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The Palliative Care Evaluation Tool Kit: A compendium of tools to aid in the evaluation of palliative care projects

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Centre for Health Service Development

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September 2004

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Table of Contents

Introduction

It is important that lessons from innovative palliative care projects and programs are analysed and the results shared to improve practice and the overall effectiveness and reach of palliative care services. The purpose of this Tool Kit is to provide a suite of tools so that such palliative care initiatives can be monitored and their impacts measured from an evaluation perspective.

Palliative care services and projects differ in terms of their goals, target groups, size, duration, resource levels, locations, settings and the evaluation skills and experience of the participants. This diversity poses challenges in terms of evaluation design and the types of tools needed for effective information collection and valid analysis. This Tool Kit meets these challenges by providing a range of tools that have recently been developed and field tested as well as existing evaluation tools reported in the literature. Together, these provide a choice of tools with which to collect evaluation data. Guidelines for each of the tools are included in the section 'How to Use the Tools' starting on page 4.

This Tool Kit forms part of an overall evaluation framework which was developed after a review of the international literature and after input from end users. The individual tools within the framework are supported by an electronic evaluation database which allows the user to enter data from the individual tools in the Tool Kit into a user-friendly Microsoft Access database. This database is freely available to those wishing to use it at the following address:

http://www.uow.edu.au/commerce/chsd/palliative_care.html

Acknowledgments

The need for a suite of palliative care focused evaluation tools was recognised at the first national Caring Communities Program (CCP) workshop in Canberra in May 2003. Following feedback from that workshop, each of the tools was field tested during the period June 2003 to November 2003 and the final versions included in this tool kit are based on the results of those field tests. The Centre for Health Services Development (CHSD) gratefully acknowledges the assistance of the various CCP projects that assisted us in the field tests.

Information relating to the CCP can be found at the following website:

http://www.uow.edu.au/commerce/chsd/caring_communities.html

The Evaluation Framework

This diversity of palliative care research has important implications for the design of an evaluation. Rather than a 'one size fits all' approach, palliative care evaluation needs to be responsive, flexible, multi-pronged and tailor-made to the particular activity being evaluated. The following evaluation framework guides the task of tailor-making each evaluation.

EVALUATION HIERARCHY	**What did you do? SERVICE/PROJECT DELIVERY**	**How did it go? SERVICE/PROJECT IMPACT**	**Can you keep going? SUSTAINABILITY**	**What has been learnt? CAPACITY BUILDING**	**Are your lessons useful for someone else? GENERALISABILITY**	**Who did you tell? DISSEMINATION**
Level I	**Impact on, and outcomes for, consumers (patients, families, carers, friends, communities)**					
Baseline, Process & Outcome Indicators	▪ Plans, reports, routine data ▪ Qualitative data	1.1 Patient / client palliative care stage of illness data set 1.2 Patient /client experiences – patient questionnaire 1.3 Patient /client experiences – staff-completed questionnaire 1.4 Carer experiences with palliative care 1.5 Community Awareness of Palliative Care 1.6 Community Awareness: Remote Aboriginal and Torres Strait Islander Communities	4. Sustainability Tool	5. Capacity Building Tool	6. Generalisability Tool	7. Dissemination Log
Level 2	**Impact on, and outcomes for, providers (professionals, volunteers, organisations)**					
Baseline, Process & Outcome Indicators	▪ Plans, reports, routine data ▪ Qualitative data	2.1 Palliative Care providers 2.2 Volunteers currently working in palliative care 2.3 New Palliative Care Volunteers 2.4 People ending their time as a Palliative Care Volunteer 2.5 Health Professionals Not Working in Palliative Care Services 2.6 Health Workers in Remote Aboriginal and Torres Strait Islander Communities	4. Sustainability Tool	5. Capacity Building Tool	6. Generalisability Tool	7. Dissemination Log
Level 3	**Impact on, and outcomes for, the system (structures and processes, networks, relationships)**					
Baseline, Process & Outcome Indicators	▪ Plans, reports, routine data ▪ Qualitative data	3.1 Palliative Care Service Self-Assessment 3.2 General health care organisational survey 8 System level impacts and outcomes	4. Sustainability Tool	5. Capacity Building Tool	6. Generalisability Tool	7. Dissemination Log

Note: The evaluation tools included in this figure are discussed in the remainder of this toolkit.

The Palliative Care Evaluation Tool Kit – source for each tool

No	Tool	Source
1. Impact on and outcomes for consumers (patients, families, carers, friends, communities)		
1.1	Patient / client palliative care stage of illness data set	CHSD. Scales within the tool - Smith M. (1996), Eagar (2004) Fries at al (1979) and Karnofsky and Burchenal (1949).
1.2	Patient /client experiences – patient questionnaire	Modified from: The Patient Outcome Scale (Hearn J and Higginson IJ 1999) with one question adapted from the McGill QoL Scale (Cohen at al 1995)
1.3	Patient /client experiences – staff-completed questionnaire	Modified from: The Patient Outcome Scale (Hearn J and Higginson IJ 1999) with one question adapted from the McGill QoL Scale (Cohen et al 1995)
1.4	Carer experiences with palliative care	1st section by CHSD based on interviews with carers in the GAPs project. 2nd section is from the Queensland Ongoing Needs Identification Tool
1.5	Community Awareness of Palliative Care	CHSD
1.6	Community Awareness: Remote Aboriginal and Torres Strait Islander Communities	Wendy Scott, Kimberley Region Palliative Care Service, Broome, WA and CHSD
2. Impact on, and outcomes for providers (professionals and volunteers)		
2.1	Palliative Care providers	Modified from: Promoting Excellence in End-of-Life Care (Weissman et al 1998)
2.2	Volunteers currently working in palliative care	CHSD
2.3	New Palliative Care Volunteers	CHSD
2.4	People ending their time as a Palliative Care Volunteer	CHSD
2.5	Health Professionals Not Working in Palliative Care Services	CHSD
2.6	Health Workers in Remote Aboriginal and Torres Strait Islander Communities	Wendy Scott, Kimberley Region Palliative Care Service, Broome, WA and CHSD
3. Impacts on the system (structure and processes, networks, relationships)		
3.1	Palliative Care Service Self-Assessment	Modified from: US Center to Advance Palliative Care Supportive Care of the Dying: A Coalition for Compassionate Care (2001)
3.2	General health care organisational survey	CHSD
4	Sustainability Tool	Modified from: Hawe H, King L, Noort M, Jordens C and Lloyd B. NSW Health indicators to help with building capacity in health promotion (January 2000) NSW Department of Health
5	Capacity Building Tool	CHSD
6	Generalisability Tool	CHSD
7	Dissemination Log	CHSD
8	System level impacts and outcomes	Modified from the NSW HACC Comprehensive Assessment Pilots by the CHSD

How to use the tools

The following is a guide for each tool in the kit. The guide briefly outlines the purpose of the tool, when it should be used, and how to administer the tool.

Evaluation Level 1 Impact on and outcomes for consumers (patients, carers, friends, communities)

Tool 1.1 Patient / client palliative care stages of illness data set

Purpose

Palliative care phase is a clinical tool that measures a patient's stage of illness. It comprises five stages: stable, unstable, deteriorating, terminal and bereaved. Definitions of each phase and a Phase Change Validation flowchart are provided with the tool. When used in conjunction with the definitions of each phase, the flowchart provides clinicians with a systematic method of correctly assigning palliative care phases.

The Palliative Care Problem Severity Scale, the Karnovsky Rating Scale and the Resource Utilisation Groups/Activities of Daily Living (RUG-ADL) score provide additional functional, psychosocial and symptom severity information relating to each palliative care phase. These tools allow a complete clinical profile of the patient/client to be established.

When should the tools be used?

Palliative care phase should be reviewed at each visit. The Palliative care phase, Palliative Care Problem Severity Scale, the Karnovsky Rating Scale and RUG-ADL should be administered each time there is a change in palliative care phase.

How to administer this tool?

The palliative care phase should be assigned based on an overall assessment of the patient/clients condition. Formal training in the use of the Palliative Care Problem Severity Scale, the Karnovsky Rating Scale and RUG-ADL is not required.

Tool 1.2 AND 1.3 Patient / Client experiences – patient questionnaire & staff- completed questionnaire

Purpose

This tool is based on the Patient Outcome Scale (POS). The original POS was devised following a systematic review of outcome measures used in palliative care. This review concluded that there was a paucity of clinical questionnaires that could adequately reflect the holistic nature of palliative care (Hearn & Higginson, 1997). The POS was designed to overcome some of the limitations associated with existing outcome measurement scales in palliative care. It evolved using a literature review of measures, work by a multi-professional project group with individuals who worked in different palliative care settings and a patient representative. The POS was then piloted in hospice, home, hospital and other community settings. The questionnaire covers: physical symptoms, psychological symptoms, spiritual considerations, practical concerns, emotional concerns and psychosocial needs.

How should these tools be used?

This tool could be used by projects with a focus on improving the outcomes for palliative care patients in an active phase of their engagement with a service provider. However, it should only be used by those projects with a suitable level of ethical approval for administering the questions to patients under the care of a palliative care service.

How to administer these tools?

There are two versions of the questionnaire, one for patients to complete and the other for staff. It is a flexible tool, the usage of which can be determined by the needs of local services. One option is that the two versions are used on an ‘either or’ basis. Patients able to complete their own assessment do so, while the staff-rated version is completed for those patients unable to complete the patient-rated version. The other option is that a service may elect to have both versions collected and to compare the ratings. Bringing together these two complementary perspectives allows the POS to identify patient's problems and enables staff to provide individualised care.

The POS showed acceptable validity when used in a variety of settings, such as, home care, hospice in-patient and day care and hospital inpatient care as well as outpatient and community services. It has also been shown to be a credible, clinical, research and audit tool, which is acceptable to both patients and staff (Hearn & Higginson, 1999). The POS can be used routinely to guide clinical practice and monitor service interventions. Moreover, the POS is a valuable audit tool that can help meet the current statutory requirements on clinical governance.

The CHSD has modified the POS for the by deleting the original question 11 in the scale and substituting it with a question from the McGill Quality of Life Scale (Cohen 1997). CHSD has renamed these tools as the Patient/Client Experiences – patient questionnaire and the Patient/Client Experiences – staff-completed questionnaire.

Tool 1.4 Carer experiences with palliative care

Purpose

The items in this tool were developed as a result of work with the patients and carers involved with the Griffith Palliative Care Service (GAPS), they were field tested by CHSD. These items are supplemented with items from the QLD/NSW ongoing needs assessment tool.

How to administer this tool

This tool is designed to be used with a carer while they are looking after the patient rather than retrospectively. It is designed to be brief and simple in order to minimise respondent burden.

When using this tool it is essential that you advise the carer that their participation is voluntary, their responses are confidential and that their responses will not effect the quality of the service they receive. Ethical permission will be needed to elicit information on the experiences of carers.

Tool 1.5 Community Awareness of Palliative Care

Purpose

The purpose of this tool is to obtain an understanding of general community awareness of palliative care in the communities where projects have a focus on influencing organisations and individuals not directly concerned with palliative care activities and services. This focus might include awareness raising in local community service agencies, schools, sporting or recreational clubs or in organisations or business groups that might find information on palliative care to be relevant to their activities, such as funeral directors or solicitors with an interest in advance care directives.

When should this tool be used?

This tool is best used 'before' and 'after' some form of promotional activity, media campaign or after specific presentations by speakers. Ideally the tool might be administered a second time in a form of 'follow up' approach after a suitable period of time has elapsed from a campaign being undertaken, to see what impact might have been made.

How to administer this tool?

The tool is best used in a survey style approach in a local community, targeted at people who are intended to have some exposure to the educational or promotional material.

Tool 1.6 Community Awareness: Remote Aboriginal and Torres Strait Islander Communities

Purpose

The purpose of this tool is to obtain an understanding of general community awareness of palliative care in Aboriginal and Torres Strait Islander communities. It was developed through a review of the literature and through consultation with agencies who have experience in providing palliative care to Aboriginal and Torres Strait Islander communities. The tool has been field tested in a remote Aboriginal community and the results indicate that the language and concepts included in the tool are appropriate and understandable.

When should this tool be used?

This tool is designed to be exploratory and can be used from the time that work begins with Aboriginal and Torres Strait Islander communities. Given the nature of the consultation process, and the developing network of contacts that evolve, it may be necessary to re-visit this tool throughout the duration of the project.

How to administer this tool?

These questions are designed to be used as a guide for community discussions, small group and individual interviews. It may be necessary to work with a local community member or translator to ensure that there is understanding of the concepts in the tool. Palliative care may be a concept that is not widely understood in some communities. Each question has a series of prompts that help the person leading the discussion or interview to obtain the information that is desired.

Evaluation Level 2 Impact on and outcomes for providers (professionals and volunteers)

Tool 2.1 Palliative Care Providers

Purpose

This tool is designed to assess the level of knowledge and awareness of palliative care of Palliative Care Providers who are working in specialist palliative care services. It also assesses their attitudes and confidence of providing palliative care in their profession.

When should this tool be used?

This tool is ideal for 'before' and 'after' comparisons in an attempt to gauge how awareness, attitudes, confidence and knowledge may have changed during the life of a specific palliative care intervention.

How to administer this tool?

This questionnaire is designed to be brief to minimise disruption to busy professionals. It can be administered either face to face or it can be sent to individuals to complete themselves.

Tool 2.2 Volunteers currently working in palliative care

Purpose

This tool is designed to explore the perceptions and experiences of volunteers currently working in palliative care. It asks volunteers about their motivations to become involved in palliative care, their training, and how long they expect to continue in this role.

When should this tool be used?

This tool is best used in the evaluation of services and projects that aim to support and strengthen volunteer programs and services.

How to administer this tool?

This tool can be administered to volunteers at any stage of their involvement. It could be administered during a regular volunteers' meeting or opportunistically with individuals. It is important to advise the respondents that their participation is voluntary and their responses will be treated confidentially.

Tool 2.3 New Palliative Care Volunteers

Purpose

This tool is designed for people who are beginning their time as palliative care volunteers. It explores their understanding of palliative care, their perceptions of the role of volunteers in palliative care and their expectations of being a volunteer.

When should this tool be used?

This tool is best used as a baseline measure in evaluating activities designed to strengthen and support volunteer programs and services.

How to administer this tool

This tool should be administered to newly recruited volunteers, and could be administered during a training session. It is important to advise the respondents their participation is voluntary and that their responses will be treated confidentially.

Tool 2.4 People ending their time as a Palliative Care Volunteer

Purpose

This tool is designed for people who are completing their time as a palliative care volunteer. It asks them about their experience of being a volunteer and if the experience corresponded with the expectations they had. The tool also asks volunteers to provide a reason for discontinuing their services.

When should this tool be used

This tool is best used in the evaluation of services and projects that aim to support and strengthen volunteer programs and services.

How to administer this tool

This tool can be administered as part of an exit interview with volunteers who are discontinuing their service. It is important to advise respondents that their participation is voluntary and that their responses will be treated confidentially.

Tool 2.5 Health Professionals Not Working in Palliative Care Services

Purpose

This tool is designed to assess the level of knowledge and awareness of palliative care of health professionals who are not working in specialist palliative care services, for example General Practitioners.

When should this tool be used?

This tool is ideal for 'before' and 'after' comparisons in an attempt to gauge how awareness and involvement may have changed during the life of a specific project or awareness raising campaign.

How to administer this tool?

This questionnaire is designed to be brief in order to minimise disruption to busy professionals. It can be administered either face to face or telephone interview or it can be sent to individuals to complete themselves.

Tool 2.6 Health workers in remote Aboriginal and Torres Strait Islander communities

Purpose

This tool aims to evaluates the level of confidence and familiarity that health workers in remote Aboriginal and Torres Strait Islander communities have in the delivery of palliative care. It may be used with clinic staff (both Aboriginal and non-Aboriginal), Aboriginal Health Workers, GPs, aged care providers, and people responsible for health education and promotion in the community.

The tool was developed through a review of the literature and through consultation with agencies that have experience in providing palliative care to Aboriginal and Torres Strait Islander communities. The tool has been field tested in a remote Aboriginal community and the results indicate that the language and concepts included in the tool are appropriate and understandable.

When should this tool be used?

This tool is designed to be exploratory and can be used from the time that work begins with Aboriginal and Torres Strait Islander communities. Given the nature of the consultation process, and the developing network of contacts that evolve, it may be necessary to re-visit this tool throughout the duration of the project.

How to administer this tool?

These questions are designed to be used as a guide for discussions with health workers in the community and may be used for small group and individual interviews. It may be necessary to work with a local community member or translator to ensure that there is understanding of the concepts in the tool. Palliative care may be a concept that is not widely understood in some communities. Each question has a series of prompts that help the person leading the discussion or interview obtain the information that is desired.

Evaluation Level 3 Impacts on the system (structure and processes, networks, relationships)

Tool 3.1 Palliative Care Service Self-Assessment

Purpose

This tool is a modified form of an instrument called ‘Supportive Care of the Dying: A Coalition for Compassionate Care Organisational Assessment: System Grid and Assumptions’ developed by The Center to Advance Palliative Care. The modifications made by CHSD involve slight changes to the language used in the tool to make it appropriate for use in an Australian setting.

The objective of this tool is stated by the developers as:

- to provide a tool for organisations and systems to use as they assess themselves looking at supportive structures which make it possible to deliver outstanding services and are not unintentionally maintaining structures that inhibit such services.

The system assessment tool will allow organisations to self-rate their structures as supportive, inhibitive, or not present. Given this rating, they will also be able to self rate their own perception of actual effectiveness in assisting to meet the stated objective or outcome. This self-analysis, along with data from patients, families, bereaved families, and professionals, will assist organisations to target interventions for rapid cycle improvement. Systems may not personally offer specific services or programs, but have a method in place to refer persons in a manner that maintains continuity of care.

How to administer this tool

The tool is designed to be completed during a meeting or group discussion. The designers estimate that the process requires 2-4 hours and suggest that it should be done in at least 2 different sessions. This could be done with existing committees, eg, palliative care committees, ethics committees, quality committees, etc., or could be done as a structured focus group within your organisation. Every effort should be made to include direct care providers with much experience in caring for those affected by life-threatening illness as well as those direct care providers with little experience..

Tool 3.2 General organisational survey

Purpose

This tool is designed to capture information about the level of awareness and involvement that a particular organisation has about palliative care.

When should this tool be used?

This tool is ideal for ‘before’ and ‘after’ comparisons in an attempt to gauge how awareness and involvement may have changed during the life of the project.

How to administer this tool?

Ideally this tool is completed during a team meeting, and as a result reflects a consensus of opinion among the team. In the case of individuals with opinions that are very different to the rest of the group it is possible for them to complete the tool alone. It is important to indicate in the box provided which method was used.

Tool 4 Sustainability tool

Purpose

This tool has been developed to assess the organisational and system level impact of a palliative care initiative and particularly focuses on the sustainability of these initiatives.

When should this tool be used?

This tool is best used at the beginning of a particular palliative care initiative, at a midpoint and at the end. It is very important to rate the project ***as it is now***, and not how you want it to be at some point in the future. Therefore at the beginning of the initiative it is likely that there may be a greater proportion of lower scores or answers of "don't know" than there will be at the mid and end points of the project.

What does this tool tell you?

This tool will be useful in indicating whether there have been any changes in the factors affecting the sustainability of a particular palliative care activity in support of its goals or objectives over time.

Tool 5 Capacity Building tool

Purpose

This tool has been developed to help assess the organisational and system level impact of a palliative care initiative and particularly focuses on the ability of the initiative to build capacity in the community and system levels.

When should this tool be used?

This tool is best used at the beginning of a particular palliative care initiative, at a midpoint and at the end. It is very important to rate the project ***as it is now***, and not how you want it to be at some point in the future. Therefore at the beginning of the initiative it is likely that there may be a greater proportion of lower scores or answers of "don't know" than there will be at the mid and end points of the project.

What does this tool tell you?

This tool will be useful in indicating whether there have been any changes over time in the ability of your project to build the capacity for local systems to provide good quality palliative care.

Tool 6 Generalisability tool

Purpose

This tool has been developed to assess the organisational and system level impact of a palliative care initiative and particularly focuses on the generalisability of that initiative.

When should this tool be used?

This tool is best used at the beginning of a particular palliative care initiative, at a midpoint and at the end. It is very important to rate the project ***as it is now***, and not how you want it to be at some point in the future. Therefore at the beginning of the initiative it is likely that there may be a greater proportion of lower scores or answers of "don't know" than there will be at the mid and end points of the project.

What does this tool tell you?

This tool will be useful in indicating whether there have been any changes in the generalisability of the lessons learnt from a particular palliative care initiative over time. In other words, are these lessons transferable to a similar organisation or service providers in a different setting?

Tool 7. Dissemination Log

Purpose

The dissemination log is a record of how information about a particular palliative care intitiative is shared with others; both within the local community and beyond. The log covers many methods of communication including newspaper articles, conference presentations, journal articles, website dissemination and interviews on radio.: The person or organisation who was responsible for the dissemination, the date of the activity, the estimate of the number of people affected by the activity and an indication of the number of people who requested follow up information can also be recorded on the log.

How to administer this tool?

The log should be updated after each dissemination activity.

What does this tool tell you?

This tool is a useful gauge of which methods of communication are most successful in terms of follow up activities.

Tool 8 System level impacts and outcomes

Purpose

This tool is designed to assess the wider impacts that a particular palliative care project or initiative has on the local palliative care system. The first part of this tool asks individuals or agencies to assess how the project or initiative influenced the way they delivered services and how the project went for clients with special needs. The second part of the tool examines the inter-agency and system effects of the project or initiative. It contains a range of attitudinal statements addressing factors such as perceptions of team work, communication between agencies and so on.

When should this tool be used?

This tool should be used during a period close to the completion of the project or initiative as it asks people to make their assessment based on their knowledge of the project as a whole and the changes it engendered.

How to administer this tool?

Ideally this tool is completed during a team meeting, and as a result reflects a consensus of opinion among the team. In the case of individuals with opinions that are very different to the rest of the group it is possible for them to complete the tool alone. It is important to indicate in the box provided which method was used.

What does this tool tell you?

This tool is useful in gauging the degree to which local stakeholders perceive the success of a particular palliative care initiative.

The Evaluation Tools

Name

Unique Record Number

__ __ __ __ __ __ __ __ __ __ __

Date of birth *dd/mm/yyyy* _____/ _______ / _________
or affix label here

Evaluation Tool 1.1

Patient/client palliative care stage of illness data set

	Date of Phase or Phase Change	**PC Phase**	**Reason for phase change**	**PC Pain Score**	**PC Other Symptom Score**	**PC Psych/ Spiritual Score**	**PC Family/ Carer Score**	**RUG ADL Score at start of Phase**				**Karnofsky Score**
								Bed Mobility	**Toilet**	**Transfer**	**Eating**	
Initial Phase												
1st Phase change												
2nd Phase change												
3rd Phase change												
4th Phase change												
5th Phase change												
6th Phase change												
7th Phase change												
8th Phase change												
9th Phase change												

PALLIATIVE CARE (PC) PHASES

1 - Stable Phase
2 - Unstable Phase
3 - Deteriorating Phase
4 - Terminal Care Phase
5 - Bereaved Phase

Reason for Phase Change

1 - Phase change 2 - Discharge/case closure 3 - Died 4 - Bereavement phase end

PALLIATIVE CARE (PC) PROBLEM SEVERITY SCORE

PC Pain
The degree of overall pain symptoms.

PC Other Symptom
Record the degree of overall other symptoms. The following list may be used as a guide:
Nausea/vomiting, anorexia, itch/irritation, constipation/diarrhoea, wound/ulcer, dysphagia, incontinence, weakness/fatigue, oedema, dyspnoea, confusion/delirium.

PC Psychological/Spiritual
Record the score for overall degree of psychological/spiritual problems of the patient. The following list may be used as a guide:
Anxiety/fear, anger, unrealistic goals, agitation, request to die, depression/sadness, confusion.

PC Family/Carer
Record score for the overall degree of family/carer problems. The following list may be used as a guide:
Denial, care giver fatigue, unrealistic goals, anger, difficult communication - non-English speaking-sensory impairment, financial, family/carer conflict, legal, family/carer anxiety, accommodation, cultural.

FOR ALL (PC) PROBLEM SEVERITY ITEMS SCORE: 0-absent 1-mild 2-moderate 3-severe

RUG-ADL SCORE

For bed mobility, toileting & transfers:
1 Independent or supervision only
3 Limited physical assistance
4 Other than 2 person physical assist
5 2 person physical assist

For eating:
1 Independent or supervision only
2 Limited assistance
3 Extensive assistance/total dependence/ tube fed

Karnofsky Rating Scale

100	Normal with no complaints or evidence of disease.
90	Able to carry on normal activity but with minor signs of illness present.
80	Normal activity but requiring effort. Signs and symptoms of disease more prominent.
70	Able to care for self, but unable to work or carry on other normal activities.
60	Able to care for most needs, but requires occasional assistance.
50	Considerable assistance and frequent medical care required; some self-care possible.
40	Disabled, requiring special care and assistance.
30	Severely disabled; hospitalisation required but death not imminent.
20	Extremely ill; supportive treatment and/or hospitalisation required.
10	Imminent Death.
0	Death.

Definitions of Palliative Care Phases

(1) Stable Phase

All clients not classified as unstable, deteriorating, or terminal.

- The person's symptoms are adequately controlled by established management. Further interventions to maintain symptom control and quality of life have been planned.
- The situation of the family/carers is relatively stable and no new issues are apparent. Any needs are met by the established plan of care.

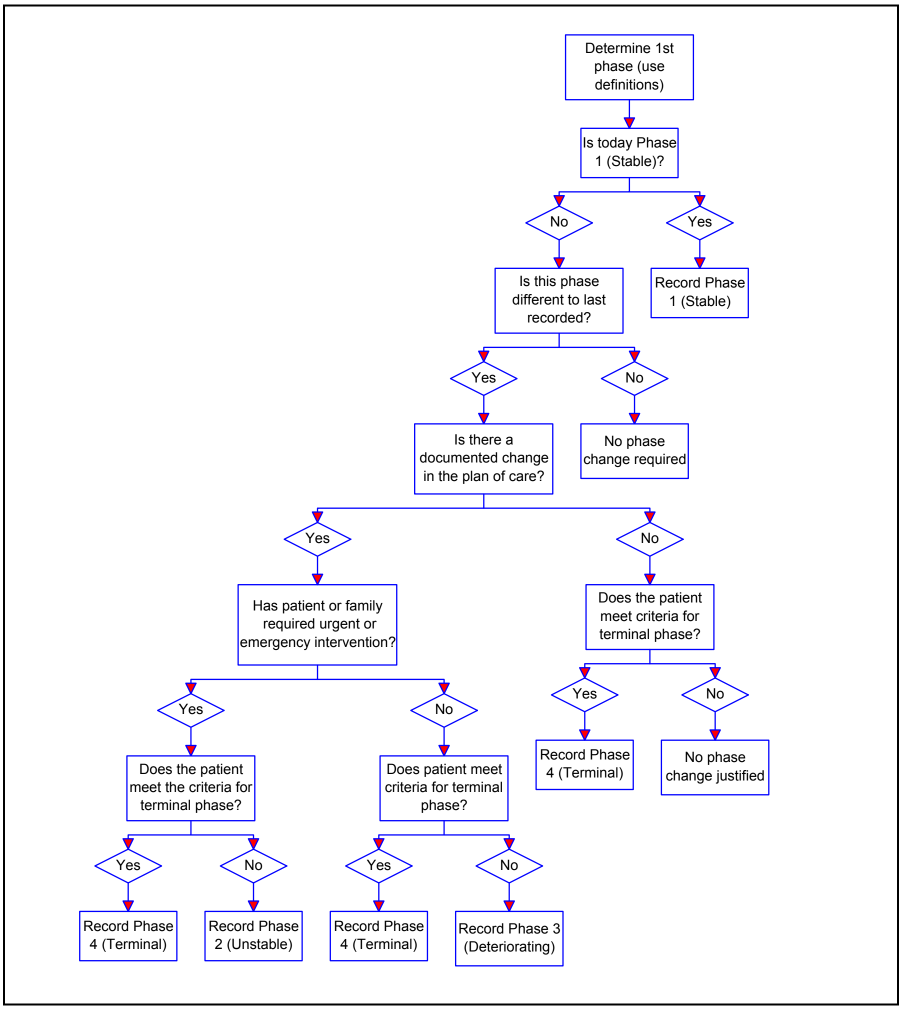
(2) Unstable Phase

The person experiences the development of a new problem or a rapid increase in the severity of existing problems, either of which require an urgent change in management or emergency treatment

- The family/carers experience a sudden change in their situation requiring urgent intervention by members of the multi-disciplinary team.

(3) Deteriorating Phase

- The person experiences a gradual worsening of existing symptoms or the development of new but expected problems. These require the application of specific plans of care and regular review but not urgent or emergency treatment.
- The family/carers experience gradually worsening distress and other difficulties, including social and practical difficulties, as a result of the illness of the person. This requires a planned support program and counselling as necessary.



(4) Terminal Care Phase

Death is likely in a matter of days and no acute intervention is planned or required. The typical features of a person in this phase may include the following:

- Profoundly weak
- Essentially bed bound
- Drowsy for extended periods
- Disoriented for time and has a severely limited attention span
- Increasingly disinterested in food and drink
- Finding it difficult to swallow medication
- This requires the use of frequent, usually daily, interventions aimed at physical, emotional and spiritual issues.
- The family/carers recognise that death is imminent and care is focussed on emotional and spiritual issues as a prelude to bereavement

(5) Bereaved Phase

Death of the patient has occurred and the carers are grieving. A planned bereavement support program is available including counselling as necessary.

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Project URN:

Date:

Evaluation Tool 1.2

Patient experiences

About you

Your sex Male ☐ Female ☐ Your age __________

Do you identify as Aboriginal or Torres Strait Islander? Yes ☐ No ☐

Do you identify with a particular ethnic origin or cultural background? Yes ☐ No ☐

If yes, please specify your ethnic origin or cultural background: ______________________________

About how you have been feeling

Please answer the following questions by ticking the box next to the answer that is most true for you. Should you require assistance in filling in this form, feel free to ask someone to help you. Your answers will help us to keep improving your care and the care of others. Thank you.

1. Over the past 3 days, have you been affected by pain?

☐ Not at all, no effect ☐ Slightly – but not bothered to be rid of it ☐ Moderately – pain limits some activity ☐ Severely – activities or concentration markedly affected ☐ Overwhelmingly – unable to think of anything else

2. Over the past 3 days, have other symptoms (eg, feeling sick, having a cough or constipation) been affecting how you feel?

☐ Not at all ☐ Slightly ☐ Moderately ☐ Severely ☐ Overwhelmingly

3. Over the past 3 days, have you been feeling anxious or worried about your illness or treatment?

☐ Not at all ☐ Occasionally ☐ Sometimes – affects my concentration now and then ☐ Most of the time – often affects my concentration ☐ Can't think of anything else - completely pre-occupied by worry and anxiety

4. Over the past 3 days, have any of your family or friends been anxious or worried about you?

☐ Not at all ☐ Occasionally ☐ Sometimes – it seems to affect their concentration ☐ Most of the time ☐ Yes, always preoccupied with worry about me

5. Over the past 3 days, how much information have you and your family or friends been given?

☐ Full information – always feel free to ask what I want ☐ Information given but hard to understand ☐ Information given on request but would have liked more ☐ Very little given and some questions were avoided ☐ None at all

6. Over the past 3 days, have you been able to share how you are feeling with your family or friends?

☐ Yes, as much as I wanted to ☐ Most of the time ☐ Sometimes ☐ Occasionally ☐ Not at all with anyone

7. Over the past 3 days, have you been feeling depressed?

☐ No, not at all ☐ Occasionally ☐ Sometimes ☐ Most of the time ☐ Yes, definitely

If you have ticked 'Most of the Time' or 'Yes, definitely' for this question, please speak with your nurse or doctor at your next visit.

8. Over the past 3 days, how much time do you feel has been wasted on appointments relating to your health care (eg, waiting around for transport or repeating tests)?

☐ None at all ☐ Up to half a day wasted ☐ More than half a day wasted

9. Over the past 3 days, have any practical matters resulting from your illness, either financial or personal, been addressed?

☐ Practical problems have been addressed and my affairs are as up to date as I would wish ☐ Practical problems are in the process of being addressed ☐ Practical problems exist which were not addressed ☐ I have had no practical problems

10. Have you been involved in decisions about your treatment or practical matters as much as you would like?

☐ Yes, all of the time ☐ Most of the time ☐ Sometimes ☐ Occasionally ☐ No, not at all

11. Please list or describe the things that had the greatest effect on your quality of life in the past three (3) days. Please say whether each thing you list made your quality of life better or worse during this time. If you need more space, please use a separate page.

12. How did you complete these questions?

☐ On my own ☐ With the help of a friend or relative ☐ With help from a member of staff

If, after completing these questions, you feel you would like more help with any symptoms or problems, please speak with your doctor or nurse.

This is the end of the survey. Thank you for your time.

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Project URN:

Date:

Evaluation Tool 1.3

Patient experiences – staff rated version

About the patient

Sex Male ☐ Female ☐ Age ___________

Does the patient identify as Aboriginal or Torres Strait Islander? Yes ☐ No ☐

Does the patient identify with a particular ethnic origin or cultural background? Yes ☐ No ☐

If yes, please specify ethnic origin or cultural background: ______________________________

About how the patient feels

Please answer the following questions by ticking the box next to the answer that you think most accurately describes how the patient has been feeling. Thank you.

1. Over the past 3 days, has the patient been affected by pain?

☐ Not at all, no effect ☐ Slightly – but not bothered to be rid of it ☐ Moderately – pain limits some activity ☐ Severely – activities or concentration markedly affected ☐ Overwhelmingly – unable to think of anything else

2. Over the past 3 days, have other symptoms (eg, feeling sick, having a cough or constipation) been affecting how they feel?

☐ Not at all ☐ Slightly ☐ Moderately ☐ Severely ☐ Overwhelmingly

3. Over the past 3 days, has the patient been feeling anxious or worried about their illness or treatment?

☐ Not at all ☐ Occasionally ☐ Sometimes – affects their concentration now and then ☐ Most of the time – often affects their concentration ☐ Patient does not seem to think of anything else - completely pre-occupied by worry and anxiety

4. Over the past 3 days, have any of their family or friends been anxious or worried about the patient?

☐ Not at all ☐ Occasionally ☐ Sometimes – it seems to affect their concentration ☐ Most of the time ☐ Yes, they are always preoccupied with worry

5. Over the past 3 days, how much information has been given to the patient and their family or friends?

☐ Full information – patient feels free to ask ☐ Information given but not always understand by patient ☐ Information given on request – patient would have liked more ☐ Very little given and some questions have been avoided ☐ None at all

6. Over the past 3 days, has the patient been able to share how they are feeling with family or friends?

☐ Yes, as much as they wanted to ☐ Most of the time ☐ Sometimes ☐ Occasionally ☐ No, not at all with anyone

7. Over the past 3 days, do you think that the patient has been feeling depressed?

☐ No, not at all ☐ Occasionally ☐ Sometimes ☐ Most of the time ☐ Yes, definitely

8. Over the past 3 days, how much time do you feel has been wasted on appointments relating to the health care of the patient (eg, waiting around for transport or repeating tests)?

☐ None at all ☐ Up to half a day wasted ☐ More than half a day wasted

9. Over the past 3 days, have any practical matters resulting from their illness, either financial or personal, been addressed?

☐ Practical problems have been addressed and their affairs are as up to date as they would wish ☐ Practical problems are in the process of being addressed ☐ Practical problems exist which were not addressed ☐ The patient has had no practical problems

10. Has the patient been involved in decisions about their treatment or practical matters as much as they would like?

☐ Yes, all of the time ☐ Most of the time ☐ Sometimes ☐ Occasionally ☐ No, not at all

11. Please list or describe the things that you think had the greatest effect on the quality of life of the patient in the past three (3) days. Please say whether each thing listed made their quality of life better or worse during this time. If you need more space, please use a separate page.

12. How did you complete these questions?

☐ Without discussing it with the patient or their family/carer ☐ After discussion with the patient ☐ After discussion with the patient's family or carer

This is the end of the survey. Thank you for your time.

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Project URN:

Date:

Evaluation Tool 1.4
Carer experiences with palliative care

About you

Your sex Male ☐ Female ☐	Your age ___________

Do you identify as Aboriginal or Torres Strait Islander? Yes ☐ No ☐

Do you identify with a particular ethnic origin or cultural background? Yes ☐ No ☐

If yes, please specify your ethnic origin or cultural background: ______________________________

About your experience with the palliative care service

Please answer the following questions. If the question does not apply to your situation, please tick the Don't know box.

	Agree	Disagree	Don't know
I feel that adequate attention is paid by the service to my needs as a carer			
I have been provided with all the equipment I need to help me in my caring role			
I feel confident about using the equipment that has been supplied			
I have been supplied with clear instructions about what to do in an emergency			
I feel confident that every effort is being made to keep the person I am looking after free of pain			
I know who to contact for help if I need it			
I feel secure that help and advice is available 24 hours a day for me			
The palliative care staff are helpful and friendly			
I feel comfortable with the palliative care staff visiting my home			
Respite is available so that I can have a break if I need it			
I know there are people I can contact for support after the person I am caring for has died.			

Overall the support and assistance I have received has been:

Excellent (no improvement necessary) ☐

Good (my needs are met, but the service could be improved) ☐

Satisfactory (most of my needs are met) ☐

Poor (few of my needs are met) ☐

Please continue by answering the questions over the page

Have you had someone to help you with practical tasks?

☐ Yes, I've had all the help I need ☐ yes, but not enough ☐ I haven't needed help ☐ No

Did anyone give you information on whether you would qualify for a Carer Payment or Allowance?

☐ Yes, I was given all the information I need ☐ Yes, it was mentioned but not in any detail ☐ I haven't needed any financial help ☐ No

Did someone give you information about available support services?

☐ Yes, I was given all the information I need ☐ Yes, it was mentioned but not in any detail ☐ I haven't needed any help ☐ No

Did someone give you practical training in lifting, managing medicine or other tasks?

☐ Yes, I was given all the training I need ☐ Yes, I was given a bit, but not enough ☐ I haven't needed any help ☐ No

This is the end of the survey. If you would like to add any comments about your experience, please do so in the box below. Thank you for your time.

Comments about your experience

Evaluation Tool 1.5 - Community Awareness of Palliative Care

About you

Your sex Male ☐ Female ☐ | Your age ________

Do you identify as Aboriginal or Torres Strait Islander? Yes ☐ No ☐

Do you identify with a particular ethnic origin or cultural background? Yes ☐ No ☐

If yes, please specify your ethnic origin or cultural background: ______________________________

About palliative care

1. Have you heard of palliative care? Yes ☐ No ☐ Not sure ☐

2. How would you rate your knowledge of palliative care?

No knowledge ☐ General knowledge only ☐ Professional / extensive knowledge ☐

If you ticked 'no knowledge', please skip the next questions and move straight to Question 8 (over the page). Otherwise, please proceed with the questions on this page.

3. What does a palliative care service do?

____

____

____

____

4. What services or organisations provide palliative care in your community?
(tick all that you know provide palliative care in your local community)

Hospital ☐

Nursing homes/residential aged care ☐

Hospice ☐

Community Health Centre ☐

Community nursing services ☐

General Practitioners ☐

Other (please describe): ______________________________

____

5. Do you think these services meet the palliative care needs of your community?

Yes ☐ No ☐ Don't know ☐

6. If no, how could palliative care be improved in your community?

We need a hospice ☐

We need home based care ☐

More volunteers in palliative care ☐

We would like the hospital to be more aware of the needs of palliative patients ☐

We need a 24 hour a day helpline ☐

Other (please describe below): ☐

____

____

____

7. Where did you learn about palliative care? (tick all that apply)

General Practitioner ☐ Community health centre ☐ Community nursing service ☐

Nursing home ☐ Hospital ☐ Hospice ☐

Television/radio ☐ Relatives/friends ☐ Internet ☐

Other (please describe):

8. Have you ever looked after someone who was dying?

Yes ☐ No ☐ ***If no, move straight to Question 12***

9. In what capacity have you looked after someone who was dying? (tick all that apply)

Relative ☐ Friend ☐ Volunteer ☐

Health care professional ☐ Manager of services ☐ Member of the Clergy ☐

Other (please describe):

10. How confident did you feel when looking after the person who was dying?

☐ Confident all of the time ☐ Confident most of the time ☐ Undecided ☐ Somewhat confident ☐ Not at all confident

11. Did you feel that you had enough support to undertake this role?

Yes ☐ No ☐ Don't know ☐

12. How important is each of the following in palliative care? Please use a scale from 1 to 6 to rank the importance of each service. Please write '1' next to the most important service, '2' against the next most important and so on.

Choice for the patient ☐ Home based care ☐ 24 hour a day call out service ☐

The provision of information/education ☐ The provision of equipment / home modifications ☐ Hospice care ☐

Other (please describe):

This is the end of the survey. Thank you for your time

Evaluation Tool 1.6 - Community Awareness, Remote Aboriginal and Torres Strait Islander Communities

1. Have you ever heard of palliative care before? What do these words mean to you?

Prompt: Sometimes people get sick and they can't get better. Care for people who are like this is called palliative care.

2. Is there any support in the community to help people who are not going to get better? (people who are finishing up?)

Prompt: People who have this kind of sickness may want to stay on their country and be looked after by their families. Do you know anyone like this? Do you know if their families are getting any help? What sort of help are they getting?

3. Do you know that there are services that can help people and their families?

Prompt: The Palliative care service can provide help for people and their families. They can provide things like wheelchairs and comfortable beds. They can make sure that the sick person doesn't have any pain.

4. What sort of help do you think people who are finishing up might want in this community?

Prompt: Help to stay at home, perhaps making the house more safe to move around, help to move around, perhaps getting a wheelchair.

5. What sort of help do you think that the people looking after them might need?

Prompt: How to keep the sick person comfortable, what sorts of food to give them, who do I ask for help?

6. If a sick person needs lots of care, like care all through the night, where is the best place for them to go?
Prompt: Do you think they could be cared for at home, or do you think they would need to go to a hospital?

7. When a person is dying (finishing up) in hospital, do you think they should be able to come home to their community?
Prompt: How important is it for people to die on their own country with their families?

8. Do you think that there are people in this community who would be interested in getting training to look after dying people (people who are finishing up) in this community?
Prompt: Find out people's names, if they have volunteered themselves or another person, and if they have had any prior caring experience.

9. Do you think that the Council here would support a program to train local people to care for people who are dying (finishing up)?

10. Is there anyone who can share a story about caring for someone who was finishing up?
Prompt: Did you look after them at home. Who helped? Did you think you needed more help?
What could be done to make things easier for you and the person you were looking after?

Evaluation Tool 2.1

Palliative Care Providers

About you

Your sex Male ☐ Female ☐	Your age ____________		
Your discipline:	Your Palliative care training (tick all that apply)	Specialist qualification ☐ Short courses or other formal training not leading to a specialist qualification ☐	On the job training only ☐ No training ☐

Do you identify as Aboriginal or Torres Strait Islander? Yes ☐ No ☐

Do you identify with a particular ethnic origin or cultural background? Yes ☐ No ☐

If yes, please specify your ethnic origin or cultural background: ________________________________

About your views on palliative care

Please rate your degree of confidence with the following patient / family interactions and patient management topics, by ticking the relevant box below

1 = Need further basic instruction	2 = Confident to perform with close supervision / coaching
3 = Confident to perform with minimal consultation	4 = Confident to perform independently

No	**Patient/family interactions and clinical management**	**1**	**2**	**3**	**4**
1	Answering patients questions about the dying process				
2	Supporting the patient or family member when they become upset				
3	Informing people of the support services available				
4	Discussing different environmental options (eg hospital, home, family)				
5	Discussing patients wishes for after their death				
6	Answering queries about the effects of certain medications				
7	Reacting to reports of pain from the patient				
8	Reacting to and coping with terminal delirium				
9	Reacting to and coping with terminal dyspnoea (breathlessness)				
10	Reacting to and coping with nausea / vomiting				
11	Reacting to and coping with reports of constipation				
12	Reacting to and coping with limited patient decision-making capacity				

Please continue over the page

Views about death and dying

Please indicate how much you agree or disagree with each of the following statements, by ticking the box that best describes how you feel. (There are no right or wrong answers).

No	Statement	Agree Strongly	Agree	Unsure / Mixed	Disagree	Disagree Strongly
1	The end of life is a time of great suffering.					
2	Little can be done to help someone achieve a sense of peace at the end of life.					
3	The use of strong pain medication can cause the person to stop breathing.					
4	I am not comfortable caring for a dying patient.					
5	I am not comfortable talking to families about death.					
6	When a patient dies I feel that something went wrong.					
7	Feeding tubes should be used to prevent starvation at the end of life.					
8	Nursing homes/hospitals are not good places to die.					
9	Families have the right to refuse a medical treatment, even if that treatment prolongs life.					
10	Dying patients should be referred to a hospice or acute care.					

Attitudes towards Palliative Care

No	Statement	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Disagree Strongly
1	Pain at the end of life is an inevitable part of the dying process					
2	Pain medication should be given as needed to terminally ill patients					
3	Spiritual care should include counselling the terminally ill patient					
4	I do not like talking about death and dying with patients					
5	Palliative care should be the standard medical treatment for patients who are suffering from a terminal illness					
6	Patients should have the right to determine their own degree of medical intervention					
7	Addiction to oral morphine is not a serious issue given that terminally ill patients have a short time to live					
8	Opening discussions of end-of-life care should be deferred until there is no further effective curative treatment available					
9	Estimation of pain by an MD or RN is a more valid measure of pain than patient self-report					
10	Complete pain relief is a reasonable goal even when the pain is not caused by a terminal condition such as cancer					
11	Patients have the right to determine their own degree of psychosocial intervention					
12	The most appropriate person to make end-of-life decisions is the patient's primary care provider					
13	A patient should experience discomfort prior to receiving the next dose of pain medications					
14	Patients should be maintained in a pain-free state					
15	As a rule, terminally ill patients prefer not to talk about death and dying					

Please indicate the importance of the issues below in terms of the problems they create for you in caring for a dying patient by ticking the box that best describes your feelings. (There are no right or wrong answers).

No	Statement	Very important	Important	Unsure	Less important	Not important
1	Control of pain					
2	Managing depression					
3	Legal concerns					
4	Ability to meet spiritual needs					
5	The patient's emotional needs					
6	Communication with family					
7	Communication with other palliative care staff					
8	Communication with (other) doctor/s					
9	Uncertainty about what is best care					
10	Other (please describe)					

Please tick the boxes to indicate whether you would like future education on any of the following topics:

Pain assessment and management		Dealing with terminal delirium	
Dealing with nausea and vomiting		Dealing with terminal dyspnea	
Dealing with constipation		Use of intravenous hydration and/or non-oral feeding in end-of-life care	
End-of-life communication skills - giving bad news, talking with family, discussing prognosis, discussing various treatment options		End-of-life ethics: DNR orders, advance directives, decision-making capacity	
Spirituality and cultural aspects of end-of-life care		Other (please specify below)	

Please list any other topics here

This is the end of the survey. Thank you for your time.
If you wish to make any further comments, please do so over the page

Other comments:

Evaluation Tool 2.2 - Volunteers currently working in palliative care

About you

Your sex Male ☐ Female ☐ Your age ___________

Do you identify as Aboriginal or Torres Strait Islander? Yes ☐ No ☐

Do you identify with a particular ethnic origin or cultural background? Yes ☐ No ☐

If yes, please specify your ethnic origin or cultural background: ______________________________

About your experience with palliative care

1. How long have you been a palliative care volunteer?

☐ Less than 3 months ☐ 3 months to a year ☐ One to three years ☐ More than 3 years ☐ Can't remember / Don't know

2. Why did you initially decide to become a volunteer? ______________________________

____

____

____

____

3. Did you have any previous experience as a volunteer? Yes ☐ No ☐

4. If yes, what sort of volunteering had you done prior to volunteering for palliative care? (please describe)

____

____

5. Prior to commencing as a volunteer, had you ever been a carer for a person with a disability or a frail older person?

Yes ☐ No ☐

6. If yes, please tick the box that best describes your role:

Health professional ☐ Family member ☐ Friend ☐

7. On average, how much time do you spend as a volunteer?
(Please estimate the number of hours per month). ______________________________

8. What sort of volunteer work do you undertake? (tick all that you have ever done)

Home based visits	☐	Hospital/Hospice based visits	☐	Assistance to visit the doctor	☐
General assistance with transport	☐	Shopping assistance	☐	Recreation/leisure activities	☐
All of the above	☐				

Other (please describe): ______________________________

9. Did you receive any training before beginning as a volunteer?

Yes, a formal training program ☐ Yes, on the job/informal program ☐ No ☐

10. What do you think are the most important elements of a training package for volunteers in palliative care? Please use a scale from 1 to 6 to rank the importance of each element. Please write '1' next to the most important, '2' against the next most important and so on.

General awareness of palliative care	☐	Dealing with grief/anxiety	☐	Dealing with bereavement	☐
Assistance with activities of daily living	☐	Spiritual issues	☐	First Aid	☐

Other (please describe): ____________________

____

11. How much support do you receive from the organisation where you work as a volunteer?

☐ None at all ☐ Some support, but not enough ☐ As much as I want

12. Do you know who to contact if you have any problems?

☐ No ☐ Sometimes ☐ Yes

13. How long are you planning to continue to work as a volunteer in palliative care?

For years	☐	I don't know. It will depend on how I feel about it when I'm actually working as a volunteer	☐
For a year or so	☐	I don't know. It will depend on other things happening in my life such as my family responsibilities and other activities I'm involved in	☐
For less than a year	☐	I don't know, for other reasons (please describe):	☐

____

____

____

14. What is the best part of being a palliative care volunteer? ____________________

____

____

____

15. What is the worst part or the thing that most concerns or worries you about being a palliative care volunteer?

____

____

____

This is the end of the survey. Thank you for your time.

Evaluation Tool 2.3 - New Palliative Care Volunteers

About you

Your sex Male ☐ Female ☐ Your age __________

Do you identify as Aboriginal or Torres Strait Islander? Yes ☐ No ☐

Do you identify with a particular ethnic origin or cultural background? Yes ☐ No ☐

If yes, please specify your ethnic origin or cultural background: ______________________________

1. **Why did you decide to become a volunteer?** ______________________________

2. **Have you any previous experience as a volunteer?** Yes ☐ No ☐

3. **If yes, what sort of volunteering have you done?** (please describe)______________________________

4. **Have you been in the role of a carer for a person with a disability or a frail older person in the past?**
   Yes ☐ No ☐

5. **If yes, please tick the box that best describes your role:**
   Health professional ☐ Family member ☐ Friend ☐

6. **How much time are you prepared to commit to volunteering?**
   (Please estimate the number of hours per month). ______________

7. **What sort of volunteer work would you feel most comfortable undertaking?**

Home based visits ☐ Hospital/Hospice based visits ☐ Assistance to visit the doctor ☐

General assistance with transport ☐ Shopping assistance ☐ Recreation/leisure activities ☐

All of the above ☐

Other (please describe): ______________________________

8. What do you think are the most important elements of a training package to assist you in your role? Please use a scale from 1 to 6 to rank the importance of each element. Please write '1' next to the most important, '2' against the next most important and so on.

General awareness of palliative care	☐	Dealing with grief/anxiety	☐	Dealing with bereavement	☐
Assistance with activities of daily living	☐	Spiritual issues	☐	First Aid	☐

Other (please describe): ____

9. How long are you planning to work as a volunteer in palliative care? (tick all that apply)

For years	☐	I don't know. It will depend on how I feel about it when I'm actually working as a volunteer	☐
For a year or so	☐	I don't know. It will depend on other things happening in my life such as my family responsibilities and other activities I'm involved in	☐
For less than a year	☐	I don't know, for other reasons (please describe):	☐

____

____

10. What are you most looking forward to in your role as a volunteer? ____________________

____

____

____

____

11. Is there anything that worries you about becoming a palliative care volunteer?

Yes ☐ No ☐

If yes, please describe

____

____

____

____

This is the end of the survey. Thank you for your time.

Evaluation Tool 2.4 - People ending their time as a Palliative Care Volunteer

About you

Your sex Male ☐ Female ☐ Your age __________

Do you identify as Aboriginal or Torres Strait Islander? Yes ☐ No ☐

Do you identify with a particular ethnic origin or cultural background? Yes ☐ No ☐

If yes, please specify your ethnic origin or cultural background: ______________________

About your experience with palliative care

1. How long have you been a palliative care volunteer?

☐ Less than 3 months ☐ 3 months to a year ☐ One to three years ☐ More than 3 years ☐ Can't remember / Don't know

2. Why did you initially decide to become a volunteer?

____

____

3. Did you have any previous experience as a volunteer? Yes ☐ No ☐

4. On average, how much time have you spend as a volunteer?

(Please estimate the number of hours per month). ______________________

5. What sort of volunteer work did you undertake? (tick all that you have ever done)

Home based visits	☐	Hospital/Hospice based visits	☐	Assistance to visit the doctor	☐
General assistance with transport	☐	Shopping assistance	☐	Recreation/leisure activities	☐
All of the above	☐				

Other (please describe): ______________________

6. Did you receive any training before beginning as a volunteer?

Yes, a formal training program ☐ Yes, on the job/informal program ☐ No ☐

7. What do you think are the most important elements of a training package for volunteers in palliative care? Please use a scale from 1 to 6 to rank the importance of each element. Please write '1' next to the most important, '2' against the next most important and so on.

General awareness of palliative care	☐	Dealing with grief/anxiety	☐	Dealing with bereavement	☐
Assistance with activities of daily living	☐	Spiritual issues	☐	First Aid	☐

Other (please describe): ______________________

____

8. How much support did you receive from the organisation where you have been working as a volunteer?

☐ None at all ☐ Some support, but not enough ☐ As much as I wanted

9. Did you know who to contact if you had any problems?

☐ No ☐ Sometimes ☐ Yes

10. Why are you ending your time as a volunteer in palliative care? (tick all that apply)

For reasons directly related to my experience as a volunteer ☐

For reasons that have nothing to do with palliative care such as family responsibilities and other activities I'm involved in ☐

Comments on why you are ending your time as a palliative care volunteer

11. What was the best part of being a palliative care volunteer?

12. What is the worst part or the thing that most concerned or worried you about being a palliative care volunteer?

13. Would you recommend being a palliative care volunteer to your friends?

Yes, definitely ☐ Maybe, it would depend on the person ☐ Don't know ☐ No, definitely not ☐

14. Is there anything that the palliative care service could have done that would have influenced your decision to give up being a palliative care volunteer?

Yes, definitely ☐ Maybe ☐ Don't know ☐ No, definitely not ☐

If so, please identify what the palliative care service could have done or done differently

This is the end of the survey. Thank you for your time

Evaluation Tool 2.5 - Health Professionals Not Working in Palliative Care Services

About you

Your sex Male ☐ Female ☐	Your age	Your country of birth	
Your discipline:	Have you ever had any palliative care training? (tick all that apply)	Specialist qualification ☐ Short courses or other formal training not leading to a specialist qualification ☐	On the job training only ☐ No training ☐

About your views on palliative care

1. How would you rate your knowledge of palliative care?

No knowledge ☐ General knowledge only ☐ Professional / extensive knowledge ☐

If you ticked 'no knowledge', please skip the next questions and move straight to Question 5. Otherwise, please proceed with the questions below.

2. What services or organisations provide palliative care in the community?

(tick all that you know provide palliative care in the community in which you work)

Hospital ☐

Nursing homes/residential aged care ☐

Hospice ☐

Community Health Centre ☐

Community nursing services ☐

General Practitioners ☐

Other (please describe):

____

____

3. Do you think these services meet local palliative care needs?

☐ Yes, local needs are fully met ☐ Most local needs are met ☐ Don't know / undecided ☐ Some local needs are met ☐ No, the needs are not met at all

4. If local needs are not being met now, how could palliative care be improved in your community? Please use a scale of 1 to 6 to rank the following possible ways that services might be improved, with 1 being the most important improvement required and 6 being the least important.

This community needs a hospice or dedicated palliative care beds at the hospital	☐	The hospital needs to be more aware of the needs of palliative patients	☐
This community needs more home based care	☐	This community needs a 24 hour a day telephone service	☐
More volunteers in palliative care	☐	The local hospice or hospital needs more palliative care beds	☐

Other (please describe below):

____

____

____

5. Have you ever looked after someone who was dying?

Yes ☐ No ☐ ***If no, move straight to Question 9***

6. In what capacity have you looked after someone who was dying? (tick all that apply)

Relative ☐ Friend ☐ Volunteer ☐

Health care professional ☐ Manager of services ☐ Member of the Clergy ☐

Other (please describe):

7. How confident did you feel when looking after the person who was dying?

☐ Confident all of the time ☐ Confident most of the time ☐ Undecided ☐ Somewhat confident ☐ Not at all confident

8. Did you feel that you had enough support to undertake this role?

Yes ☐ No ☐ Don't know ☐

9. What do you think are the essential elements of a palliative care program? How important is each of the following in palliative care? Please use a scale from 1 to 6 to rank the importance of each service, with 1 being the most important element and 6 being the least important.

Choice for the patient ☐ Home based care ☐ 24 hour a day call out service ☐

The provision of information/education ☐ The provision of equipment / home modifications ☐ Hospice or hospital care ☐

Multidisciplinary service provision ☐ Bereavement support ☐ Other (please describe below): ☐

10. Please use the box below to record any other comments you would like to make about palliative care services in the area where you work

This is the end of the survey. Thank you for your time.

Evaluation Tool 2.6 – Health Workers in Remote Aboriginal and Torres Strait Islander Communities

Use this tool to evaluate how confident community carers (including clinic staff and health workers) are in delivering palliative care.

These questions are intended to be used as a guide for discussions with carers in the community. Please ask them in a way that you feel will be most appropriate/effective.

1. Have you ever heard of palliative care before? What do these words mean to you?

Prompt: Sometime people get sick and they can't get better. Care for people who are like this is called palliative care.

2. What is the word you use to talk about the time when someone is dying?

Prompt: Some people round here call it slow sickness or finishing up

3. Have you looked after someone who is dying (finishing up)?

Prompt: what did you do for that person, did anyone help you?

4. Did you have everything you needed to look after the sick person?

Prompt: what could have made it easier for you? Did you need equipment to help the person, did you need training so that you knew what to do and what to expect?

5. Did you feel confident looking after this person?

Prompt: Did you always feel that you knew what to do for this person? Or did you feel that you needed some help?

6. What sorts of medicine did the person you were looking after have?

Prompt: What did they have to stop their pain? What did they have when they were vomiting?

7. What sort of training would you like to have?

Prompt: How often, who to deliver such training?

8. Do you know about the Regional Palliative Care Service?

Prompt: Do you know how to contact them and who to ask for?

9. Do you have a information manual?

Prompt: Do you know where it is kept? Have you used it? Is it useful?

Evaluation Tool 3.1

Palliative Care Service Self-Assessment

ITEM		**P=Present, NP=Not Present**	**Rate the degree to which the statement is true of your service** **0= Not at all** **10 = Fully implemented and effective**	**Rate priority for future action** **0= Not at all – no action required** **10= Undertake as a matter of urgency**
Vision and Management Standards				
	We have a vision for excellence in end of life care			
	Our service objectives include a focus on end of life care			
	Administrative executive staff support implementation of initiatives to improve care at end of life			
	Medical staff support implementation of initiatives to improve care at end of life			
	Management objectives include a focus on end of life care			
	Education resources are designated to support development of competencies and practices in end of life care			
	Excellent caregivers (both formal and informal) and caregiving examples are honoured and their stories made visible			
Practice Standards (procedures, policies, care protocol)				
	The population we served is defined and communicated			
	Confidentiality standards are clearly communicated			
	Cultural / religious guidelines are integrated			
	Organ / tissue donation guidelines are implemented			
	Comfort, care and palliative care standards are implemented. Includes guidelines for pain and symptom management, and hydration / nutrition			
	Hospice care is available			
	Complementary or integrative therapies are supported			
Space Standards (inpatient/hospice services only)				
	Patient room is comfortable, homelike, supports family visiting, and confidentiality			
	Family homelike or living room type space is available			
Visiting Standards (inpatient/hospice services only)				
	Welcoming for Families			
	Support for family ADL's available			
	24 hour visiting with number, hours and age, for close friends / family as defined by ill person / family with respect of other patient care needs			
	Families participate in care as desired			
	Children are welcomed with supervision			

ITEM	**P=Present, NP=Not Present**	**Rate the degree to which the statement is true of your service** **0= Not at all** **10 = Fully implemented and effective**	**Rate priority for future action** **0= Not at all – no action required** **10= Undertake as a matter of urgency**
Pet visiting with supervision and respect of other patient care needs is welcomed			
Spiritual, Religious, and Cultural Standards			
Support is available 24 hours a day			
Links / communication with community established			
Prayer and other spiritual / religious practices overtly available			
All staff are expected to integrate spiritual / cultural care within practice			
Support for professional caregivers readily available			
Bereavement Support Standards			
Bereavement support groups offered			
Follow-up is available for 100% who have died			
Follow-up contact to address clinical questions initiated by clinicians / primary care providers within 2-4 weeks of death			
Memorial services conducted for staff and families			
Bereavement support 1:1 for families is available			
Bereavement support 1:1 for professionals is available			
Psychosocial and Emotional Standards, including Pastoral Care			
Referral and support is available 24 hours			
Support available for professional caregivers			
Support groups for patient / families easily accessible			
Virtual support groups available (eg. chat groups, telephone conference groups)			
Communication Standards			
Care preference, values, spiritual, emotional, and relationship needs as well as decisions routinely and accurately communicated and honoured			
Doctor communication during the dying process occurs frequently			
Transfer of care occurs with communication of preferences, values, spiritual / emotional, and relationship needs and patient / family care decisions.			
Standards and expectations about excellent end-of-life care routinely communicated to community			
Communication with community spiritual care providers routine as well as specific			

ITEM		**P=Present, NP=Not Present**	**Rate the degree to which the statement is true of your service** **0= Not at all** **10 = Fully implemented and effective**	**Rate priority for future action** **0= Not at all – no action required** **10= Undertake as a matter of urgency**
Professional Experiential Education during Orientation and as Continuing Education The following issues are addressed in initial and ongoing education and training programs provided to the leadership team, employed staff and visiting doctors				
	Organisation values and strategic objectives			
	Ethics – End of life Care			
	Practice standards			
	Quality improvement standards			
	Communication			
	Grief and Bereavement			
	Patient / Family supports			
	Professional caregiver / staff support			
	Spiritual / religious / cultural standards			
	Individual performance expectations			
Quality Improvement Standards				
	Routine feedback from patients, family caregivers and bereaved family, and community partners is obtained			
	Quality priorities include response to above			
	Significant events are assessed for learning and quality improvement			
	"Stories" are shared and used to teach about care and to set standards			
	Research to continue developing new ways to improve care is developed or findings are applied to practice change initiatives			
	Annual objectives and priorities include focus on end of life care			
Staff Support Standards (This area includes items to support palliative care providers as professional caregivers and as ill person, caregiver, or bereaved family)				
	There are systems and policies that support bereavement leave for those the person defines as close or family			
	There are systems and policies that allow flexibility in work time during illness, caregiving and bereavement			
	Palliative care providers are supported in reaching out to fellow providers with practical help			
	Acuity and patient assignments provide time to "be with" the patient and family during the process of dying			
	Professional caregiver is supported to attend memorial / funeral service of patients.			

ITEM		P=Present, NP=Not Present	Rate the degree to which the statement is true of your service 0= Not at all 10 = Fully implemented and effective	Rate priority for future action 0= Not at all – no action required 10= Undertake as a matter of urgency
Community Network and Partnerships				
	Palliative care is available within the community to the extent that patients and their families want it			
	Healthcare and church ministry linked in meeting care needs at end of life			
	Partnerships with community assist community to meet support needs			
	Services are provided that achieve continuity of care within and between community and health care organisations			
	Education and information about palliative care is integrated within schools, workplaces, parishes, and other community areas			

This is the end of the self-assessment. Thank you for your time.

Use this space to record any actions arising from the self-assessment

Evaluation Tool 3.2

General health care organisational survey about palliative care

Agency name (optional)	**This survey was completed (tick one)**	
Location (optional)	Through an agency / group meeting to consolidate one response	☐
Date completed	By an individual expressing their own views, and not necessarily those of the agency	☐

Description of your agency/service

Hospital ☐

General practice, medical centre ☐

Multipurpose health centre ☐

Community health service ☐

Community organisation ☐

Other (please describe):

Community nursing service ☐

Training organisation ☐

---

1. How does your organisation define Palliative Care?

2. What services or organisations provide palliative care in the community?

(tick all that you know provide palliative care in the community in which you work)

Hospital ☐

Nursing homes/residential aged care ☐

Hospice ☐

Community Health Centre ☐

Community nursing services ☐

General Practitioners ☐

Other (please describe):

3. What information sources about Palliative Care are recommended by your organisation?

General Practitioner	☐	Community health centre	☐	Community nursing service	☐
Nursing home	☐	Hospital	☐	Hospice	☐
Television/radio	☐	Relatives/friends	☐	Internet	☐

Other (please describe):

---

4. To what extent does your organisation provide information about Palliative Care?

Not an information provider	☐	Provides information in some areas of Palliative Care	☐
Provider of general knowledge only	☐	Provides professional/ extensive information about Palliative Care	☐

5. How is your organisation involved in Palliative Care?

Carer support	☐	Direct care provider	☐	Providing specialist palliative care services	☐
Volunteer training and support	☐	Providing general palliative care services	☐	This organisation is not involved	☐

Other (please describe):

---

6. To what extent does your organisation coordinate with (other) Palliative Care services in your community?

Do not coordinate with Palliative Care services (no others exist)	☐	Coordinate with a limited number of (other) Palliative Care services	☐
Do not coordinate with other Palliative Care services (others do exist)	☐	Coordinate extensively with (other) Palliative Care services	☐

This is the end of the survey. Thank you for your time.

Evaluation Tool 4

Palliative Care Program Sustainability Checklist

About the person completing this assessment

Project Title: ____ Name: ____

Date Completed: _______/______/________

What is your goal after project funding ends?

☐	☐	☐
The project will be over and it's impact will end soon after	The project will be over but it will keep having an impact	By the time funding ends, we will have found other ways to keep the project going

If your goal is for your project, or its effects, to continue after funding ends, please circle the number that best describes your situation.

The first set of items is about project design and implementation factors				
1 People with a stake in the project - funders, administrators, consumers/beneficiaries, other agencies – have been aware of the project and/or involved in its development	2	1	0	DK
2 The project has shown itself to be effective. Effects are visible and acknowledged	2	1	0	DK
3. The organisation which you intend to host the project in the future has been making some real or in kind support to the project in the past	2	1	0	DK
4. Prospects for the project to acquire or generate some additional funds or resources for the future are good	2	1	0	DK
The next set of items is about factors within the organisational setting which are known to relate to the survival of a project				
5. The organisation that you intend to host the project in future is mature (developed, stable, resourceful). It is likely to provide a strong organisational base for the project	2	1	0	DK
6. The mission of the project is compatible with the mission and activities of the intended host organisation	2	1	0	DK
7. Part of the project's essential 'business' is integrated into other aspects of the host organisation eg. in policies, practices, responsibilities etc. That is, the project does not simply exist as an entirely separate entity	2	1	0	DK
8. The project is well supported in the organisation. That is, it is not under threat and there are few rivals in the organisation who could benefit from the closure of the project	2	1	0	DK
9. The intended host organisation has a history of innovation or developing new responses to situations in its environment	2	1	0	DK
The next set of items is about factors in the broader community environment which affect how long projects last				
10. There is a favourable external environment for the project, that is, the values and mission fit well with community opinion, and the policy environment	2	1	0	DK
11. People in the community, or other agencies and organisations, will advocate for and maintain a demand for the existence of the project should it be threatened	2	1	0	DK

2 = yes, fully

1 = yes, in part

0 = no

DK = don't know

Evaluation Tool 4. Modified from: Hawe H, King L, Noort M, Jordens C and Lloyd B. NSW Health indicators to help with building capacity in health promotion *(January 2000) NSW Department of Health*

Goals, Objectives and Strategies for Sustainability

Project Title: ______________________________________ Name: ____

DATE COMPLETED: __/__/____

Write a set of goals, objectives and strategies for your project about sustainability: eg, to keep the impact of your project going after funding ceases.

Goal/s for Sustainability

Remember:

- A goal is an overarching statement about the desired outcome - not usually directly measurable.

Objective/s for Sustainability

Remember:

- Objectives (sometimes called aims) dissect a goal into a series of action statements that say what is going to be different, are specific, have time frames and are measurable.
- Objectives are evaluated (including the analysis of PI's) to ascertain whether a goal has been achieved, partially achieved or not achieved at all.

Strategies for Sustainability

Remember:

- Strategies are the detail of what you need to do to achieve each objective. A strategy need not be linked to only one objective, but can be used to achieve multiple objectives.

Evaluation Tool 5

Capacity Building Checklist

Project _______________________________ Name ______________________________ Date Completed: _____/_____/____

The first set of items is about project design and implementation factors				
1. People with a stake in the project – consumers/ beneficiaries, other agencies, health care providers – have been able to contribute to the development of the project.	2	1	0	DK
2. People involved with the project have been able to establish links with other organisations and providers of palliative care in the community.	2	1	0	DK
3. People involved with the project have taken a leadership role in the local community with regard to palliative care.	2	1	0	DK
4. People involved with the project have been able to resolve conflicting interests in the area of palliative care in the community.	2	1	0	DK
5. This project has been able to engage the local media in promoting relevant palliative care issues.	2	1	0	DK
6. The project has involved formal and/or informal training of people whose skills and interests are retained in the project or its immediate environment	2	1	0	DK
The next set of items is about factors within the organisation's setting that relate to capacity building				
7. This organisation has been able to establish agreed policies or memoranda of understanding with other organisations regarding the provision of palliative care services in this community.	2	1	0	DK
8. This organisation has generated and supported community skills to direct, provide, lead or otherwise contribute to the provision of palliative care services in this community.	2	1	0	DK
9. More organisational resources have been directed to the area of palliative care services in this community.	2	1	0	DK
10. There is someone in authority or seniority, other than the director of the project itself, who is an advocate for the project at high levels in the organisation	2	1	0	DK
The next set of items is about factors in the broader community that affects the community's capacity to support the provision of palliative care services.				
11. Community coalitions have formed to promote and advocate for palliative care services in this community.	2	1	0	DK
12. Community coalitions and organisations have a shared view of what comprises palliative care services in this community.	2	1	0	DK
13. Key community leaders have engaged in critical appraisal of the need for palliative care services in this community.	2	1	0	DK
14. Community members have taken a leadership role to promote palliative care services in this community.	2	1	0	DK
15. Community events have occurred to acknowledge, promote or provide funds for palliative care services.	2	1	0	DK
16. Community members directly involved in or affected by palliation are actively engaged in the oversight of the development, provision or management of palliative care services in this community.	2	1	0	DK
17. People in the community, or other agencies and organisations, will advocate for and maintain a demand for the existence of the project should it be threatened	2	1	0	DK
18. Community organisations that are similar to the intended host organisation have taken the step of supporting projects somewhat like your project	2	1	0	DK

2 = yes, fully
1 = yes, in part
0 = no
DK = don't know

Goals, Objectives and Strategies for Capacity Building

Project Title: ______________________________________ Name: ____

Date Completed: __/__/____

Write a set of goals, objectives and strategies for your project on capacity building, eg to develop knowledge and skills to do the job.

Goal/s for Capacity Building

Remember:

- A goal is an overarching statement about the desired outcome - not usually directly measurable.

Objective/s for Capacity Building

Remember:

- Objectives (sometimes called aims) dissect a goal into a series of action statements that say what is going to be different, are specific, have time frames and are measurable.
- Objectives are evaluated (including the analysis of PI's) to ascertain whether a goal has been achieved, partially achieved or not achieved at all.

Strategies for Capacity Building

Remember:

- Strategies are the detail of what you need to do to achieve each objective. A strategy need not be linked to only one objective, but can be used to achieve multiple objectives.

Evaluation Tool 6

Generalisability Checklist

Project ________________________________ Name _______________________________ Date Completed: _____/_____/____

Please circle the number that best describes your situation.

1 Our project is designed specifically to meet our own local needs	2	1	0	DK
2. Other regions/services/organisations will learn useful lessons/information from our project	2	1	0	DK
3. It is reasonable to expect that the outcomes of our project could be replicated elsewhere	2	1	0	DK
4. Our project will depend on how sensitive and appropriate it is to our target population	2	1	0	DK
5. Our project is designed to develop capacity (skills and/or knowledge) in palliative care in our region/service/organisation	2	1	0	DK
6. Our project is designed to enable people not directly involved in our project to develop capacity (skills and/or knowledge) in palliative care	2	1	0	DK
7. We already have a strategy in place to ensure that our experience and findings are shared with other people who want to develop and improve palliative care	2	1	0	DK
8. By the time the project ends, we will have a strategy in place to ensure that our experience and findings are shared with other people who want to develop and improve palliative care	2	1	0	DK

2 = yes, fully

1 = yes, in part

0 = no

DK = don’t know

Goals, Objectives and Strategies for Generalisability

Project Title: ______________________________________ Name: ____

Date Completed: __/__/____

Write a set of goals, objectives and strategies for your project on generalisability: eg, to make your project's lessons useful for someone else

Goal/s on Generalisability

Remember:

- A goal is an overarching statement about the desired outcome - not usually directly measurable.

Objective/s on Generalisability

Remember:

- Objectives (sometimes called aims) dissect a goal into a series of action statements that say what is going to be different, are specific, have time frames and are measurable.
- Objectives are evaluated (including the analysis of PI's) to ascertain whether a goal has been achieved, partially achieved or not achieved at all.

Strategies on Generalisability

Remember:

- Strategies are the detail of what you need to do to achieve each objective. A strategy need not be linked to only one objective, but can be used to achieve multiple objectives.

Evaluation Tool 7

Dissemination log

This log is designed to be a record of how information about your project is shared with others. We are interested in all ways you shared information over the course of the project.

Please use the following codes

1. Presentation or talk to staff at one service or agency in the local area (eg, talk at a staff meeting, during a hospital grand round)
2. Talk to staff from more than one service or agency in the local area (eg, talk at an interagency meeting)
3. Story in the local newspaper
4. Story or article in a local magazine or newsletter (eg, GP news, hospital newsletter, community agency newsletter)
5. Story or article in a professional or industry magazine or newsletter
6. Presentation or poster at a local conference
7. Presentation or poster at a State/Territory conference
8. Presentation or poster at a national conference
9. Peer-reviewed journal article
10. Information provided on a website
11. Radio
12. Other

How (use code above)?	Who did the dissemination?	When (month/year)?	Estimate of number of people who heard/read about the project	Did anyone hearing about the project follow-up seeking more information? If so, estimate number who did

Thank you for this information. If you need more space, please continue overleaf

How (use code above)?	Who did the dissemination?	When (month/year)?	Estimate of number of people who heard/read about the project	Did anyone hearing about the project follow-up seeking more information? If so, estimate number who did

Thank you for this information. If you need more space, please append an additional page

Evaluation Tool 8

System level impacts and outcomes of the project

Agency name (optional)	**This survey was completed (tick one)**	
Location (optional)	Through an agency / group meeting to consolidate one response	
Date completed	By an individual expressing their own views, and not necessarily those of the agency	

Description of your agency/service

Hospital ☐
General practice, medical centre ☐
Multipurpose health centre ☐
Community health service ☐
Community organisation ☐
Other (please describe):
Community nursing service ☐
Training organisation ☐

How did the palliative care project go?

Did it change the way you deliver services? Yes, positively ☐ Yes, negatively ☐ No change ☐

Was the impact on consumers acceptable? Yes ☐ No ☐ Don't know ☐

Comments?

How did the project go for people with special needs?

Did the project have any impact or outcomes for people from culturally and linguistically diverse backgrounds, Aboriginal people, people with dementia, financially disadvantaged people or people living in remote areas?

Yes ☐ No ☐

If yes, please specify:

If yes, are there any specific issues relating to these groups that you encountered during the project? (please describe).

Agency, inter-agency and system effects of the project

Please tick the appropriate boxes. Where a statement is irrelevant to your project, tick the box marked 'Irrelevant'.

Impact statement	**Agree**	**Unsure/ don't know**	**Disagree**	**Irrelevant**	**Comment**
Different professionals and services now work better as a team to improve the services that people receive.	☐	☐	☐	☐	
The project has improved the way that professionals providing palliative care in our area communicate with each other.	☐	☐	☐	☐	
The project was effective in improving information sharing between professionals providing palliative care.	☐	☐	☐	☐	
The project has resulted in more patients receiving palliative care.	☐	☐	☐	☐	
The project has resulted in a more streamlined and efficient referral process for our clients/patients.	☐	☐	☐	☐	
The project has resulted in better treatment and support for our clients/patients.	☐	☐	☐	☐	
The project has resulted in better volunteer services.	☐	☐	☐	☐	
The project has resulted in better support for volunteers.	☐	☐	☐	☐	
The project has raised community awareness about palliative care	☐	☐	☐	☐	
The project has increased the skills and knowledge of staff working in palliative care	☐	☐	☐	☐	
The project has increased the palliative care skills and knowledge of staff working in other parts of the health system	☐	☐	☐	☐	
The project has increased the palliative care skills and knowledge of staff working in the community care sector	☐	☐	☐	☐	
The project has resulted in better services and support for carers	☐	☐	☐	☐	
The project has improved the availability of bereavement support	☐	☐	☐	☐	
The project has improved the quality of bereavement support services	☐	☐	☐	☐	
We want the changes that the project has achieved to continue.	☐	☐	☐	☐	

Add any further comments on consumer, agency or system-level issues raised by any of the questions above (note the number of the question) or on any other matters not already covered in this feedback sheet.

This is the end of the survey. Thank you for your time.