

Chapter 39

**Monitoring and Evaluation**

**Overview**

Monitoring and evaluation (M&E) is critical for ensuring that successful interventions become part of an integrated health service. M&E offers powerful tools to ensure that funders, policy makers, implementers, and researchers remain abreast of the impact, efficacy, efficiency, and overall ‘success’ of programmes.

M&E also allows managers to follow the progress of their activities, compare what was planned to what is actually occurring, and assess the cost-effectiveness of the service. This enables managers to make informed decisions when planning services and to optimally utilise both human and financial resources to benefit patients and their families. In short, M&E tracks performance, measures results, and reports progress of service delivery.

Palliative care is a relatively new concept within the African region. One of the keys to its successful acceptance throughout the region is in showcasing best practices, highlighting deficiencies and constraints and making available new models of implementation for public scrutiny. Governments and funders often are keen to invest in these programmes, which can often be more cost-effective than the current care provision.

There are different ways of carrying out M&E within the palliative care setting, and a variety of tools can be used to do it. The important thing is that it is done. As measures of efficiency and effectiveness, good systems of monitoring and evaluation are key to the development of palliative care, and can be powerful tools in advocating for expanded services within the region.

**Authors**

Julia Downing

Liz Gwyther

Robert Pawinski

**At a Glance**

What is Monitoring and Evaluation?

Why M&E?

M&E Frameworks

M&E Tools

The Process of M&E

M&E Challenges in Palliative Care

References

Suggested Resources

***Monitoring and Evaluation***

***Table of Contents***

|  |     |
|--|-----|
| Overview .....                           | 517 |
| What is Monitoring and Evaluation? ..... | 519 |
| Why M&E? .....                           | 520 |
| M&E Frameworks .....                     | 522 |
| M&E Tools .....                          | 527 |
| The Process of M&E.....                  | 529 |
| M&E Challenges in Palliative Care.....   | 531 |
| References .....                         | 532 |
| Suggested Resources.....                 | 533 |

## What is Monitoring and Evaluation?

Monitoring and evaluation form the essential elements of a control and reporting system. It is important to accurately assess what has or is happening compared to what was expected to happen (Young, 2003). Monitoring helps to determine whether any change that has occurred due to a programme has been worthwhile or effective.

Monitoring is an ongoing process. It is carried out routinely and is usually quite structured. It helps managers keep an eye on things in a simple way (Whiteley, 1996). It entails routinely collecting data and measuring progress towards a programme's objectives. It addresses to what extent planned activities are realised, what services are provided, how well the services are provided, and the cost per unit (FHI, 2004).

Monitoring is similar to the concept of evaluation but with an important difference: M&E focuses more on ongoing feedback to improve a programme's functioning. Evaluation can do the same but tends to look at programmes in terms of whether they have made a difference. Evaluation is 'the process of determining the merit or worth or value of something; or the product of that process' (Scriven, 1981) by systematically collecting and analysing information to assess an organisation's effectiveness in achieving its goals. It provides regular feedback to help analyse impact, outcomes, and results of activities, and helps assess relevance, scope, and sustainability (McCoy, 2005). It addresses the outcome — what has been observed as a result of a programme, what it means, and whether or not the programme makes a difference (FHI, 2004).

It is challenging to ensure that an effective M&E system is in place within a palliative care programme. The programme's goals and objectives need to be clear and precise so they can be effectively monitored and evaluated. The timing of M&E activities and method for gathering information need to be thought through clearly. One can get different results depending on when one looks at something and how it is looked at. For example, in talking to students in a palliative care course, one will get different answers depending upon whether questions are asked during the course or after the course. This is why the time of data collection depends on the type of information required and the time and funds an organisation has to collect the data (Whiteley, 1996).

The achievement of results is key to M&E. Results must be the consequence of a particular activity carried out by an organisation (e.g., providing palliative care). The organisation must attain these results in whole or part and willingly be accountable for them. Besides having M&E strategies in place, organisations must have an integrated reporting system that systematically and regularly provides essential and useful information to inform stakeholders on progress, challenges, successes, and lessons learnt (McCoy, 2005).

M&E is important at all levels of palliative care and for all organisations, whether small or large. It is not a policing exercise but an opportunity to promote palliative care, share our success, and learn from one another. M&E is one of the most talked-about, but least-practised, aspects of organisational management (McCoy, 2005). Whilst many see the importance of good M&E systems, they are often perceived as being hard to implement and integrate into an already busy workload.

## Why M&E?

It is important for organisations to assess whether and how well they are achieving their aims and objectives. M&E often is seen purely as a requirement of funding agencies and therefore as an external necessity. But the goals are much broader than that, and should be seen as a strategic system for assessing organisational capacity and economic effectiveness and predicting future sustainability. See Box 39.1 for the specific goals of M&E in palliative care organisations as identified by the African Palliative Care Association.

An effective M&E system gives palliative care organisations the ability to:

- Evaluate how effectively they promote change.
- Monitor how efficiently they promote change.
- Foster public and political cooperation and support particular information needs for target audiences (e.g., on the safe utilisation of oral morphine in the African context).
- Equip managers with a tool to gain timely information on the progress of activities, allowing comparison of what was planned to what is occurring. If, for example, five palliative care training programmes were planned, how many have been delivered? If the number differs, M&E will show why there is a difference and its implications.
- Promote organisational learning and encourage adaptive management (e.g., measuring how well a palliative care training programme went, the changes that need to be made, and how to do it differently next time) (McCoy, 2005).

It is impossible to judge whether or not a palliative care programme is moving in the right direction, or what changes are needed, without an efficient M&E system integrated into all aspects of the programme. Within the context of palliative care in Africa, an effective M&E system can act as an advocacy tool as results and lessons learnt are shared, which will enable others to learn from existing palliative care organisations and prevent others from making similar mistakes. The information cycle illustrated in Figure 39.1 shows how M&E can also help increase funding when results at all levels can be shown to donors.

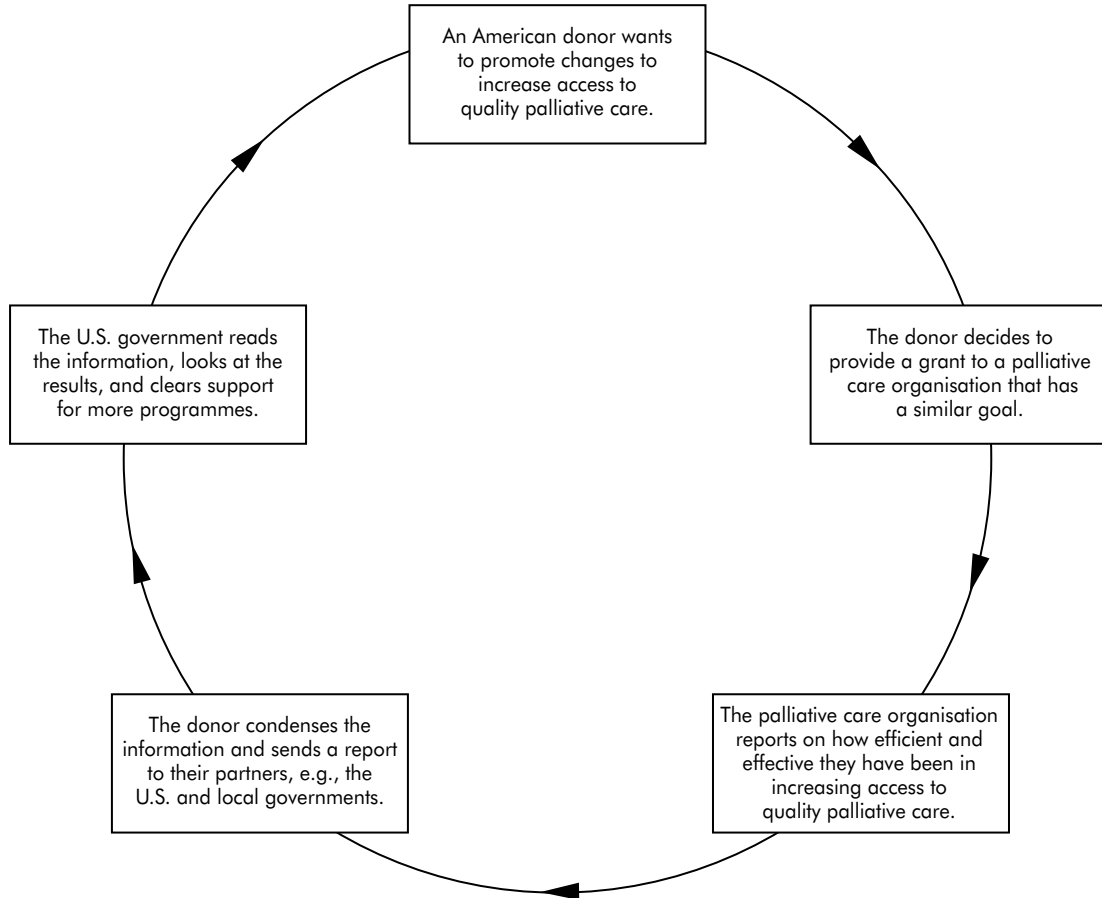
### Box 39.1:

#### APCA's Goals of M&E for Palliative Care

- Achieving the best possible care for consumers/program improvement
- Measuring palliative care and training activity
- Cost effectiveness
- Feedback for staff (based on successes, achievements, needs)—inventory of palliative care and training successes within the region
- Reappraising objectives of APCA
- Course correction and program improvement/improving efficiency
- Program decision-making—determining what works and what doesn't work (fast-tracking and scaling-up effective programs)
- Learning from mistakes, training other programmes in best practices and proven models in Africa and beyond
- Accountability to donors
- Increased credibility to obtain additional resources
- Advocacy for funding/policy

*Source: Developed by the African Palliative Care Association in November, 2004.*

**Figure 39.1: An Example of How M&E Information Can Help Solicit Funds**



Source: Adapted from McCoy, 2005.

**M&E Frameworks**

Monitoring and evaluation take place at different stages of a programme. Different information is collated at different times which, together, will give a holistic picture of the programme. There is no one way to conduct M&E within a palliative care programme. Different M&E frameworks exist and can be applied as appropriate. The M&E frameworks presented in this section can be used in conjunction with one another.

***Comprehensive M&E framework***

Family Health International discusses a comprehensive M&E framework (FHI, 2004) as including four types of monitoring and evaluation (see Box 39.2).

Using this approach, it can be demonstrated how a programme has been conducted and what has resulted from it. Some of the stages may overlap, so it is not clear-cut in practice and the method of gathering data is crucial.

**Box 39.2:**

**A Comprehensive M&E Framework**

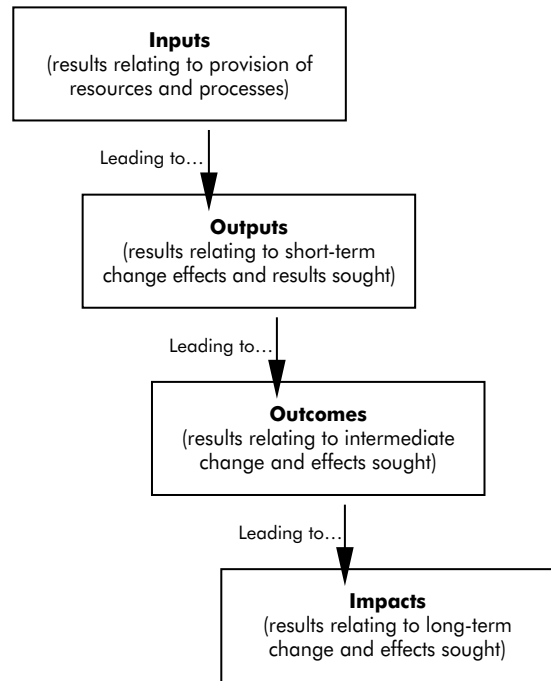
| Types of Monitoring and Evaluation  |  |   |  |
|---|--|---|--|
| Formative assessments and research (concept and design)   | Monitoring (monitoring inputs, processes, and outputs; assessing service quality)  | Evaluation (assessing outcome and impact)   | Cost-effectiveness analysis (including sustainability issues)  |
| Questions Addressed By the Different Types of M&E   |  |   |  |
| <ul style="list-style-type: none"> <li>• Is an intervention needed, e.g., palliative care?</li> <li>• Who needs the intervention, e.g., people with HIV/AIDS or cancer?</li> <li>• How should the intervention be carried out, e.g., what model of palliative care delivery best suits the need?</li> </ul> | <ul style="list-style-type: none"> <li>• To what extent are planned activities actually realised, e.g., has the palliative care service been set up?</li> <li>• How well are the palliative care services provided?</li> </ul> | <ul style="list-style-type: none"> <li>• What outcomes are observed, e.g., is there better pain control?</li> <li>• What does the outcome mean (e.g., what does it mean if pain is not controlled)?</li> <li>• Does the programme make a difference?</li> </ul> | <ul style="list-style-type: none"> <li>• Should programme priorities be changed or expanded?</li> <li>• To what extent should resources be reallocated?</li> </ul> |

Source: Family Health International, 2004.

**Monitoring, Evaluation, and Reporting (MER) Results-Based Framework**

Traditional M&E methods have focused on the implementation of programme tracking targets at the input and output levels, although this is often haphazard and unsystematic. As illustrated in Figure 39.2, PACT (McCoy, 2005) discusses how a results-based MER (Monitoring, Evaluation and Reporting) framework helps to see things within the larger picture and look at how a programme’s results contribute to achieving the highest level and longest-term impact that can be anticipated for an intervention—such as increasing access to quality palliative care. The MER system will mirror the expected programme results at different levels when using a results-based framework.

**Figure 39.2: The Different Levels at Which Results are Measured in a Results-Based MER Framework**



Source: Adapted from McCoy, 2005.

**Participatory M&E Framework**

Traditional methods of monitoring and evaluation involve ‘experts’ measuring performance against pre-set indicators and implementing programme tracking targets at the input and output level. A participatory M&E framework offers new, more inclusive ways of assessing and learning from change. It also rethinks the issue of who initiates and undertakes the process and who learns or benefits from the findings (IDS, 1998).

A participatory M&E framework works best at the community level. When evaluating a community-based palliative care service, such a framework can help to motivate and sustain local involvement and support for the services provided. Box 39.3 describes how participatory M&E compares with conventional M&E.

**Box 39.3:**

**Beyond the Conventional Approach**

|   | Conventional M&E                                   | Participatory M&E  |
|---|--|--|
| Who plans and manages the process?                          | Senior managers or outside experts                 | Local people, project staff, managers, and other stakeholders, often helped by a facilitator       |
| Role of ‘primary stakeholders’ (the intended beneficiaries) | Provide information only                           | Design and adapt the methodology, collect and analyse data, share findings and link them to action |
| How success is measured                                     | Externally defined, mainly quantitative indicators | Internally defined indicators, including more qualitative judgements                               |
| Approach  | Pre-determined                                     | Adaptive   |

Source: Institute of Development Studies, 1998.

Participatory M&E is based on four main principles (IDS, 1998):

**Participation:** In the palliative care setting it is hard to have those most directly affected participate in M & E. However, the family can be involved, and it may work better for palliative care training at the different levels.

**Negotiation:** When trying to get people involved, one needs to negotiate how and what data will be collected and analysed, what it means, how the findings will be shared and what action will be taken. The negotiating process, often lengthy and drawn-out, requires specific negotiating skills.

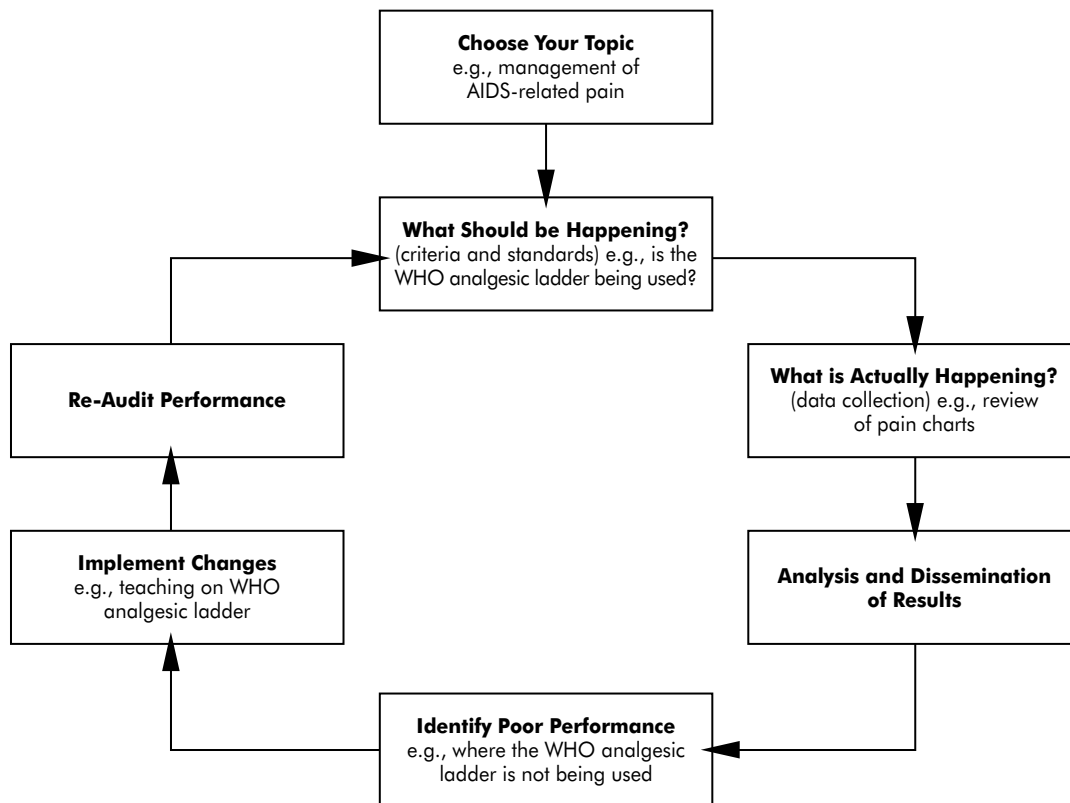
**Learning:** What is learnt through the process is the basis for subsequent improvements in such areas as palliative care provision or training.

**Flexibility:** This is important when using a participatory approach and dealing with multiple stakeholders, especially given the challenges of working in a palliative care situation.

**A Framework for Clinical Audit**

Measurement is an important part of health care. Illustrated in Figure 39.3, clinical audit is a method of reviewing clinical practice against agreed standards of care to identify areas for improvement in the quality of care. It is a ‘systematic critical analysis of the quality of clinical care, including the procedures used for diagnosis and treatment, use of resources and resulting outcomes and quality of life of the patient’ (Wright, 2003). It is a framework for looking at what you and your colleagues are doing in relation to clinical care, learning from it, and changing practice. Clinical audit is greatly needed to ensure the quality of palliative care as palliative care services develop throughout Africa.

**Figure 39.3: The Audit Cycle**



Source: Adapted from Wright, 2003.

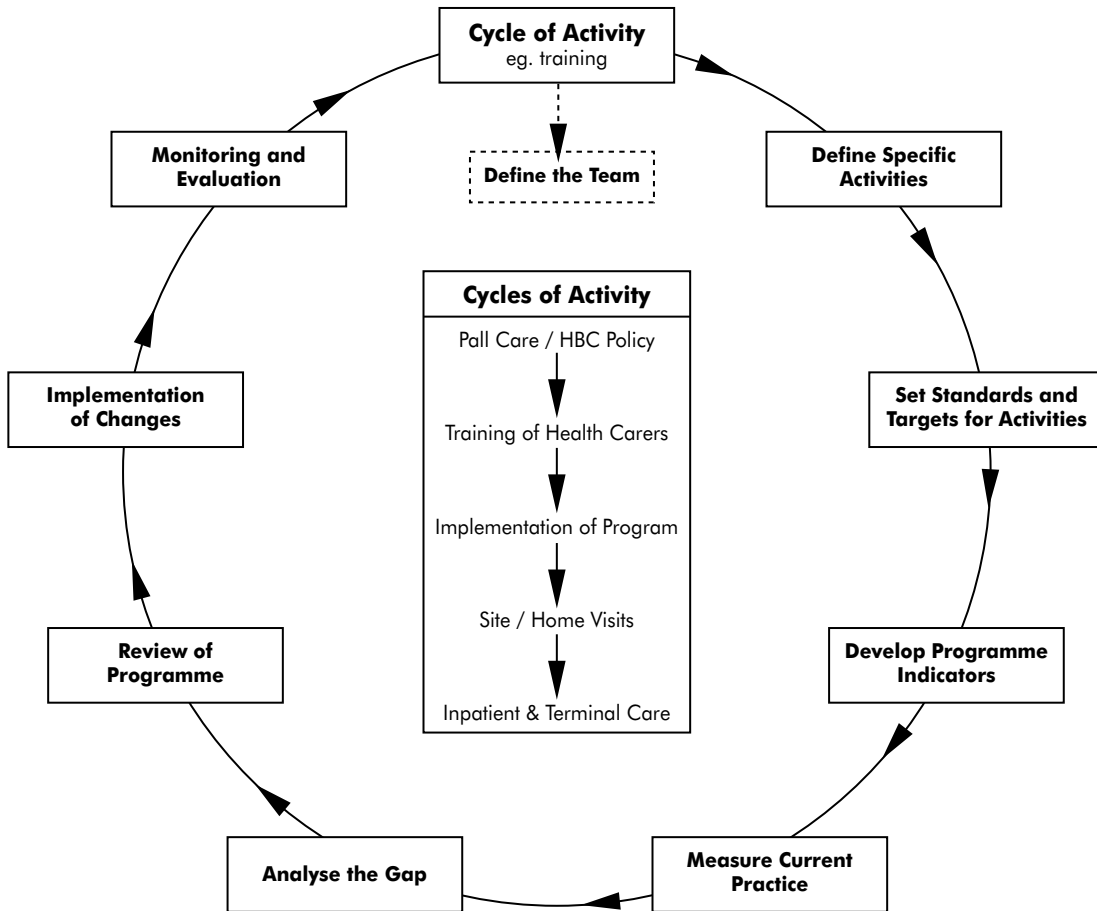
Clinical audit has had a major impact on the development of palliative care in Europe, Canada, and Australia. The results have helped to develop programmes and provide outcome information enabling programme leaders to advocate for increased funding and demonstrate effectiveness. Within the African setting, where the burden of disease is so great and there are relatively few health care professionals trained in palliative care, the tools utilised elsewhere need to be adapted. Individual programmes must be capable of seeing the largest possible number of patients and families in the most effective way whilst still providing a quality service. By developing a robust audit system it will be possible to set a good foundation and standards of care for patients and families that can be replicated in different settings (Higginson, 2002).

The standards by which practice is measured are key to clinical audit. But many countries in Africa have not yet defined standards for palliative care. South Africa is the most advanced in this area, having developed standards for palliative care that are used to audit and accredit hospices and palliative care services through the Hospice Association of South Africa. If an audit reveals that a facility does not meet the standards for accreditation, it will be helped to develop and improve their practice until it meets an acceptable level of care. Zimbabwe has standards for home-based care, which incorporate standards for palliative care. Uganda is developing generic palliative care standards. It is hoped that the African Palliative Care Association will be able to assist new and developing palliative care services with information about palliative care standards and help them to meet the standards as required. This is important for both palliative care services and training. (See Chapter 41: Palliative Care Associations.)

### ***Quality Improvement Framework***

The quality improvement cycle provides an easy means of ongoing monitoring and evaluation. This generic process can be adopted for any activity that requires ongoing assessment. It is an ideal tool to collect, analyse, and process data, rapidly converting data into practice based on needs and identified constraints. Following the quality improvement cycle for all activities related to a program ensures ongoing M&E and that future action is based on data collected in the evaluations. Figure 39.4 illustrates the Quality Improvement Cycle.

Figure 39.4 The Quality Improvement Cycle



Source: Brown (no date).

## M&E Tools

### *Workplan*

It is important to plan the M&E process well. Bad planning can waste time and resources (Whiteley, 1996). An M&E workplan needs to be flexible and show the steps used to document a programme's activities and assess progress towards achieving its goals and objectives. An organisation must be clear about what needs to be measured and how it will be measured. When considering what to measure it is important not to over measure. The tendency is to collect more data than is needed and data that does not really mean anything. An organisation must decide and concentrate on what is appropriate, feasible, relevant, and essential (FHI, 2004). One needs to be able to interpret and draw conclusions from information that is collected.

### *Indicators*

Most programmes will have 'indicators', which they or their donors have identified as the key things that need to be measured. An indicator is a unit of information measured over time so that change can be documented. It gives specific information providing evidence of the achievement (or not) of results and activities. Indicators help to examine trends and highlight problems and can be compared with a programme's targets (McCoy, 2005). Indicators identify what should be measured in order to know whether conditions have or have not changed (e.g., whether palliative care training has made a difference to the care given).

Indicators cannot be developed for every issue, and indeed are not needed for every aspect of a programme, but they should reflect the issues deemed most important for M&E. Indicators are not just anything that you can think of to measure. They are not objectives, targets or results, and they are not biased and do not specify a particular level of achievement (McCoy, 2005).

Required data for indicators can be measured using both quantitative and qualitative data collection methods:

**Quantitative data** documents numbers associated with programmes and focus on what and how often different elements of a programme are being carried out (e.g., number of home visits or number of palliative care trainings conducted). Gathering this data tends to involve record keeping and numerical counts.

**Qualitative data** looks at how well elements of a programme are being carried out. They can show change in behaviour or attitude (e.g., how well palliative care is being provided in the community) (FHI, 2004). It is often necessary to collect both quantitative and qualitative data in order to get a more complete picture of a programme or activity. Organisations, especially small and developing ones, must consider whether they have the level of knowledge and skills required to collect and analyse different types of data.

Box 39.4 offers examples of quantitative and qualitative data.

The methods for collecting data for M&E include:

- Structured or semi-structured questionnaires
- Structured or semi-structured interviews
- Discussions and focus group discussions
- Review of documents and existing data
- Logs or diaries
- Observation
- 'Off-the-shelf' audit packages
- Satisfaction surveys
- Review of comments and complaints (Whiteley, 1996)

**Box 39.4**

| <b>Qualitative or Quantitative?</b>              |   |
|--|---|
| <b>Quantitative</b>                              | <b>Qualitative</b>                                  |
| Considers 'how many?'                            | 'Softer' approach                                   |
| Provides generalisable results                   | Looks at perceptions and experience                 |
| Open to statistical analysis                     | Looks at 'why and how'                              |
| Systematic/ predetermined approach               | Is an adaptable approach according to what you find |
| Sometimes seen as 'scientific'                   | Seeks patterns of response                          |
| Provides a snapshot, or longitudinal information | Useful for sensitive topics                         |

Source: Whiteley, 1996.

It is fine to use existing indicators and instruments, but they should be adapted to the local situation (WHO, 2004). This poses a challenge for many organisations involved in palliative care in Africa, as many of the available tools have been designed for use in countries with a western outlook and more resources. Whilst these can still be useful, it is important that they are tested within the African context and adapted as appropriate.

One example of an instrument designed in the U.K. but used widely, and which will soon be piloted and adapted for the African context, is the Palliative Care Outcome Scale (POS) (Aspinal, 2002). The POS is an assessment and measurement tool which has been designed to prospectively assess clinical palliative care practice with regards to patient needs and palliative care outcomes. It is simple and easy to use, and it is hoped that it will adapt well to the African setting.

In the United States, the National Hospice and Palliative Care Organization has developed a minimum data set for hospices which includes a wide variety of measures of clinical care and organisational performance (Connor, 2004). Analysis of the data set is aimed at answering the following:

- Who provides care?
- Who are the patients cared for?
- How much and what type of care do they receive?
- How much does it cost?
- How good is the care provided?

The Hospice Association of South Africa has developed a similar tool for use by hospice and palliative care organisations to assess care and training. It is hoped that in the future the African Palliative Care Association will have some simple tools that newly developing palliative care services will be able to utilise.

## The Process of M&E

### *Who Should Carry Out M&E?*

M&E should be an integral part of every palliative care programme and needs to be well co-ordinated and integrated into the programme from the start. WHO recommends that M&E activities should be proportional to a programme's resources and account for about 10 percent of a programme's budget (WHO, 2004).

Although different people will be involved in different types of M&E, it is important that all key stakeholders are involved to increase utilisation of results. M&E will be carried out in different ways and may be done internally, by peers, or externally:

**Internal audit:** The hospice or palliative care organisation should identify one or two people who are trained as assessors to carry out an internal audit. An added benefit is the building of capacity within organisations.

**Peer review:** The regional or national organisation should identify one or two people who are trained as peer assessors.

**External audit:** This would be carried out by the donor or an organisation appointed by the donor with an agreed-upon notice period (e.g., one month).

Who does the audit and how it is done will depend on the M&E framework being used, who needs the information (e.g., programme managers or donors), and what they need.

### *When Should M&E Take Place?*

M&E is a dynamic process as things change and the process continually needs to be reviewed (FHI, 2004). It is an ongoing process that needs to take place continually, with some indicators being measured more frequently than others—such as measuring the number of patients seen monthly, while less frequently measuring the impact of care on patients and their families. Box 39.5 shows sample indicators, how data could be collected, and how often.

**Box 39.5:****Sample Palliative Care Indicators****Inputs**

| Indicator   | Method of data collection                         | Frequency                        |
|---|---|----------------------------------|
| Number of health professionals trained in palliative care | Training records                                  | 6 monthly                        |
| Availability of resources (e.g., guidelines, medications) | Audit tool / on site inspections<br>Record Review | Baseline /<br>every 2-3<br>years |

**Outputs**

| Indicator   | Method of data collection    | Frequency |
|---|------------------------------|-----------|
| Number of patients seen at home                                 | Health Care records          | Monthly   |
| Number of patients seen as inpatients in a palliative care unit | Palliative care unit records | Monthly   |

**Outcomes**

| Indicator                                  | Method of data collection                                     | Frequency |
|--|---|-----------|
| Number of accredited palliative care units | Palliative care association records<br>Health service records | Annually  |

**Impact**

| Indicator                  | Method of data collection        | Frequency          |
|----------------------------|----------------------------------|--------------------|
| Quality of palliative care | Client and family questionnaires | Every 2–3<br>years |

*Source: Adapted from McCoy, 2005.*

## M&E Challenges in Palliative Care

Although a good M&E system can be time-consuming, it is very important for every organisation. There are challenges in all forms of M&E, including:

- Under- or over-doing it. If one does not do enough M&E, the system might not be comprehensive, looking only at the inputs and outputs and not the outcomes or impact. If one does too much it becomes burdensome and does not get done (McCoy, 2005).
- Waiting until the last minute to set up a data system, enter, or analyse data (McCoy, 2005).
- Knowing when people are telling you what they really think vs. telling you what they think you want them to say. The 'fear factor,' for example, can worry people about whether the care they receive will be affected by what they say (Whiteley, 1996).
- Difficulties with memory or perceptions. It is best to ask people about recent events to get accurate responses (i.e., within the last six months) (Whiteley, 1996).
- Challenging the notion of vigorous data collection, analysis, validity, and reliability by using a participatory M&E approach that incorporates different ways of looking at the world (IDS, 1998).
- Difficulty in scaling-up the M&E process. It is best to start small and be selective about what you monitor and evaluate (IDS, 1998).
- The fine line between research and M&E.

Additional challenges in Africa for palliative care M&E have to do with the nature of what is being monitored and evaluated. These include:

- Defining what, exactly, we are trying to measure when talking about palliative care.
- Determining what we mean by quality palliative care, how to measure it, and whether it is the same everywhere.
- Defining what we mean by a 'good death.' Is it the same regardless of age, race, or culture? Or does it vary between individuals, tribe, and culture? If so, how do we capture that?
- Clients' expectations determine how they rate a service. For example, if they do not expect their pain to be relieved, they may rate the service excellent if it is relieved even just a bit and they are unaware that they could be pain-free.
- Ethical and cultural issues.
- Evaluation of the palliative care services by relatives of the actual person who received care and has died.
- The lack of M&E expertise within some of the palliative care organisations in the region and the need for technical assistance in this area (Harding, 2004).
- Integration of M&E into palliative care services (Harding, 2003).
- Concerns about the use and relevance of outcome scales within the palliative care setting (Hearn, 1997). The feasibility of their use also has been questioned although the consensus is that palliative care should be evaluated (Paci, 2001).

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## Suggested Resources

Building, Monitoring, Evaluating and Repeating (MER) Systems for HIV/AIDS Programs Monitoring. 2005. Washington, DC: PACT. Available at: <http://www.pactworld.org>.

HRSA/HAB Quality Center: Technical resources for U.S.-based HIV/AIDS programs, funded by HHS, Health Resources and Services Administration, HIV/AIDS Bureau. Available at: <http://www.ihl.org/IHI/Topics/HIVAIDS/>. Accessed 8/05.

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See also publications listed under References.

