Metro South Palliative Care Service

Queensland Government

Metro South Health

phn BRISBANE SOUTH
An Australian Government Initiative

Improving End-of-Life Care for Residential Aged Care Facility Residents Initiative

Final Report

February 2019

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Table of Contents

Figures and Tables

Abbreviations

AAM	Area account manager
ACP	Advance care planning
AMA	Australian Medical Association
BSPCC	Brisbane South Palliative Care Collaborative
BSPHN	Brisbane South PHN
EoI	Expression of interest
GP	General Practitioner
MoU	Memorandum of understanding
MSH	Metro South Health
MSPCS	Metro South Palliative Care Service
PALN	Palliative approach link nurse
PEPA	Program of Experience in the Palliative Approach
RACF	Residential aged care facility
RE&E	Resources, education and events programme
SDM	Substitute decision maker
SPCS	Specialist palliative care service
SPSS	Statistical Package for the Social Science

Executive Summary

This report concerns a year-long initiative commissioned by the Brisbane South Primary Health Network (BSPHN) and developed and implemented by the Brisbane South Palliative Care Collaborative (BSPCC), Metro South Palliative Care Service (MSPCS), Metro South Health (MSH). It represents part of an on-going collaboration between BSPHN, MSPCS and volunteering residential aged care facilities (RACFs) to help deliver sustainable resident-centred end-of-life care, at the right time and in the place of the residents' choice.

The purpose of the initiative was multifaceted:

- To design and implement an intervention that further supports local RACFs to provide sustainable evidence-based end-of-life care for residents
- To rollout the three sentinel clinical processes contained within the MSH End-of-Life Care Strategy within local RACFs
- To evaluate intended outcomes of the initiative activities using process, staff and resident/proxy outcomes
- To further cement the working relationship between BSPHN and MSH.

The strategy of the developed multifaceted initiative was to build upon earlier work conducted by BSPCC and commissioned by BSPHN. The strategy was based upon the MSH Strategy for End-of-Life Care[1] inclusive of the *End-of-Life Care framework – Last 12 Months of Life* (see Figure 1). The Framework recognises that provision of quality palliative care includes three sentinel clinical processes based on a resident's needs – advance care planning, case conferencing and use of an end-of-life (terminal) care pathway[2]. Advance care planning (ACP) is integral to ensuring that end-of-life care delivered to residents is aligned with their wishes by enabling individuals to state their preferences should they become unable to participate in decision-making. Palliative care case conferencing allows for the documentation of resident-centred clinical goals of care into the future, particularly generation of a care plan to be followed when the resident inevitably deteriorates. A terminal care pathway, suitable for residents in the last week or days of life, guides clinical decision making around key aspects of care including symptom control, comfort measures, anticipatory prescribing of medications, discontinuation of inappropriate interventions, psychological and spiritual care and care of the family[3].

The initiative comprised two projects – one based on embedding advance care planning processes into routine practice, one based on up-skilling volunteer palliative approach link nurses to champion a palliative approach within their facility – and an extensive resource, education and events programme using various learning modalities including mentoring, on-line educational modules and conferences tailored to the RACF workforce. The initiative targeted facility managers and clinical staff and sought feedback from these two groups as well as residents or their decision-making proxy to determine the success of the initiative.

Evaluation involved 24 RACFs, 89 ACP and palliative approach link nurses, 10 residents or their proxy and 123 clinical RACF staff who attended the conferences. Two hundred and twenty-nine after-death audits were completed to allow pre- and post-intervention outcome measures to be compared. Unfortunately, no general practitioners (GPs) volunteered to be part of the initiative.

Evaluation demonstrates that, using a programme of ongoing education, training and professional development activities, motivated RACFs can implement processes associated with a framework of care

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[1] Queensland Government. *Metro South Health End-of-Life Strategy*. 2016.

[2] Reymond L, Parker G, Gilles L, Cooper K. Home-based palliative care. *AJGP*. 2018; 47(11):747-752.

[3] Reymond L, Israel FJ, Charles MA. A residential aged care end-of-life care pathway (RAC EoLCP) for Australian aged care facilities. *Aust Health Rev*. 2011; 35:350-356.

that improves resident end-of-life care. Important outcomes include: significant increases in the accessibility of residents' advance care plans for treating clinicians, increased numbers of case conferences to ensure medical management plans are known and available when a resident invariably deteriorates as well as more appropriate admissions of residents transferred to hospital in their last week of life. These outcomes are impressive as they were obtained in a short period of time and are applicable to about 25% of eligible RACFs within the BSPHN and MSH catchment area. It is likely that with sustained efforts, the longer-term impact of this initiative would be that residents have access to patient-centred right care, at the right time and delivered in the environment of a resident's choice. However, much more needs to be done.

Based on evaluation of the initiative, recommendations include:

- BSPHN and MSPCS continue structured interventions that enhance the translation of evidence-based best end-of-life practice into clinical care delivery to promote aspects of sustainable high-quality end-of-life care for residents of RACFs and their significant others. This recommendation is in direct alignment with the jointly developed *Brisbane South Older People's Health and Wellness Strategy, 2019-2024* and the MSH *What Matters to Bill and Betty Frail Older Person's* project

- Both BSPHN and MSH work to increase resident and clinician interest in ACP for RACF residents using an educational programme to raise awareness and understanding of the benefits of ACP

- BSPHN and MSH develop a shared model of sustainable recurrent RACF staff education focussing on aspects of end-of-life care. Staff retention and turnover in aged-care is high[4] and a long-standing problem for the sector. Consequently, RACFs need ongoing access to education about end-of-life care for replacement staff. The model could incorporate the learning modalities rated as most important by the ACP and palliative approach link nurses (see Tables 20 and 21) as well as the Qstream platform

- MSPCS continue to develop sustainable resources for uploading to the web site www.EoLcareRACF.com.au

- BSPHN commission an in-depth study into why residents of RACFs within the BSPHN catchment area are transferred to hospital in the last week of life. Such a study will help to inform strategies that facilitate residents dying in their preferred environment of care.

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[4] Fildes D, Westera A, Masso M. *Evaluation of the Encouraging Better Practice in Aged Care (EBPAC) Initiative: Final Report*. Wollongong: Centre for Health Service Development, Australian Health Services Research Institute, University of Wollongong; 2015. 168 p.

1.0 Introduction

National Context and Background

There is agreement across Australian government policy makers, peak professional bodies in aged care and palliative care, and carers that residents should be able to be well-cared for and, if possible, to die ‘in place’ in their RACF.[5,6]

There is also agreement that management and staff of RACFs need to be supported to provide high quality end-of-life care for this growing and vulnerable population including supporting residents to die in their RACF, if that is their preferred wish, and that facilities have adequate capacity to enable this to occur.[7]

In Australia, the proportion of people dying in RACFs has steadily increased and will continue to rise.[8,9] In addition, those entering residential aged care are increasingly frail, often highly dependent and have multiple co-morbidities. The complex needs of these residents and their families have prompted policy recognition of the importance of providing quality palliative care in the residential aged care setting.[9]

It is well known that operationally palliative care is challenging in RACFs and that quality improvements would be beneficial.[10] However, present data on the end-of-life journeys of Australians is fragmented and incomplete[8]. Consequently, it is challenging to know how best to support residents and the RACFs who care for them[7]. Improved understanding of the current capacity and practices in end-of-life resident care within RACFs will assist with development of sustainable models of care to meet the expected increase in care demand.

Care Delivery

Across Australia, care of dying RACF residents is mostly delivered by General Practitioners (GPs) and internal RACF staff augmented with some consultative input from SPCS, though specialist palliative care is not a standard component of service delivery in RACFs.

Issues associated with GPs servicing RACFs include workforce shortages, increased time required to care for the RACF population and poor remuneration[9,11,12]. The 2017 Aged Care Survey report by the Australian Medical Association (AMA) found that one third of GP respondents intended, in the next two years, to either not see new RACF patients, decrease their patient numbers or stop visiting RACFs

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[5] Palliative Care Australia. *End of Life Care is everyone’s affair – tackling the challenge of ‘end of life’*. Submission to the National Health and Hospitals Reform Commission. Canberra, 2008.

[6] Abbey J. *The reality for aged and community care and end of life*. [Presentation] Palliative Care Australia national stakeholder forum A Matter of Life and Death: Confronting the New Reality. Canberra. March 2008.

[7] Etkind SN, et al. How many people will need palliative care in 2040? Past trends, future projections and implications for services. *BMC Med*. 2017; 15(1):102.

[8] Australian Institute of Health and Welfare. *Residential aged care and home care 2014-15: supporting data*. Available from: https://www.gen-agedcaredata.gov.au/Resources/Access-data/2015/December/Residential-aged-care-and-Home-Care-2014%E2%80%9315-suppo

[9] Australian Government. Department of Health. *Guidelines for a Palliative Approach in Residential Aged Care*. National Health and Medical Research Council. Canberra: Enhanced version – May 2006.

[10] Productivity Commission. *Caring for Older Australians: Overview*. Final Inquiry Report, Canberra. Report Number: 53, 2011.

[11] Australian Medical Association. *Aged Care Survey*. AMA [Internet]. 2017.

[12] Reed RL. Models of general practitioner services in residential aged care facilities. *Aust Fam Physician*. 2015; 44(4):176-179.

entirely[11]. RACF staff report that the current fee-for-service model of care is contributing to difficulty accessing GPs, suboptimal quality and access to care and rising rates of acute service usage[13].

Nurses in RACFs are aware that their workforce is struggling to provide quality, resident-preferred care in RACFs[14]. Complex care demands, high task-focussed workloads, lower professional and community status and poor pay parity have all contributed to low recruitment and greater attrition of qualified nursing staff in RACFs[14]. Further, all RACFs whether public, private or not-for-profit exhibit tensions between provision of quality end-of-life care, resource utilisation and cost minimisation[6]. This situation is complicated by an increase in international nursing graduates seeking employment in RACFs, who present with unique cultural, professional and educational needs[15]. RACF nurses fear that without adequate support, staff will continue to experience increasing rates of anxiety, frustration and burnout[14,15].

It is likely that the relative absence of SPCS in RACFs reflects funding sourcing constraints that promote service silos. SPCS, in general, are funded by State and Territory governments and RACFs by the Australian Government. SPCS struggle to meet palliative care demands of in-patients and people in private residences. Consequently, State and Territory governments do not encourage services to become involved in RACFs and the Australian Government does not fund SPCS for RACFs.

Overall it would appear that current end-of-life care in RACFs is worthy of closer assessment with consideration of new and innovative models of care that facilitate provision of the right care, at the right time and in the right place for RACF residents.

Local Context

The initiative, reported here, attempts to empirically address some aspects of end-of-life care in RACFs that lie within the catchment area of BSPHN and MSH. Both organisations recognise the need to improve end-of-life care for aged-care residents and the two organisations have an ongoing and maturing working relationship in this field. BSPHN commissioned this initiative and MSPCS provided in-kind and specialist palliative care support.

The initiative is based upon the MSH Strategy for End-of-Life Care[16] inclusive of the *End-of-Life Care framework – Last 12 Months of Life* (see Figure 1). The Strategy recognises that provision of quality palliative care includes three sentinel clinical processes based on a resident's needs – advance care planning, case conferencing and use of an end-of-life (terminal) care pathway[17]. Advance care planning (ACP) is integral to ensuring that end-of-life care delivered to residents is aligned with their wishes by enabling individuals to state their preferences should they become unable to participate in decision making. Palliative care case conferencing allows for the documentation of resident-centred clinical goals of care into the future, particularly generation of a care plan to be followed when the resident inevitably deteriorates. A terminal care pathway, suitable for residents in the last week or days of life, guides clinical decision making around key aspects of care including symptom control, comfort measures, anticipatory prescribing of medications, discontinuation of inappropriate interventions, psychological and spiritual care and care of the family[18].

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[13] Meade C, Ward B, Cronin H. Implementation of a team model for RACF care by a general practice. *Aust Fam Physician*. 2016; 45(4):218-222.

[14] Chenoweth L, et al. Attracting and retaining qualified nurses in aged and dementia care: outcomes from an Australian study. *J Nurs Manag*. 2014; 22(2):234-247.

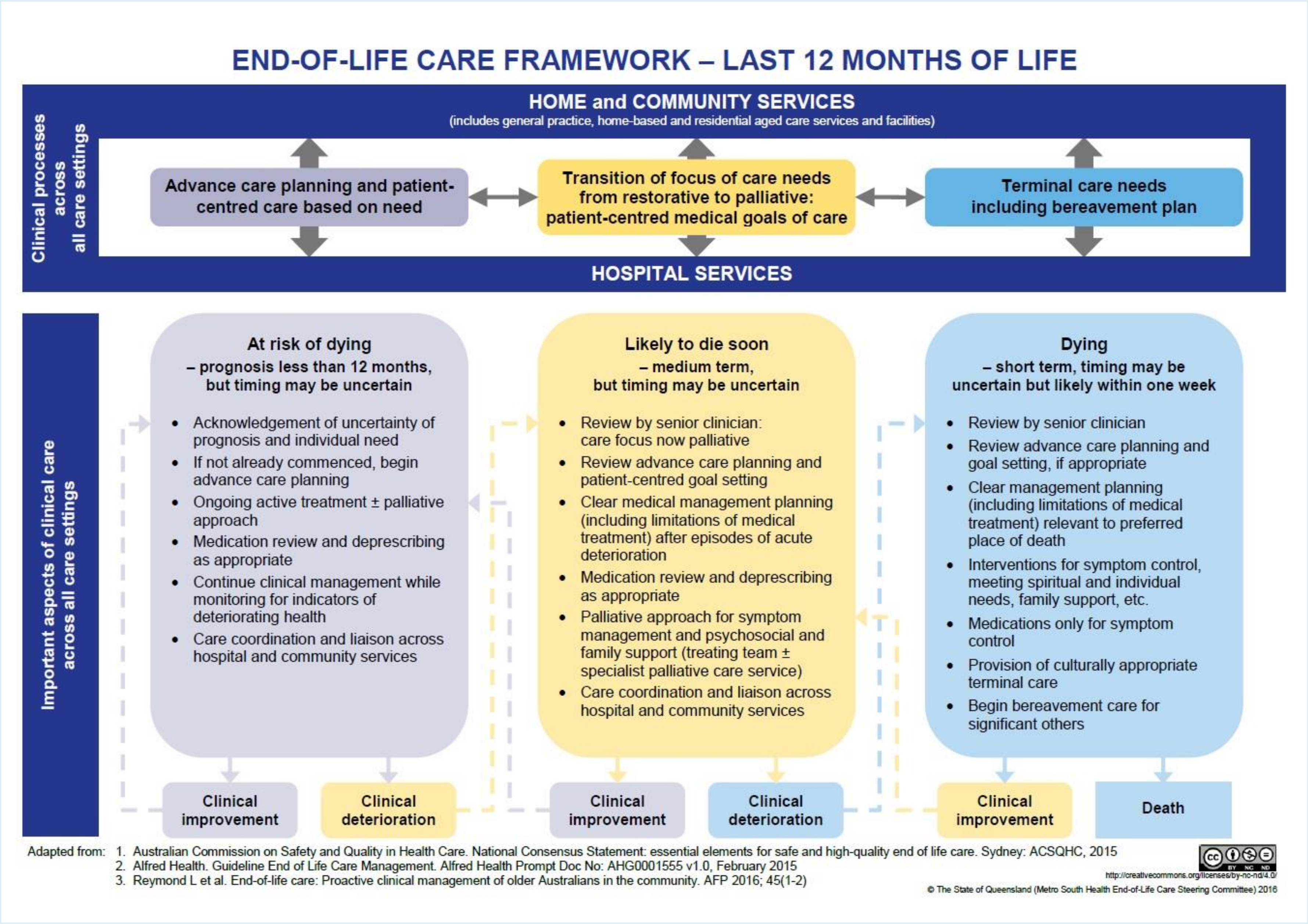
[15] Coyne E, et al. I-Kiribati nursing graduates experience of transition from university to residential aged care facilities in Australia. *Nurse Educ Today*. 2016; 36:463-467.

[16] Queensland Government. *Metro South Health End-of-Life Strategy*. 2016.

[17] Reymond L, Parker G, Gilles L, Cooper K. Home-based palliative care. *AJGP*. 2018; 47(11):747-752.

[18] Reymond L, Israel FJ, Charles MA. A residential aged care end-of-life care pathway (RAC EoLCP) for Australian aged care facilities. *Aust Health Rev*. 2011; 35:350-356.

Figure 1: Diagrammatic representation of the MSH End-of-Life Care Framework – Last 12 Months of Life



END-OF-LIFE CARE FRAMEWORK – LAST 12 MONTHS OF LIFE

Clinical processes across all care settings

HOME and COMMUNITY SERVICES
(includes general practice, home-based and residential aged care services and facilities)

Advance care planning and patient-centred care based on need

Transition of focus of care needs from restorative to palliative: patient-centred medical goals of care

Terminal care needs including bereavement plan

HOSPITAL SERVICES

Important aspects of clinical care across all care settings

At risk of dying
– prognosis less than 12 months, but timing may be uncertain

- Acknowledgement of uncertainty of prognosis and individual need
- If not already commenced, begin advance care planning
- Ongoing active treatment ± palliative approach
- Medication review and deprescribing as appropriate
- Continue clinical management while monitoring for indicators of deteriorating health
- Care coordination and liaison across hospital and community services

Likely to die soon
– medium term, but timing may be uncertain

- Review by senior clinician: care focus now palliative
- Review advance care planning and patient-centred goal setting
- Clear medical management planning (including limitations of medical treatment) after episodes of acute deterioration
- Medication review and deprescribing as appropriate
- Palliative approach for symptom management and psychosocial and family support (treating team ± specialist palliative care service)
- Care coordination and liaison across hospital and community services

Dying
– short term, timing may be uncertain but likely within one week

- Review by senior clinician
- Review advance care planning and goal setting, if appropriate
- Clear management planning (including limitations of medical treatment) relevant to preferred place of death
- Interventions for symptom control, meeting spiritual and individual needs, family support, etc.
- Medications only for symptom control
- Provision of culturally appropriate terminal care
- Begin bereavement care for significant others

Adapted from:
1. Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safe and high-quality end of life care. Sydney: ACSQHC, 2015
2. Alfred Health. Guideline End of Life Care Management. Alfred Health Prompt Doc No: AHG0001555 v1.0, February 2015
3. Reymond L et al. End-of-life care: Proactive clinical management of older Australians in the community. AFP 2016; 45(1-2)

The initiative builds upon previous work involving both institutions. BSPHN and MSH have conducted several pilot projects to support RACFs to improve end-of-life care including:

- In 2016, BSPHN and MSPCS commenced a pilot project[19], aimed at increasing ACP activity within local RACFs. The most important outcome of this project was the demonstrated improvement in ACP activities in the participating RACFs. This was evidenced by significant increases in ACP discussions documented within resident clinical notes[20].
- MSPCS, through its Specialist Palliative Care Service to Residential Aged Care Service clinical team, conducted a small, pilot project aimed at creating Link Nurses within seven RACFs who would champion quality end-of-life care within their facility. The Link Nurses were mentored to increase the capacity of other RACF staff to deliver a comprehensive palliative approach to care within RACFs. This pilot was not formally evaluated though anecdotally it was well received by clinicians.

Both BSPHN and MSH recognise that much more needs to be done in the area of end-of-life care for RACF residents.

The purpose of the initiative reported here was multifaceted:

- To design and implement an intervention that further supports local RACFs to provide sustainable evidence-based end-of-life care for residents
- To rollout the three sentinel clinical processes contained within the MSH End-of-Life Care Strategy within volunteer local RACFs
- To evaluate intended outcomes of the initiative activities using process and staff and resident/proxy measures
- To further cement the working relationship between BSPHN and MSH.

Aim, Objectives and Benefits

Overall Aim of Initiative

The overall aim of the initiative was to support volunteering RACFs to further embed evidence-based practice concerning three sentinel end-of-life clinical processes (advance care planning, case conferencing and use of an end-of-life (terminal) care pathway[17]) into routine care, using strategies of resource creation, ongoing education, training and professional development activities, thus promoting high quality end-of-life care for residents and their families.

Benefits of Initiative

The expected benefits are access to resident-centred right care, at the right time and delivered in the environment of the resident's choice.

Major components of the initiative

For reporting convenience, the major components of the initiative are presented as two separate projects augmented by a resources, education and events programme. In the results and evaluation section much of the data has been aggregated.

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[19] Pilot project title: Improving end-of-life care for residential aged care residents

[20] Reymond L, Charles M, Cooper K. *Improving end-of-life care for residential aged care residents: Final Report*. Brisbane South Palliative Care Collaborative. Submission to Brisbane South PHN. January 2018.

A. Advance Care Planning (ACP) Project

The aim of this project was to expand the 2016 pilot project to support more RACFs to embed an evidence-based ACP programme, adapted for individual facilities, into routine clinical care.

Objective

The primary objective of this project was to increase the number of advance care plans completed by residents/substitute decision makers from participating RACFs and uploaded on the Queensland Health internet platform (The Viewer).

Secondary objectives included:

1. Increases in the number of residents who die in their place of choice as documented in their advance care plan
2. Reduction in the number of avoidable hospital transfers in the last week of a resident's life
3. Reported high levels of consumer satisfaction with the ACP discussion
4. Improved health professionals' knowledge, confidence and skills concerning ACP

Main Activity

In this project, volunteering RACFs participated in a multifactorial ACP implementation strategy, based on evaluation of the 2016 pilot project[19] and best available evidence. The project team worked intensively with these RACFs to increase their uptake of ACP. Activities included engagement with management and clinicians to embed an ACP programme supported by system facility-level changes into their clinical processes, direct education of ACP champions, offering of education for general practitioners (GPs) and a process and outcome evaluation of the project.

B. Palliative Approach Link Nurse (PALN) Project

The aim of this project was to support RACFs to embed within their routine clinical practice a comprehensive evidence-based palliative approach to care that focussed upon the three sentinel clinical processes within the MSH Strategy for End-of-Life Care. Methodology was based upon further development of the pilot Link Nurse Project.

Objectives:

The primary objective of this project was to improve the knowledge, confidence and skills of aged-care staff concerning end-of-life care.

Secondary objectives included:

1. Increase the number of residents who have a palliative care case conference conducted within the last six months of life
2. Increase the number of residents who have an end-of-life pathway commenced
3. Increase in the number of residents whose ACP choices are considered at end of life
4. Reduction in the number of avoidable hospital transfers in the last week of a resident's life.

Main Activity

In this project, volunteering RACFs participated in a multifactorial implementation strategy, based on the earlier Link Nurse pilot project and best available evidence. Activities included engagement with RACFs to embed a palliative approach to care and system facility-level changes to their processes (including the important quality improvement process of conducting after-death audits to iteratively improve care), education for palliative approach link nurses and a process and outcome evaluation of the project.

C. Resources, Education and Events (RE&E) Programme

The aim of this programme was to:

- develop a range of service facility-level end-of-life resources suitable for use by RACF management
- offer and deliver professional development and educational events for RACF nurses
- develop online educational resources as a sustainable strategy to help support ACP champions and palliative approach link nurses in RACFs to provide quality end-of-life care to residents and their families on an on-going basis.

Objectives:

The objectives of this programme were to:

1. Create Example ACP and Palliative Approach Policy and Procedure documents
2. Develop four-day long PEPA (Program of Experience in the Palliative Approach) placements within MSPCS for all palliative approach link nurses to provide specialist palliative care mentoring
3. Develop and present half-day workshops, focussed on the facilitation of ACP discussions, to all ACP champions and, for sustainability, to develop a Train-the-Trainer ACP Workshop Manual
4. Develop and launch the website www.EoLcareRACF.com.au , using existing ACP modules with three additional training modules and other content, to encourage sustainability
5. Deliver two RACF End-of-Life Care Conferences open to all nurses within the participating RACFs
6. Create a Blog for initiative stakeholders to encourage networking across facilities, online communication and feedback
7. Pilot the usefulness of Qstream, an educational platform, using multiple choice questions based on case studies, linked to participants' smart phones.

Main Activity

Educational resources about ACP and end-of-life care were developed, some of which were made available online for sustainability. Evaluation of this activity was limited to a process evaluation due to project time constraints.

2.0 Methodology

Table 1 lists a summary of the activities and tasks undertaken as part of the initiative. The time-line of the initiative is presented in Attachment 1.

Table 1: Summary of initiative activities and tasks

Components	Activities
Governance	• Project Schedule signed 29/11/2017 • Cost centre created • Steering Committee and terms of reference established • Project team and meeting dates established • Staff recruited
Design of the multicomponent initiative	• Development of initiative strategies, inclusive of two projects and the resources, education and events programme • Initiative Management Plan endorsed by Steering Committee, 24/9/2017
Recruitment of RACFs	• Expression of Interest (EoI) • Memorandum of Understanding (MoU)
Recruitment of and initial engagement with participants	• RACF managers • ACP champions • Palliative approach link nurses • Residents and/or substitute decision maker(s) (SDMs)
Development of resources and delivery of education	• Review of Example ACP policy and procedure and create Example Palliative Approach policy and procedure • Development and launch of website www.EoLcareRACF.com.au • Online modules development • Development of Qstream pilot • Development of RACF End-of-Life Conference materials • Workshop development for ACP champions and creation of Train-the-Trainer ACP Workshop manual • Organisation of PEPA placements for Link Nurses with MSPCS and reimbursement for RACFs • Information for residents, families and/or SDMs
Evaluation	• Evaluation programme logic plan developed • Evaluation tools developed
Ethics	• Ethics applications prepared and submitted
Pre-implementation and Implementation	• Pre-implementation (base-line end-of-life care) data collection commenced 1/10/17 • Initiative projects rollout • Evaluation data collection completed 30/9/18 • Data collation and analysis
Note: Methodological change	• Despite the efforts of BSPHN Area Account Managers (AAMs), no GP surgeries opted for the lunchtime education, so this component was neither developed nor implemented

Governance

Steering Committee

The primary role of the Steering Committee was to provide the opportunity for members to contribute their experience, knowledge and perspectives to the achievement of the projects' outcomes, including identifying potential risks. The committee met every three months.

The members of the Steering Committee included representatives from the project team, BSPCC and the aged care sector.

The Terms of Reference (including list of members) for the Steering Committee are in Attachment 2.

Project team

The project team met regularly to oversee the operation of the projects. The members of the project team were the Project Director, Project Manager, Manager of Brisbane South Palliative Care Collaborative (BSPCC), the Clinical Nurse Consultant, the clinical nurse and administrative assistant.

Staff

A project manager, clinical nurse consultant, clinical nurse and administrative assistant were recruited to conduct the project.

Design of the multicomponent initiative

Development of the multicomponent initiative was based on findings reported in the January 2018, Final Report "Improving end-of-life care for residential aged care residents"[20] produced for the BSPHN and the experience of the RACF Specialist Palliative Care Service within MSPCS in conjunction with the Brisbane South Palliative Care Collaborative.

Similar to the project above, this current initiative was designed to target different levels of influence within RACFs including system level (facility managers), clinicians (facility staff and attending clinicians) and residents, their families and/or substitute decisions makers.

As described earlier, the initiative included three complexly inter-related components i.e. the ACP project, the Palliative Approach Link Nurse project and the Resources, Education and Events programme.

Recruitment of RACFs

Facility Expression of interest (EoI) and memorandum of understanding (MoU)

An information pack concerning the initiative was posted to all RACFs (80) in the BSPHN area that met eligibility requirements. Those requirements were that the facility provides high-care beds, has twenty-four-hour registered nurse support and internet access for the nursing staff. The pack included:

- Letter of invitation (see Attachments 3A & 3B)
- EoI application (see Attachments 4A & 4B)
- Factsheet about the project (see Attachment 5)
- Draft copy of non-legally binding memorandum of understanding (MoU) that managers would be expected to sign (see Attachments 6A & 6B)

A convenience maximum target number of participating RACFs was set at 25 for the ACP project and at 9 RACFs for the Palliative Approach Link Nurse project as that project was comparatively more resource intensive.

Recruitment of and initial engagement with participants

Across the initiative projects there were four participant groups (see Table 2).

Table 2: List of participant groups

Participant group	Recruitment process	Key role
RACF managers	Identified by RACF governance	• Commitment to the uptake and promotion of the initiative in their facility • Completion of pre and post-intervention audits concerning organisational policy and structures
ACP champions	Recruited, with consent, by RACF manager	• Participate in the project peer supervision programme and facilitate ACP discussions with residents and/or SDMs • Complete educational requirements and training events • Ensure completion of pre and post project death audits
Palliative approach link nurses	Identified, with consent, by RACF manager	• Participate in a PEPA placement and the project education programme and act as palliative care mentor for other RACF staff • Complete other educational requirements and training events • Ensure completion of pre and post project death audits
Residents/family member/SDMs	Identified, with consent, by ACP champion and RACF manager	• Complete satisfaction survey after an ACP discussion

RACF Managers

A project clinical nurse met with managers in each participating RACF with the aim of informing them about the project and explaining the role of the manager, inclusive of the important task of completing pre- and post-intervention audits concerning organisational policy and structures (Attachments 7 A-D). A pack of resources (see Attachments 8A & 8B for list of resources) containing a Project Brief for RACF Managers (see Attachments 9A & 9B) was provided.

A key outcome of the meeting was to gain engagement in developing/reviewing the RACF's ACP and End-of-Life Care policies and procedures based on the example policy and procedures for ACP and End-of-Life Care developed (see Attachments 10A & 10B) during the initiative.

ACP champions and palliative approach link nurses

A project clinical nurse met with the ACP champions and palliative approach link nurses in each RACF with the aim of informing them about the project and explaining their operational roles. The project nurse explained their requirements to complete pre- and post-intervention education surveys (Attachments 11 A-D), attend educational and training events as well as ensuring completion of pre- and post-intervention death audits (see Attachments 12A & 12B). They were provided with an information pack of resources (see Attachments 13 A-C for list of resources) including Project Brief (see Attachment 14) and invited to attend both RACF End-of-Life Care Conferences.

The key outcome of the meeting was to ensure that ACP champions and palliative approach link nurses understood their role and the commitment it required.

Residents/Family/SDMs

After completing an ACP discussion with an RACF staff member, residents and/or their family member or SDM were approached by RACF staff and invited to complete a satisfaction survey (see Attachments 15A & 15B) to be delivered by a research clinical nurse.

Development of Resources and Delivery of Education and Events

Review of Example ACP policy and procedure and creation of Example Palliative Approach policy and procedure

An *Example Policy and Procedure: Implementation of Advance Care Planning in Residential Aged Care Facilities* (see Attachment 10A) and an *Example Policy and Procedure: Applying a Palliative Approach in Residential Aged Care Facilities* (see Attachment 10B) were developed and reviewed for participating RACFs to use to either develop or review their own documentation to support the implementation of the initiative in their facility. These examples were not meant to be prescriptive. Managers in RACFs could adapt the content of the examples to meet their own identified and unique local needs.

Resources, education and events for ACP champions and palliative approach link nurses

The resources, education and events programme developed for RACF staff was multifaceted. Elements common to both the ACP and PALN Projects included:

- Access to www.EoLcareRACF.com.au that contains end-of-life care news updates (monthly), three educational modules concerning ACP and three new Train-the-Trainer modules concerning cultural considerations for end-of-life care, use of the PREPARED framework in conducting difficult end-of-life discussions and how to complete and ensure availability of the Queensland Health Statement of Choices (SoC) document

- Two one-day conferences that specifically focussed on issues associated with end-of-life care in RACFs. Each conference included multiple speakers and concluded with a hypothetical case conference that encouraged interaction between conference participants and an expert panel. Participants and speakers had adequate time to network and consolidate earlier online learnings.

Elements specific to ACP champions included:

- Four half-day interactive ACP workshops facilitated by a specialist grief counsellor and a specialist palliative care clinical nurse consultant. The workshop supported participants to undertake their role as an ACP champion. Through role playing it allowed skills to be mastered and developed confidence to discuss ACP with residents, family members and/or SDMs. Participants were given educational resources (including an ACP Champion Guide) to train other staff in their facilities about ACP

- Translation of the content in the ACP workshop into a Train-the-Trainer ACP Workshop Manual to allow for post-intervention sustainability

- ACP peer support. This entailed three hours of face-to-face education for each Champion within their RACF and follow-up telephone support delivered by the project clinical nurses. Options for this education included a demonstration conversation with a resident, feedback to the ACP Champion after they conducted an ACP conversation, critique of a completed ACP document and/or a small group discussion about progressing ACP in their facility

- Interactive education via a microlearning platform (Qstream), that utilised “bite-sized”, case-based challenges was developed with an ACP focus. Fourteen ACP multiple-choice questions (a Qstream set) were created and two questions sent every two days for two weeks to voluntary participants. If questions were answered incorrectly they were resent to the participant with explanations about why the answer was incorrect and guiding the participant to the correct answer. The use of Qstream was piloted to explore its utility within the RACF workforce.

Elements specific to palliative approach link nurses included:

- PEPA placements. All palliative approach link nurses undertook a four-day PEPA placement with MSPCS. Each facility was reimbursed for the nurses' time out of the facility. The overall goal of this clinical placement was to experience palliative care approaches, strategies and fundamentals of practice. An outline of the clinical placement is summarized in Attachment 16.

- Palliative Approach Link Nurse peer support. Project nurses provided either face-to-face or telephone mentoring, on an as-needed basis, after completion of the PEPA placement and until the end of the project to enhance each Palliative Approach Link Nurse's knowledge, confidence, skills and attitudes regarding end-of-life care.

Information for Residents/family members/SDMs

To ensure that residents/family members and SDMs were informed of the initiative and its benefits, information presented as fact sheets and brochures were produced specifically for them (see Attachment 17). They were informed that they may be approached by a facility staff member to consent to a survey after they had had an ACP conversation with a facility member. The voluntary nature and confidentiality of this survey was stressed.

Evaluation

The primary purpose of the evaluation was to analyse objective measures of changes in intended outcomes (see Table 3: A-C) as a result of the initiative compared with pre-initiative implementation (baseline) outcomes measures.

A Programme Logic model of evaluation was chosen as this is well suited to evaluating health interventions that wish to focus on intended outcomes. A logic model is a systematic and visual way to present and share understanding of the relationships between project activities and the outcomes expected.

A logic model is the first step in evaluation (see Figures 2 & 3). The two boxes on the left of the diagram in the upper table represent project activities and participants. The two boxes on the right represent the intended outcomes of the project.

Please note that due to project time constraints, only short-term outcomes could be evaluated. The box on the bottom presents a table showing the indicators for measuring the projects' processes and the short and long-term outcomes.

A summary of the evaluation tools used is listed in Attachment 18. A copy of all the evaluation tools used are included in the attachments.

Figure 2: Advance Care Planning project logic model

ACTIVITIES (What we do)	PARTICIPANTS (Participation)	SHORT TERM OUTCOMES	LONG TERM OUTCOMES
Develop implementation model Develop template policies/guidelines/procedures Recruit RACFs into project Develop education programme Deliver education to RACF staff Deliver education to GPs including medical deputising services Identify resources for residents and carers Promote project	• RACF managers • ACP champions • GPs • RACF residents and their family/SDM	**Nurses** **Knowledge** • Knowledge of ACP • Knowledge of ACP legislation **Attitudes** • Positive towards ACP **Confidence** • To initiate and discuss ACP **Skills** • To practise ACP **Residents and family/SDM** • Awareness of ACP • Satisfaction with ACP process **RACFs** • ACP discussions initiated • Advance care plans completed and uploaded • Residents dying in place of choice • Hospital transfers recorded by reason • ACP policies/procedures embedded	• Service profile meets the needs of the population • Improved access to the right care, at the right time in the right place for residents

PROCESS TRACKING		INTERVENTION OUTCOMES	
Indicators: Implementation strategy model Education programme for ACP champions Education programme for GPs Delivery of education programme Resources for residents and families	**Indicators:** • # RACFs participating • % identified GPs participating • # ACP champions • # ACP champions and GPs completing education programmes • # educational programmes delivered	**Measures:** **Evaluation of education** • % showing increase in knowledge • %showing increase in confidence • % showing increase in skills • % showing increase in positive attitude to ACP **Residents/families satisfaction with ACP** • % showing increased awareness • % indicating satisfaction with ACP **RACFs** • #,% increase SoCs uploaded to The Viewer • #, % increase documented ACP choices considered • # of residents dying in place of choice increases • # hospital transfers decreases • #, % increase in RACFs with embedded ACP policies/procedures/guidelines	**Measures:** Brisbane South PHN WORNA

Figure 3: Palliative Approach Link Nurse project logic model

ACTIVITIES (What we do)	PARTICIPANTS (Participation)	SHORT TERM OUTCOMES	LONG TERM OUTCOMES
Develop implementation model Develop template policies/guidelines/procedures Recruit RACFs into project Develop education programme Deliver education to RACF staff Deliver education to GPs including medical deputising services Identify resources for residents and carers Promote project	• RACF managers • Palliative approach link nurses • GPs	**Nurses** **Knowledge** • Knowledge of a palliative approach and framework of care • Knowledge of symptom management **Attitudes** • Positive towards a palliative approach **Confidence** • To provide a palliative approach • To provide appropriate referrals to specialist palliative care **Skills** • To manage symptoms • To communicate openly about death and dying • To make clear referrals **RACFs** • ACP discussions initiated • Use of case conferences • Use of end-of-life care pathways • Residents dying in place of choice • Hospital transfers recorded by reason • Palliative approach policies/procedures embedded	• Service profile meets the needs of the population • Improved access to the right care, at the right time in the right place for residents
PROCESS TRACKING		**INTERVENTION OUTCOMES**	
Indicators: Implementation strategy model Education programme for Link Nurses Education programme for GPs Delivery of education programme Resources for residents and families	**Indicators:** • # RACFs participating • % identified GPs participating • # Link Nurses • # Link Nurses and GPs completing education programmes • # educational programmes delivered	**Measures:** **Evaluation of education** • % showing increase in knowledge • %showing increase in confidence • % showing increase in skills • % showing increase in positive attitude to a palliative approach **RACFs** • #,% increase SoCs uploaded to The Viewer • #, % increase case conferences • #, % increase end-of-life (terminal) care pathways • #, % increase documented ACP choices considered • # of residents dying in place of choice increases • # hospital transfers decreases • #, % increase in RACFs with embedded palliative approach policies/procedures	**Measures:** Brisbane South PHN WORNA

Outcome measures

The intended initiative outcomes, associated data sources and objectives for the three components, are listed in Table 3.

Table 3: Intended initiative outcomes, associated data sources and component objectives

A. Advance Care Planning Project

OUTCOME		DATA SOURCE	LINKED TO OBJECTIVE
1	Increased number of advance care plans completed by residents/substitute decision maker(s) from participating RACFs and uploaded on the Queensland Health internet platform	• Number of advance care plans uploaded to The Viewer (Office ACP, Qld Health) • Pre and post after-death audit	ACP Primary objective
2	Increased number of residents who die in their place of choice as documented in their advance care plan	• Pre and post after-death audit	ACP Secondary objective 1
3	Reduction in the number of avoidable hospital transfers in the last week of life	• Pre and post after-death audit	ACP Secondary objective 2
4	Reported high level of consumer satisfaction with ACP discussion	• Satisfaction survey	ACP Secondary objective 3
5	Improved health professionals' knowledge, confidence and skills re ACP	• Pre and post education surveys	ACP Secondary objective 4

B. Palliative Approach Link Nurse Project

OUTCOME		DATA SOURCE	LINKED TO OBJECTIVE
1	Aged care staff report an increase in knowledge, confidence and skills concerning end-of-life care	• Pre and post education surveys	PALN Primary objective
2	Increase in the number of residents who have a palliative case conference conducted in the last six months of life	• Pre and post after-death audit	PALN Secondary objective 1
3	Increase in the number of residents who have an end-of-life (terminal) pathway commenced	• Pre and post after-death audit	PALN Secondary objective 2
4	Increase in the number of residents whose ACP choices were considered at end of life	• Pre and post after-death audit	PALN Secondary objective 3
5	Reduction in the number of avoidable hospital transfers in the last week of life	• Pre and post after-death audit	PALN Secondary objective 4 and ACP Secondary objective 2

C. Resources, Education and Events Programme

OUTCOME		DATA SOURCE	LINKED TO OBJECTIVE
1	Example ACP and Example Palliative Approach policy and procedure documents available to RACF managers	• www.EoLcareRACF.com.au	RE&E Objective 1
2	All Link Nurses attend PEPA mentoring programme with MSPCS	• PEPA Attendance lists	RE&E Objective 2
3	All ACP champions attend ACP workshop	• ACP Workshop attendance lists	RE&E Objective 3
4	Launch of website with three new end-of-life care training modules and other content to encourage sustainability	• www.EoLcareRACF.com.au	RE&E Objective 4
5	2 RACF End-of-Life Care Conferences delivered	• Conference reports	RE&E Objective 5
6	Creation of Blogs	• www.EoLcareRACF.com.au	RE&E Objective 6
7	Qstream educational programme piloted	• Automated reports provided by Qstream	RE&E Objective 7

Data Analysis

All data was entered into SPSS Statistics software.

Data concerning numbers of ACP uploaded to the Queensland Health system were obtained from the Office of Advance Care Planning, Queensland Health.

As all information sheets, surveys and audits were anonymous, pre- and post-intervention data could not be matched for individuals. Independent samples t-tests were used to test for significant changes from pre- to post-intervention or chi-square tests for categorical data.

Due to the complex interaction of initiative components, where intended outcomes across initiative components were similar e.g. number of avoidable hospital transfers in the last week of life, it was decided to aggregate clinician data, unless otherwise specified.

Ethics

To ensure that this initiative was conducted in accordance with principles in the National Statement of Ethical Conduct in Human Research it was submitted to the MSH Princess Alexandra Hospital Ethics Committee. Ethics approval was obtained in August 2017 (HREC/17/QPAH/552:SSA/17/QPAH/553).

Subsequent ethics approvals were required, and approved, by the BlueCare Ethics Committee.

3.0 Results and Evaluation

Overview

Participating RACFs

Eighty RACFs were invited to be a part of the initiative. Thirty-two MoUs were signed. Twenty-four RACFs volunteered for the ACP project and three subsequently dropped out, two ACP project RACFs did not return any after-death audit data; 10 RACFs volunteered for the more intensive PALN project and two dropped out. RACFs were not required to provide a reason for not volunteering or leaving the initiative, though changing employment circumstances and heavy workloads were cited as reasons by facility managers.

Outcome measures

A range of resources to enhance end-of-life care in RACFs was developed including example ACP and Palliative Approach policy and procedure documents, a Train-the-Trainer ACP Workshop Manual and three on-line ACP training modules.

Professional development activities (ACP workshops and PEPA placements) aimed at sustaining end-of-life care practices were completed by all volunteering nurses. Two conferences, focussed on end-of-life care were convened and opened to all nursing staff members of local RACFs. The website www.EoLcareRACF.com.au was launched and six educational end-of-life care modules uploaded to the site. A blog, associated with the website, was created. A Qstream pilot educational package, based on ACP content, was implemented.

System facility-level pre-intervention outcome measures of aspects of end-of-life care were obtained from 24 managers of RACFs who completed standard organisational policy and structures audits. These measures were compared against 20 post-intervention organisational policy and structures audits.

Clinician-level baseline measures of aspects of end-of-life care were obtained from 70 nurses who completed 125 pre-intervention death audits. These measures were compared against 104 post-intervention death audits.

Seventy-one aged-care staff completed pre- and post-intervention surveys aimed at determining changes in knowledge, confidence and skills concerning aspects of end-of-life care as a result of the intervention.

Ten resident-level measures of satisfaction with ACP discussions were obtained from those who consented to completing a satisfaction survey.

Clinical Care Staff involvement

In total, 72 ACP champions were recruited to the ACP project and 53 completed all aspects of the education programme – online modules, workshop, conference attendance and peer support. Seventeen palliative approach link nurses were recruited to the PALN project and 12 completed all aspects of the education programme - online modules, PEPA placement, conference attendance and peer support.

One hundred and twenty-three RACF clinical staff attended the End-of-Life conferences.

Forty-nine ACP champions were invited to sign-up for the Qstream pilot and 34 subsequently participated.

No GP surgeries requested educational material for the initiative.

Resident/family/SDM involvement

Two ACP satisfaction surveys were received from residents and eight from residents' family members or other SDM.

Data collection period

Pre-intervention data collection began October 1, 2017 and continued until all ACP workshops and PEPA placements were completed; February, 2018 and May, 2018 respectively. Post-project data collection began as soon as each facility had completed ACP workshops and/or PEPA placements and completed on September 30th, 2018.

Findings

Evaluation findings of the ACP and PALN projects are presented according to the intended outcomes of the two projects as documented in Table 3. Process outcomes of the resources, education and events programme are then listed.

It should be noted that the components of this intervention were interrelated and interacted in complex ways, including cross-facility and service dialogue. Consequently, presentation of the findings incorporate, where appropriate, results from the organisational and policies structures audits and the resident/family/SDM audits, as well as data from the resources, education and events programme. Also, where appropriate, data from the ACP and PALN pre- and post-death audits have been aggregated.

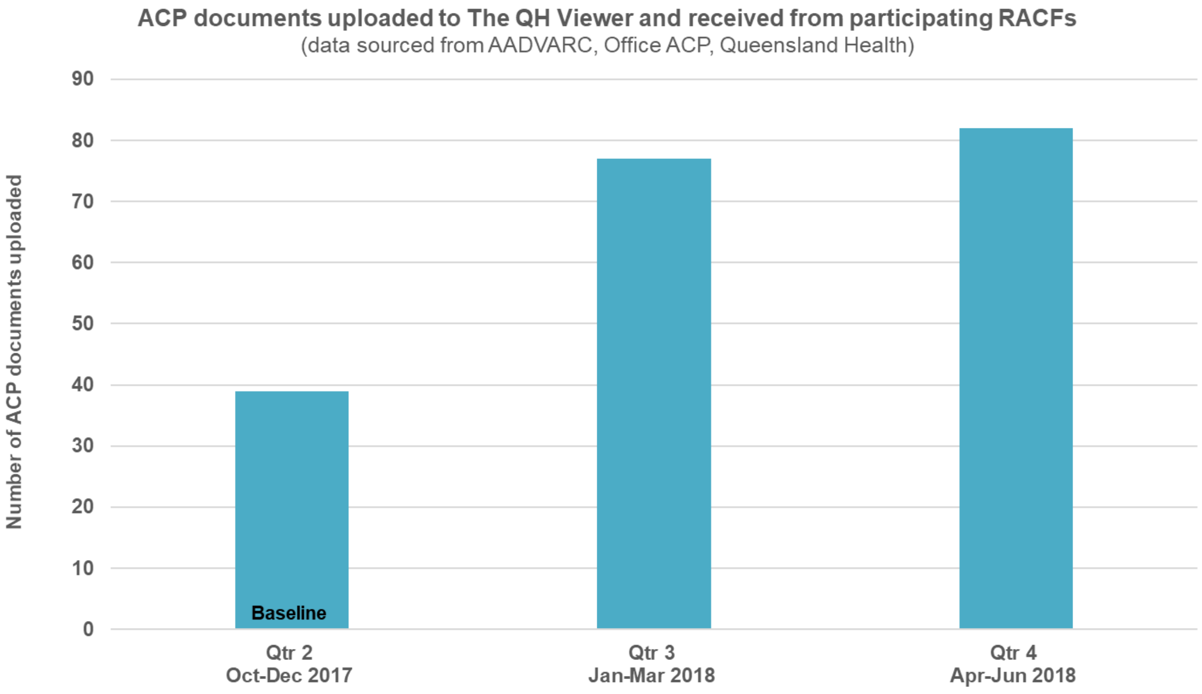
Advance Care Planning Project

Primary objective

The primary objective of the ACP project, to increase the number of advance care plans completed by residents/SDMs from participating RACFs and uploaded to the Queensland Health Viewer, was achieved.

Primarily, this is evidenced by the increased numbers of advance care plans from participating RACFs within the Queensland Health Viewer (see Figure 4). In the pre-intervention baseline three-month period, 39 documents were uploaded, compared to 79 in the first three month period after ACP training workshops. This increase is statistically significant in a chi-square goodness of fit test (chi-square = 12.4, df = 1, p <.05). The increase from baseline was maintained at six months after ACP training, when 82 new documents were uploaded (chi-square =15.3, df = 1, p < .05).

Figure 4: ACP documents received from participating RACFs and uploaded to The Queensland Health Viewer



In the pre-intervention period, 125 resident deaths were audited. Of these, 101 (80.8%) had documented advance care plans. In the post-intervention audit there were a total of 104 deaths, and 91 of those (87.5%) had advance care plans documented. This 6.7% increase is in the intended direction, though not statistically significant (chi-square = 1.88, df = 1, p = 0.17). Table 4 displays the types of documented advance care plans completed by residents in pre- and post-intervention periods.

Table 4: Types of ACP documentation (residents may have completed more than one type of document).

ACP document type	Pre-Intervention Audit % (N=101)	Post-Intervention Audit % (N=91)
Advance Health Directive	35.6% (36)	33.0% (30)
Enduring Power of Attorney (personal/financial decisions)	48.5% (49)	51.6% (47)
*Statement of Choices	37.6% (38)	61.5% (56)
*Other##	24.8% (25)	11.0% (10)

* Differences between the pre- and post-intervention period are statistically significant in a chi-square test of independence.

Other refers to any type of ACP document unable to be uploaded to the Queensland Health Viewer

The proportion of decedents who had documented an Advance Health Directive or Enduring Power of Attorney did not change significantly across the intervention (p >.05). However, there was a statistically significant increase in the number of Statement of Choices completed (chi-square = 10.96, df = 1, p < .05), and a significant reduction in the number of Other forms of ACP documentation (chi-square = 6.08, df = 1, p <.05).

The expansion of ACP activity was supported by facility-level interventions: comparisons of managers' responses in the pre- and post-intervention organisational policies and structures audits show statistically significant increases in ACP related activities (see Table 5). For all items in Table 5, ratings could range from 1 to 5; for items 1 and 2, the associated endpoints were labelled 1 (not at all) and 5 (very comprehensive), and for items 3-6, endpoint labels were 1 (strongly disagree) and 5 (strongly agree).

Table 5: Managers' ratings on pre- and post-intervention organisational policies and structures audits

Item	Pre-Intervention Mean (SD) N=24	Post-Intervention Mean (SD) N=20	95% Confidence Interval for the mean difference
*1. Our facility has in-service education for nursing and care staff about ACP	2.17 (1.05)	2.95 (0.95)	0.17-1.40
*2. Our facility has educational materials available for resident/families to inform them about ACP and its benefits	2.50 (1.06)	3.65 (0.93)	0.54-1.77
*3. ACP is routinely discussed at an appropriate time, when an individual moves into our facility	3.29 (1.04)	4.15 (0.75)	0.30-1.42
*4. Each resident, who has agreed to engage in ACP, has an advance care plan filed in a specific area of their chart	3.29 (1.08)	3.95 (0.95)	0.03-1.21

*5. Mechanisms have been established by our facility for transferring residents' advance care plans from residential aged care to hospital	3.58 (1.14)	4.20 (0.70)	0.03-1.21
*6. Residents' deaths are reviewed by our facility to assess if a resident's ACP preferences were met	2.96 (1.40)	4.15 (0.75)	0.49-1.89

* Difference between pre- and post-intervention mean is significant at .05 level in an independent samples t-test.

Further questions in the managers' audits related to use of an ACP template for residents. Pre-intervention 21/24 (87.5%) managers reported that their facility had an advance care plan template for residents, but post-intervention, that figure reduced to 14/20 (70.0%). This change is not in the intended direction, nor is it statistically significant (chi-square = 2.05, p = .15). Within that template, changes in items relevant to ACP were tracked (with ratings from 1 [strongly disagree] to 5 [strongly agree]), and are reported in Table 6.

Table 6: Content of facility ACP templates for residents

Our facility's ACP template includes:	Pre-Intervention Mean (SD) N=21	Post-Intervention Mean (SD) N=14	95% Confidence Interval for the mean difference
1. establishing and documenting the goals of care for each resident	3.48 (1.08	4.07 (0.73)	-.08-1.27
*2. potential to regularly review the resident's changes in preference with regard to future health care	3.43 (0.93)	4.14 (0.77)	0.11-1.32
3. potential to regularly review the resident's preferences with regard to life sustaining or prolonging treatments	3.38 (0.97)	3.93 (0.92)	-0.12-1.22
*4. potential to regularly review the resident's preference with regard to preferred place of death	3.24 (1.14)	4.00 (0.78)	0.05-1.47

* Difference between pre- and post-intervention mean is significant at .05 level in an independent samples t-test.

All mean changes are in the intended direction, but in only two of the four items were the improvements statistically significant at the .05 level: the potential to review the resident's change in preference with regard to future health care and preferred place of death.

Secondary objectives

1. **Increased number of residents who died in their place of choice, as documented in their advance care plan**

An important intended outcome of the intervention was an increase in the number of residents who died in their place of choice as documented in their advance care plan. Of all audited deaths, both the preferred and actual place of death were recorded for 201 residents. Pre-intervention 86.5% (N=96/111) of residents died in their preferred environment of care, and post-intervention 83.3% (N=75/90) were able to do so. This change is not statistically significant (chi-square =0.39, df = 1, p=0.53), nor is it in the intended direction. These outcomes are presented in terms of concordance between preferred and actual place of death (see Table 7).

Table 7: Concordance between residents' preferred and actual places of death.

	Pre-Intervention % (N = 111)	Post-Intervention % (N = 90)	Total % (N)
Actual and preferred place of death concordant	86.5% (96)	83.3% (75)	85.1% (171)
Actual and preferred place of death differ	13.5% (15)	26.7% (15)	14.9% (30)

Tables 8A and 8B show the documented preferred and actual places of death, pre- and post-intervention.

Table 8A: Residents' documented preferred place of death, pre- and post-intervention.

Preferred Place of Death	Pre-Intervention % (N = 111)	Post-Intervention % (N = 90)	Total % (N)
RACF	96.4% (107)	94.4% (85)	95.5% (192)
Hospital	3.6% (4)	5.6% (5)	4.5% (9)

Table 8B: Residents' actual place of death, pre- and post- intervention.

Actual Place of Death	Pre-Intervention % (N = 111)	Post-Intervention % (N = 90)	Total % (N)
RACF	82.9% (92)	80.0% (72)	81.6% (164)
Hospital	17.1% (19)	20.0% (18)	18.4% (37)

As can be seen from the tables above, most decedents had expressed a preference to die in their RACF, though a small proportion wanted to die in hospital. These preferences remained stable over the intervention (i.e. there was no significant change in preferences from pre- to post-intervention, chi-square = 0.44, df = 1, p = 0.51).

The actual places of death did not differ significantly pre- to post-intervention with more residents dying in hospital than had requested (chi-square = 0.28, df = 1, p = 0.60). The actual place of death was RACF for 81.6% of documented cases, with 18.4% of deaths taking place in hospital.

2. Reduction in the number of avoidable hospital transfers in the last week of life

Another important intended outcome of the intervention was that there would be a reduction in the number of avoidable hospital transfers in the last week of a resident's life. For this analysis an avoidable hospital transfer was considered to have occurred if the resident's death was expected, prior to transfer. During the audit periods, there were 173 expected deaths, 98 pre-intervention and 75 during post-intervention. In the pre-intervention period, 29.6% (N= 29) were transferred to hospital in the final week of life, and 28.0% (N= 21) were transferred in the post-intervention period. This difference is not statistically significant (chi-square =.05, df = 1, p = 0.82).

For 46 residents who were transferred to hospital in the last week of life, length of hospital stay was documented. Results are shown in Table 9.

Table 9: Documented length of hospital stay for residents transferred to hospital in the final week of life.

Length of stay	Pre-intervention (N=25)	Post-intervention (N= 21)
Seen in Accident and Emergency but not admitted	3	0
1 - 3 days	14	6
Greater than 3 days	8	15

These lengths of stay were analysed according to whether the resident's length of stay was three days or less or greater than three days (Table 10). It was assumed that a longer length of stay indicated that the resident was experiencing a complex condition that could not be managed in the RACF.

Table 10: Length of hospital stay for residents transferred to hospital in the final week of life.

Length of hospital stay	Pre-intervention % (N=25)	Post-intervention % (N=21)
3 days or fewer	68.0% (17)	28.6% (6)
More than 3 days	32.0% (8)	71.4% (15)

Length of hospital stays differed significantly across pre- and post-intervention (chi-square = 7.10, df = 1, p <.05). Post-intervention, there were fewer short stays of three days or less, and more longer stays of greater than three days.

The principal reasons that residents were transferred to hospital in their last week of life are listed in Table 11.

Table 11: Principal reasons for transfer to hospital in last week of life. (More than one reason could be recorded)

Principal Reason for Transfer	Pre-Intervention (N)	Post-Intervention (N)
Symptom Management	6	7
Sudden, unexpected deterioration or event	12	9
Following a fall	3	0
Request of resident and/or family	5	6
Request of GP	5	3
Other	1	2

3. Reported high level of consumer satisfaction with advance care planning discussions

It was considered essential to gauge resident/family or SDM satisfaction with the process of nurse-initiated ACP discussions within the RACF. Disappointingly, only two residents and eight SDMs (seven of whom were family to the resident) volunteered to complete surveys about their satisfaction with the process. Given the small number of respondents and lack of a comparator group, no statistical analysis was attempted.

Of the target residents, six were more than 80 years of age, and four were aged 70-79 years. In no case was the resident's health reported as good, but six were neither good nor poor, and four were poor. One resident had not been admitted to hospital in the previous 12 months, seven had been one or two times, and two had had three or more admissions.

Responses to the survey are shown in Table 12. High levels of satisfaction with the ACP discussions are shown in the responses.

Table 12: Resident and Substitute Decision Maker reactions to ACP discussions[#]

Statement	Disagree	Uncertain	Agree
Fitting to be approached while in the RACF to hear about ACP			100%
Would have preferred to hear about ACP before moving into RACF	10%	30%	60%
Satisfied with the way the nurse introduced the topic of ACP		20%	80%
The nurse who spoke about ACP cared about me			100%
I got all the information I wanted about ACP		10%	90%
Prefer to have ACP discussions with GP rather than facility nurse*	30%		60%
Hearing about ACP was confronting for me*	60%		30%
Hearing about ACP was a relief for me		10%	90%
Overall satisfied with experience of ACP			100%

[#] Responses were recorded on a 6 point scale from strongly disagree to strongly agree. For purposes of clarity of reporting, the responses were reclassified into 3 categories: disagree (= strongly disagree and disagree), uncertain (=somewhat disagree and somewhat agree), and agree (=agree and strongly agree). Although based on small N (maximum 10 cases), results are reported as percentages for ease of detecting patterns.

* One respondent did not answer

For three of the statements, all respondents agreed, i.e. that it was fitting to hear about ACP in the RACF, that the nurse cared about the resident, and that overall they were satisfied with the experience of ACP.

At least 80% agreed that they were satisfied with the way the nurse introduced the topic, that they got all the information they wanted about ACP, and that hearing about ACP was a relief to them.

There was less overall agreement in some other items: whether respondents would have preferred to hear about ACP before entering the RACF, to deal with the resident's GP rather than the facility nurse, and whether they found the topic confronting. These items were included to canvass the range of resident and SDM opinions on ACP and when they considered it appropriate to learn about it.

Respondents realised the importance and benefits of ACP after the discussion with the nurse, and most indicated that they planned to complete an ACP document (see Table 13).

Table 13: Resident/family/SDM perceived importance and benefits of ACP

Statement	Disagree	Uncertain	Agree
The discussion convinced me of the importance of ACP		10%	90%
The discussion motivated me to talk to my family about ACP		20%	80%
Since hearing about the benefits of ACP, I plan to complete one*		10%	80%

* One respondent did not answer

Before the ACP discussion, residents/family members or their SDM revealed some awareness of issues and processes related to their future care. Responses to relevant statements are shown in Table 14.

Table 14: Residents' future care arrangements prior to the ACP discussion in the RACF.

Statement	Total % Yes
Had talked about choices for future health care	60%
Was aware of ACP	70%
Had formally appointed an Enduring Power of Attorney for Health	100%
Had informally chosen a person to make future health decisions	100%
Had already completed an Advance Health Directive	20%

The majority of residents had talked about future health care, were aware of ACP, had appointed an Enduring Power of Attorney for Health, and informally chosen a person to make future health decisions, but only 20% had already completed an Advance Health Directive.

In summary, the ACP discussions were well received by residents in the RACFs, who reported that it was appropriate that the issue be raised in the facility, were relieved to learn about ACP and expressed high levels of satisfaction with their ACP experience.

4. Improved health professionals' knowledge, confidence and skills regarding advance care planning

Pre-intervention, 50 ACP champions returned surveys, and post-intervention 35 surveys were returned. A snapshot of the context can be seen in the pre-intervention information: 94% were RNs or ENs, 92% worked in facilities with at least 50 residents, 90% had worked there for more than one year, and for 92% their clinical role in caring for residents accounted for more than 50% of their job.

The survey assessed rated knowledge about ACP technicalities, skill in discussing ACP with residents, family and other staff, and confidence in applying their knowledge and skills. Pre- and post-education ratings to specific items are shown in Table 15. Changes in ratings from pre- to post-intervention were assessed with independent samples t-tests.

Table 15: ACP champions rated knowledge, skill and confidence pertaining to ACP activities, pre- and post-intervention#.

Item	Pre-Intervention Mean (SD) N = 50	Post-Intervention Mean (SD) N = 35	95% Confidence Interval for the mean difference
Rated **Knowledge** of:			
*Advance Care Planning	2.55 (1.12)	3.86 (0.65)	0.89-1.73
*Laws related to ACP in QLD	1.86 (1.29)	3.63 (0.60)	1.30-2.24
*Steps involved in getting a Statement of Choices uploaded to The Viewer	3.29 (1.04)	4.15 (0.75)	1.61-2.65
*Accessing additional resources about ACP	1.88 (1.41)	4.00 (0.73)	1.60-2.64
Rated **Skill** in:			
*Introducing discussions about the benefits of ACP with residents and/or family	2.38 (1.34)	4.06 (0.64)	1.19-2.16
*Teaching other RACF staff about the benefits of ACP	2.18 (1.47)	3.94 (0.68)	1.23-2.29
*Explaining differences between ACP documents used in QLD	1.48 (1.37)	3.80 (0.76)	1.81-2.83
Rated **Confidence** in			
*Recognising the appropriate time to introduce discussions about ACP	2.56 (1.37)	4.06 (0.68)	1.00-2.00
*Approaching the resident's GP to complete the resident's advance care plan	2.96 (1.44)	4.34 (0.73)	0.86-1.91
*Teaching other facility staff about the benefits of ACP	2.50 (1.37)	4.21 (0.69)	1.20-2.21

* Difference between pre- and post-intervention mean is significant at .05 level in an independent samples t-test.

Ratings could range from 0 to 5, where 0 indicated no knowledge, skill or confidence, and 5 indicated high levels of same.

For all items the benefits of the education sessions are apparent, with statistically significant increases in rated knowledge, skill and confidence in all assessed aspects of ACP.

The agreement of ACP champions that ACP is important did not change significantly from pre- to post-intervention, as it was already high (4.88 pre-intervention on a scale from 0-5). The post-intervention mean of 4.91 did not differ significantly from the pre-intervention mean (p>0.05).

Palliative Approach Link Nurse Project

Primary objective

The primary objective of the PALN project, to improve the knowledge, confidence and skills of aged-care staff concerning end-of-life care, was achieved.

This was evidenced primarily through the palliative approach link nurses' survey responses that were returned by 17 nurses pre- and 11 nurses post-intervention.

Contextual information gained from the pre-intervention survey indicates that 70.6% (12/17) of the nurses worked in facilities with more than 100 residents, and the rest in facilities with fewer than 100 residents. Eighty-two percent (14/17) had worked in RACFs for at least one year, and their clinical role accounted for more than 50% of their duties.

The survey assessed rated knowledge about elements of end-of-life care, skill in end-of-life communications with fellow staff, residents and families, and other professionals; provision of symptom management, use of a terminal care pathway, and confidence in communicating with families, residents, and their GP. Pre- and post-intervention education ratings for specific items are shown in Tables 16 A, B and C. Changes in ratings from pre- to post-intervention were assessed with independent samples t-tests.

Table 16A: Palliative Approach Link Nurse rated knowledge pertaining to a palliative approach to care, pre- and post-intervention#.

Item	**Pre-Intervention Mean (SD) N = 17**	**Post-Intervention Mean (SD) N = 11**	**95% Confidence Interval for the mean difference**
Rated **Knowledge** of:			
*End-of-life terminal care framework	2.18 (1.29)	4.00 (0.45)	0.99-2.66
*Advance Care Planning	2.35 (1.32)	4.09 (0.54)	0.87-2.60
*Elements and value of a palliative care case conference	1.88 (1.50)	4.00 (0.63)	1.13-3.10
*Criteria for commencing an end-of-life (terminal) care pathway	2.41 (1.23)	4.09 (0.70)	0.84-2.52
*Symptom management consistent with a palliative approach	2.41 (1.23)	4.18 (0.41)	0.98-2.56
*Accessing resources about a palliative approach to care	2.06 (1.39)	4.36 (0.67)	1.38-3.23

* Difference between pre- and post-intervention mean is significant at .05 level in an independent samples t-test.

Ratings could range from 0 to 5, where 0 indicated no knowledge and 5 indicated high levels.

The intervention was successful in increasing nurses’ knowledge of a palliative approach to care in RACFs; for all items there was a statistically significant increase in rated knowledge.

Table 16B: Palliative Approach Link Nurse rated skill in activities pertaining to a palliative approach to care, pre- and post-intervention#.

Item	**Pre-Intervention Mean (SD) N = 17**	**Post-Intervention Mean (SD) N = 11**	**95% Confidence Interval for the mean difference**
Rated **Skill** in:			
*Introducing discussions about a palliative approach to care with residents and families	1.94 (1.44)	4.18 (0.60)	1.30-3.18
*Introducing ACP discussions with residents and families	1.94 (1.35)	4.09 (0.54)	1.27-3.03
*Coordinating and participating in a palliative care case conference	1.76 (1.44)	3.91 (0.54)	1.21-3.08

*Providing evidence-based symptom management consistent with a palliative approach	2.35 (1.27)	4.00 (0.45)	0.82-2.47
*Providing evidence-based terminal care guided by an end-of-life (terminal) care pathway	2.24 (1.48)	4.09 (0.54)	0.89-2.82
*Teaching other RACF staff about the value of a palliative approach to care	1.82 (1.47)	4.00 (0.63)	1.21-3.14
*Providing appropriate referrals to the specialist palliative care service	2.00 (1.50)	3.91 (0.70)	0.91-2.91

* Difference between pre- and post-intervention mean is significant at .05 level in an independent samples t-test.

Ratings could range from 0 to 5, where 0 indicated no ability and 5 indicated high ability.

The intervention was successful in increasing nurses' skills regarding a palliative approach to care in RACFs; for all items there was a statistically significant increase in rated skill.

Table 16C: Palliative Approach Link Nurse rated confidence in activities pertaining to a palliative approach to care, pre- and post-intervention#.

Item	**Pre-Intervention Mean (SD) N = 17**	**Post-Intervention Mean (SD) N = 11**	**95% Confidence Interval for the mean difference**
Rated **Confidence** in:			
*Initiating end-of-life discussions in response to cues from residents and families	2.00 (1.46)	4.18 (0.75)	1.20-3.16
*Approaching colleagues to change the focus of care for a resident after recognising that the resident's condition has changed	2.53 (1.18)	4.18 (0.75)	0.83-2.48
*Initiating a conversation with the GP to consider commencement of an end-of-life (terminal) care pathway	2.35 (1.50)	4.27 (0.65)	0.93-2.91
*Initiating a conversation with the GP to complete the resident's advance care plan	2.35 (1.41)	4.09 (0.70)	0.79-2.68

* Difference between pre- and post-intervention mean is significant at .05 level in an independent samples t-test.

Ratings could range from 0 to 5, where 0 indicated not confident and 5 indicated very confident.

The intervention was successful in increasing nurses' confidence in providing a palliative approach to care in RACFs; for all items there was a statistically significant increase in rated confidence.

The agreement of palliative approach link nurses that a palliative approach is important in providing continuing high-quality care for residents and their families did not change significantly from pre- to post-intervention, as it was already high (4.56 pre-intervention on a scale from 0-5). The post-intervention mean of 4.91 did not differ significantly from the pre-intervention mean (p>0.05).

Clinical nurse improvements in knowledge, skills and confidence regarding a palliative approach to care were paralleled with improvements in some relevant facility-level practices. Ten managers returned a pre-intervention organisational policies and structures audit, and seven returned a post-intervention audit. Reported audit items were subsumed under three broad headings: a) existence of relevant service-level policies and procedures, b) service-level education initiatives, c) use of advance care planning templates and processes. Results are reported in Tables 17 A, B and C, where ratings were on a scale of 1 (strongly disagree) to 5 (strongly agree). Note that the numbers of managers submitting an organisational policies and procedures audit was small, particularly at post-intervention, reducing the likelihood of statistically significant changes.

Table 17A: PALN project audit of organisational policies and structures: service-level policies and procedures

Item	Pre-Intervention Mean (SD) N = 10	Post-Intervention Mean (SD) N = 7	95% Confidence Interval for the mean difference
*Our facility has a written statement of the principles or policy regarding care of residents requiring a palliative approach	3.40 (1.17)	4.83 (0.41)	0.36-2.51
Our facility has a palliative care working party responsible for promoting and facilitating a palliative approach	3.00 (1.76)	4.14 (1.46)	-0.59-2.88
Our facility has specific policies/guidelines or protocols for:			
• Identifying when a resident requires a palliative approach	3.30 (1.42)	4.43 (0.79)	-0.14-2.40
• Assessing and managing pain	3.80 (1.14)	4.57 (0.55)	-0.22-1.76
• Assessing and managing shortness of breath or dyspnoea	3.70 (1.25)	4.57 (0.54)	-0.21-1.95
• Assessing and managing oral health	3.80 (1.14)	4.57 (0.55)	-0.22-1.76
• Arranging for specialist palliative care review when appropriate	3.60 (1.51)	4.43 (0.79)	-0.50-2.16
• *Palliative care case conferences	3.30 (1.16)	4.57 (0.54)	0.26-2.28
• Terminal care (last weeks or days of life)	3.80 (1.14)	4.71 (0.49)	-0.07-1.89
*Our facility has educational materials available for residents/families on decision-making and care for those requiring a palliative approach and/or terminal care	2.70 (1.16)	4.57 (0.55)	0.86-2.88
Quality assurance mechanisms have been established for:			
• Monitoring the outcomes for palliative care case conferences	3.30 (1.16)	3.86 (1.07)	-0.62-1.74
• Monitoring the outcomes related to the use of end-of-life care pathways	3.30 (1.06)	4.29 (0.95)	-0.08-2.05
• Transferring residents' ACP documentation across settings from RACF to hospital	3.30 (1.25)	4.43 (0.79)	-0.02-2.27
Residents' deaths are reviewed to assess quality of care at the end of life (e.g. after-death audit)	2.70 (1.49)	3.86 (1.57)	-0.45-2.76

* Difference between pre- and post-intervention mean is significant at .05 level in an independent samples t-test.

For facility-level policies and procedures, all the differences from pre- to post-intervention are in the intended direction, i.e. increased agreement that these policies and procedures are available in the manager's RACF. However, the only increases that reached statistical significance were the presence of a written statement of the policy regarding care of residents requiring a palliative approach, protocols for conducting palliative care case conferences, and availability of educational materials for residents and families concerning terminal care.

Table 17B: PALN project audit of organisational policies and structures: service-level education initiatives

Item	Pre-Intervention Mean (SD) N = 10	Post-Intervention Mean (SD) N = 7	95% Confidence Interval for the mean difference
Our facility has a staff member(s) responsible for promoting and facilitating a palliative approach	2.60 (1.71)	4.14 (1.46)	-0.16-3.24
Ongoing in-service education for nursing and care staff (RN/EN/care worker) includes:			
• *Basic knowledge of legal and other regulations pertaining to ACP	2.70 (1.42)	4.29 (0.76)	0.33-2.84
• *Communication skills for understanding and supporting dying residents and their families (e.g. conducting a palliative care case conference);	3.20 (1.40)	4.43 (0.54)	0.03-2.42
For residents requiring a palliative approach:			
• *Pain assessment and management	3.40 (1.50)	4.71 (0.49)	0.05-2.58
• Assessment of symptoms, other than pain (e.g. shortness of breath, delirium)	3.30 (1.42)	4.29 (0.76)	-0.27-2.24
• *Issues related to nutrition and hydration (e.g. dysphagia, benefits and risks of feeding tubes)	3.30 (1.42)	4.83 (0.41)	0.25-2.82
• *Issues related to oral care	3.60 (1.27)	4.86 (0.38)	0.20-2.32
• *Utilising an end-of-life care pathway	3.50 (1.27)	4.86 (0.38)	0.29-2.42
• *Cultural, religious and spiritual beliefs and preferences related to end-of-life care.	3.60 (1.08)	4.57 (0.54)	0.02-1.92
• *Bereavement care for staff and families	2.50 (1.08)	4.14 (0.69)	0.65-2.63

* Difference between pre- and post-intervention mean is significant at .05 level in an independent samples t-test.

Post-intervention all facility-level education initiatives had changed in the intended direction, that is there was an increased level of agreement that they were available within the facility, but due to the small sample size not all reached statistical significance. Those that reached statistical significance related to basic knowledge of legislative requirements for ACP, communication skills for understanding and supporting dying residents and their families, utilising an end-of-life care pathway, cultural, religious and spiritual beliefs and preferences related to end-of-life care, and bereavement care for staff and families. Issues of symptom control for patients requiring a palliative approach also demonstrated significant increases in in-service education, namely pain assessment and management, and issues related to nutrition, hydration and oral care.

Table 17C: PALN project audit of organisational policies and structures: advance care planning templates and processes

Item	Pre-Intervention Mean (SD) N = 10	Post-Intervention Mean (SD) N = 5	95% Confidence Interval for the mean difference
Our facility's current advance care plan template and advance care planning process includes:			
• Establishing and documenting the goals of care for each resident, consistent with a resident's personal preferences or values	4.10 (0.88)	4.80 (0.45)	-0.21-1.61
• Potential to regularly review the resident's changes in preference with regard to future health care	3.90 (0.88)	4.60 (0.55)	-0.23-1.63
• Potential to regularly review the resident's preferences with regard to life sustaining or prolonging treatments	3.90 (0.74)	4.60 (0.55)	-0.11-1.51
• *Potential to regularly review the resident's preference with regard to preferred place of death	3.60 (1.08)	5.00 (0.00)	0.34-2.46

* Difference between pre- and post-intervention mean is significant at .05 level in an independent samples t-test.

Not all managers reported the presence of an advance care planning template for residents. Post-intervention questions about the contents of ACP templates and ACP processes are based on five managers' audits, further reducing the sample size for these items. For all four items changes in mean levels of agreement that the item is part of the template or processes were in the intended direction, but only one was statistically significant: the potential to regularly review the resident's preference with regard to preferred place of death.

Secondary objectives

1. Increase the number of residents who have a palliative care case conference conducted within the last six months of life

Of the 125 deaths in the pre-intervention phase, 46.4% (N=58) of residents had had a palliative case conference within the last six months of life. The corresponding figure post-intervention was 68.0% (N=70). This increase in palliative care case conference activity was statistically significant (chi-square = 10.66, df = 1, p = 0.001) (see Table 18).

Table 18: Palliative care case conferences conducted within last six months of life, pre- and post-intervention

Pre-Intervention (N=125)	Post-Intervention (N=103[#])	Total (N=228)
46.4% (N=58)	68.0% (N=70)	56.1% (N=128)

[#] Post-intervention one decedent after death audit was missing information on whether or not a palliative care case conference had been conducted.

2. Increase the number of residents who have an end-of-life (terminal) care pathway (EoLCP) commenced

Data analysis regarding commencement of an EoLCP was subject to exclusion criteria because evaluation of this intervention only relates to care received in a resident's RACF and commencement of an EoLCP is only relevant if a resident's death is expected. For these reasons, deaths that occurred in hospital and those deaths that were unexpected were excluded from the analysis.

Consequently, deaths included in this analysis relate to those decedents for whom commencement of an EoLCP would be considered appropriate, i.e. the resident's death was expected, and it occurred in their RACF. Relevant results are shown in Table 19.

Table 19: Information regarding the commencement of an end-of-life care pathway.

	Pre-Intervention (N = 125)	**Post-Intervention (N=104)**
Excluded deaths (unexpected deaths and deaths in hospital)	*43*	*42*
Included deaths for which commencement of an EoLCP would have been appropriate (expected deaths in RACF)	82	62
Included deaths where an EoLCP was commenced	65	55
% included deaths where an EoLCP was commenced	79.3%	88.7%

The data show that there was an increased proportion (9.4%) of residents who were commenced appropriately on EoLCP. Certainly this change is in the intended direction but when tested in a chi-square test of independence; the result was not statistically significant (chi-square = 2.27, df = 1, p = 0.13).

3. Increase in the number of residents whose ACP choices were considered at end of life

It was expected that for residents who had documented advance care plans that their end-of-life preferences would have been considered as they approached death. In total 185 residents (101 at pre-intervention and 84 at post-intervention) had both their ACP preferences recorded and a record of whether or not their preferences had been considered at end of life. At pre-intervention, in 81.2% of cases (N=82) there was documented evidence that ACP choices had been considered, and at post-intervention, documented evidence that ACP choices had been considered was reported in 82.1% of cases (N=69). This is not statistically significant (chi-square = 0.03, df = 1, p = 0.87).

4. Reduction in the number of avoidable hospital transfers in the last week of a resident's life.

This objective, common to both projects, was considered in the ACP project evaluation.

Resources, Education and Events Programme

All seven objectives of this programme were achieved. Outcomes, many of which have already been reported, can be summarised as:

- Uploaded examples of ACP and Palliative Approach Policy and Procedures documents available, via www.EoLcareRACF.com.au for use by RACF managers
- All palliative approach link nurses experienced PEPA placements with MSPCS
- All ACP champions attended an ACP workshop
- The website www.EoLcareRACF.com.au launched with three educational modules and three Train-the-Trainer modules to encourage sustainability

- Two End-of-Life conferences targeted specifically to aged-care staff were convened and favourably received by aged-care staff (see Attachment 19)

- A blog, associated with the website, commenced to allow current communications between stakeholders and attracted 2,482 views

- Qstream ACP educational platform piloted.

For the purpose of improving future educational interventions, it was appropriate to ask clinicians to feedback their impressions of the usefulness of various aspects of the resources and educational items used in this intervention.

Post-intervention ACP champions were asked to rate, in terms of importance, how much each of the ACP resources and educational activities contributed to developing their knowledge, skills and confidence. (See Table 20).

Table 20: ACP champions' importance ratings of ACP resources and educational activities for development of knowledge, skills and confidence[#]. (Champions could rate more than one item)

Activity	Mean (SD)	N
Online education modules	4.40 (0.65)	35
ACP Workshop	4.65 (0.60)	34
ACP mentoring support activities:		
• Champion observes a mentor providing an ACP discussion with a resident	4.69 (0.54)	32
• Mentor feedback after observing a champion ACP discussion	4.60 (0.60)	20
• Educating others about ACP	4.52 (0.79)	29

[#] Scale ranged from 0 (not important) to 5 (extremely important).

From Table 20 it would appear that all items were equally important.

Similarly, post-intervention palliative approach link nurses were asked to rate, in terms of importance, how much each of the resources and educational activities contributed to their development of knowledge, skills and confidence. (See Table 21).

Table 21: Palliative Approach Link Nurse importance ratings of resources and educational activities for development of knowledge, skills and confidence.[#] (Nurses could rate more than one item)

Activity	Mean (SD)	N
Online education modules	4.55 (0.69)	11
Workshop	4.82 (0.41)	11
PEPA placement	4.82 (0.41)	11
Palliative approach mentoring peer support activities:		
• Peer support – palliative approach	5.00 (0.00)	8
• Peer support – ACP discussion	5.00 (0.00)	8
• Peer support – educating others	5.00 (0.00)	8

[#] Scale ranged from 0 (not important) to 5 (extremely important).

All resources and educational activities were rated highly, and the peer-support activities were unanimously rated as extremely important in the professional development processes.

Qstream pilot

Seventy percent (34/49) of ACP champions invited to sign up for Qstream participated in the trial. Automatically generated reports from Qstream indicated that participants took an average of four weeks to complete the Qstream set of 14 multiple choice questions. The set generated an overall increase in ACP knowledge of 11%.

4.0 Discussion

This initiative represents an on-going collaboration between BSPHN, MSPCS and volunteering RACFs to help deliver sustainable evidence-based end-of-life care for residents of RACFs.

The initiative demonstrates that, using a programme of ongoing education, training and professional development activities, motivated RACFs can implement processes associated with a framework of care that improves resident end-of-life care. The initiative focussed on the rollout of the three sentinel clinical processes contained within the MSH End-of-Life Care strategy – advance care planning, case conferencing and use of an end-of-life (terminal) care pathway. Important outcomes include: significant increases in the accessibility of resident advance care plans for treating clinicians, increased numbers of case conferences to ensure medical management plans are known and available when a resident invariably deteriorates as well as more appropriate admissions of residents transferred to hospital in their last week of life. These outcomes are impressive as they were obtained in a short period of time and are applicable to about 25% of eligible RACFs within the BSPHN and MSH catchment area. It is likely that with sustained efforts, the longer-term impact of this initiative would be that residents have access to patient-centred right care, at the right time and delivered in the environment of a resident’s choice. However, much more needs to be done.

While each intervention component or activity was independent, most overlapped with others and interacted in unquantifiable ways – for instance the PALN project nurses received education about ACP and the ACP champions completed the same after-death audits as the PALN sites. For ease of discussion of the impact of the entire intervention, evaluation findings are considered in relation to the three sentinel processes within the MSH End-of-Life Care Framework: ACP, palliative care case conferencing and use of an end-of-life (terminal) care pathway.

Advance Care Planning

ACP is the cornerstone of quality resident-centred end-of-life care and the first important clinical process within the End-of-Life Care Framework. For these reasons the initiative placed major emphasis on promoting a coordinated and systematic approach to ACP within participating RACFs.

Primary objective Advance Care Planning Project: to increase the number of advance care plans completed by residents and uploaded to the Queensland Health Viewer

During the ACP project there was a significant increase in the number of advance care plans completed by residents/substitute decision makers from participating RACFs and uploaded to the Queensland Health Viewer for accessibility by clinicians. The impact of this outcome is that more residents are having the opportunity to discuss their values and preferences thereby increasing the opportunity to receive care in alignment with their wishes.

Various facility-level mediations contributed to this outcome, such as development of policies and procedures for ACP, implementation of mechanisms for transferring ACP documents to hospitals, routine in-service ACP education and the existence of RACF educational materials available to residents and their important others to inform them about ACP and associated benefits. Post-intervention, however, there were still gaps in facility-level processes that could further support clinical ACP practice, particularly a systematised approach to establishing, documenting and reviewing a resident’s goals of care, in relation to their preferences for life-sustaining or life-prolonging treatments and transfer to hospital. Residents change their minds as their clinical situation evolves and it is important that documentation is updated to reflect these changes.

The significant increase in documents uploaded to The Viewer was accompanied by a non-significant increase (6.7%) in the number of advance care plans completed, as reported in the post-intervention after-death audits. The reason for this significance mismatch is that some uploaded documents related to residents still living at the time of completion of the after-death audit period.

Interestingly, post-intervention there was a significant increase in the number of SoCs completed, presumably at the expense of “other” less formal documents that cannot be uploaded to The Viewer. The SoC is particularly suited for use in Queensland RACFs because its structure facilitates a conversational approach to end-of-life decision-making where residents, or their proxy, can make known the person’s values, preferences and choices for care. Further, the SoC is the only Queensland-wide ACP document that specifically requests residents to nominate a preferred place of death. Such conversations and decisions are integral to ensuring that holistic end-of-life care is aligned with residents’ wishes and can guide resident-centred care.

Secondary objectives Advance Care Planning Project:

1. **Increased number of residents who died in their place of choice, as documented in their advance care plan**

2. **Reduction in the number of avoidable hospital transfers in the last week of life**

Two important ACP related objectives that were not realised during the project were an increase in the number of residents dying in their place of choice and reduction in the number of avoidable hospital transfers in the last week of a resident’s life. These outcomes require reflection.

Achieving a preferred place of death is considered a quality marker of palliative care[21]. To achieve that outcome there are two important pre-requisites; the person’s preferred place of death must be known and sufficient care must be available in that environment to avoid unwanted transfers to hospital. In participating RACFs the first pre-requisite was met; a clear majority of residents (95.5%) had documented that their preferred place of death was their RACF, though only about 82% achieved that outcome because others were transferred to hospital in their final week of life.

Reasons residents were transferred to hospital remained relatively constant across pre- and post-intervention periods and included a range of broad issues, principally symptom control and unexpected deterioration. These issues are fairly coarse and they were not explored in any depth in the after-death audits, so little can be said about why or what symptoms could not be managed in the RACF nor what constituted an unexpected deterioration. The amount of time that patients remained in hospital pre- and post-intervention differed. In the pre-intervention period some residents were not even admitted after transfer and most remained in hospital for less than three days, indicating that these transfers may have been avoidable had the required care been available in the facility. Post-intervention all residents transferred were admitted and their length of stay was significantly longer than pre-intervention residents indicating that the transfers were appropriate. This suggests that following the intervention RACF staff were able to appropriately identify which residents required more complex care than was available in their RACF. This is an important observation and a more granular investigation of why residents are transferred to hospital in their last week of life is required.

It is known that avoidable, or unwanted, hospitalisations result from a complex interplay of many factors such as inability to access medical practitioners when necessary, inadequate or unavailable facility care staff, lack of RACF staff training and education, uncertain prognostication, medical complexity of the resident’s condition and lack of understanding by residents and families of the consequences of hospitalisation of the frail elderly.[22]

Clearly, while documentation of a resident’s preferred place of end-of-life care is necessary it is not sufficient to guarantee resident-centred quality end-of-life care. Avoidable or unwanted hospitalisations cannot be overcome by addressing ACP alone, on the simplistic assumption that that component is causal and so will affect the system in a proportionally linear fashion. The clinical reality is much more complex.

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[21] Chapman M, et al. Avoiding costly hospitalisation at end of life: Findings from a specialist palliative care pilot in residential care for older adults. *BMJ Support Palliat Care*. 2018; 8:102-109. 10.1136/bmjspcare-2015-001071.

[22] Krones T, Budilivschi A, Karzig I, et al. Advance care planning for the severely ill in the hospital: a randomized trial. *BMJ Support Palliat Care*. Epub ahead of print. 2019;0:1-13. 10.1136/bmjspcare-2017-001489.

3. **Reported high level of consumer satisfaction with advance care planning discussions**

Disappointingly, only a few residents and their proxies volunteered to return ACP discussion satisfaction surveys. Nonetheless, responses were positive – residents and proxies thought it appropriate to discuss ACP in the RACF environment, thought that the nurse cared about the resident and that overall they were satisfied with their ACP experience. Clearly the nurses sensitive approach was effective as most reported that it had convinced them of the importance of ACP and that they intended to complete an ACP document.

4. **Improved health professionals' knowledge, confidence and skills regarding advance care planning**

On a clinical level, there were significant improvements in ACP champions' knowledge, skills and confidence across all aspects of ACP explored. ACP champions were able to initiate, within their scope of practice, sensitive ACP discussions.

Palliative Care Case Conferencing

A palliative care case conference, the second sentinel clinical process of the End-of-Life Care Framework, is appropriate when it is clinically timely to transition a resident's focus of care from curative or restorative to palliative in intent. It is the next step to ensuring patient-centred end-of-life care. A palliative care case conference translates a resident's advance care plan into medical treatment orders. It identifies the resident's goals of care and, importantly, matches those with specific medical escalations and limitations of active treatments (such as withholding cardiopulmonary resuscitation, de-prescribing or transfer to hospital).

Primary objective PALN project: to improve the knowledge, confidence and skills of aged-care staff concerning end-of-life care

The PALN project was successful in achieving significant increases in the knowledge, skills and confidence of nurses across all important areas of a palliative approach to end-of-life care, particularly those related to the value of case conferencing. Post-intervention nurses understood reasons for, and important elements of, a case conference, had the confidence to approach colleagues when they recognised that a resident's focus of care required change and had the skills to coordinate and participate in a palliative care case conference. They could discuss symptom management consistent with a palliative approach and were confident to initiate end-of-life discussions in response to cues from residents and families.

These outcomes were paralleled with facility-level improvements that supported nurses' case conferencing practice, though there were some post-intervention gaps, particularly relating to quality assurance mechanisms such as monitoring the outcomes of case conferences.

Secondary objectives PALN project:

1. **Increase in the number of residents who have a palliative care case conference conducted within the last six months of life**

Consequent to the education and mentoring undertaken by the palliative approach link nurses significantly more case conferences were held and management plans documented for residents in their last six months of life.

The impact of this outcome is that more residents, their significant others and their treating clinicians are "all on the same page" so that when the resident inevitably deteriorates everyone knows what care is required, according to the resident's wishes. Case conferencing avoids decision making in a crisis, saves distress and confusion and can impact favourably on relatives' grief.

2. **Increase in the number of residents who have an end-of-life (terminal) care pathway commenced**

When prognosis is limited to the last week or days of life, a shared documented terminal care plan, focussed on regular assessment of resident comfort and relief of carer/family distress, is the final important process to facilitate a good death[18,23,24]. Successful implementation of such pathways requires palliative care expertise, skills, compassion and the ability to proactively predict resident and family needs.

Consequent to the initiative nearly ten percent more residents, with a diagnosis of dying, were commenced on an end-of-life care pathway, though this trend was not significant. The impact of this outcome is that more residents are able to achieve a comfortable death and this can impact favourably on the grief of their important others[25,26,27].

3. **Increase in the number of residents whose ACP choices were considered at end of life**

Central to a palliative care approach philosophy is the principle of patient-centred care. It was surprising that post-intervention there was little increase in the number of residents with documented evidence that their ACP choices were considered at end of life. The reasons for this finding requires further exploration, but likely reflect the difficulty of translating education concerning evidence-based practice into clinical reality in the RACF setting.

A contributing factor may have been the inability to engage GPs in the intervention. Despite the work of BSPHN Area Account Managers, inviting all GP surgeries to receive medically-led lunch-time education about end-of-life care in RACFs, no surgeries responded. Lack of GP involvement is likely to have limited the effectiveness of the intervention. Engagement of GPs, or a substitute workforce, with end-of-life care in RACFs is a topic that requires further research[28].

Limitations of the initiative

The initiative was only one year long. Practically this time period was simply too short to develop resources and education, mentor staff, implement new facility-level and clinical practices and then accurately assess impact on resident care. This may have resulted in conservative measures of the project outcomes. Reasonably five years would be required to affect the necessary culture changes required of such a complicated intervention. Translation of any evidence-based practice into clinical care is known to be challenging and time consuming in all areas of medicine but given the fluctuating workforce for aged-care it maybe even more problematic.

The ability to generalise the findings of this intervention to other facilities within the BSPHN catchment area may be limited. The RACFs that volunteered for this intervention appear to be those already offering above average end-of-life care; many baseline facility-level measures of performance were high and participating RACF clinical staff already recognised the importance of ACP and a palliative approach to care as reflected in pre-intervention average ratings above 4.5 out of 5 for both the ACP and PALN

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[23] Forbat L, et al. Integrating specialist palliative care into residential care for older people: a stepped wedge trial (INSPIRED trial). *Final report*. Australian Catholic University. 2019.

[24] Forbat L, et al. Improving specialist palliative care in residential care for older people: a checklist to guide practice. *BMJ Support Palliat Care*. 2018; 8:347-353. 10.1136/bmjspcare-2017-001332.

[25] Rietjens JAC, Sudore RL, Connolly M, et al. Definition and recommendations for advance care planning: an international consensus supported by the European association for palliative care. *Lancet Oncol*. 2017; 18(9): e543-e551.

[26] Houben CHM, Spruit MA, Groenen MTJ, et al. Efficacy of advance care planning: a systematic review and meta-analysis. *J Am Med Dir Assoc*. 2014; 15(7):477-89.

[27] Detering KM, Hancock AD, Reade MC, et al. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ*. 2010; 340:c1345.

[28] Gilissen J, Pivodic L, Smets T, et al. Preconditions for successful advance care planning in nursing homes: a systematic review. *Int J Nurs Stud*. 2017; 66:47-59. Epub December 2016.

project nurses. Further, volunteering RACFs were only accepted if they were staffed all day with suitably qualified clinical nurses who had internet access.

Overall impact of the initiative

The primary objectives of both initiative projects were achieved as well as all objectives of the resources, education and events programme. Given the intensity of the staff up-skilling and the number and quality of resources produced, these outcomes are impressive. Taken together they will facilitate the longer term impact of providing resident-centred care, at the right time and in the environment of the residents' choice.

The initiative also demonstrates that much more needs to be done. At a facility-level, resident care would be advantaged with the embedding of quality improvement processes related to areas such as: development of protocols to identify when a patient requires a palliative approach to care, regular review of residents' preferences for future care, mechanisms to ensure that residents' end-of-life preferences are taken into account in clinical management plans and development of guidelines for assessing and managing symptoms other than pain. At a clinical level, routine review of after-death audits and monitoring of residents' outcomes would allow for iterative and sustainable improvements in care.

5.0 Recommendations

Ongoing commitment between BSPHN and MSH to improve end-of-life care for residents of RACFs will facilitate sustainable improvements in care for this vulnerable population.

Recommendations based on findings from this initiative include:

- BSPHN and MSPCS continue structured interventions that enhance the translation of evidence-based best end-of-life practice into clinical care delivery to promote aspects of sustainable high-quality end-of-life care for residents of RACFs and their significant others. This recommendation is in direct alignment with the jointly developed *Brisbane South Older Peoples's Health and Wellness Strategy, 2019-2024* and the MSH *What Matters to Bill and Betty Frail Older Person's* project, 2019

- Both BSPHN and MSH work to increase resident and clinician interest in ACP for RACF residents using an educational programme to raise awareness and understanding the benefits of ACP

- BSPHN and MSH develop a shared model of sustainable recurrent RACF staff education focussing on aspects of end-of-life care. Staff retention and turnover in aged-care is high[29] and a long-standing problem for the sector. Consequently, RACFs need ongoing access to education about end-of-life care for replacement staff. The model could incorporate the learning modalities rated as most important by the ACP and palliative approach link nurses (see Tables 20 and 21) as well as the Qstream platform

- MSPCS continue to develop sustainable resources for uploading to the web site www.EoLcareRACF.com.au

- BSPHN commission an in-depth study into why residents of RACFs within the BSPHN catchment area are transferred to hospital in the last week of life. Such a study will help to inform strategies that facilitate residents dying in their preferred environment of care.

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[29] Fildes D, Westera A, Masso M. *Evaluation of the Encouraging Better Practice in Aged Care (EBPAC) Initiative: Final Report*. Wollongong: Centre for Health Service Development, Australian Health Services Research Institute, University of Wollongong; 2015. 168 p.