



FINAL REPORT

Palliative Care Connect Pilot Evaluation

Prepared for SA Health

30 April 2026





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Document Review and Authorisation

Version	Date Distributed	Issued to	Comments
1.0	27/03/2026	Mariana Ricci, Amber Bisset	First Draft for review
2.0	01/05/2026	Mariana Ricci, Amber Bisset	Final Report

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Last saved	20/08/2026 12:14 PM
Clear Horizon Reference No.	#25036

Cite this report

Liston, E., O'Connor, K., Jongsma, F., Halburd, V. & Binns, B (2026). Palliative Care Connect Evaluation Report. Prepared by Clear Horizon for SA Health, April 2026.

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Dictionary

Acronyms	Description
HELP App	Healthy End of Life Planning App
PCC-SNS	Palliative Care Connect Statewide Navigation Service
BNS	Bereavement Navigation Service
PCC	Palliative Care Connect
SA	South Australia
SACC	South Australia Community Care
TACSI	The Australian Centre for Social Innovation
ToC	Theory of Change
ToA	Theory of Activities
EoL Care team	End of Life Care team
VAD	Voluntary assisted dying



Acknowledgements

Acknowledgement of Country

We acknowledge the Traditional Custodians of the many lands and waters across South Australia on which the Palliative Care Connect Pilot is delivered. We pay our respects to Elders past, present, and emerging, and recognise the enduring connection Aboriginal and Torres Strait Islander Peoples have to Country, culture, and community.

Acknowledgement of contributors

This report draws on the contributions of many people who gave generously of their time, knowledge, and experience across more than two years of evaluation. We are deeply grateful to all of them.

The PCC service teams contributed far beyond their role as pilot implementers. Throughout the evaluation, they welcomed ongoing access to their work, made time across multiple rounds of data collection, and facilitated connections with the many stakeholders, partners, and professionals whose insights have enriched this report. That openness has been foundational to the quality of the findings presented here.

The health professionals, aged care workers, and community practitioners who participated in interviews did so despite schedules that rarely leave room for a conversation with an evaluator. Their willingness to contribute reflects a genuine commitment to improving end-of-life care in South Australia, and their perspectives have meaningfully strengthened the analysis.

We also wish to thank the SA Health End of Life Care team for their leadership throughout the pilot and their close partnership with the evaluation. Their guidance, responsiveness, and pivotal role in facilitating service user interviews have been central to the strength of the findings. We acknowledge the members of the PCC Steering Committee, whose governance and oversight helped steer the pilot through both its establishment and its evolution.



Finally, and most importantly, we acknowledge the people who shared their personal experiences as part of this evaluation, many of whom did so while navigating grief, loss, or the demands of caring for someone. Their willingness to reflect on those experiences has given this report its humanity. We are also mindful that behind every data point in this report is a person whose life held meaning, depth, and value that no number can capture. Many of those people are no longer with us. This report is, in part, a record of the difference made to them and to those who cared for them.

Palliative Care Connect *Evaluation in brief*

Palliative Care Connect (PCC) is a Commonwealth-funded pilot operating in South Australia since October 2023 and extended through to June 2026. It was established to address long-standing gaps in how people with life-limiting illness, their families, carers, and the professionals supporting them navigate palliative and end-of-life care across a fragmented, health, aged care and community systems.

The evaluation found that PCC has delivered consistently high-quality support at some of the most difficult moments in people's lives and it is beginning to influence how the broader system functions. Early system-level contributions indicate potential for broader impact if the model continues.

The pilot brings together two palliative care navigation services (the PCC Statewide Navigation Service, and the PCC Aboriginal Navigation Service), a Bereavement Navigation Service, a central information Website, the Healthy End of Life Planning (HELP) app, short-term bereavement counselling, and palliative care volunteering coordination.

The evaluation makes clear that the functions PCC performs are real, valued and currently unmet elsewhere in the system.

Palliative Care Connect

Snapshot summary of PCC in numbers

Combined:

1,363 episodes of care
2,023 people supported



PCC Website:

47,985 total users
average of 1,919 per month

97,369 total views
average 3,895 per month

HELP app:

113 active Networks
average of 7.2 new networks
per month

Palliative Care Connect Statewide Navigation Service:

931 episodes of care
average of 32 per month

Regional Navigation Service:

119 episodes of care
average of 7.9 per month

Palliative Care Volunteering SA service:

600 enquiries received

Bereavement groups and individual bereavement counselling:

156 people supported

Bereavement Navigation Service:

263 episodes of care
average of 11.4 per month

Aboriginal Navigation Service:

50 episodes of care
average of 2.2 per month

486 from individuals

114 from organisations

Bereavement counselling:

63 people supported

Bereavement groups:

93 people supported

Key findings

- ✓ PCC fills a gap not addressed elsewhere in the system, providing navigation and psychosocial support that individuals, families and clinicians are otherwise left to manage during diagnosis, deterioration, and bereavement.
- ✓ Impact is strongest at the individual and family level, with consistent improvements in understanding, confidence, emotional containment, and ability to access appropriate services.
- ✓ PCC Navigation works because it is relational, trusted and time-limited, rather than transactional or ongoing case management. Trust is the primary mechanism that enables disclosure, engagement, and informed decision making.
- ✓ The model has achieved high reach and sustained use, with steady growth over the pilot period driven by referrals and establishing relationships.
- ✓ User experience and satisfaction are consistently high with people describing PCC support as clear, knowledgeable, compassionate and available when it is most needed.
- ✓ The PCC Aboriginal Navigation Service is effective by operating with cultural safety, sustained presence and relationship -first practice.
- ✓ Early system level contributions are emerging, including improved care coordination, clearer referral pathways, and reduced pressure on general practice, aged care and acute services.

Why navigation matters

- Without trusted navigation, system complexity becomes a barrier to care
- Earlier understanding and engagement improves decision making and coordination, reducing crisis driven care and inappropriate service use.
- Relational navigation addresses gaps created by workforce and capacity constraints, supporting clinicians and services rather than duplicating their roles.
- Culturally safe end of life support requires time, trust and continuity.

Implications

If continued PCC is well positioned to consolidate and extend its impact, strengthen system-level coordination, and embed navigation as a core support alongside clinical care across health, aged care and community sectors.

If ceased individuals, families and clinicians lose a trusted point of orientation and support. The referral pathways built over the last 3 years will dissipate and the burden of coordination will revert to carers, palliative patients or stretched frontline workers.

Recommendation

- It is recommended that PCC be continued beyond the pilot period, with a focus on consolidating and scaling its navigation function as a core system support alongside clinical palliative care. The evaluation demonstrates that PCC fills a gap not met elsewhere in the health, aged care, and community system, delivering clear and consistent benefits for individuals, families and frontline services.
- Continuation of PCC will preserve and build on the trust, referral pathways, and culturally safe practices established over three years, and enable PCC to strengthen its emerging system-level contributions. The infrastructure and navigation workforce developed will also be maintained.
- Ceasing the service would result in the loss of a proven and trusted function, at a time when demand for end of life support continues to grow and system capacity remains constrained.



Executive Summary

Why Palliative Care Connect was needed

The palliative care system is complex, spanning health, aged care, and community sectors. For people encountering it at the moment of a diagnosis, deterioration, or bereavement, understanding what is available and how to access it can be genuinely difficult. In practice, a referral often means being provided with details at the end of a consultation, with the expectation that the person or family will follow up. For people managing a diagnosis, deterioration, or bereavement, that follow-through is not always possible. Palliative care is also widely misunderstood as being only for the final stages of life, which delays engagement and limits earlier planning, symptom management, and psychosocial support.

Some populations face greater barriers than others. People in regional and remote South Australia have fewer palliative care options locally and must either travel to access support or receive more limited care close to home. First Nations people access specialist palliative care at around half the rate of the broader population nationally, reflecting both limited availability of culturally safe services and approaches to dying that carry deep cultural meaning and do not fit neatly within standard service models. People with non-cancer conditions or disability encounter less visible pathways into care. Families without prior experience of the system carry a heavier navigation burden at precisely the moment it is hardest to do so.

Within aged care, where many people now spend their final months, capability to provide end-of-life care is not consistently embedded.

This contributes to transfers between aged care and hospital settings that do not always reflect people's wishes. General practitioners, who are central to a quality aged care network, often do not have the availability required to provide sustained end-of-life support. The result is a system that functions, but unevenly, and that leaves too much of the coordination burden with families and individuals navigating it during crisis.

Navigation cannot resolve workforce shortages or the underlying capacity constraints that produce these gaps. What it can do is support earlier planning, improve coordination between services, and help people and providers identify appropriate alternatives when specialist palliative care is not the right fit. This is the gap PCC was established to address.





What Palliative Care Connect delivered

The Commonwealth committed \$7.27 million to establish the pilot, with a 12-month extension taking delivery through to mid-2026, to a **total investment of \$10.2 million**.

The pilot delivers three active navigation services: **the Statewide Navigation Service, the Bereavement Navigation Service, and the Aboriginal Navigation Service**. A Regional Navigation Service also operated during Phase 1 until mid-2025, when delivery was streamlined. Alongside the navigation services, the HELP app provides a digital tool for coordinating informal care networks, the PCC website serves as an accessible information hub, and short-term bereavement counselling and palliative care volunteering coordination complete the model.

Across the full pilot period, PCC has supported **1,363 episodes of care** involving around **2,023 people**.

Of those reported, **236 episodes of care** were delivered to or initiated by **health professionals, aged care providers or community care services**.

The **PCC Website** has recorded close to **48,000 users** over two years.

The palliative care volunteering coordination service (branded Palliative Care Volunteering SA) has responded to more than **600 enquiries** from individuals and organisations.

More than **150 people** have received support through **bereavement groups or individual counselling**. These figures reflect a service that established itself, built referral relationships, and grew steadily across the pilot, rather than one that peaked early and plateaued.

How navigation works in practice

The three navigation services operate in different ways, and those differences reflect the people they serve and the conditions required to support them well.

The PCC **Statewide Navigation Service** provides telephone-based navigation to anyone in South Australia seeking to understand palliative care and access relevant support. Most contacts are episodic, a person or family member reaches out at a point of uncertainty, a navigator helps them clarify their situation and identify next steps, and engagement often concludes within a single interaction. Over time, the service has increasingly positioned itself as a connector and service broker across the broader end-of-life system, supporting hospital teams, aged care providers, and primary care professionals alongside direct contacts from individuals and families.

The **Bereavement Navigation Service** works with people experiencing grief, for whom support more often unfolds over weeks or months. Grief is non-linear, and the service is structured accordingly. It combines information, referral, and direct emotional support, and, in response to an identified gap in accessible community counselling, has integrated a short-term counselling function for people assessed as low to moderate risk. This integration allows people to receive both counselling and practical navigation through one familiar relationship, reducing the burden of retelling their story or being referred on before they are ready.

The PCC **Aboriginal Navigation Service** operates in a relationship-first way, grounded in cultural safety and recognition that end-of-life conversations cannot be reduced to brief or transactional interactions. Navigators build trust over multiple interactions and across family groups before deeper conversations about care preferences or end-of-life planning become possible. The model has also developed Yarning Together workshops in partnership with health



services, creating culturally grounded spaces for conversations about end-of-life planning.

Across all three services, the navigation role evolved during the pilot. What was initially conceived primarily as a referral function developed into a more relational practice, with navigators drawing on multidisciplinary professional backgrounds and moving fluidly between information provision, emotional support, coaching, and advocacy within a single interaction. Navigation has remained episodic and time-limited rather than becoming ongoing case management, and this clarity of scope has strengthened both its relevance and its usefulness.

Reach and access

People reach PCC at many different points across the end of life journey, not only via a single clinical referral. Family members and carers make up a substantial share of contacts, alongside individuals themselves and health, aged care, and community providers. Contact is often made during periods of uncertainty or deterioration, well before any crisis point, and people return to the service when their situation shifts. PCC is being used for planning, orientation, and decision support earlier in the journey. People who engage earlier are better positioned to understand their options, make informed decisions, and access appropriate care before needs escalates.

Navigation services have reached people across both metropolitan and regional South Australia. While most PCC Statewide Navigation Service contacts are from metropolitan areas, the geographic make-up of service users broadly reflects the distribution of the South Australian population. The place-based design of the Regional, Aboriginal and Bereavement Navigation Services extended coverage into parts of the state that a metropolitan-based model could not have reached on its own. The PCC Aboriginal Navigation Service predominantly served people in outer regional communities; the Bereavement Navigation

Service reached users from regional and outer regional areas. Collectively, the services complemented one another geographically as well as functionally.

PCC services were built over time through relationship and referral pathways rather than marketing alone. Two statewide marketing campaigns generated short-term spikes in website traffic and PCC Statewide Navigation Service enquiries, but sustained referral growth relied on the relationships built with GPs, hospital teams, aged care providers, and community services through direct engagement over the pilot period. The Bereavement Navigation Service's Grief Literacy Workshops are the clearest example: 45 workshops reaching more than 660 participants converted improved understanding of grief into reliable, appropriate referral pathways with health and community services that have continued to strengthen over time.

Quality of support and trust

Once engaged with PCC, people consistently describe support that is clear, unhurried, and adapted to their circumstances. User satisfaction has averaged **9.9 out of 10** for the PCC Statewide Navigation Service and **9.6 out of 10** for the Bereavement Navigation Service. People describe navigators as knowledgeable, patient, empathetic, and direct, and report leaving interactions feeling clearer about their situation and more capable of taking next steps.

Navigators draw on multidisciplinary professional backgrounds spanning nursing, social work, counselling, and related fields. This breadth enables them to respond across health, emotional, and social domains within a single interaction, rather than treating these as separate concerns. Internal consultation processes, in which navigators seek input from colleagues before providing uncertain or complex information, reinforce the accuracy and credibility of what people receive. The result is support that people describe as deep system knowledge, rather than following a script.



Trust is the enabling mechanism underpinning PCC's outcomes. It is not a by-product of good service design; it is the enabling condition that makes navigation effective.

When people trust a navigator, they disclose information they have not shared elsewhere. They articulate fears they have kept to themselves, raise questions they were reluctant to ask clinicians, and consider supports they had previously declined. They engage more confidently in decisions about their own care or the care of someone close to them. Family members and carers who do require sustained support often return to the same navigator across weeks or months, even after being connected to other professionals, because the relationship itself becomes a source of orientation.

For the PCC Aboriginal Navigation Service, trust is not established in a single interaction. It is built through sustained presence, cultural safety, and the willingness to move at the pace set by the person or family. Navigators reported needing four or five visits before deeper conversations about end-of-life planning could occur. This is not a limitation of the model; it is the model. The time required to work this way is not optional.

Outcomes for people

In line with the pilot's Theory of Change, the evidence indicates that PCC is contributing to meaningful change for the people who access it, as outlined below:

People are connected and less alone

People describe PCC contact as a moment of being heard and understood. Carers and family members, in particular, describe it as a space to think through complex situations without judgement. Many leave interactions feeling calmer, lighter, and better able to cope, even when the practical circumstances are unchanged. For people reaching out during a diagnosis, deterioration, or early grief, this emotional containment is not a minor benefit; it is often what makes the next step possible.

Navigation evolved during the pilot to include a psychosocial support function. Navigators draw on counselling skills in almost every interaction, including listening, validating, and helping people make sense of what they are facing. In the Bereavement Navigation Service, where a gap in accessible psychosocial support in community settings was identified, short-term counselling has been integrated into the model. This allows people with low to moderate needs to receive both emotional support and practical navigation through a single, familiar relationship.

Beyond immediate reassurance, PCC connects people to ongoing sources of peer, social, and community support. This is most visible in bereavement, where people are linked to counsellors and groups that help reduce isolation. For users of the PCC Aboriginal Navigation Service, connection is shaped by family and community as much as by individual need, and navigators work with those networks rather than around them.

"When I got off the phone... a weight had been lifted off my shoulder." — PCC-SNS service user



People have the information they need

People describe PCC information as clear, relevant, and tailored to what they are trying to work out. For many, the interaction reshapes their understanding of palliative care itself. They realise it can be accessed earlier than expected, that it supports carers as well as patients, and that it offers more than end-of-life care alone. Bereaved users describe being given new language and frameworks to understand their grief. This shift in understanding is a recurring and significant, given how widely palliative care continues to be misunderstood.

Users rate PCC's contribution to their understanding of palliative care at **9.5 out of 10** for the PCC Statewide Navigation Service and **9.4 out of 10** for the Bereavement Navigation Service. Empowerment and informed decision-making is the most frequently recorded outcome across all navigation services: 76 per cent of bereavement cases, 57 per cent of statewide cases, and 46 per cent of PCC Aboriginal navigation cases. People describe feeling more confident to ask questions, advocate for themselves or others, and engage proactively with services they are already using. The tailoring of information to the person in front of the navigator, rather than offering a generic response to a category of need, is central to this outcome.

"[Had I not contacted the Bereavement Navigation Service] I would have had less resources, and would have been coping less, and I would be carrying [around] the dark heavy weight of the grief." — BNS user

People access the services and supports they need

PCC helps people reach services they would not have found, reached, or persisted with on their own. For some, this involves clear guidance and accurate contact information. For others it requires active enablement: making referrals, following up with providers, supporting handovers, and intervening when parts of the system stall. This contribution matters most during periods of deterioration or acute need, when the burden of navigating services often falls to families already under pressure.

The nature of this contribution differs across services, reflecting the populations they serve. Most people contacting the PCC Statewide Navigation Service already have elements of support in place; the primary value is clarity and coordination within systems they are already navigating. Timely, accurate guidance and reassurance that they are on the right track is itself a significant outcome. The Bereavement Navigation Service more often results in a new referral, but the quality of the match is what distinguishes the service. Many users report previous experiences of unhelpful referrals or repeated retelling of their story; careful person-centred matching to the right support is the key value offered. The PCC Aboriginal Navigation Service rarely introduces new services. Instead, navigators help families make sense of existing arrangements, coordinate appointments, and support culturally aligned decision-making, including around patient preferences and end-of-life planning.

Across all services, people describe PCC as enabling faster access to support when it is needed. Practical supports are often arranged within 24 hours, referrals occur more quickly, coordination improves, and families spend less time holding the system together themselves.

"That support was initiated by Palliative Care Connect and without making that contact, that support wouldn't have happened." — PCC-SNS service user



Emerging contributions to system functioning

PCC aims over time to contribute to broader system-level outcomes, including smoother care transitions, more coordinated palliative care, and reduced unnecessary pressure on acute and specialist services. Change at this level was not expected within the pilot timeframe, and the evaluation does not identify widespread evidence of it. What it does identify is a set of concrete, emerging examples indicating that PCC is beginning to shape how the surrounding system functions. These are early signals, but they point clearly to the mechanisms where PCC exerts influence.

The Bereavement Navigation Service identified a consistent gap in access to bereavement-specific counselling, particularly in regional areas where cost, distance, and availability meant some people went without support. In response, it integrated short-term counselling into the navigation model for people assessed as low to medium risk. Navigators move flexibly between information provision, referral, and counselling within a single relationship as circumstances evolve. Feedback from a regional GP clinic indicates this has reshaped how bereaved patients are managed: rather than clinicians carrying extended appointment time without a clear referral pathway, they now have a direct and trusted option. The service has improved patient experience while easing pressure on primary care.

The PCC Statewide Navigation Service is increasingly acting as a connector across different parts of the end-of-life system. In one case, a patient in a geriatric ward who wished to be discharged home remained in hospital because the pathway could not be coordinated by the hospital team and family alone. The PCC Statewide Navigation Service worked alongside the hospital team and community palliative care to clarify the Support at Home End-of-Life Pathway, identify appropriate providers, compile clear information for the family, and coordinate

practical arrangements. The patient was discharged home within days, an outcome staff reported would not have been achieved without PCC's involvement. Emerging evidence also suggests the service is contributing to more appropriate referrals into specialist palliative care, supporting regional teams that currently spend significant time triaging referrals that could be redirected to primary care or community services.

The PCC Statewide Navigation Service is also increasingly operating at the interface of palliative care and aged care, where new aged care pathways have created uncertainty about roles and responsibilities. Aged care staff describe the service as easing the burden of system navigation and providing psychosocial support to residents and families that is otherwise difficult to access. These functions were either not occurring elsewhere in the system or were being performed incompletely.

While these examples do not yet constitute systemic change, they represent credible early evidence that PCC can influence care coordination, referral flows, and how pressure is distributed across a stretched end-of-life system. The direction of travel aligns with the pilot's intent, and the mechanisms producing these effects are now better understood.





The value of what PCC has built

Over three years, PCC has built relational capital that is now embedded in how parts of the system operate. This trust extends to people navigating the most difficult moments of their lives, to families making decisions on behalf of others, to clinicians who have developed a shared understanding of when and how to refer, and to Aboriginal communities where those relationships took years to establish. Relational capital of this kind is specific to the people and services that built it and cannot be transferred quickly or easily.

The PCC Statewide Navigation Service has grown from a referral and orientation function into a connector used by hospital teams, aged care providers, and specialist palliative care professionals when care coordination requires work across conventional boundaries. Referral pathways that did not exist at the start of the pilot are now embedded in how particular services and sectors operate. In parallel, the Bereavement Navigation Service has built a network of relationships with GPs, community services, and regional providers, becoming a reliable and trusted referral option in settings where grief support pathways were previously limited.

For the people who accessed PCC, the evidence across the pilot period is consistent. They encountered a service that understood their situation, provided accurate information, and did not leave the coordination burden with them. Families managing deterioration, bereaved people without affordable counselling options, and Aboriginal families navigating end-of-life decisions within systems that do not always accommodate their practices are the people PCC reached. For many, this form of support was not otherwise available.

For the person who calls PCC in the middle of a crisis, none of the system complexity is what matters. What matters is that someone answered, understood the situation, and helped carry the weight. PCC has been that for thousands of people over three years. It is worth asking who does that if it stops.





Introduction

This report contains the findings of the Palliative Care Connect (PCC) evaluation which Clear Horizon undertook between June 2023 and February 2026. An overview of the report's structure and its key content can be found below.

Report structure

1. **About the Evaluation:** Describes the approach and methodology underpinning the evaluation.
2. **About Palliative Care Connect:** Provides context setting for the PCC pilot, including definitions for key concepts and the PCC Theory of Change.
3. **Effectiveness of Palliative Care Connect:** Provides a visual snapshot of the PCC pilot's reach and caseload.
4. **Reach and Access:** Describes who was reached by the PCC pilot and how they accessed different PCC service components, and the service's timeliness.
5. **Quality of Support:** Explores attributes of PCC support and users' experiences with the pilot, including appropriateness of support received and accuracy and clarity of information shared.
6. **Outcomes and Impact:** Includes a summary of the outcomes achieved by the three navigation services, and evidence of how the pilot has made progress against its three outcomes pathways.
7. **Coherence:** Examines changes in PCC service providers understand their role in pilot, their relationship with other providers, and their position in the broader system.
8. **Recommendations:** Considerations for the PCC pilot in terms of its current design, a scaled-up model, and future navigation and coordination pilots.

Annexes

The main report is supported by 3 annexes.

- **Annex 1:** PCC Services Theories of Action
- **Annex 2:** Geographic Reach of Navigation Services
- **Annex 3:** Developmental Evaluation Learning Briefs

1. About the Evaluation

This chapter describes the approach and methodology underpinning the evaluation.

The evaluation was intentionally designed to combine developmental evaluation to support learning and adaptation during implementation, and a pilot (theory based) evaluation to assess effectiveness, coherence, and outcomes. These two streams were designed to be mutually reinforcing, ensuring that real time learning informed service development while also generating robust evidence about impact.





Purpose

The evaluation of the PCC pilot was designed with two complementary purposes:

1. **Learning:** To generate real-time insights that support reflection and adaptation during implementation, highlighting what is working well, what is not, and where service delivery can be strengthened.
2. **Impact:** To assess the effectiveness and impact of PCC, examining how the pilot influences outcomes for service users and how services operate within, and interact with, the broader system.

Scope of the evaluation

The evaluation examines the activities, service models, and interactions within the PCC pilot, including how consumers access services, how they experience support, and what changes are occurring for those who engage with PCC services. It focuses on understanding the functioning and effects of PCC components as they operate in practice.

The evaluation does not assess specialist palliative care services or broader palliative, and bereavement supports operating outside the PCC model, unless those services intersect directly with the pilot and influence its implementation or outcomes.

Evaluation audiences

The primary audience for this evaluation comprises stakeholders who require, or will directly use, the findings to inform decisions about the PCC pilot. The secondary audience includes those with a broader interest in the pilot or palliative care system who may read the report but were not the focus of the evaluation design.

Primary audiences

An overview of the evaluation's primary audiences is provided in table 1.

Table 1. Primary evaluation audiences

Audience	Information needs
SA Health EOL Care Team	<ul style="list-style-type: none">• Outcomes, learnings, and examples of success to inform decision-making, including business case and proposals for continuation or scaling.• Insights from the pilot's implementation.• Outcome information for reporting requirements.
Project Sponsor (Federal government)	<ul style="list-style-type: none">• Outcomes, learnings, and examples of success to inform decisions about continuation, refinement, or scaling of the pilot or its services.
PCC Steering group	<ul style="list-style-type: none">• Key learnings from implementation.• Outcomes and examples of what is working well.
PCC Service Providers	<ul style="list-style-type: none">• Learnings to inform adjustments to the design and delivery of their service.• Outcome information demonstrating the impact of their work.



Secondary audience

The secondary audiences for the PCC Pilot evaluation include:

- PCC consumers who contributed information to the evaluation
- The broader Palliative Care sector
- SA Health
- Aboriginal health organisations
- Academics and journalists

Key evaluation questions

The evaluation is guided by four key questions:

1. **Learning:** What has been learned about PCC models, activities, and adaptations?
2. **Effectiveness:** To what extent do PCC services reach the people who need them, in a timely way, with information and support that is appropriate to their needs?
3. **Outcomes:** What changes are being observed for people who access PCC services, and are these consistent with PCC's theory of change?
4. **Coherence:** How well do the PCC services work together and complement the broader palliative care system

The structure of this report does not map directly onto the four KEQs. Learning was a central focus of the developmental evaluation and was primarily supported through a series of Learning Loops, which are structured cycles of reflection, sense making, and rapid feedback that informed ongoing service adaptation throughout the pilot. In this report, learnings are integrated throughout the findings rather than presented as a standalone chapter, and they form a significant part of the evidence base underpinning the analysis of PCC's key enablers.

The effectiveness KEQ is addressed across two chapters of this report - one examining the reach and accessibility PCC services, and one examining the quality of support provided. This structure was chosen to improve readability and reflect the natural distinctions in the evidence.

Outcomes are assessed using a theory-based approach, examining whether the enabling conditions outlined in the PCC Theory of Change are present and contributing to expected changes.

The coherence section examines the extent to which collaboration occurred between the services delivering PCC and highlights the ways in which services worked to establish recognition within the broader system. Both facets grew and evolved over the course of the pilot and this section describes how this played out in practice.



Methodology

Evaluation design

The original evaluation plan and Theory of Change (TOC) were co-designed with the EoL Care Team and PCC service providers in late 2023 and early 2024 to align with the PCC pilot as it was initially funded through June 2025. This design work, which drew heavily on an initial planning workshop held in December 2023, established the foundations for learning and assessment during what later became known as Phase 1 of the pilot.

Following Phase 1 implementation, and the announcement of a 12-month funding extension, a second workshop was held in July 2025 to update and refine the TOC based on what services had learned during Phase 1. The updated TOC appears in the [About PCC section](#) of this report.

Clear Horizon employed a two-pronged approach to evaluate the PCC Pilot:

1. **Developmental evaluation:** To support real-time learning and adaptation throughout implementation.
2. **Pilot evaluation:** To assess the effectiveness, coherence, and impact of the pilot using a theory-based evaluation approach.

The two streams were intentionally designed to be mutually reinforcing. Insights generated through the developmental evaluation's Learning Loops informed the pilot evaluation, while findings from the pilot evaluation fed back into ongoing learning and adaptation during implementation.

What is developmental evaluation?

Developmental evaluation is an approach designed to support innovation and learning in real time. Rather than waiting until the end of a program to assess what worked, it involves ongoing data collection and reflection throughout implementation, helping those delivering services to test ideas, identify what is and isn't working, and adapt accordingly. It is particularly suited to complex, evolving pilots where the model is still being refined.

What is theory-based evaluation?

Theory-based evaluation assesses a program by examining whether the conditions and mechanisms expected to produce change are actually present and operating as intended. Rather than simply measuring outcomes, it asks how and why change is occurring. In this evaluation, PCC's Theory of Change provides the framework against which findings are assessed.

As noted above, in early 2025, a funding extension was announced for the PCC pilot, enabling a second phase of evaluation to be undertaken. The evaluation therefore spans two phases, each with a distinct but complementary focus. Phase 1 (June 2023 - April 2025) was formative in character, focused on understanding how services were establishing themselves, identifying the conditions



enabling effective delivery, and generating learnings to support ongoing adaptation. Phase 2 (July 2025 - March 2026) built on this foundation with additional data collection, bringing a more summative focus - assessing the extent to which PCC was effective, how that effectiveness was created, and how it translated into outcomes for service users. This report draws on evidence gathered across both phases.

Developmental evaluation

The developmental evaluation was structured around a series of Learning Loops, designed to explore the KEQs and support continuous improvement throughout the pilot. The focus and structure of these loops evolved across the two phases as services matured and the evaluation shifted emphasis.

Learning Loops were structured, repeatable cycles of inquiry designed to generate evidence informed learning during implementation. Each Learning Loop typically involved targeted data collection (such as interviews with service providers, review of service documentation, and analysis of bimonthly service reports), followed by facilitated reflection with PCC service teams. These reflective discussions focused on interpreting findings, identifying emerging issues or opportunities, and considering implications for service design and delivery. Each Learning Loop concluded with a Learning Brief, which documented key insights, learnings, and opportunities for improvement. Collectively, the Learning Loops formed the primary mechanism through which learning was generated and fed back into service adaptation during the pilot.

Phase 1 - Formative evaluation (June 2023 -- April 2025)

Five Learning Loops were conducted during Phase 1. These brought services together to reflect on early implementation, build shared understanding across the model, and identify opportunities for improvement.

Phase 1 also produced a series of case studies derived from the developmental evaluation, which captured how individual services were working in practice and how they were contributing to outcomes. These case studies formed a significant part of the Phase 1 evaluation outputs. Condensed versions are carried forward into this report, where they provide contextual grounding and continuity with the Phase 1 findings.

Phase 2 - Summative evaluation (July 2025 -- March 2026)

As services became more established, the developmental evaluation shifted to a more targeted, service-specific approach. Three Learning Loops were conducted during Phase 2, each tracking a specific adaptation or focus area for an individual service. These included

- **Bereavement Navigation Service:** Testing short-term bereavement counselling for low- to moderate-risk clients.
- **Aboriginal Navigation Service:** Expanding into additional regional areas through recruitment of a navigator based in Ceduna and Port Lincoln.



- **Palliative Care Connect Statewide Navigation Service:** Supporting implementation of the Support at Home End-of-Life Pathway and examining the role of face-to-face support for higher complexity cases.
- **HELP App:** Refining promotional strategies and understanding uptake across South Australia.
- **PCC Website:** Implementing and enhancing the “*identify your needs*” referral function.
- **Palliative Care Volunteering navigation service:** Trialling a study tour model to strengthen regional palliative care volunteering capability.

This targeted approach enabled deeper examination of how individual services were evolving in practice and how these adaptations contributed to outcomes across the broader PCC model. All DE Learning Briefs are included in Annex 2 (link).

Pilot Evaluation

The pilot evaluation ran in parallel with the developmental evaluation but took a more structured and linear approach. Its primary purpose was to assess the overall impact, coherence, and effectiveness of the PCC Pilot using a theory-based approach, with PCC's Theory of Change providing the framework against which findings and outcomes were examined.

Data collection

A mixed methods approach was used, drawing on both qualitative and quantitative data from multiple sources. Table 2 summarises the data sources included in the evaluation.

Table 2. Data sources

Data source	Number of data points
Semi-structured interviews with PCC-SNS users	30
Semi-structured interviews with BSN users	18
PCC-SNS user satisfaction survey respondents	83
BNS user satisfaction survey respondents	11
Semi-structured interviews with professional stakeholders (system and referral perspective)	10
Semi-structured summative group interviews with PCC service providers (end of each phase, distinct from developmental learning loops)	14
PCC service administrative dataset (case-level data for Statewide, Bereavement, Aboriginal and Regional Navigation Services)	1,160 cases (de-identified dataset covering all cases from service commencement to February 2026)
PCC bi-monthly service reports (activity metrics, qualitative reflections, learnings, short case studies)	Reports produced bi-monthly from service commencement to February 2026
Learning Briefs produced through developmental evaluation Learning Loops	8

In addition to the sources listed in the table, the evaluation team drew on participatory observation data accumulated through direct involvement in the pilot. This included supporting individual services



during DE Learning Loop sessions and observing the monthly PCC provider Working Group meetings throughout the pilot. This provided contextual understanding of the pilot's implementation and informed the interpretation of findings throughout the report.

A document review was also undertaken, drawing on materials produced by stakeholders as part of the evaluation, as well as relevant grey and academic literature. These sources were used to contextualise and support the analysis and are referenced throughout the report using footnotes.

Data analysis

A combination of qualitative and quantitative methods was used to analyse data from across the Pilot.

Qualitative analysis: Qualitative data was analysed thematically. Comments were grouped into inductively generated themes to identify common patterns and divergent perspectives. Selected quotes are included throughout the report to illustrate findings and elevate the voices of service users, providers and stakeholders.

Quantitative analysis: Quantitative data was analysed using descriptive statistics to identify patterns and trends across service components and stakeholder groups. Both percentages and case numbers (n=) are reported where relevant.

All data sources were consolidated and mapped against the key evaluation questions. Where feasible, findings were triangulated across multiple lines of evidence to strengthen the validity and confidence in the conclusions.

Note on qualitative data: Because interviews used open-ended questions and themes were generated inductively, the prevalence of themes is described using hedged language (such as "most participants" or "a number of participants") rather than numerical counts. Where a theme did not arise in a given interview, this reflects the nature of open-ended inquiry rather than absence of experience. Participant counts (n=) are therefore not used, as the number of times a theme was mentioned does not reliably reflect how widely it was experienced.

Joint sensemaking

To ensure comprehensive coverage and accuracy of the evaluation findings, a joint sensemaking workshop was held on 19 February with 15 participants, representing six different pilot services and SA Health's End-of-Life Care team. The session was used to test preliminary findings and identify inaccuracies, gaps and opportunities for improvement.



Limitations

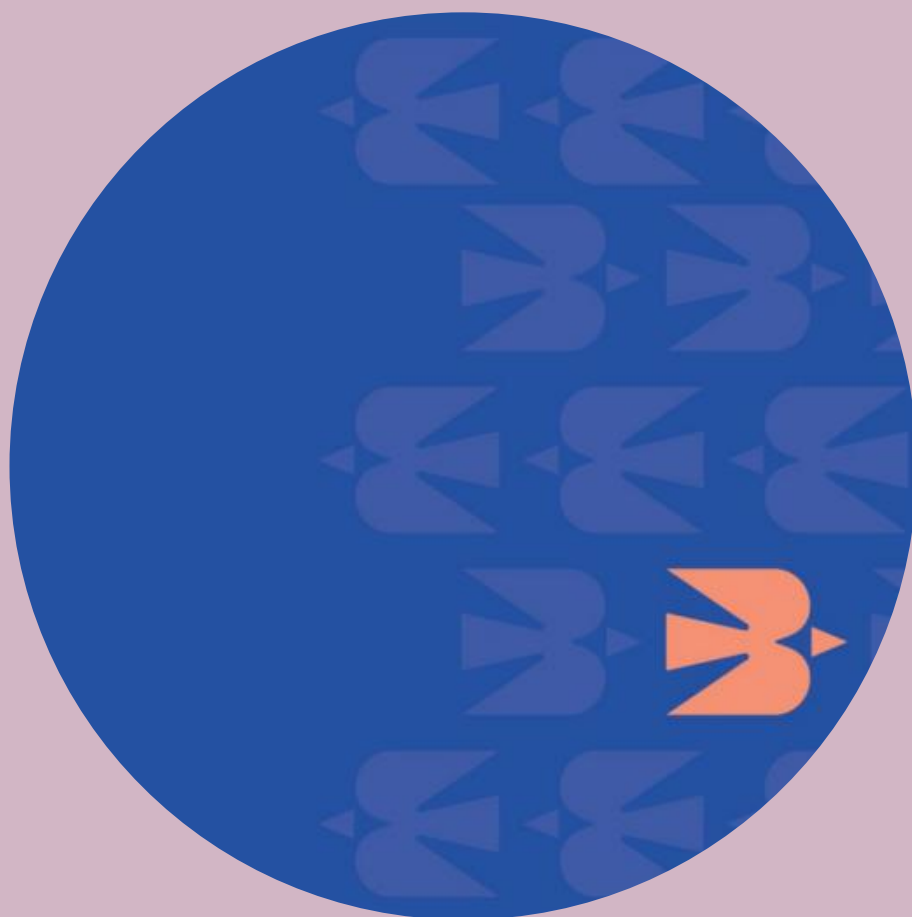
Despite efforts to uphold the rigour of the evaluation process and its findings, certain limitations need acknowledgment.

Table 3. Evaluation limitations

#	Limitations
1	Uneven depth of evidence across service components The evaluation has richer qualitative and quantitative evidence for PCC-SNS and BNS than for other components. The Aboriginal Navigation Service had only 42 cases and no service user interviews; the Regional Navigation Service concluded during the pilot; the HELP App and Volunteering Coordination Service have limited user-level outcome data. This means findings for some services are more tentative.
2	Self-selection and survivorship bias in interview and survey samples Service users who agreed to be interviewed or completed satisfaction surveys are likely to have had more positive experiences than those who did not respond or who disengaged from services early.
3	No First Nations service users were interviewed No First Nations users were able to be interviewed as part of the evaluation. This significantly limits the depth of insight into how those users experienced PCC.
4.	Incomplete administrative data fields The administrative dataset covers 1,160 cases but navigator data collection was guided by the needs of each interaction rather than systematically collecting all fields. As a result, many fields are not populated for all cases, and analysis is based on the subset of cases where a given data point was recorded.
5.	Availability of service staff to participate in developmental evaluation activities Staff delivering PCC components frequently held additional roles within their organisations alongside their pilot responsibilities. This made it difficult to consistently schedule reflection time with the evaluation team, and participation in Learning Loop sessions and interviews was sometimes constrained by competing demands. This may have resulted in some implementation insights or emerging learnings not being fully captured in real time.

2. About Palliative Care Connect

This chapter introduces the PCC Pilot and provides context for the evaluation findings that follow.





Palliative Care Connect

PCC is a statewide navigation service in South Australia, established to help individuals with life-limiting illnesses, and their families, carers, and health professionals, access palliative care, bereavement support, and volunteering opportunities. Its main objective is to provide guidance, build connections, and offer emotional and practical support through a single-entry point.

Foundations of palliative care, bereavement support and palliative care volunteering

This section outlines key definitions and descriptions of palliative care, bereavement support, and palliative care volunteering to provide context for the evaluation findings.

Palliative care

Palliative care is person and family-centred care for individuals of all ages with a life-limiting illness, focusing on optimising quality of life rather than curing the illness.¹²

Core principles central to palliative care include:

- It is responsive to the needs, preferences, and values of individuals, families, and carers, emphasising effective communication, shared decision-making, and personal autonomy.
- It is available to all individuals with life-limiting illnesses, and the families and carers who support them, regardless of diagnosis.
- It affirms life while recognising the inevitability of death, focusing on comfort rather than hastening or delaying death.

Palliative care encompasses a wide range of care and support options that address physical, emotional, cultural, social and spiritual needs of a person. Depending on the individual and their needs, care can be received either in community (including at home) or facility settings (including at a hospital, at a residential aged care or disability facility), or in a palliative care unit (hospice).

Many health and aged care professionals can provide palliative care services and may be part of a multidisciplinary team of care providers including general practitioners, counsellors or psychologists, social workers, pharmacists, and other specialists based on an individual's diagnosis and needs (e.g., their oncologist if they have received a terminal cancer diagnosis). Specialist palliative care services are provided by practitioners with advanced expertise in managing the complex needs that can arise for people living with life-limiting illness.

¹ Palliative Care Australia 2018, *Background Report to the Palliative Care Service Development Guidelines*, prepared by Aspek Consulting, Melbourne

² SA Health. Palliative Care Connect. Website. [Link](#)



Bereavement support

Bereavement support refers to a range of services provided to anyone who has experienced the death of a loved one, including the lead up to their death and the adjustment period following.³ It is an essential component of palliative care services, supporting individuals to navigate their grief and loss, a non-linear journey which can take weeks, months or years. A small group of individuals may be at risk of developing complicated grief or prolonged grief disorder; for them, access to this service is particularly critical.⁴

Bereavement support may include therapeutic care from a bereavement counsellor or social worker, bereavement support groups, or information and referrals from a GP or palliative care service provider. While bereavement support can be provided by palliative care providers, specialist bereavement practitioners have additional skills and training that enable them to manage more complex or severe experiences of grief.

According to the Bereavement Support Standards, bereavement support should be part of a holistic palliative care service, offered at a minimum to all caregivers throughout an individual's palliative care journey and after death. Screenings, risk assessments, and provision of information along the grief journey can be used to identify the needs of bereaved carers and family members and ensure access to the right services, which can help mitigate the impact of their loved one's death.

Palliative care volunteering

The National Palliative Care Standards recognise volunteers as part of the palliative care workforce.⁵ Volunteers play a critical role in both facility and community-based palliative care, particularly in providing psychosocial, spiritual and practical support to palliative care service users as well as their caregivers and family members.⁶

Volunteers offer complimentary support to that of paid staff and can help fill certain gaps, creating a more holistic network of palliative care support. For example:

- Volunteers with lived experience can provide a peer perspective
- Culturally and linguistically diverse volunteers can connect with service users of similar backgrounds through shared language and culture
- Volunteers may be able to spend more time with service users than paid staff are able to.

Volunteers are expected to receive appropriate and regular training and support to ensure that they are able to safely and competently deliver services; this includes education about loss, grief and bereavement. Volunteers are also expected to regularly reflect on their practices and engage self-care strategies. Volunteers may also participate in non-client facing roles, by providing support to palliative care service providers such as assistance with administration, advocacy, or fundraising.

³ Hall C, Hudson P, Boughey A 2012, *Bereavement support standards for specialist palliative care services*, Department of Health, State Government of Victoria, Melbourne

⁴ Hall C, Hudson P, Boughey A 2012, *Bereavement support standards for specialist palliative care services*, Department of Health, State Government of Victoria, Melbourne

⁵ Palliative Care Australia 2018, *National Palliative Care Standards 5th edn*, PCA, Canberra

⁶ Palliative Care Volunteering SA, *Research Project Survey Results*, Palliative Care Connect SA



Service Context

The following section outlines key contextual factors that influence access to palliative care and bereavement support in Australia.

First Nations Context

Nationally, only 1.4% of people accessing specialist palliative care services identified as Aboriginal and/or Torres Strait Islander.⁷ When compared to the national population (2.8%), this indicates a low utilisation rate of specialist palliative care services among First Nations people. Significant differences in how death and dying are viewed and spoken about may limit the availability of culturally appropriate specialist palliative care services.

First Nations people living in regional or remote communities may face additional barriers to access, such as a limited availability of services where they live, transport and accommodation costs to travel to nearby services, and language barriers. Given the cultural significance of 'dying on country', community-based palliative care models are the safest and most appropriate options for some First Nations people and families. However, not all community-based service models are resourced with the staffing, clinical capacity, or supports required to provide comprehensive palliative care, particularly in rural or remote regions, which can lead to negative impacts for individuals and families.

Regional Context

People living in rural and remote regions often have fewer palliative care options available than those living in metropolitan areas, particularly for individuals with complex care needs. Availability of 24-hour care support also varies across regions, with some communities relying on the support of volunteer paramedics to address palliative care needs afterhours. Furthermore, people living in outer regional centres have less access to medical staff qualified in providing palliative care support, and access to about half as many allied health professionals as people in metropolitan centres. These factors can affect access to timely, comprehensive, and well-integrated palliative care within regional communities, and may result in people needing to travel to access services, receiving more limited care locally, or not accessing some services altogether.⁸



⁷ Palliative Care Australia 2018, *Background Report to the Palliative Care Service Development Guidelines*, prepared by Aspex Consulting, Melbourne

⁸ SA Health, 2019. Palliative care needs in South Australia. Government of South Australia.



Issues leading to the pilot's inception

The PCC pilot was developed in response to a combination of structural, workforce, and access-related challenges within the palliative care system. Together, these issues highlighted gaps in system coordination, navigation, and equitable access to support, particularly at times of heightened vulnerability, and underscored the need for a more integrated, person-centred approach.

A siloed and fragmented system

The palliative care system is less integrated than many other parts of the healthcare system, with services often operating in silos. Healthcare professionals frequently make 'cold referrals', providing individuals and families with information about services and expecting them to initiate contact themselves, rather than actively linking them to appropriate providers. This places responsibility for coordination on people at a time when they may be experiencing distress, uncertainty, or grief.⁹

Referrals to palliative care can also occur late in the end-of-life journey, rather than earlier when people and families could be better supported to understand their options and make informed decisions about their care needs and preferences. For many people, palliative care is not discussed while they are receiving active treatment or is not recognised as relevant until very late in the course of illness. Palliative care is also commonly misunderstood as being limited to the final stages of life, which can delay engagement and limit opportunities for early symptom management, psychosocial support, and advance care planning.

Information provided at the point of a diagnosis can be overwhelming, and in the absence of clear, consistent guidance, individuals and families may struggle to make sense of the palliative care system. Without someone with intimate knowledge of the system, it can be difficult to navigate the different options in service types and providers.¹⁰

In this context, the absence of a consistent point of guidance contributes to delayed access, unmet needs, and increased distress, reinforcing the need for a navigation function that can support people earlier and more effectively through the system.¹¹

Limited palliative care capability within the aged care workforce

National surveys show that over 70 per cent of people would rather die at home, but most die in hospital instead.¹² While end-of-life care should be 'core business' for residential aged care providers, many facilities lack staff qualified to provide those services, resulting in people being transferred back and forth between their aged care facility and the hospital.

General practitioners, who are central to a quality aged care network, may not always have the time and availability required to provide the level of attention required in end-of-life care. Integrated

⁹ Clear Horizon. (2025). Interview with Senator Stirling Griff.

¹⁰ SA Health. (2023). *Palliative Care Services Navigation Pilot*. Presentation. Government of South Australia.

¹¹ TACSI. (2022). *End of Life Care Navigation*. Prepared for SA Department of Health and Wellbeing.

¹² Palliative Care Australia, Submission PFR329 – Palliative Care Australia (PCA) – Identifying Sectors for Reform Productivity Commission Preliminary Findings (2016),



community care models make sense but require greater coordination of service providers to ensure comprehensive coverage that can respond rapidly to emergency situations.¹³

Although navigation cannot resolve workforce shortages, it can support earlier planning, improve coordination between services, and help families and providers identify appropriate alternatives, contributing to reduced hospital transfers and system strain.

Barriers to accessing high-quality palliative care services

Certain population groups face significant disparities in accessing specialist palliative care, including individuals with non-cancer conditions, who are often under-referred due to a lack of recognition of their palliative needs compared to cancer patients.¹⁴ People living with a disability frequently encounter service gaps, particularly those under 65 who may find themselves in "limbo" between the NDIS and the health system.¹⁵ Regional and remote communities are hindered by lower specialist-to-population ratios and a reliance on transient workforces, and Aboriginal and Torres Strait Islander people are substantially under-represented in specialist care despite having higher rates of premature mortality.¹⁶ Barriers may be structural (such as limited service availability), informational (not knowing what services exist or how to access them), or cultural (including lack of culturally safe or appropriate care).

Families may not know where to start to look for information about palliative care services in their area, may not recognise palliative care as something that could support them alongside other treatments or care, or may be unaware of alternative options that may better suit their needs and circumstances. These barriers are often cumulative, compounding disadvantage for individuals and families who experience multiple forms of exclusion. This reinforced the need for a flexible, accessible entry point that could respond to diverse needs and contexts.

Together, these issues highlighted the need for a coordinated, person-centred navigation model to support people earlier, more effectively, and more equitably through the palliative care system.

What is 'Navigation'?

As originally defined in the PCC pilot, navigation "...builds relationships, problem solves and helps locate resources, serving as a link between community, health and psychosocial services. It involves advocacy on behalf of people to empower them to access and make the palliative care choices that are right for them. A key purpose is to ensure patients experience seamless, joined up care, and support."¹⁷

¹³ SA Health, (2019). *Palliative care needs in South Australia*. Government of South Australia.

¹⁴ Palliative Care Australia (2018). *Background Report to the Palliative Care Service Development Guidelines*, prepared by Aspex Consulting, Melbourne.

¹⁵ Nous Group. (2025). *Evaluation of the Implementation Plan for the National Palliative Care Strategy*. Prepared for the Department of Health, Disability and Ageing

¹⁶ Palliative Care Australia (2018). *Background Report to the Palliative Care Service Development Guidelines*, prepared by Aspex Consulting, Melbourne.

¹⁷ SA Health, 2024. *Palliative Care Connect Launch Event*. Presentation. Government of South Australia.



Some key components of navigation include:

- **Personalised support** that considers an individual's needs rather than putting them on a single path.
- **Coordination** of services, appointments, referrals, information, and processes required to access care.
- **Integration** of services across health, social, and civic sectors.¹⁸

Navigation programs are proven to be effective at improving users' experience within the healthcare system. Studies have shown that navigator programs can help people access and utilise more appropriate healthcare services and improve the quality of care received.¹⁹ Community-based navigator programs for end-of-life cancer patients have been shown to help reduce overall care costs, hospitalisations and emergency department visits, and the need for hospice care.²⁰ A navigator program for caregivers was shown to reduce caregiver fatigue and resentment of their role, and increase their feelings of being supported by others, their confidence to ask for help, and their ability to find resources and support.²¹

Navigation does not necessarily need to be delivered by one single person; it can be embedded as a way of working across services, teams, and professionals within and across health, aged care, disability, and community service systems that support people living with life-limiting illness and those close to them. However, in practice, some models also include a dedicated role responsible for facilitating navigation for people receiving end-of-life care and their caregivers.

How navigation worked across PCC's service contexts

PCC brought navigation to life across three distinct service types, each shaped by the needs of the people it served and the context in which it operated. While they share a common goal of personalised, person-centred guidance through a complex system - they are not variations of the same model. They differ in the depth and duration of engagement they required, the relationships they depended on, and what effective support actually looked like.

The **Palliative Care Connect Statewide Navigation Service (PCC-SNS)** was designed as an episodic, orientation-focused service. Most people who contacted PCC-SNS were at a point of confusion or uncertainty and were unsure what services existed, how to access them, or where to start. Many already had some supports in place. Navigators drew on their knowledge of service systems and referral pathways, including access to the relevant referral unit, to provide clarity and timely connection. A high proportion of cases were resolved in a single interaction or a small number

¹⁸ Health Education England, 2016. *Care Navigation: A Competency Framework*. NHS.

¹⁹ Teggart K, Neil-Sztramko S, Nadarajah A, Wang A, Moore C...& Ganann R. 2023. Effectiveness of system navigation programs linking primary care with community-based health and social services: a systematic review. *BMC Health Services Research*; 23:450. <https://doi.org/10.1186/s12913-023-09424-5>

²⁰ Colligan, EM. 2017. *Innovative Oncology Care Models Improve End-of-Life Quality, Reduce Utilisation and Spending*. AcademyHealth Annual Research Meeting, Centers for Medicare and Medicaid Services. Presentation.

²¹ Greene A, Aranda S, Tieman JT, Fazekas B and Currow DC. 2011. Can assessing caregiver needs and activating community networks improve caregiver-defined outcomes? A single-blind, quasi-experimental pilot study: Community facilitator pilot. *Palliative Medicine*; 26(7), 917-923. DOI: 10.1177/0269216311421834



of contacts. The emphasis was on reducing overwhelm, facilitating the right referral, and empowering people to take next steps.

The **Bereavement Navigation Service (BNS)** operated in a different context. Grief is non-linear and it does not follow a predictable arc, and people's needs can resurface. An episodic model built around brief, referral-focused contact does not suit this. BNS users needed time, space, and often more than one encounter. Navigators built trust over time and adapted to where a person was in their experience of grief rather than moving through a structured sequence of steps. Over the course of the pilot, the BNS also integrated short-term counselling alongside navigation, in response to identified gaps in accessible therapeutic support - particularly in regional areas.

The **Aboriginal Palliative Care Navigation Service (ANS)** was grounded in a relationship-first, culturally embedded approach that the other models could not replicate or substitute. In Aboriginal communities, trust is a key facet the support. Navigators could not arrive as service providers and immediately discuss end-of-life planning or care options. Sensitive conversations about dying, care preferences, and family decision-making emerged gradually, over multiple visits, as relationships deepened. This required sustained engagement that was incompatible with brief or transactional interactions. Navigating the health system and community values, facilitating challenging conversations, and supporting family-centred decision-making was central to what the service did. That cultural dimension cannot be reduced to a series of efficient referral interactions.

A fourth service, the **Regional Navigation Service (RNS)**, operated during Phase 1 of the pilot with a place-based model that became more face-to-face and relational over time than originally intended. The RNS depended on active stakeholder engagement and community-led referrals to build caseload. It was retired in 2025. Where relevant, findings from the Regional Navigation Service are included in the analysis, but the three services described above were the ongoing navigation models at the time of this evaluation's completion.

Original vision of the Palliative Care Connect pilot

The catalyst for the PCC pilot was a letter written by Senator Stirling Griff in September 2021, following his experience of navigating the palliative care system following his wife's terminal cancer diagnosis. The family faced numerous challenges in finding information about palliative care services, making informed decisions about service options, and securing referrals; this experience is not an uncommon one for many families at the end-of-life stage. Senator Griff proposed a centralised system that at its core would facilitate information sharing, care coordination, and service referrals for palliative and bereavement care. An initial commitment of \$7.27 million in federal funding for the pilot was secured by March 2022, and the pilot was established by July 2023. Following a two year rollout period, the Commonwealth provided a further 12 months of funding for PCC.

Foundational research and early design considerations

To support early thinking about palliative and end-of-life navigation, SA Health commissioned The Australian Centre for Social Impact (TACSI) to undertake scoping research between May and August 2022. This work examined the current end-of-life landscape, existing navigation models, and the role of volunteers and non-clinical supports.

The TACSI scoping report identified a set of model design considerations and supporting practices expected to characterise effective delivery of a palliative and end-of-life care navigation service.



These informed the design of the PCC pilot and provided useful context for understanding how services were intended to operate.

The navigation role

- Navigation was understood as a broad, relational function encompassing guidance, bridging, and elements of emotional support, not limited to information provision or referral
- Navigators were intended to act as intermediaries, advocating for individuals and facilitating continuity across the system
- A tailored, person-centred approach was central, with support designed to respond to individual needs and circumstances rather than a fixed service model
- A trauma-informed, trauma-responsive approach was embedded as a foundational practice, with ongoing supportive engagement seen as central to building trust

Wayfinding and wayfaring

The TACSI report introduced a distinction between two complementary dimensions of navigation:

- **Wayfinding:** helping people orient within a complex system and understand available pathways and options
- **Wayfaring:** recognising that navigation is an ongoing, non-linear journey shaped by changing needs over time

These positioned navigation as a continuous, relational process spanning the full trajectory from diagnosis through to bereavement, rather than a single point-in-time interaction.

Supporting operational considerations

- Drawing on the TACSI foundational research, several operational considerations were identified as important enablers of effective navigation.
- Privacy and information sharing managed in ways that minimise trauma and support continuity of care
- Staff wellbeing, supervision, and caseload management recognised as essential to sustainable delivery
- Services seen as having a role in building broader community understanding of death, dying, and bereavement
- Culturally responsive and locally grounded approaches highlighted as essential, including for Aboriginal communities

Development of the PCC service concept

Drawing on the broader system context, the pilot's aim was to increase knowledge of and access to end-of-life care, as well as improve the quality of care experienced by users through a system that



was easier to enter and navigate. The pilot would deliver system navigation to increase linkages between palliative care network services, rather than replacing clinical care.

A Steering Committee was established during the design and development phase to provide advice, drawing on a range of expertise and sector perspectives to inform the development of the pilot.

The original design contained five components:

1. **Palliative Care Service Navigators** – staff with specialist knowledge and skills to deliver personalised support to pilot users.
2. **Information line** – for users to be able to ask questions and be directed to palliative care resources and services.
3. **Palliative Care information platform** – online platform with information and self-assessment tools.
4. **Bereavement Coordinators** – staff who would work with PC Service Navigators and community to support bereaved family members and friends.
5. **Volunteers/Peer support** – to help create community and link users to community services.²²

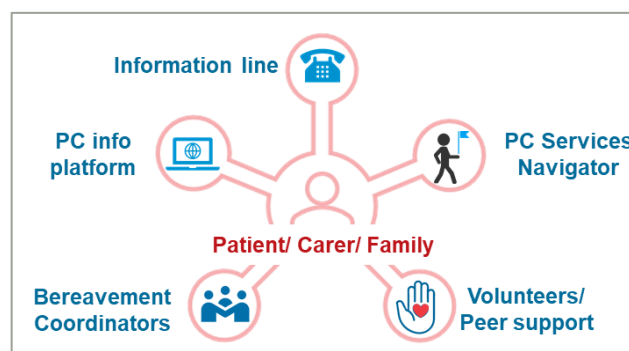


Figure 1: Palliative Care Navigation model initial vision

Community testing and refinement

Following the development of the initial PCC service components, Think Human was engaged in 2023 to test the proposed PCC model with community members and practitioners. Consultations were held with 47 community members with lived experience of the palliative care system including service providers, service users, and family members across metropolitan and regional South Australia to test the pilot's purpose and design.

Participants largely recognised the potential value of a centralised navigation service, while also raising questions about the broader system's ability to deliver quality palliative care support (e.g., clinicians with the skills and discernment to discuss death and dying with patients, availability of adequately funded and resourced palliative care support services, etc.). There was also uncertainty of who was eligible to access the pilot, given confusion around the term 'palliative'. These insights highlighted that while navigation was seen as valuable, its effectiveness would depend on how it operated within existing system and service constraints.

²² SA Health: Palliative Care Services Navigation Pilot Project Plan, June 2023 (internal document)



What did Palliative Care Connect look like at launch?

By the time the pilot was launched in February 2024, it had expanded from five to seven-component service model delivered by government and non-government organisations. SA Health maintained responsibility for delivery of PCC-SNS and oversight of the pilot, while implementation of the six other service components was outsourced to partner organisations.

Table 4. PCC Service Components

#	Service Component	Delivered By	Description of Service
1	Palliative Care Connect Statewide Navigation Service	SA Health Based in Adelaide	Providing centralised telephone-based navigation, information and service linkages for individuals, carers, and professionals seeking guidance on palliative care and related supports across South Australia.
2	Aboriginal Navigation Service	Country & Outback Health Based in Port Augusta, Ceduna and Port Lincoln	Providing culturally safe navigation and support tailored to the needs of Aboriginal and Torres Strait Islander people and communities, primarily via telephone and face-to-face in Port Augusta and Whyalla.
3	Regional Navigation Service	Sonder Located in Kadina	Providing place-based navigation support for individuals living in the Yorke Peninsula, Barossa, and surrounding regions, connecting them with palliative care and local supports. ²³
4	Bereavement Navigation Service	FocusOne Health Located in Berri and Mount Gambier	Providing bereavement navigation and referral support via a statewide telephone service, with face to face support available in selected locations including Adelaide, Whyalla, Port Augusta, the Riverland and Limestone Coast.
5	Palliative Care Volunteering SA	Palliative Care South Australia ²⁴	Strengthening volunteer involvement in palliative care through targeted training, resource development, and organisational support.
6	PCC Website	Research Centre for Palliative Care, Death and Dying (RePaDD), Flinders University	Serving as an online hub providing comprehensive information, resources, and an interactive directory to help consumers access relevant support.
7	Healthy End of Life Planning (HELP) App	La Trobe University	A digital tool designed to coordinate informal social and practical support networks for individuals with life-limiting conditions, reducing carer burden and enhancing community-based support.
8	Bereavement counselling	Adaptive Grief Counselling and Healthy Life Psychology	Facilitating structured group sessions to assist individuals coping with grief and fostering social connections through shared experiences.

How the pilot evolved

The pilot was initially scheduled to run from July 2023 to June 2025 but subsequently received an extension to continue delivering services until mid-2026. This extension created additional opportunities to embed the model, strengthen coordination across partners and generate deeper insights into the effectiveness and impact of the PCC approach.

²³ Note: This service concluded in June 2025.

²⁴ Delivered in collaboration with Volunteering SA&NT, Northern Volunteering (SA), and Southern Volunteering (SA)



In the early stages of delivery, PCC services focused on establishing core functions and responding to initial patterns of demand. During this period, a number of practice-level and operational adjustments were made as services became established, including:

- Introduction of Grief Literacy workshops through the Bereavement Navigation Service
- Training of Navigators to support referrals to the HELP app
- The Palliative Care Connect Statewide Navigation Service securing access to a government vehicle to enable community outreach
- Establishment of Yarning workshops through the Aboriginal Navigation Service

As the pilot progressed, and following the extension of funding, learning from Phase 1 informed the second phase of the pilot, which was characterised by a combination of consolidation, refinement, and targeted expansion across different components of the pilot. During this period, PCC made more deliberate structural adjustments to refine service delivery and support targeted testing of service approaches in additional regional contexts. These included:

- An increased emphasis on psychosocial support within the Palliative Care Connect Statewide Navigation Service
- Conclusion of the Regional Navigation Service as part of streamlining of navigation delivery
- Reconfiguration of the Bereavement Navigation Service, including the introduction of a counselling function for people assessed as having low to moderate bereavement risk
- Expansion of the Aboriginal Navigation Service to Ceduna and Port Lincoln to test delivery of the model in additional regional settings
- Clearer positioning of the Palliative Care Connect Statewide Navigation Service as trusted source for information and access to the Support at Home End of Life Pathway
- These changes reflect how PCC evolved over time, moving from initial establishment and testing towards a more focused and responsive model shaped by experience and demand. A more holistic view of the PCC journey is provided in the below Journey map. This map was created collaboratively during the sensemaking workshop.





PCC Journey map

Legend

SPCNS	Bereavement Navigation	Website	Volunteering
Regional Navigation Service	Aboriginal Navigation	HELP App	SA Health EoL Care Team

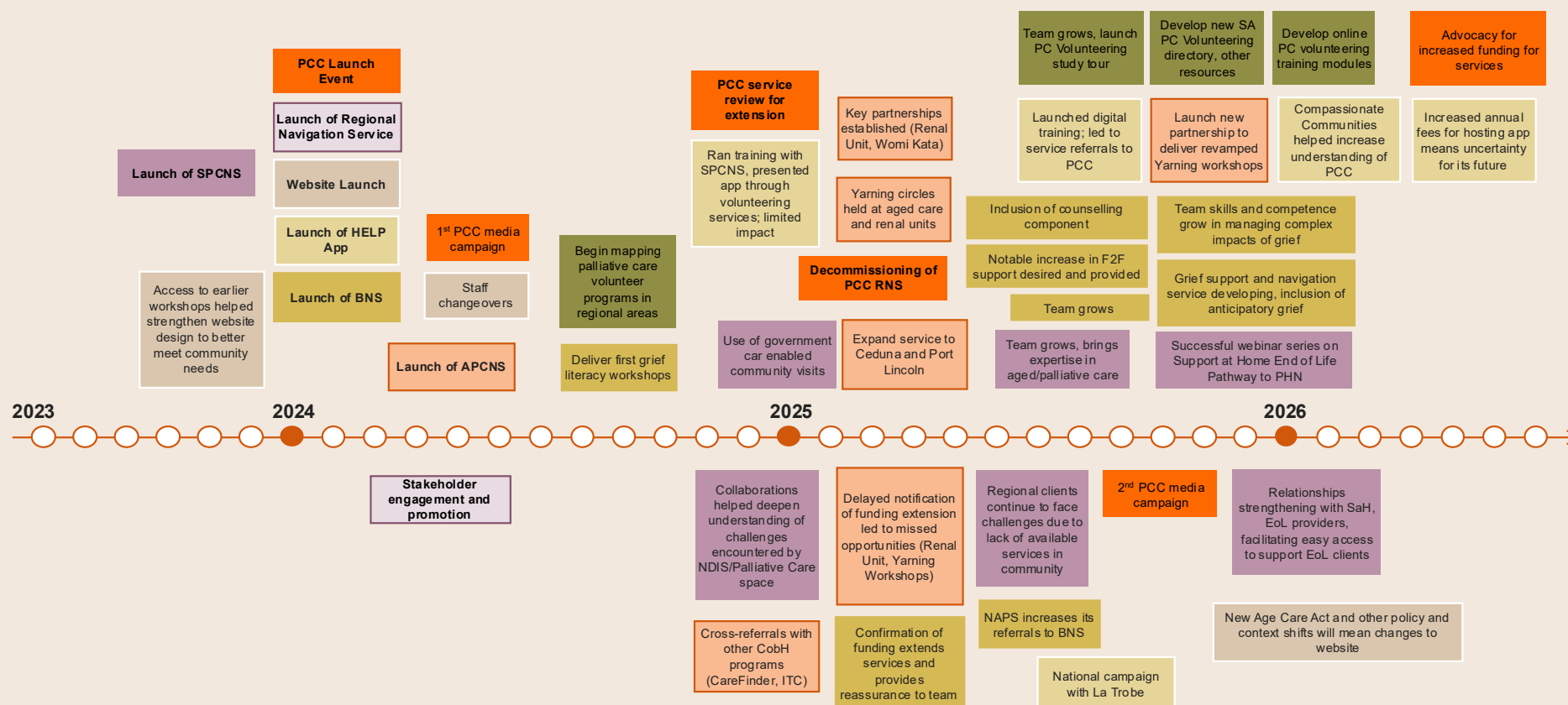


Figure 2: PCC Pilot Journey Map



Theory of Change

PCC's Theory of Change describes how its service components work together to create change. It was originally developed during Phase 1 of the pilot and updated in July 2025 through a workshop with PCC providers and the SA Health End of Life Care team. A summary version of the Theory of Change is presented in Figure 2 below. The full Theory of Change, along with the individual Theories of Action for each PCC service, is provided in Annex 1.

At its foundation are six enabling outcomes that need to be in place for services to generate impact: accessibility (reaching people across metropolitan, regional, rural and Aboriginal communities); timeliness (providing support when it is most needed, including early in the end-of-life journey); appropriateness (offering the right type and intensity of support for each person's situation); accuracy and clarity (ensuring people receive reliable, up-to-date information and understand what PCC can and cannot do); collaboration (services sharing learnings and making relevant referrals to one another); and system awareness (natural touchpoints in the health and family service system knowing about PCC and perceiving it as effective).

When these enabling conditions are in place, the ToC anticipates change through three outcome pathways:

- **Outcome Pathway 1:**
People are connected - consumers feel heard and emotionally supported, build trusted relationships, and develop sustained connections to support networks and peers over time.
- **Outcome Pathway 2:**
People have the information they need - consumers receive timely, clear and tailored information, reducing confusion and building the confidence to make informed, values-aligned decisions.
- **Outcome Pathway 3:**
People access the services and supports they need - needs are identified and responded to early, consumers are linked to the right supports, and care is better coordinated, reducing the risk of escalation or crisis.

Across these pathways, a set of longer-term, cross-cutting outcomes are anticipated: consumers feel connected, informed and empowered throughout their journey; people with palliative care needs experience the best possible quality of life; and those providing support are supported to maintain their own wellbeing.

Broader system and community outcomes - such as more collaborative palliative care, streamlined care transitions, and a more grief-literate population - are longer-term aspirations that the pilot alone cannot achieve, but aims to contribute toward.

Alongside the overarching Theory of Change, individual Theories of Action (ToAs) were developed for each PCC service. These describe how each service's specific activities are expected to contribute to the enabling conditions and outcome pathways, providing a shared framework for reflection and a basis for identifying, testing and adapting service-level strategies. The Theories of Action are provided in Annex 1



PCC Theory of Change

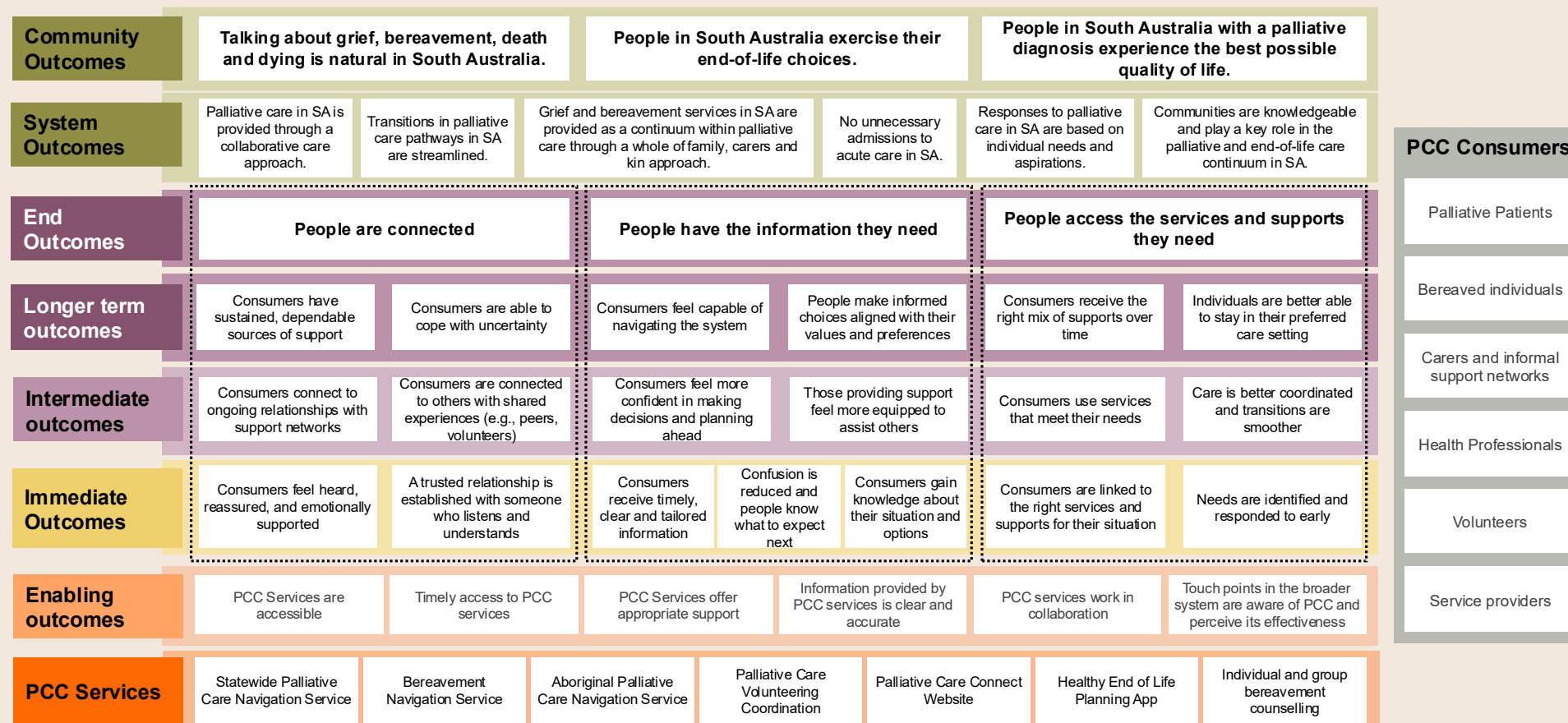


Figure 3. PCC Theory of Change

3. Effectiveness of Palliative Care Connect

Palliative Care Connect is a multi-service model comprising several interconnected navigation, bereavement, digital and volunteer services.

This section provides a quantitative snapshot of activity across PCC services, demonstrating uptake, scale and utilisation of the model during the pilot period. Reach, access and pathways into PCC are explored in the following section.



Snapshot summary of PCC in numbers

Combined:

1,363 cases

2,023 people supported



PCC Website:

47,985 total users
average of 1,919 per month

97,369 total views
average 3,895 per month

Palliative Care Connect

Statewide Navigation Service:

931 total cases
average of 32 per month

Regional Navigation Service:

119 total cases
average of 7.9 per month

Bereavement Navigation Service:

263 total cases
average of 11.4 per month

Aboriginal Navigation Service:

50 total cases
average of 2.2 per month

Palliative Care Volunteering SA service:

600 enquiries received

486 from individuals

114 from organisations

HELP app:

113 active Networks
average of 7.2 new networks per month

Bereavement groups and individual bereavement counselling:

156 people supported

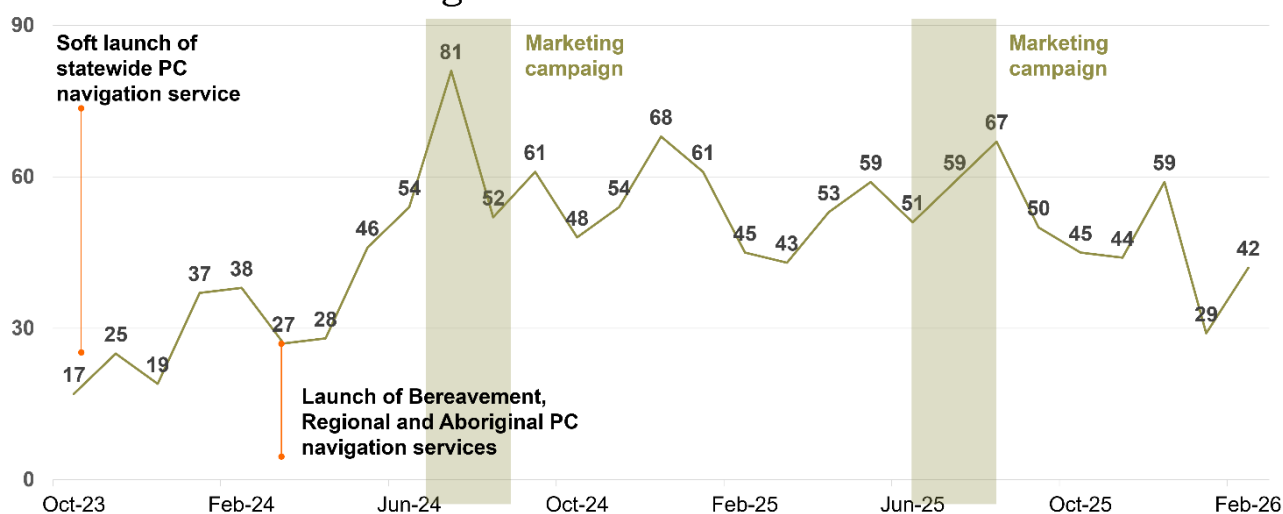
Bereavement counselling:

63 people supported

Bereavement groups:

93 people supported

PCC Navigation Services cases over time



4. Reach and Access

Summary of key findings

PCC services reached individuals across South Australia through a diverse mix of referral and discovery pathways, including self discovery, health and community referrals, digital platforms, and volunteer networks. Sustained uptake was driven less by marketing campaigns - which created short-term spikes in awareness but had uneven effects on demand - and more by ongoing relationship-building and embedding PCC within existing referral pathways. The Bereavement Navigation Service's introduction of Grief Literacy Workshops is a strong example, translating stakeholder education into reliable and consistent referral connections over time.

Across the navigation services, PCC reached people in both metropolitan and regional South Australia. The place-based design of several services, particularly the Aboriginal Palliative Care Navigation Service and the Regional Navigation Service, extended PCC's geographic reach beyond what a metro-based model could have achieved alone.

Services were generally experienced as timely and responsive. People accessed PCC at multiple points in their palliative care journey, with navigators maintaining engagement through proactive follow-up and continued support over time.





How people connected with PCC

PCC services were accessible through a range of entry points, allowing individuals, families, carers and professionals to engage in different ways. In practice, access to navigation services occurred through self discovery – meaning individuals or family members contacting PCC on their own initiative - primarily via telephone, alongside referrals from health and community providers. Digital platforms such as the PCC website and HELP app, as well as engagement through community and volunteer networks, supported awareness of and connection to PCC.

For PCC-SNS, almost two thirds of enquiries were made by family members (60.3%, n=536), while 19.4% (n=173) were made by the individual themselves. Health and aged care providers also acted as referral sources, with 7.5% (n=67) of contacts coming from healthcare providers and 6.6% (n=59) from aged care or disability providers. In contrast, users of the Bereavement Navigation Service were more likely to seek support directly, with 62.1% (n=157) contacting the service themselves.

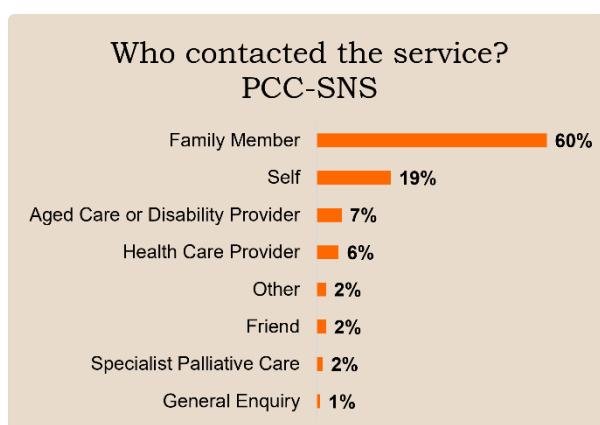


Figure 4: Who contacted PCC-SNS (Oct '23 - Feb '26)

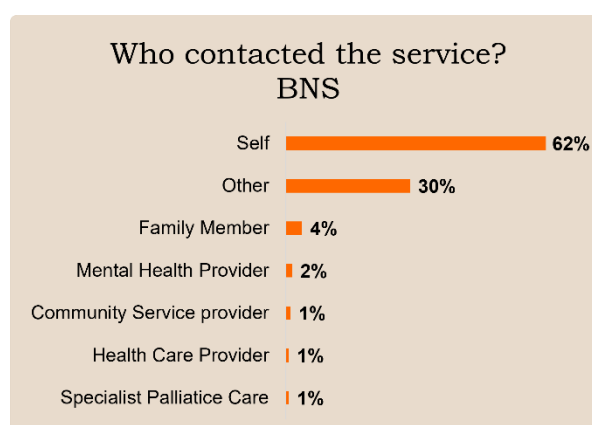


Figure 5: Who contacted BNS (Mar '24 - Feb '26)

People became aware of PCC through a variety of channels. For PCC-SNS, the most common entry point was an online search (33%, n=69), followed by medical specialists (13%, n=39), palliative care specialists (8%, n=25), word of mouth (10%, n=29), general practitioners (8%, n=23), and community services (6%, n=17). This mix of referral pathways suggests that awareness of PCC was supported by users doing their own research as well as healthcare and other services.

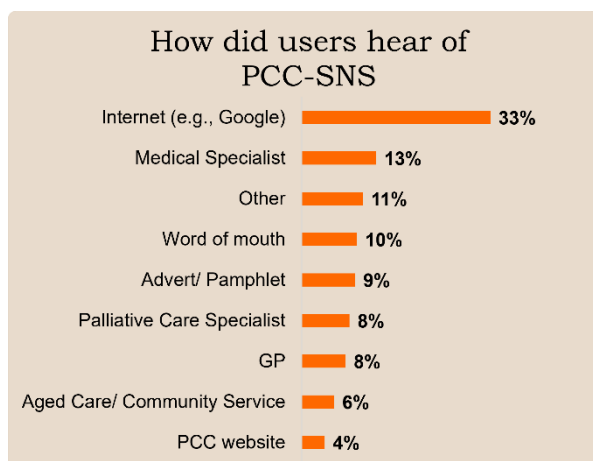


Figure 6: How did users hear of PCC-SNS (Oct '23 - Feb '26)

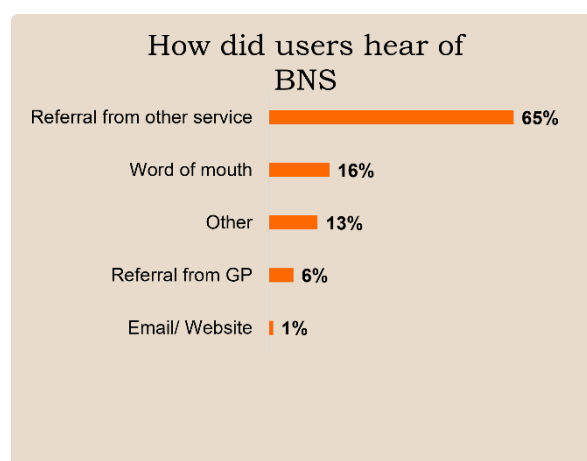


Figure 7: How did users hear of BNS (Mar '24 - Feb '26)



For the Bereavement Navigation Service, referrals from service providers were the most common entry pathway (65%, n=170), with 16% (n=42) finding out about the service through word of mouth. Service provider interviews support this pattern:

"We have less [people] that find us themselves, more that are coming from a service... most of what we see is referrals in from either a palliative care team or from a phone line service or a doctor or a library or a community service or whatever that might be." – Bereavement Navigator

PCC marketing campaigns

Two statewide marketing campaigns, run from May to July 2024 and July to September 2025, contributed to increased awareness of Palliative Care Connect. The PCC website saw a clear surge in traffic during these periods, rising from an average of around 600 users per month to peaks of 6,397 in June 2024 and 9,521 in July 2024. PCC-SNS also experienced increased demand, with monthly cases reaching 55 in July 2024. However, these effects were not consistent across all PCC services, with some reporting little change in demand.

Post-campaign research found that while the campaign was effective in shifting perceptions and improving understanding among those who were exposed to it, its broader population-level impact was constrained by relatively low reach. This suggests that awareness of PCC is likely to build gradually over time through ongoing outreach and word-of-mouth²⁵. Overall, the findings suggest that while broad marketing generated short-term visibility, sustained uptake has relied more on relationship-building and trust within the service system.

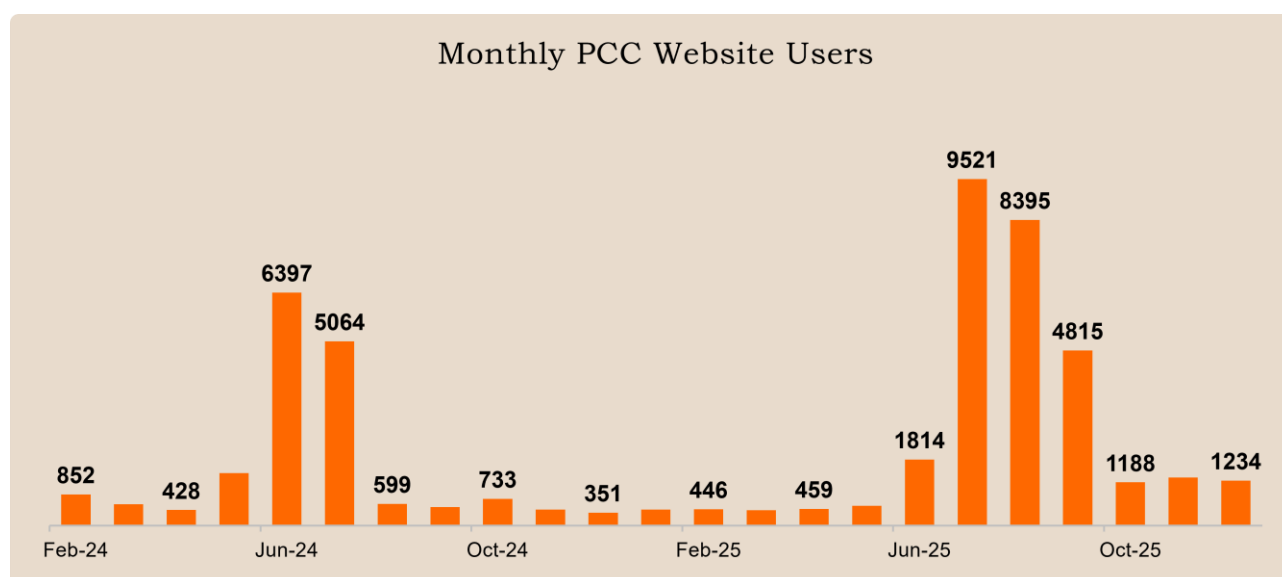


Figure 8: Monthly PCC website users (Oct '23 - Feb '26)

²⁵ Haymakr, Palliative care post-campaign research results, prepared for SA Health, August 2024 (unpublished).



Building referral pathways: the Bereavement Navigation Service

In response to initially low engagement, the Bereavement Navigation Service introduced Grief Literacy Workshops to build understanding of grief and strengthen relationships with potential referral partners across health, community and social service sectors. Up to February 2026, the service delivered **45 workshops and education sessions** to metropolitan and regional services across South Australia, reaching more than **660 participants** from hospitals, palliative care, aged care, mental health, community, and government organisations, including services supporting multicultural and Aboriginal and Torres Strait Islander communities. These workshops served both as an education tool and relationship-building mechanism: as participants gained confidence in recognising grief and understanding referral options, they become more likely to refer people in a timely and appropriate way.

One concrete example is the emerging relationship with Medicare Mental Health provider NEAMI Head to Health, a mental health referral service. Staff described that the workshops improved their ability to identify when grief was a primary concern and gave them confidence that individuals would be "looked after" by the Bereavement Navigation Service. This illustrates how capability-building went beyond awareness-raising, helping to embed the service within existing referral pathways. Strengthening these pathways proved critical for a service model that relies on other providers to identify and refer people experiencing grief.

Digital platforms provided alternate access points

PCC Website

Between February 2024 and February 2026, the PCC website recorded 47,985 users, averaging just under 2,000 per month. Traffic peaked during the marketing campaigns, rising to 6,397 users in June 2024 and 9,521 in July 2025, before returning to a lower but consistent baseline. Traffic sources included social media (Facebook and Meta: 22,614 users), search engines (Yahoo: 6,030; Google: 2,824), direct visits (5,364), and referrals from partner organisations such as SA Health, Palliative Care SA, Focus One Health, (2,506).

A pop-up survey completed by 78 website users provides some insight into who was visiting and what they needed. Respondents included carers and family members (29), health, aged care or community professionals (24), bereaved people (9), patients (5), and friends or community members (5). Nearly two-thirds (64%) found the information on the site useful, with 27% unsure and 9% reporting it was not useful.

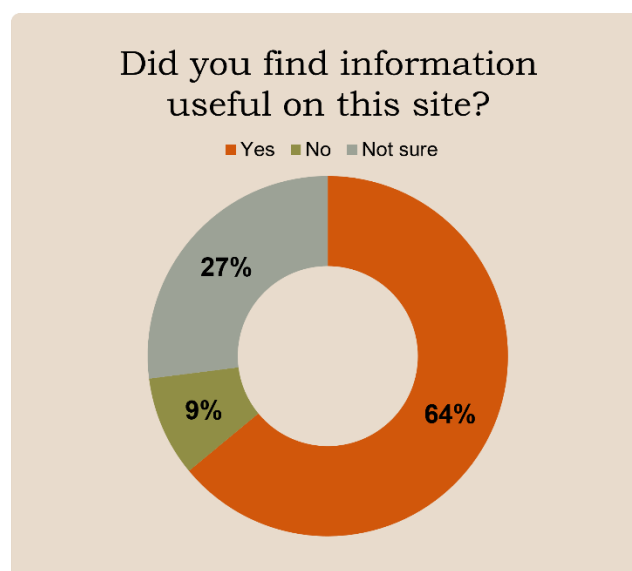


Figure 9: % of website users who found the information useful (Feb '25 - Feb '26)



Data from 87 users who completed the website's self-referral form points to the profile of need among people actively seeking support. While 53% reported understanding what palliative care is and how it can help, only 25% said they knew how to seek a referral to palliative care in SA - suggesting the website was reaching people at an uncertain point in their journey. The most identified need was knowing where to find palliative care services and supports (90%), followed by information on advance care planning (51%). Notably, 43% indicated a need for help with grief - a proportion that, alongside their identification as current carers or family members rather than bereaved people, may reflect anticipatory grief among those supporting someone who is still living.

Palliative Care Volunteering South Australia

As part of the Palliative Care Volunteering SA project, the Palliative Care Volunteering Hub was developed as a publicly accessible online directory of palliative care volunteer organisations. The directory serves a dual purpose: health professionals can use it to identify volunteer support options for clients, and individuals can use it to find opportunities to volunteer. Alongside the directory, the service produced 17 volunteer stories designed to help prospective volunteers understand what palliative care volunteering involves in practice, addressing one of the key barriers to recruitment - that the nature and emotional demands of the role are widely misunderstood.

Beyond the development of online resources, community and volunteer networks provided further pathways into PCC. Across the pilot, the Palliative Care Volunteering SA project received 486 enquiries from individuals interested in volunteering and 114 from organisations seeking support, established 18 new partnerships, and delivered 24 training sessions attended by 310 participants. Of 70 survey respondents, over 90% reported that training increased their understanding of palliative care volunteering. The service also ran 24 presentations and webinars on different aspects of volunteer coordination, and facilitated five palliative care volunteer coordinator network meetings to support shared learning across the sector. Together, these activities created multiple entry points for both individuals and organisations to engage with PCC. .

HELP App

The HELP app provided a distinct digital pathway for coordinating informal care networks, referred to as network centred care. Between February 2024 and February 2026, 109 support networks were created across South Australia, involving 263 participants and generating 1011 tasks. The types of support most commonly nominated at sign-up included family and social connection (46% of networks), food and home support (42% of networks), and health and personal care (39% of networks), alongside end-of-life planning (30% of networks), grief and funeral support (17% of networks), and pet care (13%). This breadth reflects the wide range of practical and social needs that informal care networks organise around.

Uptake was modest but gradual, with an increase in August 2025 coinciding with La Trobe University running its own marketing campaign. Referrals from PCC services accounted for 11 of the 109 networks, with the majority coming from palliative care services more broadly (29), word of mouth (6), and health services (5), noting that some referral sources may reflect uncertainty in distinguishing PCC from other palliative care services.

Because uptake was influenced by how and when the app was introduced through existing care pathways, the implementation approach evolved over the course of the pilot. Early efforts focused on embedding the app into PCC-SNS calls, but referrals remained limited; – reflecting that many



contacts occurred at times of acute need. As the HELP app team reflected, navigators were dealing with immediate priorities, and in that context, introducing an additional digital tool could easily fall away. The strategy therefore broadened to include professional training and direct public outreach, aiming to reach people earlier in their journey, at or closer to the point of diagnosis, when network-building is more feasible.

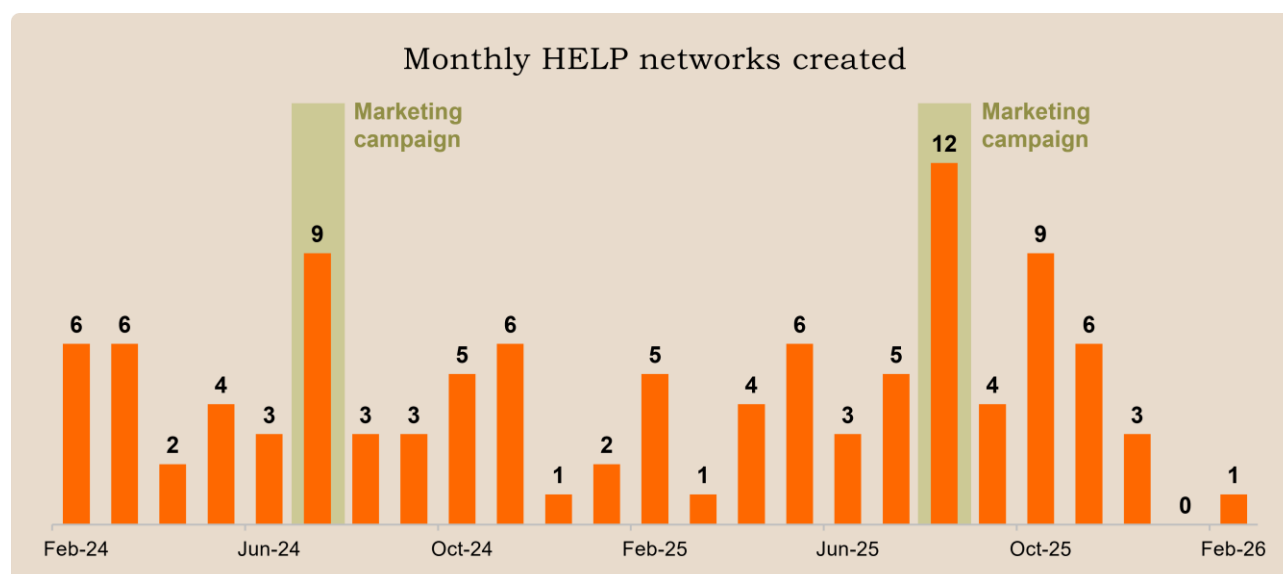


Figure 10: Number of HELP networks created per month (Feb '24 - Feb '26)

Community and volunteer networks

Reach of Palliative Care Connect Services

PCC services reached a reasonably diverse cross-section of the community

Available data suggests PCC services reached individuals from a range of backgrounds across South Australia. However, demographic information was not systematically collected across all services - details such as cultural background or language needs were typically recorded only if disclosed during engagement. Percentages below therefore represent the proportion of users for whom a given data point was recorded, and should be interpreted with caution, as some groups may be underrepresented.

Geographic Reach

Of the 987 navigation cases where postcode data was recorded, PCC services reached individuals across a wide geographic spread. While most users of PCC-SNS were based in metropolitan areas (77.9%, n=438), the service also supported people in inner regional (11%, n=62) and outer regional (10.5%, n=59) locations. This broadly reflects the distribution of the South Australian population where four in five people live within Greater Adelaide²⁶, suggesting the service was able to extend its reach into regional areas despite being metro-based.

²⁶ Australian Bureau of Statistics, 2021. Available at <https://www.abs.gov.au/articles/snapshot-sa-2021>



The Regional Navigation Service supported people primarily in outer regional (65.8%, n=77) and inner regional (30.8%, n=36) areas, as intended. The Aboriginal Navigation Service predominantly reached people in outer regional communities (93.8%, n=45), consistent with its place-based design and community-embedded delivery model. The Bereavement Navigation Service reached both metropolitan users (51%, n=132) and those in regional areas, including 41.3% (n=107) from outer regional locations.

These patterns indicate that different PCC complimented one another, collectively reaching people across metropolitan and regional South Australia.

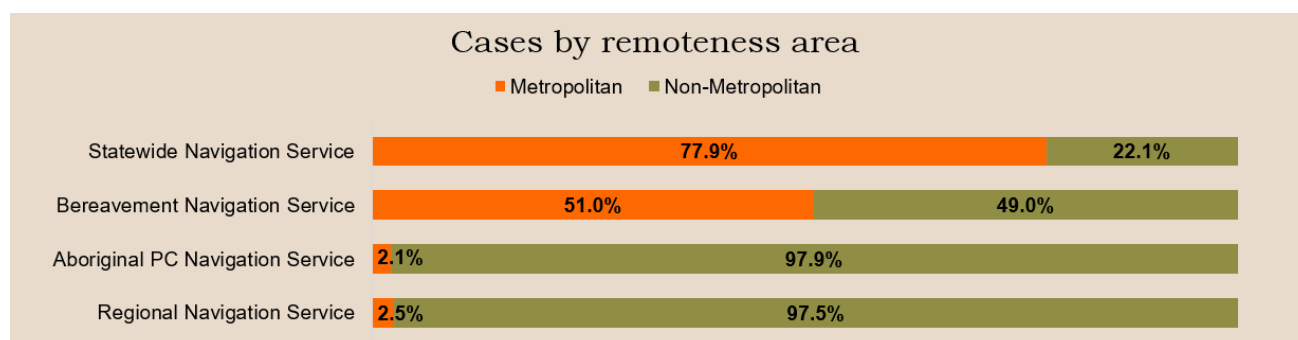


Figure 11: Navigation Service cases by remoteness area (Oct '23 - Feb '26)

The map below illustrates the geographic reach of PCC navigation services, based on 815 cases where postcode data was recorded. Each shaded area represents at least one service user in that postcode. Taken together, the navigation services reached individuals across a substantial portion of South Australia, spanning Greater Adelaide and a wide range of regional areas.

The map also reflects how the place-based design of individual services extended PCC's collective reach. The Aboriginal Palliative Care Navigation Service contributed coverage across the Port Augusta region and west of the Eyre Peninsula; the Bereavement Navigation Service added reach into the Riverland and Limestone Coast; and the Regional Navigation Service was concentrated across the Yorke Peninsula and surrounding areas. Individual maps for each navigation service are provided in Annex 3.

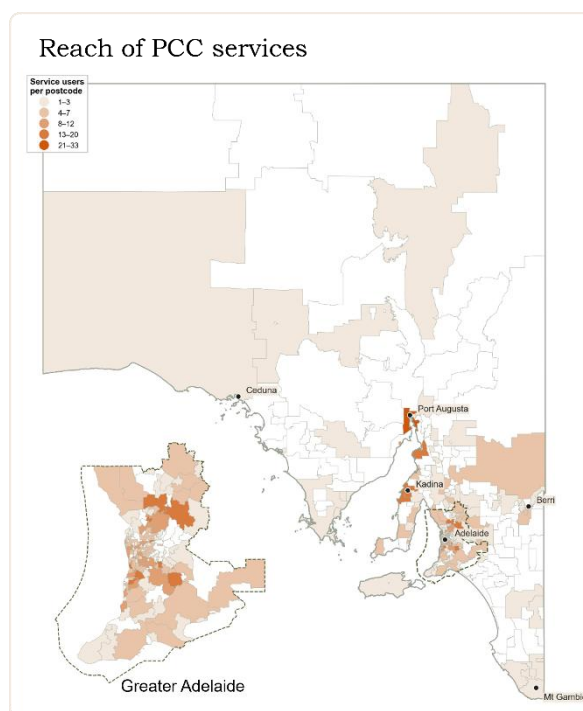


Figure 12: Geographic reach of PCC services (Oct '23 - Feb '26)



Gender reach

Gender patterns differed across PCC services, reflecting the nature of support provided. For PCC-SNS and the Aboriginal Navigation Service - where gender refers to the patient rather than the caller - distributions were relatively balanced (PCC-SNS: 52.9% female, n=351; ANS: 48.9% female, n=23). Services focused on bereavement support, however, were accessed more frequently by women: 76.3% (n=187) of Bereavement Navigation Service users were female (23.3% male, with a small number identifying as gender fluid). Women also accounted for 79.4% (n=69) of those accessing individual bereavement counselling and 74% (n=50) of participants in bereavement groups. This pattern aligns with existing research showing that men are less likely to seek psychological or bereavement support.²⁷

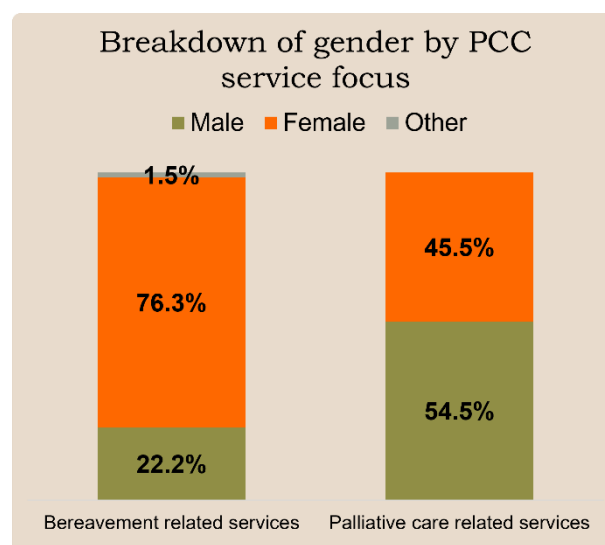


Figure 13: Breakdown of gender for Bereavement focused services vs palliative care focused services (Oct '23 - Feb '26)

Reach into culturally and linguistically diverse communities

Limited data is available on engagement with culturally and linguistically diverse communities. Across the Statewide, Bereavement, and Regional Navigation Services, no cases were recorded where an interpreter was required, and over 91% of all navigation users were born in Australia (where this information was captured). This may suggest limited uptake among people requiring language support.

The Aboriginal Navigation Service was specifically designed for Aboriginal and Torres Strait Islander communities, and all recorded users identified as First Nations; three accessed the service with interpreter support. Smaller numbers of First Nations users were recorded across other services: 18 in the Bereavement Navigation Service, five in PCC-SNS, and two in the Regional Navigation Service. Within the Bereavement Navigation Service specifically, First Nations users accounted for approximately 7% of total cases - a proportion notably higher than the 2.4% of South Australia's population²⁸ who identify as Aboriginal and/or Torres Strait Islander. The reasons for this pattern are not clear from the available data.

No First Nations users were interviewed as part of the evaluation, which limits the depth of insight into how these users experienced PCC services beyond what can be drawn from the Aboriginal Navigation Service data.

²⁷ Addis, M. E., & Mahalik, J. R. (2003). Men, masculinity, and the contexts of help seeking. *American Psychologist*, 58(1), 5–14. <https://doi.org/10.1037/0003-066X.58.1.5>

²⁸ Australian Bureau of Statistics (2022), South Australia: Aboriginal and Torres Strait Islander population summary available at <https://www.abs.gov.au/articles/south-australia-aboriginal-and-torres-strait-islander-population-summary>



Socioeconomic accessibility

Service provider interviews suggest the Bereavement Navigation Service helped address cost barriers to psychosocial support. Staff described how out-of-pocket counselling costs, even when partially subsidised through mental health care plans, were prohibitive for some individuals. The availability of free support through the service enabled access for people who may not otherwise have engaged with bereavement support.

Toward the end of the evaluation period, the Bereavement Navigation Service began exploring how to provide support to incarcerated South Australians and subsequently supported individuals in custodial settings. Although socioeconomic data was not systematically collected, bereavement navigators observed that many referrals involved individuals who were unable to access fee-based alternatives:

"People cannot afford [fee-based mental health services] ... even with a mental health plan, they cannot afford the difference. And so that's why they're not going to those services, even though they are there... And the people that we have had have been low socioeconomic... they would not have had the money to make up the difference." – Bereavement Navigation Service Navigator

Timeliness

PCC services were generally experienced as timely and responsive, with support available at multiple points across the palliative care journey and sustained through proactive follow-up over time.

PCC services were consistently described by users as responsive, with contact often made sooner than expected. This was particularly evident in PCC-SNS, where prompt responses appeared to reduce distress and help people feel supported at moments of uncertainty.

"I rang and at the time I rang I got told they'd get back to me. It was only half an hour later that I had someone back talking to me." – BNS Service User

Palliative Care Phases

The palliative care phases provide a way of understanding when support is accessed.

- **The stable stage** refers to a period where patient problems and symptoms are adequately controlled by established plan of care
- **The unstable stage** involves sudden worsening of symptoms requiring rapid adjustment to the care plan.
- **The deteriorating stage** is where the care plan is addressing anticipated needs but requires periodic review due to a gradual decline with increasing care needs.
- **The terminal stage** relates to the final days or hours of life,
- **The bereavement stage** refers to support following death.²⁹

²⁹ Palliative Care Outcomes Collaboration (PCOC), [Phase definitions](#), University of Wollongong, 2026.



When people accessed PCC

Administrative data from PCC-SNS shows that people accessed PCC at multiple points across the palliative care journey. The largest proportion engaged during the stable phase (55.5%, n=477), followed by the deteriorating phase (30.7%, n=264), with smaller proportions in the unstable (9.2%, n=79), terminal (2.8%, n=24) and bereavement (1.9%, n=16) phases.

This distribution suggests PCC is being accessed both earlier in the care journey when planning and information needs are prominent, and again at points where needs escalate. Rather than functioning solely as an end-of-life service, PCC supported people across multiple stages depending on when they chose to engage.

Timeliness beyond first contact

Timeliness extended beyond the speed of initial response. Many users experienced PCC as a service they could return to as their needs evolved, with navigators actively maintaining engagement through proactive follow-up. This included checking whether referrals had been successful, revisiting options when initial pathways were unsuitable, and confirming next steps with users. This combination of user-initiated re-engagement and proactive outreach meant support was available at the moments when it mattered most, rather than being limited to a single interaction.

"I got so much information that made me feel like I knew where to start." – PCC-SNS service user

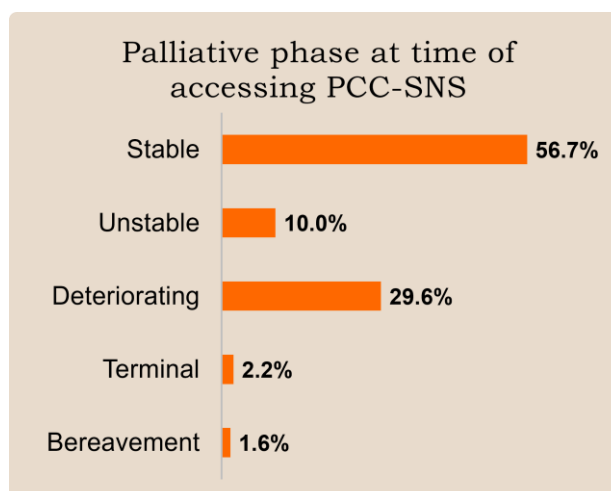


Figure 14: Palliative phase at time of accessing PCC-SNS (Oct '23 - Feb '26)

"[navigator] also initiated a follow up call. He wanted to make sure I was even more stable emotionally. I really appreciated that. He called the next day as well." – PCC-SNS service user

"[They] followed up to confirm the referral had been done and that we'd need to follow up with the doctor for the referral. [They] had given the palliative care service the heads up that the referral would be coming. [They] confirmed we should hear from them shortly and to get back in touch if not." – PCC-SNS service user

5. Quality of Support

Summary of key findings

Once engaged with PCC, service users consistently experienced support that was flexible, person-centred and highly attuned to their individual circumstances. Across services, navigators combined emotional sensitivity with practical problem-solving, adapting their approach to people's readiness, preferences and cultural contexts. For Aboriginal clients, the PCC Aboriginal Navigation Service provided culturally safe, relational and locally grounded support that was described as particularly meaningful.

The quality and accuracy of information provided were rated exceptionally highly, with average satisfaction scores of 9.9 (PCC-SNS) and 9.6 (Bereavement Navigation Service). Navigators drew on multidisciplinary backgrounds, internal consultation processes and strong system knowledge to tailor information to each person's situation rather than offering generic guidance. Over the course of the pilot, the navigation role evolved beyond its initial referral-focused vision into a more relational, adaptive and holistic model of practice. Importantly this evolution did not shift navigation into case management: navigation remained inherently episodic and time-limited, focused on providing timely situation specific support rather than ongoing monitoring or regular check ins. This clarity of purpose strengthened both the relevance and usefulness of the support provided.

Together, these qualities generated deep and consistent trust between service users and navigators. Trust emerged not only as a marker of positive experience but as a critical enabling condition: it allowed people to speak openly, seek support they might otherwise avoid, and make complex decisions with greater clarity and confidence. The presence of trust, adaptability and relational continuity suggests that PCC is meeting needs that extend beyond information-giving alone, positioning it as a service that is both appropriate and meaningful across diverse contexts and stages of the palliative care journey.





Appropriateness of the support

PCC support was widely experienced as appropriate to individual needs, with navigators combining empathy and practical problem-solving, adapting to diverse cultural and personal circumstances, and consistently safeguarding consent, agency and choice. Across all services, support was tailored rather than standardised: navigators adjusted the duration, intensity and mode of engagement to reflect the nature and complexity of each situation.

Tailoring support to the level and duration of need

Administrative and interview data show that PCC services calibrate their support to presenting needs rather than applying a uniform model.

PCC-SNS supported a high volume of short, lower-complexity interactions. Based on available administrative data, PCC-SNS resolved 68% (n=334) of cases on the same day, and 46% (n=274) were assessed at Level 1 intensity.³⁰ Case closure data was not recorded uniformly across all cases, and should therefore be viewed as an administrative indicator rather than a definitive measure of service duration or workload.

By contrast, the Bereavement Navigation Service supported people experiencing grief, for whom support more often involved longer and deeper engagement. Only 5.4% (n=9) of cases were recorded as closing on the same day, while 71.1% (n=118) remained open for more than a month. Most Bereavement Navigation Service cases were assessed at Level 2 or 3, indicating moderate to higher-complexity needs.³¹

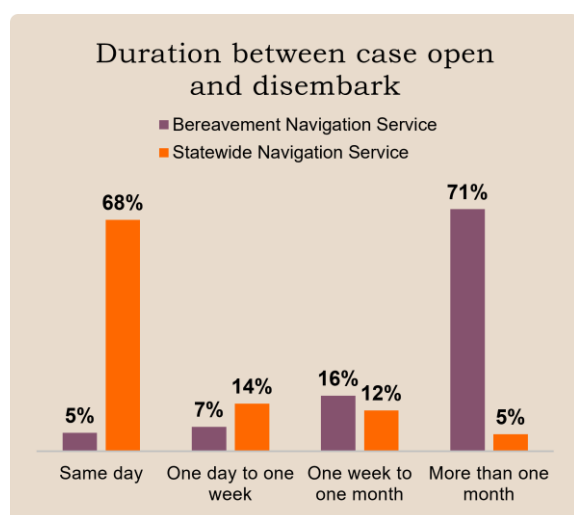


Figure 15: Duration between case open and close (Oct '23 - Feb '26)

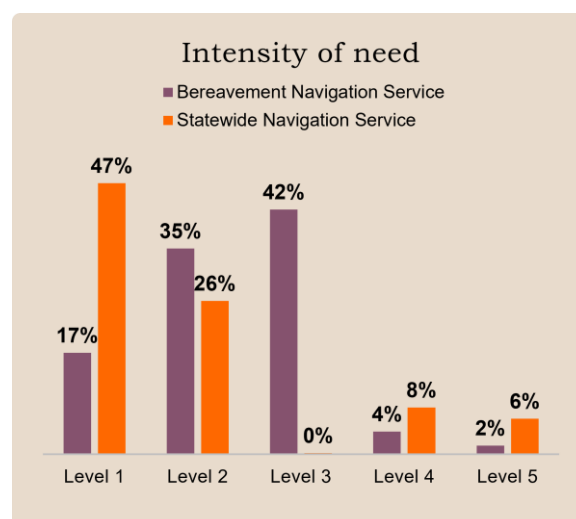


Figure 16: Breakdown of intensity of needs (Oct '23 - Feb '26)

³⁰ Intensity ratings are given based on the following: Level 1 – Self-management, friends, family & social network; Level 2 – Low intensity services; Level 3 – Moderate intensity service. Requires establishment of new services. May be some delay in accessing and commencing services, possibly several weeks - referral needed, could be self or clinician initiated; Level 4 – High intensity services– services need to be accessed promptly ≥ 72 hours or hospital presentation likely; Level 5 – Urgent Navigation, requiring acute and or specialist -services need to be accessed immediately ≤ 24 hours

³¹ Differences in how intensity of need is assessed and recorded across navigation services were identified, and the specific processes used by each service were not documented.



Interpretation

These patterns suggest that PCC services are not standardised in duration or depth but adapt support to the complexity of each case. In the BNS, this often involved extended, emotionally attuned engagement and careful referral planning. Even within PCC-SNS, while many contacts were brief, the minority of more complex cases require follow-up with multiple services, meaning case numbers alone provide only a partial picture of the work involved.

We sit in a much more time consuming space. But that I think is only because I am getting those complicated cases. And on top of trying to sit with them and figure out how I can support them [emotionally], I'm also trying to set them up with services outside of our service." – Bereavement navigation service navigator

Important considerations

Differences in how “intensity of need” is assessed across services should be kept in mind when interpreting these comparisons.

Flexible and person-centred engagement

Users consistently described PCC as flexible and person-centred, with multi-modal access, continuity of contact and unhurried interactions that allowed people to engage in ways that suited them.

Multi-modal access

Phone-based support offered immediate connection in stressful moments:

"The first thing was that I actually got to talk to a human. And that was super important because, for me, there's a lot of things going on in there at times, quite stressful and quite complicated." (PCC-SNS user)

Face-to-face contact helped when more sensitive or detailed conversations were needed:

"They looked at me... it was face to face and that is so helpful. You feel like you're actually being looked at and listened to." (BNS service user)

Continuity of contact

Speaking with the same navigator helped reduce emotional burden and build trust:

"Making sure I can get to [the same Navigator] so I don't have to repeat myself. That's really important. Not having to repeat, repeat, repeat" – PCC-SNS service user

Unhurried and relational interaction

Navigators allowed time for people to express emotions and circumstances before moving to practical steps:

"[Navigator] let me ramble... and then said, 'right, let's break it down'." – PCC-SNS service user



Applying flexibility to support complex situations

One case illustrates how this flexibility worked in practice. A person contacted PCC-SNS with concerns about housing instability, difficulty navigating aged care and income systems, and limited informal supports. Recognising that phone-based support alone would be insufficient, the team arranged a face-to-face visit.

Meeting in person allowed the navigator to see and understand the full context of the person's situation, including family dynamics, financial pressures and emotional distress, and provide appropriately tailored support. The navigator helped the person to access aged care services and income support, plan for future bereavement needs, and communicate with service providers.

The navigator reflected that meeting in person enabled them to gather a more accurate and complete picture and respond more effectively. The individual similarly reported feeling less overwhelmed, more supported, and better able to cope. As appropriate services were put in place, PCC support was gradually stepped down, with the person expressing increased confidence in managing their situation and navigating future stages.

Balancing empathy with practical focus

Users described PCC support as both emotionally attuned and practical:

"[navigator] was sensitive to what I was going through and my emotions. It wasn't only about a process; he was connecting with me." – PCC-SNS service user

Navigators helped people identify priorities and explore realistic options:

*"She talked about what she could do for me... We worked on the solution together."
— BNS user*

"[Navigator] was really good at balancing compassion with saying, 'I can see there's a lot going on here. What is it that we can really help you solve today?'" – PCC-SNS service user

When people felt overwhelmed, navigators used grounding strategies. One navigator described this as "reducing the noise... so you're just hearing what's important", framing it as a grounding question:

"If I could do one thing for you today, what would it be? I can't fix everything straight away, but that one thing... what would you really want us to concentrate on?" – PCC-SNS Navigator

Respect for preferences, agency and consent

Navigators supported, not directed, decision-making and tailored communication to each person's understanding:

"We specifically wanted comfort care... [Navigator] understood why we were asking for what we were asking for and we didn't feel interrogated or not believed by her." – PCC-SNS service user

Communication was tailored to each person's level of understanding, and professional boundaries were clear: navigators provided guidance without stepping into clinical advice. Consent processes were consistently upheld, creating a safe foundation for open and honest discussion:

"The consent was key to having an open discussion, it really opened up what could be discussed." – PCC-SNS service user



Culturally safe and locally adapted practice

The Aboriginal Palliative Care Navigation Service grounded its approach in culturally safe, relationship-based engagement. Navigators adapted language, built trust over multiple visits and worked with family groups. Their support included attending oncology appointments, facilitating family meetings and interpreting medical information in culturally meaningful ways.

Sensitive conversations, such as end-of-life planning, emerged gradually:

"I'm not here to talk about dying... how can we help you live better?" – Aboriginal Palliative Care Navigation Service staff

"Sometimes it'll take four or five visits before we start talking about that. It's just building that trust, that relationship first." – Aboriginal Palliative Care Navigation Service staff

Navigators emphasised that cultural practice is inherently local:

"What works well here is different to Ceduna... there's not a one-size-fits-all aspect of it." – Aboriginal Palliative Care Navigation Service staff

Yarning Together for Decision-making

In Port Augusta, the Aboriginal Palliative Care Navigation Service identified a gap in culturally appropriate palliative care conversations, particularly for Aboriginal people living with chronic kidney disease. Drawing on existing relationships with the local hospital and renal unit, the service developed "Yarning Together for Decision-making", a series of informal sessions grounded in clinical yarning principles that prioritise connection and trust before information-giving.

Between September 2024 and April 2025, four sessions were delivered with 12 participants across group and one-to-one formats within renal and aged care settings. These sessions brought together patients, their families and local health professionals in familiar, non-clinical environments.

"They have such amazing knowledge and connection... and other ways that they can support and provide which benefits the client, but then also takes that load off us and we can focus more on managing their symptomology." – Local Hospital Staff Member

The approach created space for participants to engage at their own pace and in culturally comfortable ways. It generated follow-up conversations, particularly around advance care planning, that had not occurred through formal clinical appointments. The sessions also strengthened relationships between providers, positioning the Aboriginal Palliative Care Navigation Service as a trusted partner for both patients and clinicians.

"We've worked with them like those train tracks that go along and we work with each other at different points, they can support some aspects while we can do others."
– Local Hospital Staff Member



Accuracy and clarity of information

PCC services consistently provided information that users experienced as clear, reliable and directly relevant to their circumstances. This was underpinned by navigators' strong knowledge base, multidisciplinary expertise and deliberate internal processes to ensure accuracy. Together, these elements enabled PCC to deliver high-quality guidance in moments where people were often overwhelmed, distressed or unsure where to turn.

High confidence in the accuracy and relevance of information

User satisfaction scores were exceptionally high across both navigation services, 9.9 for PCC-SNS and 9.6 for the Bereavement Navigation Service, indicating strong confidence in the clarity and usefulness of support provided.

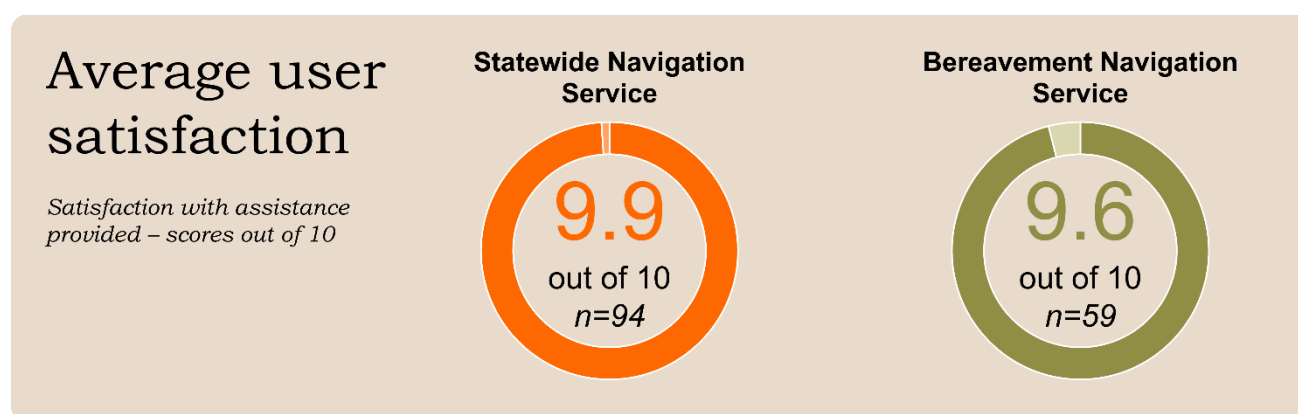


Figure 17. Average user satisfaction of PCC services (Oct '23 - Feb '26)

Users repeatedly described information as easy to understand, tailored to their needs and grounded in a clear grasp of their circumstances. Rather than offering generic responses, navigators listened carefully before shaping the information they provided:

"[Navigator] was able to... listen to where I was at and then pitch his response to address my most immediate concerns... and put me on a bit of a roadmap of where I was going next." – PCC-SNS service user

[Navigator] pointed me towards different directions: counselling, group, financial assistance... [they] gave me all of these avenues to try and choose the one that suited my needs at the time." Bereavement Navigation Service user

A key part of this confidence came from users' perception that navigators "knew the system," rather than reading from a script:

"I really felt like the person I talked to knew the system... I didn't feel like I was being read the spiel." – PCC-SNS service user



Enablers of accurate, clear and relevant information

Internal processes strengthened accuracy

Behind the scenes, navigators actively ensured accuracy by consulting colleagues, exploring options and following up rather than providing uncertain or incomplete information. This collaborative checking process was highly valued by users:

"Took the time... consulted with people in the team... [Navigator] got back to me... He was exploring different options to get a better understanding and then to come back." – PCC-SNS service user

"She followed up with another call and that was after the first session with [bereavement counsellor] to check that we were both compatible, which we are." — BNS user

This commitment to follow-through reinforced credibility, strengthened relationships and enhanced users' confidence in the advice provided.

Multidisciplinary expertise supported holistic responses

The navigation teams drew on diverse professional backgrounds—including nursing, social work, counselling and related fields—enabling them to respond holistically across health, social and emotional domains:

"There was the benefit of having an equal nursing social work split within the team... we are doing, I think, very holistic care for the people that are calling us." – PCC-SNS staff

In the Bereavement Navigation Service, clinical backgrounds supported stronger risk identification and clearer judgement on when to escalate or seek additional support:

"it was the blend between... [being] a nurse and also navigating, coaching and counselling - ... it was this very fluid thing." – BNS staff

An evolving navigation role

The evaluation found that the navigation role evolved significantly during the pilot. Originally envisioned as primarily referral-based, it shifted into a more relational, adaptive and multi-modal practice aligned with user needs.

Navigators moved seamlessly between system navigation, coaching, emotional support and education—often within a single interaction—drawing on professional judgement to determine what was most appropriate at the time:

"When you think of navigation, you think of a one-off interaction where you point someone somewhere, but that's really not what any of the services are doing. It's much more involved and ongoing." – Aboriginal Palliative Care Navigation Service staff



This evolution reflected responsiveness, not scope creep. However, it also introduced some ongoing ambiguity about the navigation role's position within the broader palliative care system—particularly in relation to clinical roles and specialist pathways. These issues are discussed further in the Coherence chapter.

Despite variations across services, a consistent pattern emerged: navigation practice relies on professional judgement, therapeutic skill, and the ability to build trust quickly.

"There's so much skill that goes into having actually a very quick, therapeutic, useful conversation that keeps people safe." – PCC-SNS staff

Trust as a core enabler of effective navigation

Across all PCC services, users described high levels of trust in navigators, built through empathy, consistency, cultural safety, accuracy and personalised support. Trust emerged as a core enabling condition for effective navigation, not just a positive by-product.

Users reported feeling comfortable disclosing sensitive information and engaging more openly than they had with other services:

"I found courage and strength from it and I was able to open up... I felt comfortable and brave enough to disclose." – Bereavement Navigation Service user

For some, navigators became a trusted source of advice when other information sources felt confusing or misaligned:

"Sometimes I'll just ring her to get advice I didn't feel comfortable with some of the things [others were telling me, so] I ended up using [Navigator] for advice. – PCC-SNS user

For the Aboriginal Palliative Care Navigation Service, trust required sustained relationship-building and multiple visits before deeper conversations could take place—an essential foundation for culturally safe end-of-life support.

Users frequently expressed willingness to recommend PCC to others, reflecting both trust and satisfaction:

"Isn't it amazing that within such a short ... time [of] knowing it [the service] exists, I'm already in a position to pass on this information to someone else." – Bereavement Navigation Service user

6. Outcomes and impact for Palliative Care Connect Service users

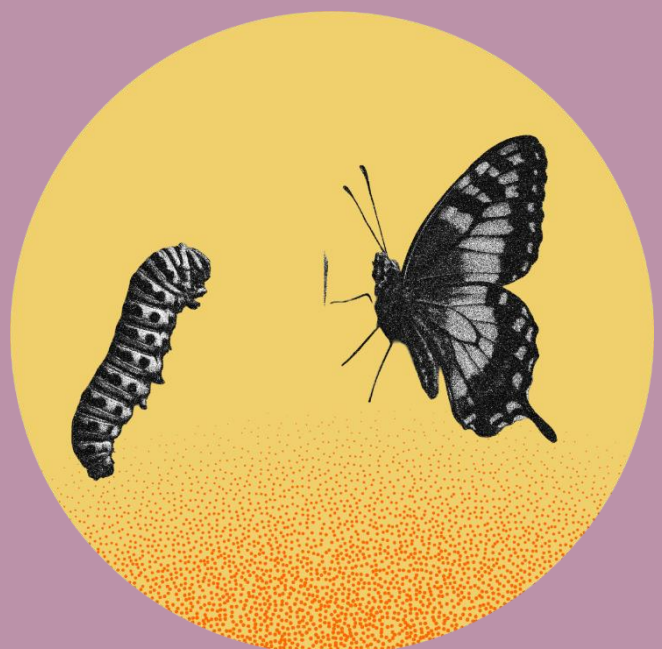
Summary of key findings

Evidence across the three outcome pathways of the PCC Theory of Change indicates that PCC services are contributing to meaningful changes for people accessing them, with the strongest and most consistent evidence at the level of immediate and intermediate outcomes.

PCC contributed to people feeling heard, reassured and less alone. Navigators consistently drew on psychosocial and counselling skills in practice, providing emotional containment and support at moments of distress, grief and uncertainty. Users described feeling calmer, less burdened and better able to cope following contact with PCC. While the services varied in design and client population, this relational quality was a consistent feature.

Access to clear, timely and tailored information supported people to better understand their situation and feel more confident taking next steps. Empowerment and informed decision-making was the most frequently recorded outcome across all navigation services, ranging from 46% of Aboriginal Navigation Service cases to 76% of Bereavement Navigation Service cases. Users described feeling better equipped to ask questions, advocate for themselves or their family members, and engage with services more proactively. For some, PCC opened up conversations about death and dying that had previously felt too difficult to have.

PCC also helped people access the services and supports they needed, including individuals who may not have reached those supports independently. The nature of this contribution varied across services: for PCC-SNS users, who often already had some supports in place, the primary value was guidance and coordination rather than new referrals. For Bereavement Navigation Service users, the focus was on facilitating access to the right support, not just any support, given many had previously experienced unhelpful referrals. For Aboriginal Navigation Service users, navigators helped people and their families navigate existing service connections more effectively, attending appointments and supporting family decision-making in culturally grounded ways.



Snapshot summary of outcomes for navigation services

The visuals below summarise the context in which each navigation service operated, including the supports users already had in place, the services they were referred to, and the outcomes recorded by navigators. Together, these snapshots show that the three services worked with distinct populations with different levels of complexity and types of need, and that the nature of navigation, and the pattern of outcomes varied accordingly. These differences provide important context for interpreting the findings that follow across the three outcome pathways that follow.

Palliative Care Connect Statewide Navigation Service

Why are users contacting the service?



Average of **2.3 reasons** for contacting service

41% navigating healthcare systems

20% home-based care coordination

45% accessing palliative care services

22% end of life planning

18% psychosocial/emotional support

What supports are already in place?



Users had an average of **1.7 supports** in place

Of those with at least 1 support in place:

18% were in residential aged care

18% of users had no supports in place

94% were connected to a GP or other medical specialist

15% were receiving specialist palliative care support

28% were receiving aged care support in the home

What supports are provided or services are users being referred to?



Users are not always referred to a specific service with emotional support and advice playing a key role

35% of users receive general navigation support or advice

10% were referred to South Australia Community Care

16% were referred to specialist palliative care

9% were referred to psychosocial/emotional support

Top outcomes for service users



Empowerment and informed decision making

58%

Improved care coordination

26%

Access to support services

20%

Enhanced symptom management

16%

Bereavement Navigation Service

Why are users contacting the service?



Average of **2.4 reasons** for contacting service

94% bereavement support

78% psychosocial/emotional support

What supports are already in place?



Users had an average of **1.7 supports** in place

Of those with at least 1 support in place:

63% were connected to some form of psychosocial or emotional support

11% of users had no supports in place

77% were connected to a GP or other medical specialist

What supports are provided or services are users being referred to?



Users of the Bereavement Navigation Service typically were referred on to a service.

0.8% were provided general support without a referral

14% were referred to Bereavement groups

77% were referred to Bereavement support

Top outcomes for service users



Empowerment and informed decision making

76%

Access to support services

72%

Timely access to services

65%

Improved care coordination

7%

Aboriginal Navigation Service

Why are users contacting the service?



54% needing support to advocate for preferences of patient

54% needing support with end-of-life planning

44% needing support with cultural or spiritual needs

What supports are already in place?



Users had an average of **1.7 supports** in place

Of those with at least 1 support in place:

41% were connected to a GP

26% of users had no supports in place

62% were connected Aboriginal Health Services

30% were connected to Specialist Palliative Care Services

What supports are provided or services are users being referred to?



The navigation process for users of the Aboriginal Navigation service tends to be more intensive, with navigators supporting users at multiple points in their journey

72% received general navigation support

26% were supported with end-of-life planning

12% were referred to specialist palliative care services

Outcomes for service users



Empowerment and informed decision making

89%

Improved care coordination

39%

Advanced Care Planning

39%

Access to support services

23%



Outcome Pathway 1: People are connected

PCC services contributed to people feeling heard, reassured and less alone, with relational support reducing emotional distress and enabling connection to peer, social and community networks over time.

This pathway examines how PCC supported people to feel listened to, understood and emotionally contained, and how initial relational support created the conditions for deeper connection — to services, peers, communities and culturally grounded networks. As outlined in the Theory of Change, these outcomes span immediate effects (feeling supported and reassured) through to intermediate outcomes (reducing isolation, connecting to services and strengthening networks of support).

Relational, emotionally attuned support reduced distress and Isolation

Across interviews, users consistently described PCC interactions as providing a strong sense of being heard, understood and supported during moments of distress, uncertainty or grief. For carers and family members in particular, PCC provided a space to talk through complex emotions and situations without judgement. Many reported feeling “lighter,” calmer or more able to cope after contact with a navigator, demonstrating that even brief interactions had a meaningful impact on emotional wellbeing.

"[Navigator] made me feel at ease. I don't normally talk to people but [they] made me feel really relaxed. I could really talk to [them]. It put me in a lot better place than before." – BNS user

"When I got off the phone... a weight had been lifted off my shoulder." – PCC-SNS service user

This reflects the **foundational relational outcome** within this pathway: PCC helped stabilise people emotionally, reducing immediate distress and creating the conditions for further engagement.

Psychosocial support emerged as a core element of navigation

Navigation within PCC evolved to encompass a significant psychosocial support function. Across both PCC-SNS and the Bereavement Navigation Service, interactions were often emotionally intensive, with many people reaching out at times of distress, uncertainty or grief. Although navigators are not formally positioned as counsellors, they consistently drew on counselling skills in practice, including listening, validating emotions, and helping people make sense of complex situations. This emotional support played an important bridging role, helping people feel contained and stabilised before being linked to other services, or in situations where formal supports were not yet in place.

"You would talk to someone for an hour or 90 minutes, and they don't even know that you've been using all your counselling skills. They think they've just been debriefing... but they're crying, they're debriefing, they're getting stories off their chest, they're getting advice, they're getting emotional support." – PCC-SNS staff member

The Bereavement Navigation Service in particular, identified a systemic gap in accessible psychosocial support, especially in community and aged care settings. In response, the service



integrated short-term counselling into its model, enabling clients to access both counselling and practical navigation through a single, familiar entry point. Early evidence suggests this reduced the need for multiple referrals and handovers, an important improvement for people with low to moderate needs who might disengage if asked to retell their story multiple times.

Trust created a safe entry point for engagement

As outlined in the Effectiveness chapter, trust emerged as a cross-cutting theme across all PCC services. In the context of outcomes, trust was not simply a positive experience - it was an enabling condition.

High trust allowed people to:

- disclose sensitive information
- express uncertainty or fear
- articulate needs they had not raised elsewhere
- explore supports they previously avoided
- engage more confidently in decision-making

"I found courage and strength from it... I felt comfortable and brave enough to disclose." – BNS user

For the Aboriginal Palliative Care Navigation Service, establishing trust relied on sustained engagement over multiple visits, grounded in cultural safety, relational continuity and family-centred practice. Only once trust was established could deeper conversations about care needs or end-of-life planning occur.

Users also described turning to navigators for ongoing advice, even when they were already connected with other professionals, because they trusted their judgement, felt understood, and valued the clarity they provided. This trust also created a ripple effect: many users reported recommending PCC to family members, peers and others in similar situations.

Connection to peer, social and community supports reduced isolation

Beyond immediate emotional reassurance, PCC played a key role in connecting people to ongoing sources of social, peer and community support. This was particularly evident in bereavement services, where users were linked to counselling, bereavement groups and other supports that helped them feel understood and less alone.

"It helped me understand that I wasn't the only person in the world that was lonely, sad." – BNS user

These peer connections helped normalise grief, reinforced coping strategies and strengthened users' sense of belonging, aligning directly with the intermediate outcomes described in the Theory of Change.



Building connections and capability through the palliative care volunteering study tour

To strengthen coordination and shared understanding across the palliative care volunteering system, Palliative Care Volunteering SA piloted a two-day study tour bringing together regional volunteer coordinators, metropolitan services, and sector partners.

The tour combined a masterclass with site visits to four metropolitan palliative care services. This design enabled participants to see how different volunteering models operate in practice. All regional participants reported that the tour improved their understanding of palliative care volunteering roles and models. Site visits were identified as the most valuable component, with participants noting the benefit of seeing how services differ depending on local context and resources.

The tour also created space for direct engagement between regional and metropolitan coordinators. Participants described the opportunity to share experiences, compare approaches, and build relationships across services. This helped to develop a more connected understanding of how volunteering is delivered across the system.

Alongside increased understanding, participants reported greater confidence in supporting volunteers in palliative care contexts. This learning translated into action, with participants identifying practical next steps such as reconnecting with local palliative care teams, introducing new volunteer roles, and sharing insights within their organisations.

“I feel that I now have a better understanding of how to support my volunteers when they begin their palliative care roles.” – Study tour participant

The study tour also highlighted areas where the system is less developed. In particular, participants consistently identified a gap in training, noting that while coordinators are able to recruit and manage volunteers, they often lack the resources to prepare them for the specific demands of palliative care. As one participant reflected, “they need a lot of training... it’s not like an admin volunteer role.”

In response, the service has begun developing more structured and accessible training approaches, including online modules. This reflects a shift toward not only connecting services, but supporting capability across the system.





Outcome Pathway 2: People have the information they need

PCC improved users' understanding of palliative care and available supports, with clear and tailored information contributing to increased confidence, more informed decision-making, and greater capability to navigate the system.

This outcome pathway explores how PCC enabled people to understand their situation, clarify options and make informed decisions. As outlined in the Theory of Change, it spans immediate enabling outcomes, receiving clear, relevant and actionable information, through to intermediate outcomes, including increased confidence, improved system understanding, and greater capability to plan and make decisions.

Clear, understandable and actionable guidance supported sensemaking

Users consistently described PCC information as easy to understand, relevant, and actionable. This was particularly important for people encountering palliative care for the first time, or feeling overwhelmed by competing demands and information. Many reported leaving interactions with a clearer sense of direction and concrete next steps.

"[Navigator] pointed me towards different directions: counselling, group, financial assistance... [they] gave me all of these avenues to try and choose the one that suited my needs at the time."
– BNS user

Survey data reinforces this: users rated the extent to which PCC improved their understanding of palliative care at 9.5/10 for PCC-SNS and 9.4/10 for the Bereavement Navigation Service.

These findings highlight PCC's role not just in answering questions, but in helping people make sense of complex, emotionally charged situations.

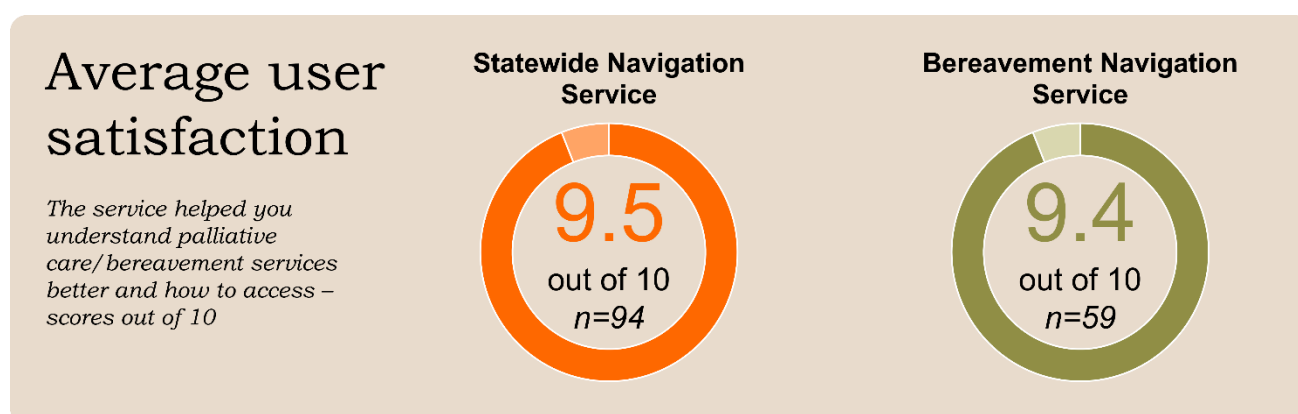


Figure 18. Average rating of understanding of PCC services (Oct '23 - Feb '26)



Improved understanding of palliative care, grief and available supports

For many users, PCC contact led to a fundamental shift in understanding. People described realising that palliative care:

- can be accessed earlier in the illness journey,
- supports carers as well as patients,
- includes far more than end-of-life care, and
- offers a wide range of supports, not just hospice services.

These shifts are important given the widespread misconceptions around palliative care. PCC helped “re-story” palliative care for many users, reframing it as a source of support rather than a sign of imminent decline.

"I thought palliative care was only for right at the end... I know now that palliative care is for ... [anyone] with an incurable disease... It really changed the story ... for me ... It opened my eyes to how much was available." – PCC-SNS service user

Bereaved users reported similar experiences, describing how PCC gave them new language and frameworks to make sense of their grief:

"[Had I not contacted the Bereavement Navigation Service] I would have had less resources, and would have been coping less, and I would be carrying the dark heavy weight of the grief. One of the lovely phrases I learnt: 'you grow around the grief'." – Bereavement Navigation Service user

These insights align closely with the Theory of Change, which **identifies increased system literacy and reduced confusion** as key early outcomes.

Tailored information enabled informed and values-aligned decision-making

Users emphasised that PCC information was not only clear, but tailored - adapted to their circumstances, readiness and preferences. Navigators shaped both the content and timing of information, focusing on what mattered most to the person in that moment.

This tailoring included:

- Breaking complex processes into manageable steps,
- Aligning information with people's values and goals,
- Prioritising immediate needs while preparing for future decisions.
- Highlighting relevant, practical and realistic options.
- Avoiding overwhelming people with unnecessary detail.



"Instead of scrolling, googling and going down rabbit holes, it provided a more individualised service. They listen to individual needs, first providing information about palliative care and then more specific about my mum and how it might help her." – PCC-SNS service user

Tailoring supported informed and values-aligned choices, not simply greater knowledge.

Increased confidence and capability to navigate the system and make decisions

Across interviews, users described feeling more confident, more able to ask questions, and more empowered to advocate for themselves and their family members. PCC helped them understand who to contact, what steps to take, and how to communicate effectively with health and aged-care systems.

"This week ... I stepped up a bit ... I've felt empowered to do that, and that might have actually come from his conversation ... [that] it's OK to be strong when you need to be." – PCC-SNS service user

Service data further supports this finding. **"Empowerment and informed decision-making"** was the most frequently recorded outcome across all navigation services

57%

of PCC-SNS cases

75%

of Bereavement
Navigation cases

46%

of Aboriginal
Navigation cases,

65%

of Regional Navigation
cases





Outcome Pathway 3: People access the services and supports they need

PCC enabled people to access services and supports they may not have reached independently, with navigators facilitating timely, appropriate and well-coordinated access, particularly for those with complex needs or for whom existing pathways had stalled.

This pathway examines how PCC helped people identify the right supports, reach services more easily and navigate pathways more confidently. As described in the Theory of Change, it spans immediate outcomes; needs identified and responded to early, people linked to relevant supports, through to intermediate outcomes; timely access, smoother coordination and reduced likelihood that needs escalate or go unmet.

Understanding variation in outcomes across services

Before examining the evidence, it is important to understand why recorded outcomes vary across PCC services. These differences reflect the distinct contexts, user profiles and service models rather than inconsistencies in practice.

Palliative Care Connect Statewide Navigation Service

Most PCC-SNS users already had some supports in place:

- 68% were connected to a GP or medical specialist
- 18% lived in residential aged care
- 15% were receiving specialist palliative care

A third of users received general navigation support or advice, and the most frequently recorded outcome was empowerment and informed decision-making (57%), with 20% recorded as accessing new services. Many people contacting PCC-SNS were not seeking new services, but clarity, reassurance and guidance within systems they were already navigating. Ensuring people are on the right track, and not over-referred to specialist services, is itself a valuable and appropriate outcome.

Bereavement Navigation Service

For the BNS, the pathway was more straightforward:

- 94% sought bereavement support
- 77% were referred to bereavement services
- 72% had “access to support services” recorded as an outcome

However, as described in the previous chapters, it is the process that distinguishes this service and the quality of matching mattered. Many had previously been given inappropriate referrals or had retold distressing stories repeatedly. PCC’s contribution here was not just linkage but careful, person-centred matching to the right support.



Aboriginal Palliative Care Navigation Service

The Aboriginal Palliative Care Navigation Service supported people with more complex, family-centred and culturally specific needs: 86% received general navigation support.

Contact reasons commonly included:

- Advocacy for patient preference 54%
- End-of-life planning 54%
- Cultural or spiritual needs 40%

Rather than linking people to new services, APCNS navigators primarily helped families make sense of existing arrangements, coordinate appointments, and support culturally aligned decision-making.

These differences reflect PCC's flexibility and responsiveness across diverse contexts.

PCC enabled access to support people may not have reached independently

Across all PCC services, a consistent pattern emerged: PCC helped people access services they would not have found, reached or persisted with alone, particularly when overwhelmed or unsure where to start. This included access to:

- Palliative care services
- Group-based peer supports
- Aged-care supports
- Carer services
- Bereavement counselling

For some, navigators provided clear contact details and guidance. For others, navigators played a more active role, making referrals, liaising with providers, or ensuring handovers occurred, going beyond signposting to **active enablement**.

"That [support] was initiated by Palliative Care Connect and without making that contact, that support wouldn't have happened." – PCC-SNS service user

Service data shows "access to support services" recorded as an outcome in:

20%

of PCC-SNS cases

72%

of Bereavement
Navigation cases

12%

of Aboriginal
Navigation cases

23%

of Regional Navigation
cases



PCC services supported more timely access to care and support

Users frequently described PCC as enabling quicker access to the supports they needed. This included:

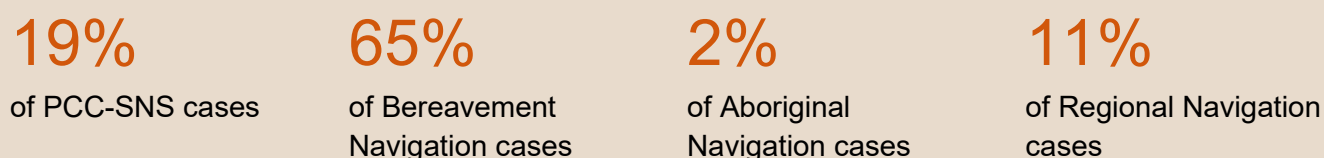
- Same-day advice
- Practical supports arranged within 24 hours
- Timely referrals to specialist or community services

Timeliness mattered because people often contacted PCC during periods of deterioration, uncertainty or increased stress. Prompt action reduced distress, clarified next steps, and helped families regain a sense of control.

“Mum had bed sheets within 24 hours and organised a nurse from RDNS within 24 hours as well.” – PCC-SNS service user

“I would still be seeking someone rather than seeing someone. It was really good for me that I had that opportunity to straight up get the information and pick and choose what I wanted.” – Bereavement Navigation Service user

Service data records timely access as an outcome in:



PCC supported access to services that fit users' needs and preferences.

Beyond speed, PCC achieved more appropriate access. Navigators worked closely with people to identify supports aligned to their:

- Needs
- Preferences
- Readiness
- Cultural context
- Location
- Family and community situation

This mattered because many users were not simply seeking “a service,” but the right service. PCC helped avoid repeated referrals, reduced the emotional toll of retelling stories, and supported families to weigh their options.

“I have been to so many counsellors and then get pushed on ... it's traumatic retelling my story. Seeing [the counsellor that BNS referred them to] has been really great.” - Bereavement navigation service user



A co-designed resource for Aboriginal communities in regional South Australia

Late in the pilot, the HELP app team was connected with Pangula Mannamurna, a new Aboriginal health service serving communities across a large region of southern South Australia, from Keith to Mount Gambier, without a dedicated palliative care unit.

In response to feedback that digital tools present a significant barrier for many of the communities they work with, the HELP app team co-created a paper-based version of their network-centred care resource in partnership with the health service. The resulting resource, which credits both Palliative Care Connect and Pangula Mannamurna, is designed to be nationally applicable and provides a more accessible alternative for communities with limited digital access. It represents a **tangible legacy outcome of the pilot**, particularly in a region that has historically had limited access to palliative care support.

Improved coordination reduced follow-up burden for users and families

A further outcome was **improved care coordination**. Navigators frequently:

- communicated needs to providers,
- clarified care pathways,
- followed through on referrals,
- ensured handovers occurred,
- reduced the burden on families to “chase services”, and
- intervened when parts of the system stalled.

This was particularly valuable during transitions between care settings or when multiple providers were involved.

"The [nurses] that came initially are still coming. That was initiated by Palliative Care Connect and without making that contact, that support wouldn't have happened." – PCC-SNS service user

"What [the navigator] did is actually ... what the doctors said they would do." – PCC-SNS service user

Service data shows coordination recorded as an outcome in:

26%

of PCC-SNS cases

7%

of Bereavement
Navigation cases

20%

of Aboriginal
Navigation cases

23%

of Regional Navigation
cases



BNS contact may have reduced escalation for clients

BNS navigators also logged the escalations they believed their involvement had prevented. While these represent navigator judgements rather than confirmed outcomes, there is a consistent pattern. The most frequently recorded avoided outcome was delayed access to services, in 80% of cases, followed by extended professional time managing client grief (77%), GP presentations (64%), psychological deterioration including relapse (60%), unresolved grief (59%), occupational decline or disengagement (55%), and mental health treatment plans (54%). This may suggest the BNS is not only supporting people to access the right services but potentially reducing the downstream burden of unmet grief on individuals and the broader system.

7. Contribution to system and community outcomes

The Theory of Change identifies a set of longer-term system and community outcomes that PCC aims to contribute to, including streamlined care transitions, more collaborative palliative care, and reduced unnecessary admissions to acute care. While measurable impact at these levels was not expected within the pilot timeframe, and widespread evidence of changes at these levels have not been observed, early evidence indicates emerging system-level shifts. These examples are isolated rather than widespread, but they offer important insight into how PCC could influence the system over time as practice matures and implementation deepens.

The case studies below illustrate shifts in conditions towards system change:

- Strengthening service pathways
- Reducing burden on overstretched parts of the system
- Improving continuity of care
- Enabling more culturally and clinically appropriate responses
- Supporting better alignment of roles across palliative, primary, acute and aged-care systems

These instances demonstrate how PCC could contribute to long-term outcomes if these practices continue to embed and scale.





Case study 1. Addressing bereavement support gaps to relieve pressure on primary care

Early in the pilot, the Bereavement Navigation Service identified a consistent gap in access to bereavement-specific counselling. While some bereavement counselling services existed, many people could not access them due to cost, availability, or transport barriers. In regional areas in particular, out-of-pocket costs and travel requirements meant that some individuals went without support altogether.

In response, the service introduced short-term counselling for people assessed as low to medium risk who were unlikely to access private services. Rather than creating a separate service stream, counselling was integrated into the existing navigation model. This enables staff to flexibly shift between information-giving, referral support and emotional care, ensuring people receive the type of support most appropriate to their needs at that point in time. Since launching counselling support in late 2025, the service delivered 40 counselling episodes in total

A case from a regional GP clinic illustrates how this works in practice. A patient experiencing complex grief was connected to the BNS after presenting in distress. Over a series of conversations, the navigator provided space to process grief, supported the person to manage immediate risks, and helped connect them with additional supports. The support adapted as circumstances changed, with navigation, coaching, and counselling operating as an integrated approach.

"It was the blend between the navigating and the coaching and the counselling and it kind of was this very fluid thing... it went backwards and forwards." – Bereavement Navigator

Feedback from the clinic indicated that the support had made a meaningful difference to

the individual's wellbeing. The experience also contributed to growing confidence among clinic staff in referring patients to the service.

The introduction of counselling has strengthened the Bereavement Navigation Service's position within the local care system. Clinic staff described how GPs often spend extended time supporting bereaved patients during appointments, often without a clear pathway for follow-up care. The Bereavement Navigation Service now provides a direct and accessible referral option, allowing clinicians to connect patients to appropriate support more quickly and with greater confidence.

In addition to this, navigators recorded that 77% of cases involved prevention of extended professional time managing client grief, and 64% involved prevention of a GP presentation. While these are navigator assessments rather than confirmed outcomes, they align closely with what clinic staff described: a service that absorbs the informal counselling burden that may otherwise fall to primary care professionals.

"It's really nice to be able to say... this is these people... all you have to do is ring a phone number... we don't need to spend an hour with the patient." – Medical Professional.

The following two case studies illustrate the emerging role of PCC-SNS as a **connector across different levels of care**, supporting more appropriate movement through the system, enabling timely end-of-life care, and reducing burden on specialist services.



Case study 2. Enabling timely discharge home at end of life

A patient admitted to a geriatric ward was identified as approaching end of life. Their expressed wish was to return home, yet the hospital team struggled to coordinate this. The newly introduced End-of-Life Pathway was not well understood, and staff and family were uncertain about available services, costs, and how care could be coordinated at home.

The patient's spouse had attempted to contact multiple providers but received inconsistent information, increasing distress and delaying decision-making. The hospital team also found it difficult to identify suitable providers in the large service directory.

PCC-SNS became involved following a referral and provided support to both staff and family.

Navigators:

- clarified how the End-of-Life Pathway could be applied,
- identified appropriate in-home service providers,
- compiled clear guidance on service options, costs and inclusions,
- worked alongside the hospital team and community palliative care services to develop a feasible care plan, and
- supported arrangements for in-home support visits, equipment, and clinical oversight.
- This combined effort enabled the patient to be discharged home within days, a result that would likely not have been achieved without PCC-SNS involvement.

"it was a huge team effort... if the community palliative care team didn't do the prescription, [patient] wouldn't be home. And if Palliative Care Connect didn't find us a provider, [patient] wouldn't be home" - Health professional

A manager reflected:

"if we hadn't had that information, I don't know if we were able to get that [patient] home" – Health professional

This case demonstrates how PCC-SNS can **untangle system complexity**, align providers around a common plan and enable people to return home in line with their wishes.



Case study 3. Reducing pressure on specialist palliative care through better referral pathways

Specialist palliative care teams, particularly in regional areas, work in resource constrained environments, where clinicians must manage both clinical and administrative tasks. This creates pressure on teams, particularly when time is spent assessing referrals that are not appropriate for specialist palliative care.

In this context, there is emerging evidence that PCC-SNS can play a role in supporting more appropriate referral pathways across the end-of-life continuum. Drawing on their system knowledge and understanding of available services, navigators are seen as well positioned to help determine what level of care is needed and direct people accordingly.

"I would like a service like Palliative Care Connect to have a [point] where all the referrals went first, so palliative care teams only got the appropriate referrals." – Regional Specialist Palliative Care Nurse

Specialist palliative care is intended for individuals with complex needs requiring support beyond what primary care, aged care, or community services can provide. However, referrals are often made for people who do not meet this threshold, including those with manageable needs or those better suited to other services. Assessing these referrals can require significant time, particularly in regional settings where administrative support is limited.

"Not every referral to palliative care is appropriate... specialist palliative care is not about looking after everyone who's dying, it's looking after the most complex people who require extra support above and beyond what the GP and other service providers can give them." - Regional Specialist Palliative Care Nurse

Interview data indicates that PCC-SNS is beginning to help address this gap by acting as an early point of contact, where people's needs can be explored and clarified before a referral is made. This includes identifying when individuals may be better supported through aged care pathways, primary health care, or community-based services, and assisting them to access these options.

This emerging function has the potential to reduce the administrative and coordination burden on specialist palliative care teams, who currently spend considerable time triaging referrals that do not require specialist intervention. By ensuring people are directed to the appropriate level of care earlier, PCC-SNS allows specialist teams to focus on individuals with the most complex needs. While this role is still developing, it aligns with PCC-SNS's broader positioning as a system connector, supporting more appropriate movement across the end-of-life continuum.



Case study 4. Enhancing aged care capacity through flexible psychosocial navigation support

As PCC-SNS became more established, it increasingly operated at the intersection of palliative care and aged care, particularly in response to growing demand from providers navigating end-of-life care within aged care settings. This has been shaped in part by broader system changes, including the introduction of new aged care pathways, which have created uncertainty about roles, responsibilities, and how best to support residents approaching end of life.

Within this context, PCC-SNS has positioned itself as a flexible, complementary support rather than duplicating existing roles. A key feature of this has been its multimodal approach to engagement. Support is provided via phone, virtual platforms, and where needed, in-person interactions, allowing aged care staff to seek advice in real time while continuing to manage their day-to-day responsibilities. This flexibility has made it easier for staff to access support at the point of need, particularly in time-sensitive situations.

Alongside this, the psychosocial support that the service provides is often difficult to access within aged care settings. Rather than focusing solely on referrals or information provision, navigators work with staff, residents, and families to talk through complex situations, provide reassurance, and support decision-making. This has been particularly valuable where aged care staff are managing both clinical and emotional aspects of care.

“They have such amazing knowledge and connection ... and other ways that they can support and provide which benefits the client, but then also takes that load off us and we can focus more on managing their symptomology.” - Palliative Care Advanced Practice Nurse

In practice, this support has helped reduce the time aged care staff spend navigating the system or providing extended emotional support during appointments, allowing them to focus on their core role while remaining confident that residents and families are being supported.

“We didn't really have anywhere to refer people before... you'd spend a lot of time trying to support them yourself. Now we know we can link them in and that makes a big difference.” Palliative Care Advanced Practice Nurse

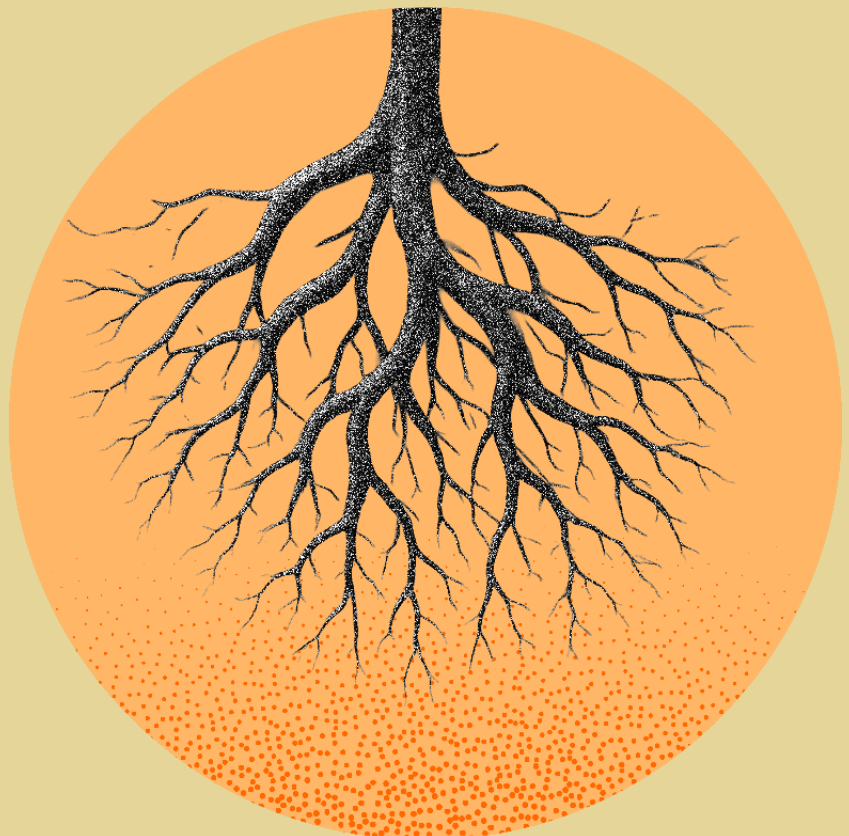
Through system knowledge, flexible delivery, and relational support, PCC-SNS is strengthening coordination between aged-care and palliative-care teams and contributing to more supported end-of-life care within aged-care settings.

8. Coherence

Summary of key findings

Collaboration between PCC services grew as the pilot matured but remained largely informal and relationship-driven rather than embedded in formal structures. Cross-service referrals did occur, though at a modest scale relative to total caseloads and concentrated in specific pathways rather than spread evenly across the model. Formal mechanisms such as working group meetings created opportunities for awareness-building but were less effective at generating sustained collaboration.

All PCC services invested substantially in outreach to the broader system alongside their core delivery work, with the scale and approach varying considerably across services. Recognition within existing referral networks grew over the pilot period but unevenly, shaped by local conditions, time, and the groundwork required to build credibility within established systems. PCC's positioning within the broader end-of-life system is still developing, with emerging but not yet widespread evidence of PCC services contributing to more coordinated movement across the end-of-life care continuum.





Collaboration within PCC

Collaboration between PCC services strengthened over the course of the pilot but remained uneven and largely relationship-based rather than embedded in formal systems. Services initially focused on establishing their own models and refining their role within the system, with cross-service collaboration emerging more gradually over time. While there is clear evidence that services connect and refer to one another, this interaction appears selective and purpose-driven rather than routine or highly integrated.

Collaboration developed over time as services became established and roles became clearer

Findings from the formative evaluation report indicate that early in the pilot, PCC services largely operated in parallel, with limited communication or integration between teams. As services became more established and developed a clearer understanding of their role, collaboration increased, driven by growing awareness of each service's purpose and activities, relationship-building, and informal interactions.

This reflects the broader evolution of the navigation role described earlier in the report: as services gained clarity about their own value proposition, they also became better positioned to recognise when and how to connect with one another for the benefit of users.

Referrals between PCC services occurred but selectively and modest levels

Service data shows that referrals between PCC services did occur, but at a relatively modest scale relative to overall caseloads. Of 1,160 recorded navigation cases:

- 117 listed another PCC service in the “referrals made” field
- 19 identified a PCC service as the origin of the case
- 12 of the 331 cases where service awareness had been recorded identified the PCC website as a source of awareness
- 16 referrals to the HELP app

Referrals were not evenly distributed. They were most frequently directed to:

- Bereavement supports
- The HELP App
- PCC website resources

Services such as Aboriginal Navigation or Palliative Care Volunteering SA received fewer referrals, reflecting both their more specialised roles and their distinct client groups. The data suggests that cross-service interaction was concentrated in specific pathways rather than occurring consistently across the model.



An insight around the HELP App is that, although only 16 PCC-to-HELP referrals were formally recorded, 11 networks created in the app listed PCC services as a referral source. This suggests that navigator endorsement (“social prescribing”) may be prompting uptake in ways not fully captured by referral data.

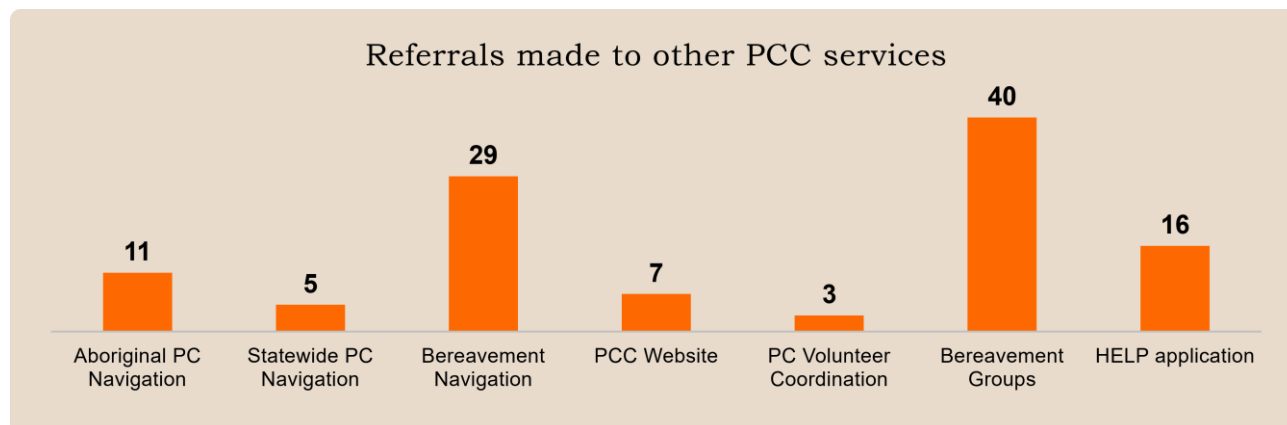


Figure 19: Referral made to other services (Oct '23 - Feb '26)

Service providers confirmed that referrals tended to be occasional and need-driven:

“there’ve been a few... smattering of times where I’ve been directly involved with the bereavement service” (PCC-SNS Navigator)

Collaboration was relationship driven rather than structurally embedded

Collaboration across PCC services was primarily driven by relationships, trust and practical needs, rather than formalised systems. Team members described connecting when there was a clear purpose, such as a referral, a shared client, or a joint activity, rather than through routine interaction.

Although several mechanisms were established to support collaboration, including:

- Monthly working group meetings
- An evaluation planning workshop
- Developmental evaluation reflection sessions

These structures were more effective for information sharing than for fostering deeper, ongoing operational collaboration.

“we’ve had a lot of working group meetings, but it’s really been kind of general... updates from each service... that kind of sometimes feels... can perpetuate the sense of being siloed” (HELP App)

Overall, collaboration strengthened but did not yet reach the level required for a fully connected, system-wide navigation model.



System awareness and recognition

PCC services built meaningful presence within the broader system over the pilot period, but recognition grew unevenly across services and contexts, shaped by local conditions, the relational groundwork required, and the time needed to establish credibility within existing networks.

All PCC services invested in outreach alongside their core delivery work

Throughout the pilot, PCC services engaged with referral partners, health professionals, and community organisations, extending well beyond their traditional direct navigation role. This occurred through both structured outreach activities and the day-to-day relational work of building trust and awareness among potential referral sources.

The scale of this outreach was considerable.

- The Regional Navigation Service connected with 50 community groups, 41 GPs, 32 aged care facilities, 25 pharmacies, 17 hospitals, and 68 specialists across 11 council areas.
- The Palliative Care Volunteering SA Service ran events, trainings, and developed online resources like the *Where to Start* guide.
- The Aboriginal Navigation Service conducted 357 stakeholder engagements.
- The Palliative Care Connect Statewide Navigation Service leveraged its knowledge of aged care and the end-of-life pathway ran promotional stalls at shopping centres, expos, and field days.

The Bereavement Navigation Service developed a particularly deliberate outreach strategy through its Grief Literacy Workshops. As described in the Reach and Access section, these workshops were introduced in response to initially low referral volumes and functioned both as a capacity-building mechanism and as a relationship-building tool. By building understanding of grief among potential referral partners, the workshops converted that understanding into more reliable and appropriate referral connections over time.

These efforts demonstrate the significant relational work required to become embedded in complex end-of-life and community systems.

System recognition grew, but unevenly across services and contexts

The Palliative Care Connect Statewide Navigation Service described initial challenges in building trust with specialist palliative care services, with relationships improving as the team's experience, professional credibility, and existing networks became more established. Even so, engagement continued to be impacted by local dynamics, staff turnover, and longstanding hierarchies within hospital systems.

The Regional Navigation Service faced more persistent barriers to embedding within local referral networks, reflecting the added complexity of building relationships across a geographically dispersed area with less established infrastructure. This variation across services illustrates that system recognition depends not on outreach effort alone, but on local conditions and the time required to develop meaningful working relationships.



PCC's role within the broader system continues to evolve

Across the pilot, PCC services increasingly engaged with the system not just as service providers but as connective actors seeking to fill gaps and demonstrate their value to other stakeholders. PCC's place within the broader system is not yet fully settled, and some ambiguity remains about where navigation sits in relation to clinical and specialist services. As discussed in the Contributions to systems and community outcomes chapter, there is emerging evidence that PCC services, and PCC-SNS in particular, are beginning to contribute to more coordinated movement across the end-of-life continuum. This positioning is still developing, but the direction of travel points toward a more integrated and recognised role.

"I think we come at it from quite a unique perspective... we just take a step back and look how it all works together" – PCC-SNS navigator

9. Recommendations

The following recommendations were developed collaboratively through a joint sensemaking workshop held in February 2026, bringing together representatives from each of the five remaining PCC services and SA Health's End-of-Life Care team.

Drawing on the evaluation findings presented in this report, the workshop identified key areas for action across three horizons:

1. Strengthening PCC in its current form
2. Considerations for scaling the model to other states and territories
3. Lessons for future navigation and coordination pilots more broadly.





Strengthening Palliative Care Connect in its current form

PCC has established a strong foundation during the pilot, with clear evidence of value across the end-of-life system. The following recommendations focus on consolidating this progress, strengthening core functions and ensuring the model remains sustainable as demand grows. Together, these actions aim to preserve what is working well while enhancing PCC's capability, consistency and impact in its current South Australian context.

Recommendation 1. Continue PCC services beyond the pilot period

PCC services have become established providers of value within South Australia's end-of-life system, with growing recognition among referral partners including specialist palliative care services, aged care providers, and medical professionals. Each service addresses a distinct part of the end-of-life continuum, and the relational capital built over the pilot period would be difficult to reconstitute if services were discontinued.

Recommendation 2. Advocate for PCC to be embedded within existing service pathways

The pilot has demonstrated, through specific instances, that PCC services can add meaningful value to other parts of the health system, including supporting hospital avoidance, reducing burden on GPs, and improving the appropriateness of referrals to specialist palliative care. Building on this, there is a case to actively advocate to embed PCC as a referral point within relevant service pathways, rather than relying on informal relationship-building alone.

Recommendation 3. Undertake a systems mapping exercise to identify where PCC adds value and where opportunities remain

A structured systems mapping exercise of where PCC services have successfully engaged with the system, and where gaps remain, would support more strategic outreach and help services prioritise their relationship-building efforts. This mapping could also serve as a communication tool, making visible the ways in which PCC supports other parts of the system, including by reducing inappropriate referrals to specialist palliative care and providing a resource for aged care and primary care providers.

Recommendation 4. Continue to lean into the flexibility and educative value of PCC services

One of the distinctive contributions of PCC across the pilot has been its ability to operate beyond direct service delivery, building capability and awareness in the broader system through activities such as the Grief Literacy Workshops, the palliative care volunteering study tour, and end-of-life pathway education. This positions PCC as more than a navigation service; it functions as a sector educator and connector while acting as a valuable mechanism to drive service awareness.



Recommendation 5. Develop a demand management strategy for navigation services

As the profile of PCC services continues to build and referral pathways become more embedded, navigation services will face increasing pressure on capacity. Without proactive planning, this risks compromising accessibility, user experience, and navigator workloads. A demand management strategy should consider how to triage and prioritise cases, manage wait times, and ensure that quality of support is maintained as volumes grow.

Recommendation 6. Assess and strengthen workforce safety measures to address the risks of vicarious trauma and compassion fatigue

The navigation role has evolved significantly beyond its original conception, with navigators regularly sitting with emotional distress, complex grief, and end-of-life conversations. This is a meaningful contribution but carries real risk for staff wellbeing. PCC services should assess what psychosocial safety measures are currently in place, including supervision arrangements, access to debriefing, and organisational policies recognising the emotional demands of the role, and ensure these are adequate, given how the work has developed in practice.

Recommendation 7. Ensure coaching and professional development structures are in place to sustain navigator capability

The skill and professional judgement of navigators is a consistent enabler across the evaluation findings and maintaining this as services grow and staff change is important. As the role has deepened to include elements of counselling, coaching, and emotional support, ensuring that new and existing staff are well supported through coaching and ongoing professional development becomes increasingly important.

Recommendation 8. Continue to strengthen connections and shared understanding across PCC services

Cross-service collaboration within PCC has grown over the pilot but remains uneven and largely informal. Where services have connected around a shared purpose or client need, there has been clear value for users. Sustaining efforts to build mutual awareness across PCC services, so that navigators understand what each service does and when to refer, remains worthwhile. This takes time to develop but creates a more coherent experience for people moving across the end-of-life continuum.

Recommendation 9. Extend data collection to better capture the impact of navigation interactions

Interviews conducted through the evaluation have provided rich insights into how PCC services work and why, but do not indicate how widely these experiences are shared across the broader user population. Now that the outcome mechanisms of PCC are better understood, there is an opportunity to extend the service user survey to include items on key dimensions of support quality, such as



responsiveness, clarity of information, and sense of agency, as well as items aligned with the outcome pathways in the Theory of Change. This would provide a more complete picture of impact. To maximise response rates, consideration should also be given to making the survey opt-out by default, sent automatically when a case is closed unless a navigator actively chooses not to send it.

Considerations for scaling the Palliative Care Connect model

As interest grows in expanding PCC beyond South Australia, it will be important to clarify what elements of the model must remain consistent and what can adapt to local context. The recommendations below outline key considerations for ensuring the model can be scaled sustainably while preserving the relational, flexible and system-connected features that underpin its impact. They aim to support thoughtful, deliberate expansion that strengthens, rather than dilutes, the core strengths demonstrated through the pilot.

Recommendation 10. Clarify and consolidate the PCC model before scaling

Before extending the PCC model to other states and territories, it is worth investing in a clearer articulation of what the model is. The pilot has generated evidence about what works, but questions remain about how the different service components relate to one another. Is navigation the central function around which other services are organised, or does PCC operate as a network of complementary navigation services? Resolving this will provide a stronger foundation for replication and help new services understand how they fit within the broader model.

Recommendation 11. Scale in ways that preserve the relational and human elements of navigation

Relationships are central to how PCC services generate value, both with users and within the system. This is particularly true for services working in regional and community contexts, where trust takes time to build and cannot easily be substituted by process or technology. Scaling efforts should deliberately protect the conditions that enable relational practice, including allowing new services the time and space to establish themselves within their local context before volumes are expected to be high. Services should be encouraged and empowered to work beyond their core navigator role to build system relationships, as this pilot has shown that this groundwork pays dividends over time.

Recommendation 12. Build in mechanisms for navigators to stay ahead of changes and opportunities

A notable feature of this pilot was the ability of some services to identify and respond to changes in the broader system, such as the introduction of the end-of-life pathway, in ways that added value to their work and to the people they support. Any scaled model should include mechanisms for navigators to stay informed about system changes, emerging trends, and new opportunities relevant to their role. Equally important is creating structures that allow navigators across a scaled system to share these observations with one another, so that insights generated in one context can inform practice elsewhere and the model as a whole remains responsive and forward-looking.



Recommendation 13. Map the individual journey before establishing services in new areas

When establishing PCC services in a new state or territory, it would be valuable to begin by mapping the end-of-life journey from the perspective of an individual navigating the system in that context. This can help clarify where each service is likely to have touch points, how the components relate to one another in practice, and where gaps or opportunities exist that may be specific to that local context.

Recommendation 14. Draw on the processes and learning already established by SA PCC services

The South Australian pilot has generated not just findings but operational knowledge, including approaches to stakeholder mapping, referral pathway development, that took time and effort to develop. Services established in new areas should remain connected to the SA model to understand what has already been worked through, and where established protocols can be adapted rather than rebuilt from scratch.

Recommendation 15. Recruit for both professional capability and relational skill, and build multidisciplinary teams

The quality of navigators has been a consistent enabler of positive outcomes across the pilot. Recruitment for scaled services should give deliberate attention to the human and relational qualities that make navigators effective, including the ability to hold difficult conversations, build trust quickly, and adapt to diverse needs and contexts, alongside relevant professional qualifications. Where possible, building multidisciplinary teams that draw on nursing, social work, counselling and related fields replicates one of the structural strengths of the SA model.

Lessons for future navigation and coordination pilots

As new navigation and coordination models continue to emerge across health and social care systems, this pilot offers valuable insights into what enables these services to take root and deliver meaningful value. The recommendations below distil key lessons about how to design, establish and sustain navigation services so they complement, rather than duplicate, existing system structures. These insights aim to support future pilots to build strong foundations, navigate local complexity and realise impact more efficiently.

Lesson 1. Allow time for services to establish and expect the navigation role to be emergent

New navigation services will inevitably start slowly in terms of user numbers and system recognition. This is not a sign of failure. The role itself will take time to define in practice, and funders and planners should build in realistic expectations about the establishment phase and allow space for the service model to develop through experience.



Lesson 2. Map the landscape carefully to ensure the service adds value rather than duplicates

Before establishing a navigation service, understand what already exists. The value of navigation lies in filling gaps and connecting people to the right supports, not in replicating what other services already do. A mapping of existing services and referral pathways is a necessary starting point.

Lesson 3. Place the individual journey at the centre of service design

Understanding the experience of someone navigating the system from the inside should inform how services are designed and where they focus their efforts. Journey mapping is a practical tool for achieving this, helping services identify where people are most likely to need support and how different components of a navigation model can best complement one another.

Lesson 4. Invest in data literacy alongside data collection

Good data does not happen by default. High-quality, consistent and meaningful data requires deliberate investment in the people responsible for recording it. Staff involved in recording and reporting data should receive training not only on how to capture information consistently, but also on why it matters and how the data will be used. This is a prerequisite for building an evidence base that can demonstrate impact over time.

Lesson 5. Recognise the cultural load carried by Aboriginal health practitioners

Where navigation services include Aboriginal practitioners working with First Nations communities on complex and sensitive issues, it is important to acknowledge and actively manage the cultural load this work carries.

Lesson 6. Invest in communicating what navigation means to people seeking support

People accessing a navigation service for the first time or those who may refer to such a service may not understand the full depth of what is on offer. Clear, accessible communication about what navigators can do, and how the service differs from a simple information or referral line, helps people engage more fully and get more from their interactions.



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