Evaluation of 4CEHR and Living Well Dying Well

Final report

2 December 2014
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<tr>
<td>4CEHR</td>
<td>Cradle Coast Connected Care Electronic Health Record</td>
</tr>
<tr>
<td>Seven C's</td>
<td>Seven C’s of Care</td>
</tr>
<tr>
<td>ACAT</td>
<td>Aged Care Assessment Team</td>
</tr>
<tr>
<td>AHHA</td>
<td>Australian Healthcare and Hospitals Association</td>
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<tr>
<td>BAPC</td>
<td>Better Access to Palliative Care</td>
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<tr>
<td>BSPCC</td>
<td>Brisbane South Palliative Care Collaborative</td>
</tr>
<tr>
<td>CAP</td>
<td>Clinical Action Plan</td>
</tr>
<tr>
<td>CCMS</td>
<td>Collaborative Care Management Solution</td>
</tr>
<tr>
<td>COMPAC</td>
<td>Guidelines for a Palliative Approach for Aged Care in the Community Setting</td>
</tr>
<tr>
<td>Decision Assist</td>
<td>Specialist Palliative Care and Advance Care Planning Advisory Service</td>
</tr>
<tr>
<td>DHHS</td>
<td>Department of Health and Human Services</td>
</tr>
<tr>
<td>DoH</td>
<td>Department of Health</td>
</tr>
<tr>
<td>DoHA</td>
<td>Department of Health and Ageing</td>
</tr>
<tr>
<td>DPAG</td>
<td>Dignity, Preferences, Advance Care Directive, Goals of Care (LWDW approach to advance care planning)</td>
</tr>
<tr>
<td>DSS</td>
<td>Department of Social Services</td>
</tr>
<tr>
<td>EoLC</td>
<td>End of Life Care</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>GSF</td>
<td>Gold Standards Framework</td>
</tr>
<tr>
<td>Hotel Staff</td>
<td>Staff employed by a RACF to conduct hotel style services for residents</td>
</tr>
<tr>
<td>ICT</td>
<td>Information Communications Technology</td>
</tr>
<tr>
<td>IHI</td>
<td>Individual Healthcare Identifier</td>
</tr>
<tr>
<td>iPM</td>
<td>Tasmania’s hospital management information system</td>
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<td>LWDW</td>
<td>Living Well Dying Well</td>
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<tr>
<td>NeHTA</td>
<td>National E-Health Transition Authority</td>
</tr>
<tr>
<td>Abbr</td>
<td>Description</td>
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<tr>
<td>-------</td>
<td>--------------------------------------------------</td>
</tr>
<tr>
<td>NSW</td>
<td>New South Wales</td>
</tr>
<tr>
<td>NWAHS</td>
<td>North West Area Health Service (predecessor to THO-North West)</td>
</tr>
<tr>
<td>NZ</td>
<td>New Zealand</td>
</tr>
<tr>
<td>PCEHR</td>
<td>Personally Controlled Electronic Health Record</td>
</tr>
<tr>
<td>RAC EoLCP</td>
<td>Residential Aged Care End of Life Care Pathway</td>
</tr>
<tr>
<td>RACF</td>
<td>Residential Aged Care Facility</td>
</tr>
<tr>
<td>RACPA</td>
<td>Residential Aged Care Palliative Approach</td>
</tr>
<tr>
<td>RPC</td>
<td>Respecting Patient Choices</td>
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<tr>
<td>TAHPC</td>
<td>Tasmanian Association for Hospice and Palliative Care</td>
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<td>THAP</td>
<td>Tasmanian Health Assistance Package</td>
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<tr>
<td>THCI</td>
<td>Tasmanian Health Client Index</td>
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<tr>
<td>THO</td>
<td>Tasmanian Health Organisation</td>
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<tr>
<td>THO-North West</td>
<td>Tasmanian Health Organisation – North West</td>
</tr>
<tr>
<td>US</td>
<td>United States of America</td>
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1 Executive Summary

Grosvenor Management Consulting (Grosvenor) was engaged by Better Access to Palliative Care (BAPC) within the Department of Health and Human Services (DHHS) to conduct an evaluation of Living Well Dying Well (LWDW) and the Cradle Coast Connected Care Electronic Health Record (4CEHR) system. Both LWDW and 4CEHR were developed to improve the quality of end of life care and support/facilitate advance care planning within Residential Aged Care Facilities (RACFs) in North West Tasmania.

LWDW is an Australian adaption of the Gold Standards Framework (GSF) approach to advance care planning. The LWDW project aimed to adapt and utilise the GSF approach to implement person-centred advance care planning processes within Tasmanian RACFs. LWDW was piloted at five RACFs within North West Tasmania from late 2010 until early 2013.

The 4CEHR system was developed to pilot an electronic health record which would facilitate advance care planning. The 4CEHR system was piloted in conjunction with the LWDW project. Specifically, this system was designed to support the development and communication of advance care planning information between health care settings.

This evaluation was informed by a range of stakeholder consultations as well as extensive desktop research and analysis and sought to answer the following six Key Evaluation Questions (KEQ’s).

Is the LWDW the most appropriate approach to advanced care planning in aged care for application across Tasmania? (KEQ5)

Overall, stakeholders were positive about LWDW, and the participating RACFs have continued to incorporate elements of the approach into business as usual activities. Despite this, the evaluation identified a range of alternative approaches which are currently used within Tasmania and mainland Australia.

Analysis revealed that the nationally supported Residential Aged Care Palliative Approach (RACPA) to advance care planning is very similar to LWDW. There are a number of advantages supporting use of RACPA over LWDW:

- RACPA is supported as the national approach in Australia
- the RACPA tools and guidance are well developed, available online, and free of charge (LWDW requires a licence fee and the adapted tools are not well established)
- RACPA has broader reach in Tasmania and nationally. As of September 2014, 96 individuals from 44 Tasmanian RACFs had attended an RACPA workshop.
- there is ongoing support for the RACPA toolkit via the Department of Health’s Decision Assist program.

Combined these advantages support RACPA as a more appropriate approach for Tasmania.
What will it take to establish a sustainable LWDW program state-wide in Tasmania? (KEQ4)

A number of key strengths and learnings from the LWDW pilot were identified throughout the evaluation which could be used to inform the establishment of a state-wide advance care planning program. It is believed that these learnings would be relevant to the implementation of any advance care planning approach and should not be considered specific to LWDW.

Learnings included, but were not limited to:

- the importance of encouraging and supporting organisational change
- the importance of ensuring advance care planning outputs are recognised and accepted across health settings
- roll-out of the approach should be staggered by ‘hubs’ of relevant stakeholders within a geographical area, not setting type. These ‘hubs’ should include at least one RACF and all health providers servicing that RACF (for example, local GPs, pharmacies, ambulance services and hospitals)
- all health settings and professionals should be engaged throughout the development and implementation of the program
- the support of senior management within the participating organisations and all affected health care providers should be sought at the commencement of the project
- participants should be provided with clear expectations around the project, including required resources, costs and timeframes.

Does 4CEHR have the capacity to support the goals of LWDW in Tasmania? (KEQ2)

Note: In responding to this question, the evaluation also considered whether 4CEHR is the most appropriate system to support LWDW and advance care planning in Tasmania.

Due to the limited 4CEHR project timeframes extensive pilot testing was not undertaken. As a result, insufficient information is available to assess the suitability of the system to support LWDW within Tasmania. Since development, the 4CEHR system was not widely adopted by the participating RACFs and is not currently being used in Tasmania.

While 4CEHR was able to deliver on some of its project aims, a number of issues were encountered during development and implementation which limited the uptake and use of the system. A number of system limitations and barriers were identified during this evaluation which suggests that 4CEHR does not have the capacity to support the goals of LWDW. These limitations and barriers would need to be rectified prior to conducting any further pilot testing to assess the system’s suitability.

Should it be determined that 4CEHR does not have the capacity to support LWDW (or an alternative approach), a number of other options are available...
to support the communication of advance care planning information including: the use of common forms; future capability of the PCEHR (based on intended functionality) or use of the DHHS Connected Care Platform.

**Is 4CEHR consistent with the approach of LWDW? (KEQ1)**

While data collected as part of this evaluation suggested that 4CEHR is consistent with the approach of LWDW, further piloting would be required to validate and confirm this finding.

The system encompasses functionality which aligns with the LWDW approach such as coding, the use of diagnostic tools and the storage of enduring guardian and person responsible details. Despite this, a number of gaps were identified in 4CEHR’s coverage of the LWDW approach.

The evaluation also identified that it is not clear if 4CEHR would be suitable to support an LWDW approach which was adapted for different (non-RACF) healthcare settings.

**How does 4CEHR interface with the national program to implement a PCEHR? (KEQ3)**

While the 4CEHR system is technically capable of uploading information into the PCEHR, this functionality has not been enabled. Additionally, at the time of this evaluation, the PCEHR did not contain advance care plans. It is unknown when this functionality will be introduced into the PCEHR and what it will include.

**How can Tasmania move beyond trials and establish a state-wide program of coordinated communication for advance care planning? (KEQ6)**

With regard to the 4CEHR system, this evaluation identified that 4CEHR is not ready to proceed to a state-wide rollout. During this evaluation stakeholders identified:

- features and functionality required in a state-wide approach to advance care planning
- activities and actions which would be required to successfully implement a state-wide approach.

These actions focused on, but were not limited to; ensuring effective communication, stakeholder engagement, and seeking support and approval throughout the development and implementation of the approach. This was identified as being particularly important to ensure the specific requirements of the various health professionals are addressed and that the approach is appropriately supported.

As a range of State and Commonwealth initiatives are gaining traction and supporting advance care planning, the implementation a state-wide approach should also:

- take into account pre-existing programs and activities to avoid duplication and achieve sufficient integration
- address the acceptability of existing and alternative approaches within a state-wide model
- encourage and monitor uptake and implementation
- leverage any existing relevant training materials (particularly those approved under LWDW).

**Recommendations:**

It is recommended that DHHS:

1. Supports RACPA as the advance care planning approach for Tasmanian RACFs.

2. Considers investing in a supported implementation model for RACPA to embed and improve advance care planning in Tasmanian RACFs.

3. Ensures appropriate change management practices are utilised to support the state-wide implementation of RACPA (or another approach). Change management activities should focus upon ensuring organisational readiness for the change, and draw upon the strengths of LWDW in facilitating culture change and supporting on the ground implementation.

4. In order to ensure the ongoing sustainability of a state-wide approach, it is recommended that DHHS ensures the state-wide approach:
   - is practical and appropriate for the capabilities and limitations of each health care setting
   - is able to be supported from within the healthcare setting (ie. within the available resources)
   - educates each health settings about the support which is available, including from experts such as the Specialist Palliative Care Service.

   It is recommended that DHHS draws upon other projects such as Enhancing Aged Care through better Palliative Care and the GSF to inform how advance care planning can be implemented beyond RACFs, that is, in the community and other health settings.

5. Engages sufficiently with all health settings to overcome barriers to the recognition and use of advance care planning outputs across health settings.

6. Engages more broadly with health professionals to implement a system wide approach to advance care planning which includes the community and acute care settings. DHHS should ensure all stakeholders and health care settings are appropriately engaged and commit to the state-wide approach. Any engagement should be undertaken with clarity of purpose and requirements/commitments. In particular DHHS should engage:
• all relevant health professionals during the development and implementation of the approach to ensure that their unique needs are identified and appropriately addressed

• senior management within affected health organisations to seek endorsement of the implementation and ongoing use of the approach within their facility.

7. Identify any data collection requirements during implementation of the state-wide approach.

8. Implements a state-wide approach through a ‘hub’ model which concurrently targets cross sector health professionals in the same location at the same time as RACFs.

9. Considers how the hub-based implementation model can support the sharing of experiences and practices between providers in the same and across health settings to improve practices.

10. Integrates the roll-out of a state-wide advance care planning approach with the BAPC framework to simultaneously raise community awareness of advance care planning.

11. Targets those RACFs which have the greatest opportunity to improve under the approach. This should be assessed against their willingness to participate, quality of advance care planning and hospitalisation rate.

12. Considers the options for supporting communication of advance care directives in Tasmania and make a decision on the further investment in a 4CEHR pilot. In making this decision, DHHS should analyse the core functionality of the 4CEHR to determine whether it can be integrated into existing systems, including the Connected Care Platform.

If further investment in 4CEHR is supported:

• it should be integrated with relevant software and platforms

• it should be appropriately named in a descriptive manner and have state-wide relevance (rather than a regional focus)

13. If further investment in 4CEHR is supported it is recommended that DHHS:

• review the existing content of 4CEHR and only retain that which is considered to be a ‘core’ requirement by stakeholders/users

• analyse the 4CEHR system to identify any duplication between its functionality/content and existing DHHS tools and materials

• provide appropriate linkages to existing DHHS materials within the system rather than further developing the 4CEHR specific content
• conduct a gap analysis to identify any omissions in the system’s ability to address the requirements of/support LWDW or the RACPA and determine whether the inclusion of this capability is required.

14. Actively seeks to avoid duplication and achieve integration with other State and Commonwealth approaches to advance care planning through the state-wide approach.

15. Reviews the appropriateness of any approved LWDW training materials to the state-wide approach. If relevant and appropriate, DHHS should refine and utilise these materials to support state-wide implementation.

16. Monitors the uptake and implementation of the state-wide approach to advance care planning to ensure it has been consistently adopted across the various healthcare settings.
2 Introduction

2.1 Background

Living Well Dying Well (LWDW) and the Cradle Coast Connected Care Electronic Health Record (4CEHR) system were developed to improve the quality of end of life care within Residential Aged Care Facilities (RACFs) in North West Tasmania. The LWDW approach and 4CEHR system were piloted in five RACFs from late 2010 to early 2013.

The Australian Government has provided funding to government and non-government agencies throughout Tasmania for the implementation of the Better Access to Palliative Care Program (BAPC). This funding was provided as part of the Tasmanian Health Assistance Package (THAP).

As part of BAPC, the Department of Health and Human Services (DHHS) intend to develop a palliative care framework. This will include the development of a Healthy Dying Framework which will underpin improvements in the management of palliation and end of life care.

Grosvenor Management Consulting (Grosvenor) has been engaged by BAPC within DHHS to conduct an evaluation of the LWDW pilot and the 4CEHR system. This evaluation will inform the development and implementation of the Healthy Dying Framework.

2.2 Evaluation scope

This evaluation is focused upon understanding the successes and challenges of the LWDW and 4CEHR approach and implementation. Specifically, the evaluation seeks to answer the following six evaluation questions, identified by DHHS:

1. Is 4CEHR consistent with the approach of LWDW?
2. Does 4CEHR have the capacity to support the goals of LWDW in Tasmania?
3. How does 4CEHR interface with the national program to implement a PCEHR?
4. What will it take to establish a sustainable LWDW program state-wide in Tasmania?
5. Is the LWDW the most appropriate approach to advanced care planning in aged care for application across Tasmania?
6. How can Tasmania move beyond trials and establish a state-wide program of coordinated communication for advanced care planning?

2.3 Terminology

There is a range of terminology used in relation to end of life care and inconsistency in its use. The lack of consistency causes confusion and a lack
of clarity. These issues were still apparent among stakeholders consulted during the evaluation.

This was raised as a key issue in the 2011 National Framework for Advance Care Directives. The Framework recommended the adoption of the following lexicon nationally (Table 1). This report is consistent with the recommended lexicon.

**Table 1 National lexicon for Advance Care Directives**

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition / description</th>
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<tbody>
<tr>
<td>Advance Care Directive</td>
<td>ACDs [Advance Care Directives] are one way of formally recording an advance care plan. An ACD [Advance Care Directive] is a type of written advance care plan recognised by common law or authorised by legislation that is completed and signed by a competent adult. An ACD [Advance Care Directive] can record the person’s preferences for future care and appoint an SDM [substitute decision maker] to make decisions about health care and personal life management. ACDs [Advance Care Directives] are focused on the future care of a person not on the management of his or her assets.</td>
</tr>
<tr>
<td>Advance care planning</td>
<td>Advance care planning is a process of planning for future health and personal care whereby the person’s values, beliefs and preferences are made known so they can guide decision-making at a future time when that person cannot make or communicate his or her decisions. Formal advance care planning programs usually operate within a health, institutional or aged care setting after a life-limiting condition has been diagnosed, frequently requiring the assistance of trained professionals. However, people can choose to discuss their advance care plans in an informal family setting.</td>
</tr>
<tr>
<td>Advance care plan</td>
<td>An advance care planning discussion will often result in an advance care plan. Advance care plans state preferences about health and person care and preferred health outcomes. They may be made on the person’s behalf, and should be prepared from the person’s perspective to guide decisions about care. There are many ways of recording an advance care plan including oral and written versions.</td>
</tr>
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| Clinical care plan      | ACDs [Advance Care Directives] written by a person are distinct from clinical care or treatment plans written by health care professionals for a patient. Resuscitation plans, treatment plans and No CPR (cardiopulmonary

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<table>
<thead>
<tr>
<th>Term</th>
<th>Definition / description</th>
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<td>resuscitation) Orders are clinical care plans. A clinical care plan sets out treatment directions to be followed by health professionals in a medical or aged care facility. It is appropriate that clinical care plans be put in place whether or not the person has made an ACD [Advance Care Directive], but when there is an existing ACD [Advance Care Directive] that records directions about care, the clinical care plan complements, and therefore should be informed by, the person’s ACD [Advance Care Directive].</td>
<td></td>
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</table>
| Competence | Competence is a legal term used to describe the mental ability required for an adult to perform a specific task. Competence is recognised internationally and in common law as a requirement for completing a legal document that prescribes future actions and decisions, such as a will or an ACD [Advance Care Directive]. A person is deemed to be either competent or not competent to complete an ACD [Advance Care Directive]; there are no shades of grey. Competence must be assumed unless there is evidence to suggest otherwise. There must be evidence that the person completing an ACD [Advance Care Directive] was incompetent at the time the ACD [Advance Care Directive] was written before its terms can be ignored on those grounds.

A person is deemed to be either competent or not competent to complete an ACD [Advance Care Directive]; there are no shades of grey. Competence must be assumed unless there is evidence to suggest otherwise. There must be evidence that the person completing an ACD [Advance Care Directive] was incompetent at the time the ACD [Advance Care Directive] was written before its terms can be ignored on those grounds.

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Having the capacity to make a decision means the person has the ability to understand the information provided about his or her health condition, including options for treatment. It also means that the person has the ability to consider the possible choices in terms of his or her own personal values and preferences, make a decision, and communicate that decision.

Decision-making capacity is assessable, and its assessment depends on the type and complexity of the decision to be made. A person’s loss of decision-making capacity may be partial or temporary, and may fluctuate. Decision-making capacity should be assessed at the time a significant decision is required, in order to establish the person’s level of cognitive ability to make decisions (or to make a particular decision) about personal or health care matters.

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6 Ibid
3 Approach

Grosvenor conducted the evaluation using a six step approach, as depicted in the following methodology. Further detail about steps two to six is provided below.

**Figure 1 Methodology**

**Step 1** Establish project
- meet project team (PT) and key stakeholders
- confirm project objectives
- identify project risks and mitigations
- confirm:
  - approach
  - deliverables
  - timelines
  - responsibilities
- agree project management, reporting and communication protocols
- identify stakeholders and agree consultation expectations
- finalise and submit project plan

**Step 2** Review program material
- review program materials and relevant literature, e.g.: - policy objectives - agreements - plans/guidelines - 4C Clinical Repository Report - program statistics and reports - RCEHR
- obtain demo of 4CEHR system
- assess available quantitative data
- workshop Program Logic and identify and confirm program's:
  - policy objectives
  - inputs & outputs
  - activities
  - stakeholders
  - etc

**Step 3** Develop evaluation criteria and questions
- workshop evaluation criteria / questions to measure achievement of policy objectives and address other questions in brief
- identify potential data sources for each question including existing data that can be used
- identify gaps
- confirm qualitative data to be collected and source (target audience)
- determine best method for collecting qualitative data, eg:
  - surveys
  - semi-structured interviews
  - focus groups
  - document evaluation matrix (criteria, question data source and method of collection)
- test with PT

**Step 4** Collect data
- collect quantitative data (statistics)
- develop tools to collect qualitative information for evaluation criteria / questions:
  - survey instrument
  - semi-structured interview questionnaire
  - focus group run sheet
  - test with PT

**Step 5** Analyse results
- analyse results against each criteria / question
- identify themes, eg:
  - achievements
  - alignment and fit for purpose
  - enablers
  - issues and barriers
  - areas for further improvement
- implementation lessons learned
- identify improvements and lessons learned to improve future outcomes
- test with PT and follow up as required
- draft progress report
- conduct desktop research on alternate eHealth systems and approaches
- compare 4CEHR with alternatives for application across TAS:
  - functionality
  - best fit
  - alignment with RCEHR
  - potential cost
  - risk

**Step 6** Develop conclusions on future roll-out
- identify application of 4CEHR and LWDW learnings to BAPC, eg:
  - behaviour and change mgmt
  - system issues
  - changes to pilot approach
- finalise conclusions and recommendations
- test with PT

**Step 7** Prepare report
- draft writing plan and test with PT:
  - format
  - content
  - structure
  - draft report
    - executive summary
    - background
    - approach
    - findings (against each criteria)
    - conclusions (achievements, lessons learned)
    - recommendations (for wider roll-out)
  - attachments (evidence)
  - submit drafts for review
  - obtain feedback, update and finalise
  - present as required

3.1 Review program material

The Tasmanian Health Organisation – North West (THO-North West) project team made all existing documentation relevant to either 4CEHR or LWDW available to Grosvenor at the commencement of the evaluation. This data was used to inform Grosvenor’s understanding of the LWDW and 4CEHR approach and objectives.

A demonstration of the 4CEHR system was provided by the THO-North West Clinical Nurse who was involved in the systems development and implementation. This demonstration provided an overview of the systems functionality, capability and known issues.

Any gaps in the provided documentation were identified. Requests for additional documentation were made to the appropriate personnel within THO-North West as required.
3.2 Develop evaluation criteria and questions

The evaluation addressed six key evaluation questions as outlined in the original RFQ. Grosvenor analysed these questions to determine their appropriateness and to identify data requirements and potential data sources.

A workshop was held with the evaluation steering committee on 4 August 2014 to discuss and confirm:

- Grosvenor’s understanding of the LWDW and 4CEHR
- the evaluation questions
- data to be collected
- required data collection methods and activities.

3.3 Collect data

Data was collected through a range of stakeholder consultations and desktop. Specific data collection activities included:

- interviews and focus groups with key stakeholders
- survey of RACFs throughout Tasmania (RACF Survey)
- collection of documentation from the project team, stakeholders and online research.

Focus Groups

Focus Groups were conducted at four of the five Residential Aged Care Facilities which piloted the LWDW program and 4CEHR system. These focus groups involved key staff from each RACF who had been involved in the implementation and use of both LWDW and 4CEHR.

Interviews

A total of 22 interviews were conducted to inform the evaluation. This included a range of face to face and telephone interviews with stakeholders from the following groups:

- RACF residents
- families of existing and/or previous RACF residents
- DHHS and THO-North West (including IT, My Aged Care, Home and Community Care (HACC) and staff involved in 4CEHR and/or LWDW)
- Cradle Coast Authority
- Health Care Providers (including General Practitioners (GPs), RACF management and Community Nurses)
• UTAS personnel involved in LWDW, 4CEHR and/or palliative care research
• Tasmania Medicare Local (TML)
• Tasmanian Association for Hospice and Palliative Care (TAHPC).

Where individuals were unable to participate in an interview written feedback was requested. This was provided by two stakeholders from:
• Primary Health Services within TML
• Department of Health.

**Future stakeholders workshop**

Stakeholders who had not been directly involved in either 4CEHR or LWDW, but would be impacted by any state-wide changes to advance care planning were invited to attend a future stakeholders workshop. Three stakeholders participated in this workshop.

**Survey**

An online survey was distributed to all RACFs who are members of Aged and Community Services Tasmania (ACST). A total of 16 survey responses were received. A summary of the survey responses is included in Attachment A

**Desktop research**

Grosvenor undertook desktop research to identify additional information about the Tasmanian context and health care environment, 4CEHR and LWDW.

Full details of the consultations conducted to inform this evaluation are included in Attachment B.

**3.4 Analyse results**

All collected data was analysed against the six key evaluation questions to confirm the appropriateness of the collected information. This allowed gaps to be identified, informing the collection of additional data as required.

A series of key themes and findings were identified from the consultations and data collection activities. Initial themes and findings were documented in the project’s progress report. The progress report grouped the findings against:

• LWDW
• 4CEHR
• alternative models and approaches
• developing a state-wide approach.
Successes and barriers were identified for each theme.

3.5 Develop conclusions on future roll-out

Desktop research was undertaken to identify any alternative eHealth systems and approaches with a similar focus to the 4CEHR system. This research sought to identify both domestic and international systems.

The functionality of the identified systems was compared to 4CEHR to determine whether an alternative approach would be suitable in Tasmania.

Conclusions and recommendations for the evaluation were developed based on the analysis of the collected data and alternative systems and approaches. The conclusions are structured around the six key evaluation questions.

3.6 Evaluation limitations

A number of limitations were encountered during this evaluation which should be considered when reading/utilising this report.

Limited GP engagement

Despite efforts to engage GPs during the consultation period, feedback and input was only provided by a small number of GPs. This included feedback from GPs working in General Practice and those working in a hospital and other specialist healthcare settings. While the views expressed by these GPs have been used to inform this evaluation, they should not be considered as exhaustive or representative of all GPs.

Limited resident and family engagement

The four RACFs which were engaged as part of the consultation process were asked to identify current residents and/or the family members of residents who had been involved in the pilot to provide feedback.

Only one RACF was able to identify, and arrange for, consultations with residents and family members. This resulted in a lower number of consultations with these groups compared to what was originally planned. The RACFs noted that:

- the vast majority of residents who had been involved in the pilot had passed away
- there was limited (or no) ongoing engagement with the families of former residents.

Incomplete LWDW data

The available data and documentation about the LWDW program was often incomplete and/or in draft format. As a result, there were some gaps and inconsistencies in the available data and program information/tools. While every effort has been made to ensure that the LWDW information presented in this report is accurate, some inconsistencies or gaps may be present.
4 Structure of this report

This report is structured around the following key topics:

- current situation and context (Section 5)
- Living Well Dying Well (Section 6)
- 4CEHR system (Section 7)
- approaches to advance care planning (Section 8)
- ICT support for advance care planning (Section 9)
- a consistent approach for Tasmania (Section 10)
- conclusions and recommendations (Section 11).
5  Current situation and context

There are a range of contextual factors relating to Tasmania’s demographics and health care system which demonstrate the relevance and need for a focus on end of life care. Those consulted with also raised other situational and contextual issues which need to be addressed to facilitate dying well.

This section presents an overview of these issues and considerations.

5.1  Tasmania has an ageing population

The 2011 census identified that Tasmania has the oldest median age (40.4 years) of all Australian states and territories. The median age increased from 39 years in 2006 and is much higher than the 2011 Australian median age of 37 years.\(^7\)

The Tasmanian population has been ageing for some time. Between 2001 and 2011 the number of Tasmanians aged 65 years or above increased by 27%, while those aged 80 years or above increased by 35\(^8\).\(^8\)

In 2011, 16.3% (1 in 6) of the Tasmanian population were aged 65 years or over. Projections detailed by the Council of the Ageing in the report ‘Facing the Future’ suggest that the Tasmanian population will continue to age over the next few decades. The proportion of Tasmanians aged over 65 is projected to increase from 1 in 6 (2011) to 1 in 4 (2030).\(^9\)

Table 2 Proportion of the Tasmanian population aged 65 or above

<table>
<thead>
<tr>
<th></th>
<th>2011</th>
<th>2020</th>
<th>2030</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1 in 6</td>
<td>1 in 5</td>
<td>1 in 4</td>
</tr>
</tbody>
</table>

5.2  Capacity on entry to RACF

Elderly Tasmanians are remaining in their own homes for longer, with 79% of Tasmanians aged 80 years or above residing in their own homes in 2011. The Australian average age of admission to an RACF increased between 1997 and 2009 from 82.8 to 84.3 years for a female and 79.5 to 81.6 years for a male.\(^10\)

As shown in Table 3 over 50% of permanent aged care residents in Tasmania in 2011-12 were aged 85 years or above.

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\(^9\) Ibid

Table 3: Permanent aged care residents aged 65 years and above (2011-12)\(^\text{11}\)

<table>
<thead>
<tr>
<th>Age group (years)</th>
<th>Residential aged care (permanent)</th>
<th>Percent of permanent aged care residents (65+)</th>
</tr>
</thead>
<tbody>
<tr>
<td>65-69</td>
<td>215</td>
<td>3.7%</td>
</tr>
<tr>
<td>70-74</td>
<td>374</td>
<td>6.5%</td>
</tr>
<tr>
<td>75-79</td>
<td>588</td>
<td>10.2%</td>
</tr>
<tr>
<td>80-84</td>
<td>1,131</td>
<td>19.6%</td>
</tr>
<tr>
<td>85-89</td>
<td>1,621</td>
<td>28.2%</td>
</tr>
<tr>
<td>90+</td>
<td>1,827</td>
<td>31.7%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>5,756</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

Older individuals entering RACFs are commonly at more advanced stages of any chronic conditions. Anecdotal evidence suggests that increasingly individuals entering aged care may no longer be in a position to make informed decisions about their care.

In these cases it is not always possible to conduct advance care planning discussions which include the resident, potentially preventing the alignment of care with a resident’s wishes and values.

Pilot RACFs strongly supported the commencement of advance care planning in the community setting, before capacity is lost.

5.3 Length of stay in RACFs

RACFs consulted with as part of this evaluation believed that length of stay within an RACF is decreasing. One RACF consulted with during this evaluation highlighted that of 127 beds there is an annual turnover of approximately 30 beds per year. Anecdotal evidence suggested that it is increasingly common for residents to be admitted only weeks or months before they die, rather than many years.

Data collected by the former Department of Health and Ageing (DoHA) found that between 1997-98 and 2007-08 the median length of stay in an RACF had generally remained constant. Over the 10 year period this ranged from 683 days (1998-99) to 751 days (2003-04)\(^\text{12}\).

The DoHA report also identified a relationship between age at admission and length of stay within an RACF. The median length of stay ranged from 930

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days for those admitted between 0 and 59 years to 570 days for those admitted at over 90 years of age.

As the length of stay within RACFs decreases, staff will have less time to develop an understanding of the resident, making it increasingly important to conduct advance care planning at, or soon after, admission.

5.4 Individuals prefer not to die in hospital

Studies have shown that many Australians have a preference to die in their own homes. A survey conducted by Palliative Care Australia found that 68% of respondents wanted to die in their own home, with only 13% preferring to die in hospital.

Despite individual’s preferences to die at home, approximately 54% of Australians currently die in hospitals. Of the remainder, 16% die in their own homes, 20% in a hospice and 10% in an RACF.

This suggests a need to ensure that appropriate care, processes and systems are in place to support individuals to die in their preferred place and avoid unnecessary hospitalisation at the end of life.

5.5 Low level of health literacy in Tasmania

Tasmanians have low levels of health literacy. In 2006, ABS data found that 63% of Tasmanians aged 15–74 did not have adequate health literacy to meet the demands of everyday life. This was above the Australian figure of 59%.

An individual’s level of health literacy informs their ability to understand medical terms, conditions and treatments. Low health literacy may prevent a person from comprehending and participating in discussions about their medical conditions and/or treatments which they are receiving. This can impact upon their ability to make informed decisions about their preferred care.

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The low level of health literacy has implications for the communication of all health care information, including advance care planning.

5.6 Tasmania has many internationally trained GPs

Under section 19AB of the Health Insurance Act 1973 overseas trained doctors and foreign graduates of accredited medical schools are subject to Medicare number provider restrictions. These doctors and graduates are required to work in designated districts of workforce shortage to access Medicare benefits, referred to as the 10 year moratorium period.

The Rural Health Workforce Strategy (RHWS) Incentive Program enables overseas trained doctors and foreign graduates to access scaling discounts. These scaling discounts allow overseas trained doctors and foreign graduates to reduce the 10 year restriction period to access Medicare benefits by working in regional, rural and remote areas. As many areas of Tasmania are classed as ‘outer regional’ (including North West Tasmania), doctors willing to practice in these areas can reduce the moratorium from 10 to seven years, incentivising practice in these areas.\(^\text{18}\)

In 2012, 35.1% (690) of Tasmanian GPs received their initial qualifications overseas. The proportion of GPs who received training overseas was higher in regional and remote areas, as shown in Table 4.\(^\text{19}\)

Table 4 Proportion of Tasmanian GPs who received their initial training outside Australia (2012)

<table>
<thead>
<tr>
<th>Remoteness area</th>
<th>Number of GPs</th>
<th>Proportion of GPs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Major city</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>Inner regional</td>
<td>447</td>
<td>29%</td>
</tr>
<tr>
<td>Outer regional</td>
<td>228</td>
<td>57%</td>
</tr>
<tr>
<td>Remote</td>
<td>12</td>
<td>39%</td>
</tr>
<tr>
<td>Very remote</td>
<td>3</td>
<td>47%</td>
</tr>
<tr>
<td><strong>Tasmania</strong></td>
<td><strong>690</strong></td>
<td><strong>35.1%</strong></td>
</tr>
</tbody>
</table>

While the incentivisation under the RHWS increases the availability of GPs in regional and remote areas, it was reported by stakeholders to be a contributing factor to high GP turnover in the region as the GPs satisfy requirements and move to places of their choosing. High rates of GP turnover was associated by stakeholders with:

- an ongoing need for familiarisation and training in end of life care approaches

\(^\text{19}\) Health Workforce Australia, www.hwa.gov.au
• individuals potentially having only a short history with their GP.

5.7 Shift in mindset required by many health professionals to adequately understand and appropriately care for the dying

It is acknowledged that the skills and capability of health professionals to provide high quality end of life care requires improvement. In particular, health professionals may:

• not adequately understand the dying process
• be unfamiliar with care approaches for the last year of life
• be uncomfortable holding discussions with patients and families about death and dying
• lack the skills to effectively communicate about death and dying
• be unable or unwilling to manage care in a person-centred way either due to structural barriers or differences in values and attitudes.

Health professionals may have difficulties reconciling their own, and their patient’s, values and attitudes in relation to death and dying and therefore effectively planning care which meets the patient’s needs.

The traditional medical paradigm focuses on saving or extending life. The transition from treating a patient’s condition to managing their symptoms can be a significant change in focus for a health professional, which some have identified as being confronting.

“One of the fundamental barriers to achieving quality care at the end of life arises from the inability or unwillingness of health professionals to recognise those who are dying and treat them appropriately... Health professionals have the ability and the strongly held desire to treat and cure. Our systems of care and training limit our capacity to recognise that a person is dying.”

5.8 Tasmanians’ families may be geographically distant

The families of some elderly Tasmanians reside in mainland Australia or overseas. As a result of the geographic distance, communication may be less frequent and families may be unaware or have incomplete knowledge of the individual’s wishes and preferences for end of life care.

This can present difficulties when wishes are known to RACF staff, or locally residing friends, which differ from familial wishes, particularly when they have not been documented and/or there is no clear substitute decision-maker.

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6 Living Well Dying Well

6.1 Description

The Living Well Dying Well (LWDW) project commenced in August 2010 as a pilot implementation of the UK Gold Standards Framework (GSF) by the North West Area Health Service (NWAHS) in Tasmania.

The LWDW project aimed to achieve the implementation of person-centred advance care planning processes. It also sought to promote the delivery of care during the last year of life which upholds a resident’s dignity by respecting their values, wishes and preferences.

LWDW combines elements of the GSF program with tailored content and materials to provide an integrated approach to end of life care. LWDW includes the following elements:

- Australian adaptation of the GSF
- DPAG process (Dignity, Preferences, Advance Care Plan, Goals of Care) used for advance care planning
- supportive and palliative pathways and Clinical Action Plans (CAPs)
- 4CEHR system to support the approach.

The 4CEHR system is discussed separately in section 7 of this report.

The project was delivered to five RACFs, and involved education to GPs with patients in those facilities.

6.1.1 Pilot sites

RACFs in North West Tasmania were able to apply to be one of the five pilot sites for LWDW. The following five RACFs were selected from the initial round of applications:

- Umina Park, Burnie
- Meercroft Care, Devonport
- Baptcare Karingal, Devonport
- Mount St Vincents, Ulverstone
- Wynyard Care Centre, Wynyard (formerly known as Ibis Care)

Due to internal changes in leadership, Umina Park was unable to continue with the pilot and withdrew from the project. Following the withdrawal of Umina Park, Emmerton Park in Smithton commenced the project in March 2012.

Despite expressing significant interest in participating in the LWDW project, Emmerton Park was not initially accepted as the project team felt that the
RACFs location could be problematic. The project team acknowledged that the enthusiasm of the RACF meant that it was a good candidate for the project and should have been included from the start.

**Figure 2 Participating RACF locations**

With the exception of Umina Park, all RACFs that participated in the project completed all training activities.

### 6.1.2 What is the Gold Standards Framework?

The GSF was developed in 2000 to improve primary palliative care in the UK. GSF seeks to provide a “systematic, evidence based approach to optimising care for all patients approaching the end of life, delivered by generalist care providers”\(^{21}\). The aims of the GSF within the RACF setting include:

- to improve the **quality** of end of life care for all residents living in an RACF
- to improve **collaboration** with GPs, primary care teams and specialists
- to reduce **hospitalisations** in the last stages of life.

The GSF program provides a range of training programs, tools, resources and measures to improve and benchmark the quality of end of life care.

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Since 2000 the program has expanded to include programs for a range of health care settings including hospices, primary care, care homes (RACFs) and hospitals. The program is now widely used in the UK, and has been piloted in a range of countries including Australia (through LWDW), New Zealand, the USA, Canada, Belgium and Holland.

GSF tools and processes are available to organisations under license. While some materials and tools are provided for free non-commercial use in UK National Health Service primary care, organisations outside the UK must apply for use, and pay a licence fee.

6.1.3 Australian adaptation of the GSF

The LWDW project tailored the GSF content and tools for use within the Australian context. Specific details of the adaptations were not recorded in the project documentation made available. Nor were the original GSF materials available for comparison to the LWDW materials.

During consultation the following general areas of adaptation were identified:

- changes to reflect different language use, health systems and legal frameworks
- alterations to the training package, including a reduction in content detail, changes to clinical assessments and addition of an introductory workshop.

The GSF care home training program includes four workshops spaced over approximately 12 months and covering the seven core concepts of care (the “Seven C’s“). Table 5 details the delivery of the Seven C’s within the LWDW RACF workshops.

Table 5 Seven C’s of Care

| Communication (C1) | LWDW workshop 2 and 3 | • identify residents in the final 6-12 months of life  
|                    |                        | • discuss patients at regular team meetings 
|                    |                        | • code residents to identify illness stage 
|                    |                        | • discuss proactive planning, anticipate needs, prioritise care 
|                    |                        | • offer and conduct advance care planning discussions |
| Coordination (C2)  | LWDW workshop 2       | • coordinate care across boundaries 
|                    |                        | • share information and planning between staff and GPs 
|                    |                        | • align care with resident’s dignity and preferences |

### Control of Symptoms (C3)

**LWDW workshop 3**

- assess physical symptoms
- anticipate possible symptoms and possible consequences of deterioration with, for example, anticipatory prescribing
- use of CAPs

### Continuity of Care (C4)

**LWDW workshop 3**

- goals of comfort
- prevention of crisis
- outside hours care
- anticipatory prescribing

### Continued Learning (C5)

**LWDW workshop 4**

- use event analysis to review deaths, admissions and other events
- identify and plan for learning needs
- consider ongoing audits to clarify areas requiring further improvement

### Carer Support (C6)

**LWDW workshop 4**

- inform and include carers as ‘care partners’ if desired
- discuss carer’s own needs and concerns
- develop bereavement plan after every death
- identify ‘pathological’ grief
- debrief and support yourselves and staff

### Care in the dying phase (C7)

**LWDW workshop 4**

- recognise end of life
- conduct anticipatory prescribing
- keep carers informed
- consider spiritual needs

The first LWDW workshop was introductory and aimed to identify concerns about the program as well as desired outcomes.

The fifth LWDW workshop covers embedding and sustaining the approach and explores quality of life, delirium, depression, demoralisation and dementia. Example agendas for LWDW workshops two to five are included at Attachment C.

#### 6.1.4 Aims of LWDW

While the aims of the two programs are similar in nature and concept, the GSF aims are articulated in a much a simpler manner, focusing on the outcomes that the program is seeking to achieve. The LWDW aims can be directly aligned with the three GSF steps; identify, assess and plan (as shown in Table 6).
Table 6 Comparison of LWDW aims and GSF steps

<table>
<thead>
<tr>
<th>LWDW</th>
<th>GSF</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identify residents who are likely to be in their last year of life (or less).</td>
<td>Identify which resident is likely to be in the last year or less of life.</td>
</tr>
<tr>
<td>Assess each resident’s needs, symptoms, preferences and plan care enabling them to live well and die with dignity.</td>
<td>Assess current and future person centred and clinical needs (physical and psychological).</td>
</tr>
<tr>
<td>Help primary care teams to prepare all individuals involved in the persons care (including families) for changes by:</td>
<td>Plan. Use and support matrix of needs and clinical action plans for likely deterioration and anticipate approaching and actual dying.</td>
</tr>
<tr>
<td>• realising realistic and achievable aims within the four main Clinical Goals of Care (Comfort, Prevention, Function and Length of Life)</td>
<td></td>
</tr>
<tr>
<td>• identifying a clinical pathway that suits the residents priorities and wishes</td>
<td></td>
</tr>
<tr>
<td>• identifying and planning for likely expected deteriorations, approaching death and the actual dying phase.</td>
<td></td>
</tr>
</tbody>
</table>

6.1.5 LWDW implementation approach

The LWDW project was designed to be implemented in three stages (preparation, training and consolidation) over a 12 to 18 month period. The original RACF training schedule is included at Attachment D.

A range of training activities were conducted by the project team which targeted the participating RACFs and other health professionals involved in the care of residents (such as GPs). These activities largely focused on educating participants about the elements of LWDW, including how the content and tools can be implemented and applied.

The various implementation activities are detailed in Table 7. A brief description of each activity is included in Attachment E.

Table 7 LWDW implementation activities

<table>
<thead>
<tr>
<th>Stakeholder group</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>RACFs</td>
<td>• prepare and commit</td>
</tr>
<tr>
<td></td>
<td>• collect baseline data through a pre-training survey</td>
</tr>
<tr>
<td>Stakeholder group</td>
<td>Description</td>
</tr>
<tr>
<td>------------------</td>
<td>-------------</td>
</tr>
<tr>
<td></td>
<td>about RACF culture and conducting after death audits</td>
</tr>
<tr>
<td></td>
<td>• introductory workshop</td>
</tr>
<tr>
<td></td>
<td>• four GSF ‘gear’ workshops, implementation and consolidation (note, these sessions included the DPAG training)</td>
</tr>
<tr>
<td></td>
<td>• ongoing training and support</td>
</tr>
<tr>
<td></td>
<td>• after death audits (ongoing)</td>
</tr>
<tr>
<td></td>
<td>• review (conducted following each workshop)</td>
</tr>
<tr>
<td>GPs</td>
<td>• GP engagement</td>
</tr>
<tr>
<td></td>
<td>• GP training (after hours workshops)</td>
</tr>
<tr>
<td>Coordinators</td>
<td>• action learning groups</td>
</tr>
<tr>
<td>Consumers and Community</td>
<td>• engagement</td>
</tr>
<tr>
<td></td>
<td>• community forums</td>
</tr>
</tbody>
</table>

LWDW was primarily developed and implemented by a DHHS palliative care nurse and palliative care doctor. A range of clinical, administrative and project staff from the other participating organisations also provided support to the project. All project management tasks were undertaken by the clinical staff who reported directly to the CEO of the NWAHS.

The clinical staff were involved in all aspects of the LWDW project, including developing the approach, refining content, delivering training and providing ongoing support to the RACFs.

The development of the 4CEHR system was managed and delivered by the same, broader project team in conjunction with a contracted service provider.

Stakeholders identified that there was poor communication between the LWDW and 4CEHR project team members and that they were often working to separate timeframes.

### 6.1.6 LWDW approach to advance care planning

LWDW is an approach to delivering advanced care planning in the RACF setting. A range of content and materials have been developed and adapted from GSF as part of LWDW. This content specifically seeks to support the three LWDW aims, as shown in Table 8.

Additional details about specific content and materials are provided in Attachment F.
### Table 8 LWDW content and materials by aim

<table>
<thead>
<tr>
<th>LWDW aim</th>
<th>Content and materials (How)</th>
<th>Description</th>
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</table>
| Identify residents in their last year of life (or less) | Illness trajectories | Three illness trajectories are used to provide RACF staff with an indication of the expected deterioration for residents with particular conditions. The three trajectories are:  
- short period of evident decline (typically cancer)  
- long term limitations with intermittent acute, serious episodes (typically organ failure)  
- prolonged dwindling (typically frail and aged with multiple comorbidities). |
| | Prognostic Indicator Guide | A series of indicators (such as the resident’s level of activity, decline and response to treatments) which are used to assist in the identification of residents in their last year of life. |
| | Use of the ‘surprise’ question | Designed to assist RACF staff in determining the resident’s prognosis by asking whether staff would be surprised if the resident died within years, months, weeks or days. |
| | Resident coding | Categorisation of residents according to whether they are expected to live for years, months, weeks (approaching the dying phase) or days (the dying phase). The coding of residents is informed by their identified illness trajectory, prognostic indicators and the outcome of the surprise question. |
| | Assessing resident’s needs, symptoms, preferences and planning care to live well and die with dignity | DPAG | Tool designed to assist in, and prompt, advance care planning discussions. The tool focuses on identifying the wishes and preferences of the resident by considering:  
- **Dignity** – what dignity means to the resident and how this can be achieved and maintained  
- **Preferences** – identification of the resident’s preferences for care (such as |
<table>
<thead>
<tr>
<th>LWDW aim</th>
<th>Content and materials (How)</th>
<th>Description</th>
</tr>
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</table>
| Help primary care teams to prepare all individuals for changes. | Clinical Pathways | Clinical pathways which are aligned to the residents goals of care. These pathways are used to inform the types of care which the resident receives. The following three pathways are taught as part of the LWDW approach:  
- aggressive disease focused pathways  
- less aggressive disease focused emphasising supporting care pathways  
- supportive and palliative pathways. |
| | CAPs for Deteriorations | Specific plans for the management and provision of care to a resident as they deteriorate. The plans can be pre-authorised by the GP and actioned as required by the RACF staff. |
6.2 Findings from the LWDW pilot

6.2.1 Project management

**Project management skills were needed**

Stakeholders agreed that management of the LWDW project would have benefitted from a greater level of project management skills and focus within the LWDW team.

The core team had a high level of clinical skill and knowledge and the drive to deliver high levels of care. The skills, knowledge and drive of the team led them to sometimes become the deliverers of the care rather than facilitating delivery and implementation by the RACF staff.

The clinical skills of the core team were not sufficiently guided and directed by an individual with the program management skill to effectively and efficiently deliver the complete project.

**Poor quality project documentation**

Much of the LWDW documentation is poor quality and appears to be incomplete. This is another area where the project would have benefited from additional project management oversight.

In many areas the LWDW resources and documentation available to DHHS Tasmanian Health Organisations (THO’s) is not sufficient to support future delivery of the project without substantial effort to review and finalise the documentation. The quality and availability of project documentation also negatively impacted this evaluation.

**Changes to the project name**

The project name was changed to the NWAHS LWDW project in December 2011 to acknowledge that the program had been ‘Australianised’. Changing the name of the project resulted in some confusion, with stakeholders being unable to clearly articulate the differences between LWDW and GSF. This was identified by both the participating RACFs and some members of the project team.

Confusion around the name change is believed to have created some challenges during implementation. Some participating RACFs expressed that they felt uncertain around the future of the project at this time and felt reluctant to commit large amounts of resources to a project which may change without warning. They noted that they received limited communication about the name change, why it occurred, and what impact it would have on the program and participating RACFs.
**Communication and relationship management is vital**

LWDW was primarily developed and implemented by a DHHS palliative care nurse and palliative care doctor. A range of clinical, administrative and project staff from the other participating organisations also provided support to the project.

During consultations it was noted that the various members of the project team often had different work schedules and availability. This presented a challenge for the project team who needed to collaborate on the various tools and activities associated with LWDW and the delivery of the 4CEHR system. Stakeholders reported that, at times, they were unable to contact or receive input from necessary team members within appropriate/required timeframes.

**Obtaining commitment**

Prior to commencing the LWDW program, the boards of all participating RACFs were engaged to ensure that the RACF was committed to participation. All participating RACFs were required to gain a GSF licence during this phase.

The commitment and engagement of management within each of the RACFs was considered to be essential to the successful implementation of LWDW and realisation of the required culture change. Consultations suggested that RACFs whose management were more engaged and supportive of their staff had greater success implementing and using the content and materials. The LWDW project team noted that it was challenging to implement the approach where appropriate preparation had not been undertaken.

**Hands-on implementation support**

The participating RACFs highly valued the input of the various LWDW team members during the implementation period. The project team’s clinical specialists were identified as being able to provide necessary support to the RACFs.

Following the project, RACFs within North West Tasmania have continued to receive part-time support from a palliative care specialist nurse (0.5FTE). The ability to access this expert advice has provided ongoing benefits to the RACFs in implementing the LWDW approach and providing appropriate care to residents.

**6.2.2 Licencing arrangements**

The requirement to pay the GSF licence fee was considered to be a financial burden by the participating RACFs. At the time of the project, the GSF licence cost was a one-off payment of approximately $20 per bed.
Based on a rudimentary assessment it appears that not all of the LWDW activities rely on, or use, GSF tools and intellectual property. Table 9 provides an overview of the key features of LWDW, identifying those which require users to secure a GSF licence.

**Table 9 LWDW elements**

<table>
<thead>
<tr>
<th>LWDW / 4CEHR</th>
<th>GSF elements requiring a licence</th>
</tr>
</thead>
<tbody>
<tr>
<td>DPAG (LWDW approach to Advance Care Planning)</td>
<td>The content and materials from the GSF Care Home Training Programme which are used in the four LWDW workshops. This includes the Seven C's of care:</td>
</tr>
<tr>
<td>CAPs</td>
<td>• Communication is enhanced</td>
</tr>
<tr>
<td>Clinical pathways:</td>
<td>• Coordination</td>
</tr>
<tr>
<td>• supportive of palliative</td>
<td>• Continuity of Care</td>
</tr>
<tr>
<td>• less aggressive diseased focused care which emphasises supportive care</td>
<td>• Care of the dying</td>
</tr>
<tr>
<td>• aggressive diseased focused care</td>
<td>• Control of symptoms</td>
</tr>
<tr>
<td>Workshops:</td>
<td>• Care of Carers</td>
</tr>
<tr>
<td>• Wish list workshop</td>
<td>• Continued learning</td>
</tr>
<tr>
<td>• DPAG communication / assessment</td>
<td></td>
</tr>
<tr>
<td>• GP training</td>
<td></td>
</tr>
<tr>
<td>Illness trajectories</td>
<td></td>
</tr>
<tr>
<td>Adapted coding from the ABCD prognostic coding model used by GSF</td>
<td></td>
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</tbody>
</table>

6.2.3 Not all project tasks were completed

A number of evaluation and consolidation activities were planned to be conducted in the LWDW project. A number of these evaluative components were either not documented or not completed for the project and impacted the information available for this evaluation. Additional details about some of these activities are included in Attachment G.

These included:

- before and after staff confidence assessment

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23 Not to be relied upon as legal advice.
24 A licence will still be required regardless of whether content and materials have been adapted. See: [http://www.goldstandardsframework.org.uk/terms-amp-conditions](http://www.goldstandardsframework.org.uk/terms-amp-conditions)
• baseline and post-implementation after death audits

• analysis of any cultural change that had been achieved at each RACF, including changes to staff practice or systems

• results of evaluation questions which formed part of the training workshops.

Members of the project team noted that all LWDW consolidation and evaluation activities had not been completed as originally intended. As at January 2014, the LWDW project team noted that some of the participating RACFs had completed up to three of the post-implementation after death audits. No RACFs were reported to have completed the full five required as part of the planned evaluation.

No results from the post-implementation after death audits or any evaluation activities conducted in early 2014 were made available, or referenced, during this evaluation.

6.2.4 Who should be involved in advance care planning

The pilot RACFs were highly supportive of LWDW’s multidisciplinary approach, which allowed all interested staff to attend workshops. The majority of RACFs indicated that attendance at all levels was supported. However, at least one of the RACFs only allowed care staff to attend the workshops which was seen as a barrier to LWDW’s adoption and implementation.

Participation in the workshops was stated as having improved the quality of care overall and that staff at all levels took more responsibility for providing daily care in accordance with a resident’s wishes and preferences.

For example: hotel staff recognising and raising with care or nursing staff that the lowest risk food texture option may not fit with an individual’s wishes.

In relation to undertaking advance care planning discussions (e.g. DPAG) with residents and their families, RACFs agreed that senior or specialist staff are those most suited to this task. Overall it was felt by the majority of RACFs that it is generally best if responsibility for ensuring that advance care planning is completed rests with one or a few individuals. This does not mean that others cannot be involved in the delivery, but that someone takes overall responsibility for ensuring it is undertaken.

RACFs were highly supportive of the need for GP engagement and training in the LWDW approach to achieve buy-in and successfully implement improved advance care planning (rather than relying upon RACFs to convince and educate GPs themselves). RACFs also supported concurrent GP training, rather than offset training (which saw GPs receive training after the RACFs) as occurred in the project. Specific information about the GP training is included in Attachment H.

Furthermore RACFs indicated that concurrent engagement of hospitals would have further improved the use of advance care planning and advance care directives.
6.2.5 Not everyone will be willing or have appropriate skills

It was acknowledged that not every individual will be willing or necessarily suited/skilled to undertake advance care planning. RACFs in the project believed that the inclusiveness of the LWDW approach allowed for varying levels of comfort and skill, while still promoting holistic culture change within the organisation.

There was recognition that staff roles and responsibilities should take into account skill sets and interests to promote good practice and positive culture. All RACFs indicated that they felt confident that individual staff who were not comfortable having a discussion themselves would act on a resident’s concern or request by raising it with someone more appropriate.

Addressing GP resistance

It was indicated that not all GPs were receptive to the approach. RACFs indicated that the following assisted in overcoming GP resistance:

- closer engagement with and use of specialist palliative care services to provide ‘expert advice’
- the workshops and approach improved staff confidence in discussing care with GPs
- the person-centred approach empowered RACF staff to act as a patient advocates ‘i.e. able to convince GP on the basis of the patient’s wishes, rather than it being their (staff) view/opinion’.

6.2.6 When to start advance care planning

When to start Advance Care Planning (overall)

RACFs identified that waiting until admission to a RACF to commence advance care planning is too late. All believed that there should be greater awareness of advance care planning in the community, and advance care planning should be facilitated in other health settings, particularly primary care.

The main rationale was that (as discussed in section 5.2) increasingly residents do not have the capacity to participate fully in this process upon entry to a RACF.

GPs were commonly identified as being the most appropriate profession to conduct advance care planning in the community. Limitations to GPs conducting advance care planning in the community were identified, and included:

- GPs do not have sufficient time to conduct advance care planning
- GPs are not able to bill for advance care planning discussions.

The engagement of a Practice Nurse or Care Coordinator with linkages to chronic care models and programs could be used to conduct advance care planning in conjunction with a GP. This would allow advance care planning to
occur within the General Practice setting without the limitations of GPs standard consultation lengths.

It should also be noted that GPs are able to claim for time spent conducting advance care planning for residents with chronic or terminal medical conditions and/or complex care needs using chronic disease management Medicare items.

**When to start Advance Care Planning (in RACFs)**

The timing of commencing Advance Care Planning varied among the RACFs in the pilot and those who responded to the RACF survey. Times ranged from before admission to up to 6 weeks after admission. Some indicated there was no ‘set’ time to commence discussions.

Some RACFs indicated that they had found it beneficial to introduce the topic gradually. For example:

- by including some information in pre-admission documentation or having a brief conversation prior to admission
- touching on the topic during the first days to gauge the level of resident comfort for participating in these discussions
- holding a detailed discussion once the resident is settled.

Two distinct viewpoints were expressed in relation to the appropriate time:

- those who believed that introduction as early as possible was best
- those who felt it inappropriate to discuss advance care planning prior to, or at admission, as this is already a significant life event which may be traumatic or overwhelming for the resident and/or their family. It was suggested that discussing advance care planning may increase the trauma associated with admission.

### 6.2.7 When to revisit Advance Care Plans and Advance Care Directives

Stakeholders identified that once an advance care directive was in place it was important to revisit a person’s wishes:

- regularly – the frequency depended on the person’s health status and health care setting (at least annually in a RACF)
- when a change in health status occurs, either deterioration or improvement
- when a change in health setting occurs
- at the request of the individual.
It was emphasised that advance care planning does not stop once an advance care directive is prepared. Individual’s views can change when events become real rather than hypothetical, as a result of their accumulated experiences, or due to a change in family situation.

The LWDW approach promotes regular review of advance care planning.

6.2.8 Use of the LWDW approach and tools

RACFs reported using different aspects of the LWDW approach and tools with differing levels of consistency (i.e ad hoc to routine). Specific details of the various approaches and tools used in the LWDW approach are included in Attachment F.

Identify residents in their last year of life

Of the four RACFs consulted as part of the evaluation:

- one indicated that the coding and illness trajectories had been well received and were continuing to be used by staff
- one noted that while they no longer routinely code residents, some staff still discuss the coding at meetings
- one noted that the coding is less helpful as it is often hard to predict an individual’s prognosis until they reach the final stages of life. The RACF commented that they had trialled displaying the coding but found that the resident’s deteriorations and death did not align with the anticipated timeframes/prognosis. The approach was ceased due to the constant need to change the coding.

Differences in the perceived use and appropriateness of these tools may further reflect variable understanding and ability to apply the approach and tools between the participating RACFs.

There was also a perception among staff at one of the RACFs that the coding was mostly conducted for the benefit of GPs. Coding was believed to enable GPs to easily identify when a change in one of their patients has occurred which may require a change in care. Despite the perceived benefits of coding, the RACF staff noted that the GPs at their facility had not received training about coding and, as such, could not utilise or apply it. It is unclear why the GPs at this facility reportedly did not receive the training about coding.

Advance care planning

LWDW teaches participating RACFs to utilise the DPAG approach to advance care planning.

Only one of the consulted RACFs has incorporated advance care planning as a routine practice. Some of the others consistently provide information about advance care directives (or similar) but do not routinely engage in an advance care planning discussion with all residents, record the outcomes and regularly follow up with residents (and families).
One RACF noted that only a small proportion of its residents had a current advance care directive. No RACFs were able to provide exact information about the proportion of residents with an advance care directive.

The variable uptake of advance care planning and creation of advance care directives may be attributed to a range of factors, such as, but not limited to:

- resident willingness to participate in advance care planning discussions
- the capacity of residents to actively participate in advance care planning discussions
- time and effort for staff to hold discussions and document outcomes.

The RACFs identified some residents are not willing to participate in discussions about end of life care and their wishes or values. There was no indication of how often advance care planning is revisited with residents who have expressed a reluctance to participate. One RACF highlighted that there can be variability in a resident’s level of comfort with advance care planning discussions, noting that different residents may wish to:

- discuss and document their wishes and preferences
- only document their wishes and preferences
- only discuss their wishes and preferences (but not document them).

Despite this, RACFs with low proportions of residents with an advance care directives still considered the LWDW approach to be successful and beneficial.

It was identified that improvements to care were able to be identified even where the resident lacked capacity. For example, one RACF was able to identify that a resident with severe dementia had enjoyed a particular drink every afternoon prior to entering the RACF. This was previously unknown to the RACF staff and identified during an advance care planning discussion involving the resident and a family member. Following the advance care planning discussion, the provision of the drink was incorporated into their care.

During consultations a number of RACFs referred to particular successes using the DPAG process. This included one RACF which discharged a resident so that they were able to spend their final weeks of life at home with their family. Spending their final weeks together in the home environment was a particular preference identified by the resident and their family. The RACF was pleased to have been able to enable this and attributed this to successful and appropriate advance care planning.

All RACFs involved noted that they endeavour to provide a copy of any advance care directive (and other relevant information) when a resident is transferred to hospital.
A number of barriers to advance care planning were still experienced by the participating RACFs during and after the LWDW project:

- **Time** - As part of the implementation of LWDW, the two project leads attended each of the RACFs to develop DPAGs for some patients. Stakeholders reported that, at times, the project team members spent up to five hours with a single resident conducting the DPAG. RACF staff do not have capacity to spend this amount of time with a single resident.

- **Format and content of DPAG** - It was reported that the advance care planning document the project leads developed could be up to six or seven pages in length. Lengthy documents were not considered to be usable for the RACF staff or GPs, who prefer short and concise documents. While LWDW provided the RACFs with the DPAG model to structure advance care plans, it did not provide a consistent template. As a result, the advance care plans/directives being produced by the participating RACFs may vary considerably.

- **Recognition in other settings** - Stakeholders reported that the advance care planning documents which are being produced may not be recognised in different health settings. One stakeholder noted that hospitals commonly require specific features in a document. Without being produced in the particular format, provided documents may not be used to inform decisions about care. For example, it was identified that hospitals will only read/use documents which are presented in the official format, including having a hospital barcode. Recognition of document validity was also a problem experienced when using ambulance services²⁶.

- **Awareness/communication** - A number of stakeholders identified that problems had been encountered where an individual (including those in the community) had an advance care directive that was not known of by family members or health care professionals and thus not complied with. The reasons for lack of awareness varied.

**Clinical action plans (CAPs)**

Under the LWDW approach, CAPs are used to enable prior planning for expected or likely deteriorations. A range of CAPs were developed and promoted as part of the LWDW program to assist GPs and other health professionals in making decisions about a resident’s end of life care. An example CAP is included in Attachment F.

Following the completion of the DPAG process, a GP can select and authorise the appropriate CAP in alignment with the resident’s preferences and wishes. The authorised CAPs can then be activated when appropriate by the RACF staff²⁷.

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²⁶ Note: Ambulance services were not directly engaged with during this evaluation. It was evident from consultations that they are an important future stakeholder for state-wide advance care planning.

²⁷ eHospice, Living Well and Dying Well, [http://www.ehospice.com/australia/Default/tabid/10688/ArticleId/1187](http://www.ehospice.com/australia/Default/tabid/10688/ArticleId/1187)
Use of the CAPs also enables GPs to undertake anticipatory prescribing. GPs are able to identify and pre-approve the specific medications which would be appropriate for the resident as they deteriorate. The RACF is then able to enact this anticipatory prescribing as required to provide the most appropriate care for each event.

RACFs were supportive of anticipatory prescribing. However, the CAPs as represented in the 4CEHR system were reported to be underdeveloped and unsuitable for use. It was suggested by some that GPs may find the CAPs overly prescriptive and it was questioned whether the content was appropriately supported by current literature and how it would be maintained into the future.

Specific issues about the current format of the CAPs are identified in the document “Tasmanian Health Organisation – North West 4C System Change Requests” (page 7). These include:

- names of the CAPs are inconsistent and confusing
- there are inconsistencies in the description of options within the CAPs
- it is difficult to identify some required options without knowledge of which problem (deterioration) to select.

General feedback suggested that the dying phase CAPs should be the highest priority for further development as they are the most relevant and useful to support the dying.

Other projects in which DHHS are involved also focus upon the development of guidance and tools to support and ensure consistency in clinical decision making. Notably this includes the Tasmanian HealthPathways project (see section 8.1.10) and Better Access to Palliative Care – Palliative Care Formulary Project. As these projects should result in regularly maintained information to assist health professionals in making clinical decisions and prescribing medications, it is unclear whether the CAPs developed as part of LWDW (and included in the 4CEHR system) are necessary.

**After Death Audits**

After death audits were considered to be useful for staff debriefing and for identifying areas in which future care could be improved. An example after death audit is included in Attachment G.

There was evidence of ongoing ad hoc use of after death audits; however, the approach has been modified by some of the participating RACFs. For example, despite not conducting formal after death audits, one of the participating RACFs holds regular ‘tool-box’ discussions with staff during which recent deaths are discussed.
6.2.9 Feedback from residents and family members

Residents and families who were interviewed as part of the evaluation expressed that they are comfortable engaging in end of life care planning discussions. Identified benefits included:

- the discussion and documentation of residents wishes provides reassurance for some residents and their families
- some residents welcome the ability to document their end of life wishes to relieve pressure on their families to make difficult decisions
- the use of advance care directives and documented advance care plans has been used as a tool to avoid family conflict in decision making. For example, during the consultations, one participant indicated that accessing the documented advance care plan had enabled the family to recognise and share the resident’s wishes, avoiding disagreements on the best course of action and care.

While there were many reported instances of families benefiting from the advance care planning discussions, it should be noted that indirect feedback was received indicating that residents had varying levels of comfort and wishes about who should be present at advance care planning discussions. In some instances it was noted that the resident may prefer a friend, rather than a family member. LWDW supports the inclusion of any person with whom the resident is comfortable in advance care planning discussions.

6.2.10 Overall RACF view of the LWDW project

RACFs views were divided about the overall experience of the project.

Two of the RACFs consulted with viewed the project in a positive light, and two negatively. While the two who view it negatively acknowledged they have realised some benefits, overall they believed they had been required to invest a lot of effort without fully realising the benefits that were promised.

The two RACFs who had a negative perception of the program specifically did not like the following:

- perception of discontinuing/inadequate support (4CEHR)²⁹
- uncertainty surrounding the project
- lack of clear communication from the project team/ lack of clarity/disjointed project management
- training (one of the two)
- having to pay for the GSF licence

²⁹ Note: Ongoing support to the 4CEHR system was provided by a systems administrator. The two RACFs with a negative perception of the system did not reference or identify the availability of this support.
• order of training – GP training was too late, hospital engagement was not visible to them.

6.3 Outcomes of LWDW

The LWDW pilot sought to achieve a number of key outcomes within the participating RACFs:

• culture change and staff empowerment, including increasing staff confidence in undertaking advance care planning
• recognition of suffering, death and dying, including the identification of deteriorations and resident pain/discomfort
• delivery of person centred care which is appropriately tailored to the needs, preferences and wishes of residents
• cost savings through a reduction in hospitalisations.

6.3.1 Ongoing use of the LWDW approach

All of the RACFs consulted with as part of this evaluation noted that they had experienced benefits as a result of the LWDW project. As discussed in section 6.2.8, each consulted RACF has adopted elements of the LWDW approach. Despite the uptake of particular aspects of LWDW, the content and tools have not been used consistently, with each RACF adopting only those elements they feel add value. Within the participating RACFs, selected LWDW content and tools are taught to new staff within all roles (including nurses and GPs). The fact that the RACFs are taking time to teach the approach to new staff demonstrates that the LWDW approach is considered to be valuable.

6.3.2 Culture change and staff empowerment

Throughout the consultations, stakeholders identified that a culture change has been evident within the RACFs as a result of LWDW. This has included the following:

Normalised discussions about death and dying

Death has now been accepted as a natural part of life and is openly discussed by RACF staff. The ability to provide quality end of life care is now seen as a ‘privilege’ by one RACF.

Empowered all staff to participate in care planning

The RACFs reported that all staff are now more willing, and able, to have these discussions with residents and families and record information about residents preferences and wishes.

Increased the understanding of the care which is being provided

All staff (including those in non-clinical positions) now have a better understanding why particular care is being provided. For example, kitchen staff have a better understanding of why residents need to have particular
Increased staff confidence in undertaking more complex care

Nurses are reportedly adopting greater responsibility in the care of residents, including using the information contained in the CAPs to discuss the care that is being provided with GPs.

Increased the confidence of some RACFs to manage more conditions

One RACF identified that the facility as a whole is now more confident about the conditions which it is able to manage. They have been working with the local hospitals to provide care to residents with a wider range of needs. In some cases the hospital has worked with the RACF to train nursing staff to enable residents to be discharged back to the RACF. While the RACF attributed this to the greater confidence of its staff, it is unclear whether this is a result of the LWDW program.

6.3.3 Recognition of suffering, death and dying

Prior to the LWDW program, stakeholders believed that the RACFs were often not expecting and were not prepared for the death of a resident. The focus of LWDW on the recognition of death has enabled staff to become more prepared for the death of a resident, reducing the overall level of staff distress following a resident’s death.

It was also reported that the earlier recognition of the dying phase has allowed residents families to be engaged, allowing them time to prepare. Death is now considered to be less of a surprise for families. Despite this, only one RACF reported conducting specific bereavement activities.

The LWDW program also taught RACF staff about recognising the suffering of residents. Staff have reportedly responded well to this aspect of LWDW and are now more aware of, and responsive to, resident’s pain symptoms. The LWDW project team believe that the training has allowed all staff to appropriately manage care in a way which acknowledges and minimises the pain of residents. This has assisted in the achievement of person-centred care which is tailored to the needs and requirements of the resident.

6.3.4 Impact on hospitalisations

While each of the RACFs noted during the consultations that they felt the hospitalisation rate had been reduced as a result of LWDW, none have actively collected quantitative data to support this.

The rationale for the reduction of hospital admissions under LWDW is premised on research that shows a much higher proportion of people die in hospital, compared to expressed preferences for place of death. LWDW aims to reduce hospitalisations by acknowledging dying and death and complying with preferences for place of death.

Preliminary analysis in the 2012 4C Final Report suggested that LWDW may have resulted in some cost savings through reduced hospitalisations. This analysis only included data for the participating RACFs over a three month
period (January to March) from 2010 to 2012, with the report noting that additional analysis would be required.

As part of this evaluation, THO-North West provided data about the emergency attendance and hospital admissions of RACF residents in North West Tasmania from January 2010 to September 2014. A number of data constraints were identified which may impact on the data’s accuracy. The following constraints should be considered when interpreting the data:

- the data does not include admissions to rural hospitals such as Smithton District Hospital
- RACFs are identified based on a free-text data field. Any variations in the entered address may impact on the identification of the participating RACFs
- the emergency data system only captures the patient’s postcode and suburb, not their full address. Where an individual attends the emergency department, but is not admitted, the postcode and suburb are matched against the RACF addresses to identify RACF residents. This may result in some non-admitted patients being incorrectly recorded as RACF residents.

Analysis of THO-North West data revealed that the number of emergency attendances (Figure 3) decreased for both the participating RACFs and non-participating RACFs between 2010 and 2013. Despite an overall decrease, there was a slight increase in attendances from the participating RACFs between 2011 and 2012.

**Figure 3 Emergency attendances by year**

While hospital admissions decreased for non-participating RACFs between 2010 and 2013, limited change was observed in the participating RACFs (Figure 4).
The average length of stay in the hospitals for RACF residents from both the participating and other RACFs decreased between 2010 and 2013.
7 4CEHR

7.1 Background and purpose

In 2011 funding of $3,278,707.26 was provided by DoHA under the Wave 2 Sites for the Personally Controlled eHealth Record (PCEHR) to develop and pilot an electronic health record to facilitate advance care planning in RACFs across five pilot sites in North West Tasmania.

The successful funding bid united two projects which had both commenced in 2009 – the implementation of the Gold Standards Framework in RACFs (later known as the Living Well Dying Well Project) and the Cradle Cost Electronic Health Information Exchange Project.

The Electronic Health Exchange Project was a consortium of the:

- Cradle Coast Authority
- University of Tasmania Rural Clinical School
- TML
- Tasmanian Health Organisation – North West (THO- North West).

The 4C system was intended to both support the development of advance care plans and facilitate the communication of such plans between health care professionals. The system also incorporates information and tools to assist relevant health professionals in planning care to align with the wishes of residents.30

7.2 Development and design

7.2.1 Timeframes

The 4C project was originally to be delivered over 18 months; however, by the time the successful Wave 2 projects were announced the timeframes had been reduced to 12 months from 1 July 2011 – 30 June 2012.

The timeframes for development of the 4C system were further impacted by the delay to contract execution with Alcidion, the service provider engaged to build the system. Planned for July 2011, the contract was not executed until December 2011, leaving only six months for the project.

The restricted timeframes for the development of the 4C system negatively impacted the project’s ability to deliver on its original aims. As it was important for the project team to meet the prescribed timeframes, not all activities associated with the development of the 4C system had been appropriately finalised and tested prior to the initial roll-out.
The short project implementation timeframes limited the ability of the project team to undertake appropriate system testing and review. This contributed to system limitations and barriers in the current product. Details of system limitations and barriers to use are discussed in section 7.3.2.

7.2.2 Scope and functionality

Table 10 compares the intended elements of the 4C system with what was actually achieved. This includes discussion of the integration and design of the system, as well as its key features/components.

**Table 10 Comparison of the intended and actual scope of the 4CEHR system**

<table>
<thead>
<tr>
<th>Scope</th>
<th>Intended</th>
<th>Actual</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Integration</strong></td>
<td>Integration between a DHHS Shared Electronic Health Record and 4C was planned. Integration with existing GP and nurse software was excluded from the scope.</td>
<td>The Shared Electronic Health Record project did not go ahead. As a result this functionality was not delivered. The 4C system has its own infrastructure separate from the broader DHHS ICT environment.</td>
</tr>
<tr>
<td><strong>NeHTA compliant standards</strong></td>
<td>4CEHR was to be compliant with NeHTA standards to be a PCEHR conformant repository. The 4C repository was to become the foundation for the Tasmanian PCEHR conformant repository, integrating with the Tasmanian Shared Electronic Heath Record (SEHR).</td>
<td>The Tasmanian SEHR project did not occur as planned. The interface with the PCEHR was not implemented as it was not available within the timeframes.</td>
</tr>
<tr>
<td><strong>Users</strong></td>
<td>RACFs Yes – limited use</td>
<td>Yes – limited use</td>
</tr>
<tr>
<td></td>
<td>General Practices No – ability to use, but no actual use</td>
<td>No – ability to use, but no actual use</td>
</tr>
<tr>
<td></td>
<td>Acute hospital facilities No – ability to use, but no actual use</td>
<td>No – ability to use, but no actual use</td>
</tr>
<tr>
<td></td>
<td>After hours GP services No – ability to use, but no actual use</td>
<td>No – ability to use, but no actual use</td>
</tr>
<tr>
<td>Scope</td>
<td>Intended</td>
<td>Actual</td>
</tr>
<tr>
<td>-----------------------</td>
<td>--------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Allied Health providers (eg. pharmacy)</strong></td>
<td>No – ability to use, but no actual use</td>
<td></td>
</tr>
<tr>
<td><strong>Different views relevant to the various health professions:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• GPs</td>
<td></td>
<td>Delivered with some delays/barriers</td>
</tr>
<tr>
<td>• RACF nurses</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• GP Assist</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Residents of RACFs</strong></td>
<td><strong>4C’s scope did not include residents of the community living at home</strong></td>
<td>Delivered</td>
</tr>
<tr>
<td><strong>Send, receive and acknowledge</strong></td>
<td></td>
<td>No</td>
</tr>
<tr>
<td><strong>Access to education content only.</strong></td>
<td><strong>4C’s scope did not include the delivery of a consumer portal which provided access to health information.</strong></td>
<td>Consumer educational content was delivered on both the 4CEHR project webpage and DHHS webpages[^32].</td>
</tr>
<tr>
<td><strong>Screen providing an overview of the status of each RACF resident, including trajectory and prognostic code, completed elements of the care plan and any current/active deteriorations</strong></td>
<td>Delivered</td>
<td></td>
</tr>
<tr>
<td><strong>Records and displays Enduring Guardian or Person Responsible Prompts initiation of an</strong></td>
<td>Delivered with some design limitations</td>
<td></td>
</tr>
</tbody>
</table>

### Scope

<table>
<thead>
<tr>
<th>Scope</th>
<th>Intended</th>
<th>Actual</th>
</tr>
</thead>
</table>
| DPAG  | Enduring Guardian for residents with capacity  
Records all existing documents relating to the residents wishes | Delivered; however, generally considered to be immature |
| CAPs  | Records important baseline clinical information, including comfort and functionality.  
Information obtained through discussion with the resident and their family regarding values, preferences and goals of care is documented.  
Expected deteriorations are recorded\(^{33}\) | Immature  
CAPs were supplied by the clinical specialists; however these were not provided within the required timeframes and were not appropriately reviewed prior to inclusion in the system.  
The CAPs are currently underdeveloped and require refinement. |

As referenced in Table 10, the following features were specifically excluded from the scope of the 4C project:

**Table 11 4C scope exclusions**

| Scope exclusion\(^{34}\) | Integration of 4C with existing software was identified as being crucial for the ongoing use and implementation of the system. The lack of system integration was identified as a barrier to uptake and use (see System Integration within section 7.3.2). |

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\(^{33}\) Cradle Coast Connected Care (4C) Clinical Repository Final Report, v1.0 13 May 2013, page 3  
\(^{34}\) Cradle Coast Electronic Health Information Exchange, Annex A – Project Context and Scope, v1.1 27 May 2011, page 14
A consumer portal which provides access to individual health information

It was originally intended that the PCEHR infrastructure would provide consumer access to individual health information. As the PCEHR has been delayed, this has not been delivered to date.

Residents of the community living at home

As the system was only piloted in the RACFs, functionality for community members was not required. Community use was included in the 2013 draft business plan for state-wide implementation of the 4C system.

All plans for expected and unexpected deteriorations

A broader range of CAPs were included in the 4C system than originally intended. Stakeholders suggested that it may have been beneficial to limit the initial scope of CAPs to the dying phase, presenting more refined and usable information.

Data entry of all existing residents to the 4C system at ‘Go Live’

Due to difficulties registering residents (see Resident Registration within section 7.3.2), members of the 4C project team provided assistance with the registration process.

7.3.1 Successes

A number of successes have been identified in the design and implementation of the 4C system. This includes particular features which align with the needs and preferences of the users.

**RACFs have continued to use elements of the LWDW approach which can be supported by the 4C system**

The 4C system was ultimately designed in a way which was aligned with, and allowed it to support, a range of features from the LWDW approach. This includes the following:

- coding
- use of diagnostic tools (such as Karnofsky and CAMS)
- storage of enduring guardian/person responsible and Advance Care Directive information
- DPAG approach to advance care planning (including documentation and recording of advance care planning discussions).

As discussed in section 6, the participating RACFs have continued to use some of these elements of the LWDW approach following the pilot period. Despite the ongoing use of these LWDW tools/content, no RACFs are currently using the 4C system to support these processes.
The system has the potential to support processes which are being undertaken within the RACFs.

**There is support for the ability to communicate Advance Care Directives**

Originally, the 4C system was intended to support the communication of Advance Care Directives both within and between healthcare settings. It was widely accepted that advance care planning information needs to be shared with a variety of health professionals. As identified in the RACF survey, this may include a range of professionals including GPs, GP Assist, nurses in RACFs and the community, hospital staff, ambulance staff and specialists.

During consultations, stakeholders expressed support for a system or approach which would enable and assist the communication and sharing of this information among relevant professionals. However, the existence of an electronic system does not achieve this simply by existing – it also needs to be used. Achieving uptake and use of any communication mechanism, including electronic systems was an acknowledged barrier. The same issues currently exist with the PCEHR.

**There is support for functionality in relation to clinical care planning, in particular anticipatory prescribing**

The participating RACFs were very supportive of undertaking clinical care planning and anticipatory prescribing to support the delivery of care, especially out of hours and during the dying phase. While it was possible for both of these activities to be supported by/undertaken within the 4C system, this functionality was not widely used during the pilot. Despite this, RACFs indicate that care planning has been enhanced through the LWDW approach and is beneficial.

As clinical care planning and anticipatory prescribing are highly valued by RACF staff, the inclusion of these features in the 4C system is considered to be relevant and appropriate.

### 7.3.2 Barriers

A number of system limitations and other barriers were identified which limited the implementation and uptake of the 4C system. The consequences of these issues were considered to be quite significant by the participating RACFs and ultimately became barriers to the use of the 4C system.

**System limitations and security concerns**

During the consultations a number of system limitations and security concerns were identified which impacted upon stakeholder willingness and ability to use the 4C system. These are detailed in Table 12.

### Table 12 4C system limitations and security concerns

<table>
<thead>
<tr>
<th>Limitation</th>
<th>Impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Structural issues within the system including:</td>
<td>Inconsistencies in the layout of the various 4C screens and other technical issues</td>
</tr>
<tr>
<td>Limitation</td>
<td>Impact</td>
</tr>
<tr>
<td>---------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>• inconsistent placement of buttons between screens</td>
<td>decrease the usability of the 4C system.</td>
</tr>
<tr>
<td>• cursor moving while correcting typos</td>
<td></td>
</tr>
</tbody>
</table>
| Key terminology is not consistent, defined and appropriate for all healthcare settings | Different RACF staff may have different understandings/definitions of the data recorded in the 4C system. This may result in:  
  • residents being rated inconsistently by different RACF staff  
  • RACF staff interpreting information about residents differently, for example, their functional ability  
  Inconsistent ratings and understandings may further limit the ability of the RACF staff to provide person-centred care. |
| Documents are grouped by type of document rather than date                | Where a resident has multiple versions of each document type, it may be difficult for the RACF staff to determine what information (document types) is available. This may limit their ability to access and use recorded information in a crisis situation / when decisions need to be made quickly. |
| Changes to a GPs default medication preferences will retroactively be applied to all of the GPs residents without warning | Retroactive updates to resident’s medications may result in inaccuracies within the 4C records. The system will not record information about the medication and doses which the resident actually received. |
| Inaccuracies in medication charts as a result of:                         | 4C users are unable to rely on printed medication charts due a number of known inaccuracies.  
  • automatic population from the CAPs  
  • errors in the opioid calculator  
  The 4C system automatically populates the name of the CAP for prescription from the CAPs documents. This may not accurately reflect the reason a resident has been prescribed a particular medication, potentially resulting in errors and inaccuracies within the resident’s record.  
  The opioid calculator currently does not calculate correct dosages. |
<p>| GPs were able to approve medications which can only be authorised by palliative care specialists (eg. Ketamine) | Potential to generate non-compliance and inappropriate prescriptions. This has been corrected. |
| All 4C users were able to                                                 | RACF staff will be able to inappropriately                                                      |</p>
<table>
<thead>
<tr>
<th>Limitation</th>
<th>Impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>access and print the medications chart</td>
<td>access and update information about prescribed medications. This was considered to be particularly problematic by the participating RACFs who refused to use the system until this had been rectified. This has been corrected.</td>
</tr>
</tbody>
</table>

**Resident registration**

The registration of residents within the 4C system relies upon the Healthcare Identifiers (HI) Service. Specifically, the RACF is required to enter basic information about the resident (such as name, date of birth and Medicare number) which is matched against the resident’s Individual Healthcare Identifier (IHI).

This process resulted in some difficulties for the participating RACFs. Where a resident (or their family) were unsure about exactly what information was recorded in Medicare, it was difficult to match the IHI and register the resident. For example, the participating RACFs reported that some residents used a name on a daily basis which is different to that recorded by Medicare (and thus, against their IHI).

Medicare requires a person to attend a Medicare office to confirm or update their information. As many RACF residents were physically unable to do this, it was not possible to determine what was in the Medicare record to assist in matching an IHI. These residents could therefore not be registered within the system.

Use of the Tasmanian Health Client Index (THCI) has also been identified as a system enhancement in the 4CEHR Draft Project Business Plan for statewide rollout of the 4C system. This plan suggested that the 4C system could be enhanced by linking the THCI to the IHI to simplify the registration process.

**System integration**

A range of medical software is currently used within Australian RACFs. This includes pieces of software which are specifically designed for either RACF nursing staff or GPs. GPs tend to have a preference to use the same software which is being used in their practice within the RACF setting.

Table 13 details the software which is commonly used within the participating RACFs. This Table 13 should not be considered to be an exhaustive list of all software used by Tasmanian RACFs and GPs.

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36 4CEHR Draft Project Business Plan, 30 July 2013, page 18
Table 13 Software commonly used in RACFs by nurses and GPs

<table>
<thead>
<tr>
<th>Nurse</th>
<th>GP</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autumn Care</td>
<td>Medical Director</td>
</tr>
<tr>
<td>iCare</td>
<td>Best Practice</td>
</tr>
</tbody>
</table>

The 4C system was introduced in addition to the main software which was already being used within the participating RACFs. No integration with the existing software was included in the final version of 4C, nor was it in scope. However, the lack of integration created a number of key challenges for the RACF staff:

- duplication of data entry
- risk of inconsistent records.

Additionally, it was reported that GPs would generally be unwilling to use different software in addition to their practice software.

**Simultaneous development of the 4C system and LWDW was problematic**

While the 4C project was intended to be developed in a way which supported the LWDW approach, the two projects were delivered in relative isolation.

During consultations it was identified that there was limited communication and interaction between the two project teams, with key team members feeling isolated from each other’s project. This lack of communication prevented appropriate collaboration from being undertaken and was a barrier to development of a 4C system which could fully support the requirements of the LWDW approach.

Further, the LWDW approach was not fully developed or embedded within the participating RACFs when the 4CEHR system was developed and implemented. This created some confusion for the participating RACFs who were unclear about the changing project scope. Stakeholders noted that the changes and developments to the project were highly confusing as:

- RACFs first agreed to participate in the NWAHS GSF project
- the project then changed to become the NWAHS LWDW project
- finally, the project expanded to include the implementation of an ICT system (4CEHR).

Stakeholders noted that these changes to the project resulted in significant differences between the final project scope and what was originally intended and agreed to.

The parallel development of the LWDW approach also impinged on the timeliness and quality of the current 4CEHR system. For example, stakeholders noted that the CAPs were still being drafted the day prior to system release and, as such, had not been appropriately reviewed.
It was suggested that it would be more beneficial to ensure that the approach was fully developed, piloted and refined prior to the commissioning of a supporting system.

**Lack of sufficient testing and uptake impacted on the quality of the final deliverable**

Due to the short 4C project timeframes, limited user testing was undertaken. This restricted the ability of the project team to identify system and content flaws, inconsistencies and other issues which ultimately became barriers to system use and uptake.

**RACFs still commonly use paper based records**

RACFs generally have a preference for the use of paper based records. This was identified through consultations with the participating RACFs and the RACF survey.

Sixty-four percent of the 11 respondents to the RACF survey only use paper based records to store Advance Care Directives and advance care planning information. A further 27% use both electronic and paper records while 9% use only electronic records. Despite this, the majority of respondents indicated that an electronic system to support advance care planning would be of value.

The implementation of the 4C system therefore requires some cultural change within the participating RACFs, moving away from the existing system of paper based records. It is possible that RACF staff will be unwilling to change their practice in this manner, creating a barrier to the ongoing use of a system such as 4C.

**RACF staff have relatively low computer literacy**

Throughout the stakeholder consultations it was suggested that RACF staff have relatively low computer literacy. This may impact upon the users understanding of how to appropriately navigate and use the system, as well as potentially limiting their confidence in its use. This has the potential to become a barrier to the ongoing use of the system. RACF staff who are uncomfortable with, or unable to appropriately use, the system will be unlikely to support its ongoing use.

**‘Help’ section immature**

There is a lack of ‘help’ information in the current system. This may prevent users from accessing the necessary information to assist them in proper use of the system.
7.4 Uptake and use

Following conclusion of the project 30 June 2012, and after the target date for the go-live release (14 June 2012\(^{37}\)) had elapsed, the current version of the system was released 29 November 2012\(^{38}\).

The 4CEHR system is not currently used by RACFs who participated in the pilot.

Due to problems primarily related to permissions for prescriptions approvals and IHI matching issues (described in section 7.3.2) the system was not significantly used after go-live. However, work was undertaken by the system administrator (and some RACFs) to register and load relevant documentation for residents that had completed advance care planning activities and provided consent for the information to be loaded and shared via 4CEHR.

The key barriers that prevented initial and ongoing use of the system were:

1. The project concluded prior to release of a system version that was suitable for use. **(Opportunity for improved functionality)**

2. End-users were not resourced sufficiently for system implementation. **(Implementation support requirements)**

3. The conclusion of the project led to the withdrawal of personnel and funding. End-user stakeholders doubted that the system would be supported or adopted by others, and therefore were no longer willing to commit resources to pilot its use. **(Project certainty and stakeholder engagement)**

7.4.1 Functionality

Since conclusion of the 4CEHR project a number of reviews have been undertaken and documents have been produced outlining opportunities to improve the functionality of the system. These have been prepared based on the experiences and feedback of users to date. Documents of this nature that were made available during this evaluation are detailed in Table 14 below. Further feedback was collected as part of this evaluation including from RACFs and future stakeholders.

**Table 14 Documents detailing future improvement opportunities**

<table>
<thead>
<tr>
<th>Title</th>
<th>Description</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cradle Coast Connected Care (4C) Clinical Repository Final Report</td>
<td>Details the status, risks, issues and lessons learnt.</td>
<td>13 May 2013</td>
</tr>
<tr>
<td>4CEHR State-wide</td>
<td>Business plan to achieve state wide rollout of 4CEHR (and ...</td>
<td>30 July</td>
</tr>
</tbody>
</table>

\(^{37}\) 4C Annex D Project Implementation Approach V2.0 27 May 2011, page 10

\(^{38}\) 4C Clinical Repository Final Report v1.0 13 May 2013, page 3
<table>
<thead>
<tr>
<th>Title</th>
<th>Description</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rollout Business Plan</td>
<td>LWDW</td>
<td>2013</td>
</tr>
</tbody>
</table>
| Tasmania Health Organisation – North West 4C System Change Requests | Details:  
- urgent system fixes (4)  
- urgent improvement requests (30) | May 2014 |

While the above documents detail a number of fixes required to improve the usability of the 4C system, they do not address the key concern of uptake across settings.

Only one of the participating RACFs indicated that 4C would have value as a standalone system. Despite expressing this view, the RACF is not currently utilising the system. All other RACFs and GPs felt that the system would only have value if it was integrated with existing RACF software and enabled the communication of advance care planning information between health settings. Without the inclusion of this functionality, it is unlikely that there would be widespread use of the 4C system.

7.4.2 Implementation support

Support was provided to each of the participating RACFs during the implementation of the 4C system. This support was provided in addition to the formal 4C training and included project team members registering residents at each participating RACF.

Such additional assistance was considered to be highly valuable by the participating RACFs. As the registration of residents was considered to be time consuming and difficult, additional assistance to complete this was well received.

Upload of resident records

The 4C project had a target of having 500 RACF residents ready for enrolment in the system. As shown in Table 15, the project did not meet this target.

It should be noted that the target of 500 registrations was developed when Umina Park was still included in the project. As the capacity of Umina Park is greater than that of Emmerton Park it was unlikely that this target would be achieved following the withdrawal of Umina Park from the project\(^\text{39}\).

---

Table 15 Target and actual registration of RACF residents in the 4C system

<table>
<thead>
<tr>
<th>Target of RACF residents ready to be enrolled&lt;sup&gt;40&lt;/sup&gt;</th>
<th>Actual (1 July 2012 - 1 May 2013)&lt;sup&gt;41&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>500</td>
<td>73% - 366</td>
</tr>
</tbody>
</table>

While an information booklet and consent form for RACF residents was developed as part of the 4C project, this was generally considered to be overly complex and difficult to use.

Stakeholders reported that the information booklet was not written in a manner which could be easily understood by residents, and may have become a barrier to participation. It was generally believed that residents who did not understand the content of the booklet and consequently the nature of the 4C system may have been unwilling to consent to registration. These residents reportedly found it too difficult to participate or attempt to understand the system. This highlights the importance of communicating details of any system or health initiative to the target audience in a way which can be understood.

The overly complex nature of the 4C information booklet does not align with the approach of LWDW which seeks to communicate information in an appropriate manner that can be easily understood by residents and families. The detail and content of the consent booklet were driven by the PCEHR project.

7.4.3 Project certainty and stakeholder engagement

The system name, Cradle Coast Connected Care Electronic Health Record (4CEHR), carries negative perceptions for some past RACF stakeholders due to the failure of the system to become operationalised, in combination with the resources, effort and support required by them throughout the project.

The disappointment and negativity also speaks to the need to clearly set expectations for stakeholders and engage regularly with them to ensure there is a shared understanding.

Despite being a pilot, there was a strong belief that the project would be continued beyond the initial period. This belief was shared by the project team and participating RACFs. While we do not have specific details of how or what was communicated to stakeholders with regard to the project’s continued support, it is believed that there was no communication to suggest the project may not continue until late in the project. During interviews undertaken as part of this evaluation, no RACF stakeholders indicated understanding that, as a pilot, the outcome could be to discontinue support for the 4CEHR system.

<sup>40</sup> Cradle Coast Electronic Health Information Exchange, Annex A – Project Context and Scope, v1.1 27 May 2011, page 12
<sup>41</sup> Cradle Coast Connected Care (4C) Clinical Repository Final Report, v1.0 13 May 2013
Future stakeholders may also be put off by the system name due to its ‘ownership’ by North-West Tasmania. This is within context of historically strained relationships between the three areas of Tasmania. As Tasmania adopts a single health area model it may also be inappropriate to use regionally based names.

7.4.4 Cost to enhance and roll-out

As detailed throughout this section, a number of improvements to the functionality and capability of the 4C system would be required to support and encourage the future use of the system.

DHHS and THO-North West provided an estimation of the costs associated with the ongoing implementation and maintenance of the 4C system (Table 16).

**Table 16 Estimated implementation and maintenance costs for the 4C system**

<table>
<thead>
<tr>
<th>Purpose</th>
<th>Estimated cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ongoing licences, support and maintenance</td>
<td>$500,000 (per annum)</td>
</tr>
<tr>
<td>System enhancements, implementation and state-wide roll-out</td>
<td>$3,800,000</td>
</tr>
<tr>
<td>Project management</td>
<td>$950,000</td>
</tr>
</tbody>
</table>

---

42 Note: These costs were provided by DHHS and THO-North West and have not been validated by Grosvenor.
43 Note: The cost estimate excludes the change management component.
8 Approaches to advance care planning

A number of different approaches and tools for conducting advance care planning are currently used throughout Australia. This includes specific approaches and tools which are used and promoted by:

- Medicare Locals
- State and Commonwealth Government Departments
- health care providers (including hospitals and RACFs)
- peak bodies such as Palliative Care Australia and Alzheimer’s Australia.

National guidance has been provided through the 2011 ‘National Framework for Advance Care Directives’ which aims to encourage consistency between the different approaches to end of life care planning. The framework was developed to be an aspirational document which describes goals for policy and practice, rather than presenting the current law and practice across Australia.

As identified in the framework, different legislation in each state and territory has contributed to the development of different Advance Care Directives. Further, the framework identifies that the ‘high level of variability makes it difficult for one jurisdiction to legally recognise an ACD [Advance Care Directive] from elsewhere’44. The framework seeks to address the challenges presented by the different laws as well as concerns about the use of and application of Advance Care Directives] throughout Australia.

The Commonwealth Government has provided funding and support for a number of national palliative care projects which relate to advance care planning. This includes:

- funding for Austin Health’s Respecting Patients Choices program (section 8.1.1)
- support for the Residential Aged Care Palliative Approach and funding for the development of the Residential Aged Care Facility End of Life Care Pathway (section 8.1.2)
- establishment of the Specialist Palliative Care and Advance Care Planning Advisory Service (Decision Assist – section 8.1.3).

This section discusses some of the major approaches to advance care planning which are currently used in Australia. Each of the approaches which have received either Commonwealth funding or support are discussed, along with some of the other approaches used within Tasmania or referenced by the LWDW pilot RACFs.

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8.1.1 Respecting Patient Choices

Respecting Patient Choices (RPC) was first piloted by the Austin Hospital, Melbourne, in 2002. The pilot program was supported by the National Institute of Clinical Studies within DoHA\textsuperscript{45}. The Australian implementation of RPC was based on the RPC program developed in La Crosse Wisconsin.

Today, RPC program is run from the Austin Health Offices in Melbourne. The program offers a two part training package targeted towards health professionals. The program is particularly targeted towards:

- nurses
- social workers
- allied health staff in general practice
- people working in aged care, palliative care and with people who have a chronic illness\textsuperscript{46}.

<table>
<thead>
<tr>
<th>Table 17 Respecting Patient Choices training program</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cost</strong></td>
</tr>
</tbody>
</table>
| Part 1 – E-learning | Free | • Six module e-learning course  
• Broad introduction to Advance Care Planning principles, legal aspects and documents  
• Background information about having a conversation regarding medical treatment |
| Part 2 – Practical workshop | $300 | • Designed to increase the skills, confidence and knowledge of people working in health care to have Advance Care Planning discussions  
• Provides skills to:  
  - complete a Medical Enduring Power of Attorney  
  - identify an Advance Care Directive  
  - understand how to introduce Advance Care Planning |

\textsuperscript{45} Respecting Patient Choices, Respecting Patient Choices in Australia,  
\textsuperscript{46} Advance Care Planning Australia, Respecting Patients Choices Training brochure,  
Since the initial pilot program, a number of hospitals have conducted the training and implemented the approach. This includes the Royal Hobart Hospital in April 2006. The approach has also been implemented in a number of RACFs, particularly within Austin Health Victoria. When contacted as part of this evaluation, RPC indicated that it is common for health providers who undertake the training to apply the content in a modified format that is appropriate for their facilities. Therefore, while a hospital or RACF may have undertaken the training, they may not identify as using the RPC approach.

The RPC team currently also maintain the Advance Care Planning Australia website. This website is intended to provide general information about Advance Care Planning within Australia and does not focus exclusively on the RCP approach.

### 8.1.2 Residential Aged Care Palliative Approach

The Residential Aged Care Palliative Approach (RACPA) was initially developed in 2004. The associated RACPA toolkit was developed and pilot tested in 2009-10 by a consortium led by the University of Queensland and Blue Care Research & Practice Development Centre. This approach provides a toolkit of resources to assist RACFs to “build their internal capacity to implement a comprehensive, evidence-based palliative approach to care for appropriate residents.”

The toolkit project aims to “strengthen the capacity of residential aged care staff to deliver high quality, evidence-based care for residents by:

- providing training on how to use the PA toolkit in the day-to-day provision of palliative care,
- developing new clinical, educational and management resources for inclusion in, and to support the implementation of, the PA toolkit.”

The toolkit was expanded in 2013 to include an additional six resources developed by a consortium led by the Brisbane South Palliative Care Collaborative (BSPCC). These resources focus on supporting the introduction of a framework of care based upon:

- advance care planning
- palliative care case conferences
- end of life care pathways.

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This included the addition of the Residential Aged Care End of Life Care Pathway (RAC EoLCP) discussed below.

A national rollout of the toolkit has been funded by the Department of Social Services under the Encouraging Better Practice in Aged Care (EBPAC) Initiative. The rollout is being led by BSPCC in partnership with clinical, industry and academic organisations.

The RACPA Toolkit website contains a range of tools and educational resources for participating/interested RACFs. This includes the full PA toolkit\(^ {51}\) which features a range of tools including:

- training videos and DVDs
- training support guides
- brochures for health professionals and families
- relevant guidelines.

Details of the full content of the toolkit are available in the project brochure\(^ {52}\) and website\(^ {53}\).

The approach includes use of the surprise question along with general and disease specific indicators to assist RACF staff in determining a resident’s trajectory. The approach uses three trajectories:

**Table 18 Palliative Approach to Residential Care\(^ {54}\)**

| Trajectory A | • expected prognosis of greater than 6 months  
| | • annual nurse led case conferences, including advance care planning  
| | • six monthly review |
| Trajectory B *The Palliative Phase* | • expected prognosis of six months or less  
| | • palliative case conference conducted, including review of advance care planning  
| | • assessment and management of palliative clinical symptoms  
| | • monthly review |
| Trajectory C *The Terminal Phase* | • expected prognosis of less than one week  
| | • commence RAC EoLCP  
| | • review daily |

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\(^{54}\) The Palliative Approach Toolkit, Module 1: Integrating a palliative approach, [http://www.uq.edu.au/bluecare/docs/Module%201.pdf](http://www.uq.edu.au/bluecare/docs/Module%201.pdf)
Free workshops (funded by the Department of Social Services (DSS)) are being conducted for RACF managers, clinical leaders and educators. Up to two representatives were able to attend the workshops from each RACF. As the workshops focus on introducing the toolkit and training staff how to use the resources and specifically target managerial and clinical staff, recommended attendees include:

- the RACF Manager (Care Director or Director of Nursing)
- a Registered Nurse or Enrolled Nurse employed in a clinical area who is able to become the RACFs ‘Link Nurse’.

Workshops were scheduled to be held throughout Australia from October 2013 to December 2014. In Tasmania, these workshops were held in Hobart and Launceston in March 2014. No further funding has been provided to extend the training beyond these dates.

A total of 96 individuals from 44 RACFs in Tasmania participated in the training sessions. This included at least one of the five LWDW pilot RACFs.

Material from the RACPA is to be included in the Department of Health’s Decision Assist Program. To avoid duplication, with Decision Assist, the RACPA project team advised that no further broad workshop programs will be conducted. Despite this, fee for service education may be available in the future.

It is expected that all material associated with the RACPA (including additional factsheets and podcasts) will be made available online by December 2014.

An evaluation of the RACPA is currently being conducted, with the findings to be presented to DSS in May 2015.

**Residential Aged Care Facility End of Life Care Pathway**

In 2013, BSPCC received funding from DoHA to ‘develop, implement and evaluate an End of Life Care Pathway specifically for use in… RACFs’. This resulted in the development of the Residential Aged Care End of Life Care Pathway (RAC EoLCP) which was designed to guide the provision of end of life care in RACFs.

As part of DoHA funding, the RAC EoLCP was evaluated against Palliative Care Australia’s best practice standards across 299 deaths. The results of this evaluation showed that:

- when the RAC EoLCP was implemented with a supportive framework, dying residents were significantly less likely to be transferred to hospital

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55 The Link Nurse has a range of specific duties within the RACF to promote and implement a palliative approach.
there were improvements in the quality of palliative care provided by RACFs

the RAC EOLCP increased the confidence of RACF clinical staff to deliver palliative care.

The RAC EoLCP has been further evaluated against the EBPAC project. From this project it was recommended that the RAC EoLCP document be made widely available to RACFs. It is now available with a supporting webinar on the RACPA Toolkit website58.

Under the RAC EoLCP approach, training should be made available to all staff within the RACF involved in end of life care. Specifically, the following elements of the implementation framework have been identified:

- “establishment of dedicated Palliative Care Link Nurses within each RACF
- creation of palliative care educational resources
- establishment of a RACF Medication Imprest System that allows for timely access to drugs commonly used at end of life
- mechanisms to link RACF staff with Specialist Palliative Care colleagues to improve complex case management
- mechanisms to facilitate GP support to provide end of life (terminal) care ‘in place’59.

At this stage, the RACPA and RAC EoLCP only focus upon RACFs.

8.1.3 Specialist Palliative Care and Advance Care Planning Advisory Service (Decision Assist)

The Australian Government has funded the Specialist Palliative Care and Advance Care Planning Advisory Service (Decision Assist) Project to enhance the national provision of palliative care and advance care planning services60.

There are several key aspects to Decision Assist, as outlined on the care search website. The project includes:

- the establishment of a national advice based telephone service for GPs and aged care providers
- development of standard clinical practice guidance for specialist palliative care and advance care planning.

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focus on up skilling and educating GPs and aged care providers

increasing the linkages between aged care and palliative care services.\(^{61}\)

Respecting Patient Choices is the lead agency for Decision Assist. The project also involves:

- Palliative Care Australia
- Care Search
- The University of Queensland
- Queensland University of Technology
- The Australian and New Zealand Society of Palliative Medicine
- Leading Age Services Australia
- Aged and Community Services Australia.

A range of educational activities have been designed as part of Decision Assist for GPs and Aged Care Providers.

The ‘Decision Assist Aged Care Training Package – Residential’ will combine e-learning modules and face to face workshops to provide training about palliative care and advance care planning. The two workshops are designed as follow on training from the Palliative Approach Toolkit.\(^{62}\)

While only two face to face workshops will be conducted, these are scheduled two months apart to enable participants to implement the content of the first session. This is similar to the LWDW approach. Attendance at the workshops will cost $150 per attendee.\(^{63}\)

8.1.4 Enhancing Aged Care through better Palliative Care

Enhancing Aged Care through better Palliative Care seeks to provide intensive community-based palliative care services for aged care clients living in the community and in RACFs. The project specifically aims to:

- “enhance client choice in their end-of-life care
- reduce client admissions to emergency departments, where possible
- increase client satisfaction and quality of life, through reduced delays to receive specialist palliative care services, the availability of a 24/7


home service and the ability of the NP [nurse practitioner] to liaise with hospital care services and GPs on the client’s behalf”\textsuperscript{64}.

A pilot of the project is currently being undertaken and is expected to conclude on 31 December 2014. This project is funded by the Better Health Care Connections grant program\textsuperscript{65}.

\subsection*{8.1.5 Peak bodies and area specific programs}

A number of peak bodies within Australia and individual Medicare Locals provide information about advance care planning through their websites. Examples of these programs include:

- Alzheimer’s Australia’s Start2Talk Program\textsuperscript{66}
- the My Wishes program managed by Sydney South West Area Health Service\textsuperscript{67}
- MyChoice, NSW North Coast\textsuperscript{68}.

Depending upon the organisation, the information may be targeted towards health professionals or individual members of the community. The content of these websites is often similar, aiming to provide the skills and knowledge required to complete an advance care directive.

Additionally, some health care providers and RACFs have established or adopted their own approaches to advance care planning. This includes Southern Cross Care in South Australia which has implemented LWDW under the support of Dr Robyn Brogan\textsuperscript{69}.

\subsection*{8.1.6 Healthy Dying Framework}

At the time of this evaluation, DHHS was developing the Tasmanian Healthy Dying Framework. This framework has been designed to

“support and guide community-wide efforts towards making Tasmania a place where the idea of healthy dying is familiar and unexceptional, and the prospect of natural death is recognised, acknowledged and supported by all parts of the Tasmanian community and its services”\textsuperscript{70}

\textsuperscript{64} University of Queensland, Evaluation of the Enhancing Aged Care through Better Palliative Care, http://www.uq.edu.au/bluecare/evaluation-of-the-enhancing-aged-care-through-better-palliative-care
\textsuperscript{66} Alzheimers Australia, Start2Talk, https://www.start2talk.org.au/
\textsuperscript{67} NSW South Western Sydney Local Health District, My Wishes Advance Care Planning Program, www.mywishes.org.au
\textsuperscript{69} Southern Cross Care, Living Well Dying Well Project, http://www.southerncrosscare.org.au/?p=254
\textsuperscript{70} Department of Health and Human Services, An approach to healthy dying in Tasmania: a policy framework, October 2014 Draft v0.D
The framework is structured around three essential components referred to as ‘pillars’:

- Having the Conversation - Building capacity to talk about death and dying and engage in advance care planning for end of life care
- Delivering End of Life Care - Building a Tasmanian community and a service system network that supports and provides person-centred, timely and appropriate end of life care
- Bereavement Care - Building capacity to access and deliver bereavement support

A number of key elements are identified throughout the framework to ensure its successful delivery and implementation. This focuses upon actions required and targeted towards the Tasmanian Government, health professionals and the community.

The framework acknowledges and builds upon the range of end of life care initiatives which are currently used within Tasmania. This includes references to:

- the 4CEHR and LWDW pilot and evaluation
- the healthy dying initiative and Medical Goals of Care Plan (see section 8.1.7)
- activities undertaken by TAHPC.

8.1.7 Medical Goals of Care Plan

The Medical Goals of Care Plan is a component of the Tasmanian Healthy Dying Initiative. This plan aims to:

“ensure that patients who are unlikely to benefit from medical treatment aimed at cure, receive care appropriate to their condition and are not subjected to burdensome or futile treatments.”

This aim is underlined by seven principles. The plan provides a tool to assess any patients being admitted to hospital to identify their goals of care.

The Medical Goals of Care Plan was initially implemented by the Royal Hobart Hospital and has recently been made available for use throughout Tasmania.

While the original Medical Goals of Care Plan was developed for use in the acute setting, an adapted version of the plan is available for use in the

community and RACFs. The community and RACF form is considered to be a template which may be updated and modified as required.

A Medical Goals of Care Plan developed in the acute setting may be endorsed for use out of hospital following the transfer or discharge of a patient. The plan must be endorsed by the Consultant, Specialist responsible or delegate as remaining active and provided to the ambulance crew transferring the patient for palliative or terminal care. During consultations it was identified that the plan is being used by some RACFs within Tasmania; however, it was noted that the manner in which it is used is likely to be inconsistent. Stakeholders suggested that the form could be used by RACFs in multiple ways, including:

- incorporating a form which was previously completed in another healthcare setting into end of life care planning for a newly admitted (or readmitted) resident
- completing the form as part of end of life care planning for residents who have not previously undertaken advance care planning.

The BAPC project intends to increase the uptake of the form within the public health services. The identification and documentation of medical goals of care is also referenced throughout the draft Healthy Dying Framework.

### 8.1.8 COMPAC Guidelines

In 2013, the Australian Healthcare and Hospitals Association (AHHA) commenced training in Tasmania about the implementation of the Guidelines for a Palliative Approach for Aged Care in the Community Setting (known as the COMPAC Guidelines). This was funded as part of the Tasmanian Health Assistance Package and has sought to encourage uptake and use of the COMPAC Guidelines. The Tasmanian face-to-face training has been offered in addition to online training available across Australia. The face-to-face training is delivered through two streams which are combined into one session:

- professional stream (including paid health workers, unregistered care workers, nurses, allied health professionals and GPs)
- volunteer/family carer stream.

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8.1.9 TAHPC training

The Tasmanian Association for Hospice and Palliative Care (TAHPC) provides a number of training programs and tools for health professionals and community members interested in advance care planning and end of life care.

TAHPC is currently conducting advance care planning workshops for health professionals involved in care coordination or case management. These workshops seek to educate attendees about the principles of advance care planning and how this can be introduced to a client.

TAHPC is also operates a program of peer education to improve advance care planning and advance care directives. The role of these educators is to:

- provide information to aged and health care service providers, volunteer groups and the wider community about advance care planning
- to explain the advance care directive document
- to explain the role and responsibilities of substitute decision makers
- encourage conversations about end of life care\(^79\).

8.1.10 Tasmanian HealthPathways

The Tasmanian HealthPathways project has developed and implemented a range of specific health pathways for use within Tasmania. This project is based on the approach used in New Zealand’s Canterbury Initiative which has been adopted in various areas of New Zealand and Australia.

The health pathways provide agreed approaches for the management of medical conditions in Tasmania and will ultimately address both palliative care and advance care planning. This should align the management of medical conditions across various health care professionals (including those in hospitals and the community)\(^80\).

All health pathways are accessible to health professionals through an online portal. Specifically, the portal provides information on how to assess and manage a wide range of medical conditions, and how to refer patients to local specialists and services in the most timely and efficient way\(^81\).

A broad range of health professionals (including GPs, specialist and allied health providers) will be involved in the ongoing development and review of the health pathways.

9 ICT support for advance care planning

A high-level desktop analysis was conducted to identify if there are alternative ICT approaches to support the development and communication of advance care planning documentation across health care settings.

The following alternative ICT solutions were identified:

- My Health Care Wishes - Advance Care Plan app (US)
- HSA Global - Collaborative Care Management Solution (NZ).

In addition the current status of the PCEHR and DHHS ICT platform were explored.

9.1.1 Alternative ICT solutions

Table 19 Existing software and systems

<table>
<thead>
<tr>
<th>Solution</th>
<th>Description</th>
<th>Use and reach</th>
</tr>
</thead>
<tbody>
<tr>
<td>My Health Care Wishes - Advance Care Plan app</td>
<td>Smartphone app that allows you to store and share an advance directive. Lite version of the app is free. Pro app with additional functionality costs AU$4.33</td>
<td>Origin: US  Developed by: American Bar Association Commission On Law And Aging  Android (Lite)  Installs: 1,000-5,000  Rated: 4.4 by 9 users iTunes does not provide a rating due to the low number</td>
</tr>
<tr>
<td>Collaborative Care Management Solution (CCMS)</td>
<td>CCMS is a purpose built connected software platform which is designed with to work existing IT systems. Advance Care Planning functionality has been included in this software.</td>
<td>Origin: NZ  Developed by: HSAGlobal  The system is reportedly widely used within NZ, including:  • Auckland’s National Shared Care Project  • Canterbury’s Collaborative Care Program  • South Eastern Sydney Medicare Local currently</td>
</tr>
</tbody>
</table>

83 HSA Global Connecting Care, Connected Care Management System, http://www.hsaglobal.net/products-services/connected-care-management-system
<table>
<thead>
<tr>
<th>Solution</th>
<th>Description</th>
<th>Use and reach</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>uses CCMS to manage two mental health programs. HSAGlobal has engaged DoH and NEHTA on how Advance Care Plans in CCMS could be published to the PCEHR. Operates using a licensing model.</td>
</tr>
</tbody>
</table>

9.1.2 PCEHR

The PCEHR provides a potential mechanism for the storage and sharing of advance care directives. There is intent to include capture of advance care directives within the PCEHR. There is no current agreement for the functionality of this component of the PCEHR. Nor is there a current timeframe for the inclusion of advance care directive functionality. Currently the PCEHR includes an Advance Care Directive Custodian component. This allows for the custodian of an individual’s advance care directive to be recorded, but does not allow for the advance care directive itself to be captured.

9.1.3 iPM

iPM is the patient administration system used in Tasmania. There is a clinical alert within iPM called 'Advance Care Directive'.

9.1.4 DHHS ICT platform

The Connected Care Strategy seeks to deliver an information services platform, offering a single, longitudinal view of patient / client information.

There is potential for this platform to provide the ability to interface with:

- 4CEHR and/or
- a community targeted mobile app for advance care directives and/or advance care planning.

The Connected Care Strategy sets out that "all ICT systems within Tasmanian Health will continue to use THCI as their primary identifier, mapping to the IHI as required for PCEHR related activity. Nevertheless, front-line staff will be empowered and encouraged to collect and update

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85 Written advice received from Department of Health, 29/08/2014


87 Connected Care Strategy v1.3 FINAL 29 November 2013, page 34
Medicare numbers to enable increased rates of matching with the IHI and enable online billing processes.\textsuperscript{88}

As a result if the 4CEHR system was to be adopted it would need to use the THCI (which it currently does not) to interface with the future DHHS platform. It should be noted that the 4CEHR system has been built on the same platform and is compatible with the systems proposed under the Connected Care Strategy. It would therefore be possible to interface 4CEHR with the portal in the future, potentially avoiding the duplication of data entry and facilitating the communication of advance care directives across health settings.

9.1.5 Comparison to 4CEHR

With the exception of the Collaborative Care Management Solution all of the identified ICT solutions relate to enabling the communication of advance care directives between individuals and their health care providers, rather than supporting the process of advance care planning.

The PCEHR and DHHS Connected Care platform may both provide alternative options to local interfaces between 4CEHR and other health management information systems\textsuperscript{89}.

\textsuperscript{88} Connected Care Strategy v1.3 FINAL 29 November 2013, page 44
\textsuperscript{89} Note: The PCEHR is currently an opt-in system which does not provide this functionality. It is unclear when this functionality will be introduced.
10 A consistent approach for Tasmania

Throughout this evaluation it was widely acknowledged that many palliative care activities (including different approaches and training programs) are currently being conducted within Tasmania. Stakeholders from both within the State and other areas of Australia noted that this is often quite confusing, with health professionals being presented with a range of different approaches and tools.

Stakeholders were generally supportive of the development of a state-wide approach to advance care planning. Throughout the consultations, a variety of views were expressed regarding the development and implementation of a consistent advance care planning approach or system in Tasmania.

Specific feedback was sought from stakeholders about what would be required in a state-wide system, as well as how this should be implemented.

This section of the report considers what would be required to develop and implement a state-wide approach to advance care planning. This will address:

- the design of a state-wide approach, including scope, stakeholders and outcomes sought (section 9.1)
- how a state-wide approach could best be implemented (section 9.2).

10.1 Developing a state-wide approach

During the consultations, stakeholders expressed a range of suggestions and requirements for what a state-wide approach would need to include. These have been broadly grouped into:

- involvement of health professionals
- required personal skills of health professionals
- applicability and documents access across settings
- content and detail
- community education and promotion
- systems.

Involvement of health professionals

As individuals are remaining in their own homes for longer, it was generally agreed that a state-wide approach to advance care planning would need to target all levels of the health system, including primary care. Engaging a variety of health professionals within the community may support more recent models for palliative care. During consultations, stakeholders referred to changes in the palliative model as shown in Figure 5.
Stakeholders suggested that there has been (or needs to be) a shift in palliative care from a model where curative and palliative care are conducted in isolation (A) to one where the two forms of care overlap (B). The inclusion of advance care planning in the community setting may assist in developing an environment where this can occur.

Despite common acceptance that advance care planning should occur in the community, there was no consensus on the most appropriate time, or setting, for this to occur. No health professional identified their profession as being the most appropriate point to commence advance care planning.

Professions which were identified as potentially being appropriate to conduct advance care planning in the community included:

- GPs
- Practice Nurses
- Care Coordinators
- Community Nurses
- Allied Health Professionals (such as Social Workers)
- Aged Care Assessment Teams.

Time and resource constraints were generally cited as reasons it would be inappropriate to conduct advance care planning within particular health care settings. Advance care planning discussions reportedly vary in time, ranging from 10 to 15 minutes to several hours across multiple days/sessions (as experienced using the LWDW approach). This time requirement was considered to be a particular barrier to the completion of advance care.

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**Figure 5 Approaches to palliative care**

Stakeholders suggested that there has been (or needs to be) a shift in palliative care from a model where curative and palliative care are conducted in isolation (A) to one where the two forms of care overlap (B). The inclusion of advance care planning in the community setting may assist in developing an environment where this can occur.

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planning by those professions who only have short consultations with their patients (such as GPs).

Additionally, it was identified that current billing arrangements may be a barrier to the completion of advance care planning in some health care settings. Health professionals will be unlikely to spend time conducting advance care planning discussions if this is not something that they can easily claim/bill for.

**Required personal skills of health professionals**

A range of skills were identified as being necessary for health professionals involved in advance care planning and end of life care discussions. Stakeholders believed that these skills should be introduced and promoted as part of any state-wide training. It was emphasised that advance care planning should not be undertaken by health professionals who do not have the required personal skills.

**Identifying suitable times to conduct advance care planning**

Stakeholders suggested that it may not always be appropriate to discuss a patient’s or resident’s preferences for end of life care. This conversation should not be forced onto the person, instead, health professionals should be educated to identify when the patient or resident is ready to have this discussion and/or introduce it sensitively.

**Appropriate, sympathetic and simple communication**

Stakeholders suggested that health professionals need to be able to communicate in a sympathetic manner which is easily understood by the patient and their family. Avoiding the use of medical jargon was identified as being particularly important in Tasmania due to the low level of health literacy within the community. Communicating in an appropriate manner will assist in ensuring that all parties understand and are comfortable with the outcomes of the discussion. It will also assist in minimising the distress of advance care planning discussions on individuals and their families.

**Applicability and document access across settings**

As discussed in section 6.2.8, different forms are accepted and recognised in different health settings. This may result in a lack of transferability of advance care planning information between the health settings.

To overcome this lack of transferability and recognition, it would be beneficial for a state-wide approach to use consistent forms in all health care settings. This would ensure that health professionals were familiar with the format of the information and were easily able to identify such information in a paper (or digital) file.

As multiple health professionals may be involved in the care of one person, any advance care planning information also needs to be accessible. For example, ambulances attending an emergency situation should be easily able to determine whether someone has an advance care directive in place.
RACF survey respondents identified a range of health professionals who they believe should have access to any documented advance care plan. Identified health professionals are shown in Table 20.

**Table 20 What health professionals should have access to the information contained in a resident’s advance care plan? (N=10)**

<table>
<thead>
<tr>
<th>Response</th>
<th>Response count</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP and/or GP Assist</td>
<td>8</td>
</tr>
<tr>
<td>Nurses (including community nurses)</td>
<td>5</td>
</tr>
<tr>
<td>All relevant health professionals</td>
<td>3</td>
</tr>
<tr>
<td>Hospital and emergency</td>
<td>3</td>
</tr>
<tr>
<td>Palliative Care Team and other specialists</td>
<td>5</td>
</tr>
<tr>
<td>Allied Health</td>
<td>1</td>
</tr>
<tr>
<td>Paramedic</td>
<td>1</td>
</tr>
</tbody>
</table>

**Content and detail**

Health professionals noted that information and forms need to be clear, concise and easy to use. This is particularly necessary in the acute setting where health professionals may be required to make decisions within very short timeframes. In order to accommodate this, any approach to advance care planning may require the use of short and consistent forms which would facilitate and support timely decision making.

**Community education and promotion**

There was strong support for raising community awareness of advance care planning. It was felt that by making individuals living in the community aware of advance care planning they may be prompted to develop their own advance care plans, appoint an enduring guardian or would have had time to prepare to have this discussion with their health professionals. This would enable an individual to consider what was important to them and develop an understanding of what care they would like to receive.

Areas of the health setting which were identified as being able to facilitate the provision of information about advance care planning ranged from GPs and community nurses to the Aged Care Assessment Teams (ACAT).

Additionally, it may be possible to promote advance care planning through the legal profession. For example, information about advance care planning could be provided when an individual decides to make a will. In a sample of 15 Tasmanian law firms:

- none mention information about advance care planning or Advance Care Directives
seven (47%) mention enduring guardians, however, none provided an explanation

14 (93%) mentioned wills.

**Systems**

Some stakeholders felt that benefits may be experienced through the use of a state-wide system. Specific system requirements were identified which may encourage its use:

- designed in a way which is simple, practical and easy to use
- should assist GPs and other staff in making complex decisions (for example, calculating dose and providing transparency around the prescription of opioids)
- integrate with other systems to avoid duplication of data entry or multiple sources of truth.

While there was broad support for simplifying the communication of advance care planning information, there was not universal support for the use of a system to achieve this. Stakeholders provided a number of examples of why a system may not be used/ideal. This included:

- lack of alignment with existing DHHS tools and systems
- lack of consistency with the broader ICT work being undertaken by DHHS
- a reluctance to use multiple systems to complete a task (especially if multiple log-ins are required)
- concerns around the duplication of data which may result in conflicting patient records.

It should be noted that the barriers above are general in nature and are not specifically targeted at 4CEHR. As discussed in section 9.1.4, it is acknowledged that the 4CEHR system has been built to be compatible and integrate with other DHHS systems to be established under the Connected Care Strategy.

**Learnings from the review of the Liverpool Care Pathway**

Similar to LWDW and the other advance care planning approaches, the Liverpool Care Pathway was designed to improve end of life care for all patients. The pathway specifically targets the final days of life and can be used regardless of care setting. Following numerous criticisms of the approach in the media, a major review of this pathway was undertaken.

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Learnings from this review should be considered in the development and implementation of any state-wide approaches in Tasmania. Some of the relevant learnings/recommendations include:

- variable definitions and understanding of the term ‘end-of-life’ (from last year of life to last days of life) lead to incorrect use of the pathway
- the term ‘pathway’ should not be used in relation to care in the last year of life as it can carry connotations of assisted death
- the use of a dying pathway should not be financially incentivised
- evidence gaps exist for care provision in the last year of life
- honest communication was fundamental to providing appropriate care – acknowledging death and dying, futility of medical intervention and uncertainty
- the need to plan for and support ‘out of hours’ care to avoid crisis
- the importance of documentation
- that staff competence and resourcing level were a serious concern.

**Duplication and communication**

While it was suggested that all health professionals should be educated and able to undertake advance care planning, potential barriers were identified to the practical use of this approach. The involvement of multiple individuals in advance care planning may result in confusion around which is the latest (and most accurate) version of a patient’s advance care directive. Additionally, it is possible that some health professionals engaged with a patient may be unaware that an advance care directive exists, preventing its appropriate use.

To overcome this, the importance of regular communication with the patient, and if relevant, substitute decision maker was emphasised.

**Current practice in RACFs**

As part of this evaluation an online survey was made available to all RACFs within Tasmania. The RACF survey sought to identify existing and preferred approaches to advance care planning within each of the RACFs.

All RACF survey respondents (100%, N=15) indicated that their RACF engaged residents in conversations about their end of life care. Despite this, the RACF survey responses showed inconsistencies in the way that advance care planning is conducted in RACFs.

The proportion of residents at each RACF engaged in these discussions varied (Figure 6). Additional consultation and analysis would be required to determine why some of the facilities only engaged ‘some’ or ‘few’ residents in these discussions.
Figure 6 What proportion of residents does your Residential Aged Care Facility engage in discussions about their end of life care? (N=14)

The time at which Advance Care Planning discussions are conducted within an RACF also varied considerably (Figure 7).

Figure 7 When does your Residential Aged Care Facility typically engage new residents in conversations about their wishes and preferences for end of life care? (N=14)

The RACF survey also sought information from RACFs throughout Tasmania about which staff are involved in Advance Care Planning (Figure 8).

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Figure 6: What proportion of residents does your Residential Aged Care Facility engage in discussions about their end of life care? (N=14)

- All residents: 57.1%
- Most residents: 14.3%
- Some residents: 14.3%
- Few residents: 14.3%
- Very few residents: 0.0%

Figure 7: When does your Residential Aged Care Facility typically engage new residents in conversations about their wishes and preferences for end of life care? (N=14)

- Prior to admission: 28.6%
- At the time of admission: 21.4%
- Within 2-3 weeks of admission: 14.3%
- Within 2 months of admission: 0.0%
- More than 2 months after admission: 0.0%
- The time varies depending upon the residents care requirements and condition: 35.7%
As shown in the above figure, advance care planning discussions at the respondent’s facilities commonly involve the Resident, Family and a Registered Nurse. However, a broader range of staff may be involved, including the GP (85.7%), Enrolled Nurses (50%) and care staff (35.7%).

RACF survey results suggest that the formal documentation of advance care plans is a common practice throughout the state with 92.9% (13) respondents currently completing this. Of the respondents formally documenting advance care plans, 91.7% (11) do this in an internally consistent format.

RACFs within Tasmania are still largely reliant upon paper based records to store advance care planning information (Figure 9). This was also identified through the consultations conducted with LWDW participants.

Figure 9 How are the documented advance care plans generally stored? (N=11)

Despite currently relying on paper based records, seven (87.5%) of eight RACF survey respondents felt that the implementation of an electronic end
of life care planning system would be of value for their RACF. Respondents noted that such a system would be of value providing it was consistent and recognised by all stakeholders. One respondent also noted that it would be of value if such a system could be applied both in the community and RACF settings.

10.2 Implementing a state-wide approach

A range of factors were identified as being crucial to achieving consensus for and successfully implementing a state-wide approach. These factors are discussed below and have been broadly grouped into:

- authority and management
- communication, engagement and consultation
- clarity of purpose
- certainty
- understanding of benefits
- meeting the specific needs of health professionals
- systems.

Authority and management

In order to successfully implement a state-wide approach, it is important to have a well-managed project. Stakeholders highlighted that it would be particularly beneficial to have both an appropriate steering committee and project team while implementing a state-wide advance care planning system or approach.

Stakeholders suggested that it would be necessary to establish one steering group which has the appropriate authority to drive the project’s development and/or implementation.

The different health professions and regions within Tasmania each have different needs and requirements. In order to ensure that a system appropriately meets the needs of all health professionals and stakeholder groups, they would require appropriate representation on the steering committee.

Stakeholders highlighted the importance of ensuring that a diverse range of individuals were included in the steering group. It was identified that this should include not only representatives from each health profession impacted by the state-wide approach, but also representatives from each of the different regions and consumers.

By ensuring diverse membership to the steering group, it is possible each health profession within each region will feel that their particular needs and requirements have been heard and incorporated. This may assist in increasing the uptake and ongoing use of any state-wide approach or system.
In addition to the steering group, stakeholders highlighted the importance of having an appropriate project team with sufficient project management resources and skills. This team would need to have the authority and project management skills to manage the project timeframes and deliverables, engage with stakeholders, as well as having appropriate health and medical knowledge.

**Communication, engagement and consultation**

Mutual benefits can be achieved through the ongoing engagement and consultation of health professionals who would be required to use a new system or process.

Stakeholders noted that they become frustrated if they are unable to regularly access information about a project in which they are interested or will be impacted by. This will assist in managing stakeholder expectations, particularly if delays are encountered or changes occur.

During the consultations a number of opinions about what stakeholders considered would be appropriate, beneficial and useful in an advance care planning system or approach were identified (as discussed in section 10.1). These views should be taken into account during the development (or selection) and implementation of a state-wide approach or system.

Understanding the requirements and views of the different stakeholders will provide a better understanding of what the end-users will demand, and therefore what they are likely to accept. The state-wide approach or system can then be tailored (or selected) to best fit these needs and requirements, providing users with what they consider to be useful. Aligning the approach with the needs and requirements of the stakeholders may assist in encouraging uptake and use.

**Clarity of purpose**

In order to encourage its uptake and ongoing use, the purpose and intent of a state-wide approach or system would need to be clearly articulated to all relevant health care professionals. This will ensure that all health professionals have a common understanding and expectations of the system or approach.

**Certainty**

As discussed in section 7.3.2, multiple changes occurred to the LWDW project during its development and implementation. These changes resulted in some of the RACFs feeling uncertain about whether the training they were receiving and system that they were using would ultimately be replaced or changed. This feeling was exacerbated when the 4C system was not ultimately used or further developed.

As a result of this, the RACFs expressed some reluctance to engage with new approaches or systems until they were certain that they would be used and supported on an ongoing basis.
Understanding of benefits

Health professionals are commonly driven to adopt or use a new system or approach based on available evidence about the benefits of changing. This often involves relying on academic and scholarly articles about the ability of the approach or system to achieve its intended outcome and result in benefits to users and/or patients. These health professionals are unlikely to undertake the additional work associated with learning how to use and implement a new approach or system if the benefits are unclear.

It would therefore be important to highlight the benefits of a state-based approach to health professionals to encourage its uptake and ongoing use. This may include any benefits and achievements which were realised during a pilot program or which have been published in academic journals.

Meeting the specific needs of health professionals

The specific needs and requirements of health professionals should be considered as part of any state-wide approach or system. For example, consulted health professionals often highlighted that they were time poor and may be unable to take on additional tasks. The time requirements of using any state-wide system or approach on participating health professionals would therefore need to be carefully considered.

Any state-wide approach or system should also be simple and easy to use, complementing the other tools and systems currently in use.

Systems

A number of ICT projects are currently being progressed by DHHS and the THO’s which would potentially impact upon the implementation of a state-wide Advance Care Planning system. This includes the recently developed Connected Care Strategy.

The Connected Care Strategy has been designed to provide a clear, well-articulated ICT vision and strategy for DHHS. It "defines the vision, goals, principles, architecture and plans that will be delivered by 2016, in order to place care consumers at the centre of their own care, and to be better utilise ICT as an important lever in delivering a more accessible, equitable and sustainable Health and Human Services system"92.

The vision of the Connected Care Strategy is to develop a Connected Care Platform which:

- "underpins an increasingly accessible, equitable and sustainable Tasmanian Health and Human Services system by enabling and supporting new and emerging models of care, based on the provision of high quality, longitudinal care consumer centric information"

- ... support[s] improving care consumer access and engagement, streamlining and standardising the care consumer journey and

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92 Connected Care Strategy v1.3 FINAL 29 November 2013, page 8
improving care consumer safety through the increased use of decision support tools

- ...drive[s] ... greater continuity of care across multiple care settings, increasing the productivity and connectedness of staff.

- ... provide[s] stable, secure and highly available ICT infrastructure to support critical applications, and will be resilient to future changes in Health, Human Services and ICT governance structure.\(^{93,94}\)

The Connected Care Strategy details 12 objectives and goals to assist in achieving this vision. This includes the following:

**Table 21 Extract of Connected Care Strategy Objective and Goals\(^{95}\)**

<table>
<thead>
<tr>
<th>Objective / Goal</th>
<th>Metrics / Measures</th>
</tr>
</thead>
</table>
| Improve Consumer Access and Engagement | • provision of a care consumer portal  
• development of mobile apps for self-management by Tasmanian patients / clients  
• % of Tasmanian population signed up for the Patient / Client Portal and Mobile Applications |
| Streamline and Standardise the Patient / Client Journey | • provision of key EMR functions (in an EMR / EHR) for clinical assessments and handover across care settings, electronic observations management, care planning, pathway and chronic disease management  
• Provision of shared care planning capabilities  
• implementation of a strategic eForms platform |
| Improve Quality and Safety through Decision Support | • implementation of electronic ordering (in the Connected Care Portal) for radiology, pathology and medications with appropriate Clinical / Case Management Decision Support to assist these processes  
• implementation of a clinical / risk alerting system based on results outside defined parameters  
• implementation of an electronic solution to manage patient/client alerts and allergies to provide clinical / case management decision support and improve patient / client safety |
| Improve Continuity of Care Across Multiple Care Settings | • implementation of a case management and pathways (i.e. community and mental health) system  
• implementation of a single view of patient / client (across acute and community care sectors) in the Connected Care Portal |

\(^{93}\) Connected Care Strategy, v1.3, 29 November 2013, page 27.  
\(^{94}\) Note: emphasis added by DHHS  
\(^{95}\) Connected Care Strategy, v1.3, 29 November 2013, page 27-28
As the Connected Care Strategy and Platform are being developed to be used by all DHHS clinicians in both the acute and community care sectors, they are likely to have a wide reach and impact.

Members of the DHHS IT team expressed reluctance for standalone, independent systems to be implemented for use within the Tasmanian Health System. There is a preference for all new ICT projects to align with both the Connected Care Strategy and Platform where possible. The stakeholders also commented that any systems which are built should be on a flexible platform.

Any state-wide system to support advance care planning should be developed and implemented in the context of the broader ICT work being undertaken by DHHS. This will assist in ensuring that the system aligns with, and is supported by, the broader DHHS ICT environment, potentially increasing the robustness of the system.

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96 Note: While the 4CEHR system intended to meet these criteria this was not realised. As discussed in section 10.1, both 4CEHR and the Connected Care Platform are built on the Miya Platform and could therefore be integrated if required.
11 Conclusions

11.1 Is the LWDW the most appropriate approach to advance care planning in aged care for application across Tasmania? (KEQ5)

To answer this question Grosvenor canvassed other approaches to advance care planning in residential aged care homes in Tasmania. We found that the RACPA approach to advance care planning is very similar to LWDW, and has a number of advantages over LWDW. Namely;

- the RACPA toolkit is supported by DSS as the national approach
- the RACPA tools and guidance are well developed, available online, and are free of charge
- RACPA has broader reach, in Tasmania and nationally
- there is ongoing support for the RACPA toolkit via Decision Assist.

Given that RACPA appears to have a more substantial reach than LWDW in Tasmania, and is supported as the national approach, it may be a more appropriate choice for Tasmania.

**Recommendation 1:** It is recommended that DHHS supports RACPA as the advance care planning approach for Tasmanian RACFs.

11.2 What will it take to establish a sustainable LWDW program state-wide in Tasmania? (KEQ4)

As we have found that RACPA appears to be a more appropriate choice for Tasmania, we have not sought to describe how to establish LWDW as a sustainable program. Instead we have drawn upon the information collected in the evaluation to describe the key strengths and learnings from the LWDW pilot and reflect how Tasmania could further support the implementation of RACPA, or another advance care planning approach, using these strengths and learnings.

**Change management and implementation support**

The implementation of a state-wide approach to advance care planning is a major endeavour requiring engagement and change across the health care system in Tasmania. The importance of organisational readiness for successful implementation was particularly apparent in the LWDW pilot. For example the changes in leadership at Umina Park during the pilot created an organisational environment that was no longer ready to implement LWDW.

The primary strength of the LWDW approach that is not present in the RACPA approach to the same extent is the facilitated culture change and implementation support approach. This key strength of the LWDW program could be utilised in conjunction with RACPAs broad use, online presence and polished documentation to further improve advance care planning and end-of-life care.
Recommendation 2: It is recommended that DHHS considers investing in a supported implementation model for RACPA to embed and improve advance care planning in Tasmanian RACFs.

Recommendation 3: It is recommended that DHHS ensure appropriate change management practices are utilised to support the state-wide implementation of RACPA (or another approach). Change management activities should focus upon ensuring organisational readiness for the change, and draw upon the strengths of LWDW in facilitating culture change and supporting on the ground implementation.

Advance care planning approach across health settings

It is acknowledged that the RACPA currently focuses on the RACF setting and does not address the need for advance care planning in the community or hospital settings.

The different health settings within Tasmania are likely to have different requirements and resources available to conduct and support advance care planning. The ‘how to’ guidance and support provided to healthcare professionals as part of a sustainable state-wide approach needs to recognise the constraints of each setting and be able to be supported within the available resources and finances and meet the user needs.

That is, implementation design needs to consider:

- when to do something
- how long it will take on average
- what needs to be achieved
- how it will be used and by whom
- cost and risk
- resources and sources of knowledge available and relevant to each health setting and how these can be accessed (including expert support).

These may vary in each setting based on the practice and processes already in place. For example, conduct of a DPAG process over five hours is not practical within RACF resourcing. However, a short preliminary introduction, followed by a detailed conversation, and then a short follow-up to conclude and confirm the planning over two weeks may be.

Tailoring the state-wide approach to each healthcare setting and ensuring its appropriateness given the available resources will assist in achieving its sustainability. Healthcare settings are much less likely to use an approach on an ongoing basis which is not considered to be practical and/or relevant to their needs.
A number of other projects (such as Enhancing Aged Care through better Palliative Care) provide examples of how advance care planning can be implemented in the community setting. Additionally, the GSF could be utilised by DHHS as an example of how the central principles of an advance care planning approach can be tailored to, and applied within, a range of health care settings.

Further, the pilot identified that it is important for the outputs of an advance care planning approach to be known and accepted across health settings to be effective. I.e. An advance care plan developed in a RACF needs to be used outside of this setting to be effective, including by ambulance, hospital and after hours GP services.

**Recommendation 4:** In order to ensure the ongoing sustainability of a state-wide approach, it is recommended that DHHS ensures the state-wide approach:

- is practical and appropriate for the capabilities and limitations of each health care setting
- is able to be supported from within the healthcare setting (i.e. within the available resources)
- educates each health settings about the support which is available, including from experts such as the Specialist Palliative Care Service.

It is recommended that DHHS draws upon other projects such as Enhancing Aged Care through better Palliative Care and the GSF to inform how advance care planning can be implemented beyond RACFs, that is, in the community and other health settings.

**Recommendation 5:** It is recommended that DHHS engage sufficiently with all health settings to overcome barriers to the recognition and use of advance care planning outputs across health settings.

**Engage and seek commitment and support from all health settings and professionals**

In order to successfully implement a state-wide approach it is necessary to engage and gain commitment from all health settings and professionals that will be impacted by the changes.

The LWDW and 4CHER projects highlighted:

- the differing needs and preferences of the various health professions which would need to be identified and addressed during the development and implementation of any state-wide system/approach

- the importance of engaging GPs to ensure the successful adoption of improved advance care planning within RACFs and the community. This also extends to engagement of afterhours services such as GP Assist to ensure advance care plans are appropriately used in crisis situations occurring outside of business hours. Failure to engage GPs is likely to hinder acceptance and use of any state-wide approach
• the criticality of securing senior management support to successfully achieve and embed culture and practice changes

• the importance of engaging senior management and senior staff with clarity of purpose and requirements/commitments. At the outset a clear road map of the journey should be provided as well as realistic estimates of resource effort and costs.

It is noted that health professionals can be difficult to engage in a timely manner. For example, both the LWDW project and this evaluation found it problematic to appropriately engage GP Assist. Early engagement with these groups is likely to provide the best opportunity to gain their input and views within the required timeframes, and ensure that these can be used to inform development and implementation.

If there are data collection requirements for evaluative purposes these should also be made clear from the outset and along with any guidance and tools to support data collection.

**Recommendation 6:** It is recommended that DHHS engages more broadly with health professionals to implement a system wide approach to advance care planning which includes the community and acute care settings. DHHS should ensure all stakeholders and health care settings are appropriately engaged and commit to the state-wide approach. Any engagement should be undertaken with clarity of purpose and requirements/commitments. In particular DHHS should engage:

• all relevant health professionals during the development and implementation of the approach to ensure that their unique needs are identified and appropriately addressed

• senior management within affected health organisations to seek endorsement of the implementation and ongoing use of the approach within their facility.

**Recommendation 7:** It is recommended that DHHS identify any data collection requirements during implementation of the state-wide approach.

**Engage with hubs**

A key learning from the LWDW pilot is not to stagger roll-out by setting type, but rather engage ‘hubs’ of relevant stakeholders concurrently. A hub could be relatively small or large, but it would include at least:

• 1 RACF

• each GP servicing that RACF (and potentially the entire general practice of each relevant GP)

• the pharmacy servicing the RACF

• the hospital (or hospitals) primarily used by the RACF

• local ambulance services
- allied health professionals who work at the RACF
- specialist palliative care services in the area.

Within the same localised hub other activities in the BAPC framework could be promoted simultaneously to raise awareness in the broader local community and allow for a system wide advance care planning approach to be implemented. The education of community health professionals alongside professionals from RACFs, hospitals and general practices within their local region will ensure that all health sectors represented within the region are aware of and using the same approach.

It makes sense to start with smaller hubs at first. Once the project is fully established (and if there is sufficient capacity) larger sized hubs could be engaged (i.e. multiple RACFs and by extension larger groups of other health providers). There are benefits to be gained by involving multiple providers of one type in capacity building/culture change sessions. The benefits are derived primarily from the sharing of experiences and practice with each other.

Targeting of RACFs for engagement could involve are range of factors, such as:

- willingness (including senior management support as detailed above)
- quality of advance care planning (e.g. facilitated by state-wide use of the National Standards Assessment Program (NSAP)), and/or hospitalisation rates as indicators of quality).

**Recommendation 8:** It is recommended that DHHS implements a state-wide approach through a ‘hub’ model which concurrently targets cross sector health professionals in the same location at the same time as RACFs.

**Recommendation 9:** It is recommended that DHHS consider how the hub-based implementation model can support the sharing of experiences and practices between providers in the same and across health settings to improve practices.

**Recommendation 10:** It is recommended that DHHS integrates the roll-out of a state-wide advance care planning approach with the BAPC framework to simultaneously raise community awareness of advance care planning.

**Recommendation 11:** It is recommended that DHHS targets those RACFs which have the greatest opportunity to improve under the approach. This should be assessed against their willingness to participate, quality of advance care planning and hospitalisation rate.
11.3 Does 4CEHR have the capacity to support the goals of LWDW in Tasmania? (KEQ2)

AND Is 4CEHR the most appropriate system to support LWDW and advance care planning in Tasmania?

The 4CEHR system does not currently have the capacity to support the goals of LWDW (or another advance care planning approach such as RACPA) in Tasmania. This is for a number of reasons:

- the initial pilot of 4CEHR in residential aged care homes was not completed, so there is not detailed knowledge of its suitability
- substantial updates would be required to prepare the 4CEHR system prior to the commencement of any further pilot testing.

Thus there is need for further investment prior to determining 4CEHR’s capacity to be utilised state-wide and support the goals of an approach such as RACPA. While there is evidence supporting the need to improve end of life care through advance care planning approaches, this alone does not make 4CEHR the most appropriate option or necessarily worth investment.

To inform this investment decision the following should be considered:

1. How will widespread uptake of the system be achieved across settings (eg RACF, GP, acute) sufficient to justify investment?
2. Is achievement of downstream outcomes incumbent upon (or sufficiently promoted by) an ICT system?

These are demonstrated by the draft program logic in Figure 10.

The qualitative information provided in this evaluation indicated system uptake/use will be difficult to achieve.

There is not sufficient information available to provide any indication on the likely outcomes of question 2 above.

Other options for supporting or enabling the communication of advance care directives include:

- use of common forms within settings and gaining endorsement and recognition across settings (we note that this has already commenced)
- wait for PCEHR functionality and continue to promote uptake of PCEHR in the interim
- migrate core functionality of the 4CEHR into the Connected Care platform.

Advance care planning functionality may be further supported by investigating the willingness of major RACF and GP software providers to further develop their products in this area in a way that is consistent with the RACPA approach.
Recommendation 12: It is recommended that DHHS considers the options for supporting communication of advance care directives in Tasmania and make a decision on the further investment in a 4CEHR pilot. In making this decision, DHHS should analyse the core functionality of the 4CEHR to determine whether it can be integrated into existing systems, including the Connected Care Platform.

If further investment in 4CEHR is supported:

- it should be integrated with relevant software and platforms
- it should be appropriately named in a descriptive manner and have state-wide relevance (rather than a regional focus)

11.4 Is 4CEHR consistent with the approach of LWDW? (KEQ1)

A key caveat to answering this question is the fact that piloting of 4CEHR by residential aged care facilities was not completed due to system issues and uncertainty of future support. The conclusion to this key evaluation question is limited by the lack of a true pilot to generate the necessary data for evaluation.
Furthermore, given conclusion 1, it appears necessary to comment upon the capability of 4CEHR to support other advance care planning approaches, especially RACPA. We have done so below.

At a high level the 4CEHR system appears to be consistent with the approach of LWDW. It encompasses functionality which is likely to have the ability to support many of the key LWDW processes and activities for advance care planning in residential aged care facilities. Such as: coding, use of diagnostic tools (Karnofsky, CAMS), storage of current enduring guardian or person responsible details and advance care directives, supports DPAG.

The similarity of RACPA and purposeful decoupling of 4CEHR from GSF, also gives 4CEHR the potential to support other advance care planning approaches.

However, some 4CEHR content such as the CAPs and opioid calculator is less mature and duplicates other existing sources of information some of which are maintained by DHHS. For example, some duplication has been identified between:

- the Tasmanian Palliative Care HealthPathways and 4CEHR CAPS
- Tasmanian Palliative Care formularies and 4CEHR opioid calculator.

Where an existing information source is already available and maintained, there may be redundancy in including this functionality in the 4CEHR system. Instead a link could be provided to existing materials through the 4CEHR system. The inclusion of existing DHHS tools within the system would assist in ensuring that all health professionals are accessing and utilising the same guidance materials (consistency of care).

In comparing the LWDW approach and 4CEHR system there were also gaps in coverage identified. It is unclear whether it would be necessary for a state-wide system to include/support this functionality. These gaps are detailed below:

- after death audits (or other performance reporting capability for continuous quality improvement and performance monitoring)
- guidance/support within the system is limited (i.e. ‘help’ function)
- there is potential for person centeredness to be further facilitated – eg. patient able to access via PCEHR integration
- care of carers and family/friends is not covered by the system
- unclear how aligned/suitable it would be to a LWDW program adapted to other settings. For example in the community would more emphasis need to be placed on the ‘identify’ task.
**Recommendation 13:** If further investment in 4CEHR is supported it is recommended that DHHS:

- review the existing content of 4CEHR and only retain that which is considered to be a ‘core’ requirement by stakeholders/users
- analyse the 4CEHR system to identify any duplication between its functionality/content and existing DHHS tools and materials
- provide appropriate linkages to existing DHHS materials within the system rather than further developing the 4CEHR specific content
- conduct a gap analysis to identify any omissions in the system’s ability to address the requirements of/support LWDW or the RACPA and determine whether the inclusion of this capability is required.

11.5 How does 4CEHR interface with the national program to implement a PCEHR? (KEQ3)

4CEHR provides supportive functionality to undertake advance care planning and improve end of life care based on the LWDW approach. The system is technically able to upload information to the PCEHR, although this is not enabled, and the PCEHR does not currently contain advance care directives.

The PCEHR has the potential to support sharing of advance care directives between health settings in the future (with or without 4CEHR). The ability to do this, and for it to be used, is still some time off.

No recommendation can be made at this time due to the uncertainty around the PCEHR.

11.6 How can Tasmania move beyond trials and establish a state-wide program of coordinated communication for advance care planning? (KEQ6)

4CEHR is not ready to proceed to state-wide roll-out. It requires two key decisions going forward:

- whether to invest further in 4CEHR and run a pilot
- whether to proceed to roll-out based on the pilot outcomes.

As detailed in section 11.1 RACPA appears to be a better supported, lower cost option for Tasmania to adopt as a state-wide advance care planning approach in RACF settings than LWDW.

There is already a range of initiatives at a State and Commonwealth level, which are gaining traction and supporting advance care planning (e.g. implementation of Medical Goals of Care across the acute sector with
potential adaption and adoption in RACFs and the community). The development of a state-wide approach needs to:

- take into account pre-existing programs and activities to avoid duplication and achieve sufficient integration
- address the acceptability of existing and alternative approaches within a state-wide model
- encourage and monitor uptake and implementation.

A range of resources and training materials are available in these alternative approaches which could be leveraged as part of a state-wide approach. For example, GP training activities were developed and approved for LWDW which could be utilised during the implementation of the state-wide approach. It would be necessary to review the appropriateness of these training materials prior to use.

Some key advance care planning initiatives and approaches which are currently being utilised were identified as part of this evaluation and have been highlighted throughout this report. While the approaches detailed in this report should not be considered to be exhaustive, they provide an overview of the types of activities which are presently being conducted. It is also evident through this evaluation that greater awareness and knowledge of advance care planning is required within the community and across the health sector prior to/as part of the implementation of any state-wide approach.

Considerations for establishing a state-wide approach are detailed in section 1010.

**Recommendation 14:** It is recommended that DHHS actively seeks to avoid duplication and achieve integration with other State and Commonwealth approaches to advance care planning through the state-wide approach.

**Recommendation 15:** It is recommended that DHHS review the appropriateness of any approved LWDW training materials to the state-wide approach. If relevant and appropriate, DHHS should refine and utilise these materials to support state-wide implementation.

**Recommendation 16:** It is recommended that DHHS monitors the uptake and implementation of the state-wide approach to advance care planning to ensure it has been consistently adopted across the various healthcare settings.
12 Attachments

12.1 Attachment A – Summary of RACF survey responses

Q1 In what region is your Residential Aged Care Facility located?

<table>
<thead>
<tr>
<th>Region</th>
<th>Responses</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>South Tasmania</td>
<td>37.50%</td>
<td>6</td>
</tr>
<tr>
<td>North Tasmania</td>
<td>43.75%</td>
<td>7</td>
</tr>
<tr>
<td>North West Tasmania</td>
<td>16.75%</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>15</td>
</tr>
</tbody>
</table>

Implementation of a Tasmania wide advance care planning process and record
Q2 Does your Residential Aged Care Facility engage residents in conversations about their end of life care?

Answered: 15  Skipped: 1

<table>
<thead>
<tr>
<th>Answer Choices</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>100.00%</td>
</tr>
<tr>
<td>No</td>
<td>0.00%</td>
</tr>
<tr>
<td>Total</td>
<td></td>
</tr>
</tbody>
</table>
Implementation of a Tasmania wide advance care planning process and record

Q3 What proportion of residents does your Residential Aged Care Facility engage in discussions about their end of life care (e.g. wishes and preferences)?

Answered: 14  Skipped: 2

<table>
<thead>
<tr>
<th>Answer Choices</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>All residents</td>
<td>57.14%</td>
</tr>
<tr>
<td>Most residents</td>
<td>14.39%</td>
</tr>
<tr>
<td>Some residents</td>
<td>14.29%</td>
</tr>
<tr>
<td>Few residents</td>
<td>14.39%</td>
</tr>
<tr>
<td>Very few residents</td>
<td>0.00%</td>
</tr>
<tr>
<td>Total</td>
<td></td>
</tr>
</tbody>
</table>
Implementation of a Tasmania wide advance care planning process and record

Q4 When does your Residential Aged Care Facility typically start to engage new residents in conversations about their wishes and preferences for end of life care?

Answered: 14  Skipped: 2

<table>
<thead>
<tr>
<th>Answer Choices</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prior to admission</td>
<td>28.57%</td>
</tr>
<tr>
<td>At the time of admission</td>
<td>21.43%</td>
</tr>
<tr>
<td>Within 2-3 weeks of admission</td>
<td>14.29%</td>
</tr>
<tr>
<td>Within 2 months of admission</td>
<td>0.00%</td>
</tr>
<tr>
<td>More than 2 months after admission</td>
<td>0.00%</td>
</tr>
<tr>
<td>The time varies depending upon the resident's care requirements and condition</td>
<td>35.71%</td>
</tr>
<tr>
<td>Total</td>
<td>14</td>
</tr>
</tbody>
</table>
Implementation of a Tasmania wide advance care planning process and record

Q5 Who is commonly involved in discussions about patients wishes and preferences for end of life care? (please select all that apply)

Answered: 14  Skipped: 2

<table>
<thead>
<tr>
<th>Answer Choices</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resident</td>
<td>100.00%</td>
</tr>
<tr>
<td>Family</td>
<td>100.00%</td>
</tr>
<tr>
<td>Friends</td>
<td>21.43%</td>
</tr>
<tr>
<td>GP</td>
<td>65.71%</td>
</tr>
<tr>
<td>Palliative care specialist</td>
<td>14.29%</td>
</tr>
<tr>
<td>Registered Nurse</td>
<td>100.00%</td>
</tr>
<tr>
<td>Enrolled Nurse</td>
<td>50.00%</td>
</tr>
<tr>
<td>Care staff</td>
<td>35.71%</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>28.57%</td>
</tr>
</tbody>
</table>
### Implementation of a Tasmania wide advance care planning process and record

<table>
<thead>
<tr>
<th>#</th>
<th>Other (please specify)</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Engagement manor</td>
<td>9/2/2014 1:26 PM</td>
</tr>
<tr>
<td>2</td>
<td>Social Worker</td>
<td>9/2/2014 9:38 AM</td>
</tr>
<tr>
<td>3</td>
<td>Chaplain as appropriate</td>
<td>9/1/2014 6:38 PM</td>
</tr>
<tr>
<td>4</td>
<td>Clinical and Medical staff</td>
<td>9/1/2014 4:23 PM</td>
</tr>
</tbody>
</table>
Implementation of a Tasmania wide advance care planning process and record

Q6 Does your residential aged care facility currently document formal advance care plans for its residents?

Answered: 14  Skipped: 2

<table>
<thead>
<tr>
<th>Answer Choices</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>92.86% 13</td>
</tr>
<tr>
<td>No</td>
<td>7.14% 1</td>
</tr>
<tr>
<td>Total</td>
<td>14</td>
</tr>
</tbody>
</table>

#  Yes, please describe  Date

There are no responses.
Implementation of a Tasmania wide advance care planning process and record

Q7 Do you record the documented advance care plans in a consistent format?

Answer: 12  Skipped: 4

<table>
<thead>
<tr>
<th>Answer Choices</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>91.67%</td>
</tr>
<tr>
<td>No</td>
<td>8.33%</td>
</tr>
<tr>
<td>Total</td>
<td></td>
</tr>
</tbody>
</table>
Implementation of a Tasmania wide advance care planning process and record

Q8 Please describe the content of the documented advance care plans.

<table>
<thead>
<tr>
<th>#</th>
<th>Responses</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>ACD form</td>
<td>9/2/2014 1:28 PM</td>
</tr>
<tr>
<td>2</td>
<td>Statement of Wishes form</td>
<td>9/2/2014 10:44 AM</td>
</tr>
<tr>
<td>3</td>
<td>Act per THOS ACD</td>
<td>9/2/2014 9:40 AM</td>
</tr>
<tr>
<td>4</td>
<td>An Advance Care Directive is provided to resident prior to admission, this is then followed up on the day of admission, dependent on when this is completed. Noted that some residents/families can take a considerable amount of time to complete the ACD and return to staff despite ongoing follow up. Once the completed form has been provided, this information is then fed into a resident specific care plan.</td>
<td>9/1/2014 5:42 PM</td>
</tr>
<tr>
<td>5</td>
<td>We use the statement of wishes document put out by Medicare Local.</td>
<td>9/1/2014 4:25 PM</td>
</tr>
<tr>
<td>6</td>
<td>The initial discussion is documented on the entry data form which is a very brief discussion about their wishes. The next discussion is more detailed and discusses their preference for care and plans of care if they should suffer a serious event from which there is little hope of recovery. We also discuss their funeral arrangements and their personal preferences for care. After some months we usually revisit and do their ACD using the DPAG process. This drifts down a bit further and talks about issues that might be important, i.e. dignity, emotional, spiritual and psychosocial considerations. At that time we also estimate their hospitability score. We often do the last two at the same time. These are reviewed 12 monthly at the family/resident conferences or more often if requested.</td>
<td>9/1/2014 3:43 PM</td>
</tr>
<tr>
<td>7</td>
<td>asking resident what are their wishes for end of life</td>
<td>9/1/2014 2:50 PM</td>
</tr>
<tr>
<td>8</td>
<td>If resident requests hospital transfer for immediate treatment only or for admission and invasive diagnostic procedures - expected deteriorations - end of life wishes - who their nominated person is / responsible person -</td>
<td>8/25/2014 10:34 AM</td>
</tr>
<tr>
<td>9</td>
<td>requirement of CPR or not, religion, if resident would like to go to hospital or stay pain free and comfortable at the facility, who they would like in attendance on their last days.</td>
<td>8/24/2014 4:00 PM</td>
</tr>
</tbody>
</table>
Q9 How are the documented advance care plans generally stored?

Answered: 11  Skipped: 5

<table>
<thead>
<tr>
<th>Answer Choices</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Electronically</td>
<td>0.05%</td>
</tr>
<tr>
<td>In a paper record</td>
<td>63.64%</td>
</tr>
<tr>
<td>Both electronically and on a paper record</td>
<td>27.27%</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>0.00%</td>
</tr>
<tr>
<td>Total</td>
<td></td>
</tr>
</tbody>
</table>

# Other (please specify)  Date

There are no responses.
Implementation of a Tasmania wide advance care planning process and record

**Q10 How does your Residential Aged Care Facility communicate the content of advance care plans? Please describe whether your Residential Aged Care Facility uses a particular system, who is provided with a copy of the advance care plan and at what time the advance care plan is communicated.**

*Answered: 9, Skipped: 7*

<table>
<thead>
<tr>
<th>#</th>
<th>Responses</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>on electronic system, provided as part of any hospital transfer</td>
<td>9/2/2014 1:29 PM</td>
</tr>
<tr>
<td>2</td>
<td>Documentation in progress notes. Statement of Wishes form is filed into history and if requested by resident copy is given to family/friends etc.</td>
<td>9/2/2014 10:44 AM</td>
</tr>
<tr>
<td>3</td>
<td>Hand copy on residents notes. Front of file.</td>
<td>9/2/2014 9:40 AM</td>
</tr>
<tr>
<td>4</td>
<td>As noted above - copies of the ACD is provided to resident/families at their request and a copy provided to the GP if this is requested.</td>
<td>9/1/2014 5:42 PM</td>
</tr>
<tr>
<td>5</td>
<td>GP is given copy and usually involved in the initial discussion anyway.</td>
<td>9/1/2014 4:25 PM</td>
</tr>
<tr>
<td>6</td>
<td>The advanced care plan is stored in the resident's file. Copies are not sent to family members or left with the resident at this time. We do have their end of life wishes document stored in a trailer in the Nurses Office. We access those to inform the Doctor of the resident's wishes if required. Family members may ask to see these documents but they could only do so with resident's permission.</td>
<td>9/1/2014 2:43 PM</td>
</tr>
<tr>
<td>7</td>
<td>raised with the family and resident at time of initial interview that this will be discussed after admission</td>
<td>9/1/2014 2:50 PM</td>
</tr>
<tr>
<td>8</td>
<td>All staff have access to ACD via electronic documentation system - family and resident and GP involved in compiling info.</td>
<td>8/25/2014 10:34 AM</td>
</tr>
<tr>
<td>9</td>
<td>the facility an GP if requests a copy of keeps the advanced care plan, handed over at handovers and written on weekly handover sheet.</td>
<td>8/24/2014 4:09 PM</td>
</tr>
</tbody>
</table>
Implementation of a Tasmania wide advance care planning process and record

Q11 What activities do you believe should be undertaken to facilitate and encourage appropriate end of life care? This may include activities in your own or other health care settings.

Answered: 9  Skipped: 7

<table>
<thead>
<tr>
<th>#</th>
<th>Responses</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Community discussion about death/dying and ACD</td>
<td>9/2/2014 1:29 PM</td>
</tr>
<tr>
<td>2</td>
<td>Open discussion with family and friends encourage staff to be active in the process of end of life care</td>
<td>9/2/2014 10:45 AM</td>
</tr>
<tr>
<td>3</td>
<td>More open discussion on admission, yearly reviews.</td>
<td>9/2/2014 9:41 AM</td>
</tr>
<tr>
<td>4</td>
<td>We need to obtain detailed information from residents and their families re their requests and expectations surrounding their advance care planning - and then implement activities to ensure that their needs are met at the appropriate time.</td>
<td>9/1/2014 5:49 PM</td>
</tr>
<tr>
<td>5</td>
<td>Acute services do not place any weight on advance directives and generally have a distrust of aged care services.</td>
<td>9/1/2014 4:27 PM</td>
</tr>
<tr>
<td>6</td>
<td>I find that there are no many departments looking after palliative care (resources, support, education). I would simplify things if there was more collaboration between these groups.</td>
<td>9/1/2014 3:50 PM</td>
</tr>
<tr>
<td>7</td>
<td>Establishing the end of life care discussion prior to admission at the facility, while still active in the community</td>
<td>9/1/2014 3:36 PM</td>
</tr>
<tr>
<td>8</td>
<td>Open discussion, comfortable surroundings. Family education, GP interaction</td>
<td>8/12/2014 2:55 PM</td>
</tr>
<tr>
<td>9</td>
<td>Close communication between RACF and Hospitals</td>
<td>8/25/2014 10:43 AM</td>
</tr>
</tbody>
</table>
### Implementation of a Tasmania wide advance care planning process and record

**Q12 Based on your knowledge of current forms or processes used for advance care planning, are there any key improvements or gaps which you think need to be addressed? Please describe.**

<table>
<thead>
<tr>
<th>#</th>
<th>Responses</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Consistent use of ACD for Care at End of Life (Tasmania) form</td>
<td>9/2/2014 1:29 PM</td>
</tr>
<tr>
<td>2</td>
<td>Nil</td>
<td>9/2/2014 10:45 AM</td>
</tr>
<tr>
<td>3</td>
<td>Yes, have been a bit hit and miss in the past. Need to tighten up process.</td>
<td>9/2/2014 9:41 AM</td>
</tr>
<tr>
<td>4</td>
<td>Despite all the very best care planning, at times it can be difficult to get residents to make decisions regarding what they want to happen. Some residents and families do not wish to discuss this topic.</td>
<td>9/1/2014 5:49 PM</td>
</tr>
<tr>
<td>5</td>
<td>Acute sector education, particularly medical field, some GPs also have poor understanding of advanced planning and good palliation in general.</td>
<td>9/1/2014 4:27 PM</td>
</tr>
<tr>
<td>6</td>
<td>It would probably be helpful if there was a generic form that everyone used. Then residents could bring their directives in with them and we would have that information straight away.</td>
<td>9/1/2014 3:50 PM</td>
</tr>
<tr>
<td>7</td>
<td>More guidance on correct phrasing.</td>
<td>9/1/2014 3:38 PM</td>
</tr>
<tr>
<td>8</td>
<td>To facilitate the best possible care and ensure each individual’s end of life wishes are respected it would be best if all RACP’s used the same forms - easier for hospital staff to recognize form</td>
<td>8/25/2014 10:43 AM</td>
</tr>
</tbody>
</table>
Implementation of a Tasmania wide advance care planning process and record

**Q13 What health professionals should have access to the information contained in a resident's advance care plan?**

*Answered: 18  Skipped: 5*

<table>
<thead>
<tr>
<th>#</th>
<th>Responses</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>GP, Hospice, Psychologist</td>
<td>9/2/2014 1:29 PM</td>
</tr>
<tr>
<td>2</td>
<td>GPs, Nursing staff, Palliative care team</td>
<td>9/2/2014 10:45 AM</td>
</tr>
<tr>
<td>3</td>
<td>Nursing staff, GP, Licensed Allied Health staff</td>
<td>9/2/2014 8:41 AM</td>
</tr>
<tr>
<td>4</td>
<td>All relevant staff - ensuring that resident confidentiality is maintained at all times.</td>
<td>9/1/2014 5:49 PM</td>
</tr>
<tr>
<td>5</td>
<td>GP practice and on-call GPs.</td>
<td>9/1/2014 4:27 PM</td>
</tr>
<tr>
<td>6</td>
<td>Everyone involved in the resident's care.</td>
<td>9/1/2014 3:50 PM</td>
</tr>
<tr>
<td>7</td>
<td>All health professionals (on transfer) of a resident. It should remain private and shared as required.</td>
<td>9/1/2014 3:38 PM</td>
</tr>
<tr>
<td>8</td>
<td>GPs, nursing staff, paramedics, Emergency Dept, Palliative care team</td>
<td>9/1/2014 2:55 PM</td>
</tr>
<tr>
<td>9</td>
<td>Nurses, GPs, Hospitality staff, community nurses including palliative care, GP, AHP, DSWAS, GP Assel</td>
<td>8/25/2014 10:43 AM</td>
</tr>
<tr>
<td>10</td>
<td>General Practitioner</td>
<td>8/24/2014 4:08 PM</td>
</tr>
</tbody>
</table>
Implementation of a Tasmania wide advance care planning process and record

Q14 Would the implementation of an electronic end of life care planning system which records the wishes, values and anticipatory care for each resident be of value for your facility? Please describe why/why not.

Answer Choices: 8 Skipped: 8

<table>
<thead>
<tr>
<th>Answer</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>87.50%</td>
</tr>
<tr>
<td></td>
<td>7</td>
</tr>
<tr>
<td>No</td>
<td>12.50%</td>
</tr>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td></td>
</tr>
<tr>
<td></td>
<td>8</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>#</th>
<th>Please describe</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Currently use electronic documentation would complement this system</td>
<td>9/2/2014 12:56 PM</td>
</tr>
<tr>
<td>2</td>
<td>We do not operate using an IT based system - need distinct document currently in paper based.</td>
<td>9/12/2014 5:50 PM</td>
</tr>
<tr>
<td>3</td>
<td>If it was integrated by all stakeholders, not just the aged care facility.</td>
<td>9/12/2014 4:29 PM</td>
</tr>
<tr>
<td>4</td>
<td>We already have this in our electronic documentation system, however if there was one that was generated in the community and remained appropriate when they are admitted we would find that very useful.</td>
<td>9/12/2014 4:02 PM</td>
</tr>
<tr>
<td>5</td>
<td>We are already electronic so would suit us, enabling easier transfer for documentation. It would be great if it was uniform state wide.</td>
<td>9/12/2014 3:39 PM</td>
</tr>
<tr>
<td>6</td>
<td>But only with a staff member working with the facility to support or answer questions.</td>
<td>9/12/2014 2:56 PM</td>
</tr>
<tr>
<td>7</td>
<td>Only if all RACP’s were using the same form</td>
<td>8/25/2014 10:44 AM</td>
</tr>
</tbody>
</table>
### Implementation of a Tasmania wide advance care planning process and record

**Q15 What functionality would be included in your ideal electronic end of life care planning system? (please consider content, tools and integration with other systems)**

<table>
<thead>
<tr>
<th>#</th>
<th>Responses</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Key functionality is to ensure it can be accessed by all systems in acute/primary care</td>
<td>9/2/2014 1:31 PM</td>
</tr>
<tr>
<td>2</td>
<td>User friendly</td>
<td>9/2/2014 12:56 PM</td>
</tr>
<tr>
<td>3</td>
<td>THOS has a good document which could be used.</td>
<td>9/2/2014 9:42 AM</td>
</tr>
<tr>
<td>4</td>
<td>It would be simplistic as possible, easy to use, easy to access and easily updated.</td>
<td>9/1/2014 4:29 PM</td>
</tr>
<tr>
<td>5</td>
<td>Our current system integrates with all our other electronic care plans, forms and progress notes. That is very helpful. It would be useful if this particular information could be accessed from the Doctor's Surgery and hospital.</td>
<td>9/1/2014 4:02 PM</td>
</tr>
<tr>
<td>6</td>
<td>tick boxes, copy and paste, drop down boxes of pre populated responses</td>
<td>9/1/2014 3:39 PM</td>
</tr>
<tr>
<td>7</td>
<td>Other healthcare professional access</td>
<td>9/1/2014 2:56 PM</td>
</tr>
<tr>
<td>8</td>
<td>Would need to &quot;Talk to&quot; all electronic documentation programe currently used in RACP - Icona, Lee care etc</td>
<td>8/25/2014 10:44 AM</td>
</tr>
</tbody>
</table>
Implementation of a Tasmania wide advance care planning process and record

**Q16** What do you think would be required to successfully implement state wide changes in advance care planning?

Answered: 7   Skipped: 9

<table>
<thead>
<tr>
<th>#</th>
<th>Responses</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>consistent forms/electronic systems</td>
<td>9/2/2014 1:31 PM</td>
</tr>
<tr>
<td>2</td>
<td>regional education with ongoing support available i.e. online packages.</td>
<td>9/2/2014 12:58 PM</td>
</tr>
<tr>
<td>3</td>
<td>Consistency in approach and application.</td>
<td>9/1/2014 4:32 PM</td>
</tr>
<tr>
<td>4</td>
<td>Collaboration with all care providers.</td>
<td>9/1/2014 4:04 PM</td>
</tr>
<tr>
<td>5</td>
<td>Someone to take control of it, roll it out, develop the online tool or electronic tool to do it, and then have a dedicated professional team who in consultation with GPs &amp; ACAT, and facilities visited people (like the ACAT team) pre admission to get the required information.</td>
<td>9/1/2014 3:41 PM</td>
</tr>
<tr>
<td>6</td>
<td>IT systems that were integrated</td>
<td>9/1/2014 2:56 PM</td>
</tr>
<tr>
<td>7</td>
<td>As in Q15 - and also be compatible with GP software</td>
<td>8/25/2014 10:46 AM</td>
</tr>
</tbody>
</table>
Implementation of a Tasmania wide advance care planning process and record

Q17 Are there any barriers which would need to be overcome to implement a state wide approach to advance care planning?

<table>
<thead>
<tr>
<th>Answer Choices</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>12.56%</td>
</tr>
<tr>
<td>Yes, please specify</td>
<td>87.50%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>#</th>
<th>Yes, please specify</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>electronic functionality between acute/primary care</td>
<td>9/2/2014 1:31 PM</td>
</tr>
<tr>
<td>2</td>
<td>Better education of GPs (not all just some)</td>
<td>9/2/2014 12:58 PM</td>
</tr>
<tr>
<td>3</td>
<td>Access to GP/practice medical officers.</td>
<td>9/1/2014 5:51 PM</td>
</tr>
<tr>
<td>4</td>
<td>Parochialism, issues around acute versus aged care, distrust between services, paternalistic approach of palliative services, unwillingness to collaborate and share resources.</td>
<td>9/1/2014 4:32 PM</td>
</tr>
<tr>
<td>5</td>
<td>Acute and residential need to work together to provide best practice end of life care.</td>
<td>9/1/2014 4:04 PM</td>
</tr>
<tr>
<td>6</td>
<td>Distance, access to palliative care specialists, education of residents.</td>
<td>9/1/2014 3:41 PM</td>
</tr>
<tr>
<td>7</td>
<td>We do not need nor will have compliance with another electronic database - must be able to auto populate from existing software.</td>
<td>8/25/2014 10:16 AM</td>
</tr>
</tbody>
</table>
Implementation of a Tasmania wide advance care planning process and record

Q18 Do you have any other comments?

Answer Choices | Responses
--- | ---
No | 88.89% | 8
Yes, please describe | 11.11% | 1
Total | | 9

<table>
<thead>
<tr>
<th>#</th>
<th>Yes, please describe</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Although Advanced Care planning is discussed/trained with residents and family it is most common that quite a number do not wish to participate in the completion of the document</td>
<td>8/12/2014 2:58 PM</td>
</tr>
</tbody>
</table>
12.2 Attachment B – Consultations

A range of consultations were conducted to inform the evaluation of LWDW and 4CHER.

Consultations

17 consultations were conducted with various stakeholders throughout the project. An additional two stakeholders were able to provide written input into the evaluation.

Stakeholders included:

<table>
<thead>
<tr>
<th>Area</th>
<th>Position</th>
</tr>
</thead>
<tbody>
<tr>
<td>THO</td>
<td>Director, eHealth</td>
</tr>
<tr>
<td></td>
<td>RACF Project Officer (Nursing)</td>
</tr>
<tr>
<td></td>
<td>Palliative Care Medical Officer</td>
</tr>
<tr>
<td></td>
<td>GP Liaison Officer</td>
</tr>
<tr>
<td></td>
<td>Acting CEO</td>
</tr>
<tr>
<td></td>
<td>CO-Director of Nursing</td>
</tr>
<tr>
<td>RACFs</td>
<td>Director of Care, Emmerton Park</td>
</tr>
<tr>
<td>UTAS</td>
<td>4C Project Manager</td>
</tr>
<tr>
<td></td>
<td>Research Assistant</td>
</tr>
<tr>
<td>TML</td>
<td>Director Primary Health Services(^{97})</td>
</tr>
<tr>
<td></td>
<td>Program Support</td>
</tr>
<tr>
<td>Hospitals</td>
<td>Staff Specialist, Director of Intensive Care</td>
</tr>
<tr>
<td>DHHS</td>
<td>Community Care, Transition (HACC and My Aged Care)</td>
</tr>
<tr>
<td></td>
<td>eCare Strategy and Planning</td>
</tr>
<tr>
<td>Department of Health</td>
<td>Director, Engagement and Education, eHealth Change and Adoption Branch(^{98})</td>
</tr>
<tr>
<td>TAHPC</td>
<td>BAPC Project Manager</td>
</tr>
<tr>
<td>Cradle Coast Authority</td>
<td>Former CEO</td>
</tr>
<tr>
<td>Other</td>
<td>LWDW Clinical Lead (former)</td>
</tr>
</tbody>
</table>

All stakeholders were asked a range of questions which focused around the questions below.

1. Your involvement with 4CEHR and LWDW. What were your perceptions and experiences with 4CEHR and LWDW?

\(^{97}\) Written input was received from this stakeholder
\(^{98}\) Written input was received from this stakeholder
2. What processes and/or approaches are currently used for advance care planning?

3. How could the communication of advanced care plans (ACPs) and advance care directives (ACDs) be improved? What are the key requirements to ensure adequate communication of ACPs and ACDs across the health sector?

4. What is required to increase the quality and promote the use of ACPs by:
   - health professionals?
   - individuals?

5. What would be required to achieve state wide implementation of an:
   - ACP approach or process?
   - ACP system?

**Future stakeholders workshop**

A workshop was conducted with individuals identified as being ‘future stakeholders’ to gain an understanding of the impact any changes to advanced care planning may have across the state.

Individuals invited to participate in this workshop included:

- General Manager, THO North-West
- Director of Nursing Health West
- Staff Specialist, Emergency Medicine
- Co-Director, UTAS Rural Clinical School
- Project Manager, Streamlined Care Pathways, TML
- Representatives from Community Nursing

Three individuals were available to attend this workshop.

**RACF consultations**

Consultations were sought with four of the five RACFs that participated in the pilot program. These consultations were conducted with:

- Mt St Vincents, Ulverstone
- Emmerton Park, Smithton
- Baptcare Karingal, Devonport (via telephone)
- Meercroft Care, Devonport
The RACFs were engaged to participate in three forms of consultation:

- focus group with staff involved in the implementation and/or use of LWDW and 4CEHR
- a process review with a key staff member to discuss the processes used prior to, during and following the pilot program
- individual interviews with existing residents and/or family members of those residents that were involved in the LWDW/4CEHR pilot.

Both the focus group and process review were conducted simultaneously at the four RACFs.

While all RACFs were asked to identify suitable residents and/or families to participate in the interview, these interviews were only conducted at one site. The other RACFs indicated that these consultations would not be possible as they were no longer in communication with appropriate families, or existing residents would not have the capacity to participate in an interview.

A total of three consultations were conducted with family members and two interviews with current residents. Participants in these interviews were provided with a plain English overview of the evaluation and asked to sign consent forms.
12.3 Attachment C - Example RACF workshop agendas

Example agendas for each of the workshops are provided below. While each of these agendas was taken from LWDW materials, it is unknown whether any variation occurred in the final delivery of the workshop.

**Table 22 Agenda - LWDW Workshop 2**

<table>
<thead>
<tr>
<th>Indicative timing</th>
<th>Topic</th>
</tr>
</thead>
<tbody>
<tr>
<td>0930</td>
<td>Introduction</td>
</tr>
<tr>
<td>0940</td>
<td>Appreciating your contribution</td>
</tr>
<tr>
<td>0945</td>
<td>Plan of day and Learning Outcomes</td>
</tr>
<tr>
<td>0955</td>
<td>A Good death, A Dignified death Small groups table discussions</td>
</tr>
<tr>
<td>1005 1015 1025</td>
<td>Dignity - participants’ words, small groups Film Explore and Debrief</td>
</tr>
<tr>
<td>1045</td>
<td>Break</td>
</tr>
<tr>
<td>1055</td>
<td>3 trajectories, Q Who Dies, Nursing Homes Indicators Coding: Approaching Death Coding and Dying Who Dies Table discussion</td>
</tr>
<tr>
<td>1135</td>
<td>Standards Table Discussion</td>
</tr>
<tr>
<td>1155</td>
<td>Coding Surprise Question</td>
</tr>
<tr>
<td>1230</td>
<td>Lunch</td>
</tr>
<tr>
<td>1300</td>
<td>Head Heart Hands</td>
</tr>
<tr>
<td>1310</td>
<td>Communication – 3 scenarios</td>
</tr>
<tr>
<td>1405</td>
<td>Debrief How I listen to discover values, dignity How could you promote dignity in EP</td>
</tr>
<tr>
<td>1450</td>
<td>The Advance Care planning process The DPAG form, Changing the Goals of care Clinical Action Plans What ACP are you using</td>
</tr>
<tr>
<td>1525</td>
<td>Your next steps: Starting a register, GSF coding, dignity: values, and preferences,</td>
</tr>
</tbody>
</table>
### Table 23 Agenda - LWDW Workshop 3

<table>
<thead>
<tr>
<th>Indicative timing</th>
<th>Topic</th>
</tr>
</thead>
<tbody>
<tr>
<td>0900-</td>
<td><strong>Register</strong></td>
</tr>
<tr>
<td>0930</td>
<td><strong>GSF Coding.</strong> Code everyone&lt;br&gt;The Register - Supportive +Palliative Approach to care. ABCD, Colours, mounting</td>
</tr>
<tr>
<td>1030</td>
<td><strong>Short break</strong></td>
</tr>
<tr>
<td>1040</td>
<td><strong>LDW Project: Person Centred approach to Advance Care Planning</strong>&lt;br&gt;CASE frail, aged, early dementia, PVD + gangrene, DM, sepsis (leg and chest), delirium + pain + dyspnoea + panic +odour&lt;br&gt;&lt;br&gt;<strong>Codes → Group develop Matrix of Needs</strong>: yellow and red&lt;br&gt;<strong>Group exercise DPAG process</strong>&lt;br&gt;Communicating and documenting skills. Using Standards.&lt;br&gt;Nurses’ and Carers’ roles: The DPAG process&lt;br&gt;Dignity in Living, Dignity in Dying</td>
</tr>
<tr>
<td>1230</td>
<td><strong>30 min lunch</strong></td>
</tr>
<tr>
<td>1300</td>
<td><strong>GSF process for Suffering: Identify + Assess + Plan + COMMUNICATE.</strong>&lt;br&gt;Identify common symptoms (yellow, Red) in group&lt;br&gt;EOL care: Identify + C + Assess + C + “pepsicola” suffering, pain, delirium, dyspnoea, panic:&lt;br&gt;TOOLS (CAM, 4 pain tools)&lt;br&gt;&lt;br&gt;<strong>Clinical Action Plans for EOL</strong> Clinical Action Plans in Dying Phase.</td>
</tr>
<tr>
<td>1430</td>
<td><strong>15 min break</strong></td>
</tr>
<tr>
<td>1445</td>
<td>(identify and assess) + C + Plan + C&lt;br&gt;&lt;br&gt;&lt;strong&gt;Preventing crises**: planning ahead for Expected</td>
</tr>
</tbody>
</table>
### Table 24 Agenda - LWDW Workshop 4

<table>
<thead>
<tr>
<th>Indicative timing</th>
<th>Topic</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>0900-</strong></td>
<td>Intro Reflective practice: <strong>Sharing experiences across sites</strong>: Advanced Care Planning, Symptom control. Learning from each others’ progress. <strong>Sharing experiences</strong>: Register, Coding, Coordinators, Getting all staff engaged, management support, organising GP meetings?</td>
</tr>
<tr>
<td>0930</td>
<td><strong>Teamwork at your RACF</strong>: Sharing, notes <strong>Let’s have an open discussion</strong>: Q’s Reflective practice</td>
</tr>
<tr>
<td>1020</td>
<td><strong>Recognising C’s and D’s</strong>: approaching death, then dying 20 their experience – what are the challenges, SEA</td>
</tr>
<tr>
<td>1205</td>
<td>Break</td>
</tr>
<tr>
<td>1245-</td>
<td><strong>Preparing everyone</strong> Staff – everyone • Primary health team</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Indicative timing</th>
<th>Topic</th>
</tr>
</thead>
<tbody>
<tr>
<td>1530-1630</td>
<td><strong>Allow a Natural Death</strong>: design it? Policies, forms. <strong>Review of this day’s learning group.</strong> <strong>Next Steps.</strong> Homework, Delegating, RACF’s needs for support. <strong>Staff roles</strong>: Doing the DPAG’s enables you to do ACP’s well. <strong>GP training plan.</strong> <strong>Evaluation and Close</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Table 24 Agenda - LWDW Workshop 4</th>
<th>Indicative timing</th>
<th>Topic</th>
</tr>
</thead>
<tbody>
<tr>
<td>0900-</td>
<td>Intro Reflective practice: <strong>Sharing experiences across sites</strong>: Advanced Care Planning, Symptom control. Learning from each others’ progress. <strong>Sharing experiences</strong>: Register, Coding, Coordinators, Getting all staff engaged, management support, organising GP meetings?</td>
<td></td>
</tr>
<tr>
<td>0930</td>
<td><strong>Teamwork at your RACF</strong>: Sharing, notes <strong>Let’s have an open discussion</strong>: Q’s Reflective practice</td>
<td></td>
</tr>
<tr>
<td>1020</td>
<td><strong>Recognising C’s and D’s</strong>: approaching death, then dying 20 their experience – what are the challenges, SEA</td>
<td></td>
</tr>
<tr>
<td>1205</td>
<td>Break</td>
<td></td>
</tr>
<tr>
<td>1245-</td>
<td><strong>Preparing everyone</strong> Staff – everyone • Primary health team</td>
<td></td>
</tr>
</tbody>
</table>

**Deteriorations, and for Dying.**  
**Team work**: enabling the GP’s involvement in anticipatory planning  
group Discussions: Preventing avoidable hospital admissions
<table>
<thead>
<tr>
<th>Indicative timing</th>
<th>Topic</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Resident</td>
</tr>
<tr>
<td></td>
<td>• Their family</td>
</tr>
<tr>
<td></td>
<td>• Other residents and families</td>
</tr>
<tr>
<td></td>
<td>• Continued learning: ADA and SEA</td>
</tr>
<tr>
<td>1410</td>
<td><strong>The Dignity in Dying</strong></td>
</tr>
<tr>
<td></td>
<td>Aligning care with dignity, preferences, their ACP, and Goals of Care</td>
</tr>
<tr>
<td></td>
<td><strong>SEA and ADA</strong></td>
</tr>
<tr>
<td>1455</td>
<td><strong>Anticipatory grief</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Bereavement</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Spiritual care</strong></td>
</tr>
<tr>
<td></td>
<td><strong>SEA and ADA</strong></td>
</tr>
<tr>
<td>1535</td>
<td><strong>Spiritual care - Introduction</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Questions?</strong></td>
</tr>
<tr>
<td>1550</td>
<td>Implementation</td>
</tr>
</tbody>
</table>

**Table 25 Agenda - LWDW Workshop 5**

<table>
<thead>
<tr>
<th>Indicative timing</th>
<th>Topic</th>
</tr>
</thead>
<tbody>
<tr>
<td>09.00</td>
<td>Registration and coffee</td>
</tr>
<tr>
<td>09.30</td>
<td>Welcome and introduction</td>
</tr>
<tr>
<td></td>
<td>Plan and learning outcomes of the day</td>
</tr>
<tr>
<td>10.00</td>
<td>Looking back (in mixed groups)</td>
</tr>
<tr>
<td></td>
<td>1. Coding, register (?) +ACP process: dignity, preferences, goals</td>
</tr>
<tr>
<td></td>
<td>2. Continued learning, reflections: ADA, SEA, Carer support, Care of the dying, spirituality</td>
</tr>
<tr>
<td>11.15</td>
<td>Coffee (15 mins)</td>
</tr>
<tr>
<td>11.30</td>
<td>Looking forward</td>
</tr>
<tr>
<td></td>
<td>Next Steps – ‘Bringing it all together’ – tricky topics</td>
</tr>
<tr>
<td></td>
<td>Sailing with the seven Cs (building on your progress) (video clip)</td>
</tr>
<tr>
<td></td>
<td>Successes &amp; Challenges, possible solutions (using sticky notes)</td>
</tr>
<tr>
<td>13.00</td>
<td>Lunch (45 mins)</td>
</tr>
<tr>
<td>13.45</td>
<td>Topic Presentation – Dementia and the Goal of Person Centred Care (video clip)</td>
</tr>
<tr>
<td></td>
<td>Looking at disease focus model / supportive and palliative model</td>
</tr>
<tr>
<td>Indicative timing</td>
<td>Topic</td>
</tr>
<tr>
<td>-------------------</td>
<td>-------</td>
</tr>
<tr>
<td>14.45</td>
<td>Tea and coffee</td>
</tr>
</tbody>
</table>
| 15.10             | Key tasks – Portfolios  
|                   | - Next steps |
| 15.35             | Any Questions? |
| 15.50             | Reflection and – video clip – ‘Live like you are dying’ |
| 16.00             | Close & Evaluations |

Topic – ‘Living Well’ with Dementia – making the most of life – How do we look after our residents with dementia?
12.4 Attachment D - RACF Training Schedule

The RACF training schedule was designed to allow an implementation period of three months between each workshop.

The following table provides an overview of the originally scheduled/intended dates for the implementation of LWDW\textsuperscript{99}.

*Table 26 Original RACF training schedule*

<table>
<thead>
<tr>
<th>Round 1</th>
<th>LWDW Workshop 1</th>
<th>LWDW Workshop 2</th>
<th>LWDW Workshop 3</th>
<th>LWDW Workshop 4</th>
<th>LWDW Workshop 5</th>
</tr>
</thead>
</table>

\textsuperscript{99} Note: It was intended that the pilot RACFs would participate in round 1 of the training.
### 12.5 Attachment E – LWDW implementation activities

The following table provides an overview of the implementation activities which were conducted as part of the LWDW program.

**Table 27 LWDW implementation activities**\(^{100}\)

<table>
<thead>
<tr>
<th>Activity</th>
<th>Objectives</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preparation</td>
<td>Introduction and overview of LWDW/ GSF to facility. Engagement of Board. Requires commitment at all levels of the organisation, signed Agreement by Management and Board, and GSF licence prior to commencement.</td>
<td></td>
</tr>
<tr>
<td>Pre and post surveys</td>
<td>Staff self-assessment survey conducted to establish baseline of existing culture.</td>
<td>GSF Component</td>
</tr>
<tr>
<td>After Death Analysis (ADA) Audit</td>
<td>Formal process of reviewing 5 individual cases post death. Opportunity for staff to provide input on what worked well, what needs to be improved. Provides a baseline of existing culture.</td>
<td>GSF Component</td>
</tr>
<tr>
<td>Introduction Workshop</td>
<td>Identify wish list, introduce program and concept of illness trajectories, surprise question and coding. Look at existing Advance Care Planning processes. Explore concept of dignity. Explore concept of anticipating dying. Identify coordinators to act as change champions within the organisation. (See Role of Coordinators)</td>
<td></td>
</tr>
<tr>
<td>GSF 1st Gear Workshop</td>
<td>To understand context of end of life care. To understand the GSF RACF programme To review tasks from preparation stage. To learn key tasks C1 &amp; C2</td>
<td>GSF component for RACF’s. Sessions preferably conducted with all participating RACF’s together and cross section of staff to enable</td>
</tr>
</tbody>
</table>

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\(^{100}\) Note: This table is presented as it was originally included in the LWDW project documents made available to inform this evaluation. With the exception of identifying the LWDW workshop numbers, no alterations have been made to the content.
<table>
<thead>
<tr>
<th>Activity</th>
<th>Objectives</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Set up register and code residents</td>
<td>shared contribution to learning.</td>
</tr>
<tr>
<td></td>
<td>Needs support matrices, planning meetings</td>
<td>Multiple workshops may be required to ensure access to as many staff as possible.</td>
</tr>
<tr>
<td></td>
<td>Collaboration /involvement of GPs, PCT</td>
<td>Potential for Train the Trainer so that information is disseminated to all staff in each facility.</td>
</tr>
<tr>
<td></td>
<td>Role of Coordinator(s)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Involvement of other staff</td>
<td></td>
</tr>
<tr>
<td></td>
<td>To understand Dignity at end of Life care</td>
<td></td>
</tr>
<tr>
<td></td>
<td>To understand Advanced Care planning</td>
<td></td>
</tr>
</tbody>
</table>

**Activity**

**Objectives**

- Set up register and code residents
- Needs support matrices, planning meetings
- Collaboration /involvement of GPs, PCT
- Role of Coordinator(s)
- Involvement of other staff
- To understand Dignity at end of Life care
- To understand Advanced Care planning

**Comments**

- shared contribution to learning.
- Multiple workshops may be required to ensure access to as many staff as possible.
- Potential for Train the Trainer so that information is disseminated to all staff in each facility.

**DPAG Processes**

Provide formal and informal training in using the principles of the DPAG for Advance Care Planning, defining Goals of Care and developing anticipatory care plans in collaboration with GP. Training encompasses how to have difficult discussions and allowing a natural death. Apply DPAG to individual residents with facility staff.

**Comments**

- DPAG = LWDW
- Tool to prompt and capture discussions with residents and significant others about Dignity, Preferences, Advance Care Plan and Goals of Care.

**Implementation activities in facilities.**

Facilities are expected to commence coding of residents.

Coding is to be displayed in an area that can be viewed by all relevant staff but not residents/ families and to be reviewed/ updated weekly by the care team. Implementation of the Summary of Care Register.

(See attached)

Facilities are expected to ensure that Advance Care Planning occurs for all residents (as close as possible to admission for new residents and especially if there is a status change for existing residents, plus all residents likely to be in last days/ weeks/ months of life. Initiate weekly Toolbox Meetings with teams in each facility.

Toolbox meetings provide opportunity to raise questions, explore issues, reflect on practice,

**Comments**

- Coding involves asking the question “Would you be surprised if this resident died in the next Days (red)? Weeks (yellow)? Months (green)? Years (blue)? Coloured dots are used to identify current status.

- Using the DPAG process for advance care planning is encouraged and supported.
<table>
<thead>
<tr>
<th>Activity</th>
<th>Objectives</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>GP Engagement</strong></td>
<td>Learn specific skills and implement Significant Event Analysis (SEA) and ADA’s.</td>
<td>Where possible GP training is conducted at the facility and involving facility staff (change champions).</td>
</tr>
<tr>
<td><strong>GSF 2nd Gear Workshop</strong></td>
<td>Preliminary engagement of GP’s and preparation for training. Includes overview of processes occurring in facilities and development of agreed training schedule. Engagement of pharmacists in this process is also beneficial.</td>
<td></td>
</tr>
<tr>
<td><strong>LWWDW Workshop 3</strong></td>
<td>To share and learn from others C1 C2</td>
<td>GSF Component as above</td>
</tr>
<tr>
<td></td>
<td>To understand the next stage and learn key tasks C3, C4: Control of symptoms – assessment tools Continuity- use OOH handover forms To understand avoidance of admission issues. To learn more about Advance Care Planning, Not for CPR, and related EOLC issues <strong>Second Gear:</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Symptom control and Assessment C3 • Advance care Planning C1 • Out of hours continuity C4 • Key topics: 1. Advanced Care Planning-communication skills 2. Decreasing Hospitalisation, DNAR (NFR)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>To share learn from others experiences of implementing C 5,6,7 To understand the importance of embedding and sustain of GSF. To learn the process of the next stage – consolidation and</td>
<td></td>
</tr>
<tr>
<td>Activity</td>
<td>Objectives</td>
<td>Comments</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>----------------</td>
</tr>
<tr>
<td></td>
<td>accreditation.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>To understand Quality of life issues- “living well until you die”,</td>
<td></td>
</tr>
<tr>
<td></td>
<td>To understand the detection and management of the 4 D’s: depression, delirium, demoralisation and dementia.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>To understand the specific issues /challenges around EoLC for people with Dementia.</td>
<td></td>
</tr>
<tr>
<td>GP Training</td>
<td>Encompasses concepts covered in 1\textsuperscript{st} and 2\textsuperscript{nd} Gear workshops with facility staff.</td>
<td>Includes culture change, ADA’s and the DPAG process.</td>
</tr>
<tr>
<td>GSF 3\textsuperscript{rd} Gear Workshop</td>
<td>To share and learn from others implementation of C3&amp;4.</td>
<td>GSF Component as above</td>
</tr>
<tr>
<td><strong>LWDP Workshop 4</strong></td>
<td>To understand the next stage and learn the key tasks C5,6,7</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Continued learning</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Carer support</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Care of the dying</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Includes staff support</td>
<td></td>
</tr>
<tr>
<td></td>
<td>To learn communication skills and discussing dying.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>To discuss aspects of spiritual care.</td>
<td></td>
</tr>
<tr>
<td><strong>Third Gear</strong></td>
<td>- Reflective practice and education C5</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Relatives support and bereavement C6</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Care in the final days C7</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Key topics</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1. Discussing dying</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2. Spirituality</td>
<td></td>
</tr>
<tr>
<td>Consolidation</td>
<td>Staff should be gaining confidence in coding, identifying illness trajectories, using DPAG process, developing clinical action plans, preventing unnecessary suffering and preventing avoidable hospital admission.</td>
<td></td>
</tr>
<tr>
<td><strong>Activity</strong></td>
<td><strong>Objectives</strong></td>
<td><strong>Comments</strong></td>
</tr>
<tr>
<td>-------------</td>
<td>----------------</td>
<td>--------------</td>
</tr>
<tr>
<td><strong>admissions.</strong></td>
<td>Using DPAG to develop clinical action plans and anticipatory prescribing. Look at care plans for common symptoms.</td>
<td></td>
</tr>
<tr>
<td><strong>GP Training</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>GSF 4th Gear Workshop</strong></td>
<td>To share learn from others experiences of implementing C 5,6,7</td>
<td>GSF Component as above</td>
</tr>
<tr>
<td><strong>LWDW workshop 5</strong></td>
<td>To understand the importance of embedding and sustain of GSF. To learn the process of the next stage – consolidation and accreditation. To understand Quality of life issues- “living well until you die”, To understand the detection and management of the 4 D’s: depression, delirium, demoralisation and dementia. To understand the specific issues/challenges around EoLC for people with Dementia. <strong>Fourth Gear</strong> - Sustain, embed, extend - Consolidation - Introduction to the accreditation process “going for Gold” - Key topics: 1. Quality of life/ living well/ depression/ demoralisation /delirium 2. Dementia</td>
<td></td>
</tr>
<tr>
<td><strong>Coordinators Action Learning Groups</strong></td>
<td>4-6 weekly workshops for coordinators provide professional support to ensure competence with the DPAG and other processes and to ensure momentum with culture change is sustained.</td>
<td></td>
</tr>
<tr>
<td><strong>Consumer and Community</strong></td>
<td>Consumers are provided information at point of care concerning involvement in and</td>
<td></td>
</tr>
<tr>
<td>Activity</td>
<td>Objectives</td>
<td>Comments</td>
</tr>
<tr>
<td>----------------------------------</td>
<td>-----------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Engagement</td>
<td>consent for the LWDW DPAG process. Community Forums provide opportunity for input and education.</td>
<td></td>
</tr>
<tr>
<td>Ongoing Training and Support</td>
<td>Continued period of training and support to ensure culture change is embedded and reflected in organisations activities and attitudes. Commence implementation of processes, activities and strategies for facilities to incorporate changes into ongoing business activities.</td>
<td></td>
</tr>
<tr>
<td>After Death Analysis Audit</td>
<td>Formal process of reviewing individual cases post death. Opportunity for staff to provide input on what worked well, what needs to be improved. Provides a yardstick to measure culture change when compared with ADA Audits conducted prior to implementation of training.</td>
<td></td>
</tr>
<tr>
<td>Review</td>
<td>(Evaluation occurs at the conclusion of each workshop/ training session). Are advance care planning/ DPAG processes in place for all residents? Do teams regularly review days/ weeks/ months/ years and illness trajectories? Do teams initiate anticipatory care planning and prescribing for expected deteriorations? Do teams regularly reflect, review and discuss their approach to end of life care for individuals?</td>
<td></td>
</tr>
</tbody>
</table>
12.6 Attachment F – Living Well Dying Well Content and Materials

12.6.1 Illness trajectories

Three distinct illness trajectories are presented as part of the LWDW approach. These trajectories have been described by a range of health professionals for people with progressive chronic illness.

The three illness trajectories provide RACF staff with an indication of the expected deterioration for residents with particular conditions over time. They may also be used to assist in determining the likely prognosis for a resident.

1) Short period of evident decline (typically cancer)

2) Long term limitations with intermittent acute, serious episodes (typically organ failure)

3) Prolonged dwindling (typically frail and aged with multiple comorbidities)

Gaining an understanding of the expected illness trajectory of a resident allows the RACF staff to plan ahead and work to prevent crises. As it provides them with an indication of what may be expected in the future they can be prepared to provide appropriate care. For example, if a resident is on trajectory two, they are likely to experience frequent serious episodes.

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101 Note: The three illness trajectories are described in detail in the article ‘Illness trajectories and palliative care’. This article is available at: http://www.cphs.mvm.ed.ac.uk/groups/ppcrg/images/pdf/Murray%20SA%202007%20Scot%20Prim%20Care%2066%2017-19.pdf
12.6.2 Prognostic indicators

LWDW teaches a range of prognostic and general indicators to assist RACF staff and other health professionals in identifying residents in the last year of life. A range of general and specific indicators may be taken into account, for example:

- level of activity
- co-morbidity
- physical decline
- need for support
- response to treatments
- choices regarding treatment
- weight loss
- Sentinel events such as a serious fall or bereavement.

Specific Prognostic Indicator Guidance is available on the GSF website\(^\text{102}\). Along with the Prognostic Indicators, this document also provides guidance about other tools used as part of both GSF and LWDW which are used to identify and assess residents in their last year of life.

12.6.3 Coding and the ‘surprise question’

LWDW seeks to enable participants to code residents based on their likely prognosis. In order to identify residents in their final year of life, participants are taught to ask the ‘surprise’ question. This question asks:

Would you be surprised if the resident died in days/hours, weeks, months or years?

It is expected that experienced health professionals will be able to instinctively respond to this question based on their knowledge of illness trajectories and the resident. Considerations from the application of the illness trajectories and prognostic indicators are also applied.

The implementation of coding activities is used to prepare everyone involved in the residents care for periods of decline and ultimately death, including doctors, staff, carers and the family. It provides a sense of how long the resident can reasonably be expected to live, and allows plans to be made accordingly for their care.

Figure 11 Needs based coding

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
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</thead>
</table>
| **A - Years** | Team would be surprised if the resident died within the next six to 12 months.  
Adjusting to Living Well in a new environment  
Regular review of care |
| **B - Months** | Team would not be surprised if the resident died within the next six to 12 months.  
Regular proactive review of patient needs and care.  
Would be advisable to consider a Supportive and Palliative pathway now- if not on it already |
| **C - Weeks** | Team would not be surprised if the resident only had weeks of life left.  Reasonably expect death within six weeks.  
Prepare for final stage. |
| **D - Days** | Reasonably expect death within hours or a few days.  
Preparation for death in preferred place – resist transfers at this time  
Only a palliative pathway |

Residents who are considered to have weeks remaining (yellow) are considered to be ‘Approaching the Dying Phase’ while those with days/hours remaining (red) are in the ‘Dying Phase’. No specific terminology was identified to describe the phase of residents with years (blue) or months (green) remaining.

12.6.4 DPAG tool

The DPAG tool was designed to assist in conducting advance care planning and is used to prompt and record discussions with residents about their care. This allows RACF staff to ensure that care is appropriately tailored to the condition, needs and wishes of each individual resident.

LWDW encourages RACFs to conduct DPAG discussions with all residents. There is also a particular emphasis on conducting and revisiting these discussions with residents who are expected to only have weeks or days/hours of life remaining. This was particularly evident in the GSF materials.

The four elements/aspects of the DPAG are detailed in the table below.

Table 28 DPAG

<table>
<thead>
<tr>
<th>DPAG Element</th>
<th>Description/purpose</th>
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<tbody>
<tr>
<td>Dignity</td>
<td>Understanding the resident’s views on dignity, including what dignity means to them and how this can be achieved and maintained.</td>
</tr>
<tr>
<td>DPAG Element</td>
<td>Description/purpose</td>
</tr>
<tr>
<td>--------------</td>
<td>---------------------</td>
</tr>
</tbody>
</table>
|             | This may include the identification of actions which can be undertaken to ensure that the resident maintains a sense of dignity throughout their care, and that the resident’s values are respected. Assessing dignity will involve taking into account and having respect for the resident’s values. A range of values should be considered such as:  
- Freedom, autonomy, independence, choice  
- Comfort, pleasure, enjoyment  
- Safety, certainty, security |
| Preferences  | Identification of the resident’s preferences for care, such as:  
- Receiving information about their condition and prognosis  
- Being involved in decisions and discussions about their care  
- Particular requirements for their care, including where they would prefer to receive treatment and the extent of medical interventions they would like to occur  
Information collected about the preferences of a resident can be used to directly inform their advance care plan. |
| Advance Care Directives | Identify and clarify the meaning of any existing ACDs. This should explore:  
- Enduring Guardian/Person Responsible,  
- Extent and type of medical treatment wanted and/or not wanted  
- Specific personal requests |
| Clinical Goals of Care  | Identify realistic and achievable outcomes for the four main clinical goals:  
1) Length of life (may range from prolonging life at all costs to allowing a natural death)  
2) Function (whether failing function will be treated/restored or accepted)  
3) Comfort (to what extent symptoms will be treated and/or relieved)  
4) Prevention of avoidable crises (the degree to which any complications will be treated)  
LWDW encourages the use of a variety of tools to develop an understanding of what would goals of care would be realistic for each resident. The following tools are taught as part of LWDW to support decisions about the Clinical Goals of Care:  
- **Karnofsky Performance Scale** - used to measure a residents day to day level of function on a scale from 0 |
<table>
<thead>
<tr>
<th>DPAG Element</th>
<th>Description/purpose</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(&quot;Comatose or barely rousable&quot;) to 100 (&quot;Normal, no complaints, no evidence of disease&quot;)(^{103,104}). The score can also be used to assist in validating a resident's likely prognostic code or category (see ‘Coding and the ‘surprise’ question’ below).</td>
</tr>
<tr>
<td></td>
<td><strong>Confusion Assessment Method (CAM)</strong> - a bedside tool used by carers to assess delirium. The CAM provides a structured format to identify the key features of delirium (fluctuating symptoms, an acute onset and a change in cognition)(^{105}). The CAM tool recognises that the presence of delirium within a resident may change overtime(^{106}).</td>
</tr>
</tbody>
</table>

LWDW teaches RACF staff to undertake a baseline Karnofsky and CAMs assessment for each resident. By comparing the results of further assessments to the baseline, the RACF staff are able to monitor and track deteriorations and adjust care.

### 12.6.5 Clinical Pathways

LWDW utilises three categories of Clinical Pathways:

- aggressive disease focused pathways
- less aggressive disease focused emphasising supporting care pathways
- supportive and palliative pathways.

The goals of care identified as part of the DPAG process are used to inform the selection of the most appropriate clinical pathway for the resident. The clinical pathway is then used to assist in the planning for an individual’s end of life care. Each pathway is described in the Table 29.

---


### Table 29 Overview of Clinical Pathways

<table>
<thead>
<tr>
<th></th>
<th>Aggressive diseased focused pathways</th>
<th>Less aggressive disease focused with supportive care</th>
<th>Supportive and palliative approach</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Resources</strong></td>
<td>Maximal use of emergency and acute care services</td>
<td>Hospital presentations and readmissions are expected</td>
<td>Community care. Plan ahead to prevent avoidable crises and avoidable admissions.</td>
</tr>
<tr>
<td><strong>Clinical Goal: Length of Life</strong></td>
<td>Prolong life at all costs.</td>
<td>Prolong life, but not at all costs. Limit overly burdensome or increasingly futile treatments.</td>
<td>Allow a natural death. Aim to neither prolong nor shorten life.</td>
</tr>
<tr>
<td><strong>Clinical Goal: Function</strong></td>
<td>Restore, maximise or take over function</td>
<td>Aim to increase function, while accepting there are limits to improvement.</td>
<td>Accept failing function. Relieve symptoms and suffering.</td>
</tr>
<tr>
<td><strong>Clinical Goal: Comfort</strong></td>
<td>Symptoms and suffering are inevitable. Control disease and avoid symptom relief if it may reduce function.</td>
<td>Treat symptoms primarily through controlling disease.</td>
<td>Relieve symptoms. Address the person’s wider needs, including social, psychological, cultural and spiritual.</td>
</tr>
</tbody>
</table>

As shown in the above table the three pathways can be aligned against a resident’s goals of care (identified during the DPAG). By comparing the wishes and preferences of the resident with the goals of care, it is possible to determine what sort of treatment they should be provided with to meet their wishes.

Additionally, the three pathways can also be enacted as resident’s progress through the different trajectories. When a resident reaches the dying phase
it would be appropriate for them to be moved on to the supportive and palliative approach.

12.6.6 Clinical Action Plans

An example Clinical Action Plan (CAP) is provided overleaf.
1. Delirium - simple

*Delirium - not complicated in 'Approaching Dying Phase' – primary health team would not be surprised if the person died within weeks - not months*

Assess:

If CAM tool suggests the presence of delirium (ie A + B AND either C OR D):

A = Onset of NEW and FLUCTUATING changes in the following:

B = Deterioration in ATTENTION

Changes from the person’s usual ability to focus or maintain concentration, or shift attention

C = Disorganisation or Confusion in behaviour, thinking or conversation.

D = HYPER-active type: increasing agitation (~30% of patients)

HYPO-active type: decreased alertness (~30% of patients)

MIXED type: has alternating or coexisting elements of hypo + hyper-active (~30%)

- Recognise delirium early.
- Assess type: hypoactive, hyperactive or mixed type.
- Assess safety risk to self and others particularly if hyperactive type.
- Consider potentially modifiable causes and whether stage of illness and person’s preferences will influence decision to investigate or treat causes.

Primary Health Team and GP:

- Consider stage of illness, and person’s preferences: Treat Symptoms.
- Any potentially modifiable causes appropriate to investigate and treat at this late stage of illness?

Environmental Recommendations:

- Ensure safety for all involved.
- Reduce environmental ambiguity (worrying shadows across walls).
- Reduce sudden stimulation (abrupt and loud approaches from staff or visitors).
- Reduce overstimulation (loud TV, alarming news reports, harsh music, too many questions or people present).
- Ensure environment is comfortably warm.
- Offer frequent drinks.
- Reassuring photos and comforting personal possessions may help to soothe.

**Communication:**

- Approach gently, identifying yourself, and reason for entering the room.
- Respectfully ask permission before any intervention, and wait gently and patiently for a reply.
- S sensitively acknowledge any perplexity or emotional distress that the person shows.
- If appropriate, give reassurance that perceptual disturbances (e.g., hallucinations) are a result of their underlying illness.
- Respectfully do not play along or collude with delusions and hallucinations - as you risk losing the person’s trust, especially if any insight returns.
- Do not force interventions.

**Explanation for other Staff, family:**

The person’s changed behaviour is a result of the illness (e.g., new drowsiness, irritability, increased confusion, anxiety and agitation, strange behaviour or speech, accusations, hallucinations). Engage family’s understanding and empathy and willingness to give feedback. Enlist their involvement in providing a reassuring and familiar presence to soothe and support the resident. Appropriate use of trained volunteers can provide an added support alongside appropriate treatment.

**Pharmacology:**

**Haloperidol 0.5 mg Oral or Subcut q4hr PRN,**

If > 3 PRN’s used in 24hr ask for a medical review (only rarely will larger doses be required, e.g., maximum of 3-5 mg/24 hrs for elderly as side effects are more at higher doses: akathisia - motor restlessness, Parkinsonism – rigidity, tremor, mask face, uncomfortable muscles and joints)

Or

**Risperidone 0.25 mg buccal bd PRN** *(Quicklet dissolves inside moistened cheek)*

If 2 PRN’s used in 24hr ask for a medical review. (max 1 mg/24 hrs as side effects are more likely at higher doses akathisia -motor restlessness, Parkinsonism – rigidity, tremor, mask face, uncomfortable muscles and joints).

Or
If sedative side effects are clinically useful: Olanzapine 2.5 mg buccal q8hrPRN (half a 5mg wafer inside a moistened cheek), if 3 PRN’s used in 24hr ask for a medical review. (maximum od 1 mg in 24)

If delirium persists:

- Consider regular q 12 hrly + PRN as above of the medication of choice – Haloperidol, OR Risperidone OR Olanzapine if delirium worsens.
- Suggest involving Specialist Services: Psycho-Geriatrician, Geriatrician, Specialist Palliative Care Service
- Benzodiazepines are not usually recommended treatment for delirium. Although benzodiazepines may initially appear to be calming, it is likely they will lead to worsening of the underlying delirium, particularly when causes are no longer modifiable due to advance disease.
- Benzodiazepine are recommended for benzodiazepine withdrawal delirium.
- If already on long term benzodiazepine for other reasons, do not cease the regular benzodiazepine as a withdrawal delirium will be precipitated.
12.7Attachment G – Evaluation activities

12.7.1 Before and after staff confidence assessment surveys

As part of the LWDW training program, all RACFs were expected to complete before and after staff confidence assessment surveys. This survey is designed to self-assess the competence and confidence level of staff in completing tasks associated with each of the seven C’s.

An example survey tool is included overleaf.
# Before and After Staff Baseline Confidence Assessment Survey Questionnaire

## Gold Standard Framework Care Homes Programme (GSFCH)

**Care Home:** 

**Name:** 

**Date completed:** 

**Qualifications:** 

---

### Please indicate your competence levels.

Insert date of initial self-assessment and then achievement of acquired competencies, following education and training undertaken. This document demonstrates improvement in levels of knowledge and skills and can be part of the accreditation evidence.

<table>
<thead>
<tr>
<th>Competence/Confidence level</th>
<th>Score before training</th>
<th>Score after training</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Where 1 = not confident and 10 = very confident date________________</td>
<td>Where 1 = not confident and 10 = very confident date________________</td>
</tr>
</tbody>
</table>

### C1 Communication

1. If a close family member was dying and was a resident, how confident would you feel about the care they receive? 
2. How confident do you feel in having and recording advance care planning (ACP) discussions with residents and their families?

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</thead>
<tbody>
<tr>
<td>C1 Communication 1</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
</tr>
<tr>
<td>C1 Communication 2</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
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### C2 Co-ordination

3. How confident do you feel in identifying or recognising residents who may be in the last year of life? 
4. How confident do you feel in involving other people in a resident’s care?

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<tbody>
<tr>
<td>C2 Co-ordination 3</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
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<td>10</td>
</tr>
<tr>
<td>C2 Co-ordination 4</td>
<td>1</td>
<td>2</td>
<td>3</td>
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### C3 Control of symptoms

5. How confident do you feel in assessing their clinical needs? 
6. How confident do you feel in anticipating and recognising problems? 
7. How confident do you feel in caring for people nearing the end of life?

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<tbody>
<tr>
<td>C3 Control of symptoms 5</td>
<td>1</td>
<td>2</td>
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<td>6</td>
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<tr>
<td>C3 Control of symptoms 6</td>
<td>1</td>
<td>2</td>
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<td>6</td>
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<tr>
<td>C3 Control of symptoms 7</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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</table>

### C4 Continuity of care

8. How confident do you feel in planning cross boundary care e.g. out of hours, in care homes, in hospital etc?

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</thead>
<tbody>
<tr>
<td>C4 Continuity of care 8</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
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</table>

### C5 Continued Learning

9. Have you any identified learning needs?

### C6 Care Support

10. How confident do you feel in working as a coordinated team?

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<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>C6 Care Support 10</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
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<td>10</td>
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</tbody>
</table>

### C7 Care of the dying

11. How confident do you feel in caring for dying people in the final days of life?

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<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>C7 Care of the dying 11</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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</table>
12.7.2 After death Audits

LWDW encourages after death audits within each of the RACFs. These are used to review recent deaths and are a tool for continued learning.

The after death audit process provides staff with the opportunity to consider and discuss the death, including whether the care that was provided aligned with the wishes and needs of the resident.

During after death audits, the RACF staff will review the death to identify:

- what went well?
- what didn’t go so well?
- what could have done better?
- how can we do better?

In considering ‘how can we do better?’ the staff identify specific improvement opportunities for each of the 7C’s. This is then used to develop an action plan for future improvements within the RACF.

As part of the LWDW program, each of the participating RACFs were expected to conduct five baseline after death audits prior to the training and an additional five following the completion of the pilot program.

The completion of these pre- and post-training audits was intended to assist the participating RACFs in measuring the extent to which cultural and practice change had been achieved.

An example after death audit tool is provided overleaf\(^{107}\).

\(^{107}\) Note: The example after death audit form has not been formatted. It is presented as it appears in the LWDW project documentation which was reviewed to inform this evaluation.
Living Well & Dying Well Project – Wynyard Care Centre: Audit tool

Staff Reflections auditing quality improvements opportunities of the care of the dying

**Audit of care, after the death of a Resident**

**What went well?**
Strengths:

**What didn’t go so well?**
Opportunities to improve: when care or outcomes that haven’t gone so well?

**What could be done better?**
Aspirations to do better:

**How can we do better?**
Results & Next Steps using GSF 7C’s.
Communication C1, Coordination C2, Continuity C3, Control of Symptoms C4, Continued Learning C5, Care of Carers C6 (i.e. family carers & Staff) Care of the Dying C7.
# The Gold Standard Framework: The Team’s Cycle of Continued Learning

<table>
<thead>
<tr>
<th>7 C’s</th>
<th>Was there anything that could have been done better?</th>
<th>How can I or Team do this?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Comments, issues within each of the 7C’s (give example from this case)</td>
<td>Anything I want to change, improve or strengthen? How important is this? Why?</td>
</tr>
<tr>
<td></td>
<td>Was there anything that could have been done better?</td>
<td>How can I or Team do this?</td>
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<td>Anything I want to change, improve or strengthen? How important is this? Why?</td>
<td>My ideas, strategies, solutions, Others’ ideas or solutions?</td>
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<td>How can I or Team do this?</td>
<td>My next steps? Team’s next steps?</td>
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| Communication C1 | Coding: Identify residents need for palliative care, daily handover, ACP noting dignity, preferences & preferred place of care |
| Coordination of care C2 | Link person Communication with GP, PHT, family etc. |
| Control of symptoms C3 | Symptom Assessment tool, ACP completed for all residents & updated when coding changes, PRN subcut medication prescribed |
| Continuity of Care C4 | GP updated & out of hours. ACP or Allow a Natural Death form held in records |
| Continued Learning C5 | Regular reviews. Audit deaths with staff & if possible with GP. What do you feel is required? |
| Care of all the Carers C6 | Staff issues & learning points + feedback after death All staff supported |
| Care of the Dying C7 | Minimal protocol for last days of life. Support for bereaved families Support for all staff and other residents as needed. |
Reflections and comments

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<th>Action Plan</th>
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<td><strong>Actions</strong></td>
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12.8 Attachment H – GP Training

Small Group Learning Sessions were conducted to educate GPs about the LWDW program and key concepts. The training consisted of four, two hour sessions (total of eight hours training) conducted after business hours to accommodate GPs working hours.

Attendance at all four sessions entitled the GP to 40 continuing professional development (CPD) points.

GP training sessions were scheduled to occur in locations near participating RACFs to target appropriate GPs who are providing care to residents. This training was not delivered concurrently to the RACF training.

As detailed in the original training application to the Royal Australian College of General Practitioners (RACGP), the GP training sessions sought to:

"examine illness trajectories for RACF residents, assist in constructing individual clinical care plans for a number of patients in a multidisciplinary environment and provide the GP with the tools to audit the care of patients after their death”.

The following five learning objectives were identified for this training:

1. To understand the three main trajectories of life limiting advanced chronic illness

2. Demonstrate competency in using prognostic indicator guidelines, identify residents likely prognosis (years, months, weeks, days, hours)

3. To strengthen GPs capacity within Primary Health Teams, working together to promote supportive and palliative care pathways for patients in their last year of life

4. To provide GPs with an opportunity to contribute to the resident’s advance care planning process

5. To use the DPAG document and Clinical Action Plan templates that are aligned with the resident’s preferences.