

Evaluation of the National Palliative Care Projects and the End of Life Directions for Aged Care

Final Report

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ALLEN + CLARKE CONSULTING



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Glossary of key terms and acronyms

Term	Definition
ACPA	Advance Care Planning Australia
AIHW	Australian Institute of Health and Welfare
CALD	Culturally and Linguistically Diverse
Department	Australian Department of Health, Disability and Ageing
ELDAC	The End of Life Directions for Aged Care Grant Opportunity is a closed non-competitive grant opportunity. The End of Life Directions for Aged Care is a project that seeks to improve the care of older Australians through palliative care connections and advance care planning activities.
ELLC	End of Life Law for Clinicians
EoLE	End-of-Life Essentials
IPEPA	Indigenous Program of Experience in the Palliative Approach
KEQs	Key Evaluation Questions
NPCPs	The National Palliative Care Projects grants program has existed since the 1990s to support the provision of high-quality palliative care in Australia through a range of activities including workforce development, quality improvement, data development activities, and advance care planning. Currently funded grants programs include: • The National Palliative Care Projects – Open Grant Opportunity is an open competitive opportunity for National Palliative Care Projects that focus on designated action areas from the Implementation Plan for the National Palliative Care Strategy 2018. • The National Palliative Care Projects – Core Projects Grant Opportunity provides funding to continue seven established National Palliative Care Projects that are fundamental to the delivery of palliative care in Australia.
PaCE App	Palliative Care Education Directory App
palliAGED	Palliative Care Aged Care Evidence
PCA	Palliative Care Australia
PCC4U	Palliative Care Curriculum for Undergraduates
PCOC	Palliative Care Outcomes Collaboration
PeSAS	Psycho-existential Symptom Assessment Scale
PEPA	Program of Experience in the Palliative Approach
PHN	Primary Health Network
PREMs	Patient-Reported Experience Measures
Priority populations	Priority populations refers to the eight under-served population groups identified in the National Palliative Care Strategy 2018. These include people who identify as: Aboriginal and Torres Strait Islanders; culturally and linguistically diverse; lesbian, gay, bisexual, transgender and intersex; living with disability; living with cognitive impairment such as dementia; experiencing homelessness; living in long-term institutional care; ageing and frail; and living in rural and remote areas.
Project ECHO	Educational community of practice in Palliative Care
PROMs	Patient-Reported Outcome Measures
QuoCCA	Quality-of-Care Collaborative Australia

EXECUTIVE SUMMARY

The NPCP grants program has existed since the 1990s to support the provision of high-quality palliative care in Australia through a range of activities including workforce development, quality improvement, data development activities, and advance care planning. Funded projects operate across a broad range of settings and engage with specialists and non-specialists across the workforce.

The Specialist Palliative Care and Advance Care Planning Advisory Services grant was established in 2012-13. Since 2017-18, this program has been delivered as ELDAC by a consortium led by Queensland University of Technology. ELDAC provides information, guidance and resources for all aged care staff to support palliative care and advance care planning.

In 2024, the Australian Government Department of Health, Disability and Ageing (the department) engaged ***Allen + Clarke*** to conduct an independent evaluation of the National Palliative Care Projects (NPCPs) and End of Life Directions for Aged Care (ELDAC) grants programs. The 2020-23 and 2023-26 grants rounds were in scope of the evaluation. A full list of projects is at Figure 1,[1] and an overview of each project is provided in **Appendix A.**

The evaluation was designed to answer eight key evaluation questions (KEQs). The evaluation used a mixed-method approach which included qualitative and quantitative data from project reports and other literature, interviews and focus groups with stakeholders across Australia's palliative care landscape, and a survey for the palliative care workforce.

Key findings

The program substantively delivered against its objectives and remains relevant

Across the two funding rounds, the NPCP and ELDAC projects substantively delivered against the Grant Opportunity Guidelines and the National Palliative Care Strategy Implementation Plan. Projects aligned their activities with the Strategy's goals, and the portfolio collectively addressed most eligible activity categories and priority populations. Two areas without dedicated investment were bereavement support and support for people experiencing homelessness. Stakeholders considered education, resource development, advance care planning, data and quality improvement, and workforce capability, appropriate domains for national investment.

Projects strengthened workforce capability and contributed to changes in practice

Projects increased palliative-care knowledge and confidence across the health and aged-care workforce, particularly among staff working outside specialist palliative-care settings. Service providers described changes in practice, including palliative care being considered earlier and incorporated into care planning rather than managed only when a person was actively dying. These changes were attributed particularly to engagement with ELDAC, PEPA and Caring@home.

[1] Throughout this report, the various NPCPs and ELDAC are on occasion referred to as 'projects'. The term 'the program' refers collectively to NPCPs and ELDAC grants programs

Evidence of direct patient and carer outcomes was more limited. PCOC provides the strongest patient-level evidence, with benchmarking data from more than 200 services showing improvements in pain management, symptom control and psychological wellbeing over time. ELDAC's Linkages program also demonstrated improvements across its organisational and after-death audit measures. For most other projects, evidence of impact relies primarily on workforce reports of changed knowledge, confidence or practice rather than systematically measured patient outcomes.

The portfolio is broadly aligned with the reform agenda

The grants program contributes to aged-care reform, home-based care, workforce capability, advance care planning and voluntary assisted dying education. ELDAC's quality-improvement model aligns closely with the strengthened expectations of aged-care providers, while Caring@home, CarerHelp, PEPA, CareSearch, palliAGED and other projects support care in home and community settings. End of Life Law for Clinicians, End-of-Life Essentials and Project ECHO have responded to the rollout of voluntary assisted dying legislation.

Recent reforms have increased demand for capabilities and infrastructure that many projects already provide. The main aspects that should be considered for strengthening are the visibility and practical application of existing resources, coordination between initiatives, reach into primary, home and community care, and the scale at which effective models can operate.

Partnerships, co-design and sustained investment supported effective delivery

Effective projects shared several features. Cross-project and external partnerships extended reach and improved relevance. Involving end users in resource development created products that better reflected their needs. Projects that promoted their work through trusted intermediaries, including Primary Health Networks and peak bodies, generally achieved greater reach than those relying on users to find resources independently. Free access reduced barriers for rural, remote and resource-constrained services. Sustained investment over multiple funding cycles enabled established projects to build relationships, embed resources into sector systems and demonstrate outcomes over time.

The grant structure is broadly fit for purpose

The combination of established and competitively funded projects has been broadly effective. Longer-running projects have provided national infrastructure and continuity, while competitive funding has enabled innovative responses to emerging needs and delivery for priority populations. The Department's coordination of cross-project meetings and sector forums, together with formal collaboration requirements in activity work plans, has strengthened relationships across the portfolio.

However, the growth in projects and resources has created a navigation burden for some users. Providers do not always understand the respective roles of projects or know where to find the most relevant support. Stronger coordination and clearer pathways through existing resources would improve accessibility. The program also lacks a consistent mechanism for assessing its collective outcomes. Finally, there is no consistent process for maintaining resources when project funding ends.

Overall, NPCP and ELDAC provide national infrastructure that has strengthened workforce capability and supported the sector to respond to evolving needs and reforms. Building on these foundations through clearer coordination, stronger outcomes evidence and sustainable funding would increase the portfolio's collective impact.

Appendix C outlines the achievement of the NPCPs and ELDAC in relation to the short and medium-term outcomes identified in the **Program Logic** for this evaluation.

Opportunities

Seven opportunities are identified in response to the evaluation findings. Progressing these opportunities would enable the department to build on project outcomes, and strengthen project administration, design, accessibility, equity and sustainability.

1. **Strengthen partnerships and consortium-based delivery,** by embedding proportionate expectations for collaboration in grant design and reporting.

2. **Strengthen portfolio-level outcomes measurement** to improve consistency in outcomes reporting and, where appropriate, support the collection of patient and carer outcome data and data-sharing arrangements.

3. **Plan for the sustainability of project outputs** by establishing maintenance responsibilities and transition arrangements, with consideration given to appropriate stewardship and maintenance funding after development funding ends.

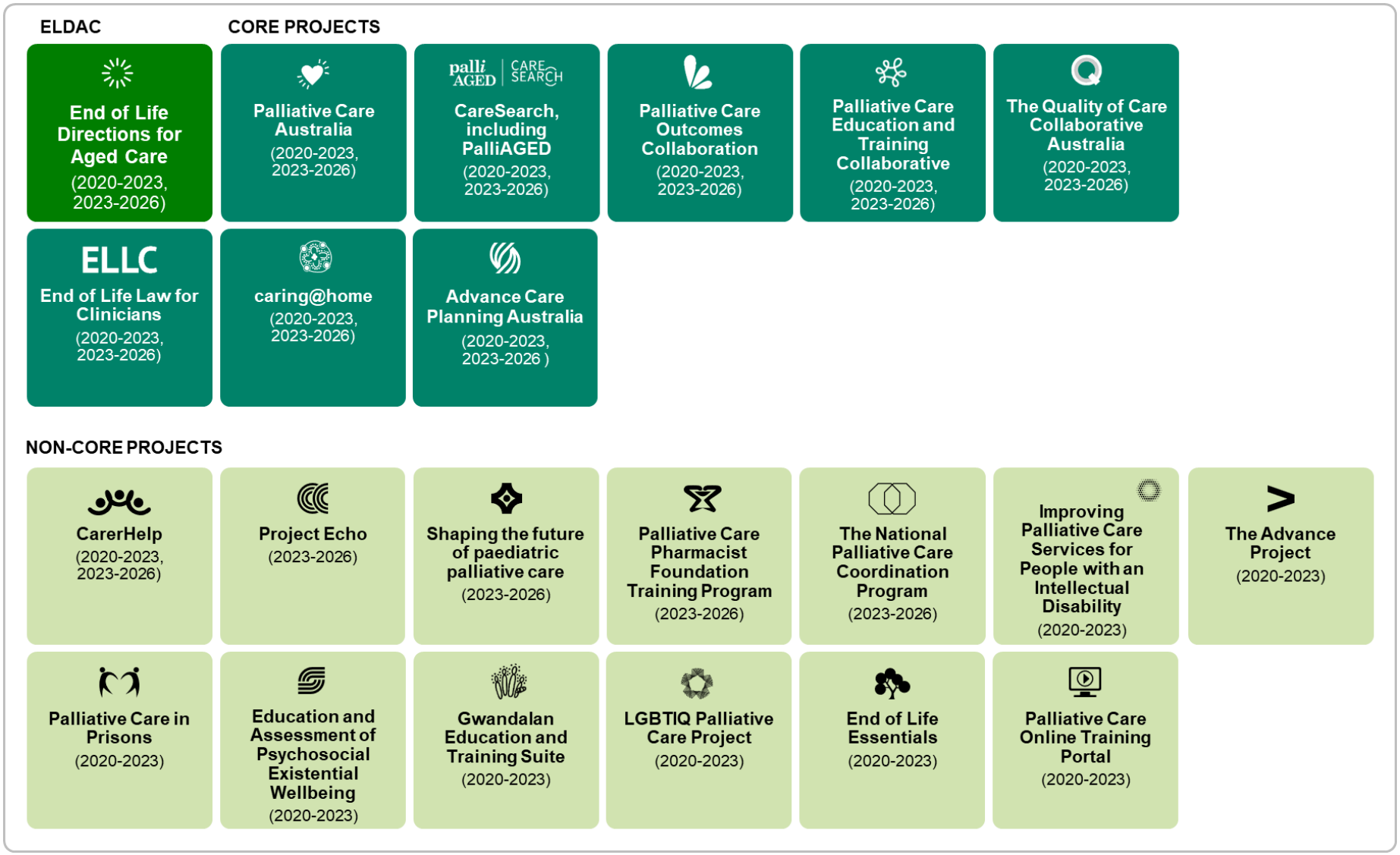
4. **Improve coordination and navigation of resources** to provide clearer pathways through available resources, organised around user needs and care settings.

5. **Strengthen support for priority populations** by continuing targeted investment and project design for priority groups, including people experiencing homelessness, culturally and linguistically diverse communities, and Aboriginal and Torres Strait Islander peoples.

6. **Build on the program's alignment with the reform agenda,** connecting existing project capabilities with implementation of the strengthened Aged Care Quality Standards, the Support at Home End-of-Life Pathway and jurisdiction-specific volunteer assisted dying education and guidance.

7. **Strengthen governance mechanisms for jurisdictional reach** through coordinated engagement with PCA, PHNs and other intermediaries; and align funding cycle length aligned with the nature and strategic horizon of projects.

Figure 1: **Projects in scope of the evaluation**



1 INTRODUCTION

In 2024, the department engaged ***Allen + Clarke*** to conduct an independent evaluation of the National Palliative Care Projects (NPCPs) and End of Life Directions for Aged Care (ELDAC) grants programs for the 2020-23 and 2023-26 grants rounds.

The NPCP grants program has existed since the 1990s to support the provision of high-quality palliative care in Australia through a range of activities including workforce development, quality improvement, data development activities, and advance care planning. Funded projects operate across a broad range of settings and engage with specialists and non-specialists across the workforce. The Specialist Palliative Care and Advance Care Planning Advisory Services grant was established in 2012-13. Since 2017-18, this program has been delivered as ELDAC by a consortium led by Queensland University of Technology. ELDAC provides information, guidance and resources for all aged care staff to support palliative care and advance care planning.

The evaluation used a mixed-method approach which included qualitative and quantitative data from project reports and other literature, interviews, and focus groups with stakeholders across Australia's palliative care landscape, and a survey for the palliative care workforce. The evaluation was designed to answer the following eight key evaluation questions (KEQs):

Table 1: Key Evaluation Questions (KEQs)

No.	Key Evaluation Question
1	To what extent have the NPCPs and ELDAC delivered against the Grant Opportunity Guidelines and Implementation Plan?
2	What key achievements, outcomes, and impacts have the NPCPs and ELDAC delivered?
3	Considering recent and future health and aged care reforms, are NPCPs and ELDAC targeting the right areas?
4	What are the key features of NPCP design, delivery and governance that lead to the best project outcomes
5	Have the NPCPs and/or ELDAC had any positive or negative unintended impacts?
6	Is the current structure of the grant programs achieving the best outcomes for government and the community?
7	Were the findings and recommendations of the previous NPCPs and ELDAC evaluations implemented? What were the impacts?
8	Are there suggestions for the department to improve administration of future grant rounds?

Methodology

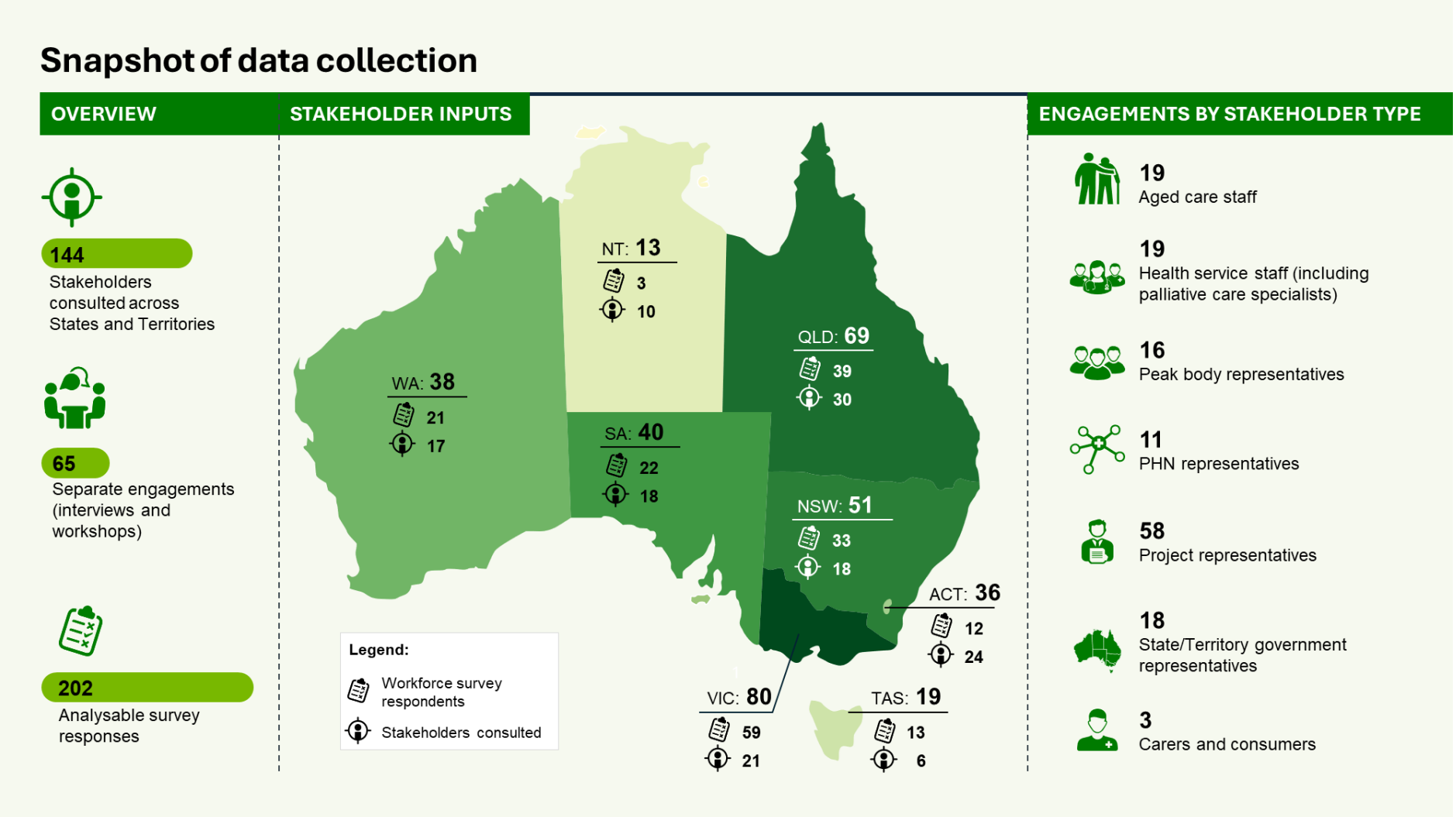
The evaluation employed a comprehensive mixed-method approach to data collection and analysis in order to respond to the eight KEQs (see).

Figure 2: Summary of data collection and analysis



Figure 3 provides further details of consultation and survey data collection undertaken nationally, and across each state and territory.

Figure 3: Survey responses and stakeholder consultation by State and Territory



1.1 Workforce survey

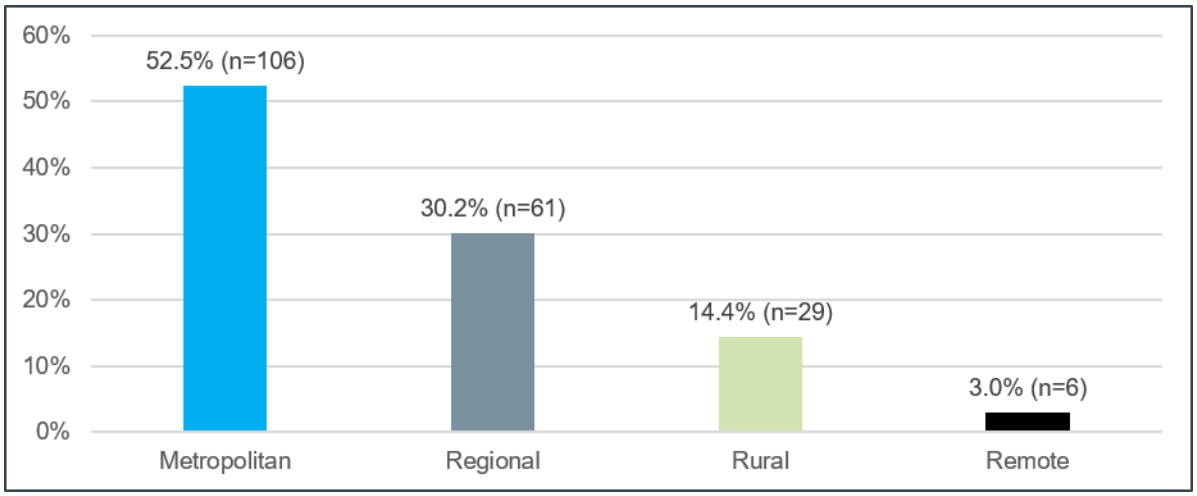
A national survey to seek the views of Australia's palliative care workforce was open from 7 October 2024 to 31 January 2025. Of the 283 responses, 202 were deemed analysable.

Survey participants were recruited primarily through project representatives circulating the survey to their workforce networks or contact lists provided to the evaluation team. Additional promotion occurred during stakeholder consultations and at two conferences in 2024 – the Palliative Care Nurses Conference in Melbourne, and the National Rural Health Conference in Perth.

Figure 4 shows the location of survey respondents, and

Figure 5 outlines their professional roles. Notably, regional, rural and remote survey respondents (96, or 48%) accounted for a relatively higher proportion compared with metropolitan respondents (106, 52%).[2] This may be due to survey recruitment undertaken at the National Rural Health Conference.

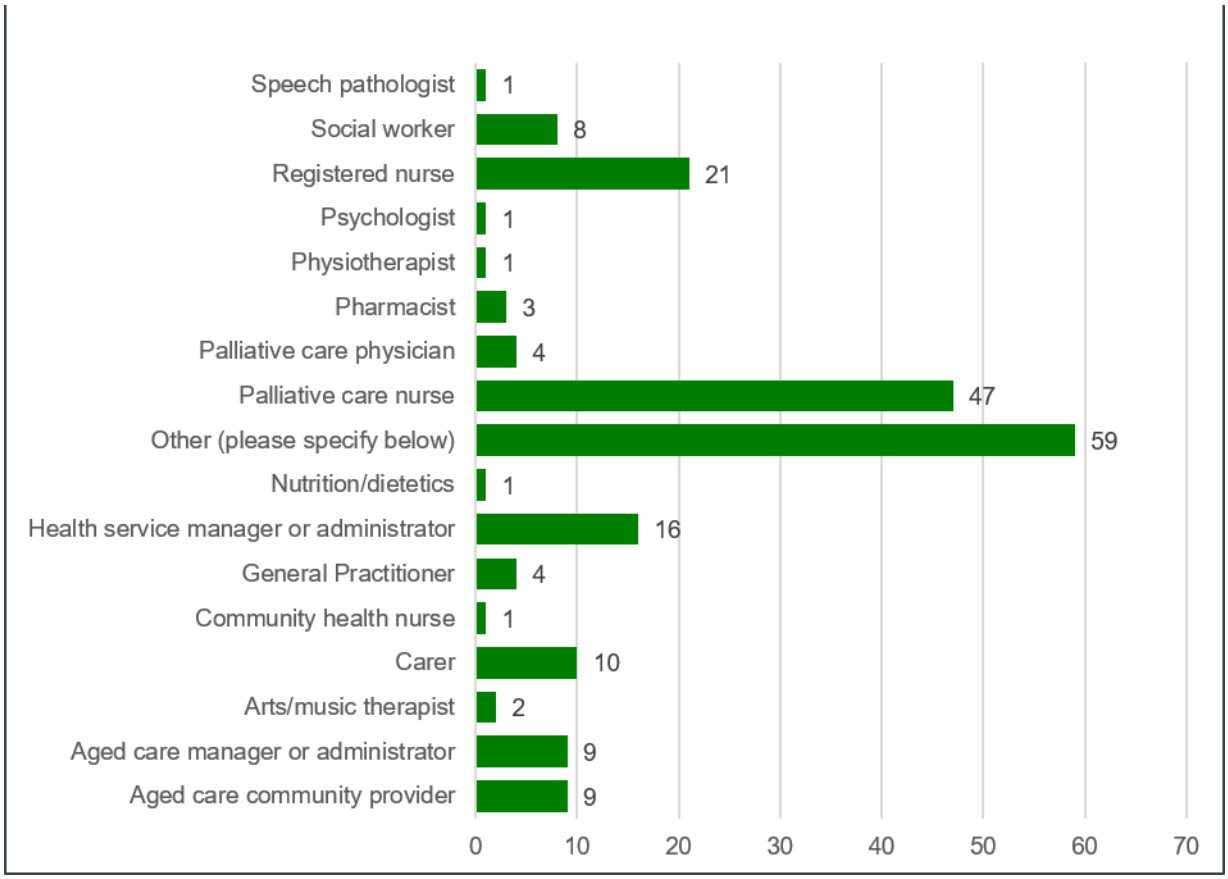
Figure 4: Location of survey respondents



Most survey respondents were palliative care nurses (47, or 24%), or registered nurses (21, or 11%). This may be due to survey recruitment being undertaken at the Palliative Care Nurses Conference. The 59 respondents (30%) who selected 'other' included administrators, managers, nurse practitioners and assistants, advocates, students, educators, community service officers, and occupational therapists.

[2] 73% of Australia's population reside in major cities, while 25% live in regional areas and 1.9% live in remote areas. **https://www.aihw.gov.au/reports/australias-health/profile-of-australias-population**. Accessed 4 May 2025.

Figure 5: Roles held by survey respondents



1.2 Evaluation limitations

The evaluation was conducted across a complex portfolio of projects at different stages of implementation and reporting, which creates several limitations that should be borne in mind when interpreting the findings.

Incomplete coverage of the 2023–26 round

The evaluation does not capture activities or outcomes delivered by the NPCPs and ELDAC during the remaining grant period from April 2025 to June 2026. Projects funded for the first time in 2023–26 are at early stages of implementation, and their outputs, outcomes and impacts are not yet fully visible. The aggregated outputs and activities detailed in this report therefore do not represent the full scope of the 2023–26 round. For projects recommissioned from 2020–23, this evaluation draws primarily on evidence from the completed round, with 2023–26 activity providing supplementary context only.

Outcome measurement limitations

As discussed in sections 4.4 and 4.6, direct measurement of patient and carer outcomes is limited across most of the portfolio. No overarching outcomes framework was available to projects during the evaluation period, making it difficult to assess the program's collective impact from existing data. PCOC and ELDAC's Linkages program are the principal exceptions, providing pre- and post-outcome data. Findings about patient and carer

outcomes for other projects are based primarily on workforce and service-provider accounts rather than direct measurement and should be read accordingly.

Workforce survey representativeness

The workforce survey achieved 202 analysable responses. While this provides a useful signal of workforce views, it is not a representative sample of the Australian palliative care workforce and should not be treated as such. Respondents were primarily people who had already engaged with one or more national projects, meaning the survey is likely to overrepresent positive views relative to the broader workforce population.

Attribution

The evaluation cannot attribute changes in palliative care quality or workforce capability solely to the NPCPs and ELDAC. The programs operate within a complex system shaped by concurrent reforms, including the Royal Commission into Aged Care Quality and Safety, the rollout of jurisdictional voluntary assisted dying legislation, and broader health workforce pressures. These reforms and contextual factors independently influence the outcomes the programs are designed to achieve. Where this evaluation makes contribution claims, these are based on triangulated evidence across multiple sources rather than on controlled evaluation designs.

Self-reported project data

Much of the quantitative evidence in this report draws on project self-reporting through activity work plans, performance reports, and final reports. This data has not been independently verified. Where figures are drawn from project reporting, this is noted in the text.

Qualitative sample

The qualitative evidence base comprises 70 interview and workshop events conducted between August 2024 and January 2025. While this is a substantial qualitative sample for an evaluation of this kind, it cannot be assumed to be representative of all project leads, service providers, or community members with a stake in the program. In particular, consumer and carer voices are underrepresented in the qualitative dataset, reflecting the difficulty of engaging people who are dying or recently bereaved in evaluation processes.

2 DELIVERY AGAINST THE GRANT OPPORTUNITY GUIDELINES AND IMPLEMENTATION PLAN

KEQ1: To what extent have the NPCPs and ELDAC delivered against the Grant Opportunity Guidelines and Implementation Plan?

Main messages:

- The NPCPs and ELDAC were designed in alignment with the Strategy and Grant Opportunity Guidelines. Projects mapped their activities to specific objectives, responded to the strengthened requirements in the 2023–26 round by expanding their scope, and documented delivery challenges alongside mitigation strategies.
- Bereavement support is a gap in the portfolio relative to the guidelines' priority activities. No dedicated project addressed this in either round, despite carers being an explicit priority in the National Palliative Care Strategy.
- People experiencing homelessness had no dedicated project across either round, despite being identified in the guidelines as a priority group.
- Aged care is a priority setting under the guidelines, but structural barriers such as staff turnover, regulatory burden and limited organisational capacity are limiting reach and uptake of the projects in the sector. The ELDAC Linkages model demonstrates that direct, sustained facilitation is what actually works in this context, and the program should invest accordingly.
- The guidelines require projects to demonstrate progress toward outcomes. However, the reporting framework primarily asks projects how many people they reached, not what changed for those people. The 2023-26 round introduced a stronger accountability framework, requiring alignment with the Implementation Plan Action Areas and providing draft performance indicators.

2.1 Strategic alignment with the Grant Opportunity Guidelines

The Grant Opportunity Guidelines (Department of Health and Aged Care, 2020; 2023) set out the objectives, eligible activities, performance requirements, and accountability obligations that funded projects were required to meet. This evaluation assessed whether projects were designed in alignment with these requirements.

The Grant Opportunity Guidelines framework strengthened its strategic focus between the 2020-23 and 2023-26 rounds

The guidelines governing the two funding rounds set out the objectives, eligible activities, performance requirements, and accountability obligations that funded projects were required to meet. The 2020-23 guidelines aligned projects with Strategy Goals 1 to 5 (core projects) and Goals 1 to 6 (ELDAC). The 2023-26 guidelines extended this to Goals 1 to 7 across all

funded programs, and for the first time required alignment with the four Implementation Plan Action Areas. The shift between the rounds is summarised in Table 2.

Table 2: Key changes in the Grant Opportunity Guidelines framework between the 2020–23 and 2023–26 rounds

Feature	2020-23 round	2023-26 round
Strategy goals addressed	Goals 1–5 (core projects); Goals 1–6 (ELDAC)	Goals 1–7 across all Grant Opportunity Guidelines
Implementation Plan Action Areas	Not referenced	Action Areas 1–4 (core); 1–3 (ELDAC); 1–2 (open competitive)
Performance indicators	Negotiated individually after award; no Grant Opportunity Guideline-level indicators	Draft indicators provided in each Grant Opportunity Guideline as a starting point
Core projects	Six named organisations	Seven named organisations (Caring@home and ELLC added)
Eligible entity types (open competitive)	Company, association, charity, government body, Indigenous corporation, trust	Expanded to include Corporate Commonwealth Entities, Local Government, Cooperatives, Statutory Entities

Source: Grant Opportunity Guidelines GO1992, GO1993, GO1995 (2020–23); GO5952, GO5972, GO6007 (2023–26).

The addition of Goal 7 (Accountability) and alignment with the Implementation Plan Action Areas in 2023–26 introduced a more demanding accountability framework than the preceding round. The extent to which this translated into stronger accountability for outcomes in practice is discussed in section 2.4.

Projects across both rounds structured their activities around the Strategy goals and guidelines objectives

Review of activity work plans across all 26 funded projects in both rounds found that project design and delivery was structured in alignment with the Strategy and guidelines objectives. The 2020-23 activity work plans all reference Goals 1 to 5 as their organising framework and map their planned activities to specific guideline objective categories. The 2023-26 activity work plans additionally reference Goals 6 and 7, consistent with the expanded requirements. All activity work plans across both rounds include structured milestone schedules, performance indicators with agreed targets, and financial acquittal commitments consistent with grant agreement requirements.

Several projects expanded their scope in direct response to the strengthened guidelines requirements. For example:

- ACPA's 2023-26 plan introduced a national ACP prevalence study as a new deliverable. This was intended as an evidence-generation activity in response to the Guidelines' strengthened data and accountability requirements.

- ELDAC's 2023–26 plan restructured its website into a ‘knowledge hub’ and set equity targets for geographic and population reach, including at least 30% of participants from outside metropolitan areas and dedicated targets for CALD, Aboriginal and Torres Strait Islander, and LGBTIQ+ services.

- ELLC expanded its scope in 2023-26 to include a new aged care course and an implementation pilot in primary care and aged care settings, directly responding to the Guidelines’ Action Area alignment requirements.

Where projects encountered delivery challenges, such as COVID-19 disruptions, jurisdictional approval complexity in the Prisons Project, or workforce capacity pressures in aged care settings, activity work plans documented these challenges alongside mitigation strategies and revised timelines. This demonstrates active engagement with grant obligations and suggests that the grant management framework provided sufficient flexibility for projects to adapt without compromising their core objectives.

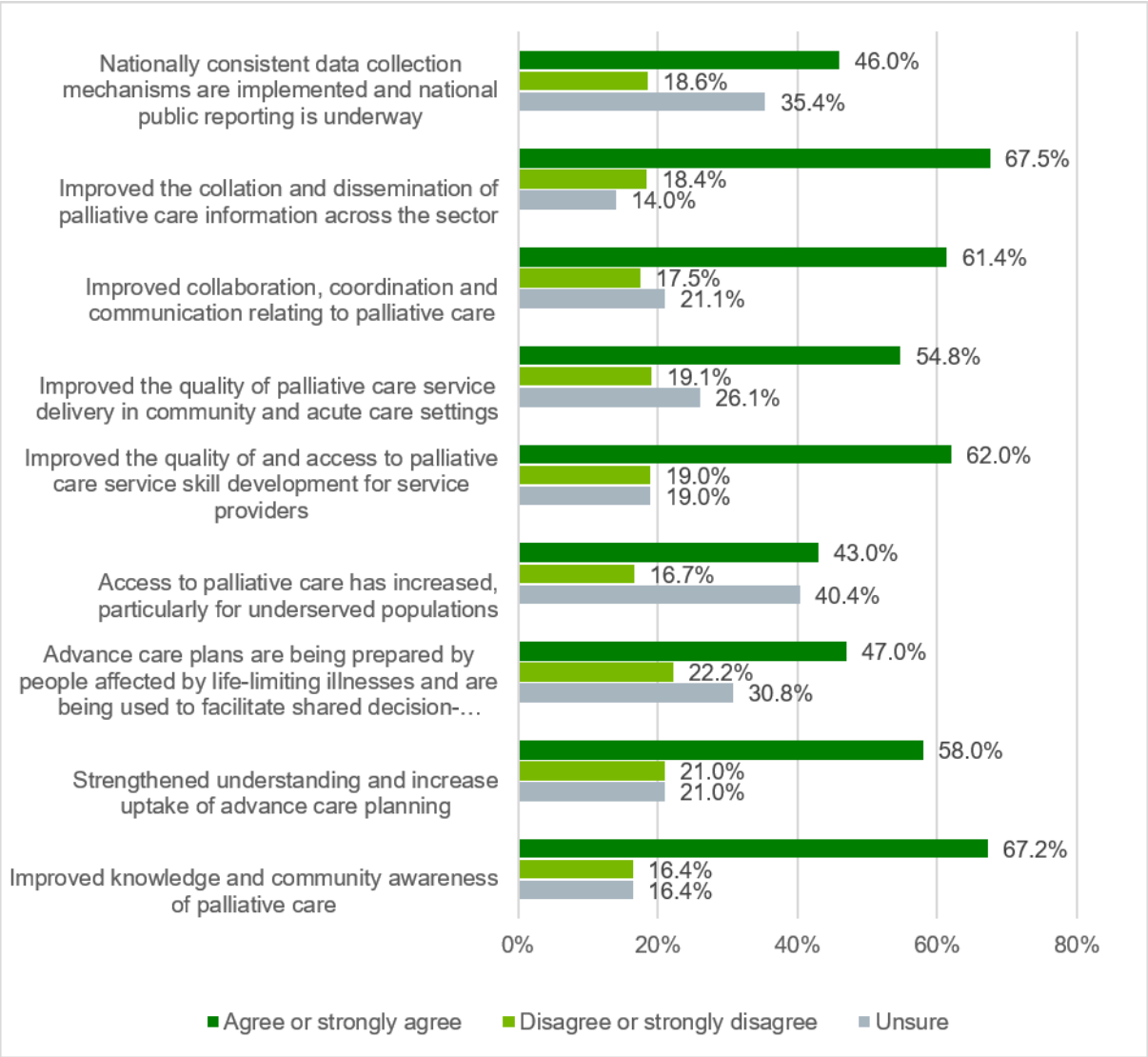
Most workforce survey respondents were confident that the NPCPs and ELDAC met the objectives in the guidelines and Implementation Plan

Workforce survey findings (Figure 6) are broadly consistent with the documentary evidence from activity work plans; between 43 and 67.5% of survey respondents agreed or strongly agreed that the NPCPs and ELDAC met each of the objectives in the guidelines and Implementation Plan. Agreement was highest for improving knowledge and community awareness of palliative care (67.2%) and improving the collation and dissemination of palliative care information (67.5%). It was lowest for nationally consistent data collection mechanisms being implemented (46.0%) and advance care plans being prepared and used to facilitate shared decision-making (47.0%).

Between 16 and 22% of respondents disagreed with each focus area being achieved, and 14 to 35% were unsure. Interview evidence suggests this reflects the complexity of the system the program operates in rather than projects not meeting their objectives. Several of the objectives in the guidelines depend on infrastructure, behaviour change, and policy alignment that extend beyond what could be achieved through this program.

Uncertainty levels were highest for the data collection and advance care planning objectives. Regarding data collection, interviewees consistently noted that projects reported primarily on activity measures rather than outcomes, and that the absence of a common measurement framework made it difficult to assess whether nationally consistent data collection had been achieved across the portfolio. On advance care planning, community uptake was described as slow and likely to take longer than can be captured within the evaluation period.

Figure 6: To what extent did the NPCPs and ELDAC meet objectives in the Grant Opportunity Guidelines and the Implementation Plan?



2.2 Portfolio coverage of priority categories and populations

The Grant Opportunity Guidelines specify a list of eligible activity categories and priority populations that funded projects are expected to address. Assessing whether the portfolio collectively covered these categories and populations is a measure of delivery against the guidelines.

The portfolio collectively addressed most Grant Opportunity Guideline activity categories, with a gap in bereavement support

Taken as a whole, the NPCP project portfolio addressed most of the eligible activity categories across both rounds. This included workforce skill development, service delivery improvement in community and acute care, advance care planning, knowledge and community awareness, collaboration and coordination, and the collation and dissemination of palliative care information. Table 3 maps the portfolio's collective coverage.

Table 3: Project coverage of Grant Opportunity Guidelines eligible activity categories

Activity category	Projects addressing this category	Assessment
Service provider skills development through education and training	PEPA/IPEPA, EoLE, ELLC, QuoCCA, ELDAC, Gwandalan, LGBTIQ+, PCC4U, Project ECHO, Pharmacist Training	Strong coverage across settings and populations
Service delivery improvement in community, acute care, and disability settings	PCOC, QuoCCA, Caring@home, ELDAC Linkages, NPCC	Good coverage in community and acute care settings; coverage for people living with disability limited to one dedicated project and partial coverage through other projects
Advance care planning activities	ACPA, Caring@home, ELDAC, Advance Project	Addressed; community uptake remains slow
Knowledge and community awareness	PCA, CareSearch/palliAGED, CarerHelp, EoLE	Broad reach; digital platforms well developed
Collaboration and coordination of services	PCA, PCOC, NPCC, ELDAC, Project ECHO	NPCC new in 2023–26; fills a systems coordination gap
Collation and dissemination of palliative care information	CareSearch/palliAGED, PaCE App, ELDAC Knowledge Hub	Strong; fragmentation remains a usability challenge
Bereavement support	No dedicated project in either round. Partial coverage through CarerHelp, PSA, QuoCCA	Only partially addressed through secondary coverage in three projects
Clinical information sharing for care transitions	NPCC, PCOC, ELDAC	Addressed at system level; service-level gaps remain

As noted in the table, bereavement support is an eligible activity under the Grant Opportunity Guidelines and is embedded in the Strategy's guiding principle that carers are valued and receive the support and information they need (National Palliative Care Strategy, 2018). An analysis of project descriptions and activity work plans across both rounds shows it does not appear as a primary focus of any project in either round's portfolio. Performance reports note some secondary coverage, including bereavement referral as a quality indicator in ELDAC's After Death Audit, a single educational module on after-death care, and integration of a grief resource into aged care toolkits. However, none of these constitutes a dedicated bereavement support offer for carers. The department could consider whether more dedicated investment in this activity category is warranted in the next round's design.

Most priority populations were covered by the projects, but people experiencing homelessness was a gap

Table 4 summarises the position by population group. However, as section 3.8 describes, breadth of coverage does not always translate to depth of reach for these groups.

Coverage of the Grant Opportunity Guidelines priority populations was broad across both rounds, with Aboriginal and Torres Strait Islander peoples, CALD communities, LGBTIQ+ people, and people in rural and remote areas all addressed by multiple projects.

However, coverage was uneven, and some populations remained without dedicated investment across both rounds. People experiencing homelessness had no dedicated project across either round, despite being identified in the guidelines as a priority group. People in long-term institutional care were addressed by a single project whose delivery was significantly constrained by the complexity of securing jurisdictional ethical approvals. People with disability were addressed by one dedicated project alongside some partial coverage through other projects.

Table 4: Project coverage of Grant Opportunity Guidelines priority populations

Activity category	Projects addressing this category	Assessment
Aboriginal and Torres Strait Islander peoples	Gwandalan, IPEPA, Caring@home (ATSI), ELLC Module 12, ACPA	Multiple projects; qualitative data identified concerns about depth of community reach
Culturally and linguistically diverse communities	CarerHelp Diversity, ELDAC companion guides, ACPA	Multiple projects; translated resources available but coverage incomplete
LGBTIQ+ people	LGBTIQ+ Palliative Care Project, ELLC Module 13, ELDAC companion guides	Dedicated project in 2020-23; continued through resources in 2023-26
People living with disability	Improving Services for People with Intellectual Disability, PEPA (workshops)	Single dedicated project; broader disability coverage limited
People experiencing homelessness	No dedicated project in either round	Gap in portfolio coverage
People in long-term institutional care (including prisons)	Prisons Project	Single project; delivery constrained by jurisdictional approval complexity
People living in rural and remote areas	CarerHelp Rural Connect, PEPA (rural placements), Project ECHO, QuoCCA (regional sessions)	Multiple projects; geographic inequity remains
People who are ageing and frail	ELDAC, ACPA, Caring@home, EoLE	Broad coverage through aged care focus of multiple projects

2.3 Delivery in the aged care context

Both the ELDAC guidelines and the core project guidelines identify aged care as a priority setting, with ELDAC specifically funded to improve palliative care capability and linkages across the aged care sector. The extent to which projects achieved reach and impact in aged care is therefore central to assessing delivery against the guidelines.

Aged care was a challenging delivery context, and reach into the sector remains incomplete

Aged care was consistently identified as the setting where the gap between available resources and actual uptake was largest. About half of the project-level interview participants described aged care delivery as the most significant implementation challenge of the two rounds. This finding was strongly corroborated from the service side: most service-level participants raised aged care capacity constraints during interviews.

Interview evidence identified a range of reasons underpinning challenges in the aged care context:

- High staff turnover in this sector means that knowledge and relationships built through project engagement are frequently lost, requiring services to re-engage from a lower base with each new cohort of staff.
- The regulatory and reform burden following the Royal Commission into Aged Care Quality and Safety (Royal Commission into Aged Care Quality and Safety, Final Report, 2021) was reported to be substantial, with providers navigating new quality standards, new funding models, and new workforce requirements.
- Organisational capacity is often limited, particularly in smaller residential aged care facilities and home care providers, where there may be no designated quality improvement or education role.
- The workforce is composed substantially of personal care workers rather than registered nurses. Several projects (including ELDAC, PalliAGED, PCC4U and Caring@Home) provide resources and training specifically aimed at this group, although many of the national projects' broader resources are designed primarily for clinicians. Given the size and continued growth of the personal care workforce, there may be scope to further expand and tailor resources for non-clinical and direct-care staff delivering the majority of hands-on care.
- For rural and remote facilities, geographic isolation compounds these factors: access to specialist support is limited, staff recruitment is harder, and the administrative infrastructure to engage with externally offered programs is thinner.

These pressures combined mean that aged care providers often have little capacity to engage with externally offered programs such as NPCP and ELDAC, particularly when engagement requires additional staff time. Peak body representatives described aged care providers as consumed by day-to-day operations, which was echoed by facility managers and care coordinators across multiple jurisdictions.

> *"It's that opportunity to move out of the day-to-day work that is the barrier. In some circumstances, engagement with ELDAC might mean the*

engagement of extra resources, whether that be staff or time. So, they find themselves in that precarious position." (Peak body representative)

ELDAC's Linkages program was an effective model for reaching aged care services

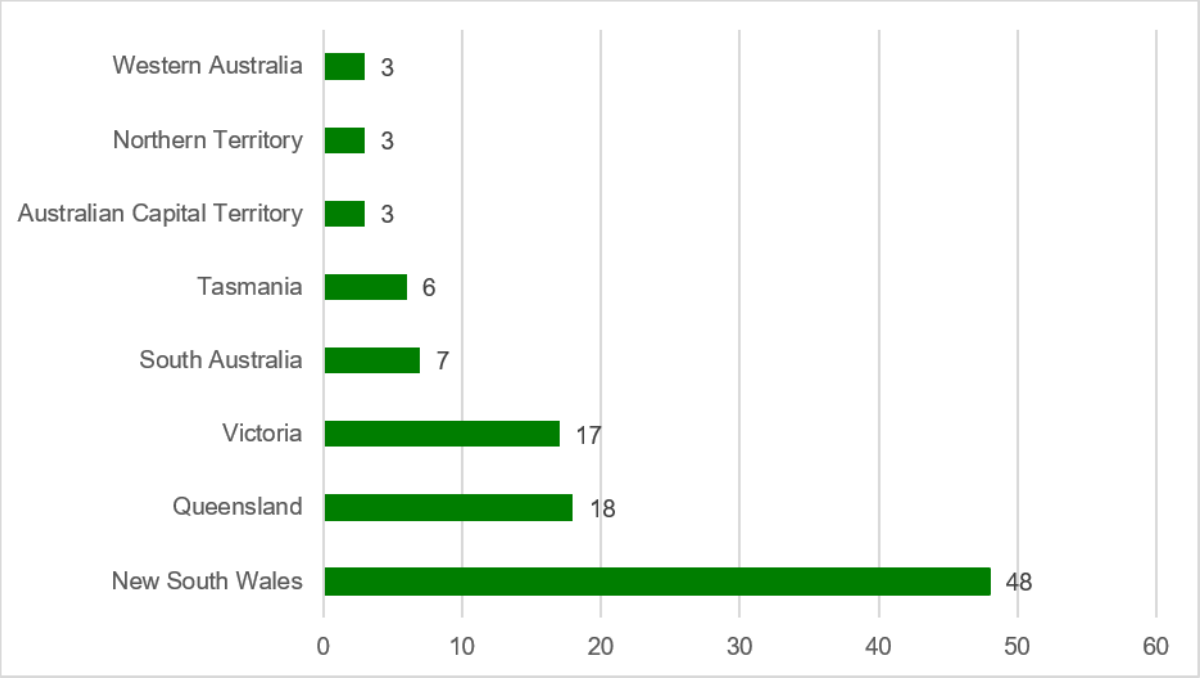
Discussion with aged care providers and facility staff found that ELDAC's Linkages program consistently activated aged care engagement. This project sent facilitators directly into aged care services rather than relying on services to find and navigate an online knowledge hub. Over six to twelve months, facilitators worked alongside staff on tailored quality improvement plans, with follow-up data showing significant changes across all domains of the Organisational Audit and After Death Audit (ELDAC Performance Report 6, 2023).

Interview participants from ELDAC Linkages sites across a range of jurisdictions described the facilitator relationship as an enabling factor and considered that without it, competing demands would have prevented meaningful engagement.

"Without our facilitator keeping us accountable and meeting with us regularly, we wouldn't have got there. Honestly, with everything else we have to do, setting time aside for this probably wouldn't have happened." (Aged care facility manager)

ELDAC performance reporting data shows the geographic and setting distribution of the 107 services that completed the Linkages program across Phase II (Figure 7). The project reached services across all states and territories, with the largest share in New South Wales (45%).

Figure 7: Participating services in ELDAC Linkages program by state and territory (Phase II)



Source: ELDAC Performance Report 6, 2023

ELDAC reporting data (ELDAC Performance Report 6, 2023) shows that the majority of participating services were residential aged care (78%) rather than home care (22%). The home care sector's lower representation likely reflects the smaller number of home care providers nationally and the additional complexity of engaging a more dispersed workforce.

ELDAC interviewees estimated working through the Linkages program with around nine percent of the aged care sector. This is meaningful reach for an on-the-ground intensive program, but leaves the majority of services unreached. In future rounds, it will be important to consider whether the scale of facilitated engagement is sufficient to achieve the sector-wide improvement the guidelines intend, and what resourcing would be required to extend it.

2.4 Reporting and accountability

The Grant Opportunity Guidelines require projects to report against agreed performance indicators and demonstrate progress toward outcomes, not just activity completion.

The reporting framework enabled consistent reporting of activities, but not consistent reporting of outcomes

A key finding from project-lead interviews was that the activity work plan and performance reporting structures worked well for reporting on activities, reach and deliverables, but did not consistently support projects to demonstrate change in practice, service capability, or patient and carer outcomes. Some projects gathered evidence of change in their own right, such as pre- and post-training data, organisational audits, or service-level quality improvement measures. These approaches were developed independently and therefore are not comparable across the portfolio. This limits the department's ability to assess what the program has achieved collectively, beyond delivery of outputs and gains in workforce knowledge and confidence.

> *"We far exceeded our targets. The problem is the reporting asks how many, not what changed. Those are very different questions and we need to be answering both." (Project representative)*

Part of the reason projects defaulted to output reporting is that outcome data from this population is hard to collect. For example, Caring@Home project personnel reported sending over 5,000 resource boxes to families caring for someone dying at home, each with an evaluation survey. Fewer than one percent of surveys were returned. Interviewees noted that reaching dying people and bereaved carers with evaluation surveys is difficult, and that low response rates in this context say little about whether the project worked.

The 2023-26 round's introduction of draft performance indicators, including patient outcome measures and knowledge and confidence improvements, at the guidelines level was seen by project representatives as a step toward outcome-oriented accountability.

The department could consider how to build stronger reporting mechanisms that systematically capture practice change and broader outcomes. It would be beneficial to develop the common cross-portfolio indicators that would enable assessment of what the program has collectively achieved.

3 ACHIEVEMENTS, OUTCOMES, AND IMPACTS

KEQ2: What key achievements, outcomes, and impacts have the NPCPs and ELDAC delivered?

Main messages:

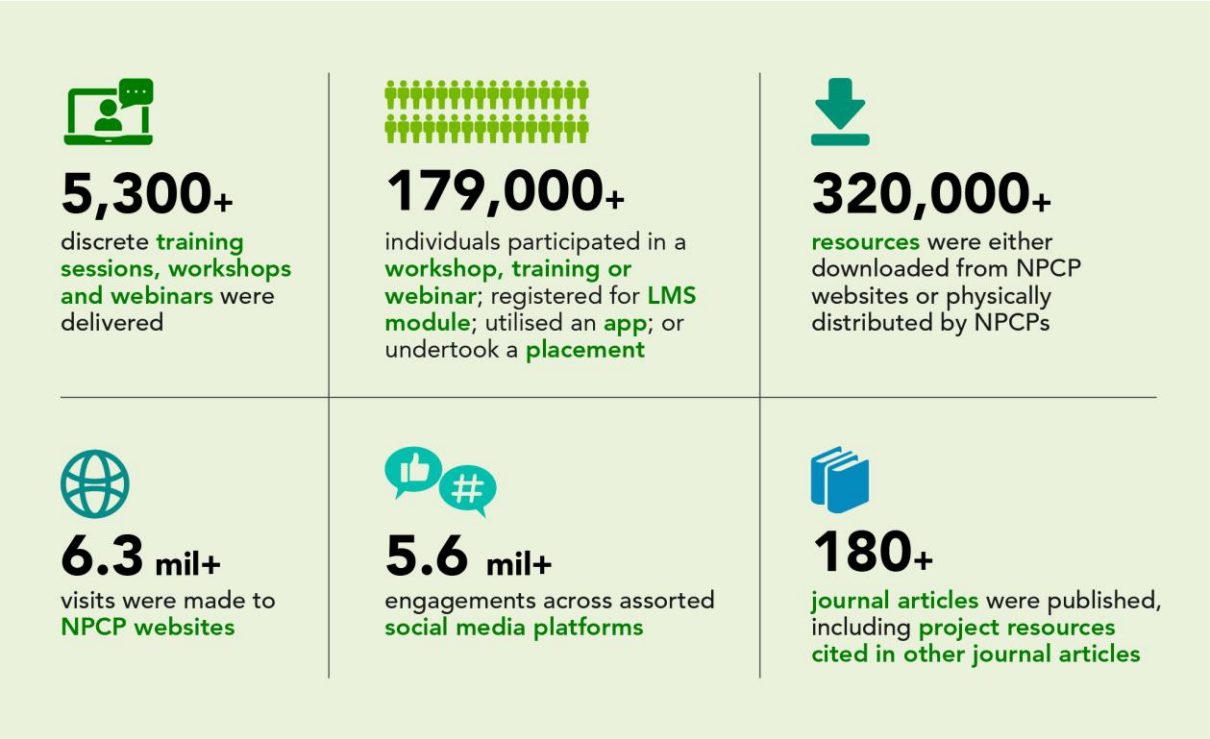
- Pre- and post-training data shows the program increased palliative care knowledge and confidence across the workforce. This finding was consistent across interviews, survey data, and project reporting.
- Placement-based and interactive learning was more effective in prompting changes in clinical practice than online learning alone.
- The program produced a suite of resources that are used and trusted by the workforce. These resources were described by rural and remote providers as the only nationally available, evidence-based support for their palliative care work. Resources developed through co-design were more relevant and more used.
- The volume of resources available has created navigation difficulties. End users described spending significant time finding what they needed.
- There is qualitative evidence of practice change across aged care, home care, and community settings. This includes services shifting from managing palliative care reactively to embedding it in care planning from admission. ELDAC's Linkages program provides systematic pre- and post-data, showing improvement across all assessed indicators. A further, more durable form of change is the embedding of palliative care into medical and university curricula, which will support the palliative care capability of the future workforce.
- Community uptake of advance care planning has been slow. Workforce training and awareness-raising has been delivered, but a longer term cultural shift of social norms around death and dying will be required before population level change is observable.
- Program reach to Aboriginal and Torres Strait Islander communities was described as insufficient relative to need.
- PCOC is the only project for which patient-level outcome data is available and shows consistent improvement over time.
- For most other projects there is no available patient outcome data. Available evidence is limited to outputs and reach, and qualitive reports of improved workforce practice. Without outcome data it is not possible to assess whether the investment was proportionate to need and there is limited ability to assess broader outcomes.

3.1 Outputs and activities

The NPCPs and ELDAC delivered a substantial volume of activity across both funding rounds. Figure 8 provides a snapshot of outputs across the portfolio during the evaluation

period, giving context for the findings that follow. The sections below assess what these activities achieved for the workforce, for services, and for people at the end of life.

Figure 8: Project outputs and activities



3.2 Workforce knowledge, confidence and capability

Improving palliative care knowledge and confidence across the health and aged care workforce was a central intended outcome of the program. This subsection assesses the evidence that projects achieved this.

The program demonstrated improvements in workforce knowledge and confidence

A consistent finding across interviews, survey responses, and project reporting is that the NPCPs and ELDAC have increased palliative care knowledge and confidence among health professionals, particularly those working outside specialist settings. This finding was confirmed by most interview participants (approximately 80% of interview sources) and is corroborated by pre- and post-training data from projects:

- End of Life Law for Clinicians collected pre-training surveys from over 8,000 people (ELLC Final Report, 2023). Post-training results, published in peer-reviewed literature, showed mean legal knowledge scores rising from 5.65 to 7.92 out of 10 following module completion, with statistically significant improvements across all five assessed legal domains and median confidence moving from "not confident" to "confident" (Feeney et al., 2023).

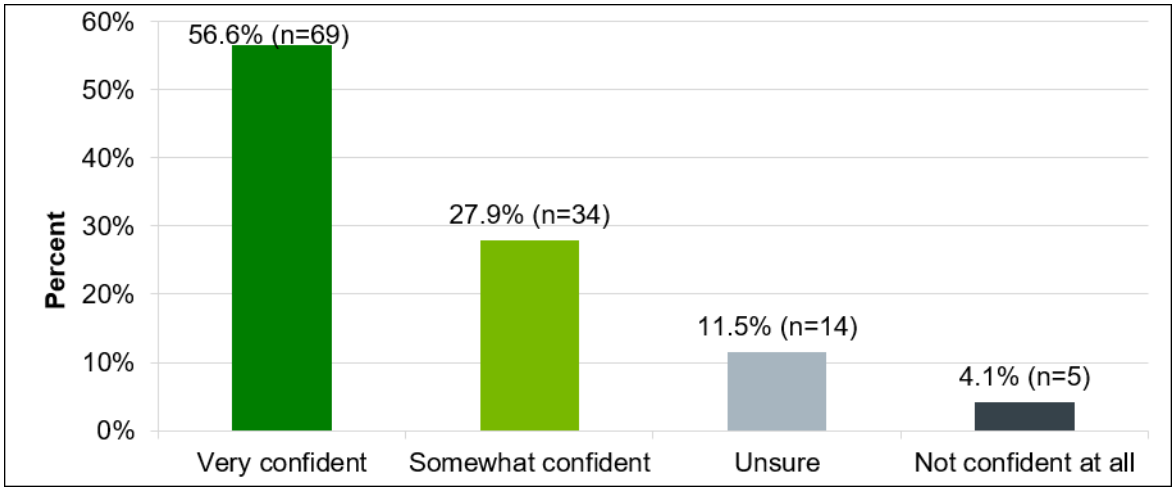
- End of Life Essentials reported consistent increases in knowledge, skill, and confidence across module completions, and is conducting a retrospective audit in

which learners describe specific practice changes the training produced (EoLE Final Report, 2023).

- The Education and Assessment of Psychosocial and Existential Wellbeing project found cumulative mean improvements in clinician confidence across a suite of skills ranging from 10.99 to 42.89%, based on pre- and post-training assessment from 501 participants (PeSAS Independent Evaluation, Moore, 2023).

The findings of the workforce survey conducted as part of this evaluation align with this (Figure 9). Most survey respondents (56%) reported being very confident that their capacity to deliver improved palliative care had been enhanced through project engagement, with a further 28% reporting that they were somewhat confident.

Figure 9: Workforce survey respondents' confidence that their capacity to deliver improved palliative care to patients has been enhanced through project engagement



Improvements in knowledge and confidence were reported across all respondent types, including specialist clinicians, generalists, aged care staff, community care workers, pharmacists, and paramedics. Several attributed significant shifts in their practice to project engagement, both at the individual level and in terms of observed changes in colleagues and teams.

> *"I had no confidence prior to doing this training. It has completely transformed my practice." (Community care worker)*

> *"I know from the feedback of clinicians I train, that the End of Life Essentials modules increase their knowledge and confidence in providing palliative care and end of life care. I receive very positive feedback about the modules." (Palliative care nurse educator)*

Many interview participants considered that placement-based learning was more effective in producing changes in practice than online learning alone. Placement based training allows relationship-building with specialist teams, observation of real palliative care practice, and the development of confidence through doing. Several participants noted that online learning could build knowledge, but that placement and experiential learning shifted how practitioners behaved in clinical situations.

> *"Learning from online open access courses does not necessarily transfer to clinical practice. Practical application is essential." (Palliative care educator)*

This was demonstrated through the PEPA, IPEPA, and QuoCCA programs, which used placement and workshop models as their primary delivery approach (PEPA Final Report, 2023; QuoCCA Final Report, 2023). Service-level participants from aged care providers and community services described changes following placement engagement, such as registered nurses who had previously relied on hospital transfer when a resident deteriorated now managing those residents in place, with family confidence in the facility's capability as the key enabling factor.

The feasibility of placement-based learning varied by geography. Covering staff absences for off-site training was a primary barrier for rural and remote facilities, where the workforce is thinner and backfill harder to arrange. Several facilities described the reverse model (where a specialist comes to the facility rather than staff travelling out) as the most practically achievable form for their context, given the operational difficulty of covering staff absences for off-site training.

> *"The reverse placement in particular provided lots of education and improved understanding on how we can better promote the importance of advance care planning." (Community care provider)*

However, this model has limits in the most remote and under-resourced contexts, where a single part-time trainer may be responsible for an enormous geographic area, making meaningful and sustained community relationships very difficult to maintain at current resourcing levels.

Interactive learning reduced professional isolation and enabled peer collaboration on emerging issues

Many interview participants described the value of live, interactive, collaborative formats that brought non-specialist clinicians together with specialist panels to discuss real cases. This enabled participants to ask questions, share challenges, and learn from peers across jurisdictions. Project ECHO used this model and was reported to grow from 30 attendees in its first national session to over 258, reaching all states and territories (Project ECHO Final Report, 2023). Nearly half its attendees were already working in palliative care, creating a community of practice.

The value of the live format was particularly evident where voluntary assisted dying was legalised. A national session convening all state-based voluntary assisted dying clinical leads attracted over 200 attendees; almost double the usual audience. Participants were able to ask questions of people who had implemented voluntary assisted dying frameworks in their own jurisdictions in real time. This enabled immediate peer response to a real time policy development issue.

3.3 Access to high-quality palliative care information and resources

A key intended outcome of the program was that the health and aged care workforce, and the community more broadly, would have access to high-quality, relevant, and usable palliative care information. This subsection assesses the extent to which this was achieved.

The program produced a suite of resources that are used, trusted, and embedded in practice

Most interview participants (approximately two thirds) stated that the program had provided them with resources they used regularly and trusted in their day-to-day practice. CareSearch, End of Life Essentials, PalliAGED, and ELDAC's toolkit suite were frequently named resources across both project-lead and service-level interviews. PEPA and Caring@Home were the projects most frequently cited for their education and practical support activities respectively. Participants described these resources as valuable due to a rigorous and continuously updated evidence base, practical clinical orientation, and accessibility across different settings and levels of expertise.

> *"The Caring@Home kit is fantastic, easy to teach with and the app has the right mix of information required by prescribers to start with the basics." (Pharmacist)*

Further, CareSearch was described by many participants as core infrastructure (rather than a 'project') as it had become embedded in clinical practice. This was valued by evaluation participants as it maintains a systematic review collection across all palliative care domains with automated harvesting and formal quality review, keeping content current.

End of Life Essentials was identified by specialist clinicians in acute settings as the resource they used to onboard new staff and reach generalist clinicians outside specialist services, with the quality of its embedded videos identified as particularly valuable for demonstrating communication skills.

PalliAGED was valued by aged care staff for being pitched at the right level, using straightforward language, having a practical focus, and being appropriate for care workers rather than clinicians. This was considered important, as the aged care workforce is composed mainly of personal care workers who often find clinician-facing resources inaccessible.

End of Life Law for Clinicians is the only program dedicated to legal knowledge for end-of-life clinicians. A pre-post survey of module participants found that 82% had not undertaken any other recent continuing professional development on end-of-life law before completing the modules, confirming that ELLC is addressing a gap not covered by other training (Feeney et al., 2023).

Resources reached a substantial and growing audience across the sector

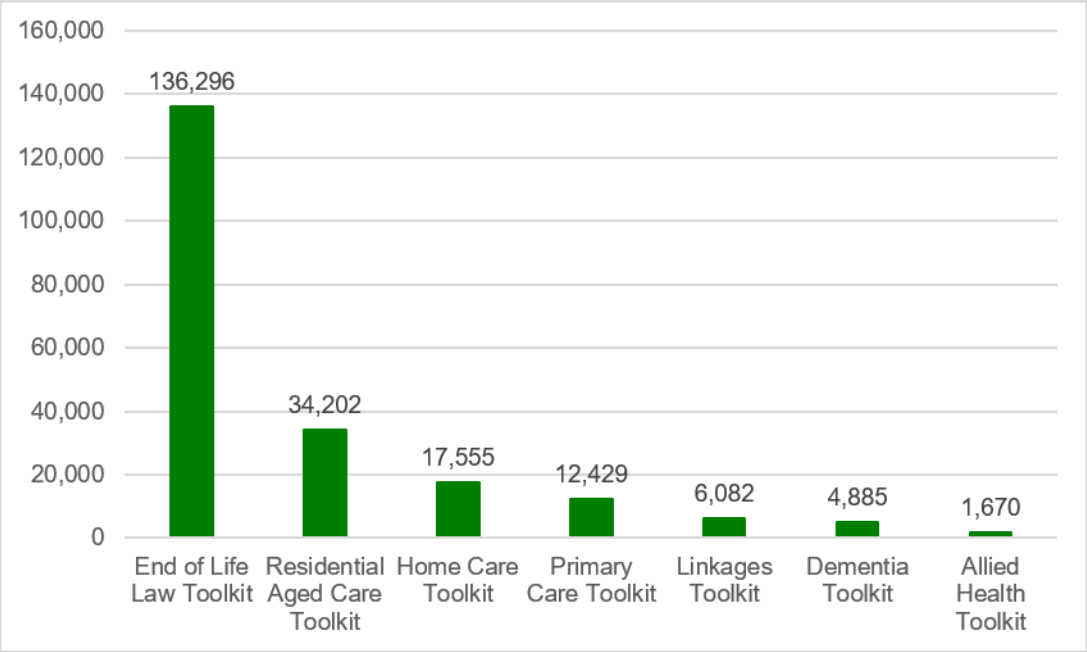
Project reporting data indicates that resources produced by the program achieved significant reach across the health and aged care workforce during the evaluation period. For example, CareSearch reported over five million website visits across both rounds (CareSearch Final Report, 2023). End of Life Essentials reported 94,000 module completions by 39,000 learners across the 2020-23 round (EoLE Final Report, 2023). PCC4U achieved integration

into 93 percent of entry-to-practice university courses. ELLC delivered 50 workshops nationally to over 4,100 attendees alongside its online modules (ELLC Final Report, 2023).

ELDAC's toolkit suite provides the most detailed reach data available (Figure 10). Across Phase II (2020–23), the suite reached over 210,000 users, with the End of Life Law Toolkit the most heavily used, reflecting the sustained demand for voluntary assisted dying-related legal guidance as legislation rolled out progressively across states and territories (ELDAC Performance Report 6, 2023).

The After Death Audit was the most downloaded single resource, with 6,346 downloads. This is a quality improvement tool that requires engagement from a service. Interviews indicated that people downloaded this resource to use for practice improvement.

Figure 10: Cumulative Phase II users by ELDAC toolkit



Source: ELDAC Performance Report 6, 2023. Users = unique IP addresses per Google Analytics.

Service-level interviews found that for many parts of the workforce these resources filled a gap that no other source was meeting. Survey respondents in remote and regional settings described specific resources (particularly Caring@Home's clinical resources and the ELDAC toolkit suite) as the only nationally available, evidence-based support for the palliative care work they were doing.

> *"These resources are part of the essential infrastructure for palliative care provision and provide us with free access to the tools that we need as part of a palliative care community of practice. This is absolutely essential for a team that is remote." (Remote palliative care clinician)*

Resources developed through co-design with end users were more relevant and more used

Project representatives described co-design with end users as producing resources that were more relevant, more usable, and more likely to be adopted in practice than those developed through expert-led processes alone. Project personnel stated that co-design processes identified needs that health professional-led design processes would likely not

have otherwise been anticipated. This included practical challenges that only became visible through direct engagement with carers, community members, and people with lived experience of the conditions being addressed.

Service-level participants described the difference co-design made to how useful they found resources in practice. Resources designed without community input were described as not working well for all priority populations, particularly for aged care facilities with high proportions of residents from CALD backgrounds, where national resources tended to assume a mainstream Australian cultural relationship with death and dying that did not fit their context. Co-design with these communities was identified as an area requiring more deliberate and better-resourced investment in future rounds. The design principles underlying effective co-design are discussed further in section 5.2.

Finding the right resource from a large and growing suite was not always straightforward for end users

While individual resources were valued, service-level interviews found that the large number of projects and resources had created confusion and navigation fatigue for some end users. For example, a clinical nurse educator described spending a large portion of their palliative care workshops teaching staff how to navigate the available resources. Several clinicians independently described assembling their own informal resource guides or internal intranet pages to help colleagues find what they needed.

> *"I've got a whole page I've built on our intranet. You need to teach people how to find the resources they need. That's a sign something's not working at a system level." (Clinical nurse educator)*

This may indicate an issue that has arisen as the program has grown organically across multiple funding rounds without a coordinating architecture to help users navigate what exists and what is relevant to their context. This is discussed further in section 7.2.

3.4 Changes in organisational practice and capability

An intended outcome was improving the quality of palliative care service delivery. This includes not just building individual knowledge, but changing what organisations do and how care is delivered.

Qualitative evidence indicates that project engagement prompted organisational change

Service-level interviewees described organisational changes that they attributed to their engagement with projects, particularly ELDAC, PEPA, and Caring@Home. Multiple participants from aged care facilities described a shift from palliative care being something that happened when a resident was actively dying (often managed through hospital transfer) to something that began at admission, was embedded in care planning processes, and was owned by all clinical staff rather than deferred to a specialist.

The interviews identified specific examples of practice change, such as staff who had previously defaulted to hospital transfer when families pushed back on palliative care now having the language, the clinical tools, and the confidence to have those conversations and

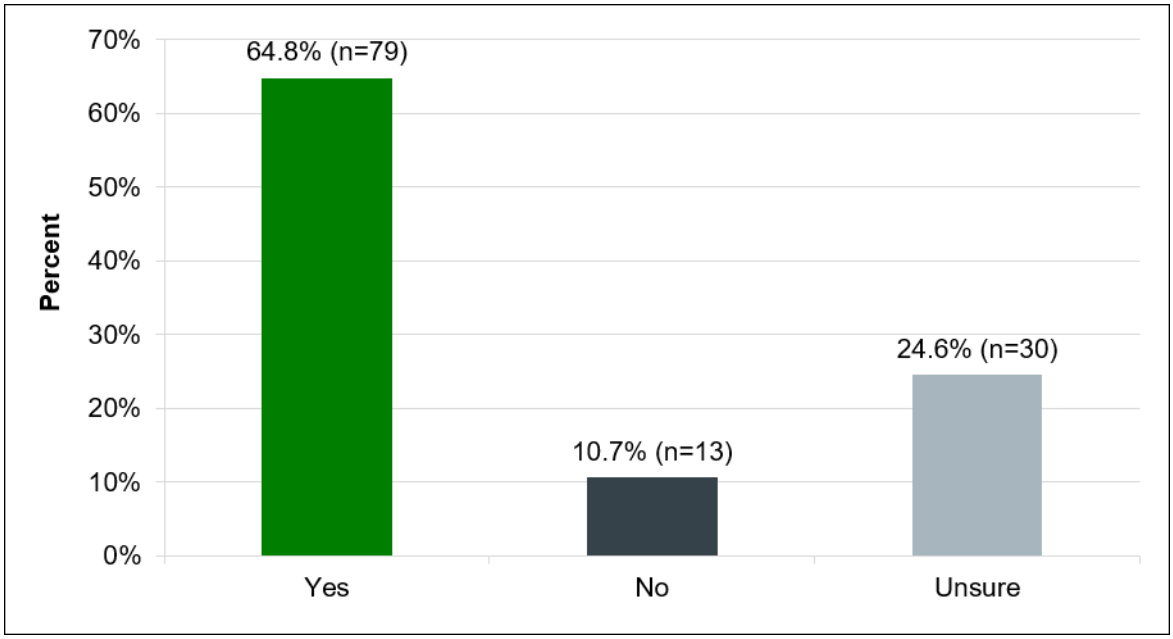
maintain a palliative approach. Several aged care staff described changes in where their residents die, with more dying in the facility in previous years. Participants attributed this shift to the support and structured accountability that engagement with the program had provided.

> *"We are now known as a good place for palliative care. We take referrals from the hospice. That is a real change from where we were."*
> *(Aged care facility manager)*

> *"I think if you're wanting a metric to say, has it been effective? I can definitely say it has. Whether it was the guidance, the support, the tools, the integration, we have shifted. That's been a really big win."*
> *(Aged care manager)*

This aligns with the perception of the workforce. Most survey respondents (64.8%) reported improved standards of palliative care within their organisation as a result of project engagement (Figure 11).

Figure 11: Workforce survey respondent's view on whether the standard of palliative care within their organisation improved due to engagement with NPCPs/ELDAC



In the open text questions, survey respondents described shifts in their organisation's practice, such as the introduction of new palliative care frameworks, policies, and procedures that had changed how the entire organisation approached end-of-life care rather than just upskilling individual staff members. Others described increases in family satisfaction, with families noticing and commenting on improvements in how staff communicated about and managed the dying process.

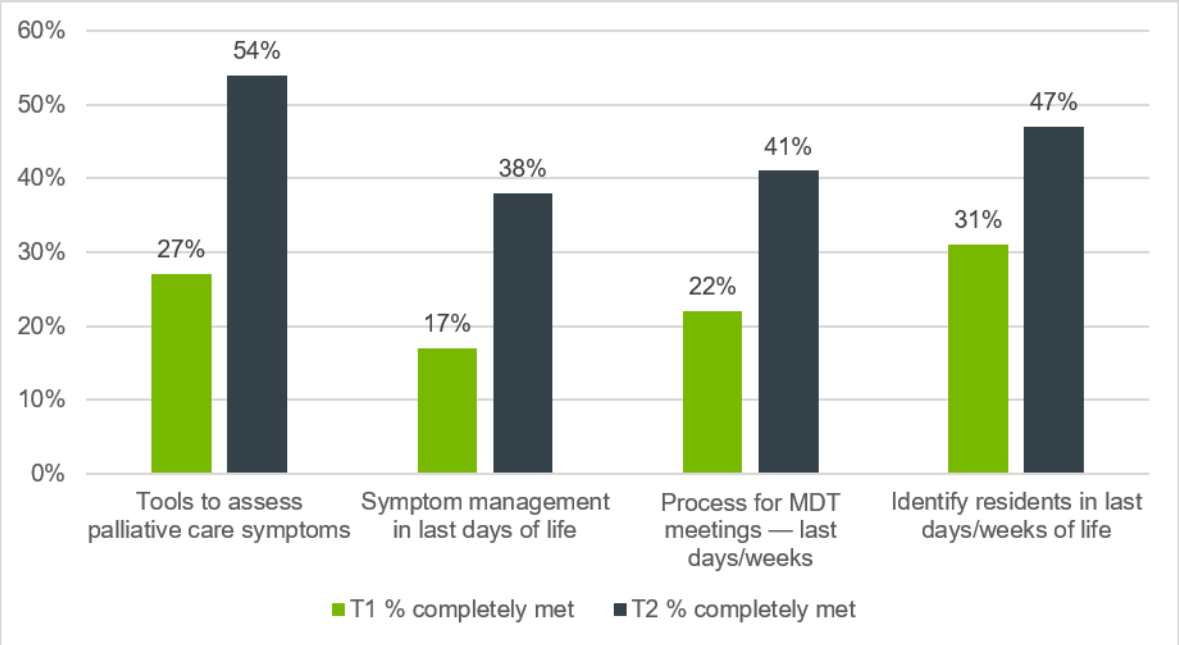
ELDAC's Linkages program provides documented evidence of organisational change

While there is qualitative evidence regarding organisational change from engagement with NPCPs or ELDAC, there is little quantitative evidence available. ELDAC's Linkages program is the only project with systematic pre- and post-implementation data collection. Audit data (presented in Figure 12) collected from 107 aged care services across Phase II shows

consistent improvement across all domains of the Organisational Audit and After Death Audit (the two instruments used to measure organisational palliative care capability) after Linkages engagement (ELDAC Performance Report 6, 2023).

The most substantial improvements were in the Clinical Care domain. The proportion of services that had completely met the standard for using tools to assess palliative care symptoms rose from 27% to 54% over the six-to-twelve-month engagement period. Services with a process for multidisciplinary team meetings in the last days and weeks of life rose from 22% to 41% over the same period.

Figure 12: ELDAC Linkages selected pre- and post-program improvements, Organisational Audit (Groups 2 and 3, n=94 T1; n=93 T2)

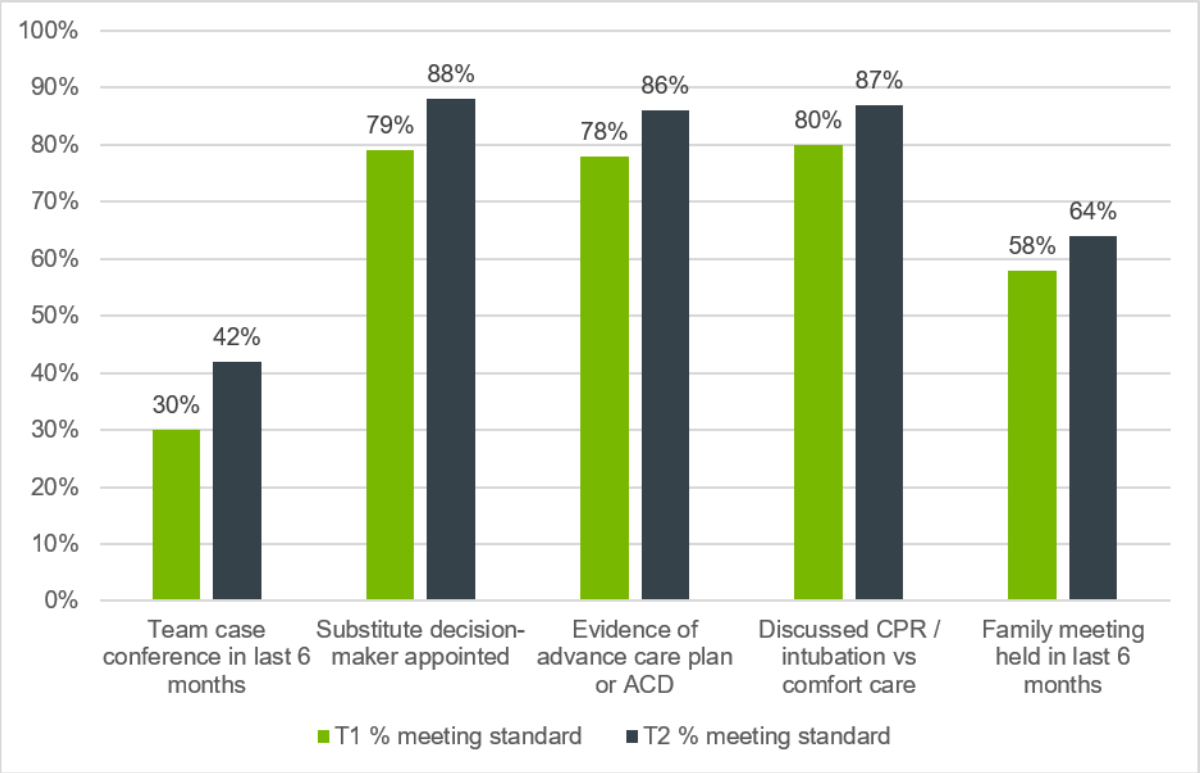


Source: ELDAC Phase II performance reports, PR6 Figure 4.

The After Death Audit (

Figure **13**) showed improvements in advance care planning documentation, family meeting frequency, substitute decision-maker appointment, and team case conferencing. The largest improvement was in team case conferences held in the last six months of life, rising from 30% to 42% over the six-to-twelve-month engagement period.

Figure 13: ELDAC Linkages selected pre- and post-program improvements, After Death Audit (Groups 2 and 3, n=348 T1; n=336 T2)



Source: ELDAC Phase II performance reports, PR6 Figure 5

These improvements cannot be attributed solely to ELDAC, given concurrent reforms during this period. The Royal Commission into Aged Care Quality and Safety, the revised Aged Care Quality Standards, and the Australian National Aged Care Classification funding changes all created pressure on aged care providers to improve their palliative care practice. However, qualitative evidence from the stakeholder engagement indicates that ELDAC was viewed by the aged care workforce as supporting their organisation to improve its practice.

Embedding palliative care into education pipelines contributes to system-level change that may compound over time

In addition to supporting service-level change, several projects aimed to embed palliative care into the education systems that will shape the future workforce. For example, PCC4U achieved integration into 93% of entry-to-practice university courses nationally (PCC4U Final Report, 2023), meaning that the majority of health professionals entering the workforce will now have some exposure to palliative care principles before they begin practising. Similarly, ELLC embedded its modules into nine undergraduate medical school curricula, ensuring that end of life law is part of the foundation knowledge of future cohorts of doctors rather than something they encounter only if they seek it out later in their career (ELLC Final Report, 2023).

As these are investments in the future workforce pipeline, their impact will not yet be visible in the data available to this evaluation. However, interviewees with careers in palliative care education emphasised the lack of palliative care from undergraduate training has previously been a barrier to a generalist workforce that is confident and knowledgeable about palliative care. Access to ongoing funding through the NPCP created the conditions for projects to embed their content into institutions.

"The next generation of health professionals is being educated in an area which traditionally hasn't been a focus. They're coming into practice prepared to confront common legal issues at the end of life. That is quite significant compared to, say, a doctor who might have been practising for 30 or 40 years." (Project representative)

3.5 Patient and carer outcomes

The overall purpose of the NPCP and ELDAC is to improve the experience and outcomes of people at the end-of-life and those who care for them. This subsection assesses what the evaluation can say about impact at the patient and carer level.

Patient-level outcome measurement is not feasible or appropriate for most individual projects

Most NPCPs and ELDAC-funded activities were not designed around direct service delivery to patients or carers; their focus is on workforce education, resource development, sector coordination, or awareness-raising. As such, direct measurement of patient outcomes was not always feasible or appropriate for these projects, and collecting such data may raise ethical, consent, and governance considerations disproportionate to a project's scope and resourcing.

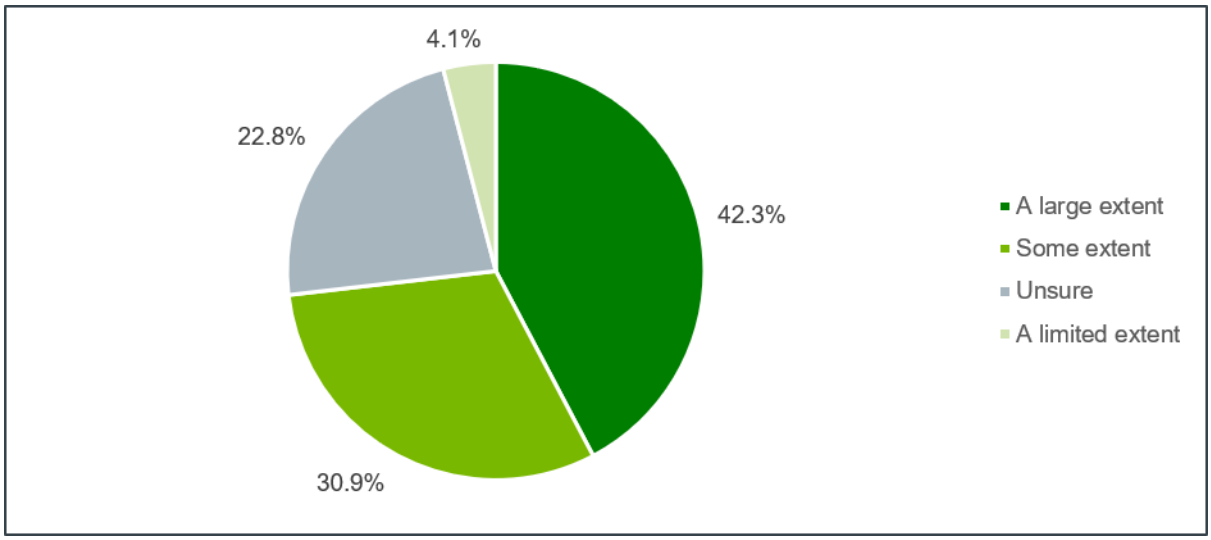
Population-level outcome measurement for palliative care nationally is supported through PCOC and PACOP. PCOC is the one project in this evaluation for which patient-level outcome data is available (discussed below), reflecting that outcomes measurement is intentionally embedded in its design. PACOP is a voluntary quality improvement program in which participating aged care homes submit assessment data every six months, receiving individual and organisational benchmarking reports to support continuous improvement in palliative and end-of-life care.

Service providers described improvements in end-of-life care that they attributed to program engagement

In the qualitative interviews, service providers described changes in care practice, that they are more confident, and have improved the experiences of people in their care. This included multiple aged care facilities stating that more residents now died in the facility rather than being transferred to hospital. Home care providers described being able to support clients through the dying process at home where they would previously have had to refer to residential settings.

Most survey respondents (73%) agreed to some or a large extent that the program had improved quality of life for people receiving palliative care and their families and carers, with only 4.1% feeling this had been achieved to a limited extent (Figure 14).

Figure 14: Workforce survey respondents' perceptions of the extent NPCPs and ELDAC have improved quality of life for people receiving palliative care, families and carers



Open text survey responses described practices that had enhanced quality of care for patients and carers. Improved staff knowledge had led to better conversations with patients and families about dying; better conversations had led to fewer unnecessary hospital transfers; and better resources had enabled carers to support people dying at home more confidently. Several respondents described outcomes such as improved family satisfaction and anticipatory medications put in place earlier that they attributed to program engagement.

> *'It's been hugely impactful. It made me more aware of the gaps in my practice and others in my team and made me want to act on it. Having resources sparked quality improvement ideas and implementation was made easier because we don't have to re-invent the wheel." (Aged care staff)*

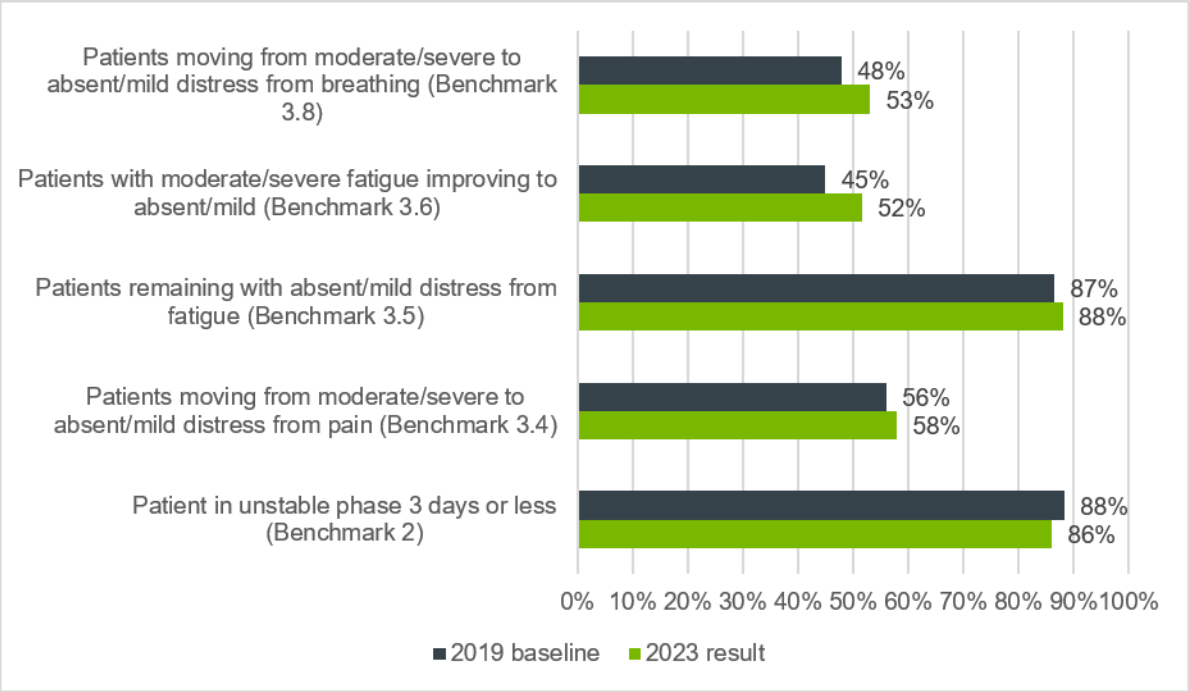
Several interviewees stated that there was a need for investment in health economic analysis as a more tractable way of demonstrating the program's value, noting that preventing one hospitalisation at end of life generates more savings than the cost of many palliative care interventions. The scale of palliative care hospitalisations in Australia (94,800 in 2021–22, with an average length of stay of 10.3 days) suggests the economic case for investment in community-based capability may be substantial (AIHW, 2023).

Patient-level outcome data for PCOC shows improvement over time

PCOC is the only funded project for which longitudinal, patient-level outcome data is available. Its benchmarking data, collected from over 200 services and encompassing 90,000 episodes of care in 2023, shows consistent improvements in pain management, symptom control, and psychological wellbeing for people receiving palliative care (PCOC Final Report, 2023; AIHW, 2023). The number of participating services rose from 101 in 2014 to 219 by June 2023, and the number of patients receiving palliative care from participating services rose from 47,214 to 70,067 between 2019 and 2023 (AIHW, 2023).

Figure 15 shows benchmark improvements across five key indicators for the period 2020–23, with the most substantial gains in fatigue management (45 to 51.6%) and breathing-related distress (47.9 to 53.1%) (PCOC Final Report, 2023).

Figure 15: PCOC selected benchmark improvements, 2020-23



Source: PCOC Final Report 2020–23; AIHW Palliative Care Services in Australia, 2023.

3.6 Advance care planning

Strengthening advance care planning was an intended outcome of the program. This subsection assesses the evidence of progress.

The program contributed to workforce capability in advance care planning, with community uptake remaining slow

ACPA and ELDAC were the primary projects addressing advance care planning, supported by Caring@Home and the Advance Project. ACPA reported that 84% of workshop participants improved their ability to assist people with advance care planning, and the National Advance Care Planning Support Service recorded satisfaction of 83% among clinicians and 96% among consumers (ACPA Final Report, 2023). ELDAC's After Death Audit showed that the proportion of services with evidence of an advance care plan or advance care directive for their residents rose from 78 to 86% across the Linkages program (ELDAC Performance Report 6, 2023).

Despite this progress, the qualitative engagement conducted as part of this evaluation indicated that community uptake of advance care planning has been slow. Stakeholders described this as an ongoing challenge that the program has not yet resolved. Issues included a resistance to discussing death and dying that was ingrained across many population groups, with the discomfort extending in some contexts to the health and aged care workforce itself.

Interviewees stated that the awareness-raising and workforce training activities delivered by projects are important, but insufficient on their own to shift population-level advance care planning uptake. They noted that changing social norms around death requires community-level effort over a long period of time, and that the time horizons required to shift community attitudes are lengthy. This finding applies across the program but is particularly relevant for advance care planning, where the objectives include a cultural shift in how Australians relate to death and dying.

> *"We're only just now, five to six years on, able to have more of those conversations around end of life. It's a very hard nut to crack. People don't want to talk about it. We're slowly getting there, it's just that stigma around end of life is very difficult." (Project representative)*

Inconsistency in advance care planning legislation across jurisdictions remains a structural barrier

Advance care planning is governed by state and territory laws rather than Commonwealth legislation, creating inconsistent legal requirements across jurisdictions. Interviewees noted that these differences can create practical challenges. The terminology used for advance care documents varies across jurisdictions. What is called an 'Advance Care Directive' in one jurisdiction may be called an 'Advance Health Directive' or a 'Medical Treatment Decision' in others. The legal status of documents prepared in one jurisdiction when a person moves to or receives care in another is not always clear. The witnesses required, the forms to be used, and the circumstances under which a document can be overridden all differ. For clinicians working across state borders, or for people who move interstate in their final years, this inconsistency creates confusion.

For nationally funded projects, this creates a challenge, in that resources and training developed for a national audience must either be generic enough to apply across all jurisdictions (which risks being too vague to be clinically useful) or jurisdiction-specific (which multiplies the resource development burden and limits reach). To address this issue, ACPA engaged with health departments to map these variations and improve communication around ACP systems and processes (ACPA Final Report, 2023), and ELLC developed dedicated content on the legal dimensions of advance care directives for each jurisdiction (ELLC Final Report, 2023). However, the underlying jurisdictional fragmentation sits beyond any project's capacity to resolve and may require a policy response.

3.7 National data and quality improvement infrastructure

Nationally consistent data collection and quality improvement was an intended outcome of the program.

Progress toward nationally consistent data collection has been uneven

The 2019 NPCP evaluation (Urbis, 2019) and the 2020 ELDAC evaluation (HealthConsult, 2020) both identified the absence of consistent, project-level outcome data as a weakness of the program. This finding is echoed in the current evaluation. Most projects in the 2020-23 portfolio continued to measure reach, activity and participation, with some projects also

measuring changes in knowledge, confidence, capability or organisational practice. However, measurement of sustained practice change and patient or carer outcomes was not consistent across the portfolio. It was strongest where outcome measurement was built into the project design from the outset, as with PCOC and ELDAC's Linkages program. While some projects produced evaluation-related publications, reviews or project outputs, there was limited evidence of standalone, publicly released independent evaluation reports that assessed outcomes in a way that was comparable across the portfolio.

National palliative care data published by the AIHW covers service usage, aged care needs, workforce statistics, and expenditure, but gaps in coverage and timing, combined with the complexity of the health system, make it difficult to link specific projects to system-level changes (AIHW, 2023). Attribution of national trends to individual projects is not possible from available data, and has not been attempted in this evaluation.

Several projects made progress in connecting their work to national reporting mechanisms. The Improving Palliative Care Services for People with Intellectual Disability project engaged with PCOC to explore introducing intellectual disability into national datasets, and ACPA discussed opportunities with the AIHW and PCOC to develop advance care planning indicators for national reporting. These are positive steps toward a more integrated national data picture.

PCOC is the only project in which outcome measurement was built into its design from the start. Its steady growth in participating services (from 101 in 2014 to 219 by June 2023) has expanded national coverage, and its benchmarking infrastructure now functions like a national palliative care quality dataset (AIHW, 2023).

> *"PCOC has helped us shift our quality improvement programs. It's been useful to benchmark the care in the ward and the changes in quality of care." (Health service representative)*

The department's introduction of draft performance indicators in the 2023-26 round, including patient outcome measures, represents a step toward addressing the absence of outcome measurement across most projects. Future funding rounds would benefit from outcome measurement being resourced, mandated, and built in from the start.

3.8 Reach to underserved populations

The Grant Opportunity Guidelines identified eight priority population groups: Aboriginal and Torres Strait Islander people; people from CALD backgrounds; LGBTIQ+ communities; people with disability; people with dementia; people in long-term institutional care; people living in rural and remote areas; and people who are ageing and frail. Table 4 in section 2.2 maps portfolio coverage against each of these groups. This subsection assesses the evaluative evidence of what reach was achieved to priority populations and where gaps remain. As was reported in section 2.2, the program invested in reaching a range of underserved populations across both rounds:

- Aboriginal and Torres Strait Islander communities were addressed by multiple projects including Gwandalan, IPEPA, and Caring@Home's Northern Territory resources. However, as discussed below, interview evidence indicates that the reach

and impact of these projects in communities with the greatest need was limited, and the scale of investment has not been commensurate with the scale of need.

- LGBTIQ+ people had a dedicated project in the 2020–23 round and continued resource coverage in 2023-26.
- People living with intellectual disability were supported through a dedicated project that developed clinically practical, co-designed strategies for health professionals.
- People in rural and remote areas were reached through PEPA placements, Project ECHO's national sessions, and CarerHelp's rural connect initiative.
- People with dementia were addressed through the Advance Project and ELDAC's Dementia Toolkit.
- People in long-term institutional care were addressed through the Palliative Care in Prisons Project.
- People who are ageing and frail were the primary focus of ELDAC, PEPA, Caring@home, and End-of-Life Essentials across both rounds.
- People experiencing homelessness had no dedicated project, despite being identified in the guidelines as a priority group. The settings in which projects operated, including primary care and hospitals, may have generated some indirect benefit, but this cannot be assumed and ways to reach this population group could be considered in future round design.

Project reporting provides evidence of the outputs targeted at population groups, but little about the effectiveness of these activities

Several projects delivered targeted activities for specific priority populations, and project reporting provides evidence of the outputs and reach achieved. Where interview participants described impact, it was primarily for people who are ageing and frail in aged care settings and for Aboriginal and Torres Strait Islander families who had engaged with Caring@Home's co-designed resources.

For most other priority populations, the available evidence is of outputs and activities rather than demonstrated outcomes, reflecting the broader measurement limitations discussed in the methodology section of this report. Examples of outputs and the success in reaching priority populations include:

- The Advance Project delivered dementia-specific training and resources in direct response to identified gaps in advance care planning and palliative care access for people living with dementia. It substantially exceeded its targets: 1,383 people registered for resources against a target of 400, and 998 participants enrolled in eLearning courses against a target of 200 (Advance Project Final Report, 2023). Aged care and primary care staff reported improvements in knowledge and confidence following engagement with the project's tools and training.

- Caring@Home for Aboriginal and Torres Strait Islander Families distributed over 600 Palliative Care Clinic Boxes nationally, with evaluation data showing improved symptom management and more standardised, person-centred care (Caring@home Final Report, 2023). The resources were praised for their cultural relevance, which interviewees attributed to the two rounds of consultation with participants across all states and territories that informed their design.

- The Improving Palliative Care Services for People with Intellectual Disability project provided evidence on access and outcomes for this population, co-designed and trialled a tailored model of care supported by a sector-wide toolkit, and established a mechanism for future routine data collection (Improving Services Final Report, 2023).

- PEPA delivered 12 workshops on palliative care for people with disability across the 2020–23 round, attended by 142 participants, with post-workshop surveys showing consistent improvements in knowledge, confidence, and willingness to recommend the training (PEPA Final Report, 2023).

- For people in rural and remote areas, QuoCCA delivered 52 education sessions in outer regional, remote, or very remote locations across the 2020–23 round **(**QuoCCA Final Report, 2023). End of Life Law for Clinicians received Australian College of Rural and Remote Medicine accreditation, extending its reach to rural clinicians through their professional development framework (ELLC Final Report, 2023). Survey respondents in rural and remote settings described the projects as filling a gap that no other source was meeting.

Taken together, these examples show that the program invested in reaching priority populations and, in several cases, substantially exceeded its targets for doing so. However, with the exception of the ELDAC Linkages evidence for people who are ageing and frail, and the Caring@Home evaluation data for Aboriginal and Torres Strait Islander families, the evidence base stops at outputs and reach and is not able to demonstrate what changed for people in these groups as a result of the program.

This is a significant limitation, because without outcome data it is not possible to assess whether the investment was proportionate to the scale of need, or whether the approaches used were the most effective available. Strengthening outcome measurement for priority population groups should therefore be a design requirement for future rounds.

Reach to Aboriginal and Torres Strait Islander communities was described as insufficient relative to need

Despite multiple projects targeting Aboriginal and Torres Strait Islander communities (Gwandalan, IPEPA, Caring@home for Aboriginal and Torres Strait Islander Families, ELLC Module 12, and ACPA), interview data indicates that there was a gap between intent and impact for this population. Aboriginal and Torres Strait Islander people experience life-limiting illness at a younger age than non-Indigenous Australians and are nearly twice as likely to be hospitalised for palliative care (AIHW, 2023).

However, there was a view amongst interviewees that the scale of investment in reaching this population has not been commensurate with the scale of need. For example, an aged care worker who had worked across NT aged care facilities (where Aboriginal and Torres

Strait Islander people make up a substantial proportion of residents) described being aware of only two of the national projects from the full suite. A Primary Health Network representative working in a region with high First Nations population stated that GPs are largely unaware that specialist palliative care services existed. In jurisdictions with the most significant First Nations palliative care need, the national program's footprint was described as partial at best.

> *“We never saw outcomes on the ground for mob." (First Nations palliative care leader)*

Interviewees described cultural barriers to engagement in remote First Nations communities, including concerns about morphine being seen as a ‘cause’ rather than a ‘manager’ of death, beliefs about blame and responsibility for a person's dying and the significance of where a person dies in relation to Country and ceremony. Addressing these barriers requires the development of resources through co-design with communities, engagement of senior First Nations palliative care leaders that are properly resourced and remunerated, and accountability mechanisms that close the loop between advice given and action taken. Caring@Home's NT discussion cards were cited as an example of what this looks like in practice.

4 ALIGNMENT WITH SECTOR REFORMS AND FUTURE NEEDS

KEQ3: Considering recent and future health and aged care reforms, are NPCPs and ELDAC targeting the right areas?

Main messages:

- The program is investing in relevant domains, targeting education, resource development, advance care planning, data and quality improvement, and workforce capacity.
- The aged-care reform agenda has increased and clarified providers' responsibilities for palliative and end-of-life care. The program, particularly through ELDAC, provides infrastructure, resources and quality-improvement support that align with these requirements. However, awareness and uptake remain uneven, creating opportunities to improve the visibility, application and scale of support.
- The implementation of voluntary assisted dying legislation across most states and territories created demand for workforce guidance that ELLC, End of Life Essentials, and Project ECHO responded to effectively. Opportunities exist to extend and cross-promote this existing guidance among generalist, aged-care, home-care and community workforces, complementing the implementation responsibilities of states and territories.
- Home and community settings are important to palliative and end-of-life care. The program contributes through Caring@home, ELDAC, CarerHelp, PEPA and other projects that build community workforce capability and support carers. Stakeholders supported extending the reach, coordination and scale of this work.
- The end-of-life care allocation under Support at Home is an opportunity for the program to demonstrate its value. Providers who had engaged with ELDAC were better positioned to use this funding effectively than those who had not.
- GP engagement remains a cross-system challenge. Aged care providers identified GP reluctance, shortage, and limited palliative care knowledge as primary clinical barriers to high-quality end of life care in their facilities.

4.1 Relevance to the sector reform context

Qualitative engagement affirmed that education, resource development, data, advance care planning, and workforce capacity are the right domains for national investment

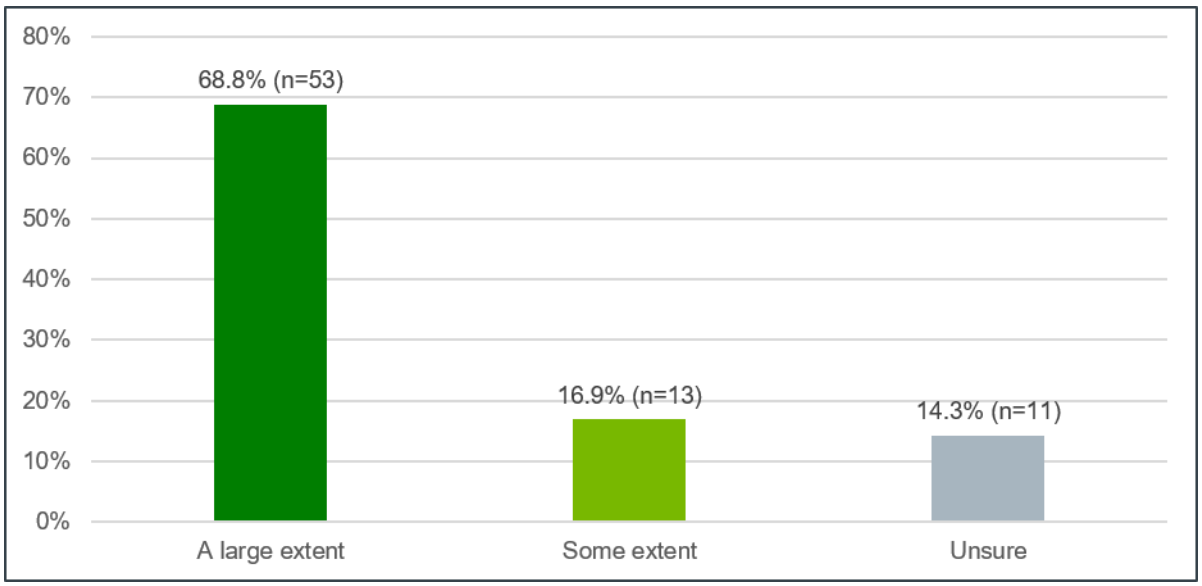
The National Palliative Care Strategy was published in 2018, before the Royal Commission into Aged Care Quality and Safety and many of the subsequent reforms, and before voluntary assisted dying was legislated across most states and territories. The Strategy encompasses many of the directions emphasised by these reforms, including care in home and community settings, coordination across services, workforce capability and advance care planning. Assessing the program's relevance therefore requires considering how its existing investments contribute to implementing the reform agenda and whether changes in

the operating environment have created opportunities to strengthen their coordination, reach or application.

The majority of interviewees agreed that education, resource development, data and quality improvement, advance care planning, and workforce capacity remain appropriate domains for national investment. The projects they identified as most important varied by stakeholder type, but several (PCOC, ELDAC, CareSearch, PEPA, and Caring@Home) were consistently cited across peak bodies, jurisdictional representatives, and service providers as valuable components of the national infrastructure.

Workforce survey findings are consistent with this view. Most survey respondents (over two thirds) strongly supported continued funding beyond the current grant period, with a further 17% agreeing to some extent. No respondents opposed continuation.

Figure 16: Workforce survey respondents' view of the extent to which funding should continue



While the program's core domains remain relevant, interviewees identified opportunities to strengthen how existing investments support the reform agenda. These related primarily to coordination across initiatives, practical implementation of established resources, reach into primary, home and community care, and the capacity to sustain and scale effective approaches. These opportunities are discussed below.

The grants portfolio supports the aged-care reform agenda, with opportunities to strengthen implementation, visibility and scale

The Royal Commission into Aged Care Quality and Safety made 148 recommendations, several of which addressed palliative and end of life care. Recommendation 2 enshrined the right of people in aged care to receive fair, equitable and non-discriminatory access to palliative and end-of-life care. Recommendation 80 called for the implementation of dementia and palliative care training for aged care workers. Recommendation 114 called for funding for education and training to improve the quality of aged care, including in dementia and palliative care. The program's investment in aged care workforce capability, dementia-specific resources, and the ELDAC Linkages program's quality improvement focus are all responsive to these recommendations. This contribution extends across the

portfolio, including projects supporting advance care planning, medicines management, workforce education, evidence access, outcome measurement and care in home and community settings.

The new Aged Care Act and the strengthened Aged Care Quality Standards have increased and clarified providers' responsibilities for palliative and end-of-life care. These include recognising when a person may benefit from palliative care or is approaching the end of life, undertaking end-of-life care planning, managing pain and symptoms, involving families and other supporters, facilitating access to specialist care, and supporting people to receive care in their preferred setting. The strengthened Standards apply in residential, home and community aged-care contexts, although provider responsibilities vary according to the services delivered.

These requirements closely align with capabilities and resources already supported through NPCP and ELDAC. The National Palliative Care Strategy and the grants program were not designed as mechanisms for implementing aged-care regulation. However, their focus on workforce capability, advance care planning, care quality, coordination and preferred place of care positions them well to contribute to reform implementation. Interviewees identified opportunities to make this contribution more visible and to connect existing projects more deliberately with the regulatory and implementation environment in which providers are operating.

Addressing the provider palliative and end-of-life care requirements was described as challenging at a time when the sector's workforce is under pressure. Aged care facility managers stated that they need practical, actionable support in navigating new requirements. This included translating what the standards require into what good palliative care practice looks like in their setting. This suggests that there is opportunity to help providers identify, access and implement existing resources and models of support, rather than a need to establish new areas of investment.

The ELDAC Linkages program was identified as the most immediately useful model because its quality improvement focus already aligns with the regulatory improvement agenda. Its facilitator model involves working alongside staff to develop tailored action plans, which those that had engaged with the project described as valuable. Future NPCP and ELDAC rounds could consider whether this model can be scaled and whether other projects can be more deliberately connected to providers' regulatory requirements and implementation pathways. This could include improving coordination between projects, avoiding multiple initiatives approaching the same providers independently, and making the respective roles and practical applications of available resources clearer.

The voluntary assisted dying legislative rollout created demand that some projects responded to well, with opportunities to extend support to general and community workforces

Approximately one third of interview sources raised voluntary assisted dying as an important area of intersection with palliative care. The End of Life Law for Clinicians project was frequently cited as having responded effectively to this legislation, updating its voluntary assisted dying content as jurisdictions progressively legislated, and generating a 94% increase in End of Life Law Toolkit users in Year 2 of ELDAC Phase II (ELDAC Performance Report 6, 2023). Other projects also responded to the legislative roll out. End-of-Life Essentials developed a voluntary assisted dying communication module for acute

hospitals, and Project ECHO convened all state voluntary assisted dying clinical leads on a live panel after ACT legalisation, attracting over 200 attendees. The pharmacist training project also worked with End of Life Law for Clinicians to develop content addressing pharmacists' legislative and regulatory responsibilities in relation to palliative care and voluntary assisted dying.

Interviewees identified opportunities to extend the reach and application of existing support, particularly among workers and organisations that do not operate primarily within specialist palliative care. Some service staff reported uncertainty about what they could and could not discuss regarding voluntary assisted dying. Others described instances in which families confused palliative care with voluntary assisted dying and clinicians felt uncomfortable navigating the intersection. These findings indicate uneven workforce confidence and awareness of available support, rather than an absence of response from the NPCPs and ELDAC.

Voluntary assisted dying legislation and its clinical implementation remain responsibilities of states and territories. The appropriate role of the program is therefore to complement jurisdictional activity through education, communication guidance, ethical and clinical support, and access to current jurisdiction-specific information. Future activity could build on and more widely promote existing project content for aged-care, homecare, disability and community-support workforces, as well as practitioners involved in advance care planning.

> *"There is a real space for a program like ELDAC to be a strong educational force for organisations like ours that don't sit in the palliative space but may come across those conversations, helping us understand what we can and can't say when someone brings up VAD with a support worker." (Community support organisation)*

Most palliative care in Australia is delivered in home and community settings, and there are further opportunities to strengthen support in these contexts

Many people prefer to receive end-of-life care and die at home or in another familiar setting. However, AIHW reported that 67% of primary palliative-care hospitalisations ended with the patient dying in hospital (AIHW, 2023). Interviewees identified home- and community-based palliative care as an area in which the reach and scale of existing support could be strengthened. They described workforce capability, coordination and access to practical support as uneven across home-care providers, general practice and other community settings, particularly when compared with specialist palliative-care services. These challenges were commonly attributed to workforce pressures, staff turnover, limited clinical infrastructure and the complexity of coordinating care across providers.

A range of projects aim to strengthen home and community-based palliative care:

- Caring@home supports symptom management and access to medicines at home
- ELDAC works with residential and home-care providers to strengthen organisational capability
- CarerHelp supports families and carers; PEPA builds generalist workforce capability
- CareSearch and palliAGED provide evidence and resources for community and aged-care settings.

Other projects, including Project ECHO, QuOCCA and the pharmacist training and service-model pilots, also build capability and coordination among community-based practitioners.

Interviewees considered that there is opportunity to extend, connect and scale this work so that it reaches more providers and is more consistently embedded in practice. This included strengthening support for GPs and home-care workers, improving referral and escalation pathways, supporting family carers, and making the respective roles and resources of different projects easier to identify. Some workforce survey respondents also called for greater engagement with community groups, carers and citizen-led initiatives.

> *"95% of our time when we die is in the context of family and friends. Yet all the resourcing focuses on the 5% of time people interact with the formal health system. The program needs to adopt a compassionate communities approach." (Sector advocate)*

The Support at Home End-of-Life Pathway provides eligible older people with approximately $25,000 for additional home-care services over a 12-week period. Interviewees identified this as an opportunity for home-care providers to strengthen palliative-care capability and help older people remain at home near the end of life. Providers that had engaged with ELDAC described themselves as better positioned to use the funding effectively because they had developed relevant policy frameworks, care-planning processes and service connections. Other providers described uncertainty about how to translate the funding into effective end-of-life care.

> *"The Support at Home funding for end-of-life care is enormously timely. But organisations need to actually know what palliative care looks like at home to use it well. That's exactly what programs like ELDAC have been building. The timing couldn't be better - or worse, depending on whether you've been engaged." (Home care provider)*

These findings support building on the program's existing home- and community-care infrastructure. Future activity could focus on extending the reach of established models, connecting projects more deliberately with Support at Home implementation, and ensuring that providers can readily identify and apply the resources and support already available.

5 DESIGN, DELIVERY AND GOVERNANCE

KEQ4: What are the key features of NPCP design, delivery and governance that lead to the best project outcomes?

Main messages:

- Collaboration across projects extended reach, improved relevance, and generated resources that were more comprehensive than a single project could have produced.
- Well-functioning consortium structures enabled projects to bring together research, policy, and practice expertise. Where accountability was clearly defined at the outset, consortia worked well. Where it was ambiguous, lead organisations sometimes lacked the authority to hold partners to account.
- Co-design with end users produced resources that were more relevant and more used.
- Projects that actively sought out their audience achieved greater reach than those that waited for the audience to find them. PHNs have established relationships across the sector and could facilitate more systematic engagement with NPCPs if engaged consistently.
- Free and open access to resources enabled equitable reach across the sector, particularly for rural and remote providers.
- Continuity of funding, through the ‘core project’ designation enabled longer term planning which led to embedded curricula, trained specialists, and mature data systems.
- The department's program governance role has strengthened over time, and is valued by project leads.
- While projects align to the shared goals of the National Palliative Care Strategy, there is no common framework for measuring progress against them. For example, multiple projects deliver education and training activities, but each uses different indicators and methodologies, so it is not possible to assess what the effort has collectively achieved across the portfolio.

5.1 Collaboration and partnerships

Collaboration across projects and with external stakeholders enhanced project reach, relevance, and impact

Collaboration and partnerships were identified as a feature of effective project design, delivery and governance. The evaluation found that both NPCPs and ELDAC demonstrated strong commitment to collaboration. Projects engaged a range of collaborative activities, including joint development of training materials, factsheets and blogs, cross-promotion of resources via websites and newsletters, and participation in multi-organisation steering committees and consortia.

> *"What I've found from inception was that all of the funded organisations were brought together on a regular basis, and there was linkage and exchange between them all and an opportunity to collaborate and work together." (Project representative)*

For example, End-of-Life Essentials attributed its success in exceeding engagement targets to partnerships with health organisations, peak bodies, and other projects, which enabled effective promotion and ensured resources were fit for purpose (EoLE Final Report, 2023). In another example, the Palliative Care Foundation Training for Pharmacists project identified during its stakeholder consultation phase that End of Life Law for Clinicians had no pharmacist-specific content on the legal and regulatory requirements for palliative care medications. Rather than duplicating ELLC's broader work, the two projects collaborated to develop pharmacist-specific modules that extended both projects' reach. In addition, PSA identified that CarerHelp's rural connect project needed consumer-facing resources explaining what community pharmacists could offer people receiving palliative care at home, and developed content specifically for this purpose.

These collaborations meant that the workforce benefited from resources and training that were more comprehensive and better coordinated than any single project could have produced, with each project's reach extended through the other's networks and expertise.

> *"I was invited to contribute to the foundation course for pharmacists. The connections I was provided with through other projects showed how well project leads communicate with each other to deliver consistent and high-quality information." (Clinician)*

Consortium structures enabled projects to bring together capabilities and skills

The evaluation found that well-functioning consortia enabled projects to bring together expertise in areas such as research, policy, practice, and community engagement. Several projects operated through multi-organisation consortia that combined university research capability, peak body sector knowledge, and on-the-ground delivery capacity. This includes:

- ELDAC being delivered by a consortium of universities and peak bodies, with each member's strengths contributing to sector-wide impact.
- Caring@Home for Aboriginal and Torres Strait Islander Families being led by Brisbane South Palliative Care Collaborative, in partnership with Australian Indigenous HealthInfoNet, the Congress of Aboriginal and Torres Strait Islander Nurses and Midwives, and PCA.
- CarerHelp being led by St Vincent's Hospital Melbourne, in partnership with Flinders University, the National Rural Health Alliance, and Grief Australia.

Engagement with representatives from these projects found that in well-functioning consortia each organisation’s role, decision-making authority, and accountability measures were documented and agreed at the outset (rather than assumed on the basis of goodwill and shared purpose). Several interviewees noted that where accountability sat ambiguously between partners, the lead organisation sometimes lacked the authority or mechanisms to hold consortium members to account for their deliverables.

> *"The consortium approach is an important one. Someone has to do the coordination. The challenge between research, practice, and policy is that*

all three of those domains have an interest in palliative care that needs to be represented in how projects are designed and governed." (Project representative)

The competitive structure of grant funding risks creating tension that works against collaboration

A small number of project stakeholders described a perception that competition for funding had in some cases created reluctance to share resources or approaches that might strengthened a competitor's bid.

"There can be competition for resources, with 20 projects where all stakeholders are competing for some airspace and attention. We have created competition between organisations and resources which are already operating in a small, underfunded space." (Project representative)

While this view was not widespread, it may be beneficial for future rounds to consider how to capitalise on the benefits of competition (such as accountability, innovation) while still encouraging collaboration and partnership.

5.2 Co-design with end users

Co-design was a key feature of effective project design, and ensured resources were relevant to users

Projects that invested in co-design with end users produced resources that were described by service level users as more relevant, more usable, and more embedded in practice than those developed through expert-led processes.

For example, Caring@Home used in-depth carer engagement to design resources, which found that one of carers' biggest practical challenges was not knowing how to make time with the dying person meaningful. Project personnel stated that this was not something a health professional-led design process would have anticipated, but it became one of the most-used sections of the resource.

"One of the things that came through was how to make the time pleasant. That is not something I, as a health professional, would have put in a resource. But because carers told us it was the biggest practical challenge they faced, it's now one of our most-used sections." (Project representative)

The Improving Palliative Care Services for People with Intellectual Disability project ran an intensive co-design process across multiple rounds of Delphi consultation. This process was resource-intensive, but it produced strategies that were achievable.

"We ran six rounds of Delphi. That is a lot. But people kept saying 'that's not how it works' or 'that's not going to be achievable.' We wanted strategies that would actually work in real life, not nice things to say. You cannot get there without going back to people repeatedly." (Project representative)

Co-design produced stronger engagement and ownership at service level

Interviews at the service level found that when end users had been involved in shaping a resource or program, they were more likely to use it, and champion it within their organisation. Aged care providers who considered that their specific contextual needs had been taken seriously, whether through formal co-design processes or through a facilitator who adapted the program to their context, described higher engagement and ownership than those who felt that national resources had been designed for more generic use.

On the other hand, aged care facilities with high proportions of residents from culturally and linguistically diverse backgrounds described needing to adapt national resources for their context because the national versions assumed a mainstream Australian cultural relationship with death and dying that did not fit. Co-design with these communities was identified as an area requiring more deliberate and better-resourced investment in future rounds.

5.3 Active outreach and distribution through trusted intermediaries

The projects that reached the most people invested in how their resources and training reached the workforce

The projects that were most visible to frontline clinicians and aged care providers were almost always those that had actively come to them. This could be through face-to-face visits, through trusted intermediaries like state peak bodies or PHNs, or through personal relationships with a facilitator or project officer. Projects that communicated purely through newsletters, websites, and conference appearances were generally less well known to service-level providers.

End of Life Law for Clinicians illustrates how this strategic relationship-building enhanced project reach. It was reported that a member of ELLC's advisory committee made an introduction that led to an agreement with the College of Intensive Care Medicine to host ELLC's modules directly on the College's own website. This means that intensive care specialists now access ELLC content as part of the College's professional development offering, rather than having to seek it out.

Free and open access was a further distribution enabler, particularly for rural and remote providers and resource-constrained settings where paid professional development is not accessible. Survey respondents described the national palliative care projects as providing essential infrastructure because they could access high-quality tools and training at no cost. In addition, the Continuing Professional Development (CPD) points offered by End of Life Essentials on module completion were noted as a design feature that made the training easier to justify to managers and to schedule within working time, given the course itself was free.

> *"All of the projects I have mentioned are part of the essential infrastructure for palliative care provision, and provide us with free access to the tools and resources that we need as part of a palliative care community of practice. This is absolutely essential for a team that is remote."*
> *(Remote specialist palliative care team)*

PHNs, state and territory governments, and the department all played important roles in amplifying project reach

A range of stakeholders identified PHNs as playing a significant role in amplifying project reach at a local level. Through the Greater Choice for At Home Palliative Care program, PHNs promoted resources, hosted events, and connected projects with local aged care and health services. Their ability to tailor their approach to local contexts and relationships made them effective intermediaries between projects and the workforce.

> *"We held a workforce symposium with presenters from LGBTIQ+ Australia and PCOC. We help promote advance care planning at various events and we have weekly newsletters to promote key messages. We invited ELDAC to discussions on aged care and networking events to discuss what they are doing in the aged care sector." (PHN representative)*

In addition, state and territory health departments supported project reach by facilitating connections with clinical networks and sector stakeholders. Interviewees also stated the department took a leadership role in recent grant rounds, hosting cross-project meetings, supporting outreach, and supporting PCA and other projects to convene forums and events that foster collaboration.

State peak bodies that were interviewed considered that they could act as conduits to service-level audiences, but noted that most projects did not actively engage them in this function. Several described having to advocate to be included in project communications rather than being included as a matter of course. Caring@Home was cited as the exception, having actively engaged state peaks as distribution partners and being more visible in those jurisdictions as a result.

> *"It is always us reaching out to bring national projects into our state. As a state peak body, we should be a natural conduit for these projects to reach our sector." (State peak body representative)*

5.4 Longevity and continuity of funding

Longevity and continuity of funding were identified as foundational to project quality and reach

Sustained investment across multiple cycles created the conditions for improvement in project quality and reach, and for deeper embedding of palliative care capability across the sector. The evaluation found that projects that were designated as ‘core projects’ were able to undertake a longer-term view regarding project design and implementation, without the disruption of open competitive tendering. The projects in which this is most clearly demonstrated are PCOC, PEPA, ELDAC, CareSearch, Caring@Home, and QuoCCA. These were all core projects, which provided funding continuity across multiple cycles. A more detailed discussion of the core and non-core model is provided in section 7.1.

Certainty of ongoing funding enabled projects to undertake longer-term activities that would not have been possible under uncertain or short-term funding arrangements. This resulted in achievements such as palliative care curricula embedded in medical schools, resources integrated into hospital IT systems, clinical fellows trained and now working as specialists, and data systems mature enough to generate longitudinal outcome evidence.

QuoCCA's workforce transformation illustrates what funding certainty enabled over four cycles. Project reporting indicates that over 20 medical fellows have been trained, with three specialists from the Queensland program alone. Nursing cadetships and fellowships have provided placements across most states and territories. Face-to-face communication workshops, developed in collaboration with the paediatric palliative care project, now reach regional communities that would not otherwise have had access to this training.

Service-level evidence reinforces this from the demand side. Aged care providers, home care organisations, and specialist services described trusting projects that had been around long enough to demonstrate reliability and build relationships with the sector. For example, providers who had engaged with ELDAC across multiple Linkages rounds described the program as an embedded part of how they do things now.

5.5 Governance

The department's program governance role has strengthened over time, and is valued by projects

Approximately half of interview sources noted improvement in the department's program governance and coordination role since previous rounds. Project leads attributed improvements in cross-project collaboration to three specific governance actions: hosting cross-project meetings that facilitated networking and information sharing; supporting PCA and other projects to host their own forums and events; and embedding collaboration expectations into activity work plans as a formal governance requirement.

PHNs, state and territory governments, and the department all played important roles in connecting projects with the broader sector, with PHNs described as valuable governance intermediaries, sharing resources through their networks, connecting projects with local services, and tailoring their approach to local contexts.

> *"One previous recommendation we had was for the department to be more collaborative and provide more guidance rather than taking a back seat. That's something that I've really noticed having been on these projects now for seven or more years. They have also facilitated a lot of connections for us." (Project representative)*

Program governance needs to extend beyond project-lead level to create accountability at the service delivery level

While there were reported governance improvements at the project-lead level, service-level evidence found that the department's program governance role had not translated into a coherent program at the service delivery level. Aged care providers, home care organisations, and specialist clinicians described engaging with individual projects rather than experiencing a coordinated system of support. This meant the services often find resources through personal networks and word of mouth rather than through any systematic outreach. The governance improvements in how projects work together at the national level had not yet translated into a coordinated and visible program at the frontline.

This could be improved through enhanced governance mechanisms. For example, Primary Health Networks, with their established local relationships across aged care, primary care, and community providers, are well placed to facilitate this kind of engagement at a service

delivery level. Further, dedicated communities of practice for the program, with clear membership, defined roles, and a Terms of Reference could offer a structure to connecting projects with each other and with providers on a more consistent basis. These are all governance levers that sit with the funder (i.e., the department) and strengthening them would create systematic accountability for reach and impact that currently relies on individual projects choosing to prioritise it.

> *"Only the department can do this. PCA as an independent body cannot tell projects what to do. The structures, the accountability mechanisms, the reporting requirements that would make coordination systematic." (Project representative)*

The absence of a common outcomes framework meant that project-level governance could not drive portfolio-level accountability

As discussed in section 3.7, a governance gap identified by interview sources was the absence of a common outcomes framework across the portfolio. While projects are all aligned to the shared goals of the National Palliative Care Strategy, and the 2023-26 round introduced draft performance indicators at the guidelines level, these indicators were project-specific starting points rather than a common framework applied consistently across all projects. The documentary and interview evidence shows most projects continued to use different evaluation approaches, different indicators, and different methodologies. This meant that even where multiple projects contribute to the same strategic goal, such as education and training, it is difficult to assess what has been collectively achieved.

> *"There was never a clear answer about which metrics they wanted all projects to pay attention to. So really we are all adhering to our own activity work plans. The result is that meaningful comparison across the program is not possible." (Project representative)*

Grant governance could be strengthened to improve jurisdictional reach and equity

Uneven jurisdictional reach was also highlighted as a governance concern. Interviewees reported that projects headquartered in major cities tend to have higher awareness and uptake in those cities. State peak bodies in smaller states and territories described having to actively seek out national projects rather than being engaged by them, and several described being unaware of projects that should have been a natural fit for their networks. Under the current grant governance arrangements, there is no requirement for projects to demonstrate reach across all jurisdictions.

Actions to address this could include embedding jurisdictional reach into grant conditions as a key performance indicator. Requiring projects to demonstrate specific engagement with each state and territory peak body would create a governance mechanism for national reach accountability.

6 UNINTENDED OUTCOMES

KEQ5: Have the NPCPs and/or ELDAC had any positive or negative unintended impacts?

Main messages:

- Some projects reached audiences beyond their intended target, reflecting demand for palliative care knowledge across the broader health workforce.
- COVID-19 accelerated digital adoption across the portfolio, producing online alternatives that were more scalable and accessible than face-to-face delivery.
- The volume of projects and resources has created 'navigation fatigue' for end users. This could be improved by developing a coordinating architecture that helps users find what is relevant to their context.

Projects reached audiences beyond those they were designed for

Several projects reported unanticipated engagement with their resources from professionals outside their intended target audience. The Australian Healthcare and Hospitals Association, End-of-Life Essentials, End of Life Law for Clinicians, and Project ECHO all reported uptake by both palliative care specialists and generalist clinicians who had not been the primary target of their design. In some cases the unintended audience was substantial, and project leads described adapting their approach in response.

For example, Project ECHO reported that half its attendees are already working in specialist palliative care; a population the program was not originally designed to serve (Project ECHO Final Report, 2023). Interviewees described this as having created a community of practice effect that had become one of the program's most valued features: bringing specialist and generalist clinicians together in the same virtual space, each learning from the other's perspective.

> *"It's bringing palliative care people together with non-palliative care people. That is exactly what needs to happen if we are going to shift how the health system as a whole thinks about end of life." (Project representative)*

It was also reported that resources, developed by several projects specifically for Aboriginal and Torres Strait Islander communities, have been widely accessed by mainstream health professionals. Project representatives attributed this to the quality and accessibility of the resources rather than to any active promotion to a mainstream audience, suggesting that co-designed, community-specific resources have broader applicability than is typically assumed.

COVID-19 accelerated digital adoption and demonstrated program adaptability

The COVID-19 pandemic disrupted planned face-to-face delivery across most projects in the 2020-23 round, forcing rapid adaptation to online and hybrid models. While this created some delivery challenges (such as delayed co-design activities and reduced uptake in aged care settings) it also accelerated digital capability. Projects that had relied primarily on face-

to-face workshops developed online alternatives that were more scalable and accessible to rural and remote providers than other modalities.

The program's capacity to absorb this disruption without significant loss of output (evidenced by projects meeting or exceeding their performance targets despite the pandemic context) is a positive achievement. Interviewees highlighted the department's flexibility in approving carry-forward of underspends as an important enabling factor, which was noted by multiple project leads as an example of responsive grant governance.

The proliferation of projects may have created navigation fatigue among the workforce

The breadth and volume of resources produced across the portfolio is a marker of the program's productivity, and the sector now has access to a larger and more diverse suite of palliative care resources than existed before these projects were funded. However, as discussed in section 3.3, the growth in the number of national projects and resources has created a navigation burden for end users that limits the collective reach of the portfolio. This was an unintended consequence of a program that has grown organically across multiple funding rounds without a coordinating architecture to help users find what is relevant to their context (see section 7.2).

7 GRANT PROGRAM STRUCTURE

KEQ6: Is the current structure of the grant programs achieving the best outcomes for government and the community?

Main messages:

- The evaluation found that the current structure of the NPCP and ELDAC grant programs is broadly the right model for the Commonwealth's role in palliative care.
- A nationally funded portfolio of projects addressing workforce capability, resource development, advance care planning, data and quality improvement, and priority population reach is appropriate, necessary, and valued by the sector. The evidence does not support wholesale restructuring.
- The evaluation identified three structural features that are limiting what the model can achieve: fragmentation without adequate coordination, funding cycles that are too short to allow projects to embed their work and demonstrate outcomes, and inadequate planning for the sustainability of project outputs after funding ends.

7.1 Core and non-core project structure

For the 2020-23 grant period, the department adopted a new approach involving the establishment of two separate grant opportunities which continued for the 2023-26 round. The first grant opportunity was for:

- core projects: identified by the department as foundational to the Commonwealth's contribution to palliative care.
- non-core projects: funded through a competitive grant round, open to both existing NPCPs and to new applicants, with a focus on priority populations and emerging needs.

The core and non-core structure has provided stability that enables the sector to take a longer-term view

The evaluation found that the core and non-core structure has been broadly effective, with the majority of interviewees supporting the principle. The shift to designating some projects as core has provided stability that enables forward planning, staffing, and stakeholder engagement that was not possible within the fully competitive model. Stakeholders noted that this approach has supported both system-level stability and diversity in project design.

The projects that were most consistently known and used by frontline services that participated in the evaluation are all core projects funded across multiple cycles. These include PCOC, PEPA, Caring@Home, and ELDAC. The stability provided by the core project designation supported frontline service uptake of the projects by building awareness, relationships, and embedded infrastructure that would not have been possible in competitive, three-year funding cycles.

> *"The fact that End of Life Essentials has been consistently refunded has allowed us to undertake longitudinal studies and implement the learnings from each cycle. Access to sustained funding has created the conditions for projects to embed their content into institutions in a way that a single funding cycle could never achieve." (Project representative)*

The non-core competitive stream has served a complementary function, enabling innovation and targeted responses to emerging needs that the core project suite was not designed to address. Projects funded through the non-core stream, including the LGBTIQ+ Palliative Care Project, the Improving Palliative Care Services for People with Intellectual Disability project, the Prisons Project, and the Pharmacy Society of Australia's foundation training program, addressed population groups and practice areas that may not otherwise have had dedicated national investment.

Projects with core designation should continue to be assessed for relevance and fitness for purpose

While most evaluation participants viewed the core and non-core model as appropriate, they also noted that sector reforms have changed the palliative care context and the needs of the workforce over time. Several stakeholders raised the importance of ensuring that grant renewal processes for core projects go beyond assessing delivery against activity work plans, to consider whether the project's model, scope, and mode of delivery remain the best fit for current sector needs, and whether the project has evolved accordingly

> *"The long-standing projects…are really important, but some of them weren't designed to still be operating 20 to 25 years later in similar models to when they started. Should they be challenged to evolve?" (Project representative)*

7.2 Strengthening coordination and navigation

The program has grown across multiple funding rounds into a suite of more than 20 projects. Most interviewees affirmed that the diversity of lead organisations, approaches, and audiences within this suite is a strength of the model. However, evaluation participants identified a need for stronger coordination, particularly in the education and training space. Stakeholders also emphasised the need for a visible framework connecting the projects to each other, and to the sector standards that palliative care providers are accountable for meeting.

A coordinating architecture would help frontline providers navigate the program more effectively

About a third of the frontline clinicians and aged care providers that were interviewed stated that they experienced navigation difficulty across the program. They described needing to access too many separate websites, diverse resource collections, and overlapping or similar-sounding offerings without clear guidance about which was right for their context. As discussed in section 3.3, some service providers had invested significant effort in curating resources for their colleagues, such as building intranet pages, or spending workshop time on navigation.

> *"There are too many platforms. We can't have nine different apps doing a similar thing with a slightly different interface or end user." (Health service representative)*

The program has not yet provided a clear navigation function at a national level. The most commonly cited need was a visible logic connecting projects to each other and to the standards providers are accountable for meeting. Queensland Health's palliative care education framework was cited as an example of what a well-structured national navigation tool could look like. This is a framework which maps all available state and national resources against the clinical capability framework and allows clinicians to select resources by profession and development level. Developing something equivalent at the national level would reduce the navigation burden on frontline providers.

> *"There's no strategic framework on what the national palliative care projects are trying to achieve for the service. As an aged care provider, I don't know how ELDAC relates to PCOC relates to other projects in terms of meeting the national non-specialist standards." (Aged care provider)*

7.3 Sustainability of project outputs

Resource sustainability was identified by evaluation participants as a structural gap in the current program design. The previous NPCP evaluation (Urbis, 2019) identified this as a problem; this evaluation finds it has not yet been completely addressed.

Sustainability of project outputs requires clearer planning for what happens when funding ends

The evaluation found that there is no clear process for ensuring sustainability of project outputs once a project's funding ends. Service-level evaluation participants described discovering that resources they had been directing staff to had been taken down or had not been updated, eroding frontline trust in the national program. Interviewees gave an example of a suite of online palliative care training modules developed by the Australian Healthcare and Hospitals Association. These modules were handed to another organisation at the end of the funding period, but technology incompatibility meant that the content could not be hosted and became unavailable to the sector. In another instance, an organisation agreed to keep the Advance Project's digital resources accessible after its funding ended, but did so through individual organisational commitment rather than through any planned arrangement.

Several stakeholders described a situation in which projects produce outputs and then 'scramble' at the end of their funding period to find a way to maintain them. Requiring projects to agree upfront on what platform their outputs will be built in, and what will happen to those outputs when the project ends, would prevent this kind of avoidable loss from recurring.

> *"At the end of a funding period, things come to a scramble. Someone has to absorb the product. They find it's too expensive to maintain a learning management system, to promote it, to keep it current. So the products go dark. That is a straightforward waste of Commonwealth investment." (Project representative)*

A potential model suggested by the sector include providing 'maintenance funding' to sustain outputs after the initial grant that funded the development of resources. There was also broad support for the creation of an overarching entity with a standing mandate to maintain and update national palliative care resources beyond individual project funding cycles. CareSearch and PCA already perform elements of this function. Formalising and resourcing it would give the sector a more durable infrastructure than the current project-by-project model provides.

> *"There is an opportunity for an overarching body that can sustain resources beyond their funding, that could maintain and update them when a project ceases. This would keep the infrastructure alive for the sector rather than leaving each project to solve this at the last minute." (PHN representative)*

7.4 Funding cycle length

Three-year funding cycles limit what projects can achieve

The funding cycle length was a consistently raised grant administration issue across interviews. While the current three-year allocation is enough to establish a project and begin delivery, it does not provide the opportunity to refine resources over time, demonstrate practice change, or embed outputs into sector systems.

> *"In a three-year grant, by the time you have staff on board, have your stakeholder engagement going, and have your activities up and running, you are down to two years. And then you need to have your product and your evaluation. It is simply not long enough." (Project representative)*

The most commonly proposed approach was differentiated cycle lengths: five-year cycles for established core projects, and three-year cycles for first-cycle and innovation projects.

Funding continuity also influences the extent to which providers are willing to invest in building internal capability. For example, home care and aged care providers engaged in the ELDAC Linkages program described uncertainty about program continuation as a disincentive to developing internal capability that depended on the program's resources.

8 RECOMMENDATIONS OF THE PREVIOUS NPCP AND ELDAC EVALUATIONS

KEQ7: Were the findings and recommendations of the previous NPCPs and ELDAC evaluations implemented? What were the impacts?

Main messages:

- The recommendations of both the 2019 NPCP evaluation (Urbis, 2019) and the 2020 ELDAC evaluation (HealthConsult, 2020) have been substantially implemented.
- Progress is most clearly demonstrated on collaboration, strategy alignment, and the department's leadership role.
- Progress on outcomes measurement and resource sustainability has been uneven.
- The ELDAC team responded to all seven recommendations from the 2020 evaluation, with documented evidence of action against each. The most substantial impact was achieved through the expansion of the Linkages program, which produced the strongest outcome evidence in the evaluation.

8.1 Previous evaluation of the NPCPs

The independent evaluation of the NPCPs (Urbis, 2019) made four recommendations. Evidence from stakeholder interviews and project reports indicates that three of four recommendations have been implemented successfully, and progress has been made towards developing outcome measures and reporting mechanisms.

Recommendation 1 - Implemented: Ensure core and non-core projects align with existing and emerging sector needs identified in the Strategy and support core projects to collectively address sector needs.

As documented in section 2.1, all projects across both funding rounds align with the Strategy's goals in their activity work plans, with the 2023-26 round strengthening this through mandatory alignment with the four Implementation Plan Action Areas. Core and non-core projects have aligned with and supported delivery of the National Palliative Care Strategy 2018 and contributed to addressing sector needs.

The impact is visible in the portfolio's collective coverage. The suite of projects addresses all but one of the Strategy's eligible activity categories, and multiple projects are working toward the same strategic goals across different settings and populations. The department's introduction of cross-project forums and the PCA leaders network has further supported projects to address sector needs collectively.

Recommendation 2 – Implemented: Strengthen the department's strategic leadership and increase support provided for collaboration between projects and the wider sector.

Project reporting and stakeholder feedback indicates that the department increased its role in sector and system leadership and has fostered increased collaboration between projects and other stakeholders. This was achieved through hosting cross-project meetings, supporting PCA and other projects to convene forums and events, and embedding collaboration expectations into activity work plans. The evaluation found that there has been an increased focus on outcome measurement and reporting under the current and previous grant round.

Recommendation 3 - Partially implemented: Increase focus on outcomes through the development of outcome measurement and reporting mechanisms.

The 2023-26 round introduced draft performance indicators at the guidelines level, including patient outcome measures and knowledge and confidence improvements. This represents a step toward outcome-oriented accountability that project representatives welcomed. Where possible, project reporting now embeds a focus on outcomes and progress against key performance indicators, and some projects have demonstrated positive impacts on palliative care access and service quality. However, as discussed in sections 3.7 and 5.5, outcome measurement across the portfolio remains uneven. Projects continue to use different evaluation frameworks, different indicators, and different methodologies, making portfolio-level assessment of collective impact difficult.

Recommendation 4 - Partially implemented: Ensure project outputs remain current and useful through the ongoing upkeep of materials during procurement and work planning and by encouraging cross-project distribution and promotion of resources

This recommendation has been partially implemented. There is evidence that projects have given greater attention to output sustainability than in previous rounds. Sustainability planning is now embedded as a reporting requirement, and cross-project partnerships have supported distribution and promotion of resources beyond what individual projects could achieve alone. However, as discussed in section 7.3, resource sustainability remains a structural gap. There is still no clear process for ensuring project outputs remain available after funding ends, and high-quality resources have become unavailable to the sector when funding periods concluded without adequate transition arrangements in place. The risk to project resources associated with short funding cycles remains present.

8.2 Previous evaluation of ELDAC

An independent evaluation of ELDAC (HealthConsult, 2020) included seven recommendations to improve the delivery of ELDAC. Through interviews with ELDAC staff and other stakeholders, and review of project resources and reports, the current evaluation found that the ELDAC team took action to respond to all the concrete elements that were raised in the previous recommendations.

Recommendation 1 – Implemented: Consider reallocating the resources used to run both the telephone and email Helpline into other activities that have a higher uptake.

The Helpline was decommissioned in 2020, and resources were reallocated to expand the ELDAC online hub, improve navigation, and develop additional toolkits and interactive

resources. The impact of this reallocation is visible in the reach data: ELDAC's toolkit suite reached over 210,000 users across Phase II, with the End of Life Law Toolkit alone accounting for 136,296 users (ELDAC Performance Report 6, 2023). This is greater reach than the Helpline was achieving, and the reallocation to digital infrastructure has been validated by the uptake data. ELDAC maintained an email response service for those requesting specific information, ensuring that personalised support remained available for those who needed it.

Recommendation 2 – Implemented: Broaden input from intended users during the future design and development work of the digital dashboard

The 2020-23 activity work plan included detailed performance indicators for digital dashboard development, and project reporting demonstrates progress. The dashboard was implemented and trialled in four residential aged care services, demonstrating feasibility and identifying barriers and facilitators to uptake. ELDAC subsequently developed the Becoming Digital Ready booklet and established the ELDAC Technology Network Community of Practice to support ongoing sector engagement with digital tools.

The Home Care App and PaCE Aged Care App, released in 2022 and 2023 respectively, extended digital access to end-of-life care resources across the sector. The Home Care App reached 1,456 installs by June 2023 (ELDAC Performance Report 6, 2023). Service-level evidence suggests digital infrastructure in aged care remains a work in progress, with uptake constrained by the sector's variable digital readiness. This finding reinforces the value of the Becoming Digital Ready resource.

Recommendation 3 – Implemented: Review the format of the roundtables and implement mechanisms to influence policy that reflect the topic chosen. Future strategies may also improve communication to ensure attendees are clear on the purpose, outputs and future actions associated with the activity, as well as involving consumers in the activities.

Roundtables were replaced with Special Projects, which undertook focused evidence reviews and research activities designed to generate deeper analysis on specific topics and provide a stronger basis for policy engagement than the roundtable format allowed. Completed Special Projects include studies on PHN involvement in palliative care delivery, carers' experiences in home care, innovations in primary care palliative care, and managers' experiences under the Home Care Package Program. The shift to a research-based model has produced more substantive, publishable evidence, and ELDAC's engagement with the aged care reform agenda (including targeted campaigns responding to the strengthened Aged Care Quality Standards) reflects the organisation actively applying its evidence to the policy context.

Recommendation 4 – Implemented: Explore the feasibility of expanding the Working Together Program, as there is a clear need for aged care providers to link with specialist palliative care services.

The Working Together Program was renamed the ELDAC Linkages Program and expanded substantially, with 344 services registered since 2020, including 107 completing the full program in Phase II alone (ELDAC Performance Report 6, 2023). The impact is shown in pre- and post-implementation audit data from 107 services, which shows consistent improvement across all domains of the Organisational Audit and After Death Audit, including

a 27% improvement in the proportion of services meeting the standard for symptom assessment tools, and a 12% improvement in team case conferencing in the last six months of life.

Recommendation 5 – Implemented: Continue marketing activities using the methods utilised to date, although alternative strategies to market the Helpline (if it continues) to optimise uptake should be considered.

A comprehensive Marketing and Promotions Plan was developed for both the 2020-23 and 2023-26 phases, incorporating ongoing communications through newsletters, blogs, and social media, alongside an active conference presence. New marketing activities included the My Care Matters campaign (2022-23), targeted campaigns for the Home Care App and Self-Care Room, and campaigns specifically addressing the strengthened aged care standards. A detailed Engagement Plan was developed to ensure tailored strategies for all relevant stakeholders. The impact is observable in reach data; ELDAC website user numbers grew by 60% in Year 2 of Phase II (ELDAC Performance Report 6, 2023).

Recommendation 6 – Implemented: Continue to align with the relevant national policies, strategies, definitions, activities and priorities, including the goals of the National Palliative Care Strategy, and flexibility to adapt to changing State and Territory funding arrangements and data collections.

ELDAC engaged in ongoing environmental scanning and policy alignment, reviewing toolkits to reflect strengthened aged care standards, hosting campaigns to promote policy reforms, and integrating policy reform discussions into Linkages projects. The Volunteer Assisted Dying legislative rollout generated demand for updated legal guidance that ELDAC responded to, with the End-of-Life Law Toolkit user numbers growing by 94% in Year 2 (ELDAC Performance Report 6, 2023). The impact of this responsiveness is that ELDAC remained relevant and current through a period of rapid change in the policy environment.

Recommendation 7 – Implemented: Make adaptations to governance of, and engagements with, the National Reference Group to ensure that their input can be used in a more meaningful way.

The National Reference Group's membership expanded to include representatives from nearly 20 organisations, including universities, peak bodies, and government agencies. Reference Group representatives interviewed for this evaluation described the ELDAC governance model as having continued to evolve, with a range of opportunities to contribute to priority-setting and activity delivery. The breadth of Reference Group membership has supported ELDAC to maintain alignment with diverse stakeholder perspectives and identify emerging issues, contributing to the organisation's capacity to respond quickly to sector developments such as the aged care reform agenda.

8.3 Impacts of implementing the previous recommendations

The impact of implementing the previous recommendations is visible in the program's overall trajectory across the two funding rounds. Projects are now more consistently aligned with the National Palliative Care Strategy (2018) than at the time of the 2019 evaluation, with the 2023-26 guidelines mandating alignment with all seven Strategy goals and the four Implementation Plan Action Areas. The evaluation also found that cross-project collaboration

has increased, and the department's coordination role has become more active, reflecting the 2019 NPCP recommendations. The ELDAC team's response to its 2020 recommendations produced the expansion of the Linkages program, with pre- and post-audit data showing consistent improvement across all assessed domains of the Organisational Audit and After Death Audit. The reallocation of resources from the Helpline to digital infrastructure produced substantially greater reach than the Helpline had achieved.

Where implementation has been partial, particularly on outcomes measurement and resource sustainability, the impact of the gap was raised through the current evaluation. The absence of a common outcomes framework means the program cannot yet demonstrate its collective achievements, and the risk of project outputs ‘going dark’ after funding ends has not been resolved.

9 CONCLUSION

The NPCPs and ELDAC are intended to ensure that the workforce, services, and systems that support the delivery of palliative care in Australia are capable, coordinated, and continuously improving. This evaluation has found that the program is mostly achieving this. Overall, the findings demonstrate that the investment is well placed to enhance palliative care in Australia, building workforce capability, producing resources that are trusted and used, and in some settings demonstrably changing how organisations approach end-of-life care.

The evaluation found that the program was effective in supporting workforce development. Across interviews, survey responses, and project reporting there is evidence that health and aged care professionals working outside specialist settings are more knowledgeable, more confident, and more capable than they were before the projects were funded. The evidence is strongest for ELLC, End of Life Essentials, PEPA, and the PeSAS project, where pre- and post-training data shows measurable improvements. This is reinforced by qualitative engagement with providers, many of whom described a cultural shift in how their organisations think about end of life from something managed reactively when a resident is actively dying, to something embedded in care planning from the point of admission.

The program has also built infrastructure that has become embedded into the sector. CareSearch, palliAGED, and ELDAC's toolkit suite are described by frontline providers as essential resources they rely on to support their practice. The projects most trusted and most used at the frontline tend to be those that have operated across multiple funding cycles, demonstrating reliability, responding to updates, and building relationships with the sector over time.

However, the evaluation also found that there is a gap between what the program does and what it can demonstrate. For most projects, the evidence of impact stops at workforce knowledge and confidence. The program is based on the logic that training leads to changed practice, which leads to improved patient experience and better outcomes at the end of life. While these effects have been described qualitatively by those working in the sector, and are corroborated for ELDAC and PCOC by pre- and post-data, most projects have not yet demonstrated this chain of impact through measurable outcomes data. This reflects several factors: the inherent challenge in collecting outcome data from palliative care patients and their families, limited data infrastructure in primary care and other non-hospital settings where much palliative care is delivered, and a governance gap that the program has the capacity to address. There is a need for a common outcomes framework that makes projects collectively accountable for what the program achieves, not just individually accountable for what they deliver.

The program is operating in a reform environment that has continued to evolve since the National Palliative Care Strategy was published in 2018. While the Royal Commission into Aged Care Quality and Safety, the rollout of voluntary assisted dying legislation and the transition to Support at Home has changed the operating context, the Strategy already reflects key directions including home- and community-based care, care coordination, workforce capability and advance care planning. Recent reforms have increased demand for capabilities that the projects provide. The main areas for strengthening are the visibility, coordination, practical application, reach and scale of existing support, so that aged-care providers implementing strengthened regulatory standards, home-care providers using End-

of-Life Pathway funding, and clinicians navigating voluntary assisted dying alongside palliative-care conversations can find and apply relevant guidance.

The evaluation's findings demonstrate that the program is structured in broadly the right way and well placed to achieve its aims. The core and non-core model is working well, and cross-project collaboration is producing outcomes that single projects could have achieved alone. The department's coordination role has strengthened over time and is valued by project representatives.

9.1 Opportunities for future grant rounds

The evaluation identified the following opportunities to continue building upon the positive outcomes of the NPCPs and ELDAC.

1. **Embed a stronger focus on partnership and consortium-based projects.**

Ongoing development of partnerships and consortia will support project efficiency, collaboration, and quality. Improved collaboration between projects will enhance the sustainability of project materials and increase clarity among the workforce about resource availability and relevance. Embedding partnership development as a key performance indicator in the Grant Opportunity Guidelines would ensure partnerships are progressed through project design and implementation.

2. **Establish a common outcomes framework to more consistently measure changes in practice and support collection of patient-level data.**

The evaluation found that for most projects, the evidence of impact is limited to changes in workforce knowledge and confidence. The department could identify a common outcomes framework, with a consistent set of indicators for assessing whether education and capability-building activities lead to changes in practice. Where appropriate and feasible, this could draw on available patient-level data and existing data-sharing arrangements. This would enable the program to move from demonstrating what it does to demonstrating what it achieves for people at the end of life.

3. **Undertake sustainability planning for project outputs and consolidate resources.**

The evaluation found that high-quality resources have become unavailable to the sector when funding periods concluded without adequate transition arrangements. There is a need for a clear process for sustaining project outputs after funding ends. Requiring projects to agree upfront on platform standards and transition arrangements would protect the Commonwealth's investment. The department could also consider maintenance funding to sustain outputs after the initial development grant ends, and explore formalising and resourcing an overarching body (building on the functions already performed informally by CareSearch and PCA) to maintain and update national palliative care resources beyond individual project funding cycles.

4. **Further consolidate and improve navigation of palliative care resources.**

The growth in the number of projects and resources across multiple funding rounds has created navigation difficulty for end users. The department could encourage further consolidation of resources into a central repository, funding and supporting an existing

platform for this purpose and organising material by palliative care setting to support usability and access.

5. Address gaps in support for priority population groups.

The needs of priority populations should continue to be addressed through the funding of targeted projects, and ongoing consideration of their needs in projects targeting broader cohorts. Opportunities include:

- funding projects targeting people experiencing homelessness, who had no dedicated project across either round despite being identified in the guidelines as a priority group
- funding projects targeting the needs of CALD communities, including ensuring resources are translated into relevant languages and reflect different beliefs and practices around death and dying
- embedding cultural safety in the design and delivery of palliative care for Aboriginal and Torres Strait Islander people.

6. Strengthen the connection between existing project capabilities and reform implementation

Future grant rounds could build on the program's existing alignment with the reform agenda by making relevant resources and support easier for providers and workforces to identify and apply. This includes supporting implementation of the strengthened Aged Care Quality Standards and the Support at Home End-of-Life Pathway, and extending access to jurisdiction-specific education and guidance on the intersection between voluntary assisted dying and palliative-care practice.

7. Strengthen governance mechanisms for jurisdictional reach, funding cycle length, and grant administration.

Opportunities to enhance governance include the following:

- Establishing coordinated pathways through PCA, PHNs and other intermediaries to connect projects with jurisdictional stakeholders, including state and territory peak bodies where appropriate.
- Aligning funding duration with project maturity and strategic horizon. Longer funding periods may be appropriate for established national infrastructure and work requiring sustained implementation, while three-year funding may remain suitable for pilot, innovation and first-cycle projects.
- Earlier and more predictable communication of upcoming grant rounds and faster contract execution following notification of success would reduce operational costs currently borne by projects at the start of each cycle.

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Appendix A: Overview of projects in scope of the evaluation

The following section provides a snapshot of the projects in scope of the evaluation.

End of Life Directions for Aged Care

Overview

ELDAC is a national specialist palliative care and advance care planning advisory service that provides information, guidance, and resources to health professionals and aged care workers to support palliative care and advance care planning for older Australians.

Implementing organisations

Queensland University of Technology; Flinders University; University of Technology Sydney; Palliative Care Australia; Ageing Australia; Australian Healthcare and Hospitals Association; Catholic Health Australia.

Objectives

- Provide palliative care and advance care planning advice to aged care providers
- Improve linkages between aged care services and palliative care services
- Improve the palliative care skills and advance care planning expertise of aged care service staff and general practitioners
- Improve the quality of care for aged care recipients, prevent unnecessary hospital admissions and shorten hospital stays

Funding

- $15,900,000 (2020-2023)
- $15,900,000 (2023-2026)

Alignment with the Strategy

- **Goal 1:** Understanding
- **Goal 2:** Capability
- **Goal 4:** Collaboration
- **Goal 5:** Investment

Key achievements

- Strengthened connections with other NPCPs and with the broader sector to promote aged care workforce development opportunities
- Exceeded targets in delivering toolkits (including Dementia Toolkit, Managing Risk Toolkit, and Allied Health Toolkit) to sector participants
- 107 services recruited to ELDAC Linkages project, with all services developing action plans and implementing knowledge exchange and upskilling activities
- Supported implementation of technological solutions (including ELDAC Home Care App, Self Care Room) in aged care services to improve workforce awareness and knowledge to deliver quality care
- Consistent improvements in palliative care workforce knowledge and confidence
- Improvement in After Death audit scores

Core projects

Palliative Care Australia (2020-2023 and 2023-2026)

Overview

PCA was funded through the NPCPs to continue its work in leadership, policy, coordination advocacy, and public awareness for the sector

Implementing organisations

Palliative Care Australia

Objectives

- National leadership and advocacy
- Quality improvement
- Consultation and collaboration with underrepresented communities
- Promote increased awareness of palliative care

Funding

- $5,800,000 (2020-2023)
- $6,350,000 (2023-2026)

Alignment with the Strategy

- **Goal 1:** Understanding
- **Goal 4:** Collaboration
- **Goal 7:** Accountability

Key achievements

- Supported delivery and coordination of NPCPs
- Developed and implemented the National Palliative Care Standards for both specialist palliative care, and primary palliative care provision
- Delivered National Palliative Care Week annually
- Coordinated Grant Recipients Forums and Leaders Network
- Coordinated the Palliative Care Yarning Circle
- Managed development of and access to the National Register of Palliative Care Consumers and Carers

CareSearch, including palliAGED (2020-2023, 2023-2026)

Overview

CareSearch, including palliAGED, provides interactive websites that connect health practitioners, aged care workforce, patients, carers and families, and the wider community with evidence-based palliative care information and resources in palliative care.

Implementing organisations

Flinders University

Objectives

- Maintain CareSearch and palliAGED availability, and ensure up to date evidence-based content
- Communications and campaigns to promote awareness and use of resources
- Develop and implement an impact assessment framework to monitor performance

Funding

- $3,700,000 (2020-2023)
- $3,700,000 (2023-2026)

Alignment with the Strategy

- **Goal 2:** Capability
- **Goal 4:** Collaboration
- **Goal 6:** Data and Evidence

Key achievements

- Over 284,000 website visits per annum
- Formal agreements and partnerships with PHNs, aged care services, state government health departments, and NPCPs
- Scoping review of measures for evaluating the impact of online information resources
- Delivered a range of new content, including an updated smartphone application for GPs and clinical evidence summaries

Palliative Care Outcomes Collaboration (2020-2023, 2023-2026)

Overview

PCOC aims to improve palliative care patient and carer outcomes, through the collection of population-level palliative care outcomes data. PCOC analyses data and delivers reports to participating services to improve service quality and provide sector oversight on palliative care outcomes.

Implementing organisations

University of Wollongong; University of Technology Sydney; Queensland University.

Objectives

- Improve quality of palliative care service delivery
- Support palliative care providers to identify and measure impact
- Establish palliative care outcome measures and benchmarking processes

Funding

- $8,700,000 (2020-2023)
- $8,700,000 (2023-2026)

Alignment with the Strategy

- **Goal 4:** Collaboration
- **Goal 6:** Data and evidence

Key achievements

- Over 20 years of patient outcome data, demonstrating measurable improvements in palliative care
- Increase in number and diversity of services participating in PCOC
- High user satisfaction and confidence with PCOC
- Development of implementation, QI resources, and impact framework
- Delivery of education and facilitated QI

Palliative Care Education and Training Collaborative (2020-2023, 2023-2026)

Overview

The Palliative Care Education and Training Collaborative delivers the Program of Experience in the Palliative Approach (PEPA), Indigenous Program of Experience in the Palliative Approach (IPEPA), Palliative Care Curriculum for Undergraduates (PCC4U), Aboriginal and Torres Strait Islander Palliative Care Workforce Development, and the National Palliative Care Workforce Development Action Plan. These projects aim to build the capability and capacity of the health workforce to provide quality palliative care to all Australians.

Implementing organisations

Queensland University of Technology

Objectives

- Improve palliative care skills, knowledge and confidence in the health and aged care workforce
- Improve organisational capacity to deliver palliative care
- Improve outcomes for patients and their families

Funding

- $12,500,000 (2020-2023)
- $12,500,000 (2023-2026)

Alignment with the Strategy

- **Goal 2:** Capability
- **Goal 3:** Access and choice

Key achievements

- Significant sector engagement with communication material through e-newsletters, social media, web resources, and communities of practice
- High uptake and implementation of PCC4U in university courses
- Delivery of placements, workshops and training beyond targets

The Quality of Care Collaborative Australia (2020-2023, 2023-2026)

Overview

The QuoCCA project is a consortium of national, state, and tertiary paediatric services, led by the Children's Health and Hospital Service Queensland. The project aims to improve and enhance access to high quality care for paediatric patients requiring palliative and end-of-life care, and their families, across all Australian states and territories, including regional, rural, and remote locations.

Implementing organisations

Children's Health and Hospital Service Queensland

Objectives

- Improve the quality of palliative care for children
- Build health professionals' capacity, capability, and confidence to deliver quality palliative care to children with life limiting conditions and their families. This includes advance care planning

Funding

- $4,200,000 (2020-2023)
- $4,200,000 (2023-2026)

Alignment with the Strategy

- **Goal 2:** Capability
- **Goal 3:** Access and Choice

Key achievements

- Exceeded scheduled education sessions
- High levels of reported satisfaction across capacity building participants
- Contributions to broader palliative care sector with research publications and conferences

ELLC End of Life Law for Clinicians (2020-2023, Core from 2023-2026)

Overview

ELLC is a free national training program for medical practitioners, nurses, allied and other health professionals, and students about the law on end-of-life decision-making. The training supports delivery of high-quality end-of-life, palliative and aged care to individuals, families and decision-makers, consistent with the National Safety and Quality Health Care Standards and Aged Care Quality Standards.

Implementing organisations

Australian Centre for Health Law Research; Queensland University of Technology

Objective

- Improve clinicians' knowledge and awareness of end-of-life law, confidence applying the law in practice, and access to legal information

Funding

- $789,092 (2020-2023)
- $899,719 (2023-2026)

Alignment with the Strategy

- **Goal 1:** Understanding
- **Goal 2:** Capability
- **Goal 3:** Access and Choice

Key achievements

- Delivered 14 online modules addressing all aspects of end-of-life law, for all health professionals (medical practitioners, nurses and allied health) in acute, primary and aged care
- Developed modules focused on underserved populations including Aboriginal and Torres Strait Islander peoples, LGBTIQ+ people, people from CALD and refugee backgrounds, people with disability, and people with frailty
- Pre-and-post training survey data demonstrates significant changes to participants' legal knowledge and confidence applying the law in practice
- Embedded modules into curriculum and teaching resources of nine undergraduate medical schools nationally

Caring@home (2023-26) (including Caring Safely for Aboriginal and Torres Strait Islander Australians at Home) (2020-2023)

Core from 2023-26

Overview

Caring@home aims to increase access to quality and timely end-of-life care for patients who choose to be cared for, and die at home, Caring@home develops and delivers nationally consistent, practical and evidence-based clinical resources and education for health professionals to support proactive end-of-life care planning with families and carers and to support families and carers to help manage end-of-life symptoms at home. The 2020-2023 funding cycle focused on palliative care for Aboriginal and Torres Strait Islander people.

Implementing organisations

Metro South Health and Hospital Service; Brisbane South Palliative Care Collaborative

Objectives

- Improve access to quality palliative and end-of-life care for home-based patients
- Improve capability of health professionals to deliver a standardised best-practice approach to symptom management for home-based palliative patients
- Empower families and carers to manage palliative and end-of-life physical symptoms

Funding

- $1,556,722 (2020-2023)
- $3,000,000 (2023-2026)

Alignment with the Strategy

- **Goal 2:** Capability
- **Goal 3:** Access and Choice

Key achievements

- Majority of survey respondents agreed resources increased confidence, knowledge and skills
- Disseminated 213 palliative care clinic box hard copies, and 82 standard Caring@home resource packages for carers hard copies
- Exceeded targets for downloads of clinical resources (523 downloads against a targeted 400 downloads)
- Exceeded targets for engagements for eNews subscribers (3,446 subscribers against a target of 1,400), website visits (2,061 visits against a target of 800 visits and 8,225 website views per month against a target of 1,500 views)
- Exceeded targets for number of health professionals reached and engaged

Advance Care Planning Australia (2020-2023, 2023-2026)

Overview

ACPA is the national voice on advance care planning. ACPA supports community and the health and aged care workforce to help Australians make informed choices about their future health care. We aim to promote and improve advance care planning for all Australians. Our vision is for people to:

- Have a say in their future health care
- Record and share their wishes and preferences
- Be heard by their care providers
- Have their wishes and preferences respected

Implementing organisations

Austin Health (2020-2023); Metro South Health (2023-2026)

Objectives

- Help everyone understand advance care planning and improve participation
- Educate the health and aged care workforce about advance care planning
- Improve the systems that support advance care planning
- Build and share knowledge through research and evidence

Funding

- $4,100,000 (2020-2023)
- $5,000,000 (2023-2026)

Alignment with the Strategy

- **Goal 1:** Understanding
- **Goal 2:** Capability
- **Goal 3:** Access and Choice

Key achievements

- Delivered an annual multi-channel National Advance Care Planning Week campaign
- Delivered a national communications program, including website, monthly eNewsletter, social media on Facebook and LinkedIn, media and public relations outreach strategy, stakeholder engagement, resources, and events
- Delivered the National Advance Care Planning Advisory Service
- Delivered a National Symposium to share advance care planning best practice and support the aged and health care sectors.
- Delivering a landmark National Prevalence Study designed to establish a national benchmark and inform recommendations to improve advance care planning uptake

Non-core projects in scope of the evaluation

CarerHelp Diversity (2020-2023)
CarerHelp Rural Connect (2023-2026)

Overview

CarerHelp provides online information and resources to Australian families and carers caring for someone with an advanced disease. CarerHelp has practical resources and information on palliative care and end-of-life care topics including practical care, self-care, finding services and supports, managing common symptoms, having important discussions, recognising dying, and bereavement. CarerHelp has been funded since 2017-18.

Implementing organisations

St Vincent's Hospital Melbourne

Objective

- CarerHelp Diversity – expand the reach and impact of CarerHelp by providing resources that meet the needs of carers from underserved population groups.
- CarerHelp Rural Connect – provide support and resources to carers and families from regional, rural and remote parts of Australia.

Funding

- $1,086,778 (2020-2023)
- $1,289,648 (2023-2026)

Alignment with the Strategy

- **Goal 1:** Understanding
- **Goal 3:** Access and Choice

Key achievements

- Consultation with key stakeholders, including individuals from priority populations
- Education and consultation sessions with health services to raise awareness of the resources and demonstrate how health care professionals can use the resources to support family carers
- Development and delivery of resources to support carers from underserved population groups, including translated resources for cultural and linguistically diverse communities, resources for Aboriginal and Torres Strait Islander carers, resources to support LGBTIQ+ families and resources for carers in rural areas
- Collaboration with Carers Australia and other National Palliative Care Projects
- Rapid literature review on the needs of rural carers caring for someone with advanced disease

Project Echo (2023-2026)

Overview

Palliative Care ECHO is a series of interactive virtual mentoring sessions that addresses a range of palliative care topics chosen by health professionals in the primary care sector. It aims to significantly strengthen primary healthcare support of palliative care through workforce development and palliative care coordination.

Implementing organisations

The University of Queensland

Objectives

- Increase the reach and accessibility of palliative care in underserved populations by upskilling local primary healthcare professionals, especially in regional, rural and remote communities
- Collaborate with services to deliver training in relevant areas of interest

Funding

- $923,030 (2023-2026)

Alignment with the Strategy

- **Goal 2**: Capability

Key achievements

- Palliative care ECHO established in all states and territories
- Administered educational needs survey, and pre-implementation survey
- Completed 10 ECHO sessions from July 2023 to June 2024
- Post-session feedback surveys showed self-reported increases in palliative care knowledge, improved confidence to care for someone with a life-limiting illness and decreased professional isolation
- 10 monthly live interactive sessions delivered per year, with between 100 to 226 participants per session
- Facilitating multidisciplinary specialist teams from across the country to present and support health workers in each session

Shaping the future of paediatric palliative care (2023-2026)

Overview

The Shaping the future of paediatric palliative care project supports families and healthcare professionals in paediatric palliative care. The project takes a comprehensive approach to awareness-raising, advocacy and inclusive involvement of those affected by life-limiting illnesses.

Implementing organisations

Palliative Care Australia

Objectives

- Implement elements of the National Paediatric Palliative Care Action Plan (published in 2024)
- Increase skills of palliative care workforce to enhance the safety and quality of care provided to infants, children, young people and their families
- Increase access to quality paediatric palliative care through the development of improved referral strategies, and transition pathway to empower young people and families in preparing for and transitioning between paediatric and adult services
- Support healthcare providers to initiate difficult conversations with empathy and compassion through structured communication training
- Raise awareness of paediatric palliative care

Funding

- $1,250,000 (2023-2026)

Alignment with the Strategy

- **Goal 1:** Understanding
- **Goal 2:** Capability
- **Goal 3:** Access and Choice

Key achievements

- Established Steering Committee
- Consulted and established working relationships with key organisations
- Delivered communication modules and training for specialist palliative care providers
- Developed clinical guidelines and best practice

Palliative Care Foundation Training Program for Pharmacists and Service Model Pilots (2023-2026)

Overview

The Palliative Care Foundation Training Program for Pharmacists aims to upskill pharmacists with the foundational knowledge, skills and compassion needed to provide palliative care support to patients through quality use of medicine. The vision for the Service Model Pilots is to enhance the quality of palliative care by adding pharmacist expertise to community-based palliative care teams.

Implementing organisations

- Pharmaceutical Society of Australia Limited

Objectives

- Develop and implement a Palliative Care Foundation Training Program for Australian pharmacists in all practice settings
- Develop and pilot community palliative care pharmacist service models

Funding

- $1,865,665 (2023-26)

Alignment with the Strategy

- **Goal 2:** Capability

Key achievements

- Systematic scoping review to inform project development
- Developed course structure and content for an eight-module training program
- Established six service model pilots with pharmacists integrated into community-based Specialist Palliative Care Services

The National Palliative Care Coordination Program (2023-2026)

Overview

The National Palliative Care Coordination (NPCC) Project aims to improve the timely identification of palliative care needs in general practice, both generalist and specialist, and facilitate the timely and appropriate referral or escalation to specialist palliative care, based on complexity of needs.

Implementing organisations

University of Wollongong

Objectives

- Enhance general practice capability in the timely identification of palliative care needs
- Develop and test the feasibility of cyclic palliative care needs screening and referral protocol
- Improve timely access to palliative care and appropriate referrals to meet specialist palliative care needs

Funding

- $2,823,090 (2023-26)

Alignment with the Strategy

- **Goal 4:** Collaboration
- **Goal 6:** Data and evidence

Key achievements

- Established expert working group
- Completed literature review on palliative care identification in general practice, including screening tools, implementation barriers, and facilitators
- Scoped education opportunities for general practice staff and identified patient and carer resource needs
- Undertook extensive stakeholder consultations and established ongoing engagement with PHNs

Education and assessment of psychosocial existential wellbeing (Completed 2020-2023)

Overview

Education and assessment of psychosocial existential wellbeing aimed to improve the quality of, and access to, palliative care skill development for clinicians. The project included face-to-face experiential training and an online program for clinician education to address psychosocial existential symptoms.

Implementing organisations

University of Notre Dame Australia

Objectives

- Improve the quality of, and access to, palliative care skill development relating to psychosocial existential wellbeing
- Improve the quality of palliative care delivery on inpatient units
- Improve the identification, and management, of patient symptoms leading to improved quality of life

Funding

- $1,062,342 (2020-2023)

Alignment with the Strategy

- **Goal 2:** Capability

Key achievements

- Delivery of 71 workshops to 629 clinicians
- Delivery of online training models in collaboration with End-of-Life Essentials
- Implemented a standardised patent screening tool for psycho-existential symptoms

Gwandalan Education and Training Suite (2020-2023)

Overview

'Gwandalan' is a word from the Darkinjung and Awaba language meaning *rest*, *peace*, or *resting place*. The Gwandalan National Palliative Care Project was a co-designed national initiative aimed at strengthening the cultural safety and responsiveness of palliative care services for Aboriginal and Torres Strait Islander peoples. AGPAL led the project to develop a suite of education and training resources to support culturally appropriate care at the end-of-life.

Implementing organisations

Australian General Practice Accreditation Limited

Objectives

- Build capability in the palliative care workforce to deliver culturally safe, respectful, and relevant care
- Increase access to and engagement with palliative care services among Aboriginal and Torres Strait Islander communities
- Empower individuals, families, and communities to make informed choices in palliative care
- Strengthen coordination and quality of care through culturally informed education and training

Funding

- $1,199,797

Alignment with the Strategy

- **Goal 1:** Understanding
- **Goal 2:** Capability
- **Goal 3:** Access and choice
- **Goal 4:** Quality
- **Goal 5:** Collaboration
- **Goal 6:** Accountability

Key achievements

- Community Engagement Strategy
- Five eLearning modules for frontline health workforce and digital toolkit (Dillybag) for the frontline health workforce
- 11 webinars
- Developed bespoke eLearning platform

LGBTIQ+ Palliative Care Project (2020-2023, extended to 2024)

Overview

The LGBTIQ+ Palliative Care Project aims to increase LGBTIQ+ inclusion in the delivery of palliative care. LGBTIQ+ Australia, with the Australian College of Applied Professions, undertook research into inclusive palliative care for LGBTIQ+ people. LBGTIQ+ Health Australia co-developed an eLearning package with Australian General Practice Accreditation Limited (AGPAL) for the palliative care workforce.

Implementing organisations

National LGBTI Health Alliance

Objectives

- Increase capacity of palliative care workforce to provide LGBTIQ+ inclusive care
- Improve the experiences of LGBTIQ+ people and their loved ones accessing palliative and end-of-life care

Funding

- $1,271,418 (2020-2024)

Alignment with the Strategy

- **Goal 2:** Capability
- **Goal 3:** Access and choice

Key achievements

- Established palliative care workforce and advisory committee
- LGBTIQ+ Inclusive Palliative Care eLearning package
- Research, including scoping review, interviews and national survey completed by over 850 people
- National community of practice

End of Life Essentials (2020-2023)

Overview

EoLE is an online education platform and practice resource for acute health sector clinicians, educators, senior managers and quality assurance staff, designed to support the quality and safety of end-of-life care in hospitals. The evidence-based materials are designed to equip clinicians, at any career stage, with the knowledge and skills required to provide high-quality end-of-life care.

Implementing organisations

Flinders University

Objective

Address organisational quality and safety and skill development through the delivery of online education modules and accreditation resources associated tool kits on end-of-life care in acute hospitals

Funding

- $996,125 (2020-2023)

Alignment with the Strategy

- **Goal 2:** Capability
- **Goal 4:** Collaboration
- **Goal 5:** Investment

Key achievements

- A total of 16,981 learner registrations, 44,864 module completions and 16,707 Toolkit downloads (1 July 2020 – 30 June 2023), across all states and territories
- Reviewed, promoted and delivered 10 education modules
- Delivered and evaluated new modules on States of Mind at the End of Life, Assessing Patient States of Mind at the End of Life, and Clinical Management of Anxiety, Depression and More
- Designed, tested and delivered four new education modules and resource hub (Patient Coordination; End-of-Life Care for Diverse Communities; Clinical Change Management; Meeting the Standards)
- Implemented EoLE toolkits and managed online resource hub
- Delivered two national workshops
- Launched a new learning management system to enhance learner accessibility and usability
- Established a National Accreditation Collaborative Database

Palliative Care Online Training Portal (2020-2023)

Overview

The Palliative Care Online Training Portal delivered an online training portal aimed at frontline palliative care workers, predominantly those working with older persons in community settings. The Portal offers free, non-clinical, interactive palliative care training for carers, community aged care workers, students, volunteers, family members, and clinicians who want to build their skills caring for someone with a life-limiting illness.

Implementing organisations

St Vincent's Hospital Melbourne

Objectives

- Improve the quality of and access to palliative care service skill development
- Improve the quality of palliative care service delivery in community and acute settings

Implementing organisations

- $1,101,564 (2020-2023)

Alignment with the Strategy

- **Goal 1:** Understanding
- **Goal 2:** Capability

Key achievements

- Provided relevant and accessible training to registered users
- High percentage of participants experienced self-reported improvement in knowledge and skills



Improving palliative care services for people with intellectual disability (2020-2023, extended to 2024)

Overview

The Improving Palliative Care Services for People with Intellectual Disability project utilised a mixed-methods approach incorporating large, linked datasets and other quantitative and qualitative data to examine access to and the impact of palliative care for people with intellectual disability. Collective findings were translated into the co-design of a tailored model of care and supporting toolkits and resources.

Implementing organisations

University of New South Wales

Objective

- Improve palliative care services for people with intellectual disability

Funding

- $1,140,915 (2020-2024)

Alignment with the Strategy

- **Goal 1:** Understanding
- **Goal 2:** Capability
- **Goal 3:** Access and Choice

Key achievements

- Continued engagement with Project Advisory Group including people with intellectual disability, supporters of people with intellectual disability, and representatives from health, disability and advocacy services.
- International Delphi survey to support model development
- Developed a tailored model of palliative care for people with intellectual disabilities
- Developed accessible information resources for people with intellectual disabilities and their supporters
- Developed toolkits on improving palliative care for people with intellectual disability

The Advance Project (2020-2023, extended to 2024)

Overview

The Advance Project provides practical, evidence-based resources and training for frontline residential and community aged care professionals, as well as GPs, nurses and support staff in general practice and primary care, initiating team-based advance care planning and palliative care.

Implementing organisations

Hammond Care

Objective

- Tailor existing Advance Project resources to be used with people living with dementia, and develop new resources and training to enable aged and primary care professionals to develop skills in initiating conversations about advance care planning and palliative care needs assessment with people with different stages of dementia

Funding

- $1,200,000 (2020-2024)

Alignment with the Strategy

- **Goal 1:** Understanding
- **Goal 2:** Capability
- **Goal 3:** Access and Choice
- **Goal 4:** Collaboration

Key achievements

- Environmental scan and rapid literature review of existing tools and resources
- Recruited expert advisory group
- Stakeholder engagement to develop dementia specific resources and training
- Delivered dementia specific model, suite of resources, and training program (including eLearning)

Palliative Care in Prisons (2020-2023, extended to 2025)

Overview

The Palliative Care in Prisons Project aims to understand current palliative care provision in Australian prison, to identify the barriers to and facilitators of evidence-based palliative and end-of-life care and to co-design a National Framework of Palliative Care for Australian Prisons.

Implementing organisations

University of Technology Sydney (2020 – 2023)

Queensland University of Technology (2023 – 2025)

Objective

- To map the palliative care needs of people in prison with advanced progressive illnesses and the capacity of the sector to meet these needs
- To co-design a new National Framework of Palliative Care for Australian Prisons that is inclusive of national policies, correctional health workforce capacity building strategies, clinical service model of care and a toolkit of resources

Funding

- $1,199,965 (2020-2025 – project continued beyond 2023 due to delays)

Alignment with the Strategy

- **Goal 1:** Understanding
- **Goal 2:** Capability
- **Goal 3:** Access and Choice

Key achievements

- Established National Consortium Project Advisory Group and Aboriginal and Torres Strait Islander Engagement Group
- Delivered a Rapid Review of existing literature
- Undertook ethics processes in each Australian jurisdiction
- Delivered co-designed capacity building workshops and consultations

Appendix B: Evaluation Program Logic

SITUATION	GOALS	OBJECTIVES	INPUTS	ACTIVITIES	OUTPUTS	SHORT-TERM OUTCOMES	MID-TERM OUTCOMES	IMPACTS
Around 80,000 people may benefit from palliative care (PC) each year Demand for PC is increasing Health system is complex and fragmented. PC is often siloed away from other healthcare Collaboration among projects, and sharing of resources and learnings could be strengthened Need to ensure that all people affected by life-limiting illnesses get the care they need to live as well as possible for as long as possible	**Understanding**: Improve awareness and understanding of PC and advance care planning (ACP)	• Increase awareness of how to access PC services • Improve understanding of benefits of PC and ACP • Influence the de-stigmatisation of death and dying	Funding Grant-making 26 projects (2020-2026) Grant administration and management Organisations and service providers Workforce Governance and overarching strategy	• Information and advisory services • Marketing and promotion • Education and training • Workforce development activities • Service delivery initiatives • Service navigation supports • Equitable access initiatives • Home care support • Relationship building activities • Collaborative processes • Data collection by projects • Project reporting • Project-level evaluation • Support from Department grant managers • Jurisdictional reporting • Alignment of projects with National Strategy and best practice	• Information on PC and ACP developed and communicated • Education materials developed • Workforce training delivered • Barriers to access addressed • Consumers know how to access PC • Tools in place to support care in the home • Stronger linkages between care settings and services • Collaborative tools and processes established • Projects integrated into services • PC embedded into education and training materials • System-wide processes and procedures developed • Data gaps identified and addressed • Reporting inconsistencies addressed • Data access issues resolved • Processes in place to capture consumer voice • Projects aligned to best practice	• Increased awareness of PC services • Increased number of people with documented discussions about ACP • Increased number of people with ACPs • Increased understanding of PC services and ACP practices • Improved confidence of workforce to discuss ACP and provide PC • Increased provider capacity in all care settings • Increased early referrals and access • More people receive timely access to pain relief and symptom control • Increased period of time that people get to spend in their preferred place of care as the end of life approaches. • Improved collaboration across projects, services, and sectors • More patients experience continuity of care and shared decision making • Carers receive appropriate support through linked services and referrals • More healthcare professionals trained in providing PC • PC and ACP considered part of core business, not just specialist care • Data consistently collected • Meaningful information reported against KPIs • Data used for continuous improvement • Reduced duplication • Increased efficiency and cost-effectiveness • Clearer understanding of value of investment and future priorities	People understand the benefits of PC, know how to access services, and are involved in decision making Knowledge and practice of palliative care is embedded in all care settings People affected by life-limiting illnesses receive care that matches their needs and preferences All relevant stakeholders work together to create a consistent experience of palliative care across care settings A skilled workforce and systems are in place to deliver palliative care in any setting Robust national data and a strong research agenda strengthen and improve palliative care Project decision-making is well-informed and evidence-based	Improved quality of life and death for people receiving PC, their families and carers Improved quality of PC services through more informed and capable healthcare professionals working in a more coordinated and collaborative service system Reduced need for hospital-based care with more people choosing their location of death
	Capability: Increase knowledge, skills, and capability of the healthcare workforce to deliver high-quality PC	• Improve knowledge and skills of workforce and capability of services to provide PC and ACP • Improve quality of PC received by people living with a life-limiting illness						
	Access and Choice: Enable people affected by life-limiting illnesses to have timely access to care that aligns with their needs and preferences	• Achieve equity of access to PC • Ensure those with life-limiting illness have choice of care options • Improve quality of care through person-centred approach						
	Collaboration: Improve health-sector and cross-sector collaboration in the delivery of PC	• Improve linkages and transitions between primary care, aged care and specialist services • Improve care coordination and ensure patients and carers receive the support they need						
	Investment: Invest in system-level improvements and innovation to support delivery of PC	• Invest in workforce development through education and training • Invest in quality improvement • Ensure sustainability of projects and/or their outputs into the future						
	Data and Evidence: Strengthen data collection, sharing, and reporting processes to facilitate evidence-based decision making	• Improve consistency and quality of data collection • Improve communication and information sharing • Strengthen evidence-based decision making						
	Accountability: Drive action, improvement and collaboration	• Ensure projects achieve objectives in line with overarching strategy • Avoid unnecessary duplication • Maximise cost-effectiveness						

ASSUMPTIONS

Stable core funding | Workforce to deliver projects | Responsive authorising environment

EXTERNAL FACTORS

Changes to legislation/change in government | Connection and collaboration with wider service sector | Climate disasters or pandemics | Significant funding changes/destabilisation | Organisational change within lead organisations

Appendix C: NPCPs and ELDAC achievements against short and medium-term outcomes in Program Logic

PROGRAM LOGIC OUTCOME		EVIDENCE		
Short-term outcomes	**Mid-term outcomes**	**Stakeholder interviews + workforce survey**	**NPCP reports**	**ELDAC reports**
Increased awareness of palliative care services	People understand the benefits of palliative care, know how to access services and are involved in decision-making	Stakeholders confirmed greater public and workforce understanding. **67.2%** of survey respondents reported improved knowledge and community awareness of palliative care.	Projects used diverse channels (e.g. training, social media, webinars) to raise awareness and engage priority populations.	ELDAC distributed toolkits and digital resources (e.g. Home Care App, Self Care Room) to support aged care staff and improve consumer involvement.
More people are discussing and documenting their care preferences	Advance care plans are being used to guide shared decision-making.	Stakeholders noted slow community uptake, highlighting the need for continued education. **58.0%** of survey respondents reported increased understanding and uptake. **47.0%** agreed that advance care plans are being prepared and used effectively.	Projects promoted advance care planning through services like ACPA's National Advance Care Planning Advisory Service.	ELDAC supported aged care staff through training, resources and marketing initiatives.

PROGRAM LOGIC OUTCOME		EVIDENCE		
Short-term outcomes	**Mid-term outcomes**	**Stakeholder interviews + workforce survey**	**NPCP reports**	**ELDAC reports**
Greater understanding of palliative care and advance care planning. Increased workforce confidence and capacity across care settings.	Palliative care knowledge and practice are embedded across the system.	Stakeholders reported improved confidence and capability at both individual and organisational levels. Project resources were widely used to train junior staff and non-specialist teams. **58%** of survey respondents reported increased understanding and uptake of advance care planning. **67.2%** noted improved awareness of palliative care. **56.6%** felt more capable of delivering quality care. **64.8%** saw improved standards within their organisation.	Project reporting shows workforce members gained confidence and capability in delivering palliative care and advance care planning through training and use of project resources. Training modules were embedded in university and workforce systems, with high levels of participation.	ELDAC's Linkages program improved organisational capacity and staff confidence. ELDAC's After Death audit showed consistent quality improvements.

PROGRAM LOGIC OUTCOME		EVIDENCE		
Short-term outcomes	**Mid-term outcomes**	**Stakeholder interviews + workforce survey**	**NPCP reports**	**ELDAC reports**
Earlier referrals and better access to palliative care Timely pain and symptom relief More time spent in preferred place of care	Care aligns with individual needs and preferences	Stakeholders observed increased choice in end-of-life care due to improved workforce knowledge. **53.0%** of survey respondents reported improved access to palliative care had increased, particularly for priority populations. **73.2%** noted better quality of life for patients, families, and carers.	Projects enhanced referral pathways through training, research, and clinical guidelines. Quality improvements were measured using PROMS and PREMs. Health services participating in PCOC reported improvements in outcomes. PCA's managed the National Register of Palliative Care Consumers and Carers, which fosters consumer and carer engagement in policy and project design.	ELDAC strengthened workforce systems and communication to support timely, preference-based care.
Improved collaboration across projects, services, and sectors Improve continuity of care and shared decision making Better support carers through linked services	Stakeholders work together to deliver consistent palliative care across care settings	Stakeholders and carers confirmed increased support and resources access. **61.4%** of survey respondents reported better coordination, and communication.	Projects fostered collaboration through joint activities, shared learning, and cross-sector engagement.	ELDAC consortium model and National Reference Group enabled broad stakeholder input. The Linkages program and Toolkit strengthened partnerships between aged, primary and palliative care services.

PROGRAM LOGIC OUTCOME		EVIDENCE		
Short-term outcomes	**Mid-term outcomes**	**Stakeholder interviews + workforce survey**	**NPCP reports**	**ELDAC reports**
More healthcare professionals trained in palliative care Palliative care and advance care planning considered part of core business, not just specialist care	A skilled workforce and systems are in place to deliver palliative care in any setting	The workforce gave positive feedback on training, which improved their skills and reinforced palliative care and advance care planning are increasingly viewed as core business across the sector. Survey respondents: **62.0%** reported improved quality and access to skill development. **54.8%** saw better service delivery in community and acute care settings. **84.5%** felt more confident delivering palliative care.	Project Training resources were embedded in curriculums and learning management systems at universities, health, and aged care services. Projects high uptake and self-reported improvements in knowledge and confidence.	ELDAC supported clinicians with training, conversation tools and a digital community of practice.
Data consistently collected Meaningful information reported against KPIs Data use for continuous improvement	Strong national data and research drive better palliative care	**46.0%** of survey respondents confirmed nationally consistent data collections. Stakeholders highlighted PCOC's role in benchmarking and quality improvements. Stakeholders described the importance of research and evaluation activities being undertaken by projects in improving project delivery and establishing a deeper evidence base.	PCOC has driven development of nationally consistent data. ACPA's National Prevalence Study set benchmarks for advance care planning. Projects used data to track outcomes, inform design, and support continuous improvement, and undertook independent evaluations and research (e.g. scoping reviews, literature reviews). Consumers, carer and family input was embedded in project design.	ELDAC collected meaningful data (e.g. After Death Audits) and led research to strengthen care.

PROGRAM LOGIC OUTCOME		EVIDENCE		
Short-term outcomes	**Mid-term outcomes**	**Stakeholder interviews + workforce survey**	**NPCP reports**	**ELDAC reports**
Reduced duplication Increased efficiency and cost effectiveness Clearer understanding of value and future priorities	Project decisions are informed by evidence and collaboration.	Stakeholders praised the quality and evidence base of project resources. Some stakeholders noted confusion due to the volume of materials and perceived duplication. **67.5%** of survey respondents reported better collation and sharing of palliative care information.	Projects used evaluations and research to guide design and prioritise investments. Collaboration between projects helped reduce overlap and improve clarity.	Resources were consolidated via websites and apps (e.g. ELDAC's Home Care and PaCE Aged Care Apps).

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