FINAL REPORT

Name of Project	**Hunter Collaborative Palliative Dementia Care Framework - HCPDCF**
Name of Participant	**Hunter New England Local Health Network**
Target population and/or geographic area the Project covered	**Newcastle and surrounding areas**

Part 1 – Project definition

Purpose of Project	The purpose of the project was to establish and implement a sustainable collaborative palliative dementia care framework within targeted aged care facilities in the Hunter region**.** ***How was the objective achieved? (maximum 250 words)*** The objective was achieved through a collaborative approach led by a Clinical Nurse Consultant project manager, employed by the lead agency Hunter New England Health. Working with funded facility champions, the position worked to research, design, resource, pilot, and market the implementation of a palliative dementia care framework that would improve the quality of life for people with advanced dementia and their families as they approached end of life. Sustainability has been well supported through: 1. Sourcing, developing and printing quality resources & publications for families, formats will remain available on www.hapcn.com.au 2. Sourcing and developing tools and education modules for health professionals to use in Advance Care Planning, End-of-Life Care and cross sector communication. *3.* Close liaison and direct involvement and support of key managers in each of the participating organisations. *The project has exceeded objectives in that 5 of the 6 facilities will retain a paid Champion role.* *4.* Liaison with Hunter Division of General Practice and roll out of resources and education to medical practices through Practice Nurses and uploading documents on Gp computer programs. Evaluation: 1. Pre and post project data shows high staff, family and medical satisfaction with the processes that have been implemented at each site. *2.* A reduction in hospital transfer and futile medical interventions towards end of life in people with advanced dementia.

Estimated number of people impacted by the project (if known)	*How many people (e.g. patients, carers, staff, other health professionals) were directly impacted by the project? How many people do you estimate will benefit indirectly from the project?* 10 Aged Care Organisations involved in project – 6 funded and four unfunded. Three organisations have over 6 sites including high and low care facilities – all organisations are rolling out framework across sites. Education delivered to residential and aged care facility and community services aged care staff (180). Included: Registered nurses (55), care workers, lifestyle workers and managers. Education delivery extended to cultural community groups – Filipino and Polish community. (46) Education delivery to GP's and to specialist Palliative Care physicians and nurses (35) Information resources printed & distributed 2,000 of each and also sourced and distributed 4,000 'Dying with Dementia' UWS booklets.
Service infrastructure	1. *1 FTE - Project Manager* 2. *1 x.4 EFT Administration Support* 3. *6 x .4 EFT - Aged Care Facility Champions* 4. *Development and publication of Resources* 5. *Education Delivery, backfill & resources* 6. *Education packages with online delivery option* 7. *Evaluation of Project*

Part 2 – Project objectives and outcomes

Notes:

- The sections ***Project objectives*** and ***Key activities*** should contain information based on your grant submission.
- The following sections should contain information that explains **W*hat actually happened***, as well as ***Revised objectives*** and the ***Rationale for any changes*** if applicable.
- ***Outcomes*** and ***Performance indicators*** should describe the actual outcomes (qualitative and quantitative) that the project achieved and how these were measured.

Where applicable, attach any tools, resources and other material produced for this Project, in support of this Report.

Project objectives:

1. Form a Consortium of key stake holders, including Residential Aged Care Facilities caring for people with dementia up to the end of life that represent diversity in size, location, cultural mix & both low & high
2. Appoint project officer CNC
3. Recruit and appoint facility Champions. Form a working group consisting of RACF champions and HNEAH staff to progress project.
4. Literature search on current research, best practice, other projects to inform framework development & review attended
5. Establish Leadership Group meetings (Expert Advisory Committee) & parameters
6. Develop Hunter Collaborative Palliative, Dementia Care Framework. Developed by project manager, evaluation and research service, education consultant and project officer in consultation with expert advisory committee & working group.
7. Pilot framework and strategy in one facility
8. Implement the framework
9. Educate and train the target group

Revised objectives (if applicable):

Objective 7. Pilot site not able to complete prior to rolling out framework due to time constraints – facilities invited to 'trial' one aspect of framework and gradually roll out what they felt they could achieve – this was effective as Champions could share their experiences of what was working and what was more challenging to implement.

What actually happened:

1. Invited key stakeholders and community leaders to join advisory committee – developed terms of reference and communication strategy.- scheduled meeting dates in calendars.
2. Identified facility champions and implemented schedule of monthly meetings, developed Terms of Reference and standing agenda for central dissemination of project strategy & reporting.
3. With champions, using evidenced based practice, identified resources / tools applicable to project and worked with champions to identify and structure the Palliative Dementia Care Framework.
4. Worked within HAPCN to build in sustainable elements, i.e.: brochures, website and online training – also marketed project and resources though this avenue.
5. Printed tools that would be needed in multiple amounts and worked with the aged care organisations to establish marketing of the project and anticipated outcomes to other staff, residents and their families.
6. Established evaluation process and commenced surveys, engaged University of Newcastle for pre and post data entry and analysis.
7. Identified education and training needs, developed training resources and selected training delivery team, booked schedule and commenced delivery across sites.

8. Networked and established communication stream with Hunter Division of GP's, JHH Emergency Department, HNEH Geriatricians, Mater Hospital Specialist Palliative Care Unit and Community Aged Care Teams both regional and rural.
9. Commenced site visits with on site implementation support, provision of printed resources and liaison at a facility management level.
10. Provided a full day comprehensive education program at 9 different sites using a number of professional 'experts' to provide a broad spectrum of information related to legal and ethical issues, advance care planning and EOL care. Integrated workshop activities – this was a highly successful strategy with over 150 participants of which 55 were Registered Nurses.

Rationale for change (if applicable):

Time constraints

Key activities:

- Monthly Champion meetings with education, supervision and networking support
- Onsite localised education delivery by CNC and other HNEH clinicians
- Ongoing onsite support and trouble shooting, liaison with management
- Printing and distributing resources to support family awareness, ACP discussion, EOL care.
- 3 monthly Advisory Meetings to scope, structure and design project.
- Monthly Champion meetings, with education, supervision and networking support, individual and group supervision
- Onsite education and training on Palliative Approach the HCPDC Framework tools
- Onsite mentoring, trouble shooting and implementations support
- Marketing and promoting framework across key stakeholders and wider community
- Evaluation process with Ethics approval and end of project focus group

Identified outcomes:

Current evaluation is showing a significant paradigm shift in facilities involved with the project. i.e. Reduced presentations to hospital, greater advocacy for residents, improved communication with GP's - increased skills, knowledge with empowerment to conduct ACP discussions. Primary carer and family satisfaction with advance care planning, care at time of death and post death support.

Population outcome - families stating they are experiencing less anxiety, grief sorrow or depression following death, when involved in a palliative approach and care of their loved one throughout the end stage of life.

Strengthened links & information sharing across sectors both internally and externally – ie: with CACS, EDAC, Specialist Palliative Care, GP Access, Community Health Strategy Unit, Community Aged Care organisations.

Hunter Aged Palliative Care Network is providing sustainable outcomes through the Website – www.hapcn.com.au Ie: Short, relevant online education modules available & accessible for download / use / Project resources and tools on line in PDF and linked.

Contextual examples: i.e.: Few hospital admissions and ED presentations – Facility 'A' - 24 deaths in 10 months – only two (2) died in hospital Only one (1) presentation to ED in week prior to death other facilities showing similar stats.

MOLST record well accepted in both aged care sector and acute sector, GP's using tool as communication strategy following Nurse led ACP discussions.

End of Life pathway – utilised in most facilities, supports ACFI funding claims and improved end of life care and symptom management.

Pain management improved through use of NOPAIN as carer led tool, also many facilities implementing an RN led 'pain clinic' utilising natural therapy and comfort care focus.

Barriers:

- Lack of understanding of systems and constraints across acute / residential aged care sectors – poor acute care understanding of difference between low and high care facilities.
- Lack of understanding about the focus of specialist palliative care – complex EOL symptoms, expectations that palliative care should be referred onto 'specialist' PC
- Gap in support services for delivery of more generalist palliative care / case management.
- Time frames short so limited scope – project really taking off . . . . . Now!
- Engagement and involvement of GP's time consuming and unproductive, GP's – time scarce – GP's often unskilled in discussing EOL issues with families.
- Low numbers of RN's and poor base knowledge in advanced Dementia and/or EOL planning, low skill level in conducting 'impeccable' assessment of end of life symptoms (WHO 2002) – RN's consumed with medication delivery (S8's)
- Perceptions & understanding around the broader dimensions of Advance Care Planning as a nursing wellness model as opposed to Advance Care Directives as a medical model – both needed.
- Lack of understanding across sectors of the Palliative Approach in chronic diseases and dementia, being a much broader issue with very little infrastructure to support transition for curative to palliative care.

Performance indicators:

1. Improved aged care facility staff awareness of dementia as a life limiting disease and recognition of approach to End-of-life. (Evaluation data & focus groups)

2. Increased knowledge and skills of staff in delivering a Palliative Approach – (evaluation data and focus group) observed & stated as**:**

    1. Increased confidence observed within staff in discussing with, and caring for, the whole family at End-of- life,
    2. Improved advocacy and involvement in EOL care planning and symptom management as part of multidisciplinary team.

3. Increased awareness in families about dementia as a life limiting disease, treatment and decision making in advanced dementia and recognition of approach to End-of-life in loved one with dementia, (evaluation data and focus group) - observed & stated as**:**

    1. Increased involvement I decision making and choices in regards to a loved one with advanced dementia.
    2. Satisfaction in care, palliative care information provided and ongoing support as their loved one reaches end of life

4. Champion feedback indicating high level of carer / family satisfaction with discussing and planning for EOL care and feeling well supported at time of, and after death occurs. (Focus group)

5. Increased uptake of Advance Care Planning discussion within participating facilities. (survey data)

6. Increased uptake of the HCPDC Framework and use of resources available. (survey data)

7. Hospital admissions and/or emergency room presentations from aged care facilities significantly reduced following ACP process. (survey data and focus group)

8. Participating facilities are retaining a paid champion role for at least one day a week

9. Uptake in promoting and completing MOLST across GP's, Acute Care and facility Staff)

10. Carer and care worker uptake of NOPAIN and introduction of RN led 'pain clinics'

Part 3 – Evaluation

While there is no provision for an overarching national evaluation of this project, it would be most helpful if you could provide information about the following aspects of your project to aid planning for future funding directions.

Project title: ‘ **Hunter Collaborative Palliative Dementia Care Framework - HCPDCF**	
Keywords	Palliative-Dementia Care, Dementia-Care-Framework, End-of-Life-Dementia,
Project organisation	Hunter New England Local Health Network
Partner organisations	Anglican Care; Uniting Care, CatholicCare, Maroba Manor, Fig Tree Point Aged Care, Wallsend Aged care Facility.
Project funding	$545,900.44
Project timeframe	13 months
Were there any issues in designing the methodology?	Very short timeframe, recruiting champion roles and establishing framework to be implemented.
Were there any issues with governance in the course of the project?	Project Manager changed early in project implementation with minimal disruption to project. Collaborative relationships worked very well.
Comments on what worked	**What worked:** • Funding a champion role was a critical success factor • Leadership of a Senior Clinician (Dr John Ward) • Regular meetings with champions, outcomes driven with their desire to change / improve practice within facility. • Previous work / resources from similar projects being available to adapt and utilise – familiarity with tools. • Facility / Organisational management involvement and support in meeting expected outcomes / timeframes. • Collaborative HNEH internal networks and support systems • Leadership from local area health and solid aged care base – Community Aged Care Services and Geriatrician support. • Project manager’s clinical skill base and working history within sector – onsite presence and availability. • Close links with Hunter Aged Palliative Care Network (HAPCN & website www.hapcn.com.au). • Networking with an established group of people with strong background in Aged Palliative Care. • Multidisciplinary advisory committee and representation on champion working party from GP division, specialist palliative care and HNE community Advance Care Planning. • Close working links with Alzheimer’s Australia, Dementia Advisory Services and HNE Community Aged Care Services CNC’s
How was the project evaluated?	Through pre and post implementation surveys – one focus group with facility champions at close of project.

Was the project completed on time and within budget?	Project completed and within budget, HNEH has allocated funding which will allow for the evaluation process to be finalised and for a review of the relationship with facilities and what supported their progress, time lines and sustainability factors.
Were there any factors which impacted the cost of the project and its purpose?	Limited number of facilities involved in project – unfunded facilities very keen but unable to sustain the required investment of time to manage and monitor change process.
Were there things which, in hindsight, you would have done differently?	The evaluation process would be more rigorous in the planning phase, selecting more 'aged' focussed tools and fine tuning what data we really wanted to collect.
Were there any unexpected issues or unintended consequences identified in the course of implementing this project? List the positive and negative issues.	• Great feedback on family satisfaction, reduced grief and more positive wellbeing in family and care workers involved in any part of framework. Facility staff embraced change process. • RN ratio's (one RN to 40-60 people – sometimes higher, especially after hours) – impeded good assessment and pain / symptom management. • Residential Aged Care Facilities do not always see themselves as responsible for unstable or more complex End-of-Life care and symptom management – challenged by some expectations • General Aged Care Workers have a highly variable skill & knowledge base, often well below that needed for the role they play in aged palliative care. • Although 'Ageing in Place' is encouraged – low care facilities often have a Part-time Registered Nurse during office hours only – sometimes less than three days a week. • Registered Nurses are often unskilled in pain and symptom assessment and are time poor in being able to conduct adequate assessment. – referring to a GP often results in hospital transfer. • Many GP's have little or no skills in recognising EOL or futility of treatment – they also are heavily time constrained so transfer to hospital is often default response to calls from RN
If the project involved contact with people with dementia or mental illness and their carers/family/friends, was there positive/negative feedback?	**Sample**: *"I was so afraid of my husband dying and I can't believe how positive I feel about those last few weeks, it has made such a difference to my grief over him going"* *" It was such a relief to know there was one person who knew me and Mum well enough to know what we wanted at the end, having it all written down was good so all the staff knew what was happening, they were fantastic.* *" I loved the music and aromatherapy, I felt useful in helping with Dad's care and I know that without that time at the end just focussing on what dad would have wanted, both my brother and I would still be estranged, instead we have become close and have some lovely memories of the end."*
Was there any feedback from other groups of people impacted by the project?	**Sample:** *" I have been an RN for 20 years and this has totally changed my approach to aged care"* *"As a care worker this approach empowers me to really change my practice and to encourage others to join me in being an active member of the care team in talking about end of life and the*

	choices people have about care and treatment" *" This approach makes so much sense, everyone should wake up to the fact that older people entering aged care are at the end of life and that we are actually delivering palliative care – our facilities are 'hospices for the aged' in reality.*

Part 4 – Future directions

Please use the following sections to describe:

- the extent to which the project or the outcomes achieved by the project will be sustainable beyond the timeframe for the project funding received under the Local Palliative Care Grant Program Round, including comments on contributing factors or barriers to sustainability
- issues that impacted on the achievement of the intended objectives of the project, overall Program design, and suggestions for improvement to the Program in the future
- any additional comments you would like to make.

Sustainability
Hunter Aged Palliative Care Network: Website – resources, tools and online education. Monthly professional meetings & peer review, senior clinicians providing specialist support on request. Facilities are funding champion positions as ongoing commitment to Advance Care Planning and End of Life Care Resources, tools and marketing materials are all available on the HAPCN website with generic branding (HAPCN) and a local printer provides a cost effective service. Networks across disciplines have been strengthened and extended so that there is a true cross sectoral collaborative knowledge and skill base that can be and is, utilised by the community.
Issues and suggested improvements related to Program design
Time frames need to be much longer for change process to become imbedded.
Additional comments
This project has been highly successful in terms of changing practice and providing sustainable outcomes in each of the 6 organisations involved. Strong area health leadership, with its sound infrastructure and network of supportive professionals, provided the ability to succeed in most areas within a relatively short time frame. Duplicating the model, working with other aged care facilities / organisations, would hopefully produce similar outcomes – As facilities / organisations realise the benefits of this approach (e.g.: reduced complaints, higher consumer satisfaction, greater attraction of people wanting to enter the service and increased ACFI income) so they may demonstrate a willingness to fund the ongoing role of leading such a model of care. As the framework is established and resources are available a higher number of facilities could be engaged in changing their approach to advanced dementia care. This is unlikely to occur however, without seed funding to support the champion role within the facility for at least 12 months and coordinated leadership as with this project.