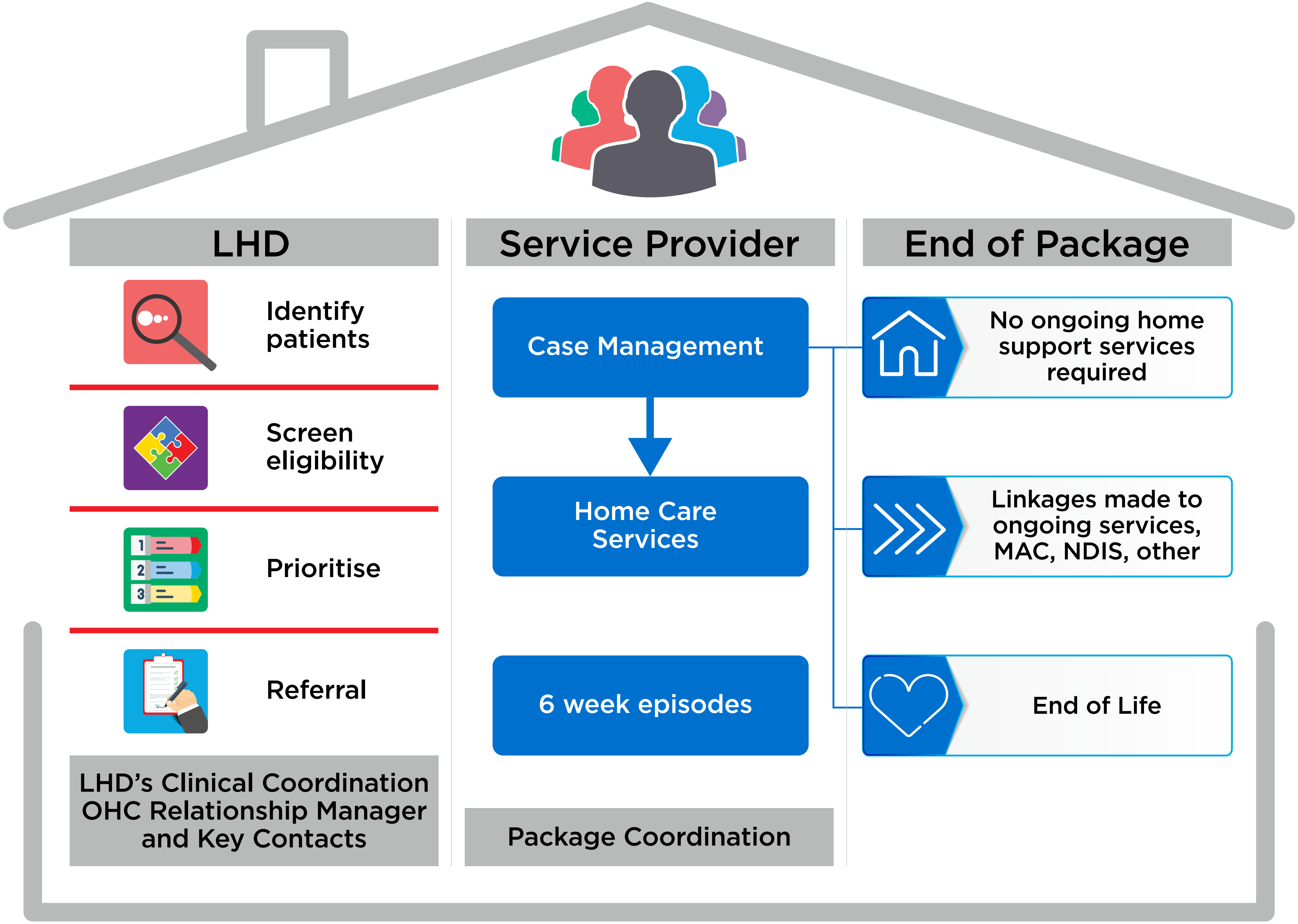
[1] In some circumstances patients who receive low level community services such as the CHSP or Home Care Packages (HCP) Levels 1-2 may be eligible for the OHC provided there is no duplication in service provision.

Diagram 2. The Out of Hospital Care Model



ComPacks

To be eligible for ComPacks, the patient:

- must be discharged from a NSW participating public hospital,[2]
- has been identified as medically stable by the LHD in-patient treating team and no longer requires hospitalisation,
- is at risk of readmission unless ComPacks is utilised and
- can be of any age although the packages generally do not cater for the specific needs of children. Instead they are there to support parents in their caring role.

Safe and Supported at Home (SASH) Packages

To be eligible for the SASH package, the patient:

- must be aged between 18 and 64 years,
- has functional impairments that impact on their ability to manage activities of daily living. This may include a sensory, functional, or psychosocial disability,
- has limited or no informal supports,
- has commenced the NDIS application process and has received a reference number and
- has had their application to the NDIS rejected or requires support while re-applying for the NDIS or appealing an access decision. In some cases, the SASH package can support people waiting for a NDIS support plan to be implemented or reviewed.

Referrals for SASH packages can be made from either the inpatient or community setting. A risk of hospitalisation tool such as the NSW Chronic Conditions Patient Selection (CCoPS) Tool may be used to identify and prioritise patients at higher risk.

End of Life (EoL) Packages

To be eligible for EoL packages the patient:

- must be experiencing functional decline and is in the deteriorating* or terminal** phase of a progressive life limiting illness/condition,[3] (typically this could be 3 months or less before death),
- can be of any age although the packages generally do not cater for the specific needs of children. Instead they are there to support parents in their caring role,
- requires non-clinical home care services to be able to manage at home for as long as possible,[4]
- has a carer/family member that require non-clinical home care services to support the patient to die at home or to remain at home for as long as possible.

Palliative Care Phases – (PCOC Palliative Care Outcomes Collaboration)

***Deteriorating**

- the patient's overall functional status is declining and/or
- the patient experiences a gradual worsening of an existing problem and/or
- the patient experiences a new but anticipated problem and/or
- the family and carers experience gradual worsening of distress that impacts on the patient's care

****Terminal**

When death is likely within days

2.4 Special Considerations

The following categories of patients may be eligible for the OHC program in certain circumstances provided they meet the program criteria:

Hospital in the Home (HITH)

Hospital in the Home (HITH) services provide acute or subacute care to adults and children as substitution or prevention for in-hospital care. Patients receiving daily care as hospital substitution are eligible for OHC during and after the completion of their HITH episode.

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[2] ComPacks is specifically funded to support patients being discharged from **NSW public hospitals. Referrals cannot be accepted for patients from private hospitals**. It is the responsibility of private hospitals to undertake discharge planning while patients are under their care, including making referrals to community services to assist patients with safe and timely discharge.

[3] The term life-limiting is used where it is expected that death will be a direct consequence of a specified illness or condition. This may include conditions/diseases such as; Cancer, End stage chronic disease Dementia, Neurodegenerative Disease, Degenerative illnesses or significant deterioration, related to ageing.

[4] The Australian-Modified Karnofsky Performance Scale (AKPS) can be used to identify eligible patients for the EoL packages. It is used by Palliative Care teams to identify what phase of palliative care a patient may be experiencing. Those patients who are identified as being in the deteriorating or terminal phase of Palliative Care score <50 on the scale and is an indicator that the patient's functional status is in decline and a referral to community services is recommended. These patients may have a few months or weeks left to live see Appendix 2.

Medicare Ineligible Patients

As a rule, patients who are Medicare ineligible are not eligible for OHC however exemptions may apply. It is the responsibility of the referrer to determine a patient's eligibility in this situation, based on a patient's status documented during hospital or community registration.

According to *NSW Health policy PD2016_055 Medicare Ineligible and Reciprocal Health Agreement – Classification and Charging*: An individual visiting from a country that has a Reciprocal Health Care Agreement (RHCA) with Australia is eligible for the OHC program. Note however that Overseas Students are not eligible for the OHC Program regardless of whether they are from a country that has a reciprocal agreement with Australia.

Refugees, humanitarian entrants or Permanent Protection Visa holders may be entitled to public health services and consequently would be eligible for the OHC Program if they meet the eligibility criteria. The relevant NSW Health policies are:

- PD2011_014 – NSW Refugee Health Plan 2011-2016,
- PD2016_055 Medicare Ineligible and Reciprocal Health Agreement – Classification and Charging,
- PD2020_039 Medicare Ineligible Asylum Seekers – Provision of Specified Public Health Services and
- Fees Procedures Manual for Public Health Organisations

Patients Eligible for Workers Compensation or Third-Party Insurance

Patients who have an accepted Workers Compensation or Third-Party insurance claim at the time of hospital admission are ineligible for the OHC Program.

If such a patient requires home care post discharge, the referrer needs to make private arrangements with an appropriate agency or Community Service Provider. The referrer will need to contact the relevant insurance company to seek permission for this private arrangement. These referrals are not bound by the Guidelines of the NSW Health OHC Program.

2.5 Duration of Out of Hospital Care

Table 1: Duration of OHC

Packages	Duration	Start date of the Package
ComPacks	• Up to 6 weeks	Date of discharge
Safe and Supported at Home (SASH)	• 6 weeks • Repeat packages if required	Date of discharge or Date of assessment at home
End of Life (EoL)	• Up to 6 weeks • Repeat packages if required	Date of discharge or Date of assessment at home

In exceptional circumstances if there is a delay in the start of home care services (over one week), then the Case Manager can use the date of the first brokered service as the start date of the package.

2.6 Patient Contribution

OHC patients are asked to contribute to the cost of their package and this co-payment is capped at $10 per week. Referring staff must advise the patient that they will need to contribute towards the cost of their service. The Service Provider arranges the patient contribution to the program in consultation with the patient. EoL patients are exempt from this fee.

Please note: A person's inability to pay does not exclude them from receiving OHC.

2.7 Participating Hospitals

ComPacks

LHDs have nominated specific hospitals to participate in the program. These are generally hospitals that experience high admission rates and pressure on bed availability. A list of current participating hospitals is available on the NSW Health website: http://www.health.nsw.gov.au/

Interstate Hospitals

LHDs may identify that NSW residents are presenting at their facilities requesting OHC after being discharged from hospitals interstate. It is important for LHDs to assess the overall demand and flow of NSW patients from interstate hospitals in these instances. There is scope for LHDs to accept referrals from these hospitals for public patients on a case by case basis. If the demand is consistent a Memorandum of Understanding may be required between a LHD and an interstate hospital. The MoH OHC Team can work with LHDs to facilitate these arrangements.

2.8 Allocation of Packages

Service Providers accept OHC referrals from LHDs in NSW and deliver packages to patients residing in designated catchment areas. A catchment area is made up of specific Local Government Areas (LGAs) belonging to the LHD. The allocation of packages to Service Providers is based on projected demand and previous activity.

The OHC Program has been designed so that any person who is eligible can be referred to a Service Provider covering their local government area. A directory of Service Providers and specified catchment areas is available on the NSW Health website: https://www.health.nsw.gov.au/

Example: *A person may be admitted to a participating hospital outside of their place of residence whilst on holiday or visiting family. If they are eligible for OHC, they can be referred to their local Service Provider to arrange discharge home with the ComPacks, SASH or EoL Packages.*

At times of peak demand an LHD may purchase additional ComPacks to support hospital discharges. This can occur through consultation with the Service Provider regarding capacity to provide additional packages and following an internal LHD approval process including the identification of a funding source. The MoH OHC team will then facilitate the purchase process.

2.9 Out of Hospital Care – Package Types

At the end of each 6-week episode OHC patients are coded by Service Providers into the following package types based on complexity and cost: see Table 2 below. The current price of each band is detailed in the NSW OHC Services Agreement the MoH has with each Service Provider. Rates may be subject to an annual CPI adjustment.

Table 2: Package Types

Package Type	Description
Assessment Only	The patient is assessed by a Case Manager but does not go on to receive home support services. Reasons may include death, ineligibility or the patient withdrawing from the service.
Band 1 **Low package care**	May include patients who required a low level of services, have withdrawn from the program or were readmitted to hospital and did not complete the 6 week episode.
Band 2 **Medium package care**	May include patients who required a medium level of case management and two or more community support services for up to 6 weeks.
Band 3 **High package care**	May include patients who required an intense level of case management and home care for the 6-week period.
Extensions	In exceptional circumstances ComPacks packages can be extended beyond 6 weeks. See Section 3 – Extensions.
Repeats	SASH and EoL packages are subject to review at the fourth week of the package. A repeat package can be applied for. See Section 3 – Repeat Package.

SECTION 3

Service Delivery

3.1 Case Management

Non-clinical Case Management is key to ensuring that patients receive a package of care that meets their needs. Case Management is provided directly by the Case Manager and begins with the patient assessment and ends with case closure.

Case Managers have the skills and experience to work with patients who are elderly, have chronic and complex health conditions, have sensory, functional, or psychosocial disability or are nearing the end of their life.

3.2 Wellness and Reablement Approach to Case Management

Service Providers that have been selected to deliver the OHC Program are organisations that use a 'Wellness and Reablement' approach as a basis for their Case Management and home care service delivery.

The Commonwealth CHSP Good Practice Guide 2020 defines wellness as *'an approach that involves assessment, planning and delivery of supports that builds on the strength, capacity and goals of individuals, and encourages actions that promote a level of independence in daily living tasks, as well as reducing risks to living safely at home.'* (Page 10) Reablement is defined as '*time-limited interventions that are targeted towards a person's specific goal or desired outcome to adapt to some functional loss or regain confidence and capacity to resume activities.* (Page 12)

Living well at home: CHSP Good Practice Guide. Australian Government, Department of Social Services. June 2020.

3.3 Key Components of Case Management

Assessment

Once a referral is accepted, the Case Manager will conduct a comprehensive assessment working collaboratively with the patient and where required their family or carer to gather information. This includes identifying the patient's goals, needs and availability of formal and informal support. A holistic assessment will consider the following life domains:

- standard of living (housing, income)
- health (physical, mental & emotional)
- achievements in life (employment, education)
- personal relationships (family, social networks)
- community connection (cultural, spiritual)
- personal safety
- future security.

The Case Manager will demonstrate cultural and social awareness by being sensitive and responsive to people of ATSI and CALD communities, people of LGBTIQ, people with disability and people with palliative care needs.

During the assessment phase the Case Manager will undertake an environmental risk assessment to ensure the safety of the patient, the Case Manager, Care Workers and others attending to the home.

The Patient/Family/Carer and the Case Manager will agree on the home care services required and discuss what is likely to occur at the completion of the package. For example, exit planning for the SASH packages may involve a streamlined transition to services under the NDIS.

Care Planning

Based on the assessment the Case Manager develops a Care Plan that documents the patient's goals. The Care Plan will include a review date and:

- identify and prioritise long and short-term goals with the patient,

- determine strategies and actions tailored to the patient to achieve these goals,
- build in opportunities for and indicators of success,
- clarify roles of Case Manager, patient, other stakeholders, and timeframes,
- identify other organisations and supports to refer to,
- co-ordinate resources and services,
- incorporate SMART goals. These include: Specific goals, Measurable outcomes, Attainable, Relevant and, where possible, Time limited and
- exit plan.

Coordination

The Case Manager will roster care workers from their organisation or arrange care workers from one of their sub-contracted agencies to deliver the services in the patient's home.

The Case Manager will develop a Service Plan for the patient which includes the days and times when specific services such as personal care will be provided. The Case Manager will maintain progress notes for the patient for the duration of the package and will document any feedback received from the sub-contracted agency.

Monitoring

The Care Plan, Service Plan and package budget are closely monitored by the Case Manager, who liaises with the patient and or family/carer and others involved in providing services, throughout the duration of the package.

The Case Manager will monitor the patient throughout the package episode and respond to or adjust services to meet a patient's changing health status or home care needs.

The Case Manager may identify and report incidents of witnessed or disclosed violence, abuse, or neglect to the appropriate authorities.

Reviews

SASH and EoL packages are available in six-week increments. Case Managers will review the care plan with the patient and/or family/carer to determine whether the patient's goals have been achieved and to decide whether the patient will exit the program or continue to receive another package for 6 weeks.

The LHD OHC Relationship Manager will be required to approve repeat packages. This will be done in consultation with the Case Manager, LHD SASH Co-ordinator and other relevant key contacts or clinicians if necessary.

Linking

Case Managers make referrals early in the package episode to link the patient to community supports if required as part of planning for case closure. Case Managers can refer patients to other health and community service providers for services that are not available through OHC. The Case Manager may refer patients to the following services:

- Clinical out-patient and community health services
- National Disability Insurance Scheme (NDIS)
- My Aged Care – Regional Assessment Service (RAS) for an assessment of eligibility for the Commonwealth Home Support Program (CHSP)
- My Aged Care – Aged Care Assessment Team (ACAT) for an assessment of eligibility for the Home Care Packages (HCP) Program, Short-Term Restorative Care Program or Residential Aged Care services
- Department of Veterans' Affairs (DVA)
- Carer Gateway
- Centrelink
- NSW Department of Communities and Justice – Housing
- Informal supports such as community groups, clubs and places of worship
- The Case Manager will often work together with partner agencies to facilitate a successful outcome for the patient. This may involve: attending case conferences with LHD staff, Disability Advocates, NDIS Local Area Co-ordinators (LACs) and other relevant organisations.

Case Closure

The Case Manager must prepare the patient and their family/carer for what will occur after the completion of the package. Case closure occurs when a patient:

- refuses assessment or support,
- no longer requires support,
- has transitioned to ongoing services,
- has reached the maximum threshold of support a package can offer or
- has reached the end of life.

3.4 Documentation Guidelines for Case Management

Case Managers are required to keep specific documentation outlining the patient's care and the services delivered. The format of this documentation is at the discretion of the individual Service Provider, but it must contain the following components:

- a Service Agreement between the Service Provider and the patient, signed by the patient or their representative,
- relevant background and demographic information on the patient, the patient's family/carer, and significant others,
- results of the initial assessment and periodic reviews of the patient,
- the Care Plan that includes details of the patient's goals and proposed action plan,
- a service schedule (Service Plan) detailing all services to be delivered during the package duration. This document will include the patient's sign-off prior to commencement of the services,
- details of referrals to other agencies or resources and the outcomes. For example: whether referrals have been accepted or the patient has been waitlisted and
- documentation of the exit plan for the patient.

3.5 Home Care Services

OHC services are delivered by the Service Provider's own care workers or by care workers brokered from sub-contracted agencies. It is the responsibility of Service Providers to ensure that Service Agreements are in place with all their sub-contracted agencies and that the agencies comply with the conditions specified in the NSW Health OHC Services Agreement.

Care Workers

Service Providers will aim to match care workers with the needs of their patients. This may include specific gender or cultural needs identified by the patient or their family/carer during the initial assessment. Service Providers or their sub-contracted agencies may have care workers with greater experience working with the frail elderly, patients with dementia, disability, mental health or palliative care needs.

Care workers can escalate a change in the patient's condition or carer stress and fatigue to the Case Manager who will promptly bring these matters to the attention of the key LHD treating clinicians. Care workers will deliver care in a wellness and reablement approach, 'doing with' the patient rather than 'doing for'.

Service Types

The OHC Program can offer eligible people a combination of some or all (but is not limited to) the home care services listed in Diagram 3.

Hoarding and Squalor Cleaning Services

Some patients may be living in conditions which can result in illness, hospitalisation or prevent Service Providers from delivering the necessary services required. In extraordinary cases, the OHC Program can support an initial clean of the property so that home care services can commence. For this to occur Case Managers must consider the following:

Assessing Hoarding and Squalor Situations

- Do the patient's hoarding behaviours and/or squalor conditions present a health and safety threat to the patient, their neighbours and/or community services staff entering the property?
- Is access to and within the home greatly restricted? This would include access by emergency services if required.
- Are there are any fire hazards due to hoarding or squalor?
- Are there any biohazards such as animal or human bodily waste or other unhealthy conditions in the home?
- Is the home structure compromised and or in danger of failure such as wall and floor coverings, electrical systems and plumbing systems?
- Is there an infestation of pests or rodents?
- Is the patient at risk of being hospitalised?
- Is the patient at risk of being evicted and facing homelessness?

If the assessment identifies a 'yes' to one or more of the questions above, Service Providers are to select one of the options below:

For Patients aged 50 years or over (45 years and over for Aboriginal and Torres Strait Islanders)

Patients within this age group who reside in hoarding or squalor conditions and are at risk of eviction and/or homelessness may be eligible for Assistance with Care and Housing (ACH) under the Commonwealth Home Support Program (CHSP). Please see the CHSP Program Manual 2020-2022, Section 3.2.3 Assistance with Care and Housing Sub-Program for more information.

If they meet the above criteria, the Regional Assessment Service (RAS) or Aged Care Assessment Team (ACAT) may refer patients.

Referrals for RAS or ACAT assessment are made via My Aged Care on 1800 200 422 or via www.myagedcare.gov.au/referral

For Patients aged 49 years and under

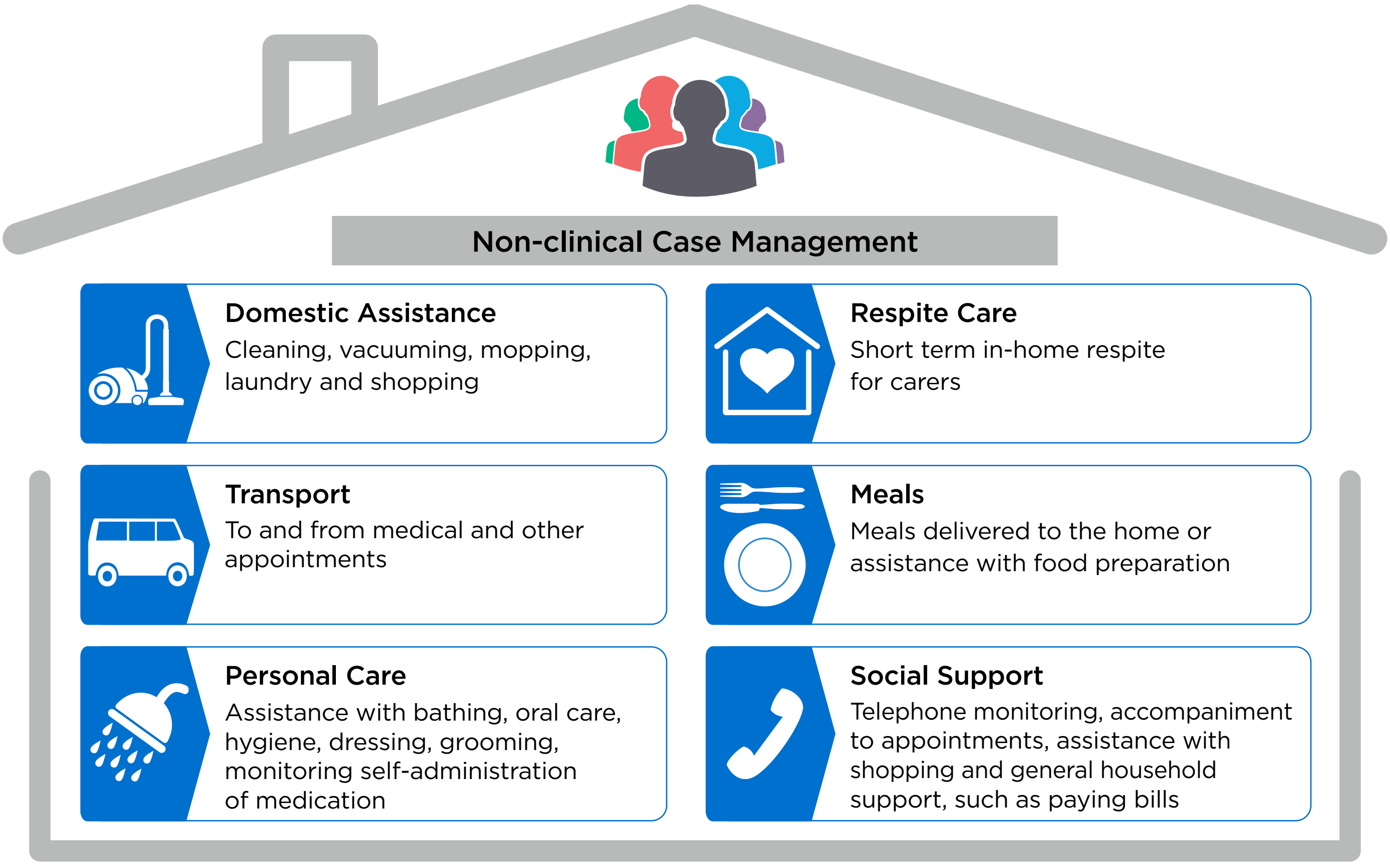
If a squalor clean falls within the costs of the patient's current band of service, then this service can go ahead. If the squalor clean is outside the costs of a current band 1, 2 or 3, service approval must be sought from the LHD Relationship Manager and the MoH OHC Team for an extension to cover the cost. This can be done in the following ways:

- obtain a minimum of 2 quotes from Providers of hoarding and squalor cleaning services,
- complete an OHC extension form and outline the reason for the clean and the projected band extension,
- submit the extension form and quotes to the MoH OHC Team via MoH-OutOfHospitalCare@health.nsw.gov.au and
- if the quotes exceed the SASH extension bands, the Service Provider must contact the MoH OHC Team to discuss.

Please note:

- Not all the components of the CHSP Assistance with Care and Housing sub-program are available in all LHDs.
- Please contact the MoH OHC Team in situations where My Aged Care has refused to accept a referral for a patient aged 50 years and over (or 45 years and over for ATSI patients) for an assessment and the team will escalate this matter to the MoH Aged Care Unit.

Diagram 3. The types of services available to patients



Non-clinical Case Management

Domestic Assistance
Cleaning, vacuuming, mopping, laundry and shopping

Respite Care
Short term in-home respite for carers

Transport
To and from medical and other appointments

Meals
Meals delivered to the home or assistance with food preparation

Personal Care
Assistance with bathing, oral care, hygiene, dressing, grooming, monitoring self-administration of medication

Social Support
Telephone monitoring, accompaniment to appointments, assistance with shopping and general household support, such as paying bills

3.6 Out of Hospital Care Case Studies

ComPacks

Phuong is 63 years old. He was recently discharged from hospital following a severe fracture of his right tibia and fibula after falling in the street. He has been told by his surgeon that he cannot weight bear on his right leg for up to 6 weeks. He is using crutches or a frame indoors and a wheelchair for outings. Phuong lives alone in his own home and is normally independent with daily living and domestic tasks. He has 2 sons who both work fulltime and can only provide limited assistance. Phuong works for the local council in an administrative role but will not be able to return to his job until he can walk independently.

Phuong can manage all transfers independently in/out of his wheelchair and in/out of a chair, bed and toilet but requires assistance with showering using a shower chair. He is independent using an over-toilet aid and urinal bottle for night-time. Phuong cannot manage vacuuming, his laundry/changing bedclothes etc. He can heat up meals in the microwave but will have difficulty preparing meals. His sons can assist in the evening.

The OHC Case Manager was able to arrange a male care worker to provide personal care services to assist Phuong 3 times per week. This involves assistance with showering and dressing. ComPacks is also assisting with vacuuming, mopping, and shopping on a weekly basis.

Phuong's sons are assisting with evening meals and are assisting their father on the weekend.

The Case Manager reviewed Phuong's progress at the 4-week mark and found that Phuong had developed more confidence and was managing well with his showering. It was agreed that Phuong would not need services after the end of the ComPacks package as his sons would manage the domestic duties from that time onwards. Phuong arranged with his employer to work from home until he was ready to return to the office.

Safe and Supported at Home (SASH) Packages

Joanne is 61 years old, lives alone and is estranged from her 2 children who live interstate. She resides in a small private rental property some 20km from the nearest health facility. She was referred to the SASH packages by the LHD Community Health Social Worker for support with tasks such as cleaning, laundry, shopping, and preparing meals.

Joanne has multiple health conditions including Chronic Fatigue Syndrome, heart failure, anxiety and depression. She has associated impairments such as: breathlessness, insomnia, and impaired mobility. Her depression has been exacerbated by her deteriorating health and she has attempted to take her own life on 2 occasions. Her last Psychiatry review was in 2018.

Joanne has applied to the NDIS on 3 occasions, but her latest Access Request was declined because there was insufficient evidence to support her case. Joanne has become withdrawn and reluctant to seek further medical and allied health assessments to enable her to contest the NDIA decision.

The OHC Case Manager met with Joanne at her home to assess her needs and establish a Care Plan. Joanne's plan included assistance with shopping and meal preparation weekly and domestic tasks such as cleaning and washing fortnightly. To reapply to the NDIS was her long-term goal.

The OHC Case Manager worked with Joanne's Disability Advocate and the LHD SASH Co-ordinator to encourage Joanne to appeal the latest NDIA decision. This included several Case Conferences some of which included Joanne. Together they reviewed the latest Access Request Form and medical reports that were supplied to the NDIA. They discovered that the form lacked the correct information to support Joanne's case. Joanne's SASH care plan was updated to include a referral for an occupational therapy assessment and transport to a psychiatrist for a more comprehensive mental health review. Personal care and domestic assistance services were also upgraded to meet her changing needs.

Joanne was assessed by an OT and Psychiatrist and reports were made to reflect her lifelong impairments. Joanne and her Disability Advocate commenced the appeals process to the NDIA. The LHD SASH Co-ordinator also contacted the NDIA highlighting Joanne's situation and her urgent need to access the NDIS. Joanne's appeal was successful and through her NDIS support plan, she is now able to access home support, therapy, and psychiatry services. Joanne continued with the SASH packages until her NDIS Support Plan was finalised and her long-term services were put in place.

End of Life Packages

Selma is 55 years old and has terminal ovarian cancer. She lives with her husband Rami and their daughter Christina who is in her early 20s. Rami has given up work to care for Selma. Christina is working full time to support her family.

Selma was referred to the End of Life (EoL) packages by the Oncology Social Worker following a stay in hospital where she was told by her Specialist that she may only have weeks to live. Selma is still able to mobilise, shower and dress herself however is finding that the process is now exhausting and leaving her with little energy for activities that she might enjoy. Selma desperately wants to return home from hospital, advising her Social Worker that she wishes to die at home surrounded by her family.

The OHC Case Manager visited Selma at home where she was able to undertake a thorough assessment and develop a care plan in conjunction with Selma and Rami around the needs of the family. Selma and Rami decided that Rami would attend to Selma's personal care for now. Selma was concerned about the stress placed on her family and requested support with shopping, laundry, cleaning and some in-home respite so Rami can attend to errands.

The Case Manager was able to arrange a Care Worker to provide biweekly domestic services to support the family. After 3 weeks Rami contacted the Case Manager to report that Selma's condition had deteriorated, and he had been told she may die within the next week. The Case Manager attended the home the next day where Selma was now bed-bound. The LHD Palliative Care team was managing the clinical aspect of Selma's care and Rami was still wanting to attend to her personal care. He wanted the Care Workers to be able to prepare meals for him and his daughter and to sit with Selma while he had a shower. The Case Manager was able to adjust Selma's Care Plan and daily support was organised from the next day onwards.

Selma died in her home 4 days later. Rami contacted the Case Manager the day after Selma's death to thank her for the great support provided by the Care Workers which allowed him to spend some quality time with his wife at the end of her life.

3.7 The Provision of Daily Living Equipment

The OHC Program does not have funds to purchase daily living equipment and mobility aids. Any daily living and mobility aids should be issued or recommended to the patient by the appropriate health staff, either at the time of leaving hospital or while at home to prevent avoidable hospital admissions.

Equipment can be accessed through general LHD equipment loan pools, (ELP), LHD ELPs quarantined for Palliative Care patients, Enable NSW, or purchased or hired by the individual. In some circumstances an OHC Service Provider may hire low cost equipment such as shower chairs or over toilet aids for use during the period of the package when recommended by an appropriate health professional, such as an occupational therapist or physiotherapist.

3.8 Extensions

ComPacks can be extended beyond the six-week package period in exceptional circumstances.

***Example:** Josie is a 55-year-old lady who lives alone. She fractured her ankle and received ComPacks for personal care and domestic assistance post discharge. Josie was mobilising on crutches and was told she would be non-weight bearing on her ankle for six-weeks. A review by her surgeon at the six-week mark indicated that the fracture had not yet healed and she would be non-weight bearing for another two weeks. To be able to manage at home for the additional two-week period, she would require the personal care and domestic assistance to continue. The Case Manager was able to extend the package for two-weeks knowing that at the end of this period, the patient would be able to exit from the program.*

A Case Manager should consider the following when assessing a person for an extension:

- estimated date of package completion,
- reasons why the patient was not able to exit ComPacks,
- the patient's goal and the appropriateness of ComPacks and
- the contingency plan following the end of the extension period.

If the cost of a total package, including the extension beyond six weeks, is anticipated to be in excess of the cost of a Band 3, pre-approval is required from the MoH OHC Team using the Extension Application form.

3.9 Repeat Packages

Patients receiving SASH and EoL packages may require more than one 6-week package episode of care. It is important that prior to this decision being made the Case Manager has a discussion with the LHD SASH Co-ordinator/Key Contact or LHD Relationship Manager. It is important to consider what the long-term goal is for SASH patients and whether they still require the package of care or if there are other appropriate long-term options that can be accessed.

To obtain approval for repeat packages, Case Managers must complete a Repeat Package Application form and submit it to the LHD OHC Relationship manager or delegate: www.health.nsw.gov.au. Applications for SASH repeat packages can be made for up to three (3) additional six weeks packages. Approval decisions are informed by the patients NDIS status, goals, and alternative longer-term options.

3.10 Privacy and Confidentiality

It is the responsibility of Case Managers to protect the privacy of patients and comply with all laws relating to the use of personal information. In alignment with the *Privacy Act 1988* information regarding the patient cannot be shared amongst Service Providers without their consent.

Each LHD will have a local policy for Case Managers accessing and recording OHC action plans in a patient's medical records. Case Managers should discuss this issue with their LHD Relationship Manager.

Each LHD will have a local policy regarding Case Managers advising the referrer of the action plan. This may be done either by providing a written plan that can be uploaded into the electronic medical record (eMR) or by the LHD giving the Case Manager contingent worker status to access the eMR to enter the action plan.

SECTION 4

The Coordination of Out of Hospital Care

The OHC Program can be used by LHDs to support patient flow by facilitating early discharge from hospital or to prevent avoidable admissions. The impact of OHC on patient flow and hospital avoidance depends on how effectively access is coordinated by the LHDs.

Funding for OHC is limited and there is often a greater demand than packages available. By prioritising the allocation of packages to patients who will benefit most hospitals can relieve bed pressure while maximising the use of resources.

All LHDs should have a structure in place that incorporates the key principles of coordination outlined below. Integral to this coordination is the role of the nominated LHD SASH Co-ordinator and/or Key Contacts in a Hospital, Community Health setting or Palliative Care team. Key Contacts ensure that eligible people are identified by staff and referrals are coordinated; these governance responsibilities are further outlined in Section 7, OHC Governance.

More information regarding care co-ordination can be found at NSW Health Policy PD2011_015 Care Co-ordination: Planning from Admission to Transfer of Care in NSW Public Hospitals.

Identification	OHC patients need to be identified early by referrers as those who may have home care needs.
Eligibility	Patients should be assessed by appropriate hospital or community health staff (allied health, nursing etc) to determine suitability for OHC before referrals are made to the Service Provider.
Prioritise	Referrals to the Service Provider must be prioritised by the SASH Co-ordinator and/or Key Contact based on: • The individual needs of the patient • The availability of packages in the program • Patient flow priorities for inpatient referrals to support flow at a local and district level.
Availability	Nominated LHD staff must regularly communicate with the Service Providers to monitor package availability.

4.1 Referrals to Out of Hospital Care

Referring staff need to consider the principles discussed in Section Four – Co-ordination of the OHC Program before making a referral.

4.2 ComPacks

ComPacks referrals must occur while a person is still in hospital and as per the individual hospital's protocol. The exception is referrals made by Hospital in the Home (HITH) clinicians or for people requiring HaH–ComPacks to prevent avoidable admissions.

4.3 SASH and EoL Packages

Referrals for the SASH and EoL packages mostly occur from the out-patient or community setting but can also occur from hospital.

4.4 When to Refer

A referral for ComPacks from the hospital should be made as soon as:

- an estimated date of discharge (EDD) has been established,
- a patient's hospital discharge destination has been determined as being their home or similar and
- a patient's functional status is determined or can be predicted at discharge.

A referral for Out of Hospital Care should be made as soon as:

- a patient's eligibility for the OHC has been determined – see Section 2 'Who is Eligible for Out of Hospital Care'.
- for the SASH packages, staff must consult with the SASH Coordinator or the LHD key contact regarding eligibility and package availability.
- for the End of Life packages, the LHD key contact should be consulted re: Patient eligibility and package availability.

4.5 How to Refer

Once a potential patient has been identified and screened by staff, LHD referral protocols need to be followed. This may include:

- a direct referral to the Service Provider using the OHC referral form,
- a direct referral via the Service Providers Intake Portal and
- a referral via the LHD centralised intake service.

The LHD and Service Provider will agree on the specific process for making referrals at the time of establishing the Local Service Level Agreement (LSLA). All LHD referral processes will comply with the steps outlined in Diagram 4.

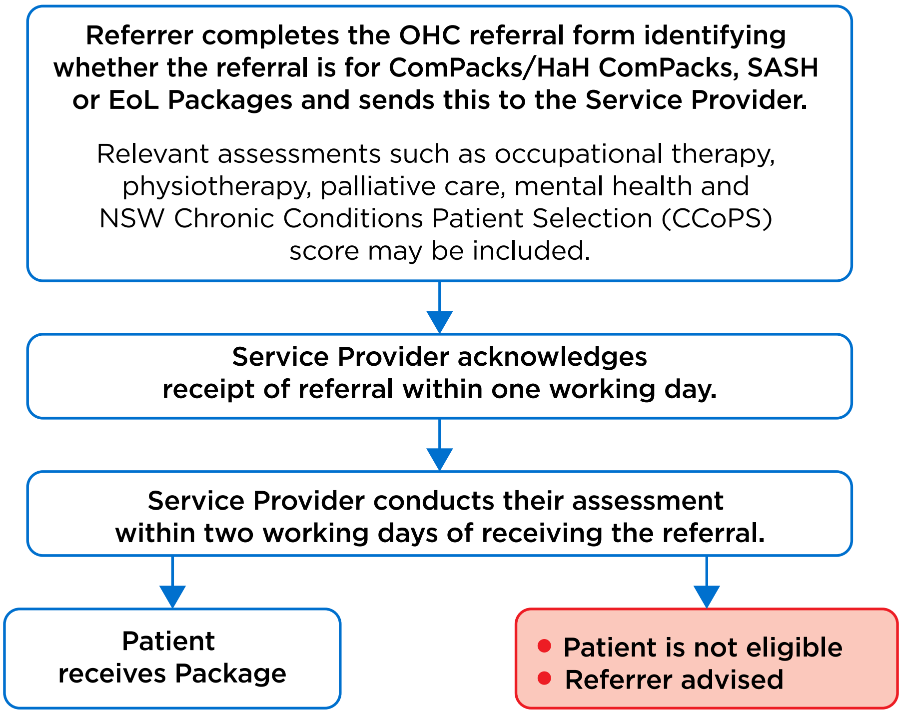
4.6 Referral Response

Service Providers are required to acknowledge the receipt of a referral within one working day of receiving it.

4.7 Referrals from Emergency Departments

Service Providers can receive referrals from Emergency Departments for the OHC Program. It is essential that the Referrer contact the Service Provider to confirm the patient's eligibility and package availability prior to making the referral. Once this has been established, a referral form with additional information about the patient's functional status and home situation is forwarded to the Service Provider.

Diagram 4. The Referral Process for Out of Hospital Care



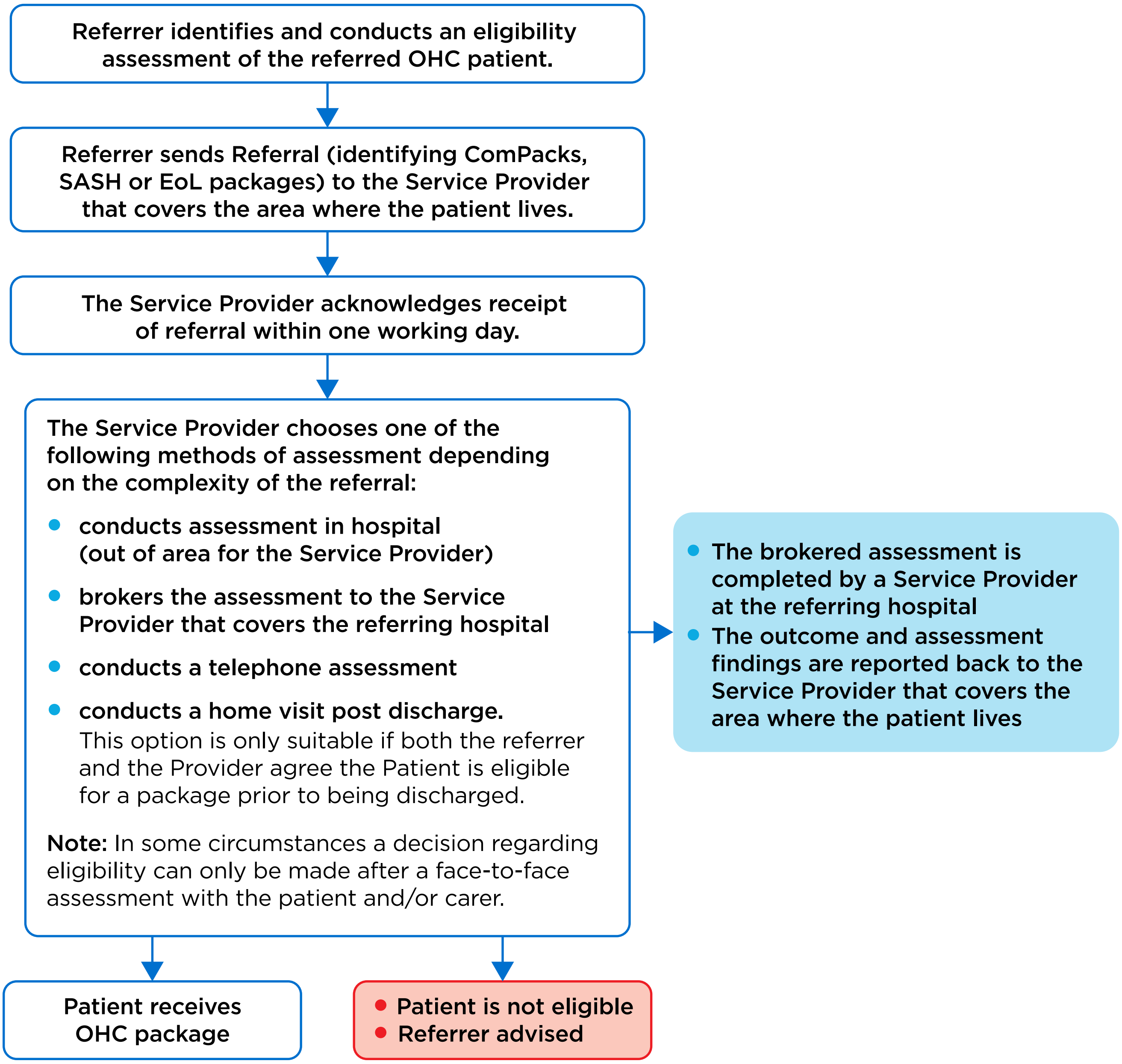
For the ComPacks and SASH packages the Service Provider is required to conduct an assessment within two working days of receiving the referral. This may be at the hospital or within the person's home. For patients referred to the EoL packages the assessment will take place within 1 working day of confirmation of the referral being received.

4.8 Out of Area Referrals

At times, a patient may be admitted to a hospital that is outside their local area. As the OHC Program is statewide, the patient can receive a package in their local area. This involves referring the patient to the Service Provider that covers the area where the patient lives.

The process for out of area referral is outlined in the Diagram 5. The Service Provider can determine the type of assessment required depending on the complexity of the patient.

Diagram 5. Out of Area Referral Process



Referrer identifies and conducts an eligibility assessment of the referred OHC patient.

Referrer sends Referral (identifying ComPacks, SASH or EoL packages) to the Service Provider that covers the area where the patient lives.

The Service Provider acknowledges receipt of referral within one working day.

The Service Provider chooses one of the following methods of assessment depending on the complexity of the referral:

- **conducts assessment in hospital (out of area for the Service Provider)**
- **brokers the assessment to the Service Provider that covers the referring hospital**
- **conducts a telephone assessment**
- **conducts a home visit post discharge.** This option is only suitable if both the referrer and the Provider agree the Patient is eligible for a package prior to being discharged.

Note: In some circumstances a decision regarding eligibility can only be made after a face-to-face assessment with the patient and/or carer.

- **The brokered assessment is completed by a Service Provider at the referring hospital**
- **The outcome and assessment findings are reported back to the Service Provider that covers the area where the patient lives**

Patient receives OHC package

- **Patient is not eligible**
- **Referrer advised**

SECTION 5

Assessment

Service Providers are required to assess a patient within two working days of receiving the referral. For patients requiring EoL packages the assessment will occur within one working day of receiving the referral.[5] The purpose of this assessment is to:

- confirm eligibility,
- identify patient goals, home care needs and develop the Care Plan and
- ensure the patient or family/carer understand what is involved in the program and the patient or their representative sign the Service Agreement with the Service Provider.

It is the responsibility of the Case Manager to ensure that the patient and/or family/carer understands the details of the Care Plan and has formally agreed to the package being undertaken.

5.1 Assessment Location

Hospital Assessments:

If being referred from hospital the OHC assessment should take place while the patient is still an inpatient. The patient and/or family/carer will need to be present as well as any health professionals involved with the patient, so the Case Manager can establish clear goals and needs for the package.

Home Assessments:

For OHC referrals that are made from the community, home assessments will occur. Home assessments can also occur when a patient has been referred by the Emergency Department or when a patient lives in a different geographical area to the hospital (see out of area referral process). In this instance it is the Service Provider's responsibility to ensure that a home assessment occurs within two working days of discharge home for people referred to the ComPacks and SASH packages and one working day for people referred to the EoL packages.

Telephone Assessments:

A telephone assessment may occur while the patient is still in hospital or when the person lives in a different geographical area to the hospital. Once the patient is ready to be discharged home the referrer should contact the Case Manager to advise them of the discharge date. Telephone assessments may also occur at times of natural disaster, pandemics or when an EoL referral needs to be accelerated.

5.2 Delayed Discharge from Hospital

In some cases, a patient may have been assessed at the hospital, but their discharge date has been delayed. Such delays should be communicated to the Case Manager as soon as possible.

If a patient's discharge date has been significantly delayed (more than three weeks) or there is a change in their health or functional status, the Case Manager may need to reassess the patient. If it is determined that a patient's functional status or personal circumstances have changed, the OHC Program may no longer be the most suitable option.

5.3 Readmission to Hospital from the OHC Program

Admission to Hospital while Receiving ComPacks or EoL Packages

If a patient requires admission to hospital while receiving a ComPacks or EoL package, a place can be held open by the Case Manager for up to one week. This means that the existing package is placed 'on hold' and recommences when the patient is discharged home. The week in hospital is not counted as part of the 'six weeks' package. This includes HaH-ComPacks packages.

Should read "for up to two weeks". Revised guidelines to be amended. Advised by MoH 07/06/2021

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[5] For patients referred to the EoL, the assessment should take place within 1 working day of the confirmation of the referral being received.

The Case Manager must actively follow up on the patient's status. If the patient's functional status or personal circumstances have changed while in hospital the Case Manager may request further information from hospital staff and review the patient prior to discharge.

The referrer is responsible for communicating any updates to the patient while they are in hospital.

Admission to Hospital while Receiving SASH packages

If a patient requires readmission to hospital while receiving a SASH package a place may be held open by the Service Provider for longer than 1 week provided that the patient still meets the eligibility criteria for the program. Please note that for SASH this may be up to 4 weeks (or 28 consecutive days).

After a longer hospital readmission there are two likely scenarios:

- **The patient's needs may have changed**, and they are no longer eligible for the program. In this case the Case Manager will exit the patient from the program and the hospital team will need to organise an alternative discharge plan.
- **The patient is still eligible for the program.** If a patient's functional status or personal circumstances have changed, a review is required by the Case Manager and the original care plan may need to be amended.

5.4 Temporary Leave Arrangements –SASH Packages

Patients often receive SASH packages for a longer period than the other types of packages. In this case patients may take leave from their SASH package for the following reasons:

- residential respite and care
- social reasons e.g. holidays

A patient's place on the SASH package is not affected while they are on leave and patients will not be charged a fee during this time.

Leave Type	Arrangement
Residential Respite	If the patient has an ACAT approval for residential respite or instances where the patient is receiving alternative respite care, the allowable respite period for the SASH/EoL package is for up to 28 consecutive days.
Social Leave e.g. holiday	A patient may take social leave from the SASH package for up to 28 consecutive days.
Other	If a patient requests leave for longer than 28 days for special circumstances. ***Service Providers must contact the MoH OHC Team to discuss.*** MOH-OutOfHospitalCare@health.nsw.gov.au

SECTION 6

Out of Hospital Care Evaluation

6.1 Monitoring and Reporting

Service Providers are required to submit monthly activity reports to the NSW MoH, as per their contract, by the fifth day of each month. This is done by uploading data to the ComPacks Information Management System (CIMS).

Standard Reporting Templates

The data specifications for the program are outlined below. Data is to be submitted by Service Providers using the standard OHC reporting templates. A full explanation of these specifications is available in the NSW Health OHC Reporting Guidelines 2021.

Data Specification	Description
Package Type	The type of Out of Hospital Care Package the patient is receiving (ComPacks, SASH or EoL)
MRN	The Medical Record number as allocated by the referring hospital
LAST Name	Last name of patient
DOB	Date of birth of patient
Aboriginal or Torres Strait Islander Origin	In accordance with NSW Department of Health mandatory policy PD2005_547 on identification. Selected from a drop-down list.
Referring Hospital Identification	Code of the referring hospital. Selected from a list of Codes provided.
Funding LHDs	The LHD which provides funding for the package based on patient's home location
Referral Date	The date specified on the Out of Hospital Care Referral form
Referral Acknowledgement Date	Date referral is acknowledged by the Service Provider
Type of Package	Assessment Only
	Band 1: Low cost e.g. the recipient only required 2 weeks of a 6-week package
	Band 2: Mid cost e.g. the recipient used the full 6 weeks of the package (the majority of recipients are in this band)
	Band 3: High cost e.g. the recipient required an intense level of community support
	Ex 1: Low cost extension of a package for ComPacks
	Ex 2: Mid cost extension of a package for ComPacks
	Ext 3: High cost extension of a package for ComPacks
	Band 1 RPT: Low cost repeat package of care for SASH & EoL recipients
	Band 2 RPT: Mid cost repeat package of care for SASH & EoL recipients
	Band 3 RPT: High cost repeat package of care for SASH & EoL recipients

Data Specification	Description
Assessment Completed Date	The date the assessment has been completed by Out of Hospital Care Programs Service Provider
Date of Discharge from Hospital	The date the patient is discharged from hospital
Date of First Home Care Service	The date of first home care service (brokered or delivered directly)
Exit Date	The date the patient exits Out of Hospital Care Program
Reason for End of Package	Reason for the end of Out of Hospital Care Program – to be selected from a list of possible reasons provided
Ongoing Services	To be chosen if the patient has been referred to any ongoing services on the completion of their Out of Hospital Care Program. The Service Provider selects from a list of services.
Services received by patient	The number of hours/occasions of each service type provided to the patient by the Service Provider.

6.2 Performance & Activity Reports

Local Health Districts and St Vincent's Health Network

All LHD Relationship Managers can access the OHC Program activity reports via the CIMS database. A password can be obtained by contacting the MoH OHC Team on MOH-OutOfHospitalCare@health.nsw.gov.au.

Service Provider Reports

Service Providers can access performance reports directly via CIMS.

6.3 Key Performance Indicators

The key to the success of OHC is twofold:

1. The number and quality of referrals from LHDs.
2. The responsiveness of Service Providers to acknowledge referrals, conduct assessments and commence service delivery in the home.

The Key Performance Indicators (KPIs) for the program are centred on these elements. Service Providers submit data to NSW MoH monthly providing information on the KPIs summarised in the table below.

Table 3. Key Performance Indicators – Service Providers

KPIs	Indicator	Measure	Frequency	Recipient
Referral Response	Service Provider contacts the referrer within one working day of receiving referral to confirm that the referral has been: • accepted • declined • outcome pending assessment	KPI = >90%	Monthly via CIMS (Mandatory)	NSW MoH
Assessment Timeliness	Service Provider conducts the assessment for ComPacks and SASH packages within two working days of confirmation of the referral being received. Service Provider conducts the assessment for EoL package within one working day of confirmation of the referral being received.	KPI = >90%	Monthly via CIMS (Mandatory)	NSW MoH
Community Support	Home care services must commence within three working days of hospital discharge or home assessment (depending on program). Community supports must commence earlier for patients receiving the EoL packages.	KPI = >80%	Monthly via CIMS (Mandatory)	NSW MoH

Table 4. Local Health Districts

KPIs	Indicator	Measure	Frequency	Recipient
Funding – Activity	Performance against YTD financial targets = > 90% of the budget	KPI = > 90%	Monthly via CIMS	NSW MoH
Appropriate Referrals made by LHDs	"Assessments only" rate is = < 3% of overall allocation	KPI = < 3%	Monthly via CIMS	NSW MoH
Package Utilisation	Performance against YTD targets (packages)	KPI = > 90%	Monthly via CIMS	NSW MoH
Types of Referrals	The annual activity is within the following parameters: Band 1: 15% Band 2: 65% Band 3: 20%	Band 1: 15% Band 2: 65% Band 3: 20%	Monthly via CIMS	NSW MoH

SECTION 7

Out of Hospital Care Governance

The OHC Program is funded and administered by the NSW MoH. The governance structure is outlined below in Diagram 6. The MoH has established the NSW Health OHC Panel. Service Providers appointed to the Panel following a procurement process have signed an OHC Services Agreement (Head Contract) with the NSW MoH. This agreement outlines the program governance and terms of engagement.

LHDs select Service Providers from the NSW Health OHC Panel to deliver the OHC in their regions. To formalise this arrangement a Local Service Level Agreement (LSLA), which details local operations, is in place between the LHD and their chosen Service Provider/s. The LHD OHC Relationship Manager and the Service Provider Relationship Manager administer this LSLA.

7.1 Payments

Service Providers are paid monthly. Payments are made based on completed activity (completed activity is defined as a completed 6-week package episode). Providers are required to lodge a monthly report/invoice to MoH outlining the number of patients who have completed 6-week package episodes and the corresponding band allocations. Payments are set as a fixed price per band. The OHC Services Agreement outlines the pricing schedules.

7.2 Roles and Responsibilities of Participating Agencies

Key agencies have specific roles in the delivery of OHC. Diagram 7 outlines the Roles and Responsibilities of each key agency. For OHC to work effectively it is important that all stakeholders have a clear understanding of these roles and how they work together.

7.3 NSW Ministry of Health, Out of Hospital Care Team

It is the responsibility of the MoH OHC Team to:

- undertake financial management for OHC, including program budget, LHD funding allocations, and payments to Service Providers,
- manage the NSW Health OHC Services Agreement (Head Contract) with Service Providers,
- work with the LHD OHC Relationship Managers regarding future funding, planning and allocation of OHC packages,
- provide guidance for LHD OHC Relationship Managers regarding operational or service delivery issues as appropriate,

Diagram 6. Out of Hospital Care Governance

- work with LHDs and Service Providers when there is a dispute or question regarding eligibility or services required,
- manage complaints related to the program that have not been resolved through the Service Providers or LHD complaint mechanisms,
- monitor demand, performance, utilisation, and quality of OHC at a State level and generate reports for the MoH, LHD and Service Providers,
- coordinate the overall program communication strategy, marketing, and promotional material,
- ensure evaluation of the OHC Program is conducted regularly against MoH Key Performance Indicators and through Patient Experience Interviews,
- implement quality improvement activities to enhance patient care,
- implement strategies to minimise risks for Patients, Service Providers, LHDs and the MoH and
- facilitate bi-monthly and extraordinary meetings with LHDs and Service Providers as required.

7.4 Local Health Districts

It is the responsibility of the LHD to:

- comply with the terms outlined in the Local Service Level Agreement with Service Providers,
- establish a governance structure to address any operational issues associated with OHC. This includes systems to coordinate and prioritise OHC referrals and assessments and
- nominate an LHD OHC Relationship Manager to manage the Local Service Level Agreement with the selected Service Provider/s and be the key contact for both the MoH OHC Team and the selected Service Provider/s.

LHD OHC Relationship Manager

It is the responsibility of the LHD OHC Relationship Manager to:

- work closely with the SASH Co-ordinator in LHDs where this role has been established.
- identify Key Contacts at all participating hospitals, community health centres and within palliative care teams.
- ensure that all operational aspects of OHC within the LHD and facilities are managed effectively including:
  - Identification of potential patients
  - Prioritisation of referrals
  - Monitoring of availability
  - Assessment of eligibility
- develop and implement plans for annual capacity and seasonal demand management,
- arrange the purchase of additional OHC packages at times of peak demand in consultation with the Service Provider and the MoH OHC Team,
- ensure the LHD is meeting the terms of the Local Service Level Agreement and its KPIs by monitoring:
  - the demand and utilisation of OHC across the LHD
  - the number of 'assessment only' packages
- ensure LHD staff are orientated to and educated regarding OHC,
- ensure effective relationships with Service Providers, hospital, community health and palliative care staff by scheduling regular strategic and operational meetings to address any issues regarding service delivery,
- address any complaints and disputes in a timely manner and escalate to the MoH OHC Team, when necessary and
- participate in bi-monthly meetings with the MoH OHC Team.

LHD Key Contacts

The LHD Key Contacts (Nursing or Allied Health managers) are nominated by the LHD and located across in-patient and community settings. Their role is to screen and prioritise patients for the OHC Program.

LHD SASH Co-ordinators

The LHD SASH Coordinator is the Key Contact in LHDs for the SASH packages. All SASH referrals must be sent to the SASH Coordinator for screening and prioritisation. If the LHD does not have a SASH Co-ordinator, Key Contacts may take on this role for the SASH packages. Their role is to:

- educate LHD staff about the SASH packages,
- monitor program utilisation and waiting lists where required,
- attend case conferences with the Service Provider to monitor patient needs and progress with their NDIS access requests,
- escalate patient concerns with LHD NDIS Co-ordinators or their equivalent/ACAT Team leaders where required,
- help to progress NDIS access requests by working closely with NDIS Local Area Co-ordinators (LACS) and Disability Advocacy Services and
- participate in bi-monthly meetings with the MoH OHC Team.

7.5 Service Providers

Service Providers are required to:

- enter and work within the boundaries of the NSW Health OHC Services Agreement and ensure that each subcontractor complies with all provisions of the Agreement,
- have agreements and systems in place to monitor the quantity and quality of services delivered by their subcontractors,
- comply with the terms outlined in the LHD Local Service Level Agreement,
- accept referrals from NSW participating hospitals, community health centres and palliative care teams according to the NSW Health OHC Program Interim Guidelines 2021,
- provide Case Management and coordinate home care services for OHC patients,
- deliver OHC Programs within a safety, quality, and risk management framework to ensure the health and safety of patients, care workers, case managers and others visiting the home,
- plan and make referrals to ongoing community services and provide appropriate information to the patient or carer as required,
- support SASH patients to engage with the NDIS application, planning or review process to plan for exit from the SASH package by working closely with NDIS Local Area Co-ordinators (LACS) and Disability Advocacy Services,
- refer suitable patients to My Aged Care (MAC) for an ACAT or RAS assessment to determine eligibility for aged care services,
- support the EoL package patient, their family/carer in a sensitive and appropriate way to achieve their goals, including end of life plan,
- maintain relationships with LHD, hospital, community health and palliative care staff by attending regular meetings as per the Local Service Level Agreement,
- establish a process with LHD staff to regularly review and communicate Service Provider capacity availability and discuss any process/operational issues,
- notify key LHD staff of:
  - standard hours of operation and contact details
  - intake system (including all contact details)
- promote OHC to LHD, SVHN and hospital, community health and palliative care staff as appropriate,
- respond to patient concerns, as per the Service Provider’s complaints mechanism, and escalate to LHD or MoH as appropriate,
- submit data regarding activity to NSW MoH monthly, via CIMS as per contracted requirements,
- participate in program evaluation and risk management activities as requested by the MoH OHC Team and
- participate in bi-monthly and extraordinary meetings with the MoH OHC Team.

7.6 Dispute Resolution

If a dispute occurs between Service Providers and LHDs, SVHN or hospital, community health or palliative care team it is necessary for all the parties involved to attempt to resolve the issue. If not resolved the dispute can be escalated by the LHD or Service Provider Relationship Manager to the MoH OHC Team.

Diagram 7. Roles and responsibilities of key agencies

NSW Ministry of Health

Program Governance

- System-wide program management
- Budget determination and payments to Service Providers
- Package allocations across NSW
- Administer and manage the NSW Health OHC Services Agreement
- Performance management of LHDs
- Conflict resolution and mediation
- Data collection and formulation of performance reports for both LHDs and Service Providers
- Quality review of Service Providers

Local Health Districts
and St Vincent's Health Network

Operational Management

- Developing and meeting the terms of the Local Service Level Agreement with Service Providers
- Manage Program expenditure within the budget outlined in the LSLA
- Comply with LHD responsibilities as outlined in the LSLA
- Day to day coordination of OHC program referrals including identification of patients and prioritisation strategies
- Implement quality improvement process

Service Providers

Service Delivery

- Meet the terms and conditions of the NSW Health OHC Services Agreement with the MoH
- Deliver OHC Programs as per the LSLA
- Manage the relationship with LHD hospitals, community health and palliative care teams
- Quality improvement

SECTION 8

Glossary of Terms

Term	Definition
ACAT	Aged Care Assessment Teams are multidisciplinary teams of health professional responsible for determining eligibility for entry to residential aged care, community care and flexible care.
ATSI	Aboriginal and Torres Strait Islander
CALD	Culturally and linguistically diverse
Carer Gateway	Assists carers with practical information, advice, services, counselling, and coaching.
CHSP	The Commonwealth Home Support Program provides entry-level support and episodic care for older people who need help to stay at home. The CHSP also has sub-programs such as Assistance with Care and Housing for people aged under 65 years who are at risk of eviction and homelessness. Regional Assessment Service (RAS) approval is required to access.
CIMS	ComPacks Information Management System. Web data base & reporting system administered by MoH for Service Providers to upload data regarding program activity. Generates reports for Service Providers and LHDs regarding the activity and performance of the OHC programs.
DVA	Department of Veterans' Affairs
EDD	Estimated Date of Discharge from hospital.
EOL	End of Life packages
ENABLE NSW	This organisation provides equipment and services to people in NSW with chronic health conditions or disability to assist them with mobility, communication, and self-care.
HCP Program	The home care packages program is available for people aged 65 years and over. ACAT approval is required to access. Four levels of package are available, ranging from low to higher levels of care.
HAH	ComPacks – Healthy at Home Packages
HITH	Hospital in the Home
Key Contact	A delegate of the Relationship Manager in a Hospital, Community Health Centre or Palliative Care team who is responsible for the Key Principles of Coordination.
LAC	Local Area Co-ordinator. The role of the LAC is to assist people to understand and access the NDIS.
LGBTIQ	Lesbian, gay, bi-sexual, transgender, intersex, and questioning.
LHD Relationship Manager	Nominated LHD Manager who manages the Local Service Level Agreement with OHC Service Providers. Key Contact for Ministry of Health.
LSLA	The agreement between the LHD and the OHC Service Provider. The LSLA is Schedule 5 of the NSW Health OHC Services Agreement.

Term	Definition
MAC	My Aged Care
NDIS	National Disability Insurance Scheme
OHC	The NSW Health Out of Hospital Care Program
Patient	This term has been used to describe a person who is currently admitted into a hospital facility or a person in the community setting who is receiving a ComPacks, HAH, SASH or EoL package.
RAS	Regional Assessment Service. The RAS provides assessment for patients aged 65 years and over who require access to entry level aged care services.
Referrer	NSW Health staff member who refers a patient to ComPacks (e.g. hospital discharge planner), HaH (e.g. community health clinician) or SASH or EoL (e.g. community health clinician, Hospital discharge planner or Palliative Care team member).
SASH	Safe and Supported at Home
SASH Co-ordinator	A person appointed in the LHD to co-ordinate the Safe and Supported at Home packages. This position works closely with the LHD Relationship Manager.
Services Agreement	The Head Agreement (Contract) between NSW Health and the Service Provider.
Service Provider	A government or non-government organisation that has a Services Agreement with NSW Health to deliver the ComPacks, SASH and EoL packages.
STRC	The Short Term Restorative Care Program is funded by the Australian Government. This provides services to older people for up to 8 weeks to help them delay or avoid long-term care. ACAT approval is required access.
TACP	The Transitional Aged Care Program is funded by the Australian Government. This package is available post discharge from hospital. It provides goal orientated, time limited and therapy focussed care and is targeted at older people. ACAT approval is required for access.

SECTION 9

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NSW Health Hospital in the Home Guidelines 2018, NSW Ministry of Health

My Age Care website https://www.myagedcare.gov.au/, Australian Government, Department of Health

SECTION 10

Appendix 1

Table 1: Key Support Programs available at the point of Discharge

Program	Hospital in the Home (HITH)	OHC ComPacks	OHC Safe and Supported at Home (SASH)	OHC End of Life (EoL)	Transitional Aged Care Program (TACP)
Target Cohort	Patients are referred to HITH from an NSW public hospital or GP as an alternative to inpatient care. If HITH care were not available, the patient would be admitted in hospital.	Patients must be referred by a participating NSW public hospital to a residence in NSW. Following assessment of risk of readmission using the NSW Chronic Conditions Patient Selection (CCoPS) Tool.	Patients referred by a participating NSW LHD to a residence in NSW. Following assessment of risk of hospitalisation using the NSW Chronic Conditions Patient Selection (CCoPS) Tool.	Palliative Care Patients referred by a participating NSW LHD to a residence in NSW.	Patients can only enter the program directly upon discharge from hospital. An assessment by the Aged Care Assessment Team (ACAT) is required.
Program Description/ Eligibility	Services provide acute or sub acute care to adults and children as a substitution or prevention for in-hospital care. Patients receiving daily care as hospital substitution are eligible for ComPacks, SASH and EoL packages during and after the completion of the HITH episode. Referral to ACAT for assessment can be made during an admitted HITH episode to consider eligibility for TACP services after discharge.	The patient requires immediate Case Management and a combination of non-clinical home care services for the patient to be discharged home. No other programs are immediately available from My Aged Care (for example Home Care Package, CHSP, DVA). Limited or no informal supports are in place or available to provide home care support.	Have reduced functional capacity, who have had their application to the National Disability Insurance Scheme (NDIS) rejected or require support while applying for the NDIS or appealing an access decision. In some cases, it can support those awaiting an NDIS plan review or for an NDIS plan to be implemented.	Palliative care needs and are reaching the end of life and wish to die in their own home or to remain at home for as long as possible. Identified as being in the 'unstable' or 'deteriorating' Palliative Care phase. The packages will also provide support for the patient's family and carer.	The TACP program is goal orientated, time limited and provides therapy focussed care, targeted towards older people at the end of their hospital stay. TACP is provided either at home or in a residential care setting.
Type of Care	Patients who consent receive selected types of acute or post-acute clinical care at their home. Care is available seven days per week and is provided by a multidisciplinary team.	Package of care involves non-clinical case management and home care services.	Package of care involves non-clinical case management and home care services.	Package of care involves non-clinical case management and home care services.	Clinical case management and Low-intensity therapy including allied health services (physiotherapy, podiatry, social work, and occupational therapy). Nursing support and non-clinical home care services.
Duration of Care	Care is available for one to two weeks.	A package is available for up to six weeks.	A package is available for up to six weeks with the option of repeat packages.	A package is available for up to six weeks with the option of repeat packages until the end of life.	The package of care is available for up to a maximum of 12 weeks.
Age	No age restriction for eligible patients.	Available to all people, irrespective of age.	Aged between 18 – 64 years. This is different to the criteria listed on page 9.	No age restriction for eligible patients.	Older people eligible for ACAT assessment.
Fees	No fees	Patients pay a nominal fee.	Patients pay a nominal fee.	Patients pay a nominal fee.	For the home based TACP, the maximum care fee is 17.5% of the basic daily rate of the single pension.

Table 2: Key Support Programs available from the Community

Program	Commonwealth Home Support Program (CHSP)	OHC Healthy at Home (HaH)	OHC Safe and Supported at Home (SASH)	OHC End of Life (EoL)	Short Term Restorative Care Program (STRC)
Target Cohort	Provides entry-level support for older people who need some help to stay at home. Urgent referral is an option. A longer-term program that can also be provided to patients who require episodic care to improve their function or capacity.	Patients must be referred by a participating NSW LHD to a residence in NSW. Following assessment of risk of hospitalisation using the NSW Chronic Conditions Patient Selection (CCoPS) Tool.	Patients referred by a participating NSW LHD to a residence in NSW. Following assessment of risk of hospitalisation using the NSW Chronic Conditions Patient Selection (CCoPS) Tool.	Palliative Care Patients referred by a participating NSW LHD to a residence in NSW. Identified as being in the 'unstable' or deteriorating' phase.	The STRC Program is early intervention to reverse or slow ' functional decline' in older people. An assessment by the Aged Care Assessment Team (ACAT) is required. A patient can access 2 episodes of STRC within a 12-month period.
Program Description/ Eligibility	Service providers work with them to maintain their independence and keep them as well as possible. It also provides respite services to give carers a break. Most people in the CHSP only need 1 or 2 services to help them stay independent.	The patient requires Case Management and a combination of home care services for the patient to be discharged home. No other programs or informal supports are in place or available to provide the home care required.	Have reduced functional capacity, who have had their application to the National Disability Insurance Scheme (NDIS) rejected or require support while applying for the NDIS or appealing an access decision. In some cases, it can support those awaiting an NDIS plan review or for an NDIS plan to be implemented.	Palliative care needs and are reaching the end of life and wish to die in their own home. The packages will also provide support for the patient's family and carer.	To be eligible for STRC a person must be at risk of losing their independence and be able to improve their independence with STRC. STRC is provided either at home or in a residential care setting.
Type of Care	Direct urgent service options. Nursing, Personal Care, Transport and Meals. Patients must be advised that a home assessment is also required.	Package of care involves non clinical case management and home care services.	Package of care involves non clinical case management and home care services.	Package of care involves non clinical case management and home care services.	STRC services are tailored for each person and can involve clinical case management, several different health professionals, and non-clinical home care services.
Duration of Care	An assessment by the Regional Assessment Service (RAS) is required within two weeks of commencement of urgent services to determine ongoing care needs.	A package is available for up to six weeks.	A package is available for up to six weeks with the option of repeat package.	A package is available for up to six weeks with the option of repeat package until the end of life.	Provides services to older people for up to 8 weeks to help them delay or avoid long-term care.
Age	Aged 65 years or older (50 years or older for Aboriginal or Torres Strait Islander people).	Available to all people, irrespective of age.	Aged between 18 – 64 years. Differs from page 9.	No age restriction for eligible patients.	Older people eligible for ACAT assessment. Consult with ACAT for when NDIS or CHSP can be accessed at the same time as STRC.
Fees	Patient contribution framework guides service providers in the amount charged.	Patients pay a nominal fee.	Patients pay a nominal fee.	Patients pay a nominal fee.	For the home based STRC, the maximum care fee is 17.5% of the basic daily rate of the single pension.

Appendix 2

Australian-modified Karnofsky Performance Status (AKPS)*

The Australian-modified Karnofsky Performance Status (AKPS) Scale is a measure of the patient's performance across the dimensions of activity, work and self-care at phase start. It is a single score between 10 and 100 assigned by a clinician based on observations of a patient's ability to perform common tasks relating to activity, work and self-care. A score of 100 signifies normal physical abilities with no evidence of disease. Decreasing numbers indicate a reduced performance status. A score of 0 indicates the patient has died, however this score is not used as no further patient assessments are documented following the death of a patient. Further information and videos on AKPS assessment is available on the PCOC website.

AKPS ASSESSMENT CRITERIA	SCORE
Normal; no complaints; no evidence of disease	100
Able to carry on normal activity; minor sign of symptoms of disease	90
Normal activity with effort; some signs or symptoms of disease	80
Cares for self; unable to carry on normal activity or to do active work	70
Able to care for most needs; but requires occasional assistance	60
Considerable assistance and frequent medical care required	50
In bed more than 50% of the time	40
Almost completely bedfast	30
Totally bedfast and requiring extensive nursing care by professionals and/or family	20
Comatose or barely rousable	10
Dead	0

Potential actions following AKPS assessment	
Point on AKPS Scale	**Recommended Action**
Patient has AKPS of 90, 80 or 70 at episode start	• Consider completing an advance care planning discussion with the patient and their substitute decision-makers.
Patient has AKPS of 60	• Consider referral to allied health if patient has been in active work and is no longer able to work.
Patient has AKPS of 50	• Consider discussion at multidisciplinary team meeting and review care plan • Provide appropriate equipment as required • Consider referrals for community packages • Complete a caregiver assessment.
Patient has AKPS of 40 or 30	• Consider discussion at multidisciplinary team meeting and review care plan – patient may be commencing deterioration and further supports may be required. • Consider pressure area care. • Provide appropriate equipment as required (for example, alternating pressure mattress). • For community patients – consider impact of care on family caregiver. Complete a caregiver assessment.
Patient has AKPS of 20 or 10	• Commence end of life care planning • If death is likely in days, change to Terminal Phase.

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* PCOC Clinical Manual April 2018, page 32

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PalliativeCare
AUSTRALIA

Investing to save

The economics of increased investment in palliative care in Australia

Palliative Care Australia and KPMG

May 2020
kpmg.com.au

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SNOW
FOUNDATION

Foreword

At Palliative Care Australia, it is our mission to influence, foster and promote the delivery of timely and quality palliative care for all who need it.

As a palliative medicine specialist, I work with people with life-limiting illness and their families every day and I know the extraordinary benefits that palliative care can provide.

I know that when people have access to timely and quality palliative care, their symptoms can be relieved, their psycho-social needs met, and they can live as well as possible for as long as possible in the place of their choosing.

I also know from experience that this care means people are less likely to receive unnecessary treatments which will not offer them benefits, they are less likely to need to go to Emergency Departments and they spend less time in hospital or Intensive Care Units.

This is all about offering good quality and proactive appropriate care and supporting decisions about clinical treatments for people living with life-limiting illness.

I also know the importance of economics. For this reason, Palliative Care Australia commissioned health economics experts at KPMG to undertake this thorough investigation of the economic value of palliative care, to look at the nation's future palliative care needs and to model effective interventions, under the guidance of a steering committee of clinical and academic experts. Most importantly, we asked KPMG to make recommendations to better prepare the nation to meet the nation's rapidly escalating palliative care needs.

I extend my thanks to the KPMG team for the thoroughness and diligence in the way they have explored the evidence, research and experience of people working in palliative care to write this report, keeping the needs of people with life-limiting illness and their families at the centre.

I also extend my thanks to all the people who contributed to this report and urge all Governments to study and implement the recommendations, which will deliver tangible benefits across the health system.

Professor Meera Agar
Chair, Palliative Care Australia

Introduction

There is a clear economic case for increased investment in palliative care in Australia.

There is a clear need to improve the way we care for people nearing the end-of-life, both for the elderly and those with a terminal illness. The majority of Australians die in hospital when most would prefer to spend more time at home. Talking about death can be difficult and seen as something to avoid. Government funded palliative care services are predominantly delivered over the last days and hours of life. Despite considerable reform over the past 30 years, palliative care has remained an optional extra rather than 'core business' within our health and aged care systems, which defaults to extending life, rather than improving the quality of time we have left.

Investing to Save – Palliative Care outlines the economic argument for increased investment in palliative care. The huge costs associated with death are not inevitable; this report highlights practical 'win-win' recommendations for investment in palliative care that deliver lower end-of-life costs to Government at the same time as achieving positive health and social outcomes for people experiencing life-limiting conditions. Savings in health care expenditure can be achieved when incentives are provided for health services to support advance care planning and greater investment in coordinated home, community and aged care (including residential care) services that avoid significantly higher end-of-life costs.

Achieving these improvements will require agents of change, or *enablers*. Funding models need to be broadened to encourage rather than hinder the provision of integrated palliative care across settings. More comprehensive administrative data on service provision is required for system planning, to sit alongside the outcomes data tracked through the world-leading Palliative Care Outcomes Collaboration. Further investment in community awareness, expansion of the specialist palliative care workforce, and increased palliative care training of the broader health and aged care workforce, are all required for palliative care to become core business. *Investing to Save – Palliative Care* highlights these key enabling steps and the practical recommendations with strong evidence bases that will improve the quality of the last years of life for people who are dying, their carers and families.

We are proud that KPMG is able to contribute to the ongoing discussion on palliative care reform as a key advisor to Governments and other organisations in the health and aged care sector. We sincerely thank Palliative Care Australia for the opportunity to partner with them on this report. *Investing to Save – Palliative Care* is not a silver-bullet, but instead we hope that the evidence and recommendations presented here can help Governments and others take the next steps towards ensuring palliative care becomes a core component of our health system.

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KPMG and Palliative Care Australia also thank all Palliative Care Australia member organisations who provided feedback on a draft version of the report.

Palliative Care Australia’s acknowledgement and gratitude to The Snow Foundation

Palliative Care Australia has been able to commission this important work thanks to the generous support of The Snow Foundation.

Starting in Canberra, The Snow Foundation was established in 1991 by Terry Snow and his brother George to support people experiencing hardships and challenges. Almost 30 years later, The Snow Foundation remains dedicated to the Canberra region coupled with a commitment to back key National initiatives supporting social entrepreneurship and stand out leaders with ambitious agendas for social change.

The Snow Foundation has been particularly generous in supporting people living with life-limiting illness. In approaching The Snow Foundation to assist in financing this report, PCA found an enthusiastic and willing partner in commissioning a major economic study about the value of palliative care – not just the caring value, but the economic imperative to invest in services which people need and also generate savings in other more cost intensive parts of the health system.

The Snow Foundation are also benefactors to Clare Holland House in Canberra and LifeCircle.

Clare Holland House, Canberra ACT

Clare Holland House is a palliative care facility in Canberra. The team at Clare Holland House provide outpatient clinic services, care in the home or residential setting, and also inpatient hospice services.

The service at Clare Holland House is tailored to each patient, with the main objective being to enable each patient to enjoy a fulfilling and comfortable lifestyle while still receiving appropriate and patient-centred care.

Through funding from the Snow Foundation, Clare Holland House is undertaking an exciting expansion to enable an increase in the number of specialist inpatient palliative care beds and expand facilities for families to stay with patients on site and for the development of administration and clinical space. The support will also provide more in-home, palliative care for people who wish to stay in their own home. Already the team at Clare Holland House is providing a widely acclaimed and awarded service to residents in residential aged care facilities. This is known as the Palliative Care Needs Rounds, where a Palliative Care Nurse Practitioner from Clare Holland House meets regularly with staff in residential aged care facilities to discuss residents who are at risk of dying and to put care plans in place.

LifeCircle

LifeCircle is an independent, national social enterprise that prepares families and organisations as they care for people through the last stages of life.

Leveraging 30 years of practice and insights with a global evidence base, contemporary principles of human-centred design and lean scaling, LifeCircle partners as integrators and catalysts to drive a whole-of-system approach, improving the experience for all Australians.

LifeCircle provides online delivery of information, resources, and 1:1 Guided Support Programs for carers and families. The anticipated outcomes of these services include improved wellbeing of those caring; less regret and complex bereavement; less time spent in hospital; and more Australians having an end-of-life experience that is aligned with their preferences.

With LifeCircle’s tools and training, organisations can excel in care and communication through the last stages of life, while also improving business metrics such as employee wellbeing, workforce stability, productivity, and customer satisfaction.

Contents

Disclaimer

This report has been prepared as outlined in the Scope Section. The services provided in connection with this engagement comprise an advisory engagement, which is not subject to assurance or other standards issued by the Australian Auditing and Assurance Standards Board and, consequently no opinions or conclusions intended to convey assurance have been expressed.

No warranty of completeness, accuracy or reliability is given in relation to the statements and representations made by, and the information and documentation provided by, Palliative Care Australia personnel and stakeholders consulted as part of the process.

KPMG have indicated within this report the sources of the information provided. We have not sought to independently verify those sources unless otherwise noted within the report.

KPMG is under no obligation in any circumstance to update this report, in either oral or written form, for events occurring after the report has been issued in final form.

The findings in this report have been formed on the above basis.

Third Party Reliance

This report is solely for the purpose set out in the Scope Section and for Palliative Care Australia's information, and is not to be used for any other purpose without KPMG's prior written consent.

This report has been prepared at the request of Palliative Care Australia in accordance with the terms of KPMG's contract dated 25 June 2019. Other than our responsibility to Palliative Care Australia, neither KPMG nor any member or employee of KPMG undertakes responsibility arising in any way from reliance placed by a third party on this report. Any reliance placed is that party's sole responsibility.

Glossary

ABS	Australian Bureau of Statistics
ABF	Activity Based Funding
ACFI	Aged Care Funding Instrument
ACP	Advance Care Plan
AIHW	Australian Institute of Health and Welfare
ALOS	Average Length of Stay
BEACH	Bettering the Evaluation and Care of Health
CHD	Coronary Heart Disease
COPD	Chronic Obstructive Pulmonary Disease
ED	Emergency Department
GP	General Practitioner
ICD	International Classification of Disease
ICU	Intensive Care Unit
IHPA	Independent Hospital Pricing Authority
IHPC	Integrated Home-based Palliative Care
MBS	Medicare Benefits Schedule
NHCDC	National Hospital Costs Data Collection
NHMRC	National Health and Medical Research Council
PC	Productivity Commission
PCA	Palliative Care Australia
PCOC	Palliative Care Outcomes Collaboration
RACFs	Residential Aged Care Facilities
ROI	Return on investment
RCT	Randomised controlled trial
SPC	Specialist Palliative Care
WHO	World Health Organisation

Executive summary

This report presents the economic case for increased investment in palliative care. It highlights opportunities for Governments to generate significant returns on their investment in palliative care, focusing on targeted practical interventions where the evidence base about what works is strong.

Executive summary

Background

Palliative care in Australia is amongst the best in the world. State and Federal funding for palliative care services is provided across primary care, community, residential aged care, hospital and specialist palliative care unit settings; patient reported outcome data is collated and published; and there are education and training pathways to become palliative care specialists for both doctors and nurses.

Yet, across the lifespan, too many Australians with life-limiting conditions miss out on appropriate palliative care. Just 2,595 individuals received a Medicare Benefits Schedule (MBS) funded palliative care home visit in 2017-18, less than two per cent of the deaths in that period. Just four to 12 per cent of Australians die at home, despite the majority of people preferring to spend more time at home in their last months of life. Only one in 50 residents of an aged care facility receives palliative care under the Aged Care Funding Instrument (ACFI). Palliative medicine specialist numbers are half of what is expected under a minimum model of care.

Over the last 20 years, a large body of reviews, reports and inquiries have highlighted these shortcomings, and presented recommendations for reform. However, most previous reports have presented the case for reform in terms of the social and moral imperative to improve the end-of-life for all Australians. This report takes a different perspective. It draws on a pragmatic, evidence-based approach to estimate the economic benefits from these reforms. It shows that we can achieve better social and moral outcomes, while also reducing the almost $8 billion spent on death in Australia each year.

Many of the recommendations presented here are not new. Facilitating people to live well at home in their last months, ensuring advance care plans are completed and followed, providing integrated palliative care that allows individuals to seamlessly access services, and significantly increasing the number of palliative care specialists in residential aged care facilities (RACFs) are consistent themes across much of the previous research.

However, this report highlights that there are good economic reasons for Government to adopt these interventions. The return on investment (ROI) to Government comes from reducing costly end-of-life emergency department visits and transport, hospitalisation stays and intensive care unit (ICU) admissions. Although not quantified, there are also likely to be cost savings to individuals and employers from reduced bereavement costs and increased productivity of families and carers.

By making the economic case, the report aims to help inform policy makers who are faced with challenging decisions about how to best allocate scarce resources and funding. It recognises that there are always trade-offs when considering complex social issues, and that economic evidence can shine a new light on the nature of these trade-offs.

In addition to recommendations for specific interventions and investments, there are also a range of key system-wide reforms that are required to deliver a more efficient and effective palliative care sector. Palliative care needs clear stewardship and a funding model that promotes rather than hinders integrated and patient-centred care. The health workforce needs clear career pathways to palliative care roles, and community education needs to be systematic and consistent if discussions about death and the role of palliative care are to become core business. These reforms are not simply ‘nice to haves’ but essential to ensure the benefits from increased investment in palliative care are achieved.

Scope and methodology of this report

KPMG was engaged by Palliative Care Australia (PCA) to model the economic case for increased palliative care by identifying practical recommendations that had a strong economic argument, were supported by the evidence base or offered a practical innovation, and improved the health and wellbeing of Australians.

The methodology for this report involved three distinct stages:

1) Evidence gathering, including reviews of the literature and stakeholder consultations, to highlight gaps and opportunities in current palliative care services;
2) Analysis and modelling, using a pragmatic evaluation approach that captured the key costs and benefits associated with palliative care reforms;
3) Recommendations, prioritised using a set of criteria established with the project steering group, including scope and reach, ROI and feasibility of implementation.

Key recommendations

Following on from the detailed analysis described above, PCA and KPMG have developed the following recommendations, broken down by key setting: home, residential aged care and hospital. The recommendations all deliver strong ROIs, either breaking even and being cost-neutral in the case of home-based care, or providing significant cost savings in the case of the residential aged care and hospital interventions.

In addition, a number of ‘enabling’ recommendations have been provided. These recommendations address the stumbling blocks that continue to restrict the sector from delivering the patient-centred models of care that have been recommended over decades of research.

Overall, our analysis highlights that investing in better care for those experiencing life-limiting illnesses will reduce rather than increase costs. KPMG estimate that the cost of death in Australia is $7.8 billion per year, with more than half, $4.0 billion, in hospital costs. The interventions presented here can significantly reduce the hospitalisation costs of dying by nearly 12 per cent, or $460 million per year, while also improving the quality of death.

ES Table 1: Key recommendations for this report

Improve access to home and community-based palliative care services	**Investment**	**Return (%)**
Recommendation 1.1: Increase funding and timely access to home and community-based palliative care services **Recommendation 1.2:** Develop a key performance indicator to monitor access to home and community-based palliative care	**$240m**	**100%**
Expand palliative care services in residential aged care	**Investment**	**Return (%)**
Recommendation 2.1: Invest in specialist palliative care (SPC) and integrated support across residential aged care **Recommendation 2.2** Explicitly identify palliative care in the Aged Care Quality Standards	**$75m**	**182%**
Increase investment in earlier and more integrated palliative care services in hospitals	**Investment**	**Return (%)**
Recommendation 3.1: Increase palliative care services in hospitals **Recommendation 3.2:** Track the incidence of non-beneficial care in end-of-life hospital admissions, and systematically measure the impact of palliative care on hospitalisation costs	**$50m**	**168%**
Deliver system-wide reform to unlock the potential of palliative care	**Investment**	**Return**
Recommendation 4.1: Establish a permanent National Palliative Care Partnership Agreement with State and Territory Governments and appoint a National Palliative Care Commissioner **Recommendation 4.2:** Reform funding models to facilitate integrated, patient centred care **Recommendation 4.3:** Develop a palliative care minimum dataset **Recommendation 4.4:** Expand the palliative care workforce and increase palliative care literacy across the wider health sector **Recommendation 4.5:** Deliver community awareness and education programs	**Enabling interventions**	

Source: KPMG 2019

Limitations

The scope of this report has been necessarily limited to a small number of targeted recommendations. Importantly, the report is not:

- a comprehensive evaluation of the entire palliative care system;
- economic modelling of all prospective palliative care interventions;
- a whole of Government plan for reform.

KPMG and PCA identified a range of potential areas for reform that are worthy of additional analysis, but are being progressed through other avenues or had considerable complexity that could not be addressed within the scope of this analysis.

Additionally, the scope of this project has limited the report's capacity to focus on the needs of specific cohorts. In particular, it is recognised that Aboriginal and Torres Strait Islanders may require additional targeted, culturally appropriate supports, as will children experiencing life-limiting illnesses (paediatric palliative care) and the carers of such individuals.

Scope and context for this report

This section provides background context for this report and defines the concept of palliative care.

Scope and context for this report

Scope and limitations

KPMG was engaged by PCA to model the economic case for increased palliative care. The scope of this engagement included:

- modelling the need for palliative care in Australia by 2060;
- conducting ROI analyses for various palliative care interventions;
- identifying practical recommendations that had a strong economic argument, were supported by the evidence base or offered a practical innovation, and delivered both improved palliative care and economic outcomes.

It should be noted that the scope of this report does not include:

- a comprehensive evaluation of the entire palliative care system;
- economic modelling of all prospective palliative care interventions;
- a whole of Government plan for reform.

> ***"With a rapidly growing and ageing population, Australian Governments – federal, state and territory – need to invest now if we are to meet the nation's current, let alone future, palliative care needs."*** [1]
>
> *Professor Meera Agar*

Defining palliative care

What is palliative care?

According to the World Health Organisation (WHO), palliative care is:

> *"An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification, impeccable assessment, treatment of pain and other problems, physical, psychosocial and spiritual".* [2]

Who uses palliative care?

Palliative care is provided to both the young and old with life-threatening (or life-limiting) illness. The term 'life-limiting illness' is used to describe illnesses which are expected to directly cause death. [3] This includes individuals with cancer, heart disease, chronic obstructive pulmonary disease (COPD), dementia, frailty, heart failure, neurodegenerative disease, chronic liver disease, renal disease, and more.

Palliative care also includes the provision of bereavement support and capacity building for affected families and carers of those with life-limiting illness. [4]

Who provides palliative care?

The holistic nature of palliative care means that it is the business of all health care professionals. This includes doctors, nurses, allied health professionals, volunteers, carers and more. The involvement and level of expertise of these health care professionals varies depending on the complexity of patients' needs. [5]

What does palliative care involve?

Palliative care includes services and treatments that: [6]

- provide relief from pain and other distressing symptoms;
- affirm life and regards dying as a normal process;
- neither hasten nor postpone death;
- integrate the psychological and spiritual aspects of patient care;
- offer a support system to help individuals live as actively as possible until death;
- offer a support system to help the family cope during the individual's illness and in their own bereavement;
- use a team approach to address the needs of individuals and their families, including bereavement counselling, if indicated;
- enhance quality of life, and may also positively influence the course of illness;
- apply care early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Importantly, the provision of these palliative care services can differ along the pathway to death. For some patients this trajectory is predictable, and for others it is not. Recognising that multimorbidity (the co-occurrence of two or more chronic conditions) creates diverse pathways to death, Box 1 provides three disparate examples of the disease trajectories commonly associated with chronic illness.

Box 1: Pathways to death associated with chronic illness


Short and severe | **Long and episodic** | **Prolonged and slow**

According to Lynne et al. (2003), these trajectories represents a typical person with…

Cancer	*Heart and lung failure*	*Dementia*
- Rapid decline; no sign of recovery; short period between functional decline and death.	- Slow decline in function, sharp periodic decline and recovery; longer onset from decline to death.	- Low function to start, progresses slowly over time; longest period between decline and death.

According to Sleeman et al. (2019)…

- Palliative care is relevant for 90 per cent of cancer deaths.	- Palliative care is relevant for 35 per cent of deaths related to heart failure; 80 per cent of deaths related to COPD and 50 per cent of deaths lung disease.	- Palliative care is relevant for 80 per cent of dementia related death.

Sources: Lynne et al. (2003), Sleeman et al. (2019)

Palliative care services therefore attend to needs with ranging complexity.

The largest patient cohort are those with non-complex care needs. Typically, these needs can be met by a range of primary care and non-SPC personnel; and can include (but are not limited to) symptom management, case conferencing, care coordination, counselling and after-hours support. [7]

Patients with complex care have unstable and persistent needs which are not effectively controlled by standard therapies. This cohort requires the regular and active involvement of a multidisciplinary team to assess and manage intense symptoms, provide access to after-hours telephone advice, nursing and medical support, active implementation of advance care planning including effective documentation and communication with other health professionals to ensure concordance with patients' care goals, as well as psychosocial support for the patient, their families and carers. [8]

Complex care commonly involves 'SPC' services, which can be defined as:

- a multidisciplinary health care service whose substantive work is with individuals who have a life-limiting illness;
- delivery by SPC professionals who have recognised qualifications or accreditation in palliative care; and
- provision of consultative and ongoing care for individuals with a life-limiting illness and provide support for their primary carer and family during and after the individual's illness. [9]

By definition, SPC is not directly required where needs are uncomplicated. Importantly, where specialist care providers are not directly involved in the care they provide leadership and consultative role to hospital and community care settings.

Where is palliative care provided?

Palliative care is provided across home, RACFs, hospital and SPC units. Each setting serves a different purpose, and provides accommodation for individuals with varying needs. The delivery of palliative care across these settings is therefore diverse (Box 2).

Box 2: Palliative care by setting

1. Home

- Home-based palliative care supports patients who wish to be cared for at home for as long as their needs can be met, and where possible, to die in the place of their choice. General practitioners (GPs) play an important role in this setting to identify palliative care needs, facilitate discussions around treatment goals and develop care management plans.
- Services within this setting can also include symptom management and assessment, specialist nursing, allied health, emotional support, education, bereavement, personal care, food services, transport and more.

2. Residential aged care

- Palliative care in residential aged care consists of long-term care and management of those with life-limiting conditions.
- Residential aged care staff are available to provide personal, heath and nursing care at all hours. Patients and staff in this setting have access to SPC support and community palliative care services where needs become complex.

3. Hospital

- Palliative care can be provided in the hospital alongside curative treatment and/or where patients' needs are complex. These services may occur via inpatient care in beds, outpatient clinics, ICUs or EDs.
- Hospital palliative care can include advance care planning, complex symptom management and assessment, psychological bereavement support and more.

4. Specialist palliative care units

- Specialist palliative care units provide short-term care for those with serious illness, near the end of their life, who are in most cases no longer receiving curative treatment. These units aim to provide a home-like environment, including some accommodation for family and significant others when possible, in addition to personal belongings. This care can be provided within hospital and/or community care settings (home/RACFs). Teams of these units can include specialist nurses, doctors, social workers, and other professionals to provide symptom management, psychological bereavement support and more.
- **Note:** Many people in the community may be familiar with the term "hospice". The meaning of the word hospice has changed over the years. What is offered in terms of care at a hospice can be different across countries and even across Australian jurisdictions. In some instances a hospice may include the full suite of services offered by a specialist palliative care unit. In other situations the hospice may be a community facility offering care and support for patients and their families but not always with the full range of clinical care. In this report, specialist palliative care units is used as the term for services that bring together multidisciplinary teams to provide a comprehensive range of clinical and supportive care at the one service.

Source: KPMG analysis of The Department of Health (2019); PCA (2018)

Methodology for this report

This section provides an overview of the methodology for this report.

Methodology for this report

Phase by phase

A high-level overview of the methodology used to formulate the recommendations in this report is presented below:

1	**Evidence gathering** • Literature review and data collection to understand the current state of the industry, identify the key issues and list potential recommendations for reform from past reports and inquiries; • Consultation with members of industry and the Steering Group Committee to test initial findings and gain detailed insight into palliative care services in Australia.
2	**Analysis and modelling** • Assessment of publicly available data to verify the system-wide and setting-specific issues in palliative care; • Generation of a baseline model of palliative care need and cost of death in Australia; • Development of criteria to prioritise palliative care interventions from the literature; • ROI analyses from improved palliative care.
3	**Recommendations** • Evaluation of interventions and recommendations against the prioritisation criteria; • Consolidation of findings, identification of limitations and development of recommendations with the Steering Group Committee; • Review and refinement of recommendations in final consultation with the Steering Group Committee.

Evidence gathering

Key reports and inquiries

Extensive research and strategic policy reviews have been undertaken by the Government, Productivity Commission (PC), peak bodies, academics, and leading practitioners over a period of 20 years to further improve palliative care services in Australia.

Table 1 outlines some of the more recent major reports and key studies that have been considered as part of our analysis. As a whole, recommendations in past reports have been relatively consistent. These have been considered in formulating the recommendations presented here.

Table 1: Key past reports and inquiries

Year	Author and Title	Summary
2019	**Royal Commission into Aged Care Quality and Safety** [10] *"A history of aged care reviews"*	- Background of the reviews conducted on aged care in Australia. - Review of national aged care quality and regulatory processes. - Review of funding, accreditation and effectiveness of the aged care.
2018	**Palliative Care Australia** [11] *" Palliative Care 2030: Working towards the future of quality palliative care for all"*	- Guiding principles for palliative care 2030. - The principles include whole of Government involvement, strengthening of the workforce, community awareness and mobilisation, research and technology, access to medicine, service on grief and bereavement, effective funding models, best practice and innovative models.
2018	**Department of Health** [12] *" National Palliative Care Strategy 2018"*	- Evaluated the vision, principles and goals of palliative care in Australia. - Aligned a strategic framework for all stakeholders to achieve goals. - Ensured that goals are based on the principles of understanding, capability, access and choice, collaboration, investment, data and evidence and accountability.
2018	**Department of Health and Human Services, Victoria State Government** [13] *" Palliative care funding model review"*	- Outlined a new funding framework for community and hospital-based palliative care services to improve and integrate between care settings. - Forming service system support for short-term funding models (1-2 years) and medium-term funding models (3-5 years).
2017	**Productivity Commission** [14] *"Introducing competition and informed user choice into human services: Reforms to human services. Chapter 3: End-of-life care in Australia"*	- The inquiry assessed palliative care and provided recommendations. - Recommendations included interventions to increase access of community-based palliative care, promote advance care planning, set the standard of care, and improve the funding model.

Year	Author and Title	Summary
2016	**Gomes et al.** [15] *"Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers (Review)"*	- The systematic review provided evidence of cost-effectiveness of home-based palliative care for people with malignant conditions. - The review also demonstrated that home-based care helps individuals to die at home with reduced symptom burden and less grief on caregiver.
2015	**Goldsbury et al.** [16] *"Acute hospital-based services used by adults during the last year of life in New South Wales, Australia: a population-based retrospective cohort study"*	- Measured health care utilisation of hospital-based services in the last year of life in NSW.
2014	**Grattan Institute** [17] *"Dying well"*	- The report reviewed the changing trend and patterns of death in Australia. - Provided recommendations that include a national public education campaign of palliative care, transparency in end-of-life plans, better coordination and implementation of care and support for carers in home-based setting.
2014	**Burbeck et al.** [18] *"Understanding the role of the volunteer in specialist palliative care: a systematic review and thematic synthesis of qualitative studies"*	- Systematic review to understand the role of volunteers in palliative care in both settings. - The key result highlighted that the role was distinctive and volunteers may act as mediator between the individual and health specialists.
2010	**Australian Health Ministers** [19] *"Supporting Australians to live well at the end of life"*	- The focus of the paper was palliative care including improved awareness and understanding, appropriateness and effectiveness, leadership and governance, and capacity and capability. - It highlighted the need for a skilled workforce in palliative care, and recommended improved funding models.
2004	**Department of Human Services Victoria** [20] *"Promoting Partnerships in Palliative Care Services"*	- The review provided a strategic framework to promote partnership in palliative care. - The key objective was to enhance services in which providers at every level of care (hospital and community) can provide high-quality pathways to people in their end-of-life stage.
1999	**Calder et al. and Department of Human Services Victoria** [21] *"Separating payments to integrate care: A palliative care classification and funding model"*	- The report proposed improved access to palliative care, integrated with community and hospital services. - Suggested to establish a classification system and funding model for providers and Governments.

Source: KPMG analysis (2019)

Steering Group Committee and stakeholder consultation

Table 2 lists the members of the Steering Group Committee consulted throughout this report. The methodology for this report also included a broader consultation with other key stakeholders. These consultations are also summarised in Table 2.

Importantly, the majority of recommendations presented here have built on recommendations in previous PCA research, which have been extensively tested with PCA members and others in the sector.

Table 2: Stakeholders consulted for this report

Personnel	Description	Discussion points
Meera Agar	Professor Meer Agar, Palliative Medicine, IMPACCT, University of Technology Sydney	• Timeliness of palliative care services; • Preference for dying at home – place of death versus time spent at home.
Jane Fischer	Dr Jane Fischer, General Manager and Medical Director, Calvary Health Care Bethlehem	• Awareness of palliative care in Australia; • Workforce capacity and skill gaps in palliative care; • Improved models of care in the community.
Gregory Crawford	Professor Gregory Crawford, Senior Consultant in Palliative Medicine and Director of Research and Education, Northern Adelaide Palliative Service	• Key State-based issues in today's care models; • Strengths of the current system in South Australia; • Research into the economics of palliative care.
Rosemary Calder	Professor Rosemary Calder, Health Policy at Mitchell Institute, Victoria University	• Effective and ineffective funding models in palliative care; • Minimum datasets and KPIs; • Stigma of palliative care.
Helen Walker	Helen Walker, Nurse Unit Manager, Laurel Hospice	• Addressing patient need in the community (person-centred care); • Triage and fragmentation; • Funding models.
Palliative Care Outcomes Collaboration (PCOC)	Dr Barbara Daveson, Manager, PCOC Samuel Allingham, Statistician and Data Manager, PCOC	• Variation in outcomes across regions of Australia; • Data reporting and coverage.
St Vincent's Hospital	Associate Professor Mark Boughey, Director of Palliative Medicine, St Vincent's Melbourne	• After-hours palliative care in Victoria; • Funding and consultative services; • Timely palliative care which individuals can trust.
Australian Institute of Health and Welfare (AIHW)	Gary Hanson, Unit Head for Mental Health and Palliative Care, AIHW	• Data challenges (coding, availability, reporting); • National Best Endeavours Dataset; • Research and data.

Source: KPMG (2019)

Analysis and modelling

Need for palliative care in Australia

The need for palliative care in Australia will increase significantly as the number of old people, and very old people, continues to grow. [22] To determine the need for palliative care in Australia, we first estimated the current and future deaths from the Australian Bureau of Statistics (ABS) population projections and life table data. [23]

The next step was to identify the proportion of deaths that were associated with palliative care need. This was informed by the Lancet Commission's report on Palliative Care and Pain Relief which estimated physical and psychological symptom prevalence in 20 conditions (International Classification of Disease (ICD)) most commonly related to palliative care up to the year 2060. [24] These estimates were then applied to the Australian population and death projections.

Overall, the model estimated palliative care need in Australia from 2017 to 2060 in context of Australia's ageing population and the increasing burden of non-communicable disease in high income countries.

Cost of death in Australia

The methodology for estimating the cost of death by care setting followed a study by the Grattan Institute. [25]

- Cost of death in RACFs and home care was derived from Part F of the 2018 Report on Government Services. [26] The data included the average annual subsidy per occupied residential aged care place and average expenditure per home care resident. Cost of death in hospital was estimated from Activity Based Funding (ABF) and the associated hospital care costs informed by Kardamanidis et al. [27]
- Cost of death in the last year of life was estimated from patient utilisation data in Goldsbury et al. (2015); and health care costs from the National Hospital Costs Data Collection (NHCDC) – Independent Hospital and Pricing Authority (IHPA) – including costs per separation and day, ED presentations, and ICU days. [28]

Assessment of the evidence base

Appendix A outlines the evidence base for the ROI modelling and interventions. KPMG and PCA have not attempted to undertake a systematic review or identify all available evidence. Rather, a pragmatic approach to collecting evidence has been taken, relying on systematic reviews and meta-analyses where possible. Evidence has been rated according to the National Health and Medical Research Council (NHMRC)'s levels of evidence hierarchy.

Quality ratings of the evidence base have been adapted from the Cochrane GRADE Working Group grades of evidence:

- **High quality:** Further research is very unlikely to change our confidence in the estimate of effect.
- **Moderate quality:** Further research is likely to have an important impact on our confidence in the estimate of effect and may change the estimate.
- **Low quality:** Further research is very likely to have an important impact on our confidence in the estimate of effect and is likely to change the estimate.
- **Very low quality:** We are very uncertain about the estimate.

The outcomes of the evidence base have been rated as one of: Effective; Mixed; and Not effective.

Return on investment analysis

The ROI methodology for this report differs from the traditional intervention cost approach as it does not seek to estimate all potential costs of palliative care, but rather to quantify the major direct returns potentially available across the health system through investment in effective palliative care interventions and services.

The specific methods used for modelling the ROIs varied according to the intervention being assessed. Intervention costs were sourced from the literature with unit cost data from relevant agencies such as the AIHW, IHPA and NHCDC or the ABS. Savings were considered mainly in health care cost savings achieved through a reduction in care costs and health service utilisations, e.g. reduced ED visits, hospitalisation and ICU admissions. Savings were only included in the modelling when the evidence base and magnitude of impact were significant and allowed for quantification. Sensitivity analyses were then conducted to highlight how the ROI may vary under different conditions. For more technical details on the ROI analysis, see Appendix B.

The context of return on investment

This report focuses on interventions that show a positive ROI (ROI greater than 1). As palliative care helps to reduce the high health care costs associated with death, and to improve quality of life for people with life-limiting illness, many investments in palliative care have the potential to deliver a strong ROI. In health economics, these interventions are known as 'dominant' because they deliver both better outcomes and reduced costs. Across the wider health sector, dominant interventions are unusual because normally it costs money to improve health. In that context, an intervention with an ROI of just 1.0 is a very attractive intervention because it delivers health benefits with no net costs.

The overlap of interventions and the potential for double counting

One of the challenges with palliative care is the complexity between care setting and the model of care available to the individual. There are a range of causal factors that contribute to palliative care, and therefore a range of potential areas to intervene. This means that interventions have the potential to overlap with each other: it could be that the effectiveness of one intervention is enough to render another intervention obsolete. For example, an advance care plan intervention in a hospital setting could be part of the service provision of an integrated home-based service.

These complexities with palliative care are difficult to untangle: individual interventions are typically evaluated within a narrow scope rather than as part of a collective within a wider health system. We have attempted to avoid 'double counting' by focusing on specific care settings (home, residential aged care and hospital) and ensuring our recommendations for expansion are realistic at the overall level.

Recommendations

Prioritisation framework

Table 3 outlines the criteria used to prioritise recommendations outlined in Phase 3 based on findings from Phase 1 (evidence gathering) and Phase 2 (analysis and modelling).

Table 3: Criteria for prioritisation

Criterion	Key questions	Where is this analysis evident in the recommendations?
Prevalence	• How many people could this intervention potentially impact?	• Each recommendation has introductory text that considers this criterion.
Economic impact	• What are the costs of this intervention? • What are the economic benefits of this intervention? • What is the ROI for this intervention?	• Each sub-recommendation has the sub-heading 'What is the economic impact of intervening in this area?'
Strength of evidence base	• What is the quality of the available evidence base? • How effective have the outcomes been in the identified evidence base?	• Each sub-recommendation has the sub-heading 'What does the intervention involve, and how strong is the evidence base?'
Alignment with existing policy directions	• Is this recommendation aligned with existing policy directions, or is it a recommendation that could be contentious?	• Each sub-recommendation has the sub-heading 'Is this intervention aligned with existing policy directions?'
Ease of implementation	• Are there existing opportunities that could be leveraged to implement this recommendation? • What are the challenges of implementing this recommendation?	• Each sub-recommendation has the sub-heading 'What are the opportunities or challenges of implementation?'

Source: KPMG (2019)

Death, dying and palliative care in Australia today

Death, dying and palliative care in Australia today

Death and dying in Australia today

Mortality and morbidity

In 2017, there were 160,000 deaths in Australia, with 82 per cent aged over 65 years. [29] While indicators of mortality suggest Australians are living longer, measures of quality show we are not necessarily living 'better'. Since 2012, years of life lost due to disability from non-communicative diseases have increased from 19,664 to 20,400 per 100,000 population in Australia in 2017. [30]

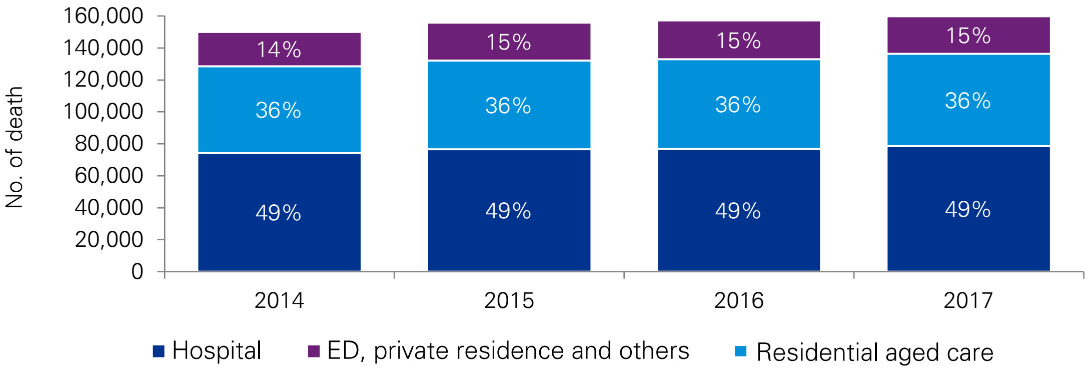
Place of death

Under Australia's current health system, the most common place of death are hospital and residential aged care. In 2017, almost half of all deaths in Australians occurred as an admitted patient (78,525); 36 per cent in residential aged care (57,769), four per cent in home care (6,813); three per cent in EDs (4,705); while the remaining eight per cent cannot be identified in the current data collections (12,099). See Figure 1 and Table 4. [31] [32]

Previous estimates suggested that the proportion of deaths occurring in the home setting was approximately 14 per cent. However, this was calculated as the residual deaths after accounting for deaths in the hospital and aged care settings. [33] The PC Inquiry into Human Services notes that this overstates the true rate as it omits those who died in EDs. [34] Accounting for this, KPMG estimates that the proportion of deaths at home range between four (home care only) and 12 per cent (home care plus 'other') of all deaths in Australia for 2017.

Estimates suggest that this rate contrasts starkly with patients' preferences, with 70 per cent of Australians wishing to die at home. [35] Studies also show that preferences for location of care can change across time, particularly as pain becomes more acute. In the last week of life preferences for home care fell from 90 to 52 per cent of patients, most often due to the factors related to symptom management and control. [36] This indicates that while patients wish to die at home, they do not feel comfortable doing so. This is a failure on behalf of the healthcare system.

Figure 1: Place of death by setting 2014-2017



Sources: KPMG Analysis of AIHW (2019)

Causes of death

Chronic and progressive illnesses are the leading contributor to death in Australians. Between 2015 and 2017, older individuals were most often subject to lung cancer, coronary heart disease (CHD), dementia, COPD, cerebrovascular disease, colorectal cancer, heart failure, in addition to influenza and pneumonia.[37] As Figure 2 shows, these diseases impact a range of people across the age profile. From 2015 to 2017, the prevalence of those with dementia or CHD was much greater in those aged over 85 compared to 65-74 year olds – who were more likely to die due to lung cancer or COPD.

Figure 2: Leading causes of death in Australians aged over 65 (2015-2017)

Age	1	2	3	4	5
65-74	Lung cancer	CHD	COPD	Colorectal cancer	Cerebrovascular disease
	7,885	7,704	4,614	3,525	3,106
75-84	CHD	Dementia	Cerebrovascular disease	Lung cancer	COPD
	13,864	9,588	8,370	7,531	7,381
85-94	CHD	Dementia	Cerebrovascular disease	COPD	Heart failure and other
	23,165	22,054	14,444	7,062	5,262
95+	Dementia	CHD	Cerebrovascular disease	Influenza and pneumonia	Heart failure and other
	5,656	5,654	3,358	1,774	1,640

Sources: KPMG analysis (2019): AIHW (2019)

The cost of dying in Australia

While less than one per cent of the Australian population dies in a given year, the economic cost of death is significant. Previous studies have estimated that the cost of death to Government is AU$5 billion per year.[38] KPMG analysis suggests that this has since grown to AU$7.8 billion in 2016-17, 94 per cent of which stemmed from deaths in hospital and aged care settings (48 and 46 per cent, respectively), while just two per cent of costs were attributable to deaths at home (see Table 4). As in previous analyses, the cost of dying in hospital exceeds that of both residential aged care and home care settings.

Table 4: The cost of death in Australia by setting (2016-2017)

Setting	Deaths	%	Unit cost	AU$ million	%
Acute inpatient	55,502	**35%**	$66,868	**$3,711**	**48%**
Subacute	23,023	**14%**	$14,601	**$336**	**4%**
Residential aged care	57,769	**36%**	$62,124	**$3,589**	**46%**
Home	6,813	**4%**	$22,821	**$155**	**2%**
Emergency departments	4,705	**3%**	$969	**$4**	**0%**
Other	12,099	**8%**	-	**-**	**-**
Total	**159,911**	**100%**		**$7,796**	**100%**

Source: KPMG analysis (2019)

The cost of bereavement in Australia

The cost of bereavement in Australia has not been rigorously quantified. Research is scarce, and highlights the general lack of information and data about the effects of bereavement.[39] Nonetheless, the following literature and evidence identify a range of costs associated with bereavement:

- A systematic review [40] of the health outcomes of bereavement found that people who have been bereaved are more likely to have health problems and higher rates of medication use and hospitalisation than the non-bereaved;
- A randomised controlled trial (RCT) study [41] applied cost-utility analysis to a community bereavement intervention by adding regular specialist and counselling services. The examined costs included direct medical costs and non-medical costs such as the ability to perform domestic tasks. The results indicated that the intervention group used fewer health care services than the control group;
- A recent study [42] of bereavement in Scotland showed that the primary care cost of bereavement was estimated at around AU$4.2 million. [43] The average individual health care cost of a bereaved person, including GP consultations, was estimated between AU$95 and AU$135; [44]
- There is some evidence that productivity losses including increased absence from work (absenteeism) and reduced output while at work (presenteeism) can be significant for bereaved people; [45] [46]
- Individual counselling provided by a specialist bereavement counsellor in Australia may cost between AU$160 and AU$230 per session. [47] A Government carer allowance payment is also available where a bereaved person or carer can receive a lump sum payment of up to AU$6,509 for up to 14 weeks after a person's death. [48]

Need and provision of palliative care service

Need for palliative care services in Australia

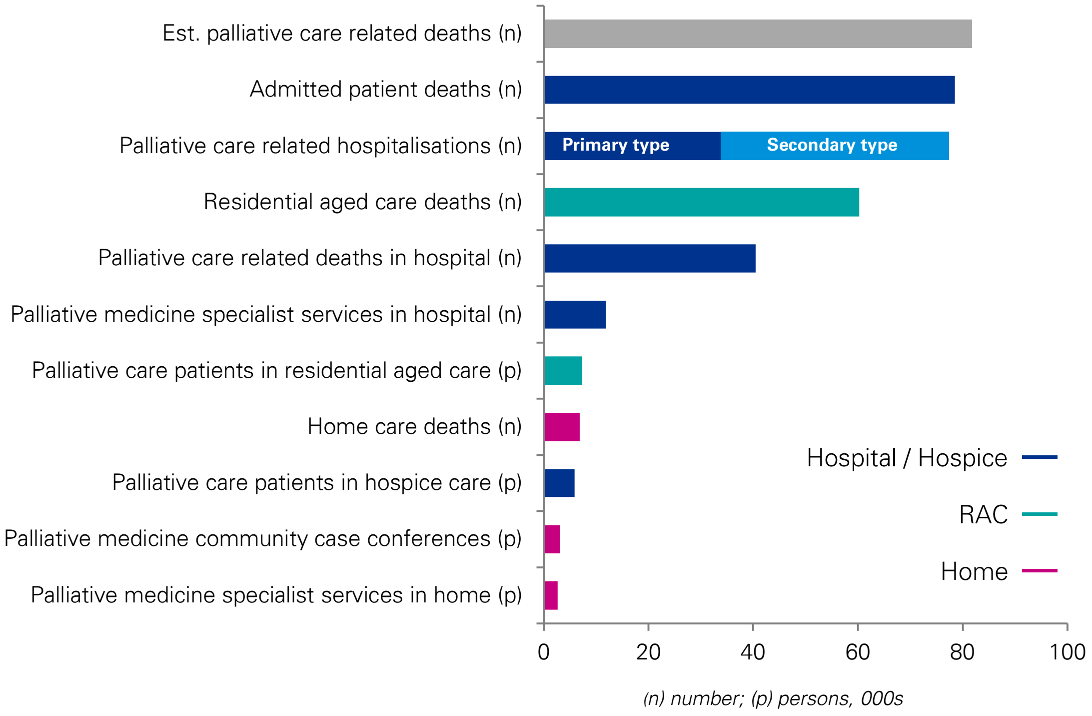
Several studies [49] have attempted to quantify the need for palliative care. Estimates range from 50 to 90 per cent of total deaths, based on low medium and high assumptions. More recently, Sleeman et al. [50] conducted a study into serious health related suffering in the top 20 conditions (ICD-10) associated with palliative care. Using this as a proxy for palliative care need, the authors suggested that around 51 per cent of deaths required palliative care in 2016 for high income countries (including Australia). Adopting this value in today's context suggests that there are 82,000 deaths in Australia which would benefit directly from palliative care each year.

Provision of palliative care services in Australia

Palliative care services in Australia are considered among the best in the world.[51] Nonetheless, comparing the need for palliative care services with provision of services highlights some stark gaps, particularly in non-hospital settings such as RACFs, the community and the home. Key statistics for 2017, highlighted in Figure 3, include:

- There were approximately 77,000 palliative care related hospitalisations (primary care diagnosis – 44,484; secondary care diagnosis – 33,885);
- 40,490 deaths were recorded in subacute care – equivalent to half of the 'estimated' need for palliative care (82,000).
- The number of individuals receiving MBS subsidised specialist palliative medicine services was 14,930 – 12,000 of which occurred in hospital or surgery; and 2,600 by home visit;
- Nearly 6,000 individuals were admitted to hospice care units in private acute and psychiatric hospitals – staying for an average of 11.7 days.

Figure 3: Utilisation of palliative care services in Australia for 2017

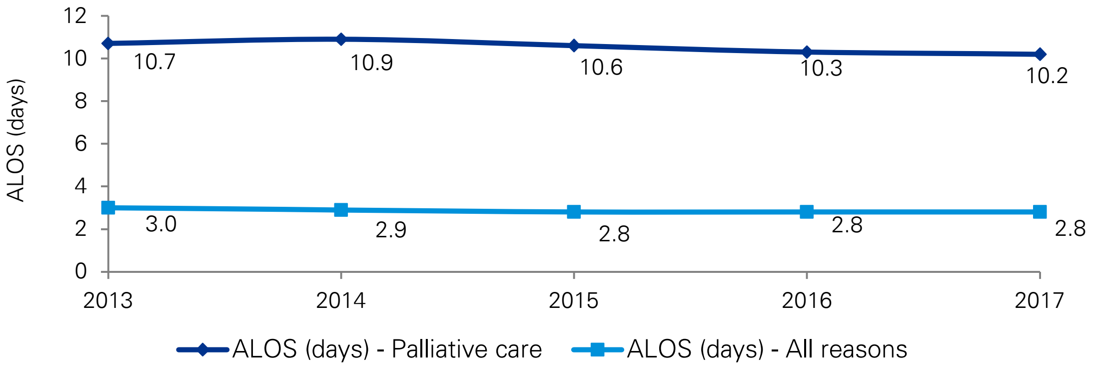


Source: KPMG analysis of AIHW (2019)

Palliative care in hospitals

The number of palliative care related hospitalisations in 2017 was 77,369 or 0.7 per cent of all hospitalisations. By age group, 75 per cent of palliative care hospitalisations are for people aged 65 years and older, and this has remained steady over time. By gender, the number is also stable with males higher than females at 54 per cent. The majority of palliative care related hospitalisations were in public hospitals (85 per cent) and in major cities (68 per cent). Cancer is the principal diagnosis for close to 50 per cent of services. Palliative care patients were involved in at least one overnight stay with average length of stay (ALOS) of 10.5 days from 2013 to 2017. This is more than three times the ALOS of hospitalisation for all reasons (Figure 4).

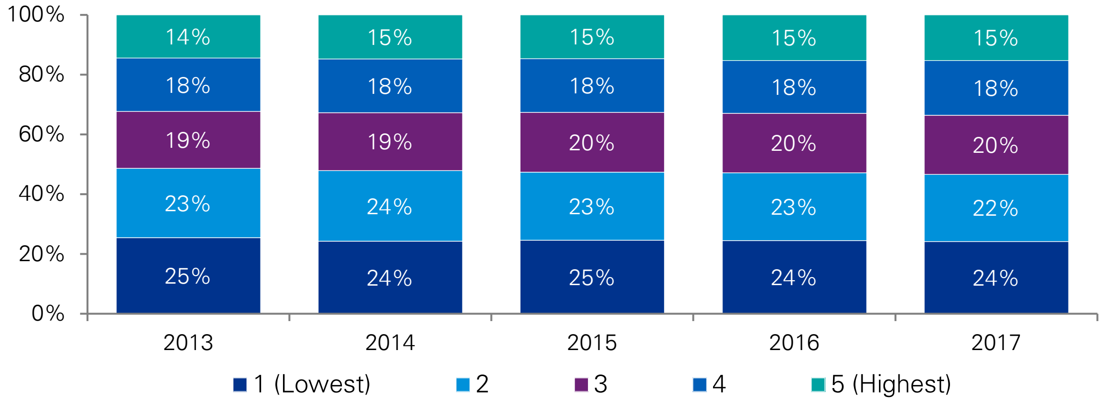
Figure 4: Length of stay palliative care-related hospitalisation



Source: AIHW (2019)

Data stratified by the socio-economic indexes for areas (SEIFA) shows that close to half of palliative care related hospitalisations come from low socio-economic areas. About a quarter of palliative care patients come from the lowest SEIFA quintile, compared with 16 per cent of patients for all hospitalisations (Figure 5).

Figure 5: Palliative care related hospitalisations by socio-economic status 2013-2017



Sources: AIHW (2019)

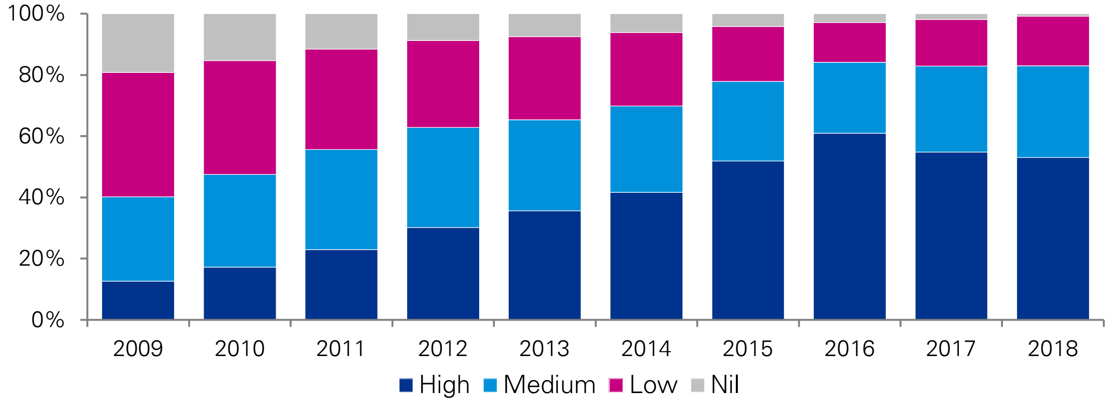
Palliative care in residential aged care

The number of permanent residential aged care admissions and residents related to palliative care has been on the decline. Between 2013 and 2018, permanent admissions dropped from 5,488 (eight per cent of total admissions) to 3,024 (four per cent) and residents decreased from 12,107 (five per cent of total residents) to 4,793 (two per cent). The AIHW analysis of the ACFI asserted that changes in aged care funding arrangements may have affected these numbers where only one in 50 of residents received ACFI funded palliative care services.[52]

The volume of people with complex care needs in residential aged care, and with highly complex needs in particular, has grown rapidly in the last ten years. As seen in Figure 6, 10 per cent of residents in aged care during 2008-09 had highly complex needs; today (2017-18) this rate has surged to 53 per cent. [53]

Combined, these data highlight that the provision of palliative care has been declining while complexity of need has been growing.

Figure 6: Complexity of care need in permanent aged care residents at first assessment (2009 - 2018)



Source: GEN Aged Care Data 2018

Palliative care in primary care

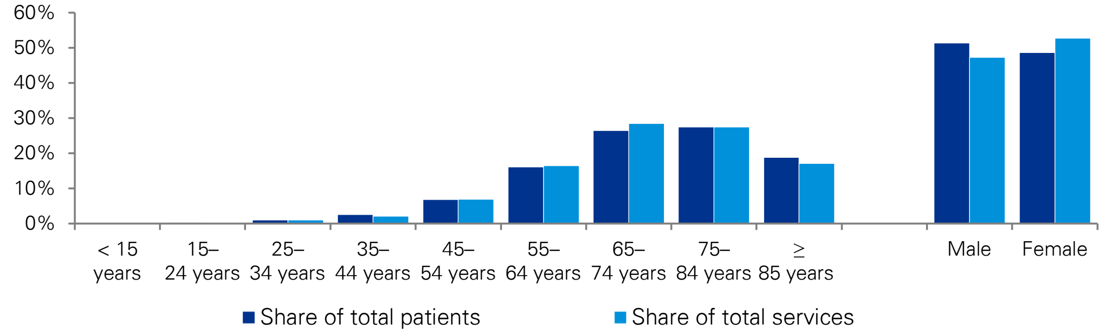
Primary care palliative medicine services funded under the MBS covered 16,159 individuals for 2017-18, or around 10 per cent of deaths for that year, and 20 per cent of deaths estimated to benefit from palliative care. These individuals received a total of 87,805 services, on average approximately five per individual.

MBS-funded palliative care is evenly split across gender, and provided predominantly but not exclusively to the older population, with 73 per cent of individuals and services provided to those aged 65 or above.

Since 2013-14, MBS-funded palliative care activity per 100,000 population has grown by 4.3 per cent per annum. Encouragingly, home attendances (10.8 per cent) and case conferences (15.0 per cent) have grown faster than hospital or surgery attendances (1.4 per cent), albeit of a much lower base.

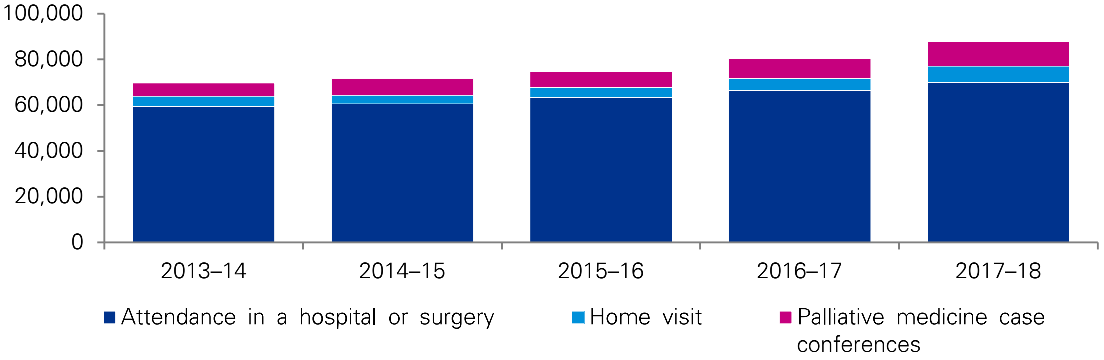
Total expenditure on MBS-funded palliative care services totalled AU$6.8 million in 2017-18, with the average costs of AU$69.25, AU$112.28 and AU$107.44 for a hospital or surgery attendance, a home visit and a case conference, respectively (KPMG analysis of AIHW Palliative care services in Australia: Medicare-subsidised palliative medicine services. 2017-18. Tables MBS.7-9). The Aged Care Access Incentive provides $1,500/$3,500 to GPs who provide at least 60 out-of 140 eligible MBS services within aged residential care facilities each year.

Figure 7: Distribution of MBS-funded Palliative Care



Sources: AIHW Palliative care services in Australia: Medicare-subsidised palliative medicine services. 2017-18. Table MBS.2.

Figure 8: Growth in MBS-funded palliative care activity



Sources: AIHW Palliative care services in Australia: Medicare-subsidised palliative medicine services. 2017-18. Table MBS.7.

Non-admitted palliative care

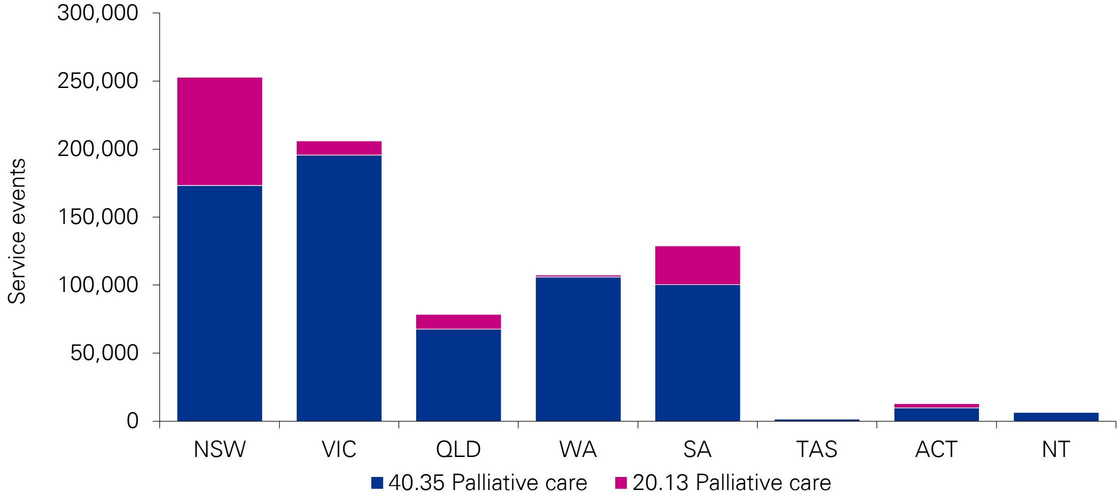
In the last five years non-admitted palliative care services have doubled to 794,000 (2017-18). This accounted for only two per cent of all non-admitted service events in 2017-18 (39 million). When provided, 83 per cent of palliative care events received allied health and/or clinical nurse specialist interventions, while the remaining were described as medical consultations provided by palliative medicine specialists, medical oncologists, or medical practitioners providing palliative care (as per Tier 2 classification 20.13 and 40.35). See Figure 9.

These events include care delivered to ED patients, outpatients or those treated by hospital employees off the hospital site (excluding non-clinical care services). Part of this care is facilitated through State and Territory Government's funding of community based palliative care. Some examples of this funding include:

- $58.7 million in block funding allocated to support patients and families in their usual place of residence in Victoria in 2017-18; [54]
- Western Australia's 2019-20 State budget announced an additional $41 million investment in enhanced community-based palliative care across the region; [55]
- $17 million of funding over two years announced in the Queensland Health Budget to support community based palliative care services; [56]
- $100 million in funding for palliative care funding in NSW in 2017-18 to increase the number of community health workers and 'round-the-clock' services, and support the integration of services in line with community expectations and need; [57]
- $16 million over four years was announced in the 2018-19 State budget to extend palliative care community outreach services operating hours to 24/7.[58]

Importantly however, visibility of the activity which results from this funding is limited. The current data does not support the disaggregation from total non-admitted palliative care service events to those that are community-based (e.g., in day centres, community facility, GP clinics, residential aged care, private residence and other hospital). So while the data reported captures the activity, it is difficult to determine exactly 'how much'.

Figure 9: Non-admitted palliative care service events by State and Territory 2017-2018



Source: AIHW (2019)

Note: *Tier 2 classifications categorise the nature of delivered non-admitted services. Classifications 20.13 and 40.35 refer to non-admitted palliative care services categorised as medical consultation and allied health/clinical nurse specialist interventions, respectively.*

The palliative care workforce

Palliative medicine specialists

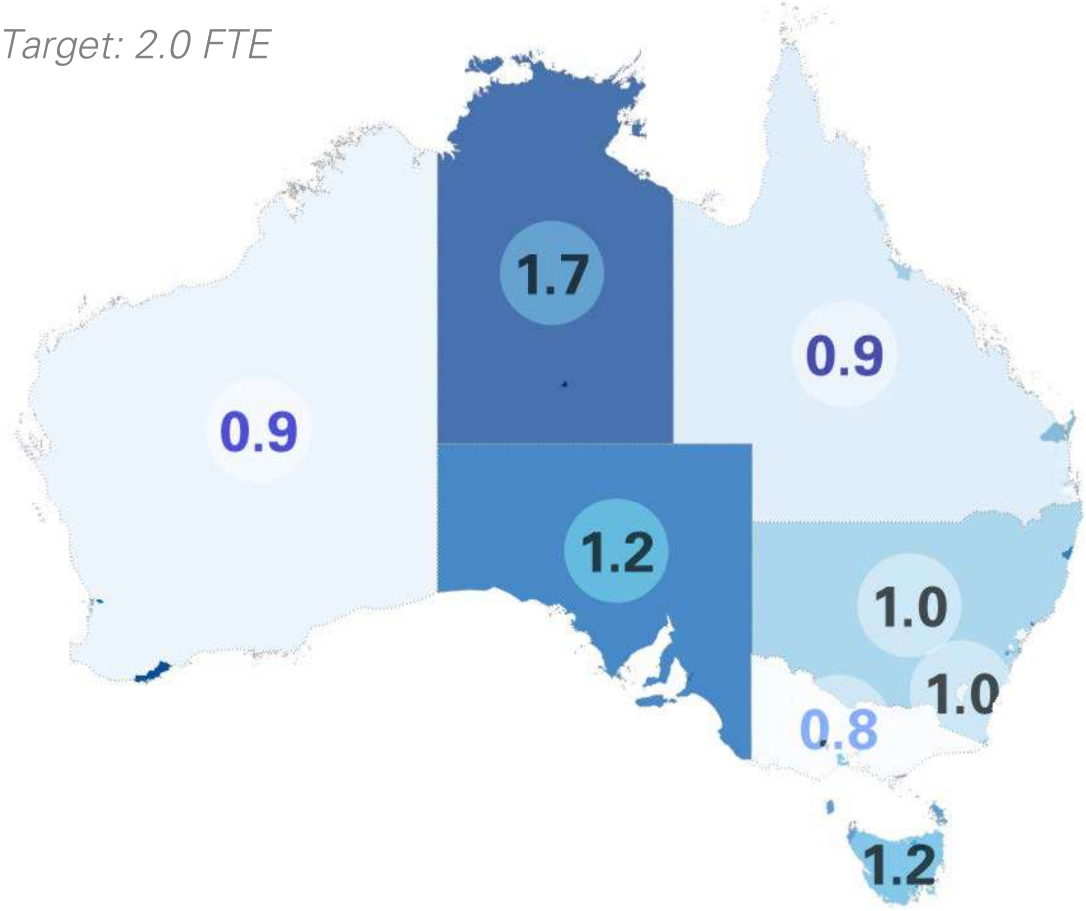
The number of employed palliative medicine specialists in 2017 was 249, up from 171 in 2013. Relative to population, the number of employed FTE palliative medicine specialists has grown by 5.9 per cent per annum. Relative to total medical practitioners, palliative medicine specialists have grown at 7.8 per cent per annum, and now make up 0.25 per cent of total medical practitioners. [59]

The age demographic of palliative medicine specialists has improved over the last 5 years, with 32 per cent aged over 55 in 2018, versus 39 per cent in 2013. The replacement rate of palliative care workers is also considered strong. [60] In 2017, 11 university graduates specialised in palliative care. In 2018, 40 advanced trainees specialised in palliative care, allowing them to practice in the field. [61]

The majority of palliative medicine specialists are employed in hospitals (74 per cent), community health care services (eight per cent) and outpatient services (six per cent). Nearly 60 per cent of palliative medicine specialist were located in New South Wales and Victoria.[62]

Importantly however, the current level of palliative care workforce is still below the minimum benchmark set by PCA in 2018 of two full-time equivalent palliative medicine specialists per 100,000 population. [63] This deficit is present across all Australian States and Territories. See Figure 10.

Figure 10: FTE employed palliative medicine specialists per 100,000 population (2017)



Source: KPMG analysis of the National Health Workforce Data Set (2017)

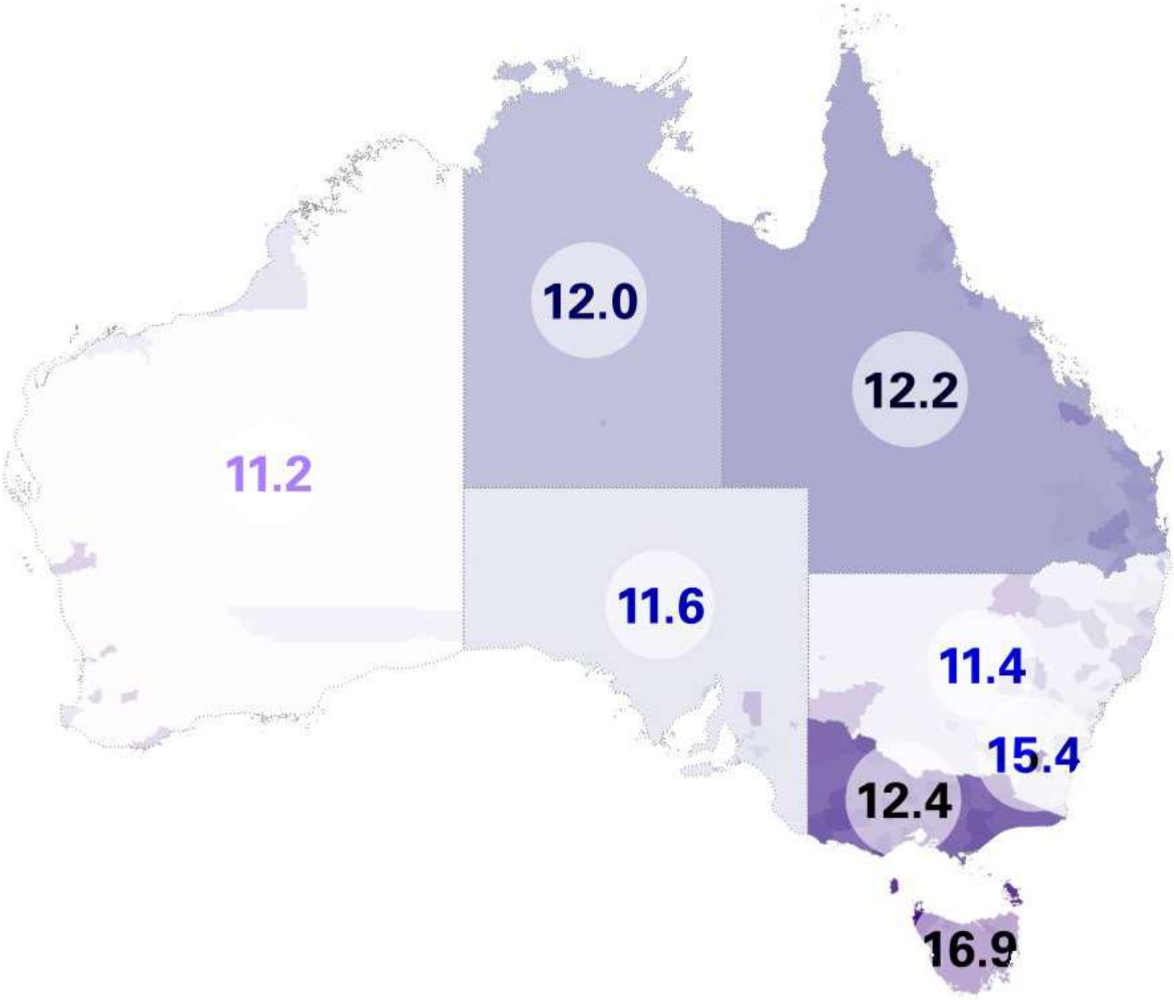
Nurses in palliative care

The number of employed nurses with a palliative care job area in 2017 was 3,430, up slightly from 3,203 in 2013. Relative to population, this number has remained constant. Relative to total nurses, nurses with a palliative care job area have declined slightly to just over one per cent of all nurses, as total nurse growth over the last five years (2.3 per cent per annum) has outstripped growth in those working in palliative care (1.2 per cent).[64]

The age demographic of nurses working in palliative care has a moderate level of ageing, with 33 per cent of nurses aged over 55 in 2017, versus 30 per cent in 2013. The majority of these nurses are employed in hospitals (53 per cent), community health care services (24 per cent) and hospices (14 per cent). [65]

In 2017, there were 12 FTE employed nurses with a palliative care job area across Australia per 100,000 population, based primarily in major cities and inner regional areas.[66] See Figure 11.

Figure 11: FTE employed nurses with a palliative care job area per 100,000 population (2017)



Source: KPMG analysis of the National Health Workforce Data Set (2017)

Note: The reported data is based on the nurse labour force survey. In this case the data illustrates the number of nurses working in a specific job area (i.e. palliative care) at a point in time: 1) this does not perfectly capture 'palliative care nurses' (certified palliative care nurses); 2) the data may be understated, as some nurses that have a primary responsibility for palliative care are not recognised (i.e. aged care and community settings).

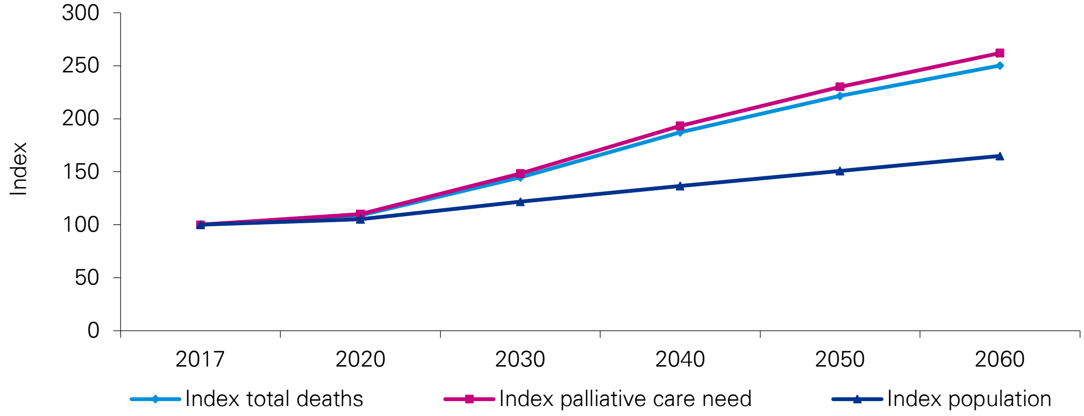
The increasing need for palliative care

In 2017, 15 per cent of all Australians were aged 65 years and over. Of the 160,000 deaths in 2017, 82 per cent were aged in this cohort.[67] With expectations that 8.2 million individuals aged 65 and over will be added to the population by 2060 (approximately 20 per cent of the estimated population in that period), death will become increasingly prevalent in Australian society.[68]

Following the method from Sleeman et al. [69], combined with WHO mortality projections, KPMG estimate that between now (2019) and 2060:

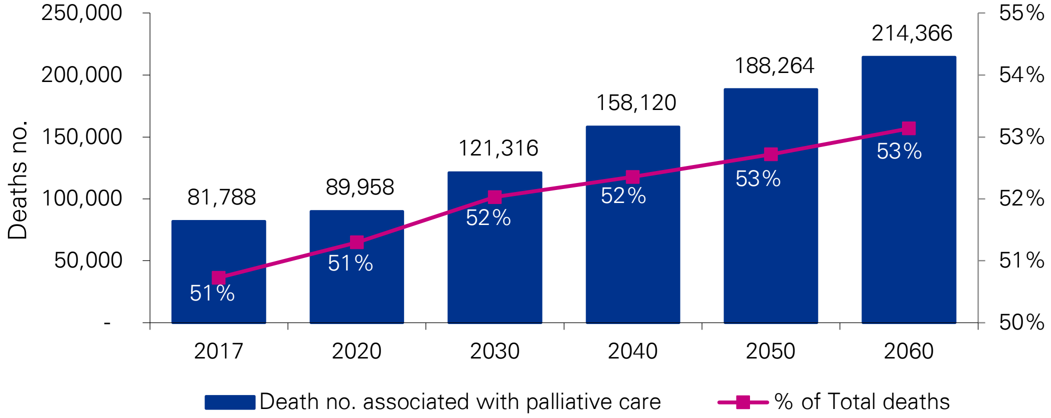
- The population will increase by 60 per cent to 40.5 million individuals;
- Total deaths will surge by 135 per cent to 400,000, of which 214,000 will require palliative care services.
- Need for palliative care will grow faster than both the population and total deaths.

Figure 12: Growth in the estimated population, total deaths, and palliative care need (2017-2060)



Sources: KPMG analysis (2019): ABS cat. no. 3303 (2018)

Figure 13: Estimates of need for palliative care in Australia 2017-2060



Source: KPMG analysis (2019); Sleeman et al. (2019)

The economic case for increased investment in palliative care in Australia

The economic case for increased investment in palliative care in Australia

There are strong economic arguments for increased investment in palliative care. A scan of the research into palliative care services and medicines highlights a range of key benefits that palliative care can provide. These include:

- **Reduced health service utilisation**
  Palliative care services provided by multidisciplinary specialists can result in less hospitalisations. [70] Studies reviewing the impact of coordinated care for symptom management and improved pain control can lead to fewer ED visits and ICU admissions. [71] [72] An experimental study in Australia of palliative care involving active SPC, which includes support from nurses in clinical decision-making and timely access to medicine, highlighted reduced length of hospital stays for residents in aged care. [73] [74] [75]

- **Improved coordination of the healthcare system**
  A systematic review of RCTs demonstrated that palliative care integrated with oncology services can provide better allocative efficiency of health care resources. [76] This can also extend to medications: a study of palliative care interventions administered by pharmacists within a multidisciplinary team suggested improved medication prescribing that might reduce direct medical costs. [77]

- **Improved wellbeing and productivity for carers**
  Psychological and educational support from palliative care specialists can deliver positive outcomes for carers. [78] In one example, family and informal carers of individuals with incurable cancers that received regular visits by a trained nurse showed a reduction in emotional distress. [79] In another example, palliative nurses that provided health promotion and assisted carers were associated with lower caregiving hours which can reduce productivity losses of carers. [80]

- **Lower bereavement costs**
  Inclusive palliative care can provide better coping mechanisms for carers during their bereavement. [81] A review of the literature indicated that bereaved people are likely to have health problems. [82] Providing emotional support for carers during the end-of-life suggested lower costs of bereavement in health care providers. [83]

The following section highlights a number of examples of palliative care that provide not only positive social and health outcomes, but also deliver wider economic benefits:

- Integrated home-based palliative care;
- Advance care planning;
- Palliative care Nurse Practitioners in residential aged care;
- Integrated palliative care teams in hospitals.

In health economics, these interventions are called ‘dominant’ interventions because they dominate the status quo models of care on both cost and outcome measures. Health interventions are often able to provide improved patient outcomes, but doing so while also reducing costs is much rarer. When health interventions can do both, they provide a clear economic rationale for investment.

These analyses are then used to inform the recommendations in the next chapter.

Integrated home-based palliative care

What is integrated home-based palliative care?

Integrated home-based palliative care services (hereafter 'IHPC') support individuals, families and caregivers outside institutional settings of care. The aim of this care is to afford individuals the greatest chance to live well at home and achieve their preferred place of death. [84] To do this, IHPC recipients are surrounded by a multidisciplinary team of personnel who are led and proactively coordinated by a GP. These personnel (e.g. nurses, allied health professionals, volunteers and other community workers) provide a range of services as the individuals' needs change. In the event that needs are complex, SPC services can also be enlisted to support the team and manage the patients' symptoms. [85]

Examples of this care include but are not limited to:

- Symptom management and assessment;
- Case conferencing, care management planning and coordination;
- Access to after-hours care;
- Knowledge and skill sharing for all those involved in patients' care;
- Spiritual and psychosocial support for patients, carers and families; [86] [87]
- Personal care, food and transport services.

Who is this intervention targeted towards?

IHPC services are for individuals with life-limiting disease whose preference for place of care is in the home. [88] While these services are vital and utilised across all regions of Australia, IHPC services can be particularly valuable to those in rural and remote areas – or where alternative providers or services are limited. [89]

What are the benefits of integrated home-based palliative care and how strong is the evidence base?

The Cochrane Collaboration published a systematic review of 23 studies on the effectiveness of home palliative care services for adults with advanced illness and their caregivers. [90] 16 of these studies were RCTs, of which six were deemed high quality. Since their review, a number of studies have been reported in Australia, both in Western Australia (SilverChain) and New South Wales (PEACH pilot). [91] [92] [93]

A synthesis of the local and international literature provides strong evidence that these services are twice as likely to fulfil individuals' wishes to die at home and can do so without impacting their symptom burden or caregivers grief. [94] [95] Studies reporting on the subsequent impact of this on resource usage have found that timely integrated home care can:

- **Reduce presentations to the ED:** individuals receiving IHPC services visited the ED by between two and 13 per cent less in the last year of life. [96] [97]
- **Lead to less time spent in hospital:** studies of IHPC recipients have reported fewer average total bed days of between 4.5 and 7.5 in the last year of life; [98] rates of hospitalisation were also seen to fall by between one and 66 per cent. [99]

What are the costs of integrated home-based palliative care in the Australian setting?

Past inquiries have had much to say about the cost of implementing integrated home care services. [100] [101] [102] The PC's assessment of 12 not-for-profit providers of these services suggests that this cost is between AU$6,000 and AU$10,000 per person – or AU$8,000 on average (Australian Dollars, price year not reported). The Grattan Institute's 'Dying well' reported the cost of community care at $6,000 per person (Australian Dollars 2013/14) – adjusting for a three-month length of stay. In the Senate Community Affairs References Committee's (SCARC) 2012 inquiry, Eastern Palliative Care Association Inc. highlighted that the per person cost in the community was much lower than in the sub-acute setting ($7,700) at $2,567 (Australian Dollars 2009). A trial of specialist home-based care intervention yielded similar results, reporting a costs ranging from $2,170 to $4,943, and a mean of $3,489 per person (Australian Dollars 2010). [103]

Overall, the Australian evidence suggest that IHPC can be delivered from as low as $2,000 to as high as $10,000 per person. In current prices (2019), KPMG estimate that implementation of IHPC is likely to cost between $3,913 and $8,516, with an average of $6,508, per person.

What is the potential return on investment for integrated home-based palliative care in Australia?

Based on the resource savings calculated above, in the last year of life IHPC is expected to save between $4,544 and $6,109 (2019 Australian Dollars) per person from reduced ED and hospitalisation costs. Compared with the implementation cost associated with these interventions, **KPMG estimates that a $1.00 investment in IHPC can return between $0.53 and $1.56 – or cost neutral on average (2019 Australian Dollars).** See Table 5**.**

Table 5: ROI per person for IHPC (2019 Australian Dollars)

Scenario	Low case	Medium case	High case
Cost of implementation	**$8,516**	**$6,508**	**$3,913**
Average health savings	$4,544	$6,032	$6,109
Bereavement savings	-	-	-
Employment savings	-	-	-
ROI	**$0.53**	**$0.93**	**$1.56**

Source: KPMG analysis 2019

Note: *In this analysis, potential bereavement and employment benefits are acknowledged but not quantified.*

Advance care planning

What is advance care planning?

Advance care planning allows patients to express how they would like to receive care in the event they are unable to communicate this themselves. Advance care planning includes the development of an advance care plan (ACP), which is a living document of the individuals' personal values and care preferences. Some ACPs also appoint a substitute decision maker (i.e. a family member) who will be responsible for guiding care decisions. ACPs can help to inform the clinical decision-making process most effectively where the document is well-maintained and is legally binding (i.e. an advance care directive). [104]

Overall, ACPs can facilitate: [105]

- Discussions related to prognosis and treatment with the inclusion of family, friends, and health practitioners who understand the individual;
- The appointment of a substitute decision maker;
- The concordance between care received and patients' goals of treatment.

Who is this intervention targeted towards?

While these interventions are particularly relevant for older aged individuals with life-limiting disease, ACPs are an important document for anyone who wishes to articulate their preferences for treatment and care. This can include people: [106]

- who are aged or frail;
- of any age with chronic progressive and life-limiting conditions;
- approaching the end-of-life;
- with multiple comorbidities and/or at risk of conditions such as stroke or heart failure;
- with early cognitive impairment; and
- who are isolated or vulnerable.

What are the benefits of advance care plans and how strong is the evidence base?

Nine systematic reviews and meta-analyses have assessed the efficacy of ACPs. Across low, moderate and high grade analyses, there is a general consensus that ACPs positively impact the concordance between individual preferences and care, quality of life, and family and carer burden.

The evidence also suggests that compared to a control group ACPs can generate savings from reduced:

- **Hospitalisations and length of stay** – ACPs can reduce rates of hospitalisations from nine to 26 per cent; [107] and length of stay between 0.35 to 3.5 days in the last year of life. [108]
- **ICU admissions and usage –** For individuals at high risk of death, ACPs can generate a mean reduction of 37 per cent in the probability of ICU admission. [109] More broadly, ACPs have the capability to reduce the overall use of the ICU by nine per cent in the last six months of life. [110]
- **Emergency calls to ambulance –** Improved understanding of treatment goals can also reduce unnecessary calls to emergency services and subsequent admission to the ED in nursing home residents by around 20 per cent. [111]

What are the costs of advance care plans in the Australian setting?

Two studies have evaluated the cost of ACPs in the Australian context. [112] [113] While different in methodology, estimates were consistent, ranging from $250 per person for small packages; up to $1,000 for large packages (2015 Australian Dollars). The average per person cost of an ACP ranged between $516 and $820 depending on the authors' assumptions.

After inflating these estimates by the ABS Health CPI and the June 2019 MBS item schedule (where applicable), KPMG estimate that the cost of implementing an ACP is likely to range from $596 (low), $684 (medium), and $833 (high) per person in 2019 Australian Dollars.

What is the potential return on investment for advance care planning in Australia?

Using the resource savings informed from the literature, investment in ACPs is estimated to save between $395 and $1,783 per person in health costs during the last year of life from reduced hospitalisations costs; ICU costs (captured in reduced hospitalisations); and ED costs. Combining the implementation cost associated with delivering these benefits, **KPMG estimates that a $1.00 investment in ACPs can return an average between $0.47 and $2.99 (2019 Australian Dollars).** See Table 6.

Table 6: ROI per person for advance care planning (2019 Australian Dollars)

Scenario	Low case	Medium case	High case
Cost of implementation	**$833**	**$683**	**$596**
Average health savings	$395	$1,096	$1,783
Bereavement savings	-	-	-
Employment savings	-	-	-
ROI	**$0.47**	**$1.60**	**$2.99**

Source: KPMG analysis (2019)

Note: *In this analysis, potential bereavement and employment benefits are acknowledged but not quantified.*

Specialist palliative care in residential aged care

What is specialist palliative care in residential aged care?

Palliative care services in residential aged care provide support to residents to better manage their health and disease trajectory, and help for carers and the residential aged care workforce to improve their palliative care literacy. A particularly effective model appears to be SPC that includes both:

- Direct support in the form of clinical support for residents;
- Indirect support such as a 'needs round' that bring together staff, palliative care nurses and other health professionals to provide improved symptom management, advance care planning, and medication management. [114]

Who is this intervention targeted towards?

This model of care focuses primarily on those with complex care needs in a residential aged care facility.

What are the benefits of specialist palliative care in residential aged care and how strong is the evidence base?

A recent stepped wedge Australian trial across 12 residential aged care sites (the INSPIRED trial) found that SPC services and needs rounds in residential aged care can:

- **Reduce presentations to hospital –** hospitalisation admissions reduced from 5.6 to 4.3 per facility per month (observed);
- **Lead to less time spent in hospital –** total bed days reduced from 39 to 27 per facility per month (observed). [115]

It is important to note that these benefits are not necessarily exclusive to the INSPIRED model of care. Alternative models may be more appropriate to deliver these clinical competencies depending on remoteness, workforce capability and other demographics characteristics which impact the nature of care. As in the case of the INSPIRED model, these approaches must also be evaluated from an economic perspective.

What are the costs of providing specialist palliative care in residential aged care?

The Australian trial used two Nurse Practitioners across the 12 sites, at a total cost of $381,716 per annum, covering both salaries and on-costs. [116] In addition, KPMG estimate that the increased utilisation of wider health services (for example, GP visits at needs rounds, and case-conferencing) adds costs of approximately $250 per person discussed at a needs round, based on the lower end of the costs of ACP discussed previously. The lower end of the ACP is used as it is assumed that the Nurse Practitioner roles cover part of the increased service demand. This adds an extra $180,000 per annum in associated health service costs, for an estimated total cost of $561,716.

What is the potential return on investment for specialist palliative care in residential aged care in Australia?

Based on the estimated resource savings of $1,286 per hospital bed day, [117] and transport costs of $983 per hospital admission, [118] this intervention is expected to save:

- $941,920 (adjusted) to $2,140,727 (observed) in hospitalisation costs per annum;
- $80,885 (adjusted) to $183,830 (observed) in reduced emergency transport costs per annum.
- In the low case, transportation savings have been excluded to represent regions where these benefits may not accrue.

KPMG estimates that a **$1.00 investment in palliative care nurses in residential aged care can return between $1.68 and $4.14** (2019 Australian Dollars)**.**

Table 7: ROI per annum for palliative care Nurse Practitioners in 12 RACFs (2019 Australian Dollars)

	Low case	Medium case	High case
Cost of implementation	**$561,716**	**$561,716**	**$561,716**
Health savings:			
Reduced bed days	$941,920	$941,920	$2,140,727
Reduced ICU admissions	-	-	-
Reduced ED transport costs	-	$80,885	$183,830
Other savings:			
Bereavement savings	-	-	-
Employment savings	-	-	-
Total savings	$941,920	$1,022,805	$2,324,557
Net savings	**$380,204**	**$461,089**	**$1,762,841**
ROI	**$1.68**	**1.82**	**4.14**

Source: *KPMG analysis (2019)*

Note: *In this analysis, potential bereavement and employment benefits are acknowledged but not quantified.*

Palliative care in hospitals

What palliative care services are provided in hospitals?

Palliative care services in hospital can provide an increased level of targeted support to individuals, and carers of individuals, with complex health needs.

In the hospital setting, palliative care can be provided both in SPC beds, as well as in other beds for individuals receiving treatment or other types of care in acute or sub-acute beds. Both types of palliative care are associated with reduced costs and health service utilisation compared to hospitalisations without palliative care. [119] [120]

Importantly, palliative care in the hospital need not be confined to the last hours of life. The benefits of palliative care in hospital increase the earlier the palliative care is introduced. [121]

Who is this intervention targeted towards?

This model of care is targeted at individuals admitted to hospital with life-limited illnesses.

What are the benefits of palliative care in the hospital and how strong is the evidence base?

- A recent Australian study identified an incidence rate of non-beneficial end-of-life admissions of 12.1 per cent, with an average length of stay of 15 days for these admissions, with an associated cost of $12.4 million.[122]
- Another Australian retrospective cohort study of almost 20,000 DVA clients found the cost of death for those with access to palliative care services was on average $5,364 cheaper ($6,776 in 2019 dollars) than those without access to palliative care[123]. While the study did match with and without palliative care access cohorts for disease, complexity or other factors associated with costs of death, they featured similar proportions of cancer.
- International studies have also reported significant reductions in inpatient costs. A systematic review of 10 inpatient consultation programs reported statistically significant cost savings from hospital palliative care teams of between nine and 25 per cent. [124]
- A recent meta-analysis found cost savings from hospital palliative care consultations of US 2015 $3,237 (CI: $2,893 to $3,581) [125] or $5,511 ($4,925 to $6,096) in current Australian Dollars, although we note that costs in the United States health system are appreciably higher than Australia.
- There is also evidence to suggest that the timing of palliative care in hospital has an impact on the cost savings it delivers. One study found cost savings increased by 71 per cent when palliative care was integrated within two days of admission instead of after six days from admission. [126] A randomised trial of early palliative care integrated with oncology care found improved patient and economic outcomes, although the small sample size meant many of the cost savings were not significant at the 10 per cent level. [127]

What are the costs of providing palliative care in the hospital?

The literature above tends not to report specific palliative care interventions that deliver cost saving, but simply notes hospitalisation costs for those with and without access to palliative care. It is therefore difficult to directly cost the intervention.

The Independent Hospital Pricing Authority report sub-acute palliative care costs of $410 million across 277 hospitals and 53,000 separations. The national average cost of a separation is $7,697 for an ALOS of six days [128], however this varies dramatically across jurisdictions: in Victoria the cost is $12,131 per separation; while in New South Wales, the cost is $5,087.

Palliative care teams that provide services to individuals in other hospital beds may be cheaper. For example, one study reported integrating palliative care into oncology treatment added US$1,250 in palliative care costs[129], or approximately $3,000 in current Australian dollars.

Similarly, the literature is unclear as to how much of the costs of palliative care is captured within the reported overall cost savings. Correspondence with one study author suggests that the cost savings are 'net' of the direct costs of palliative care including staff costs spent with the patient, but the author noted there may be further indirect costs associated with setting up the services such as land, capital and training that can add around 20 per cent to direct costs. [130]

What is the potential return on investment for palliative care in hospitals in Australia?

Based on the cost savings identified in the literature, and low, mid and high cost assumptions based on the IHPA cost of sub-acute palliative care, KPMG estimates that a **$1.00 investment in palliative care in hospital delivers a return of between $1.36 and $2.13** (2019 Australian Dollars)**.**

Table 8: ROI per admission for palliative care services in hospitals (2019 Australian Dollars)

	Low case	Mid case	High case
Cost of implementation	**$12,131**	**$7,697**	**$5,087**
Health savings	$16,481	$12,933	$10,845
Reduced bed days	-	-	-
Reduced ICU admissions	-	-	-
Reduced ED transport costs	-	-	-
Other savings:			
Bereavement savings	-	-	-
Employment savings	-	-	-
Total savings	$16,481	$12,933	$10,845
Net savings	**$4,350**	**$5,236**	**$5,758**
ROI	**1.36**	**1.68**	**2.13**

Source: *KPMG analysis (2019)*

Note: *In this analysis, potential bereavement and employment benefits are acknowledged but not quantified.*

Recommendations

Recommendations

This section outlines recommendations for reform, each with several specific sub recommendations and enablers. These recommendations were selected in accordance with the criteria highlighted in the methodology.

Table 9: Summary of recommendations for reform

Improve access to home and community-based palliative care services
Recommendation 1.1: Increase funding and timely access to home and community-based palliative care services
Recommendation 1.2: Develop a key performance indicator to monitor access to home and community-based palliative care
Expand palliative care services in residential aged care
Recommendation 2.1: Invest in SPC and integrated support across residential aged care.
Recommendation 2.2 Explicitly identify palliative care in the Aged Care Quality Standards
Increase investment in earlier and more integrated palliative care services in hospitals
Recommendation 3.1: Increase palliative care services in hospitals
Recommendation 3.2: Track the incidence of non-beneficial care in end-of-life hospital admissions, and systematically measure the impact of palliative care on hospitalisation costs
Deliver system-wide reform to unlock the potential of palliative care
Recommendation 4.1: Establish a permanent National Palliative Care Partnership Agreement with State and Territory Governments and appoint a National Palliative Care Commissioner
Recommendation 4.2: Reform funding models to facilitate integrated, patient centred care
Recommendation 4.3: Develop a palliative care minimum dataset
Recommendation 4.4: Expand the palliative care workforce and increase palliative care literacy across the wider health sector
Recommendation 4.5: Deliver community awareness and education programs

Source: KPMG (2019)

Recommendation 1

Improve access to home and community-based palliative care services

In the current system, palliative care needs are not always met with the appropriate access to services. Living well at home is commonly desired, yet of the $6.8 million worth of palliative care services subsidised by the MBS in 2017-18, only 20 per cent of activity occurred outside the hospital. In the same period, just 2,595 individuals received a MBS-funded palliative care home visit, less than two per cent of the deaths in that period. See Figure 14.

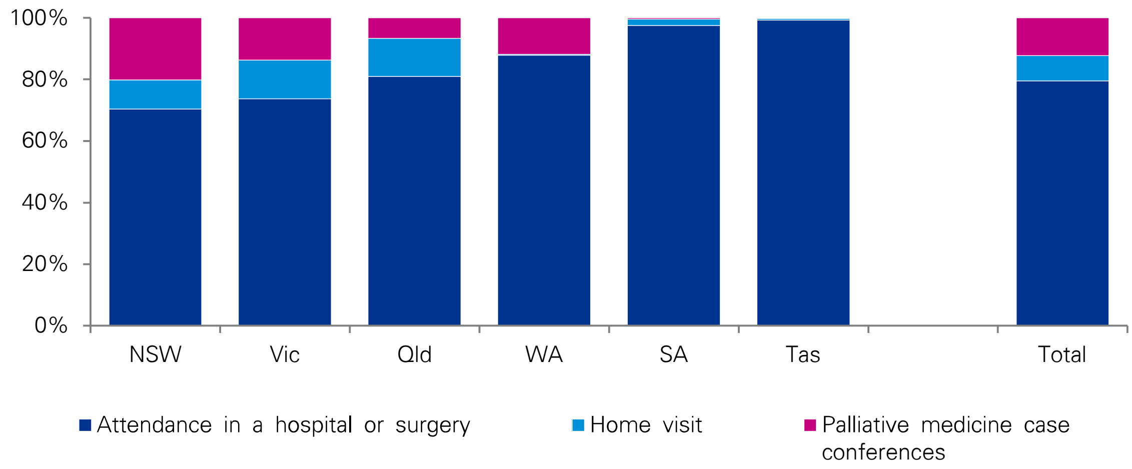
Most Australians prefer to die at home, however only four to 12 per cent do (KPMG estimate). This is low compared to countries like the United Kingdom and New Zealand where between 23.5 and 30 per cent of deaths occur at home each year. [131] [132]

While the cost of death in Australia is almost AU$8 billion per annum, State funding for community palliative care services are sporadic and insufficient, totalling to approximately AU$90 million across the country for 2019-20 (KPMG estimate from budget announcements).

Importantly, the PC has noted that many of those who could benefit from palliative care did not know of its existence or missed out as a result of no coordination between the primary carer and the provider. [133] The Victorian Auditor General also highlights that community palliative care services are struggling to meet the increasing demand. [134]

The National Palliative Care Standards 2018 (5th Edition) recognises that much of patients' expectations and needs have changed in the past decade. Their revision to the Standards suggests that service delivery models of today must organise capabilities (general and specialist) to support a framework which provides timely, person-centred palliative care irrespective of the level or location of need. [135]

Figure 14: MBS-funded palliative care services



Sources: AIHW Palliative care services in Australia: Medicare-subsidised palliative medicine services.

Recommendation 1.1 Increase funding and timely access to home and community-based palliative care services

The rationale for this recommendation

From a patient perspective, there is a large discrepancy between Australian's preference for place of care, and where people actually receive care. Improving access to timely and coordinated home and community-based palliative care services will allow thousands more Australians to live well at home during their last months of life, and achieve their preferred place of death at little cost to Government. [136]

The recommendation

We recommend an increase in funding of AU$240 million per annum for integrated home and community-based services based on models of care that have been shown to be effective.

The evidence base

- There is strong international and domestic literature suggesting the efficacy of home-based palliative care. Not only does home-based care improve concordance with individual preferences, but it can do so without impact on quality of life or caregiver burden. [137] [138]
- Examples in Australia have also found this can generate health care savings from reduced hospital length of stay and presentations to the ED in the last year of life. [139]

The potential savings from this recommendation

KPMG estimate that the funding increase of AU$240 million would be fully offset by equivalent savings from:

- 37,000 more people dying at home;
- 230,000 less hospital bed days;
- 47,500 fewer ICU days; or
- 225,000 fewer presentations to the ED.

Recommendation 1.2 Develop a key performance indicator to monitor access to home and community-based palliative care

The rationale for this recommendation

Current reporting and monitoring of palliative services that are delivered in the home and community is poor.

The New South Wales Auditor General noted that NSW Health has a limited understanding of the quantity and quality of palliative care provided across the State. [140]

MBS data covers but a fraction of total expenditure on home and community-based palliative care. State-based reporting of expenditure on palliative care is ad-hoc and inconsistent across the country.

The recommendation

We recommend the development of a specific metric to track access to home and community-based palliative care across Australia. This would allow stakeholders to clearly monitor current levels of access and track improvement over time.

Such a metric may be derived from a sample estimate initially, and develop over time to an administratively derived metric as funding models are aligned to the service capability frameworks currently being developed.

We suggest that PCOC and the AIHW are natural homes for this indicator.

The opportunities and challenges of implementation

The opportunities from the implementation of these recommendations include:

- Delivering a patient-centred service that brings care to the individual;
- Clear reporting and understanding of levels of access of palliative care in the home and community.

Challenges for implementation include:

- Living and dying at home can increase the burden on informal carers. To ensure this recommendation delivers a cost saving, and not simply a cost shift from the healthcare system to individuals and their families, support must be provided to informal carers. This form of support has been well demonstrated by organisations such as LifeCircle. See Box 3;
- A person who chooses to die at home is not excluded from traditional health services. Care must still be integrated, and funded in a way that promotes coordination;
- Discussing death is still not core business;
- Current State-based reporting and monitoring systems may not easily integrate;
- Full coverage of access outcomes remains difficult without the consistent funding models that provide administrative data.

Box 3: LifeCircle

When palliative care is provided in the home and community, caregivers of the palliative care patient play a critical role: as key influencers in decision-making, while also providing a range of practical and emotional support. As cited by research, one of the core capabilities required to deliver systemic and structural change is support for caregivers, as they can have a significant impact on the end-of-life experience.

LifeCircle exists to prepare and support the carers of people who have a life-limiting illness or are elderly and frail (**https://www.lifecircle.org.au**/). LifeCircle's Guided Support Programs facilitate acceptance, conversations, preparation and planning, and address the complex behavioural barriers that exist around the end-of-life. This work helps families and carers who are unaware of the essential role of palliative care, or who may be too frightened or anxious to engage with it, to be referred to appropriate services.

Recommendation 2

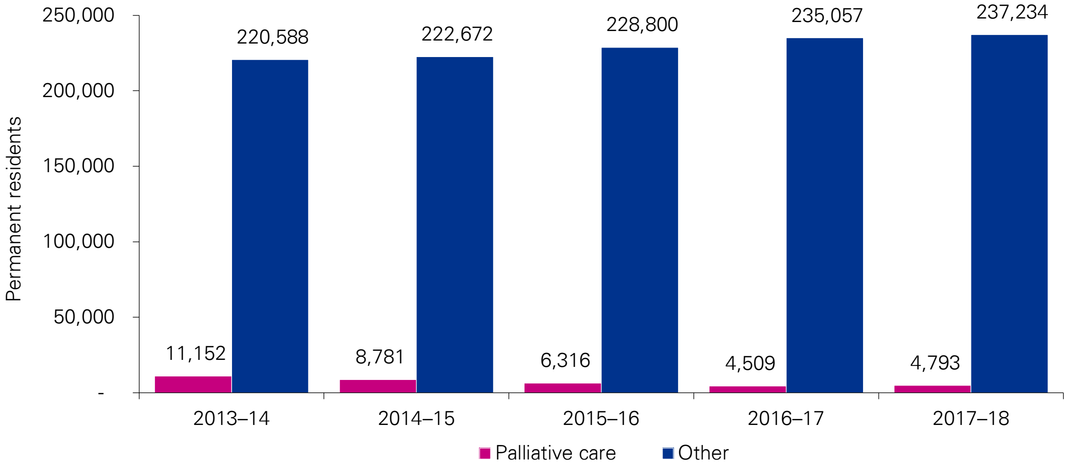
Expand and fund increased palliative care services in residential aged care

Palliative care services in RACFs are underfunded and underserviced. Through ACFI, palliative care is only funded for the last days of life. As a result, only a token amount of palliative care services are provided in residential aged care, with just one in 50 permanent residents receiving ACFI-funded palliative care. [141] A new funding model has been proposed (the Australian National–Aged Care Classification (AN–ACC)), but its ability to ensure residents' palliative care needs are met is still being evaluated. Despite growth in palliative medicine specialists, the number per 100,000 population remains half of the target rate, and is predominantly provided in hospitals. [142]

Poor integration of residential aged care with hospital settings leads to high-cost low-value care. The overlap between systems and boundaries across settings promotes confusion, conflict of responsibility, and inequitable care management. These problems are exacerbated further by the opaque funding models. The intensity of care and poor conditions are often inconsistent with individuals' care preferences – and typically lead to sub-optimal outcomes.

Palliative care requires coordination from the primary carer, palliative care specialists, and health workers, in deciding the plan of care. Uptake of advance care planning, even with RACFs, remains relatively low. [143]

Figure 15: ACFI appraised palliative care permanent residents in aged care (2013-14 to 2017-18)



Sources: AIHW Palliative care services in Australia: Palliative care in residential aged care

Note: Changes in the ACFI are involved in the declining trend of palliative care recognised residents.

Recommendation 2.1 Invest in specialist palliative care and integrated support across residential aged care

The rationale for this recommendation

Nearly as many people die in residential aged facilities as in hospitals, yet the provision of palliative care remains low. ACFI is available only for the last days of life, and as a result integrated and proactive palliative care is not incentivised.

The recommendation

- Invest $75 million per annum to increase the provision of palliative care within residential aged care. The investment should include both direct SPC support, and integrated support that includes residential aged care workforce and other health professionals such as GPs. Clinical palliative care expertise should be provided as a 'core business' of residential aged care.
- A specific example of models of care that have been shown to work in the Australian setting are the INSPIRED trial 'needs round' concept. [144] This model used Nurse Practitioners to provide proactive, integrated palliative care to high complex needs individuals in RACFs. A $75 million investment would fund 265 extra staff to provide SPC support.

The evidence base

- Successful recent stepped-wedge randomised control trial run across 12 Australian sites; [145]
- Observed hospitalisation bed day reductions and ROI as highlighted in the previous chapter.

The potential savings from this recommendation

Currently around 53 per cent of residents in aged care facilities have high complex needs. [146] Each of these individuals deserves access to SPC services. Using the INSPIRED trial as an exemplar model of care, an investment of around $75 million per annum would provide funding for an extra 150 Nurse Practitioners and wider multidisciplinary services. Such an investment would deliver between $135 and $310 million in reduced hospitalisation and emergency transportation costs, and free up between 100,000 and 220,000 hospital bed days, or up to 600 beds at full utilisation.

Importantly, this model is offered as an example of how increased availability of staff with clinical palliative care competencies in residential aged care can generate positive outcomes. Alternative models may be more appropriate to deliver these competencies depending on factors of remoteness, workforce capability and other demographics characteristics which impact the nature of care.

Recommendation 2.2 Explicitly identify palliative care in the Aged Care Quality Standards

The rationale for this recommendation

Palliative care in residential aged care is often confined to the last hours of life and not systematically integrated into core business residential aged care services.

While the current Aged Care Quality Standards contain components of palliative care (for example Standard 3c), it does not effectively describe the expectations for palliative care in a holistic or systematic manner. [147] In light of the clear need for palliative care for this population cohort, and the high degree of complex needs with residential aged care, the Standards should be altered such that they define what 'good care should look like', and include specific minimum competencies for palliative care.

An important way to drive quality improvements is to require systematic reporting and measurement of key indicators, as per the National Aged Care Mandatory Quality Indicator Program. The development of palliative care quality indicators, while not straight-forward, would enable such an approach to be used to improve the provision of quality palliative care across residential aged care.

The recommendations

- The Aged Care Quality Standards be revised to include a specific palliative care standard.
- The development of National Mandatory Quality Indicator/s for Palliative Care.

The opportunities and challenges of implementation

Improving the provision of palliative care services in residential aged care would deliver significant economic gains. However, to achieve these benefits would require a range of key factors, including, but not limited to:

- **Ensuring fidelity of the model of care** - the trial found that reductions in hospital bed days were dependant on fidelity to the model of care; low fidelity sites achieved much poorer outcomes. Similarly, a recent white paper highlighted that good practice can be lost once key actors (managers and staff) depart. To ensure turnover does not impede on the model of care, changes must be imbedded in day-to-day practice. [148]
- **Delivering the required workforce –** such an expansion of new Nurse Practitioners is a significant increase for a registered current workforce of just 1,904. [149] Growing these numbers would require further investment in education and training, and a more coordinated and strategic approach to the development of growth of Nurse Practitioner roles. This is similarly true should the competencies be provided by other types of palliative care staff.

Recommendation 3

Increase investment in earlier and more integrated palliative care services in hospitals

The majority of Australians die in a hospital. Providing integrated palliative care that commences early on in the individual's pathway to death can increase satisfaction and quality of dying, and reduce the associated hospitalisation costs. [150] [151]

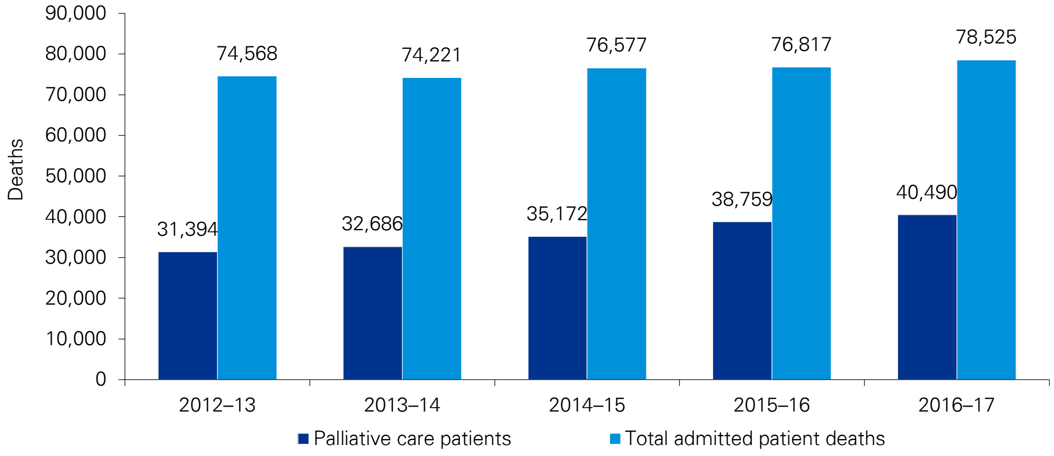
In the hospital setting, palliative care can be provided both in SPC beds, as well as in beds for individuals receiving treatment or other types of care in acute or sub-acute beds. Both types of palliative care are related with reduced costs and health service utilisation. [152] [153]

Importantly, palliative care in the hospital need not be confined to the last hours of life. The benefits of palliative care in hospital increase the earlier the palliative care is introduced. [154]

However the levels of palliative care workforce in hospitals falls well short of minimum targets. [155] As a result, of the 80,000 deaths in Australian hospitals each year, only around half receive palliative care (see Figure 16). The minimum model of care recommends that 6.7 designated specialist inpatient palliative care beds are required for every 100,000 population, equating to 1,650 beds for 2016-17. [156] [157] By comparison, current data suggests there were 281 designated specialist inpatient palliative care beds in private acute and psychiatric hospitals across Australia in that period. [158]

While this count does not represent the total number of specialist inpatient palliative care beds in Australia, there is an opportunity to increase both the number of these beds and the number of palliative care teams to better support those dying in hospitals.

Figure 16: Palliative care individuals who died as an admitted patient (2012-13 to 2016-17)



Sources: AIHW Palliative care services in Australia: Palliative care in residential aged care

Note: Palliative care individuals refers to individuals for whom palliative care was the principal clinical intent during part or all of the hospitalisations that ended with their death.

Recommendation 3.1 Increase palliative care services in hospitals

The rationale for this recommendation

Over 80,000 people die in Australian hospitals each year. The use of palliative care services has grown steadily in hospitals but still lags well short of minimum ratios, where 6.7 specialist inpatient palliative care beds are required for every 100,000 population. [159] Palliative care services make up less than one per cent of total hospitalisations. [160]

The recommendation

- Invest an extra $50 million per year to support more dedicated specialist inpatient palliative care beds, broader in-hospital palliative care teams, and ED triaging directly to specialist inpatient palliative care beds.

The evidence base

- A recent Australian retrospective cohort study, international studies and a recent meta-analysis all highlight statistically significant reductions in hospitalisation costs [161] [162] when palliative care is provided in hospitals. The cost savings are greater the earlier palliative care is provided.

The potential savings from this recommendation

Currently 51 per cent of hospital deaths occur in palliative care. [163] An investment of $50 million on inpatient palliative care services could help increase this to 60 per cent, and provide palliative care support to a further 6,500 deaths each year. KPMG estimate such an investment would deliver savings of around $84 million per year in wider hospitalisation costs.

Recommendation 3.2 Track the incidence of non-beneficial care in end-of-life hospital admissions, and systematically measure the impact of palliative care on hospitalisation costs

The rationale for this recommendation

National standards for hospitals already include a range of actions around comprehensive care at the end-of-life (e.g. Actions 5.15-5.20 of the National Safety and Quality Health Service Standards)[164], yet the incidence of non-beneficial care in hospitals remains high. Regularly tracking non-beneficial care would ensure a focus on actioning the Standards.

Similarly, while the economic case for early inpatient palliative care is strong, there is little systematic Australian evidence that supports the case for inpatient palliative care.

The recommendation

- Fund and complete Australian-based research to measure the incidence of non-beneficial care in Australian hospital settings. This could follow methodologies already adopted in Australia[165], and be repeated over time to monitor progress against the Standards.
- Fund and complete Australian-based research to highlight the economic savings that inpatient palliative care delivers. This could follow the methodologies from similar studies conducted overseas and on veteran cohorts, and be repeated at regular intervals to highlight and monitor the ongoing impact of inpatient palliative care. [166] [167]

The opportunities and challenges of implementation

The opportunities from implementation of these recommendations include:

- Ensuring palliative care teams are appropriately funded so that hospitals will be incentivised to invest;
- Providing robust and current Australian evidence of the impact of inpatient palliative care on wider hospitalisation costs.

Challenges of implementation include:

- One of the challenges with expanding the use of palliative care in hospital is ensuring that the extra costs of palliative care are not born by the hospital.
- To complete a retrospective cost comparison across one or more hospitals will require a clear study design, good administrative data and ethics approval.
- Streamlined processes and dedicated specialist inpatient palliative care beds are important for early and cost-effective integration of palliative care in inpatients settings. Current processes may hinder the ability to keep palliative patients out of hospital.

Recommendation 4

System-wide reform to unlock the potential of palliative care

The final set of recommendations are enabling recommendations that foster and support the earlier recommendations, and ensure that they can be delivered. There is strong consensus on the models of care that deliver better health and economic outcomes, yet the problems of under provision of palliative care remain. These recommendations directly address the stumbling blocks that restrict the sector.

They are not specific palliative care interventions and do not directly generate a return on investment, but they are essential levers to maximise the health and economic benefits from increased investment in palliative care.

Recommendation 4.1 Establish a permanent National Palliative Care Partnership Agreement and appoint a National Palliative Care Commissioner

The rationale for this recommendation

A consistent theme across the various reviews into palliative care is the lack of coordination across Federal, State and Local stakeholders, resulting in difficulty for patients and indeed providers to navigate the complex web of funding models and service provision. A review of National Aged Care Quality Regulatory Processes identified that the fragmented regulatory system resulted in miscommunication between care providers and authorities. [168] The Royal Commission into Aged Care Quality and Safety asserted that the lack of service coordination has resulted in poor access across the aged care system, especially for those who require palliative care. [169]

The recommendation

Table 10: Recommendations for a coordination across Federal, State and Local stakeholders

#	Recommendations for change
1	We recommend a State and Federal partnership agreement that defines the levels of responsibility across each stakeholder, and forms a united front for promotion and delivery of palliative care across Australia.
2	We recommend the appointment of a National Palliative Care Commissioner to act as a champion for improved awareness and promotion of palliative care. The Commissioner should be overseen by an independent board of experts and policy makers.

Source: KPMG (2019)

The opportunities and challenges of implementation

The opportunities from implementation of these recommendations include:

- The ability to reform the sector to provide coordinated, patient-centred palliative care.

Challenges of implementation include:

- Status quo bias (despite clear consensus on the current problems with overlapping and unclear ownership) and an unwillingness to forego current funding.
- Costs associated with transitioning from current arrangements.

Recommendation 4.2 Reform funding models to provide integrated, patient-centred care

The rationale for this recommendation

Funding mechanisms for palliative care are varied and complex across jurisdictions. State and Territory Governments apply different end-of-life care policies. There is no flexibility for funding to move across settings and no linkage with outcomes assessment.

In residential aged care, Federal funding under ACFI is restricted to the last days of life, limiting any possibility for earlier and more integrated palliative care services.

In primary care, there is no MBS-item for advance care planning, and uptake of case-conferencing has been low. [170]

In the home, the Commonwealth Home Support Programme explicitly excludes palliative care services as these are deemed out-of-scope '*because funding is already provided for them through other Government programs*.' [171]

Moving to more integrated and flexible funding arrangements have been shown to have a positive impact on access and quality of services. [172] A recent white paper reiterates this point further, stating that national and regional organisations must prioritise effective funding mechanisms to support palliative care in long-term facilities. [173]

One of the common issues with activity-based funding services in health care is the potential for over-servicing, including supplier-induced demand. However palliative care is limited by death numbers, and is less susceptible to this type of behaviour.

Importantly, much of the thinking has been done, including funding model reviews completed in Victoria [174], a wide range of discussion documents and research papers. [175] Similarly, experience with Hospital in the Home (HITH) has highlighted that funding models can adapt across settings, and benefit from existing administrative frameworks. HITH is funded in a Weighted Inlier Equivalent Separation basis and reported in standard admitted episode datasets, as per inpatient activity.

The recommendation

Table 11: Recommendation for generalised funding mechanisms in palliative care

#	Recommendations for change
1	In conjunction with recommendation 4.1 ('A National Palliative Care Partnership'), we recommend a formal review of current palliative care funding, with the potential for overall stewardship to be transferred to either the States or the Commonwealth. This could then result in a reformed funding model that deletes ACFI funding of palliative care in RACFs, and revises block funding of community and home-base care to fund, measure and report palliative care services using a common unit that can span service complexity and setting.

** The sequence of care refers to the concept of "triangle of care", recognising that a person with life-limiting illness often move between care settings: home, specialist palliative care units and acute hospital.*

The opportunities and challenges of implementation

The opportunities and challenges of implementation

The opportunities from implementation of these recommendations include:

- Equitable access of funding for palliative care will facilitate better care coordination and reduce gaps in service provision as many people with life-limiting illness have the ability to set their care preferences;
- Transparency and easy access of funding will provide individuals and carers with clinically cost-effective and credible providers which in turn deliver better palliative care services;
- A consistent funding model would support more effective reporting of what services are provided in each setting.

Challenges of implementation include:

- Current models are diverse and varied; gaining agreement on reforms and stewardship is likely to be difficult;
- Transitioning may cause some providers to lose funding.

Recommendation 4.3 Develop a palliative care minimum dataset

The rationale for this recommendation

Routine collection of a wide range of palliative care service data, such as hospital activity, primary care services and death registry can be used to improve service delivery. [176] Yet in Australia, the collection of data on palliative care is unusual. For most health services, detailed administrative data on services is available, but little outcomes data is collected. However for palliative care, the reverse is true. PCOC collect detailed patient level outcomes data at admission and discharge, and their coverage, already excellent, continues to expand.

As acknowledged by PCA:

> *"The Palliative Care Outcomes Collaboration (PCOC) is a national program that utilises standardised clinical assessment tools to measure and benchmark patient outcomes in palliative care. Based within the Australian Health Services Research Institute at the University of Wollongong, PCOC is a world leader in data collection and research related to palliative care. Palliative care providers can voluntarily participate in PCOC's outcome data collection and be part of a patient outcome improvement framework.*
>
> *PCA is grateful for the work of PCOC in identifying the need for palliative care in Australia and for supporting palliative care providers benchmark their services and work towards quality improvement."*

Despite this, there is less data on the level of palliative care service provision, perhaps because palliative care in many settings is not directly funded.

The AIHW recognised that data and information related to palliative care are not integrated or complete. [177] For example, the discontinuation of the Bettering the Evaluation and Care of Health (BEACH) survey has limited information on GPs' palliative care-related activity that is not explicitly billed as palliative care.

The recommendation

Table 12: Recommendations for a national minimum dataset for palliative care

#	Recommendations for change
1	Following on from a revision to the funding models in palliative care, we recommend the development of a national minimum dataset to capture service provision by setting, stage and provider; linked with patient outcomes data through PCOC. Ideally this dataset would be collected by the AIHW and able to be linked with other AIHW datasets across inpatient and community settings.

Source: KPMG (2019)

The opportunities and challenges of implementation

The opportunities from implementation of these recommendations include:

- Development of a fundamental source of evidence for palliative care research, evaluation and training that can foster continual and long-lasting improvement.
- Sufficient data will assist all stakeholders including whole Governments in shaping health policy for palliative care.

Challenges of implementation include:

- Compliance requirements for a national minimum dataset can be difficult to achieve in the short-term; an interim goal might be the development of a survey-based sample of key jurisdictions.

Recommendation 4.4 Expand the palliative care workforce and increase palliative care literacy across the wider health sector

The rationale for this recommendation

The current palliative care workforce is well below required minimum staffing ratios, and the projected increase in need for palliative care will exacerbate the shortage. [178] The economic benefits highlighted earlier are all dependent on the availability of a trained and educated workforce to deliver the increased levels of palliative care services. Workforce planning from across the country seems to acknowledge these issues, yet the shortages remain. [179]

Palliative care is everyone's business, and is provided across the spectrum of health professions. Yet palliative care literacy and skills amongst non-palliative care specialists remains varied. For example, a 2017 Department of Health study found that GPs are doing more palliative care than what is commonly thought, with 25 per cent of GPs providing expert palliative care services.

However that still leaves 75 per cent of GPs who either avoid palliative care (14 per cent) or do not feel skilled enough or inclined to offer increased levels of palliative care services (61 per cent). [180] Research shows that doctor's discomfort with dying and limited understanding of patient goals (among other factors) can contribute significantly to non-beneficial treatment. [181] Further educating the healthcare workforce to better identify and refer palliative care need would improve the value, quality and comprehensiveness of care.

The recommendation

Table 13: Recommendations for increased health workforce awareness of palliative care

#	Recommendations for change
1	Development of specific palliative care pathways to drive more nurses and allied health workers into palliative care and SPC. Nurse Practitioners, for example, are typically left to build their own ad-hoc business case for advancement. This needs to be replaced with national strategic support to help train and place palliative care Nurse Practitioners across Australia. Similarly, positions for allied health workers in SPC are currently limited, and support for up-skilling allied health workers is required[182].
2	Following the recommendation from the PC [183] that end-of-life care should be a core business for RACFs, we recommend compulsory education and training of palliative care for staff in RACFs. Vocational education and training (VET) for aged care workers, specifically Certificate III in Individual Support and Certificate IV in Ageing Support should include palliative care as mandatory units in recognition that palliative care is core business in aged care.
3	Extension of funding for education of the wider health workforce such as *CareSearch*, past 2020, to utilise and build on the National Palliative Care Workforce Development Framework and the level of palliative care literacy that has already been achieved. Ensure palliative care is a standard part of the health workforce training curriculum.

Source: KPMG (2019)

The opportunities and challenges of implementation

The opportunities from implementation of these recommendations include:

- An increased provision of appropriately trained palliative care staff will help meet the projected increase in need of services and deliver the cost savings associated with increased palliative care, particularly in residential aged care and community settings.
- Compulsory education and training for nurses or carers in aged care facilities will help to provide more integrated, patient-centred care.
- Continued funding of education and training programs for the wider health workforce will continue to raise palliative care literacy across other health professionals such as GPs and community workers.

Challenges of implementation include:

- Workforce shortages are not confined to palliative care, but are present in some other parts of the health workforce. In a tight labour market, attracting more staff is difficult. Palliative care must be seen as an attractive profession, with appropriate remuneration, flexibility and career progression.
- Large scale training volumes are difficult to implement, particularly when on-site resident training is required.

Recommendation 4.5 Deliver community awareness and education programs

The rationale for this recommendation

Continuous education and awareness are essential to mobilise appropriate use of palliative care. As the National Palliative Care Strategy 2018, notes, ideally: [184]

> **“*People understand the benefits of palliative care, know where and how to access services, and are involved in decisions about their own care”***
>
> Palliative Care Strategy 2018, p12.

Palliative care and discussions about dying need to become core business so that people and their families and carers feel empowered to be active participants in their end-of-life decisions. For example, in Victoria, a one-off grant round funded 17 organisations to support home and community-based services and palliative care literacy. [185] While this community funding is welcome, a rapid review of the evidence base for public awareness campaigns highlights the need to situate local investments within broader national public health campaigns. [186]

There are also lessons to be learned from the strategies and funding models applied to the mental health sector over the last decade to improve community education and awareness of mental health issues. Importantly, funding did not simply focus on interventions and treatments, but also on ‘core’ awareness and de-stigmatisation activities. For example, *BeyondBlue*’s core national operational funding covers activities to ‘bring about positive change concerning depression, anxiety and suicide prevention through activities such as promotion, community awareness and de-stigmatisation, information and community support and research.’ (*BeyondBlue* Annual Report 2014/15).

The recommendation

Table 14: Recommendations for community education and awareness for palliative care

#	Recommendations for change
1	We recommend multi-year, multi-pronged core funding for palliative care for national community education activities to help increase awareness and reduce the stigma around palliative care.
2	In addition, innovative solutions should supplement the national campaign, including the use of social media, and education in schools to promote positive dying to tomorrow's adults. [187]

Source: KPMG (2019)

The opportunities and challenges of implementation

The opportunities from implementation of these recommendations include:

- Consistent public awareness programs will help people to better understand palliative care. In turn, carers, families and communities will be able to talk more openly of an individual's wishes and specific needs to live well during end-of-life care.
- A better-informed population will demand and benefit from increased utilisation of palliative care services. This will compliment a better-informed health workforce recognising and supplying an increased level of palliative care.

Challenges of implementation include:

- Consistency messaging requires core funding that extends past traditional short-term budgetary cycles.

The overall impact of investing in palliative care

The overall impact of investing in palliative care

This report has highlighted evidence-based palliative care interventions that provide significant ROI. The ROI to Government comes from reducing ED visits, ICU admission and hospitalisation stays. Other cost savings to individuals and employers, although not quantified as evidence was not yet mature, are from reduced bereavement cost and increased productivity of families and carers.

Our estimations suggested that a $1.00 investment in integrated home-based care can return between $0.53 and $1.56; Advance care planning can return an average between $0.47 and $2.99; SPC services and ‘needs rounds’ in RACFs can deliver a return of $1.68 to $4.14; and palliative care in hospital can deliver a return of between $1.36 and $2.13 (2019 Australian Dollars).

Following on from the detailed analysis described above, PCA and KPMG have developed the following recommendations, broken down by key setting: home and community, RACFs and hospital. The recommendations all deliver strong ROIs, either breaking even and being cost-neutral in the case of integrated home-based care, or providing significant cost savings in the case of the residential aged care and hospital interventions.

In addition, a number of ‘enabling’ recommendations have been provided.

Overall, our analysis highlights that investing in better care for those experiencing life-limiting illnesses will save rather than increase costs. KPMG estimate that the cost of death in Australia is $7.8 billion per year, with over half, $4.0 billion, in hospitalisation costs. The interventions presented here can significantly reduce the hospitalisation costs of dying by nearly 12 per cent, or $460 million per year, while also improving the quality of death.

Table 15: ROI from key recommendations

Improve access to home and community-based palliative care services	**Investment**	**Return (%)**
Recommendation 1.1: Increase funding and timely access to home and community-based palliative care services	**$240m**	**100%**
Recommendation 1.2: Develop a key performance indicator to monitor access to home and community-based palliative care		
Expand palliative care services in residential aged care	**Investment**	**Return (%)**
Recommendation 2.1: Invest in SPC and integrated support across residential aged care	**$75m**	**182%**
Recommendation 2.2 Explicitly identify palliative care in the Aged Care Quality Standards		
Increase investment in earlier and more integrated palliative care services in hospitals	**Investment**	**Return (%)**
Recommendation 3.1: Increase palliative care services in hospitals	**$50m**	**168%**
Recommendation 3.2: Track the incidence of non-beneficial care in end-of-life hospital admissions, and systematically measure the impact of palliative care on hospitalisation costs		

Source: KPMG (2019)

Appendices

Evidence for interventions and ROI estimations

Appendix A: Evidence for the ROI modelling and interventions

Intervention	Studies	Description	Method	Setting	Participants
Advance care planning	Martin et al. (2019)	The objective was to determine whether the "Goals of patient care" (GOPC) medical treatment orders were more effective than advance care planning alone in preventing ED visits (no hospitalization), ED visits (with hospitalization), and deaths outside the RACFs.	The study was a prospective cluster RCTs, with the intervention being the completion of GOPC process by a geriatrician, following a shared decision-making process, incorporating ACP documents or residents' preferences.	The study took place in six RACFs in Northern Metropolitan Melbourne, Australia. With the follow-up assessment after 6-12 months.	Eligible participants included all permanent residents in participating RACFs for whom written informed consent could be obtained. Intervention n = 181, control n = 145.
	Molloy et al. (2000)	The study examines the effect of systematically implementing an advance care directive in nursing homes on individual and family satisfaction with involvement in decision making on health care costs.	Conducted RCTs between 1994 and 1998. The intervention (*Let Me Decide*) is an advance care directive program which includes the education of staff in local hospitals and nursing homes. The main outcomes included resident and family care satisfaction with health care and health service utilisation over 18 months compared to the control group.	The study involves six nursing homes in the US.	A total of 1,291 residents in 6 Ontario nursing homes with more than 100 residents in each.
	Caplan et al. (2006)	The study evaluates a system of educating residents, their families, staff and GPs about outcomes of dementia, advance care planning (ACP) and hospital in the home.	The method applied a controlled evaluation monitoring emergency admissions to hospital by comparing hospitals and nursing homes based in different locations.	Two hospitals and 21 nursing homes to be compared with one hospital and 13 nursing homes in NSW, Australia.	1000+ yearly nursing home residents between 2000 and 2004.
	Bond et al. (2018)	Advance care planning (ACP) documents individual wishes and increases awareness of palliative care options. The study aims to assess the association of outpatient ACP with advanced directive documentation, utilization, and costs of care.	The method used a case–control study (matched 1:1) with ACP cases who died versus a control group. It used 12 months of data pre-ACP/pre-match and pre-death, then compared rates of documentation with *logit* model regression and conducted a difference-in-difference analysis using generalized linear models for utilization and costs. It reduced the overall cost.	Large rural-suburban-small metro multi-site accountable care organization in the US.	Medicare beneficiaries attributed to a large rural-suburban-small metro multisite accountable care organization from January 2013 to April 2016. Intervention n = 325; control n = 325.

Intervention	Studies	Description	Method	Setting	Participants
	Chapman et al. (2015)	This study examined whether the addition of a proactive model of SPC reduced resident transfer to the acute care setting, and achieved a reduction in hospital deaths.	A quasi-experimental design was adopted, with participants at 4 residential care facilities. The intervention involved a palliative care nurse practitioner leading 'Palliative Care Needs Rounds' to support clinical decision making, education and training. Outcome measures included participants' hospitalisation in the past 3 months of life and the location of death.	Residential aged care in Canberra ACT, Australia.	Participants were matched with historical decedents using propensity scores based on age, sex, primary diagnosis, comorbidities and the Aged Care Funding Instrument rating. Resident sample (Nov 2014 - May 2015). Intervention n = 104, control n = 173.
	Khandelwal et al. (2015)	A systematic review which included studies that reported RCTs assessing the impact of advance care planning of primary and specialty palliative care interventions on ICU admissions and ICU length of stay for critically ill adult individuals.	Most of reviewed studies applied RCTs	ICUs.	Numerous participants based on each study included within the systematic review.
	Nicholas et al. (2011)	The study examines the association between advance care use, end-of-life Medicare expenditure and use of intensive palliative care in the context of regional variation.	Survey data from the Health and Retirement Study for Medicare beneficiaries linked to Medicare claims and advance care use who died between 1998 and 2007.	Hospital setting in the US	3,302 of Medicare beneficiaries.
	Sellars et al. (2019)	The study aimed to examine hospital costs and outcomes of a nurse-led ACP intervention compared with usual care in the last 12 months of life for older people with end-stage kidney disease managed with haemodialysis.	The method simulated the natural history of decedents on dialysis, using hospital data, and modelled the effect of nurse-led ACP on end-of-life care. Outcomes were assessed in terms of individuals' end-of-life treatment preferences being met or not, and costs included all hospital based care. Model inputs were obtained from a prospective ACP cohort study among dialysis individuals and the published literature.	Australia	Hypothetical cohort of individuals who were receiving dialysis; one half received the ACP intervention and the other half did not.
	Nguyen et al. (2016)	This study aims to evaluate the cost-effectiveness of delivering a nationwide ACP program within the Australian primary care setting.	A decision analytic model was developed to identify the costs and outcomes of an ACP program for people aged 65+ years who were at risk of developing dementia. Inputs for the	Primary care, Australia wide	Individuals at risk of dementia.

Intervention	Studies	Description	Method	Setting	Participants
			model was sourced and estimated from the literature. The reliability of the results was thoroughly tested in sensitivity analyses.		
	Wright et al. (2008)	The study determines whether end-of-life discussions with physicians are associated with fewer aggressive interventions.	A US multisite, prospective, longitudinal cohort study of individuals with advanced cancer and their informal caregivers (September 2002-February 2008). Individuals were followed up from enrolment to death, a median of 4.4 months later. Bereaved caregivers' psychiatric illness and quality of life was assessed a median of 6.5 months later	Multisite in the US.	Individuals with advanced cancer and their informal caregivers (n = 332 dyads), September 2002-February 2008.
	Teo et al. (2014)	The study evaluates the economic impact of Project Care at the End-of-Life for Residents in homes for the Elderly (CARE) programme on nursing home residents compared to usual end-of-life care.	Project CARE was introduced in seven nursing homes to provide advance care planning and palliative care for residents identified to be at risk of dying within 1 year. The cases consisted of nursing home residents enrolled in the Project CARE programme for at least 3 months. A historical group of nursing home residents not in any end-of-life care programme was chosen as the matched controls. Cost differences between the two groups were analysed over the last 3 months and final month of life. Substantial cost savings associated with this program.	Nursing homes in Singapore.	Intervention in nursing homes n = 48 ; control n = 197 participants
	O'Sullivan et al. (2016)	The study assessed the economic impact (gross savings) of the *Let Me Decide* (LMD) ACP programme in Ireland, specifically the impact on hospitalisations, bed days and location of resident deaths, before and after systematic implementation of the LMD-ACP combined with a palliative care education programme.	The LMD-ACP was introduced into three long-term care (LTC) facilities in Southern Ireland and outcomes were compared pre and post implementation. In addition, 90 staff were trained in a palliative care educational programme. Economic analysis including probabilistic sensitivity analysis was performed.	Nursing homes in Ireland.	Three LTC facilities were recruited from the south of Ireland. These included two private and one publically funded (community nursing unit) nursing homes, totalling 290 beds at baseline. All residents, aged ≥65 years, in participating units were eligible for inclusion in the programme. Residents

Intervention	Studies	Description	Method	Setting	Participants
					were recruited throughout the study period.
Integrated home-based palliative care	Youens et al. (2016)	Community-based palliative care may potentially benefit individuals by offering their preferred care at the end of life and benefit systems by reducing hospital use. The study compares place of death and acute care hospital use in the last year of life between cancer decedents who did and did not access a community-based palliative care service (PCS).	Retrospective observational cohort study is applied using linked individual administrative records from cancer registry, hospital, ED, mortality, and PCS databases. Propensity score-weighted regression methods were used.	Health system in Western Australia	Whole of population study incorporating 28,561 West Australian cancer decedents from 2001 to 2011.
	Spilsbury et al. (2017)	The study objective was to determine how the association of community-based palliative care with reduced ED visits in the last year of life varied by individual factors.	A retrospective cohort study of decedents who died with neoplasms, heart failure, renal failure, chronic obstructive pulmonary disease and/or liver failure in Western Australia 2009-2010. Outcome measures were adjusted hazard ratios (HR) and daily (hazard) rates of ED visits.	Health system in Western Australia	11,875 decedents who died with neoplasms, heart failure, renal failure, chronic obstructive pulmonary disease and/or liver failure in Western Australia 2009-2010.
	McCaffrey et al. (2013)	The aim of this study was to evaluate the cost-effectiveness of a home-based palliative care model relative to usual care in expediting discharge or enabling individuals to remain at home.	Mean costs and effectiveness were calculated for the Palliative Care Extended Packages at Home (PEACH) and usual care arms including: days at home; place of death; PEACH intervention costs; SPC service use; acute hospital and palliative care unit inpatient stays; and outpatient visits.	Community care in South West Sydney, NSW.	The PEACH trial was a pilot, Phase II, parallel arm RCT involving 32 consented participants with predominantly advanced cancer. Individuals were eligible if they had complex or unstable symptom management and high care needs.
	Brumely et al. (2007)	The study aimed to determine whether an in-home palliative care intervention for terminally ill patients can improve patient satisfaction, reduce medical care costs, and increase the proportion of individuals dying at home.	RCT: Usual versus in-home palliative care plus usual care delivered by an interdisciplinary team providing pain and symptom relief, individual and family education and training, and an array of medical and social support services.	Health system in Colorado and Hawaii, USA	Homebound, terminally ill individuals (N = 298) with a prognosis of approximately 1 year or less to live plus one or more hospital or emergency department

Intervention	Studies	Description	Method	Setting	Participants
					visits in the previous 12 months.
	Ling et al. (2018)	The study objective is to compare annual costs of an intervention for acutely unwell older residents in residential age care facilities (RACFs) with usual care. The intervention, the Aged Care Emergency (ACE) program, includes telephone clinical support aimed to reduce avoidable ED presentations by RACF residents.	The method used costing estimation from providers. ACE was implemented in 69 RACFs in the Hunter region of NSW, Australia. Analysis used 14 weeks of ACE and ED service data (June–September 2014). The main outcome measure was the net cost and saving from ACE compared with usual care. It is based on the opportunity cost of implementing ACE and the opportunity savings of ED presentations avoided.	Residential Aged Care in New South Wales, and EDs in the Hunter New England Local Health District.	Aged care residents in NSW. N = 5922 beds.
	Cassel et al. (2016)	The study aimed to evaluate the nonclinical outcomes of a proactive palliative care program funded and operated by a health system for Medicare Advantage plan beneficiaries.	Observational, retrospective study using propensity-based matching. Outcomes included hospital costs, other health care costs, readmission rates, hospital admissions and bed days, ICU use in final 30 days of life, and death within 30 days of an admission.	Health system in Southern California.	There were 368 participants who received the intervention between 2007 and 2014. These individuals were paired with 1,075 other individuals (non-intervention group)
	Rabow et al. (2004)	The study aimed to assess the use of palliative care for outpatients who continue to pursue treatment for their underlying disease or whether outpatient palliative medicine consultation teams improve clinical outcomes.	The study conducted a year-long controlled trial involving 50 intervention individuals and 40 control individuals in a general medicine outpatient clinic. Primary care physicians referred individuals with chronic conditions. In the intervention group, the primary care physicians received multiple palliative care team consultations, and individuals received advance care planning, psychological support, and family caregiver training. Clinical and health care utilisation outcomes were assessed at 6 and 12 months.	Outpatient clinic, USA.	50 intervention individuals and 40 control individuals in a general medicine outpatient clinic. Primary care physicians referred individuals with advanced congestive heart failure, chronic obstructive pulmonary disease, or cancer who had a prognosis ranging from one to five years.
	Higginson et al. (2009)	This study evaluated the cost-effectiveness of a new palliative care service (multi-professional palliative care team) for people with multiple sclerosis (MS).	The method used a randomized fast-track Phase II controlled trial. Individuals in South East London who were severely affected by MS were referred by clinicians to the trial. After baseline interview, individuals were	South East London, UK.	Individuals in South East London who were severely affected by MS; 52 interviewed individuals.

Intervention	Studies	Description	Method	Setting	Participants
			randomly allocated to either a multi-professional palliative care team (PCT) immediately (fast track) or the control care group who continued best usual care for three months and then were offered the PCT. Data were collected at baseline, 6, 12, 18, and 26 weeks on use of services, patient symptoms, other outcomes, and caregiver burden.		
Specialist in residential aged care	Forbat et al. (2020)	The study analysed the impact of providing palliative care specialist on the quality of death and dying of patients in residential aged care.	RCTs were applied by randomly assigned control and intervention groups from 12 participating home cares. The findings is a reduced time in acute hospital submissions.	12 care homes in the ACT Canberra were involved in the study.	Around 1,700 participants were reviewed between 2017 and 2018. Of the total residents 471 had completed the review for data analysis.
	Chapman et al. (2016)	A pilot study of SPC intervention in Australian aged care, which is not a standardised component of service delivery in the nursing home care. New approach of SPC is to support nursing home residents to avoid unnecessary hospitalisation and improve dying and death.	The study implemented a quasi-experimental design from four RACFs. It involved a palliative care nurse practitioners to implement the program. The data demonstrated that the intervention is associated with significant reductions in the length of hospital stays.	Resident from four RACFs were assigned for the study. Participants were matched using historical decedents.	104 residents were included in the intervention group and 173 residents as a control group.
	Johnston et al. (2016)	The study aimed to improve access for older adults in residential care of palliative care services using integrated SPC.	The study applied a qualitative approach of focus group followed by thematic analysis to the data. Three major themes were identified: normalising death and dying in the aged care, timely access to SPC and better decision-making and plan care for residents.	Criteria was set for recruited participants by sending invitations to families or relatives.	From four RACFs, 57 participants were selected of 104 invitations.
Palliative care in Hospitals	May et al. (2018)	The study estimated the relationship between palliative care consultations (PCC) with direct hospital cost for patients with serious illness.	The method was reviewing systematic review and meta analyses over the period 2013-2017, with study selection applying economic evaluation in the hospital setting of palliative care consultation (PCC) versus usual care only. The key finding was patients receiving PCC have a significant reduction of hospital costs.	Inpatient setting of patients that receive palliative care consultation and patients receive usual care.	Participants were from 6 samples from selected studies with a total of 133,118 patients.

Intervention	Studies	Description	Method	Setting	Participants
	Greer et al. (2016)	The study analysed several trials of integrated palliative care and oncology care to improve quality of life from patients with advanced cancers.	The method used secondary data from trials in hospital setting. Costs were estimated from intravenous chemotherapy and hospice costs in hospital refer to Medicare reimbursement rate. It appears that the integrated palliative care service in the oncology department does not increase overall medical care expenses.	Hospital setting from trials of palliative care in the oncology department.	Participants from samples were 151 patients.

Appendix B: Technical details for the ROI analysis

The following section provides the technical step-by-step details for the ROI calculations.

Key inputs

- Baseline utilisation data were informed by Goldsbury et al, which contained data on health care utilisation in the last year of life in New South Wales, Australia. [188]
- The unit cost of this utilisation was informed by IHPA's National Hospital Cost Data Collection 2016-17. [189]
- Costs were inflated to current 2019 Australian Dollars using the ABS Health CPI. [190]
- Currency conversions were completed using the Purchasing Power Parity obtained from the OECD. [191]

Table: Baseline utilisation and costs in the last year of life

Baseline Input	Utilisation	Nominal cost	2019 ($)
Hospitalisations	Median 2 hospitalisations	$8,027 per hospitalisation	**$8,545**
	Total median stay of 17 days	*$944 per day*	*$1,005*
ICU admissions	Median 1 ICU admission	$14,625 per admission	**$14,625**
	Total median stay of 3 days	*$4,895 per day*	*$4,875*
ED presentations	Median 1 ED presentation	$969 per presentation	**$1,031**
	Total median stay of 6 hours	*$162 per hour*	*$172*

Intervention	Benefits	Costs
Integrated home-based palliative care	- **Reducing presentations to the ED:** individuals receiving IHPC services visited the ED by between two and 13 per cent less in the last year of life. [192] [193] Given the unit cost per ED presentation is AU$1,031 (2019) the minimum and maximum savings in reduced ED visits is between AU$21 (2 per cent x $1,031) and AU$134 (13 per cent x $1,031), respectively. - **Less time spent in hospital:** studies of IHPC recipients have reported fewer average total bed days of between 4.5 and 7.5 in the last year of life; [194] rates of hospitalisation were also seen to fall by between one and 66 per cent. [195] Based on the average hospitalisation costs presented above, the savings from reduced days per hospitalisation therefore ranges between $4,524 ($1,005 x 4.5 days) and $7,540 ($1,005 x 7.5 days), average of $6,032; - **Overall –** the treatment yields a minimum savings of ~AU$4,544 ($4,524 + $21) and a maximum of AU$7,674 ($7,540 + $134). On average the treatment yields a savings of AU$6,109 ([$4,544 + $7,674] / 2). - For the ROI analysis, a conservative range of benefits was used – low $4,544 (minimum savings); medium $6,032 (average hospitalisation savings only); high $6,109 (average total savings).	Overall, the Australian evidence suggest that IHPC can be delivered from as low as $2,000 to as high as $10,000 per person. [196] [197] [198] [199] The average cost across all estimates was $5,396 per person (various price years). Inflating these estimates by the appropriate ABS 2019 Health CPI, KPMG estimate that implementation of IHPC is likely to cost $6,508, per person on average. A low and high range of $3,913 and $8,516 was then derived after deeming the upper bound of the PC estimate too high for the intervention.

Return on investment

Based on the resource savings calculated above, in the last year of life IHPC is expected to save between $4,544 and $6,109 (2019 Australian Dollars) per person from reduced ED and hospitalisation costs. Compared with implementation cost associated with these interventions, KPMG estimates that a **$1.00 investment in IHPC can return between $0.53 and $1.56 – or cost neutral on average (2019 Australian Dollars).**

ROI per person for IHPC (2019 Australian Dollars)

Scenario	Low case	Medium case	High case
Cost of implementation	**$8,516**	**$6,508**	**$3,913**
Average health savings	$4,544	$6,032	$6,109
ROI	**$0.53**	**$0.93**	**$1.56**

Note: In this analysis, potential bereavement and employment benefits are acknowledged but not quantified.

Advance care planning	• **Hospitalisations and length of stay** – ACPs can reduce rates of hospitalisations from nine to 26 per cent; [200] and length of stay between 0.37 to 3.5 days in the last year of life. [201] From above, the unit cost per hospital day is AU$1,005 (2019). Estimated savings from reduced days per hospitalisation therefore ranges between $372 ($1,005 x 0.37 days) and $3,518 ($1,005 x 3.5 days); • **ICU admissions and usage –** For individuals at high risk of death, ACPs can generate a mean reduction of 37 per cent in the probability of ICU admission. [202] More broadly, ACPs have the capability to reduce the overall use of the ICU by nine per cent in the last six months of life. [203] For this analysis, the benefits from reduced admission to ICU were conservatively deemed captured in hospitalisations savings; • **Emergency calls to ambulance –** Improved understanding of treatment goals can also reduce unnecessary calls to emergency services and subsequent admission to the ED in nursing home residents by around 22 per cent. [204] Given the unit cost per ED presentation is AU$1,031 (2019) the savings in reduced ED visits is around AU$227 (22 per cent x $1,031). As the study did not report confidence intervals, we have calculated 10 and 50 per cent of the treatment effect to inform low ($23) and medium ($113) savings from reduced ED visits, respectively. • **Overall –** the treatment yields a minimum savings of AU$395 ($372 + $23) and a maximum of AU$3,773 ($3,518 + $227). The average hospital savings is $1,662 ([$372 + $1,096 + $3,518] / 3); while the average ED savings was $121 ([$23 + $113 + $227] / 3). The sum of average hospital and ED savings informed the high case savings – totalling to $1,783. • For the ROI analysis, a conservative range of benefits was used – low $395 (minimum savings); medium $1,096 (medium hospitalisation savings only); high $1,783 (average total savings).	Two studies have evaluated the cost of ACPs in the Australian context. [205] [206] While different in methodology, estimates were consistent, ranging from $250 per person for small packages; up to $1,000 for large packages (2015 Australian Dollars). The average per person cost of an ACP ranged between $516 and $820 depending on the authors' assumptions. After inflating these estimates by the ABS Health CPI [207] and the June 2019 MBS item schedule (item 131, 732), KPMG estimate that the cost of implementing an ACP is likely to range from $596 (low), $684 (medium), and $833 (high) per person in 2019 Australian Dollars.

Return on investment

Using the resource savings calculated above, investment in ACPs is estimated to save between $395 and $1,783 per person in health costs during the last year of life from reduced hospitalisations costs; ICU costs (captured in reduced hospitalisations); and ED costs. Combining the implementation cost associated with delivering these benefits, **KPMG estimates that a $1.00 investment in ACPs can return an average between $0.47 and $2.99 (2019 Australian Dollars).**

ROI per person for advance care planning (2019 Australian Dollars)

Scenario	Low case	Medium case	High case
Cost of implementation	**$833**	**$683**	**$596**
Average health savings	$395	$1,096	$1,783
ROI	**$0.47**	**$1.60**	**$2.99**

Note: In this analysis, potential bereavement and employment benefits are acknowledged but not quantified.

Nurse practitioners in RACFs

A recent stepped wedge Australian trial across 12 residential aged care sites (the INSPIRED trial) found that SPC services and needs rounds in residential aged care can:

- **Reduce presentations to hospital –** hospitalisation admissions reduced from 5.3 to 4.6 per facility per month (observed). The cost per bed day was estimated at $1,286 (higher than our baseline but we stay consistent with the study); multiplied by the bed days saved per month per facility (5.09 – adjusted; 11.56 observed) yields hospital savings per month per facility between $6,541 and $14,866. Annualised across 12 facilities, hospital savings equate to between $941,920 and $2,140,727.
- **Transport savings** – transport savings were included for the medium and high scenarios based on the assumption that a reduction in hospital presentations from the RACF also delivered transportation savings. The cost per trip to the ED was $982; [208] multiplied by the reduction in hospital admissions (0.57 – adjusted; 1.3 – observed) yields transport savings per month per facility between $562 and $1,277. Annualised across 12 facilities, transport savings equate to between $80,885, and $183,830.
- **Overall -** for the ROI analysis, the following estimation of benefits was used – low $941,920 (adjusted hospitalisation savings only); medium $1,022,805 (adjusted hospitalisation savings and transport savings); high $2,324,557 (observed hospitalisation savings and transport savings).

The Australian trial used two Nurse Practitioners across the 12 sites, at a total cost of $381,716 per annum, covering both salaries and on-costs. [209] In addition, KPMG estimate that the increased utilisation of wider health services (for example, GP visits at needs rounds, and case-conferencing) adds costs of approximately $250 per person discussed at a needs round, based on the lower end of the costs of ACP discussed previously. The lower end of the ACP is used as it is assumed that the Nurse Practitioner roles cover part of the increased service demand. This adds an extra $180,000 per annum in associated health service costs, for an estimated total cost of $561,716.

Return on investment

Based on the estimated resource savings of $1,286 per hospital bed day, and transport costs of $983 per hospital admission, this intervention is expected to save: $941,920 (adjusted) to $2,140,727 (observed) in hospitalisation costs per annum; $80,885 (adjusted) to $183,830 (observed) in reduced emergency transport costs per annum; In the low case, transportation savings have been excluded to represent regions where these benefits may not accrue.

KPMG estimates that a $1.00 investment in palliative care nurses in residential aged care can return between $1.68 and $4.14 (2019 Australian Dollars).

ROI per annum for palliative care Nurse Practitioners in 12 RACFs (2019 Australian Dollars)

	Low case	Medium case	High case
Cost of implementation	**$561,716**	**$561,716**	**$561,716**
Health savings:			
Reduced bed days	$941,920	$941,920	$2,140,727
Reduced ICU admissions	-	-	-
Reduced ED transport costs	-	$80,885	$183,830
Other savings:			
Bereavement savings	-	-	-
Employment savings	-	-	-
Total savings	$941,920	$1,022,805	$2,324,557
Net savings	**$380,204**	**$461,089**	**$1,762,841**
ROI	**$1.68**	**1.82**	**4.14**

Note: In this analysis, potential bereavement and employment benefits are acknowledged but not quantified.

Integrated palliative care in hospitals

Two studies were used to estimate the difference in hospitalisation costs where palliative care was available versus where it was not available.

- An Australian study of 19,907 elderly patients dying in hospital found a cost difference of $5,364, which when converted to 2019 dollars using the Health CPI equates to $6,776.
- A meta-analysis of 6 studies and 133,118 patients with serious illness from the United States found a statistically significant difference in costs of $3,237 (95% CI $3,581 to $2,893)[210] when palliative care was available. When converted to Australian 2019 dollars using the PPP and Australian health CPI, this equates to $5,511.
- After discussion with the one of the paper's authors, it was established that the cost-differentials presented above were net of the cost of providing the 80 per cent palliative care. The overall benefits from palliative care for the ROI analysis, we therefore needed to add 80 per cent of the

The costs of providing palliative care in hospitals is particularly disparate and dependent on the type of models adopted. We therefore used a range of costs based on average subacute palliative care separation costs from IHPA[211]:

- Low: $5,087 – New South Wales average (lowest of major states)
- Mid: $7,697 – national average
- High: $12,131 – Victorian average (highest of major states)

cost of providing palliative care (estimated in the next section) to the cost differentials provided above. While the cost differentials from both studies were similar, the figure from the Australian study was adopted for the calculations.

Return on investment

Based on the cost savings identified in the literature, and low, mid and high cost assumptions based on the IHPA cost of sub-acute palliative care, KPMG estimates that a **$1.00 investment in palliative care in hospital delivers a return of between $1.36 and $2.13** (2019 Australian Dollars)**.**

Table 8: ROI per admission for palliative care services in hospitals (2019 Australian Dollars)

	Low case	Mid case	High case
Cost of implementation	**$12,131**	**$7,697**	**$5,087**
Health savings	$15,774	$12,933	$10,845
Reduced bed days	-	-	-
Reduced ICU admissions	-	-	-
Reduced ED transport costs	-	-	-
Other savings:	-	-	-
Grief and productivity	-	-	-
Total savings	$15,774	$12,933	$10,845
Net savings	**$4,350**	**$5,236**	**$5,758**
ROI	**1.36**	**1.68**	**2.13**

Note: In this analysis, potential bereavement and employment benefits are acknowledged but not quantified.

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