Evaluation of the National Palliative Care Projects

Final Report

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Table of Contents

[Acronyms 1](#_Toc29297134)

[Executive Summary 2](#_Toc29297135)

[Background 2](#_Toc29297136)

[Methodology 2](#_Toc29297137)

[Summary of supporting findings 2](#_Toc29297138)

[Summary of recommendations 3](#_Toc29297139)

[Introduction 4](#_Toc29297140)

[Background 4](#_Toc29297141)

[Overview of 2017-2020 NPCPs 5](#_Toc29297142)

[Overview of the evaluation 7](#_Toc29297143)

[This document 7](#_Toc29297144)

[Limitations 8](#_Toc29297145)

[NPCP future funding 8](#_Toc29297146)

[NPCPs Overview 9](#_Toc29297147)

[Details of current NPCPs 9](#_Toc29297148)

[Project activities and reach 10](#_Toc29297149)

[Project profiles 14](#_Toc29297150)

[Activities delivered by the NPCPs 22](#_Toc29297151)

[NPCPs usage and reach summary 22](#_Toc29297152)

[Activities delivered 22](#_Toc29297153)

[Development of resources and training 24](#_Toc29297154)

[The role of communication activities 26](#_Toc29297155)

[Research activities 26](#_Toc29297156)

[Cost efficiency analysis 27](#_Toc29297157)

[Key outcomes delivered by the NPCPs 28](#_Toc29297158)

[Activities met sector needs 28](#_Toc29297159)

[Collaboration with the sector 28](#_Toc29297160)

[Impacts of collaboration 29](#_Toc29297161)

[Supporting consistency 30](#_Toc29297162)

[Unexpected outcomes 31](#_Toc29297163)

[Alignment to the policy setting 31](#_Toc29297164)

[Evidence of longer-term impact 33](#_Toc29297165)

[Enabling factors and challenges 35](#_Toc29297166)

[Enabling factors 35](#_Toc29297167)

[Challenges faced 36](#_Toc29297168)

[Recommendations 37](#_Toc29297169)

[Recommendation 1: Align grants process and ongoing engagement with core projects to the national strategy 37](#_Toc29297170)

[Recommendation 2: Adopt a stronger leadership position with specific focus on collaboration 39](#_Toc29297171)

[Recommendation 3: Increase focus on outcomes 40](#_Toc29297172)

[Recommendation 4: Incorporate new approaches to ensure project outputs remain current and useful 41](#_Toc29297173)

[Disclaimer 42](#_Toc29297174)

[Appendix A - Evaluation methodology 43](#_Toc29297175)

[Evaluation details 43](#_Toc29297176)

[Appendix B - Program logic and mapping 46](#_Toc29297177)

[Appendix C - Summary table of NPCP alignment to funding objectives 49](#_Toc29297178)

[Appendix D - Analysis of NPCP audience 51](#_Toc29297179)

Tables:

[Table 1 – Definition of acronyms used in this report 1](#_Toc29297110)

[Table 2 – Summary of 13 projects 5](#_Toc29297111)

[Table 3 – Evaluation domains 7](#_Toc29297112)

[Table 4 – Overview of this document 7](#_Toc29297113)

[Table 5 – NPCP snapshot 9](#_Toc29297114)

[Table 6 – Overview of the NPCPs activities 10](#_Toc29297115)

[Table 7 – Overview of the NPCPs target audience 12](#_Toc29297116)

[Table 8 – Project profile: Advance Care Planning Australia (ACPA) – Austin Health 14](#_Toc29297117)

[Table 9 – Project profile: Australian Care Toolkit for Advanced Disease (Carer Toolkit) – St Vincent’s Hospital Melbourne 14](#_Toc29297118)

[Table 10 – Project profile: CareSearch – Flinders University 15](#_Toc29297119)

[Table 11 – Project profile: Caring Safely for Australians at Home (Caring @ Home) – Metro South Hospital and Health Service 15](#_Toc29297120)

[Table 12 – Project profile: End of Life Law for Clinicians (ELLC) – Queensland University of Technology 16](#_Toc29297121)

[Table 13 – Project profile: End of Life Essentials (EOLE) – Flinders University 16](#_Toc29297122)

[Table 14 – Project profile: Palliative Care Australia Project (PCA) – Palliative Care Australia 17](#_Toc29297123)

[Table 15 – Project profile: Palliative Care Education and Training Collaborative (E&TC) – Queensland University of Technology 18](#_Toc29297124)

[Table 16 – Project profile: Palliative Care Online Training & Information Portal (Online Training Portal) – Australian Healthcare and Hospitals Association 18](#_Toc29297125)

[Table 17 – Project profile: Palliative Care Outcomes Collaboration (PCOC) – The University of Wollongong 19](#_Toc29297126)

[Table 18 – Project profile: Quality of Care Collaborative Australia 2 (QuoCCA 2) – Children’s Health Queensland Hospital and Health Service 19](#_Toc29297127)

[Table 19 – Project profile: Talking End of Life (TEL) – University of Sydney and Western Sydney University 20](#_Toc29297128)

[Table 20 – Project profile: The Advance Project (Advance) – Hammond Care 20](#_Toc29297129)

[Table 21 – Training types and target audiences across NPCPs 25](#_Toc29297130)

[Table 22 – Alignment of NPCPs to National Strategy goals 32](#_Toc29297131)

[Table 23 – Summary of recommendations and supporting rationale 37](#_Toc29297132)

[Table 24 – NPCP alignment to funding objectives 49](#_Toc29297133)

Figures

[Figure 1 – Palliative care policy context as described in the National Palliative Care Strategy 2018 4](#_Toc29297100)

[Figure 2 – Overview of range of activities undertaken 23](#_Toc29297101)

[Figure 3 – Spectrum of NPCP collaboration 29](#_Toc29297102)

[Figure 4 – Role of National Strategy and Implementation Plan for NPCPs 41](#_Toc29297103)

[Figure 5 – Evaluation methodology overview 43](#_Toc29297104)

[Figure 6 – Program logic 46](#_Toc29297105)

[Figure 7 – Program Mapping (part 1) 47](#_Toc29297106)

[Figure 8 – Program Mapping (part 2) 48](#_Toc29297107)

[Figure 9 – Audience of NPCPs 51](#_Toc29297108)

# Acronyms

Table 1 – Definition of acronyms used in this report

| Acronym | Meaning |
| --- | --- |
| ACPA | Advance Care Planning Australia |
| ELLC | End of Life Law for Clinicians |
| EOLE | End of Life Essentials |
| E&TC | The Palliative Care Education and Training Collaborative |
| FY | Financial Year |
| GP | General practitioner |
| GPN | General practice nurses |
| NPCPs | National Palliative Care Projects |
| PCA | Palliative Care Australia |
| PCC4U | Palliative Care Curriculum for Undergraduates |
| PCOC | Palliative Care Outcomes Collaboration |
| PEPA | Program of Excellence in the Palliative Approach |
| PHN | Primary Health Network |
| QuoCCA 2 | The Quality of Care Collaborative Australia 2 |
| TEL | Talking End of Life |

# Executive Summary

## Background

Palliative care is a holistic approach to improving the quality of life for people affected by life-limiting illness. In Australia, the Commonwealth Department of Health (the Department) and state and territory governments work together to deliver a shared vision for palliative care, "people affected by life-limiting illnesses get the care they need to live well".[[1]](#footnote-2)

Since the 1990s the Department has funded National Palliative Care Projects (NPCPs) which focus on building capacity to deliver quality palliative care services. The most recent NPCPs include 13 individual projects funded for the 2017 – 2020 period under the Public Health and Chronic Disease Grant Program. They provided a range of education, awareness, research and capacity building activities to the sector.

In 2018, the Department commissioned Urbis to conduct an evaluation of the current NPCPs, and this document is the final report for the evaluation.

## Methodology

The evaluation was conducted in four phases over 2018 and 2019. It utilised a ‘nested evaluation’ design, where each of the individual projects have been examined as part of a larger investment to inform evaluation findings. The evaluation objectives were to assess the NPCPs across five domains: effectiveness, appropriateness, efficiency, contribution and sustainability. Evaluation activities included the design of a Program Logic and Evaluation Framework, site visits and interviews with all project teams, as well as consultation with broader sector stakeholders. Comprehensive analysis of project data was also completed, with all qualitative and quantitative data sources triangulated to form the key findings and recommendations.

## Summary of supporting findings

**Projects delivered or exceeded their workplans** - A wide range of activities were planned by the NPCPs, including the creation and distribution of communications, resources, training and research. Many projects also had a focus on developing sector networks. All projects delivered their key activities as per their workplans, and some exceeded activity and/or reach targets.

**Project activities met sector needs -** All NPCPs effectively reached their target audiences, reflecting the design and delivery of project activities were appropriate for sector needs. Some projects also demonstrated engagement with audiences beyond their core target groups, which addressed unmet sector needs.

**Collaboration delivered clear benefits -** All NPCPs collaborated with other project teams, and some also engaged with the broader sector. The benefits of inter-project collaboration were highly evident, and related to the cross-promotion of project outputs, identification and reduction of duplication, sharing of subject-matter expertise and provision of advice from existing project teams for new projects. Sector collaboration benefits related to some of the NPCPs providing leadership and stability to other parts of the palliative care sector, and an improved evidence base for continuous improvement.

**National focus supports sector consistency** - As national projects, all activities were designed and delivered to be appropriate for application across Australia. This national focus provided sector stakeholders with access to consistent palliative care information, resources and evidence regardless of which jurisdiction or care setting they work in.

**Alignment to the broader palliative care policy setting evident** - The NPCPs demonstrated strong alignment to the previous and current National Palliative Care Strategy, with particular alignment noted between the current projects and the 2018 Strategy's goal to build capacity in palliative care delivery. Some projects also take an active role in contributing to policy change, delivering advocacy activities to influence sector change. Some opportunities to improve integration with the broader health sector were identified.

**Four key factors were identified as enablers of outcomes** - The delivery of outcomes was enabled by four key factors, including: accessibility of project outputs to target audiences; flexibility and responsiveness in activity planning and delivery; expert knowledge held and shared by project teams; and project maturity which provided some projects with a strong foundation on which to build to deliver their workplan.

**Key challenges related to procurement and providing evidence of impact** - Some challenges were faced by the projects, including complications arising from the procurement process and project-specific implementation issues. Some projects also had difficulties in providing evidence of the longer-term impact of their activities, in part due to the nature of their activities and also the evaluation timeline. The evaluation also found that some project outputs have sustainability risks if funding for ongoing maintenance is not provided.

## Summary of recommendations

### Recommendation 1: Align Grant, work planning and ongoing engagement with core projects to the National Strategy.

The Department should align future projects to the National Palliative Care Strategy, define expectations for how different projects can contribute to existing and emerging sector needs, and engage core projects as a collective to address needs at a strategic level.

### Recommendation 2: Adopt a stronger leadership position with specific focus on collaboration.

Opportunities exist for the Department to play a stronger strategic role as commissioner by actively working with all projects to refine and monitor activities and outcomes to best align to sector needs. The Department should also take active steps to optimise the benefits of project collaboration demonstrated in the current Grant round.

### Recommendation 3: Increase focus on outcomes.

As the NPCPs and sector reach a new stage of maturity, the Department has the opportunity to raise the expectations of NPCPs in collecting and measuring their impact. This can be achieved through developing standardised outcome measurements which capture the extent to which the NPCPs are addressing sector needs. Opportunities to analyse the economic benefits of the NPCPs should also be investigated.

### Recommendation 4: Incorporate new approaches to ensure project outputs remain current and useful.

There are opportunities for the Department and projects to improve the lifespan of project activities and outputs. Some valuable resources are likely to need updating in the future to keep them current, even though the project that developed them is no longer funded. The evaluation has identified that there are opportunities to plan for ongoing upkeep of materials during procurement and work planning. Cross-project distribution and promotion of resources can also help to mitigate usability risks.

# Introduction

## Background

Palliative care is a holistic approach to improving the quality of life of people affected by life-limiting illness. Within Australia, most palliative care is delivered by state and territory governments. Palliative care settings range from inpatient services through to community-based services, and care in the home.

The Commonwealth Department of Health (the Department) as well as state and territory governments have developed the following vision for palliative care: “people affected by life-limiting illnesses get the care they need to live well”.[[2]](#footnote-3) This vision was established in the National Palliative Care Strategy 2018 (the National Strategy or Strategy) which is a commitment by governments to improve palliative care. The Strategy also sets out the roles of the Commonwealth and state and territory governments in relation to palliative care as follows.

“The responsibility for the implementation of the National Strategy rests with the Commonwealth, state and territory governments, with the Commonwealth providing national leadership and policy direction as well as supporting national research and other programs, and the state and territory governments providing quality palliative care and policy development within their jurisdictions.”[[3]](#footnote-4)

Since the 1990s, the Department has funded National Palliative Care Projects (NPCPs) to build capacity to deliver quality palliative care services across Australia. The NPCPs play a key role within the national palliative care policy landscape and the wider sector. Their role is specified in the National Strategy alongside state and territory policies and national guidance, as shown in Figure 1.

Figure 1 – Palliative care policy context as described in the National Palliative Care Strategy 2018 [[4]](#footnote-5)

Figure 1
International Policies Including: World Health Assembly Resolution 67.19 – Strengthening of palliative care as a component of comprehensive care throughout the life course. 
Council of Australian Governments (COAG) Health Council Australian Health Ministers’ Advisory Council (AHMAC). 
National Palliative Care Strategy 2018 supports National Palliative Care Projects; National Palliative Care Guidance (including): 
- National Consensus Statement: Essential elements for safe and high-quality end-of-life care. 
- National Palliative Care Standards .
- A National Framework for Advance Care Directives. 
- Palliative Care Services Delivery Guidelines.
State and Territory Palliative Policies and Care Policies are supported by the National Palliative Care Strategy 2018 and National Policies including: 
- National Carer Strategy. 
- National Framework for Action on Dementia (2015-2019). 
- National Strategic Framework for Chronic Conditions. 
- National Safety and Quality Health Service Standards. 
- National Disability Strategy 2010-2020.
- National Aboriginal and Torres Strait Islander Health Plan (2013-2023).
- Cultural Respect Framework for Aboriginal and Torres Strait Islander Health 2016-2026.
Other relevant policies include International Policies: 
- WHO Global Action Plan for the Prevention and Control of Non-Communicable Diseases 2013-2020. 
- International Covenant on Economic, Social and Cultural Rights.  


The NPCPs have been funded under a range of grant programs, the most recent being the Public Health and Chronic Disease Grant Program (the Grant Program) which commenced in 2015. Projects funded since 2015 have focussed on seven objectives specified in the Grant Program guidelines[[5]](#footnote-6).

* improve the quality of and access to palliative care service skill development for service providers
* improve the quality of palliative care service delivery in community and acute care settings
* build and enhance research and data collection capacity within the palliative care sector
* strengthen understanding and increase uptake of advance care planning
* improve knowledge within the palliative care sector and community awareness of palliative care
* improve collaboration and linkages between the Commonwealth and state and territory Governments' palliative care activities
* improve the collation and dissemination of palliative care information across the sector.

In 2017, the Department funded 13 NPCPs under the Grant Program for the 2017 – 2020 period (the current Grant period). In 2018, the Department commissioned Urbis to conduct an evaluation of the NPCPs. This is the final report for the evaluation.

## Overview of 2017-2020 NPCPs

The 2017 – 2020 NPCPs have been delivered by 11 organisations across Australia, and provide a range of education, awareness, research and capacity building activities. All projects aim to have a national impact and have varying audiences, from community members providing care to a person with life limiting illness, through to health professionals providing paediatric palliative care. The following pages provide an overview of each project, as well as their individual alignment to each of the seven Grant Program objectives.

A summary of the 13 projects is included in Table 2 below, and the next chapter provides greater details of each project including scale, remit and key achievements.

Table 2 – Summary of 13 projects

| Organisation | Project Name | Project Description |
| --- | --- | --- |
| Advance Care Planning Australia | Advanced Care Planning Australia | Strengthening understanding and uptake of advanced care planning for the health and community sectors |
| St Vincent’s Private Hospital | Helping family carers to support a relative or friend with advanced disease: the Australian carer toolkit for advanced disease | Increasing knowledge of palliative care for carers with adults with advanced diseases. |
| Flinders University | CareSearch including palliAged | Increasing palliative care knowledge for patients, carers, families and health professionals |
| Metro South Hospital and Health Service | Caring Safely for Australians at Home | Providing resources for health care professionals to support carers to manage breakthrough symptoms at home. |
| QUT End of Life Law of Clinicians | End of Life Law of Clinicians | Providing legal information regarding end-of-life law for doctors (medical specialists, GPs, interns and medical students). |
| Flinders University | End of Life Essentials | Strengthening palliative care knowledge for hospital-based staff through evidence-based training and resources. |
| Palliative Care Australia | Palliative Care Australia Project | Increasing quality of care and understanding of palliative care across the wider community through national leadership. |
| QUT | The Palliative Care Education and Training Collaborative: Palliative Care Curriculum for Undergraduates | Strengthening the resources and standards for tertiary palliative care education providers. |
| QUT | The Palliative Care Education and Training Collaborative: Program of Experience in the Palliative Approach | Increasing palliative care knowledge for specialist non-palliative care health professionals |
| QUT | The Palliative Care Education and Training Collaborative: National Palliative Care Workforce Action Plan | Developing a blueprint for the palliative care workforce in Australia. |
| Australian Healthcare & Hospitals Association | Palliative Care Online Training Portal | Increasing knowledge of palliative care approach for care providers in aged care, primary care, and the acute and community sectors. |
| University of Wollongong Australia | Palliative Care Outcomes Collaboration | Improving standards of palliative care services through development and distribution of an evidence base. |
| Children’s Health Queensland Hospital and Health Service | Quality of Care Collaborative Australia 2 | Improving the quality of paediatric care through education and support of health professionals involved in the care of children, and young people with palliative care needs. |
| The University of Sydney | Talking End of Life | Strengthening understanding of delivering palliative care for carers and practitioners who discuss dying and death with people with intellectual disabilities. |
| HammondCare | The Advance Project | Building capacity of primary health professionals to initiate conversations about advance care planning and assess patients’ and their carers’ palliative and supportive care needs. |

## Overview of the evaluation

The evaluation was conducted over 2018 and 2019, and has focussed on the delivery and outcomes of the NPCPs. The evaluation utilised a ‘nested evaluation’ design, where each of the individual projects have been examined as part of a larger investment to inform evaluation findings.

The evaluation was designed to deliver findings across five key domains outlined in Table 3 following.

Table 3 – Evaluation domains

| Evaluation Domain | Details |
| --- | --- |
| Effectiveness | The extent to which the project/s achieved their intended outcomes |
| Appropriateness | The extent to which the design of the project/s was suitable for achieving the intended outcomes |
| Efficiency | The extent to which the project/s were operationally and cost effective |
| Contribution | The contribution of the projects to the National Palliative Care Strategy, as well as to any other areas beyond their expected scope |
| Sustainability | The extent to which the projects demonstrated financial sustainability |

Appendix A contains a detailed evaluation methodology.

## This document

This report includes all key findings of the evaluation, as well as a discussion and recommendations. The information is presented over four chapters, as follows:

Table 4 – Overview of this document

|  |  |
| --- | --- |
| Chapter | Overview of contents |
| Introduction | * (This section) Background and overview of the evaluation including limitations to the evaluation report |
| NPCPs Overview | * An overview of each individual project, including their primary activities, funding, alignment to the National Strategy, and key achievements from the current Grant round. A cumulative summary of the projects’ usage and reach is also included at the end of this section |
| Supporting Findings | * Key findings relating to the activities which were delivered, relating to common themes across projects * Key findings relating to outcomes delivered by the projects, as a result of the activities undertaken * Identified enablers and challenges which influenced the delivery of activities and/or the achievement of outcomes |
| Recommendations | * Presentation of recommendations, and supporting rationale |

## Limitations

There are four areas of limitation that should be taken into consideration when reading this report.

* The evaluation has concluded before the end of the current Grant round on 30 June 2020, and only includes data and findings relating to the July 2017 to March 2019 period. This means that this report will not represent activities and outcomes delivered by the NPCPs in the remainder of the Grant period from April 2019 to June 2020.
* There were mixed levels of data availability relating to the long-term behavioural change outcomes specified in the Program Logic. Where data was not available this was partly due to timing. Some projects did not have time to demonstrate long-term outcomes by the time the evaluation concluded (this was sometimes dependent on the maturity of a project, with newer projects not expected to demonstrate long-term outcomes at this point in time). Limited behavioural change outcomes data was also reflective of many NPCP activities not easily lending themselves to outcomes measurements (e.g. awareness campaigns, fact sheets). This challenge is explored in detail in this report, and forms the basis of some of the recommendations.
* The evaluation intended to complete an economics analysis to quantify the benefits delivered by the NPCPs. Due to the diversity of activities completed across the different projects, diversity of organisational infrastructure and settings (and the implications of these for project costs and resources) and mixed levels of outcomes and financial data available, it has not been possible to complete the economic analysis.
* While the evaluation team did consult with a small cohort of end-users (e.g. training recipients, website users) during the 2018 site visits, the wide dissemination and open availability of many resources meant that it was not possible to identify and contact a large number of end-users for this evaluation. Where possible, information from interviews with end-users has been incorporated into this report. Existing data gathered from the projects’ own evaluations or end-user consultations were also included in the evaluation. Necessarily, consultation for the evaluation focussed primarily on project delivery teams and sector stakeholders, in line with the focus on the evaluation of the NPCPs as a whole rather than conducting individual evaluations of each project. This approach also sought to reduce the burden placed on end-users and to use existing available data where possible. This means that the findings in the report may not be fully representative of the views and opinions of end-users of the NPCPs.

## NPCP future funding

At the time of writing, the Department has adopted a new grant approach for the 2020 – 2023 period. Where the current and previous Grant rounds utilised funding for a single set of National Palliative Care Projects, there are two separate grant opportunities available for the 2020 – 2023 period.

The first is a closed grant opportunity titled National Palliative Care Projects – Core and provides up to $39m in grants for the 2020 – 2023 period. This opportunity is only available to six organisations which were identified by the Department as providing core projects underpinning the Commonwealth’s contributions to palliative care in Australia (this identification was made on the basis of an evaluation in 2016 of the previous *National Palliative Care Strategy 2010*). These organisations were Palliative Care Australia, Flinders University of South Australia, University of Wollongong, Queensland University of Technology, Austin Health and the Children’s Health Queensland Hospital and Health Service.

The second grant opportunity is called National Palliative Care Projects, and provides for up to $12m of grants for the 2020 – 2023 period. This grant is an open and competitive opportunity. All current NPCPs, as well as new organisations have an opportunity to apply. These grants are focussed on funding projects which target specific priority populations who have limited access to palliative care.

This new approach helps to provide the sector with greater certainty of ongoing funding for key infrastructure and activities, while still enabling opportunities for new and innovative initiatives to be delivered. While this change has not affected the methodology or results of this evaluation, considerations for measuring its efficacy are included in the recommendations of this report.

# NPCPs Overview

## Details of current NPCPs

Table 5 – NPCP snapshot

|  |  |
| --- | --- |
| Total number of projects | 13 |
| Main project purpose | 1 out of 13 projects were providing leadership  3 out of 13 projects were providing information and evidence  9 out of 13 projects were providing training and education |
| Focus on under-served groups | 6 out of 13 projects had a focus on under-served population groups |
| Mode of delivery | 6 projects were delivering content online and face to face  6 projects were delivering content online only  1 projects were delivering content face to face only |
| Main focus area | 6 projects had the palliative approach to care as their main focus  2 projects had carer support as their main focus  3 projects had specialised support such as legal issues, people with disability and paediatric palliative care as their main focus  2 projects had advance care planning as their main focus |
| Funding | 1 project received NPCP funding of less than $100,000  4 projects received NPCP funding of between $100,000 and $1,000,000  3 projects received NPCP funding of between $1,000,000 and $3,000,000  4 projects received NPCP funding of between $3,000,000 and $9,000,000  1 project received NPCP funding of over $10,000,000 |
| Target health setting (some projects with various target audiences are represented in multiple categories) | 5 projects involved the whole of the sector, including community  4 projects involved hospital professionals or specialists  3 projects involved community health workers  3 projects involved carers  2 projects involved general practice  2 projects involved tertiary students |
| Alignment with funding objectives (projects with strong or partial alignment – see Appendix C) | 11 projects aligned with improved quality in community and acute settings  10 projects aligned with improved quality and access  7 projects aligned with knowledge and community awareness  6 projects aligned with collation and dissemination of information  5 projects aligned with linkages between jurisdictions  5 projects aligned with research and data collection  4 projects aligned with advance care planning |

## Project activities and reach

Table 6 – Overview of the NPCPs activities

| Project | Communications materials | Resources and tools | Training | Research | Collaboration |
| --- | --- | --- | --- | --- | --- |
| Advance Care Planning Australia | Yes | Yes | Yes | Yes | Yes |
| Australian Carer Toolkit for Advanced Disease | Yes | Yes | No | No | No |
| CareSearch | Yes | Yes | Yes | Yes | Yes |
| Caring Safely for Australians at Home | Yes | Yes | Yes |  |  |
| End of Life Law for Clinicians | No | Yes | Yes | No | No |
| End of Life Essentials | Yes | Yes | Yes | Yes | No |
| Palliative Care Australia | Yes | Yes | No | Yes | Yes |
| Palliative Care Education and Training Collaborative | Yes | Yes | Yes | No | Yes |
| Palliative Care Online Training Portal | No | Yes | Yes | No | Yes |
| Palliative Care Outcomes Collaboration | Yes | Yes | Yes | Yes | Yes |
| Quality of Care Collaborative Australia 2 | No | Yes | Yes | Yes | Yes |
| Talking End of Life | No | Yes | Yes | No | No |
| The Advance Project | No | Yes | Yes | Yes | Yes |

Table 7 – Overview of the NPCPs target audience

| Project | Patients | Carers | Hospital health professionals | Community health professionals and care workers | Education providers | Students | Other |
| --- | --- | --- | --- | --- | --- | --- | --- |
| Advance Care Planning Australia | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| Australian Carer Toolkit for Advanced Disease | No | Yes | No | No | No | No | No |
| CareSearch | Yes | Yes | Yes | Yes | No | Yes | Yes |
| Caring Safely for Australians at Home | No | Yes | Yes | Yes | No | No | Yes |
| End of Life Law for Clinicians | No | No | Yes | Yes | Yes | Yes | No |
| End of Life Essentials | No | No | Yes | No | No | No | No |
| Palliative Care Australia | Yes | Yes | Yes | Yes | No | No | Yes |
| Palliative Care Education and Training Collaborative | No | No | Yes | Yes | Yes | Yes | Yes |
| Palliative Care Online Training Portal | No | Yes | Yes | Yes | No | No | Yes |
| Palliative Care Outcomes Collaboration | Yes | Yes | Yes | Yes | No | No | Yes |
| Quality of Care Collaborative Australia 2 | No | Yes | Yes | Yes | No | Yes | Yes |
| Talking End of Life | No | Yes | No | Yes | No | No | No |
| The Advance Project | No | No | No | Yes | No | No | No |

## Project profiles

This section provides a summary of the NPCPs. It includes an overview of each project and its objectives, the grant funding received, and key achievements within the evaluation timeframe.

Table 8 – Project profile: Advance Care Planning Australia (ACPA) – Austin Health

| Overview | ACPA is focussed on increasing advance care planning awareness and uptake, building workforce capacity and providing an evidence base to help Australians consider their current and future health goals, values and beliefs. The project was previously known as Respecting Patient Choices and the name was changed to Advance Care Planning Australian in 2016. |
| --- | --- |
| Objectives | * Coordinate and support national advance care planning initiatives * Increase uptake of advance care planning education resources * Enhance research and data collection of advance care planning |
| Funding | $4,111,236; funded via the Grant Program since: 2011 |
| Alignment to National Palliative Care Strategy 2018 | * Goal 1: Understanding * Goal 4: Collaboration |
| Key Achievements | * Delivery of extensive ACP awareness activities, including a National Advance Care Planning Week * Delivery of a national ACP advisory service * Three national advisory groups convened * Development of draft ACP competency framework, and extensive delivery of ACP training and education |

Table 9 – Project profile: Australian Care Toolkit for Advanced Disease (Carer Toolkit) – St Vincent’s Hospital Melbourne

|  |  |
| --- | --- |
| Overview | The Carer Toolkit will provide information to family carers supporting people with advanced disease (such as cancer, dementia or liver disease) to help improve the care provided in line with the National Standards for Palliative Care. |
| Objectives | Help family carers to support a person with advanced disease by providing access to high quality information via a national e-health toolkit. |
| Funding | $932,616; funded via the Grant Program since: 2017 |
| Alignment to National Palliative Care Strategy 2018 | * Goal 1: Understanding |
| Key Achievements | * Completed literature review and scoping study to inform toolkit design * Establishment of National Reference Group * Consultation with from carers and health professionals to inform toolkit design * Creation of carerhelp.com.au resources |

Table 10 – Project profile: CareSearch – Flinders University

|  |  |
| --- | --- |
| Overview | CareSearch is an online community with resources, training and tools for individuals and organisations seeking palliative care information and support. CareSearch operates as a mechanism for networking, evidence building and broad engagement across the palliative care sector. The project also administers palliAGED which is an evidence and practice resource for aged care. |
| Objectives | * Support health professionals and health consumers through the provision of high quality and relevant palliative care information and resources * Enhance knowledge and information resources for palliative care in aged care * Improve the uptake and use of CareSearch resources through structured engagement with the aged care sector, the allied health sector and patients, carers and families |
| Funding | $3,600,000; funded via the Grant Program since: 2008 |
| Alignment to National Palliative Care Strategy 2018 | * Goal 2: Capability * Goal 4: Collaboration * Goal 6: Data and evidence |
| Key Achievements | * Delivery of the Dying2Learn Massive Open Online Course (MOOC) * Review of large volume of literature to maintain website resources * Over 100,000 webpage visits each month * Received HONCode and HealthDirect accreditation for both CareSearch and palliAGED resources * Additional activities outside of workplan were undertaken to source and incorporate new resources into the CareSearch website. |

Table 11 – Project profile: Caring Safely for Australians at Home (Caring @ Home) – Metro South Hospital and Health Service

|  |  |
| --- | --- |
| Overview | Caring @ Home creates resources to help community service providers and health care professionals support carers to manage breakthrough symptoms safely using subcutaneous medicines. |
| Objectives | * Improve access to quality palliative care for home-based Australians across all communities * Decrease carers’ stress by increasing confidence to provide timely symptom control * Enhance quality of palliative care by standardising aspects of best practice whilst ensuring compliance with jurisdictional legislation regarding medication handling * Provide a patient-centred healthcare intervention which can generate healthcare savings |
| Funding | $3,000,000; funded via the Grant Program since: 2017 |
| Alignment to National Palliative Care Strategy 2018 | * Goal 1: Understanding |
| Key Achievements | * Development of state and territory specific guidelines for handling medications in the community * Development and launch of online education materials * Creation of carer resources and translation into five languages * Development and roll-out of workshops for medical professionals in rural and remote areas |

Table 12 – Project profile: End of Life Law for Clinicians (ELLC) – Queensland University of Technology

|  |  |
| --- | --- |
| Overview | ELLC provides online training and resources to improve medical practitioners’ knowledge and application of end of life law. |
| Objectives | * Improve knowledge and awareness of end of life law throughout the medical community * Improve access to end of life law information across the palliative care and wider medical sector nationally * Enhance medical practitioners’ knowledge of the law at end of life |
| Funding | $706,124; funded via the Grant Program since: 2017 |
| Alignment to National Palliative Care Strategy 2018 | * Goal 2: Capability |
| Key Achievements | * Development and launch of 10 online training modules * Development of tailored training workshops and presentations * Engagement with specialist medical colleges and professional bodies including accreditation of training by the Royal Australian College of General Practitioners and the Australian College of Rural and Remote Medicine * Registrations and module completions in the first three months of the training were much higher than anticipated   Note: The ELLC training modules were launched just prior to the data collection for this evaluation and therefore longer-term improvements in knowledge were not able to be reported. |

Table 13 – Project profile: End of Life Essentials (EOLE) – Flinders University

|  |  |
| --- | --- |
| Overview | EOLE provides clinically relevant and evidence based palliative care learning materials, implementation toolkits and web-based resources for those working in acute hospital settings. |
| Objectives | * Continue to promote existing education modules * Develop and evaluate new education modules * Extend and evaluate existing toolkit to facilitate practice change * Conduct research into practice change as a result of undertaking education |
| Funding | $746,061; funded via the Grant Program since: 2015 |
| Alignment to National Palliative Care Strategy 2018 | * Goal 2: Capability |
| Key Achievements | * New website launched * Increased registrations for online education modules * Four new learning modules developed based on peer-review and user testing * Extended toolkit available to be downloaded |

Table 14 – Project profile: Palliative Care Australia Project (PCA) – Palliative Care Australia

|  |  |
| --- | --- |
| Overview | PCA is the national peak body for the palliative care sector and provides leadership to increase awareness of palliative care, and build knowledge and collaboration across key stakeholder groups. |
| Objectives | * Provide national leadership to harness expert knowledge to support decision-making and policy development * Support services to improve the quality of their service * Support people to reflect on their preferences for care at the end of life * Support people affected by life-limiting illness to maximise their quality of life by facilitating access to services, providing resources and empowering them to make decisions about their care |
| Funding | $5,500,000; funded via the Grant Program since: 1998 |
| Alignment to National Palliative Care Strategy 2018 | * Goal 1: Understanding * Goal 4: Collaboration |
| Key Achievements | * Facilitation of forum for NPCPs * Recruitment and training of consumer engagement panel * Organisation of Voluntary Assisted Dying Symposium * Publication of the 5th ed. National Palliative Care Standards * Development and launch of an information portal targeting Aboriginal and Torres Strait Islanders |

Table 15 – Project profile: Palliative Care Education and Training Collaborative (E&TC) – Queensland University of Technology

|  |  |
| --- | --- |
| Overview | The project has three main streams:   * *Program of Experience in the Palliative Approach (PEPA)* provides palliative care training to non-palliative care health professionals through placements and workshops * *Palliative Care Curriculum for Undergraduates Project (PCC4U)*provides and monitors a palliative care curriculum within tertiary education courses across Australia * *National Palliative Care Workforce Action Plan* aims to develop a blueprint |
| Objectives | To apply a collaborative, whole-of-workforce approach to build the capability and capacity of the health workforce to provide quality palliative care to all Australians. |
| Funding | $12,000,000; funded via the Grant Program since: 2003 |
| Alignment to National Palliative Care Strategy 2018 | * Goal 2: Capability * Goal 4: Collaboration |
| Key Achievements | * Continued over-subscription to PEPA placements * PCC4U online course for Registered Nurses rolled out in 27 institutions * Development of the National Palliative Care Workforce Action Plan * Contributed to outcomes beyond funding objectives through improving patient access to palliative care as around 90% of care providers undertaking PEPA placements identified that they had provided care for a person with a life-limiting illness that they would have not had the skills to do without the PEPA training |

Table 16 – Project profile: Palliative Care Online Training & Information Portal (Online Training Portal) – Australian Healthcare and Hospitals Association

|  |  |
| --- | --- |
| Overview | The Palliative Care Training and Information Portal delivers non-clinical training in the palliAGED care guidelines. |
| Objectives | * Improve the quality of and access to palliative care service skill development for service providers * Improve the quality of palliative care service delivery in community and acute care settings |
| Funding | $982,650; funded via the Grant Program since: 2013 |
| Alignment to National Palliative Care Strategy 2018 | * Goal 2: Capability |
| Key Achievements | * Migration of portal across to a new technology platform * Review of content to reflect palliAGED care guidelines * Continued promotional activity |

Table 17 – Project profile: Palliative Care Outcomes Collaboration (PCOC) – The University of Wollongong

|  |  |
| --- | --- |
| Overview | PCOC measures and benchmarks palliative care patient outcomes in Australia. Outcomes are measured using standardised clinical assessment tools and benchmarked from data across Australia. Data is used to drive quality improvement. |
| Objectives | * Systematically improve palliative care patient outcomes. |
| Funding | $7,832,313; funded via the Grant Program since: 2008 |
| Alignment to National Palliative Care Strategy 2018 | * Goal 2: Capability * Goal 6: Data and evidence |
| Key Achievements | * Production and dissemination of patient outcome, patient profiles and transitional reports * Working with PCA to develop new service levels in palliative care * Development of profile data set for non-specialist palliative care settings * Contributed to outcomes beyond funding objectives through improving patient access to quality palliative care through the quality improvement activities initiated as a result of PCOC data. |

Table 18 – Project profile: Quality of Care Collaborative Australia 2 (QuoCCA 2) – Children’s Health Queensland Hospital and Health Service

|  |  |
| --- | --- |
| Overview | QuoCCA 2 educates and trains local health professionals in providing paediatric palliative care. The project provides hands on education through both pop-up and scheduled training sessions, and also upskills Medical Fellows in paediatric palliative care. |
| Objectives | * Deliver best practice education modules and resources to medical staff in rural, regional and remote areas * Increase the knowledge and confidence of health providers in delivery paediatric palliative care * Harmonise resources regarding advance care planning in children across jurisdictions * Provide linkages between Commonwealth and State paediatric palliative care services |
| Funding | $4,000,000; funded via the Grant Program since: 2015 |
| Alignment to National Palliative Care Strategy 2018 | * Goal 2: Capability * Goal 3: Access and choice * Goal 4: Collaboration * Goal 5: Investment |
| Key Achievements | * Exceeded target number of scheduled and pop-up education sessions * Collaborating with other NPCPs to provide paediatric palliative care content * Developed and implemented bereavement pop-ups * Exceeded targets for pop-up and scheduled training |

Table 19 – Project profile: Talking End of Life (TEL) – University of Sydney and Western Sydney University

|  |  |
| --- | --- |
| Overview | TEL is focussed on creating resources to help carers and practitioners discuss dying and death with people with intellectual disabilities.. |
| Objectives | * Increase the knowledge and confidence of carers and practitioners to discuss dying and death with people with intellectual disabilities * Develop resources and tools to help service providers to develop policies that help enable people with intellectual disabilities to express their wishes about end of life care |
| Funding | $70,643; funded via the Grant Program since: 2017  (this project was for one year only, and data on current promotion and distribution of the TEL resources was not available for this evaluation) |
| Alignment to National Palliative Care Strategy 2018 | * Goal 1: Understanding |
| Key Achievements | * Existing hard copy resources adapted to create 12 online learning modules * Communications disseminated to build awareness of the training |

Table 20 – Project profile: The Advance Project (Advance) – Hammond Care

|  |  |
| --- | --- |
| Overview | Advance is focussed on improving the capacity of general practice nurses (GPNs) and general practitioners (GPs) to have conversations and undertake screening around end of life needs. |
| Objectives | * Develop clinicians’ skills in initiating conversations about advance care planning and screening for palliative care needs * Facilitate earlier attention to end of life care planning in primary and chronic or complex care settings * Enable clinicians in primary and chronic/complex care settings to more efficiently address identified end of life needs and concerns |
| Funding | $2,000,000; funded via the Grant Program since: 2016 |
| Alignment to National Palliative Care Strategy 2018 | * Goal 2: Capability |
| Key Achievements | * Development and launch of new and updated online modules * Endorsement of adapted toolkit by Australian Primary Health Care Nurses Association * Delivery of tele-mentoring * Engagement of champion sites and networks |

# Activities delivered by the NPCPs

## NPCPs usage and reach summary

The following figure provides a summary of the various areas of usage and reach across all the NPCPs as a collective cohort. This shows that the projects as a whole undertook a wide range of activities and achieved significant reach. The data used in this infographic reflects the information provided to the evaluators by the NPCP teams.

### NPCP usage and reach overview

* 1,400+ face to face training sessions held
* 9,000+ workshop and training participants
* 4,300,000+ website visits
* 11,200,000+ e-resource downloads or views
* 109,000+ video streams
* 131 citations
* 50+ presentations (including conferences, talks to relevant industry bodies and posters of flyers)
* 18 advisory, steering or review groups formed
* 9 academic papers published
* 45,000+ social media followers (including Facebook ‘Likes’, Twitter and LinkedIn ‘Followers’)
* 32,000+ newsletter subscribers
* 10,000+ webinar views

Note: These figures 4 are an aggregate of the reporting provided by each of the projects as at 30 March 2019. Due to the high level of the reporting it was not possible to identify duplication, for example one person could be following several projects on social media and they will be counted more than once. It should also be noted that reporting on the areas presented was not possible for all projects due to their data collection or technology systems or that the project was not at the stage of the workplan.

## Activities delivered

Analysis of the activities delivered across all projects demonstrated that the NPCPs performed appropriately, and in some cases delivered beyond their agreed scope of work. There was a wide variety in the focus and type of activities delivered by each project. Projects funded for the first time in 2017 undertook start-up activities, while projects funded previously had more of a focus on expansion, continuity and quality improvement. This is detailed further in Figure 2

Figure 2 – Overview of range of activities undertaken

Projects focussed on initiating new activities were:
Carer Toolkit
Caring @ Home
TEL
ELLC
These projects were all funded for the first time in 2017.
Projects with more of a focus on continuity and quality improvement were:
ACPA
Advance
PCOC
PCA
E&TC
EOLE
QuoCCA2
CareSearch
Online Training Portal.
All of these projects have been funded in previous funding rounds.

The projects funded for the first time under the current Grant had experience in their relevant fields and a strong evidence base for their activities. They were able to utilise this in project delivery to minimise effort required to initiate the new projects.

**Examples:**

Caring @ Home had previously created an education and resource package for carers in Queensland to administer subcutaneous injections to palliative patients to assist in pain management. The funding provided by the Grant Program enabled the development of state and territory specific guidelines and distribution of resources to new states and territories.

TEL was an adaptation of the existing Dying to Talk educational toolkit. The Grant Program allowed the toolkit to be developed into 12 online learning modules.

Two of the projects (ACPA and Advance) which had received previous funding under the Grant Program undertook significant new activity. This included adapting existing resources for new audiences and establishing new initiatives to increase reach and effectiveness.

**Examples**

Advance developed resources targeting General Practice Nurses in the previous Grant round. The current NPCP Grant allowed them to tailor the resources to GPs and other clinicians working in primary and chronic or complex care. This also included creating a champions network to deliver face-to-face training.TEL was an adaptation of the existing Dying to Talk educational toolkit. The Grant Program allowed the toolkit to be developed into 12 online learning modules.

ACPA was funded in the previous Grant round under the Respecting Patient Choices Project which focussed on developing advance care planning resources for the health and aged care sectors. The current NPCP Grant widened the focus of the project to include the establishment of new activities such as National Advance Care Planning Week, increase coordination of advance care planning training and education, and extend the development of research and academic publications to enhance the evidence available around advance care planning.

Several projects were focussed on the expansion of activity funded previously. For some, this included developing further training modules or resources, while others focussed on increasing the scope and reach of existing activities.

**Examples:**

EOLE extended their education resources to include modules on end of life care in advanced chronic complex disease and care at the time of death and immediately after death. They also widened their target audience to include emergency department multidisciplinary staff.

QuoCCA 2 increased the number of planned pop-up and scheduled training sessions, including initiating bereavement pop-ups and developed paediatric palliative care education modules to support the training sessions.

E&TC undertook activity to develop a National Palliative Care Workforce Development Plan. This work aimed to provide an overview of the workforce skills and requirements across specialist and non-specialist palliative care settings.

Two projects (CareSearch and Online Training Portal) were funded to primarily continue the activities they had been undertaking in the previous funding round.

**Examples:**

Both CareSearch and the Online Training Portal primarily focussed on maintenance of the existing resources.

There was also evidence of some projects performing beyond the remit of their work plan. Some projects were over-performing on the targets established in their funding agreement, while others had undertaken work in addition to the activities in their workplan (note, these additional activities were not undertaken at the expense of their agreed scope of work).

**Examples:**

‘ELLC achieved 1,089 registrations and 3,020 module completions in the first three months of the training (to 30 April 2019). While no targets had been established within the funding agreement, the utilisation of the resources was much higher than had originally been anticipated by the project.

CareSearch undertook additional activities outside of their original workplan to source and assess new resources to be included on the CareSearch website.

QuoCCA 2 had delivered 96 pop-up training sessions (160% of target) and 120 scheduled training sessions (162% of target) between July 2017 and March 2019. They had also identified the opportunity to support people affected by the death of a child after the child had passed away and developed and undertook 13 bereavement sessions

## Development of resources and training

All projects undertook activities to develop resources and training.

The types of resources ranged widely from guidance and policy documents through to factsheets on treatment options. Some resources were developed as stand-alone activities (such as the PCC4U learning resources developed by the E&TC) while others aimed to complement other activity (such as the Symptom Assessment Scale visual aid ruler developed by PCOC).

The types of training and the target audience of the training also varied. Table 21 below provides a summary of the different training types and audiences.

Table 21 – Training types and target audiences across NPCPs

| Type of Training | ACPA | CareSearch | Caring @ Home | ELLC | EOLE | E&TC | Online Training Portal | PCOC | QuoCCA 2 | TEL | Advance |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Face to face workshops and education |  |  | Patients and carers  Health prof. | Health prof.  Students |  | Health prof. |  | Health prof. | Patients and carers  Health prof. |  | Health prof. |
| On-the-job training |  |  |  |  |  | Health prof. |  | Health prof. | Health prof. |  |  |
| Web-based training | Patients and carers  Health prof.  Students |  | Patients and carers  Health prof. | Health prof.  Students | Health prof. | Health prof. | Patients and carers  Health prof. | Health prof. | Health prof. | Health prof. | Health prof.  Students |
| Webinars | Patients and carers  Health prof.  Students |  |  | Health prof. |  |  |  |  |  |  |  |
| Massive Open Online Course (MOOC) |  | Health prof. |  |  |  |  |  |  |  |  |  |
| Telephone support | Patients and carers  Health prof  Students |  |  |  |  |  |  |  |  |  | Health prof |

Note: PCA and the Carer Toolkit did not product training and therefore are not included in the table.

## The role of communication activities

Many projects completed communications activities, often for the purpose of promoting their training and resources. Common communications activity included the production of website content, email newsletters, social media (including Twitter, Facebook and LinkedIn) and promotion during industry conferences

**Examples:**

EOLE used Twitter (@EOLessentials) and Linkedin to promote their training resources. They had almost 1,500 Twitter followers and over 3,000 Linkedin followers.

The Online Training Portal utilised commercial advertising include That’s Life magazine, the New Idea Facebook page and sponsored Google advertising to reach a wider audience to promote their training resources. This online advertising received 14,000 click throughs.

There were three projects that had a strong focus on the development of communications as a standalone activity. These were ACPA, PCA and CareSearch which all centred on building awareness of palliative care to a range of audiences.

**Examples:**

ACPA and PCA ran National Advance Care Planning Week and Palliative Care Week respectively. Both of these events had a very strong communications focus with advertising campaigns, social and mainstream media content, web resources and collateral being developed and distributed.

The CareSearch website achieved over 100,000 visits per month between July 2017 and March 2019 and over 50 Palliative Perspective blog posts were published which achieved almost 30,000 reads.

## Research activities

The NPCPs delivered a range of research activities, and most were completed as part of a broader workplan. PCOC was the only project to focus primarily on research, and providing the sector with collection, analysis and reporting on patient, family and carer outcomes. PCOC data supports other research undertaken across the sector and the PCOC project team reports that PCOC data was referenced by other organisations in 5 journal articles, 8 conference papers and 31 reports during the current funding period.

Research conducted by NPCPs other than PCOC often supported the delivery of other project activities either through targeted research to inform activity design, or through research conducted for quality improvement processes. Some projects also completed academic research. Examples of research undertaken are as follows (note, this list is not exhaustive):

* Qualitative data collection (ACPA, EOLE, ELLC, QuoCCA 2, Carer Toolkit, E&TC – workforce development)
* Evaluation (ACPA, CareSearch, Caring @ Home, EOLE, ELLC, Online Training Portal, PCOC, QuoCCA 2, Advance, Carer Toolkit)
* Literature or evidence review (CareSearch, Carer Toolkit, Advance)
* Conference papers, presentations or posters (Advance, CareSearch, EOLE, PCOC, QuoCCA 2, and Online Training Portal)
* Academic papers (ACPA, EOLE, PCOC, QuoCCA 2, Caring @ Home).

Several projects also brought together existing research to create an evidence base for improving care. CareSearch’s focus on ensuring online access to trustworthy evidence-informed information is the best example of this, as well as several other projects who bought together research to help inform practice.

**Examples:**

ELLC is supported by the End of Life Law in Australia online resource that provides detailed information on the law around end of life.

PCA promoted many resources including information on the paediatric dying process (viewed over 119,000 times) and facts about morphine and other opioids in palliative care (viewed almost 38,000 times).

## Cost efficiency analysis

As discussed in the previous Limitations section, cost efficiency analysis was not possible for the evaluation. This was due to the lack of sufficient, complete and comparable outcomes and cost data across all 13 projects. Project financial data was analysed to identify expenditure trends over the funding period. The following is a summary of the key findings of this analysis.

### Total funding

A total of $45.48 million in funding was allocated over the three financial years FY17/18, FY18/19 and FY19/20.

### Employment

Project funding supported 68 full-time equivalent employees in FY17/18 and 77 in FY18/19.

### Funding distribution

81% of the total funding was provided to the six projects: ACPA; CareSearch; PCA; E&TC; PCOC and QuoCCA 2. Funding was allocated evenly over the three financial years for most of the projects. The exceptions were TEL with a one-year agreement, Online Training Portal with a larger amount in FY17/18, and Carer Toolkit with double the funding in FY19/20 compared with the previous two years. For the period between June 2018 and March 2019 approximately two-thirds of project expenditure was spent on employment costs, and the remainder was spent on operational costs.

### Project differences

Due to the differing focus, structure and size of the projects, and differences in the size and structure of the organisations funded to deliver them, there was significant variety in expenditure breakdown. For example, employment costs made up 96% of QuoCCA 2’s expenditure and only 17% for TEL. These variations in expenditure breakdown are to be expected, given the diversity of projects and organisations.

### In-kind contributions

The projects also received a significant amount of in-kind contributions predominantly in the form of staff and administrators volunteering their time to the projects.

# Key outcomes delivered by the NPCPs

The NPCPs have delivered a range of outcomes across each of the areas outlined in the Program Logic (refer to Appendix B). The following section explores these in detail and provides examples from individual projects.

## Activities met sector needs

NPCP activities were highly appropriate in meeting sector needs. This was evidenced by the reach and usage data reported previously, with many projects reporting they achieved or surpassed the level of engagement they expected with their target cohort. Additional qualitative data provided by end-users reflected the high degree of utility of resources and training. Two examples of feedback received are provided below:

“the course should be a compulsory requirement for anyone providing end of life care” – Caring @ Home

“the resource is clearly written and provides a range of tools that are useful aids to enhance patient care.” – Advance

In addition to meeting the reach objectives, some projects were also found to meet the needs of additional audiences beyond their original target cohorts.

**Examples:**

The CareSearch MOOC Dying2Learn originally targeted the general public but received a lot of traction with care professionals who were wanting to reflect on their own experiences.

ELLC training aimed to improve clinicians’ and medical students’ legal knowledge, however there has been a large number of people accessing the training who are nurses and health professionals.

The successful engagement and reach to the target audiences demonstrates that the activities undertaken by the NPCPs were relevant to the needs of the palliative care sector specifically. The projects also demonstrated their capability to successfully engage audiences beyond the palliative care sector including GPs, carers and even extending to the general population. Further analysis on the NPCP engagement achievements with various audiences can be found at Appendix D.

## Collaboration with the sector

Building sector networks has been one of the key areas of activity for the NPCPs, and there is strong evidence of NPCPs working together and building partnerships with the wider sector.

The Project Forum hosted by PCA in February 2018 provided a strong initial introduction and foundation for each of the projects to understand each other’s activities and to identify opportunities to work together. Throughout the funding period, every project team collaborated with other NPCPs, with knowledge sharing being a key focus of collaboration. Projects that had participated in previous funding rounds report there had been a marked improvement in the ongoing communication and collaboration between projects during the current funding round. This was often facilitated by members of other projects taking on a formal or informal advisory roles, including on advisory committees or as subject matter experts.

NPCPs also built relationships with the wider sector. Target audiences varied from general practitioners, carers, and specialist palliative care providers through to politicians, medical students and even the general population. NPCPs have been successful in collaborating with a wide group of stakeholders involved in care at the end of life, with the diagram following providing further examples of the wide spectrum of sector collaboration undertaken by the projects.

Figure 3 – Spectrum of NPCP collaboration

Collaboration ranged from informal networking to formal partnerships.
Examples of collaboration going from informal networking to formal partnerships are:
-EOLE presented the project to National Palliative Care Nurses Conference
-PCA convened a symposium on Voluntary Assisted Dying attended by 85 people
-ET&C worked closely with palliative care services facilitate hosting of PEPA placements
-CareSearch were involved in several advisory or reference groups including Connecting End of Life Care - Townsville and the SA Health End of Life Strategy Board
-Advance have established a champions network to deliver training
-Caring @ Home, E&TC, PCOC and QuoCCA2 have been run as collaboratives or consortia between several organisations.

Two projects (E&TC and PCOC) were also able to demonstrate collaboration with groups outside of Australia. These relationships have come about due to the unique activity and leadership of these projects within the international palliative care sector.

**Example:**

PCOC established a stream of work to support international participation in the program to benchmark outcomes with Australian palliative care services. This provided an opportunity for high performing Australian services to measure themselves against international counterparts and to share knowledge with similar services.

## Impacts of collaboration

Collaboration between projects and with the wider sector had several positive outcomes, as detailed below.

### Collaboration between NPCPs

There were four identified outcomes of inter-project collaboration:

* cross-promotion of activities
* identification and reduction of duplication
* sharing of subject-matter expertise
* provision of advice for new projects in navigating the sector.

All projects identified that there had been some level of cross-promotion with other projects. This included sharing information on social networks on the launch of training resources, promotion in email newsletters and inclusion of web links. This helped projects reach audiences they would not have otherwise had access to.

**Example:**

Almost one-in five people (16%) registered for ELLC training learnt about the training from the E&TC website.

In relation to reducing the risk of duplication, initially the NPCPs expressed some concern that different projects had been funded to deliver similar activities. This came to light during the 2018 PCA Forum where projects were invited to present on their planned activities and goals, and areas of similarity were noted. This was particularly apparent for projects whose core focus was on delivering training and resources to the sector.

Through the activity and reach mapping exercise completed to develop the Project Logic for this evaluation (summary included in Appendix B), it was identified that while no direct duplication of activities had been funded, there were areas of very close alignment where multiple projects were producing resources and training on similar or related topics for the same and related target audiences.

The NPCPs were proactive in managing the risk of duplication, with many project teams working together to share resources and findings. An example was PCA and Carer Toolkit both being funded to develop a carer resource kit, and subsequently working together to reduce the risk of duplication. A further example was ELLC electing to use E&TC’s learning management system rather than engaging a separate provider.

The sharing of subject-matter expertise was also common and highly valued by project teams. In some cases, senior project leaders had become the go-to resource to provide specific advice to other NPCPs, often as investigators.

Many of the new projects’ advisory or governance committees included leaders from existing projects who assisted with navigation of the palliative care sector. These groups were identified by several of the projects funded for the first time in the 2017 – 2020 funding round as providing important insight and leveraged the networks of these individuals.

**Examples:**

The project lead of QuoCCA 2 provided content regarding paediatric palliative care to EOLE and ELLC. Prior to the lead approaching these projects there was no plan to include paediatric palliative care in these resources.

CareSearch was a representative on the advisory or management group or identified as a project investigator for eight of the NPCPs. This provided opportunities for these projects to utilise CareSearch’s knowledge of the sector to maximise reach and impact.

### Collaboration with the wider sector

Collaboration between NPCPs and the wider sector drove two areas of outcomes: leadership and stability; and an improved evidence base for continuous improvement.

Several of the projects provide leadership within and outside the sector, often as an integral part of their workplan (PCA, ACPA and CareSearch). Other projects have adopted leadership roles as a result of their maturity and visibility as palliative care experts (PCOC, E&TC, QuoCCA 2, Advance).

**Example:**

PEPA (part of E&TC) was identified by several PHN and state and territory stakeholders as providing important, ongoing ‘grass roots’ support to the sector. This included influencing the cultural appropriateness of care through PEPA’s focus on this area, as well as the work of the Aboriginal Project Officers or Managers.

NPCPs collaborating with the sector also enabled broader access to evidence which could inform and improve the delivery of palliative care. The research outputs of many of the projects provided opportunities for sector stakeholders to reflect on and improve their practices. A primary example of this occurring is the uptake and application by the sector of the PCOC evidence base. Facilities which participate in collecting PCOC data are provided with summary reports which detail their own performance in patient outcomes and how this compares to sector benchmarks. Facilities can then use this information to inform continuous improvement activities.

## Supporting consistency

The national focus of the NPCPs helped support consistency across the sector, which is a key priority within the National Strategy. While service delivery itself is managed at a state and territory level, the national focus of the projects helped to provide people delivering services or in carer roles to have access to consistent information, resources and training regardless of which jurisdiction or care setting they were practicing in.

An enabler of this national focus was that many NPCPs ‘de-branded’ their outputs. In these instances, rather than distributing a national resource using their own organisational branding (e.g. colours, logos, fonts), projects used neutral or non-identifying branding on these resources. This reduced the risk of target audiences mistaking resources created in other jurisdictions or care settings as not being relevant to their own.

Projects working in areas which had strong jurisdictional variations (such as legal systems) also played an important role in driving a national approach (e.g. ELLC, Caring @ Home). These projects helped users to not only understand the issues within their own jurisdiction but also the settings in others. This knowledge is important for service providers or carers who are delivering national services, dealing with transient populations or who are active in facilities close to the state or territory border.

The national focus of NPCPs also helps support the goal within the National Strategy which aims “to create a consistent experience of palliative care across all settings”.[[6]](#footnote-7) Overall, the level of consistency across jurisdictions and care settings the NPCPs have achieved reflects the importance of projects maintaining a broad focus that can be adjusted and tailored to local needs.

## Unexpected outcomes

There were two noted outcomes demonstrated by projects beyond the scope of improving the quality of palliative care service delivery in Australia.

The first relates to the collective impact of the NPCPs. Together, they have developed a broad sense of ownership and commitment to success of the palliative care sector, beyond their specific project objectives. This is driven by the commissioning structure as a national cohort of projects and the explicit encouragement to collaborate with one another. This provides a significant benefit to the sector of a coordinated cohort of engaged sector stakeholders proactively addressing palliative care needs across Australia.

A further outcome delivered beyond the scope of the funding objectives relates to improvements in patient access to palliative care demonstrated by some projects, including PCOC and E&TC.

**Example:**

Approximately 90% of non-medical practitioners (such as nurses, allied health professionals or personal care workers) undertaking PEPA placements (as part of E&TC) identified that they had cared for people with life-limiting illness after their placement (that they would not have otherwise had the appropriate skills to care for prior to participating in PEPA).

As palliative care is mostly delivered and managed at a state and territory level this impact on care delivery is a significant result for the NPCPs and demonstrates their capacity to deliver outcomes beyond the capacity-building focus specified in the Grant Program guidelines.

## Alignment to the policy setting

The NPCPs demonstrated strong alignment to the national strategies which were active during the current funding round. The first of these was the National Palliative Care Strategy (2010) which was active until 2019. A review of the 2010 Strategy found that the projects funded for the 2015 – 2017 funding period had assisted to drive the ambitions identified within it.

“…the suite of projects funded by the Commonwealth has made a demonstrable and significant contribution towards furthering the goals of the Strategy” [[7]](#footnote-8)

The NPCPs also demonstrate alignment to the current National Strategy (2018). The current Strategy was released in early 2019 and provides guidance on the goals and priorities to ensure that “people affected by life-limiting illnesses get the care they need to live well” [[8]](#footnote-9).

Analysis of the level of alignment between project activities and the goals of the current Strategy is provided in Table 22.

Table 22 – Alignment of NPCPs to National Strategy goals

| Goal within National Palliative Care Strategy [[9]](#footnote-10) | ACPA | Carer Toolkit | CareSearch | Caring @ Home | ELLC | EOLE | PCA | E&TC | Online Training Portal | PCOC | QuoCCA 2 | TEL | Advance |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| 1. Understanding | Strong | Strong | Moderate | Strong | None | None | Strong | None | Some | None | Moderate | Strong | Some |
| 1. Capability | Moderate | None | Strong | Some | Strong | Strong | Moderate | Strong | Strong | Strong | Strong | Some | Strong |
| 1. Access and choice | Some | Some | None | Some | None | Some | Some | Moderate | None | Some | Strong | Moderate | Moderate |
| 1. Collaboration | Strong | Some | Some | Some | None | Moderate | Strong | Strong | Some | Some | Strong | None | Moderate |
| 1. Investment | None | Some | Some | Some | None | Some | Some | Moderate | None | Some | Strong | None | Some |
| 1. Data and evidence | Moderate | None | Strong | None | None | None | Moderate | Moderate | None | Strong | None | None | None |

In addition to aligning to the National Strategy, the NPCPs contributed to policy change through completing advocacy activities. Examples include PCA as the national peak body for the palliative care sector, as well as PCOC and ACPA’s support of various submissions as detailed following.

**Examples:**

PCOC reported on relevant data to support submissions regarding palliative care provision in WA as part of the Joint Select Committee Inquiry into the need for laws in Western Australia to allow citizens to make informed decisions regarding their own end of life choices in 2017.

ACPA contributed to multiple submissions regarding advance care planning across Australia and played a leading role in advocating for advance care planning practices for patients as well as care providers.

There was some evidence of the NPCPs integrating with existing state and PHN-based palliative care initiatives, but not at a consistent or strategic level across the projects as a collective.

For example, there was proactive development of partnerships with jurisdictions by the Caring @ Home Team, E&TC and QuoCCA 2 to support the delivery and reach of their project activities. In other instances however, PHN stakeholders funded to implement the Greater Choice for At Home Palliative Care Measure noted that much of the engagement they had with NPCPs was ad hoc and often arose from shared personnel or networks.

There was, however, limited other evidence of the NPCPs engaging with PHNs and/or jurisdictions. Where this had occurred it was more often due to proactivity of specific personnel within the PHNs and jurisdictions rather than occurring at a strategic or organisational level. Given that PHNs, jurisdictions and NPCPs all have a shared focus on palliative care, it is likely that there are more opportunities to increase engagement between these areas of the sector.

There are also opportunities for greater collaboration with other national initiatives such as the Dementia and Aged Care Services Fund delivered by the Department. While some projects (such as PCA) received funding under these initiatives, stakeholders from these initiatives within the Department expressed strong interest in greater collaboration where relevant.

Overall, the strong level of NPCP alignment and integration with the policy setting is significant. While contributing to the broader sector is not an explicit objective under the Grant Program, it is implicit in the required national scale and focus of the NPCPs. While the current NPCPs have demonstrated they are a strong support to the palliative care sector given their alignment to the National Strategy, a greater degree of coordinated engagement with other initiatives which are focussed on or related to palliative care would strengthen the role of NPCPs.

## Evidence of longer-term impact

Using the project numbering system shown on the Program Logic, the projects were collectively expected to demonstrate evidence for a total of 69 short-term outcomes, 49 medium-term outcomes and 49 long-term outcomes (total outcomes excepted calculated by summing the total number projects specified in each box for each outcome layer of the Program Logic).

Analysis of available data found that there was evidence for 96% of expected short-term outcomes, 57% of medium-term outcomes and 45% of long-term outcomes. In this way, while NPCPs could demonstrate they were undertaking activity and that their outputs were being accessed and used (reflecting the short- and medium-term outcomes in the Program Logic), there was mixed levels of evidence as to whether the projects were influencing behaviour change in the delivery of palliative care (with behaviour change reflecting the long-term outcomes specified in the Program Logic).

The evidence that was available for behaviour change mainly related to long-term outcomes of training and collaboration activities.

**Examples:**

PCC4U, part of E&TC conducts audits of the education providers using their resources. This audit showed that 83% of entry-to-practice or higher education courses are implementing or reviewing PCC4U resources which is above the 80% target.

83% of participants of the Online Training Portal identified that their knowledge and/or skills in palliative care had improved as a result of undertaking the training. A similar proportion (84%) identified that they were confident or very confident in delivering best-practice palliative care after training, compared to 34% prior to the training.

PCA was identified by many stakeholders as providing coherence to the sector and helping foster integration and partnerships through their work with NPCPs and other initiatives.

Where outcomes data was not available, this was generally driven by one of three factors:

1. It was too early for some projects to demonstrate a specific outcome given their stage of delivery at the time of the evaluation, despite meeting expectations in their workplan (predominantly newly funded projects).
2. Project activities did not easily lend themselves to outcomes measurement, and data was not able to be collected. These include the creation and distribution of communications, resources and research which do not have a captive audience where pre- and post-measures can be applied (comparative to training where participants need to register and can be followed up for data collection). Further, even if projects are able to capture data from end-users of these materials, it would be difficult to attribute evidence of behaviour change to any single resource accessed.
3. Projects may not have achieved their expected outcomes (extent to which this occurred not able to be substantiated in full given factor 2 above).

In this way, the lack of data on long-term outcomes does not necessarily reflect poor performance by the NPCPs. It does however highlight an opportunity for a shift in emphasis from measuring output to reporting the impact of activities.

# Enabling factors and challenges

Overall the NPCPs have been delivered successfully and demonstrated several positive outcomes for the sector. This is a significant achievement for such a large body of work being delivered by a diverse group of organisations across Australia. In analysing the activities delivered and outcomes achieved, a number of enabling factors and challenges were identified which are explored below.

## Enabling factors

### Accessibility

Program activities were highly accessible to the target audiences. As outlined above, individual projects sought to reach a wide diversity of audiences, including patients, carers, health workers, educators and students, as well as people from the broader community. Each project team actively sought to engage these audiences through a range of difference modalities and channels.

In addition to offering this wide range of modalities, the NPCPs also enabled engagement by generally being low or at no cost for their target audiences. This clear focus on offering highly accessible opportunities for learning and development are clear enablers of outcomes.

### Evidence-based practice

All projects adopted an evidence-based approach to designing, and then continually reviewing and improving their activities. Some projects also worked with partner organisations or third parties to complete a formal evaluation, with evaluation findings used to inform continuous improvement.

Projects demonstrated flexibility in adapting planned activities to address evidence gathered. For example, ELLC worked with clinicians to collect data on their needs, and tailored the content accordingly. The Carer Toolkit also undertook extensive research to inform development of their resources, including a literature review, as well as comprehensive sector consultation.

The Department also demonstrated a commitment to evidence-based practice, agreeing on multiple occasions to support project teams in changing an activity or direction, or by allowing the grant funding to be used for new activities which better met sector need.

### Expert knowledge

There are longstanding members of the palliative care sector within a number of project teams who contribute expert knowledge and guidance to the design and delivery of the NPCPs. Examples include the senior sector leadership embedded within the CareSearch, PCOC, ACPA and the E&TC teams. This contribution provides a strong foundation for many of the projects, with activities reflecting key individuals’ deep expertise and understanding of palliative care.

These leaders also contribute to other projects’ activities, most often through in-kind support often through membership on project committees and reference groups. Ad hoc support is also provided through project teams connecting with one another throughout the funding round.

### Project maturity

Nine projects had received continuous funding from 2015 – 2020, with a number of these also receiving funding under grant programs prior to 2015.

The long-term nature of funding for these projects has enabled them to build strong processes and deliverables over time. When these projects were re-commissioned in 2017, they were starting with a strong track record in implementing and delivering their planned activities. They were able to focus on refining and expanding existing activities, and also providing support to newly funded projects.

Projects in receipt of long-term funding were also better able to demonstrate long-term outcomes in the current evaluation. This is because projects in this position had often already demonstrated short- and medium-term outcomes from the Program Logic in previous funding rounds, and could build on this foundation to focus on influencing behaviour change.

## Challenges faced

### Procurement processes contributed to duplication concerns

The concerns identified by NPCPs about the potential for duplicate activities (as outlined above) were exacerbated by the procurement process undertaken for the current Grant round. As projects were assessed and approved individually rather than collectively, projects which individually met the Department’s criteria for funding were approved without full differentiation of their planned activities compared to other projects. As discussed, this challenge was addressed by projects proactively working together to agree on which projects would deliver what activities.

These challenges did not substantially impact the delivery of project activities or outcomes. However, there was an impact on project commencement due to the time for projects required to gain clarity and initiate delivery.

### Difficulties in providing evidence of long-term outcomes

As noted above, for many projects it was not possible to demonstrate evidence of their impact on long-term outcomes relating to behaviour change. Many projects are aware of this challenge and are actively seeking to improve their outcomes measurement to demonstrate the impact of their activities.

### Project-specific delivery challenges

There were some project-specific implementation challenges which affected delivery, although it is important to note that none significantly impeded project performance.

These challenges include delays in completing project tasks, difficulties with digital infrastructure, difficulties in engaging target audiences or key stakeholders needed to support delivery (such as jurisdictional health departments), and end-user related issues such as limited computer literacy preventing the use of resources.

Project teams demonstrated a high level of responsiveness to overcome these challenges, with no project workplans significantly affected by these issues. Given the scale and breadth of the NPCPs, the smooth delivery of all workplans is a significant achievement that reflects the level of expertise and skill in the NPCP project teams.

# Recommendations

The evaluation identified key findings that support four recommendations regarding the NPCPs. These are summarised below in Table 23.

Table 23 – Summary of recommendations and supporting rationale

|  |  |
| --- | --- |
| Recommendation | Rationale |
| 1. Align grants process and ongoing engagement with core projects to the national strategy | * The NPCPs are an important investment for the palliative care sector * The projects are delivering against their funding objectives, and are supporting the broader policy landscape * Opportunities exist to increase the strategic focus of the NPCPs |
| 1. Adopt a stronger leadership position with specific focus on collaboration | * Collaboration has enabled outcomes, and there is untapped potential for greater impact * There could also be greater ongoing connection between the Department and projects |
| 1. Increase focus on outcomes | * Data challenges meant NPCP impact could not be fully measured * The ongoing evolution of the sector means that future NPCP activities may be more focussed on directly influencing behaviour change (compared to a focus on awareness raising and education activities), and this potential change could support future outcomes measurement |
| 1. Incorporate new approaches to ensure project outputs remain current and useful | * Some valuable resources are likely to need updating in the future to keep them current, even though the project that developed them is no longer funded |

The following sections present the four recommendations in detail, including their rationale and specific recommended actions.

## Recommendation 1: Align grants process and ongoing engagement with core projects to the national strategy

### Rationale

#### The NPCPs are an important investment for the palliative care sector

The sector has been on an evolutionary journey, starting as an emergent field of healthcare to become a specialist field. Since the 2010 National Strategy, the sector has been making a dedicated shift to broaden its remit, and enable palliative care evidence and treatment methodologies to be understood and applied across a broad range of health care contexts.

The NPCPs’ focus on capacity building has been a key part of this journey, as the projects have focussed on building palliative care capacity across a range of health care and community settings. The current funding round has seen the NPCPs demonstrate high levels of capacity building outputs, and some evidence of these activities influencing the delivery of palliative care across Australia is emerging. Further, the long-term nature of funding for a number of core projects has provided the sector with a foundation on which to build and grow new and innovative capacity building initiatives.

#### The projects are delivering against their funding objectives, and are supporting the broader policy landscape

This evaluation has demonstrated the NPCPs have achieved strongly against the seven program objectives. NPCP achievements most evident in relation to the objectives focussed on improving quality and access to skill development and the quality of service delivery in community and acute care settings.

Importantly, all objectives were supported by at least one project. By collectively aligning to all seven funding objectives, the NPCPs have demonstrated a cohesiveness in their delivery of activities and outcomes, focussed on building palliative care capacity in and beyond the sector.

The NPCPs have also demonstrated alignment to the wider palliative care policy landscape, and in particular the 2010 and 2018 National Palliative Care Strategies. While opportunities exist to strengthen engagement between the NPCPs and other relevant initiatives (i.e. the Dementia and Aged Care Services Fund, and PHN-commissioned and managed health services), overall the NPCPs have demonstrated that they are an integral part of the palliative care sector with a well-established national presence.

#### Opportunities exist to increase the strategic focus of the NPCPs

The design and delivery of the NPCPs has largely been successful, however there are opportunities for increasing the level of strategic intent with which the NPCPs activities are procured and planned. This will enable the 2020 – 2023 NPCPs to optimise their alignment to program objectives, as well as the goals of the National Strategy.

### Recommended actions

#### Ensure alignment of future projects to the National Palliative Care Strategy

There is an opportunity for the 2020 – 2023 NPCPs to directly support the implementation of the National Strategy and to utilise the significant investment the Department has made over many years to drive service delivery that is evidence-based and continuously improving. The Strategy, and accompanying Implementation Plan (currently under development), should be used to identify the specific areas of need which can be supported by the projects, and workplans should be developed with a clear link to how activities meet recognised needs.

#### Define expectations for core projects to meet existing and emerging sector needs

The Department has an opportunity to work with the core projects as a collective, to identify and implement more innovative ways to optimise agreed activities, address emerging needs, and investigate areas of work which can support the sector needs identified in the Strategy and Implementation Plan (e.g. data collection, improving access for underserved populations such as Aboriginal and Torres Strait Islander people).

The establishment phase for core projects for the 2020 – 2023 NPCPs provides the opportunity for the Department to clearly set expectations for these projects regarding their contribution as a core versus grant-only funded project. The clear identification of expectations will provide stability and assist with effective implementation. A more agile, partnership-based ongoing approach to managing core projects should be implemented to foster ongoing accountability and transparency among this cohort.

By working closely with the core projects regarding their remit, the Department will be well positioned to balance the funding for sector infrastructure with the funding available for investing in emerging needs via additional non-core projects.

#### Engage the core projects to work together to address sector needs

While the focus for each of the core projects will be the delivery of their specific activities, there is potential for the combined expertise of the core projects to be utilised to address specific sector needs, such as improving community knowledge and awareness, consistent data collection and use of advance care plans. This shared focus on the national perspective will support the continued growth and maturity of these core projects and help to drive the sector forward in a way that would not otherwise be possible if each project was singularly focused on delivering its own activities.

## Recommendation 2: Adopt a stronger leadership position with specific focus on collaboration

### Rationale

#### Collaboration has enabled outcomes, and there is untapped potential for greater impact

A key finding of the evaluation has been the value of collaboration between projects. NPCPs have been proactive in engaging with one another to share resources and learnings, and through these connections have been able to minimise the risk of duplication across projects. In addition to inter-project collaboration, most projects have also collaborated with the wider sector.

Given the demonstrated benefits of the collaboration which has occurred, and the interest from the broader health sector to engage with the NPCPs (as reflected in stakeholder feedback from the PHNs and jurisdictions), there are opportunities to enhance the scale and impact of collaboration in the 2020 – 2023 funding round.

The Department could play a more active role in encouraging and supporting inter-project collaboration, as well as facilitating individual NPCPs to engage with jurisdictions and PHNs in a coordinated way.

#### Existing contact between the Department and NPCPs could become more strategic

The Department has a high degree of involvement with the NPCPs, including regular contact with project teams, overseeing governance arrangements, providing contract management support and collecting and reviewing project reporting. These activities are typical of what is required for a large-scale Grants program, and reflect that there is an appropriate level of engagement between the Department and the NPCPs. The Department is also a member of the governance or advisory committee on most projects, which also provides an important connection between the projects and the Department.

The Department has an opportunity to explore ways to enhance the collective impact of the NPCPs by focussing on the Grant program as a cohort, building on the Department’s existing relationships, and facilitating the NPCPs to have a stronger focus on the National Strategy and a whole of sector context (as per Recommendation 1).

### Recommended Actions

#### Strengthen strategic leadership

To best support the National Strategy and leverage the maximum value of the NPCP investment, the Department should extend their leadership role as commissioner.

In practice, this means the Department could work more closely with all projects during the Grants process and establishment phase to further shape activities and outcomes in support of the Strategy and NPCP funding objectives. During the implementation phase, the Department should review the performance reports for the NPCPs specifically to assess and ensure ongoing alignment of the overarching investment through the Grant program with the National Strategy.

#### Build on the collaboration between projects

The Department should continue to support collaboration between NPCPs and building on existing relationships between projects. This should involve setting out or clarifying expectations of collaboration to all projects, and funding activities which enable projects to meet these expectations.

The PCA Forums should be continued, as these provide an opportunity for ongoing information sharing, collaborative efforts and cross-project capacity building. Ideally multiple Forums should be held during the 2020 – 2023 Grant round, with one at the beginning, middle and conclusion of the period. This staging will enable the projects to connect early, and then consolidate learnings and relationships at regular intervals throughout the Grant round.

The Department may also wish to investigate opportunities to enable more regular communications and sharing of learnings across projects. This could occur through a regular communication channel such as a newsletter, or an online platform (similar to the Google Classroom which was intended to be accessed in the current Grant round). With the Department either directly managing such a communication process, or by delegating this responsibility to a core project, inter-project communication would happen more frequently than it has to date. This would likely amplify the benefits of the ad hoc inter-project collaboration which has occurred in the current Grant period.

#### Take a more active role in facilitating NPCP collaboration with the wider sector

The Department has an overarching view and knowledge of all project focus areas and activities, as well as how these activities may integrate with the broader policy context. Given this position, the Department can take a strategic approach to facilitating coordinated engagement between the NPCPs and the broader sector.

This could involve the Department reviewing opportunities where sector collaboration may be of benefit (such as with PHN or jurisdictional palliative care initiatives and activities, or other Commonwealth activities in related areas such as the Dementia and Aged Care Services Fund), and then providing direction and support to the NPCPs (either collectively or individually as appropriate for the opportunity identified) to connect with sector stakeholders.

## Recommendation 3: Increase focus on outcomes

### Rationale

#### Data challenges meant NPCP impact could not be fully measured

As outlined above, mixed levels of evidence were available to demonstrate the medium-and long-term outcomes of the NPCPs.

While all projects were able to collect evidence on their activities’ reach to target audiences, and demonstrate some changes in awareness and knowledge, only a few projects were able to collect evidence which showed that target audiences were able to translate this increased awareness and knowledge into better palliative care delivery. This challenge is partially reflective of the nature of the activities undertaken by the NPCPs, as well as projects’ current maturity.

The result of this challenge is that the main evidence base for the NPCPs is an extensive amount of activity reporting, with much less data on outcomes available for analysis, so the true impact the NPCPs is not able to be fully measured.

#### The ongoing evolution of the sector could support future outcomes measurement

Historically, it has been valuable for the Grant funding to support the sector to develop foundational capacity building tools and resources (e.g. awareness raising campaigns, training in the palliative approach to care, fact sheets and webpages). The development of these tools and resources does not easily lend itself to outcome measurements, due to difficulties in tracking wide-spread dissemination of resources (i.e. fact sheets, toolkits which can be downloaded by an end-users, and then copied and shared more widely), and their subsequent impact on end-users. In this regard, the data challenges outlined above have in some ways been unavoidable.

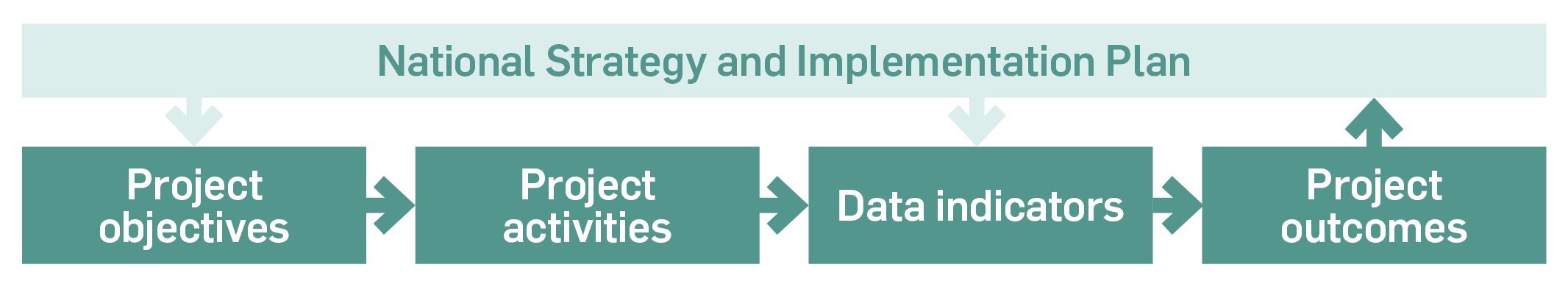
However, as the sector evolves and awareness and uptake of palliative care increases throughout the community, the NPCPs can shift focus from the creation and distribution of awareness-raising activities to the development of initiatives which have a greater influence on behaviour change in palliative care delivery by the health workforce. Outcome measurement for such activities is less complex, as pre-and post-measures of behaviour as well as the impact of health practices on patient experience can be measured.

### Recommended action

#### Develop ongoing measurement and reporting of outcomes

The work plans of 2020 – 2023 NPCPs should include not only the activities to be undertaken but also clear identification of what outcomes are expected and how these outcomes will be measured. The Department should work with projects to identify which indicators in the Implementation Plan for the National Strategy (currently under development) will enable projects to report on their long-term impact, as this will directly link planned activities and their measurement to identified needs for the sector (as per Recommendation 1 above). This data may already exist, or it may be necessary to undertake additional work to develop and establish data points which support these indicators. The figure below illustrates how the National Strategy and Implementation Plan can inform project objectives and outcome measurement.

Figure 4 – Role of National Strategy and Implementation Plan for NPCPs



## Recommendation 4: Incorporate new approaches to ensure project outputs remain current and useful

### Rationale

#### There are risks to project deliverables maintaining their currency

Some resources developed in the current funding round will have a natural lifespan that is dependent on the emergence of new evidence or changes in the service delivery or policy context. Over time, as new practices need to be imparted to the workforce, these resources will need to updated or replaced (e.g. the Carer Toolkit, TEL resources).

Other resources developed in the current funding round inherently require ongoing review and updates to ensure their timeliness. Key examples include the ELLC resources, and Caring @ Home national guidelines where the accuracy of these documents over time is directly dependent on whether any changes are made to the legislation they reflect.

These two risks are particularly applicable to projects from the current funding round that may not receive funding for 2020 – 2023. Without funding to monitor, maintain (or in some cases host) the resources and tools developed, these could become inaccessible or obsolete which would lesson the value of the investment the Department has made in these projects.

A plan is needed to ensure that resources are reviewed regularly and updated as necessary. In future, this could be incorporated during procurement and activity planning.

#### Impact of existing project resources may reduce over time

There is also a risk that the impact of the resources which have developed by the current NPCPs may reduce over time. This could occur if current NPCPs’ focus on promoting and distributing these resources to the sector shifts due to new activities, or if currently funded NPCPs do not receive ongoing funding and can no longer promote the resources.

### Recommended actions

#### Consider the ongoing upkeep of materials during procurement and work planning

The procurement of resources and tools should include identification of how NPCP project teams are able to support the ongoing updating, promotion and distribution of resources they are funded to create.

This may involve consideration of the NPCP’s ‘business as usual’ activities to determine whether it is likely that they would have ongoing capacity to continue updating and promoting the materials they had created beyond any single funding round (either due to Grant funding no longer being received, or the NPCP’s funded activities changing in subsequent Grant funds). NPCPs could also be encouraged to articulate their plans for sustainability of resources in their workplans at the beginning of each Grant round.

#### Encourage cross-project distribution and promotion of resources

In addition, project teams should be supported to utilise existing communication infrastructure and sector networks within core projects to support the distribution and promotion of materials. The existing NPCPs have done this very successfully through the CareSearch portal, and this should be included. Other opportunities for cross-promotion should be encouraged.

# Disclaimer

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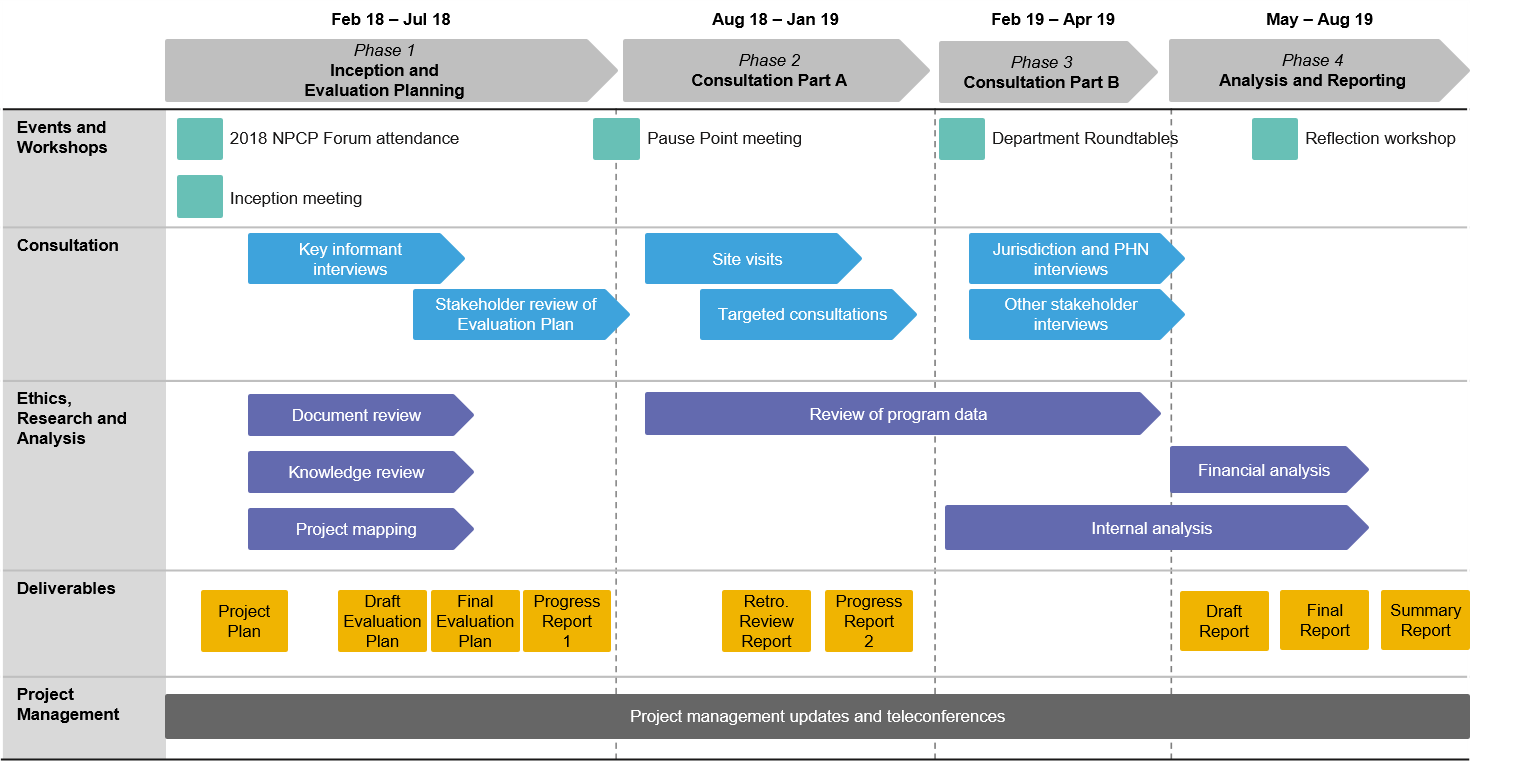
This report has been prepared with due care and diligence by Urbis and the statements and opinions given by Urbis in this report are given in good faith and in the reasonable belief that they are correct and not misleading, subject to the limitations above.

Appendix A - Evaluation methodology

## Evaluation details

The evaluation was delivered over four phases, as shown below in Figure 7. A description of each phase is detailed below.

Figure 5 – Evaluation methodology overview

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### Phase 1: Inception and evaluation planning

#### Program Logic and Evaluation Framework

The evaluation commenced with the design of a Program Logic and Evaluation Framework, as well as a mapping exercise of all activities and reach of the NPCPs. This process involved interviews with the Department and all NPCPs to gain an understanding of each projects’ reach, activities and expected outcomes. Background documents were also provided on each program by the Department, and these were reviewed by the evaluation team. During the design phase, the evaluation team also attended the 2018 PCA Forum and met with all project teams.

The Program Logic, mapping and Evaluation Framework were first developed in draft, on the basis of the stakeholder interviews and the document review completed. The draft was provided to the Department and all project teams for review. Feedback received was then applied to finalise these documents.

The final versions of the Program Logic are included in Appendix B of this report. To assist with interpreting the NPCP outcomes as documented in this report, it is important to note that that the Program Logic specifies that it was anticipated the NPCPs would demonstrate awareness change outcomes in the short-term, knowledge change outcomes in the medium-term and behaviour change outcomes in the long-term. It is with this lens that the outcomes reported by projects have been assessed and documented in this report.

#### Evaluation Plan

The finalised Program Logic and Evaluation Framework were incorporated into an Evaluation Plan which detailed the activities and timeline for the evaluation. The plan also included details of evaluation governance, potential evaluation data sources, stakeholder engagement and risk management.

### Phase 2: Consultation Part A

#### Site visits

Phase 2 commenced with site visits to all NPCPs in September and October 2018. Each site visit involved meeting with senior members of each project team to discuss implementation, activities, reach, and any outcomes delivered to date.

#### Retrospective Review

In addition to evaluating the current funding round of NPCPs, the Department commissioned Urbis to undertake a Retrospective Review of the activities and impact of the projects funded in the previous round from 2015 – 2017. This process was undertaken in Phase 2 of the current evaluation, and utilised input from the projects gathered during the site visits, as well as a review of available project data from the 2015 – 2017 period. The findings of the Retrospective Review were provided to the Department in a formal report in late 2018, and a summary report of each projects’ performance was also provided to individual project teams.

### Phase 3: Consultation Part B

#### Program data requests

In early 2019 all NPCPs were invited to provide detailed program data for their activities to date (to 30 March 2019) during the 2017 – 2020 funding round. This data included all activity reports each project had provided to the Department during the funding round, along with additional project-specific data such as reach and outcomes data, as well as financial data.

#### Final NPCP team interviews

Following receipt of program data, each NPCP team participated in a final telephone interview. Each interview focussed on the activities and outcomes delivered by each project since the 2018 site visits. The interviews also enabled each project team to provide additional information about the program data provided to the evaluation.

#### Sector consultation

Phase 3 also included consultation with additional sector stakeholders who could provide broader policy context to the findings of the evaluation. This consultation included a roundtable discussion with key stakeholders from the Department, interviews with each jurisdictional health department (excluding Western Australia), and interviews with 10 Primary Health Networks from across Australia which are currently participating in the Greater Choice for At Home Palliative Care measure[[10]](#footnote-11).

### Phase 4: Analysis and Reporting

#### Analysis

All data provided by the NPCPs (including financial data) and qualitative data collected from project interviews and sector consultation was entered into a detailed data capture Microsoft Excel spreadsheet for analysis. Thematic and quantitative analysis was then conducted on the data to form initial findings in relation to the evaluation objectives.

#### Synthesis and reporting

The evaluation team then completed two internal team synthesis sessions where the results of all analysis were brought together and discussed using a structured synthesis process. Key themes in relation to the evaluation objectives were identified through this process, and were then used to develop recommendations.

The outputs of both synthesis sessions form basis of the final evaluation report.

Appendix B - Program logic and mapping

Figure 6 – Program logic

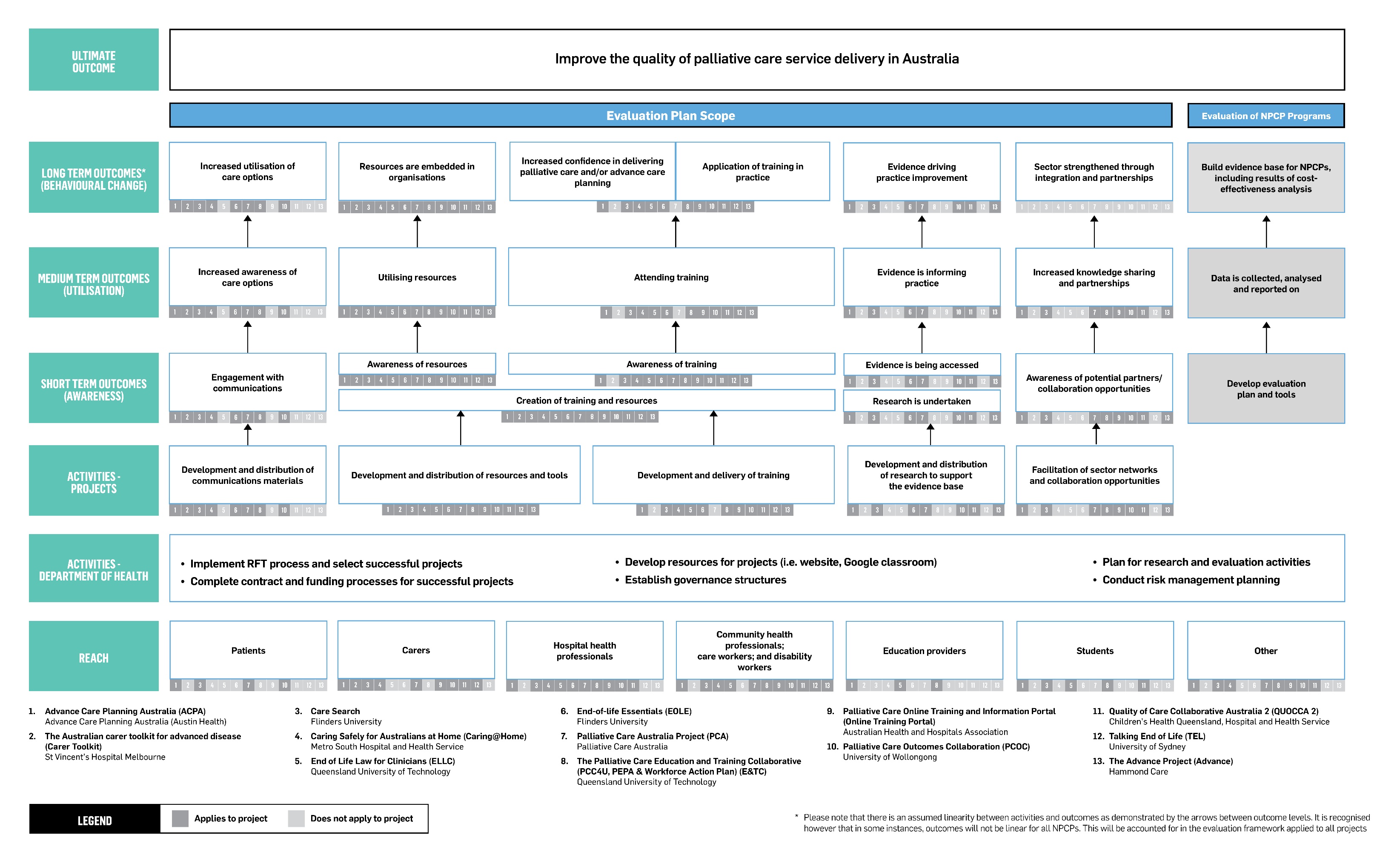


Figure 7 – Program Mapping (part 1)

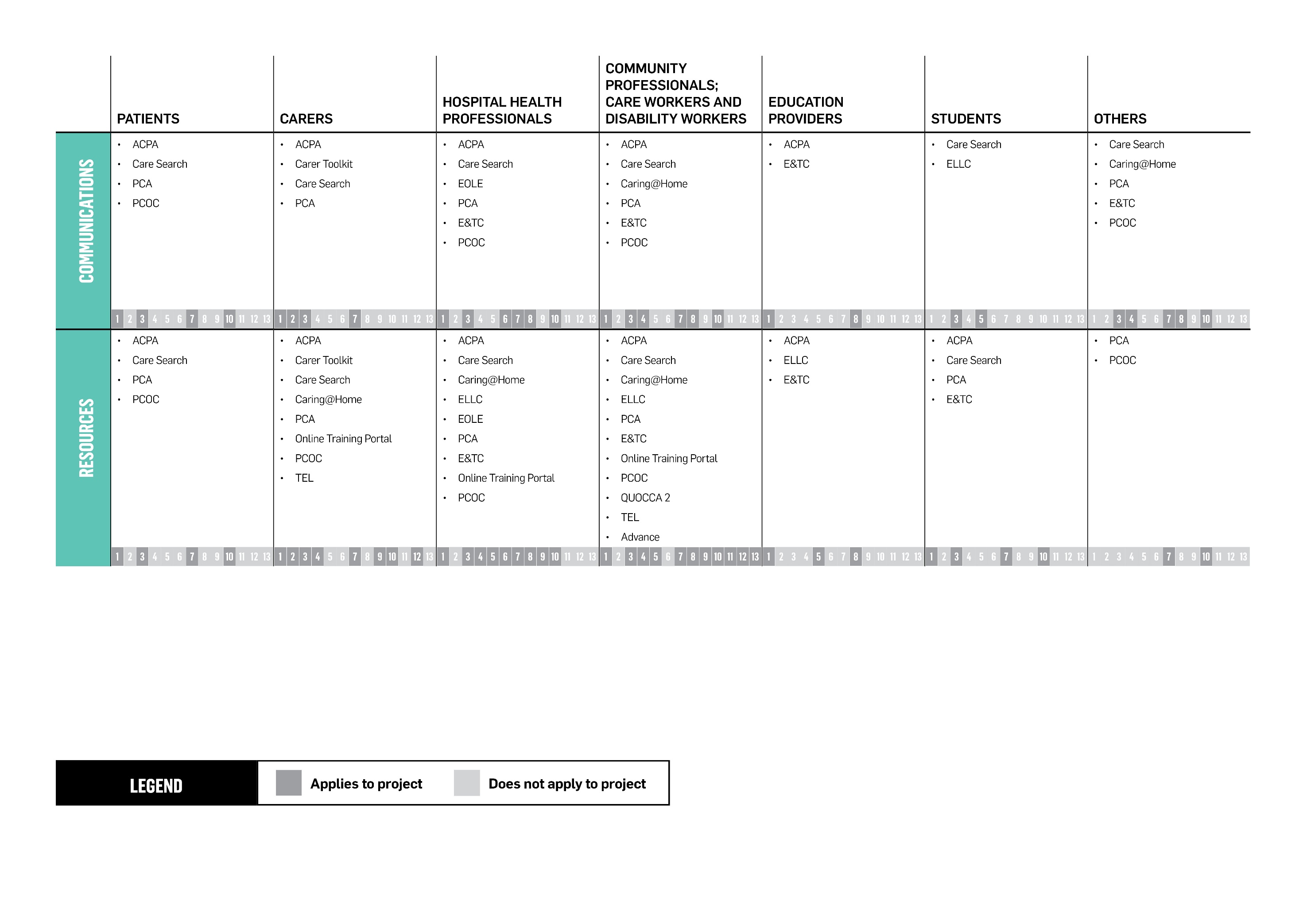
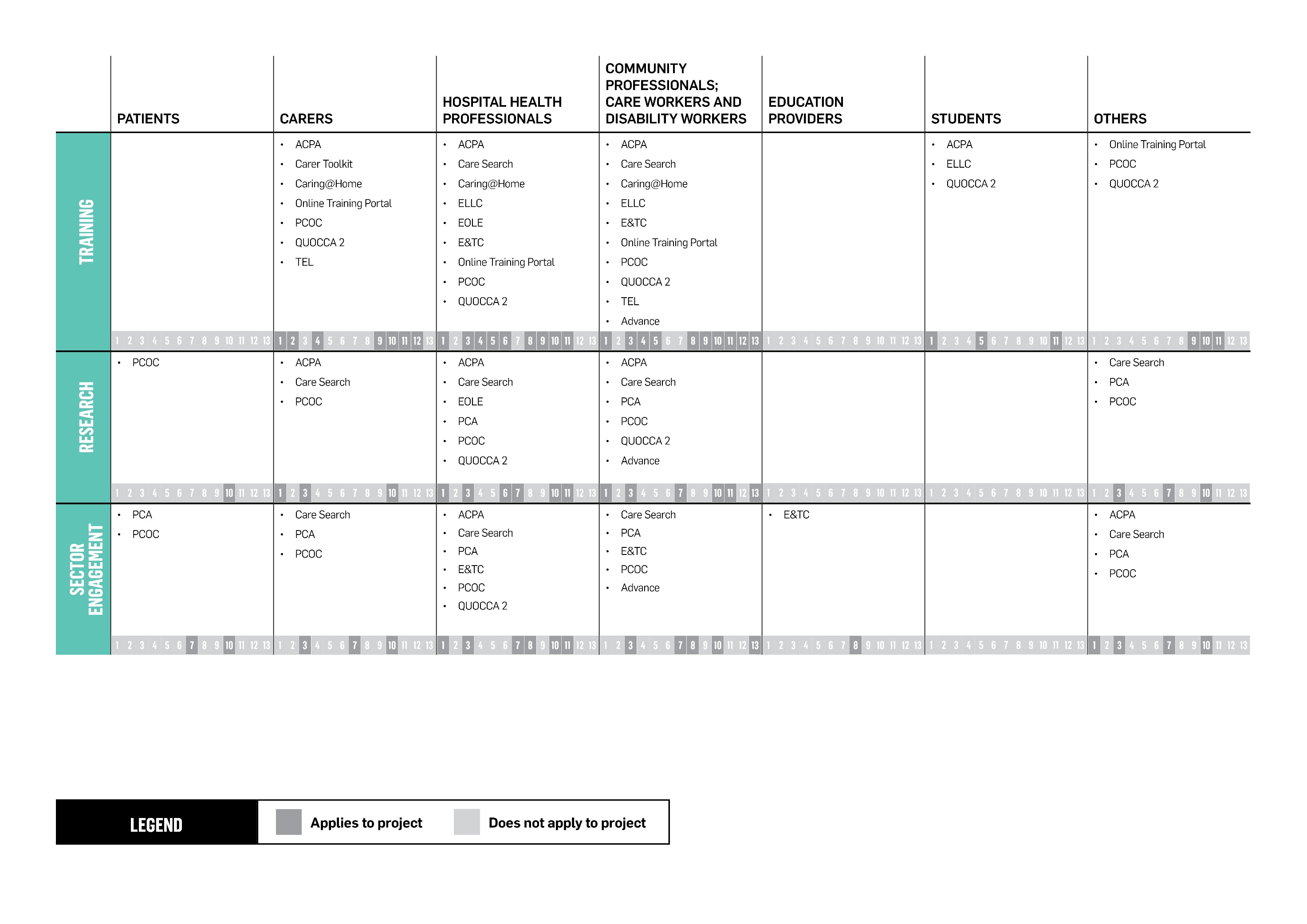


Figure 8 – Program Mapping (part 2)



Appendix C - Summary table of NPCP alignment to funding objectives

Table 24 – NPCP alignment to funding objectives

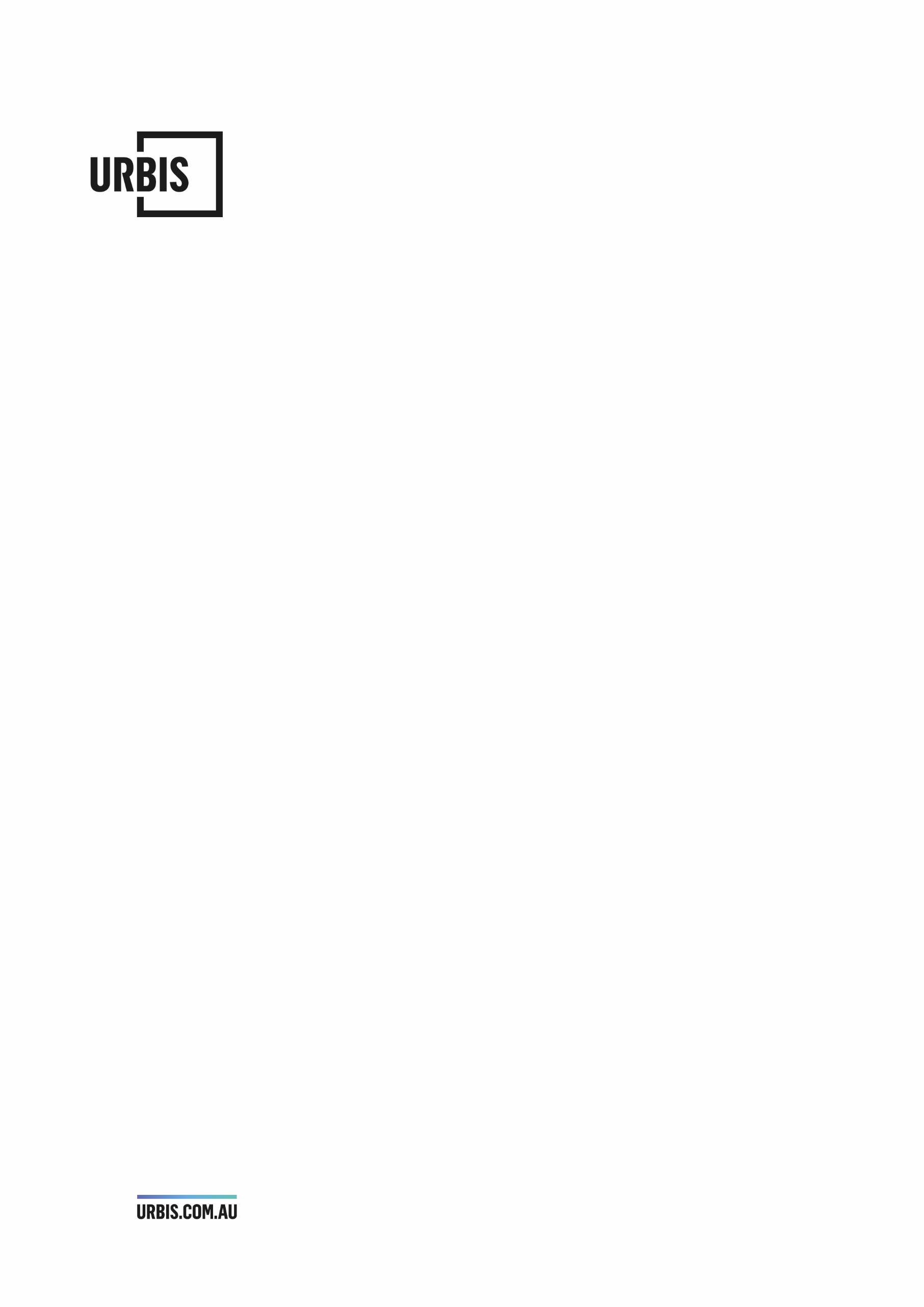
| Grant funding objective | ACPA | Carer Toolkit | CareSearch | Caring @ Home | ELLC | EOLE | PCA | E&TC | Online Training Portal | PCOC | QuoCCA 2 | TEL | Advance |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Improved quality and access to palliative care service skill development | None | Strong | Strong | Strong | Strong | Strong | Some | Strong | Strong | Strong | Strong | Some | Strong |
| Improved quality of palliative care service delivery in community and acute care settings | Some | Strong | Moderate | Strong | Moderate | Strong | Moderate | Strong | Strong | Strong | Strong | Some | Strong |
| Building and enhancement of research and data collection capacity within the palliative care sector | Moderate | None | Strong | None | None | None | Moderate | Moderate | None | Strong | None | None | None |
| Strengthening of understanding and increase of advance care planning uptake | Strong | None | None | None | Some | None | Moderate | Some | Some | None | Some | Moderate | Strong |
| Improved knowledge within the palliative care sector and community awareness of palliative care | Moderate | None | Strong | None | Some | None | Strong | Moderate | None | Moderate | Strong | Moderate | Some |
| Improved collaboration and linkages between the Commonwealth and State and Territory Governments’ palliative care activities | Moderate | None | Some | Some | Some | None | Strong | Moderate | None | Strong | Moderate | None | None |
| Improved collation and dissemination of palliative care information across the sector | Moderate | None | Strong | None | Moderate | None | Strong | Strong | None | Moderate | Some | Some | None |

Appendix D - Analysis of NPCP audience

The following chart maps the audience of the NPCPs – from palliative care specialists, through to the wider health workforce and wider still to the whole-of-population. It also analyses the contact the project has with their audience, from one-off through to ongoing relationships. The size of each bubble is commensurate with the funding the project received in the current funding round.

Figure 9 – Audience of NPCPs

Chart showing the projects mapped against level of contact with audience (one-off to ongoing) and audience (specialist palliative care to the whole population).



1. Department of Health (2018) *National Palliative Care Strategy 2018*. Page 5 [↑](#footnote-ref-2)
2. Department of Health (2018) *National Palliative Care Strategy 2018*. Page 5 [↑](#footnote-ref-3)
3. Department of Health (2018) *National Palliative Care Strategy 2018*. Page 26 [↑](#footnote-ref-4)
4. Department of Health (2018) *National Palliative Care Strategy 2018*. Page 9 [↑](#footnote-ref-5)
5. Public Health and Chronic Disease Grant Program Guidelines, Annexure A5, p. 47 [↑](#footnote-ref-6)
6. Department of Health (2018) *National Palliative Care Strategy 2018*. Page 18 [↑](#footnote-ref-7)
7. Urbis (2016) *Evaluation of the National Palliative Care Strategy 2010 Final Report. Page 41* [↑](#footnote-ref-8)
8. Department of Health (2018) *National Palliative Care Strategy 2018*. Page 5 [↑](#footnote-ref-9)
9. Goal 7 of the Strategy has not been included in this table as it deals with accountability and governance of the Strategy which is not relevant to work of the projects. [↑](#footnote-ref-10)
10. The following PHNs were engaged: South Western Sydney; Western NSW; Murrumbidgee; North Western Melbourne; Brisbane South; Gold Coast; Central Queensland, Wide Bay and Sunshine Coast; Adelaide; Country WA; Tasmania. [↑](#footnote-ref-11)