

Goal 2: Capability

Knowledge and practice of palliative care is embedded in all care settings

Why is this important?

People die in a range of care settings, including in the home, hospitals, residential aged care facilities and hospices. Palliative care may be required at all stages of a person's illness and in all settings to maintain their comfort and quality of life.³³

Those providing specialist palliative care have an essential role both in providing care to those people with complex needs, and in providing advice and support to other providers who are caring for people with life-limiting illnesses. At the same time, not everyone will have complex needs requiring specialist palliative care and there is significant potential to increase the capacity to deliver palliative care in all care settings, including the home.³⁴

There is a great need among care providers for increased knowledge of palliative care³⁵, including training in assessment and screening to identify people who would benefit from palliative care. Care providers also need to be able to recognise when an individual is ready to discuss and make choices about palliative care and be able to provide or access services that will meet their needs.³⁶

Service providers in all settings need to be able to recognise clinical deterioration and dying.³⁷ Clinical providers of palliative care also need access to evidenced-based information on the appropriate use of medicine for pain and symptom management. The World Health Assembly recognised that there is an "urgent need to include palliation across the continuum of care, especially at the primary care level, recognizing that inadequate integration of palliative care into health and social care systems is a major contributing factor to the lack of equitable access to such care."³⁸

The more that service providers can support conversations and planning for the end of life, the more individuals, their families and carers will be able to make the choices that are right for them.³⁹ A person with a life-limiting illness may be supported by an increasingly complex network of carers.⁴⁰ This requires service providers to adapt to each individual's situation to ensure that everyone who should be included in conversations and planning for the end of life can be involved.

The choices that people make may differ due to cultural, religious, or other factors. For example, we know that Aboriginal and Torres Strait Islander people access health services at lower rates than other Australians. It is imperative that policy makers and service providers consider and address barriers to Aboriginal and Torres Strait Islander patients, their families and carers accessing and using palliative care services. Strategies must be implemented to provide culturally safe, responsive and supportive environments for Aboriginal and Torres Strait Islander people at all points along the patient journey including end of life care. Meeting the needs of individuals, their families and carers requires for example good communication and listening skills to assist people in identifying their needs and preferences. These skills are also necessary to support and provide care for families and carers in bereavement.

³³ Australian Institute of Health and Welfare, 2016a

³⁴ CareSearch, 2017a

³⁵ World Health Organization, 2016

³⁶ McNamara & Hegney, 2016

³⁷ Mason et al, 2015

³⁸ World Health Assembly, 2014, Page 2

³⁹ Kellas et al, 2017

⁴⁰ Horsfall et al, 2015

Priorities

- 2.1 Medical, nursing and allied health graduates can identify and address people's palliative care needs
- 2.2 Clinical and non-clinical service providers can assist individuals, their families and carers to have discussions on palliative care including the development of advance care plans
- 2.3 The needs of people from under-served population groups are identified and respected
- 2.4 Health professionals provide early referrals for palliative care for those affected by life-limiting illness based on need with specialist palliative care services playing an important role in meeting complex needs and supporting others to provide this care
- 2.5 There are consistent assessment and screening practices across care settings
- 2.6 People providing palliative care can identify and meet the needs of carers, including during bereavement

What does this mean for...

People affected by life-limiting illnesses	Providers of care	Governments
2a The people involved in my care are skilled in talking with me and my loved ones and helping us plan for my care and my end of life	2e We are trained and provide high-quality holistic care relevant to our setting	2j We work with education providers to make palliative care education and training available for all people who may be required to provide palliative care
2b The people involved in my care respect my needs and preferences	2f We facilitate respectful discussions and planning with people about their palliative care	2k We support initiatives to increase cultural awareness and safety in palliative care
2c I am provided with culturally appropriate information on palliative care and supported to access care when I need it	2g We identify when someone would benefit from palliative care or specialist palliative care and know how to assist them	2l We support initiatives to increase the number of people in both clinical and non-clinical settings skilled in discussing end-of-life issues and providing the relevant support to all people affected by life-limiting illness
2d My family and friends who care for me are supported and able to access the care they need and to advocate for my wishes	2h We acknowledge the important role of informal carers and provide the support and care they need	
	2i We promote collaboration and partnerships with Aboriginal and Torres Strait Islander Community Controlled Health Services	

Goal 3: Access and choice

People affected by life-limiting illnesses receive care that matches their needs and preferences

Why is this important?

At the heart of palliative care is the goal of ensuring that people may live as well as possible for as long as possible.⁴¹ Australia is a world leader in the development and delivery of palliative care services, and has been at the forefront of innovative research and development initiatives which seek to improve individuals' experience of the dying process.⁴² All states and territories have structures in place to provide palliative care in a range of settings, including the home.⁴³

At the same time, not everyone is able to receive the palliative care they need to live well. There are underserved groups (refer to page 8) that experience various barriers in accessing and choosing the care they wish to receive, including geographical, cultural, language, and other barriers. Addressing these barriers and facilitating access can help overcome health disparities, particularly for Aboriginal and Torres Strait Islander people requiring palliative care.

Carers may also experience barriers to accessing the care and support they need. Improving access and choice for people affected by life-limiting illnesses should include frameworks to identify and address the needs of carers while in the caring role and after the death of their loved one.

A person-centred approach means that people affected by life-limiting illnesses are included in all aspects of planning for their care,⁴⁴ including identifying and addressing barriers to access and choice. For example, ensuring care environments are welcoming and culturally sensitive, such as displaying signs and symbols to acknowledge local Aboriginal and Torres Strait Islander cultures.

Structural or system barriers to access and choice also exist such as the limited number of specialist palliative care services⁴⁵; concentration of specialist services within metropolitan areas^{46,47}; lack of generalist palliative care providers; and siloed funding mechanisms⁴⁸. These critical challenges are also addressed in Goal 2: Capability and Goal 5: Investment.

People's experience of illness will differ widely depending on diagnosis.⁴⁹ Children and young people may have a long engagement with palliative care services and need varying levels of assistance during that time. Conversely, people who are frail and aged may not require specialist palliative care until the very end of life, if at all, but may benefit from good symptom management. Improving the use of care pathways⁵⁰, including pathways for transitions between settings and over the course of the dying process, will assist people to receive more coordinated and integrated palliative care tailored to their needs⁵¹, and reduce unnecessary transfers between care settings.⁵² There is also an increasing role for technology in supporting those

⁴¹ Palliative Care Australia, n.d.

⁴² The Economist Intelligence Unit, 2015

⁴³ Urbis, 2016

⁴⁴ Productivity Commission, 2017

⁴⁵ Mitchell, 2011

⁴⁶ The Economist Intelligence Unit, 2015

⁴⁷ Productivity Commission, 2017

⁴⁸ The Economist Intelligence Unit, 2015

⁴⁹ Australian Institute of Health and Welfare, 2016a

⁵⁰ Hardy et al, 2007

⁵¹ Dy et al. 2013

⁵² CareSearch, 2017b

affected by life-limiting illnesses to access a range of services, including through remote consultations or through the use of tools in the home to support independence.

Priorities

- 3.1 People can receive timely palliative care in the place of their choice
- 3.2 A person-centred approach is embedded in all palliative care planning so that individuals, carers and families are actively engaged in care planning and ongoing needs assessment
- 3.3 More people from under-served population groups access palliative care
- 3.4 The use of technology supports people to access palliative care in all settings
- 3.5 Carers get the support they need, including in-home support, respite care and bereavement support

What does this mean for...

People affected by life-limiting illnesses	Providers of care	Governments
3a It doesn't matter who I am, or where I live, I get the care I need when I need it	3e We provide culturally safe and responsive palliative care where a person wants it and when they need it	3h We continue to support and develop community-based palliative care services
3b I receive care and die in the place that I choose	3f We actively work with the person, their family and carers when planning for and providing care	3i We support ongoing research to identify and address barriers to access and choice
3c I am involved as much as I want to be in planning and decisions about my care	3g We continuously use research to improve our services to meet the palliative care needs of everyone in our community	3j We work with all providers to improve the access to quality palliative care across care settings
3d My loved ones who care for me are cared for as well		

Goal 4: Collaboration

Everyone works together to create a consistent experience of palliative care across care settings

Why is this important?

Many people with life-limiting illnesses will move between a variety of care settings as they approach the end of life. This is particularly true for children and young people with life-limiting conditions who may have contact with a palliative care service for many years.⁵³ In many parts of Australia, local collaborative networks have been established to improve consistency of care within as well as between care settings.⁵⁴

Strengthening communication, collaboration and partnerships at local levels will contribute to improving transitions of care, including enhancing care pathways and shared care arrangements. This is evident when Aboriginal and Torres Strait Islander people, communities and organisations are actively engaged and partnered with, will contribute to improve the quality of care⁵⁵.

Primary Health Networks and local hospital or health networks as well as Aboriginal and Torres Strait Islander Community Controlled Health Services, private and non-profit providers all have a contribution to make in working together to reduce duplication and unnecessary transfers to hospital where care could be provided in a more appropriate setting.

The National Palliative Care Projects as well as Palliative Care Australia and its member organisations have an important role to play in sharing innovation and excellence as well as strengthening the evidence base for new treatments and approaches.⁵⁶ In addition, greater collaboration between general practice and state/territory health services may reduce duplication of effort⁵⁷ and assist in providing greater consistency of service experience. Greater information sharing across jurisdictions should also help to increase the consistency of service for people who may move between states or regions.

Strengthening existing networks for information sharing can help services learn from each other regarding the best ways to improve the quality of palliative care. In addition, there are structural barriers to improve communication and information sharing within and across sectors, including technology systems, such as the My Health Record and funding mechanisms. Addressing these will drive better communication and collaboration.⁵⁸

Involving individuals and their families and carers in the conversation, including in the design and monitoring of services, will improve the ability of services to provide the care that is best for the individual, their carer and family. This should include engagement with representatives from under-served population groups previously identified on page 8 of this National Strategy.

A number of policy frameworks have been developed in Australia in recent years that should align closely with the palliative care needs of particular groups of people (refer to page 6). Improving coordination and information sharing with other sectors will help to improve the consistency of experience of palliative care for people across Australia.

⁵³ Viridun et al, 2015

⁵⁴ Productivity Commission, 2017

⁵⁵ Australian Commission on Safety and Quality, 2016

⁵⁶ Urbis, 2016

⁵⁷ Productivity Commission, 2017

⁵⁸ Ibid

Priorities

- 4.1 Collaboration tools (such as technology and agreed care pathways) are used to monitor and improve the coordination of palliative care and transitions between care settings
- 4.2 Communication between and across national, state/territory, and local palliative care networks improves the consistency of care across jurisdictions
- 4.3 People affected by life-limiting illnesses are included in the development, implementation and evaluation of palliative care services
- 4.4 Funding mechanisms, including existing Medicare Benefit Schedule item numbers, facilitate advance care planning and care coordination across all settings
- 4.5 Collaboration with Aboriginal and Torres Strait Islander people and organisations, guided by the Australian Commission on Safety and Quality in Health Care, National Safety and Quality Health Service Standards user guide for Aboriginal and Torres Strait Islander Health⁵⁹

What does this mean for...

People affected by life-limiting illnesses	Providers of care	Governments
4a Everyone involved in my care is aware of their role and is accountable for doing their job	4e We work together to ensure that a person receives coordinated palliative care	4j We collect and share data to improve consistency and quality of palliative care
4b I receive high-quality, evidence-based care	4f We continue to strengthen our cultural competence to improve coordination of care for diverse population groups	4k We include people affected by life-limiting illness in the planning, delivery and evaluation of services
4c I am included and can contribute to the planning, delivery and evaluation of palliative care	4g We are actively involved in research and knowledge sharing to continuously improve the palliative care we provide	4l We facilitate the use of tools and mechanisms that enable collaboration at national, state and territory and local levels
4d I receive holistic care that is culturally safe and responsive	4h We include people affected by life-limiting illnesses in the planning, delivery and evaluation of services	
	4i We work together to review the care people receive	

⁵⁹ Australian Commission on Safety and Quality, 2016

Goal 5: Investment

A skilled workforce and systems are in place to deliver palliative care in any setting

Why is this important?

The need for palliative care will continue to increase as the Australian population ages and people live longer with chronic disease and disability.⁶⁰ An ageing workforce⁶¹ and shortages of medical and nursing staff trained in palliative care⁶² will place increased pressure on services to meet this rising demand. Investment at national, state and territory levels will be required to ensure that the systems and people are available to provide quality palliative care where and when it is needed. This will include palliative care specialists who play an important role in not only the delivery of care but building the capacity of other providers of palliative care.

Current models of palliative care rely heavily on a critical number of specialist palliative care providers working within primarily metropolitan-based in-patient environments, while individual preferences and funding constraints point to an increasing need for service delivery in the community, within homes, and in residential aged care facilities.⁶³ Research and experience have identified the benefits for individuals and families in remaining at home as much as possible.⁶⁴ Investment is needed into community-based models that are flexible to accommodate increased demand and public expectations.⁶⁵ Resources and infrastructure will be required to provide care in the place a person chooses, including technology and care aids.

Service models must allow providers to respond quickly when an individual's condition changes, to avoid inappropriate or unnecessary emergency department presentations at the end of life and support people to remain in their home, if they choose, for as long as possible.

Strategic workforce planning supports all the other goals in this National Strategy. Workforce planning will need to take into account the current services available, the anticipated increase in demand, how people are likely to want to receive care in the future, and the competencies required to provide high quality palliative care. A national framework for workforce development will assist in strengthening consistency of both availability and quality of services across jurisdictions, and also assist service users and providers who move between states and territories.

In addition to specialist and non-specialist palliative care providers, there are many volunteers and community organisations that support the holistic needs of people affected by life-limiting illnesses. Their contribution needs to be acknowledged and support provided for these essential services. All individuals involved in palliative care need to be supported to maintain their own resilience and well-being while working in this often challenging area.⁶⁶

⁶⁰ Productivity Commission, 2017

⁶¹ *ibid*

⁶² *ibid*

⁶³ Senate Community Affairs References Committee, 2012

⁶⁴ Gomes et al, 2013

⁶⁵ McNamara & Hegney, 2016

⁶⁶ Chan et al, 2016

Priorities

- 5.1 Service models deliver palliative care when and where it is required according to the individual's needs
- 5.2 A national workforce development framework for palliative care provides guidance for future workforce planning, including a competency framework suitable for all care settings
- 5.3 Care providers have the support they need to maintain their health and wellbeing
- 5.4 Technology supports the delivery of palliative care in any setting
- 5.5 Investment in palliative care in all jurisdictions includes expansion of primary, community-based and tertiary services

What does this mean for...

People affected by life-limiting illnesses	Providers of care	Governments
5a My care is flexible and able to accommodate my changing needs	5c We develop and improve the way we plan and deliver services to align with the needs of our community	5h We continue to support research to identify gaps in service provision and implement responses to address those gaps
5b My care is respectful of my cultural beliefs and practices, social and spiritual needs	5d We provide palliative care at the time and in the place that a person requires	5i We continue to ensure that there is the appropriate skilled workforce to deliver palliative care both now and in the future across primary, community-based and tertiary services
	5e All people involved in palliative care have the appropriate skills	5j We support the delivery of palliative care in all care settings to ensure that people can access the care they need when and where they need it
	5f We provide palliative care that is culturally safe and culturally responsive	5k We support the development and use of technology to deliver palliative care
	5g We support the wellbeing and resilience of people working in palliative care	5l We support strategies to increase engagement by Aboriginal and Torres Strait Islander people in Palliative Care Services
	5h We develop and strengthen the Aboriginal and Torres Strait Islander health workforce in all areas of the health system, both clinical and non-clinical	
	5i We develop a culturally skilled and responsive workforce in all areas of the health system, both clinical and non-clinical	

Goal 6: Data and evidence

Robust national data and a strong research agenda strengthen and improve palliative care

Why is this important?

The lack of consistent collection and reporting of data on palliative care has been identified as an area for improvement at both state and territory^{67,68} and national levels.^{69,70}

Many jurisdictional and national data collection mechanisms do already exist, including those supported through the National Palliative Care Projects; in addition, work continues at national, state and territory levels to improve data development, collection and interpretation activities. However, further work is required to enable linked and nationally consistent data collection to improve both routine monitoring and evaluation reporting. This can be strengthened by effective and accurate processes to routinely ask patients and record responses if they identify as being of Aboriginal and/or Torres Strait Islander origin.

The evaluation of the National Palliative Care Strategy 2010 resulted in several recommendations related to the collection of data across all care settings and the development of nationally consistent data. People who contributed to the evaluation argued strongly that data improvement is critically important to strengthen the evidence base regarding the provision, quality and effectiveness of palliative care across Australia.⁷¹

A key goal for this National Strategy is to improve the ability to evaluate palliative care at a population level and to monitor outcomes across Australia. This will allow the quality and processes of care to be assessed and improved across all care settings. It will also assist to expand the understanding of where people are able to access palliative care, who is providing the care, and the frequency and effectiveness of different treatments or services. Central to this evaluation will be the voices of those who are recipients of care, in both the design and collection of data and in research processes.

Australia has benefited for many years from a focussed national research agenda, which has created a large network of clinicians, academics, researchers and policy makers; the outcomes of this large-scale investment in research have contributed significantly to the quality of palliative care provided in Australia.⁷² Maintaining a strong national commitment to research and evidence will benefit Australia as well as help to improve services internationally by increasing the global knowledge base.

⁶⁷ Audit Office of New South Wales, 2017

⁶⁸ Victorian Auditor-General's Office, 2015

⁶⁹ Productivity Commission, 2017

⁷⁰ Senate Community Affairs References Committee, 2012

⁷¹ Urbis, 2016

⁷² Ibid

Priorities

- 6.1 Nationally consistent data collection is used to monitor, evaluate and report on access to and outcomes of palliative care
- 6.2 Palliative care providers contribute to data collection, monitoring and reporting activities
- 6.3 Data collection and reporting informs continuous quality improvement of palliative care
- 6.4 A robust national research agenda informs sector development and improvement
- 6.5 Research includes the experience of individuals affected by a life-limiting illness and these experiences inform the continuous improvement of palliative care
- 6.6 Systematic processes are in place for asking all patients and recording responses to the standard Aboriginal and Torres Strait Islander status question, 'are you [is the person] of Aboriginal or Torres Strait Islander origin?'

What does this mean for...

People affected by life-limiting illnesses	Providers of care	Governments
6a My feedback informs improvements to care	6c We collect and share data on the palliative care we provide and the outcomes of that care	6h We continue to support the improvement of nationally consistent data collection and reporting for palliative care
6b I can access quality, evidence-based information that helps me make informed decisions	6d We continuously improve the care we provide to reflect the evidence on quality palliative care	6i We support data infrastructure that informs the continuous improvement of palliative care
	6e We learn from the feedback we receive from people affected by life-limiting illnesses	6j We continue to support research to maintain a strong evidence-base for palliative care
	6f We know where to find data and evidence to improve the care we provide	6k We support the translation of research into practice
	6g We routinely ask all people and record responses if they identify as being of Aboriginal and/or Torres Strait Islander origin	

Goal 7: Accountability

National governance of this Strategy drives action

Why is this important?

A key finding of the evaluation of the National Palliative Care Strategy 2010 was the value placed on national governance structures to improve collaboration and accountability across jurisdictions. The absence of formal governance and accountability structures was noted as a barrier to improving access as well as the quality and consistency of palliative care provision across Australia.⁷³

A formal national governance structure with links to the Australian Health Ministers' Advisory Council will ensure that palliative care is recognised and resourced as an integral component of the health system, while retaining the independence of states and territories to decide how best to invest in palliative care services. Such a governance mechanism will be strengthened by including people with lived experience of palliative care and by ensuring that the voices of people affected by life-limiting illnesses are considered in service and research development.

This governance structure will be responsible for the development of the Implementation Plan for this Strategy (refer to page 23) as well as reporting on progress made towards achieving the goals within this Strategy. It will also provide a structural mechanism to support information sharing between the Commonwealth (which funds general practice and aged care services) and states and territories (which fund community, tertiary and specialist services).

As Australians live longer, and more people live with chronic and life-limiting conditions, the need for palliative care will continue to increase.⁷⁴ Embedding palliative care further within the national governance structures of the health system will facilitate the effective integration of palliative care across all service settings. This governance structure can also provide a platform for dialogue and integration with other service sectors including aged care, disability, and social services, and for promoting the use of quality standards and accreditation processes.

⁷³ Urbis, 2016

⁷⁴ Productivity Commission, 2017

Priorities

- 7.1 A national governance structure for this Strategy maintains a formal link to the Australian Health Ministers' Advisory Council
- 7.2 Oversight for the implementation and monitoring of this National Strategy includes annual reporting on progress
- 7.3 People with lived experience of palliative care are consulted in national policy development
- 7.4 The national governance structure facilitates closer integration with other policy and service sectors
- 7.5 Indicators for quality palliative care are reflected in the accreditation processes of all care settings

What does this mean for...

People affected by life-limiting illnesses	Providers of care	Governments
<p>7a I see changes being made to improve palliative care</p> <p>7b My voice is represented and informs decision making</p>	<p>7c We are involved in and knowledgeable about changes being made to improve palliative care</p> <p>7d We provide care that is aligned to best practice</p>	<p>7e We work towards fulfilling our commitments in this Strategy</p> <p>7f We regularly monitor and report on the priorities in this Strategy</p> <p>7g We include people with a lived experience of palliative care in the implementation of this Strategy</p> <p>7h We promote the inclusion of palliative care indicators in accreditation standards across all care settings</p> <p>7i We commit to strong collaborative partnerships within and across governments to improve quality and consistency of palliative care</p>

Implementation Plan

The responsibility for the implementation of the National Strategy rests with the Commonwealth, state and territory governments, with the Commonwealth providing national leadership and policy direction as well as supporting national research and other programs, and the state and territory governments providing quality palliative care and policy development within their jurisdictions.

The implementation of the National Strategy will be guided by an Implementation Plan, to be developed by Commonwealth, state and territory governments within the year following endorsement of the Strategy. The Plan will identify activities, accountability and timing for progress within a five-year timeframe. Annual reporting on the activities within the Plan will feed into the Monitoring and Evaluation Plan.

An indication of what the Implementation Plan might include is outlined in the table below.

Goals	Priorities	Activities	Responsibilities	Timing	Data sources
<i>Goal 1: Understanding - People understand the benefits of palliative care, know where and how to access services, and are involved in decisions about their own care</i>	<i>1.1 More people are aware of the benefits and the local availability of palliative care</i>	<i>The specific actions at regional, state or national levels that will be undertaken to support achieving the goal</i>	<i>The organisation(s) accountable implementing the activity</i>	<i>The expected timeframe for undertaking this activity</i>	<i>The evidence that will be used to report the progress made towards achieving the goal</i>

Monitoring and Evaluation Plan

A Monitoring and Evaluation Plan will be developed to identify how progress on the priorities in the National Strategy will be measured and reported. Data collection should contribute to annual monitoring and reporting as well as to longitudinal evaluation of achievements over the five-year timeframe for the Implementation Plan. Many indicators are already available in existing datasets; however, the National Strategy contains some aspirational priorities which will require the development of new, or enhancement of existing, datasets.

An indication of what the Monitoring and Evaluation Plan might include is outlined in the table below.

Outcomes	Evaluation questions	Indicators	Data source	Timeframe
<i>1a. I can access information on palliative care and end-of-life issues and can make informed decisions about the care that I want to receive</i>	<i>Question(s) to assess the extent to which the outcome has been achieved</i>	<i>The measure(s) used to assess progress towards achieving the outcome</i>	<i>The evidence that will be used to assess the progress made towards achieving the goal</i>	<i>The time period within which the outcome is expected (long, medium or short-term)</i>

Glossary of terms

Aboriginal (adjective): A person of Aboriginal descent who identifies as Aboriginal and is accepted as such by the community in which he[or she] lives (the original inhabitants of the Australian continent and surrounding islands).

Advance care plan – states “preferences about health and personal care and preferred health outcomes. They may be made by, with, or on the person’s behalf, and are prepared from the person’s perspective to guide decisions about care.”⁷⁵

Advance care directive – “a type of written advance care plan recognised by common law or authorised by legislation that is completed and signed by a competent adult.”⁷⁶

Bereavement – “refers to the event of death of a person with whom there has been an enduring relationship.”⁷⁷

Chronic conditions – “have complex and multiple causes; may affect individuals either alone or as comorbidities; usually have a gradual onset, although they can have sudden onset and acute stages; occur across the life cycle, although they become more prevalent with older age; can compromise quality of life and create limitations and disability; are long-term and persistent, and often lead to a gradual deterioration of health and loss of independence; and while not usually immediately life threatening, are the most common and leading cause of premature mortality.”⁷⁸

Culturally and linguistically diverse – “a broad and inclusive descriptor for communities with diverse language, ethnic background, nationality, dress, traditions, food, societal structures, art and religion characteristics.”⁷⁹

Carers – “people who provide personal care, support and assistance to people with a disability, medical condition (including terminal or chronic illness), mental illness, or frailty due to age. Carers include family members, friends, relatives, siblings or neighbours. Grandparents or foster carers providing care to a child with disability, medical condition (including terminal or chronic illness) or mental illness are included as carers.”⁸⁰

End of life – “the period when a patient is living with, and impaired by, a fatal condition, even if the trajectory is ambiguous or unknown. This period may be years in the case of patients with chronic or malignant disease, or very brief in the case of patients who suffer acute and unexpected illnesses or events, such as sepsis, stroke or trauma.”⁸¹

⁷⁵ Australian Health Ministers’ Advisory Council, 2011, Page 9

⁷⁶ Australian Health Ministers’ Advisory Council, 2011, Page 10

⁷⁷ CareSearch, 2017c

⁷⁸ Australian Health Ministers’ Advisory Council, 2017 Page 6

⁷⁹ Ethnic Communities’ Council of Victoria, 2012, Page 1

⁸⁰ Australian Government, 2011

⁸¹ Australian Commission on Safety and Quality in Health Care, 2015, Page 33

End-of-life care⁸² – “includes physical, spiritual and psychosocial assessment, and care and treatment delivered by health professionals and ancillary staff. It also includes support of families and carers, and care of the patient’s body after their death. People are ‘approaching the end of life’ when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

- advanced, progressive, incurable conditions
- general frailty and co-existing conditions that mean that they are expected to die within 12 months
- existing conditions, if they are at risk of dying from a sudden acute crisis in their condition
- life-threatening acute conditions caused by sudden catastrophic events.”⁸³

Grief – “is how bereavement affects us personally, with effects across several domains – emotional, cognitive, social, physical, financial and spiritual.”⁸⁴

Integrated care – “Integration is a coherent set of methods and models on the funding, administrative, organizational, service delivery and clinical levels designed to create connectivity, alignment and collaboration within and between the cure and care sectors. The goal of these methods and models is to enhance quality of care and quality of life, consumer satisfaction and system efficiency for people by cutting across multiple services, providers and settings. Where the result of such multi-pronged efforts to promote integration leads to benefits for people, the outcome can be called integrated care.”⁸⁵

Life-limiting illness – “a person with life-limiting illness may die prematurely. This term is often used for people living with a chronic condition that may seem life-threatening but can continue for many years or even decades.”⁸⁶

Palliative care – an approach that improves the quality of life of patients and their families facing the problems associated with life-limiting 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:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient’s illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.”⁸⁷

⁸² The Aged Care Funding Instrument (ACFI) enables a claim for a palliative care program involving end of life care for a resident of a Residential Aged Care Facility. Within this context end of life care is defined as care provided in the last week or days of life. See https://www.caresearch.com.au/caresearch/Portals/0/PA-Toolkit/Resources_2016_Update/Fact_Sheet_10_End_of_Life_Terminal_Care_Pathways.pdf

⁸³ Australian Commission on Safety and Quality in Health Care 2015, page 33

⁸⁴ CareSearch, 2017c

⁸⁵ World Health Organization 2016, page 3

⁸⁶ Department of Health and Human Services, 2016, Page 29

⁸⁷ Based on World Health Organization, 2017b

Paediatric palliative care – “Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child's physical, psychological, and social distress. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.”⁸⁸

Person-centred care – Person-centred care “is a philosophy that sees doctors, nurses and health services treating people the way they want to be treated. It allows people to make choices about the type of health services and care they access, and how and when it is delivered.

With person-centred care, each person is treated as a complete human being with their own life story, values, culture, interests and beliefs. Support from others is tailored to meet the person's individual situation, unique needs and goals.”⁸⁹

Quality of care – “the extent to which health care services provided to individuals and patient populations improve desired health outcomes. In order to achieve this, health care must be safe, effective, timely, efficient, equitable and people-centred.”⁹⁰

Respite – “Respite care refers to the provision of care for a person with a disability, severe medical condition or who is frail aged, by an organisation or another person other than the carer for a temporary period so the carer can have a break from caring.”⁹¹

Specialist palliative care – “Services provided by clinicians who have advanced training in palliative care. The role of specialist palliative care services includes providing direct care to patients with complex palliative care needs, and providing consultation services to support, advise and educate non-specialist clinicians who are providing palliative care.”⁹²

Terminal – “the stage of an illness when death is likely within days.”⁹³

Torres Strait Islander – A person of Torres Strait islander descent who identifies as a Torres Strait Islander and is accepted as such by the community in which he [or she] lives (the original inhabitants of the Torres Strait Islands).

⁸⁸ World Health Organization, 2017a

⁸⁹ Australian Government, n.d

⁹⁰ World Health Organization, 2017c

⁹¹ Australian Government, 2017

⁹² Australian Commission on Safety and Quality in Health Care 2015, page 35

⁹³ Australian Institute of Health and Welfare, n.d.

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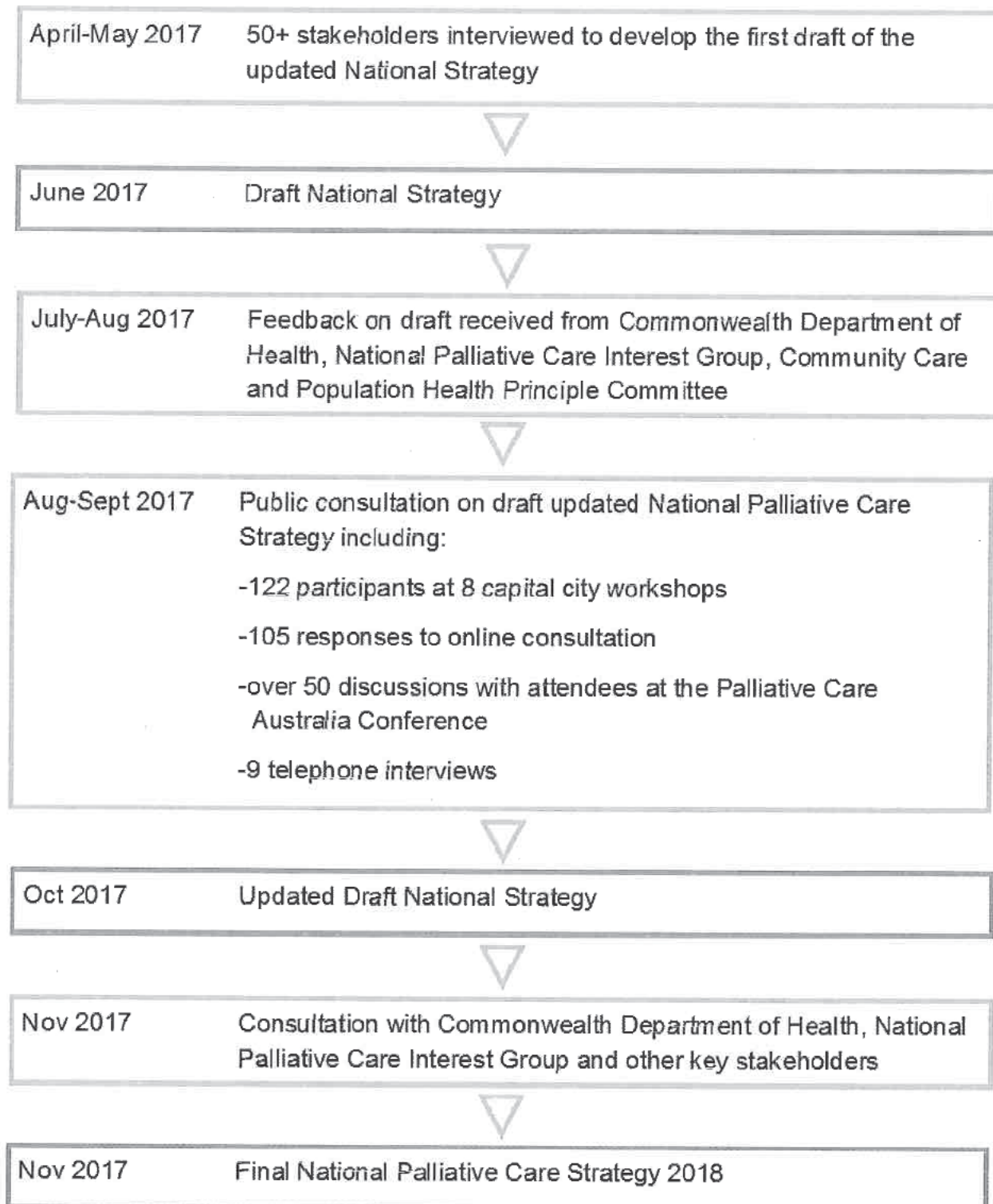
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Appendix A Consultation to develop the National Palliative Care Strategy 2018

The figure below outlines the consultation process undertaken to develop the update National Palliative Care Strategy.

Figure 3 – Consultation process



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MINISTERIAL BRIEF

Health Directorate

SENSITIVE

To:	Minister for Health and Wellbeing	Tracking No.: MIN18/1425
From:	Michael De'Ath, Interim Director General	
Subject:	Meeting with Snow Foundation on 17 September 2018 – 9am to 9.45am - Concept Design Options for a Potential Expansion of Clare Holland House	
Critical Date:	17 September 2018	
Critical Reason:	Meeting is scheduled for this date	

- DG .../.../...

Purpose

To provide you with a brief ahead of your meeting with the Snow Foundation on Monday, 17 September 2018, in regards to a potential expansion of Clare Holland House (CHH).

Recommendations

That you:

1. Note the information contained within this brief and the final draft design report (Attachment A);

Noted / Please Discuss

2. Note that Option 1, Option 1b and Option 4 have been shortlisted for consideration for the basis of an expansion of CHH, with Option 4 recommended as the preferred option (subject to funding);

Noted / Please Discuss

3. Note the recommended next steps, which include seeking in-principle funding support from the Snow Foundation, followed by execution of a project agreement with the Commonwealth for a \$4 million capital funding contribution. Following this, planning can commence in partnership with Calvary for progression of the project into design (including early engagement with the National Capital Authority);

Noted / Please Discuss

SENSITIVE

SENSITIVE

- 4. Note that under the draft Project Agreement with the Commonwealth, announcements must be made with mutual agreement of the ACT Government and Commonwealth; and

Noted / Please Discuss

- 5. Note that currently there is no identified capital contribution from the Territory. However, this could take the form of increased parking amenity for the facility.

Noted / Please Discuss

Meegan Fitzharris MLA

M. Fitzharris

17/9/18

Minister's Office Feedback

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- governance

- examples - Boundless
Charity House

SENSITIVE

Background

1. CHH is located at Block 15, Section 33 Barton, and is operated by Calvary Healthcare ACT (Calvary). The facility provides palliative care services to the ACT community and currently comprises of a 19 bed inpatient unit, specialist palliative care outpatient clinics, a home-based palliative care service and specialist palliative aged care services.
2. ACT Health has undertaken work to explore options for a potential expansion of CHH, which would respond to increased demand from the community for palliative care services. The Snow Foundation is considering to part fund an expansion, with ACT Health in the process of seeking further required funding from the Commonwealth Government.
3. The broad intent of an expansion would be to provide an additional 8 to 10 inpatient beds for the existing facility, along with additional associated education, training, administration and clinical support areas.
4. ACT Health engaged the architect Daryl Jackson Alastair Swayn (DJAS) to scope options for a potential expansion, including high-level concept designs and cost plans.
5. Your office was previously provided with a brief and advisory note in regards to this matter. This brief provides an update to these previous briefings.

Issues

6. DJAS have scoped five potential options for a potential expansion for CHH. The options have been developed with consideration given to opportunities and constraints inherent to the site (including extant trees, buildings, zoning, access and urban composition).
7. The options contained in the final draft design report (Attachment A), are summarised at Table 1 below. A detailed description of the options, draft concept designs and high-level draft cost plans are contained in the draft design report.

Table 1: Summary of Options for a Potential Expansion of CHH.

Expansion Options		Key Features	Cost (\$M)
Option 1: (shortlisted)	One Storey Western Duplication	<ul style="list-style-type: none"> • Additional 8 inpatient beds. • Existing training room demolished. 	
Option 1b: (shortlisted)	One Storey Western Duplication (Alt.)	<ul style="list-style-type: none"> • Additional 6 inpatient beds. • Reinstatement of training room. 	
Option 2:	Two Storey Southern Expansion	<ul style="list-style-type: none"> • Additional 8-10 inpatient beds. • Expansion above current inpatient area. • Inpatient areas across two-levels. 	
Option 3:	Two Storey North-Western Expansion	<ul style="list-style-type: none"> • Additional 8 inpatient beds. • Reinstatement of training room and chapel. 	
Option 4: (shortlisted)	Two Storey Western Expansion	<ul style="list-style-type: none"> • Additional 8-10 inpatient beds. • Reinstatement of training room and chapel. • Improved patient room views and design. 	

SENSITIVE

8. The following points below should be noted in reference to the high level cost plans developed for the shortlisted options (Option 1, Option 1b and Option 4):
 - Draft cost plans have been prepared on the basis of industry benchmarked square metre construction rates.
 - The high level cost estimates exclude costs for staging and decanting of services, relocation of services and temporary accommodation during the execution of construction works.
 - The high level cost estimates exclude the design, planning and construction of additional on-grade car parking for the facility.
 - Contingencies for design, planning and construction costs, are calculated at a total factor of 25 per cent of the project value. This aligns with standard industry practice for early stage project estimates based on preliminary concept design options.
9. It is recommended that shortlisted options of Option 1, Option 1b and Option 4 are considered for the basis of a potential expansion of CHH, with Option 4 recommended as the preferred option (subject to funding), as it is reflective of a best practice solution.
10. See Section 1.2 – Recommended Expansion Options (Final Draft Design Report, page 3), which provides more detail to support Option 4 as the recommended preferred option.
11. The Snow Foundation have indicated that they are considering to part fund an expansion of CHH, with \$4 million in funding to be committed by the Commonwealth Government, subject to the execution of a project agreement with the ACT Government.
12. The next steps to be undertaken to progress a potential expansion include:
 - Meeting with the Snow Foundation to present the high-level concept designs and seek in-principle funding support.
 - Undertake a process for formal confirmation of the funding contribution (\$4 million) from the Commonwealth, via the execution of a project agreement.
 - With confidence in funding (Commonwealth and Snow Foundation), commence planning in partnership with Calvary for further progression of the project into a design phase. This will include early engagement with the National Capital Authority (NCA) in regards to planning requirements and constraints.
13. As part of the next steps, discussions at an appropriate time will need to occur between the ACT Government and Calvary, in regards to contribution arrangements for recurrent operational funding for future expanded operations at CHH.

Financial Implications

14. Currently there is no identified capital contribution from the ACT Government. However, this could take the form of increased parking amenity, to address the current shortfall in required car spaces that would increase as a result of an expansion project.

Consultation

15. Limited consultation has occurred with Calvary to facilitate scoping of a potential expansion of CHH, and included a detailed site visit for DJAS and ACT Health, which was guided by Calvary in their capacity as the operator of the facility.

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SENSITIVE

Work Health and Safety

16. Not applicable.

Benefits/Sensitivities

17. It is important to note, the CHH site resides within the planning jurisdiction of the NCA. In this regard, the National Capital Plan contains a number of statutory requirements for the site. This includes building height restrictions and carpark space requirements, specifically that buildings are 'one storey' in height, and that one carpark space per bed and per staff member is provided for the facility.
18. Critically carpark space at CHH is currently a challenge and based on the NCA requirements, there is a current shortfall of some 50 car spaces which would further increase with any development or expansion.
19. There is inadequate space within the existing site to provide additional carparks and also to accommodate an expanded facility. Adjacent sites may present as potential solutions and would be subject of discussion with the NCA.

Communications, media and engagement implications

20. Not applicable.

Signatory Name: Karen Doran Phone: X52248
 Action Officer: Brad Burch Phone: X72385

Attachments

Attachment	Title
Attachment A	Final Draft Design Report – Potential Expansion of Clare Holland House (includes concept designs and high-level draft cost plans)

D **J** Daryl
+ Jackson
A **S** Alastair
Swayn

Clare Holland House
Design Report
Revision P4

August 2018

DISCLAIMER

This briefing note has been prepared by Daryl Jackson Alastair Swayn Pty Ltd for the client for the purpose agreed to within the agreement. DJAS does not take responsibility for use of the report for purposes other than that for which it was intended for.

This report is not intended for third parties, general publication or circulation. DJAS does not take any responsibility from third parties.

01 Project Overview

Clare Holland House is part of the Calvary Bruce Public Hospital, providing specialist palliative care services to the ACT and surrounding region. The facility is integrated into the ACT's public healthcare system and is operated by the Little Company of Mary Health Care. We understand ACT Health is facilitating a funding bid with the Snow Foundation to expand the facility.

Daryl Jackson Alastair Swain Pty Ltd have undertaken informal consultation with Clare Holland House and ACT Health to review the existing facility and provide concept designs to accommodate additional inpatient beds and support areas.

This report provides an overview of development risks, statutory requirements, proposed scope of works, and potential design options.

1.1 Current Services

Clare Holland House provides three core services to the public;

- + Inpatient palliative care consisting of 19 beds. Caters for adults with specialist palliative care needs.
- + Community palliative care - Education & Training
- + Home based palliative care

These services are planned to continue into the future. The focus of the funding bid is on inpatient palliative care and the associated administrative requirements.

1.2 Recommended Expansion Options

DJAS developed four options based on the available funding and requirements of Clare Holland House. Option 01 & Option 04 provide the strongest outcomes for a [REDACTED] budget respectively. Key differences between the two options are;

- + Option 01 only includes the 'essentials' i.e. replication of the existing Clare Holland house functions (8 beds and ensuite, nurse station, stores).
 - + Option 04 is a 'best practice' solution i.e. incorporates the majority of the Australasian Health Facility Guidelines (10 beds, more lounge/ family rooms, additional meeting rooms, dining room). This provides stronger amenity overall to staff and consumers, aligning with contemporary expectations of palliative care.
 - + Option 04 also enables strong landscaping outcomes for CHH.
-

02 Development Risks

2.1 Site Services

A desktop review of site services indicates strong access to the infrastructure requirements for the project, generally to the north of the facility within the adjacent road reserves.

AEP—Due to the proximity to the Molonglo River, the site is adjacent a AEP of 1%. Structures should be designed and sited so that they do not make flood levels worse, upstream or downstream. They should be capable of withstanding the forces created by flood water pressure and prevent accumulation of flood debris.

ICON—The Department of Finance indicate ICON fibre is within the vicinity. While the exact location is unknown, further discussions with DoF are strongly recommended prior to design development.

There are no service easements on site based on ACTmap.i.

2.2 Solar Access

As the site is biased towards the north with it's geometry, the majority of the site will receive reasonable solar access throughout the year. Solar access may be limited by the extent of trees retained on site. Overshadowing by adjacent sites is very unlikely, given the wetlands are to the east and the remainder of the area is used for recreation.

Inpatient beds are orientated south to view the Jerrabomberra Wetlands and Lake Burley Griffin. Consideration of direct natural light should be included within the concept design.

2.3 Ecological Considerations

Flora & Fauna

Existing trees are the primary redevelopment consideration on both blocks. There are specific requirements to retain existing composition of native and exotic trees. Furthermore, the poplar column to the south west should be retained to meet the NCA requirements.

To the east and south are the Jerrabomberra Wetlands which are a protected habitat for migratory birds. Limiting noise and uplighting should minimise any disturbance to this area.

Geological

The site is located on the Deakin fault line. The site is under a MA5 (lower slope colluvial) designation, which may require special foundations. Soil will need to be well compacted throughout to reduce permeability and saturation settlement. Due to the close proximity to a MA9/10 area (Jerrabomberra Creek/ Wetlands), suitable measures should be enacted to limit rainwater runoff, to mitigate any potential impact on the wetlands.

The site is part of the 'Pialligo soils' area. This is a reasonable risk to development and may require mitigation prior to construction.

2.4 Contamination

No contamination was apparent during a site inspection and discussions with ACT Health and Clare Holland House. No publically available records indicate the site is contaminated (as defined by the ACT Government's contaminated sites register).

2.5 Parking

Inadequate parking is a challenge for Clare Holland House. Based on the National Capital Authority's requirements, there is a shortfall of 36 car spaces, which is set to rise with any development. Refer to Section 05 for potential solutions.

03 Statutory Requirements

3.1 National Capital Authority

The National Capital Authority (NCA) is responsible for reviewing and approving any development on the proposed site. Location specific requirements were created for Clare Holland House, with a strong emphasis on creating a facility which is integrated with the foreshore landscape i.e. has a minimal impact on views into the site.

The following items are key extracts from the National Capital Plan;

<i>Item</i>	<i>Description & Comments</i>
+ Number of storeys and building height	One storey is nominated. Given the extent of existing trees, there is reasonable grounds to explore a two storey option prolonging the visual impact is minimal.
+ Setbacks	No setbacks are nominated.
+ Parking	Parking rates are one space per bed, and one space per staff. There is a shortfall of 36 car spaces based on current staff numbers. This shortfall could expand to 52 if 10 beds are included.

04 Proposed Scope of Works

There are two areas which will be accommodated by the expansion; Inpatient support and administration areas. The Australasian Health Facility Guidelines should be utilised as the basis for room sizes unless noted otherwise.

4.1 Inpatient areas

- 8 -10 palliative care beds.
- All rooms to accommodate one patient. 40% of rooms will have an extra bed to accommodate patient visitors.
- + All rooms to include capability for visitors & family
- All rooms should be on ground floor with access to wetland views.
- + Lifting equipment required for all rooms. Preference for system to incorporate ensuites
- 20% composition to cater for bariatrics
- Replicate current 'nursing hub' adjacent beds. This should include a nursing station, staff wet areas, and clean/ dirty utility rooms
- + Kitchen. The existing kitchen to be expanded to accommodate increase of inpatients. It is a staff only access area.
- + Larger gym. A treadmill to be included at a minimum
- Pharmacy
- Store areas

4.2 Administration expansion

- Reconfiguration of existing offices
- + Location of offices can be separate from inpatient areas i.e. on a second floor
- + Staff room to cater for current & proposed staff numbers

4.3 Existing facilities

- + Generally the facility is well maintained
- + Services are functioning well. Chillers and generator were recently replaced
- There is a heavy dependence on split systems in offices
- A selection of existing single bed rooms are too small
- + Lifting equipment is limited bedrooms only. Preference to incorporate ensuites
- + Limited parking for staff

Existing areas have no proposed works unless required to accommodate new inpatient facilities.

05 Site Strategies

DJAS have developed four potential strategies for the site to accommodate an expanded facility. These strategies were developed based on the interplay between opportunities & constraints inherent to the site; extant trees, buildings, zoning, access & urban composition. Refer to concept drawings for costs and considerations of each concept option.

5.1 Clare Holland House Expansion

Option 01 – One storey western duplication (minimal works)

To the west of the site a new one storey extension is proposed. This will effectively duplicate the current inpatient ward arrangement, with inpatient beds on the perimeter and nursing/ support facilities inbound. Careful consideration of privacy between existing and proposed inpatient wards will be required in the design development stage.

Option 1b enables Clare Holland House to expand parts of their training programs through additional training and education rooms. However, only 6 inpatient beds would be achievable.

Option 02 – Two storey southern expansion

There is limited land available on site to permit one storey solutions without compromising patient care i.e. nursing staff separated from patients. Accordingly, investigating a second storey is necessary. Option 02 places the new inpatient areas above the existing ward. Existing wards could be refurbished, pending cost plan advice. Decanting the facility would be required to accommodate this option.

Option 03 – Two storey north-western expansion

Limiting the scope of works required in existing areas, Option 03 demolishes the existing chapel and training area. New inpatient beds and support areas are placed on the ground floor, continuing the existing arrangement. Displaced administration areas would be relocated to the second floor.

Option 04 – Two storey western expansion (recommended)

Focusing on a creating a centralised courtyard area surrounded by low scale massing, Option 04 locates new inpatient beds and support areas along the western site boundary. Displaced administration areas would be relocated to the second floor. This option is recommended as the majority of new inpatient rooms are on the ground floor with views towards the lake. The extent of refurbishment works is also limited.

5.2 Parking Investigations

There is inadequate space within the existing site to accommodate an expanded facility and meet parking demand. Underground parking options are too cost prohibitive for the project (up to \$60,000 per underground car space provided), so alternatives are required. Areas for investigation could include;

- + Undercroft parking within Option 04. This is likely to exceed current budget allocation, however, the costs may be reasonable for the outcomes achieved.
- + Additional off-site parking for staff. Figure 01 (in blue) shows potential areas for new parking off-site. This land is TCCS public land (based on ACTmapi), and may be suitable for gravel parking. Discussions with the NCA would be a major consideration.
- + Agreements with adjacent leaseholders. There is underutilised land (Figure 01 red) adjacent an existing carpark to the west which may be transformed into a carpark for use by CHH and the leaseholder. Discussions with the NCA would also be a major consideration.

Figure 01



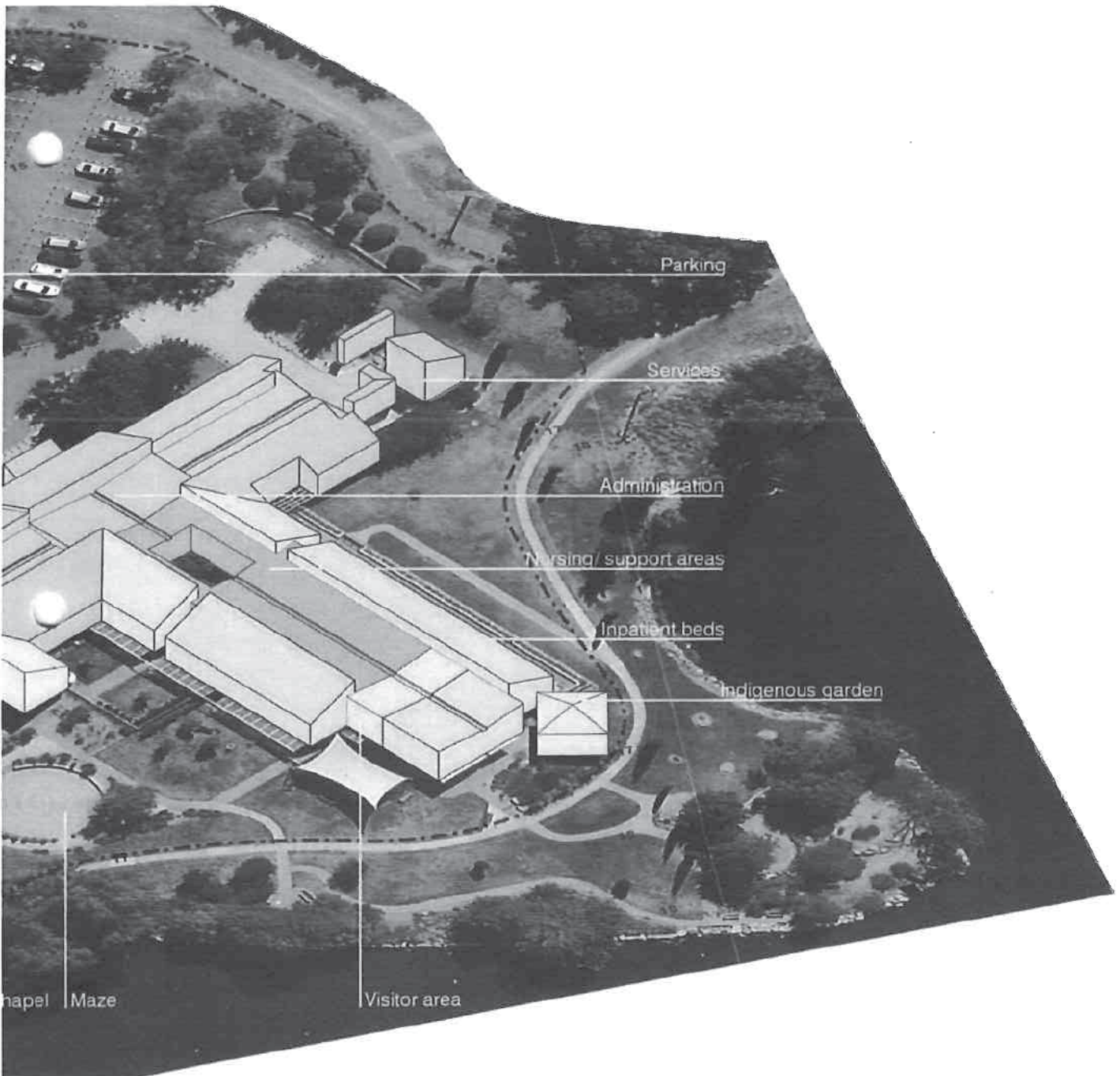
Attachment A - Drawings

- + Existing Facility – SK_WNAH_A-001
- + Site Strategy Options 01 - 03 – SK_CHH_A-901 thru 904

Legend




-  ADMINISTRATION & SERVICES
-  INPATIENT AREAS
-  PUBLIC AREAS
-  DENOTES SITE BOUNDARY

NOTES
/ DRAWINGS TO READ IN CONJUNCTION WITH SITE INVESTIGATIONS REPORT

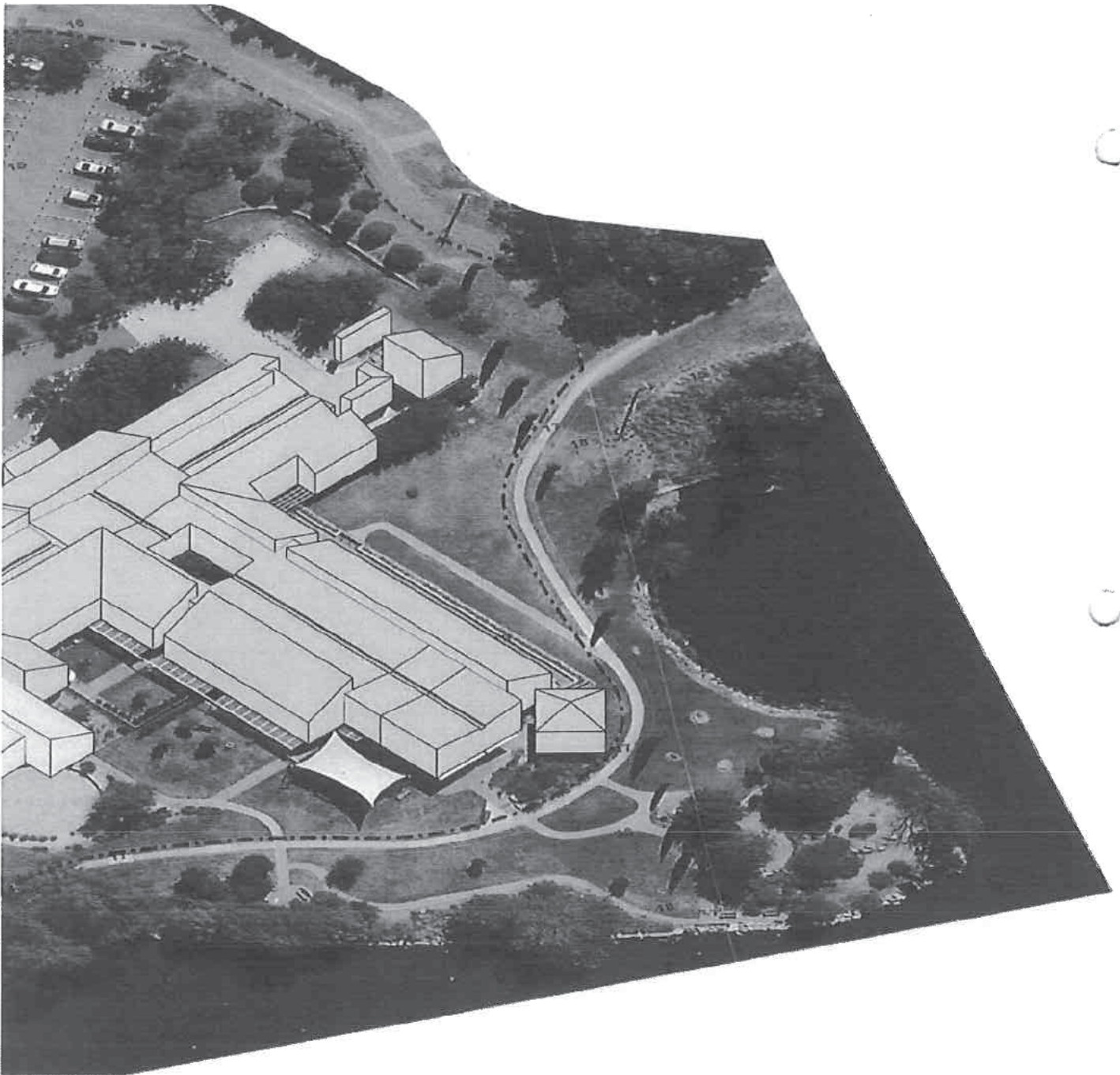


30




Legend

-  EXISTING FACILITY
-  PROPOSED EXPANSION AREA
-  DENOTES SITE BOUNDARY

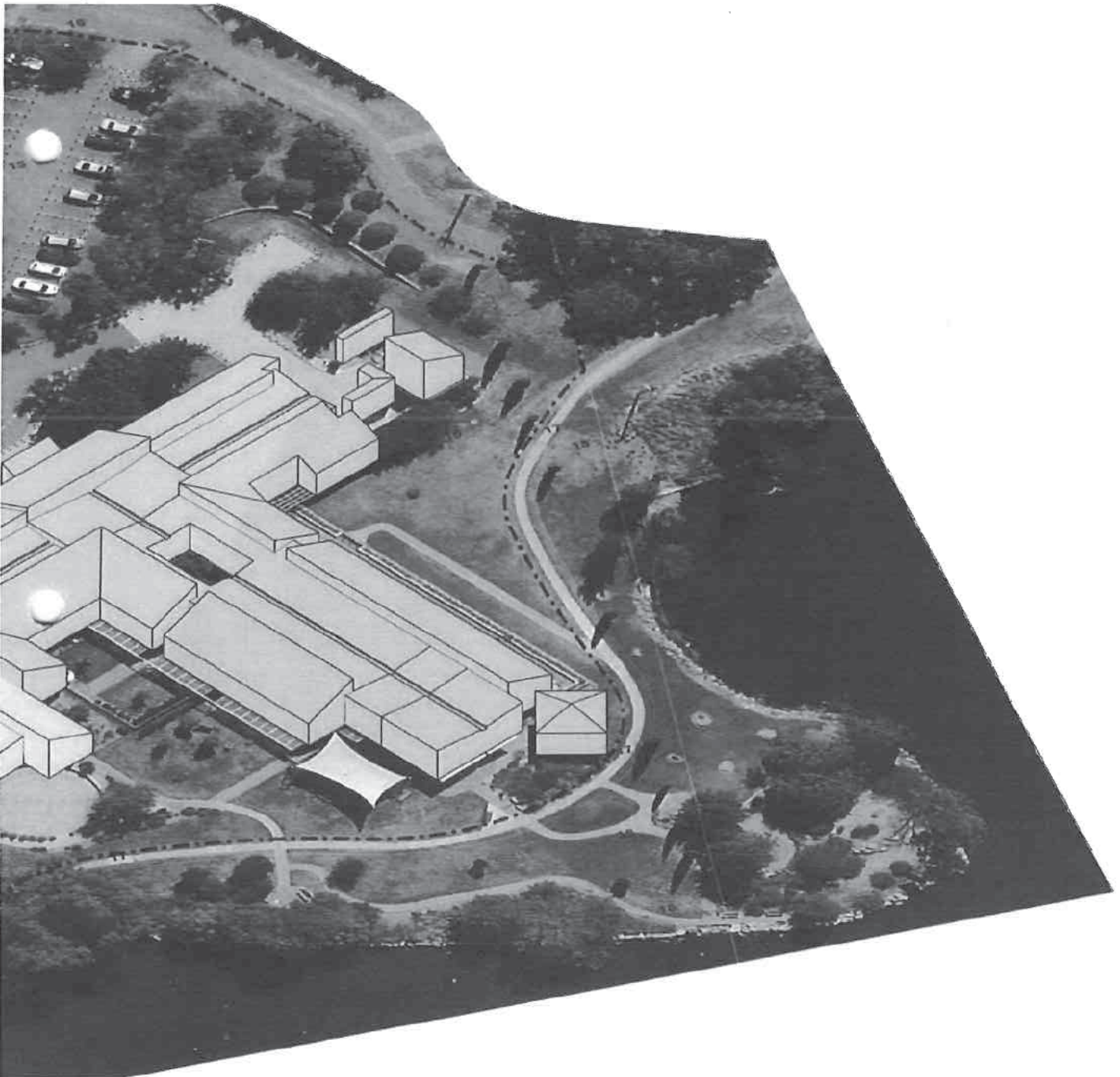
NOTES
/ DRAWINGS TO READ IN CONJUNCTION WITH SITE INVESTIGATIONS REPORT
/ PROPOSED EXTENSION IS INDICATIVE OF FLOOR AREA AND BUILDING MASSING REQUIRED



Legend




-  EXISTING FACILITY
-  PROPOSED EXPANSION AREA
-  DENOTES SITE BOUNDARY

NOTES:
/ DRAWINGS TO READ IN CONJUNCTION WITH SITE INVESTIGATIONS REPORT
/ PROPOSED EXTENSION IS INDICATIVE OF FLOOR AREA AND BUILDING MASSING REQUIRED

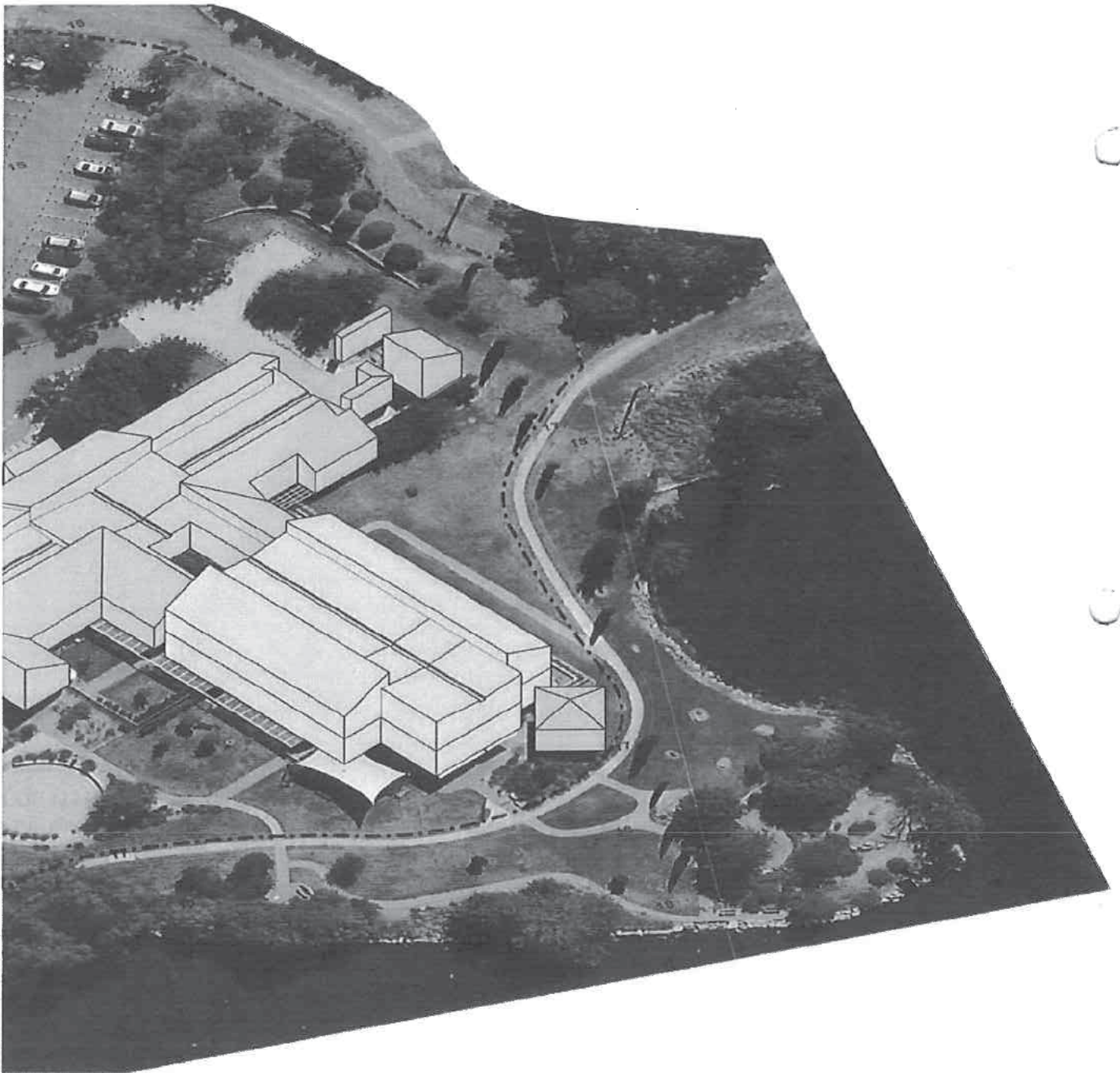


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Legend

-  EXISTING FACILITY
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-  DENOTES SITE BOUNDARY

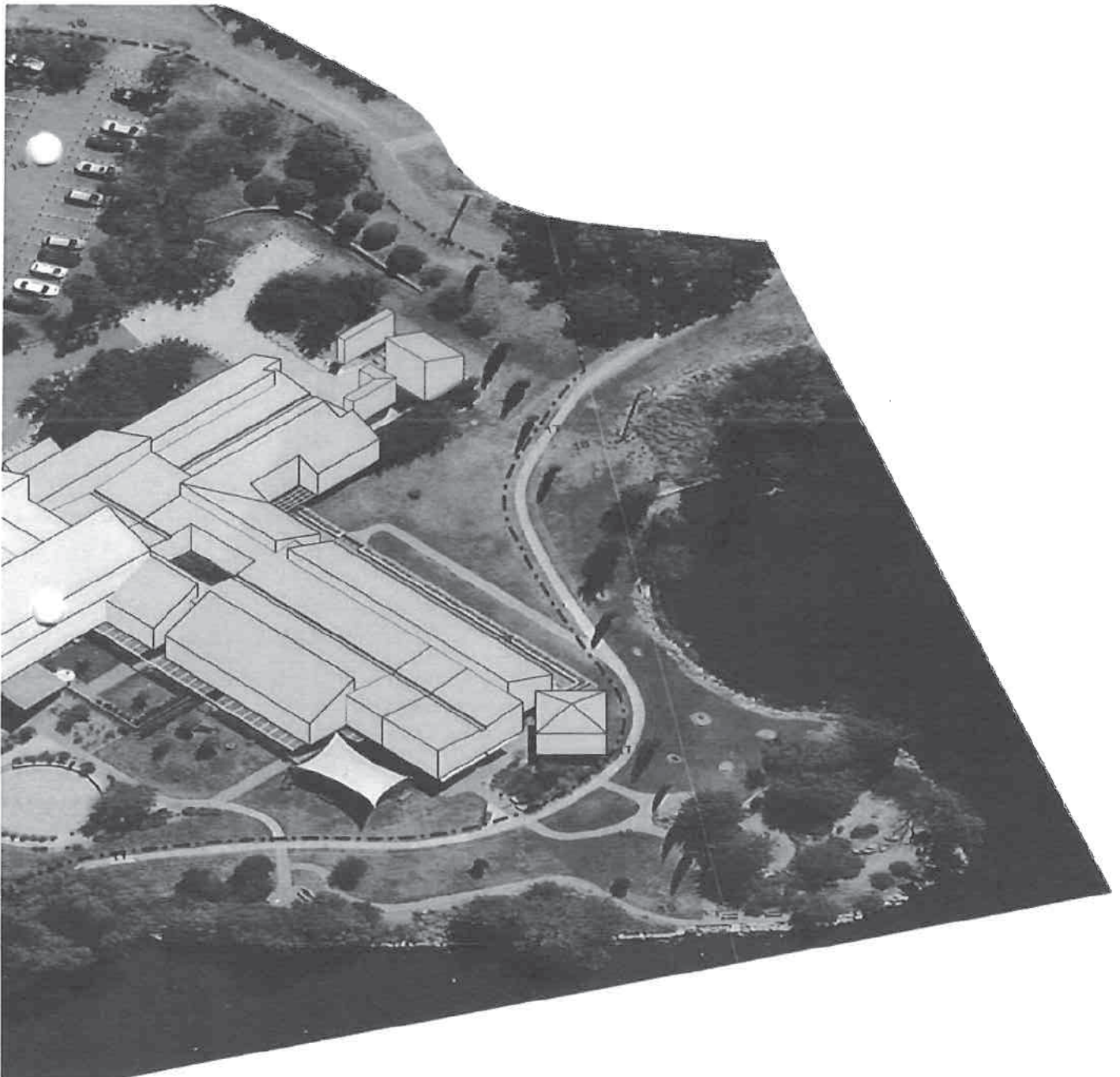
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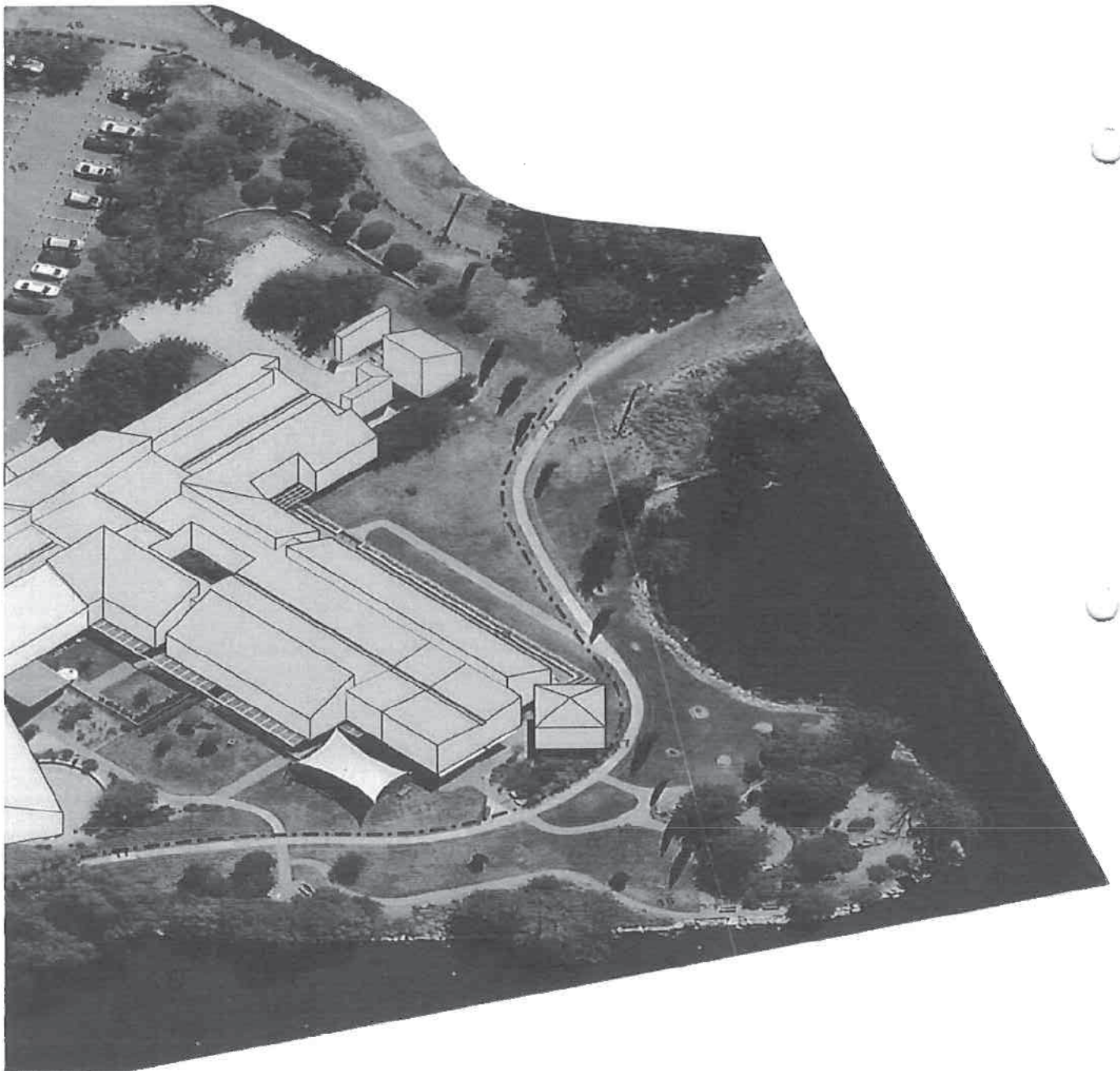
Legend

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Attachment B – Cost Plan

- WT Partnership provided costs for Option 01 & 04

