MENTORING FOR SUCCESS

A Manual for Palliative Care Professionals, Organisations and Associations

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TABLE OF CONTENTS

ACKNOWLEDGEMENTS 3
FOREWORD 4
1. INTRODUCTION 5
1.1 WHAT IS PALLIATIVE CARE? 5
1.2 WHAT IS APCA? 5
1.3 WHAT IS MENTORSHIP? 6
1.4 WHY BE MENTORED? 7
1.5 REFERENCES 7
1.6 RESOURCES 8
2. THE MENTORSHIP PROCESS 9
2.1 WHAT IS THE IDEAL MENTORSHIP PROCESS? 9
2.2 APCA MENTORSHIP MODEL 9
2.3 THE MENTORSHIP PROCESS 9
2.4 WHAT DO MENTORING PARTNERSHIPS MEAN IN PRACTICE? 10
2.5 WHAT IS THE SELECTION CRITERIA AND PROCESS? 10
3. ORGANISATIONAL DEVELOPMENT 11
3.1 HOW DO YOU SET UP A NATIONAL PALLIATIVE CARE ASSOCIATION? 11
3.2 ORGANISATIONAL DEVELOPMENT FOR PALLIATIVE CARE INSTITUTIONS 11
3.3 STRATEGIC PLANNING FOR NATIONAL ASSOCIATIONS 12
3.4 MANAGEMENT AND GOVERNANCE 12
3.4.1 Management 12
3.4.2 Governance 12
3.5 FINANCIAL POLICIES 13
3.6 REFERENCES 13
3.7 RESOURCES 13
4. STANDARDS OF CARE 15
4.1 WHAT ARE PALLIATIVE CARE STANDARDS? 15
4.2 WHY PALLIATIVE CARE STANDARDS? 15
4.3 WHO ARE THE BENEFICIARIES OF PALLIATIVE CARE STANDARDS? 15
4.4 HOW SHOULD PALLIATIVE CARE STANDARDS BE DEVELOPED? 15
4.5 WHAT IS THE STATUS OF PALLIATIVE CARE STANDARDS IN AFRICA? 16
4.6 HOW SHOULD STANDARDS BE INTEGRATED INTO PALLIATIVE CARE SERVICE PROVISION? 16
4.7 HOW CAN ADHERENCE TO PALLIATIVE CARE STANDARDS BE MONITORED? 16
4.8 WHAT IS THE ROLE OF MENTORSHIP IN PROMOTING STANDARDS? 16
4.9 RESOURCES 17
5. ADVOCACY & POLICY INFLUENCING 19
5.1 WHAT IS ADVOCACY? 19
5.2 WHAT ADVOCACY STRATEGIES ARE APPROPRIATE FOR PALLIATIVE CARE PROGRAMMES? 19
5.3 WHAT POLICY PRIORITIES IN PALLIATIVE CARE SHOULD BE ADDRESSED? 19
5.4 HOW CAN POLICY CHANGE IN DRUG AVAILABILITY BE ACHIEVED? 20
5.5 WHY, WHEN, AND WHO TO ADVOCATE TO? 20
5.6 WHICH ADVOCACY TOOLS COULD BE USED? 20
TABLE OF CONTENTS

5.7 REFERENCES 21
5.8 RESOURCES 21

6. EDUCATION AND TRAINING 22
6.1 WHAT IS THE AIM OF PALLIATIVE CARE EDUCATION AND TRAINING? 22
6.2 WHO SHOULD BE TRAINED? 22
6.3 WHAT TRAINING DO DIFFERENT TARGET GROUPS NEED? 22
6.4 WHAT ARE THE AVAILABLE TRAINING RESOURCES? 22
6.5 HOW CAN ON-GOING SUPPORT BE PROVIDED FOR THOSE WHO HAVE BEEN TRAINED? 23
6.6 HOW CAN YOUR KNOWLEDGE AND SKILLS BE SHARED WITH OTHERS? 23
6.7 RESOURCES 23

7. MONITORING AND EVALUATION 25
7.1 WHAT IS MONITORING AND EVALUATION? 25
7.2 WHY DO M&E? 25
7.2.1 A mechanism for project monitoring and evaluation 25
7.2.2 A learning or quality improvement tool 26
7.3 HOW DO YOU DO M&E? 28
7.3.1 Work plan 28
7.3.2 M&E Frameworks 28
    7.3.2.1 Comprehensive M&E Framework 28
    7.3.2.2 Monitoring, Evaluation and Reporting (MER) Results-Based Framework 29
    7.3.2.3 Participatory M&E Framework 29
    7.3.2.4 A Framework for Clinical Audit 30
    7.3.2.5 Quality Improvement Cycle Framework 31
    7.3.3 M&E Tools 32
    7.3.3.1 Logistical Framework 32
    7.3.3.2 Indicators 34
7.4 REFERENCES 35
7.5 RESOURCES 36

8. FUND RAISING & DONOR RELATIONS 37
8.1 DONOR-RECIPIENT RELATIONSHIP 37
8.2 BUILDING DONOR RELATIONS 37
8.3 DEVELOPING A FUNDING PROPOSAL 37
8.4 HOW SHOULD DONOR LIAISON AND REPORTING WORK? 38
8.5 RESOURCES 39

9. APPENDICES 40
APPENDIX 1: LIST OF CONTRIBUTORS 40
APPENDIX 2: STEPS IN STRATEGIC PLANNING 40
APPENDIX 3: AN EXAMPLE OF AN ACTION PLAN 41
APPENDIX 4: FORMAT FOR A PROJECT PROPOSAL 41
Acknowledgements

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The editors also thank the individual contributors to this manual, who are listed in Appendix 1.
The African Palliative Care Association (APCA) aims to support the scaling-up of palliative care provision across Africa for those with progressive, life-limiting illness through a culturally appropriate public health approach that strives to balance coverage with quality.

Currently in many African countries, palliative care services are either non-existent, misnamed as they only provide supportive rather than holistic care, or are restricted to the use of the fortunate minority. APCA seeks to address these deficiencies in part through its mentorship programme, in which ongoing technical support is provided to ensure programmatic initiatives are sustainable. This highly welcome manual is a key component of that mentorship programme.

The manual originates from, and is an expansion of, the mentorship manual developed by the Hospice Palliative Care Association of South Africa, also funded by the Open Society Institute (OSI). That project entailed using well-established hospices, with a strong integrated community-based home care programme, providing structured guidance and support to developing hospices in five regions of the country. Further funding from OSI enabled the programme’s expansion into the fields of education and accreditation.

This manual advances that mentorship agenda across the African continent. Directed towards the mentorship of professionals, organisations and associations involved in the field of palliative care, it focuses on the areas of: organisational development; standards of care; advocacy and policy influencing; education and training; fund raising and donor relations; and monitoring and evaluation (M&E). The need for the latter in an era of increasingly demanding international donor expectations regarding financial integrity, budgetary transparency and the proven impact value of funded work programmes, as well as the complexity of the concepts entailed, is reflected in the disproportionate length of the M&E chapter. For many emerging organisations, the very notion of being measured and assessed is, in itself, threatening. In our experience, one of the most valuable types of mentorship is helping people and organisations to accept and cope with the change that is implicit in M&E. We therefore strongly advocate linking the implementation of care standards and any audit activities to M&E and would suggest that this is an essential ingredient in terms of sustaining the quality improvement cycle that APCA so rightly endorses.

We congratulate the contributors to this manual for an impressive publication. We additionally thank the publication’s editors, Richard A. Powell and Julia Downing, for coordinating the work of individual contributors and ensuring the quality of the finished work.

Finally, it is our hope that this manual will be of great use and benefit, and be a stepping stone towards the realisation of APCA’s mission of scaling up palliative care in Africa by balancing quality with coverage.
Dr Faith Mwangi-Powell & Dr Julia Downing

This manual aims to provide a reader-friendly introduction to the purpose, process and content of mentoring provided by the African Palliative Care Association (APCA) to professionals, organisations and national associations involved in the field of palliative care and based in Africa. In order to set the context for this manual, and establish its importance and timely relevance, this introduction: provides a working definition of palliative care; describes the history, objectives and work of APCA; and outlines an overview of the concept of mentoring.

1.1 What is palliative care?

The World Health Organisation (WHO) defines palliative care as:

‘An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten or postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient's illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counselling if indicated;
- Will enhance quality of life, and may also positively influence the course of illness;
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.’ (WHO, 2002)

The WHO also highlights the need for palliative care for both adults and children, stating:

- ‘Palliative care for children is the active total care of the child’s body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres, and even in children’s homes’ (WHO, 2002).

This is particularly important in the African context where so many children are infected by HIV/AIDS who will need palliative care at some stage of their life. APCA has adopted the WHO definition of palliative care and additionally included the use of antiretroviral (ARV) therapy, to supplement chemotherapy and radiotherapy, as a ‘therapy that is intended to prolong life.’

1.2 What is APCA?

APCA was provisionally established in November 2002, and formally established in Arusha, Tanzania, in June 2004. Its mission is to promote and support affordable and culturally appropriate palliative care throughout Africa. APCA’s goal is to support the scaling-up of palliative care provision across Africa through a culturally appropriate public health approach that strives to balance quality with coverage.
Its broad objectives are to:

- Promote the availability of palliative care for all in need, including orphans and vulnerable children;
- Encourage governments across Africa to support affordable and appropriate palliative care which is to be incorporated into the whole spectrum of health care services;
- Promote the availability of palliative care drugs for all in need;
- Encourage the establishment of national palliative care associations in all African countries;
- Promote palliative care education and training programmes suitable for African countries;
- Develop and promote quality standards in palliative care training and service provision for different levels of health care professionals and care providers.

To achieve these objectives, APCA employs a four-fold approach in its work that includes:

1. Working in collaboration with those organisations and individuals championing palliative care service provision in Africa to ensure governments and other international donors accept palliative care as a vital component in the care of people with progressive, life-limiting illnesses (including HIV/AIDS) and incorporate budget lines for dedicated funding that will be used to build palliative care capacity across the region.

2. Providing technical assistance to non-governmental organisations (NGOs) and Faith-Based organisations working on HIV/AIDS to help them integrate palliative care into existing work programmes, thereby ensuring palliative care is recognised as part of the spectrum of responses for effective HIV/AIDS management.

3. Supporting identified champions of palliative care (both individual and organisational) in positions that can influence national policy so that:

- Palliative care is incorporated into the national health plans of African governments;
- Appropriate drugs for the alleviation of pain, and to combat opportunistic infections, are made available.
- Palliative care is included in the curricula for all medical and nurse training, thereby increasing the existing skills base so that palliative care provision in the region can be sustained;

4. Developing a mentorship programme for new organisations with ongoing technical support to ensure initiatives are sustainable.

APCA does not provide direct clinical care to people living with progressive, life-limiting illnesses. Rather, it plays a facilitative role, working collaboratively with existing and potential providers of palliative care services to help expand the scale of service provision by: training existing and potential service providers; providing support for effective advocacy work; offering a mentorship programme to support emerging initiatives; and improving the quality of care provision by the introduction of a quality assurance and standards of care programme.

1.3 What is mentorship?

Mentorship is an ongoing and empowering learning process that entails the provision of support and encouragement. More specifically, it involves:

- Guidance
- Support
- Leadership
- Supervision
- Advocacy
- Training

Mentorship has traditionally been seen as a personal relationship between two people. However, the concept can be expanded to include a relationship between two organisations. When viewed as an organisational partnership a monitoring and evaluation (M&E) component is added to the mentoring process given that the mentee needs to assess the value of the mentor’s work in addressing their identified needs within the agreed time frame, and the mentor needs to determine how well they are mentoring.
It is in this sense that APCA sees mentorship as a formal process of support and capacity building for national palliative care associations or, where they do not exist, palliative care organisations based within the continent. Effective mentorship is provided by a well-established palliative care organisation to a newly established or emerging palliative care programme. This programme may be an independent programme, such as a NGO, a home-based care (HBC) programme that is trying to integrate palliative care, or a government facility. Whatever the type of organisation, APCA will work to connect them to an established palliative care organisation through its mentorship programme.

1.4 Why be mentored?

The number of people within Africa in need of palliative care is substantial, especially due to the impact of HIV/AIDS and cancer. By December 2005 an estimated 25.8 million people in Sub-Saharan Africa were living with HIV/AIDS, accounting for 64 percent of the global disease burden (UNAIDS/WHO, 2006). Moreover, cancer rates in Africa are expected to grow by 400 percent over the next 50 years (Morris, 2003). The WHO estimates that there are more than 0.5 million annual cancer deaths in Africa (Sepulveda et al., 2003) and that by 2020, 70 percent of new cancer cases will be in the developing world (Ramsay, 2001).

This unprecedented need for palliative care has meant that existing palliative care services, where they exist, are often unable to meet that need; it is imperative, therefore, to achieve a rapid scale-up of palliative care within the region. With increased donor funding, many fledgling organisations are emerging across Africa in response to this need. However, those individuals, organisations and associations that are relatively new to palliative care may lack the experience and skills necessary to deliver effective services. Through a mentorship programme, such people and organisations within the region are given an opportunity to share their knowledge and expertise with established individuals, organisations and associations to enable them to develop without repeating the mistakes of others, or having to start completely from the beginning. This manual therefore outlines the primary areas that constitute the APCA mentorship programme.

SUMMARY MESSAGES

- APCA’s mission is to promote and support affordable and culturally appropriate palliative care throughout Africa.
- Mentorship is an ongoing and empowering learning process that entails the provision of support and encouragement.
- Effective mentorship is provided by a well-established palliative care organisation to individuals, organisations and national associations involved in the field of palliative care and based in Africa.
- Through an effective mentorship programme, palliative care professionals, organisations and national associations within the region are given an opportunity to share their knowledge and expertise with others.

1.5 References


1 The internet addresses provided in this manual were correct at the time of publication.
1.6 Resources

Cameron, S and Defilippi, K (Eds.) (no date) Hospice Palliative Care Association of South Africa Mentors Manual. Cape Town: Hospice and Palliative Care Association of South Africa

Web based

BMC Palliative Care
www.biomedcentral.com/bmpalliatcare/

City of Hope Pain/Palliative Care Resource Centre (COHPPRC)
www.cityofhope.org/prc

Cochrane Pain, Palliative and Supportive Care Group
www.cochrane.org/reviews/en/topics/85_new.html

Growth House
www.growthhouse.org

National Cancer Control Programmes, World Health Organisation (WHO) - Palliative care
www.who.int/cancer/palliative/en/

Palliative Care Matters
www.pallcare.info
2. The Mentorship Process

Simon Busuulwa

2.1 What is the ideal mentorship process?

Mentorship is an ongoing and empowering learning process that entails the provision of support and encouragement. More specifically, it involves:

- Guidance
- Support
- Leadership
- Supervision
- Advocacy
- Training

A mentoring arrangement is qualitatively different to that of a simple partnership: while the latter can be a straightforward organisational collaboration orientated towards a common goal, the former is a partnership that embodies a specifically educational relationship between both parties.

In a mentoring relationship, a voluntary, collegial relationship between the mentor and mentee is essential if it is to be successful. To achieve the optimal possible outcomes for the mentee, the mentorship process must be planned, agreed and facilitated in such a manner that both parties involved believe in, mutually benefit from, and are comfortable with it. The mentoring process should therefore be seen more as a dynamic sharing and learning relationship than as an ‘arranged marriage’ that must succeed irrespective of the partners’ feelings for each other. Moreover, the mentoring partner should facilitate the learning process, rather than act as the expert who conveys ‘the word’ down to a favoured individual, with open dialogue informing the mentorship process.

2.2 APCA mentorship model

APCA’s mentorship model is disseminated via a mentorship programme forged between suitably matched palliative care professionals, organisations and associations. The mentorship relationship could occur at both individual and organisational levels; that is between:

Individual mentorship relationships:
- Peers
- Key experts and individuals

Organisational mentorship relationships:
- National Associations within Africa (south-south)
- National Associations within Africa and Associations outside Africa
- Key experts and Associations.

The aim of the mentorship programme is to help mentees with accessible support in all areas, both operational and technical, to develop into viable palliative care organisations or service providers.

In terms of the national palliative care associations, for example, mentorship support helps them to:

- Develop appropriate human and organisational capacity to coordinate palliative care activities effectively.
- Advocate effectively for the development of policies and national guidelines that will enable the availability and delivery of quality palliative care.
- Build capacity and skills in implementing national palliative care training programmes.
- Initiate, and monitor adherence to, agreed minimum quality of palliative care standards.

In supporting partners to achieve this goal, APCA harnesses relevant indigenous expertise by drawing upon its extensive expert database.

2.3 The mentorship process

As a starting point, APCA encourages new organisations to join its membership, although the mentorship process is not exclusively for APCA members.

Once a newly formed organisation becomes an APCA member, an organisational assessment is conducted either through a simple questionnaire or a country visit, depending upon available funding. When country visits are possible, they are conducted by the APCA team, which is normally comprised of palliative care experts from within Africa. Occasionally these team members are also members of one of the APCA committees; but that is not necessarily the case: the person who is best suited to be part of the mentoring process is ideally
The visiting team interacts closely with the organisation and professionals being mentored. The APCA team identifies the diverse needs of the mentee organisation and develops a technical assistance (TA) programme under the following areas that is tailored to meet the organisation’s specific needs:

- Organisational development
- Standards of care
- Advocacy and policy influencing
- Education and training
- Monitoring and evaluation
- Fund raising and donor relations

Once the TA programme has been completed, APCA identifies a mentorship organisation, team, or individual which/who will provide on-going support in each of the areas mentioned above. The aim of the mentorship support is to ensure that the organisation being mentored realises the benefits arising from the TA programme. For national associations this could entail:

- Streamlined organisational policies and governance structures, and the facilitated development of a Board of Directors.
- Well-developed strategic plans.
- Workable policies and procedures.
- Operational, vibrant, accountable secretariats.
- Developed advocacy strategy guidelines to engage governments and ensure sustainable palliative care throughout respective countries.
- Established national capacity to coordinate palliative care training and the inclusion of palliative care into medical training programmes.

2.4 What do mentoring partnerships mean in practice?

The mentorship agenda is based on the recommendations of the TA team. In general, and in line with APCA’s strategic areas of operation, it would normally entail the following aspects of work: organisational development; standards of care; advocacy; education and training; monitoring and evaluation; and donor liaisons and fundraising.

All these aspects are discussed in detail in the chapters that follow.

2.5 What is the selection criteria and process?

As mentioned above, APCA is receptive to requests to provide support and facilitation from organisations based in Africa. However, priority is given to the following:

- Programmes and institutions that have a national outlook and that demonstrate a desire to reach all potential beneficiaries in their countries.
- Programmes that have demonstrable support by the wider palliative care stakeholders, government and health care structure.
- Programmes that are committed to expanding palliative care services and standards in their work.
- Programmes, institutions, and associations that are able to share and communicate and work cooperatively with others, and where there are opportunities for mentoring individuals who have demonstrated effective coaching, counselling, facilitating and networking skills for palliative care programmes.

SUMMARY MESSAGES

- A successful mentoring process should involve a voluntary and collegial relationship between the partners involved.
- Mentorship relationships can occur between individuals, organisations and associations.
- The aim of the mentorship programme is to help mentees with accessible support in all areas, both operational and technical, to develop into viable palliative care organisations or service providers.
- APCA is receptive to requests to provide support and facilitation from organisations based in Africa.
3. Organisational Development

Andre Wagner & Dr Faith Mwangi-Powell

3.1 How do you set up a national palliative care association?

Once the decision has been made to establish a national palliative care association, it is important to hold a stakeholders meeting at which all interested parties can network and share ideas. It is imperative that this meeting includes and involves as many stakeholders from the outset so that they ‘buy into’ the concept of a national association and support it actively.

As a number of palliative care associations already exist, one does not need to start from scratch. As part of its mentoring programme, APCA can help with the development of the association’s aims and objectives, along with a basic generic constitution that can be adapted to fit the context of the new association. APCA will also facilitate contact between new associations and more established associations so that a mentoring relationship can begin to be forged.

Any new association will also need to be registered officially with the relevant in-country NGO Board and an effective good governance structure implemented that ensures accountability and the association’s efficient operation.

3.2 Organisational development for palliative care institutions

Organisational Development (OD) can be defined as planned efforts or activities implemented to improve the management of an organisation. OD can be used to address the culture of the organisation, its organisational climate, employee commitment, internal conflicts, and to develop or change management.

More specifically, OD covers the following areas within an organisation:

- Governance (i.e. the role of the Board and Chief Executive Officer or Director and the interaction between the two levels)
- Organisational structures
- Internal monitoring systems
- Impact evaluations (i.e. the process of demonstrating that what you do works and finding out what does not work for future learning)
- Decision-making processes
- Finance systems
- Administrative systems
- Staff participation and information sharing
- Assessing organisational capacity
- Strategic planning, setting priorities and work planning
- Mobilising resources
- Sustainability
- Recruitment, training and retaining volunteers, and
- Human resources management.

OD interventions are used to improve performance within the organisation and ensure that it is sustained. Examples of OD interventions that can be used in palliative care institutions include:

- Diagnostic activities: These help determine the current status of the organisation or problem.
- Strategic planning activities: This focuses on vision, mission, values, internal and external scan, and the development of action plans.
- Leadership development: This focuses on the identification of leaders and developing the skills of future leaders.
- Intergroup activities: This focuses on improving the effectiveness of independent groups working together (e.g. clinical and management teams).
- Team building activities: This focuses on improving the interaction and functioning of the team.
- Education, training and development activities: This focuses on staff development and knowledge and skills development or transfer (Meyer & Botha, 2000).

While it is impossible to cover all aspects of OD in this manual, there are a number of key areas that need to be addressed before an organisation can function properly: in particular, strategic planning; and management and governance.
3.3 Strategic planning for national associations

A strategic plan shows the direction and ultimate destination an organisation is following and heading towards over a given period of time, how it plans to get there, and how it will monitor and evaluate whether it has reached that destination or not. A strategic plan focuses on the entire organisation, helping to define its purpose, establish realistic goals and objectives that are consistent with the organisation's mission statement and its capacity to implement. It communicates these multiple aspects to the organisation's key stakeholders and helps to focus on priority areas.

It is useful to develop a strategic plan at key points within the life of an organisation – for example, when an organisation is getting started, in preparation for a new major work venture, or at the end of a previous plan. However, the full strategic planning process should be conducted at least once every three years.

The development of a strategic plan normally starts with developing a vision or a mission statement, identifying the right team and agreeing the goals you want to achieve within a set period of time. Importantly, it also involves taking stock – is there a need for what you want to do? Is there funding to do it, etc.? A useful exercise to conduct in this respect is a SWOT analysis of the organisation before deciding what one wants to do (i.e. looking at the Strengths, Weaknesses, Opportunities and Threats).

It is strategically and politically helpful to involve all staff and board members in this process, notwithstanding that fact that people will be involved at different levels, as this helps to ensure co-ownership of the completed plan. Sometimes it can be helpful to have someone from outside the organisation facilitate the process, particularly if there are diverse ideas across the key stakeholders, your organisation lacks the necessary facilitation skills, no-one is willing to lead the process, or you need an objective voice pursuing the desired goal and not one with vested interests.

Moreover, someone facilitating the process from within the organisation can sometimes inhibit participation from others or mean that they do not have the opportunity to fully participate in the process themselves.

3.4 Management and governance

3.4.1 Management

In order for an organisation to function effectively, it is critical that there is an excellent working relationship between its management and governance. Management is the process of achieving the organisation's goals and objectives through and with others. The generic management functions (i.e. planning, leading and directing, organising, controlling, and financing) are prerequisites for successful management. Management has the highest level of responsibility in the organisation and therefore must play the following roles:

- Mentoring and coaching
- Developing (skills and the organisation)
- Motivating and facilitating
- Team playing and team building
- Managing change and resolving conflict.

3.4.2 Governance

Governance can be defined as the system by which organisations are directed or controlled. Governance has a five-part role that includes (Forum of Chairmen of Independent Hospices and Help the Hospices, 2005):

- Developing the strategy of the organisation
- Approval of policies
- Monitoring of organisational performance
- Ensuring compliance and accountability
- Assessing the performance of governance and senior executives
3.5 Financial policies

The area of finance and budgetary accountability is very important within national associations. Consequently, it is important that there are clear and rigorous financial policies in place that ensure transparency and accountability. These financial policies should cover the following areas:

- Purchasing
- Disbursements
- Petty cash
- Sundry receipts
- Travel
- Fixed assets
- Capturing of finance data
- Maintenance of records and confidentiality
- Staff payments and contracts
- Tax returns
- Audited financial statements

SUMMARY MESSAGES

- It is important to involve all stakeholders from the outset when setting up a national palliative care association.

- A strategic plan shows the direction and ultimate destination an organisation is following and heading towards.

- Organisational development is planned efforts or activities implemented to improve the management of an organisation.

- Organisational development interventions are used to improved performance within the organisation and ensure that it is sustained.

- There needs to be a good working relationship between an organisation’s management and governance.

- Financial and budgetary accountability is essential within organisations.

3.6 References


3.7 Resources


Web based


Business Plan Software www.planware.org/strategy.htm?source=trpanel

International HIV/AIDS Alliance www.aidsalliance.org

Help the Hospices www.helpthehospices.org.uk

INTRAC - International NGO Training and Research Centre

3. Organisational Development

Praxis Paper 6
www.intrac.org/pages/PraxisPaper6.html

Praxis Paper 7
www.intrac.org/pages/PraxisPaper7.html

NGO Manager E-Library – www.ngomanager.org
NGO Manager web site provides a selection of the best management tools and key articles available on the internet free of charge. The NGO Manager E-Library currently contains links to more than 300 commented tools and articles. NGO Manager helps managers of NGOs to find practical solutions to the following challenges:

- How to develop an organisational strategy, aims and objectives
- How to create, promote and manage projects successfully
- How to obtain funding and to use funds properly
- How to manage human resources well
- How to communicate an organisation’s aims internally and externally and how to plan and carry out a marketing strategy

Organisational Development Network
www.odnet.org
4. Standards of Care

Fatia Kiyange

4.1 What are palliative care standards?

Standards are:

- Statements that set out core functions that are achievable and measurable
- A guide towards best practices
- A quality improvement tool that encourages continuous improvement
- Indicative of a pre-agreed level of quality service provision
- Answers that help us have a common understanding of the work in question.

Palliative care standards can therefore be described as a set of criteria developed to ensure that palliative care services meet the minimum service requirements based on the World Health Organisation (WHO) definition of palliative care. In particular, any potential palliative care service should ensure a comprehensive holistic service attending to physical, psychosocial, emotional and spiritual symptoms within the cultural context of patients and their families.

4.2 Why palliative care standards?

There are a number of responses to this question. First, palliative care standards should aim to improve the care provided to all patients with life-threatening illnesses, including very vulnerable patients like children and the poor. Palliative care is currently, however, defined and understood differently in different settings, rendering it difficult to establish what those standards should be comprised of. Consequently, there is a need for a unified understanding of what minimum care standards African palliative care services should be expected to attain, as well as determining more demanding care standards.

Second, confusion over what exactly constitutes a palliative care service is compounded by substantial variation in the quality of services provided both within and between African countries. Evidence-based care standards can acknowledge this variation and establish levels of care that can be expected as a service progresses from a more rudimentary service on the path to one of being a potential centre of excellence. Moreover, standards will help to ensure that the quality of palliative care service being provided is maintained as services try to extend their operational coverage to address the unmet need for care.

Third, care standards can help inform the quality assurance audit cycle, guiding the evaluation of existing and emerging palliative care services in Africa. Establishing achievable care standards will help the process of continuous service quality improvement by determining those areas of existing service provision where problems potentially exist that require remedial attention.

Lastly, it is equally important that patients and families are made aware of what quality of care they can expect, and should demand, as service users, and that staff know what they are expected to provide.

4.3 Who are the beneficiaries of palliative care standards?

The ultimate beneficiaries of palliative care standards, in terms of the improved care they receive, are individual patients and their families. Any potential palliative care service is also a beneficiary of palliative care standards. These include, among others:

- National palliative care associations
- Palliative care providers
- Home- and community-based care programmes
- Governments and public health facilities
- Financers of palliative care
- All services seeking to integrate palliative care into existing health care services

4.4 How should palliative care standards be developed?

The development of palliative care standards requires the following:

- Wide participation of palliative care organisations and international palliative care stakeholders. This ensures that the resulting care standards are representative of the experiences of all key players, including organisations and individuals, and are interdisciplinary to ensure they are holistic in nature.
4. Standards of Care

- Drawing experiences from existing national, regional and international palliative care standards and guidelines.

- Development of minimum standards requirements for quality palliative care services but also the grading of levels of care standards to ensure that services can aspire to achieve maximum standards and can continue to improve services along pre-determined levels.

- Standards are adapted to the different countries and settings without compromising the quality of palliative care services.

- Standards are developed within the international framework for palliative care, as well as national health care frameworks.

- Standards need to be piloted, validated, implemented, monitored and evaluated.

- Users of palliative care standards need to be trained on the implementation of standards and invited to provide continuous feedback as part of the ongoing review of standards.

- Standards are regularly reviewed and based on current evidence of palliative care practice.

4.5 What is the status of palliative care standards in Africa?

The development and implementation of palliative care standards in Africa is a relatively new concept. Indeed, to date the Republic of South Africa is the only country that has approved palliative care standards. APCA is currently engaged in developing tiered care standards for palliative care services based in the continent.

4.6 How should standards be integrated into palliative care service provision?

National palliative care associations should coordinate service provision among all service providers and ensure that established standards are met. This process will involve training and mentoring stakeholders in the use of these care standards. Where they already exist, national policies on palliative care should require that service providers meet the minimum standards of care. Standards are also a resource for palliative care training, for service development and for the development of standardised data collection tools to be used by palliative care services. They are an integral part of the quality improvement cycle and clinical audit.

4.7 How can adherence to palliative care standards be monitored?

Adherence to established palliative care standards should ideally be monitored through the national palliative care associations. In some countries this may take the form of a sophisticated accreditation process (e.g. in the Republic of South Africa); however, in the majority of African countries this scenario is not achievable in the near future. Consequently, individual service provider organisations can undertake self-evaluation through, for example, quality improvement and audit exercises, thereby monitoring and evaluating their own services and ensuring that they are maintaining agreed quality standards of care.

4.8 What is the role of mentorship in promoting standards?

Mentorship has a key role in promoting and maintaining standards. First, best practices and lessons learnt can be shared and organisations helped to improve services where appropriate. Second, the mentoring partnership can help build confidence in the quality of service provision and implementation of care standards, thus leading eventually to the emergence of centres of excellence. Third, mentoring organisations can offer ongoing training in the implementation and monitoring of palliative care standards.
SUMMARY MESSAGES

- Palliative care standards are a set of criteria that have been developed to ensure that palliative care services meet the minimum service requirements based on the WHO definition of palliative care.

- Palliative care standards should help improve care provided, establish levels of care that can be expected in services, inform the quality assurance audit cycle, and inform patients and their families what they can expect from palliative care services.

- All palliative care services can benefit from standards.

Palliative care standards exist in some countries within the region and APCA is reviewing existing standards and developing generic palliative care standards for the region.

National palliative care associations have a role to play in ensuring that established standards are met.

Mentorship has a key role in promoting and maintaining standards.

4.9 Resources

Standards of care have been developed in many countries for palliative care, many of which can be accessed on the internet. The following is a list of international standards and guidelines for practice that have been identified through the National Hospice and Palliative Care Organisation in the United States of America.

<table>
<thead>
<tr>
<th>Country</th>
<th>Organisation</th>
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<td>Australia</td>
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<td>Canada</td>
<td>Canadian Hospice Palliative Care Association&lt;br&gt;&lt;i&gt;Languages: English, French&lt;/i&gt;</td>
<td><a href="http://www.chpca.net/marketplace/norms_toolkit/norms_toolkit.htm">www.chpca.net/marketplace/norms_toolkit/norms_toolkit.htm</a></td>
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<tr>
<td>Germany</td>
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<td><a href="http://www.hospat.org/english/objectives.html">www.hospat.org/english/objectives.html</a></td>
</tr>
<tr>
<td>Moldova</td>
<td>Gerontological Association Second Breath</td>
<td>Contact: Mrs. Irina Baiclaus&lt;br&gt;<a href="mailto:secondbr@beltsy.md">secondbr@beltsy.md</a> (email address)</td>
</tr>
</tbody>
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### 4. Standards of Care

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<td>Poland</td>
<td>Eastern and Central Europe Palliative Care Task Force</td>
<td><a href="http://www.oncology.am.poznan.pl/cept/emen">www.oncology.am.poznan.pl/cept/emen</a> u.php</td>
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<td>Scottish Partnership for Palliative Care</td>
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<td><a href="http://www.singaporehospice.org.sg">www.singaporehospice.org.sg</a></td>
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<td>Hospice and Palliative Care Association of South Africa</td>
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<td>Switzerland</td>
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<tr>
<td>United Kingdom</td>
<td>Help the Hospices, UK</td>
<td><a href="http://www.helpthehospices.org.uk/working/index.asp?submenu=3">www.helpthehospices.org.uk/working/index.asp?submenu=3</a></td>
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<tr>
<td>United States of America</td>
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<td>Wales</td>
<td>Cancer Services Coordinating Group</td>
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**Language**:
- Dutch
- English
- Polish
- Romanian
- Hungarian
- Swedish
- French
- German
- Italian
- Mandarin
- Spanish
5. Advocacy & Policy Influencing

Dr Henry Ddungu

5.1 What is advocacy?

Advocacy for palliative care may be defined as a process that seeks to influence policy makers through information and communication strategies to design, adopt, implement or change policies and practices to ensure the availability of effective palliative care for all in need. These changes could be geared towards public policy, personal behaviour and attitudes, political and public debate, or legislation.

As well as being associated with legislative change, advocacy can be used equally successfully in other areas (e.g. funding). Advocacy can result in money being redirected into budgets for palliative care or being derived from new sources. Advocacy work with donors can raise awareness of palliative care to increase donor support.

Advocacy is a process which takes several steps, including:

- Identifying the problem
- Defining your objectives
- Deciding on your target audience
- Drawing up your messages
- Choosing the appropriate tools
- Taking action!
- Monitoring and evaluation

5.2 What advocacy strategies are appropriate for palliative care programmes?

Effective advocacy can achieve increased resources and construct the case for palliative care where it is neither recognised nor exists. For example, it can help lobby for changes in overly restrictive legislation, policies and work practices within countries that hinder, for example, the purchase, production, prescribing and dispensing of morphine.

Advocacy strategies that have proved appropriate for palliative care programmes have included:

- Lobbying – influencing through direct, private communication with decision-makers.

- Campaigning – speaking publicly on an issue with a view to generating a response from the wider public.

- Educating – building understanding of issues to provide a more receptive context for desired changes.

Whatever strategy is taken (and they are not limited to those listed above), the key to successful advocacy is the knowledge, and its effective use, of evidence to legitimate, endorse and reinforce your change agenda.

5.3 What policy priorities in palliative care should be addressed?

Government policy, education and drug availability are the three foundation measures the World Health Organisation (WHO) contends are necessary for the delivery of an effective palliative care service. Therefore, policy priorities in palliative care that should be addressed are those that reflect these measures:

- Palliative care needs to be included in national health policies, as part of the essential health care package.

- Due to the substantial number of people in Africa with palliative care needs, all health workers need to have some level of palliative care knowledge. Consequently, palliative care should be included in the training curricula of medical and nursing schools and be an examinable subject in all health training institutions.

- In many African countries, some palliative care drugs (e.g. opioids) are not readily available to those who need them due to restrictive laws and regulations on their use. Governments need to examine their current drug control policies for the presence of restrictive provisions that may impact upon the effective delivery of pain relief, and take appropriate corrective action, including changing legislation if needed.
5.4 How can policy change in drug availability be achieved?

In 1986 the WHO stated that: ‘In patients with severe pain, morphine ... a strong opioid ... is the drug of choice’ (WHO, 1986). However, in most countries, morphine and other opioids are either not available, are available only in limited and insufficient quantities or locations, or are available but underused. This is partly due to overly restrictive laws and regulations that impede the adequate availability of opioids for medical use. Consequently, both the International Narcotics Control Board (INCB) and the WHO have called on governments to evaluate their health care systems and laws and regulations, and to identify and remove impediments to opioid availability for medical needs.

Once governments have revised those national policies and laws that are hindering the availability of effective pain-relieving medication, then palliative care drugs (especially opioids) can be made readily available. However, the problem should not be seen as simply one of restrictive legislation; there is a simultaneous need to address those additional factors that can impede the use of these drugs (e.g. increasing the number of opioid prescribers, addressing public and health professionals’ misconceptions regarding opioid use), thereby addressing issues of both demand and supply for pain control. There is, therefore, a significant need for sustained and effective lobbying to national governments to ensure that these necessary changes can be implemented.

5.5 Why, when, and who to advocate to?

Whenever changes in policy and practice need to occur, advocacy has a critical role to play. Advocacy is the act of identifying a problem, speaking up about it, thereby drawing attention to the issue, and directing decision-makers towards a more appropriate alternative policy.

Put simply, advocacy for palliative care can occur whenever an opportunity arises. Important opportunities, however, include those meetings that involve key decision-makers in society (e.g. government officials, the clergy, health workers, etc).

However, targeting the advocacy message to those who have both an interest in the message and the ability to lobby on one’s behalf (i.e. those who can champion one’s cause) is also important. This approach not only ensures that the right people hear the message being advocated, but also that finite resources are used more cost effectively.

Lastly, advocacy is often a much more powerful tool if those affected by the problem or issue (e.g. HIV/AIDS) are involved with the advocacy process since they know what they are talking about (i.e. they are the experts by experience). It is also very important that the most appropriate individuals represent your organisation in communicating your advocacy message. In this respect, the person ideally suited to do this should be:

- Someone who understands the issues (i.e. palliative care) very well and who can talk with credibility.
- Someone who understands those individuals being targeted with the advocacy message and who can talk their language (e.g. doctors).

5.6 Which advocacy tools could be used?

The choice of advocacy tools available is substantial and is only limited by the lack of imagination. Moreover, they are not necessarily mutually exclusive; indeed, a combination of tools can be used to raise palliative care awareness or advocate for policy change. These tools can include:

- Mass media (i.e. radio, television, newspapers)
- Leaflets, newsletters, annual reports
- Internet
- Audio-visual materials, photographs
- Exhibitions, national events, receptions
- Face-to-face meetings with decision makers (e.g. breakfast summits)
- Building a coalition with other organisations, institutions and professional groups.

The advantages of building coalitions are: strength in numbers; a united voice; and a united, coordinated approach. Coalitions are also useful if one is campaigning on a contentious issue where one would not want to isolate the organisation and have the message being advocated attacked by critics and diluted or damaged.
SUMMARY MESSAGES

- Advocacy for palliative care is a process that seeks to influence policy makers to design, adopt, implement or change policies and practices to ensure the availability of effective palliative care for all in need.

- Effective advocacy can achieve increased resources and construct the case for palliative care where it is neither recognised nor exists.

- Government policy, education and drug availability are the three foundation measures necessary for the delivery of an effective palliative care service.

- Whenever changes in policy and practice are needed then advocacy has a critical role to play.

- The choice of advocacy tools available is substantial and is only limited by the lack of imagination.

5.7 References


5.8 Resources

Web based

An Advocacy Tool Kit for Hospices and Palliative Care Organisations – Help the Hospices and UK forum for hospice and palliative care worldwide
www.helpthehospices.org.uk/international/advocacy_toolkit.pdf

Tear Fund Advocacy Toolkit
http://tilz.tearfund.org/Publications/ROOTS/Advocacy+toolkit.htm

www.who.int/cancer/publications2/en/
Dr Julia Downing

In order that palliative care can become more accessible within the region, the World Health Organisation’s (WHO) foundation measures for an effective palliative care programme need to be in place (i.e. government policy, drug availability, and education). Therefore, effective education and training programmes in palliative care are vital to the implementation and scaling-up of palliative care services.

6.1 What is the aim of palliative care education and training?

Palliative care education and training aims to equip people working in health care settings with palliative care knowledge and skills in order to provide culturally appropriate, quality palliative care for patients and their families.

6.2 Who should be trained?

Palliative care uses a multi-disciplinary approach to care, relying on every member of that team to play their part. Anyone involved in the care of those living with a life-threatening condition and their families will therefore need some training in palliative care. This will include: health professionals; community health workers; family members; community groups/members; traditional healers; Faith-based organisations; teachers; and orphans and vulnerable children (OVC) organisations, etc.

6.3 What training do different target groups need?

Different members of the team will need different levels of training in palliative care. However, they will need to collaborate and work as a team; therefore, they will need to understand the roles of other team members so they can work together effectively. It is important that the palliative care education and training provided is appropriate to individuals’ needs. Whilst some generic aspects of the training apply to all training groups, others are specific to the level of care being provided. For example, it is important that doctors and nurses receive clinical education and training and are able to prescribe and implement appropriate treatment within the palliative care setting. For others, more basic information may be appropriate.

Training courses will vary according to the team member being trained but will also vary from introductory courses concerning the key concepts of palliative care (i.e. physical, social, emotional and spiritual care and support for patients and families), to specialised courses providing a qualification in palliative care for health care professionals.

Due to the burden of disease in Africa (especially from HIV/AIDS and cancer), it is unlikely that any health care professional will escape from caring for someone with palliative care needs. It is therefore important that education and training in palliative care should be integrated into pre-registration training programmes where possible, as well as in continuing education programmes, so that as many health care professionals can receive training at an introductory level as is possible.

6.4 What are the available training resources?

Whilst palliative care remains a relatively new concept within many African countries, within some countries (e.g. the Republic of South Africa, Zimbabwe, Kenya and Uganda) it has been practised for many years. Therefore, within the continent there are many organisations and facilitators with palliative care knowledge and experience. Many of these organisations have developed culturally appropriate training materials and are able to assist in education and training.

Education programmes can be delivered in a variety of formats (e.g. distance learning or face-to-face programmes). The type of training offered will depend on the resources available, who is to be trained, and the content to be taught. Some wholly distance learning programmes exist, although in reality most distance learning programmes have a face-to-face element embedded within the course, and this is often the most effective way of providing palliative care education and training.

APCA has access to this growing body of resources and can assist organisations to meet the training needs of different target groups.
6.5 How can on-going support be provided for those who have been trained?

Support and mentorship are vital in any palliative care training programme and is aimed at different levels: from that needed by an organisation, to that needed by a community-based health worker. It is important for organisations and health care professionals that are new to the field of palliative care to have on-going support from others who are more experienced. Therefore, organisations may be linked to other organisations, and individuals linked with other individuals.

Education programmes are only the start of the development of palliative care skills and knowledge. It is as these are put into practice that individuals need the support of someone more experienced to ask questions of, receive help from, and to generally receive feedback from on how they are getting on, what the challenges are, and discuss how these can be overcome. APCA has a role to play in the support and mentorship process and can put people and organisations in contact with an individual or an organisation that can offer such support. APCA also sees the importance of follow-up and refresher training programmes and is committed to ensuring these are provided whenever possible.

6.6 How can your knowledge and skills be shared with others?

Sharing what one has learnt with others is an important part of the education and training process, and helps one to reflect on what has been learnt, how one’s practice has changed, and what areas one needs support in. APCA can guide and support organisations and individuals in sharing knowledge and experience and in identifying in-country mentors or mentor organisations to ensure consistent training. APCA also has a database of people within the region who are experienced palliative care practitioners and who are able to teach others. If you feel that you could be one of these people, then please do contact the APCA secretariat (www.apca.co.ug).

SUMMARY MESSAGES

- Effective education and training programmes in palliative care are vital to the implementation and scaling-up of palliative care.
- Palliative care education and training aims to equip people with palliative care knowledge and skills in order to provide culturally appropriate, quality palliative care.
- Anyone involved in the care of people with a life-threatening condition will need some form of training in palliative care.
- Within the region there are many organisations and facilitators with palliative care and training knowledge and experience.
- Mentorship is a vital part of palliative care training.
- Sharing what you have learnt with others is an important part of the education and training process.

6.7 Resources

There are many good education and training resources available within Africa and from other countries. APCA is currently developing a virtual Learning Resource Centre which will eventually enable access to this wide range of available resources.

Information about different training programmes within the region can also be obtained through contacting some of the individual organisations that provide palliative care training in the region, including:

- Hospice Africa Uganda (www.hospiceafrica.or.ug)
- Hospice Palliative Care Association of South Africa (www.hpca.co.za)
- Island Hospice, Zimbabwe (http://site.mweb.co.zw/islandhospice/)
- Mildmay International (www.mildmay.org.uk/)
- Nairobi Hospice Kenya
6. Education and Training

Web based

Palliative care education and training materials from around the world can be found on the internet. Some examples include:

Family Health International training materials, including palliative care. *HIV/AIDS Care and Treatment: A Clinical Course for People Caring for Persons Living with HIV/AIDS* available for download in English and French
www.fhi.org

International Training and Education Centre on HIV (I-TECH). HIV/AIDS Clinical Training Materials Database
www.go2itech.org

The Centre for Palliative Care Education
http://depts.washington.edu/pallcare/

The Centre to Advance Palliative Care – online resources for EPCA (Education in Palliative and End-of-Life Care). Resources are available online but may need to be purchased.
www.capc.org

WHO Integrated Management of Adolescent and Adult Illness (IMAI) modules, including one on palliative care, available for download in English and French
7. Monitoring and Evaluation

Richard A. Powell & Dr Julia Downing

7.1 What is Monitoring and Evaluation?

In an era of demanding donor expectations regarding financial probity, budgetary transparency and the proven impact value of funded work programmes, monitoring and evaluation (M&E) remains one of those aspects of organisational management that is extensively discussed but rarely practised (McCoy et al., 2005).

Often arising from a combination of technically inadequate skills, exacting current staff workloads, and organisational cultural environments within which its potential role and benefits are unknown or unappreciated, M&E is currently under-utilised across Africa. In the context of palliative care on the continent, M&E is in its relatively embryonic stage of development (Downing, Gwyther & Pawinski, in press).

An M&E system, as the phrase suggests, is based around two concepts: monitoring and evaluation. Monitoring is defined as a systematic process of collecting and analysing information to track the efficiency of the organisation in achieving its goals. Monitoring provides regular feedback that helps an organisation track costs, personnel, implementation time, organisational development, and economic and financial results to compare what was planned to the ensuing actual events. In essence, monitoring entails the collection and analysis of information to track what is going on.

Evaluation is defined as a systematic process of collecting and analysing information to assess the effectiveness of the organisation in achieving its goals. Evaluation provides regular feedback that helps an organisation analyse the consequences, outcomes and results of its actions. Evaluation also provides regular feedback that helps organisations assess their relevance, scope and sustainability. In essence, evaluation entails the collection and analysis of information to assess the impact of a work programme by addressing the question of whether or not the programme made a difference (Family Health International, 2004).

Underlying these concepts is the systematic, timely and integrated reporting of operationally useful information at periodic intervals. As we shall see below when discussing M&E as a learning tool, the reporting aspect of the M&E process is pivotal in that it helps organisations inform themselves and others (e.g. partners, donors and other critical stakeholders) on the progress of a programme, as well as the challenges encountered, successes achieved, and lessons learnt from implementing it (McCoy et al., 2005).

7.2 Why do M&E?

Ultimately aimed at improving care for individual patients and their families, the rationale for undertaking M&E is two-fold:

- As a monitoring and reporting mechanism against which the processual aspects of a work programme can be tracked and accounted for, and its impact assessed;
- As an individual and organisational learning or quality improvement tool.

7.2.1 A mechanism for project monitoring and evaluation

This element of an M&E system is intended to:

- Support the management of a work programme to ensure compliance with its strategy, objectives and approach, both in terms of planned activities and financially;
- Improve the programme’s responsiveness, efficiency and effectiveness by providing constant feedback from programme staff and other stakeholders, and;
- Provide the information needed for impact-oriented programme management via the collection, processing and provision of reliable and timely information on the programme’s progress to multiple stakeholders in a format appropriate for their respective needs.
7. Monitoring and Evaluation

7.2.2 A learning or quality improvement tool

All too often, M&E is understood as a burdensome accountability requirement imposed by donors. This view is misconstrued and fails to appreciate the potential educational role that an effective M&E system can perform for an organisation. In particular, central to the success of a work programme is often the creation of a supportive learning environment within which those individuals and partner organisations which are central to its implementation are given opportunities to reflect critically upon and learn from their experiences, both positive and negative. This learning environment can help ensure that improvements are continually made to the implementation of the project, as the programme managers adopt an adaptive style of management, thereby ensuring its ultimate success.

Box 7.1 provides an example, using a hypothetical partnership project, of how this critical reflection processes can be realised in practice.

One of the most important critical reflection events in this example is the quarterly meetings of the partnership network. At these meetings, all stakeholders would be expected to discuss what is perceived to be working, what is not, why problems exist, and what needs to improve. Pivotal to this learning environment will be an acceptance by senior management that mistakes must be seen in a positive light, viewed as providing an opportunity to generate ideas for future programme improvements, and that learning is an ongoing process within the context of adaptive management. Indeed, it is essential that critical reflection on the experiences arising from implementing a work programme is viewed as a process to be encouraged and rewarded.

Consequently, in order to be realised to their maximum potential, these learning opportunities must be:

- Fully participatory, thereby increasing staff motivation, discussing real problems, real needs, and real solutions, and empowering;

- Learning events at which ideas are valued, mistakes and failures are considered important by everyone for learning and not as a source of shame or reason for criticism, and at which key stakeholders involved in project implementation communicate openly and regularly;

- Facilitated by an individual who has the appropriate skills to ensure the success of the learning opportunity: someone who can listen, is patient and respectful, and has a commitment to the goal of the process.
<table>
<thead>
<tr>
<th>CRITICAL REFLECTION EVENT/PROCESS</th>
<th>PURPOSE</th>
<th>PARTICIPANTS</th>
<th>TIMING</th>
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</thead>
<tbody>
<tr>
<td>Participatory review of project strategy</td>
<td>Aimed at updating the situation, revising problems, adjusting the objectives and activities</td>
<td>Lead organisation, partnership network organisations, additional stakeholders, funding agency</td>
<td>One-day workshop</td>
</tr>
<tr>
<td>Assess M&amp;E plan with stakeholders</td>
<td>Assess different information needs, be aware of who is already doing what to avoid duplication, refine the indicators, decide on methods and agree on roles and responsibilities</td>
<td>Lead organisation, partnership network organisations, additional stakeholders, funding agency</td>
<td>Same one-day workshop One day meeting every 4 months</td>
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<tr>
<td>Progress reviews by staff</td>
<td>Discussion of key successes and problems First-hand feedback on what is happening and how the activities are being implemented</td>
<td>Senior staff and local feedback</td>
<td>Monthly basis</td>
</tr>
<tr>
<td>Field feedback Annual project review</td>
<td>Summarise key successes and problems, ideas for changing project activities/outputs and assumptions, review of implications for the project logframe, identification of lessons learnt about project implementation, M&amp;E system adjustment</td>
<td>Field staff and regional staff Representatives from lead organisation, partnership network organisations, additional stakeholders, funding agency, and a facilitator</td>
<td>Once per year</td>
</tr>
</tbody>
</table>
7. Monitoring and Evaluation

7.3 How do you do M&E?
7.3.1 Work plan

There is no definitive way to conduct M&E; however, a highly recommended starting point is the development of an overarching M&E work plan for the intended programme. It is critical that the M&E process is discussed extensively and planned thoroughly before conducting any M&E activities; inadequate planning can waste both valuable time and resources (Whiteley, Ellis & Broomfield, 1996). An M&E work plan needs to be flexible and explicit, clearly showing the steps to be used to monitor a programme’s scheduled activities and assess the progress achieved in attaining its goals and objectives. An organisation must understand and agree upon what needs to be measured and how it will be measured. Crucially, it is important not to collect excessive data, nor data that have minimal meaning or relevance to the programme. An organisation must decide and concentrate on what is appropriate, feasible, relevant and essential (Family Health International, 2004).

7.3.2 M&E Frameworks

A M&E framework is a tool for structuring the monitoring and evaluation process. However, different M&E frameworks exist that can be applied as appropriate, sometimes in conjunction with one another. This section describes five such frameworks:

- Comprehensive M&E framework
- Monitoring, evaluation and reporting (MER) results-based framework
- Participatory M&E framework
- Framework for clinical audit
- Quality improvement framework

7.3.2.1 Comprehensive M&E Framework

Family Health International (2004) describes a comprehensive M&E framework as comprised of four distinct types of M&E (see Box 7.2): formative assessments and research; monitoring; evaluation; and cost effectiveness analysis. Using this all-inclusive framework, it can be demonstrated how a work programme has been conducted and what has resulted from its implementation.

Box 7.2 A Comprehensive M&E Framework

<table>
<thead>
<tr>
<th>TYPES OF MONITORING &amp; EVALUATION</th>
<th>QUESTIONS ADDRESSED BY THE DIFFERENT TYPES OF M&amp;E</th>
</tr>
</thead>
<tbody>
<tr>
<td>Formative assessments and research (concept and design)</td>
<td>Monitoring (monitoring inputs, processes and outputs; assessing service quality)</td>
</tr>
</tbody>
</table>

**Is an intervention needed (e.g. palliative care)?**

- To what extent are planned activities actually realised (e.g. has the palliative care service been set up)?
- How well are the palliative care services provided?
- What does the outcome mean (e.g. what does it mean if pain is not controlled)? Does the programme make a difference?
- Should programme priorities be changed or expanded?
- To what extent should resources be reallocated?

**Who needs the intervention (e.g. people with HIV/AIDS or cancer)? How should the intervention be carried out (e.g. what model of palliative care delivery best suits the need)?**

- What outcomes are observed (e.g. is there better pain control)?
- Should programme priorities be changed or expanded?
- To what extent should resources be reallocated?
7.3.2.2 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. PACT has shown how a results-based MER framework helps to locate a work programme within the wider picture, demonstrating how its results contribute to achieving the highest level and longest-term impact than can be anticipated for an intervention (e.g. increasing access to quality palliative care) (McCoy et al., 2005). As illustrated in Figure 7.3, when using a results-based framework the MER system mirrors the expected programme results at different levels.

Figure 7.3 The Different Levels at which Results are Measured in a Results-Based MER Framework

7.3.2.3 Participatory M&E Framework

Traditional M&E methods entailed using ‘experts’ who measured performance against pre-determined indicators and implementing programme tracking targets at the input and output levels. A participatory M&E framework offers new, more inclusive ways of assessing and learning from change involving all the stakeholders in a participatory manor. It also rethinks the issue of who initiates and undertakes the process and who learns or benefits from the findings (Institute of Development Studies, 1998).

A participatory M&E framework is most effective when used at the community level. For example, when evaluating a community-based palliative care service, such a framework can help motivate and sustain local involvement and support for the services provided. Box 7.4 shows how participatory M&E compares with the conventional M&E approach.
Participatory M&E is based on four main principles: participation; negotiation; learning; and flexibility (Institute of Development Studies, 1998).

**Participation:** In the palliative care setting this can be problematic; it can be difficult having 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 community level.

**Negotiation:** When trying to involve people, 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, requires specific negotiating skills.

**Learning:** What is learnt through the M&E process constitutes the basis for subsequent improvements in work programmes (e.g. 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.

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**7.3.2.4 A Framework for Clinical Audit**

As illustrated in Figure 7.5, clinical audit is a method of reviewing existing clinical practice against agreed standards of care to identify areas for improvement in the quality of care provided. As Wright and Hill observed (2003), 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.’ Clinical audit provides a framework within which health care providers can analyse what is presently being undertaken in terms of the clinical care offered, learning from it, and subsequently changing work practices. As palliative care services develop across the African continent, clinical audit is an effective means by which the quality of care of those services can be periodically reviewed and improved as part of the ongoing process of continuous quality service improvement.
Clinical audit has exerted a significant impact on the development of palliative care in Europe, Canada and Australia, including the development of work programmes and the provision of outcome information that has enabled senior managers to demonstrate clinical effectiveness and advocate more effectively for increased funding. Within Africa, where the excessive burden of disease is compounded by a relative scarcity of health care professionals trained in palliative care, clinical audit tools used elsewhere need to be adapted to ensure they are simple to understand, brief to administer and culturally valid (Higginson & Bruera, 2002; World Health Organisation, 2004). This must be supplemented by the establishment of agreed standards of care against which the audit of clinical practices can be assessed. The African Palliative Care Association (APCA) is currently developing both a simple and brief multidimensional outcome measure for palliative care using patient-level indicators – the APCA African Palliative Care Outcome Scale (POS) (Aspinal et al., 2002) – and, with funding from the Elton John AIDS Foundation (www.ejaf.org), quality standards of care for palliative care services.

7.3.2.5 Quality Improvement Cycle Framework

The quality improvement cycle provides a simple means of ongoing monitoring and evaluation (see Figure 7.6). A generic process that can be adopted for any activity requiring 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 work programme ensures both ongoing M&E and that future action is founded upon empirical data collected via the evaluations.
7.3.3 M&E Tools

There are two useful, if not necessarily essential, tools to conducting comprehensive M&E: a logistical framework and relevant indicators.

7.3.3.1 Logistical Framework

The Logical Framework (often referred to as the 'LogFrame Matrix') is a participatory planning, appraisal, monitoring and evaluation tool commonly used in results-based programme management which shows the logical sequence of cause-effect relationships among four levels of aims, of which three (i.e. goals, outcome, and outputs) are themselves results. Used as a tool for concisely summarising a programme's key features to help programme designers and stakeholders, the matrix is also a tool for monitoring the delivery of outputs and activities and also for evaluating the impact of the programme's outputs (i.e. progress in achieving purpose and goal). The matrix is most effective when it incorporates the full range of views of the programme's intended beneficiaries and others with a vested interest in the programme design.
Vertical Logic

**Goal**

This is usually described in terms of improvements in the quality of life of people towards which the programme will contribute but against which it is not held accountable. This is the macro social picture within which the programme is ultimately embedded. For example, the programme goal may be that of improving the quality of life of the population of Zambia.

**Outcome**

This is determined by asking the question 'How will this goal be achieved?' and is described in terms of use, attitudinal and/or socio-cultural changes and political commitment. It reflects the short- to medium-term results to which a programme will contribute. For example, improving the legislative environment to address the absence of effective pain-relieving medication for the public would be one of the outcomes from an advocacy programme. The end-of-programme evaluation should determine the progress made in achieving these results.

**Outputs**

These are the deliverables through which the outcomes will be achieved. They are time-bound and hence the stakeholders held accountable for their delivery by the end of the programme.

**Activities**

Though these are the principal elements of work programmes through which outputs are achieved, the matrix should not include every single planned activity that is to be undertaken. Instead the emphasis should be on clusters of key activities, rather than individual activities.

Underpinning the LogFrame Matrix is the 'means-and-end' logic; that is, if we produce certain results under certain conditions, then we can anticipate achieving certain outcomes.

Horizontal logic

A programme’s aims are measured by indicators through information collected and presented in a specified means of verification (the different types of possible indicators are discussed below). Objectively verifiable indicators (OVIs) are comprised of time-bound quantitative and qualitative measures that provide evidence of the extent to which the aims have been met at the four levels of the hierarchy. The OVIs can:

- Indicate how to realise success at each level of aim
- Assist in the refinement and clarification of aims
- Facilitate monitoring and the adoption of remedial actions where required
- Facilitate end-of-programme evaluation to determine the delivery of outputs and the progress made in achieving the goal and outcomes.

**Means of verification:** This entails determining how one secures the evidence needed to verify the OVIs. Such sources of data could include:

- Administrative records
- Finance statistics
- Supervisors’ inspections
- Media records
- NGO reports
- Plan documents
- Programme monitoring statistics
- Records
- Survey
- Training records

**Assumptions and Risks:** The final aspect of the LogFrame Matrix, these are external conditions that may be outside the control of the programme. The achievement of a programme’s aims depends on whether or not assumptions hold true and the anticipated risks do not materialise. For instance, a change in a government’s policy may adversely impact upon achieving the programme’s objectives. A focussed analysis of the validity of the assumptions underpinning a planned work programme, and the nature and extent of the potential risks that could jeopardise its success (and the possible means by which those identified risks could be minimised), will be time well invested. This analysis should ideally be conducted with the various programme stakeholders.
who may either offer different perspectives on what is planned, or who may be aware of critical information about the context within which the programme is planned.

7.3.3.2 Indicators

Most programmes have ‘indicators’ which either the programme designers or its donors have identified as needing to be measured. A unit of information which is measured over time so that change can be documented, an indicator provides evidence of the achievement (or not) of results and activities (e.g. whether palliative care training has made a difference to the care given). Box 7.8 outlines examples of possible palliative care indicators, how data could be collected and how often.

Box 7.8 Sample Palliative Care Indicators

<table>
<thead>
<tr>
<th>Inputs</th>
<th>Method of data collection</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indicator</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of health professionals trained in palliative care</td>
<td>Training records</td>
<td>6 monthly</td>
</tr>
<tr>
<td>Number of patients seen at home</td>
<td>Health care records</td>
<td>Monthly</td>
</tr>
<tr>
<td>Number of patients seen as inpatients in a palliative care unit</td>
<td>Palliative care unit records</td>
<td>Monthly</td>
</tr>
<tr>
<td>Availability of resources (e.g. guidelines, medications)</td>
<td>Audit tool / on-site inspections</td>
<td>Baseline / every 2-3 months</td>
</tr>
<tr>
<td>Record review</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Outputs</th>
<th>Method of data collection</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indicator</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of accredited palliative care units</td>
<td>Palliative care association records (Health service records)</td>
<td>Annually</td>
</tr>
<tr>
<td>Quality of palliative care</td>
<td>Client and family questionnaires</td>
<td>Every 2-3 years</td>
</tr>
</tbody>
</table>

As mentioned earlier, indicators are not needed to measure every aspect of a programme; rather, they should reflect those issues considered most important for M&E. The required data for indicators can be measured using both quantitative and qualitative data collection methods.

7.3.3.2.1 Quantitative Data

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

Source: Adapted from McCoy et al. (2005)
7.3.3.2.2 Qualitative Data

Seeking to determine how well the elements of a work programme are being implemented, these can provide evidence of changes in behaviour or attitude (e.g. how well palliative care is being provided in the community) (Family Health International, 2004).

Importantly, it is often necessary to collect both quantitative and qualitative data in order to acquire a greater insight into a work programme’s complete picture. Palliative care organisations, especially those that are less resourced or are still developing ones, must consider whether they have both the knowledge and skills necessary to collect and analyse these different data types.

Box 7.8 Examples of quantitative and qualitative data

**QUALITATIVE OR QUANTITATIVE?**

**QUANTITATIVE**
- Considers ‘how many?’
- Provides generalisable results
- Open to statistical analysis
- Systematic / predetermined approach
- Sometimes seen as ‘scientific’
- Provides a snapshot, or longitudinal information

**QUALITATIVE**
- ‘Softer’ approach
- Looks at perceptions and experience
- Looks at ‘why and how’
- Is an adaptable approach according to what you find
- Seeks patterns of responses
- Useful for sensitive topics


Potential methods for collecting this quantitative and qualitative M&E data include:

- Structured or semi-structured questionnaires
- Structured or semi-structured interviews
- In-depth discussion and focus group discussions
- Review of documents and existing data sets
- Logs or diaries
- Observation
- ‘Off the shelf’ audit packages
- Satisfaction surveys
- Review of documents and complaints

(Whiteley, Ellis & Broomfield, 1996)

**SUMMARY MESSAGES**

- Monitoring is a systematic process of collecting and analysing information to track the efficiency of the organisation in achieving its goals.
- Evaluation is a systematic process of collecting and analysing information to assess the effectiveness of the organisation in achieving its goals.
- M&E is an organisational learning tool and aids in tracking the work of an organisation.
- Various M&E frameworks exist and can be adapted for use by your organisation.
- APCA can offer mentorship with regards to M&E activities.
7.4 References


7.5 Resources

**Web based**

A training programme on monitoring HIV/AIDS programmes is available for download at the Family Health International website: www.fhi.org


Improving HIV Care: A Modular Quality Improvement Curriculum: Developed by the Institute for Healthcare Improvement through funding from the Health Resources and Services Administration, HIV/AIDS Bureau. Available at: www.ihi.org/IHI/Topics/HIVAIDS/. Accessed 8/05.


For more information on quality improvement, see materials developed by the US Department of Health and Human Sciences, Health Resources and Services Administration at: http://hab.hrsa.gov/special/qualitycare.htm
8. Fund Raising & Donor Relations

Dr Faith Mwangi-Powell

Fund raising and donor relations are important in ensuring sustainability for palliative care within the region. In this respect, it is important that an organisation is able to raise funds, has good relations with its donors, and reports promptly and efficiently on planned activities undertaken. In raising funds it is helpful to have a strategic plan for the organisation so that one can show donors who you are, what you do, and where you are heading (see Chapter 3).

8.1 Donor-Recipient Relationship

It is important that you have a good donor-recipient relationship. This relationship consists of one partnership but it can be seen from two different perspectives. From the organisational perspective, the partnership will: help generate money; help implement projects; solve problems; and ultimately hopefully make a real difference. There is also the hope that the organisation will grow and succeed.

From the donor's perspective, there is a need to know whether the problem being addressed by the organisation matches its aims and objectives, and whether the organisation is the best suited and equipped to solve the identified problem. They will also want to ensure that the organisation will deliver what it says it will. In this respect, the donor is interested in whether the organisation has a good track record in this area, can manage accountability issues efficiently, can provide value for money, and has effective governance and management structures. Results will also be very important to a donor. They will want to see evidence of a considered plan for monitoring and evaluation (M&E), with measurable programme indicators that can determine the impact of the programme as well as provide regular feedback through rigorous reporting mechanisms, and an indication of how the planned M&E framework will be used as an organisational learning tool (e.g. to document lessons learnt) (see Chapter 7).

8.2 Building Donor Relations

When trying to build and develop donor relations it is important that an organisation does its homework. In particular:

- Get to know potential donors
- Look at what they will or will not fund
- Discover when and how they fund
- Determine who the contact person is
- Communicate and keep communicating with the donor

This information will ensure that one does not spend unnecessary time submitting a funding proposal to a donor who has no interest in funding palliative care. This information can be found in a variety of ways: for example, through the internet (e.g. there is a website called Funders Online – www.fundersonline.org), by word-of-mouth and networking, or through the media. APCA is involved with many international donors and would be able to provide relevant information regarding donors who are interested in funding palliative care.

8.3 Developing a funding proposal

Once you have identified a suitable donor and found out about the process of applying for funds from them, one will need to develop a funding proposal. Each donor has specific guidelines for funding proposals that you will need to follow. However, there are various tasks that you will need to complete for all donors, including writing a professional proposal that is well written, avoids jargon and is concise. All the information required by the donor needs to be submitted and it will need to be submitted in time – if there is a deadline most donors will not even look at a proposal submitted after that time. Moreover, given the sheer number of applications a donor can receive in response to a funding call, any excuse for rejecting a submitted proposal (e.g. the omission of an annual report, financial data, or even the quality of the presentation of the final document) will be used to make the selection process more manageable – so an attention to detail is critical.

Within the proposal, try to convey your enthusiasm for the planned work; however, remember to be realistic – if a donor funds your proposal, you will need to implement it in its entirety!
Some of the principles behind developing a funding proposal include:

- State the problem one seeks to address (i.e. What is your story? Who is the audience? Why is it important? Why you? Why now?).

- How will one address the problem – state this on a step-by-step basis and do not undervalue activities - even if they are small.

- How much can they give and what is your budget? Be transparent and do not try to hide costs. Also, be realistic and prudent: consider the impact of inflation on your budget, along with currency changes and bank charges; and do not forget to include everything (e.g. national insurance contributions for staff, generators, fuel, etc.) that you will need to implement the proposal.

- State clearly how you intend to M&E the programme: include a logframe analysis with SMART objectives (i.e. Specific, Measurable, Achievable, Realistic and Time-bound); and provide clear and measurable indicators for activities.

- Avoid ‘pretty’ sentences and be clear in what you are saying (e.g. ‘We will put the project to test by studying factors that have some opportunity of enhancement of its various facets to lead to a successful working partnership’ – what does this mean? How can it be measured? Instead, use something like, ‘Project evaluation will include a pre- and post-assessment of participants with questionnaires specifically designed to measure their perceptions of the partnership.’)

**8.4 How should donor liaison and reporting work?**

Once you have been awarded a grant from a donor, you will often need to sit down with them and discuss how the process of liaison and reporting works. Each donor will have their own reporting system and requirements, which you will need to follow. Make sure you become aware of these requirements right from the start of the programme so that you do not receive any nasty surprises! It is also usual for donors to identify a particular person within their organisation who will liaise with you directly about the grant – this might be a separate person regarding the technical and financial aspects of the grant, or it could be the same person. It is also helpful for one’s organisation to identify a key liaison person as well, so that both sides are clear on how and to whom they should liaise.

One word of caution regarding reporting: submit your reports – both programmatic and financial – to the donor on time. Late submission of a report can jeopardise future funding opportunities. Moreover, donors often talk to each other and if it becomes known that your organisation does not meet its reporting requirements on time, this could affect funding not only with the one organisation but with other potential donors as well.

If you need help in setting up systems for reporting and M&E, along with writing funding proposals, do contact APCA who will be able to put you in touch with someone who can assist you.

**SUMMARY MESSAGES**

- Fundraising and donor relations are important in ensuring sustainability for palliative care.

- It is important to have a good donor-recipient relationship and this can be strengthened through getting to know your donors well and keeping them informed about activities.

- Attention to detail is required when submitting a funding proposal; it needs to be done in a professional manner and submitted on time.

- Get all reports – programmatic and financial – into the donor on time; late submission can jeopardise future funding opportunities.

- APCA can put you in touch with someone who can mentor you with regards to writing funding proposals and setting up reporting systems.
8.5 Resources

Donors

There are many donors interested in funding palliative care, particularly here in Africa, including:

- PEPFAR (USA/in-country)  
  [http://www.state.gov/s/gac/]
- The Diana Princess of Wales Memorial Fund (UK)  
  [www.theworkcontinues.org]
- Hospice Africa (UK)  
  [http://hospice-africa.merseyside.org/]
- Open Society Institute (USA)  
  [www.soros.org]
- Firelight Foundation (USA)  
  [www.firelightfoundation.org/]
- Comic Relief (UK)  
  [www.comicrelief.com]
- Elton John AIDS Foundation (UK)  
  [www.ejaf.org]
- Help the Hospices (UK)  
  [www.helpthehospices.org.uk]
- Nuffield Foundation (UK)  
  [www.nuffieldfoundation.org]
- DFID (UK/In-Country)  
  [www.dfid.gov.uk/]

Websites

Funders online gives information of different funding agencies  
www.fundersonline.org

NGO Support Toolkit, International AIDS Alliance  
www.aidsalliance.org/ngosupport/resources/253_PME_5_Section_3.doc

World Health Organisation (no date)  
Writing a funding proposal: It is as easy as 123. Geneva:  
World Health Organisation  
http://whqlibdoc.who.int/hq/1985-86/WHO_HMD_NUR_86.2.pdf
Appendix 1: List of contributors

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Richard A. Powell, M&E and Research Consultant for APCA
Andre Wagner, Organisational Development Consultant for APCA

Appendix 2: Steps in Strategic Planning

STEP ONE
Develop or review the organisations:
- Mission
- Vision
- Values and Ethics

STEP TWO
Conduct an external scan taking into consideration:
- Regulations which can impact on activities
- Donors (ascertain what the priorities are)
- Public image (what donors, stakeholders and community think of us)
- Government policies

STEP THREE
Conduct an internal scan taking into consideration:
- Technology (available or needed)
- Human Resources
- Facilities
- Board self-assessment
- Ability to differentiate

STEP FOUR
Conduct a SWOT analysis, brainstorming:
- Strengths
- Opportunities
- Weaknesses
- Threats

STEP FIVE
Using SWOT analysis, identify priorities and:
- Identify strategic opportunities
- Set goals
- Develop action plans – (see Appendix 3)

ACTION PLANS MUST BE:
- Specific
- Measurable
- Achievable
- Realistic
- Time-limited
### Appendix 3: An Example of an Action Plan

<table>
<thead>
<tr>
<th>DEPARTMENT / SECTION:</th>
<th>FINANCIAL YEAR:</th>
</tr>
</thead>
<tbody>
<tr>
<td>GOAL</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>ACTIVITY</th>
<th>WHO</th>
<th>WHEN</th>
<th>OUTCOME / EXPECTED RESULT</th>
<th>COST</th>
<th>RISK</th>
<th>COMMENTS</th>
</tr>
</thead>
</table>


Appendix 4: Format for a Project Proposal

Title Page
- Name of Project
- Prepared by: Named author, organisation and full contact details
- Date

Executive Summary
- One page summary of main points in the proposal
- Should be clear, precise and to the point
- It enables reviewers to grasp the point of the project quickly

Abbreviations List
- List and explain any abbreviations used in alphabetical order

Contents Page
- With page numbers

Introduction
- Short overview of:
  - The idea
  - Overall aim
  - How it arose
  - Your organisation
  - Briefly outline what you will discuss in your proposal

Your Organisation: Organisational Aims and Achievements
- State clearly the aims of your organisation
- Include a 'mission statement' if available
- Organisational background – history and achievements
- Services offered and those being developed

Background to the Proposal
- Discuss your needs assessment: principles and process
- Describe the findings of your needs assessment e.g.:
- Epidemiological profile
- Impact of HIV/AIDS
- Existing health structures
- Views of the people interviewed
- Importantly, this section provide an excellent opportunity to include references

Project Description
- Aims and objectives
- Project area – location, statistics, services, problem identification etc.
- Project Activities (e.g. training)
- Describe the composition of the Project Team
- Include a bar chart of intended activities / timeline (can be included in the Appendix)
- Monitoring and evaluation plan for the project
- An action plan may be included

Rationale
- Why you want to carry out the proposed project (i.e. ‘sell it’ to funders)
- Reasons why you have taken the approach that you have
- Support with references to relevant literature to strengthen your argument

Budget
- Clear presentation of the budget
- Should show all anticipated project expenses
- Need to plan the project in detail to prepare the budget
- A short ‘budget justification’ may be appropriate (e.g. why is it necessary to use two trainers or to buy a motorcycle?)

Appendices
- Include information that is important but cumbersome in the main body of the proposal (e.g. bar charts, reference lists, training curriculum)
- Other items that may be included are:
  - Curriculum vitae of each major project officer
  - Letters of support / endorsement
  - Letters showing financial support from other organisations