

Coen Community Care Centre (Multi-Purpose End-of-Life Care Centre)



Scoping Study Final Report

Updated September 2020

FINAL DRAFT



PalliativeCare
QUEENSLAND

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Acknowledgements

Palliative Care Queensland (PCQ) acknowledges the Traditional Custodians of the lands and seas on which we live and work, and pay our respects to Elders past, present and emerging.

PCQ would like to recognise the contribution of everyone who participated in this important initiative, including the Coen Centre founders Ms Jodi Hamilton, Ms Sandra Higgs and Ms Mandy Larsen, Apunipima Cape York Health Council, the Royal Flying Doctor Service Queensland, Palliative Care Australia, Collaboraide and importantly, the people of Coen and surrounding communities.

PCQ wishes to thank all of our stakeholders who have given their valuable time and provided their expertise to help guide the development of this publication. We greatly appreciate the contributions everyone has made in sharing experience, knowledge and time with us.

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We believe that the way we care for our dying is a significant indicator of the kind of society we are.

Palliative Care Queensland



About Palliative Care Queensland

Palliative Care Queensland (PCQ) is the peak body for palliative care in Queensland. PCQ has been operating for over 30 years, has over 400 members and is a founding member of Palliative Care Australia. PCQ members include health professionals across all sectors of health, specialist and generalist palliative care services, aged care, disability care, peak bodies, as well as consumers and interested members of the Queensland community. Collectively, the PCQ membership body holds tremendous knowledge and wisdom about the challenges the sector faces and the opportunities those challenges can bring.

Our organisational priorities are that all Queenslanders:

- are able to live every day until their last
- are able to have a dignified death, regardless of their illness, age, culture or location
- have access to a supportive social network at the end phase of life and have the choice of quality palliative care

Executive Summary

Palliative care is healthcare that focuses on improving the quality of life and quality of care for people with a life-limiting illness and their families, helping people live as actively as possible until death by the prevention and relief of suffering, communication about goals of care and the early identification, assessment and treatment of physical, psychological, emotional, social and spiritual symptoms.¹ Palliative care can become highly medicalised and often disconnected from the social networks and communities of the persons receiving care.

The Coen Community Care Centre (Coen Centre) concept developed by Ms Jodi Hamilton, Ms Sandra Higgs and Ms Mandy Larsen in 2017-18. They identified potential for the James Love Building to be redeveloped into a self-managed location for 24-hour support and care of community members with palliative care needs and at end of life. This recognises and responds to the growth of models of care that put people, their families and carers at the centre of planning, design and delivery. To date it is common for individuals to have to leave their community and country to access care and support, where people may die without their loved ones.

First and foremost, the voices of local Aboriginal Peoples and Torres Strait Islanders is critical to ensuring the delivery of culturally safe and accessible services. The views of the Coen community are reflected in this report, where PCQ were engaged by the project founders to assist with the scoping of the Coen Centre. **It is important to note the Coen Centre is not intended to be a clinical facility primarily. As such, this project was not focused on clinical needs or resourcing, nor was a cost-benefit analysis undertaken.**

However, for patients and families to receive that best possible care, wherever they live, local health services must have health professionals with expertise in palliative care and established links with specialist palliative care teams, as described in Queensland Health's *Palliative Care Clinical Services Capability Framework*. As outlined in the recommendations, the Coen Centre would be a place that was culturally safe for the family to care for their loved one until end of life. Equipped with the appropriate beds and associated equipment, a medication and storage room, kitchen, large community living area, chapel, laundry and garden, family members can care for their loved one following an agreed care plan that enables clinical intervention only as necessary rather than as a first resort. Further, the localised 'bricks and mortar' self-managed Coen Centre will address broader social determinants of health and bring other services and supports into this vibrant 'hub' of many vulnerable communities.

This also provides the opportunity to improve and increase clinical workforce development opportunities, leveraging off existing projects and programs that require the Coen Centres infrastructure. In addition, it will lead to longer terms capacity development within the communities accessing the Coen Centre, where families will be supported to understand chronic condition self-management, medication management and safety, and strategies to address grief and bereavement.

This Final Report is intended to build on previous reports and representation and provides an overview of the scoping project and recommendations. Importantly, the Queensland Health Palliative Care Service Review and the outcomes of the landmark Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying in Queensland provide an opportunity for identifying and funding innovative community-driven services.

¹ Queensland Government 'Palliative Care' webpage [last updated 11 July 2018].

Summary of Recommendations

Recommendation 1:

A cost benefit analysis should be undertaken to have the James Love Building and surrounding grounds refurbishment for the introduction of the Coen Centre.

Recommendation 2:

The proposed layout should take advantage of the existing building footprint and be a mixed-use facility, developed in consultation with the Coen community.

Recommendation 3:

Apunipima Cape York Health Council is engaged as the Facility Manager to maintain the importance of community control and leverage off existing strong operational processes

Recommendation 4:

Existing partnerships and services should be expanded on by the development of new care pathways, protocols and use of the infrastructure the Coen Centre would provide

Recommendation 5:

Establish an education hub for best practice Aboriginal and Torres Strait Islander palliative care and end-of-life care in Australia and internationally

Recommendation 6:

Capacity building activities will support broader wellbeing outcomes in the Coen community

The Profile of Coen

Coen is a small town located in the centre of the Cape York Peninsula in Far North Queensland, 522km from Cairns, 390km from Cooktown, and 252km from Weipa (figure 1). Coen is within the Cook Shire Council, the largest land area shire in Queensland covering more than 100,000km² and 80% of Cape York Peninsula. With a rich history of Aboriginal tradition that was deeply impacted by the removal of people from their lands, today eight Indigenous clan groups reside in or around the town and maintain several traditional languages, including the people of Lamalama, Wik Mungka, Ayapathu, Kaanju, Olkala, Southern Kaanju, Umpula and Morobalama².

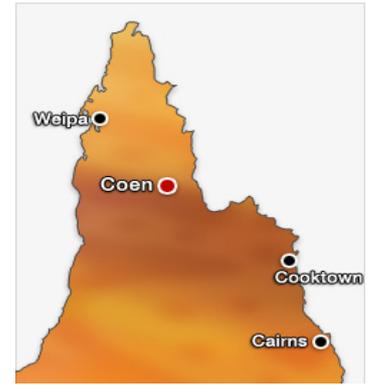


Figure 1: location of Coen
(Apunipima Cape York Health Council)

The population of Coen is small yet diverse with more than 79% of residents identifying as Aboriginal or Torres Strait Islander (2016 Census). While 'officially' there are approximately 364 residents³, non-resident populations such as the resource sector and tourists create additional demand for services. Described as 'a hub' it includes the Cape York Biosecurity Centre, Kalan and Lama Lama Ranger bases, Queensland Ambulance Service, Police Station, Magistrates Court, Queensland Parks and Wildlife Service, Queensland State Emergency Service, Volunteer Marine Rescue, Volunteer Fire and Emergency Services, primary school, library, and Centrelink.

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Our Mission is to understand our communities' needs and provide consistent service to enable them to flourish in a safe, sustainable manner.

Cook Shire Council

Coen has the largest active airstrip in the Cape outside of Cooktown, and the town is an essential supply point mid-way between Weipa and Cooktown along the Peninsula Development Road, where 27,480 tourist vehicles registered as travelling this route in 2017⁴. Being in the cyclone area of Queensland rainfall can be high, with changing road conditions often making travel impossible for periods in the wet and dry seasons.

The immediate health and wellbeing of the residents of Coen and surrounds is supported by three main providers:

- The Apunipima Health Centre, a community-run, community-driven primary health care and wellbeing centre established in 2017 by the Apunipima Cape York Health Council
- The Queensland Health Coen Primary Health Care Centre (level 2 emergency care)⁵ and
- The Royal Flying Doctor Service (RFDS) fly-in-fly-out General Practice Service out of the Cairns Base, within the Coen Primary Health Care Centre.

Within the Torres and Cape Hospital Health Service (Torres and Cape HHS) the main referring hospitals are located in Cairns (600km) or Townsville (900km) per figure 2. The Torres and Cape HHS provides public hospital and health services across 130,238 km² of northern Queensland and

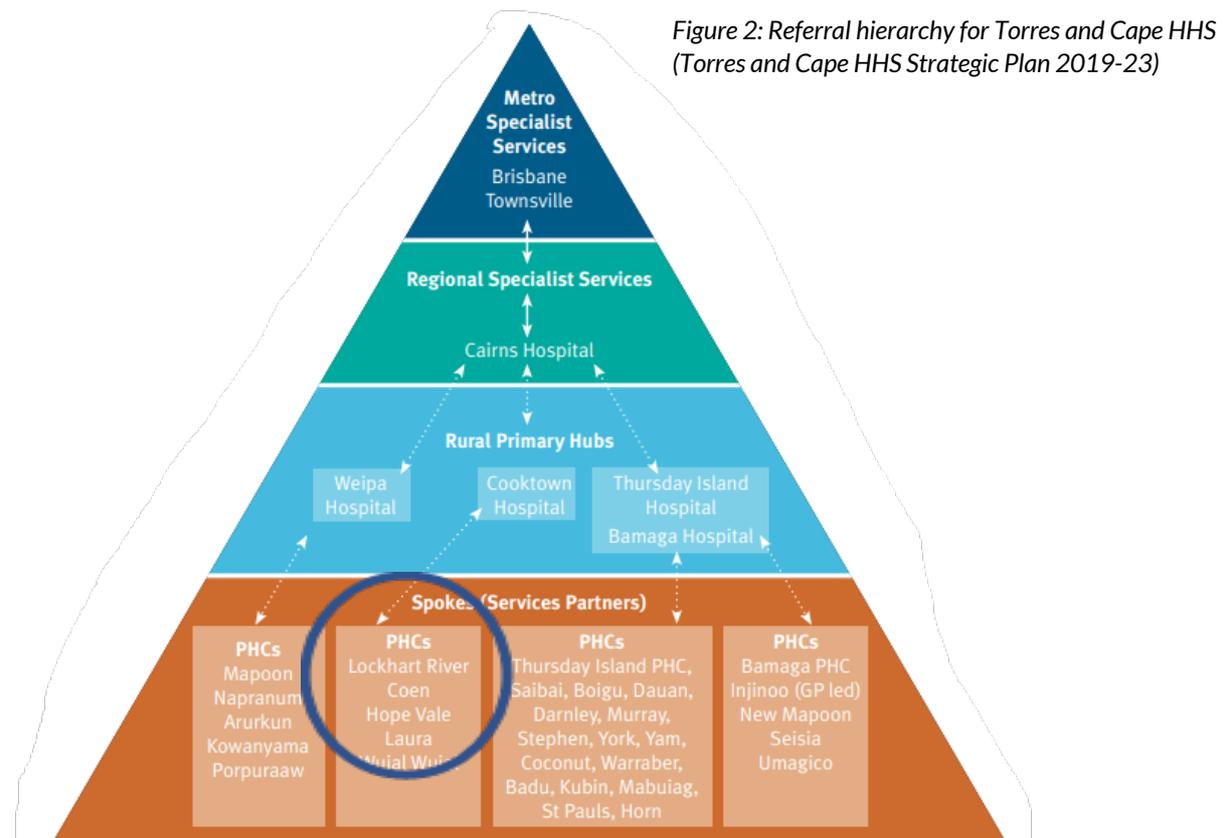
² Family Responsibilities Commission, 'Community Engagement Guidelines: Coen' [online].

³ Australian Bureau of Statistics '2016 Census QuickStats' webpage [last updated 19 July 2019]

⁴ Per. Com, Queensland Government Department of Agriculture and Fisheries, Cape York Biosecurity Centre.

⁵ Level 2 = 24 hours access to registered nurse and triage presentations. capable of providing treatment for minor injuries and illnesses and limited treatment of acute illnesses and injuries. Source: Queensland Health (2014) 'Clinical Services Capability Framework v3.2 - Emergency Services' [online]

acknowledges that significant distances between communities, between health services sites and to the major referral hospital located in Cairns as their significant challenge⁶.



To date, it is common for the people of Coen and surrounds to have to leave their community and country to access curative treatment, ongoing care and palliative care in a larger centre. These people may die without their loved ones, and there are financial and emotional issues imposed in returning the body to country for burial. For individuals and families to receive that best possible care, wherever they live, local health services must have a network of specialist and primary care providers and community partnerships, as described in Queensland Health's Palliative Care Clinical Services Capability Framework⁷.

“

...the right of each patient to make informed choices in their own time about the care they receive, and the environment in which they receive that care' being integral to effective palliative care services in Queensland.

Queensland Health Palliative Care Clinical Services Capability Framework

The Policy Context

While dying is intensely personal, it also sits within a societal and systems context. Increasing access to culturally appropriate and community-driven palliative care and end-of-life care through the infrastructure of the Coen Centre would respond to community values and priorities, as well as address the current policy environment for the Cook Shire Council, Torres and Cape HHS, and Queensland Government.

⁶ Torres and Cape Hospital and Health Service (2019) *Strategic Plan 2019-2023* [online].

⁷ Queensland Health (2014) 'Clinical Services Capability Framework v3.2 - Palliative Care' [online]

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Without policy support for palliative care and funding mechanisms, growth is restricted to whatever is achieved by pioneers making sacrifices to create hospice and palliative care services in their communities.

World Health Organisation – Global Atlas of Palliative Care

It is often assumed that palliative care would commence only once all treatment aimed at ‘cure’ had ended or when a person is dying, however it is well accepted that there are benefits in providing palliative care in association with treatment, for longer periods and earlier within a person’s illness for non-malignant conditions⁸. People who require palliative care may:

- Be at different stages, where differing illnesses (such as cardiovascular disease, dementia or renal disease) will have differing needs over various timeframes
- Be of all ages, where the needs of children and young people, and their parents and families, are often quite different from those of people facing the end of life at an older age
- Have different cultural, social, emotional, relational and spiritual needs, and
- Need palliative care for a short period of time, intermittently, or consistently over a period of months or years.

It is also essential to understand that care at the end of life or ‘end-of-life care’ represents a specific time frame, which varies and is unclear within the health sector - sometimes referred to as 12 months, 6 months or the last few days of life. End-of-life care alone narrows the focus to the dying phase, often allowing opportunities for earlier support to be overlooked.

With the growth and ageing of Queensland's population, and an increase of chronic and life-limiting illnesses, the types of patient groups requiring palliative care has widened. The leading specific causes of death in Queensland in 2018 were coronary heart disease, stroke, lung cancer, dementia and COPD⁹. The Indigenous death rate in Queensland is 49% higher than the non-Indigenous rate, with the main causes coronary heart disease, diabetes, lung cancer, COPD and suicide. Further, the Torres and Cape HHS had one of the highest all-cause death rates (30–40% higher than the state average) noting issues of remoteness and high Indigenous populations.

People receiving palliative care have been shown to have fewer hospitalisations, shorter lengths of stay and reduced visits to emergency departments, while those receiving palliative care at home have an increased quality of life and reduced need for hospital-based care, providing cost-savings for government¹⁰. The Coen Centre provides the opportunity to assist in policy implementation across sectors and governments, moving away from a top-down approach and aligning with the principles of the Queensland Health System Outlook¹¹ directions that inform the system level priorities of:

1. Transform health services to improve outcomes - how and where we deliver health care for better patient outcomes and sustainable services.
2. Optimise the system, making the best use of resources - ensure the best use of existing resources and maximise the potential for consumer satisfaction; and
3. Grow the system to improve access - ensure that additional services and infrastructure are prioritised based on population health needs and regional priorities.

⁸ Palliative Care Australia (2018) ‘Palliative Care Service Development Guidelines’ Aspex Consulting [online].

⁹ Queensland Health (2018) ‘The health of Queenslanders 2018. Report of the Chief Health Officer’. Queensland Government [online].

¹⁰ Op.Cit (8)

¹¹ Queensland Health (2019) ‘Queensland Health - System Outlook to 2026 for a sustainable health service’ [online].

A snapshot of the policy context for the Coen Centre is provided in figure 3 beginning with the National Palliative Care Strategy as a commitment of governments to ensuring the highest possible level of palliative care is available to all people¹². While not an exhaustive list given current reform processes, further appendices provide a summary of the proposed Coen Centre opportunities against the:

- Cook Shire Council Community Plan 2011-2021 (Appendix A)
- Torres and Cape HHS Health Service Plan 2016-2026 (Appendix B) and
- Queensland Government's Aged care, end-of-life and palliative care report (Appendix C).

Importantly, the Queensland Health Palliative Care Service Review¹³ and the outcomes of the landmark Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying in Queensland provide a unique occasion for the design and delivery of the community-driven Coen Centre.

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This National Palliative Care Strategy is a commitment by all Australian governments to ensure that evidence-based, quality palliative care is available to everyone who requires it.

National Palliative Care Strategy

¹² Australian Government Department of Health (2018) 'National Palliative Care Strategy' [online]

¹³ Queensland Health (2019) 'Queensland Health Palliative Care Services Review – Key Findings' [online].

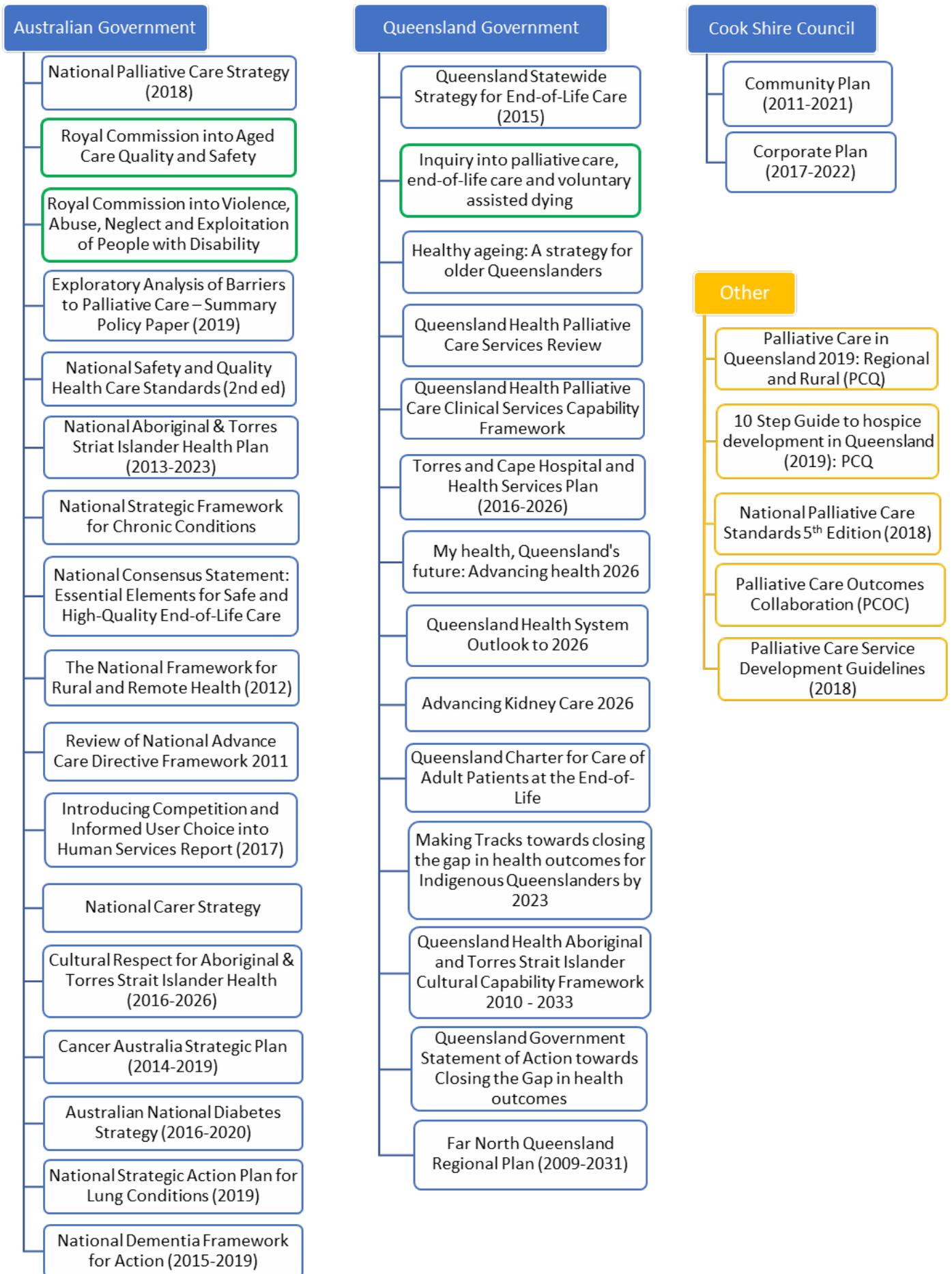


Figure 3: Snapshot of the Policy Context for the Coen Centre

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The Vision is to have an effective, efficient, sustainable and self-managed community model for 24-hour care of community members with palliative care needs and at end-of-life. The people of Coen want to utilise their community building [the James Love Building], built by the community and for the community, to stop their people having to go away to pass away, and is underpinned by the Values of respect, compassion, continuity of care, familiar faces, familiar places, and culturally appropriate innovation.

Coen Community Village Concept Founders

Scoping Project

The Coen Centre recommendations are based on the 'Coen Community Village' concept¹⁴ where community members with the support of PCQ approached the Cook Shire Council, Queensland Police Commissioner as Government Champion, and Queensland Health with a project plan and local signatures of support in March 2018 to progress with the following recommendations:

1. Cook Shire Council agree on in-principle use of the James Love Building be used for the proposed Coen Community Centre
2. Cook Shire Council agree on James Love Building refurbishment plans while the scoping project is underway, and
3. Cook Shire Council agree to a scoping study

Subsequently Queensland Health, auspiced by Cook Shire Council provided PCQ with funds to progress with a scoping study and activities (figure 4). First and foremost, the voices of local Aboriginal Peoples and Torres Strait Islanders was critical, and the views of the Coen community are reflected in this report. PCQ believes that effective partnerships with individuals and communities exist when they are treated with dignity and respect as equal partners, via shared information and support throughout engagement.



Figure 4: Scoping study phase

¹⁴ Founders of the Coen Centre concept are Ms Jodi Hamilton, Ms Sandra Higgs and Ms Mandy Larsen in 2017. Per. Com (2017).

Bush Breakfast

To launch the scoping activities a bush breakfast was held in August 2018 at the James Love Building, site of the proposed Coen Centre to promote the concept to local members of the community. Guests included Aboriginal Elders, project founders, Cook Shire Council CEO, Queensland Police Commissioner and PCQ representatives. This was a valuable opportunity to engage, discuss process and bring key stakeholders together to see the enthusiasm and support for the Coen Centre concept.

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Sustained, respectful and inclusive engagement is essential to gaining an understanding of Aboriginal and Torres Strait Islander perspectives. Each engagement with community members holds within it the opportunity for creating new relationships based on openness, trust and mutual understanding.

Queensland Government Reconciliation Action Plan 2018-2021

Literature Review

The literature review¹⁵ identified that while the development of innovative models of ‘home stay’ palliative care/multi-purpose centres in remote and First Nations communities is in its infancy, there are several critical success factors:

- Place based approaches that incorporate the social and cultural nuances of a community remain a critical first step in contemporary services design
- Sustainable models of palliative and end-of-life care incorporate partnerships with existing service providers and draw on innovations in technology, and
- Building community capacity around death and dying ensures long terms sustainability driven by members of the community.

While research in the area of palliative care service delivery to Aboriginal peoples is still in its infancy, what is known is that Aboriginal people in Australia have poor access to specialist palliative care services in mainstream facilities as these are often viewed as powerful, isolating and not relevant to their culture, way of life, family and belief systems¹⁶.

Indigenous Australians, especially those residing outside major cities, are substantially under-represented in care, where over a five-year period (2010-15) 1% of people accessing specialist palliative care were Aboriginal or Torres Strait Islander¹⁷. What literature does exist argues for the development and need for culturally specific Aboriginal palliative care models, which are culturally appropriate, locally accessible and delivered in collaboration and partnership with Aboriginal controlled health services. The key findings of the literature review outlined in figure 5 have been considered in the Coen Centre recommendations.

¹⁵ Collaboraide (2019) ‘Connecting End-of-Life Care Coen Community Care Centre: A summary report of relevant models of care report’ prepared for PCQ. Available on request.

¹⁶ Australian Government Department of Health (2019) ‘Exploratory Analysis of Barriers to Palliative Care: Issues Report on Aboriginal and Torres Strait Islander Peoples’ prepared by Australian Healthcare Associates [online]

¹⁷ Palliative Care Outcome Collaboration (2019) ‘Indigenous compared with non-Indigenous Australian patients at entry to specialist palliative care: Cross-sectional findings from a multi-jurisdictional dataset’ [online]



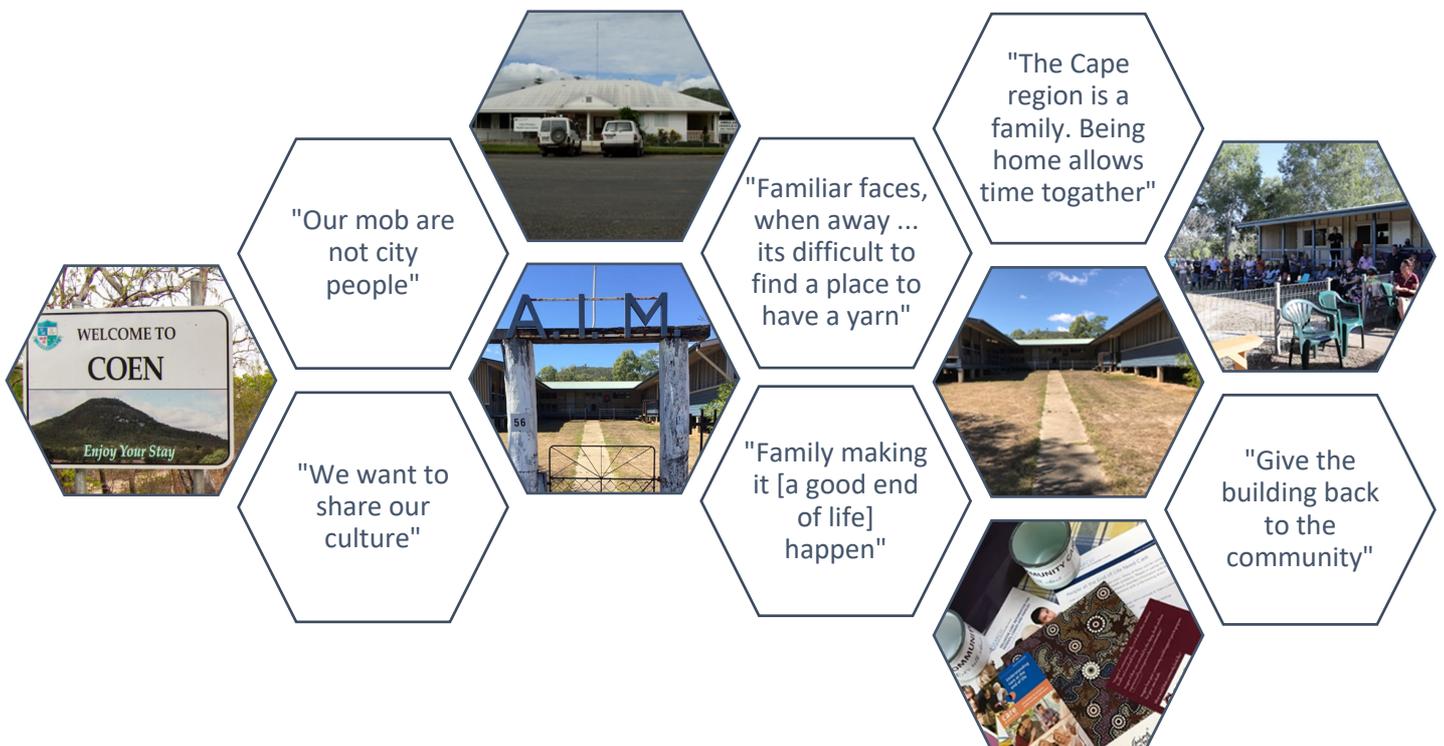
Figure 5: The essential components for future Coen Centre development

Journey Mapping

Building on the findings of the literature review, in-depth conversations with community members of Coen and surrounds occurred during journey mapping. A simple question guide was developed to assist with these conversations, as advice from community leaders was to approach the community meetings in an informal and relaxed manner. This included exploring:

- What's happening now?
 - What's working well
 - What's not working?
- Personal story – have you had an experience with someone who has died or is frail, elderly or disabled?
- Have you any experience with the James Love Building or grounds?
 - Does this experience have good or bad memories or meaning?
- What would you like to see to make it comfortable for your loved ones and family?
- Culturally appropriate – how would this look?

Three community members participated in in-depth discussions in addition to Indigenous Elders during a craft session at St John's Community Care Centre, where people expressed how very sad they are to have to leave Coen for care towards the end of their life, with preference to stay in Coen with family. The main themes revealed during these discussions were preserving dignity, the importance of family especially nearing the end of life, intergenerational engagement like story time with younger generations and traditional art with school children, and development of a bush garden to access bush medicines and to share food together.



Consulting with existing services, health professionals and stakeholder occurred either in-person or via phone. This included Queensland Ambulance, Coen Police Officers, Torres and Cape HHS, specialist palliative care physicians, Coen Primary Health Care Centre, St John's Community Care (Aged Care) and Apunipima Community Health Centre to discuss:

- What would the model of care look like?
 - How would this work with the existing services?
 - Outreach service capability
 - Home care services and packages of care?
 - Volunteer capacity
- Governance models?
- Strategic Round table – who needs to be in the room?

All interviewees agreed in-principle to the Coen Centre concept, with the need and key opportunities identified summarised in table 1. These opportunities outweighed or directly addressed the perceived challenges which were identified as:

- Workforce sustainability and skills mix
 - Current TCHHS workforce and difficulty in increasing capacity
 - Specialist palliative care already 'stretched' in Cairns so face to face visits difficult without more resources
 - Question the need as 'there are not many deaths in Coen'
 - Who will undertake family training and support
- Ongoing management of the Coen Centre, and
- Complexities of the wet season

Both the opportunities and challenges were further discussed and consolidated at the Strategic Roundtable.

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If Aboriginal and Torres Strait Islander people feel their cultural and spiritual needs are purposefully not being met during vulnerable times such as end of life, they may not feel safe and comfortable to access health services and delay accessing the hospital and health services [or] not access services at all...

Queensland Health Advance Care Planning Guidelines

Table 1: Opportunities of the Coen Centre – services and stakeholder consultation summary

<p>Build on the established level 1 palliative care service¹⁸ that exists in Coen</p>	<ul style="list-style-type: none"> • Telehealth well established, ability to mentor the Coen Centre to assist with training of workforce • Specialist palliative care telehealth consultations possible (available now at Bamaga) • RFDS model well established, links to specialist services • Ability to expand on current protocols • Medication management and pharmacist support via Cooktown and Cairns, quality use of medicines and support would work well with engagement • Provide a hub for existing Apunipima boundary activities with telehealth facilities, hands on workshops, training in use of dialysis equipment, staff mentoring • Build broader workforce – attract funding for placements, training etc
<p>Improve issues related to transport for individuals, families and the health system</p>	<ul style="list-style-type: none"> • Transport not always available when needed or enough seats • Escort required to pay for return airfare/journey and own expense • Expense to attend routine clinics, especially multiple health issues and services across locations • Less emergency room presentations
<p>Provide capacity to age in Coen until death</p>	<ul style="list-style-type: none"> • Allow patients with complex care needs to remain closer to home and family networks/support, especially for those not under ‘aged care’ • Improve access to appropriate equipment such as beds • Increase end-of-life care planning • Reduces expenses involved in returning deceased person’s body back home, often at least \$5,000 to family and community, with a broader impact on grief and bereavement
<p>Improve access to Indigenous Liaison and culturally appropriate services</p>	<ul style="list-style-type: none"> • Reduce stress in navigating the system • Being removed from country/home is frightening, particularly when escort travelling separately Limited availability of appropriate spaces – “Let people see outside” identified as a particular challenge in Cairns hospital, space to meet with family that is open air and quiet • Address privacy and dignity issues – “who knows my business”, “in room with everyone else, embarrassing” • Appropriate place to practice mourning traditions like smoking ceremonies or large gatherings
<p>Build community capacity more broadly with the Coen Centre as a ‘hub’</p>	<ul style="list-style-type: none"> • Art centre – story telling and art with local school children • A chapel • Counselling – grief, loss and bereavement that is culturally safe and sensitive • Get more people talking in the community and advance care planning • Use existing infrastructure • Employment opportunities e.g. centre manager, grounds person • Encourage people to go into health workforce - mentoring, education, training • More people visiting Coen – good impact on other businesses
<p>Reduce long-term impact on family</p>	<ul style="list-style-type: none"> • Time needed away from employment and impact on businesses • Financial costs of being away e.g. buying food, having money for taxi and accommodation • School absences for children needing to travel with family outside of Coen • Family displacement

¹⁸ Level 1 Palliative Care - people living with a life-limiting illness whose needs are straightforward and predictable should be able to access services in metropolitan and rural areas at a local level in the communities where they live, with no requirement to travel to regional centers to access minimum services (National Palliative Care Workforce Capability Framework) Source: PCA (2018) ‘Palliative Care Service Development Guidelines’ [online].

Strategic Roundtable

Held in Cairns on 25 September 2019, this provided an overview of the scoping process to that point, further engage key stakeholders, discuss on going in-principle agreement by all parties and recommendations for this Final Report.

This meeting was facilitated by the PCQ CEO and National Policy Advisor from Palliative Care Australia, and included Coen community members Jodi Hamilton, Sandra Higgs and Mandy Larsen, representatives from QLD Paediatric Services Children's Hospital, Torres and Cape HHS, Cairns HHS, Queensland Health, Queensland Government Department of State Development, Cook Shire Council, Apunipima Cape York Health Council, RFDS, Torres and Cape Health and Cairns Integrated Palliative Care Service. The Northern Queensland Primary Health Network and St John's Community Care were also invited.

At the end of the strategic roundtable all parties present agreed in-principle to proceed with seeking funding opportunities for the Coen centre as this would:

- ✓ Solidify the governance structure
- ✓ Build community capacity for long term sustainability
- ✓ Leverage current infrastructure and political interest
- ✓ Address interface issues
- ✓ Improving culturally appropriate care provision
- ✓ Reduce unnecessary/unwanted transfers outside of Coen
- ✓ Reduce burden on tertiary hubs and services including costs associated with transport
- ✓ Support workforce development and retention
- ✓ Improve biopsychosocial outcomes including schooling, employment and psychological welfare for individuals and families; and
- ✓ Allow for appropriate engagement with services.

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In the 1930s, mainly older people from the Munkan, Kaanju and Lama Lama lived scattered around Coen...the Director of Native Affairs was in favour of removing everyone to Lockhart River Mission to avoid the expense associated with providing services...the local protector opposed the proposal saying that: '[Y]our suggestion to send these old people to Lockhart River is unthinkable. If you send them there they will only walk back to their own native country. Coen is their home, their native land, and at least they might be happy in the knowledge that they might die in the place where they first saw the light of day'.

Letter - Coen Protector to the Director of Native Affairs, 17.12.1940 (QLD Government 'Coen' webpage)

The Coen Centre - Recommendations

This project was not focused on clinical needs or resourcing, nor was a cost-benefit analysis undertaken. The Coen Centre is intended to be an innovative self-managed location for 24-hour support and care including 'home-based' palliative care and end-of-life care, day respite, renal self-dialysis and community engagement activities. This is aimed at supporting individuals, families and the broader Cook Shire and Torres and Cape HHS footprint in grief and bereavement, social inclusion and access to visiting services in a culturally safe environment.

Recommendations are informed by project activities and based on the concept of 'public health palliative care', where there is growing recognition in Australia and internationally of the opportunities of aligning service delivery with the broader goals of building public policies that support dying, death, loss and grief, creating supportive environments, strengthening community action, and re-orienting the health system¹⁹.

Importantly, PCQ highlights the need to respect Aboriginal and Torres Strait Islander perspectives of death and dying and to actively explore the culture of local communities through research, genuine consultation and guidance material. Consideration has been given to factors that impact on access and quality palliative care for Aboriginal and Torres Strait Islander peoples, noting:²⁰

- Kinship and the extended family network hold increased importance, where caring for unwell and dying family members is considered by many an important family responsibility and might include the preparation of bush food, music and singing
- Family members may not have any (or adequate) support to provide care (e.g. bathing, toileting, medication safety) for a loved one at home, and in some cases, housing may be overcrowded with limited private space
- In some Aboriginal cultures, once a person has died in a house that place must be abandoned for a period of time, and
- Being displaced from community in order to access palliative care services can be traumatic for individuals and their families, bringing feelings of isolation from country and community, homesickness and sadness. It may also prevent an individual from completing cultural obligations within their community.

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... a focus on the patient to better meet their health care needs, as well as cultural and social needs of the Aboriginal and Torres Strait Islander people to produce better health outcomes is required.

Torres and Cape HHS Service Plan 2016-2026

¹⁹ PCA (2018) 'Background Report to the Palliative Care Service Development Guidelines' [online]

²⁰ Australian Government Department of Health (2019) 'Exploratory Analysis of Barriers to Palliative Care: Issues Report on Aboriginal and Torres Strait Islander Peoples' prepared by Australian Healthcare Associates [online]



Recommendation 1: A cost benefit analysis should be undertaken to have the James Love Building and surrounding grounds refurbishment for the introduction of the Coen Centre.

The James Love Building is owned and occupied by the Cook Shire Council. The Cook Shire Council considers the site as a 'planned major upgrade/replacement' activity for renewal and upgrade in 2020-21 and on-going annually, where it is currently listed as a known 'service performance deficiency' and no longer serviceable and/or not used to provide services.²¹

The following planned expenditure should be brought forward and a cost benefit analysis undertaken, for the purpose of the localised 'bricks and mortar' Coen Centre to address broad social determinants of health and bring other services and supports into this vibrant hub of many vulnerable communities:

- \$100,000 projected over 2020-21 to 'community/master planning for site services/function'
- \$100,000 in 2022 for upgrade/replacement detailed design
- \$1.4 million over 2023-24 for upgrade/replacement

Next steps must also include Involve, Collaborate and Empower engagement methods for shared decision making around planning, delivery and evaluation of the Coen Centre's services, programs and policies, noting Cook Shire Councils commitment of "Community consultation/ communication as a part of every proposed project".²²

²¹ Cook Shire Council (June 2019)'Building Asset Management Plan' [online]

²² *Ibid*

Recommendation 2: The proposed layout should take advantage of the existing building footprint and be a mixed-use facility, developed in consultation with the Coen community

The layout of the current building (figure 6) allows for a place that is culturally safe for family to care for their loved one until end of life, with the capacity to accommodate the presence of large numbers of family members, specific mourning and grieving customs.

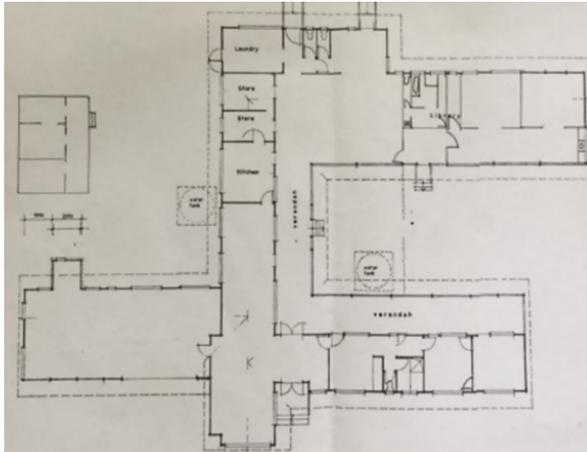


Figure 6: James Love Building Blueprint
(Source - Ms Jodi Hamilton)

The following should occur to allow for mixed-use to increase capacity and sustainability:

- Two 'wings' where each wing could have two rooms equipped to provide for 'home based' end-of-life care through a community driven hospice model
 - the separation of the rooms within wings allows for members of differing Clans to occupy the spaces, respecting independent cultural practices and the uniqueness of Coen as a culturally rich location of many language groups
 - easy access to outside areas via a wraparound veranda
 - ramps and doorways need to be widened to fit stretcher or bed through
- A room equipped for people to self-dialyse in a comfortable and supportive environment
- A space for day respite to support carers and families, and allow for social engagement
- A space for accommodation while waiting for transport to and from regional centres or larger tertiary facilities, between Coen and smaller communities
- An open plan community space that allows for:
 - group programs by the community, local organisations or visiting services
 - include access to one of the two kitchens for meal preparation and food storage
 - access to a laundry, bathroom and showering facilities, where a collaboration with Orange sky could be explored
 - a private breakaway space and a chapel
 - an area fit out for training with foldable tables, chairs and IT infrastructure.
 - a private consulting/clinic room for use by visiting services, which may be used to generate funds through hiring rates.
- A secure administration area that provides:

- office space for the Manager
- medication storage room
- storage facilities for aids and equipment (also considered for a loan scheme)
- hot desks and meeting facilities for visiting professionals to maximise use and efficiency of available space, where consideration can be given to hiring out these facilities to generate income
- refurbishment of the rear detached quarters into a potential live-in accommodation for staff accommodation (as required).
- The establishment of a mixed-use outside area
 - garden rooms including a community garden, memorial garden, firepit and water tanks
 - solar panels on the roof to reduce future electrical requirements
 - a new balcony on the north side of building to allow palliative care rooms to have open air spaces to spill out with family

Recommendation 3: Apunipima Cape York Health Council is engaged as the Facility Manager to maintain the importance of community control and leverage off existing strong operational processes

A robust governance and management model will need to be developed in partnership with the Coen community, Cook Shire Council, Torres and Cape HHS, RFDS, Primary Health Networks and other existing services. A crucial aspect will be communication and coordination with government and other stakeholders, facilitation of consultations, development and formalisation of the partnership, and provision of ongoing support as the partnership progresses. Apunipima as the largest Aboriginal Community Controlled Health Organisation in Queensland already has an established clinic in Coen delivering a family centred model of comprehensive primary health²³.

Apunipima's service delivery principles are supported by corporate and clinical governance, including a commitment to strengthen service management and leadership, workforce and human resource management, staff development, education and mentorship, financial management; administrative, legal and compliance services; infrastructure management; and appropriate information technology, underpinned by appropriate quality systems.

In addition, having an established organisation such as Apunipima ensures that community-control is at the heart of all activities and will increase trust and acceptance of the Coen Centre by the community. Maintaining community control of the Coen Centre is supported by the 2006 Deed of Commitment to transition health services in Cape York to community control signed by Apunipima, Queensland Health, Mookai Rosie Bi-Bayan, Royal Flying Doctor Service, Far North Queensland Rural Division of General Practice, Queensland Ambulance Service and the Australian Government Department of Health²⁴.

Each partner organisation should continue to provide existing staffing levels and utilise the shared infrastructure, where the Centre also provides opportunities to attract additional resources through hiring of clinic rooms, training and meeting spaces and utilising the space for visiting services and groups. Staffing and resourcing considerations require a thorough business analysis, however at a minimum the Coen Centre would require a daytime manager who would have an operational/administrative role, an overnight manager when required and, a grounds person.

²³ Apunipima Cape Your Health Council 'Apunipima Model of Care' [online]

²⁴ Cape Your Regional Health Forum (2006) 'Deed of Commitment' [online]

Recommendation 4: Existing partnerships and services should be expanded on by the development of new care pathways, protocols and use of the infrastructure the Coen Centre would provide

The types of palliative care and support that may be needed by an individual, their families and carers will vary and may include formal and informal supports. The vision of the Coen Centre is to provide a location that people can feel safe to follow an agreed care plan that enables clinical intervention only as necessary. This will benefit individuals, families, the broader communities and health system by improving access to and responsiveness of care, reduce the need for dying patients to be admitted to tertiary facilities off Country, avoid unnecessary admissions and workforce development opportunities.

At a minimum the following should be explored in the first instance:

- Establish telehealth infrastructure to engage with higher level tertiary palliative care when required should occur as a priority with support of the Queensland Health Telehealth Program
 - it is acknowledged that telehealth palliative care services are an emerging model in Queensland, enabling an innovative and patient focused service, a reduction in travel by clinicians and patients, a more efficient use of health service resources, and importantly, significant benefits to patients²⁵
- Consider 'Teams without Walls' models of integrated care, where professionals from primary and secondary care work together in teams, across traditional health boundaries, to manage patients using care pathways designed by local clinicians²⁶
- Capacity within the RFDS for specialist palliative care provision to improve the equity of access to this type of service in the region, as well as provide mentorship to other clinicians and health providers by using the Coen Centre as a hub
- While not a clinical service, access to an appropriate area for self or supported dialysis is an essential component of the Coen Centre.
 - Aboriginal and Torres Strait Islanders develop chronic kidney disease 3 times as often and are 9 times as likely to need dialysis compared with non-Indigenous populations²⁷
 - allow people who have already learnt to efficiently self-dialyse to receive reinforced messages and provide an opportunity for individuals to identify any issues, increasing compliance and safety and enabling timely referral to nurse-assisted support if required
 - improve the health literacy of the surrounding communities related to kidney disease, including lifestyle changes, support to minimise further damage and/or slow the progression of the disease and treatment choices, which are all considered Queensland priorities for good kidney care²⁸
 - increased rates of self-dialysis may improve the likelihood of remaining in employment as well as reduce travel and hospitalisations. Additionally, if the time came for the person to engage with more intensive care, or at care at the end of their life, the Coen Centre is already

²⁵ Op.Cit (11)

²⁶ Torres and Cape HHS (2016) 'Service Plan 2016-2026' [online]

²⁷ Kidney Health Australia (2019) 'National Strategic Action Plan for Kidney Disease' for the Australian Government [online]

²⁸ Queensland Health (2019) 'Advancing Kidney Care 2026' [online]

a familiar place, and palliative care may be available earlier concurrently whilst on 'active treatment'

- The collaborative model of palliative care developed by the Northern Peninsular Area Family and Community Services (NPAFCS) which features case management by an Aboriginal and Torres Strait Islander Palliative Care Health Practitioner, medical assessment and treatment provided by a NPAFACS GP, access to a specialist palliative care consultation via telehealth and bereavement support from a grief and loss counsellor²⁹
 - the success of this type of model is contingent on community involvement, which is clear in the support shown for the Coen Centre, matched with the existing infrastructure of Apunipima services
- An Indigenous Liaison Officer or Aboriginal Health Worker as a system navigator/case coordinator, and to facilitate kinship arrangements and family involvement in decision-making
- Paediatric palliative care options through the 'pop up' model delivered by the Lady Cilento Children's Hospital State-wide Paediatric Palliative Care Service, including telehealth videoconferencing
- Grief and bereavement support in collaboration with existing services
 - the whole community will experience grief and mourning and this time will set certain cultural protocols in motion, requiring sensitivity and understanding, requiring the cooperation of the extended family and friends to share the load and have the time to pay respect to the deceased³⁰
 - This support may include feeding and housing mourners, where the kitchen, laundry and showering facilities could be utilised

Future consideration could be given to dialysis services, tele-chemotherapy such as those that exist at Cooktown, Weipa and Thursday Island, and expansion of the Patient Transport Subsidy Scheme.

Recommendation 5: Establish an education hub for best practice Aboriginal and Torres Strait Islander palliative care and end-of-life care in Australia and internationally

The infrastructure the Coen Centre provides is an opportunity to facilitate improved education and training opportunities to the existing Coen health and care workforce, engage with the community and increase interest in pursuing a health career, and attract a range of visiting professionals to build a strong and supported health workforce with appropriate skills to provide culturally-safe and responsive palliative care and end-of-life care within the Torres and Cape HHS, Queensland and Australia more broadly. This is consistent with the Queensland Health's Care at end of life: Education and training framework which is intended to assist with development of a localised HHS approach to include the Queensland Health workforce, volunteers, health consumers, patients, their families and carers, community members, government and non-government partner organisations³¹.

Key to this is building on existing relationships and exploring new opportunities between the health, education and training sectors, and with organisations such as the Primary Health Networks, University Rural and Remote Health Departments and peak bodies such as CRANaplus, the Australian

²⁹ PCQ (2019) 'Palliative Care in Queensland: 2019 Regional and Rural Rapid Consultation Findings Report' [online]

³⁰ Queensland Health (2015) 'Sad News, Sorry Business: Guidelines for caring for Aboriginal and Torres Strait Islander people through death and dying (version 2)' [online]

³¹ Queensland Health (2020) 'Care at end of life: Education and training framework' [online]

College of Rural and Remote Medicine, National Aboriginal and Torres Strait Islander Health Worker Association (NATSIHWA) and Indigenous Allied Health Australia (AIHA).

At a minimum the proposed Coen Centre with training facilities and IT infrastructure would:

- Increase opportunities for Aboriginal and Torres Strait Islanders to enter the health workforce
 - encourage individuals to consider choosing healthcare careers, beginning with engagement with schools and the broader community or young people, and
 - provide a long-term strategy to more effectively address future workforce needs
- Improve mentoring and upskilling for local services and health and care professionals, enhance recruitment and retention strategies and support self-care practices
- Improve access to Queensland and Commonwealth Government programs, health professional clinical placements and continuing professional development, for example
 - the Program of Experience in the Palliative Approach (PEPA) includes capacity for palliative care specialists to visit and facilitate palliative care learning
 - the Quality of Care Collaborative Australia (QuoCCA) to deliver paediatric palliative care education to health professionals in urban, rural, regional and remote areas, and
 - the Centre for Palliative Care Research and Education (CPCRE) in Queensland
- Provide a location for interprofessional education experiences with visiting palliative care and broader health and social care workforces
 - improve cultural competence and trauma-informed approaches to care nationally
 - support remote placements to facilitate recruitment and retention of new graduates, and
 - participate in community co-designed research and evaluation activities

Recommendation 6: Capacity building activities will support broader wellbeing outcomes in the Coen community

Arguably supporting the Coen community through effective capacity building is of equal importance to meeting the infrastructure needs and initial investment and will improve the long-term sustainability and use of resources to provide 'home' palliative care, respite and kidney disease support closer to home. It is also essential to address the broader social determinants of health, underpinned by the principles of self-determination, respect for Aboriginal and Torres Strait Islander people's culture and identity, and recognition of the history of dispossession and trauma experienced by the Coen and surrounding communities.

Underpinning this is Coen as a 'compassionate community' as a core part of public health palliative care, end of life care and bereavement, in which the community play a much stronger role in the care of people at end of life and their families and carers through illness, dying, death and bereavement.³² The development of the Coen Centre as a mixed-use location will support capacity building, and provide ongoing opportunities for:

- Improved or new collaborations between local and other business, Indigenous organisations, not-for-profits organisations and government bodies

³² Nous (2018) 'Compassionate communities: An implementation guide for community approaches to end of life care' prepared for the Australian government Department of Health [online]

- Increase services to support the community in responsive to need like grief and bereavement support and intergenerational activities
- Sustain local groups or organisations such as Men's Sheds and craft groups, and
- Encourage social development activities including gardening, storytelling, community gatherings and remembrance ceremonies
- Encouraging self-reliance and use of existing strengths and assets within families and communities to build resilience and respond to future challenges
 - Combined education and practical support e.g. healthy food preparation through the community garden and kitchen, and self-dialysis
 - ability to use laundry and showering facilities if visiting from other communities during grief and bereavement practices, and
 - Activities in conjunction with the primary school and mums and bubs programs, such as story time and traditional art
- Strengthen workforce participation and economic stability of Coen and surrounding communities
 - employment opportunities at planning, building, ongoing administration and maintenance
 - mechanisms to increase interest and support entry into the health and care workforce
 - less economic disruption by people leaving employment for extended periods of time to travel with loved ones to receive treatment or care off country, in addition to funding day-to-day living expenses whilst away and transport issues, and
 - less disruption to schooling due to reduced incidences of family displacement and improved grief and bereavement support practices
- Developing trust and long-term relationships which provide an ongoing mechanism for community consultation and collaboration in future
- Creating a known safe space to talk about being really unwell, end-of-life and death
 - Encourage initiation of discussions through participation in Advance Care Planning Week, National Palliative Care Week and Dying to Know Day activities as a community
 - Reinforce information through the availability of resources, and referral to appropriate services and supports, and
 - Respond to cultural issues and practices relating initiating discussions, and develop locally relevant resources
- Improving advance care planning practices by supporting health professional activities, where effective advance care planning involves ongoing communication and is driven by the person's care needs and their willingness to participate³³
 - Advance care planning will assist the Aboriginal and Torres Strait Islander person and/or their family/community to make an informed decision about what is best for them, even if it means not accessing available services

³³ Queensland Health (2018) 'Advance Care Planning Clinical Guidelines' [online]

Appendix A - Cook Shire Community Plan 2011-2021: Goals and Strategies supported by the proposed Coen Centre

THEME	GOAL	STRATEGIES
<i>Active, Creative & Connected</i>	<p>We have a range of community groups supported through a culture of volunteering</p> <p>Our communities are enlivened through a vibrant arts culture sector</p> <p>Our communities are open, inclusive and connected, and value diversity</p>	<ul style="list-style-type: none"> To promote and facilitate use of public halls, sports, recreation and play areas To facilitate public access to structured and unstructured activities to enhance health and wellbeing To improve the viability of clubs and organisations To recognise and celebrate volunteers and the contribution they make to our communities To support the provision of arts and culture activities To increase civic participation and improve our ability as a community to recognise and respect differing views To actively include people from all cultures in our community activities and events To facilitate activities that link communities
<i>Safe, Healthy & Inclusive</i>	<p>We can access some health and social services locally and we are supported if we need specialist services elsewhere</p> <p>We value the participation of our community members and treat everyone with respect</p>	<ul style="list-style-type: none"> To advocate for local health services that meet community needs To support forward planning for adequate medical facilities To support improved services particularly for...renal needs To advocate for a reduction in hardship experienced for people attending medical appointments or hospital out of their hometown To support facilities, programs and initiatives to take care of our seniors To support families with children across all age ranges through advocacy and provision of facilities and services as resources allow
<i>Identity & Integrity</i>	<p>The range of opportunities for different lifestyles provided by our unique and diverse communities are protected and promoted</p>	<ul style="list-style-type: none"> To identify and protect elements that contribute to the identity of each place through the planning scheme To recognise our diverse values and explicitly work through responses to changes such as increasing regulations; concerns about public liability restricting voluntary effort; and community response to policing To consider local values when developing services and facilities
<i>Economic Wellbeing</i>	<p>We have a diverse economy based on primary industries, mining, government and tourism and new sectors of renewable energy and carbon farming and land management with a viable creative sector and range of niche and micro businesses</p> <p>There is a good range of jobs, proportionate to the population size and economic activity levels, and we have training and development opportunities to support those entering in the work force</p>	<ul style="list-style-type: none"> To improve recruitment and retention of appropriately skilled staff To attract and actively support investment to the area To develop a positive reputation To lobby government to regionalise services and employ locals To support the availability of relevant, effective training for workforce entrants and for existing workers to improve skills To work collaboratively with job service agencies and providers on projects which provide employment and skills training

Appendix B - Torres and Cape HHS Health Service Plan 2016-2026: Objectives and Strategies supported by the proposed Coen Centre

OBJECTIVE	STRATEGY
<i>Objective 1: Increasing focus on prevention and early detection</i>	<ul style="list-style-type: none"> • Increase community engagement thorough consistent and meaningful communication with local health groups and community administration; and development of spaces within health services that are welcoming, educational, culturally appropriate and enable access to self-help services.
<i>Objective 2: Address the priority health needs of residents</i>	<ul style="list-style-type: none"> • Better manage diabetes, COPD, cardiac and renal disease in the community by planning to source funding to establish a General Physician position to lead multidisciplinary chronic disease teams. • Improve managed care adherence and reduce avoidable hospital admissions by implementing Care Coordinators for priority diseases diabetes, COPD, cardiovascular disease, chronic kidney disease and mental health. • Introduce “Teams without Walls” for chronic disease services to expand Post-Acute Rehabilitation and Aged Care services at Thursday Island, and community-based service capacity at Weipa and Cooktown. • Expand renal dialysis services at Thursday Island and Cooktown. Renegotiate contract conditions for services and staff entitlements with Cairns nephrology service to include growth targets, expanded community-based care and improved equity of employment.
<i>Objective 3: Improve coordination and patient access through the use of collaborative care models with primary care providers</i>	<ul style="list-style-type: none"> • Work with partner groups, particularly Apunipima Cape York Health Council to develop a primary health (including chronic disease) model for discrete Indigenous communities in Cape York. • Improve working arrangements with Apunipima Cape York Health Council to introduce contract performance review processes and activity reporting for HHS contracted services. • Explore options with Cairns and Hinterland HHS to expedite referral processes, and patient transfer pre and post hospitalisation; and the expansion of telehealth provided specialist services. • Implement patient care plans as part of new digital patient record that can be developed in partnership with patients and their families to empower patients and their families to be partners in their own care and take greater responsibility for the management of their conditions. • Improve two-way communication with community members, groups, councils and other representative groups to ensure HHS services are aligned and not duplicated, and explore opportunities to ensure services meet Indigenous health needs. • Work in partnership with tertiary education and research providers to embed research into health service delivery and improve the quality and efficiency of care.
<i>Objective 5: Reshape the workforce to better meet community expectations and service demands</i>	<ul style="list-style-type: none"> • An improved career path for IHWs inclusive of senior leadership and management roles and progression to Aboriginal and/ or Torres Strait Islander Health Practitioner • Review of opportunities for the HHS to participate in Commonwealth funded initiatives • A plan for growth and decline in some workgroups associated with future service demands, and the implementation of the digital environment
<i>Objective 6: Better align enabler services with service and community needs</i>	<ul style="list-style-type: none"> • Actively plan for expansion of all telehealth components: clinical telehealth service provision; emergency telehealth; training and education; secure store and forward applications; and home monitoring.

Appendix C - Aged care, end-of-life and palliative care (Report No. 33, 56th Parliament), Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee (March 2020): Recommendations supported by the proposed Coen Centre

RECOMMENDATION NAME	DETAIL [THE COMMITTEE RECOMMENDS THAT...]
<i>Recommendation 25 - Training opportunities for Aboriginal and Torres Strait Islander people</i>	the Australian Government fund trainee positions for Aboriginal and Torres Strait Islander people to work in roles providing aged care and health care for Aboriginal and Torres Strait Islander people.
<i>Recommendation 45 - Person-centred care</i>	any changes to the delivery of and access to palliative care services in Queensland promote person-centred care.
<i>Recommendation 47 - Assistance for people wishing to die at home</i>	the Queensland Government and PHNs explore ways to fund and provide further assistance to communities and families to enable people to die at home supported by end-of-life care through: expansion of community and in-home nursing services; expansion of community care programs; supporting community-based medical aids and equipment loan schemes; and increased resources for the Hospital in the Home program which provides high-level care in the home when patients require it.
<i>Recommendation 48 - Assistance for regional hospices</i>	the Queensland Government with assistance from PHNs examine ways to help establish viable hospices outside of South East Queensland.
<i>Recommendation 50 - After hours palliative care</i>	the Queensland Government explore options to improve after-hours access to palliative care services, to ensure all Queensland palliative care patients have access to afterhours palliative care regardless of whether they are at home or in a residential aged care facility, hospice or hospital.
<i>Recommendation 51 - Centralised 24/7 telehealth service</i>	priority funding be allocated to establish a centralised 24-hour, seven day telehealth service available to practitioners caring directly for palliative patients throughout Queensland, and to develop a statewide supportive information system to allow practitioners to access real-time patient information for rapid response and appropriate treatment recommendations.
<i>Recommendation 52 - Capacity building for telehealth services</i>	further development and capacity building of telehealth or other digital services for patient consultations to enable people in regional, rural and remote areas to access health services not locally available.
<i>Recommendation 54 - Increased Queensland Government funding for palliative care</i>	the Queensland Government increase its funding for palliative care in Queensland.
<i>Recommendation 60 - Develop specialist support services</i>	the Australian and Queensland governments develop specialist support services to assist general practitioners, nurses, allied health workers and the aged care workforce, including ways to integrate services to provide support to care workers, such as through mentoring.
<i>Recommendation 65 - Respite care for informal carers</i>	the Australian Government improve the availability of respite services for informal carers providing end-of-life care to the dying, and provide for more flexible delivery to allow for short-term respite.
<i>Recommendation 66 - Palliative care community education strategy</i>	the Queensland Government work with relevant stakeholders to develop a community awareness campaign to promote palliative care and increase knowledge of services available to patients and carers.
<i>Recommendation 67 - Community understanding of death, dying and options for end-of-life care</i>	the Queensland Government support PCQ and other stakeholders to increase the community's understanding of death, dying and options for end-of-life care.
<i>Recommendation 68 - Support for community initiatives</i>	the Queensland Government consider supporting the community initiatives recommended by PCQ in their submission.
<i>Recommendation 69 - Implement public education campaigns</i>	the Queensland Government work with relevant stakeholders to roll out a public education campaign to promote awareness of Advance Care Planning and its benefits amongst the community and within the health service to encourage people to discuss their preferences and choices for end-of-life care with health professionals.

Appendix D – Draft funding proposal for Stage 1 of the Coen Community Centre 2020-2022

Synopsis of the initiative

This community initiated partnership between several organisations will provide Palliative Care Services on country for the Coen and nearby communities. An existing building will be utilised. The model involves infrastructure development and community capacity building, and support for education and training to primary care providers to improve palliative care outcomes.

Describe the proposed model of care

This proposal provides the infrastructure and partnerships to enable capacity building of the existing community based Level 1 Palliative Care Service in Coen. It involves community development and capacity building, and support for education and training to primary care providers to improve palliative care outcomes. This Centre will be supported by robust referral and care pathways with existing Level 2 and 3 Palliative Care Services, which will lead to a reduction in inappropriate or unnecessary hospitalisations and transfers off country. It will also avoid the issues related to returning to country at the end-of-life or after death. The model will increase appropriate access to health services and early intervention opportunities, creating a long-term legacy and overall health outcome of the broader community.

Why is this a priority?

Community based palliative care in Coen will improve access and choice. Prevention and relief of suffering with holistic treatment planning will improve quality end of life, by providing comprehensive, integrated palliative care in partnership with the community. Patients' experience will be enhanced by having family support; intergenerational legacies, and cultural connectedness on country. Early grief and bereavement support will assist mental health and wellbeing of indigenous community members. Early and anticipatory care planning will reduce unnecessary and unplanned admissions. This model will reduce hospital admissions by providing more confident 24 hour care by family and carers.

Why invest in this?

This utilises an existing building which has a history of significance for the community. This building has been agreed by the Cookshire Council for use of this purpose.

This innovative model draws on proven existing statewide and national models of community driven palliative care. It builds on the current community Level 1 service and the Social and Emotional Wellbeing Centre.

Care pathways will be streamlined and created to formulate a remote community based pathway. A local centre will enable partnership between organisations in the region to provide seamless continuity of care in the right setting. Familiar faces in familiar places is important to the community. This centre in Coen will provide a culturally respectful and safe place. It will improve the social capital of the community and trust within the Coen community, and beyond. Intergenerational story telling and learning will generate robust knowledge within the community to enhance future community strength.

The evaluation will inform future investment direction and policy decision making, particularly for indigenous Australians.

What outputs (e.g., occasions of service or capital) will be delivered with the funding?

1. Establish Coen Centre as a community-led hub
2. Development of referral pathways and linkages
3. Increased number of people receiving early access to palliative care services for anticipatory planning
4. Independent evaluation

What is the 'measure of success' for this proposal and how will change be evaluated?

Measure of success will be community satisfaction with Palliative Care services in Coen. External evaluation component will provide objective impact measures

Estimated cost

	2020-21	2021-22	Total (2020-21 plus 2021-22)
Labour	\$324,000	\$ 486,000.00	\$ 810,000.00
Non-Labour	\$ 195,000.00	\$ 130,000.00	\$ 325,000.00
Capital	\$ 1,309,500.00	\$ 436,500.00	\$ 1,746,000.00
Total	\$2,881,000		

Detail capacity to commence

Palliative Care Queensland will manage the infrastructure development, the training program and the tender for the evaluation component. **TCHHS and RFDS** will manage the equipment requirements. **Centre Management** will be managed by one of the existing service providers.



PalliativeCare
QUEENSLAND