PCNSW Pre-Budget Submission 2026-27

Palliative Care
New South Wales

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Title: Palliative Care NSW Pre-Budget Submission 2026 -27

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Executive Summary

Palliative Care NSW (PCNSW) submits this pre-Budget proposal to address critical and growing gaps in palliative and end-of-life care across New South Wales. As patterns of mortality shift toward chronic and non-malignant disease, population ageing accelerates, and pressure on NSW public hospitals intensifies, the current system requires targeted reform and investment. This submission outlines five priority areas that together aim to improve equity, quality, sustainability, and cost-effectiveness of palliative care in NSW.

Priority Area 1 – Equitable Access to Palliative Care

Outcome Sought: Equitable and early access to palliative care for all NSW residents with a life-limiting illness whether malignant or non-malignant

Current specialist palliative care (SPC) models remain disproportionately oriented toward cancer, despite non-malignant conditions now accounting for the majority of deaths in NSW. As a result, people living with dementia and other chronic conditions experience delayed or inadequate access to palliative care, leading to unmanaged symptoms, avoidable hospital presentations, and poor end-of-life experiences. PCNSW seeks statewide implementation of the Supportive Care for Chronic Disease model, proven in Hunter New England LHD to significantly reduce emergency department presentations and unplanned hospital bed days while improving patient and carer outcomes. Investment of $8.4 million per annum would deliver substantial system savings through hospital avoidance and improved equity of care.

Priority Area 2 - Holistic and Person-Centred Care

Outcome Sought: Address gaps in volunteer service areas to ensure people with life-limiting illnesses, their family, and carers are holistically supported through illness and bereavement.

Palliative care volunteers play a critical role in addressing psychosocial distress, social isolation, and carer burden, yet access to volunteer services remains inconsistent—particularly in rural and regional NSW. Many people not connected to SPC services are currently excluded from volunteer support altogether. PCNSW proposes targeted funding to establish and manage volunteer services in identified gap areas through an expansion of its existing Volunteer Services Support Program. An investment of $950,000 per annum would strengthen community-based care, improve wellbeing, and deliver strong economic returns, with evidence showing every dollar invested in volunteering yields approximately $5.60 in social and economic benefit.

Priority Area 3- Skilled & Confident Care Delivery

Outcome Sought: Prevent unnecessary hospital admissions for palliative care by building confidence, competency, and capacity of the aged care workforce.

Nearly half of older Australians who die expected deaths are admitted to hospital in their final weeks of life, often due to a lack of confidence and capability within aged care settings. Inconsistent access to education, fragmented cross-sector collaboration, and inequitable workforce development are contributing to avoidable hospitalisations and system strain. PCNSW seeks funding for a dedicated Aged Care Palliative Care Guidance Manager and scholarships for aged care clinicians to complete accredited palliative care education. These initiatives would improve workforce confidence, support compliance with standards, and reduce avoidable hospital admissions at modest cost with clear system offsets.

Priority Area 4 – Subacute Palliative Care

Outcome sought: That all people in NSW, their families and carers are able to be cared for in the place of their choosing, with more dedicated subacute palliative care units for those who are unable to remain at home and do not wish to die in an acute hospital setting.

While most people prefer to be cared for and die at home, many ultimately require inpatient care. In the absence of sufficient subacute palliative care units, patients are frequently admitted to acute hospital wards that do not align with their needs or preferences and are significantly more costly. PCNSW supports continuation and expansion of capital investment in dedicated palliative care units, building on the NSW Government's existing $93 million commitment. Replicating this investment would reduce acute bed block, lower costs, and improve dignity, comfort, and outcomes for patients and families.

Priority Area 5 - Peak Body Sustainability

Outcome Sought: Palliative Care NSW continues to support the community, members, the sector, stakeholders and the NSW Government with trusted information, education and advocacy.

As the peak body for palliative care in NSW, PCNSW plays a vital role in advocacy, workforce support, community education, and system integration. Despite serving the most populous state, PCNSW receives the lowest per-capita government funding of any state palliative care peak body. Demand for community education, professional support, and trusted information now exceeds current capacity, particularly in regional and rural areas. Increased recurrent funding is required to align PCNSW's role with NSW Government priorities in public health, prevention, and person-centred care, and to mitigate risks associated with misinformation and unregulated providers.

Equitable Access to Palliative Care

Outcome sought: Equitable and early access to palliative care for all NSW residents with a life-limiting illness whether malignant or non-malignant.

The palliative care landscape is changing. As the population ages, patterns of mortality are shifting. Advances in medical intervention mean more residents are living longer with multiple chronic non-malignant conditions[1]. The current specialist palliative care (SPC) model of care and the triage tools that support it have largely been built upon the cancer experience. This means people with non-malignant life-limiting illnesses are not receiving care that meets their needs.

Four of the top five causes of death in Australia are now non-malignant: dementia, coronary heart disease, cerebrovascular disease, and COPD[2]. Despite the prevalence of these conditions, cancer patients remain significantly more likely to access SPC. An AIHW report found that two-thirds of cancer patients receive SPC, and cancer accounts for 50% of the SPC population - a rate three times higher than among those not receiving specialist care[3]. There is now an urgent need to improve earlier access to supportive and palliative care for patients dying of advanced chronic disease, co-morbidities, and neurological conditions.

PCNSW seeks a commitment from the NSW Government to embed Supportive Care for Chronic Disease into all Palliative Care Services across NSW. This model has been permanently embedded in HNELHD with proven patient and carer outcomes, as well as service-level and hospital-avoidance successes.

A recent workforce survey conducted by Palliative Care Australia[4] highlights that SPC services across NSW are at capacity, increasing staff burnout. Patients with non-malignant illness needing support to die at home are being triaged as "non-urgent" unless they are in the final days of life; as a result, they are unable to access supportive palliative care and expertise when and where they need it. This gap in care often forces patients to visit hospital emergency departments for acute symptom management during a crisis, placing additional pressure on an already overburdened NSW public hospital system.

PCNSW acknowledges that equitable access to palliative care is a priority for the NSW Government within its current review of the NSW End of Life and Palliative Care Framework. To achieve this, and as demonstrated by the success in the HNELHD (see Appendix), the NSW Government must fund a model of Supportive Care for Chronic Disease in all LHDs to provide early assessments that support complex and changing needs.

Recommendations

1. Support equitable access to palliative care for people with non-malignant and life-limiting chronic illnesses:

- Fund services to adopt the Supportive Care for Chronic Disease model in all LHDs.

2. Fund improvement in current SPC models to better support the growing number of patients with Dementia.

Budget Implications and Cost Offsets

Fund services to adopt the Supportive Care for Chronic Disease model in all LHDs across NSW:

- **Cost:** $8.4 million per annum
- **Offset:** ED presentations reduced by ~50%, unplanned bed days reduced ~60% (based on HNELHD service reporting)

Holistic and Person-Centred Care

Outcome sought: Address gaps in volunteer service areas to ensure people with life-limiting illnesses, their family, and carers are holistically supported through illness and bereavement.

Palliative care volunteers play a crucial role in providing psychosocial support and carer respite, yet funding and resources for volunteer services remain insufficient, especially in rural and regional areas. PCNSW calls for funding to be allocated towards the management of palliative care volunteers to address gaps in service delivery across Local Health Districts (LHDs).

Social isolation and loneliness are key factors in poor health outcomes and are linked to psychological distress and premature death[1]. A growing body of evidence has highlighted the significant health burden associated with loneliness, with recent studies suggesting it has become an economic problem due to increased service use and demand for institutional care[2]. Volunteers play a vital role in reducing these risks by fostering community connection.

Currently, people with life-limiting illnesses not connected to specialist palliative care services are missing out on volunteer support. Psychosocial support could begin earlier if there were additional volunteer services that also accepted referrals from other specialties and generalist palliative care providers.

PCNSW recognises the good work of existing palliative care volunteer services, including those managed by LHDs and by NGOs, but understands that competing priorities means permanent funding for Volunteer Manager positions is not always available. According to the latest data[3], NSW has 38 palliative care volunteer services which collectively provided 66,495 hours of volunteer support in 2024. We have identified significant gaps in volunteer support in regional and rural areas in four LHDs: NNSWLHD, HNELHD, WNSWLHD, and MNCLHD. Priority areas include Lismore, Taree, Tamworth, Cessnock, Newcastle, Orange, Bathurst, Dubbo, Coffs Harbour, and the Hastings.

PCNSW is currently funded to deliver the Palliative Care Volunteer Services Support Program, which we initially designed and have successfully delivered for the past ten years. Additional funding would allow PCNSW to expand the scope of this program. In consultation with LHDs, PCNSW could identify local service needs and establish volunteer programs tailored to meet the needs of each community. Where LHDs cannot manage palliative care volunteer services themselves, PCNSW can step in to bridge the gaps.

Investing in palliative care volunteering aligns with the NSW Government's commitment to improving end-of-life care and meeting evolving health needs.

Equitable access to timely palliative care is essential to a high-performing, cost-efficient health system. By investing in this model, NSW can enhance patient outcomes, alleviate pressure on the broader healthcare system, and ensure quality care for all residents.

Recommendations

1. **Allocate funding for the management of palliative care volunteer services attached to each specialist palliative care service:**
    - Fund PCNSW to establish volunteer services in areas with identified gaps in service.

Budget Implications and Cost Offsets

Fund PCNSW to establish volunteer services in areas with identified gaps in service:

- **Cost:** $950 000 per annum would cover program management, volunteer leadership, and administration costs.
- **Offset:** Every dollar invested in volunteering returns around $5.60 in economic and social benefits[4].

Skilled & Confident Care Delivery

Outcome sought: Prevent unnecessary hospital admissions for palliative care by building confidence, competency, and capacity of the aged care workforce.

As Australia's population ages, there is an increasing need to ensure that aged care and palliative care services are accessible, effective, and responsive to the complex needs of older people. Older people are often supported by care workers, general healthcare professionals, and informal carers who lack the confidence and capacity to care for people with a life-limiting illness. The impact of this is that even patients without complex needs are transferred to emergency departments for care and symptom management.

Of the 132,000 people aged 65 and over who died from expected deaths in Australia in 2021-22, 48% were admitted to a public hospital in the last 4 weeks of life(1). These unnecessary hospital presentations place a burden on the NSW public hospital system and rarely address the end-of-life preferences of the patient.

Cross-sector collaboration is key to ensuring palliative care is delivered equitably to people living in a Residential Aged Care Home (RACH), receiving home-based aged care, or in hospital awaiting RACH placement. While the NSW Government is not primarily responsible for the provision of aged care, it bears the financial cost and system burden when the aged care sector fails to provide good palliative care. A proactive approach to upskilling aged care workers in palliative and end of life care is required and cannot be delayed while awaiting further intergovernmental discussions regarding funding responsibilities.

PCNSW has identified a growing demand for workforce development through extensive stakeholder engagement (2). Registered nurses working in aged care settings are often excluded from educational opportunities available to NSW Health staff (3). This exclusion significantly reduces their confidence and competency when caring for people approaching end-of-life, inevitably resulting in unnecessary hospital admissions. Furthermore, patients currently in NSW hospitals awaiting a RACH placement are less likely to be accepted by a facility due to a lack of the clinical expertise required to meet regulatory obstacles (4).

While the decentralised approach to the Comprehensive Palliative Care in Aged Care (CPCiAC) co-funding in NSW supports local needs, it has resulted in inconsistent engagement across LHDs, leading to statewide inequity (5). The risk of duplication remains high as education and engagement models are frequently developed in silos.

With additional funding PCNSW could provide statewide support to aged care providers through a dedicated Aged Care Guidance Manager role. Demand for this support is high, with Palliative Care NSW experiencing a 156% increase in calls from aged care workers and providers in the last financial year(6). PCNSW is uniquely positioned as a trusted organisation that can connect systems and work with a range of stakeholders to improve palliative and end-of-life care in aged care. This, in turn, will improve outcomes across the NSW health system. As an expansion of this support, the NSW Government should fund PCNSW to provide education scholarships to aged care clinical staff, with a focus on those in rural and regional areas.

Recommendations

1. **Improve palliative and end-of-life care in aged care settings with information sharing across both sectors**
    - Fund PCNSW for 1.0 FTE Aged Care Guidance Manager role to:
        - Improve understanding of palliative care in aged care settings
        - Support RACH and Support at Home services in meeting Palliative Care and Aged Care Standards (7)
        - Host a Community of Practice across NSW Health and Aged Care.

2. **Support clinicians to access further education to improve the delivery of palliative care within the aged care sector.**
    - Fund PCNSW to provide scholarships for 100 aged care clinical staff to complete the Certificate in Palliative Care Short Course (8), prioritising clinicians from rural and regional areas.

Budget Implications and Cost Offsets

Fund PCNSW for 1.0 FTE Aged Care Guidance Manager role:

- **Cost:** $750 000 for a 5-year period.
- **Offset:** Increased support for aged care clinicians and services to provide palliative care in RACH and community settings and prevent unnecessary hospital admissions.

Fund PCNSW to provide scholarships for 100 aged care clinical staff to complete the Certificate in Palliative Care Short Course:

- **Cost:** $170 000 per scholarship round
- **Offset:** Increased competency amongst aged care clinicians to provide palliative care in RACH and community settings and prevent unnecessary hospital admissions.

Subacute Palliative Care

Outcome sought: That all people in NSW, their families and carers are able to be cared for in the place of their choosing, with more dedicated subacute palliative care units for those who are unable to remain at home and do not wish to die in an acute hospital setting.

Up to 89% of people say they want to be cared for at home with the appropriate supports (1). This preference for place of care and care at the time of dying can change and evolve as an illness progresses influenced by factors such as disease complexity, symptom distress, and family and carer burden.

Preference for care at home is largely attributed to the home environment, the possibility of being able to be surrounded by family and friends, and association of the home to a peaceful death (2). When a person is no longer able to be cared for at home, for many across NSW the only option is to be admitted to an acute hospital ward, where they do not wish to be or need to be. An acute hospital environment does not align with patient, carer and family preferences.

Subacute palliative care units better align with care preferences, providing high-quality care in a more home like environment. Dedicated palliative care units are designed to create environments that foster emotional and cultural safety, privacy, connection, and normalcy. Features such as natural light, access to fresh air and gardens, private rooms with ensuites, communal kitchens, and quiet, flexible spaces all contribute to environments where people feel supported and respected.(3) Increasingly, research highlights that the design of spaces where people spend time as they receive palliative or end-of-life care can have a powerful influence on emotional and spiritual wellbeing, comfort, and agency.

While community based palliative care continues to be the most cost-effective solution to meet the holistic needs of those with a progressive life-limiting illness who wish to be cared for at home, investment in subacute care is essential when people are no longer able to remain at home or when respite is required.

We commend the NSW Government on the current commitment of $93 million for capital investment in the World Class End of Life Care program to redevelop and refurbish palliative care facilities across NSW. Through this program Nepean, Orange, Tamworth, Westmead, and Wyong are receiving new or expanded palliative care units.

Additional investment in this area must continue**.** The benefits as a result will be better patient, carer and family experience with improved care outcomes, while also reducing pressure on acute hospitals and

improved economic outcomes:

A palliative care patient admitted into acute care will cost the NSW Government approx. 3 times more than a patient admitted into a dedicated palliative care subacute unit. (Refer Appendix A, Table 1.)

Investment in subacute units will also assist with reducing bed block created by those unable to return to aged care or find aged care places who are in the final stage of life and who are currently dying on acute wards without the dignity and respect of specialised end of life care.

Recommendation

1. **Additional investment into dedicated palliative care units across NSW:**
    - Map palliative care and end of life care needs of the population;
    - Identify gaps in subacute facilities to meet this need;
    - Sufficiently fund a capital program to fill the gaps identified.

Budget Implications and Cost Offsets

Sufficiently fund a capital program to fill the gaps identified:

- **Cost:** An additional $93M for the next round of units to meet needs
- **Offset:** The current investment of $93M is delivering 5 new palliative care units with 52 new dedicated beds across NSW. Replicating this investment will divert approx. 180 palliative care patients per year from the acute hospital setting to a dedicated palliative care subacute setting (based on the average stay per patient of 10 days, 36 patients per year, times 5 facilities). **Saving $2,625,120 per year** while also freeing up acute hospital beds and providing an appropriate setting for high quality palliative and end of life care.

Peak Body Sustainability

Outcome sought: Palliative Care NSW continues to support the community, members, the sector, stakeholders and the NSW Government with trusted information, education and advocacy.

Palliative Care NSW is the peak body for palliative care in NSW and was founded more than 40 years ago. We are a member of Palliative Care Australia and have counterparts in all states and territories across Australia.

Our vision is that Palliative Care is understood, valued and accessible to all, with equity at its heart. Our purpose is to lead, support, and advocate for the development & provision of quality palliative care across NSW. Our FY25 Impact Report highlights the depth and breadth of the work we do.

Currently PCNSW receives the lowest amount of government funding per capita of all state palliative care peak bodies (see table below).

In order to sufficiently support anyone with a life-limiting illness, families, carers, an ageing population and both a general and specialist palliative care workforce in the most populous state in Australia, PCNSW must have funding increased to align with the strategic framework in Future Health and to support the soon to be released updated NSW End of Life and Palliative Care Framework. Acknowledging that people over age 65 will account for 45% of healthcare activity in 2031(1) providing accurate information and support based on a public health approach is crucial moving forward.

PCNSW has established strong partnerships across the NSW Health network as well as aged care, NGO's, PHNs, tertiary education and community and is a conduit that can efficiently and effectively connect and share information between these sectors. A boost in funding would cement the NSW Government's commitment to public health, preventative care and a health care system that is patient-centred.

	SA	NSW	QLD	TAS	WA	VIC
Peak body and program funding from State Government	$414,416	$896,737	$772,851	$1,180,000	$700,000	$1,323,698
Population	1 880000	8 600000	5 647468	580 000	3 008697	7 053122
Per capita Palliative Care Peak Body Spending	$0.22	$0.10	$0.14	$2.03	$0.23	$0.19

PCNSW currently provides community education under the Palliative Care NGO grant, however, even with this grant PCNSW is unable to meet demand. Currently funding has only covered 68% of requests for a Community Conversation. With additional funding, staff and resources could be immediately deployed to meet community education needs across NSW, with a focus on regional and rural areas (currently 56% of sessions are in regional and rural areas).

Formal evaluation of these sessions is ongoing, however, interim reports indicate that over 87% of attendees leave a session prepared to have conversations about their end-of-life wishes, and with a clearer understanding of the role of palliative care in their LHD.

There is a risk if this information is not provided by PCNSW, that private for-profit organisations will begin promoting services and support to vulnerable older people at significant cost. Particularly to those who are socially isolated and living in regional and rural NSW.

With additional funding PCNSW could also expand the reach of our professional education sessions. We currently deliver these to NSW multicultural health workers, NSW interpreters, TAFE NSW (Certificate 3, 4 and Enrolled Nursing students), disability support workers and community support groups. As with Community Conversations, PCNSW is currently operating at capacity and is forced to decline requests.

Recommendations

1. **Support Palliative Care NSW to meet the growing demand for information, education and advocacy.**
    - Increase Palliative Care NSW peak body funding

Budget Implications and Cost Offsets

- Increase Palliative Care NSW peak body funding
    - **Cost:** Additional $295,000 per annum (equating to $0.15 per capita total investment)
    - **Offset:** A stronger palliative care sector with increased community awareness, professional education and committed resources to implement the new End of Life and Palliative Care Framework.

Appendix A

Table 1:

Admitted Acute Care	**Subacute Care** ***ie Inpatient palliative care units***	**Non-admitted care** ***ie Community palliative care and Palliative care clinics***
Average cost per standard admitted acute care separation in NSW (4) $5,757.00 Average length of Stay (non-palliative care): 2.83 days Palliative Care Hospitalisations are on average 11 days (5) Average cost per admitted palliative care patient into acute care: **$22,374.00 per patient**	Average cost per AN-SNAP separation in NSW (4) $12,148.00 Average length of Stay: 10 days National average cost per sub-acute care type – Palliative Care: **$7,790 per patient***	Average cost per non-admitted care service event in NSW (4) $293.00 Estimated an average cost of **$6,508 per patient** for community based palliative care. (6)

* Palliative Care costs significantly less that other sub-acute care types (rehabilitation $19,603, and geriatric evaluation and mngt $19,165)

Appendix B

Hunter New England LHD
Supportive Care for Chronic Disease Service Case Study

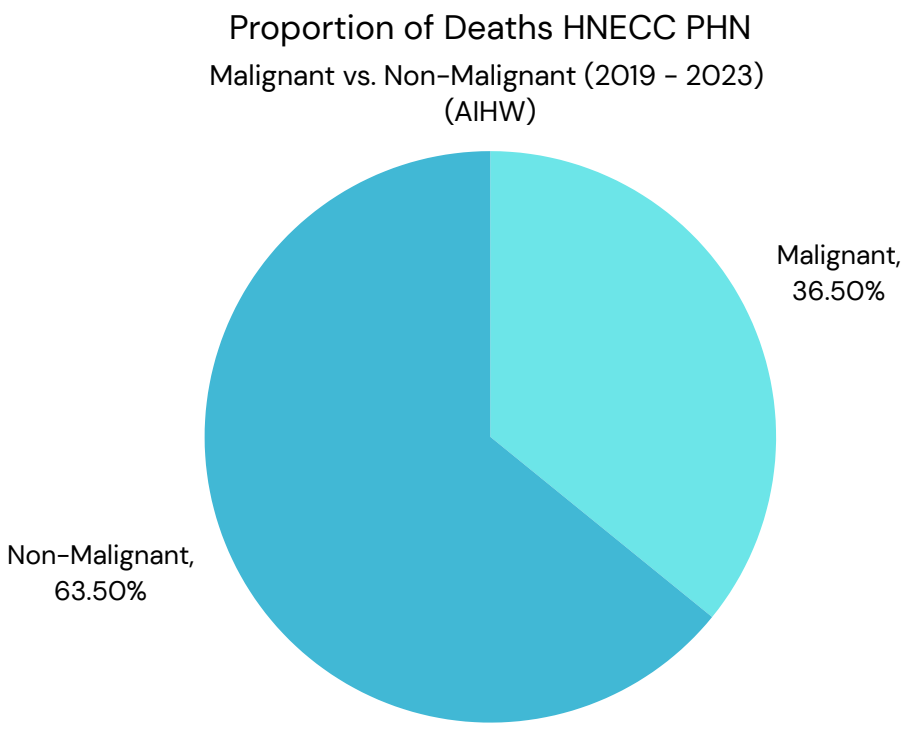
The Supportive Care for Chronic Disease (SCCD) Service was piloted in 2022 in the Hunter New England LHD. Following a successful pilot it is now an embedded program with proven patient, carer, service level and hospital avoidance outcomes.

What is the service?

A transdisciplinary team providing care to adult patients living with non-malignant chronic disease who are estimated to be in the last 2 years of life, and their carers. District-wide service piloted in the largest LHD by geographic size: hybrid model of virtual and in-person care. The team consists of Health Service Manager, Administration Officer, Social Worker, Occupational Therapist, Dietitian, Speech Pathologist, Clinical Nurse Specialist or Clinical Care Coordinator, Consultant Liaison Psychiatrist and Consultant Liaison Psychiatry Registrar. The service requires highly qualified and experienced clinicians with all allied health clinicians being level 4.

What unmet need is being addressed?

Patients dying of advanced chronic disease often suffer a symptom burden akin to those with advanced cancer, experiencing high rates of pain, breathlessness, fatigue, and depression. While the underlying causes are different, the end-of-life experience can be marked by a comparable level of symptom distress. According to MORT Data HNECC PHN 2019-2023, the top 4 leading causes of death across HNECC PHN were chronic disease. Between 2019-2023, chronic disease accounted for 9 of the 20 leading causes of death in the region and malignant conditions accounted for 6 of the top 20 leading causes. If other ill-defined or acute causes of death are excluded, non-malignant conditions account for 63.5% of all deaths, and malignant conditions account for 36.5% of deaths across HNELHD, and the central coast. AIHW data confirms that you are more likely to be referred earlier and receive specialist palliative care if you have a cancer diagnosis, yet symptom distress for non-cancer diagnosis can be similar, but with a longer trajectory. By the time non-cancer patients reach specialist palliative care, death is often imminent, leaving limited opportunity for advance care planning, comprehensive symptom management or psychosocial support, with increased trauma and negative grief and bereavement outcomes. These findings underscore an equity gap in access to specialist palliative care. The SCCD service is addressing that gap.



FY25 Outcomes

- 203 referrals to the service
- ED presentations reduced by 59%*
- Admissions from ED reduced 73%*
- Unplanned bed days reduced 67%*
- Based on avoided ED presentations and unplanned bed days, this represents a **saving of $874,950.00** in unplanned health service use.
- These reductions were sustained ≥6 months post-program.

** Health Service Utilisation data was compared at 2 timeframes: 1. during the 6 months prior to referral to SCCD, and 2. during the 6- month period following completion of the SCCD program.*

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