

Evaluation and palliative care: a guide to the evaluation of palliative care services and programs

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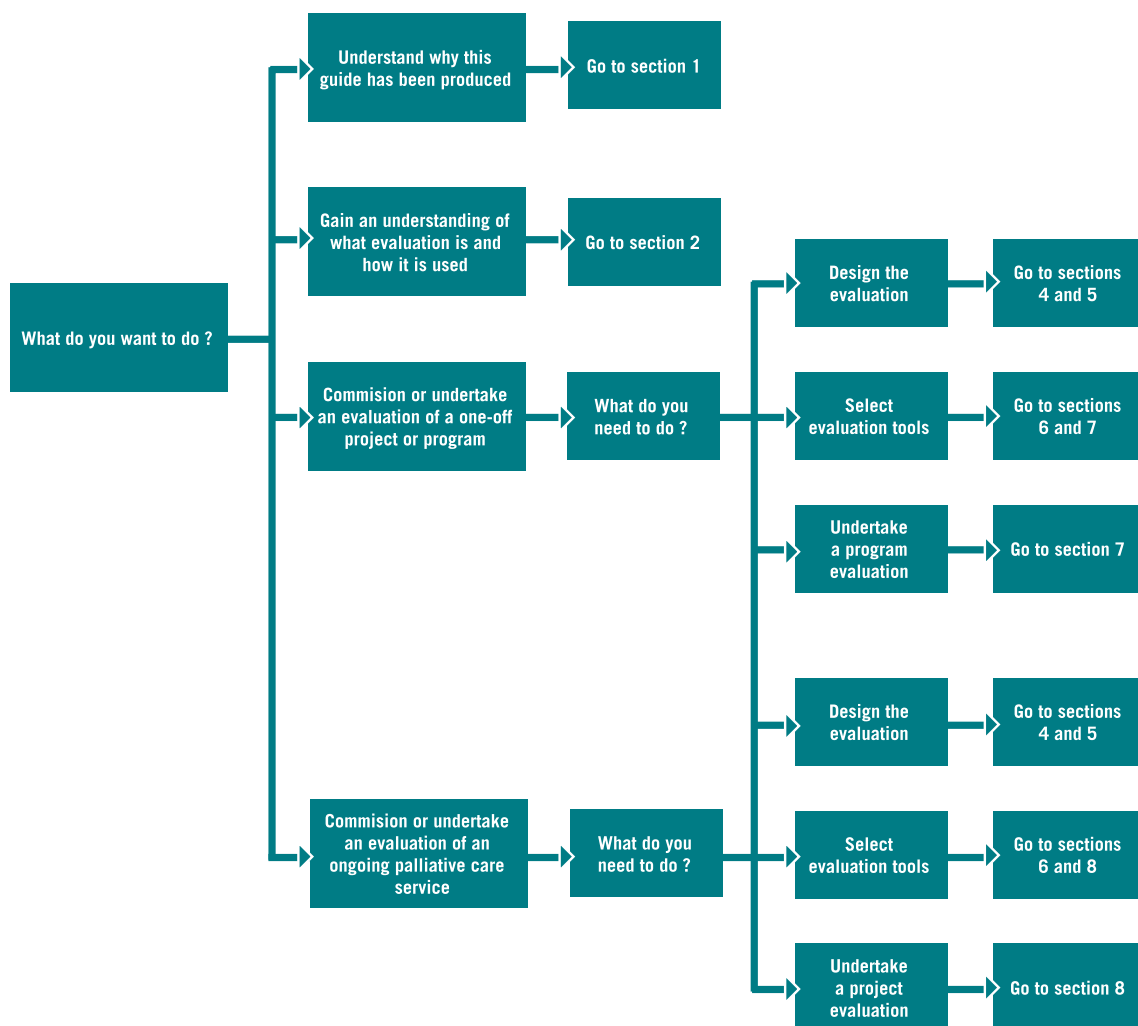
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How to use this guide



This guide is designed to assist palliative care projects and services to design, plan and implement evaluations that are consistent with National Palliative Care Program funding and accountability requirements and will inform service planning and development activities.



Contents



SECTION 1	WHY THIS GUIDE?.....	1
SECTION 2	WHAT IS EVALUATION AND HOW IS IT USED?	3
	The purpose of evaluation.....	3
	Process, impact and outcome evaluation	3
	Measurement and data collection.....	5
SECTION 3	WHAT IS BEING EVALUATED?.....	6
	Palliative care services.....	6
	Palliative care projects	6
	Implications for evaluation	6
SECTION 4	DESIGNING AN EVALUATION.....	7
	Developing the Evaluation Framework	7
	Undertaking an Evaluability Assessment	7
	Evaluation Plan.....	9
SECTION 5	FRAMEWORK FOR EVALUATING PALLIATIVE CARE.....	11
	Why an evaluation framework is useful.....	11
	The evaluation framework	11
	The evaluation hierarchy.....	11
	Deciding the level at which the evaluation will operate	13
	Evaluation issues and questions.....	13
SECTION 6	PALLIATIVE CARE EVALUATION TOOLS	16
	The Tool Kit.....	16
	Evaluation Level 1 - Impact on and outcomes for consumers	16
	Evaluation Level 2 - Impact on and outcomes for providers	18
	Evaluation Level 3 - Impacts on the system.....	19
SECTION 7	EVALUATING PALLIATIVE CARE PROJECTS	21
	Types of palliative care projects	21
	Planning the evaluation	21
	Undertaking the evaluation.....	22
	Establish a consultation process and implement the communication strategy.....	23
	Understanding and managing expectations	23
	How results will be used	23
	Context and boundary issues	23
	Distinguishing impacts from needs	24
	The evaluation report	24
SECTION 8	EVALUATING PALLIATIVE CARE SERVICES.....	27
	Types of service level evaluation	27
	Planning the evaluation	28
	Undertaking the evaluation.....	28
	Establish a consultation process and implement the communication strategy.....	28
	Needs Analysis.....	28
	Demand and demographic analysis.....	33
	Drawing out the policy and practice implications of evaluation findings.....	34
SECTION 9	HOW TO ACCESS TOOLS AND GUIDELINES.....	35
	Palliative Care Evaluation Toolkit	35
	Other resources.....	35
REFERENCES	36

Section 1 Why this guide?



This booklet provides a practical guide to the methods and tools that are available to evaluate palliative care projects, programs and services. It is designed to:

- provide a resource for palliative care managers and providers who are interested in evaluating their own projects and services
- provide a resource for program managers and project sponsors who need to evaluate and report on initiatives funded under the National Palliative Care Program and
- assist service planners and palliative care providers to design and implement effective and responsive systems of care.

The need for this guide has arisen in response to the expanding provision of palliative care services and innovative programs and projects in Australia.

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.

It is important and timely that the lessons from innovative programs and projects are analysed and the results shared to improve practice and the overall effectiveness and reach of palliative care services. Evaluation is critical to this task.

This booklet describes an evaluation framework developed for two programs funded under the National Palliative Care Program - the Caring Communities Program (CCP) and the Rural Palliative Care Program (RPCP). This same framework is also now being used for the

evaluation of another Program initiative – the Program of Experience in the Palliative Approach (PEPA).

This evaluation framework was developed after a review of the international literature and after input from end users. It can be applied to both project and service level evaluation. It is supported by a set of evaluation tools and an electronic evaluation database, both of which are freely available to those wishing to use them for other purposes. Given this, the key elements of the framework are described in detail together with the suite of evaluation tools available to assist with implementation.

This is not to suggest that there is only one framework or set of tools that can be used to evaluate palliative care - quite the reverse. Different health services evaluation frameworks and tools will be useful in different situations.

The framework in this booklet illustrates an evaluation approach that is being used to evaluate palliative care projects and programs and is supported by easily accessible evaluation tools. No doubt other frameworks will be developed, and this one improved, through the research, projects and programs funded under the National Palliative Care Strategy, as well as through the evaluation of routine palliative care practice.

Several issues that are important for evaluation in palliative care are also discussed in this booklet including:

- differences between project, program and service level evaluation
- evaluation planning and design
- practical issues involved in evaluation that involves the participation of palliative care consumers (patients and their carers).

Evaluation design and capacity for collecting qualitative and quantitative data need to be considered as an integral part of project planning. Checklists and prompts have been provided throughout the booklet to assist with the planning process.

Section 2 What is evaluation and how is it used?



Evaluation has become an integral part of policy, program development and service planning in health and social services. It 'draws from the knowledge base of many disciplines including economics, politics, statistics, sociology, engineering and business.' (Eagar, Garrett and Lin 2001)

'Evaluation is the process by which we determine the worth or value of something.' (Hawe et al 1990) 'It involves the collection and analysis of information to determine the relevance, progress, efficiency, impact, effectiveness and outcomes of ...interventions'. (Eagar, Garrett and Lin 2001)

Evaluation involves collecting and analysing information to measure the impact and effectiveness of interventions and activities against project, program or service goals.

The purpose of evaluation

The purpose of evaluation is to inform decision-making at the policy and/or operational levels. This distinguishes it from conventional research. It does so by describing how a program or intervention worked, what the impact or results were and what outcomes were achieved. It then uses these findings to draw out the policy and/or practice implications, including (if relevant) options for change and critical change management issues.

Evaluation is generally timeframe and context specific. This distinguishes it from monitoring and routine reporting against performance indicators. These activities are primarily concerned with achieving accountability and providing feedback to suggest incremental adjustments over time.

However, data collected for monitoring purposes are often useful for the purposes of evaluation. Policy making and planning in human services often involve making decisions about investing

scarce resources in competing priorities. Evaluation can assist by providing information to assist decision-making and to clarify future options. (Owen 1993).

Process, impact and outcome evaluation

Evaluation is typically described as being of three types (Hawe et al 1990):

- **Process evaluation** is concerned with the processes or strategies that were used to implement a project, service or plan. It focuses on the planning and implementation processes used, the choice of strategies and interventions and their impact and reach. Process evaluation tools can include site visits, key informant interviews, surveys of participants, analysis of reports as minutes and direct observation. These tools support and enhance the planning process itself.

Process evaluation tells us what actually happened in terms of program, project or service delivery – for example, whether and when a new volunteer service was established, or the type of media used in a community awareness campaign.

- **Impact evaluation** is concerned with evaluating the effect of an intervention, plan or project and is used to determine whether objectives have been met or not. Methods used to obtain data include surveys, focus groups, questionnaires, nominal group techniques and similar qualitative and quantitative strategies. Impact evaluation tells us about the results produced by strategies or interventions. For example, if a project objective was to involve generic community care organisations in providing support for palliative care patients and their

carers, an impact evaluation would tell us about the number of new organisations that have become involved and what type of assistance they provide.

- **Outcomes evaluation** is concerned with the long term effects of a plan, project or intervention and can help identify whether the goals have been achieved or not. Outcome evaluation is concerned with effectiveness and with identifying those outcomes that can be attributed to an intervention. It is often used to inform decision-making about the continuation of projects or services. Methods used in outcome evaluation include analyses of qualitative and quantitative data obtained from routine data collections, one-off studies, surveys, focus groups and nominal group techniques.

For example, suppose that the goal of a program or service is to increase the number of palliative care patients opting to die at home with support. In this case, an outcome evaluation would measure the shifts in place of death of the target group (ie, patients known to the palliative care service) and carer satisfaction with the level of support they received.

If, however, the goal is to improve the quality of life of the consumer (in this context generally the patient and their carers), an outcome evaluation would aim to assess quality of life related outcomes.

These two examples illustrate an important point. The outcomes selected for assessment in an evaluation are inherently linked to the goals and purpose of the activity being evaluated.

Continuing with these two examples, if the goal is simply to increase the proportion or number of patients who die at home, counting the place of death is an appropriate and sufficient outcome measure.

But palliative care, appropriately so, rarely has such simple goals. Palliative care aims to maximise the quality of life and functional status of both patients and carers and to strengthen community capacity in meeting the needs of people with life-limiting illnesses. Given these goals, the evaluation of palliative care is inherently more complex than simply counting numbers.

The form of evaluation used depends on the program or project goals and scope and the level of evaluation required. A comprehensive evaluation framework incorporates all three evaluation techniques.

A range of technical models are used in evaluation (Eagar, Garrett and Lin 2001) but four common approaches include:

- **Economic evaluation** is concerned with decisions about funding and investment. It uses tools such as cost-benefit analyses, cost-effectiveness analyses and cost-utility analyses.
- **Clinical evaluation** is used to assess the effectiveness of health interventions and treatments. It is different to clinical research, which typically measures the efficacy of health interventions. Efficacy is the level of benefit achieved when health services are applied under ideal conditions. Effectiveness is the level of benefit achieved when services are provided under ordinary circumstances by average practitioners for typical patients. (National Health Strategy 1991).

While much palliative care research assesses efficacy, palliative care evaluation inevitably assesses effectiveness.

- **Health services evaluation** focuses on the processes, impacts and outcomes of interventions at the service, program or project level.
- **Health improvement evaluation** focuses on the processes, impacts and outcomes of interventions at the population or group level.

Measurement and data collection

Gathering and analysing valid and reliable information is a crucial part of evaluation that depends on good measurement techniques (Peterson 1997).

Qualitative and quantitative data or a combination of both can be used for health service and program evaluation. The type of data selected needs to be determined by the information being sought, the type of intervention or activity being evaluated and the resources available to the evaluator.

In some cases routinely collected data such as activity or utilisation statistics or morbidity data can be used selectively as part of the evaluation data set. But many projects and interventions need to use tools and data collection processes designed to measure the specific project or service goals, impact and outcomes.

For example, if the goal of a project is to improve the patient experience of palliative care, a validated patient outcome measure would be used to collect data from groups of patients at a similar phase of illness. If changes to the interventions or processes of care were introduced to improve the patient experience, then baseline data would be collected before the new practices were introduced and collected again from a comparable group of patients at defined milestones.

Selecting the right tools and measurement approach is a key part of evaluation design. Whether qualitative or quantitative methods are used, data collection requirements need to be:

- clinically sensible
- sustainable throughout the life of the evaluation
- agreed with the participants beforehand.

Performance indicators

Performance indicators are quantitative measures used in program evaluation and in performance review to monitor the achievement of goals and objectives and to track progress. Performance indicators can be used to (Owen 1993):

- compare trends in programs or interventions at different points in time
- compare the results of an intervention with an acceptable set of standards (benchmarks) or goals
- compare the implementation of the same intervention or program at different sites or locations.

Attention needs to be paid to the selection of performance indicators and what they are used to measure. Indicators need to be:

- Valid – the indicator measures what it claims to measure.
- Reliable – reliability refers to the extent to which a measure can be replicated when repeated under the same condition.
- Available and practical – information is easy to obtain.

While the collection of performance indicator data is not an evaluation, performance indicator data can often be very useful for the purposes of evaluation.

Section 3 What is being evaluated?



The first task in undertaking an evaluation is to decide on the activity, project or service that will be the subject of the evaluation. This booklet focuses on health services evaluation and palliative care and, for this purpose, evaluation can be described as occurring at two broad levels.

Palliative care services

For the purposes of this booklet, a palliative care service:

- provides care and services with a palliative approach to people with a life-limiting illness
- has ongoing funding (ie, it is not time-limited).

In some cases, a palliative care service may sponsor or undertake one or more palliative care projects.

Palliative care projects

For our purposes, a palliative care project is any initiative that:

- has time-limited funding (such as that provided under the National Palliative Care Program) in order to develop or test specific interventions and initiatives and/or
- is a one-off activity undertaken to solve a particular problem or to test, change, improve or develop a new service or strategy.

Multiple initiatives currently underway across Australia meet our definition of a palliative care project. While these initiatives are diverse in nature, they all have specific goals and limited time frames.

Palliative care projects may be funded internally by a palliative care service to meet a specific local need. Alternately, a palliative care project may be funded through a special palliative care funding

program.

Such programs are vehicles for targeted investment in activities designed to improve existing service systems, to test new models of care or to generate new information about the needs of particular population groups. They generally act as the umbrella for a range of activities including time-limited projects and research and development activities. For the purposes of this booklet, these programs at the national or State/Territory level are the equivalent of a palliative care project because they have specific goals and finite time frames.

Implications for evaluation

The evaluation of palliative care services and palliative care projects has common elements. Both need to be planned and both require an evaluation framework (see Section 4). But there are also important differences. Specific issues relevant to the evaluation of palliative care projects are discussed in Section 7 and issues relevant to the evaluation of palliative care services in Section 8.

Section 4 Designing an evaluation?



Designing an evaluation has three key steps – developing an evaluation framework, undertaking an evaluability assessment and developing an evaluation plan.

Developing the Evaluation Framework

An evaluation framework defines the key themes or issues that the evaluation will cover, the scope and range of activities to be undertaken and the levels at which the evaluation will operate. An evaluation framework for palliative care is outlined in Section 5. Key issues are summarised below.

Focus areas

The evaluation focus areas reflect the questions that need to be answered to make decisions on the impact, benefits and value of the service or project. They are based on the goals and objectives of the service or project and include questions such as:

- What was done?
- What were the impacts?
- What were the outcomes? and
- Who benefited?

Focus areas can usually be quickly identified by asking two questions:

- Why is this evaluation being undertaken?
- What are the key questions that the stakeholders want answered?

Levels of evaluation

Different stakeholders will want different outcomes from the service or project and the concerns, priorities and aspirations of the main stakeholders need to be considered as part of

evaluation design. Understanding stakeholder needs and aspirations will help determine the levels at which the evaluation will operate. For example, the impact and benefits of the service or project for the consumer may be the priority for a clinician or carer representatives. A funder or program manager may be equally interested in cost benefit or the impact on service providers or the service system more generally.

Scope

The framework will define the scope of the evaluation. The evaluation framework discussed later in this booklet was designed to provide information at several levels.

Evaluation tools

The framework will also suggest the types of evaluation tools that will be required. A set of evaluation tools is outlined in Section 6. The type of evaluation tools required in different types of evaluations is discussed in Section 7 and Section 8.

Undertaking an Evaluability Assessment

The next step in planning the evaluation is to determine whether the project or service is capable of being evaluated. This is called the evaluability assessment. The evaluability assessment is based on information gathered from key stakeholders and from documents on the project or program goals, objectives and expected outcomes.

Issues that need to be addressed as part of this assessment include (Michnich 1981, Øvretveit 1998):

- whether objectives are well defined and quantifiable and whether data on these measures can be collected
- whether the size, scope and boundary limits of the service, project or intervention are clearly defined
- what effects (broad or specific) the service, project or intervention aims to achieve
- whether assumptions and objectives are plausible (ie the proposed activities have some likelihood of meeting the objectives)
- whether the intended uses of the evaluation information are well defined.

When the evaluability assessment has been completed, the evaluator typically consults and seeks agreement from the major stakeholders on the scope of the evaluation and the framework to be used before proceeding to finalise the evaluation plan.

Other considerations

Several practical questions need to be considered as part of evaluation planning, including:

What are the governance arrangements for the evaluation?

The governance structure needs to reflect (and where necessary protect) the interests of:

- the project sponsors/stakeholders
- the interests of the programs consumers
- the integrity of the project design and its evaluability.

Forming a representative group or steering committee to oversee and support the evaluation process may be desirable.

What resources are available to implement the evaluation?

The funds available for the evaluation, including local data and information collection, staff training and provision of technical support need to be identified early in the process.

Many projects and services have only a modest budget for evaluation and the evaluation tasks and implementation plan need to be designed with this in mind. The resources available for the evaluation need to be commensurate with the size and complexity of the activity being evaluated, the scope of the issues being addressed and the level of consultation required.

Arrangements for informed consent and ethics approvals

If evaluation activities involve seeking information from patients/carers and analysing patient level data, attention needs to be paid to data privacy issues during design. Human Research Ethics Committee (HREC) approval may also be required. If in doubt about whether HREC approval will be required, use the information and checklists in Masso et al (2004) to help you decide.

Who will do the evaluation?

One of the first tasks is to appoint an evaluator. There are essentially two options – appoint an internal evaluator or an external evaluator. Some evaluations involve both. The decision about who will undertake the evaluation will be driven by several factors:

- the complexity and scope of the evaluation. The evaluation of large scale multi-faceted services and projects is often best contracted to an independent evaluation team with a range of different skills rather than relying solely on an in-house project officer. Conversely an evaluation of a well-defined intervention over a short time frame may be able to be undertaken very effectively by

interested and motivated staff

- the skills and expertise available to undertake the evaluation. Some services and projects have staff with the skills and expertise to undertake a complex evaluation. Others have limited evaluation capacity
- the financial resources available to the evaluation
- the reason why the evaluation is being undertaken. An independent evaluation will often be seen to be more credible than one done internally. Also, some funding programs may require an independent evaluation as a condition of funding.

- confirmation of evaluation funding requirements.

When the stakeholders have signed off on the evaluation plan, the evaluation can commence.

Evaluation Plan

The next stage, the development of the evaluation plan, is not finalised until after the evaluator has been appointed. Appointing the evaluator early in the process is therefore very important.

The evaluation plan describes the activities that need to be undertaken at the project or service level to complete the evaluation. This includes:

- the types of data collection that are proposed
- the tools to be used for each aspect of data collection and (if relevant) the training and support requirements available for project staff
- arrangements for collecting baseline data for each project or activity
- proposed methods of analysis
- the timeframe in which the evaluation will be conducted
- the roles and responsibilities of the project sponsor, service staff and local or program evaluators (where relevant) in contributing to the evaluation
- reporting and feedback processes

Figure 1 Checklist before developing your detailed evaluation plan

Issue	Questions to answer in the design phase	Relevance to your evaluation?
Stakeholders		
Evaluation findings are rarely accepted if key stakeholders have no sense of ownership	<ul style="list-style-type: none"> • Who are the key stakeholders? • How will they be involved? • What are their concerns and motivations? • Are the key stakeholders in agreement? • How might evaluation findings impact on them? • How might key stakeholders impact on the evaluation findings? • What governance arrangements for the evaluation are proposed? • Will they be sufficient? • If not, what else needs to happen? 	Yes <input type="checkbox"/> No <input type="checkbox"/>
Goals		
Evaluation is concerned with whether, and to what extent, goals have been achieved	<ul style="list-style-type: none"> • Does the activity being evaluated have clear goals? • Are the goals clearly understood by key stakeholders? • What types of impacts and outcomes will you need to measure to know whether goals have been achieved? • Are these impacts and outcomes directed at consumers, providers and/or more broadly at the system level? • How might you measure them at each level? 	Yes <input type="checkbox"/> No <input type="checkbox"/>
Evaluation resources and timetable		
The resources committed to the evaluation need to be commensurate with the resources and goals of the activity being evaluated	<ul style="list-style-type: none"> • Is the timetable realistic given the scope of the task? • Are sufficient resources available given the scope of the task? • If not, can resources be increased or the scope be reduced to match the timetable and/or resources? • Does the proposed evaluator have the skills and support to successfully undertake the evaluation? • If not, how can skills or support be increased? 	Yes <input type="checkbox"/> No <input type="checkbox"/>
Data		
Evaluation methods in the real world usually depend, at least in part, on the data that are already being (or can be) collected	<ul style="list-style-type: none"> • What data (quantitative and qualitative) are already routinely collected? • What other data (quantitative and qualitative) already exist? • Will the evaluator be given access to the data? • What data (quantitative and qualitative) can realistically be collected as part of, or for, the evaluation? • What skills are required to collect the data? Will training be required? 	Yes <input type="checkbox"/> No <input type="checkbox"/>
Special approvals		
Special approvals required for the evaluation need to be achieved before you start	<ul style="list-style-type: none"> • Will HREC approval be required? • Will the approval of participating organisations be required? • How will the necessary approvals be achieved? 	Yes <input type="checkbox"/> No <input type="checkbox"/>
Evaluability assessment		
It is important to assess before you start whether the evaluation will be possible and will be likely to generate useful findings	<ul style="list-style-type: none"> • Are objectives well defined and quantifiable? • Can data on these measures be obtained? • Are the size, scope and boundary limits of the service, project or intervention clearly defined? • What effects (broad or specific) does the service, project or intervention aim to achieve? • Are assumptions and objectives plausible (ie, do the proposed activities have some likelihood of meeting the objectives)? • Are the intended uses of the evaluation information well defined? 	Yes <input type="checkbox"/> No <input type="checkbox"/>

Section 5 Framework for evaluating palliative care



Why an evaluation framework is useful

Palliative care services and projects are highly diverse. They differ in their size, duration, goals, resource levels, locations and the evaluation skills and interests of the participants. Services and projects also vary with respect to their target group/s who may include:

- people with a life-limiting illness
- the families and carers of people with a life-limiting illness
- volunteers and community support services
- local health professionals
- rural and remote communities
- specialist palliative care staff
- older Australians
- Aboriginal and Torres Strait Islander peoples
- children and adolescents
- culturally and linguistically diverse groups.

This diversity 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. An evaluation framework guides the task of tailor-making each evaluation.

The evaluation framework

We noted in Section 2 that evaluation is typically described using 'Process, Impact and Outcome' as the evaluation framework. An alternate framework, which we have found helpful, is to frame the evaluation as working at three hierarchical levels - the impact on, and outcomes for, consumers (patients, families, carers,

friends, communities), providers (professionals, volunteers, organisations) and for the broader care delivery system (structures and processes, networks, relationships). This framework is shown in Figure 2.

The evaluation hierarchy

Level 1 The impact on, and outcomes for, consumers

A palliative care service or project may have many 'consumers'. They include patients, families, carers, friends and communities. Almost all palliative care services and projects aim to have an impact on consumers. Most do so directly. But some aim to do so indirectly. For example, a project may have a direct aim of increasing community awareness of palliative care. But the underlying assumption of the project is that increased community awareness will lead to better outcomes for people with life-limiting illnesses. Raising community awareness is a means to an end, not an end in itself.

Evaluation at this level of the hierarchy is concerned about the impact on, and the outcomes for, the various 'consumers' of palliative care. Six possible evaluation tools for undertaking an evaluation at this level are described in Section 6.

Level 2 The impact on, and outcomes for, providers

Many people deliver palliative care. They include specialist palliative care professionals, primary care providers, volunteers and community care organisations.

Figure 2 Palliative Care Evaluation Framework

EVALUATION HIERARCHY	SERVICE/ PROJECT DELIVERY What did you do?	SERVICE/PROJECT IMPACT How did it go?	SUSTAINABILITY Can you keep going?	CAPACITY BUILDING What has been learnt?	GENERALISABILITY Are your lessons useful for someone else?	DISSEMINATION Who did you tell?
Level 1 Baseline, Process & Outcome Indicators	<p>Impact on, and outcomes for, consumers (patients, families, carers, friends, communities)</p> <ul style="list-style-type: none"> • Plans, reports, routine data • Qualitative data 	<p>Impact on, and outcomes for, consumers (patients, families, carers, friends, communities)</p> <ol style="list-style-type: none"> 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 Baseline, Process & Outcome Indicators	<p>Impact on, and outcomes for, providers (professionals, volunteers, organisations)</p> <ul style="list-style-type: none"> • Plans, reports, routine data • Qualitative data 	<p>Impact on, and outcomes for, providers (professionals, volunteers, organisations)</p> <ol style="list-style-type: none"> 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 Baseline, Process & Outcome Indicators	<p>Impact on, and outcomes for, the system (structures and processes, networks, relationships)</p> <ul style="list-style-type: none"> • Plans, reports, routine data • Qualitative data 	<p>Impact on, and outcomes for, the system (structures and processes, networks, relationships)</p> <ol style="list-style-type: none"> 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 Section 6

Some services and projects aim to have direct impacts on providers. For example, a service may aim to develop the skills and expertise of its staff. In this case, an evaluation would aim to assess the degree to which this has been achieved.

It may also be relevant in an evaluation to consider unintended impacts (both positive and negative) for providers. For example, a service or project may aim to provide a more responsive after-hours service for patients and carers. An evaluation is undertaken and it demonstrates improved outcomes for consumers. However, the evaluation also identifies unintended consequences for providers, such as an increased rate of staff burnout and staff turnover. The results are thus positive at Level 1 of the evaluation hierarchy but not so at Level 2. In another situation, the results may be reversed. The task of the evaluator is to report on impacts at both levels.

Six possible evaluation tools for undertaking an evaluation at Level 2 are described in Section 6.

Level 3 The impact on, and outcomes for, the care delivery system

Evaluation at this level focuses on the structures and processes, networks and relationships that exist or are developed by the service or project.

As with Level 2, some services and projects aim to have direct system impacts. For example, a palliative care service or project may aim to develop improved palliative care capacity in the primary care sector. In this case, an evaluation would aim to assess the degree to which this has been achieved.

Like Level 2 evaluation, it may also be relevant in an evaluation to consider unintended system impacts. For example, two services collaborate in running an education program for their staff. An opportunistic outcome is that staff attending the program share ideas on how to improve their care models, resulting in improvements in both services.

Two evaluation tools that may be useful in undertaking an evaluation at Level 3 are described in Section 6.

Deciding the level at which the evaluation will operate

Some services and projects aim to have an impact, and also achieve outcomes, at all three levels. But some projects aim to have an impact at just one or two of these levels. Different evaluation approaches and tools are required for each level.

Thus the first use of the evaluation framework is in determining the level, or levels, at which the evaluation will be undertaken. Issues relevant to this task in a project evaluation are discussed in Section 7 and in a service evaluation in Section 8.

Evaluation issues and questions

It is helpful to focus the evaluation on six key issues. While these are akin to 'process, impact and outcome', they give a clearer focus to an evaluation of a service or project which is aiming to have an impact at more than one level:

Project/service delivery – what did you do?

All evaluations include a description of what the project or service is and how it is delivered.

Relevant questions here, for example, include:

- What is the project or service?
- How is it managed?
- How is it delivered?

Project/service impact – how did it go?

The questions here focus on impacts and outcomes for consumers, providers and the system (see above). An assessment of the impact of the project or service is fundamental to any evaluation.

The difference between impacts and outcomes is typically described in terms of time-frames, with outcomes being the longer-term effects (see Section 2). The evaluation framework deliberately makes no such distinction because many palliative care patient outcomes are immediate.

Fourteen evaluation tools that may be useful in evaluating impacts and outcomes at different levels are described in Section 6.

Sustainability – can you keep it going?

The key questions here are about whether the service level activity or project is able to continue. In the case of a project, sustainability is concerned with what will happen after the cessation of the initial funding. Sustainability may also be concerned with maintaining the project's impact after the cessation of project funding. In the case of a service, sustainability may be concerned with issues such as whether the required workforce can be recruited.

Most, but not all, palliative care evaluation considers sustainability. In some cases, the Sustainability Tool described in Section 6 may be helpful for this purpose. Whether or not sustainability is an issue is dependent on what the service or project aims to do.

Capacity building – have skills and knowledge been developed?

Capacity building issues are an extension of the sustainability questions and can refer to skills and knowledge gained or support for on-going changes within a system. The key question is whether the service or project has made a contribution in recognising or developing palliative care capacity. As with sustainability, most (but not all) palliative care evaluation considers capacity building. In some cases, the Capacity Building Tool described in Section 6 may be helpful for this purpose. Whether or not capacity building is an issue is dependent on what the service or project aims to do.

Generalisability – are your lessons useful for someone else?

Some services or projects aim to have an impact that is broader than the immediate catchment area or target group. For example, they aim to make a contribution to the broader National Palliative Care Strategy. In these cases, the evaluation questions are about which evaluation findings (if any) can be generalised beyond the specific program and project to other settings and circumstances. For example, a professional hotline developed as part of a project to solve a workforce problem in a rural area in one state may be applicable elsewhere.

Dissemination – who did you tell?

Dissemination issues are an extension of both the capacity building and the generalisability questions. It is important to ask questions about how and when information about the service or project is communicated to others, how effective the communication was and whether disseminating information has led to direct or indirect outcomes such as improved coordination between care professionals or improved resource allocation. Dissemination of information is fundamental to both capacity building and generalisability. In some cases, the Dissemination Log described in Section 6 may be helpful for assessing dissemination. Whether or not dissemination is an issue is dependent on what the service or project aims to do.

Figure 3 Palliative Care Evaluation Framework checklist

Issue		Is this a goal of the activity being evaluated?	To be included in the scope of the evaluation?
Levels to be evaluated			
Level 1	The impact on, and outcomes for, consumers (patients, families, carers, friends, communities)	Yes <input type="checkbox"/> No <input type="checkbox"/>	Yes <input type="checkbox"/> No <input type="checkbox"/>
Level 2	The impact on, and outcomes for, providers (professionals, volunteers, organisations)	Yes <input type="checkbox"/> No <input type="checkbox"/>	Yes <input type="checkbox"/> No <input type="checkbox"/>
Level 3	The impact on, and outcomes for, the care delivery system (structures and processes, networks, relationships)	Yes <input type="checkbox"/> No <input type="checkbox"/>	Yes <input type="checkbox"/> No <input type="checkbox"/>
Questions to be answered in the evaluation			
Service or project delivery The evaluation task is to describe 'what did you do?' at each level			Yes <input type="checkbox"/> No <input type="checkbox"/>
Service or project impact The evaluation task is to evaluate 'how did it go?' at each level			Yes <input type="checkbox"/> No <input type="checkbox"/>
Service or project sustainability Is the goal to retain the service or project on an ongoing basis? If so, the evaluation task is to evaluate 'can you keep going?' at each level		Yes <input type="checkbox"/> No <input type="checkbox"/>	Yes <input type="checkbox"/> No <input type="checkbox"/>
Service or project capacity building Does the service or project aim to develop improved capacity to meet the needs of people with a life-limiting illness? If so, the evaluation task is to evaluate 'what has been learnt?' at each level		Yes <input type="checkbox"/> No <input type="checkbox"/>	Yes <input type="checkbox"/> No <input type="checkbox"/>
Service or project generalisability Does the service or project aim to have an impact that is broader than the immediate catchment area or target group? If so, the evaluation task is to evaluate 'are your lessons useful for someone else?' at each level		Yes <input type="checkbox"/> No <input type="checkbox"/>	Yes <input type="checkbox"/> No <input type="checkbox"/>
Dissemination Does the service or project aim to communicate with, or share its lessons and experiences, with consumers, providers or services? If so, the evaluation task is to evaluate 'who did you tell?' at each level		Yes <input type="checkbox"/> No <input type="checkbox"/>	Yes <input type="checkbox"/> No <input type="checkbox"/>

Section 6 Palliative care evaluation tools



Evaluation activities are likely to range from collecting activity data on patient care through to documenting changes in service procedures, cultures and relationships. Regardless of the activity, it is necessary from an evaluation perspective to measure whether the activity being evaluated has had any impact. In order to do this a suite of evaluation tools has been developed. The tools correspond with the three levels of the evaluation hierarchy as described in the evaluation framework. These tools are designed to measure impacts and outcomes for consumers (patients, families, carers, friends, communities); for service providers (professionals and volunteers) and to measure the impacts on the system as a whole (ie, structures and processes, networks, relationships).

This suite of evaluation tools is referred to as the Palliative Care Evaluation Toolkit.

The Tool Kit

The Tool Kit includes 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.

Figure 4 lists the tools and provides information relating to their source.

The following provides a brief description of each tool in the kit.

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

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

This tool is useful in providing a clinical profile of the palliative care patient. Palliative Care Phase describes a patient's stage of illness. It comprises five stages: stable, unstable, deteriorating, terminal and bereaved (see Eagar et al 2004). Other measures in the tool are the Palliative Care Problem Severity Scale (Smith and Firms 1994), the Karnofsky Rating Scale (Karnofsky and Burchenal 1949) and the Resource Utilisation Groups Activities of Daily Living scale - RUG-ADL (Fries et al 1979). The purpose of this tool in the evaluation context is twofold:

- It is useful in profiling patients receiving palliative care.
- It provides information that can be used in the interpretation of other data analysed as part of the evaluation. For example, an evaluator might want to know about carer experiences with palliative care. The stage of the patient's illness may be helpful in interpreting information on the carer experience. Likewise, severity of symptoms as reported by the patient can be compared with those rated by the clinician or can be analysed by taking into account their palliative care phase.

Figure 4 The Palliative Care Evaluation Toolkit

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	Centre for Health Service Development (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 et 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	1 st section by CHSD based on interviews with carers in the GAPs project. 2 nd 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 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

Tool 1.2 Patient/client experiences – patient questionnaire

Tool 1.3 Patient/client experiences – staff-completed questionnaire

There are two versions of this tool – one for patients to complete and another that can be completed by a palliative care provider. This tool is used to assess and evaluate impacts and outcomes for palliative care patients. Outcomes for patients may include quality of life and/or patient satisfaction (Tierney et al 1998). This tool asks questions about both. The questions cover physical symptoms, psychological symptoms, spiritual considerations, practical concerns, emotional concerns and psychosocial needs.

Tool 1.4 Carer experiences with palliative care

This tool can be used to assess and evaluate impacts and outcomes for carers. It asks about the amount of support the carer feels that they have received for their role as carer. It includes questions about practical matters such as the provision of equipment, education/training and respite care. The tool is designed to be used with a carer while they are looking after the patient rather than retrospectively. Several well-validated tools for use with carers after the patient has died are available in the palliative care literature.

Tool 1.5 Community awareness of palliative care

The purpose of this tool is to assess general community awareness of palliative care. It can be used in the evaluation of services and projects that aim to raise awareness about palliative care in organisations and individuals that are not directly concerned with palliative care activities and services.

Examples include projects that focus on 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.

Tool 1.6 Community awareness: remote Aboriginal and Torres Strait Islander communities

The purpose of this tool is to obtain an understanding of general community awareness of palliative care in Aboriginal and Torres Strait Islander communities. The questions are designed as a guide for community discussions, small group and individual interviews.

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

Tool 2.1 Palliative care providers

This tool is designed to solicit the views of palliative care providers about issues that are fundamental to a palliative approach. It also captures attitudes and confidence in providing palliative care and invites providers to identify their ongoing education needs. It can be used to evaluate specific activities or on a 'before' and 'after' basis in the evaluation of larger projects or activities.

Tool 2.2 Volunteers currently working in palliative care

This tool is designed to explore the perceptions and experiences of volunteers currently working in palliative care. It asks volunteers about their motivations in becoming involved in palliative care, their training, and how long they expect to continue in this role. It can be used in the evaluation of services and projects that aim to support and strengthen volunteer programs and services.

Tool 2.3 New palliative care volunteers

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. It can be used as a baseline measure in evaluating activities designed to train and support volunteers.

Tool 2.4 People ending their time as a palliative care volunteer

This tool is designed for people who are completing their time as a palliative care volunteer. It asks about their experience of being a volunteer and if the experience corresponded with their initial expectations. The tool also asks volunteers to provide a reason for discontinuing their services. It can be used in the evaluation of services and projects that aim to support and strengthen volunteer programs and services.

Tool 2.5 Health professionals not working in palliative care services

This tool is designed to assess the level of knowledge and awareness of palliative care of health professionals who are not working in palliative care. This tool can be used as a before and after measure to evaluate the impact of projects such as awareness-raising campaigns.

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

This tool 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 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.

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

Tool 3.1 Palliative care service self-assessment

This tool was developed to assist palliative care services in self-evaluating the quality of care and services they provide. It allows organisations to self-rate their structures and work practices in areas including vision and management standards, practice standards, bereavement support standards, communication standards, and continuous quality improvement. It also allows services to identify priorities for action. This self-analysis, together with data from patients, families, bereaved families and professionals, can be used to identify specific interventions for service improvement.

Tool 3.2 General health care organisational survey

This tool is designed to capture information about the level of awareness and involvement a particular organisation has with palliative care service provision. It addresses organisational issues such as knowledge of palliative care, service delivery in their local area, their coordination and collaboration with other services and to what degree their service disseminates information relating to palliative care. This tool can be used as a before and after measure to evaluate the impact of projects such as awareness-raising campaigns.

Tool 4 Sustainability tool

This tool is used to assess the organisational and system level impact of a palliative care initiative and particularly focuses on the sustainability of these initiatives (see Section 5). It captures factors that affect the sustainability of a service or project. The underlying assumption in the

Palliative Care Evaluation Framework is that system-level sustainability will have flow-on effects to Level 1 and Level 2 in the framework.

Tool 5 Capacity building tool

This tool is used to assess the organisational and system level impact of a palliative care initiative and particularly focuses on the ability to build capacity at the community and system levels (see Section 5). Again, the underlying assumption is that capacity building at the system-level will have flow-on effects to Level 1 and Level 2 in the framework.

This tool can be used to measure whether there have been any changes over time as the result of a particular initiative to build capacity in palliative care service provision.

Tool 6 Generalisability tool

This tool is used to assess the organisational and system level impact of a palliative care initiative and particularly focuses on generalisability (see Section 5). It asks whether the lessons learnt from a particular initiative may be useful to similar organisations or service providers in a different setting.

Tool 7 Dissemination Log

The dissemination log is a record of how information about a palliative care initiative is shared with others, both within the local community and beyond. It covers many methods of communication including newspaper articles, conference presentations, journal articles, website dissemination and interviews on radio. Additional information can be captured including 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. It is a useful tool to gauge which method of communication resulted in follow up activities.

Tool 8 System level impacts and outcomes

This tool is designed to assess the wider impacts that a 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 influenced the way they delivered services and the project's capacity to service clients with special needs. The second part of the tool examines the inter-agency and system effects of the project. It contains a range of attitudinal statements addressing factors such as perceptions of team work, communication between agencies and so on. It is useful in gauging the degree to which local stakeholders perceive the success of the palliative care initiative.

These evaluation tools are supported by an electronic evaluation database that is freely available to those wishing to use them. Section 9 provides details on how to access the tools and the database.

Section 7 Evaluating Palliative care projects



A palliative care project is a time limited initiative or activity that is undertaken by a palliative care service or related group to solve a particular problem or to test, change, improve or develop a new service or strategy.

Projects generally have specific aims, goals and target groups and use clearly defined strategies to achieve desired impacts or outcomes within a specified timeframe. While projects operate within a larger service system, they are one-off activities that need to be assessed and evaluated in their own right.

Formal evaluation is a condition of project funding under the National Palliative Care Program. However many projects are undertaken without additional resources by palliative care services and their service partners as part of local service development or system improvement activities or to raise the profile of palliative care services in the eyes of local health service management, funding bodies or the community.

In both cases effective evaluation is the key to reaping the practical benefits of these activities.

Types of palliative care projects

The National Palliative Care Strategy has three overarching goals that provide a focus for projects funded under the National Program and for many service level projects:

- Goal 1: Awareness and understanding
- Goal 2: Quality and effectiveness
- Goal 3: Partnerships in care

Palliative care projects typically involve many different interventions and strategies and diverse target groups. Projects may aim to:

- raise general community or professional awareness of palliative care issues
- test ways of addressing a gap in local specialist services
- trial improvements in care coordination between community care agencies
- assess the care options preferred by consumers including patients, carers and family members
- test innovations such as the expanded use of volunteers or options for providing access to after hours support
- research the needs of specific population groups such as Aboriginal and Torres Strait Islander Peoples.

Planning the evaluation

Project level evaluation is generally concerned with finding out what was done, whether it worked, who benefited, what the short term impacts were and what (if any) lessons can be applied to routine practice.

Project sponsors may also want to know about the impact of the project in terms of sustainability and capacity building and whether the project outputs (for example, an innovative service model for culturally and linguistically diverse communities) have wider application.

The steps involved in designing a project level evaluation are the same as the approach described in Section 4. However specific attention needs to be paid to some additional elements.

- The evaluation needs to be tailor made for each project. The palliative care evaluation framework and toolkit described in Sections 5 and 6 have been designed to support a wide range of project types. This means that

individual projects will need to select the focus areas and impact and outcome levels that are relevant to their needs. The starting point for the project evaluator is to identify:

- the aims of the project and the level and type of impact or outcome that the project is trying to achieve
- the strategies and interventions used
- the concrete results or outcomes that you want to measure.

This will enable you to select the tools and processes that are relevant to your project from the existing toolkit or to look for alternatives.

- The time limitations imposed on most projects mean that the project and the project evaluation must be planned and implemented in parallel.

In some cases planning the evaluation can actually help to drive the project. For example, the evaluability assessment is a useful tool to assist the project sponsor and/or the steering group to clarify and refine the project goals, to assess whether the planned strategies will produce the expected results and to ensure that the impacts and outcomes can be measured.

- Projects vary in scope and scale and the scale of the evaluation needs to be commensurate with the scale of the project. A large scale project intending to implement several different interventions over an extended timeframe is likely to need a different set of processes and skills to a more contained project. For example, a large scale multi-faceted project looking at intervention effectiveness and cost benefit will need a dedicated evaluation budget and the steering group may need to contract an independent evaluation team with a range of different

skills to undertake the evaluation rather than rely on an in house project officer. Conversely a small scale project testing one or two well-defined interventions occurring over a short time frame may be able to use interested and motivated staff very effectively to undertake the evaluation.

- Projects receiving funding under the National Palliative Care Program or similar initiatives have both performance reporting and project evaluation responsibilities.

Performance monitoring is primarily concerned with implementation processes and funding accountability. Project evaluation is concerned with finding out what happened and what impacts and outcomes were achieved. Information collected for an evaluation can be used for project reporting but information collected for monitoring purposes is rarely sufficient on its own for a robust evaluation.

Figure 5 on page 25 shows some examples of different types of projects and how specific tools are selected and used to measure the outcomes or impacts in scope. It also includes examples of some of the process issues that may need to be considered as part of evaluation design and implementation.

Undertaking the evaluation

Many issues and challenges can arise during the design and implementation of an evaluation that may need to be considered by the evaluator and the project sponsor or steering group.

Some common issues relevant to undertaking a project level evaluation are discussed in the remainder of this section. However, not all issues or steps in the process are described as they may not be specific to project level evaluation and are discussed elsewhere.

Establish a consultation process and implement the communication strategy

These activities should have been considered during the planning stage. They are discussed in Section 4.

Understanding and managing expectations

Understanding stakeholder expectations and concerns is an important part of project evaluation planning and implementation. Many stakeholders and palliative care staff invest a great deal in their project and are anxious to see it succeed. However no project can ever be designed and implemented perfectly and a thorough evaluation will inevitably identify some elements of the project that have been unsuccessful or under-performed.

Concerns about 'performance' can lead to unrealistic expectations about the goals and role of the evaluation process. For example, participants may see the evaluation as a 'test' with only a pass or fail result rather than as a learning opportunity. This attitude is unhelpful for the evaluator (especially when trying to assess factors such as capacity building and sustainability) and can influence the morale and productivity of the project team.

Education sessions at the beginning of the project for key staff and stakeholders on the role of evaluation and how results can be used can assist participants to clarify their expectations and commit to working through the evaluation process. These sessions need to be built into the evaluation plan.

How results will be used

It can also be important to ensure that all the key stakeholders agree in advance what the evaluation is designed to achieve and how the results will be used. An explicit and transparent process to determine how the findings will be used should

be built into the evaluation at the planning stage, especially in projects where the results are likely to be contentious or 'political'.

For example, project funding can provide an opportunity for service providers with limited resources to expand or develop a service they see as a priority. High profile projects designed to run over an extended timeframe (for example over two years or more) run the risk of becoming, by default, service development initiatives in the eyes of some stakeholders.

Some stakeholders may only be interested in participating in an evaluation process designed to demonstrate the 'success' of their project and help them to secure ongoing funding. Findings that highlight high costs, under-developed partnerships or other sustainability issues may be resisted and some stakeholders may even withdraw from the process.

These issues can generally be identified through consulting with key stakeholders during the evaluation design phase. However some may only surface and need to be managed when the evaluation is in progress.

In many instances the stakeholder issues can be clarified by the evaluator or the project sponsor and a solution agreed. In other cases the overall project steering group or an evaluation sub-committee may need to resolve the issues at the level of policy with involvement from the project funding body.

Context and boundary issues

Projects take place in a pre-existing service system and operational context and project implementation and evaluation cannot be quarantined from changes in the wider environment. Changes in the operating environment can affect the impact of the project. It might also be difficult to define the boundaries between the results of the project interventions and external influences. These issues need to

be considered as part of evaluation design and analysis. In some cases, it may also be necessary to modify the original evaluation plan once the evaluation is in progress.

For example, a project may have been designed to test consumer preferences for supported care at home or admission to a hospice. The local hospice is part of a residential care facility. During the course of the project, ownership of the residential care facility changes. The new owner begins to refurbish the facility and progressively reduces access to the beds. This restricts the choices available to referring clinicians and consumers.

While the evaluation data show a clear increase in the number of people being cared for at home, the reliability of the results are skewed by the reduction in service choices over the life of the project.

The evaluation will need to adjust for these external factors (for example by comparing the level of support for each model of care when the hospice beds were available) and using other tools (such as retrospective interviews with carers and family members) as part of the analysis.

Distinguishing impacts from needs

A final issue to consider is that projects and project evaluation are generally concerned with measuring the results of interventions and not with measuring needs. A project to raise community awareness of palliative care issues and services may be well executed, cost effective and demonstrate clear results in terms of increased awareness. The project may have achieved its goals and been technically successful.

However if the local service system is already struggling to manage demand, a project to raise community awareness further may have been unnecessary. Indeed, it may even have been counter-productive because it did not target a relevant local need.

Time limited projects offer lasting value when they are developed to meet a need or solve a specific problem that has been identified through other planning or review processes.

The evaluation report

The final evaluation should address the questions in the Palliative Care Evaluation Framework (page 12) that were selected for evaluation in the design phase. The report should describe the evaluation methodology and the types of analyses and processes involved. Figure 5 on page 25 illustrates some of these.

The impacts and outcomes need to be clearly described. If the evaluation has experienced problems with data quality or availability, the problems and the limitations should be explained. Depending on the project, the impacts and outcomes may be different for consumers, providers and the system. Impacts and outcomes at each relevant level need to be described. The final task in the evaluation is to identify implications for the future. In doing so, it is important to:

- clearly draw out whether the project has any policy implications and, if so, what they are
- clearly draw out whether the project has any practice implications and, if so, what they are
- identify (if relevant) options for the future, including issues such as resource implications, practical issues and timetables
- identify (if relevant) any critical change management issues.

Figure 5 Examples of approaches to designing different types of project evaluations

Project aim	What strategies are you using?	What do you want to measure ?	Types of possible tools	Process issues to consider
Community awareness about palliative care	Community awareness campaign including: <ul style="list-style-type: none"> • mass media • town meetings • speakers to service organisations and networks 	Changes in community awareness generally. Which interventions worked best in terms of impact and reach?	Pre and post telephone survey of sample of community testing general knowledge of PC before and after awareness campaign. Would also assess the number of people who had heard or seen the campaign. Pre and post questionnaires to participants in meetings. Data collected with Evaluation Tools 1.5 and 1.6 may be useful here.	Sample to reflect target population.
Expand care at home options for patients	Develop a formal GP network through training and structured specialist support.	Was the network established and what was its scope? Did it increase deaths at home? After training and at 6 months in the network were GPs confident in their skills? Were GPs and community nurses satisfied with specialist support at 6 months? What did the service network cost and did it offer value for money?	Process analyses describing activities undertaken to establish network, number of GPs involved and basic usage and cost data. Baseline information on place of death of known palliative care patients with review at agreed milestones. Tool to assess baseline knowledge about palliative care, change in confidence after training and at six months. Data collected with Evaluation Tool 2.1 may be useful here. Use a tool to measure participant satisfaction with support provided. Costing tools to collect information on service elements eg training, peer support, after hours consultation and GP and nurse visits from relevant sources. Benchmark unit costs per palliative care patient with similar service.	Use key informant interviews plus review of key documents and progress reports to Project Management Group/funding body to map service development process. Palliative care providers need to collect place of death information. Could use key informant interviews, a questionnaire or focus groups to assess satisfaction. May need to run separate costing study as a subset of project. Need capacity to measure project costs plus any payments for attendance. Need comparable service as benchmarking partner.

Project aim	What strategies are you using ?	What do you want to measure ?	Types of possible tools	Process issues to consider
Increase community support for care at home	Develop structured volunteer program with coordinator, training and debriefing to replace informal arrangements.	Increase in number of volunteers. Volunteer satisfaction levels.	Baseline and milestone data on number of volunteers. Survey existing and new volunteers on knowledge and satisfaction levels at beginning of formal program and agreed milestones. Data collected with Evaluation Tools 2.2-2.4 may be useful here.	Map arrangements before new service was introduced. Measure volunteer turn-over at baseline and agreed milestones.
Enhance carer/family experience	Pilot a range of carer support initiatives including: <ul style="list-style-type: none"> • Volunteer home support • Access to aids and appliances for home care • Access to an after hours consultation service 	Satisfaction of carers with support received in general. Type of support that was used most frequently. Type of support most highly rated by majority of carers.	Carer profile and patient profile to establish palliative care phase and baseline carer needs and available supports. Carer satisfaction survey at baseline and following interventions. Use of carer diary to record support needs and usage rates for each type of new support measure over a defined period. A carer and provider assessment tool to rate the support measures in terms of relief of carer burden. Data collected with Evaluation Tools 1.1-1.4 may be useful here.	This project compares three different interventions that may all be used at different times by the family/carer. It may be difficult to get clear results if participant numbers are small and the rate of usage of each support changes at different points in the patient's stage of illness. Results may need interpretation by use of palliative care phase data. Consider limiting the number of interventions used by narrowing the focus to measure similar interventions with similar goals such as the volunteer support and the after hours professional consultation.

Section 8 Evaluating Palliative care services



Evaluation is a central part of service planning in palliative care and other clinical services and is often part of a structured planning cycle at local, regional or state/territory level.

While service and project level evaluation share common features, there are several important differences.

Service-level evaluation is generally undertaken to inform decision-making about current or future investment or in response to community or professional concerns about the accessibility, appropriateness, effectiveness or sustainability of the existing service system.

Stakeholders generally require the evaluation to provide clear advice on priorities and recommendations on the type of improvements needed to the service system. This can include issues such as staffing, funding, models of care, access issues, infrastructure development and service networks or partnerships.

Unlike project evaluation, which assesses if the strategy or intervention worked and what the short term impacts were, a service evaluation is more concerned with the 'need' for the service and its likely merits compared to other alternatives, now and in the future. The evaluation framework and plan is therefore concerned with assessing the 'need' for palliative care services across a range of dimensions and generally uses tools such as benchmarks and service standards as 'evidence' to justify explicit recommendations for decision makers.

Stakeholders often have different and competing agendas and service level evaluations can be highly 'political'.

In these circumstances, the evaluator and the evaluation process needs to be transparent and impartial if the results are to be accepted by (as

opposed to being acceptable to) all parties.

Types of service level evaluation

Funders or senior operational managers commission service level reviews and evaluations for a range of reasons. The reasons for the evaluation often drive the type of evaluation undertaken:

- In response to pressures on, or within, the service system such as growing demand, waiting times for services (likely to be unacceptable in palliative care) or high levels of workforce turnover.
- In response to service needs or gaps identified by sections of the community such as people in rural areas or a specific population group with specialised needs such as children.
- To review the costs, benefits or overall system effects of incorporating new treatments or service models into the existing service system. The impact of new medications and changing patterns of specialist prescribing on primary care services is an example.
- To assess the efficiency and cost effectiveness of the current service with a view to demonstrating that additional resources are required or that current resources can be used more effectively.
- To determine if a service plan or strategy has been implemented effectively and is achieving the goals and outcomes expected or requires fine-tuning. This will include review of the efficiency and effectiveness of the current service model and the current and projected funding needs.
- As part of formalised benchmarking or quality assurance activities designed to improve service systems and the quality of palliative care.

In most instances, a service evaluation aims either to validate and reinforce the current arrangement or to identify areas in which change and improvement are required, including recommendations about how this should be achieved.

The terms of reference and background information included in the design of the evaluation (or a project brief) generally specify the rationale and objectives for the evaluation and may also identify the range of processes required.

Depending on the objectives, a service evaluation will use many of the approaches and tools described in previous sections. However, the first step in a comprehensive service-level evaluation is a needs analysis.

Planning the evaluation

The steps involved in designing a service level evaluation are the same as the approach described in Section 4 with some additional elements:

- The evaluation framework should include the concept of 'need' as a focus area and incorporate a comprehensive needs analysis as part of the evaluation plan. It therefore adds a first question that is not always necessary in a project level evaluation – 'what is the need?'
- Detailed review of information on the current service structure, organisation, resources, service model and utilisation will be required to map the current service delivery arrangements and provide baseline information for the needs assessment. Understanding the operational characteristics of the current service system will require more extensive data collection than project level process evaluation.
- Planning tasks such as demand and supply modelling and consultation with national experts may also be required to develop options and recommendations.

- The scope of a service level evaluation means that a communication strategy is likely to be required to inform the key stakeholders that the evaluation is occurring, its aims and how they will be able to contribute.

Undertaking the evaluation

Figure 6 page 31 illustrates typical examples of the questions, information and evidence that may be useful in a palliative care service evaluation. These examples also illustrate the processes that can be used for a service level evaluation in palliative care. Some specific issues relevant to undertaking a service level evaluation are discussed in the remainder of this section. Not all issues or steps in the process are canvassed as those that are not specific to service level evaluations are discussed elsewhere.

Establish a consultation process and implement the communication strategy

These activities should have been considered during the planning stage. They are discussed in Section 4.

Needs Analysis

A needs analysis is generally the first step in undertaking the evaluation. Analysis of needs is an important part of any robust service planning or service evaluation framework that aims to answer questions that will inform future policy and/or practice. However, there has been little evaluation as to how needs have been met by palliative care services so far (Franks 2000).

Figure 6 Questions, information, evidence and processes that can be useful in evaluating palliative care services

Evaluation Issue	Current Service Attributes	Normative Need	Expressed Need	Comparative Need	Felt Need	Projected Needs and Sustainability Issues
Target group and service population	<p>Diagnosis: -% patients with cancer -% non cancer</p> <p>Geographic distribution</p> <p>Age profile</p> <p>Place of treatment</p> <p>Social status eg living alone</p> <p>Clinical data such as phase of illness, functional scores, symptom service scores</p> <p>Routinely collected data may be useful here</p> <p>Data collected with Evaluation Tool 1.1 may also be useful here</p>	<p>Is the service target group consistent with the PCA guideline for mix of cancer and non-cancer diagnoses?</p> <p>Are utilisation rates consistent with planning benchmarks?</p> <p>Routinely collected data, qualitative data (collected through interviews, surveys and/or focus groups) and PCA guidelines may be useful here</p>	<p>Number registered patients and new referrals.</p> <p>Growth in patient numbers and referrals in past 5 years</p> <p>Patient profile as per clinical data</p> <p>Routinely collected data may be useful here</p> <p>Data collected with Evaluation Tool 1.1 may also be useful here</p>	<p>How does current and projected service population compare to the national or state average?</p> <p>Are there any regional differences in current service usage rates or growth rates in the past five years?</p> <p>Routinely collected data and consultation with comparable services may be useful here</p>	<p>Have any key stakeholder groups expressed concern about access to the service?</p> <p>Data collected with Evaluation Tools 1.2, 1.3, 2.1-2.6 may be useful here</p> <p>Other qualitative data (collected through interviews, surveys and/or focus groups) may also be useful here</p>	<p>What will be the impact of changes in the projected population?</p> <p>Projected cancer and non cancer incidence and projected deaths</p> <p>Population growth and ageing</p> <p>Population distribution (urban/rural)</p> <p>Numbers in groups with special needs groups eg older living alone, remote, ATSI, CALD, paediatric.</p> <p>Routinely collected data may be useful here</p>
Service Delivery Model	<p>Describe the service model including:</p> <p>Mix of inpatient and community services</p> <p>Number, distribution and role of specialist teams eg C&L, direct care.</p> <p>Linkages with primary care providers and general hospitals including referral criteria and processes and use of common clinical protocols</p> <p>Arrangements for after hours care</p> <p>Role of volunteers and community agencies</p> <p>Routinely collected data and qualitative data (collected through interviews, surveys and/or focus groups) may be useful here</p>	<p>Is the service model consistent with PCA guidelines?</p> <p>Routinely collected data, qualitative data (collected through interviews, surveys and/or focus groups) and PCA guidelines may be useful here</p>	<p>Which service types have the highest usage rates?</p> <p>Have usage rates for specific service types changed in the last five years?</p> <p>Routinely collected data and qualitative data (collected through interviews, surveys and/or focus groups) may be useful here</p>	<p>Are there regional differences in the service types (eg hospice beds, after hours services, specialist or medical staff) available and their usage rates?</p> <p>How does the model of care compare to those in regions with similar population and demographic profile elsewhere in Australia?</p> <p>Routinely collected data and consultation with comparable services may be useful here</p>	<p>Have consumers or communities identified gaps in the services available or expressed a preference for specific models?</p> <p>What do staff, GPs, Community Health Services and other stakeholders say works well and what needs improvement in the service delivery model?</p> <p>Data collected with Evaluation Tools 1.5, 1.6, 3.1 and 3.2 may be useful here</p> <p>Other qualitative data (collected through interviews, surveys and/or focus groups) may also be useful here</p>	<p>What are the priorities for changing or improving the service model?</p> <p>Will incremental adjustments/improvements to the current model satisfy projected demand and consumer needs or are new service types or operating arrangements required?</p> <p>Qualitative data (collected through interviews, surveys and/or focus groups) may be useful here</p>

Evaluation Issue	Current Service Attributes	Normative Need	Expressed Need	Comparative Need	Felt Need	Projected Needs and Sustainability Issues
Infrastructure	Staff profile in specialist teams: -Medical -Nursing -Allied health -Bereavement -Volunteers -Pastoral care Staff involved in formal network with primary care and general hospital services Routinely collected data may be useful here	How does the staff profile/100,000 population compare to PCA benchmarks? Routinely collected data, qualitative data (collected through interviews, surveys and/or focus groups) and PCA guidelines may be useful here	What are the workloads of specialist staff by discipline? Patient numbers/referrals Community OOS After hours shifts Educational and training activities for service partners. Routinely collected data and qualitative data (collected through interviews, surveys and/or focus groups) may be useful here	How does the staff profile compare to other regions or states/territories? Are there local variations in staffing between regions and in which disciplines? Routinely collected data and consultation with comparable services may be useful here	What do staff say about their workloads, working conditions, training and professional development requirements? What improvements do they suggest? What do primary care network partners and volunteers say about their support and training needs? What do volunteers say they need? What do consumers say they need? Data collected with Evaluation Tools 1.2, 1.3, 2.1-2.6 may be useful here Other qualitative data (collected through interviews, surveys and/or focus groups) may also be useful here	Are there recruitment or retention problems in the service and in what disciplines? How can these be addressed in terms of policy, training, remuneration, professional recognition and other factors identified by staff and other services as relevant? Routinely collected data and qualitative data (collected through interviews, surveys and/or focus groups) may be useful here
Efficiency	Direct and indirect funding available to the service and to different components within the service Routinely collected data may be useful here	Proportion of patients receiving care and dying in a setting of their choice Routinely collected data, qualitative data (collected through interviews, surveys and/or focus groups) and PCA guidelines may be useful here	Indicative cost per service and by service type. Cost per service changes over past five years Routinely collected data may be useful here	Differences in levels of investment and cost per service between regions. How does the service compare in relative terms to other similar states/ territories or regions? Routinely collected data and consultation with comparable services may be useful here		

Evaluation Issue	Current Service Attributes	Normative Need	Expressed Need	Comparative Need	Felt Need	Projected Needs and Sustainability Issues
Quality, impact and outcomes	<p>Are quality and performance measures reported? Is there a quality assurance program in place and what are the elements? Are there accredited primary care network partners? Are clinical data accessible for use in quality improvement problems? Routinely collected data may be useful here</p>	<p>How do arrangements compared with PCA recommendations for measuring service standards and accreditation requirements? Routinely collected data, qualitative data (collected through interviews, surveys and/or focus groups) may be useful here</p>	<p>Performance in relation to indicators such as time from referral to first assessment? Routinely collected data and qualitative data (collected through interviews, surveys and/or focus groups) may be useful here</p>	<p>Is there a consistent approach to quality across the service? What happens in other similar sized services elsewhere? How does performance on agreed indicators compare with similar services? Routinely collected data and consultation with comparable services may be useful here</p>	<p>Has the service surveyed consumers (patient and carer) about their satisfaction with services? What are the results of consumer (patient and carer) surveys? Qualitative data (collected through interviews, surveys and/or focus groups) may be useful here Data collected with Evaluation Tools 1.2, 1.3, 1.4, 2.1-2.6 3.1 and 3.2 may also be useful here</p>	

Note: Evaluation tools referred to in this figure are those described in Section 6.

Needs have been defined as ‘those states, conditions or factors in the community which if absent prevent people from achieving the optimum physical, social or mental health’ (Hawe et al 1990).

‘Inherent in the notion of health need is the sense that something that is essential or required for well-being is lacking...however this can be differently defined by the individual consumer, by the professional provider or organisations acting on behalf of communities’ (Eagar, Garrett and Lin 2001). ‘Health need is a contestable construct reflecting conflicting social values and interests (Sanderson 1996) ‘and is concerned with issues of fairness and social justice’ (Percy-Smith 1996). Inherent in most definitions is the notion that needs are quantifiable and measurable.

Need is different to the economic concepts of demand and supply. Different tools are used to measure health needs.

A useful description of different types of need was developed over thirty years ago (Bradshaw 1972) and has been widely used in the health sector. In the Bradshaw model, the ‘need’ for palliative care is evaluated from four perspectives. The idea that ‘needs’ can be defined differently for different purposes is helpful because it does not give primacy to any one type of need. The strongest evidence of ‘need’ is when these four perspectives coincide. The four different types of need that are widely used in a comprehensive needs assessment and evaluation are:

- normative need
- expressed need
- comparative need
- felt need.

The issues that are considered using each approach and the tools and types of information that can be used are discussed below.

Normative Need

Normative need is expert opinion regarding appropriate standards, required levels of service and acceptable health status for a community. It involves standards laid down on the basis of experience and consultation.

Palliative Care Service Provision in Australia: a Planning Guide (PCA 2003) is an example of expert opinion distilled into standards and planning guidelines. The Guide includes tools for assessing the target group for palliative care services, describes the attributes and components of the specialist service system and the staff to population planning ratios for specialist services that are required to meet the ‘need’.

Evidence based clinical practice guidelines, health technology assessment models and workforce planning guidelines are other tools that can be used to assess normative need.

Defining the target group

Accurately defining the target group is a key issue in normative needs assessment. The target group for palliative care is patients with a life-limiting illness and their carers. However, in practice, cancer patients are often identified as the target group because reasonable empirical data (cancer incidence and deaths) are available to assist planning.

If the palliative care service is conceived as a service for people dying from cancer then the service will target a specific group and operate in a specific way. This may not reflect the ‘need’ for palliative care.

A recent Rand Corporation study (Lynn and Adamson 2003) broadens the palliative care target group to include frail elderly people at the end of life who are living with serious chronic illness.

Here a palliative care approach is desirable but

the disease trajectory associated with cancer is not necessarily present. This group of patients may benefit from a palliative care assessment and consultation/liason but is likely to be managed by other professional teams rather than a specialist palliative care team.

These service interface issues are an important part of a flexible palliative care service and the PCA Guide describes a different referral and intervention regime for terminally ill people with a non-cancer diagnosis.

Other groups with special palliative care needs include children and adolescents (Association for Children with Life Threatening or Terminal conditions and the Royal College of Paediatrics and Child Health 2003), people in rural and remote communities and people from indigenous and culturally and linguistically diverse backgrounds.

Expressed need

Expressed need is what can be observed about a community or population by assessing patterns of service usage. Expressed need tends to reflect service supply and access to services. This means that people with better access to services (geographic, cultural and financial) tend to utilise more services than people with poorer access even though the lower access group may have greater 'need'.

Usage can also be supply or professionally driven or reflect inefficient practice such as failure to triage patients on a waiting list effectively or to discharge patients no longer in 'need' of care. 'Caution needs to be exercised when interpreting data on service utilisation as a reflection of expressed need as inappropriate interpretation of the information is possible.' (Eagar, Garrett and Lin 2001)

Service usage data are relevant to describe the current service provision arrangements but the data should be used cautiously when discussing 'need'.

Comparative need

Comparative need uses information on the services provided in one area or state to determine needs in another. A comparative needs assessment would compare the palliative care service infrastructure (eg, hospice and general beds, number of specialist teams and so on) and the staffing profile in one state or region with a range of others. We could compare the staffing profile on a state and territory basis (using a tool such as the PCA Palliative Care Census results) or use professional contacts to compare the scope of the service model operating in the region with another comparable region or area elsewhere.

This might indicate that a different service model, such as a general practitioner palliative care team working in partnership with a specialist service, can provide comprehensive service coverage for a rural population at an affordable cost with fewer barriers in relation to recruitment than a medical specialist model. Equally, we can compare the infrastructure and service usage patterns between regions or areas within a state or territory to identify differences in equity of access to services to gaps in the service model or infrastructure.

Felt need

Felt need is what people say they want. It can be elicited through consultations, key informant interviews, discussion or focus groups, surveys and public meetings. It is important to know who participated in these consultative processes and whether the participants were representative of the community whose 'needs' are being assessed or the reliability and validity of the information gathered will be limited.

Demand and demographic analysis

One of the questions often asked in service level evaluation is whether the current service infrastructure will meet future population or target group needs.

This generally refers to likely changes in the

potential service population brought about by growth or population ageing that will influence disease patterns (such as incidence and prevalence rates) or shifts in population that will concentrate demand in some regions or in urban rather than rural areas.

Demographic analysis for a service such as palliative care (where a service model may promote supported death at home) would also consider data that predict usage of inpatient or home based services. This might include the proportion of the elderly population who live alone or geographic access for people in remote areas.

Several modelling tools are available to estimate future needs. For example, models that project historical usage or supply patterns with adjustments for population growth and ageing are often used for regional and Statewide planning in acute care.

However, these models have limited or no application in palliative care planning at present. Palliative care information has been poorly coded and counted in the historical acute care data sets that underpin these projection model. Also, non-admitted patient services, which are a major component of palliative care, are not included. The increasing collection of palliative care information will support more robust projection models in the future.

Drawing out the policy and practice implications of evaluation findings

We noted in Section 2 that the purpose of evaluation is to inform decision-making at the policy and/or operational levels and that this is what distinguishes it from conventional research.

It does so by undertaking the types of analyses and processes illustrated in Figure 6 on page 29 to describe the current situation and the results that are being achieved. In the process, opportunities for improvement may also be identified. As with projects, these opportunities may include:

- ways to better meet the needs of consumers (Level 1 in the evaluation framework)
- ways to better meet the needs of providers (Level 2 in the evaluation framework)
- ways to improve the service delivery system (Level 3 in the evaluation framework).

The final task in the evaluation is to identify such opportunities for change and improvement. In doing so, it is important to:

- clearly draw out any policy implications
- clearly draw out any practice implications
- identify (if relevant) options for change, including issues such as resource implications, practical issues and timetables
- identify (if relevant) the critical change management issues.

As the old saying goes, everyone loves progress but most people hate change. A service level evaluation can be an important lever to improve palliative care services, but only if:

- sufficient attention is paid to careful design (see the checklist on page 10)
- the evaluation is undertaken in an open and transparent way, with due attention to communication and consultation
- staff involved in data collection understand and support the purpose/s of the evaluation
- the evaluation is rigorous, but realistic
- the needs and the aspirations of key stakeholders are recognised and addressed in the final evaluation.

Section 9 How to access tools and guidelines



Palliative Care Evaluation Toolkit

The Palliative Care Evaluation Tool Kit which supports the evaluation framework described in Section 5 of this booklet is freely available to anyone who would like to use it. This resource can be found on the World Wide Web at the Centre for Health Service Development, University of Wollongong:

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

This Tool Kit is supported by an electronic palliative care evaluation database that can be found at the same address. This database allows the user to enter data from the individual tools in the Tool Kit into a user-friendly Microsoft Access database.

Other resources

The tools within the Tool Kit are by no means the only resources available to evaluate palliative care initiatives and, indeed, may not suit the particular questions that you want to ask as part of your evaluation. Other palliative care evaluation resources can be found by doing an international search on the World Wide Web.

You may also find the following links useful for further information about palliative care evaluation:

Palliative Care Australia.

<http://www.pallcare.org.au>.

This website is a useful resource that provides up to date information about all aspects of palliative care. The two resources cited in Section 8 that are useful in evaluating normative and comparative need can be found on this website.

National Palliative Program.

<http://www.palliativecare.gov.au/index.htm>

This is the Australian Government's palliative care website for health professionals, service providers and the community. It provides information relating to the National Palliative Care Program and contains useful links to relevant publications and palliative care resources.

CareSearch is being developed as an electronic resource for palliative care researchers and clinical specialists providing care for people with a life limiting illness. The web address is:

<http://www.caresearch.com.au>

The CareSearch home page also includes a link to the Palliative Care Knowledge Network Project. This project is looking at whether an electronic network of resources and information to support palliative care in Australia is needed and whether it is feasible and cost-effective. It is worth book marking this site and watching it develop as it may prove to be an invaluable resource for people with an interest in palliative care.

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