Specialist Palliative Care and Advance Care Planning Advisory Services

Decision Assist Summary Report 2018
Acknowledgements

The Specialist Palliative Care and Advance Care Planning Advisory Services program (known as Decision Assist) is an Australian Government initiative. Decision Assist was a national program providing education, resources and advisory services to support aged care staff and general practitioners, and thus enhancing provision of palliative care and advance care planning for older Australians.

In 2013-2017, Decision Assist was delivered by a consortium consisting of Advance Care Planning Australia (Austin Health) as the lead agency, CareSearch (Flinders University), Queensland University of Technology, The University of Queensland, Palliative Care Australia, Australian New Zealand Society of Palliative Medicine, Leading Aged Services Australia and Aged and Community Services Australia.

Decision Assist initiatives involved engagement and expertise of other leading organisations. We acknowledge the contribution of all consortium partners, collaborators and advisory group members as well as the large number of staff who have been involved in the program. For their contributions to the program and the final report, we thank Jennifer Tieman (Flinders University), Patsy Yates and John Rosenberg (Queensland University of Technology), Deborah Parker (University of Technology Sydney) and Liz Callaghan (Palliative Care Australia).

In 2018, a comprehensive Decision Assist final report was submitted to the Commonwealth Department of Health. This report is a summary of the final report and outlines initiatives, findings and policy implications.

Disclaimer

While the Australian Government Department of Health funded the Specialist Palliative Care and Advance Care Planning Advisory Service program, the information contained in this report does not necessarily reflect the views of the Australian Government and is not advice that is provided, or information this is endorsed, by the Australian Government. The Australian Government or individual Decision Assist consortium members are not responsible in negligence or otherwise for any injury, loss or damage however arising from the use of or reliance on the information provided herein.

Recommended Citation


Further information reporting this report can be obtained by contacting the Advance Care Planning Program Director at Austin Health on phone +61 3 9496 5660 or email acpa@austin.org.au. The report will be available at advancecareplanning.org.au.

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Introduction

During 2013-2017, the Specialist Palliative Care and Advance Care Planning Advisory Services program (known as Decision Assist) was delivered to enhance specialist palliative care and advance care planning services to recipients of community and residential aged care services. This report provides an overview of the program initiatives, findings and policy implications. This is a summary report and not all Decision Assist initiatives are described.

Background

The Decision Assist program was an initiative of the Australian Government and funded via the Living Longer, Living Better aged care reform package. The primary objectives of the Decision Assist program were to:

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

The Decision Assist program was delivered by a consortium. Austin Health was the lead agency contracted by the Australian Government Department of Health and Ageing. The consortium comprised of eight national agencies with expertise in palliative care, advance care planning, and aged care. Agencies included Austin Health (Advance Care Planning Australia), Palliative Care Australia, Flinders University (CareSearch), Queensland University of Technology, The University of Queensland, the Australian New Zealand Society of Palliative Medicine, Leading Age Services Australia, and Aged and Community Services Australia.

The initial funded period (Phase 1) was 2013 until 30 June 2016 and funding was extended until 31 December 2017 to support completion of projects, transition and closure (Phase 2).

Decision Assist delivered on a range of projects targeting aged care, general practice health professionals and care workers, across all jurisdictions. Projects included:

- Program management
- National telephone advisory service (specialist palliative and advance care planning)
- National communications
- Guidance and technological innovation
- Primary care education and resources (palliative care and advance care planning)
- Aged care training and resources
- Linkages projects
- Evaluation.
A series of advisory groups were established to support program governance and the delivery of projects. These groups had membership from consortium members and other leading relevant national organisations.

Over the life of the program, the Decision Assist projects facilitated significant national consultation, including consultation with primary healthcare networks across jurisdictions, jurisdictional departments of health, and sector stakeholders. The National Specialist Palliative Care and Advance Care Planning Advisory Group and the Transitional Advisory Group provided significant advice and guidance to Decision Assist throughout the transition and closure of the program.

**Program management**

Decision Assist was a complex multi-dimensional project that required robust governance, leadership, national consultation, collaboration and coordination. The project was delivered in two phases, Phase 1 from 1 July 2013 to 30 June 2016 and Phase 2 from 1 July 2016 to 31 December 2017. In Phase 1, a governance review identified the importance of consortium member roles and responsibilities, appropriate independent governance arrangements, and the role of the lead agency.

A Program Management Office was established to coordinate national governance, projects and reporting to the Commonwealth throughout the project. The governance review informed improved program management during phase 2. The primary focus of the program management office was to:

- provide leadership and management to support the program transition and handover
- implement robust program governance arrangements
- maintain quality contract management
- provide sound and transparent financial management of program funds
- support consortium projects as required
- monitor quality of work and risk management across the program and reporting to Commonwealth
- ensure all deliverables outlined in the workplan were met.

The Decision Assist workplan outlined the contracted project deliverables for each consortium partner, see Table 1. Many other leading organisations were engaged in the delivery of these projects, for example the National Ageing Research Institute and Monash University.
# Table 1: Summary of project responsibilities for each consortium partner

<table>
<thead>
<tr>
<th>Consortium partner</th>
<th>Phase 1 2013-16</th>
<th>Phase 2 2016-17</th>
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<tbody>
<tr>
<td><strong>Advance Care Planning Australia (Austin Health)</strong></td>
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<tr>
<td>Program management</td>
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<tr>
<td>National telephone advisory service (advance care planning)</td>
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<td>National telephone advisory service (specialist palliative care)</td>
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<td>National communications</td>
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<td>Primary care education and resources for advance care planning</td>
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<td>Aged care training and resources</td>
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<td>Final evaluation and report</td>
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<td>National Advance Care Directive prevalence study</td>
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<td><strong>Palliative Care Australia</strong></td>
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<td>Environmental scans</td>
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<tr>
<td>Telephone Advisory service (setup and external contract with specialist palliative care provider)</td>
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<tr>
<td>National communications and communications strategy</td>
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<tr>
<td>Aged care training and resources – aged care scholarship to conference</td>
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<td><strong>CareSearch (Flinders University)</strong></td>
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<tr>
<td>Guidance and technological innovation</td>
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<td>✔️</td>
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<tr>
<td>Support to all projects, in particular Aged Care Training and Resources project, with access to the CareSearch learning management system</td>
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<td><strong>Australian and New Zealand Society of Palliative Medicine</strong></td>
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<td>Primary care education and resources for palliative care</td>
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<td><strong>Queensland University of Technology</strong></td>
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<td>Linkages project: national demonstration projects</td>
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<td><strong>University of Queensland</strong></td>
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<td>Evaluation: program logic, evaluation framework</td>
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<td>Ethics: program ethics for consortium projects</td>
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<td>Assistance with design of online modules and face-to-face workshop content</td>
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<td>Delivery of Queensland aged care workshops</td>
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<td><strong>Aged and Community Services Australia (ACSA)</strong></td>
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<td>Interface with aged care industry, both state and national</td>
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<td>Expert advice across all projects</td>
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<tr>
<td><strong>Leading Age Services Australia (LASA)</strong></td>
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<td>Interface with aged care industry, both state and national</td>
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<td>Expert advice across all projects</td>
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Telephone Advisory Service

The Telephone Advisory Services project facilitated national access to specialist palliative care and advance care planning advice for aged care and primary care staff. The project involved an environmental scan, communications strategy, and establishment of the services; palliative care service via St Vincent’s Hospital Melbourne and the advance care planning service via Austin Health Melbourne. From 2017, the advance care planning service delivered a combined staff and volunteer model to promote sustainability.

The uptake of services for both the specialist palliative care and the advance care planning advisory services were lower than anticipated. Calls were received from all states and territories of Australia. The main reasons for calling were palliative care clinical enquiries regarding medication advice and symptoms management; case specific advance care planning calls or advance care planning education and information enquiries. User surveys confirmed that both services provided valuable advice and effectively supported the decision-making of nurses, physicians and aged care professionals caring for people at the end of their lives. Caller satisfaction levels for both services were very high, with average satisfaction levels at 92% for the specialist palliative care advisory service and 90% for the advance care planning advisory service. However, low call volumes resulted in high service costs.

In Phase 2, operating hours for both the specialist palliative care and advance care planning advisory services were altered to reflect call time data and to promote cost-effectiveness. Despite significant promotional activities, uptake of the specialist palliative care advisory service remained low. During this time, the advance care planning advisory service volunteer pilot study confirmed that a volunteer-led service can maintain similar, if not higher levels of satisfaction compared to a health professional model. The model also demonstrated service cost-effectiveness and sustainability.

Case study 1: Brenda* and her mum (*name changed)

Brenda, who lives in the Northern Territory, phoned the advance care planning advisory service. She phoned because she wanted to know how her Mum - Diane, who lives in South Australia, could ensure her doctors would know that she (Diane) did not want cardiopulmonary resuscitation if her heart or breathing stopped. Diane was concerned that her doctors currently would not know this.

The advisory service was able to assist Brenda by directing her to the South Australian Advance Care Directive on the Advance Care Planning Australia website. The service was also able to advise the steps Diane could take, including talking with her doctors, and completing the directive. Additionally, the service provided information on how to store the completed form and who to share the completed document with. Brenda was happy that her Mum would now be able to make her preferences known to her health professionals, even if her Mum was in a condition where she unable to communicate her preferences at the time.
National communications

During Phase 1, Palliative Care Australia was responsible for communications activities. In Phase 2, Austin Health assumed responsibility for the overall strategic communications, transition and closure of the program. The National communications project involved the delivery of a strategy, branding and collateral, launch events, new and revised websites, videos, media releases, editorial coverage, advertising, direct mail, social media, conference attendance, information resources and transition.

Decision Assist communications targeted a national, multidisciplinary and across sector audience. The Decision Assist newsletter reached a subscription list of 11,427 users. The Decision Assist YouTube channel, consisting of webinars and videos, had a total of 10,987 views. There were more than 850 Decision Assist Twitter followers. The Decision Assist website was accessed by more than 50,000 users.

To optimise national engagement and dissemination, health reform programs such as Decision Assist, require robust communications strategy and resourcing.

Guidance and Technological Innovation

The Guidance and Technological Innovation project facilitated access to online specialist palliative care and advance care planning guidance and resources relevant to the aged care and primary care sectors. This initiative included environmental scans, literature reviews, development of guidance materials, website development, dissemination of national e-newsletters, eLearning module development, investigation of information channels, development and evaluation of smartphone applications, publications and more.

The Decision Assist website was launched in 2014. The website provided an online platform for housing and accessing nationally relevant guidance documents and evidence and practice resources relating to specialist palliative care and advance care planning. It included information for specific population groups including diverse communities. During 2014-17, there were approximately 770,000 website page views. The overall satisfaction of website users was high, with over 80% of survey respondents indicating that they were “likely” or “extremely likely” to recommend the website to their colleagues.

The project included the development and launch of two smartphone applications (apps). The apps palliAGEDgp and palliAGEDnurse, were designed to support health professionals to provide evidence based best practice palliative care and advance care planning to older Australians. The download rate was high with 4103 for palliAGEDgp (May 2015 to May 2017) and 1924 palliAGEDnurse (May 2016 to May 2017). In Phase 2, evaluation findings indicated that palliAGEDgp and palliAGEDnurse supported awareness, knowledge and confidence in advance care planning and palliative care. The use of apps in residential and community aged care settings, requires a focus on practical and organisational issues to support uptake. These include considerations such as organisational policies, network quality and internet accessibility. Evaluation findings also highlighted the ongoing need for promotion to continue to build awareness and encourage the use of palliAGEDgp, palliAGEDnurse and other mobile applications and web-based resources.

Phase 2 focused on evaluation, sustainability and transition of the guidance and technological innovation resources. During this phase, the website was transitioned to the Advance Care Planning Australia website and subsequently closed six months after the end of the Decision Assist program. The clinical guidance resources were moved to the CareSearch website. Advance care planning related resources were incorporated within the Advance Care Planning Australia website. The palliAGED apps continue to be promoted via the CareSearch website and within Palliative Care in Aged Evidence project.
Primary Care Education and Resources

The Primary Care Education and Resources project was designed to increase awareness of palliative care and advance care planning resources, and improve the palliative care skills and advance care planning expertise of general practitioners and general practice nurses, nationally. The primary care initiatives included the production, implementation and evaluation of a range of education materials, workshops for both palliative care and advance care planning, development of eLearning modules, and clinical audit tools. Palliative care and advance care planning workshops ran as separate programs. Online palliative care case of the month was implemented as well as videos regarding common palliative care symptoms. Advance care planning webinars, educational videos and advance care planning legal fact sheets were developed. Advance care planning factsheets were produced for Healthshare. Advance care planning was inserted into Health Pathways. ThinkGP education modules for both advance care planning and palliative care were implemented.

In Phase 1, palliative care and advance care planning training and resources were developed. Palliative care workshops were coordinated and delivered by the Australian and New Zealand Society of Palliative Medicine. Advance care planning education was coordinated by Advance Care Planning Australia. Training was delivered via a blended approach of both eLearning and face-to-face facilitated workshops. A train the trainer approach was adopted.

During Phase 1, fifty-nine palliative care training workshops were delivered nationally to general practitioners and general practice nurses. An additional 67 workshops were either completed or scheduled for delivery by the trained champions. Although registration numbers were higher, small numbers of doctors completed the palliative care Active Learning Modules and approximately 100 people completed the palliative care online modules. It was anticipated that more would complete these in the future.

In Phase 1, fifty-three advance care planning workshops were delivered to a total of 932 participants. 139 advance care planning champions were trained. Evaluation revealed that both training approaches can effectively build knowledge, skills and understanding of advance care planning and palliative care within the primary care workforce. Participants attending both “expert” and “champion” led advance care planning workshops significantly improved their confidence, knowledge, and attitudes in regards to advance care planning. Furthermore, there were no major differences identified between “expert” and “champion” led workshops, confirming the train-the-trainer model as a sustainable and scalable model for the delivery of advance care planning and palliative care training in primary care.

Phase 2 focused on the revision and implementation of advance care planning workshops and resources, nationally. eLearning modules for advance care planning in primary care were launched on the ThinkGP hub and the Advance Care Planning Australia Learning hub. A further 22 workshops with 390 participants were held in South Australia, Tasmania and Western Australia. Evaluation provided further evidence of the effectiveness of training to improve advance care planning knowledge, skills, and attitudes. The finding indicated that learning was sustained, with some early evidence of practice change.

Advance care planning education and information resources have been disseminated nationally. The Educators’ Manual was distributed to each of the 31 primary health networks across Australia. Advance care planning resources were embedded into existing primary care systems such as Health Pathways and Healthshare, as well as the Advance Care Planning Australia website.
Aged Care Training and Resources

The Aged Care Training and Resources project was designed to increase awareness of advance care planning and palliative care resources, and improve the palliative care skills and advance care planning expertise of health professionals and staff caring for recipients of aged care services. This initiative included the production, implementation and evaluation of a range of education materials, eLearning modules, workshop manuals, after-death audit tools, webinars, aged care scholarship to the Palliative Care Conference, and the national advance care planning guide for aged care.

In Phase 1, palliative care and advance care planning resources were developed and training was delivered via a blended approach of both eLearning and face-to-face facilitated workshops nationally. Training included train-the-trainer and participant manuals. Approximately 2600 participants registered for the eLearning modules; 151 workshops sets and 6 single workshops were conducted. Approximately 800 residential or community aged care services were represented in Decision Assist education initiatives. Evaluation revealed that this training increased knowledge, skills and understanding of advance care planning and palliative care within the aged care workforce. Evaluation also revealed that the aged care workforce can experience difficulties being released from work for training. ELearning such as online aged care modules and webinars, provided a free educational format that could be accessed at any time.

In Phase 2, there was a focus on further eLearning modules, webinars and resources for the aged care workforce. Ten webinars were produced, attracting in total 1,531 live views and close to 3,670 on-demand views. Webinar evaluation indicated increase in knowledge, skills and understanding of advance care planning and palliative care, with early evidence that this knowledge is sustained and can lead to practice change. Webinars were loaded onto USBs and provided to aged care facilities so they could be easily accessed for future education within their services. The advance care planning implementation guide was developed following literature review, national survey and consultation with aged care representatives. The guide was promoted and disseminated nationally to aged care providers. Resources continue to be available on the Advance Care Planning Australia website.

Linkages

The aim of the Linkages project was to expand access to palliative care for community and residential aged care facility clients, by supporting and facilitating the development of cross disciplinary networks and resources between palliative care and aged care providers. This initiative included the review of evidence-based strategies to promote linkages, toolkit and resources, demonstration projects, linkage facilitators, evaluation, dissemination of findings, publications and more.

In Phase 1, a comprehensive literature review was completed to identify mechanisms for promoting linkages between specialist palliative care services, primary care, and aged care, within various contexts and settings. Seven evidence-based linkage strategies that promote inter-organisational linkages were identified. Strategies include: multidisciplinary team structures; written and verbal communication pathways; formalised agreements and plans; designated linkage workers; role clarification; knowledge exchange and upskilling; and continuous quality improvement. Twenty demonstration project sites from six Australian states were selected to implement linkage strategies. Evaluation surveys and interviews revealed early evidence that the seven evidence-based linkage strategies have the potential to produce improved service and client outcomes. Evaluation findings highlighted: increased knowledge, skills and confidence in advance care planning and palliative care; early changes to personal and workplace practices, including increased use of linkage strategies; and increased awareness of and communication with local services and resources.

In Phase 2, a further ten demonstration project sites from five Australian states were selected. The aim of these projects was to further consolidate the learnings from phase 1. Evaluations produced evidence of improved linkages between aged care and palliative care services, with significant improvements in contact
between services, inter-organisational meetings, multidisciplinary interactions, and shared quality improvement activities. Impacts were observed across a range of domains and practices, including: organisational structures; interagency communication practices; workplace culture; and improved knowledge, skills and confidence of aged care staff. Furthermore, improvements to the quality of care provided to aged care recipients were evidenced through a number of changes, including: the completion of advance care planning; a 12% decrease in hospital transfers in the last week of life, across the ten project sites; and improved continuity of care between services.

Sustainability of Linkages project outcomes at the project sites is highly dependent on multiple contextual factors including staffing, funding, and the embedding of linkage strategies into Continuous Quality Improvement processes. Some project teams reported optimism about the sustainability of the changes made, others are more cautious. When the Linkages strategies were aligned to palliative approach and aged care standards, an incentive to continue with the organisational and practice changes was created.

Resources including: Linkages Manual; Case Study Booklet; Case study videos; and Linkages Knowledge Translation Workshop videos were disseminated and continue to be available on the Advance Care Planning Australia website.

**Evaluation**

Evaluation activities included the development of a comprehensive program logic and framework to monitor the impact and outcomes of individual projects and programs as a whole. This work was undertaken by all Decision Assist consortium members. In Phase 2, the Evaluation project also included a prevalence study to provide data regarding the current uptake of advance care planning nationally.

In Phase 1, a program monitoring and evaluation framework was developed to guide program quality processes throughout the duration of the project and to clearly identify data needs. Across the six key projects, different procedures and methods to collect the evaluation material were used. An Evaluation Advisory Group was also established. This group represented a multidisciplinary reference group of researchers, clinicians and service providers familiar with the particular contexts of aged care, palliative care, advance care planning, and evaluation.

In Phase 2, monitoring and evaluation processes were updated to reflect project data needs and to ensure the ongoing and consistent collection of data. As part of this process, the program logic framework was revised to also include program management and governance related monitoring and evaluation, and key evaluation questions to measure appropriateness, effectiveness, efficiency, and impact. The National Advance Care Planning Prevalence Study was also implemented to provide the first national, across sector, advance care planning dataset. The overall prevalence of having at least one Advance Care Directive in the person’s health record was 29.8%. It has provided much needed data regarding the prevalence and accessibility of advance care planning documentation in acute hospitals, general practices, and residential aged care facilities in Australia. The Study also assessed the quality of documentation and explored people’s views of advance care planning.
In summary, the evaluation demonstrated that the Decision Assist program, which included an extensive range of project initiatives, has achieved against all of the program objectives and has met the four primary program objectives to:

1. Provide specialist palliative care and advance care planning advice to aged care providers and general practitioners caring for recipients of aged care services in all states and territories
2. Improve linkages between aged care services in all states and territories
3. Improve palliative care skills and advance care planning expertise of aged care service staff and general practitioners caring for recipients of aged care services
4. Improve the quality of care for aged care recipients, prevent unnecessary hospital admissions and shorten hospital length of stays.

The program and consortium partners have achieved significant engagement and reach across all jurisdictions in Australia. Initiatives delivered engagement and information hubs, evidence-based guidance resources and toolkits, education and training resources, advisory services, and data. Consortium partners and their projects engaged with and delivered quality initiatives to aged care and primary care multidisciplinary staff and organisations nationally. Leading relevant organisations supported the delivery of Decision Assist via program governance and project engagement.

**Policy implications**

The Decision Assist program has resulted in an extensive range of learnings and resources. The implementation of palliative care and advance care planning policy, programs and services should remain a priority. National consortium delivered programs should consider governance arrangements, national consultation and environmental scanning, engagement of jurisdictional stakeholders including departments of health, engagement of relevant leading organisations, existing systems for embedding processes and resources (eg. Health Pathways, My Aged Care, My Health Record), adequate national communications, and robust evaluation.

Decision Assist produced quality initiatives and resources that should continue to be implemented by the individual consortium members following the closure of the program (eg. CareSearch PalliAGED apps, Advance Care Planning Australia eLearning modules, advance care planning legal fact sheets and more).

Future programs should focus on improving policy and system level change, building competency and practice change, promoting coordination of existing resources and tools, and collaboration of leading organisations.