

# Central Coast Local Health District

## Palliative Care and End of Life Care Review



Quality Living

Quality Dying

Quality Grieving

## VERSION CONTROL AND DISTRIBUTION

Version	Date	Comments and Key Changes	Author
V1.0	17.5.17	Final draft completed	Kylie Downs
V2.0	6.6.17	Editing and finalisation of sections	Kylie Downs/Sally Mecham
V3.0	17.7.17	CE request to restructure report to provide a summary review	Sally Mecham
V4.0	04.8.17	Reformatting and restructure	Sally Mecham
V5.0	17.8.17	Editing and reformatting	Kylie Downs/Sally Mecham
V6.0	25.8.17	Further editing	Kylie Downs/Sally Mecham
V7.0	11.10.17	Editing and feedback review, formatting	Sally Mecham/Kylie Downs
FINAL	8.11.17	Watermark removed and footer changed to October 2017 following endorsement at the CCLHD Board	Kylie Downs

## ACKNOWLEDGEMENTS

This Palliative and End of Life Care review of services on the Central Coast has been completed following extensive patient, staff and stakeholder engagement. The author would like to sincerely thank the patients, carers and their families, community members, staff, service providers and stakeholder organisations who have contributed to this dedicated review. Your willingness to contribute time, honesty and openness in sharing the service gaps that exist and opportunities that can be realised has been greatly appreciated.

“If only we united as a Central Coast region and shared a palliative and end of life care vision..... the patient and their loved ones’ journey from living, to dying to grieving would be more integrated, patient-centred and meaningful”.

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## GLOSSARY

When we say...	We mean...
ACD	Advance Care Directive
ACP	Advance Care Planning
AH	Allied Health
CALD	Culturally and Linguistically Diverse
CAPP	Care Awaiting Placement Program
CARPS	Computer Assisted Radio Personnel System
CCIPS	Central Coast Integrated Pain Service
CCLHD or LHD	Central Coast Local Health District or Local Health District (the District)
CE	Chief Executive
CEC	Clinical Excellence Commission
CGU	Clinical Governance Unit
CN	Community Nursing
CNC	Clinical Nurse Consultant
CNE	Clinical Nurse Educator
CNS	Clinical Nurse Specialist
DOA	Dead On Arrival
DRG	Diagnosis Related Group
ED	Emergency Department
eMR	Electronic Medical Record
EOL	End of Life
FTE	Full Time Equivalent
GP	General Practice or General Practitioner
HNECCPHN	Hunter New England Central Coast Primary Health Network
ICU	Intensive Care Unit
IMT	Information Management and Technology
KPI	Key Performance Indicator
MDT	Multi-disciplinary Team
MoH	New South Wales Ministry of Health
NFR	Not For Resuscitation
NGO	Non-Government Organisation
NP	Nurse Practitioner
NSAP	National Standards Assessment Program
NSCCH	Northern Sydney Central Coast Health
NSQHS	National Safety and Quality Health Service Standards
NSW	New South Wales
OP	Outpatient
OT	Occupational Therapist
PCLN	Palliative Care Liaison Nurse
PCROS	Palliative Care Residential Aged Care Outreach Service
PSA	Patient Support Assistant
RACF	Residential Aged Care Facility
RN	Registered Nurse
SNAP	Subacute and Non-Acute Patient
SOP	Safe Operating Procedure
SPCS	Specialist Palliative Care Service

## DEFINITIONS

When we say...	We mean...
Acute Care	Treatment or surgery that leads to cure of an illness, reduction in severity of an illness or injury or relieves symptoms of illness or injury. Mostly occurs in a hospital or in a HITH model of care. <i>(New South Wales (NSW) Ministry of Health (MoH) Care Type Policy for Acute, Sub-Acute and Non-Acute and Mental Health Admitted Patient Care PD2016-039).</i>
Acute Pain	This refers to pain that is “provoked by a specific disease or injury, serves a useful biologic purpose, is associated with skeletal muscle spasm and sympathetic system activation and is self-limited” (Grichnik, 1991)
Advance Care Directive (ACD)	“Is a written directive made by a competent person (i.e. someone with capacity) and is recognised by common law. It can record values, life goals and preferred outcomes, provide directions about health care in the event of life-threatening injury or illness, identify a patients ‘enduring guardian’ (formally appointed) or ‘person responsible’ to make decisions on your behalf” (CCLHD Advance Care Planning Brochure, CC10477).
Advance Care Plan (ACP)	“Is a process of thinking about what is important to you and your lifestyle then discussing these things with your family, friends, doctor, spiritual advisor and/or legal representative. It should be conducted regularly and may result in a written record of your preferences in either an Advance Care Plan or an Advance Care Directive” (CCLHD Advance Care Planning Brochure, CC10477). This process is important in allowing patients to have choice surrounding their future health care and decisions surrounding their palliative and EOL care.
Cancer Pain	“Pain associated with cancer, either during the treatment phase, as a complication of treatment, or in cancer survivors” <i>(NSW MoH: NSW Pain Management Plan 2012-2016).</i>
Care Plan	A plan developed by clinicians involved in care, in consultation with the patient and carer where appropriate. The care plan describes the goals of care agreed with the patient, the type of services to be provided, the frequency and actual hours of service provision, the location at which the service will be provided and the respective responsibilities of the service, its staff, the General Practitioner (GP), involved internal/external service providers and the patient and/or carer. The palliative care plan should be informed by all current care service providers involved with the patient <i>(Adapted from NSW MoH Transitional Aged Care Program Guidelines GL2013_004).</i>
Chronic or Persistent Pain	This refers to “constant daily pain for a period of three months or more in the last six months” <i>(NSW MoH: NSW Pain Management Plan 2012-2016).</i>
Clinical Handover	The transfer of professional responsibility and accountability for some or all aspects of care for a patient or group of patients, to another person or professional group on a temporary or permanent basis <i>(National Safety and Quality Health Service Standards, 2011).</i>
Coordinated Care	“Refers to the deliberate organisation of patient care activities between two or more health professionals involved in a patient’s care to facilitate the appropriate delivery of health care services” <i>(NSW Cancer Plan, 2016 p. 33)</i>
End of Life Care (EOL)	“End of life care refers to support for people who are in their last weeks or days of life. This is a time when the goals of care are palliative” <i>(NSW Cancer Plan, 2016 p. 33)</i>
Interdisciplinary Care	Involves regular collaborative meetings of all disciplines to discuss patient status and the evolving care plan. It is characterised by shared decision making and flexible leadership <i>(NSW Hospital in the Home Guideline GL2013_006).</i>
Multidisciplinary	A service that offers input to the patient from a number of different health care disciplines.
Opioids	These are “medicines with actions similar to those of morphine, including substances derived from the opium poppy (morphine, heroin, codeine and thebaine) and synthetic and semi-synthetic medicines (such as pethidine, HYDROMORPHONE, fentanyl, methadone, buprenorphine, oxycodone, dextropropoxyphene, dextromoramide, pentazocine, tramadol and others).” <i>(NSW Ministry of Health: NSW Pain Management Plan 2012-2016).</i>
Pain	Pain is defined as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” <i>(NSW Ministry of Health: NSW Pain Management Plan 2012-2016).</i>

Palliative Care	<p>“Palliative Care is an approach that improves the quality of life of patients and their loved ones facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:</p> <ul style="list-style-type: none"> <li>• Provides relief from pain and other distressing symptoms;</li> <li>• Affirms life and regards dying as a normal process;</li> <li>• Intends neither to hasten or postpone death;</li> <li>• Integrates the psychological and spiritual aspects of patient care;</li> <li>• Offers a support system to help patients live as actively as possible until death;</li> <li>• Offers a support system to help the family cope during the patients illness and in their own bereavement;</li> <li>• Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;</li> <li>• Will enhance quality of life, and may also positively influence the course of the illness;</li> <li>• Is applicable early in the course of the 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” (<i>World Health Organisation, 2017</i>).</li> </ul>
Patient	The person receiving health care.
Person-Centred Care	Providing care that is respectful of and responsive to individual preferences, needs and values and ensuring that a person’s values guide all clinical decisions ( <i>NSW Hospital in the Home Guideline GL2013_006</i> ). The <i>patient</i> and/or carer are inclusive in the decision making process.
Primary Health Care	This is “the first level of care or point of entry to the health care system for consumers. It includes (but is not limited to) services delivered by GPs, Practice Nurses, Nurse Practitioners (NPs), Community Nurses, Allied Health (AH) providers, Aboriginal health workers, Pharmacists and Dentists” ( <i>NSW MoH: NSW Pain Management Plan 2012-2016</i> ).
Subacute Care	“Specialised multidisciplinary care in which the primary need for care is optimisation of the patient’s functioning and quality of life” ( <i>Australian Institute of Health and Welfare, 2014</i> ).
Transfer of Care	The transfer of professional responsibility and accountability for some or all aspects of care for a patient to another person or professional group on a temporary or permanent basis. This is also called discharge and these words are used interchangeably throughout this document (ACI Acute Care Taskforce: <i>NSW Medical Assessment Unit Model of Care Document, 2014</i> ).

## EXECUTIVE SUMMARY

Central Coast Local Health District (CCLHD) is committed to improving the quality, safety and experience of care for patients and their families as they embark on a palliative journey and approach End of Life (EOL). There are many government and non-government agencies that provide palliative care and EOL care services to the Central Coast community. Ensuring that a patient and their family receives the right care, in the right place, at the right time, by the right service is essential in ensuring that we develop truly patient-centred processes, systems and models of care into the future.

This review report provides a summary of the multiple service gaps that exist for palliative and EOL care patients and their loved ones (summarised in *Appendix A: Summary List of Identified Service Gaps*) on the Central Coast. The provision of care to palliative and EOL care patients across the Central Coast is not well co-ordinated and governed from a District perspective. There is a siloed approach with some divisional governance structures but there is no overall strategy for palliative and EOL care from a CCLHD view. Patients and their carers are required to navigate their way through a system that does not deliver a holistic or seamless transition of care. The review highlighted that there is a lack of education and training for staff working with palliative care clients and inadequate financial, human and accommodation resources allocated to caring for palliative patients. The expected level of need for patients is not always identified and there is both a duplication of resources in some areas and lack of resources in others for the provision of timely and optimal care. Access to, and use of, high quality patient-level, service-level and system-level data on palliative patients is also lacking. This results in an inability to effectively interrogate data

to improve patient experiences, outcomes and service planning.

It is important to reiterate that this paper is a gap analysis review and has been written to identify the **service gaps and opportunities**. With this in mind, it does not highlight the many achievements and strengths of the current palliative care services provided across the LHD. There are numerous patient stories whereby patients who have been fortunate to access the Specialist Palliative Care Service (SPCS) have received excellent supportive care in the hospital or community setting for EOL care. It was evident throughout this review that there are wonderful, caring clinicians who provide compassionate care but are restricted and bound by the current system, resources, processes and restraints they are faced with when treating palliative and EOL care patients. There is widespread acknowledgment that changes need to be made. There is also a commitment from service providers and clinicians to be involved in designing sustainable solutions and service improvements to ensure that palliative care patients receive an integrated and patient-centred service moving into the future.

This paper has highlighted a significant number of opportunities for improvement so that the Central Coast is able to deliver quality care to palliative and EOL care patients. The vision and strategic CCLHD direction for Palliative and EOL Care on the Central Coast should include:

- An extended specialist palliative care **consultative and supportive care model** to work in close collaboration with acute and subacute inpatient teams at all CCLHD hospital sites and primary care providers in the community, Residential Aged Care Facilities (RACFs) and designated Palliative Care Units. The distribution and availability of services needs to ensure equitable access across the District. This should include consideration of **telehealth**.
- Provision of **24 hour access to specialist nursing and medical advice and support** at home for registered specialist palliative care patients.
- A workable Specialist Palliative Care on-call roster.
- A **direct care admission model** at acute and subacute facilities for Specialist Palliative Care physicians.
- Ability for **Specialist Palliative Care physicians to take over care** of palliative and end of life care patients requiring escalated and specialised palliative care management.
- **Multidisciplinary outpatient clinics** to facilitate care planning, specialist palliative care review, treatment and advanced care planning and coordinate symptom management for patients with palliative care prognostic indicators. These may be stand-alone clinics or link in with established subspecialty clinics.
- Access to an **ambulatory care model** where patients can have minor procedures, treatments, imaging and pathology completed without requiring Emergency presentation.
- Access to **suitable palliative care beds in both acute facilities** for acute symptom management for palliative care patients known to Specialist Palliative Care.
- Access to **suitable palliative care beds in both sub-acute facilities** within the District for EOL Care. Consideration to direct EOL Care admissions for GPs should be given.
- Access to **palliative care beds in RACFs and private hospitals** and pathways to facilitate early transfer to these facilities for eligible patients.
- Access to a **palliative care unit** for the provision of respite, educating and skilling patients and carers in self-management techniques, and providing end of life care if required.
- **Education and support to GPs, RACFs and community care providers** to be able to facilitate EOL care in the community.
- **Education and support to inpatient medical, nursing, allied and supporting teams** to be able to facilitate management of palliative and end of life care within the treating team.
- **Review advanced care planning, resuscitation plans, end of life care pathways** and comfort observation processes for palliative and end of life care patients.
- **Collaborative partnerships** with community partners involved in the care of palliative and EOL patients (e.g. Hunter New England Central Coast Primary Health Network (HNECCPHN), Cancer Council, HammondCare, Non-Government Organisations(NGOs) and private nursing services).
- **Resources** and access to various mediums of information regarding palliative care for the community and care providers.
- **Overarching CCLHD governance for palliative care and EOL care services**. This will assist in developing holistic, integrated and patient-centred models of care for patients and their families across all settings. This will also enable the District strategic direction to be realised and palliative and EOL care patient safety

systems (such as complaints, incidents, root cause analyses) to be reviewed from a patient-centred and organisational perspective.

- **Referral pathways and access to Allied Health, bereavement and volunteers** for palliative care clients in the community and inpatient settings. Models of care should be developed for these services.
- **Review of workforce capabilities** to enable consultative, admitted, outpatient and community palliative care services expand and meet the needs of the Central Coast community.
- **Multidisciplinary case conferencing, care coordination and care planning** for inpatients and patients in the community that incorporates all clinicians and service providers and view the patient holistically rather than from a clinical service perspective.
- **Data collection systems** that ensure accurate collection of palliative and end of life patients is captured (this will include review of SNAP, Electronic Medical Record(eMR), ComCare, type changing).
- **Documentation systems** that are centred around the patient rather than the service, and access to patients' care plans and health records is available to all care providers involved in the patients care.
- **Care plans and goals of care** that are documented and based on the individual assessed needs of the patient, carer and family.
- A **seamless transition across all settings** for palliative care and EOL care patients and their families.
- **Education to the community** surrounding dying and palliative care.
- Development of **palliative and EOL care services that are responsive, coordinated and flexible** in meeting the changing needs of palliative care patients.
- Provision of **funding** to enhance palliative care services on the Central Coast.
- **Ensure equitable access** to specialist palliative care for all client groups that are diagnosed with a life-limiting illness.
- To **establish expected standards for 'Dying Friendly' Hospitals and RACFs.**

## 1. BACKGROUND

An ever-increasing concern of health care providers and consumers is how to ensure that palliative and EOL care meets the needs of patients. EOL care needs are changing in Australia and at a national and state level there is currently a focus on improving policy, services and resources for palliative and EOL care patients. On the Central Coast we have an ageing population, people are living longer and they have a greater incidence of chronic disease and multiple comorbidities. In recent times, there is increased societal pressure on medical professionals and health care systems to provide treatment to patients at all costs even when death is near and quality of life is poor. This pressure is due to medical, pharmaceutical and technological advances which have meant that patients and their families expect that life is often prolonged even in what are deemed as non-beneficial situations. There is strong evidence to demonstrate that it is difficult for medical professionals to not engage in non-beneficial EOL care (Wilmott et. al, 2016).

There are a number of service delivery initiatives and reference documents which formed the framework for this review, which are from federal, state or local authorities and organisations. They include:

- NSW Health Palliative Care Plan 2012-2016
- ACI 'Palliative and End of Life Care: A Blueprint for Improvement' 2016
- National Safety and Quality Health Service (NSQHS) Standards
- Palliative Care Australia 'Standards for Providing Palliative Care for all Australians'
- NSW Cancer Plan: A statewide plan for lessening the impact of cancers in NSW, 2016
- Caring for the Coast Clinical Services Plan 2012-2022
- NSCCLHD Palliative and End of Life Care Service Review Report
- NSW Ministry of Health's Advance Care Planning for Quality and End Of Life: Action Plan 2013-2018
- NSW Ministry of Health Palliative Care Strategic Framework 2010-2013 PD2010\_003, 2010.

## 2. INTRODUCTION

The intent of this document is to provide an overview of the current palliative care and EOL care available to people residing in the Central Coast Community. This report aims to highlight the current issues and opportunities to

further enhance the patient and carer experience when receiving palliative care and approaching and reaching EOL.

## 2.1 Project Goals, Objectives and Deliverables

- To ensure that all Central Coast residents have equitable access to quality palliative care based on their assessed need as they approach EOL care. This care should be timely, accessible, integrated and cover the patient journey from diagnosis to bereavement.
- Identify current gaps and opportunities for service development and improvement for the Central Coast community inclusive of inpatient and community services.
- To make recommendations regarding palliative care and EOL care provision from a patient's diagnosis with a life-limiting illness through to EOL care and bereavement.
- Review workforce capacity and make recommendations regarding future needs.
- To develop a service delivery model/palliative care and EOL Care Plan for patients and carers requiring palliative care and EOL care on the Central Coast.

## 2.2 Project Scope

### 2.2.1 In Scope

- Patients from any diagnostic group with a diagnosis of a life-limiting illness
- Patients/carers residing on the Central Coast who require access to palliative care and EOL care.
- Patients requiring inpatient services (emergency, acute and subacute)
- Patients requiring outpatient intervention
- Patients requiring community based/domiciliary services
- Patients residing at home or in a Residential Aged Care Facility (RACF)
- Patients over 18 years of age
- Service providers from government and non-government agencies who provide palliative and EOL care services on the Central Coast.

### 2.2.2 Out of Scope

Patients under 18 years of age were excluded from this Palliative and EOL Care review. The unique requirements of paediatric patients and their parents/caregivers requires review in collaboration with designated paediatric services, paediatric care providers, Tier 3 tertiary paediatric hospitals and MoH Guidelines. The SPCS Service Manager reported that paediatric patients represent less than 0.5% of the services' engagement, with involvement in approximately 2-5 paediatric patients annually.

It should be noted that throughout this review there was considerable reference made to a lack of localised Bereavement Support services available to parents/caregivers, siblings, extended families and friends following stillbirth, neonatal death, sudden infant death syndrome, paediatric death (acute and palliative) and the provision of support to children who have experienced the loss of a parent or loved one from a palliative or acute condition. At present, the Specialist Palliative Care Bereavement Service does provide counselling to children of Specialist Palliative Care patients if a referral is made.

If a review of paediatric palliative care is conducted it would be recommended that the service gaps and opportunities identified within this paper are considered. Determination should be made as to whether they are applicable to the paediatric palliative care population residing on the Central Coast.

## 3. PROJECT METHODOLOGY & TIMELINE

This comprehensive Palliative and End of Life Care review incorporates a multi-faceted approach and involves several phases. The project has been scoped to be conducted in line with redesign methodology including project initiation and design, diagnostics (including literature review, current framework and policy review, stakeholder consultation, clinical reviews and patient journaling), solution design (service delivery model/Palliative and EOL Care Plan), implementation and evaluation. The project initiation and review commenced in late April 2016 and was completed in March 2017. There were also a number of palliative care initiatives that have been suggested and



changes implemented throughout this period.

### 3.1 Stakeholder Engagement

This review encompassed engagement with approximately 500 stakeholders. These stakeholders have included patients, consumers, clinicians, internal and external stakeholders. Stakeholders that have been consulted in this review included:

- Patients, carers and families, consumers and community members
- Volunteers – SPCS, Cancer Service, Carer Support Unit and CCLHD volunteers
- CCLHD Chief Executive and Executive Leadership Team
- Specialist Palliative Care Service – Service Manager, Head of Department, NP and Clinical Nurse Consultant (CNC), Medical, Nursing, Bereavement, volunteer, Allied Health (AH) and administration staff
- CCLHD Inpatient, Community, AH and supporting staff. This included a wide cross section of departments, services and personnel
- Non-government and community service providers and Residential Aged Care Facilities
- General Practitioners/Medical Specialists, HNECCPHN
- Various external Palliative Care organisations
- Other Local Health District (LHD) palliative care services.

### 3.2 Report Layout

This report is written to encompass a patient’s palliative care journey from diagnosis and assessment, management of the stable and unstable phases of illness, caring for the deteriorating and terminally ill patient, through to caring for the deceased patient and bereavement follow up. Careful attention has been given to weave the patient and staff experience throughout this report to ensure that it highlights the patient’s journey. The author notes that the journey for each patient is unique and there is no linear progression through each phase. Where relevant quotes have been obtained, these are denoted in the report in a blue speech box for a patient/carer quote or in a pink speech box for a staff/service quote.

“Patient/carer quote”.

“Staff/service quote”.

Some sections of the report contain statements outlining identified service gaps and suggested recommendations for improvement. These are summarised in their entirety in *Appendix A: Summary List of Identified Service Gaps*.

## 4. NATIONAL, STATE AND LOCAL PALLIATIVE AND EOL CARE INITIATIVES

There are a number of national, state and local palliative care and EOL initiatives that have developed frameworks, planning documents, palliative and EOL plans to guide service improvement and ensure that quality outcomes are achieved for patients and their families. Outlined below are the key national, state and local palliative and EOL care initiatives that have been referred to throughout this review and should be utilised to inform the Central Coast Palliative and EOL Care Provision Plan moving forward.

### 4.1 National and State Initiatives

Palliative Care initiatives include:-

- Palliative Care Australia National Standards Assessment Program (NSAP).
- NSW Health Strategic Priorities 2016-2017.
- NSW Government Flexible Funding. Two recent successful rounds for the SPCS include temporary funding for the provision of a Palliative Care Residential Aged Care Outreach Service (PCROS) service, and the provision of equipment and educational resources to carers, as well as reviewing opportunities for further integrating models of care.

- ACI Palliative and End of Life Care: A Blueprint for Improvement.
- “Push for Palliative”, a state initiative that is campaigning for increased funding for more specialist palliative care doctors and nurses throughout NSW including the Central Coast. This campaign is being led by Dr Yvonne McMaster.

**Service Gap 1:** The CCLHD SPCS does not currently participate in the Palliative Care Australia NSAP. Gaps in service delivery cannot currently be identified against these criteria and appropriate actions taken.

**Recommendations:**

- CCLHD considers commencement of participation in the Palliative Care Australia NSAP. It may be advisable to participate in this program in the 2 year cycle in between the CCLHD NSQHS Accreditation Process.

**Service Gap 2:** The LHD does not currently have a process across the District surrounding service proposals that are submitted to NSW Health for Palliative Care flexible funding.

**Recommendation:**

- Recommendations as outlined in this report can form a priority list for future Palliative Care Flexible Funding proposals.

## 4.2 Local Initiatives

### 4.2.1 District Strategic Plan

The ‘Caring for the Coast – every patient every time’ strategy for CCLHD encompasses five priority areas of Caring for Our Patients, Our Staff, Our Resources, Our Community and Our Future. In Palliative and EOL care there are opportunities for improvement, including:

- Improve patient satisfaction with palliative and EOL care services
- Improve transferring of patients who are in the terminal phase of a palliative condition
- Investigate alternative options, e.g. direct admission to a palliative care bed for symptom management or EOL care. Some patients are arriving at the ED in the terminal phase and are inappropriate to transfer to a ward
- Some patients have increased length of stay due to lack of coordinated care and access to the SPCS 24/7
- Coordinated discharge planning and increased care coordination between primary healthcare and the SPCS in the community – there is a reported increase of readmissions for palliative care patients in the last year of life
- Involve palliative care patients and their carers in staff education and training through sharing of patient stories
- Incorporate service gaps and opportunities for integrated care with primary health care for palliative care patients in areas identified within this review such as care planning, care coordination, shared documentation and Advance Care Planning (ACP).

### 4.2.2 CCLHD Clinical Service Level Agreement and Services Plan

The CCLHD Clinical Service Level Agreement is reviewed annually and has targets for palliative care service provision along with specific priorities. The CCLHD Caring for the Coast Clinical Services Plan 2012-2022 outlines a number of Strategic Directions for CCLHD palliative care service. Areas of focus include:

- Developing a business case identifying the workforce enhancements required to support an expanded inpatient consultation service including capacity to meet increased referrals, provide extended hours coverage including on-call, direct care inpatient admission to acute facilities, and outpatient clinics
- Expanding the Palliative Care Service to promote and support quality EOL Care in home settings (includes RACF) including consultative and education support for GPs, RACFs and other providers of palliative care
- Developing a proposal for provision of direct care admissions to Gosford and Wyong hospitals for episodes requiring acute management including access to beds within preferred wards and resource requirements to support this service
- Exploring options for modification and/or refurbishment of the Long Jetty sub-acute unit to include single rooms to accommodate EOL care beds
- Promoting ‘Dying Friendly Hospitals’ through supporting wider uptake of EOL care pathways across LHD facilities and promote improved referral pathways to Palliative Care Services



- Ongoing assessment and review to determine how these areas continue to align and progress with the Services Plan, and identify opportunities for realignment where appropriate.

### 4.2.3 Integrated Care

Integrated care is a particular strategy that is pertinent when considering palliative and EOL care delivery models, as patients transfer between multiple service providers and facilities following diagnosis with a life-limiting illness. Additionally, there is a recognised increasing prevalence of patients with chronic diseases and a higher percentage of older people residing on the Central Coast. These factors will have a direct impact on the palliative and EOL care resources required into the future.

### 4.2.4 CCLHD Comprehensive Cancer Plan

The most common cancer deaths in NSW are of people diagnosed with lung, bowel, prostate, breast and pancreatic cancer. Whilst the focus of cancer treatment is commonly on survivorship, it is important to ensure that patients have informed choices surrounding their treatment options. The service gaps and strategies that are identified in this report will be beneficial to link in with the planning for the Central Coast Comprehensive Cancer Plan.

**Service Gap 3:** Consideration of specific care strategies to provide support to people who are dying from cancer and their families. There are opportunities to increase support and early linkage to the SPCS for patients living with cancer.

**Recommendation:**

- Consideration be given to the gaps and recommendations identified in this review report when writing the Central Coast Comprehensive Cancer Plan.

### 4.2.5 Palliative Care Role Delineation Framework

A Palliative Care Role Delineation Framework (*GL2007\_022 Palliative Care Role Delineation Framework*) was developed and published in 2007 to provide local health services with a framework to delineate health care services, assist in local strategic planning and to support program and service evaluation, research and quality improvement. A new document outlining the role delineation of clinical services was released in January 2016 and clinical services are currently being reviewed against the revised standards by the CCLHD Health Services Planning Unit.

## 5. CENTRAL COAST DEMOGRAPHICS

The demographics of the Central Coast are referenced in the Caring for the Coast Clinical Services Plan 2012-2022 and updated by the Health Services Planning Unit (2017).

### 5.1 Population Profile of CCLHD

On average CCLHD residents have:

- Low socioeconomic status (particularly within Wyong area) with low levels of educational attainment, in low paid employment and relatively high rates of public housing.
- Very high rates of obesity (30.7%) compared to NSW (18.9%).
- Very high rates of tobacco use (21.4%) compared to NSW (13.5%).
- High rates of mental health conditions, suicide as well as high rates of drug and alcohol use.
- High rates of preventable disease and rates of presentation to the emergency department and admission to hospital for acute and chronic conditions.
- Higher cancer incidence and mortality rates than Australian average for many cancers in particular lung and melanoma. Within the CCLHD rates are higher for Wyong residents than Gosford residents.
- High death rates from all causes, in particular cancers and respiratory disease.
- Lower life expectancy for both males and females than the NSW average.
- Difficulty accessing public health services due to poor public and private transport options.
- Poor access to GPs in the Wyong area.

## 5.2 Ageing of the Population of CCLHD

The population of all age groups on the Central Coast will increase, but the greatest proportional increase will be in people 70 years plus, by 2026 they will represent about 48.4% of the Central Coast population. As older people use health services more than the rest of the population, demand for health services can thus be expected to rise substantially. This will place an increased demand on health services including the need for palliative care due to ageing and frailty.

It is also noted that the prevalence of people living alone also increases with age, in the 2011 census it was estimated that about 37% (over 2,600 people) aged 85 years and over on the Central Coast live alone. This will almost certainly rise by 2027. This will have a direct impact on the provision of social care, community care and palliative and EOL care in the home if required.

There is currently estimated to be approximately 5000 people living on the Central Coast with dementia. It is estimated that one in four people over the age of 85 years has dementia. This figure is expected to grow by more than a third by 2022.

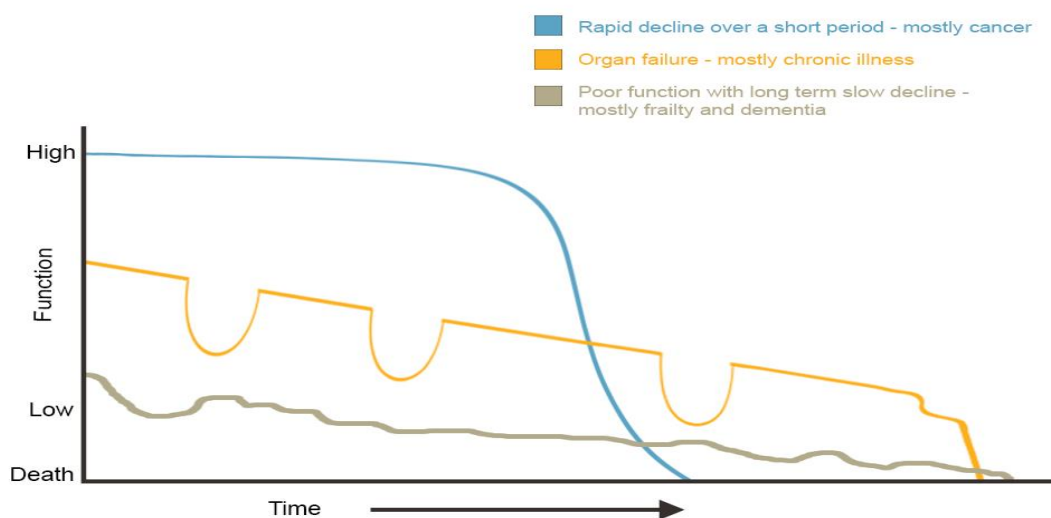
## 5.3 Palliative and End of Life Trajectories

There has been much research in recent times on the predictability of death. If clinicians and health professionals are aware of the trajectory of a patient's life limiting illness they will be able to assist the patient to prepare for the future and determine which EOL care approach to facilitate when managing the patient. The Deeble Institute highlighted that "people approaching EOL can be broadly classified into three trajectories, each requiring different EOL care priorities:

- **Cancer trajectory** – most people with malignancies are able to maintain comfort and function for some time, with rapid decline in the final weeks and days preceding deaths.
- **Organ failure trajectory** – people in this category often deteriorate over a longer time, maintaining moderate function. Periodically they experience acute deterioration followed by partial recovery, with death occurring quickly from exacerbation or complication.
- **Dementia and frailty trajectory** – function deteriorates over time, and these people generally die at an advanced age of either neurological failure (such as Alzheimer's or dementia) or generalised frailty of multiple body systems (Lynn and Adamson 2003)."

(Ref: Deeble Institute, Jones & Silk, 2016 pg. 2)

The following diagram outlines the predictive trajectories for cancer, organ failure and dementia and frailty.



Reference: Agency of Clinical Innovation, 2014.

It should be noted that in NSW, and also reflected on the Central Coast, there is a disproportionate use of SPCS by patients diagnosed with cancer. Referral to SPCS for patients who have organ failure or dementia and frailty are far less common and as a result these patient cohorts miss out on the specialised support available through the SPCS. Evidence indicates that if the trajectory of the illness is utilised then palliative and EOL care resources can be mapped to a patient's predicted decline and need for intervention.

## 6. CURRENT SERVICES – ISSUES AND OPPORTUNITIES

This review has highlighted a number of issues and opportunities which need to be addressed and discussed so that they can direct further enhancement of palliative and EOL care provision across the Central Coast throughout the patient/carer journey. The main community-based services are described in this section. Inpatient services are most often accessed in the deteriorating and terminal phase of a patient's life-limiting condition, and are listed in section 13 of this report.

### 6.1 General Practitioners

There are a significant number of GPs practicing on the Central Coast. These GPs have varying practicing conditions from working in isolation to working in large practices. GPs also vary in age, experience and familiarity with working on the Central Coast. GPs also have varying experience, knowledge and confidence working with palliative and EOL care patients and different practice capabilities i.e. practices offering after-hours, home visiting and on-call support to palliative and EOL care patients. GP practices also have differing practice set-ups with some access to practice nurses, medical imaging and AH support.

#### 6.1.1 GP Access to Specialist Palliative Care Service

There is varying uptake of the SPCS on the Central Coast. Some GPs are happy to refer to the service as they are aware of the service capabilities and limitations and are able to cater for these. There are other GP practices that will not refer their patients to the service. This has been reported to be due to limited support offered by the SPCS as it is perceived to be a predominately Nurse-led service, the referral process is too cumbersome and referrals aren't always accepted, inability to hand over care to the SPCS and the need to continue to manage patient's medication regimes. There are other GPs who reported that they were unaware that we had a SPCS on the Central Coast.

"I did not know that we had a Specialist Palliative Care Service on the Central Coast, how do I refer to them?"

"The Specialist Palliative Care Service is fantastic at coordinating care for my patients to allow them to die at home".

#### 6.1.2 GP Comments on Current Service Provision to Palliative Care Patients

There are a number of service gaps and opportunities that were identified by GPs and service providers that impact on the overall provision of seamless care to palliative and EOL care patients in the community. Comments from GPs include:

- Increased access required to specialist palliative care doctors for advice on pain management, medications and symptom control.
- Medical phone support would be great if it was available 24 hours 7 days per week.
- GPs are interested to have their voice heard when their palliative care patients are admitted to the hospital.
- GPs do not all work weekends and after hours i.e. difficulty with urgent scripts, home visiting and certification/verification of death processes.
- There is an opportunity for the SPCS to have a strong relationship with a GP as they are responsible for the overall management and care coordination of the patient.
- Improved access to palliative care beds in hospitals and RACFs.
- Access to a palliative care unit/hospice on the Central Coast so that EOL care patients who can't die at home don't have to be admitted to a hospital or RACF.

- Access to HammondCare Home Support Packages to support EOL patients to die at home.
- Improved education and systems around medication management for community palliative and EOL care patients.
- Increased education and support for GPs regarding palliative and EOL care management.
- Patient/carer activated pain response system.
- Transfer of ACP to hospital medical notes.
- Palliative care links with Practice Manager Association, GP Panel and HNECCPHN.
- Incentive-based care protocols to enable GPs who specialise in palliative care to have patients referred to them.
- If the patient does not have a GP or the GP does not wish to engage with the SPCS then the patient cannot be registered with the SPCS.
- There are a select few GPs who have admitting rights to Long Jetty hospital. These doctors admit patients to Long Jetty Hospital for EOL care depending on whether there is a bed available.
- GPs want to be involved in case conferencing and decisions surrounding palliative and EOL care for their patients.
- Lack of handover to GPs on palliative and EOL care for patients transferred back to the community.
- There is a lack of continuity of care for patients admitted to RACFs if the RACF is not covered by the GP who has always looked after the patient.
- GPs are unsure about prescribing high level of opiates to patients.

### 6.1.3 Palliative Care Resources for GPs

A Palliative Care Information Guide was produced as a joint initiative between Northern Sydney Central Coast Health (NSCCH) and the Central Coast Division of General Practice in 2009. This resource provides GPs with information on palliative care, A-Z of symptom control, medication management for palliation, an opioid conversion chart, carer information, prognostic indicators, ACP and EPC Medicare items. These flipcharts were distributed to all GPs on the Central Coast and they were reported to be a useful tool for assisting with the management of palliative care patients. These flipcharts require reviewing and updating and a working party could be undertaken to determine whether they are beneficial to GPs and if so undertaken by the HNECCPHN.

**Service Gap 4:** The Specialist Palliative Care Service is not currently offered to all patients in the community who may be suitable for referral.

**Service Gap 5:** There is an opportunity to increase education, support and resources for GPs treating palliative and EOL care patients in the community.

**Service Gap 6:** There is varying practice amongst GPs surrounding home visiting, after-hours care and interest in palliative care.

#### **Recommendation:**

- Provide education to GPs on the SPCS, its referral pathway and how they can work in partnership with GPs to provide holistic, supported care to palliative and EOL care patients.
- Consider methods of improved access for GPs to SPCS Staff Specialists
- Convene a working party with GPs and SPCS to identify opportunities for a more collaborative partnership (i.e. review Health Pathways if required, education forums, drop in lines, access to phone support).
- Identify potential ways to work with GPs interested in palliative and EOL care to provide incentives and agreements to manage palliative and EOL care patients.

## 6.2 Specialist Palliative Care Service

CCLHD currently has a SPCS that sits within the Division of Aged, Subacute and Complex Care. The service is based in the Palliative Care Building on the Long Jetty Hospital site and comprises of Nursing staff, Medical Staff Specialists and registrars, Bereavement Counsellors, Volunteer coordinator and volunteers, an Occupational Therapist (OT) and is supported by administration staff. The service provides community-based support to people in their homes and in RACFs. The SPCS also provides a consultative service to Gosford, Wyong, Woy Woy and Long Jetty inpatient sites.

The Palliative Care Staff Specialists do not provide a comprehensive on-call or after-hours service and do not admit patients due to workforce capacity. Patients requiring admission are admitted via the ED under the care of an allocated physician.

The SPCS describe themselves as a 'consultative service'. Whilst consultation is very important, family members often expect a service that has the flexibility to provide practical and hands on care as well.

### **6.2.1 Specialist Palliative Care Governance and Workforce**

The SPCS workforce currently reports to the Director of Clinical Operations via the Director of Aged, Subacute and Complex Care and the Operational Nurse Manager Community. The SPCS is managed by a full time Service Manager who is a Nurse Manager level 3. There is also a part time Head of Department of Palliative Medicine that reports operationally and professionally to the Clinical Director of Aged, Subacute and Complex Care. The Head of Department role includes a clinical load, which decreases the amount of time available to complete governance and operational functions of the role.

#### **6.2.1.1 Medical Workforce**

The current Staff Specialist workforce for the SPCS is 3.2 Full Time Equivalent (FTE). There are also 2.0 FTE of Advanced Trainees, and 0.8 FTE of an Unaccredited Trainee. The Head of Department, Palliative Medicine and the Service Manager of Palliative Care have reported that this FTE does not permit the creation of a 24/7 roster for access to specialist Medical advice for the District. All inpatients are under the 24 hour care of their admitting Medical team.

The palliative care specialist recommends treatment options to the GP and medications that should be prescribed to the patient. The GP is required to write the script for patient medications and also write the death certificate for the patient. There are no specialist palliative care inpatient beds in the CCLHD hospital facilities. The SPCS provides a hospital consultation service during Monday-Friday business hours.

#### **6.2.1.2 Nursing Workforce**

The Nursing staff within the SPCS are allocated according to six geographical locations. There is one Palliative Care Liaison Nurse (PCLN) allocated to each of these six sectors and then three relieving nurses for when staff are on planned or unplanned leave. The majority of these nurses are Clinical Nurse Specialist (CNS) Grade 2 (6.95 FTE) with 3.0 FTE of CNS1 and Registered Nurse (RN) staff.

The Nursing workforce also includes a CNC who is based in the community but is employed to support all CCLHD facilities. This FTE allocation is not adequate to support the demand on the Central Coast. A NP is also appointed to Gosford Hospital and a CNS2 to Wyong Hospital. These Nursing staff are fulltime and provide a consultative support to the hospital settings on weekdays. There is no Clinical Nurse Educator (CNE) employed in the SPCS.

#### **6.2.1.3 Allied Health Workforce**

The SPCS currently employs 1.0 FTE OT. This OT is community based and reports operationally to the Service Manager Palliative Care and professionally to the Senior Community OT. There are currently no other permanent AH staff within the SPCS. A temporary 0.8 FTE Social Worker commences in August 2017, but this is only until June 2019, and support is restricted to RACFs using the PCROS model. Patients who require AH support are required to access Community AH where possible, private AH or attend AH outpatient clinics. Current access to Community AH support is very limited and does not always meet the needs of palliative care patients.

#### **6.2.1.4 Administrative Support**

The SPCS is currently supported by 2.12 FTE designated administration staff. These staff are managed by the Service Manager.

#### **6.2.1.5 Bereavement Coordinator and Counsellors**

The SPCS currently employs a part time bereavement coordinator and two part time bereavement counsellors, total 2.34 FTE.

#### **6.2.1.6 Volunteer Coordinator and Counsellors**

The SPCS currently employs a part time volunteer coordinator (0.53 FTE) and volunteers. These are designated

specialist palliative care volunteers.

Patients and carers do not always receive access to SPCS due to resource limitations. The number and combination of existing staff FTEs appears to be insufficient to continue to manage effective service provision across the LHD and meet the “Every Patient Every Time” philosophy.

**Service Gap 7:** The SPCS workforce structure does not currently support CCLHD and community needs for Specialist Palliative Care Services.

**Recommendation:**

- Review workforce structure of the SPCS, number of staff and work locations. Identify gaps in service provision and develop strategies for improvement in line with the recommended service delivery model.
- Review current operational and reporting lines for positions employed under the SPCS to ensure that they meet professional standards and Workforce policies.

### 6.2.2 Referral to the Specialist Palliative Care Service

Some patients have more complex physical, psychosocial and spiritual needs. The severity, complexity and irreversible nature of these symptoms can often exceed the knowledge, expertise and resources of the primary treating team and for these patients referral to a SPCS is required. SPCS provides interdisciplinary care under the direction of a specialist in palliative medicine and should aim to provide care in partnership with the treating team. Specialist palliative care physicians should always be available to advise or support other Medical and Nursing professionals in their delivery of palliative care.

The NCPPC Needs Assessment Guidance (National Clinical Programme for Palliative Care, 2014) indicates that the eligibility criteria for referral to a SPCS includes patients who have both:

- a life-limiting condition and,
- current or anticipated complexities relating to symptom control, EOL care planning or other physical, psychosocial, or spiritual care needs that cannot reasonably be met by the current care provider(s). (pg. 4).

The CCLHD SPCS referral criteria are currently located on the CCLHD Intranet at <http://intranet.cclhd.health.nsw.gov.au/clinical/Allied/asacc/pallcare/Pages/Referral-Process.aspx>. The CCLHD referral criteria are not consistent with internationally documented criteria.

There is a policy that is internal to the SPCS titled *Referral, Registration and Separation Processes for the Central Coast Specialist Palliative Care Service (Internal to Department) Document Number 2014\_001*. This document is due for review in November 2016 and to date has not been updated or published on the Intranet. There are two categories of referrals accepted to the SPCS.

- External Referrals – accepted by multidisciplinary SPCS and the bereavement service
- Internal referrals – bereavement service, volunteer service and palliative care OT.

New referrals are only seen business hours Monday-Friday (not on public holidays or weekends).

- Referral Criteria – to be eligible for referral to the SPCS the patient must meet *all four* of the following referral criteria including:
  - 1) Documented evidence of a terminal illness AND
  - 2) Evidence of progression of that illness AND
  - 3) Evidence of a need for clinical care/advice or other clinical/support needs that are outside existing services’ capacity AND can be responded to by the SPCS AND
  - 4) Consent for the referral by the patient or the person responsible

In addition, community-based referrals require an identified GP before an initial assessment can occur and a primary Nursing service to be in place before registration to the service can take place. Any exceptions must be discussed with the Service Manager of the SPCS.



A referral is only a referral to the Service for assessment. Registration with the Service is a separate administrative process informed by the clinical assessment. Assessment or registration may not occur if high risk safety concerns are identified.

- Referral Pathway (community located patients including RACF)
  - 1) GP Pathway – referral form or letter is faxed to Palliative Care office. A copy of medical history and documented evidence of life-limiting illness confirmed.
  - 2) Specialist pathway (local non-inpatient) – referral form or letter plus additional information faxed. Identified GP must be included and notified and in agreement of the referral. If a GP is not identified then a single assessment will occur, however the patient will not be registered and followed up by the SPCS. This is communicated to the referring specialist.
  - 3) Specialist pathway (specialist out of area) – managed as per above. If no GP is identified then a single assessment visit will occur but no registration.
  - 4) Specialist Pathway (discharged before seen as inpatients) – if an inpatient Medical specialist refers a patient to the SPCS and they are discharged before they are seen then the SPCS will not see the patient. The Medical specialist is required to ask the GP to make a community referral.
- Response to Referrals: Once a referral is received it is reviewed and triaged (at this point additional information may be sought from the referrer). An assessment is then undertaken and then three different pathways are followed
  - Consult only (if uncertain of referral criteria 1,2, or 3),
  - Short term registration (if uncertain of referral criteria 2 or 3) and
  - Registration with the palliative care service (if the patient meets all of the referral criteria)
- Separation/Discharge from the SPCS – this occurs if the patient dies, if they are stable or if they move out of area.

In 2015-2016, a general breakdown of referrals showed 60% were received from medical specialists, and 40% were received from GPs.

The following issues have been reported by stakeholders throughout this review regarding the referral process:

- Stakeholders were not involved in the development of referral pathways
- Referral pathways do not meet the needs of patients and specialists
- The referral process is not clear to referrers and patients/carers
- The community referral process relies on faxes to and from the SPCS, and there is no electronic referral form
- The inpatient referral process is not fully electronic and requires faxes to be sent to the SPCS for further administrative processes
- All Community referrals to the Service are vetted by the Head of Department or Service Manager of Palliative Care which is potentially an unnecessary step in the referral process
- Patients require referrals from GPs even if they were referred by a specialist whilst they were an inpatient
- There is an opportunity to review the referral criteria in line with state and federal guidelines
- There are a number of referrals rejected as considered 'inappropriate'. These patients are not referred onto other services by SPCS to meet their needs.
- Data surrounding inappropriate referral numbers is not available
- The timeliness of referrals to the SPCS is often based on crisis management and has been referred to as an increase in "end of life" referrals
- The SPCS holds weekly referral meetings to review the current status of all referrals received in the preceding seven days
- Perception that Medical Specialists cannot refer to palliative care but need to request a GP to do so. If GP does not consent then patient misses out on palliative care input.

"I was unable to access the SPCS for my Mum as she did not have a primary GP".

“The referral process to the SPCS does not work. The needs of the SPCS are put ahead of the needs of the patient due to the non-documented existing processes”.

**Service Gap 8:** There is a variable understanding of the referral criteria and pathways for referring a patient to the SPCS.

**Recommendation:**

- Review the referral document in line with best practice referral standards to other palliative care services as evidenced in the literature.
- Consider acceptance of referrals from specialists in the hospital without the need to require a further one from the patient’s GP.
- Review the referral criteria to the SPCS to ensure that it is patient-centred.
- Review the referral, assessment and registration process for SPCS to ensure that it is a lean and efficient process and that the patient and referrer are informed of the steps in the process.
- Review the need for checking of referrals by Service manager and/or Head of Department and determine if there are other processes to meet this need.
- Review electronic referral pathways and Information Management and Technology (IMT) systems that could support this.

### 6.2.3 Specialist Palliative Care Service Provision

A component of the review was a process mapping session with the Specialist Palliative Care team, tag-a-longs with Nurses in the community, staff interviews, attendance at staff meetings and case conferencing, review of clinical documentation and databases, review of patient complaints, compliments, incidents and RCAs. There were also results of patient interviews considered. The following service gaps were reported by stakeholders:

- Early referral to the palliative care service is beneficial to the patient and carer. The SPCS receives the majority of their referrals for patients in the deteriorating and terminal phases of care.
- There is an opportunity for the SPCS to conduct a family assessment to determine whether there are significant family/carer stress issues. This would need to be reviewed regularly throughout the patient’s episode of care with plans documented.
- Patients are routinely admitted to hospital in the last year of their life which is consistent with the literature and symptom management in the last year of life
- There is a perception from the SPCS that when a palliative care patient is sent to hospital there is a risk that they are not treated actively and some Medical and Nursing staff in the EDs question why the patient has been sent in
- There is a lack of ACPs conducted on palliative care patients. There is an unclear view on whose role this is to facilitate and document as patients are under care of a GP and often other Medical specialists
- There is a lack of acceptance of all palliative care patients from GPs. Referrals are deemed as inappropriate when a GP does not include information regarding the client’s life-limiting illness as per referral criteria. If it is identified that a primary care provider can’t manage a patient i.e. a GP doesn’t know what to do in relation to pain management and medication prescription, then whilst the SPCS might think that it is an easy pain management problem the GP requires support, and if not provided the patient is at risk
- The community has an unknown number of perceived and actual cancer patients and patients with other life-limiting illnesses who are not referred due to capacity issues i.e. dementia, respiratory, cardiac, progressive neurological disease
- Inappropriate referrals – there are some referrals which do not proceed to assessment as they are considered to be inappropriate, and do not continue through the SPCS intake process. These can be because they are not completed properly, are missing information, or a perception that the level of symptom management required should be managed by care providers.
- Inability to measure unmet need – until late in 2016 referrals that were regarded as inappropriate were not kept or filed in the patient Medical record. There have also been reports from GP and Medical specialists surrounding lack of notification and feedback regarding inappropriate referrals. This dismissal of referrals has resulted in a culture amongst some GPs and Medical specialists of a reluctance to refer palliative care patients to the SPCS for support and management. This results in gaps in service delivery for some patients



- The majority of patients and GPs who engage regularly with the SPCS are satisfied with the service they receive
- There are no regular patient or staff satisfaction surveys completed on the SPCS. There is also no evidence of Service Rounding as indicated in the Caring for the Coast Framework
- The SPCS is predominately a Nurse-led service. Nurses phone community palliative care Specialists for advice on patients and change of medications during weekday work hours
- The referral criteria needs to be reviewed and is often person dependent rather than process driven
- Other specialists and consultants are unable to refer to the SPCS without the consent of a GP in the community
- Some patients do not have regular GPs or they use GP practices which makes continuity of care for patients with palliative care conditions challenging and not seamless
- Medication management for community patients is complex due to Specialist palliative care and GP co-involvement in medication plans and writing of scripts for palliative care symptom control
- In the community specialist palliative care Nurses respond to all distress calls of patients. Occasionally palliative care Specialists attend house visits but if unable and the patient can't access their GP they are sent to hospital
- The Palliative Care Specialists are a small workforce with no leave relief built into positions. The Medical Staff do not work after hours or on weekends. If the nurse is unable to meet the patient need then the patient is sent to hospital
- There is a perceived stigma identified by the SPCS that patients who are palliative are discouraged from attending ED. Palliative care patients in the ED should get adequate assessment like all other patients
- ACP is not supported by all Specialist palliative care staff. These documents need to be reviewed regularly throughout the patient's medical journey and do not replace conversations with the family and patient
- There is a lack of time to provide education to GPs, specialists, community and service providers surrounding palliative care. This is an important role of the SPCS and due to resource constraints it is not prioritised
- There is a need for a Palliative Care NP role in the community
- There is a lack of documented care planning for patients as they move through different phases (i.e. there is an initial plan documented, it should be rediscussed and documented each time patient moves to a new phase)
- Patients can move to the unstable phase very quickly if the current plan is inadequate or if there is not an appropriate plan in place
- There is an ad hoc person-centred Nurse-led process for when patients are referred to the palliative care Specialist for review. There is a belief communicated by some staff that Medical specialists should be seeing all unstable patients and also be involved in terminal care of patients to ensure adequate symptom control and pain management
- Medical Staff Specialists are often required to make recommendations and write orders over the phone for patients that they may not have seen. This should be formalised with appropriate documented processes
- Improved communication is required between palliative care Medical and Nursing staff
- There is an opportunity to develop a clear documented Medical model for palliative care Staff Specialists
- Medical Specialists have a need to know what is going on and what the plan is for all patients and what Nurses are doing for all patients
- There should be daily "bed board" rounds of patients under each Medical specialist
- There is an inconsistent process-driven care planning process. Patients and carers are not always involved in care plans and not told about interventions
- There is a gap in availability and access to specialised Allied Health and other support services and referral pathways into these.
- There are a lack of documented policies and procedures for the SPCS in some areas. This leads to person-dependent care rather than process dependent care. The impact of this on patients can be magnified by different nurses attending to care due to relief and days off.
- The SPCS has become an EOL service and patients are turned away when referred as they are not acute enough, symptoms aren't bad enough, or they don't have symptoms that require "Specialist input"
- The SPCS has also become an EOL service due to being the only referral pathway for Hammond Care Home Support Packages
- The caseload management of the PCLNs is difficult to observe and monitor, with no systems in place to review comparable workloads, identify surges in activity and to plan substitute care provision when the usual PCLN is on unexpected leave
- The completion of required clinical skills for patients by PCLNs in the community is dependent on the individual

skill set of the Nurse, e.g. indwelling catheter insertion. In some cases the Nurse home visiting is required to contact either a Community Nurse or an ASET Outreach Nurse to come to the house and perform the task. There are also time management reasons why this might occur

- There is a perception/expectation that the PCLNs are ‘hands off’, and do not do direct clinical care unless it is related to medication administration, e.g. syringe drivers
- The Administration staff at SPCS manage a ‘Death List’ of patients. When the service receives notification that a client has died, they add them to this list. Once a week the updated list is sent to the several work areas in CCLHD.
- The ‘Death List’ list does not always get distributed to the staff involved in a patient’s care and relies on staff within the SPCS notifying each other. The names on the weekly Death List are also checked for next of kin, and they are sent a letter and brochure about Bereavement services which are available on a self-referral basis.

“I had to see two different nurses on a daily basis in my home because they each did different things. I wasn’t really sure why the first nurse (referring to PCLN) couldn’t do what the second nurse came to do (referring to the Community Nurse), perhaps she was the senior nurse?”

“The Emergency Department should take palliative care label when patient arrives at the door and place it under the bed, they should review the patient to find out what is wrong, what they need to do to fix it in consideration of the patients ACP or directive and consultation with the GP, Medical specialists, palliative care team and in consultation with the patient and family”.

#### 6.2.3.1 Palliative Care Residential Outreach (PCROS) Model for RACFs

A PCROS model was developed by SPCS due to an identified need to support RACFs in the provision of effective EOL care. Temporary funding for a full time CNS2 and a part time Social Worker was approved until June 2019. The model aims to support ACP development in 45 RACFs across the Coast and provide follow up post ED presentation and develop increased capacity to manage EOL care provision. The model is an adaption to the existing ASET Outreach model for RACFs, however its focus is on palliative and EOL care, providing clinical advice and psychological support for patients and family pre-death. The Community Health Aged Care Nurse Practitioner will also be part of the PCROS/ASET linkage to facilitate patient care and reduce the number of avoidable ED presentations and hospital admissions wherever possible.

Service review and data analysis will occur during the period of funding, with future proposals for funding to be developed if the model meets the expected needs of RACF residents and staff and the LHD.

**Service Gap 9:** The SPCS service provision does not always meet the needs of patients, carers and referrers. This leads to service gaps, preventable hospital admissions and lack of visibility of current service workload and capacity.

#### **Recommendation:**

- Review and conduct analysis of current SPCS staffing workloads across all positions and locations.
- Review the service provision model of the SPCS to ensure that it is adequately resourced with staff, accommodation, equipment, etc. to meet the needs of the Central Coast and the LHD.

#### 6.2.4 Specialist Palliative Care Meetings

The Specialist Palliative Care team has a variety of team meetings to facilitate client care, including:-

- **Clinical Handover Weekly Meeting.** The intent of this meeting is for the on-call weekend staff to share any changes that have occurred for patients over the weekend and to discuss patients for the week.
- **New Referral Weekly Meeting.** This meeting reviews referrals on a weekly basis and is utilised as a communication tool between staff. It confirms the right staff member has been allocated to the referral to best meet the client’s needs.
- **Team Meeting** bi-monthly, varying in content to include general team issues.
- **Central Coast Palliative Care Clinical Practice Meeting** alternating bi-monthly, to discuss standards of care,

evidence-based practice and review of policies and guidelines as required. A review of the meeting minutes since 2014 highlighted that there are many issues identified and areas for improvement developed that are then not introduced within the service or evaluated.

- **Morbidity and Mortality Meetings** are held infrequently at present, and only commenced in November 2016.

**Service Gap 10:** The clinical governance and current function of SPCS meetings are not necessarily achieving the desired outcome as outlined in the Terms of Reference.

**Recommendation:**

- Review the terms of reference and governance for all the meetings held in the SPCS to ensure they meet client, service and LHD needs and requirements.

“By not discussing selected deaths at morbidity and mortality meetings in the SPCS we are missing out on the opportunity to debrief and learn from patients’ deaths to improve outcomes for future patients”.

### 6.2.5 Policies, Procedures and Safe Operating Procedures (SOP)

The SPCS is governed by a number of internal policies, procedures, SOPs and clinical guidelines. Many of these are internal to the department only and not published on the CCLHD Intranet. There are also a number of policies and guidelines that have been produced by the CNC and are published on the CCLHD Policies and Procedures link on the Intranet page.

All staff are aware of the appropriate policies, procedures, SOPS and clinical guidelines for their position requirements, however governance and monitoring compliance is extremely challenging due to the multi-disciplinary nature of the team and the widespread geographical dispersion of staff members across the LHD.

**Service Gap 11:** There are a number of SOPs developed by the SPCS that are not consistently followed.

**Recommendation:**

- Review opportunities to increase the usage of local SOPs and collaborative interdisciplinary policies, procedures and guidelines by staff in appropriate work areas throughout the LHD.

### 6.2.6 Access to Allied Health in the Community

The SPCS currently has 1.0 FTE Occupational Therapist employed within the team. Access to other AH professionals is via referral to community AH, outpatient AH services, private AH professionals or Cancer Care AH staff. There is very limited access to, and capacity for, AH support for palliative care patients.

AH professionals are equipped to provide assessment, diagnosis and management of various symptoms related to life-limiting illness. They are able to work with patients, carers and medical professionals to improve patient experience, develop patient goals and achieve outcomes. AH assist with the provision of holistic care and can contribute to the prevention of hospital admission and keeping patients well in the community.

#### 6.2.6.1 Social Worker Support

Best Practice guidelines for Palliative Care in Australia require the SPCS to have a permanent Social Worker within the team. The Central Coast SPCS does not and is one of the only Palliative Care teams in NSW who do not have a permanent Social Worker employed within the team. In August 2017, a temporary Social Worker position (0.8 FTE until June 2019) commenced in the SPCS to facilitate palliative and EOL care for patients in RACFs only.

When patients are discharged from hospital to the community there are no Social Workers to handover care to. As a result, patients do not have access to holistic psychosocial assessment by a palliative care Social Worker and therefore recognition/acceptance that a person is dying does not occur in a timely manner leaving them, their family and carers with limited time to come to terms with the approaching death and denying them the time to consider options such as dying at home. Having a palliative care Social Worker could reduce emergency hospital admissions if family/patients have timely support and can plan EOL stage in a non-crisis manner.

Social Workers in the Cancer Care Centre are often requested and consulted by Palliative Care nurses to assist with child protection, Centrelink, financial issues, young families, carer abuse, and homelessness after eviction. Cancer Care Social Workers assist with this on goodwill but are not funded to do so and are limited in what they can provide as they do not have capacity to do home visits to discuss concerns with patients. This sub-optimal care is provided by the Cancer Care Social Workers at the expense of patients who are requiring active treatment needing Social Worker support in the Cancer Care Centre.

#### 6.2.6.2 Allied Health Services Feedback

There were two focus groups held with AH staff, AH Managers and the Director of AH. Service gaps and opportunities identified by AH include:

- Limited training amongst AH staff regarding death and dying
- Limited involvement of AH in service planning and goal setting impacts on decisions surrounding palliative and EOL care and only include AH if there is a sudden need
- Access to all AH disciplines from diagnosis to EOL care for patients diagnosed with a life-limiting illness
- The SPCS reported there is a significant need for improved access to AH to support palliative and EOL care patients in the community
- Currently, there is no consistent community based support available for all AH disciplines (except progressive neurological patients). Care and follow-up is provided during inpatient admission, or during an outpatient appointment (if suitable for the patient to attend the hospital, although often not appropriate). This can lead to sub-optimal and inequitable care
- Intervention is generally provided following admission to hospital rather than access in a setting appropriate to the patient's needs to avoid hospital admission. Even when patients receive a service in the community, continuity of care is impacted with transition from home-based to inpatient services
- Cancer patients aren't able to access the Community Allied Health team. They only have access to an Occupational Therapist as there is one allocated to the SPCS. This is concerning as the majority of patients seen in the SPCS are diagnosed with cancer
- Community AH staff are managing/co-ordinating the palliative care/EOL processes for conditions that are not accepted into SPCS i.e. dementia, progressive neuro and respiratory patients, along with other services such as Complex Care Co-ordination team and the Dementia team.

"I couldn't swallow and was drooling. Whilst I was in hospital having my operation in Newcastle I saw a Speech Pathologist, I was told there are none in the palliative care team and that I had to go and see my GP to see a private Speech Pathologist – I can't afford that"

"If we are serious about delivering high quality care to palliative care patients we need to resource AH appropriately to palliative care patients in the community and hospital setting".

"It is important that we improve our ability to refer and gain access to AH staff in the community to supplement the palliative care services we deliver and keep patients out of hospital".

**Service Gap 12:** There is an opportunity to develop AH referral pathways and specialised AH resources to provide input and support for palliative care patients residing in the community.

#### **Recommendation:**

- Review the referral pathways (including NDIS), workforce and skill mix of AH staff working in the community to determine how they can support palliative care patients living in the community.
- Provide education to medical professionals, GPs and increase community awareness on how to access AH services in the community.
- Improve clinical handover of patients from the acute setting to the community for patients with a life-limiting illness.

### 6.2.7 Discharge of a Patient from the Specialist Palliative Care Service

The SPCS has a SOP 'Discharge of a Registered Patient – Palliative Care/DASCC' written that outlines the reasons for and processes to discharge a patient that is registered with the SPCS. The intent of this SOP is to ensure that only patients requiring access to specialist palliative care interventions are registered with the SPCS. Criteria for discharge of a registered patient include:

- Patient who has had no contact with the SPCS for 3 months or
- Patient in the Stable phase for a period of 3 months

Whilst this discharge process is a method of caseload management for the SPCS given their limited resources, there are a number of service gaps that have been identified from a patient and clinician perspective including:

- Patients are unaware of palliative care phasing and therefore unclear of when they would need to be referred back to the SPCS
- Patients can move from stable to unstable very quickly and there is no one to monitor them in this period and their symptoms can significantly worsen resulting in increased pressure on inpatient and primary health services
- Patients with worsening symptoms are unable to access their GP or Medical specialist in a timely fashion
- Medical staff, specialists and GPs report that they do not always receive letters from the SPCS notifying that the patient has been discharged
- The SPCS does not consistently follow the documented process for discharging clients
- Community services and other providers such as Community Nursing, Cancer Care Services, AH and NGO providers are not informed that the patient has been discharged from the Service
- The patient has to be re-referred back to the Service and go through the complete referral, assessment and registration process again
- This discharge process is not a patient-centred model but rather a resource-driven process
- This discharge process reaffirms the perception of service providers that the SPCS is an EOL service.
- The SOP is not published on the CCLHD Intranet so clinicians outside the SPCS are unaware of the discharge process.

“They discharged my mother from the palliative care team as she wasn’t sick enough, three weeks later her pain increased and we had to go back to the GP and get another referral back to the palliative care service. My GP was not impressed as he said Mum should have been seen by them”

“The Specialist Palliative Care Service are only providing an end of life service for our sickest patients and not delivering true palliative care as per the definition of a palliative care service”.

**Service Gap 13:** The discharge SOP of a patient from the Specialist Palliative Care Service does not meet the needs of patients and referrers. The discharge process has resulted in a reactive model of care for patients as referral back to palliative care is based on worsening symptoms rather than being a pre-emptive model of care.

#### **Recommendation:**

- There is an opportunity to review the discharge criteria and process for patients registered to the SPCS in line with the literature and via benchmarking with other LHDs to ensure that it meets the needs of patients, carers and the clinicians who refer patients to the service.
- Publish the revised discharge procedure for the SPCS on the CCLHD Intranet page.

### 6.2.8 Clinical Handover

The SPCS has a Clinical Handover SOP surrounding the processes related to clinical handover between members within the SPCS and to services/health professionals also seeing patients registered with the SPCS. This SOP is not published on the CCLHD Intranet page and is internal to the SPCS team only. It outlines the clinical handover that occurs between clinicians internally due to weekend cover, planned or unplanned leave and the handover that exists between services i.e. SPCS to Community Nursing or Cancer Care Services. Whilst this SOP is well defined and is

based on ISBAR principles it is not always followed. When it is followed, due to service constraints there is decreased documentation of this in the patient's medical record as required by the SOP. This has identified a number of service gaps:

- Patients do not receive seamless care and are having to repeat their information on numerous occasions to clinicians on a daily basis.
- Care is not coordinated for the patient and their carer, and they do not receive seamless and coordinated care if there are multiple clinicians involved in their care.
- There have been incidents and complaints that have indicated that clinical handover could be improved
- Whilst it is acknowledged that clinical handover occurs, it is not always documented so it is difficult to quantify.

"I had to tell the palliative care nurse what the last nurse told me was going to happen the day before. I am not sure that they had a chance to speak to each other before she went on leave"

"We often go out to see patients and are unaware that the symptoms of the patient have deteriorated and that they have been seen by the palliative care Nurse" (Community Nurse).

**Service Gap 14:** There is an opportunity to review the clinical handover process for palliative care patients.

**Recommendation:**

- Review the clinical handover process for patients registered to the SPCS in line with the literature and via benchmarking with other LHDs to ensure that it meets the needs of patients, carers and the clinicians who provide care to patients referred to the service.
- Develop a clinical handover form, conduct regular audits and publish it on the CCLHD Intranet.

### 6.2.9 Documentation

At present there is no single source that stores all documentation for palliative care patients. Patients' medical notes are documented in a variety of locations including CHOC, eMR, ComCare, ARIA, CHARM, written notes at Medical specialist rooms, GP surgeries, SPCS Specialist diaries and written notes in the patient's home.

There is a strong need to link these systems and provide an electronic database that records all palliative care patients and uploads all documentation including ACPs, medical notes, observation charts, medication regimes and care plans.

Efficient access to medical records by Emergency staff when a patient attends hospital is essential for developing an effective response to their urgent medical issues. Patients and their carers receive instructions on their paper-based home folder provided by SPCS to NOT take it to hospital with them, but to ensure they take all of their current medications with them if they need to go to hospital. As such, any relevant handwritten information in the home folder does not get accessed, and the information may not be recorded anywhere else electronically.

There are numerous examples of clinical documentation not being completed either at point of care or on the same day as service provision by SPCS staff. Reasons for this are reported to include:-

- Access to, or difficulties with, mobile technology used to complete clinical documentation in the community. Inconsistent or absent signal strength, flat batteries, out-dated equipment which is 'too slow' to cope with the work requirements
- Not appropriate to do point of care documentation in some houses and situations
- Perceived and actual time constraints where staff feel they cannot complete all of their work on the day, and they 'catch up later'.

"I went to the hospital as requested by the SPCS an hour after their visit. When I arrived the medical team told me that they were unable to see my notes as the last time they were written was five days before"



“The workload is increasing and it is more important to see patients and the documentation can follow if and when time permits”.

“The documentation system in the community at CCLHD places patients at significant risk as there are too many systems that don’t talk to each other. The SPCS uses eMR whilst the CN team who provide a lot of the care use ComCare. To bridge the gap we have to duplicate our notes and write in notes left at the patient’s house”

**Service Gap 15:** There is no District standardised electronic medical record system in place that combines the needs of palliative and EOL patients who have received care from multiple sub-specialities, service providers and locations (i.e. community palliative care, cancer care and admission to hospital).

**Service Gap 16:** Palliative care documentation is not always completed as per CCLHD Documentation standards. Patients’ medical records are not always comprehensive and therefore there is the potential for the patient to not receive timely and comprehensive care as there is information missing, which does not enable a “complete picture” to be identified.

**Recommendation:**

- Review opportunities for standardising the use of electronic medical records, and consider the most beneficial platform for the entry and storage of clinical information for the palliative and end of life patient.
- Review timeliness of documentation and ensure that it meets CCLHD documentation standards.

### 6.2.10 Data Collection and Statistics

Data collection and statistics are an important aspect of the provision of palliative care as they enable service and patient outcomes and demand to be measured, and are utilised for funding and service improvement purposes. Throughout the review a number of issues with data collection and statistics have been identified. These include:

- A discrepancy between CN and SPCS collection of statistics.
- Patient statistics were entered weekly for the SPCS which meant that at times they were unable to be entered due to the patient dying prior to data entry. This process has been modified since it was identified in the review.
- Incomplete capturing of all patient statistics in manual data collection systems.
- Data collection systems relying on the manual interrogation of access and excel databases to produce data reports.
- Specialist Palliative Care Bereavement and volunteer services not collecting statistics for all service encounters (has been started since palliative care review).
- The SPCS stored bereavement data in a database titled BART which was not supported by IMT. Since highlighted in the review, this database is no longer being used.

“We haven’t got time to do statistics everyday as the IT systems don’t always work on the road and it is more important to see patients”

**Service Gap 17:** The data collection and statistics collected by the SPCS and the CN team are not consistently defined definitions and some data relies on manual reporting.

**Service Gap 18:** Statistics are not always entered on the same day or at point of contact. There are occasions where statistics are not entered, which results in decreased funding for palliative care services through Activity Based Management.

**Recommendation:**

- Review the data collection systems used by SPCS, CN and AH to ensure that they meet the requirements of the LHD.
- Consider regular audits of the statistics collected by the SPCS, CN and other services in relation to palliative care to ensure that data is collected in a timely and standardised manner.

## 6.2.11 After-Hours On-Call Support

### *After Hours On-Call Nursing Service*

The SPCS currently provides an after-hours on-call service. PCLNs are rostered on after-hours and across the weekend. One PCLN is rostered in rotation each night from Monday to Thursday, and the weekend nurse working from 0830 to 1700 Saturday and Sunday is also on call from 1700 hours on the Friday afternoon until 0830 hours on the following Monday morning. This occurs on a varying roster between staff, and usually results in the weekend nurse working eight days straight. The main reason for contacting the PCLN after hours was for client/carer distress, urgent review of symptoms or 'other'. A CE brief was approved in July 2017 to discontinue the on-call arrangements after 2030 hours at night, and for patients and carers to be linked to the NSW Health Palliative Care After-hours Help Line between 2030 and 0830 hours. A transition plan will be implemented to ensure the changeover occurs with minimal disruption to patients and carers. An evaluation framework should be implemented to measure outcome of this change.

### *After-Hours Medical Support*

Palliative care staff specialists offer an incomplete after-hours medical support roster and are not routinely rostered on for support after hours and at weekends. They are therefore not consistently available to support the PCLN working until 2030 hours and on weekends, or to provide inpatient Medical support.

### *NSW Health Palliative Care After-Hours Helpline*

In May 2016, NSW Health launched an after-hours helpline to support and provide advice to palliative care patients, carers and health professionals in their decision making after hours. This free call number is designed to complement SPCSs and can be accessed from 5pm to 9am weekdays and from 5pm Friday to 9am Mondays over the weekends and on public holidays. The phone call is answered by a Registered Nurse with training in palliative care. If the call requires escalation it is forwarded to an experienced palliative care Nurse on the helpline. The majority of calls are for carer distress, equipment failure, symptom control and medication and pain management. A handover of all calls is provided to known palliative care service providers to ensure continuity of care.

"I was so relieved to be able to talk to someone on the phone at 2am when I had no one else to turn to for advice. I felt so alone" (Patient's carer who phoned CCLHD SPCS Nurse)

"The after-hours Nursing service provided by the SPCS assists patients when they are most vulnerable which is after-hours and on the weekend"

**Service Gap 19:** There is potential for a decreased availability of Nursing service support after-hours for SPCS patients between 2030-0830 each day due to the reduction of SPCS PCLN after-hours support. There is no standardised community after-hours medical support for the SPCS.

#### **Recommendation:**

- Review the after-hours nursing and medical support provided to palliative care patients in the community to ensure that they have appropriate access to 24/7 support and are resourced accordingly.

## 6.3 Community Nursing

The CCLHD Community Nursing (CN) Service has a strong working relationship with the SPCS and work together to achieve optimal patient outcomes. The CN service will receive a referral:

- post-hospitalisation
- when the client's phase level progresses and the referral is made by SPCS
- from NGO providers who refer the patient to CN
- when the GP determines that the patient requires extra support, or
- when the patient/carer refers themselves.



CNs work from a primary health care perspective, case managing patients and their carers to optimise their function and coping ability at home, and to advocate on their behalf as required. They undertake direct clinical tasks as required, and support patients and carers in EOL care. The service generally operates between 0800 and 1630 hours Monday to Friday, with a much reduced level of service available on weekends and public holidays during the same work hours.

There were three focus groups held with the Community Nursing teams from the Peninsula, Lakes and Coastal hubs. Issues discussed included the following:-

- Referrals to CN from SPCS are often received either 'too early' or 'too late' in the palliative/EOL trajectory.
- Duplication of information if a CN Assessment is done when a referral is received from SPCS, as they have already done an assessment. It is too much for patients and time-consuming for CNs to repeat this task when they could be doing other care co-ordination for the patient/carer.
- The mismatch between computer programs – CN use Comcare, SPCS use eMR. Not easy to find relevant information regarding a patient/carer.
- Double documentation at each visit – in paper home folder for PCLN to see, in Comcare as part of CN database and electronic medical record.
- Issues with GPs, patient either does not have one at all, visits anyone at a medical centre and therefore there is no Medical case manager for the patient. This causes issues as SPCS require a nominated GP, and there might not be one.
- Reduced coordination between services, so CN and SPCS Nurses are at the house on the same day. This is repetitive for the patient/carer, and does not contribute to case management cohesion.
- Differing expectations from patients and families about the level of care a CN can provide through the day, after-hours and on weekends.
- CCLHD should have a dedicated palliative care ward in both Gosford and Wyong Hospitals.
- Some specialists and some GPs won't refer patients to CN for palliative support until they are near death, and some will then not involve the SPCS at all. This makes it difficult to provide appropriate care.
- There is a difference between what some PCLNs will do as hands-on care and what others state is not their role, the CN is then expected to attend to the patient's clinical care urgently, and there is not always capacity to do this.
- Not enough communication with PCLNs. CN and SPCS need to meet on a regular basis, this has not happened in 2 years at one hub. PCLNs do not always advise CN when they are visiting clients, to either share information or co-ordinate case management.
- Equipment needs are difficult to accommodate at the last minute.
- Issues with some GPs not doing home visits, especially in the terminal phase or after death.
- Continuity of care is challenging due to different staffing in both CN and SPCS. It is now normal for numerous staff to be involved, not just a couple. Patients and carers find this difficult, having to retell their story/situation repeatedly.
- It is often frustrating that overall workload demands in the CN service make it difficult to provide appropriate and timely care at each visit – feeling rushed, having to cancel visits if the patient is in the stable/unstable phases and can 'manage'.
- Difficulty in planning and providing bereavement support visits post death. These are very beneficial to the carer and nurse for debriefing and mutual support/closure. Visits can be postponed multiple times by the CN due to workload pressures, and then are considered by the carer to be 'too late' and of no benefit.
- Perception that palliative and EOL care is not coordinated, as not everyone is aware of the all the services available, what criteria they have, funding limits on availability, etc.
- There used to be regular palliative care education to make sure all CNs had a good understanding of palliative care and EOL management, e.g. deciding when a symptom is managed, versus when the GP or SPCS needs to intervene in a timely manner. Now the only scheduled education CNs receive is annual re-accreditation for syringe driver management. Further education is also provided at the request of the CN NUMs/CNEs.

"There were multiple nurses seeing me at home, some had uniforms and some didn't. I am not sure what the difference was. One did a lot of talking and the other lovely nurse changed the bandage on my wound "

“There is an obvious conflict between the roles provided by the palliative care Nurses and the Community Nurses. The palliative care nurses describe themselves as a specialist service and the community nurses do all of the actual physical care need work”.

**Service Gap 20:** There are perceived deficits in communication between CN and SPCS regarding patient care co-ordination. These include concerns that the referral processes between SPCS and CN are not robust, and lead to referrals received either prematurely or ‘too late’ in the dying process.

**Service Gap 21:** CNs do not receive regular planned education from SPCS except for annual syringe driver competency renewal, so CNs are not regularly updated on changing palliative care clinical practices.

**Service Gap 22:** Workload capacity issues in CN contribute to suboptimal care management at times for palliative and EOL patients and their carers. Some clinical visits for palliative and EOL patients are cancelled or postponed due to this.

**Service Gap 23:** There is a lack of clear role delineation between SPCS and CN which results in confusion amongst patients and carers, duplication of workload and services and gaps in service provision.

**Recommendation:**

- Convene a focus group between CN and SPCS to discuss issues for both teams and develop clear role delineations, expected standards, education needs and service delivery models
- Review opportunities for hub-based planned CN education in aspects of palliative care management.
- Review and monitor CN workload capacity to ensure that have sufficient resources to provide hands on clinical care for palliative and EOL clients in a timely manner.

## 6.4 NGO Providers

There are a significant number of NGO providers who provide Nursing, home support and domestic services to palliative care patients on the Central Coast. These services are located on the Central Coast, Sydney and Newcastle and are often accessed by the patient/carer directly or following referral from the patient’s GP. Throughout the review two NGO community palliative care forums were held. These forums highlighted a number of service gaps on the Central Coast when patients are accessing NGOs:

- Unknown number of NGO providers on the Central Coast providing services to Central Coast palliative care patients
- SPCS and CN services are often unaware of the NGO providers providing services to CCLHD patients
- There is a significant gap for patients under 65 in relation to domestic and home service support
- Patients are often accessing multiple services simultaneously and there is no shared documentation or platform for care planning or coordination. This results in patients receiving duplicated and disjointed care
- There is a strong sense that we need to coordinate resources better so that we know who is linked in with a patient
- NGO providers do not know the goals of care for palliative care patients
- There is a lack of social support for patients on the Central Coast which results in admissions to hospital
- There is a need for palliative care social and domestic support packages on the Central Coast to support patients to die in the community
- Carers of EOL care patients need improved access to home support to enable them to care for their loved one
- NGO providers would like planned education on palliative and EOL care
- Private nursing services are often providing showering and respite services to palliative and EOL care patients and are unaware of the patient’s treatment goals and management plan
- There is often no handover from NGO service providers to SPCS or CN
- Access to NGO providers is often easier for patients and families with money as they can pay for what they need. The patients who don’t have access to money struggle and are often readmitted back to hospital
- Some NGO providers are only accessible by patients with certain diagnoses.

“I wish I was able to get help with the cleaning and yard. That would have taken a lot of pressure off me whilst I looked after my beautiful wife while she passed. It was a very difficult time” (Carer)

“It varies at times, patients don’t have any access to social support and assistance with showering and cleaning. On the other hand, patients have private nursing for showering, SPCS Nursing and also Community Nursing... it is not coordinated well and increased access for some patients means that others miss out”.

**Service Gap 24:** There are an unknown number of NGO providers servicing palliative care patients in the community, resulting in a lack of coordinated care for patients accessing CCLHD community services and NGO providers.

**Service Gap 25:** There is a lack of domestic and support services available to patients on the Central Coast.

**Service Gap 26:** There is inequitable access to NGO providers based on financial status, geographical location, age and diagnosis.

**Recommendation:**

- Review the NGO services available on the Central Coast and create a shared platform whereby services can publish their referral and eligibility criteria and who can access these services.
- Review how CCLHD community services and NGO providers can coordinate care for palliative and EOL care patients on the Central Coast including knowledge of involvement in care, shared goals, case conferencing and access to clinical handover and documentation.

## 6.5 Ambulance Service NSW

The Ambulance NSW service provides a valued service to the Central Coast community in relation to palliative and EOL care. The Ambulance service is often called by families to provide pain relief and manage acute symptoms for palliative patients residing in their homes and RACFs. The Ambulance service is also called when families are distressed as a loved one’s death is imminent, and provide invaluable emotional and psychological support as a patient dies in their home. Patients often require transport to the Emergency Department during the deteriorating and terminal phase of their life-limiting illness and occasionally are transported to hospital dead on arrival. Recently, Ambulance NSW has commenced authorised palliative care plans and are now able to give breakthrough pain relief if they have been given a GP authorised care plan.

### 6.5.1 NSW Ambulance Authorised Palliative Care Plans

The NSW Ambulance Service has attempted to close the after-hours gap for GPs in palliative care. In consultation with the patient and their family, the GP can now elect to complete a NSW Ambulance Authorised Palliative Care Plan. Once endorsed by NSW Ambulance this plan will enable paramedics called out to a patient’s home to initiate the plan and administer medications and other actions to relieve patient symptoms to prevent transfer to hospital.

There is strict protocol surrounding the development of an Authorised Palliative Care Plan. These can be initiated by any member of a patient’s palliative care team, however final approval is required by the GP or specialist. These plans can be initiated at any time and are valid for 12 months. If there is a change in care, the plans can be updated. It has been identified that there are a few of these plans being utilised by Central Coast GPs however, the uptake has been slow.

### 6.5.2 Verification of Death

Verification of Death is a “clinical assessment process undertaken to establish that a person has died. Using a standard regime of clinical assessment tools, a registered Medical practitioner, Registered Nurse/Registered Midwife or qualified Paramedic can establish and document that death has occurred. In September 2015, NSW MoH released a policy directive *PD2015\_040 Death-Verification of Death and Medical Certificate of Cause of Death*. This policy authorised NSW Ambulance Services and NSW Registered Nurses to perform the verification of death

procedure for patients who meet certain criteria. Ambulance NSW paramedics are required to follow protocol A13.

In response to the release of this policy directive, Ambulance NSW began education programs for ambulance officers and in July 2016, they launched an *End of Life and Verification of Death Paramedic Resource Kit*. This kit was developed to assist Ambulance Officers who are often called to assist patients when EOL is near due to increases in pain, breathing difficulties or to assist in making the patient comfortable. Paramedics are often not aware of a patient's EOL wishes at this stage. Decisions related to EOL care may be communicated via ACP, Advance Care Directive (ACD), NSW Health Resuscitation Plans or NSW Ambulance Authorised Palliative (Adult/Paediatric) Care Plans.

Prior to the release of this policy there were a significant number of patients transported to CCLHD hospitals for verification of death. This often occurred if they had a GP that did not perform home visits, did not work after hours or on call. Carers and families reported angst and concern surrounding this process as they had facilitated their loved one's wish only to have the patient transported to CCLHD hospitals and the mortuary. This process has an impact on Ambulance NSW, ED - Dead on Arrival (DOA), Mortuary and Patient Support Assistant (PSA) service resources.

"My husband was dying in pain, struggling to breathe, arms flailing and making terrible gurgling noises. I tried to phone the palliative care after-hours service again but my call was not returned. In final desperation, I phoned the ambulance who told me it was too late to transfer my husband to hospital that he would be dead on arrival. My husband died a terrible death".

"We are often called out to give pain relief and provide support to patients registered to the palliative care service who do not have adequate pain relief or an understanding of what the dying process looks like...they are frightened".

**Service Gap 27:** There is limited use of authorised adult palliative care plans on the Central Coast.

**Service Gap 28:** There is a need to share care plans and ACPs with Ambulance NSW to decrease the number of patients requiring transportation to hospital.

**Recommendation:**

- Develop a working party with relevant stakeholders from ED, Ambulance NSW, GPs, palliative care specialists and HNECCPHN to review the authorised adult palliative care plan and its implementation on the Central Coast.
- Develop a local procedure and undertake an interagency quality improvement project to determine the effectiveness of the implementation of the authorised adult palliative care plan.
- Meet with Ambulance NSW to determine solutions to areas of improvement to deliver high quality community care for palliative and EOL care patients at home in RACF to reduce the number of patients requiring transportation to hospital.

## 6.6 Supported Transitioning Care Team (STCT)

The CCLHD Supported Transitioning Care Team (STCT) Model of Care document outlines the District's approach to providing a coordinated and safe transfer of care for vulnerable patients from the acute hospital setting to a subacute and/or community-based setting. As there are many patients who are palliative that are not referred to the inpatient Specialist Palliative Care team, it has been identified that palliative care patients may be suitable for referral to the STCT and benefit from the care coordination and discharge planning that is offered by this team.

**Service Gap 29:** There is an opportunity to develop a documented pathway for palliative care inpatients at Gosford and Wyong Hospital to be referred to the STCT. A patient's discharge may not be coordinated and a safe transfer of care is not always achieved resulting in readmission of patients to hospital.

**Recommendation:**

- Review the Supported Transitioning Care Team Model of Care and determine if it is appropriate to establish pathways for palliative care patients requiring potential return home from the ED without admission and transfer of care from inpatient facilities to home.

## 6.7 Hospital in the Home (HITH)

In 2015, CCLHD appointed a Project Manager to develop a HITH model of care. This was completed and endorsed in January 2016. To date, the HITH model of care has not been introduced at CCLHD. The HITH model of care highlighted that there was potential to admit palliative care patients to HITH. Palliative care patients are typically classified into stable, unstable, deteriorating, terminal and bereavement phases. It has been identified that patients in the terminal phase receive daily visits from Medical or Nursing staff which is in keeping with the HITH eligibility criteria.

**Service Gap 30:** Patients within the terminal phase of their palliative care may be eligible for admission to HITH under the model of care being implemented within the District. Patients admitted to hospital who could be managed at home in the terminal phase could be referred to HITH and a hospital admission avoided or decreased length of stay in a traditional hospital bed reduced.

**Recommendation:**

- Consider HITH eligibility criteria and whether palliative care patients can be admitted under this model of care.

## 6.8 Medical Imaging in the Community

A number of palliative care patients require medical imaging in the community. Ambulant patients are often referred from their GP to local medical imaging services in the community and, unless indicated, avoid presentation to the ED. Patients who are non-ambulant, have transport difficulties or are residing in RACFs are transported to the ED via ambulance for medical imaging procedures. The most common indications are a patient requiring an ultrasound or x-ray following increased shortness of breath, increased abdominal pain, suspected bowel obstruction, increased pain in a particular site, suspected cord compression, ascites or following a fall. A mobile x-ray service existed on the Central Coast however, recently due to lack of support, accessibility and cost has not been a reliable option.

“I didn’t want to go to hospital for a chest x-ray, I just wanted to stay at home. I was worried they would never let me back out”

“We have to send patients into the Emergency Department as we don’t have x-ray vision and there are no other options. It is frustrating and unsettling for patients as often we are doing it as a precautionary measure”.

“Ambulance staff are often required to transport palliative care patients to the Emergency Department for medical imaging tests from RACFs as they are required to x-ray all patients who have had a fall and the mobile x-ray service is no longer available”.

**Service Gap 31:** Palliative care patients are required to access the ED for medical imaging tests that may be able to be performed in the community. This leads to increased use of ambulance and acute medical imaging resources.

**Recommendation:**

- Review indications and contraindications for patients being sent in for medical imaging procedures from the community and RACF.
- Review a proposal for a mobile x-ray and ultrasound service to be established on the Central Coast that meets the needs of the community and RACFs.

## 6.9 Central Coast Integrated Pain Service (CCIPS)

The CCIPS service is a multidisciplinary pain service that operates within CCLHD. CCIPS is a medical led service with access to pain specialists, physiotherapy, occupational therapy and psychology. The CCIPS utilises a group education

self-management program which aims to empower patients to work with their GPs to manage the functional components of their pain in the community. Patients and their carers are educated on self-management strategies to reduce the impact of living with chronic pain. Patients who have the presence of persistent or chronic pain that has not responded to standard treatments such as back pain, abdominal pain, musculoskeletal pain, post trauma or post-surgery pain are eligible for referral.

Patients with difficult to control cancer, vascular or palliative pain have been identified as patients eligible for referral to CCIPS and will be triaged as high priority and seen by the pain medical specialist. These patients are considered high complexity and will have an individual assessment, individual care plan developed and individual interventions provided by medical and allied health staff as required. The CCIPS service is a clinic-based model and is unable to provide a domiciliary service.

“With the increase in number of cancer survivors who have ongoing cancer pain there is a need to ensure that these patients have access to appropriate pain relief and self-management strategies to manage their pain”.

## 6.10 Central Coast Palliative Care Volunteer Foundation

The Central Coast Palliative Care Volunteer Foundation is a not-for-profit charity organisation that was founded in 1988 with two dedicated cottages at Wyongah and Woy Woy. The Foundation operates a volunteer service to support patients with a life-limiting illness who are under the care of the CCLHD SPCS. Volunteers are carefully selected, trained and supported to provide a caring, safe, effective and professional service. The Central Coast Palliative Care Volunteer Foundation works in close collaboration with SPCS yet is independent of CCLHD.

Volunteer services are provided in people’s homes or at community locations for group support. Volunteer services can include: social and respite visits, transportation, assistance in shopping, therapeutic massage, meditation and relaxation and assistance with facilitating bereavement support groups. The Foundation also organises an annual St. Luke’s Day service which is a remembrance day and open to the community.

In February 2017, the Central Coast Palliative Care Volunteer Foundation considered a proposed transition plan and voted to cease operation, sell the Foundation houses and transition the funds, roles and functions of the Central Coast Palliative Care Volunteer Foundation to CCLHD. The implementation of the transition plan includes the establishment of a CCLHD Palliative and End of Life Fund Committee to manage the donated funds and transition of the roles and functions of the Foundation to CCLHD.

“The closure of the Foundation is a significant part of CCLHD and the Foundation’s 30 year history. The timing of the transfer of the funding, roles and functions to CCLHD with the Palliative and EOL care review is perfect and will ensure that volunteer and bereavement services are enhanced and end of life support accessible to more patients and their families residing on the Central Coast”.

**Service Gap 32:** There is a need to ensure that there is a seamless transition of funds, roles and functions from the Foundation to CCLHD when the Foundation is closed.

### **Recommendation:**

- CCLHD Project Officer to continue to work with the Foundation and identified CCLHD stakeholders to ensure that the transition plan is implemented and a smooth transition occurs for patients and all stakeholders.

## 6.11 Other Volunteer Services

There are a number of volunteer support services that are offered to patients in the community and at CCLHD hospitals. Some of the volunteer services that were identified in this review included volunteers recruited by:

- Central Coast Cancer Council who work in the Cancer Centre and visit patients on the wards
- The Cancer Service has its own dedicated volunteers who are trained and managed by Gosford Hospital’s volunteer coordinator.
- CCLHD working in renal dialysis units, wards, equipment lending pool, Carer Support unit.



These volunteer services play a valued role in supporting palliative and EOL patients in the community and inpatient settings. This review identified that the volunteers have very different governance structures, recruitment, orientation, induction and remuneration procedures. The roles and responsibilities that the volunteers undertake when supporting palliative care patients and their families varies depending on their level of training, volunteer interests and what department/service the volunteer is affiliated with.

Whilst a review of volunteer services provided at the District is indicated, only a service review of the volunteers affiliated with the SPCS and a Palliative care volunteer need analysis was undertaken. Expanding the current palliative care volunteer service to include the provision of the appropriate activities will provide patients and their families with social, emotional and practical support to assist them to cope with their life-limiting illness and in most cases support them to maintain quality living in the community.

“All I needed was to recharge my batteries. Having someone sitting with my husband whilst I caught up on much needed sleep meant the world to me. I then had the energy to continue the fight”.

“My husband used to attend renal dialysis three times a week. Whilst he was at dialysis he sat with a lovely male volunteer and they shared stories and had a laugh. This gave me a chance to do my shopping, get my hair done or catch up with friends for a coffee. We were so excited when we were offered home dialysis...what we didn't realise was that my husband lost his friend and time out and I lost my ability to have a little time to myself. It would be lovely if there were volunteers who could support home dialysis patients in the community”.

“There is a real need for volunteers to support palliative patients and their families on the ward. With an increase in Nursing responsibilities we no longer have time to sit with patients and their loved ones to provide the emotional support we would like to”.

“Volunteers are such valued members of the palliative care delivery team. They provide social and emotional support to loved ones dealing with the gradual decline of their life partners, parents and friends”.

**Service Gap 33:** The current Specialist Palliative Care volunteer service has limited volunteers and is at risk of being unable to meet requests for volunteer support.

**Service Gap 34:** The Specialist Palliative Care volunteer service workforce is ageing, has limited current male volunteers and is restricted by geographical location of volunteers.

**Recommendation:**

- Consider recruiting additional male and female volunteers to the SPCS (action has commenced).
- Develop a register of volunteers recruited to the SPCS which includes compilation of volunteers' geographical location, skills, roles and responsibilities.

**Service Gap 35:** There is limited documentation of evidence-based referral forms, caseload management, policies and procedures surrounding reimbursement and roles and responsibilities, documentation and record keeping processes and recording of statistics.

**Service Gap 36:** There is no documented Specialist Palliative Care Volunteer Model of Care.

**Recommendation:**

- Add Specialist Palliative Care Volunteer Services to the District risk register.
- Review referral pathways, policies and procedures, record keeping processes and data collection tools that are associated with the SPCS.
- Review the recently implemented Specialist Palliative Care Volunteer Model of Care for effectiveness.

**Service Gap 37:** The current Palliative Care volunteer service works in isolation and reports to the Service Manager of the Specialist Palliative Care Service. The volunteer service does not report to the Executive Director of Nursing and Midwifery who is responsible for District volunteer services.

<p><b>Recommendation:</b></p> <ul style="list-style-type: none"> <li>Review the governance structure of the Specialist Palliative Care volunteer service.</li> </ul>
<p><b>Service Gap 38:</b> There is no community volunteer service that supports palliative care patients who are living in the community but not referred to the Specialist Palliative Care Service.</p>
<p><b>Recommendation:</b></p> <ul style="list-style-type: none"> <li>Conduct a needs analysis to determine what volunteer services are needed in the community.</li> <li>Develop a community arm of palliative care volunteers that can support all palliative care patients and their families residing on the Central Coast.</li> </ul>
<p><b>Service Gap 39:</b> There is no inpatient volunteer service that supports palliative care patients.</p>
<p><b>Recommendation:</b></p> <ul style="list-style-type: none"> <li>Conduct a needs analysis to determine what volunteer services are needed in the inpatient setting to support palliative and EOL patients</li> <li>Develop an inpatient arm of palliative care volunteers that can support all palliative care patients and their families admitted to CCLHD hospitals.</li> </ul>
<p><b>Service Gap 40:</b> There are currently an unknown number of volunteer services that work with palliative care patients on the Central Coast and within CCLHD. There is no consistent recognition of what these services provide.</p>
<p><b>Recommendation:</b></p> <ul style="list-style-type: none"> <li>Conduct a review of volunteer services within the District and on the Central Coast and develop an overall CCLHD Volunteer services MOC that incorporates community and inpatient palliative care volunteer service.</li> </ul>

## 6.12 Cancer Council

The Central Coast Cancer Council is located on the Central Coast at Erina Fair Shopping Centre. They also have a presence in the Central Coast Cancer Care Centres based at Gosford and Wyong Hospitals. The Cancer Council on the Central Coast is very active in the provision of high quality care for patients diagnosed with cancer. Their services are able to be engaged from diagnosis through to EOL care and bereavement support. They are currently lobbying the state government for more specialised palliative care doctors and nurses for the Central Coast under the campaign “*I Care for Palliative Care.*” The Cancer Council aims to raise awareness of the state-wide shortage of palliative care services required to support the estimated significant increase in patients residing and needing access to palliative and EOL care living with a cancer diagnosis on the Central Coast.

The Cancer Council fulfils a number of roles within the Central Coast community to support patients and their carers from diagnosis with cancer through to EOL care and bereavement support. The Council currently has a Memorandum of Understanding (MOU) with CCLHD for the use of space in the District’s Cancer facilities, and the training and supervision of Cancer Council volunteers. The content and expiry of this MOU is should be reviewed as part of the recommendations of this report. There are a number of service gaps that were identified and should be explored in relation to the involvement of the Cancer Council with palliative and EOL care patients including:

- Early linkage of all patients diagnosed with cancer to the Cancer Council to ensure that they receive valuable support throughout their treatment and cancer journey
- A lack of awareness by health and medical professionals of what the Cancer Council offers and what services are available to patients, carers and health professionals on the Central Coast
- Patients with cancer accessing CCLHD resources that could be obtained through the Cancer Council and thus freeing palliative care resources for patients with a non-cancer diagnosis
- Governance processes of the Cancer Council Volunteers that work in Central Coast hospitals and services need to be reviewed in line with CCLHD volunteers processes
- Decreased use of Shirley’s Shuttle by patients with cancer. These patients are often relying on Community Transport and volunteers for their transport needs
- Limited distribution of Cancer Council resources by medical specialists and health professionals not affiliated with the Cancer Care centres.



“The Cancer Council is a fantastic source of strength and has helped me financially and with transport. I wasn’t informed of the Cancer Council by the hospital I found out about the services they offer from a friend who had cancer last year.”

“I was surprised to hear that the Cancer Council offered all of the services that they do. Do we have a list of what they offer and eligibility criteria?”

**Service Gap 41:** Patients utilising District services that could be accessing services offered by the Cancer Council to free up resources for Central Coast residents with a non-cancer life-limiting illness.

**Service Gap 42:** There is a lack of awareness amongst medical and health professionals surrounding the resources, services and financial support available from the Cancer Council.

**Service Gap 43:** The contents and expiry of the MOU with the Cancer Council was not examined and should be reviewed in line with recommendations in this report.

**Recommendation:**

- Review the current CCLHD and Cancer Council MOU and ensure it meets any gaps highlighted in this review.
- Review understanding of the resources, promotional material and support available to cancer patients on the Coast and educate medical and health professionals on these services.
- Consider redirecting patients with cancer to the use of Cancer Council services where possible, to enable CCLHD resources to be utilised by patients with a non-cancer diagnosis

## 6.13 HNECCPHN

The HNECCPHN is an important partner in the provision of health care on the Central Coast. There is a need to have involvement in the development of a collaborative partnership with CCLHD to ensure that palliative patients are the centre of all their care needs and that medical and health professionals are well supported on the Central Coast. It is suggested that the collaborative partnership and subsequent development of a Central Coast Palliative and End of Life Plan may include:

- Commitment of funds to training and support of GPs and private service providers in the provision of palliative and EOL care
- RACF working group with HNECCPHN as partners
- GP service to assist management of palliative care patients in RACF
- GP incentivised practices to provide after-hours palliative care support and certification of death in the community
- Review of localised Health Pathways, palliative care resources and education
- Educational resources surrounding GP recognition of the deteriorating patient
- Assistance with strategies to improve care planning and coordination
- Development of a shared documentation platform
- Engagement of GP clinical advisors
- GP Practice management of palliative and EOL care patients
- Improved facilitation of ACP and directives
- E-referral to Specialist palliative care via Health Pathways rather than need to complete forms and rely on faxing
- Renew the palliative care flip chart developed and link this information to an internet-based platform.

### 6.13.1 Health Pathways

There is a need to review the existing, and potentially develop new, Health Pathways that incorporate care to patients with life-limiting illnesses. These will need to include any changes to the referral pathways, service provision and recommended care coordination approaches as a result of changes made from recommendations of this review.

**Service Gap 44:** Identified need to pool resources and expertise with the HNECCPHN to ensure that a coordinated and collaborative partnership is developed to inform policy and change within the Central Coast related to the delivery of palliative and EOL care services.

**Recommendation:**

- Consider developing a partnership with HNECCPHN to inform change as outlined in this review to improve palliative and EOL care services on the Central Coast.
- Consider developing a working party with HNECCPHN to promote ACP and improve palliative and EOL care in RACF and by primary healthcare providers, and review Health Pathways to incorporate palliative and EOL care on the Central Coast.

## 7. DOMAINS OF PALLIATIVE CARE

The provision of palliative and EOL care involves more than managing the disease and physical symptoms. The patient and their family's values, beliefs, culture and demographics are assessed in the first instance. Once these have been determined, the patient's care needs are assessed against each of eight domains: structure and processes of care, physical, psychological, social, spiritual, cultural, ethical and legal aspects, and care of the imminently dying. These care needs will fluctuate throughout each phase of the patient's palliative journey. Domains of care should be reviewed as patients fluctuate through the stable, unstable, deteriorating, terminal and bereavement phases of palliative care.

## 8. CONTINUUM OF CARE

Palliative care is discussed in terms of phases. "The palliative care phase type describes the stage of the patient's illness and provides a clinical indication of the level of care a patient requires. The palliative care phase is determined by a holistic assessment which considers the needs of the patients and their family and carers. A patient may move back and forth between the stable, unstable, deteriorating and terminal phase types and these may occur in any sequence" (Connolly & Bird et al, 2016).

There are five phases that a patient will be classified into following their diagnosis. It is important to note that this is a continuum and is not a linear progression. Patients can move from stable to unstable, deteriorating or terminal; move from unstable to stable and can also be diagnosed at any stage of the continuum. There are certain ideal roles that are delineated between the Primary Health Care Team (including the patient's GP and possibly a Community Nursing Service) and the SPCS.

### Phase 1: Stable

A patient's condition is managed by their primary health care team and referral to the SPCS is usually not required. During this phase, care needs may include:-

- **Primary Health Care Team**
  - Monitoring for anticipated change
  - Maintenance of medication regime
  - Patient and carer support
  - Case management
  - Management of physical symptoms
  - Advance care planning

### Phase 2: Unstable

The patient's condition is now changed and will likely involve escalation to the SPCS for assistance with managing symptoms and care planning. During this phase, care needs may include:-

- **Primary Health Care Team**
  - Those listed above in stable phase
  - Liaise and collaborate with SPCS to address unmet and unexpected symptoms

- Review equipment needs
- Review for potentially reversible conditions causing symptoms
- **Specialist Palliative Care Service**
  - Address unmet and unexpected symptoms
  - Rapid specialist care planning
  - Access to 24/7 Nursing contact
  - Support review for potentially reversible conditions

### Phase 3: Deteriorating

A patient's condition is now deteriorating and they are requiring increased input from the SPCS.

- **Primary Health Care Team**
  - Maintenance of available medication supply
  - Provision of primary Nursing care
  - Communicate concerns to SPCS
- **Specialist Palliative Care Service**
  - Monitoring for anticipated changes (frequency versus clinically indicated)
  - Carer capacity assessment and carer support
  - Access to 24/7 Nursing contact
  - Forward planning for EOL care

### Phase 4: Terminal

The patient's condition is now classed as terminal and death is imminent.

- **Primary Health Care Team**
  - EOL care
  - Management of syringe driver
  - Monitoring available medication supply
- **Specialist Palliative Care Service**
  - Complex symptom management (patient and carer)
  - Commencement of syringe driver in the community (due to access to medications and timing)
  - Medication supply of non-PBS, and S8 drugs and Special Access Scheme drugs, hospital supply only
  - Review care needs as required

### Phase 5: Bereavement

Patient's carer and family are supported.

- **Primary Health Care Team**
  - Visit bereaved
  - Collect equipment
- **Specialist Palliative Care Service**
  - Patients and carers have their bereavement risk assessed if they are registered with the SPCS
  - Bereavement follow up
  - Support groups
  - Individual bereavement counselling

## 9. DETERMINATION OF A PALLIATIVE CARE CONDITION (LIFE-LIMITING ILLNESS)

### 9.1 How is a patient determined to be palliative?

At present, Medical professionals use their clinical expertise, independent knowledge, past experience and in some cases a set of diagnosis-specific criteria to determine whether a patient is on a palliative or EOL trajectory. Medical professionals have reported that whilst it is easy to determine that a patient is in the deteriorating and terminal phase of their palliative care journey and subsequently requiring EOL care, it is more difficult and there is a

reluctance to label a patient 'palliative'. A delay in commencement of palliative care can impact on a patient's quality of life and come at a financial and resourcing cost to already overstretched health facilities. Medical professionals have reported that involvement of trained palliative care specialists in assisting with this determination would be advantageous at times, and it would be beneficial if there was a standardised tool to assist in this decision making process. It has been identified in the literature that there are standardised tools and prognostic indicators that are available to assist clinicians in screening whether a patient would benefit from palliative care planning and support such as the NECPAL-CCOMS-ICO tool.

"There is a pressure from the patient and family and an expectation that we will treat patients at all costs and that the word 'palliative' means that you have given up on the patient".

**Service Gap 45:** There are no standardised CCLHD screening tools or prognostic indicators to assist Medical professionals in the decision making process to determine whether a patient would benefit from a palliative care approach to treatment.

**Recommendation:**

- Review patient-centred prognostic indicators, screening and standardised tools that are available to assist Medical professionals to determine whether a patient would benefit from a palliative approach to treatment.
- Review internal and external screening/prognostic indicator tools for use within CCLHD.

## 9.2 Determining that a patient requires Palliative Care

Informing a patient and/or family that they have a life-limiting (palliative) condition is a difficult but important conversation that will inform the treatment options for a patient moving forward throughout their illness. It will also be a defining conversation for the patient as they are 'given permission' to redefine their life and choices for their future. Medical professionals have reported that they receive years of Medical training on how to fight illness, order tests and implement care interventions and treatment regimens but have had no equivalent training in how to have these difficult conversations or 'deliver emotional news' to patients. Patients and families have reported that they would like to be told the truth about their prognosis but doctors "dance around the subject". It was evident in this review that many of these difficult conversations are held in the hospital setting by Emergency or Intensive Care staff who often do not have a relationship with the patient and are having these discussions when a patient is at their most vulnerable, emotive and in the deteriorating or terminal phase of their illness.

"Nobody wanted to tell me that I was dying. My GP said I needed to talk to my cardiologist and my cardiologist said that I needed to discuss my overall care with my GP. It was obvious to me and my wife that I was on a downward slope. I had begun to accept that the end was near but I needed to hear it from the docs".

"I felt like I needed to reassure the oncologist that it was okay. I didn't want any more chemotherapy but I was always encouraged to try one more course. I appreciated their intentions and never wanting to give up on me but it came at a significant cost to my quality of life".

"We often do not have the time or training to have these difficult conversations in the hospital setting. It would be great to have some education and support to have these conversations with patients. Social Workers are very good at supporting families in these situations".

**Service Gap 46:** There is a need to develop consensus surrounding whose role it is to inform a patient that they are palliative.

**Recommendation:**

- Improve care coordination and communication between a patient’s medical care providers.
- Investigate avenues to have medical case conferencing with GPs and all specialists involved in the patient’s care when a patient is diagnosed with a life limiting illness.

**Service Gap 47:** There is a need for a provision of regular education for Medical and health professionals surrounding how to have difficult conversations ‘delivering bad and emotional news’ to patients and their families.

**Recommendation:**

- Provision of regular education and role playing on ‘having difficult conversations’ to Medical, Nursing and AH staff.
- Support of a District culture that is based on empathic, transparent, open and honest discussions with patients and families.
- Provide debriefing and support to Medical, Nursing and AH staff involved in palliative care discussions so that we can learn from these conversations.

### 9.3 The ‘P word’ – Palliative Care

There is a strong perception and connotation in the community, inpatient setting and amongst health professionals around the use of the word ‘palliative’. There is a perception that the word palliative means that a patient is “committed to dying”, that “there is nothing else that can be done”, that “you have been given a death sentence” and that “everyone has given up on you”. This is not the definition of palliative care and in fact it is the opposite.

“I wanted to talk about how and where I wanted to die, what I wanted to have at my funeral and what I wanted done with my organs but no one wanted to listen. It has become a topic in society like money, religion and politics you don’t go there.... the fact is we are all going to die so why aren’t we talking about it”.

**Service Gap 48:** Consistent terminology is not used by Medical professionals and the community surrounding the term ‘palliative’.

**Recommendation:**

- Develop clear consistent definitions of what palliative care is and what EOL care is.
- Revise all brochures, handouts and documentation to ensure that consistent terminology is used to describe these terms.
- Educate health professionals and service providers on what palliative and EOL care is.
- Educate the community on what palliative and EOL care means.

### 9.4 What happens when a patient is deemed Palliative?

When a patient is deemed as palliative a ‘palliative approach to treatment’ needs to be implemented. This treatment approach needs to be discussed with the patient and their family, their GP, and all Medical, Nursing and AH professionals, private service providers and agencies involved in the patient’s care. The most vital step in this process is ensuring that it is documented in the form of a care plan with the patient and carer. Expectations of care, contact details of professionals involved in the patient’s care, the domains of care, the need for ACP, escalation pathways for care, who is responsible for care-coordination and review dates surrounding the care plan all need to be documented. This care plan also needs to be given to the patient and all professionals involved in the treatment of the patient. There are a number of issues that have been identified around the provision of care planning for palliative care patients including:

- Care plan development and coordination is “reactive” and not done “pre-emptively” – there is a need to provide referral and access to services and support for patients and their families before they become a

problem

- Carers and families have reported that there is no care-coordination and they are required to coordinate the care, escalation and appointments for the patient. Care planning and coordination was noted to be significantly improved for patients registered with the SPCS
- There is no shared platform to store the care plan that is accessible to all Medical professionals, GPs, RACFs and the inpatient setting
- Ambulance services are often unaware of a patient's care plan and are required to transport them to hospital
- Patients' agreed care plans in the community are often adapted when they present to hospital causing confusions for patients, carers, GPs and health professionals
- Patients' care plans are not reviewed when they move through the phases of palliative care (stable, unstable, deteriorating, terminal).

"Nobody talks to each other. I have to explain my story over and over. I am told something different every time I see a different doctor involved in my care"

"Instead of spending valuable time with my mum being a daughter, I had to spend that time phoning palliative care staff, Community Nursing staff, the GP and Medical specialists to coordinate mum's care".

"There is a significant lack of coordinated and consistent documented care planning which is having an impact on the treatment of patients, admission to hospital and the quality of care we provide to our patients".

**Service Gap 49:** There is an opportunity to develop consistent, multidisciplinary, documented care planning for palliative care patients.

**Recommendation:**

- Develop a palliative care plan for patients with identified life-limiting illnesses.
- Establish a process to introduce multi-professional and agency case conferencing that involves the patient and their family. Consideration will need to be given to how these are held and remuneration of Medical professionals and GPs.
- Develop a care coordinator concept and pathway that ensures that regular reviews of a patient's existing care plan are conducted – these may occur at time intervals or at pre-determined phases i.e. when a patient moves through palliative care phases such as stable to unstable, deteriorating to terminal.
- Introduce a shared platform whereby all service providers involved in a patients' care (including Emergency services such as Ambulance NSW) can have access to a patient's palliative care plan.
- Develop a location whereby all palliative care plans can be stored for patients in their electronic medical record.

#### 9.4.1 Referral to Appropriate Services

Following the establishment of a coordinated care plan, patients should be assessed against the domains of palliative care and ensure that they have the required support to meet their social, spiritual, emotional, psychological and physical needs. Referral to other service providers should be documented on the care plan and may include referral to private or CCLHD service providers. The care provider the patient has been referred to should be given access to the care plan, and be invited to provide feedback and be involved in future care planning discussions.

This review and the community forums held identified that there are an overwhelming number of care providers on the Central Coast who provide care to palliative care patients. Some of these services are fee-based whilst others are not for profit or free to certain patients. Some agencies provide care to specific client groups (i.e. Cancer Council, Motor Neurone Disease Association), some have age restrictions, are time-limited, and others are open to provide care to any resident with a palliative care need on the Central Coast.

At present, there is no repository that lists all palliative and EOL care providers (their referral criteria and services available) on the Central Coast. The decreased level of understanding of government and non-government palliative

care providers on the Central Coast has resulted in:

- Inappropriate referrals being provided for patients requiring support
- Duplication of resources as patients are referred to multiple services to address their care needs
- Patients accessing CCLHD services that may be eligible for services provided by external agencies and care providers such as Cancer Council and private service providers
- A lack of awareness amongst care providers of who is involved in a patient's care and what level of service they are providing
- Decrease in coordinated care planning for patients and impact on admission to hospital from the community and delay in discharge planning for patients in the hospital setting
- Limited knowledge of, and referral to, community care providers that can assist in the social care needs of patients in the community and assist in preventing hospital admission.

"I had no idea that there were this many care providers on the Central Coast that would be able to help palliative care patients. We need a forum where we can share what we do.... the winners will be the patients" (Community Forum participant)

**Service Gap 50:** There is a need to increase the understanding of the services available to palliative care patients on the Central Coast and what their referral, exclusion and inclusion criteria involves.

**Recommendation:**

- Develop a repository of all of the palliative and EOL care providers on the Central Coast. This repository will involve referral criteria, inclusion/exclusion criteria, fees, geographical boundaries etc. Consideration will need to be given as to who collates and maintains this repository and where it is located so that it is accessible by all care providers.
- Consider holding an annual "Palliative and EOL Care Provider Forum" whereby providers are invited to showcase their services and network with other service providers.

#### 9.4.2 Case and Family Conferencing

There was evidence that there is a shortfall in case and family conferencing that occurs for palliative and EOL care patients. Whilst case conferencing occurred in silos such as SPCS and also in inpatient daily meetings, it was often ad-hoc and did not include the patient and their family, or all of the medical and health professionals involved in the patient's care. It was also noted that the case conference was not always documented and outcomes shared with all professionals involved in the patient's care including the GP.

"I should be involved in case conferences for all of my patients" (GP)

**Service Gap 51:** There an opportunity to develop a consistent process for conducting case and family conferences for palliative care patients in the community or hospital setting.

**Recommendation:**

- Develop consistent processes surrounding the requirements of a palliative care case or family conference and consider development of a form for documentation of patient outcomes and developed goals of care.
- Develop a process to ensure that all stakeholders involved in a palliative patient's care at any point in time can be involved in the family or case conference.

## 10. NEEDS ASSESSMENT OF A PALLIATIVE CARE PATIENT

It is important to conduct a needs assessment of a palliative care patient to ensure that people living with a life-limiting illness can experience the best possible quality of life. In the UK, the National Clinical Programme for Palliative Care has developed a 'Palliative Care Needs Assessment Guidance Framework' (National Clinical Programme for Palliative Care, 2014) that assists health professionals to develop a holistic view of patient and family needs and strengths. This framework suggests that best practice involves continual and routine needs assessment throughout the course of a patient's palliative condition and suggests key intervals such as:



- At diagnosis of a life-limiting condition.
- At episodes of significant progression/exacerbation of disease.
- A significant change in the patient’s family/social support.
- A significant change in the functional status.
- At patient or family request.
- At end of life.

(National Clinical Programme for Palliative Care, 2014 pg. 5)

The assessment should be undertaken by a single team member (i.e. nursing or medical staff member) identified as responsible for assessing a patient’s needs. The patient’s GP and treating Medical specialist should be involved in the decision to undertake the assessment.

### 10.1 Palliative Care Outcomes Collaboration (PCOC)

The PCOC is a national palliative care project that is funded by the Australian Government Department of Health. It is designed to assist with clinical improvement, peer comparison and to embed clinical assessment tools into clinical practice. This program is voluntary and aims to improve patient outcomes through benchmarking with other palliative care services across Australia. The project provides palliative care services with five standardised and validated clinical assessment tools, education, point of care assessment collected and submitted every six months, outcome measurement and benchmarking and the provision of a report provided every six months. Participating palliative care services are also eligible to attend national benchmark workshops, quality improvement activities and to receive assistance with research data requests and analysis.

A standardised and validated clinical assessment tool that is utilised to measure patient outcome measures is the Symptom Assessment Scale (SAS). The ability to continuously evaluate patient symptoms and manage appropriately can reduce patient discomfort, carer distress and reduce hospital admissions.

The PCOC aims to collect patient data and outcomes against 20 benchmarks across their palliative disease trajectory to facilitate improved patient outcomes. The program is facilitated by Wollongong University and more details of the project can be obtained from the PCOC website at [www.pcoc.com.au](http://www.pcoc.com.au)

The Central Coast SPCS has not submitted data for inclusion in PCOC. There are eight clinical assessment tools that are available in the PCOC. The SPCS currently use the Phase, SAS, PSS, RUG-ADL and AKPS and record them in the Phase Assessment within eMR Powerchart. These assessments are not consistently used by the SPCS upon each client contact and they are not utilised for patients who are not registered with the SPCS.

“There is a lack of standardised assessment tools for use with palliative care patients”

**Service Gap 52:** CCLHD does not currently participate in the Palliative Care Outcomes Collaboration (PCOC) Project

**Recommendation:**

- Investigate the use of the PCOC clinical assessment tools and implement guidelines for their use across CCLHD for use with all palliative care patients.
- Consider enrolling CCLHD in the PCOC data collection with the University of Wollongong. This will enable patient outcomes to be compared to other LHDs.

### 10.2 Cancer Centre Multidisciplinary Team Meetings

There are a number of multidisciplinary team meetings that are held in the Cancer Centre to discuss newly diagnosed and ongoing treatment options for patients. At present, the SPCS staff are not able to attend any of these multidisciplinary meetings due to resourcing issues. Their attendance at these meetings has been highlighted by the chairs as being beneficial to patient care. This occurs particularly in the case of cancers that are known to have poor outcomes (i.e. lung, pancreatic, brain). Patients are reported to be receiving potentially unnecessary chemotherapy, radiotherapy and/or surgery, whereas they may have opted for a palliative approach if this option was holistically explored with a palliative care physician.

“I recently had a case where a 70yr old with dementia presented at the MDT meeting with a history of alcohol liver failure, had incurable cancer. There were two options presented - oncology or surgery. This patient would have been more appropriate for a palliative approach but as the family was unable to discuss this with the team they went with the surgical active treatment option”.

**Service Gap 53:** The SPCS do not currently participate in Cancer Centre Multidisciplinary Team Meetings due to a lack of resourcing.

**Recommendation:**

- Determine relevant Cancer Centre Multidisciplinary Meetings that would benefit from Specialist Palliative Care input.
- Consider resourcing requirements to enable the SPCS clinicians to attend identified multi-disciplinary meetings.

## 11. STABLE PHASE OF PALLIATIVE CARE

Patients who are in the stable phase of their life-limiting illness are best managed by their GP. During this phase of their palliative care condition patients are in contact with their GP and may be referred to see specialists to provide input into their care. During this phase patients symptoms should be monitored closely and referral to SPCS made as appropriate.

### 11.1 Health Support Programs

There are a number of programs that patients can be referred to during this phase of their illness to assist patients to learn about their illness, connect with other patients and carers and ensure that they have quality living following diagnosis with a life limiting illness. Throughout this review it was evident that patients are not routinely referred to these programs during the stable phase of their condition. Patients are often referred late in their illness and there were many Medical staff who had no knowledge of the programs/services listed below:-

- Better Health Self-Management.
- Chronic and complex Care Programs.
- Coast CanCare Wellness Programs.
- Alternative Therapies such as massages, aromatherapy and meditation.
- Local Support Groups, e.g. MND Association, Parkinson’s Disease Support Group, Dementia Support Group, Internal Cardiac Defibrillator Support Group.

“My cardiomyopathy is now advancing. I have had a pacemaker and defibrillator for 11 years and I was never told that I could access Better Health programs that would help educate me on how to manage my symptoms and live a better lifestyle”

“I was unaware that Better Health Self-Management was a service that I could refer my patients to”.

**Service Gap 54:** There is an opportunity to increase awareness and knowledge amongst patients, carers, Medical specialists, and GPs surrounding community programs and support groups.

**Recommendation:**

- Increase awareness and education amongst the community, Medical specialists and GPs surrounding the various community programs and support groups and the benefits of referral for patients diagnosed with life-limiting illnesses early in their disease process.
- Liaise with HNECCPHN regarding the compilation of a comprehensive list of support groups and community programs available for patients and carers with life-limiting illnesses on the Central Coast.

## 11.2 Sub-Specialty Outpatient Clinics

There are a number of sub-specialties that conduct outpatient clinics that would benefit from palliative care involvement and the ability to access palliative care Medical and Nursing staff to discuss the service with patients and if required link patients into the SPCS within the community. This would enable patients to be involved in their care options, interdisciplinary care plans to be developed, and referrals made to services that require their input. There are many sub-specialties with existing clinics and also sub-specialties currently writing business cases to establish outpatient clinics e.g. neurological outpatient clinics (MND, MS and Parkinson’s patients) that could benefit from palliative care input.

“It would be fantastic to have the support and professional expertise of the SPCS at my outpatient clinics to provide input and facilitate discussion with patients surrounding their life-limiting diagnosis and management”.

## 12. UNSTABLE PHASE OF PALLIATIVE CARE

As a patient’s condition changes as indicated by a phase assessment they may require access to increased level of support by their GP, treating team and/or referral to the SPCS for assistance with managing symptoms and care planning. During this phase some patients will continue to be managed by their GP and specialist whilst others will require referral to the SPCS.

### 12.1 Primary Health Care Providers

Patients diagnosed with a life-limiting illness often receive health and social care support from their GP, Medical specialists, Community Nursing and AH professionals as required. This care is often delivered by this team of health professionals from diagnosis of a life limiting illness through to death, care of the deceased and bereavement support. There are a number of patients for whom the care provided by their primary health care team is adequate and referral onto a Specialist Palliative Care team is not required. It is important to define the skill sets required by primary versus SPCS. These include:

Primary Palliative Care	Specialist Palliative Care
Basic Management of Pain and Symptoms.	Management of refractory pain and complex symptoms.
Basic Management of Depression and Anxiety.	Management of complex depressions, anxiety, grief and existential distress.
Basic Discussions about: <ul style="list-style-type: none"> <li>• Prognosis</li> <li>• Goals of Treatment</li> <li>• Suffering</li> <li>• Code Status</li> </ul>	Management of conflict regarding goals of treatment: <ul style="list-style-type: none"> <li>• Within the patient themselves</li> <li>• Within families</li> <li>• Between staff and families</li> <li>• Amongst treating teams</li> </ul>
	Assistance in addressing cases of terminal care.

## 13. DETERIORATING PHASE OF PALLIATIVE CARE

### 13.1 Aged Services Emergency Team (ASET) Service

ASET Service employs CCLHD RNs to provide in-reach and outreach to patients living in RACFs with the aim of either preventing the patient’s transfer to hospital for treatment of a resolvable clinical issue, e.g. urinary retention or to facilitate fast turnaround back to the facility if the patient presents to the ED. ASET also provide some backup to the PCLN and CN for clinical support up to 1930hrs for urgent clinical issues in the community (e.g. insertion of an indwelling catheter).

### 13.2 Emergency Department

Palliative and EOL care patients often present to the ED at Gosford and Wyong Hospitals. Presentation can be via Ambulance, sent in by a Medical specialist or GP, sent in by the SPCS, transferred from a RACF or brought in by their loved one. There are a number of reasons that a patient may present. These include:

- Patient is in terminal phase and unable to die at home or in an RACF. This can be a planned or unplanned admission, and can be due to staffing ratios in an RACF or family requesting transfer to hospital
- Patient's medical condition has become unstable, they are deteriorating or are presenting to Emergency as they require acute symptom management not managed in the community (i.e. acute pain management, deterioration in breathing status)
- Patient requires medical testing/treatment that is unable to be conducted in the community (i.e. suspected cord compression, ascites tap)
- Patient has an unrelated medical emergency not related to their palliative diagnosis (i.e. fall, stroke)
- Patient's medical condition has changed and they are unable to access the SPCS, Medical Specialist or GP as it is after-hours or weekend
- Patient has died in the community and they require transfer to hospital for verification of their death (this is currently reducing due to the implementation of Ambulance procedures surrounding verification of death)

The management of a palliative patient in ED varies depending on their reason for presentation, diagnosis and presenting problems. Patients are assessed and a management plan is developed. There are a number of service gaps that have been identified in relation to care of the palliative care patient in the Emergency Department including:

- Patients often arrive in the Emergency Department (ED) with no known ACD, ACP or resuscitation plan in place. ED has to make a quick judgement whilst the patient is on route to the hospital as to whether they will be actively treated or placed in a resuscitation bay
- ED staff often have to have conversations related to advance care planning in the department with families at a highly emotional and stressful time. The ED is often not an appropriate place to have this discussion due to the lack of privacy and inability to prioritise time with families to have these important sensitive discussions
- There are often multiple IT systems that the Emergency team need to access to develop a full picture of the patients care in the community (i.e. ComCare and eMR notes)
- RACFs are reported to send patients in as there is a lack of staffing after hours to manage pain in EOL patients due to a lack of qualified staff to administer pain medications
- Patients are often not known to any CCLHD Medical team and they therefore have difficulty finding a medical specialist to admit the patient under
- The admission policy and selection of an admitting physician differs between Gosford and Wyong hospitals. Wyong Hospital admission policy is more streamlined as they have a general medicine on-call model and the majority of palliative care patients are admitted under general medicine
- There is limited accommodation for patients in the ED that is suitable for EOL care
- Cancer patients are unable to be admitted to Wyong Hospital and require transfer to Gosford Hospital
- SPCS and the ED do not link in closely and there is a perception from the SPCS that ED staff do not have the required educational opportunities or skill sets to manage palliative care clients effectively
- Patients who are sent in from the SPCS can't be discussed with the Palliative Care specialist after hours or over the weekend as they are not available
- SPCS patients can't be admitted under specialist palliative care medical team as they do not have admitting rights
- It can be challenging to identify an appropriate admitting team to accept a patient with multiple comorbidities.
- There is limited clinical handover for palliative care patients presenting to Emergency unless they are under the SPCS
- There are a number of patients that are brought to hospital Dead On Arrival (DOA) or die in the ED. The ED is not the ideal place for a grieving family to say goodbye to their relative.

"My husband died in the Emergency Department, the staff were lovely but it was not a very private place for my children and I to say goodbye".

"Medical specialists are often accepting patients not known to them as they have had to take on the patient when admitted to Emergency as palliative care have no admitting rights".

**Service Gap 55:** The management of palliative care patients in the Emergency Department is not always streamlined due to lack of ACP, palliative care planning, and access to documentation and GP/palliative care specialists for clinical handover.

**Service Gap 56:** The admission policy for palliative care patients is person dependent and difficult due to patients with multiple comorbidities, lack of palliative care admitting rights and no general medicine at Gosford Hospital.

**Recommendation:**

- Review the admission criteria for palliative and EOL care patients at Gosford and Wyong hospitals.
- Review the process of clinical handover from community palliative care patients to the Emergency Department so that seamless care can be provided.
- Review the management of palliative and EOL care patients in the Emergency Department to ensure that appropriate accommodation is available and ACD/ACP are available to Emergency physicians to guide treatment options.

### 13.2.1 Palliative Care Patient with Suspected Cord Compression

The SPCS has developed an internal guideline titled ‘Guideline for emergency community management of suspected malignant spinal cord compression’. This evidence-based guideline has been developed by the Specialist Palliative Care Clinical Practice Group and aims to provide a protocol for the emergency management of suspected malignant cord compressions in the community setting. This guideline was written in 2012 and has not been published on the CCLHD Intranet page and is pending approval by Central Coast Cancer Care Centre. The guideline also includes the completion of a form and letter that is sent with the patient to the ED. There has been a reported lack of cohesion in the management of patients identified in the community as having a suspected cord compression and the treatment received when presenting to the ED. This has been highlighted as due to a lack of agreement around the management of these patients and lack of acknowledgement of the SPCS internal guideline for the management of suspected cord compression as stakeholders have not provided feedback during the development of this guideline. These patients have been identified as those that may be suitable for treatment under an Acute Medical Unit model of care.

“There is a lack of urgency by the Emergency Department surrounding the assessment of patients sent in by the Specialist Palliative Care service with a suspected cord compression”.

**Service Gap 57:** There is a perceived lack of coordinated assessment and management of patients with suspected malignant cord compression in the ED, which leads to the potential for the patient to experience longer periods of unrelieved pain.

**Recommendation:**

- Develop a working party to review and modify the existing guideline for the emergency management of a community patient with suspected cord compression in line with the literature and via benchmarking with other LHDs to ensure that it meets the needs of patients, carers and the clinicians.
- Publish the developed guideline on the CCLHD Intranet page and provide education to all staff involved in the implementation of the guideline.

### 13.3 Inpatient Specialist Palliative Care Service

The current inpatient specialist palliative and EOL care provision is via consultation and patients remain under the direct care of their primary treating team.

Hospital-based nurses report that referrals to the inpatient specialist palliative care team are ad hoc and dependent on the admitting Medical team plan. It is at the discretion of the treating or admitting Medical team as to whether they would like to engage Specialist Palliative Care with their patients. Nurses report that when SPCS palliative care is engaged it is usually in the terminal phase which is “too late”. Consultants or other members of the treating team are required to complete an eMR consultation request form and then fax this form to SPCS at Long Jetty for administration purposes. Treating teams are asked to call the SPCS specialist to provide background and to discuss

the urgency of the referral. There can be a delay in when the assessment occurs due to demand for service, and the fact that the service only operates during business hours Monday to Friday.

The Specialist Palliative Care team document their recommendations in eMR and it is at the discretion of the treating team as to whether these recommendations are followed. Issues reported include:

- The SPCS is a consultative service only in the inpatient setting
- Unlike most other specialties, the SPCS are not able to take over care for patients even if it seems appropriate.
- There is an inconstant response from the Palliative Care specialists within the SPCS to see patients in EDs and this is related to the service being a consultative service
- As per SPCS referral procedure, the inpatient SPCS cannot see a patient unless referred to them by the treating medical team even if the patient is registered with the SPCS.

### 13.3.1 No Patients are Admitted to Hospital under the Specialist Palliative Care Service

The SPCS does not admit patients to the acute facilities. This results in a number of service gaps and impacts on patients care, including:

- Patients are not always receiving seamless care. Some are seen by the SPCS in the community and then admitted under a different treating team due to care requirements such as treating side effects of chemotherapy, exacerbation of Chronic Obstructive Pulmonary Disease, etc.
- There can be multiple Medical officers involved in the patient's clinical management when they admitted for palliative care or EOL care. In some situations, this can create a duplication of Medical professional resources that may be reduced if the SPCS had admitting rights.
- Patients who have been identified as requiring SPCS in the community do not receive continuity of care and are not always able to be consulted by the SPCS team when they arrive in hospital
- There are an increased number of incidents and complaints (formal and informal) from patients, families and Nursing and Medical staff
- Medical staff feel isolated in their decision-making and are prescribing suboptimal pain management regimes to patients
- Patients may be receiving inadequate complex symptom management and EOL care during their inpatient stay.

**Service Gap 58:** The SPCS do not exercise admitting rights to the acute facilities due to their coverage limitations within the existing workforce.

**Recommendation:**

- Review the provision of admitting rights to the SPCS. This may require additional resourcing and will require budget allocation to accommodate the change.

### 13.3.2 No Specialist Palliative Care Service After-Hours or On-Call Support

The SPCS do not currently provide an inpatient on-call or after hours support service to meet the increasing demand for palliative and EOL care support and advice. The service currently has 3.2 FTE Staff Specialists (1.0 FTE, 0.6 FTE, 2 x 0.8 FTE) appointed to the service who work Monday-Friday 8:30-17:00pm. The Specialist Palliative Care Service do not provide an on-call after hours service to the hospital. They report there is not adequate FTE to provide an appropriate on-call roster. Junior Medical officers and Nursing staff rely on the support of their own sub-specialty on call/after-hours support system to seek guidance and advice on complex palliative symptom management, opiate medication charting and EOL care decisions. Medical treating teams are activating Rapid Responses or calling for Intensive Care Unit (ICU) consults to review patients. There are an increased number of incidents and complaints (formal and informal) from patients, families and Nursing and Medical staff. Medical staff are calling SPCSs in other LHDs or CCLHD Acute Pain service after hours to receive advice on complex patients.

“It is appalling that the Medical team was unable to contact the Palliative Care team for further advice for two days as they don't work on weekends. The Medical team was unable to adequately address mum's pain and they needed support from these doctors” (Patient complaint)



“As a new doctor to this area I was shocked to hear that we do not have an on-call palliative care service at any of our hospitals. People don’t conveniently die during business hours”.

“Nursing staff and Medical officers rostered at night and weekends suffer the most. There is no support for treating palliative and end of life care patients from the experts in palliative care. Patients are suffering unnecessarily and staff are extremely frustrated as they know this”.

**Service Gap 59:** There is no access to on-call or after hours inpatient support from the Specialist Palliative Care Medical team.

**Recommendation:**

- Review the on-call FTE requirements for the SPCS and introduce access to on-call and after hours support at all acute and subacute facilities.

### 13.4 Role of Specialist Palliative Care Nurse Practitioner

The Central Coast SPCS currently employs 1.0 FTE Nurse Practitioner (NP). The NP is based at Gosford Hospital and works Monday-Friday 8:30-17:00. Throughout this review, the NP role was identified as one of the most valuable aspects of the SPCS and frequently referred to as “the face of palliative care”. The Palliative Care NP has a unique role to play in palliative care provision as they are able to run family conferences, deal with complex family dynamics, manage complex symptoms, prescribe medications and implement effective symptom control and pain management strategies in consultation with the Medical team.

Within Gosford Hospital, the NP is able to establish a relationship with referred patients and provide them with supportive care that minimises their pain and suffering as a result of their life-limiting illness. The NP is also able to establish relationships with treating Medical, Nursing and AH teams and provide advice, education and recommendations surrounding quality palliative and EOL care.

Whilst the NP is seen as a significantly valued aspect of the District’s service to palliative and EOL care patients there are a number of service gaps and opportunities that have been identified:

- At Wyong Hospital, there is no equivalent NP role. A Palliative Care CNS 2 is rostered at Wyong, which means that they are not able to prescribe medications to patients. Subsequently, patient’s treatment can be delayed as they await the Medical team to implement any medication strategies recommended
- There is an inequitable workload between Gosford and Wyong Hospital for the Palliative Care NP and CNS 2 roles
- There is no leave relief with an equivalent NP at Gosford Hospital
- The NP role is not available on-call, after hours or on weekends.
- The NP can only be involved in a patient’s care if they are referred by the Medical team treating the patient
- The workload for the NP is not manageable on a daily basis due to an increase in referrals, and this results in patients having to wait to be seen and treatment recommendations delayed
- The caseload for the NP is predominately cancer-related with most referrals based on Medical Ward 2 at Gosford
- Due to resource constraints and the need to prioritise patients, the NP role is predominately involved in complex unstable, deteriorating and terminal patients and has limited time to allocate to stable patients within the hospital setting
- The significant patient caseload impacts on the time allocated for the NP to provide education, conduct quality activities and professional development of hospital staff.

“The Nurse Practitioner was an angel. She made the time to answer all of our questions, explained what would happen when the syringe driver was commenced and what death would look like. She assured us every step of the way and checked in on us each day and made sure that Dad was comfortable and not suffering. She arranged a Social Worker to talk with us and followed up parking vouchers. She made a difficult time bearable”.

“There needs to be access to a Nurse Practitioner at Wyong Hospital, subacute sites and in the community. There is not enough of her to go around and we are providing two standards of care for our patients”.

“There needs to be strong consideration given to expanding the Nurse Practitioner role at Gosford Hospital following the introduction of the Cancer Care Centre. Patients are missing out on linking in with this valuable service and there needs to be access 7 days per week”.

**Service Gap 60:** The Palliative Care Nurse Practitioner role is constrained by its location and allocated hours.

**Recommendation:**

- Review Palliative Care NP role and position description as required and consider allocation of additional resourcing to service Gosford Hospital, Wyong Hospital, the community and sub-acute sites.

### 13.5 Skill Level of Medical, Nursing and Allied Health Staff

The provision of palliative and EOL care requires a specific knowledge base and skill set. The time to be respectful and sensitive to a patient and family needs, displaying empathy, compassion and flexibility in care approach are all interpersonal skills that are required when working with palliative care patients.

Throughout CCLHD there are many passionate staff who specialise in the care of the patients with a particular diagnosis i.e. neurological, cancer, renal, gastroenterology patients. Palliative and EOL care requires education and training in a specific set of skills to ensure that the patient and their loved one receive a positive experience of care. Patients who are fortunate to have been referred to the Specialist Palliative Care inpatient Nursing and Medical team during their inpatient stay report a more positive and consistent experience. Patients report that there are many Nurses and AH staff who deliver their care and that many contradict each other and some appear to be more experienced in working with dying patients. Palliative care team involvement also causes confusion to patients and carers due to advice given by these teams who are not responsible for their care.

Nursing staff also report a lack of education and that they are not specialist palliative care Nurses and that they often feel that they provide less than ideal nursing care to palliative and EOL care patients.

Nursing staff have access to the Specialist Palliative Care NP/CNS and CNC during business hours but there is no one for them to call after hours or on the weekend.

**Service Gap 61:** There is a lack of specialist education and training for Medical, Nursing and AH staff working with palliative and EOL patients.

**Recommendation:**

- Review competencies, education and training for Nursing, Medical and AH staff in managing the deteriorating and terminal phases of palliative care.

### 13.6 Specialist Palliative Care Consultation Service

The SPCS provides a consultative service to inpatients at Gosford and Wyong Hospitals. This service is only provided business hours Monday-Friday. The service is provided by SPCS including:

- SPCS Staff specialist who provides support five days per week across both sites, including ward rounds twice weekly
- A Registrar at both sites five days per week
- A Nurse Practitioner based at Gosford Hospital five days per week
- A CNS2 based at Wyong Hospital five days per week
- A consultative service available to patients at Woy Woy or Long Jetty facilities

There were a number of issues associated with the consultative model reported during the review:

- Clinical recommendations made by the SPCS can be not accepted by the treating Medical team
- Decisions and care coordination of patients involved with the SPCS consultative service sometimes requires lengthy conversation between teams to coordinate care
- Patients and carers are confused as to who their doctor is, and not getting consistent information
- The consultative service only works Monday to Friday business hours, there is no after-hours or weekend support from this service
- There is a discrepancy between the level of care provided at Gosford and Wyong hospitals due to the differing scope of practice between a NP and a CNS2
- The consultative service provides an inconstant response to patients in EDs and this is related to the service being a consultative service
- The SPCS consultative are not consistently involved in patient ward rounds with the treating team which results in the patient/carer having questions that cannot be answered by the treating team
- There is 1.4 available FTE SPCS staff specialist cover for both Wyong and Gosford Hospitals which results in the reduced ability to provide the desired support and education to other medical staff on palliative and EOL care.

“I had no idea who the doctor was that was in charge of Mum’s care and I am convinced that they did not discuss her care as it changed every time the door opened”.

“I kept seeing all of these different doctors involved in my sister’s care but I never saw the doctor whose name was on the board behind my sister’s bed”.

“The SPCS is a fantastic service for the patients that they see, but for the volume of palliative and EOL care patients requiring their advice in our hospitals it is sub-optimal. There is a desperate need for after-hours and on-call support”.

**Service Gap 62:** The Specialist Palliative Care consultative service does not meet the needs of inpatient palliative and EOL patients and health professionals.

**Recommendation:**

- Review staffing levels, functional roles and interaction with treating medical teams of the Specialist Palliative Care Consultative service to ensure that it addresses the above needs.

### 13.7 Patient Support Services

Patient support services play an important role in palliative and EOL care. They fulfil a number of roles related to patient care (assisting with bathing, turning and positioning patients), transportation of patients to tests and x-rays, delivery of items (medications, equipment), assist in ensuring that the patient is comfortable during their hospital stay, cleaning of rooms and ward and finally transporting the deceased patient to the mortuary.

There are a number of service gaps that were identified that include:

- Computer Assisted Radio Personnel System (CARPS) – the nurses across all sites highlighted the difficulty with the CARPS system for patients
- Cleaning ward environment and patients’ rooms
- Isolation room cleans on wards and the delay in having these attended to, impacting bed flow
- Neutropenic cleans are reported to not meet benchmark standards
- Require multiple PSAs to assist with washing of patients
- The removal of designated PSAs from the ward has caused increased delays in patient care and a reduction in cleanliness of the ward environment (response to spills in a timely manner)
- Need to use CARPS for transport of items and equipment
- Collecting and transferring a deceased patient to the mortuary is sometimes delayed due to the processes involved.

“My room was not cleaned every day. I had to ask the nurse to get a cleaner to clean my bathroom”.

“The CARPS system has a considerable impact on the management of palliative and EOL patients. Waiting for a PSA causes considerable delays with cleaning rooms, transporting patients and overall patient and staff safety on the ward”.

**Service Gap 63:** There is an opportunity to review the PSA and Environmental Services staff roles to ensure they fulfil the requirements that are identified by the wards to deliver safe and quality care to palliative and EOL patients.

**Recommendation:**

- Review the CARPS process, role of the PSA, ward cleaning process and allocation of PSAs to support palliative and EOL care patients.

### 13.8 Medical Imaging and Pathology

Palliative care patients are often required to access medical imaging and pathology tests during their inpatient stay. This can involve assessment via CT, MRI or x-rays and multiple blood tests. Whilst in the stable, unstable and occasionally deteriorating phase this can be appropriate to assist with treatment planning, there is concern from patients, families and Nursing staff that patients are being referred for unnecessary tests when they are in the deteriorating and terminal phase of their illness. This is reported to be due to uncertainty around committing a patient to an EOL care pathway and is linked to lack of ACP discussions with patients and their families.

“Mum had a lot of x-rays and tests at Gosford Hospital while she was on the cancer ward. In the end she died two days later, I wonder if it was worth putting her through the trauma of all those tests, when we all knew the outcome was inevitable”.

“Due to lack of clear treatment plans and reluctance to withdraw active treatment and commence end of life care, patients are routinely sent for x-rays and CT scans”.

**Service Gap 64:** Patients in the terminal phase of their palliative care journey may be exposed to unnecessary medical imaging and pathology procedures. Costs and resources associated with performing medical imaging procedures and pathology tests may not add value to a patient’s treatment plan.

**Recommendation:**

- Improved ACP and appropriate discussions around placing patients on EOL care pathways.
- Team discussion amongst Medical professionals inclusive of junior Medical officers surrounding medical imaging procedures and pathology and their indications/contraindications during each phase of palliative care.

### 13.9 Patient Flow and Bed Management

The provision of palliative and EOL care has an impact on patient flow at Gosford and Wyong hospitals. Nursing staff and Patient Flow Managers reported concerns surrounding the pressure to ‘clear beds’ and the inability to do so as patients are often occupying acute beds in the terminal phase of their illness and there is no clearly defined timeline around when the bed will be able to be occupied. Staff reported the following concerns in relation to patient flow:

- Patients who require palliative and EOL care require a single room. These can be difficult to acquire due to other terminal patients or patients with infections requiring these rooms
- Daily pressure at patient flow meetings to transfer patients off the ward into the community
- Limited community services available to support people to die and as a result they occupy a single room in an acute facility
  - No hospice or palliative care unit
  - RACF difficulty to access due to waiting list, My Aged Care and also not always appropriate for younger patients.
  - Some patients are unable to die at home or it is not suitable for them to die at home

- EOL care can take up to 30 days. This has a significant impact on bed flow
- Unable to transfer EOL care patients to sub-acute sites as long waiting list or they are not stable and have ongoing medical conditions
- There are often patient outliers all over the wards due to bed block from palliative and EOL care patients
- Patients in the terminal phase of their illness are often unable to be transferred home to their RACF as it is medically inappropriate to do so.

“There is a constant focus on bed flow daily. It is important that we continue to look at the person occupying the bed and what their palliative and EOL process might be”.

**Service Gap 65:** Patients who will remain in hospital for their EOL care have an impact on patient flow and bed management.

**Recommendation:**

- Review patient flow and bed management processes for EOL patients including discussions in patient flow meetings and daily pressure surrounding terminal patients’ bed occupancy.
- Review allocation of single rooms to EOL patients and where these patients are best located to meet their medical and care needs.

### 13.10 Multi-disciplinary Inpatient Palliative Care team

At present there is only a consultative palliative care service within Gosford and Wyong Hospitals. AH staff consult on patients as required. There are suggestions that a multi-disciplinary team should be established for particular palliative care conditions i.e. MND team and also an interdisciplinary palliative care team that consults patients throughout the hospital regardless of their diagnosis or ward location. This team would be an extension of the community SPCS and transfer patients in and out and have specialist knowledge, skills and competencies related to the management of palliative and EOL care patients, equipment needs, diets and care. This team would be able to do case conferencing and conduct ward rounds and ensure care plans and end of life pathways are consistently completed.

“The care provided to palliative and EOL care at Gosford and Wyong Hospitals is fragmented. There is a need to have a specialised multidisciplinary palliative care team that includes allied health, medical and nursing and travels to where the patient is and is not restricted by ward allocation”

**Service Gap 66:** There is an opportunity to deliver consistent multidisciplinary care for palliative and EOL care patients on the wards. Patients currently receive different levels of care, and access to Multi-Disciplinary Team (MDT) staff is dependent on the ward that they are admitted to.

**Recommendation:**

- Consider in workforce redesign the appointment of a specialised MDT team that manage patients throughout the hospital and follow them on their journey rather than being ward allocated.

### 13.11 Allied Health Service

Palliative and EOL care patients require access to AH services to manage symptoms related with their Medical condition and to assist with transfer of care from hospital. AH services that may be involved include:

- Social Workers
- Speech Pathologists
- Occupational Therapists
- Physiotherapists
- Dietitians
- Psychologists
- Pharmacy

AH accept referrals via eMR and prioritise patients according to discipline specific prioritisation matrices. There are

no designated Palliative Care AH inpatient staff and AH are allocated to patients via the ward they are admitted under or in smaller disciplines via Medical teams. It has been highlighted that there is a lack of AH resources to support palliative and EOL care patients.

“My dad saw five different Occupational Therapists throughout his admission. He was transferred from Emergency to a surgical ward and then to a Medical ward where he died. There was a different therapist on each ward and on the last ward different therapists on certain days. We had to keep repeating our story in order to plan Dad’s discharge”.

“It is very hard to access AH. There are not enough staff and the majority of AH services work business hours and have limited weekend service”.

“Social Workers are a wonderful support to families during the deteriorating and terminal phase of a patient’s admission. They offer a fabulous service but unless you are in Emergency you are not able to access after-hours or weekend support following a patient’s death”.

**Service Gap 67:** Consistent AH staffing is not accessible for palliative and EOL care patients in acute hospitals during the week.

**Recommendation:**

- Review AH staffing structure and consider allocation of clinicians to patients to ensure continuity of care for palliative patients.
- Consider employment of AH staff to be based on a palliative care unit or affiliated with the palliative care service if they were given admitting rights.

**Service Gap 68:** Reduced AH staffing is available after-hours or on weekends for palliative patients. Patient’s length of stay and transfer of care can be delayed due to inability for AH to continue with transfer plans over a weekend.

**Recommendation:**

- Review AH services available on a weekend.

### 13.12 Patient and Staff Rounding

Patient and staff rounding is conducted on wards to hear the concerns of patients and staff surrounding the provision of palliative and EOL care. When problems are identified they are escalated and discussed at team meetings. There are particular wards that do this well. The barriers to conducting this consistently are reported as time, inconsistency in method, and they are usually only conducted during business hours Monday to Friday due to staff ratios.

**Service Gap 69:** Patient rounding is absent or inconsistently conducted with palliative and EOL care patients. Patients care needs may be missed or not communicated in a timely manner which may result in compromised care, incidents and complaints.

**Recommendation:**

- Review patient rounding tools and their use with palliative and EOL care patients.

### 13.13 Junior Medical Workforce

CCLHD has a significant junior medical workforce which is routinely managing day to day care of palliative and EOL care patients with the support of their supervisor. There were a number of Junior Medical Officers who raised concerns surrounding EOL care at CCLHD. These included:

- No support after-hours or on weekends from the SPCS
- Conflicting views of Junior Medical Officers, SPCS and the treating consultant regarding EOL management which



results in confusion for patients

- Labelling of patients' EOL care in ED
- No training and support in having EOL conversations
- Lack of advance care planning
- Patients given non-beneficial treatment particularly by cancer services
- Patients denied SPCS support as treating physician will not allow referral to the SPCS when patient known to the SPCS in the community.

"There is a disregard of putting patients first and making EOL decisions. There is a fear amongst JMOs that we cannot speak up but there are definitely consultants who will refuse to allow us to refer to SPCS".

**Service Gap 70:** There is an education gap and inability to consistently escalate care and support amongst the JMO workforce.

**Recommendation:**

- Liaise with JMO workforce regarding education needs in palliative and EOL care (i.e. advance care planning, difficult conversations)

### 13.14 Non-Beneficial Surgery

The ultimate goal of performing surgery for patients with a life-limiting illness is to prevent non-beneficial treatment and improve their quality of life. Non-beneficial treatment not only prolongs patient suffering, but it also places a significant financial and resource burden on the health care system. Currently, there is no system or robust hospital policy that promotes and supports a Medical officer to question whether aggressive or invasive surgical or medical interventions are in the patient's best interests. The surgical division is working on improving the awareness of both surgeons and anaesthetists of the issues in selecting appropriate patients for surgical intervention, and to consider the likelihood of protracted ICU admissions, probability of meaningful recovery and quality of life post intervention in the medically frail and palliative population. A risk assessment tool is being developed to help identify high-risk surgical patients and to determine whether the patient would benefit from aggressive/invasive surgical and medical treatment of the patient, or to adopt conservative treatment measures and palliation.

"We decided to proceed with the bowel surgery on Mum as we thought it was the best option to prolong her life. We wish we hadn't, mum went to ICU following the surgery and died one week later".

"As Surgical teams we often over-treat patients as there are no other options to present to the patient. It would be good to have palliative care as an active member of the team to discuss patients and their suitability for surgery. We could then present patients and their loved ones with a number of treatment options and let them make an informed choice. Often the outcomes and quality of life following surgery is poor and the family regret it".

"In determining if a surgery is non-beneficial versus an emergency, there needs to be robust decision making around high- risk situations linked in with patients advance care directives and advance care plans".

**Service Gap 71:** Patients are reported to be receiving non-beneficial surgery, as their family/carer often request it.

**Recommendation:**

- Continue to liaise with the Division of Surgery and ICU surrounding the project being undertaken on non-beneficial surgery.
- Consider development of patient/carer resources and further education/support when making decisions surrounding surgical options.

### 13.15 Palliative and EOL Care Ward

There are no specific palliative care beds located across CCLHD. This means that patients are allocated to acute beds throughout the hospital. At Gosford Hospital, patients who are palliative or in the deteriorating or terminal phase of their illness, are generally admitted to Medical Ward 2 or Medical Ward 4 as these wards have a higher number of single rooms. At Wyong Hospital, palliative care patients are generally admitted to Medical Ward 3 or Surgical Ward 1 and throughout the hospital dependent on where there is a single room available. Following this, patients are allocated to a ward appropriate to the subspecialty they have been admitted under. There are a number of issues that have been reported due to not having a designated palliative care unit. These include:

- Reduced access to beds for chemotherapy for patients
- Limited access to specialised Nursing, AH and Medical staff
- Inequity of care for patients requiring syringe driver which is dependent on which hospital and ward they are located on
- Inability to bring flowers, food and drink (including alcohol) onto the ward
- Inability to smoke outside the ward or bring pets in to visit
- Lack of open visiting hours on the wards, inability to go outside
- Carer comforts such as beds, access to room to meet with Medical team/family, access to showers and tearooms
- Inconsistent use of EOL Care pathway/comfort assessment chart
- The surroundings and environment are not appropriate for EOL care patient (very clinical)
- Access to support services i.e. PSAs
- Displacement of patients who are not receiving end of life care who have an equivalent clinical need for accommodation in a speciality ward for their illness

“The room that my wife died in was very hospital-like. It was very different to the hospice at Newcastle that my mother died in”.

**Service Gap 72:** There are no designated palliative or EOL care wards or beds at CCLHD. Patients are not receiving access to the comforts available on a designated palliative care ward and there is inconsistent assessment and management of palliative and EOL care patients.

**Service Gap 73:** There are no designated palliative care beds or wards proposed in the current Gosford or Wyong Hospital redevelopments.

**Recommendation:**

- Review the need for designated palliative and EOL care beds at CCLHD.

### 13.16 Sub-Acute Hospitals

The CCLHD has two sub-acute sites based at Long Jetty and Woy Woy. At present, there are no specific palliative care beds allocated at either site. At Long Jetty Hospital, some local GPs have admitting rights and in the past if a bed is available they have admitted patients who are unable to die at home for EOL. Both hospital sites have a number of single rooms available however they are funded as Transitional Care Unit beds. There have been a number of discussions surrounding whether there should be palliative care beds allocated at the sub-acute sites. The following considerations have been raised:

- Patients with symptoms requiring a high level of intervention (e.g. investigations, palliative surgery, or interventional anaesthetics) and access to medical support 24 hours/day are not suitable to admission to a sub-acute bed due to the risk of requiring transportation to acute hospitals
- Many patients prefer to stay in their current acute hospital rather than being transferred elsewhere
- The timing of the transfer needs to be early before patients deteriorate and can no longer be transferred
- Current waiting lists for sub-acute beds.

There are also a number of reasons that have been suggested as supportive for the allocation of sub-acute EOL beds.

These include:

- Allowing patients to be admitted to a sub-acute bed who are unable to die at home
- Provision of a preference for patients/carers for admission to hospital for EOL care
- Opportunity to manage symptom control for complex patients that has not been able to be managed in the community and does not require acute medical/surgical services
- Reduce bed block in acute care settings
- Observation of patients who are palliative and stable and awaiting RACF placement
- Terminal care when acute care is not required.

**Service Gap 74:** There are currently no designated palliative care sub-acute beds available at CCLHD.

**Recommendation:**

- Review the need for designated palliative care and EOL care beds at CCLHD on sub-acute sites.
- Review the bed utilisation in the Transitional Care Units to determine if these beds are suitable for transition to palliative care beds if this option is desired and there is capacity.

### 13.17 Intensive Care Units

The intensive care units at Gosford and Wyong Hospital often have palliative and EOL care patients admitted to their wards. The intensive care units are well-versed in managing terminal patients and the provision of EOL care. The following service gaps have been reported for provision of EOL care in the intensive care units:

- Wyong Hospital intensive care reported that patients are admitted to ICU in the terminal phase and then occupy a bed as death is imminent and the patient can't be moved to a ward
- Cost of ICU beds to manage palliative care patients
- There is an inability to refer patients to the SPCS for community follow up
- There is a lack of coordinated care and documented ACP for palliative patients
- There is an increased burden on the ICU team to respond to rapid responses on patients who are palliative who have not had an EOL care pathway initiated or resuscitation plan documented.

### 13.18 Palliative Care Pathway and End of Life Care Pathway

There is a lack of use of recognised palliative and EOL care pathways in use on the Central Coast. This can result in reactive rather than pre-emptive care of patients. A clear, utilised palliative pathway will guide health professionals in regards to early planning, EOL care and bereavement care.

#### 13.18.1 End of Life Care Pathways

The CCLHD has an EOL care pathway for use by staff when a patient is determined to be EOL. This pathway is implemented to improve EOL care for all patients no matter what ward they are on and ensures that patients receive consistent care and prompts Medical and Nursing staff as to steps that need to be considered. Issues with EOL care pathways include:

- Patients are not commenced on EOL care pathways early enough
- EOL care pathways are not completed in their entirety
- There is an increased appropriate use of EOL care pathways for patients referred to the SPCS
- The use of an EOL care pathway is dependent on the treating medical team, and is very Nurse-led
- There is varying language used by medical staff to describe EOL care (comfort care, quality of life care, ward-based care, quality of life, comfort measures, palliative approach) which can be confusing for professionals involved in the patient's care.

#### 13.18.2 Comfort Assessment Charts

The CCLHD has a comfort assessment chart that should be activated when a patient is commenced on an EOL care pathway. Patient file reviews indicated that this does not always occur and can be absent or delayed. There is also evidence of patients who commence comfort assessment charts that do not have observations routinely completed. Of concern was the duplication of observations whereby EOL patients were on an EOL care pathway however, still

having a Standard Adult General Observation (SAGO) chart completed.

“I didn’t realise what the Doc was saying when he told me that I was for ‘quality of life’ care. I said “of course I want quality of life care” I found out the next day he actually meant you are going to die here”.

“It is very distressing for nurses to watch a patient continue to receive chemotherapy when it is obvious that they need to be on an EOL care pathway. It is very hard to influence some medical specialists but we need to try to so we can advocate for the patients who can’t speak up for themselves”.

**Service Gap 75:** EOL care pathway protocols and the use of comfort assessment charts are not always activated for palliative care patients.

**Recommendation:**

- Review the use of the EOL care pathway and comfort assessment chart
- Educate the Nursing and Medical staff surrounding the use of the EOL care pathway and comfort assessment chart.

### 13.19 Rapid Response/Managing the Deteriorating Patient

A Rapid Response occurs when a patient shows signs of significant clinical deterioration. At Gosford and Wyong Hospitals, the Rapid Response team comprises of non-supernumerary ICU staff. These staff are released from the ICU ward when a Rapid Response is activated, leaving behind their current workload. The following issues were identified with Rapid Responses:

- Concern over the ability to meet future demands with the redevelopment
- Decreased recognition of the deteriorating patient which results in inappropriate rapid responses or rapid responses not being activated
- Rapid responses being called so that the ICU Rapid Response team can review and develop management plans for the patient. Many of the palliative care patients do not have a clear resuscitation plan
- Lack of advance care planning in the community and throughout the patient’s admission. This results in medical staff being unsure of resuscitation status and patient care needs
- Rapid responses are called on patients who have their treating medical team on the ward doing rounds.
- There is a lack of implementation of altered calling criteria resulting in unnecessary Rapid Responses to palliative clients.

“There is a significant waste of resources for Rapid Responses on palliative patients. It is very frustrating when these are called for palliative care patients and the medical staff are present on the ward”.

**Service Gap 76:** Rapid Responses are not always appropriately activated on palliative and EOL care patients.

**Recommendation:**

- Review the Rapid Response service at CCLHD and improve the documentation surrounding EOL care pathways and the completion of resuscitation plans. This should also include appropriate documentation of altered calling criteria.

### 13.20 Palliative Care Patient Readmissions

A Wyong Hospital Readmissions Project was recently undertaken within the District. It highlighted a number of areas for improvement. Data showed that the Relative Readmission Risk for a Palliative Care patient at Wyong Hospital is the second highest. Due to patients with a cancer diagnosis often being admitted to Gosford Hospital it is expected that this would be similar (if not higher) at Gosford Hospital.

Clinical reviews, patient complaints, staff interviews and patient journeys revealed that palliative care patient readmissions are often caused by:

- Ineffective discharge planning

- Reduced coordination and integration of care within the community
- Lack of social support and services for patients and their carers in their homes or RACFs
- Perception of an inability to refer patients to the Specialist Palliative Care team for community follow up as they require a GP referral
- Pain and acute symptom management not being managed in the community
- Lack or no evidence of ACP and EOL care discussions
- Multiple service providers involved in patient's care
- Inability to link in with GP or patients who do not have a dedicated GP
- No consistent and coordinated care plan
- Lack of after-hours and weekend support from community service providers, GPs and the SPCS
- RACF Nursing staff, patient and/or carer inability to follow discharge plan
- Escalation of symptoms and deterioration in patient's condition
- Awaiting Aged Care Assessment Team assessment or RACF placement
- Admission required and planned for EOL.

Patients requiring palliative care and EOL care often have an increased length of stay in acute beds due to inadequate coordination of care and care planning across the acute and community settings. Patients and their families have no other option than to present to the hospital (often against their wishes), and there is an increased demand on Ambulance resources to transport patients to hospital.

"I didn't want to take my wife back to hospital but there was no one to talk to at home to get more pain relief and she was in a lot of pain and vomiting. I couldn't watch her like that so I called an ambulance".

"Palliative care patients are a significant proportion of our readmissions due to inadequate support in the community from service providers, the Specialist Care Service and GPs particularly on weekends and after hours".

**Service Gap 77:** There are a number of potentially avoidable readmissions to CCLHD hospitals for palliative and EOL care patients.

**Recommendation:**

- Discussion of palliative and EOL care patients at patient flow and readmission meetings.
- Allocation of sub-acute beds and development of a model of care for palliative care patients.
- Review inpatient Specialist Palliative Care referral pathways.
- Palliative care patients to be highly recommended to have an ACP following a designated number of admissions to CCLHD hospital within a time frame (e.g. 2-3 admissions).
- Palliative care patients to be appointed a care coordinator and referred to STCT for discharge planning.
- Palliative care patients requiring repeat admissions to be considered for referral to the Specialist Palliative Care team for coordination of care and care planning.
- Link recommendations from the current Readmissions Project to the Palliative and EOL Care review and implement as appropriate.

### 13.21 Disconnect between Community Specialist Palliative Care Service and Inpatient Specialist Palliative Care Service

There is a disconnection between the inpatient and community SPCS. Whilst they identify as one service patients often fall through the gaps when transferred from the community to inpatient care as there are no specialist palliative care direct admission rights. Patients are sent to the ED by the Specialist Palliative Care Nurses and Medical staff for symptom management, uncontrolled pain in the community or inability to cope at home. Even for patients with a clear documented palliative care plan they are admitted under a treating specialist such as oncology and they are then restaged to see where they are at.

If a patient is known to the SPCS in the community, a referral is still required from the admitting medical officer to

the SPCS. There is currently a delay in documenting in eMR by the SPCS and it is not always point of care documentation. As a result, there is difficulty accessing documentation in eMR as it can be missing or in various locations such as ARIA, ComCare and eMR.

“The District does not have an admitting palliative care service. This means that when patients at EOL are admitted, they are cared for (at Gosford and Wyong Hospitals) by acute Medical teams regardless of whether or not they are known to the SPCS. The SPCS consults to the inpatient services but there are inevitable boundary issues for an acute consultant and service that may not have known the patient before their admission. We have had two recent significant complaints around this very issue and the mixed perceptions created when multiple clinicians are involved, which will inform the discussions yet to be had in the planning process”.

**Service Gap 78:** There is a disconnection between the inpatient and outpatient SPCS.

**Service Gap 79:** Patients who are known to the SPCS in the community are not able to receive continuity of care by the SPCS as they are a consultative service and require a referral from the treating team.

**Recommendation:**

- Review the SPCS consultative service and determine how to improve the link between the SPCS community and inpatient arm
- Consider commencement of admitting rights for the SPCS.

### 13.22 Equipment Needs

Patients receiving palliative and EOL care require timely access to equipment such as air pressure relieving mattresses, electric beds, shower aids, mobility aids, wheelchairs, syringe drivers and home oxygen. The provision of equipment for palliative and EOL care patients is currently provided by the CCLHD equipment loan service and from a designated pool of equipment purchased by the SPCS (if the patient is registered with the SPCS). Delivery of equipment is to patients' homes via Community Nursing, Specialist Palliative Care nurses or Occupational Therapy staff including the SPCS Occupational Therapist. Carers and families may also be required to pick up and return equipment to the CCLHD Equipment loan service at West Gosford. There are also certain equipment items (electric beds and pressure relieving mattresses) that are delivered to the patients home by an external company *Hospital at Home (Pegasus)* and home oxygen that is ordered through and delivered by BOC centres for registered SPCS patients.

There are a number of issues that have been identified in regards to the provision of equipment and home modifications required to address palliative care needs in the community:

- Delay in receipt of equipment to CCLHD hospitals for the discharge of palliative care patients to the community
- Patients and carers may be required to pick up and return equipment to CCLHD Equipment loan service at West Gosford
- Equipment available through the Equipment Loan Service is limited in range/suitability and varied in the amount of stock available
- Patients referred to the SPCS receive access to a Specialist Palliative Care Occupational Therapist and more timely access to equipment to enable them to be cared for in the community
- Inequitable access to specialised equipment such as electric beds, pressure relieving mattresses and home oxygen for people who are not registered with the SPCS
- Incomplete record keeping related to equipment that is provided to patients within the community and subsequent loss of CCLHD equipment
- Delay in timely access to equipment and home oxygen for palliative care patients due to hours of CCLHD Equipment loan service (delays after hours and weekends) as this service operates Monday-Friday business hours
- Delay in home modifications due to lengthy processing referrals and building quotes via *My Aged Care*
- Modifications referred to *My Aged Care* are reported to sometimes 'get lost', be only accessible to Under 65s and people are dying before they get their home modification, or there are significant waiting times



- Obtaining equipment through ENABLE NSW is an option, but it is restricted to patients who have been documented as not being in their last six months of life. This is difficult to determine/quantify.

“I had been waiting three months for the step to be made for the back porch. In the end in desperation we rang a builder in the yellow pages and he made it in half a day!”.

“My Aged Care has added another step to the process when requesting home modifications. As it takes so long for the referral to be approved, I phoned someone who is a builder to determine his availability”.

**Service Gap 80:** The equipment lending and home modification process is not streamlined and requires staff to develop ‘workarounds’ to enable suitable home modifications to occur.

**Recommendation:**

- Review the equipment loan and home modification processes for palliative care patients

### 13.23 Care Awaiting Placement Program (CAPP) Beds

There are a number of patients who are dying in acute and subacute facilities who would benefit from transfer to a ‘dying friendly’ RACF. The current District CAPP program enables patients who need suitable accommodation than a hospital bed to receive Nursing and Medical support whilst supported by the District CAPP Liaison Nurse. The District currently has contracted beds at four RACFs across the Central Coast including Peninsula Village Umina Beach, Opal Berkeley Vale, Opal Kanwal and Opal Norah Head. The benefits to patients include a quieter atmosphere away from the acute activity of a hospital and easier access for family and friends. Disadvantages are that the RACF bed may be a good distance away for family to visit, not be available, or not provide optimal EOL care.

“It was very time consuming and daunting to find a nursing home that was close to home and would be a suitable place for my husband to die. It would be good if someone could help with this”.

“Patients are occupying acute beds for on average two weeks to receive end of life care. This has a significant impact on families emotionally when visiting and a significant pressure on Nursing staff and patient flow”.

**Service Gap 81:** CAPP beds are currently only contracted at four RACFs and the beds at each facility are not designated for EOL care patients.

**Recommendation:**

- Investigate the number of CAPP beds required for patients to receive EOL care who are unable to die at home. Assess contracted beds against criteria for ‘Dying friendly RACFs’ and tender contracted beds with RACFs in various locations across the Central Coast.

### 13.24 Private Hospitals

The Central Coast Community is fortunate to have access to three private hospitals; Berkeley Vale Private, Gosford Private and Brisbane Water Private. Each private hospital has its own unique casemix and many of the Medical specialists that work at CCLHD also have admitting and surgical rights within the private hospital settings. Patients may be transferred from CCLHD hospitals to private hospitals for EOL care. Additionally, there are Medical specialists and GPs who admit patients directly to private hospitals for EOL care. Interviews were held with stakeholders from each of the three private hospitals to discuss the palliative care service they provide, service gaps that exist for their patients and opportunities that may be realised to provide seamless integrated care for patients.

It should be noted that prior to 2012, the SPCS Medical and Nursing staff provided service consultations to the Central Coast private hospitals. At the end of 2012, this service ceased due to concerns by SPCS Medical staff surrounding their Medical indemnity status when providing consultations to patients in private hospitals. This cessation of service was commented on by all three private hospitals and the strong desire to have increased access to SPCS support for education and to ensure continuity of care for patients being transferred back to the community.

Private hospital nurses would like to link patients to the SPCS before they leave hospital but they are unable to do this due to the referral criteria, so they refer them to their GP to make a referral, which can delay treatment plans.

“Working with palliative care patients in the private hospital can be isolating and we are concerned we are not providing best practice as we see only a small number of cases per year. The support of the Specialist Palliative Care service even if only telephone support would be extremely beneficial for patients, families and staff”.

**Service Gap 82:** There are reported improvements that can be made in private hospitals for palliative care patients to ensure that they receive quality, evidence-based care.

**Recommendation:**

- Investigate options for public/private partnerships for EOL care. Review the existing Brisbane Water Private Hospital contracted beds arrangement.
- Develop an interagency working party to discuss EOL care in private hospitals and ensure that there is a seamless transition for patients to and from the community and private hospital settings.
- Review the option for private hospitals to access SPCS medical and nursing advice and support as provided previously. Recirculate competency tools and policies related to the use of syringe drivers with the private hospitals.
- Develop an interagency working party to develop an EOL care pathway and comfort assessment chart for use across the public and private settings.
- Educate the private hospital setting on how to provide access to follow up and support for families requiring bereavement support.
- Establish an Interagency Palliative Care Interest Group on the Central Coast. This group could share case studies, debrief and support one another, perform case reviews, share resources, share issues and opportunities and review literature and best practice.

### 13.25 Centrelink

There are certain allowances that Centrelink can offer for carers supporting a loved one with a palliative condition and there are also bereavement payments available following the loss of a partner. There are specific eligibility criteria surrounding these payments and families need to be aware of these conditions. There are a number of service gaps that were identified throughout this review in relation to Centrelink including:

- There are no Social Workers in the SPCS and limited access to CCLHD Social Workers in the community
- There are lengthy waiting periods for carers to access the carers allowance through Centrelink
- The processes in Centrelink have been updated and are now accessed electronically. A lot of elderly carers are unable to do this and there is limited support available to assist
- The carer allowance often ceases immediately post-death. This is difficult for families who have funeral expenses, may have been out of work for an extended period to nurse a palliative loved one at home and are requiring additional time to grieve as part of the bereavement process.

“My husband wanted to die at home. We have our own business and two high school students to support. We applied for a carer allowance through Centrelink and three months later it still had not been processed. We had no money left so he had to be admitted to hospital to die so that I could work to pay the bills and feed the kids. He died before the carer allowance was processed”.

“Navigating the Centrelink process as a PCLN is a nightmare and very time-consuming. We need access to Social Workers who are skilled in providing this level of support”.

**Service Gap 83:** There is difficulty accessing Centrelink for additional financial support for carers of palliative and end of life care patients.

**Recommendation:**

- Develop an information package related to Centrelink benefits and share this with staff managing palliative care patients in the community and inpatient settings.
- Review access to Social Workers in the community to assist palliative care patients and their families to navigate the Centrelink process.

### 13.26 Residential Aged Care Facilities

The Central Coast community currently has access to a number of profit and not for profit RACFs. These vary in size, funding and governance. There are some RACFs that are part of a consortium group such as Aurrum and Opal Aged Care whereas others are stand-alone RACFs. Consortium groups often have governing bodies that dictate admission criteria, nursing ratios, service provision and policies and procedures. Through NGO provider forums, site visits, patient/loved one and staff interviews there were a number of service gaps identified with the current access and provision of palliative and EOL care in RACFs. These include:

- Lack of purpose built EOL care rooms for patients
- Lack of clear EOL care pathway and comfort assessment chart
- Limited access to SPCS
- Limited access to GP after hour and on call support
- Limited or no access to syringe drivers for medication management
- Lack of AH support to manage palliative and EOL care patients in RACF. There needs to be pathways to manage palliative patients in RACFs to assist with admission avoidance (e.g. ASET Outreach AH team)
- Limited access to equipment to assist with mobility, falls prevention and pressure injury management
- Limited ACP as a requirement for admission to RACF. There are a few RACF who have strongly requested that ACP/ACD must be completed for all residents on admission.
- Varied processes and documentation provided around transfer of care to and from CCLHD facilities
- Level of nursing care varies greatly. There are some RACFs that have employed a NP (e.g. Peninsula Village Woy Woy) to manage palliative and EOL care patients whereas others have no specialised staff trained in EOL care.
- Lack of education surrounding palliative and EOL care
- Workload constraints i.e. Nursing to patient ratio makes it difficult to provide time and care required to EOL patients
- Varying staffing ratios – many RACFs do not have access to a RN overnight so are unable to give S8 medications
- Patients' families going against the ACD, resulting in the need for patients to be transported to hospital
- Patients are transferred back to CCLHD facilities for acute symptom management and following falls
- Reluctance to admit palliative care patients to a facility as it is same amount of paperwork as admitting long term residents
- EOL care patients admitted to RACF without an appropriate medication chart, pain relief and care plan charted.
- Verification of death issues
- Uptake and linkage with the Ambulance Palliative Care plan has been slow
- There is a new suite of RACF being built on the Central Coast by the Aurrum Group. This group has focused on the Central Coast to establish their RACF and currently have RACF at Erina, Kincumber, Terrigal Drive, Norah Head and Wyoming. These RACF have access to menus by Karen Martini, RN overnight, GP rounds a few days per week, wellness and lifestyle programs, modern and comfortable residences, on site AH and a large majority of single rooms that could cater for EOL care
- Medication management is compromised due to perceived lack of access to syringe drivers and reluctance of Medical staff to prescribe opiates
- RACFs have reported that they have limited support for palliative care patients and require increased access to education tools.

There are a number of RACFs that have standardised access to palliative and EOL care in their facilities. These programs and services have ensured that patients care plans and needs are met within the RACF setting through

access to specialist palliative care training, education and specialised palliative care Nursing and Medical staff.

### 13.26.1 Transfer to RACF from Acute Setting for End of Life Care

There is a strong need for streamlined access to RACF beds for EOL care patients. There have been repeated reports by patients' families surrounding the pressure to find a RACF bed for their dying family member to free up an acute bed in the hospital.

"We spent six days running around looking for a suitable nursing home for Mum to be transferred to. There were lots of meetings with nursing homes and paperwork to complete, they didn't seem interested as they said it was a lot of paperwork to complete and they needed extra staffing to support a dying patient"

"I will forever regret that the doctor made me look for a nursing home for Dad. We lost one valuable week with Dad. By the time we found one and were accepted, Dad lost consciousness and they told us he had to stay in the hospital to die. We will never get that time back"

"The Social Worker came and spoke to me and said "as we cannot know when he will pass you will need to find him a nursing home within 2 days". Here is a list and if you don't find one the hospital will allocate one and it may be far away from you, so it is in your best interests to find him one".

"I was the only EN on, managing a number of patients alone overnight. I knew Mr X was dying and moaning in pain. I couldn't administer S8 medications and I couldn't sit with him while he died. There was no after-hours GP support. I called the Ambulance and he was taken to hospital where he died the next morning. He should have been able to die here but I couldn't watch him die that way".

**Service Gap 84:** There are varying levels of care provided to palliative care patients in RACFs on the Central Coast.

**Service Gap 85:** There is difficulty accessing RACFs for palliative care patients due to admission criteria and waiting lists. This results in increased admissions to hospitals for EOL care due to inadequate human and equipment resourcing in RACFs.

#### **Recommendation:**

- Develop a working party to review service provision for palliative and EOL care in RACFs and how this is supported by CCLHD. This will include improved transfer to and from RACF and CCLHD facilities and community services.
- Investigate the development of a partnership with 'Dying Friendly RACFs' to assist with access to RACF for palliative and EOL care patients.

### 13.27 Palliative Care Unit/Hospice (Elsie's Retreat)

Elsie's retreat is a vision to create a stand-alone palliative care unit on the Central Coast. Various community meetings and fundraising activities have occurred as well as discussions in parliament by local Members of Parliament. The vision is to create a home like environment with no restrictive visiting hours, where family can stay and cook meals if they choose, bring pets, drink alcohol, go outdoors, and be visited by their own GP or palliative care team. A palliative care unit will provide a homely environment for episodic care and EOL care and take the pressure off bed demand and costs associated with ED and acute hospital admissions. A purpose built palliative care unit will provide a compassionate place for patients to be cared for when home is no longer an option.

It is important to note that palliative care units are required to provide improved patient outcomes as measured with the ANSNAP data set. Submission of the PCOC data set is voluntary. Advantages of palliative care units are:

- Ability to provide dedicated individualised patient care
- Improved access to EOL care for patients under 65
- Decreased pressure on inpatient beds to provide EOL care and increased access to specialised care by medical,

- nursing, allied and support staff
- Support for carers and families through education provision
- Improved patient reported outcomes
- Engagement with the community to support the palliative care unit
- Reduction in the number of patients that require admission to an acute setting for EOL care
- Dedicated palliative care nurses and service provided. This level of service is difficult to provide with generalist nurses and in a busy acute ward
- Opening visiting hours, outdoor spaces, living arrangements for families, pets allowed.

### 13.27.1 Community Hospice

Throughout this review there has been a consistent calling from Medical specialists and GPs, Nursing staff and AH staff, carers and their support workers, volunteers, patients and community members for the need for a hospice on the Central Coast. The community wants a choice when considering access to their palliative and EOL care needs that does not always necessitate assessment at or admission to hospital or a RACF. The hospice model of care is utilised in many countries throughout the world with the UK and New Zealand advocating for the importance of access to a hospice to complete holistic palliative and EOL care services.

“My wife was 52 years old and wanted to die in a hospice which is where her mother and brother died in Newcastle. I was shocked to hear that there was no hospice on the Central Coast. Unfortunately, my wife did not get her dying wish and spent three weeks at Gosford Hospital before she finally passed”.

“I want to have a choice, I don’t want to die in a sterile hospital but I am not dying in my family home in front of my 3 and 5 year old children, why don’t we have a hospice?” (37 yr. old EOL patient).

“This is 2017, it is appalling that we do not have a hospice or palliative care unit or even a palliative care ward on the Central Coast. We are a huge regional community and we wouldn’t be in this bed crisis if we didn’t have so many people dying in our hospitals as they have no other choice! It is a disgrace” (Staff Specialist).

**Service Gap 86:** There is limited choice for where patients can die and there is no stand-alone Palliative Care Unit on the Central Coast. This increases pressure on hospital beds as they care for terminal patients who are admitted to hospital for EOL care as there is no other option.

**Recommendation:**

- Discuss the development of a stand-alone palliative care unit (hospice) on the Central Coast when considering solutions surrounding bed management and access to EOL care for patients. This will include consideration of funding source, staffing requirements and location.
- Conduct site visits to other LHDs to review the palliative care unit/hospice model of care and to discuss the risks/benefits to the Central Coast population.

## 14. TERMINAL PHASE OF PALLIATIVE CARE

### 14.1 Palliative Care Home Support Packages (HammondCare)

This is a consortium project involving Sacred Heart, Calvary and Hammond Care that is funded by the MoH to provide ‘Palliative Care Home Support’ packages to patients wishing to die at home. CCLHD signed the original MoU on 6 January 2014 and a current MoU is in place. This was recently renewed until 30 June 2018.

Referrals to HammondCare for these packages can only be made by the SPCS or directly by HammondCare RACFs (located at Erina and Woy Woy). These packages can only be utilised by palliative care patients who have been assessed as being in the deteriorating or terminal phase of their palliative condition. Each package comprises of 48 hours of care by a trained AIN from a registered community care provider affiliated with HammondCare. The allocated 48 hours of care can be consecutive or broken up and is not only for last 48 hours of life (a common

misconception). The first package was initiated on the Central Coast in December 2013. Since then, 288 patients have accessed a package and of those 204 have died at home and 53 have died in hospital.

Service gaps have been identified surrounding the allocation and provision of Palliative Care Home Support Packages, with some patients not meeting the criteria to have a package allocated to them.

**Service Gap 87:** Palliative Care Home Support Packages (HammondCare) are currently not able to be accessed by all patients requiring them on the Central Coast due to a restricted referral pathway, current prioritisation and limit of available and trained care workers.

**Recommendation:**

- Review the current Palliative Care Home Support Packages (HammondCare) provision (inclusive of referring agents, referral criteria, referral pathway, prioritisation, documentation) to the Central Coast.
- Provide education surrounding Palliative Care Home Support (HammondCare) packages to all referring agents, CCLHD staff and community care providers involved in the provision of EOL care for patients residing on the Central Coast.

## 14.2 Medication Management

The vast majority of patients receiving palliative and EOL care support require access to medications to relieve symptoms related to pain, agitation, nausea, anxiety, depression, respiratory secretions, breathing and other acute and chronic symptoms. The management of these symptoms in a timely fashion ensures that patients are kept comfortable in the community and decreases the number of calls to the Ambulance service, visits to GPs and admissions required to acute facilities. Patients in the community who are under the care of the SPCS have their symptoms monitored and discussions between the Medical and Nursing staff are held to determine if the patient's medication regime requires adjustment. Medications and syringe drivers are held at the SPCS and patients are set up with syringe drivers if required, when they are in the terminal phase. Carers are not expected to manage the syringe drivers but are left breakthrough medications at home to administer to the patient as required. Issues identified in relation to medication management include:

- Community breakthrough and drawing up processes and link between community nursing and SPCS nurses
- There are often long waiting lists for patients to get into see their GP for medication scripts
- Carers and families administering medications
- Use of syringe drivers in the community and competencies for using these
- Medication charts and authorisation
- Process for writing scripts that requires patients to access their GP to have their script filled
- Community Nursing involvement with syringe drivers
- No access to NP in the community to prescribe medications for palliative care patients
- RACF medication regimes
- GP role in medication management
- Ambulance Service report that they often have to attend homes due to pain management
- Management, authorisation and administration of S8 drugs in the community cannot follow inpatient policies and procedures
- There is an inconsistent approach to medication management and the management of pain and symptoms in palliative and EOL care patients. There is an inconsistent approach to access and the use of syringe drivers at CCLHD hospitals, private hospitals, RACFs and in the community. Nursing staff are not all competent in their use and Medical staff are not confident in the prescription of medication dosages. Syringe drivers are not always used in the inpatient setting and patients are prescribed 4 hourly morphine. This is perceived as sub-optimal and has been a focus of a number of patient and carer complaints
- There is concern surrounding the inequity of care to palliative patients' dependant on whether they are an inpatient or community patient. It is standard practice for carers in the community to administer breakthrough medications, however in the hospital setting due to the Poisons Act, families/carers are not allowed to give breakthroughs, and report they feel like they are begging for more pain relief for their family member
- It is difficult for Nurses to get appropriate pain relief and symptom management of nausea and delirium



charted, especially after hours and on weekends, and access to Pharmacy.

The SPCS has recently published on the CCLHD Intranet Page (24 April 2017) a guideline *GE2012\_016 End of Life Medication Recommendations for Symptom Management in Adults* that provides medication prescribing recommendations for symptom management in adults at the EOL when oral treatment is no longer tolerated. It has been developed to assist NPs and Medical specialists to determine appropriate medication regimens for patients experiencing common EOL symptoms such as pain, dyspnoea, delirium, agitation, nausea and respiratory tract secretions. This guideline meets a significant gap in the delivery of EOL care in the acute setting for patients who are not registered with the SPCS. It also assists with decision making for treating teams who are challenged with making decisions related to medication management after hours and on weekends when access to specialist palliative care advice or support is unavailable.

#### 14.2.1 Acute Pain Service

CCLHD currently has an Acute Pain Service that provides a consultative service to Gosford and Wyong hospitals. There is a strong working relationship that has been established between the Acute Pain Service and the inpatient SPCS. These two teams meet on a fortnightly basis at Gosford Hospital to discuss the palliative care patients with ongoing pain management needs. The Acute Pain Service also assists in the management of pain for patients. The following was noted throughout the review:

- Medical teams often refer patients to both the Acute Pain Service and the inpatient SPCS for the management of pain. This results in duplication of resources and both teams providing a consult for the patient.
- Patients with palliative pain are sometimes inappropriately treated with acute pain medications as medical teams are unsure on medication prescription for palliative pain.

“Dying should not get to the point where the patient is distressed and families are begging for additional pain relief”

“There is a strong need for advice on how to manage end of life symptoms as patients are undergoing inhumane and unnecessary suffering”.

“I was unclear on what S8 medications to prescribe the patient for his EOL care and there were no SPCS to discuss with so I prescribed regular Ketamine”.

**Service Gap 88:** There is a need for a consistent approach to the prescription, administration and monitoring of medication for palliative and EOL care patients in the inpatient and community setting.

#### **Recommendation:**

- Support increased usage of existing evidence based medication guidelines to ensure that patients have timely access and relief of their symptoms via the appropriate prescribing of medication no matter where they are located (inpatient, community, RACF) and when this symptom relief is required (within or outside business hours). Consideration should be given to the service gaps identified in this section.
- Review the need for access to a specialist pharmacist and/or pharmacy consultation to community and inpatient palliative care and EOL care patients.
- Review current processes surrounding telephone orders of S8s and how documentation of this occurs.
- Education surrounding the recently published *GE2012\_016 End of Life Medication Recommendations for Symptom Management in Adults*

### 14.3 Patient and Carer Experience

Managing the emotions and decisions required when your loved one is dying can be a difficult time. Patients and their carers are in an unfamiliar environment and away from their comforts of home. Patients and carers report a feeling of “total confusion” when describing inpatient palliative care. They explain that it is difficult to understand what treatment is being given to a loved one due to the number of clinicians involved in the patient’s care. Patients have difficulty coming to peace with what they are dealing with. Families are confused as to what is occurring and

are looking for a 'last hope'.

Patients who are older will do whatever the doctor says without questioning. Younger patients and family members will question doctors' treatment options. Families report feeling vulnerable and "like they have to try whatever the doctor suggests" for their relative. The following concerns were expressed by patients and their carers surrounding inpatient palliative care:

- There is no specialist palliative care support available to patients, families, Medical and Nursing staff on the weekends or after hours
- There is a lack of carer education on what is happening to their loved one at EOL
- There appears to be no plan in place and it changes continuously depending on who you speak to
- Nurses have varying levels of experience. Their care is very person-dependent. Nurses should not share their personal viewpoints on death with families
- Access to medication management when patients and families request it is sometimes denied
- Sleeping arrangements are poor. The lounge room is available but is also used by other families
- No family accommodation available for patients to stay overnight, families don't want to leave the hospital in case the patient dies or deteriorates and they need to come back quickly
- Access to pastoral care is limited
- Meals are not always being ordered for carers and families doing the bedside ritual
- Unable to bring meals into patients due to hospital policies
- Unable to bring pets into hospital
- Difficult to care for a loved one in a four bedded room
- Inconsistent information given on the Carer Retreat at Gosford Hospital
- "Why isn't there any information for carers or a place to go at Wyong Hospital for support?"
- Visiting hours are restricted and should be available all times of the day
- Poor communication and difficulty to access doctors to discuss care
- There is no accommodation for patients to stay overnight on campus when their loved one is actively dying.

"My greatest regret is going home from the hospital and not being there to say goodbye and comfort him when he died"

**Service Gap 89:** There is a need to improve consideration of the patient and carer experience when managing palliative care patients.

**Recommendation:**

- Engage with the Consumer and Engagement Committee, Patient Experience Manager and Carer Support Unit when forming recommendations for palliative and EOL care services
- Develop formalised patient and carer rounding tools for palliative and EOL care patients.

## 14.4 Dying Friendly Hospitals

What is a 'Dying Friendly Hospital?' There are a number of factors that need to be considered as outlined above in Section 14.3 to improve the patient experience when patients are admitted for palliative and EOL care. This report has highlighted a significant number of opportunities for improvement in all aspects of palliative care. Along with improvements in the care provided there were also a number of 'comfort factors' that were identified to ensure that patients and their families' experience of EOL care at CCLHD is improved.

Patients who are admitted to Gosford Medical Ward 2 are unable to receive flowers during their palliative or EOL stay. This policy is not consistent across the District and impacts on a small cohort of patients but on a ward with the highest number of deaths, palliative and EOL care admissions in the District. Families and friends are not adequately informed and therefore paying money for flowers and arrangements that they are then not permitted to bring onto the ward.

"Mum loved flowers and it upset me greatly that in her final waking hours she was unable to be comforted and surrounded by beautiful flowers"

“I paid \$60 for a floral arrangement at the hospital florist and was told when I got to the ward that I couldn’t bring them in. I never received a brochure as I was a close family friend, perhaps her daughter got the brochure”

**Service Gap 90:** Families and friends are not adequately informed and therefore paying money for flowers and arrangements that they are then not permitted to bring onto some wards.

**Recommendation:**

- Review policy and communication processes surrounding the restriction on flowers to Gosford Medical Ward 2 with Infection Control, the literature and other Local Health Districts.
- Review bed allocation for patients who are palliative and EOL.

#### 14.4.1 Food Services

The preparation and supply of food and fluids to patients when they are approaching EOL is an area that is often overlooked during their stay in hospital. Patients are often receiving food and fluids when their condition has deteriorated and they are no longer able to consume oral intake. Food Services staff, Nurses and patient’s families all reported feeling very uncomfortable in this situation.

“My wife has been unconscious for three days and every day at breakfast, morning tea, lunch, afternoon tea, dinner and supper I am reminded of that, as the food staff knock on the door and ask me if she would like her

**Service Gap 91:** When a patient is no longer conscious and able to consume food and/or fluids their diet is often not changed to Nil By Mouth at ward level in eMR. This results in the patient receiving regular delivery of food and fluids from Food Services up to six times per day.

**Recommendation:**

- Consider the changing of a patient’s diet status to Nil by Mouth when they are deemed unsuitable for further oral intake.
- Nursing, Medical and Speech Pathology staff to be reminded on the importance of changing a patient’s diet status in eMR when a patient is deemed unsuitable for oral intake.

### 14.5 Barriers to EOL Care in Hospitals

#### 14.5.1 Knowledge of ACP tools

Some Nurses do not have a comprehensive understanding of validity and authority of ACP instruments. While almost all Nurses knew ACDs could be changed, many were unsure as to whether ACDs needed to be witnessed by a lawyer or whether a doctor had to follow ACDs made according to proper procedures. A significant minority thought an enduring guardian was able to make decisions for a person still judged to have capacity. Many nurses thought an enduring power of attorney could make medical decisions (as well as financial decisions).

#### 14.5.2 Common Barriers to Optimal EOL care

Common barriers reported by Nurses were:

- Doctors continuing active treatment for too long
- Families who have unrealistic expectations of the patient’s prognosis
- Patients not having an ACP
- Doctors not having required discussions with patients and families
- Doctors providing inappropriate or insufficient pain relief.

**Service Gap 92:** There are a number of barriers to EOL care at CCLHD Hospitals

**Recommendation:**

- Earlier, and more comprehensive, discussions between Medical staff and patients/families.
- Earlier, and more frequent, referrals to palliative care services and access to after-hours palliative care.
- Enhanced EOL education programs for both Medical Staff and Nurses.
- Clear, early, and unambiguous documentation of patient's wishes.

### 14.5.3 CEC End of Life Program Last Days of Life Toolkit

This toolkit has been developed by the CEC to assist clinicians by providing standardised tools to manage the dying patient. These tools were piloted last year (CCLHD was not a pilot site) and were rolled out across the state in April/May 2017. It will be important for CCLHD to consider adopting these tools at a local level.

**Service Gap 93:** There is currently no standardised EOL care toolkit available for clinicians providing EOL care, and patients do not receive a standardised level of EOL care.

**Recommendation:**

- Review the CEC Last Days of Life toolkit and consider appropriateness of implementing the toolkit at CCLHD.

## 14.6 Resuscitation Plans

Clinical review of notes and discussions with Nursing and Medical staff highlighted that there is a lack of clear direction and documentation surrounding resuscitation plans. Medical staff were reported to sometimes speak to patients using medical jargon that patients and families did not understand. Clinical reviews also revealed that what is often documented on the resuscitation plan does not match what is documented in the Medical notes.

Palliative and EOL care patients are often noted to be not for resuscitation (NFR) but still for Rapid Response and transfer to ICU. It was also noted that approximately 30% of resuscitation plans were filled out in the ED with no conversations taking place with treating teams. Subsequently, when the patient arrived at the ward a conversation was had with the family by the treating team and the plan was altered. This was reported to be a significant concern within this review by patients, carers and staff.

### 14.6.1 Altered Calling Criteria

Altered calling criteria is often nurse-led in the wards. Nurses request the medical team (as they do not initiate this change) to adjust the clinical review criteria to avoid having to call rapid responses for EOL patients. If the criteria has not been documented as being altered, then Nursing staff are legally required under 'Management of the Deteriorating Patient' to call a Rapid Response. There is a strong desire by Nursing staff to reduce and prevent the number of Rapid Responses that are called.

"No-one spoke to us about a NFR for Dad until the doctors came to resuscitate him. At that point we said stop we don't want this, he was dying, we were just waiting for him to die but the paperwork hadn't been filled in. It was an awful experience - there were so many people".

"There are a lot of Rapid Responses called on palliative patients because they meet the criteria for a deteriorating patient. The nursing staff know that it shouldn't be called but have to as the treating medical team haven't initiated altered calling criteria. It is unnecessary stress for the patient and family and resources for the ICU rapid response team".

**Service Gap 94:** There is a need to include all stakeholders in the decision-making process surrounding the completion of resuscitation plans to ensure that these are completed by the correct medical team early in the patient's admission.

**Service Gap 95:** There is a delay in completing resuscitation plans and initiating altered calling criteria.

**Recommendation:**

- Review the process surrounding the completion of the resuscitation plan and altered calling criteria for palliative and EOL care patients. Ensure that it is linked to the EOL care pathway process.
- Consider development of a comprehensive training package for Medical Officers regarding use of resuscitation plans for palliative and EOL patients.

## 14.7 Withdrawal of Active Treatment

It was evident through clinical reviews and interviews with Medical and Nursing staff that there is a disjoint between the commencement of EOL care and the withdrawal of active treatment. Areas identified include:

- Lack of clear goals of care. Patients who are on EOL care pathway and patient/families are informed that they have a few weeks/days to live, yet are given NG feeds/IV fluids and given radiotherapy whilst engaged with the SPCS who are supporting their terminal care. This is confusing for patients and families
- Nursing staff are distressed at hooking patients up to chemotherapy when they are terminal
- Patients being sent for blood tests and medical imaging when they are terminal
- Lack of EOL care and ACP for patients
- Clear goals of care and treatment are not documented and shared with the patient, family and all Medical, Nursing, AH and support staff involved in the patient's care
- Different language documented in the medical record which makes it unclear as to the intent of treatment i.e. comfort care, withdraw measures, palliative care, no active treatment, quality of life care, full palliation
- Patients still have SAGO charts but are started on comfort care assessment charts
- Nurses are often concerned at the lack of care direction being provided by medical teams and have to support families and try to advocate for them
- Oncology patients can have chemotherapy running and the person dies the next day
- Cancer care coordinators often can't get to inpatient referrals immediately which results in changes to treatment plans by Medical practitioners
- There is a perception amongst Nursing and AH staff that cancer specialists have a reluctance to withdraw active treatment, and patients are receiving treatments that have significant side effects. Palliative care patients are having active radiotherapy cycles for reasons other than symptom management before going to an RACF for EOL care. This has a significant impact on patient flow
- There is confusion reported surrounding the consent process for chemotherapy for inpatients. It has been reported that there is no written consent for chemotherapy and that the decision to commence chemotherapy is made by the consultant and family following a discussion and verbal consent is obtained and documented in the medical notes
- The Medical model has become curative and many patients/families expect treatment options to be presented even when a patient is in the deteriorating phase of their illness
- As Medical staff specialise in active treatment, there is a perception from patients that some Medical clinicians disengage when the patient is deteriorating or terminal.
- There appears to be a reluctance in the clinical death reviews conducted for medical teams to palliate or withdraw treatment until Day 2 before death.

"We were told there were no further treatment options for my wife so we were preparing for her death and thought she had been through enough treatment. A doctor came along and told us that we could try some more chemotherapy two days later. We were angry as we were then left in a position to make another decision and didn't want to make the wrong one. They have no idea what that does to a family mentally".

"It is heartbreaking trying to support palliative care patients. There are no clear treatment goals documented. We support families through difficult decisions and are there to pick up the pieces when the Medical team leaves the room. To then have them change their mind which is not always documented is distressing for the patient, family and nursing staff".

**Service Gap 96:** There are unclear documented goals of care and withdrawal of active treatment for palliative and EOL care patients in the hospital setting.

**Recommendation:**

- Review the content and usage of the EOL care pathway and all documentation to ensure that it is aligned and consistent, including goals of care, advance care plans, not for resuscitation, resuscitation plans and altered calling criteria. This will ensure that it is clear what the treatment plan is for a patient, this is documented and discussed with all stakeholders including the patient and family.
- Review the withdrawal of treatment for cancer patients and process surrounding consent under the scope of the CCLHD Comprehensive Cancer review being undertaken.

## 14.8 Pastoral and Spiritual Care

Access to pastoral and spiritual care is outlined as an essential domain to ensure that a patient receives holistic palliative and EOL care. Pastoral care can assist a patient to deal with their life-limiting condition and enable them to discuss any concerns relating to the process of dying when they are approaching EOL. Patients and their carers confronted with a life-limiting condition and death can often experience spiritual distress.

### 14.8.1 CCLHD Pastoral Care Service

CCLHD has access to pastoral care at Gosford and Wyong Hospitals during business hours. There is a limited part-time service provided to Woy Woy Hospital. The Pastoral Care Service currently reports to the Executive Director of Nursing and Midwifery and operates under a MOU between the MoH and the Civil Chaplaincies Advisory Committee NSW. The pastoral care workforce is made up of paid pastoral care workers and volunteers.

### 14.8.2 Access and Referral to Pastoral Support

The CCLHD Chaplain's Department and Chaplaincy Committee has developed a CCLHD Standard Operating Procedure (*Religious Denomination Support Services*) that highlights the process for accessing religious support services for patients and their carers. This Standard Operating Procedure has not been published on the CCLHD Intranet page. The Pastoral Care service does not receive referrals via eMR and relies on Nursing and Medical staff, Social Workers and families to make referrals to the service. The pastoral care service documents patient contact, however these are not consistently recorded in eMR by pastoral care workers or volunteers. This can make holistic care and access to these notes by other members of the MDT team difficult.

### 14.8.3 Religious Considerations when Caring for the Patient

In order to provide religiously (faith or spiritually) appropriate care and support to patients, their families and significant others it is essential that religious status is confirmed on referral or admission to the service and included in the development of any care plans for the patient. It is equally important to note that there can be specific religious considerations that need to be factored into the care of the terminally ill patient and when caring for the deceased patient after death. This can include viewing of the body, washing of the patient by the family and the need for religious and cultural ceremonies.

The palliative care review has highlighted a number of service gaps related to access to and provision of pastoral and spiritual care for palliative care patients. These include:

- Patients are not able to access pastoral and spiritual care support during their continuum of care following diagnosis with a life-limiting condition
- Staff are unaware of how to refer to pastoral care
- Staff are unaware of how to care for patients from various religious denominations
- Pastoral care staff are not included in case planning and EOL care discussions.

"I was so appreciative that I was able to have Dad's last rites read prior to his death. We were lucky that he held on as the priest wasn't available over the weekend".

"I was unclear how to access pastoral care as I couldn't find anything on the Intranet page".



“There are so many religions to consider. It would be helpful if there was a guide that explained what needs to be considered for each religious denomination when caring for patients and the deceased”.

**Service Gap 97:** There is decreased awareness of and access to the pastoral care service for palliative care patients in the acute setting, sub-acute setting and community.

**Service Gap 98:** There is an opportunity to develop clear Pastoral Care guidelines surrounding referral pathways, caring for patients from varying religious denominations and documentation processes.

**Service Gap 99:** There is no dedicated Palliative Pastoral Care Chaplain on the Central Coast, or linked to the SPCS.

**Recommendation:**

- Review referral pathways, documents surrounding pastoral care and documentation standards for the pastoral care service to ensure it meets the needs of the referrer and MDT team.
- Review available resources suitable for staff to refer to surrounding various care requirements of religious denominations.
- Review the current Pastoral Care staffing in the Central Coast to ensure that it meets the needs of the Central Coast population and the policies of the MoH. An increase in hours could enable provision of pastoral care education to the community and health professionals as well as increased support for patients in the acute, sub-acute and community setting.
- Include the Pastoral Care service in the development of palliative models of care and any discussions surrounding support to designated palliative care beds or services.

## 14.9 Location of Death

It has been well documented in the literature that death has become institutionalised. There are various societal reasons including lack of social and family support, shared living arrangements, fear, emotional and economic reasons that impact on a patient’s choice to die at home. Patient age, medical condition, frailty and multiple comorbidities also impacts on place of death.

The location of death for a palliative care patient is something that can often be planned for with appropriate support, and through the development of a coordinated care plan with the involvement of the patient, family and all health professionals and service providers involved in the patients’ care. The decision to die at home is often the preferred option for patients and their family and friends as it increases their control over care, provides the comfort of familiar surroundings and privacy, access to gardens and nature, unrestricted visiting hours and drop-in support from friends and family, choice of comforts such as times to eat, watch television, go to bed and attend personal hygiene.

There are a number of issues surrounding why palliative care patients do not get to die at home including:

- Patients have limited choice about the location of their death
- Patient’s dying wish is not fulfilled due to lack of support for carers and families
- The SPCS are unable to meet the needs of all families due to resourcing to the service
- Carer fatigue and lack of support and in-home respite available to carers of palliative care patients.

There is an increase in the number of patients dying in the hospital setting which impacts on resources, finances and bed demand.

“My husband wanted to die at home and I wanted to fulfil his dying wish, it was the least I could do. The SPCS were fantastic but it just didn’t all join together. I needed help with finances, transport, respite, my GP didn’t do home visits, I was emotionally and physically exhausted. I just couldn’t do it so he was placed in a nursing home. I will always feel like I failed him.”

“There has to be more resources provided to the SPCS to enable them to do the wonderful job that they do in supporting people to die at home and out of our hospitals”(GP).

**Service Gap 100:** There is limited choice for patients on the Central Coast surrounding location of death.

**Service Gap 101:** There is a lack of resourcing for the SPCS and support services such as respite, finances, psychological support, after-hours support, equipment, education, GP support in place across the Central Coast to support carers and families and enable patients to die at home.

**Recommendation:**

- Review the SPCS workforce and support services available and required in the community to assist patients who wish to die at home and their carers and families who are supporting their choice to ensure that this dying wish can be achieved.
- Establish a consumer working party to discuss the support that is required for carers to provide “quality EOL care” in the community and develop an EOL model of care for the community.

## 15. CARE OF THE DECEASED PATIENT

The respect, dignity and compassion shown to a patient’s family when a patient is declared deceased and the time afterwards can have a lasting psychological and emotional impact on the bereavement process and person’s coping strategies when confronted with death in the future. Whilst each situation is unique, it is essential that Medical, Nursing, AH and support staff are informed on how to interact with the family during this difficult time. CCLHD has a very comprehensive procedure **PR2011\_044 Death of a Patient in CCLHD Hospitals** which outlines the administrative guidelines and procedures that should be adhered to when caring for a deceased patient.

There are a number of situations that have been highlighted by patients and staff that require further review and streamlining in this phase of the EOL care journey. These service gaps are outlined below in subsequent sections.

### 15.1 Verification of Death/Assessment of Extinction of Life

Verification of Death is a “Clinical assessment process undertaken to establish that a person has died. Using a standard regime of clinical assessment tools, a registered Medical practitioner, Registered Nurse/Registered Midwife or qualified Paramedic can establish and document that death has occurred”. (NSW Ministry of Health, PD2015\_040).

The verification of death is a process that is the first action that must occur following the death of a patient. In some instances if the patient dies at home it will be the family notifying CCLHD that the patient has died or if the patient dies in a RACF or health facility it will be healthcare staff who are aware of the patient’s death in the first instance.

#### 15.1.1 Community/RACFs

Carers caring for palliative care patients and supporting their death at home should be given the necessary contact details and the process explained surrounding what to do when their loved one dies at home. This process will vary depending on whether the patient is registered with the SPCS or a community client under the care of their GP and specialist. The process will also depend on whether the death is expected or unexpected. There have been a number of service gaps identified in this process including:

- SPCS Nursing staff do not routinely attend a patient’s home to verify death after hours
- Families feel isolated following the death of a loved one
- GP unavailability to verify death
- The Police are sometimes required to attend the home following a patient’s death to confirm that the patient’s death is an expected death. This is particularly confronting and distressing for family members when they are put through Police interviews
- Patients often require transportation to the Emergency Department following death to verify death so that the body can be released to the Funeral Director
- Decreased education for carers and families surrounding the verification of death process
- Carers are unclear on what the process is following the death of a loved one in the community
- There is a delay in transporting deceased patients to the Funeral Contractor
- Carers are confronted with unnecessary distress following the death of their loved one in the community
- RACF nursing staff are not willing or able to verify death and as a result there is increased pressure on GP,

Ambulance and Hospital resources.

“I felt so isolated after she died. I didn’t know who to call at 11pm so laid with her until the morning”.

“The Police attended after Dad died and the subsequent interview with the Police was terrible. We felt like we had to prove that we didn’t murder Dad who had been seeing the SPCS for three weeks and finally died peacefully from cancer”.

“It is such a waste of everyone’s resources when the verification of death process is not managed well in the community. When Police are involved it has lasting impacts on the bereavement process for the family members involved”.

“As a Registered Nurse who has worked for 20 years in RACFs I am very competent in knowing when a patient has died. I will not verify death though as there is often families who do not trust that a nurse can perform this task and expect that the doctor verifies death. I will not expose myself to complaints or litigation”.

### 15.1.2 Acute Setting

The verification of a patient’s death in the acute setting can be conducted by Registered Nursing staff or Medical officers. There have been no issues identified with this process and it is mostly conducted by Nursing staff.

**Service Gap 102:** The verification of death process is not consistent in the community or RACFs for palliative care patients.

#### **Recommendation:**

- Ensure that resources and education to support the *PD2015\_040 Death-Verification of Death and Medical Certificate of Cause of Death* are reviewed and implemented, and if required local procedures are implemented to support this MoH policy.
- Develop a working party with relevant stakeholders from ED, Ambulance NSW, GPs, palliative care specialists, RACFs and HNECCPHN to review the authorised adult palliative care plan and its implementation at CCLHD.
- Convene a working party to review the verification of death process for palliative patients in the community and RACFs.

## 15.2 Notification to Family that a Patient is Deceased

The importance of empathy and delivery of the message by a Medical or Nursing staff member to a loved one/next of kin that a patient is deceased cannot be understated. This conversation will remain with the person contacted for some time. Wherever possible, it is best to have the message delivered by a staff member who has met the person being contacted. This phone conversation should take place in a quiet environment and be allocated the necessary time to answer any questions that the loved one/next of kin has. Different processes for families/next of kin exist depending on whether a patient dies within business hours or not. This is not consistent with the Caring for the Coast Strategy ‘Every patient, Every time’.

“When Mum died we told the Nurse and she said that she would call the doctor to confirm that Mum had died and to get the death certificate. After two hours we were still waiting. We left the ward to make some calls and when we got back Mum was gone and had been taken to the morgue. The communication was terrible, we didn’t know what has going on or what we needed to do”.

“It is a very difficult phone call to make to a next of kin to inform them that their loved one has passed away. It is made more difficult when you are the after-hours Registrar and you have no relationship with the patient and their family”.

“I was woken at night to a phone call from a Doctor at the hospital to advise that my husband had passed away. I was so upset I forgot to ask where he would be when I arrived at the hospital in the morning. I didn’t know who to phone to ask”.

**Service Gap 103:** There is no Social Work/Pastoral Care available after hours or on weekends. Next of kin/families are sometimes unclear as to the process that occurs following the death of a palliative patient and what they are required to do.

**Recommendation:**

- Review processes surrounding provision of Social Work and pastoral care available to palliative patients after hours and wherever possible develop a process to offer access to these services the next business day to families/next of kin.
- Promote usage of handout developed by Social Work in May 2017 to next of kin/families which outlines the steps and responsibilities following the death of a patient.
- Next of kin/families be given details of a staff member who will be their liaison until they leave the ward and the patient is transported to the mortuary.

**Service Gap 104:** Palliative care patients should be supported to consider funeral arrangements as part of their EOL care pathway and ACP. Families should be encouraged to provide the hospital with details of the funeral contractor when it is determined.

**Recommendation:**

- Provision of brochures and information to families/next of kin who have families who are palliative as part of the ACP process.

### 15.3 Certification of Death

When a patient is deceased Medical officers must follow the NSW Health policy directive *PD2015\_040 Death-Verification of Death and Medical Certificate of Cause of Death*. After confirmation that the death is not a reportable death under Section 6 of the Coroners Act 2009, the Medical officer who was responsible for the patient’s medical care immediately before death, or who examines the deceased person post death must provide notification and cause of death within 48 hours. Only a Medical Practitioner can complete the Medical Certificate of Cause of Death.

#### 15.3.1 Community/RACF Medical Certification of Death

There are a number of palliative care patients living in the community and RACF for which medical certification of death is required. The review identified a number of service gaps in the community surrounding Medical Certification of Death including:

- Unavailability of GPs to certify death due to no after-hours support, no home visiting, GP on leave or patient who does not have a regular GP
- Delay in certification of death resulting in transfers to hospital and delay in initiating funeral arrangements.

“There was a delay in organising the funeral and our relatives who had come interstate to say goodbye to my sister before she died had to return home and then come back to attend the funeral. We were told it was due to a delay in getting the death certificate as the doctor was unavailable. It was a significant additional expense our family didn’t need on top of the funeral costs”.

#### 15.3.2 Inpatient Medical Certification of Death

The certification of death in the acute facility also revealed a number of areas of improvement surrounding Medical Certification of Death including:

- Delay in Medical teams’ certification of death and completion of required documentation
- Patients requiring certification of death in the inpatient setting are often transferred to the mortuary if there is a delay in the Medical Officer attending.
- At times, patients may be transported to Emergency via Funeral Contractors or Ambulance and be Dead on

Arrival. These patients will require certification of life extinct via a Medical Officer in the Emergency Department. Once this has occurred, the patient is transported to the mortuary.

“There is a lack of value placed on the importance of completing the paperwork associated with the patient’s death in a timely and comprehensive manner. The care of the palliative patient does not stop the moment they die, it continues until the body is released to the funeral home”.

**Service Gap 105:** There is a delay in completion of certification of death paperwork pertaining to the death of a palliative patient in the community due to GP availability.

**Recommendation:**

- Review the process for certification of death and the availability of Medical Officers/GPs to complete this task.

**Service Gap 106:** There is a delay in the completion of all necessary paperwork and forms in a responsive manner following the death of a palliative care patient causing delays in progressing with funeral arrangements.

**Recommendation:**

- Review the forms, policy and processes that are followed when a patient is deceased and educate all staff in their use and the process for completion.
- Determine if there is a KPI surrounding the completion of death certificates and paperwork following the death of a patient.

## 15.4 Preparing of the Body for a Viewing

After a patient dies it is important to give the family the time that they need to be with their loved one. The viewing of the body is a choice that some will make and others will choose to remember their loved one as they were. This process will be different for everyone. Consideration needs to be given to the preparation of the body for viewing and the opportunity to allow families to have time with the patient and multiple viewings if required. The way in which a body is presented to a family can be the last visual memory they have of their loved one. Providing extra care and special touches such as ensuring the patient has the hair brushed, dentures in and even flowers on their chest can be a meaningful gesture to a grieving family.

“At another hospital, when my grandfather died they asked us to leave the room whilst they prepared his body. They asked us if we wanted his eyes and mouth closed. When we returned a few minutes later, he was positioned on his back with the sheet neatly folded on his chest, his eyes and mouth closed and a lovely little stem of flowers on his chest. He looked so peaceful, the flowers were a special touch that showed they also cared for him”.

### 15.4.1 Explanation of the Process of Viewing the Body

It is also important that staff explain to family members what to expect when they are viewing a body. For some individuals it is the first time they will have viewed a deceased person. Taking the time to explain what they can expect such as the body being cold, limbs stiffening can help the family through this process.

“I wasn’t prepared for seeing my mum with her mouth open and how cold and stiff she was. It was distressing to see and I wish I hadn’t gone in”

### 15.4.2 Cooling Plates

There are certain times when for religious and cultural reasons, needing more time to grieve or waiting for families to say goodbye, that families need to consider options to preserve the body. These can include the use of cooling plates to allow families more time to say goodbye. At present this service is not offered or supplied by CCLHD and many families are unaware of cooling options. Companies outside of the Central Coast are able to come to patients homes, set up cooling plates and pick them up from families. There is a fee for this service.

“We just needed more time to say goodbye, we had relatives coming from interstate. We were told we only had eight hours before we had to have Dad removed by the funeral director”

### 15.4.3 Viewing of the Body in the Mortuary

Patients who are unable to be viewed on the ward can be viewed in the Mortuary. The Mortuary is notified that a viewing is requested and a convenient time for the Mortuary and family arranged to accommodate the viewing. The preparation of the body and level of supervision required at the viewing will depend on whether the death is a coronial or non-coronial death.

### 15.4.4 Multiple Viewings of a Patient

At times, a deceased patient’s family may request multiple viewings of a patient before he/she leaves CCLHD hospital premises. This occurs particularly when a death is unexpected, family did not get to say goodbye, for religious or cultural reasons or when a loved one needs more time to grieve. Whenever possible, multiple viewings should be facilitated and a Social Worker advised to provide psychological and emotional support to the family.

There were a few areas of improvement that were identified throughout the review related to preparation of the deceased patient for a viewing including:

- Families not prepared for viewing and have not had it explained to them what to expect. This can be very confronting
- Lack of respect and time taken to prepare the body for a viewing
- Nursing staff unaware of, and not always following, the procedure regarding the preparation of the body for viewing (e.g. patient’s no teeth, tubes connected, dirty sheets, medical items all over the room)
- No comforts offered to families (e.g. tissues, water, seating, time to grieve and say goodbye)
- Cooling plates not offered
- Religious and cultural considerations not always followed or considered
- Absence of psychological and emotional support as death occurred after-hours or on weekends when the presence of a Pastoral Care Worker or Social Worker was not available
- Family not notified of where the body would be located when they arrived for the viewing
- Delay in preparation of the body for viewing due to delay in availability of Patient Support Services to assist with the washing and preparation of the deceased patient.

“One of the greatest aspects of my role is preparing a body for a viewing by the family. I am fortunate to be able to prepare their loved one for their in most cases a final goodbye. The way in which I present the body has a significant impact on their grieving process and is the last visual memory they have of their loved one. The dim lighting, music playing and candles all help the family at this time. The final touch in presenting the family with a rose is my parting gift to the family”.

**Service Gap 107:** The palliative care deceased patient is not always prepared for a viewing according to *PR2011\_044 Death of a Patient in Central Coast Local Health District Hospital*.

**Service Gap 108:** Families are not always provided with education, psychological and/or emotional support when preparing for and viewing the deceased patient.

**Recommendation:**

- Develop a flowchart and checklist for Nursing Staff surrounding what is required when preparing a patient for viewing.
- Educate Nursing staff surrounding the preparation of the deceased patient including review of CCLHD procedure *PR2011\_044 Death of a Patient in Central Coast Local Health District Hospital*.

## 15.5 Organ and Tissue Donation

Patients who are palliative may discuss with their treating doctors and family their consent surrounding organ and tissue donation. This should be considered as part of the discussion during ACP for all people regardless of whether they are palliative. CCLHD currently has one full time (1 FTE) Donation and Specialist Nurse position shared with Northern Sydney Local Health District. This position works business hours part time across both Local Health



Districts and is part of an on-call roster after hours.

The most common tissue donation involves enucleation (removal of the eye which is replaced with a prosthetic eye), routinely conducted in the Mortuary at Gosford Hospital. The following service gaps have been identified for the CCLHD in relation to organ and tissue donation:

- There is only 0.5 FTE allocated to CCLHD for education, family support and coordination of organ and tissue donation
- There is a myth that you cannot be an organ or tissue donor if you are a palliative patient
- There is a need to raise the profile of organ and tissue donation on the Central Coast
- There is a need to include organ and tissue donations in EOL discussions and ACP
- There needs to be education amongst Medical and Nursing staff in the inpatient and community settings surrounding the importance of discussing organ and tissue donation when having EOL discussions. This is done well in the ICU and ED settings
- There needs to be routine discussion of organ and tissue donation linked to ACP/ACD discussions. It is important that patients are encouraged to register their consent with NSW Donate for Life and their wishes are shared with their family
- Staff are unaware that there are staff within CCLHD specialised in having discussions with patients and family members surrounding organ and tissue donation.

“I thought you could only donate your organs if you were in an accident not when you knew you were dying”.

“We need to dispel the myth that palliative care patients are not suitable for organ and tissue donation. It is important that palliative care patients and their loved ones can also give the gift of life”.

**Service Gap 109:** There is decreased awareness surrounding the suitability of organ and tissue donation for palliative care patients.

**Recommendation:**

- Include conversations and develop handouts surrounding organ and tissue donation for patients diagnosed with life-limiting conditions.
- Review the current Organ and Tissue Donation staffing to the Central Coast to ensure that it meets the needs of the Central Coast population.

## 15.6 Management of Belongings and Valuables & Return of CCLHD Equipment

The final exchange with a family is often the handover of patient belongings and/or return of CCLHD equipment. This is an opportunity for staff to show empathy, compassion, provide condolences and ensure that the family are well supported as they enter the bereavement process.

### 15.6.1 Handover of Belongings and Valuables

At CCLHD, the handover of belongings is completed by the Nursing staff on the ward. The patient's belongings are packaged up, valuables collected and placed in a brown paper bag. The handover of belongings is sometimes by a staff member not known to the family or via collection at the front desk in the ward. In other LHDs they have conducted projects on the handover of belongings to patients and included information on bereavement support, a care pack and also a card to offer condolences to the family. This is all presented in a lovely bag (not brown paper bag) to the family. This initiative has been very well received in other LHDs and has been reported by families to be an extension of care provided to their loved one.

“The handover of Mum's belongings was so impersonal. I was sad to think that her remaining belongings were reduced to a brown paper bag. These were handed to me by the lady at the front desk after 5 minutes trying to locate them”.

### 15.6.2 Bereavement Support Pack

The SPCS has developed a number of brochures on bereavement support groups, counselling services and some brochures and information surrounding arranging funerals. These white envelopes are located on some wards and are inconsistently provided to families following the loss of their loved one. The information in these packs is noted to be out of date with some brochures still making reference to NSLHD when we were a shared service.

“The bereavement pack that I received from the ward was very welcomed except the contact details were incorrect and some of the information was out-dated”.

### 15.6.3 Return of Equipment from the Community

Patients who die in the community under the SPCS or with Community Nursing have often been provided with equipment to assist with their care at home. This equipment is loaned to patients from the CCLHD Equipment Loan Pool and the Occupational Therapist from the SPCS. The collection of this equipment from the home is an opportunity for staff to offer their condolences and ensure that the family is supported through the bereavement process. Whilst the collection of equipment predominately goes well, there are occasions where equipment is not collected, families are required to transport it back to the Equipment Loan Pool, families drop it off to the Emergency Department or dispose of it. This can result in loss of equipment and subsequent increase in funds required to replace missing equipment.

“I wasn’t sure what to do with the equipment that was given to me by the Nurses. I didn’t want it lying around so I donated it to the Salvation Army so that others could use it”.

**Service Gap 110:** The process for the handover of belongings and valuables to a family is considered impersonal.

**Service Gap 111:** The bereavement support information provided to families is out-dated and needs to be reviewed.

**Service Gap 112:** The equipment loaned to families to care for their loved one dying at home is not always collected or returned following death of the patient.

**Recommendation:**

- Convene a working party with consumers, carers, Nursing staff, Social Workers, Patient Experience Manager and Bereavement Services to review the Bereavement package provided to families and the process related to the handover of belongings and valuables to families.
- Review the policy surrounding the collection of equipment from the community following the death of a patient known to CCLHD.

### 15.7 Staff Debriefing Sessions

The loss of a patient can be confronting for staff involved in their care due to the circumstance or personal feelings that surface. It is important to ensure that staff are referred to the Employee Assistance Program (EAP) and also given an opportunity to debrief with work colleagues as required. It is also appropriate for wards, teams and services to have internal processes in place that build resilience in staff who work in these challenging environments. These could include:

- Individual or group Clinical Supervision
- Networking with other staff dealing with palliative and EOL patient care
- Interagency support groups
- Debriefing meetings
- Clinical supervision
- Establishment of a culture of support and understanding in the workplace
- Supported breaks and opportunities to discuss feelings with EAP and/or Nurse Manager/Team Leader.

“It is important to look after the mental health of my team. Sometimes staff will deal with a death in a certain way as they relate to it more than another death. For patients who are admitted to the ward multiple times leading up to their death we build a relationship with them and their families. We are caring for them at their most vulnerable and emotional time”.

**Service Gap 113:** There is no minimum standard surrounding debriefing offered to staff following the death of a palliative care patient.

**Recommendation:**

- Review the debriefing processes available for Medical, Nursing and AH staff following the loss of a palliative care patient.

## 16. BEREAVEMENT PHASE OF PALLIATIVE CARE

### 16.1 Specialist Palliative Care Bereavement Service

Following up a carer/loved one after the patient has died is considered to be the fifth phase of palliative care. At present, the SPCS Bereavement service predominately only sees families of patients who were registered with the SPCS. If a referral is made by a GP, the bereavement service will accept the referral for clients who were not registered with the SPCS.

The SPCS provide all of their patients' families with a letter following the patient's death, inclusive of a bereavement information pack (brochures included in this package are "Some reflections on grief at anniversary time", "Information for those who are bereaved" and information on "Bereavement support groups"), invitation to attend the Annual St. Luke's Day and a card on the one year anniversary of the patients' death. Feedback from patients is extremely positive and they appreciate that their loved one has been considered as a person rather than another statistic.

The service gaps that have been identified related to the Bereavement support provided to the Central Coast include:

- The information provided in the bereavement package is out-dated and needs to be updated and have accurate contact details included (this has commenced since the review was started)
- SPCS Bereavement Service will not accept referrals from Social Workers. Social Workers often have extensive involvement with patients, carers and their families in hospitals. Instead of being able to refer patients to bereavement they are required to send their patient to a GP for a referral. Many patients will not attend a GP to gain this referral (the Service has since introduced a self-referral model)
- Until recently, only families of patients registered with the SPCS are the only ones who can access the Bereavement Service
- Some neighbourhood centres on the Central Coast do offer free bereavement counselling, and do not require a GP referral
- There is limited access to grief counselling for patients to prepare for their own death
- The majority of counselling by the Bereavement Service is post-death. There is limited pre-bereavement counselling available for patients or their families registered with the SPCS
- There are inconsistent letters to GPs and discharge letters to GPs advising of the patient treatment plan and goals of care
- There is no standardised bereavement risk assessment conducted at CCLHD following the death of a patient
- Private hospitals and RACFs have no pathway to refer a patient's family to bereavement counselling.

"I was unable to access Bereavement support as I was unable to attend the group sessions".

"There is no Bereavement support available on the Central Coast unless you have enough money to pay for a private counsellor. There are a lot of people affected by death on the Central Coast which I am sure is reflected in the depression statistics on the Central Coast".

"There is a significant lack of Bereavement services on the Central Coast. There are so many people affected by loss and grief on the Central Coast who are unable to access any support following the loss of their loved one".

**Service Gap 114:** There is an opportunity to review service issues with the current SPCS bereavement service as outlined above, to ensure it meets the needs of palliative care patients and their families.

**Service Gap 115:** There is restricted access to Bereavement Services on the Central Coast.

**Recommendation:**

- Review the bereavement counsellor workforce, clinical supervision model, professional reporting line, governance and professional accountability.
- Ensure that the gaps identified and recommendations made during the bereavement process mapping session and documented in the Bereavement Service review are implemented. Some changes have already occurred, these need to be reviewed and evaluated for their effectiveness.

## 16.2 Rounding Post-Death

Another individual service that was identified throughout the review as providing bereavement follow up was Intensive Care. Following the death of a patient in ICU they conduct a form of 'patient rounding' whereby a phone call is made to the next of kin to express condolences, ascertain from the family positives and negatives of their care experience and answer any unresolved issues or questions of concern that may be present. This patient rounding has been highlighted by carers to be compassionate, gives the family an opportunity to thank staff and enables the family to have closure surrounding any unresolved concerns they may have had. Of significance is that the results of these discussions are shared with the ICU team at team meetings and systems and processes reviewed accordingly.

"It was so lovely to receive a call after my wife passed away. We had been on the ward for three weeks. It meant the world to me that the hospital still thought of my wife after we had left the ward".

"The loved ones really appreciate the phone calls following the loss of their relative. It gives them an opportunity to have any unresolved questions and worries answered which can help with their grieving"

**Service Gap 116:** Patient rounding is a recognised Caring for the Coast tool that is not conducted consistently throughout CCLHD.

**Recommendation:**

- Develop a rounding tool that can be used to follow up with all families following death in a CCLHD hospital or community setting registered with CCLHD. Consideration will need to be given to when and who conducts these conversations.

## 16.3 St. Luke's Day

St Luke's Day is an annual memorial service held in October. It is a non-denominational service which serves as an act of remembrance for those patients of the SPCS who have died during the last 12 months. It is usual for many members of the SPCS team to also attend, with an opportunity for families to catch up with those staff who helped them care for the patient during their final months of life. The Volunteer and Bereavement coordinators develop an order of service, and arrange for an appropriate program of activities. The Bereavement counsellors are on hand to support anyone experiencing a crisis of grief during the proceedings. Associated costs involved are currently met by the Central Coast Palliative Care Volunteers Foundation.

"St. Luke's Day is a lovely day to remember and honour my beautiful husband who I miss dearly every day".

"St. Luke's Day is a special day that the SPCS can provide bereavement support to those who have lost their loved one in the previous 12 months or in the past. It is a significant part of the grief process that loved ones begin to look forward to"

**Service Gap 117:** St. Luke's Day is not widely publicised to the Central Coast Community via invite.

**Service Gap 118:** Funding for St. Luke's Day will need to be transferred to CCLHD following closure of the Central Coast Palliative Care Volunteer Foundation.

**Recommendation:**

- Continue the annual St. Luke's Day and consider advertising to a wider audience through CCLHD Social Media and public announcements.
- Transfer the funding for St. Luke's Day to CCLHD following the closure of the Central Coast Palliative Care Volunteer Foundation

## 17. OTHER CONSIDERATIONS

### 17.1 Medical Staff Sub-Speciality Feedback

There is a varying degree of knowledge, confidence and involvement by Medical professionals in palliative and EOL care. There are some Doctors who manage their patients from diagnosis through to EOL care and do not require access to, or refer their patients to, the SPCS in the community or inpatient setting. There were however, a large majority of Medical staff who recognise that their patients would benefit from access to Specialist Palliative Care. Interviews were held with Clinical Directors, Medical Head of Departments, Staff Specialists, Visiting Medical Officers, Registrars and Junior Medical Officers to discuss. Whilst there was individual feedback specific to each discipline there were consistent emerging themes and comments. These include:-

- The trajectory of palliative care patients is often predictable and access to the SPCS is not always available
- Some patients can't and don't want to die at home (particularly young palliative care patients with young children) – they need access to a hospice or palliative care unit
- SPCS is ad hoc. If patients are referred too early they are not seen by the SPCS, or too late when requiring EOL care and it is too late to build relationships and it becomes reactive care
- Need a palliative care admitting and on-call service 7 days per week and accessible at sub-acute sites
- There are instances when patients needs are complex when the SPCS should take over care
- Treating teams can manage EOL for their own patients on the ward e.g. patient has a large stroke - can place patient in a single room and manage EOL care. Need to have a consistent approach and pathways to follow
- Access to palliative care on call is required for complex cases where medication or pain management advice is required
- Sub-specialities often aren't aware of appropriate dosages of S8 medication and pain relief to give to patients, which results in patients having unrelieved pain
- There is a strong need for junior and senior Medical officer education on EOL, EOL care pathway, pain management and complex symptom control such as agitation, nausea and delirium
- There is access to syringe drivers on some wards. The Nurses are often not sure how to use these if they do not work with them often. There needs to be increased education surrounding their use. The Palliative Care team do not support use of syringe drivers on the ward however some medical and nursing staff support their use for pain management
- There are some specialties that are good at ensuring that all of their patients have resuscitation plans and ACP completed on admission to the ward
- Admitting rights in ED – difficulty getting patients to home ward – care for palliative patients is sub-optimal if not on home ward where the specialist Nursing and AH are also located
- Motor neurone disease patients are often palliative and are not always receiving coordinated care in the community and therefore have a crisis and are rushed to hospital in the deteriorating/terminal phase. These patients often clearly state that they do not want to go to hospital. These patients fall through the gaps as managed by any combination of a GP, Community Nursing, Community Allied Health team and occasionally SPCS. Difficulties arise after-hours and on weekends
- There are numerous process issues and perceived/actual blockages to patient referral to the SPCS
- There is limited care coordination once patients are referred to the SPCS that involves the specialist

- There needs to be discussions amongst hospital staff surrounding whose role it is to complete an ACP
- There needs to be access to palliative care beds at Gosford and Wyong Hospital
- There needs to be improved recognition of the deteriorating patient
- Non-beneficial, burdensome and non-beneficial treatment needs to be minimised
- The SPCS and Medical teams often work parallel to each other rather than together to support patient care
- There is no organisational governance or plan for palliative care services on the Central Coast. Management of patients is siloed and dependent on the Medical officer's palliative care knowledge and experience
- There is an increase in incidents and complaints surrounding palliative and EOL care provision.

“Medical officers and the SPCS need to put their personal and professional differences and viewpoints aside and begin to work collaboratively so that we can all work together to develop sustainable service delivery models that improve patient, carer and staff outcomes and experiences”.

**Service Gap 119:** Medical management of palliative and EOL patients is sub-optimal at times due to internal and system factors.

**Recommendation:**

- Establish shared goals and opportunities for service improvement and work collaboratively as a Medical Workforce to provide patient-centred care and improve patient experience and outcomes for palliative and EOL care patients.

## 17.2 Renal Patients

Whilst no other population group have been isolated in this review, it is noteworthy to highlight the Supportive Care model provided to renal patients. Renal patients make up a very small percentage of the referrals to the SPCS as the Supportive Care renal service they access is funded and managed through a unique service delivery model.

The Renal service at CCLHD has developed a model that manages patients through all phases of their chronic renal disease from diagnosis through to EOL care. Patients diagnosed with renal disease account for approximately 6-10 patients per calendar year (less than 1%) of all referrals to the SPCS. They also have limited engagement of the SPCS in the inpatient setting as the Renal team manage their own patients. This highlights that the Renal service has been able to manage most of their own patients' primary and specialist palliative care needs without the requirement to escalate care to the SPCS.

The following service gaps were identified throughout the review for renal patients:

- The Junior Medical officers will occasionally request a palliative care consult prior to discussion with the consultant
- There are no options other than admission to hospital or an RACF for patients requiring EOL care. There is a need for an appropriate place to palliate patients other than hospital such as a palliative care unit on the Central Coast that patients can be directly admitted to
- There is a need to continue educating the renal Nurses to continue to initiate ACP conversations with patients. They are currently receiving this training from the Manager of Carer Support
- There is a suggestion that patients should have ACPs completed earlier
- There is a need for improved transport options for dialysis patients to units
- There is an identified need from community carers to have access to volunteers to support patients and families of home dialysis patients. It would be beneficial to be able to provide renal patients with the same support from volunteers in the community and inpatient setting
- There is a need for increased Bereavement support for patients. At present this is offered by the Social Worker. It would be beneficial to be able to link in with the dedicated CCLHD Bereavement service
- There is recurrent funding for the Renal Supportive Care Service. There are limited opportunities for its scope of use as it equates to \$72,000 per annum
- Under the Renal Supportive Care Model a staff specialist is share-funded with HNELHD and is located at John Hunter Hospital. It would be beneficial to have on-call and after hours telephone advice from the SPCS to discuss medication management and complex symptom management when the needs arise.



“There is a need to establish or use existing transport services for patients to take them to dialysis sessions. Patients can miss treatment as they are unable to receive transport assistance”.

**Service Gap 120:** There is limited access to bereavement, transport and volunteer services for renal patients

**Recommendation:**

- Conduct a needs analysis for access to Bereavement, transport and volunteer services for renal patients.
- Consider inclusion of renal patients and their needs when reviewing future opportunities for the volunteer and bereavement services.

**Service Gap 121:** Advance care planning is not regularly initiated with renal patients within a coordinated and consistent process.

**Recommendation:**

- Engage in patient and loved one education programs and provision of ACP toolkits surrounding EOL care.
- Continued education of Medical and Nursing staff in ACP.
- Improve documentation of ACP and advance care directives and provision of these in the eMR Medical record.

**Service Gap 122:** There is a need for alternative accommodation for end of life care for renal patients such as a palliative care unit

**Recommendation:**

- Investigate the establishment of a palliative care unit for EOL care to support renal patients.
- Consider direct admission by renal physicians to a palliative care unit to continue their renal supported care service.

### 17.3 Culturally Appropriate Care

There are cultural considerations that need to be factored into a number of phases of the palliative and end of life care journey for a patient. These include the place of treatment and location of death, care of the terminally ill patient, communication to the patient of diagnosis and prognosis, role of health professionals, medications, attitudes, taboos and cultural beliefs, visiting and caring for the patient when unwell, caring for the deceased patient after death including viewing of the body, washing of the patient and required religious, spiritual and cultural ceremonies.

There are a number of tools, checklists, guides and forms available for health professionals to assist with the assessment and provision of services to Culturally and Linguistically Diverse (CALD) patients and their families in the community and inpatient setting. There are a number of service gaps that have been identified when dealing with CALD clients diagnosed with life-limiting illnesses and requiring palliative and EOL care. These include:

- Lack of informed decision making by patients and carers due to difficulty understanding medical conversations
- Lack of interpreter usage for consent for surgery, EOL decisions and ACP as per required guidelines
- Use of family members as interpreters
- Lack of chronic health, palliative, EOL care and ACP information and written material translated into different languages
- Lack of understanding by health professionals of the varying needs of different cultures when providing palliative, EOL care and care for the deceased

“It is often considered too hard to access interpreters so Medical staff use family members. There is a need to ensure that CALD patients are giving informed consent to surgical and medical treatment”.

**Service Gap 123:** There is a need to develop culturally appropriate care plans for CALD patients which enables them to make informed choices and takes into consideration cultural beliefs and support systems.

**Recommendation:**

- Reinforce the need to involve interpreters when discussing Medical treatment options, having EOL discussions and developing care plans for patients from CALD backgrounds.
- Coordinate access to resources for health professionals that outline the cultural considerations required when providing Medical care to a patient, caring for the dying and caring for the patient after they are deceased.
- Coordinate access to existing written material related to palliative care conditions, ACP, palliative and EOL care services into the most common non-English speaking languages identified as spoken on the Central Coast.

## 17.4 Care for Patients Identifying as Aboriginal

The term Aboriginal represents both Aboriginal and Torres Strait Islander People throughout this document. Patients who identify themselves as Aboriginal or Torres Strait Islander may have different care needs. Consideration needs to be given to the provision of culturally appropriate care that respects ‘Sorry Business’, kinship and family relationships, place of death, healing and acceptance of death, bereavement, communication styles, the provision of education and written material surrounding medical care and treatment, ACP and death and dying rituals.

There is a significant gap in median age at death between Aboriginal and Non-Aboriginal populations. The CCLHD is currently guided by the Aboriginal Health Services Plan 2013-2017. This plan highlights the target areas for the District and Services to work towards.

The following areas have been identified as service gaps in the current service provision of palliative and EOL care for Aboriginal People:

- Lack of cultural awareness of the diversity of the Aboriginal experience at EOL
- Lack of inclusion of family and carers in treatment plans that ensure cultural safety
- Lack of identification of Aboriginal clients
- Lack of use of Aboriginal Health Workers in the assessment, care planning, coordination and management of care
- Lack of a coordinated care approach and timely access to relevant referrals and support services
- Aboriginal Liaison Officers not always contactable or accessible 24 hours 7 days per week
- Limited ACP for Aboriginal population – need individualised approach sensitive to cultural and spiritual beliefs
- Issues with My Aged Care and ACAT regarding access to services for people aged under 65
- Limited direct involvement with the Aboriginal community in developing culturally appropriate support frameworks surrounding palliative and EOL care.

“I couldn’t be transferred to the ward up north as I cannot pass on that land. I need to go in a RACF on the Peninsula”.

“There is a need for better identification of Aboriginal patients so that the rituals around EOL care can be respected and accommodated”.

**Service Gap 124:** There is a lack of identification of Aboriginal people and a lack of understanding on the cultural considerations during the palliative and EOL process.

**Recommendation:**

- Improve identification of Aboriginal patients and direct appropriate referrals to Aboriginal Health Services.
- Review Northern Sydney Sorry Business guidelines and State guidelines to develop Central Coast Death and Dying in Aboriginal and Torres Strait Islander Culture (Sorry Business) Collaborative Guidelines incorporating all agencies.
- Review the palliative pathway for Aboriginal patients with chronic health conditions.
- Develop opportunities for Palliative Care team staff and Aboriginal Health staff to collaborate to increase knowledge and understanding of each other's perspective and to lead improvement across the wider CCLHD in supporting the cultural requirements for palliative and EOL care for Aboriginal people.
- Increase Community engagement by consultation, forums and focused education on EOL care.

## 17.5 Additional Client Groups who Require Special Consideration

There are a number of populations and client groups that require special consideration when managing palliative and EOL care needs. These groups require close liaison with treating teams and support services to ensure that their special needs are considered and more importantly, that the care plan developed is coordinated and needs-based. Case coordination and conferencing with all professionals is essential. These client groups include those with:-

- Cognitive Impairment.
- Severe Communication Difficulties.
- Hearing Impairment.
- Drug and Alcohol Dependencies.
- Mental Health.
- Under 65s.

**Service Gap 125:** The needs of special client groups are not always considered in the assessment, management and care planning and coordination.

**Service Gap 126:** There is a lack of formalised palliative care pathways for the special client groups listed.

**Recommendation:**

- Develop working parties to consider the referral pathways, assessment protocols, management plans, case planning and coordination for the special client groups including: patients with cognitive impairment, severe communication difficulties, hearing impairment, drug and alcohol dependencies, mental health needs and patients Under 65. The outcomes of these decisions should be incorporated into referral pathways and future models of care that are developed for palliative and EOL care patients.

## 17.6 Carer Support

The consideration of the needs of the carer and family unit of a palliative care patient is essential in ensuring that holistic care is provided to the palliative care patient. Carers are often required to navigate health care systems and coordinate services for their loved ones, assist in making EOL care decisions and advance care planning, providing emotional, psychological and physical care to loved ones at home, manage pain and administer medications, provide personal hygiene care and support activities of daily living. Carers are often unable to access respite for patients, especially respite care in their own homes so that the patient does not require relocation.

Carers reported that whilst their loved ones want to die at home that is not always what they want and they fear that they will be unable to psychologically, emotionally and physically do so. It is essential that a carer capacity assessment is carried out for each primary carer to determine if they are both able and willing to perform the caring role, and so that appropriate support strategies are put in place.

Consideration should also be given to patients who are a carer themselves. Alternative arrangements for care whilst the patient is admitted to hospital needs to be discussed with the patient/carers. Carers will also be given details and

information on the Commonwealth Carer Support Service who can provide short term respite. Further Carer information should be accessed through the Carer Support Unit and be provided through the Carer Support Unit pamphlet "What Carers Need to Know".

"Caring for your dying partner feels like a very isolated task. I provided care that I never thought I could. I had no sleep and no access to respite. If it wasn't for my beautiful friends I would never have been able to do it".

"Nobody asked me if I was happy to give my husband his breakthrough medications. I didn't want to see him suffer but I also didn't want to be responsible for giving him the last dose that put him to sleep forever. I couldn't do it so my neighbour did it for me even in the middle of the night".

"The needs of carers looking after palliative care patients are often neglected. We expect them to be carer, nurse, partner, emotional supporter, cook, cleaner all with no sleep and going through their own grieving process".

**Service Gap 127:** The needs of carers are often overlooked when managing palliative care patients in the community and inpatient setting.

**Service Gap 128:** There is a lack of respite support for carers of palliative care patients.

**Recommendation:**

- Include carers in discussions surrounding care planning, case coordination and transfer of care.
- Review the respite services available for carers of palliative care patients.
- Refer patients to the Carer Support Unit when attending Gosford Hospital.
- Consider establishment of a Carer Retreat at Wyong Hospital and a Carer Corner with resources for carers at Long Jetty and Woy Woy Hospitals.
- Increase Carer support in the community for carers managing loved ones receiving palliative and EOL care. This needs to include review of processes, and the usage of carer capacity assessments.
- Ensure carers are given details on how to access Carer Support Groups available on the Central Coast.

## 18. Advance Care Directives and Advance Care Planning

There are numerous, guidelines, toolkits, templates, education programs and quality improvement projects that support the ACD and ACP processes. CCLHD has developed a comprehensive patient information workbook and pamphlet titled *"Have a say in your health care – advance care planning. Think about it. Talk about it. Share it"*. These information guides clearly outline to patients and members of the community what ACP is, what an advance care directive is, provide patients with exercises to consider their values and beliefs and provide a template that can be utilised by patients and community members to complete their ACP and directive. The ACP and directive process is governed by the EOL/ACP committee.

### 18.1 Advance Care Planning Flagging System

There has been evidence in the literature and suggestions by many staff within the LHD that there needs to be targeted populations who are recommended to have ACP. This may include:-

- Patients over a specific age.
- Patients with chronic conditions.
- Patients with certain diagnoses.

### 18.2 Advance Care Planning Team

There are other LHDs who have improved their uptake of ACPs and ACDs through the employment of an ACP coordinator and ACP team. There are other LHDs who have targeted ACP success, including Hornsby GRACE, Prince

of Wales, Hunter New England, Austin Health (Respecting Patient Choices Program).

### 18.3 Special Populations to Consider

When implementing a framework for ACP it is important to place special consideration to the following groups:-

- Aboriginal people.
- Culturally and Linguistically Diverse population.
- Patients with an Intellectual Disability.
- Patients with Mental Illness.
- Patients with Decreased Cognitive Capacity and/or communication difficulties. There is a framework that has been developed by the Cognitive Decline Partnership Centre in conjunction with HammondCare titled *'Future Planning and advance care planning – Why it needs to be different for people with dementia and other forms of cognitive decline'* (January 2016) that should be reviewed when implementing an ACP for people with dementia and cognitive decline.

### 18.4 ACD Quality Improvement

There is currently no mandated ACD form in NSW. There are a number of issues that have been highlighted in relation to ACP throughout this review including:

- Reactive ACP – families are being forced to make stressful decisions surrounding EOL care without having discussed them with the patient first
- Need to commence earlier ACP so that patients can have an opportunity to develop an ACD or be involved in their ACP
- Patients are unaware of what they are signing
- Medical and Nursing staff are afraid of the legal implications of following or not following an ACD
- There is no ownership or whose role it is to commence ACP – Medical Specialist, GP or Hospital staff
- There are a significant number of ACPs being discussed in the ED or by the ICU team following a Rapid Response
- There is a lack of early identification of patients who would benefit from ACP
- There is reluctance amongst SPCS staff to facilitate ACD/ACP with patients as there is a perception that this document will replace a conversation with the patient
- ACP does not replace a conversation with a patient and their loved one
- There is a lack of coordination surrounding ACP at CCLHD and in the community
- There is a lack of understanding surrounding the ACP in the community and knowledge of tools to facilitate these discussions
- All patients diagnosed with cancer/chronic programs need a session and education on ACP
- Once the ACP is completed how does the hospital know it exists and where do you keep it?

“I wish someone had told us about ACP earlier. We never talked to Dad about what he wanted as he was a private man and kept brushing off the subject. It was really hard to make decisions surrounding his EOL care as we really didn't know what he would have wanted”.

“So I have completed an ACP and shared it with my family and GP. Now what happens when I come to hospital? Do I have to carry it in my back pocket? How do I make sure they don't resuscitate me?”.

“Every patient who has been diagnosed with a life limiting illness should have an advance care plan or advance care directive”.

**Service Gap 129:** There is a lack of knowledge, education and awareness of the importance of ACP amongst patients, Medical staff and within the Central Coast Community.

**Service Gap 130:** There is a lack of proactive ACP in the community and inpatient settings, resulting in reactive and emotive ACP and decisions surrounding EOL care.

**Recommendation:**

- Develop an organisation-wide approach to ACP that is governed by the ACP/EOL care committee.
- Consider ACP clinics at CCLHD. Patients would be booked into these clinics who meet a set criteria and are identified as diagnosed with cancer, dementia, progressive neurological disease or chronic conditions such as chronic heart failure, renal or liver disease.
- Develop criteria to ensure that all patients who have had a set number of readmissions and/or type changed to palliative care have an ACP in place.
- Liaise with RACFs to ensure that all patients admitted to RACFs have an ACP plan completed. These ACPs need to accompany all patients to hospital.
- Educate the community via community groups, workshops and support groups surrounding the importance of conducting ACP.
- Educate and provide Medical Specialists and GPs with a tool to assist in ACP conversations with patients.
- Develop a process whereby ACPs can be sent to the hospital to be uploaded into eMR against the eMR tab.
- Develop a clinician-led ACP model whereby patients are identified who would benefit from an ACP and the clinician is required to identify if one exists, review the ACP, locate the ACP and/or discuss with patient. Consideration of employment of staff with ACP skills and a coordinator within the LHD.
- Review the CCLHD ACP patient workbook and brochures to ensure that they still meet the needs and health literacy levels of consumers.

## 19. EDUCATION

Throughout this review there was a strong emphasis on the desire for education surrounding palliative and EOL care by patients, carers, consumers and staff in the community and hospital setting. Education was also highlighted as a gap amongst RACFs, private hospitals and NGO providers.

### 19.1 Raising Community Awareness and Expectations Surrounding Death and Dying

It was highlighted throughout the community forums and following discussions with consumers and patients that there is a lack of community awareness surrounding palliative care, ACP and how to access these services on the Central Coast. Community members mentioned how they were unaware what palliative care was and knew nothing about it until they were required to access it.

It is this lack of understanding that can lead to patients being unfamiliar with what palliative care can offer that causes them to refuse referral at the early stages of their life-limiting illness as they are frightened of the unknown and unaware of the benefits.

#### 19.1.1 National Palliative Care Week

This is an annual awareness raising week organised by Palliative Care Australia. In 2017 the theme is ‘You matter, your care matters. Palliative care can make a difference’. On the Central Coast the SPCS can use this week as an opportunity to raise awareness of palliative care within the Central Coast community and hospital setting. Each year National Palliative Care is held during the month of May. The SPCS does not conduct activities in the community or inpatient settings due to limited resources.

“This forum on palliative care has been fantastic. I had no idea what palliative care was. I thought it was only accessed when you were about to die”

“There are several staff who would like to conduct activities and raise awareness of palliative care during Palliative Care Week but we do not have the time, resources or support to do so”



**Service Gap 131:** The community don't feel informed about Palliative Care and the role it has in caring for the dying.

**Service Gap 132:** There is an opportunity for the SPCS and CCLHD to engage in National Palliative Care Awareness Week activities.

**Recommendation:**

- CCLHD could participate in National Palliative Care Awareness Week on an annual basis.
- Consider holding community forums to raise awareness of the role palliative care plays in supporting "Quality Living, Quality Dying and Quality Grieving"

## 19.2 Access to Palliative and EOL Care Education

Access to palliative and EOL education for staff can be, and is, provided in a variety of ways. Knowledge of the education options is limited amongst health professionals and it is believed that it is the role of the SPCS to share websites and information about education that is available for staff within CCLHD and within the wider Central Coast community.

Current options for increasing knowledge about Palliative and EOL care include:-

- My Health Learning
- NSW State Funded Education Initiatives, e.g. PEPA
- Education provided by the Specialist Palliative Care Service, medical student placement, full day intensive Advanced Palliative Care Study Day twice a year.
- Medical Grand Rounds

### 19.2.1 Education Requested by Staff

There are a number of internal and external Medical, Nursing, AH and support professionals who are involved in the provision of palliative and EOL care services on the Central Coast. There was a consistent theme amongst all professionals who work outside of the SPCS for a desire to receive education and training around:-

- EOL care.
- What is palliative care and when does it begin?
- ACPs and ACDs.
- Medication management – prescription of opiates and pain management.
- Managing agitation in patients.
- Complex symptom management.
- Management of syringe drivers.
- Referral pathway to palliative care.
- Bereavement Support.

"There should be palliative care education available to Nursing staff in the community and on the wards as we are treating dying patients every day".

"If the palliative care team is too busy for education, it would be useful if they could provide access to good on-line training modules that Doctors and Nurses are able to access"

"If there was access to education on managing end of life care I would be able to better treat my patients and potentially avoid sending them to hospital". (GP)

**Service Gap 133:** Medical, Nursing and AH staff do not believe they receive adequate training in palliative and EOL care.

**Service Gap 134:** Service providers such as GPs, RACFs, specialists and NGO providers receive limited education on palliative and EOL care.

**Recommendation:**

- Identify 'My Health Learning' modules that are red flagged 'Mandatory' or blue flagged 'CE directive' for certain workforce groups to ensure increased access and improved knowledge in the provision of palliative and EOL care.
- SPCS to continue to promote state-funded education initiatives to internal and external staff.
- Education provided by the SPCS to increase in frequency as resourcing allows.
- Review and promote the existing SPCS website/intranet page with access to palliative care apps and education links that would be useful to assist Medical, Nursing and AH staff to provide evidence-based and quality palliative and EOL care services.
- Conduct annual GP education nights on targeted topics.
- Continue to provide education forums to NGO provider and RACFs as resources allow.

**Service Gap 135:** Specialist Palliative Care is not included on the Medical Grand Rounds Educations roster at Gosford Hospital.

**Recommendation:**

- Suggest Specialist Palliative Care Medical staff present in Grand Rounds for an agreed number of times per year at both Gosford and Wyong Hospitals.

### 19.3 Interagency Network Group

This review identified that there is a wide variety of health professionals and support services involved in palliative and EOL care in locations such as public and private hospitals, RACFs, GP practices, other community settings and patients' homes. There is a desire and request by many stakeholders to share knowledge and resources for the advancement and benefit of patients and service providers on the Central Coast.

"It would be great if we could all pool our knowledge and resources to ensure that as a Central Coast region we are able to provide high quality evidence-based care".

**Service Gap 136:** There is no interagency Palliative Care Network on the Central Coast.

**Recommendation:**

- Develop an interagency Palliative and EOL care interagency network.

## 20. CORPORATE AND CLINICAL GOVERNANCE FOR PALLIATIVE CARE PATIENTS ON THE CENTRAL COAST

The provision of care to palliative and EOL care patients across the Central Coast is not coordinated and governed from a District perspective. There is a siloed approach with some divisional governance structures but there is no overall strategy for palliative and EOL care from a CCLHD view. There is a need for an integrated governance structure with an organisational strategic direction.

"There is a desperate need to have a strong strategic direction and governance structure from an organisational viewpoint if we are really serious about improving the patient/carer/staff experience, patient/carer outcomes and providing quality care"

**Service Gap 137:** There is currently no organisational governance structure and strategic plan which meets the needs of palliative and EOL care patients. This results in a lack of ability to review palliative and EOL service and patient outcomes from a holistic and strategic view

**Recommendation:**

- Review the governance structure for Palliative and EOL care at CCLHD to ensure that there is an integrated governance structure
- Develop a strategic plan for palliative and EOL care on the Central Coast inclusive of external agencies.
- Consider the appointment of a Director of Palliative Care to provide leadership, governance and strategic direction for palliative and EOL services in the Central Coast Community.

## 21. COMMITTEE STRUCTURES

The District has two management/operational committees that are involved in planning surrounding palliative and EOL care patients. These include:

### 21.1 EOL/ACP Committee

This meeting is chaired by the Service Manager of Specialist Palliative Care. The identified purpose of the meeting in the terms of reference is to 'lead a strategic approach that enables key elements associated with ACP; use of advance care directives (ACD); and EOL care to be appropriately incorporated within acute and sub-acute inpatients; and community-based service delivery within CCLHD'.

### 21.2 Deteriorating Patient Committee

This meeting is chaired by the Staff Specialist Intensive Care. The identified purpose of this meeting in the terms of reference is to:

- 1) Support and monitor the Clinical Emergency Response Systems; the Between the Flags; Sepsis (Adult and Paediatric) and Patient and Family Activated Response Programs; and any related initiatives as required by the NSW MoH 'pillars' and
- 2) To ensure CCLHD divisions and departments are provided with relevant information with regards to all processes associated with the identification and management of deteriorating patients.

**Service Gap 138:** There is an opportunity to review the recommendations of this report and how they link into the EOL/ACP and Deteriorating Patient Committees.

**Recommendation:**

- Establishment of working relationships with the above committees and the proposed new Palliative and EOL Care Advisory Panel and Steering Committee, to ensure an integrated approach to palliative and EOL care across the LHD.

### 21.3 Morbidity and Mortality Meetings

Morbidity and Mortality meetings (M&M) are meetings "held on a regular basis to review and critically analyse deaths and serious morbidity in patients within a specific clinical group or specialty. The focus of these meetings is on the systems and processes of care for an individual patient and not on an individual clinician's performance. There is an opportunity to identify whether optimal care was provided to the patient and if there are opportunities for system improvement(s) such as whether a patient's symptoms were controlled, appropriate conversations held in a timely manner and appropriate escalation of decisions and goals of care made" (Clinical Excellence Commission 2016: Clinician's Guide to Quality and Safety, pg. 19). It is a CCLHD requirement of sub-specialties to conduct Morbidity and Mortality meetings. There are some specialties who conduct these meetings on a monthly basis whereas others conduct these on a quarterly basis. It has been identified that some specialties do not conduct these meetings. Specialties are requested to send the minutes from these meetings to the Clinical Governance Unit who are then able to monitor trends. The review highlighted the following:-

- There is no standardised process for these meetings (how often held, patients discussed, terms of reference or

minutes taken) within the District.

- Depending on the specialty, the selection of the patients and discussion held varies.
- The SPCS do not hold regular Morbidity and Mortality meetings.
- Many of the palliative care deaths that would benefit from discussion at these Morbidity and Mortality meetings are discussed within a single discipline and not referred onto another sub-speciality for their input.
- There are no interdisciplinary meetings within the District where Palliative Care patients can be discussed with the input of all sub-specialities and health professionals involved in the patients' clinical care.
- There is no standardised process whereby a death identified by Clinical Governance through the Death Database Review, RCAs, complaints or incidents can be forwarded directly to a sub-speciality or overarching interdisciplinary meeting for a review.

“There is no Morbidity and Mortality process to review palliative care patient deaths of those who are registered with multiple services and have had input from multiple Medical sub-specialities. This results in many missed opportunities to make improvements to patient care”.

**Service Gap 139:** There is an opportunity to develop District standardised process for Morbidity and Mortality meetings to discuss palliative and EOL patients who have received care from multiple sub-specialities, service providers and locations (i.e. community palliative care, cancer care and admission to hospital).

**Recommendation:**

- Develop a process whereby palliative and EOL care patients who are seen by multiple sub-specialities and service providers can be reviewed in a standardised Morbidity and Mortality meeting process.

## 22. INFORMATION MANAGEMENT AND TECHNOLOGY

### 22.1 E-Health and Telehealth

The NSW Health Palliative Care Plan 2012-2016 highlights the increasingly important role that technology plays in linking primary and tertiary care providers to improve patient care particularly medication regimes and Medical histories. There is currently very minimal uptake of telehealth initiatives for palliative care patients to support care planning and coordination on the Central Coast. Telehealth could provide significant benefits in terms of resource allocation and remote monitoring of patients at home and in RACFs.

### 22.2 Electronic Medical Records

There are functional gaps in clinical documentation due to the diverse range of services and locations that provide palliative and EOL care. Inpatient settings in CCLHD use eMR, as do community and inpatient staff of the SPCS. CCLHD does not have access to medical records of private hospitals, private nursing services, NGOs and GPs/Specialists, and vice versa. Community Nursing and all other Community LHD services use Comcare, which means that even if all service provision for a palliative client is provided by services wholly within the District, two IT systems need to be investigated in order to develop a full picture of the patient's care needs.

**Service Gap 140:** There is minimal use of telehealth and a lack of a centralised electronic medical record for the management of palliative and EOL care patients.

**Recommendation:**

- Review telehealth options utilised in other LHDs to support the management of palliative care patients in the community and RACFs
- Investigate options for appropriate and effective ways of sharing clinical information electronically between relevant service providers

## 23. RESEARCH AND QUALITY IMPROVEMENT

The CCLHD Research Governance Office (RGO) governs the research and low risk quality improvement projects

(intended for publication) that are undertaken at CCLHD. A review of the RGO research database revealed that there are currently five Quality Improvement projects and three Research projects registered as being underway at CCLHD that are related to palliative and/or end of life care, and include:-

- ‘No CPR’ Orders: does documentation ensure compliance? 0516-057C
- Evaluation of JMO Confidence in accurate Death certification – Adequacy of current training methods in Gosford District Hospital. 0915-078C
- Rate of Resuscitation Plans completed at time of death in Wyong Hospital – an audit, 0516-058C
- Advance Care Directive Documentation: Issues for Clinicians, 0416-044C
- Carers and patients facing the end of life have significant information needs. Provision of such information may assist in improvement of Patient and Carer knowledge and reduce stress, 0316-023C
- Authorised Documentation. Evaluating the efficacy of the Palliative Care Home Support Program: an end of life support program for palliative patients and their families, 0814-063C
- Nurses view of end of life care in hospitals 0916-086C
- Efficacy of Normalisation of Advance Care Planning for People with Chronic Diseases in Acute and Community Settings. TRGA, Round 2. Project 116

**Service Gap 141:** There are a number of quality improvement and research projects that have been registered as being undertaken at CCLHD. The results or progress of these projects have not been communicated with the appropriate Tier 3 Manager and Research Office as required.

**Recommendation:**

- Quality Improvement and Research reports to be provided to the Research Office at the conclusion of the studies. These should also be shared amongst peers and encouragement to submit for quality awards, conferences and via journal articles be sought to ensure that lessons learnt are shared.

**Service Gap 142:** There is an opportunity to develop a structured written quality improvement or research plan for Palliative and End of Life Care services on the Central Coast.

**Recommendation:**

- Develop a Palliative and End of Life Care Research Plan incorporating components highlighted within this review that are relevant for future Quality Improvement projects, research projects and translational research grants.
- Recommend that resources that are being provided to projects being undertaken are deemed as high priority/service gaps for CCLHD.

## 24. INCIDENT REVIEW AND PATIENT EXPERIENCE FEEDBACK

There have been a significant number of complaints and incidents surrounding palliative care and EOL care for inpatients and patients residing in the community. Whilst some of these have centred on clinician error with medication or complaints between clinicians, there are consistent themes that emerged from three years’ worth of complaints and IIMS data reviewed. These include:

- Lack of coordinated care throughout inpatient journey and/or the community
- No on call or after hours service for specialist palliative care
- EOL care pathways and EOL care
- Activation of rapid responses
- Lack of ACP
- Lack of access to community and inpatient SPCS
- Lack of designated palliative care unit with comforts for families
- No after-hours/weekend Medical or Nursing support by palliative care team Staff Specialists
- Lack of respect for values, preferences and expressed needs of family members
- Lack of information on symptom management and the EOL care process
- Poor pain management in the acute setting, lack of access to syringe drivers and breakthrough medications that are readily available in the community provided by the Specialist Palliative Care team for patients to

self-administer

- Lack of emotional support and alleviation of fear and anxiety in the acute setting
- Unwanted opinions and comments made by Nursing staff in inpatient setting surrounding EOL process
- Continuity of care and transition of patients from specialist palliative care to the inpatient setting
- Patients scared to raise concerns they have with Medical or Nursing staff due to fear of being treated differently or changing of care being provided
- Inappropriate follow up of medication plans from the community
- Delay in providing pain medicine and feeling of guilt for requesting it
- Patient diagnosed with cancer and no counselling offered to patient or family.

There have also been a number of Ministerials and Root Cause Analyses (RCA) surrounding palliative care provision. The Ministerials and RCAs that have occurred recently have centred around lack of coordinated care, decreased access to specialist palliative care, lack of ACP, lack of support for EOL patients including carer respite and carer stress. It is relevant to note that there have been recent RCAs related to the suicides of patients registered to the SPCS. At present, incidents, complaints, Ministerials and RCAs are managed through different processes and departments according to policies and legislation. It has also been noted that often care was also impacted by external providers such as GPs, private Nursing services and RACFs. Consideration of how to share patients' negative experiences with external providers should be sought.

“Nursing staff were often giving unwanted opinions such as “you should go home tonight, they always die when you go home”.

“There was nowhere to sleep beside Mum as there were no more pull out beds available. My 80 year old father with Parkinson’s Disease fell asleep beside Mum on two chairs joined together”.

“It was as though they thought we were trying to kill our Mum but we just wanted her out of pain”.

**Service Gap 143:** There is no structured format to review palliative care incidents, complaints, Ministerials and RCAs from a holistic perspective. Establishing a format will assist in ensuring that there are lessons learnt and encourage review of systems and processes from a District rather than siloed approach.

**Recommendation:**

- Review the incident, complaint, RCA and Ministerial processes for palliative care patients to ensure that they are completed consistently and with consideration to the holistic experience of the patient and their families.
- Consider developing a process and register to enable lessons learnt from incidents, complaints, RCAs and Ministerials to be shared with the District and, when relevant, external providers.

## 25. DATA ANALYSIS

There is currently difficulty accessing an accurate representation of the palliative and EOL care activity that is conducted at CCLHD. This is due to data collection systems, patient coding and inability to know exactly what palliative care activity is being conducted. The SPCS also collect data on patients, some of which is manual.

*Palliative and End of Life Care Diagnostic Review – Activity Analysis* is a data analysis that was conducted by the CCLHD Performance and Casemix Unit which provides an overview of palliative and EOL care for the past three years of activity.

**Service Gap 144:** There is a lack of data at CCLHD regarding the true number of palliative and EOL care patients in CCLHD, including inconsistency with coding care type allocation for Casemix. This poses a financial and resource allocation risk to the District.



**Recommendation:**

- Review data analysis opportunities and strategies for improving the accuracy rate for clinical coding and data collection to demonstrate funding required.

## 26. NEXT STEPS

### 26.1 Establishment of a Palliative and EOL Care Advisory Panel and Steering Committee

It is proposed that an advisory panel be established that meets individually, virtually or collectively to provide expert advice and guidance from the members perspectives. Advisory representation may include representatives from peak bodies such as ACI, Cancer Institute, NGOs, Palliative Care Foundation, consumer representatives (Elsie's retreat or consumer representative), General Practice, HNECCPHN, Ambulance NSW, Palliative Care NSW, Palliative Care Australia, the Chief Executive and representation from the Executive Leadership team.

It is also proposed that a steering committee be established to oversee the project which includes representation from the LHD inclusive of members from the Executive Leadership Team, Clinical Directors, Divisional Managers, Specialist Palliative Care Service, Carer Support and Consumer Engagement Committee. The minutes from the Steering committee will be tabled at the Executive Leadership Team meetings.

### 26.2 Service Delivery Model and Palliative and EOL Care Service Plan

It is proposed that the final phase of this project will be to create a Central Coast vision for the future provision of palliative and EOL care on the Central Coast. This will be achieved through the development of comprehensive Central Coast Palliative and EOL Care service delivery model/s and the development of a Caring for the Coast: Palliative and End of Life Care 3-5 year Service Plan, inclusive of an implementation plan. These documents will prioritise the solutions that need to be implemented and identify which key stakeholders/agencies (internal and external) are involved in their implementation and indicate agreed timeframes. This phase will also incorporate the development of agreed KPIs, patient and service outcomes and ensure that the initiatives implemented are embedded and sustained.

## 27. RECOMMENDATIONS

This review has highlighted the current gaps in service delivery and opportunities for enhancement of services so that they reflect patient-centred care and evidence-based practice. The impacts on patients, carers, staff and the organisation have been identified and suggested recommendations will be reviewed in line with the **ACI Palliative and End of Life Care: A Blueprint for Improvement** <http://www.aci.health.nsw.gov.au/palliative-care-blueprint>.

A summary of the recommendations made in this report are listed in Appendix 1. Recommendations for each specific service gap are listed in the body of the report and directed specifically to closing the identified gap/s. Common themes include:-

- Reviewing, refining and adding to policies, procedures and guidelines to facilitate best practice patient care.
- Access to allocated palliative care inpatient beds in CCLHD, preferably in palliative care wards.
- Providing focused education and support to all clinician groups to support excellent clinical practice.
- An improved level of Specialist Palliative Care staff resources to enable a more comprehensive framework for providing palliative and EOL care for the community, including increased specialist medical support for inpatients.
- Development of a comprehensive Service Plan for the LHD to support a 'whole of community' approach to Palliative and EOL care on the Central Coast.

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## APPENDIX A: SUMMARY LIST OF IDENTIFIED SERVICE GAPS AND RECOMMENDATIONS

	Service Gap	Recommendation/s
<b>4.1 National and State Initiatives</b>		
1	The CCLHD SPCS does not currently participate in the Palliative Care Australia NSAP. Gaps in service delivery cannot currently be identified against these criteria and appropriate actions taken.	CCLHD considers commencement of participation in the Palliative Care Australia NSAP. It may be advisable to participate in this program in the 2 year cycle in between the CCLHD NSQHS Accreditation Process.
2	The LHD does not currently have a process across the District surrounding service proposals that are submitted to NSW Health for Palliative Care flexible funding.	Recommendations as outlined in this report can form a priority list for future Palliative Care Flexible Funding proposals.
<b>4.2 Local Initiatives</b>		
3	Consideration of specific care strategies to provide support to people who are dying from cancer and their families. There are opportunities to increase support and early linkage to the SPCS for patients living with cancer.	Consideration be given to the gaps and recommendations identified in this review report when writing the Central Coast Comprehensive Cancer Plan.
<b>6.1 General Practitioners</b>		
4	The Specialist Palliative Care Service is not currently offered to all patients in the community who may be suitable for referral.	Provide education to GPs on the SPCS, its referral pathway and how they can work in partnership with GPs to provide holistic, supported care to palliative and EOL care patients.
5	There is an opportunity to increase education, support and resources for GPs treating palliative and EOL care patients in the community.	Consider methods of improved access for GPs to SPCS Staff Specialists Convene a working party with GPs and SPCS to identify opportunities for a more collaborative partnership (i.e. review Health Pathways if required, education forums, drop in lines, access to phone support).
6	There is varying practice amongst GPs surrounding home visiting, after-hours care and interest in palliative care.	Identify potential ways to work with GPs interested in palliative and EOL care to provide incentives and agreements to manage palliative and EOL care patients.
<b>6.2 Specialist Palliative Care Service</b>		
7	The SPCS workforce structure does not currently support CCLHD and community needs for Specialist Palliative Care Services.	Review workforce structure of the SPCS, number of staff and work locations. Identify gaps in service provision and develop strategies for improvement in line with the recommended service delivery model. Review current operational and reporting lines for positions employed under the SPCS to ensure that they meet professional standards and Workforce policies.
8	There is a variable understanding of the referral criteria and pathways for referring a patient to the SPCS.	Review the referral document in line with best practice referral standards to other palliative care services as evidenced in the literature. Consider acceptance of referrals from specialists in the hospital without the need to require a further one from the patient's GP. Review the referral criteria to the SPCS to ensure that it is patient-centred. Review the referral, assessment and registration process for SPCS to ensure that it is a lean and efficient process and that the patient and referrer are informed of the steps in the process. Review the need for checking of referrals by Service manager and/or Head of Department and determine if there are other processes to meet this need. Review electronic referral pathways and Information Management and Technology (IMT) systems that could support this.



9	The SPCS service provision does not always meet the needs of patients, carers and referrers. This leads to service gaps, preventable hospital admissions and lack of visibility of current service workload and capacity.	Review and conduct analysis of current SPCS staffing workloads across all positions and locations Review the service provision model of the SPCS to ensure that it is adequately resourced with staff, accommodation, equipment, etc. to meet the needs of the Central Coast and the LHD.
10	The clinical governance and current function of SPCS meetings are not necessarily achieving the desired outcome as outlined in the Terms of Reference.	Review the terms of reference and governance for the all meetings held in the SPCS to ensure they meet client, service and LHD needs and requirements.
11	There are a number of SOPs developed by the SPCS that are not consistently followed.	Review opportunities to increase the usage of local SOPs and collaborative interdisciplinary policies, procedures and guidelines by staff in appropriate work areas throughout the LHD.
12	There is an opportunity to develop AH referral pathways and specialised AH resources to provide input and support for palliative care patients residing in the community.	Review the referral pathways (including NDIS), workforce and skill mix of AH staff working in the community to determine how they can support palliative care patients living in the community. Provide education to medical professionals, GPs and increase community awareness on how to access AH services in the community. Improve clinical handover of patients from the acute setting to the community for patients with a life-limiting illness.
13	The discharge SOP of a patient from the Specialist Palliative Care Service does not meet the needs of patients and referrers. The discharge process has resulted in a reactive model of care for patients as referral back to palliative care is based on worsening symptoms rather than being a pre-emptive model of care.	There is an opportunity to review the discharge criteria and process for patients registered to the SPCS in line with the literature and via benchmarking with other LHDs to ensure that it meets the needs of patients, carers and the clinicians who refer patients to the service. Publish the revised discharge procedure for the SPCS on the CCLHD Intranet page.
14	There is an opportunity to review the clinical handover process for palliative care patients.	Review the clinical handover process for patients registered to the SPCS in line with the literature and via benchmarking with other LHDs to ensure that it meets the needs of patients, carers and the clinicians who provide care to patients referred to the service Develop a clinical handover form, conduct regular audits and publish it on the CCLHD Intranet.
15	There is no District standardised electronic medical record system in place that combines the needs of palliative and EOL patients who have received care from multiple sub-specialities, service providers and locations (i.e. community palliative care, cancer care and admission to hospital).	Review opportunities for standardising the use of electronic medical records, and consider the most beneficial platform for the entry and storage of clinical information for the palliative and end of life patient.
16	Palliative care documentation is not always completed as per CCLHD Documentation standards. Patients' medical records are not always comprehensive and therefore there is the potential for the patient to not receive timely and comprehensive care as there is information missing, which does not enable a "complete picture" to be identified.	Review timeliness of documentation and ensure that it meets CCLHD documentation standards.
17	The data collection and statistics collected by the SPCS and the CN team are not to consistently defined definitions and some data relies on manual reporting.	Review the data collection systems used by SPCS, CN and AH to ensure that they meet the requirements of the LHD.
18	Statistics are not always entered on the same day or at point of contact. There are occasions where statistics are not entered, which results in decreased funding for palliative care services through Activity Based Management.	Consider regular audits of the statistics collected by the SPCS, CN and other services in relation to palliative care to ensure that data is collected in a timely and standardised manner.

19	There is potential for a decreased availability of Nursing service support after-hours for SPCS patients between 2030-0830 each day due to the reduction of SPCS PCLN after-hours support. There is no standardised community after-hours medical support for the SPCS.	Review the after-hours nursing and medical support provided to palliative care patients in the community to ensure that they have appropriate access to 24/7 support and are resourced accordingly.
<b>6.3 Community Nursing</b>		
20	There are perceived deficits in communication between CN and SPCS regarding patient care co-ordination. These include concerns that the referral processes between SPCS and CN are not robust, and lead to referrals received either prematurely or 'too late' in the dying process.	Convene a focus group between CN and SPCS to discuss issues for both teams and develop clear role delineations, expected standards, education needs and service delivery models
21	CNs do not receive regular planned education from SPCS except for annual syringe driver competency renewal, so CNs are not regularly updated on changing palliative care clinical practices.	Review opportunities for hub-based planned CN education in aspects of palliative care management.
22	Workload capacity issues in CN contribute to suboptimal care management at times for palliative and EOL patients and their carers. Some clinical visits for palliative and EOL patients are cancelled or postponed due to this.	Review and monitor CN workload capacity to ensure that have sufficient resources to provide hands on clinical care for palliative and EOL clients in a timely manner.
23	There is a lack of clear role delineation between SPCS and CN which results in confusion amongst patients and carers, duplication of workload and services and gaps in service provision.	See Gap #20
<b>6.4 NGO Providers</b>		
24	There are an unknown number of NGO providers servicing palliative care patients in the community, resulting in a lack of coordinated care for patients accessing CCLHD community services and NGO providers.	Review the NGO services available on the Central Coast and create a shared platform whereby services can publish their referral and eligibility criteria and who can access these services.
25	There is a lack of domestic and support services available to patients on the Central Coast.	See Gap #24
26	There is inequitable access to NGO providers based on financial status, geographical location, age and diagnosis.	Review how CCLHD community services and NGO providers can coordinate care for palliative and EOL care patients on the Central Coast including knowledge of involvement in care, shared goals, case conferencing and access to clinical handover and documentation.
<b>6.5 Ambulance Service NSW</b>		
27	There is limited use of authorised adult palliative care plans on the Central Coast.	Develop a working party with relevant stakeholders from ED, Ambulance NSW, GPs, palliative care specialists and HNECCPHN to review the authorised adult palliative care plan and its implementation on the Central Coast. Develop a local procedure and undertake an interagency quality improvement project to determine the effectiveness of the implementation of the authorised adult palliative care plan.
28	There is a need to share care plans and ACPs with Ambulance NSW to decrease the number of patients requiring transportation to hospital.	Meet with Ambulance NSW to determine solutions to areas of improvement to deliver high quality community care for palliative and EOL care patients at home in RACF to reduce the number of patients requiring transportation to hospital.
<b>6.6 Supported Transitioning Care Team</b>		
29	There is an opportunity to develop a documented pathway for palliative care inpatients at Gosford and Wyong Hospital to be referred to the STCT. A patient's discharge may not be coordinated and a safe transfer of care is not always achieved resulting in readmission of patients to hospital.	Review the Supported Transitioning Care Team Model of Care and determine if appropriate to establish pathways for palliative care patients requiring potential return home from the ED without admission and transfer of care from inpatient facilities to home.

<b>6.7 Hospital In the Home</b>		
<b>30</b>	Patients within the terminal phase of their palliative care may be eligible for admission to HITH under the model of care being implemented within the District. Patients admitted to hospital who could be managed at home in the terminal phase could be referred to HITH and a hospital admission avoided or decreased length of stay in a traditional hospital bed reduced.	Consider HITH eligibility criteria and whether palliative care patients can be admitted under this model of care.
<b>6.8 Medical Imaging in the Community</b>		
<b>31</b>	Palliative care patients are required to access the ED for medical imaging tests that may be able to be performed in the community. This leads to increased use of ambulance and acute medical imaging resources.	Review indications and contraindications for patients being sent in for medical imaging procedures from the community and RACF. Review a proposal for a mobile x-ray and ultrasound service to be established on the Central Coast that meets the needs of the community and RACFs.
<b>6.10 Central Coast Palliative Care Volunteer Foundation</b>		
<b>32</b>	There is a need to ensure that there is a seamless transition of funds, roles and functions from the Foundation to CCLHD when the Foundation is closed.	CCLHD Project Officer to continue to work with the Foundation and identified CCLHD stakeholders to ensure that the transition plan is implemented and a smooth transition occurs for patients and all stakeholders.
<b>6.11 Other Volunteer Services</b>		
<b>33</b>	The current Specialist Palliative Care volunteer service has limited volunteers and is at risk of being unable to meet requests for volunteer support.	Develop a register of volunteers recruited to the SPCS which includes compilation of volunteers' geographical location, skills, roles and responsibilities.
<b>34</b>	The Specialist Palliative Care Volunteer service workforce is ageing, has limited current male volunteers and is restricted by geographical location of volunteers.	Consider recruiting additional male and female volunteers to the SPCS. (action has commenced).
<b>35</b>	There is limited documentation of evidence-based referral forms, caseload management, policies and procedures surrounding reimbursement and roles and responsibilities, documentation and record keeping processes and recording of statistics.	Add Specialist Palliative Care Volunteer Services to the District risk register. Review referral pathways, policies and procedures, record keeping processes and data collection tools that are associated with the SPCS.
<b>36</b>	There is no documented Specialist Palliative Care Volunteer Model of Care.	Review the recently revised Specialist Palliative Care Volunteer Model of Care for effectiveness.
<b>37</b>	The current Palliative Care volunteer service works in isolation and reports to the Service Manager of the Specialist Palliative Care Service. The volunteer service does not report to the Executive Director of Nursing and Midwifery who is responsible for District volunteer services.	Review the governance structure of the Specialist Palliative Care volunteer service.
<b>38</b>	There is no community volunteer service that supports palliative care patients who are living in the community but not referred to the Specialist Palliative Care Service.	Conduct a needs analysis to determine what volunteer services are needed in the community. Develop a community arm of palliative care volunteers that can support all palliative care patients and their families residing on the Central Coast.
<b>39</b>	There is no inpatient volunteer service that supports palliative care patients.	Conduct a needs analysis to determine what volunteer services are needed in the inpatient setting to support palliative and EOL patients. Develop an inpatient arm of palliative care volunteers that can support all palliative care patients and their families admitted to CCLHD hospitals.
<b>40</b>	There are currently an unknown number of volunteer services that work with palliative care patients on the Central Coast and within CCLHD. There is no consistent recognition of what these services provide.	Conduct a review of volunteer services within the District and on the Central Coast and develop an overall CCLHD Volunteer services model of care that incorporates community and inpatient palliative care volunteer service provision.

<b>6.12 Cancer Council</b>		
<b>41</b>	Patients utilising District services that could be accessing services offered by the Cancer Council to free up resources for Central Coast residents with a non-cancer life-limiting illness.	Consider redirecting patients with cancer to the use of Cancer Council services where possible, to enable CCLHD resources to be utilised by patients with a non-cancer diagnosis
<b>42</b>	There is a lack of awareness amongst medical and health professionals surrounding the resources, services and financial support available from the Cancer Council.	Review understanding of the resources, promotional material and support available to cancer patients on the Coast and educate medical and health professionals on these services.
<b>43</b>	The contents and expiry of the MOU with the Cancer Council was not examined and should be reviewed in line with recommendations in this report.	Review the current CCLHD and Cancer Council MOU and ensure it meets any gaps highlighted in this review.
<b>6.13 HNECCPHN</b>		
<b>44</b>	Identified need to pool resources and expertise with the HNECCPHN to ensure that a coordinated and collaborative partnership is developed to inform policy and change within the Central Coast related to the delivery of palliative and EOL care services.	Consider developing a partnership with HNECCPHN to inform change as outlined in this review to improve palliative and EOL care services on the Central Coast. Consider developing a working party with HNECCPHN to promote ACP and improve palliative and EOL care in RACF and by primary healthcare providers, and review Health Pathways to incorporate palliative and EOL care on the Central Coast.
<b>9.1 How is a patient determined to be palliative?</b>		
<b>45</b>	There are no standardised CCLHD screening tools or prognostic indicators to assist Medical professionals in the decision making process to determine whether a patient would benefit from a palliative care approach to treatment.	Review patient-centred prognostic indicators, screening and standardised tools that are available to assist Medical professionals to determine whether a patient would benefit from a palliative approach to treatment. Review internal and external screening/prognostic indicator tools for use within CCLHD.
<b>9.2 Determining that a patient requires palliative care</b>		
<b>46</b>	There is a need to develop consensus surrounding whose role it is to inform a patient that they are palliative.	Review care coordination and communication between a patient's medical care providers. Investigate avenues to have medical case conferencing with GPs and all specialists involved in the patient's care when a patient is diagnosed with a life limiting illness.
<b>47</b>	There is a need for a provision of regular education for Medical and health professionals surrounding how to have difficult conversations 'delivering bad and emotional news' to patients and their families.	Provision of regular education and role playing on 'having difficult conversations' to Medical, Nursing and AH staff. Support of a District culture that is based on empathic, transparent, open and honest discussions with patients and families. Provide debriefing and support to Medical, Nursing and AH staff involved in palliative care discussions so that we can learn from these conversations.
<b>9.3 The 'P' word</b>		
<b>48</b>	Consistent terminology is not used by Medical professionals and the community surrounding the term 'palliative'.	Develop clear consistent definitions of what palliative care is and what EOL care is. Revise all brochures, handouts and documentation to ensure that consistent terminology is used to describe these terms. Educate health professionals and service providers on what palliative and EOL care is. Educate the community on what palliative and EOL care means.

<b>9.4 What happens when a patient is deemed Palliative</b>		
<b>49</b>	There is an opportunity to develop consistent, multidisciplinary, documented care planning for palliative care patients.	<p>Develop a palliative care plan for patients with identified life-limiting illnesses.</p> <p>Establish a process to introduce multi-professional and agency case conferencing that involves the patient and their families. Consideration will need to be given to how these are held and remuneration of Medical professionals and GPs.</p> <p>Develop a care coordinator concept and pathway that ensures that regular reviews of a patient's existing care plan are conducted – these may occur at time intervals or at pre-determined phases i.e. when a patient moves through palliative care phases such as stable to unstable, deteriorating to terminal.</p> <p>Introduce a shared platform whereby all service providers involved in a patients' care (including Emergency services such as Ambulance NSW) can have access to a patient's palliative care plan.</p> <p>Develop a location whereby all palliative care plans can be stored for patients in their electronic medical record.</p>
<b>50</b>	There is a need to increase the understanding of the services available to palliative care patients on the Central Coast and what their referral, exclusion and inclusion criteria involves.	<p>Develop a repository of all of the palliative and EOL care providers on the Central Coast. This repository will involve referral criteria, inclusion/exclusion criteria, fees, geographical boundaries etc. Consideration will need to be given as to who collates and maintains this repository and where it is located so that it is accessible by all care providers.</p> <p>Consider holding an annual "Palliative and EOL Care Provider Forum" whereby providers are invited to showcase their services and network with other service providers.</p>
<b>51</b>	There is an opportunity to develop a consistent process for conducting case and family conferences for palliative care patients in the community or hospital setting.	<p>Develop consistent processes surrounding the requirements of a palliative care case or family conference and consider development of a form for documentation of patient outcomes and developed goals of care.</p> <p>Develop a process to ensure that all stakeholders involved in a palliative patient's care at any point in time can be involved in the family or case conference.</p>
<b>10.1 Palliative Care Outcomes Collaboration</b>		
<b>52</b>	CCLHD does not currently participate in the Palliative Care Outcomes Collaboration (PCOC) Project.	<p>Investigate the use of the PCOC clinical assessment tools and implement guidelines for their use across CCLHD for use with all palliative care patients.</p> <p>Consider enrolling CCLHD in the PCOC data collection with the University of Wollongong. This will enable patient outcomes to be compared to other LHDs.</p>
<b>10.2 Cancer Centre Multidisciplinary Team Meetings</b>		
<b>53</b>	The SPCS do not currently participate in Cancer Centre Multidisciplinary Team Meetings due to a lack of resourcing.	<p>Determine relevant Cancer Centre Multidisciplinary Meetings that would benefit from Specialist Palliative Care input.</p> <p>Consider resourcing requirements to enable the SPCS clinicians to attend identified multi-disciplinary meetings.</p>
<b>11.1 Health Support Programs</b>		
<b>54</b>	There is an opportunity to increase awareness and knowledge amongst patients, carers, Medical specialists, and GPs surrounding community programs and support groups.	<p>Increase awareness and education amongst the community, Medical specialists and GPs surrounding the various community programs and support groups and the benefits of referral for patients diagnosed with life-limiting illnesses early in their disease process.</p> <p>Liaise with HNECCPHN regarding the compilation of a comprehensive list of support groups and community programs available for patients and carers with life-limiting illnesses on the Central Coast.</p>

<b>13.2 Emergency Department</b>		
<b>55</b>	The management of palliative care patients in the Emergency Department is not always streamlined due to lack of ACP, palliative care planning, and access to documentation and GP/palliative care specialists for clinical handover.	Review the process of clinical handover from community palliative care patients to the Emergency Department so that seamless care can be provided. Review the management of palliative and EOL care patients in the Emergency Department to ensure that appropriate accommodation is available and ACD/ACP are available to Emergency physicians to guide treatment options.
<b>56</b>	The admission policy for palliative care patients is person dependent and difficult due to patients with multiple comorbidities, lack of palliative care admitting rights and no general medicine at Gosford Hospital.	Review the admission criteria for palliative and EOL care patients at Gosford and Wyong hospitals.
<b>57</b>	There is a perceived lack of coordinated assessment and management of patients with suspected malignant cord compression in the ED, which leads to the potential for the patient to experience longer periods of unrelieved pain.	Develop a working party to review and modify the existing guideline for the emergency management of a community patient with suspected cord compression in line with the literature and via benchmarking with other LHDs to ensure that it meets the needs of patients, carers and the clinicians. Publish the developed guideline on the CCLHD Intranet page and provide education to all staff involved in the implementation of the guideline.
<b>13.3 Inpatient SPCS</b>		
<b>58</b>	The SPCS do not exercise admitting rights to the acute facilities due to their coverage limitations within the existing workforce.	Review the provision of admitting rights to the SPCS. This may require additional resourcing and will require budget allocation to accommodate the change.
<b>59</b>	There is no access to on-call or after hours inpatient support from the Specialist Palliative Care Medical team.	Review the on-call FTE requirements for the SPCS and introduce access to on-call and after hours support at all acute and subacute facilities.
<b>13.4 Role of the Specialist Palliative Care Nurse Practitioner</b>		
<b>60</b>	The Palliative Care Nurse Practitioner role is constrained by its location and allocated hours	Review Palliative Care NP role and position description as required and consider allocation of additional resourcing to service Gosford Hospital, Wyong Hospital, the community and sub-acute sites.
<b>13.5 Skill Level of Medical, Nursing and Allied Health Staff</b>		
<b>61</b>	There is a lack of specialist education and training for Medical, Nursing and AH staff working with palliative and EOL patients.	Review competencies, education and training for Nursing, Medical and AH staff in managing the deteriorating and terminal phases of palliative care.
<b>13.6 Specialist Palliative Care Consultation Service</b>		
<b>62</b>	The Specialist Palliative Care consultative service does not meet the needs of inpatient palliative and EOL patients and health professionals.	Review staffing levels, functional roles and interaction with treating medical teams of the Specialist Palliative Care Consultative service to ensure that it addresses the above needs.
<b>13.7 Patient Support Services</b>		
<b>63</b>	There is an opportunity to review the PSA and Environmental Services staff roles to ensure they fulfil the requirements that are identified by the wards to deliver safe and quality care to palliative and EOL patients.	Review the CARPS process, role of the PSA, ward cleaning process and allocation of PSAs to support palliative and EOL care patients.
<b>13.8 Medical Imaging and Pathology</b>		
<b>64</b>	Patients in the terminal phase of their palliative care journey may be exposed to unnecessary medical imaging and pathology procedures. Costs and resources associated with performing medical imaging procedures and pathology tests may not add value to a patient's treatment plan.	Improved ACP and appropriate discussions around placing patients on EOL care pathways. Team discussion amongst Medical professionals inclusive of junior Medical officers surrounding medical imaging procedures and pathology and their indications/contraindications during each phase of palliative care.



<b>13.9 Patient Flow and Bed Management</b>		
<b>65</b>	Patients who will remain in hospital for their EOL care have an impact on patient flow and bed management.	Review patient flow and bed management processes for EOL patients including discussions in patient flow meetings and daily pressure surrounding terminal patients' bed occupancy. Review allocation of single rooms to EOL patients and where these patients are best located to meet their medical and care needs.
<b>13.10 Multi-disciplinary Inpatient Palliative Care team</b>		
<b>66</b>	There is an opportunity to deliver consistent multidisciplinary care for palliative and EOL care patients on the wards. Patients currently receive different levels of care, and access to Multi-Disciplinary Team (MDT) staff is dependent on the ward that they are admitted to.	Consider in workforce redesign the appointment of a specialised MDT team that manage patients throughout the hospital and follow them on their journey rather than being ward allocated.
<b>13.11 Allied Health Services</b>		
<b>67</b>	Consistent AH staffing is not accessible for palliative and EOL care patients in acute hospitals during the week.	Review AH staffing structure and consider allocation of clinicians to patients to ensure continuity of care for palliative patients. Consider employment of AH staff to be based on a palliative care unit or affiliated with the palliative care service if they were given admitting rights.
<b>68</b>	Reduced AH staffing is available after-hours or on weekends for palliative patients. Patient's length of stay and transfer of care can be delayed due to inability for AH to continue with transfer plans over a weekend.	Review AH services available on a weekend.
<b>13.12 Patient and Staff Rounding</b>		
<b>69</b>	Patient rounding is absent or inconsistently conducted with palliative and EOL care patients. Patients care needs may be missed or not communicated in a timely manner which may result in compromised care, incidents and complaints.	Review patient rounding tools and their use with palliative and EOL care patients.
<b>13.13 Junior Medical Workforce</b>		
<b>70</b>	There is an education gap and inability to consistently escalate care and support amongst the JMO workforce.	Liaise with JMO workforce regarding education needs in palliative and EOL care (i.e. advance care planning, difficult conversations)
<b>13.14 Non-beneficial Surgery</b>		
<b>71</b>	Patients are reported to be receiving non-beneficial surgery, as their family/carer often request it.	Continue to liaise with the Division of Surgery and ICU surrounding the project being undertaken on non-beneficial surgery. Consider development of patient/carer resources and further education/support when making decisions surrounding surgical options.
<b>13.15 Palliative and EOL Care Ward</b>		
<b>72</b>	There are no designated palliative or EOL care wards or beds at CCLHD. Patients are not receiving access to the comforts available on a designated palliative care ward and there is inconsistent assessment and management of palliative and EOL care patients.	Review the need for designated palliative and EOL care beds at CCLHD.
<b>73</b>	There are no designated palliative care beds or wards proposed in the current Gosford or Wyong Hospital redevelopments.	See gap #73
<b>13.16 Sub-Acute Hospitals</b>		
<b>74</b>	There are currently no designated palliative care sub-acute beds available at CCLHD.	Review the need for designated palliative care and EOL care beds at CCLHD on sub-acute sites. Review the bed utilisation in the Transitional Care Units to determine if these beds are suitable for transition to palliative care beds if this option is desired and there is capacity.

<b>13.18 Palliative Care Pathway and EOL Care Pathway</b>		
<b>75</b>	EOL care pathway protocols and the use of comfort assessment charts are not always activated for palliative care patients.	Review the use of the EOL care pathway and comfort assessment chart Educate the Nursing and Medical staff surrounding the use of the EOL care pathway and comfort assessment chart.
<b>13.19 Rapid Response/Managing the Deteriorating Patient</b>		
<b>76</b>	Rapid responses are not always appropriately activated on palliative and EOL care patients.	Review the Rapid Response service at CCLHD and improve the documentation surrounding EOL care pathways and the completion of resuscitation plans. This should also include appropriate documentation of altered calling criteria.
<b>13.20 Palliative Care Patient Readmissions</b>		
<b>77</b>	There are a number of potentially avoidable readmissions to CCLHD hospitals for palliative and EOL care patients	Discussion of palliative and EOL care patients at patient flow and readmission meetings. Allocation of sub-acute beds and development of a model of care for palliative care patients. Review inpatient Specialist Palliative Care referral pathways. Palliative care patients to be highly recommended to have an ACP following a designated number of admissions to CCLHD hospital within a time frame (e.g. 2-3 admissions). Palliative care patients to be appointed a care coordinator and referred to STCT for discharge planning. Palliative care patients requiring repeat admissions to be considered for referral to the Specialist Palliative Care team for coordination of care and care planning. Link recommendations from the current Readmissions Project to the Palliative and EOL Care review and implement as appropriate.
<b>13.21 Disconnect between Community SPCS and Inpatient SPCS</b>		
<b>78</b>	There is a disconnection between the inpatient and outpatient SPCS.	Review the SPCS consultative service and determine how to improve the link between the SPCS community and inpatient arm Consider commencement of admitting rights for the SPCS.
<b>79</b>	Patients who are known to the SPCS in the community are not able to receive continuity of care by the SPCS as they are a consultative service and require a referral from the treating team.	See gap#79
<b>13.22 Equipment Needs</b>		
<b>80</b>	The equipment lending and home modification process is not streamlined and requires staff to develop 'workarounds' to enable suitable home modifications to occur.	Review the equipment loan and home modification processes for palliative care patients
<b>13.23 Care Awaiting Placement Program Beds</b>		
<b>81</b>	CAPP beds are currently only contracted at four RACFs and the beds at each facility are not designated for EOL care patients.	Investigate the number of CAPP beds required for patients to receive EOL care who are unable to die at home. Assess contracted beds against criteria for 'Dying friendly RACFs' and tender contracted beds with RACFs in various locations across the Central Coast.

<b>13.24 Private Hospitals</b>		
<b>82</b>	There are reported improvements that can be made in private hospitals for palliative care patients to ensure that they receive quality, evidence-based care.	<p>Investigate options for public/private partnerships for EOL care. Review the existing Brisbane Water Private Hospital contracted beds arrangement.</p> <p>Develop an interagency working party to discuss EOL care in private hospitals and ensure that there is a seamless transition for patients to and from the community and private hospital settings.</p> <p>Review the option for private hospitals to access SPCS medical and nursing advice and support as provided previously. Recirculate competency tools and policies related to the use of syringe drivers with the private hospitals.</p> <p>Develop an interagency working party to develop an EOL care pathway and comfort assessment chart for use across the public and private settings.</p> <p>Educate the private hospital setting on how to provide access to follow up and support for families requiring bereavement support.</p> <p>Establish an Interagency Palliative Care Interest Group on the Central Coast. This group could share case studies, debrief and support one another, perform case reviews, share resources, share issues and opportunities and review literature and best practice.</p>
<b>13.25 Centrelink</b>		
<b>83</b>	There is difficulty accessing Centrelink for additional financial support for carers of palliative and end of life care patients.	<p>Develop an information package related to Centrelink benefits and share this with staff managing palliative care patients in the community and inpatient settings.</p> <p>Review access to Social Workers in the community to assist palliative care patients and their families to navigate the Centrelink process.</p>
<b>13.26 Residential Aged Care Facilities</b>		
<b>84</b>	There are varying levels of care provided to palliative care patients in RACFs on the Central Coast.	Develop a working party to review service provision for palliative and EOL care in RACFs and how this is supported by CCLHD. This will include improved transfer to and from RACF and CCLHD facilities and community services.
<b>85</b>	There is difficulty accessing RACFs for palliative care patients due to admission criteria and waiting lists. This results in increased admissions to hospitals for EOL care due to inadequate human and equipment resourcing in RACFs.	Investigate the development of a partnership with 'Dying Friendly RACFs' to assist with access to RACF for palliative and EOL care patients.
<b>13.27 Palliative Care Unit/Hospice</b>		
<b>86</b>	There is limited choice for where patients can die and there is no stand-alone Palliative Care Unit on the Central Coast. This increases pressure on hospital beds as they care for terminal patients who are admitted to hospital for EOL care as there is no other option.	<p>Discuss the development of a stand-alone palliative care unit (hospice) on the Central Coast when considering solutions surrounding bed management and access to EOL care for patients. This will include consideration of funding source and location.</p> <p>Conduct site visits to other LHDs to review the palliative care unit/hospice model of care and to discuss the risks/benefits to the Central Coast population.</p>
<b>14.1 Palliative Care Home Support Packages(HammondCare)</b>		
<b>87</b>	Palliative Care Home Support Packages (HammondCare) are currently not able to be accessed by all patients requiring them on the Central Coast due to a restricted referral pathway, current prioritisation and limit of available and trained care workers.	<p>Review the current Palliative Care Home Support Packages (HammondCare) provision (inclusive of referring agents, referral criteria, referral pathway, prioritisation, documentation) to the Central Coast.</p> <p>Provide education surrounding Palliative Care Home Support (HammondCare) packages to all referring agents, CCLHD staff and community care providers involved in the provision of EOL care for patients residing on the Central Coast.</p>

<b>14.2 Medication Management</b>		
<b>88</b>	There is a need for a consistent approach to the prescription, administration and monitoring of medication for palliative and EOL care patients in the inpatient and community setting.	Support increased usage of existing evidence based medication guidelines to ensure that patients have timely access and relief of their symptoms via the appropriate prescribing of medication no matter where they are located (inpatient, community, RACF) and when this symptom relief is required (within or outside business hours). Consideration should be given to the service gaps identified in this section. Review the need for access to a specialist pharmacist and/or pharmacy consultation to community and inpatient palliative care and EOL care patients. Review current processes surrounding telephone orders of S8s and how documentation of this occurs. Education surrounding the recently published GE2012_016 End of Life Medication Recommendations for Symptom Management in Adults
<b>14.3 Patient and Carer Experience</b>		
<b>89</b>	There is a need to improve consideration of the patient and carer experience when managing palliative care patients.	Engage with the Consumer and Engagement Committee, Patient Experience Manager and Carer Support Unit when forming recommendations for palliative and EOL care services Develop formalised patient and carer rounding tools for palliative and EOL care patients.
<b>14.4 Dying Friendly Hospitals</b>		
<b>90</b>	Families and friends are not adequately informed and therefore paying money for flowers and arrangements that they are then not permitted to bring onto some wards.	Review policy and communication processes surrounding the restriction on flowers to Gosford Medical Ward 2 with Infection Control, the literature and other Local Health Districts. Review bed allocation for patients who are palliative and EOL.
<b>91</b>	When a patient is no longer conscious and able to consume food and/or fluids their diet is often not changed to Nil By Mouth at ward level in eMR. This results in the patient receiving regular delivery of food and fluids from Food Services up to six times per day.	Consider the changing of a patient's diet status to Nil by Mouth when they are deemed unsuitable for further oral intake. Nursing, Medical and Speech Pathology staff to be reminded on the importance of changing a patient's diet status in eMR when a patient is deemed unsuitable for oral intake.
<b>14.5 Barriers to EOL Care in Hospitals</b>		
<b>92</b>	There are a number of barriers to EOL care at CCLHD Hospitals	Earlier, and more comprehensive, discussions between Medical staff and patients/families. Earlier, and more frequent, referrals to palliative care services and access to after-hours palliative care. Enhanced EOL education programs for both Medical Staff and Nurses. Clear, early, and unambiguous documentation of patient's wishes.
<b>93</b>	There is currently no standardised EOL care toolkit available for clinicians providing EOL care, and patients do not receive a standardised level of EOL care.	Review the CEC Last Days of Life toolkit and consider appropriateness of implementing the toolkit at CCLHD.
<b>14.6 Resuscitation Plans</b>		
<b>94</b>	There is a need to include all stakeholders in the decision-making process surrounding the completion of resuscitation plans to ensure that these are completed by the correct medical team early in the patient's admission.	Review the process surrounding the completion of the resuscitation plan and altered calling criteria for palliative and EOL care patients. Ensure that it is linked to the EOL care pathway process.
<b>95</b>	There is a delay in completing resuscitation plans and initiating altered calling criteria.	Consider development of a comprehensive training package for Medical Officers regarding use of resuscitation plans for palliative and EOL patients.

<b>14.7 Withdrawal of Active Treatment</b>		
<b>96</b>	There are unclear documented goals of care and withdrawal of active treatment for palliative and EOL care patients in the hospital setting.	Review the content and usage of the EOL care pathway and all documentation to ensure that it is aligned and consistent, including goals of care, advance care plans, not for resuscitation, resuscitation plans and altered calling criteria. This will ensure that it is clear what the treatment plan is for a patient, this is documented and discussed with all stakeholders including the patient and family. Review the withdrawal of treatment for cancer patients and process surrounding consent under the scope of the CCLHD Comprehensive Cancer review being undertaken.
<b>14.8 Pastoral and Spiritual Care</b>		
<b>97</b>	There is decreased awareness of and access to the pastoral care service for palliative care patients in the acute setting, sub-acute setting and community.	Review available resources suitable for staff to refer to surrounding various care requirements of religious denominations. Include the Pastoral Care service in the development of palliative models of care and any discussions surrounding support to designated palliative care beds or services.
<b>98</b>	There is an opportunity to develop clear Pastoral Care guidelines surrounding referral pathways, caring for patients from varying religious denominations and documentation processes.	Review referral pathways, documents surrounding pastoral care and documentation standards for the pastoral care service to ensure it meets the needs of the referrer and MDT team.
<b>99</b>	There is no dedicated Palliative Pastoral Care Chaplain on the Central Coast, or linked to the SPCS.	Review the current Pastoral Care staffing in the Central Coast to ensure that it meets the needs of the Central Coast population and the policies of the MoH. An increase in hours could enable provision of pastoral care education to the community and health professionals as well as increased support for patients in the acute, sub-acute and community setting.
<b>14.9 Location of Death</b>		
<b>100</b>	There is limited choice for patients on the Central Coast surrounding location of death.	Establish a consumer working party to discuss the support that is required for carers to provide "quality EOL care" in the community and develop an EOL model of care for the community
<b>101</b>	There is a lack of resourcing for the SPCS and support services such as respite, finances, psychological support, after-hours support, equipment, education, GP support in place across the Central Coast to support carers and families and enable patients to die at home	Review the SPCS workforce and support services available and required in the community to assist patients who wish to die at home and their carers and families who are supporting their choice to ensure that this dying wish can be achieved.
<b>15.1 Verification of Death/Assessment of Extinction of Life</b>		
<b>102</b>	The verification of death process is not consistent in the community or RACFs for palliative care patients.	Ensure that resources and education to support the PD2015_040 Death-Verification of Death and Medical Certificate of Cause of Death are reviewed and implemented and if required local procedures are implemented to support this MoH policy. Develop a working party with relevant stakeholders from ED, Ambulance NSW, GPs, palliative care specialists, RACFs and HNECCPHN to review the authorised adult palliative care plan and its implementation at CCLHD. Convene a working party to review the verification of death process for palliative patients in the community and RACFs.

<b>15.2 Notification to Family that a Patient is Deceased</b>		
<b>103</b>	There is no Social Work/Pastoral Care available after hours or on weekends. Next of kin/families are sometimes unclear as to the process that occurs following the death of a palliative patient and what they are required to do.	Review processes surrounding provision of Social Work and pastoral care available to palliative patients after hours and wherever possible develop a process to offer access to these services the next business day to families/next of kin. Promote usage of handout developed by Social Work in May 2017 to next of kin/families which outlines the steps and responsibilities following the death of a patient. Next of kin/families be given details of a staff member who will be their liaison until they leave the ward and the patient is transported to the mortuary.
<b>104</b>	Palliative care patients should be supported to consider funeral arrangements as part of their EOL care pathway and ACP. Families should be encouraged to provide the hospital with details of the funeral contractor when it is determined.	Provision of brochures and information to families/next of kin who have loved ones who are palliative as part of the ACP process.
<b>15.3 Certification of Death</b>		
<b>105</b>	There is a delay in completion of certification of death paperwork pertaining to the death of a palliative patient in the community due to GP availability.	Review the process for certification of death and the availability of Medical Officers/GPs to complete this task.
<b>106</b>	There is a delay in the completion of all necessary paperwork and forms in a responsive manner following the death of a palliative care patient causing delays in progressing with funeral arrangements.	Review the forms, policy and processes that are followed when a patient is deceased and educate all staff in their use and the process for completion. Determine if there is a KPI surrounding the completion of death certificates and paperwork following the death of a patient.
<b>15.4 Preparing of the Body for a Viewing</b>		
<b>107</b>	The palliative care deceased patient is not always prepared for a viewing according to PR2011_044 Death of a Patient in a CCLHD Hospital.	Develop a flowchart and checklist for Nursing Staff surrounding what is required when preparing a patient for viewing.
<b>108</b>	Families are not always provided with education, psychological and/or emotional support when preparing for and viewing the deceased patient.	Educate Nursing staff surrounding the preparation of the deceased patient including review of CCLHD procedure PR2011_044 Death of a Patient in a CCLHD Hospital
<b>15.5 Organ and Tissue Donation</b>		
<b>109</b>	There is decreased awareness surrounding the suitability of organ and tissue donation for palliative care patients.	Include conversations and develop handouts surrounding organ and tissue donation for patients diagnosed with life-limiting conditions. Review the current Organ and Tissue Donation staffing to the Central Coast to ensure that it meets the needs of the Central Coast population.
<b>15.6 Management of Belongings and Valuables and Return of CCLHD Equipment</b>		
<b>110</b>	The process for the handover of belongings and valuables to a family is considered impersonal.	Convene a working party with consumers, carers, Nursing staff, Social Workers, Patient Experience Manager and Bereavement Services to review the Bereavement package provided to families and the process related to the handover of belongings and valuables to families.
<b>111</b>	The bereavement support information provided to families is out-dated and needs to be reviewed.	See gap #111
<b>112</b>	The equipment loaned to families to care for their loved one dying at home is not always collected or returned following death of the patient.	Review the policy surrounding the collection of equipment from the community following the death of a patient known to CCLHD.
<b>15.7 Staff Debriefing Sessions</b>		
<b>113</b>	There is no minimum standard surrounding debriefing offered to staff following the death of a palliative care patient.	Review the debriefing processes available for Medical, Nursing and AH staff following the loss of a palliative care patient.



<b>16.1 Specialist Palliative Care Bereavement Service</b>		
<b>114</b>	There is an opportunity to review service issues with the current SPCS bereavement service as outlined above, to ensure it meets the needs of palliative care patients and their families.	Review the bereavement counsellor workforce, clinical supervision model, professional reporting line, governance and professional accountability.
<b>115</b>	There is restricted access to Bereavement Services on the Central Coast.	Ensure that the gaps identified and recommendations made during the bereavement process mapping session and documented in the Bereavement Service review are implemented.
<b>16.2 Rounding Post-Death</b>		
<b>116</b>	Patient rounding is a recognised Caring for the Coast tool that is not conducted consistently throughout CCLHD.	Develop a rounding tool that can be used to follow up with all families following death in a CCLHD hospital or community setting registered with CCLHD. Consideration will need to be given to when and who conducts these conversations.
<b>16.3 St Luke's Day</b>		
<b>117</b>	St. Luke's Day is not widely publicised to the Central Coast Community via invite.	Continue the annual St. Luke's Day and consider advertising to a wider audience through CCLHD Social Media and public announcements.
<b>118</b>	Funding for St. Luke's Day will need to be transferred to CCLHD following closure of the Central Coast Palliative Care Volunteer Foundation.	Transfer the funding for St. Luke's Day to CCLHD following the closure of the Central Coast Palliative Care Volunteer Foundation.
<b>17.1 Medical Staff Sub-Specialty Feedback</b>		
<b>119</b>	Medical management of palliative and EOL patients is sub-optimal at times due to internal and system factors.	Establish shared goals and opportunities for service improvement and work collaboratively as a Medical Workforce to provide patient-centred care and improve patient experience and outcomes for palliative and EOL care patients.
<b>17.2 Renal Patients</b>		
<b>120</b>	There is limited access to bereavement, transport and volunteer services for renal patients	Conduct a needs analysis for access to Bereavement, transport and Volunteer services for renal patients. Consider inclusion of renal patients and their needs when reviewing future opportunities for the Volunteer and Bereavement services.
<b>121</b>	Advance care planning is not regularly initiated with renal patients within a coordinated and consistent process.	Engage in patient and loved one education programs and provision of ACP toolkits surrounding EOL care. Continued education of Medical and Nursing staff in ACP. Improve documentation of ACP and advance care directives and provision of these in the eMR Medical record.
<b>122</b>	There is a need for alternative accommodation for end of life care for renal patients such as a palliative care unit	Investigate the establishment of a palliative care unit for EOL care to support renal patients. Consider direct admission by renal physicians to a palliative care unit to continue their renal supported care service.
<b>17.3 Culturally Appropriate Care</b>		
<b>123</b>	There is a need to develop culturally appropriate care plans for CALD patients which enables them to make informed choices and takes into consideration cultural beliefs and support systems.	Reinforce the need to involve interpreters when discussing Medical treatment options, having EOL discussions and developing care plans for patients from CALD backgrounds. Develop resources for health professionals that outline the cultural considerations required when providing Medical care to a patient, caring for the dying and caring for the patient after they are deceased.  Translate written material related to palliative care conditions, ACP, palliative and EOL care services into the most common non-English speaking languages identified as spoken on the Central Coast.

<b>17.4 Caring for Patients Identifying as Aboriginal</b>		
<b>124</b>	There is a lack of identification of Aboriginal people and a lack of understanding on the cultural considerations during the palliative and EOL process.	<p>Improve identification of Aboriginal patients and direct appropriate referrals to Aboriginal Health Services.</p> <p>Review Northern Sydney Sorry Business guidelines and State guidelines to develop Central Coast Death and Dying in Aboriginal and Torres Strait Islander Culture (Sorry Business) Collaborative Guidelines incorporating all agencies.</p> <p>Review the palliative pathway for Aboriginal patients with chronic health conditions.</p> <p>Develop opportunities for Palliative Care team staff and Aboriginal Health staff to collaborate to increase knowledge and understanding of each other's perspective and to lead improvement across the wider CCLHD in supporting the cultural requirements for palliative and EOL care for Aboriginal people.</p> <p>Increase Community engagement by consultation, forums and focused education on EOL care.</p>
<b>17.5 Additional Client Groups who Require Special Consideration</b>		
<b>125</b>	The needs of special client groups are not always considered in the assessment, management and care planning and coordination.	<p>Develop working parties to consider the referral pathways, assessment protocols, management plans, case planning and coordination for the special client groups including: patients with cognitive impairment, severe communication difficulties, hearing impairment, drug and alcohol dependencies, mental health needs and patients Under 65. The outcomes of these decisions should be incorporated into referral pathways and future models of care that are developed for palliative and EOL care patients.</p>
<b>126</b>	There is a lack of formalised palliative care pathways for the special client groups listed.	See gap #126
<b>17.6 Carer Support</b>		
<b>127</b>	The needs of carers are often overlooked when managing palliative care patients in the community and inpatient setting.	<p>Include carers in discussions surrounding care planning, case coordination and transfer of care.</p> <p>Refer patients to the Carer Support Unit when attending Gosford Hospital.</p> <p>Consider establishment of a Carer Retreat at Wyong Hospital and a Carer Corner with resources for carers at Long Jetty and Woy Woy Hospitals.</p> <p>Increase Carer support in the community for carers managing loved ones receiving palliative and EOL care. This needs to include review of processes, and the usage of carer capacity assessments</p> <p>Ensure carers are given details on how to access Carer Support Groups available on the Central Coast.</p>
<b>128</b>	There is a lack of respite support for carers of palliative care patients.	Review the respite services available for carers of palliative care patients.

<b>18.4 ACD Quality Improvement</b>		
<b>129</b>	There is a lack of knowledge, education and awareness of the importance of ACP amongst patients, Medical staff and within the Central Coast Community.	<p>Develop an organisation-wide approach to ACP that is governed by the ACP/EOL care committee.</p> <p>Consider ACP clinics at CCLHD. Patients would be booked into these clinics who meet a set criteria and are identified as diagnosed with cancer, dementia, progressive neurological disease or chronic conditions such as chronic heart failure, renal or liver disease.</p> <p>Develop criteria to ensure that all patients who have had a set number of readmissions and/or type changed to palliative care have an ACP in place.</p> <p>Liaise with RACFs to ensure that all patients admitted to RACFs have an ACP plan completed. These ACPs need to accompany all patients to hospital.</p> <p>Develop a process whereby ACPs can be sent to the hospital to be uploaded into eMR against the eMR tab.</p> <p>Develop a clinician-led ACP model whereby patients are identified who would benefit from an ACP and the clinician is required to identify if one exists, review the ACP, locate the ACP and/or discuss with patient. Consideration of employment of staff with ACP skills and a coordinator within the LHD.</p>
<b>130</b>	There is a lack of proactive ACP in the community and inpatient settings, resulting in reactive and emotive ACP and decisions surrounding EOL care.	<p>Educate the community via community groups, workshops and support groups surrounding the importance of conducting ACP.</p> <p>Educate and provide Medical specialists and GPs with a tool to assist in ACP conversations with patients.</p> <p>Review the CCLHD ACP patient workbook and brochures to ensure that they still meet the needs and health literacy levels of consumers.</p>
<b>19.1 Raising Community Awareness and Expectations Surrounding Death and Dying</b>		
<b>131</b>	The community do not feel informed about Palliative Care and the role it plays in caring for the dying.	Consider holding community forums to raise awareness of the role palliative care plays in supporting “Quality Living, Quality Dying and Quality Grieving”
<b>132</b>	There is an opportunity for the SPCS and CCLHD to engage in National Palliative Care Awareness Week activities.	CCLHD could participate in National Palliative Care Awareness Week on an annual basis.
<b>19.2 Access to Palliative and EOL Care Education</b>		
<b>133</b>	Medical, Nursing and AH staff do not believe they receive adequate training in palliative and EOL care.	<p>Identify ‘My Health Learning’ modules that are red flagged ‘Mandatory’ or blue flagged ‘CE directive’ for certain workforce groups to ensure increased access and improved knowledge in the provision of palliative and EOL care.</p> <p>SPCS to continue to promote state-funded education initiatives to internal and external staff.</p> <p>Education provided by the SPCS to increase in frequency as resourcing allows.</p> <p>Review and promote the existing SPCS website/intranet page with access to palliative care apps and education links that would be useful to assist Medical, Nursing and AH staff to provide evidence-based and quality palliative and EOL care services.</p>
<b>134</b>	Service providers such as GPs, RACFs, specialists and NGO providers receive limited education on palliative and EOL care.	<p>Conduct annual GP education nights on targeted topics.</p> <p>Continue to provide education forums to NGO provider and RACFs as resources allow.</p>
<b>135</b>	Specialist Palliative Care is not included on the Medical Grand Rounds Educations roster at Gosford Hospital.	Suggest Specialist Palliative Care Medical staff present in Grand Rounds for an agreed number of times per year at both Gosford and Wyong Hospitals.
<b>19.3 Interagency Network Group</b>		
<b>136</b>	There is no interagency Palliative Care Network on the Central Coast.	Develop an interagency Palliative and EOL care interagency network.

<b>20 Corporate and Clinical Governance for Palliative Patients</b>		
<b>137</b>	There is currently no organisational governance structure and strategic plan which meets the needs of all palliative and EOL care patients. This results in a lack of ability to review palliative and EOL service and patient outcomes from a holistic and strategic view.	Review the governance structure for Palliative and EOL care at CCLHD to ensure that there is an integrated governance structure. Develop a strategic plan for palliative and EOL care on the Central Coast inclusive of external agencies. Consider the appointment of a Director of Palliative Care to provide leadership, governance and strategic direction for palliative and EOL services in the Central Coast Community.
<b>21 Committee Structures</b>		
<b>138</b>	There is an opportunity to review the recommendations of this report and how they link into the EOL/ACP and Deteriorating Patient Committees.	Establishment of working relationships with the above committees and the proposed new Palliative and EOL Care Advisory Panel and Steering Committee, to ensure an integrated approach to palliative and EOL care across the LHD.
<b>139</b>	There is an opportunity to develop District standardised process for Morbidity and Mortality meetings to discuss palliative and EOL patients who have received care from multiple sub-specialities, service providers and locations (i.e. community palliative care, cancer care and admission to hospital).	Develop a process whereby palliative and EOL care patients who are seen by multiple sub-specialities and service providers can be reviewed in a standardised Morbidity and Mortality meeting process.
<b>22 Information Management and Technology</b>		
<b>140</b>	There is minimal use of telehealth and a lack of a centralised electronic medical record for the management of palliative and EOL care patients.	Review telehealth options utilised in other LHDs to support the management of palliative care patients in the community and RACFs Investigate options for appropriate and effective ways of sharing clinical information electronically between relevant service providers
<b>23 Research and Quality Improvement</b>		
<b>141</b>	There are a number of quality improvement and research projects that have been registered as being undertaken at CCLHD. The results or progress of these projects have not been communicated with the appropriate Tier 3 Manager and Research Office as required.	Quality Improvement and Research reports to be provided to the Research Office at the conclusion of the studies. These should also be shared amongst peers and encouragement to submit for quality awards, conferences and via journal articles be sought to ensure that lessons learnt are shared.
<b>142</b>	There is an opportunity to develop a structured written quality improvement or research plan for Palliative and End of Life Care services on the Central Coast.	Develop a Palliative and End of Life Care Research Plan incorporating components highlighted within this review that are relevant for future Quality Improvement projects, research projects and translational research grants. Recommend that resources that are being provided to projects being undertaken are deemed as high priorities/service gaps for CCLHD.
<b>24 Incident Review and Patient Experience Feedback</b>		
<b>143</b>	There is no structured format to review palliative care incidents, complaints, Ministerials and RCAs from a holistic perspective. Establishing a format will assist in ensuring that there are lessons learnt and encourage review of systems and processes from a District rather than siloed approach.	Review the incident, complaint, RCA and Ministerial processes for palliative care patients to ensure that they are completed consistently and with consideration to the holistic experience of the patient and their families. Consider developing a process and register to enable lessons learnt from incidents, complaints, RCAs and Ministerials to be shared with the District and, when relevant, external providers.
<b>25 Data Analysis</b>		
<b>144</b>	There is a lack of data at CCLHD regarding the true number of palliative and EOL care patients in CCLHD, including inconsistency with coding care type allocation for Casemix. This poses a financial and resource allocation risk to the District.	Review data analysis opportunities and strategies for improving the accuracy rate for clinical coding and data collection to demonstrate funding required.