

# Developing palliative care

*Key lessons from programmes in Kenya and Malawi*

August 2012

# Executive summary

Palliative Care services for people with life limiting and/or life threatening conditions have been integrated into hospitals in Kenya and Malawi. These programmes suggest ten top tips for hospitals or regional programmes wanting to set up similar services:

- 1 Approach the **senior decision makers** in local areas and at government level to help them understand what palliative care is and that patients can be helped.
- 2 Ask managers to set aside **resources** for palliative care, including enough money to purchase pain relief medications regularly and maybe a motorbike or bicycle for outreach visits. This can improve staff morale, as well as reducing patient suffering.
- 3 Approach traditional leaders and other **community stakeholders** so they are aware of the programme and can pledge support publicly. Local leaders can refer others and can encourage healthcare professionals and managers to prioritise palliative care.
- 4 Include a **pharmacist** on the team helping to set up palliative care. The pharmacist can work with central medicines supply organisations to improve access to pain relief medications because professionals may become disillusioned if medicines are not available. The pharmacist can also run training about prescribing opioids.
- 5 Allocate a **hospital room** that is large enough to be used as a palliative care clinic so palliative care is visible and so a specific palliative care team can be formed.
- 6 Make sure that at least one or two people have palliative care as their **whole job** role, so they do not have to juggle doing other things.
- 7 **Train as many people as possible**, from all cadres of health professionals. Training could be run once each year to provide a refresher and to account for staff turnover. It is important to select people carefully to take part in training. These people need empathy and compassion and have to be able to use what they learn in practice.
- 8 Offer **clinical placements** as an integral part of training, rather than an add on, so professionals can see how palliative care works in practice – and include follow up support to keep professionals and managers motivated, such as regular telephone calls or mentoring visits.
- 9 Run short awareness-raising **orientation sessions** so staff on hospital wards learn about the palliative care clinic and know how to make referrals.
- 10 Set up simple ways to **monitor progress**. Keep evaluation easy and quick, and share successes regularly.

More detailed recommendations for those wishing to develop palliative care in individual hospitals or on a regional or national scale are listed on pages 29 and 30 of this report.

# Contents

<i>Introduction</i>	3
<i>Programme in Kenya</i>	4
<i>Programme in Malawi</i>	7
<i>Successes</i>	10
<i>Essential features</i>	12
Wider context	13
Managing national or regional programmes	17
Supportive activities	22
<i>Development checklist</i>	29

# Introduction

Palliative care involves supporting people who have a life limiting and/or life threatening condition. As outlined by WHO, palliative care:

*“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.”* ([www.who.int/cancer/palliative/definition](http://www.who.int/cancer/palliative/definition))

In 2011, The Diana, Princess of Wales Memorial Fund and The True Colours Trust each provided £300,000 towards the Waterloo Coalition - a time limited initiative to significantly improve access to palliative care in Malawi and Kenya. The other members of the Coalition are the African Palliative Care Association, the Global Access to Pain Relief Initiative, the International Children's Palliative Care Network and the Worldwide Palliative Care Alliance, each of whom provided technical support and expert advice. The Coalition funded the Kenya Hospice and Palliative Care Association (KEHPCA) and the Palliative Care Support Trust in Malawi to help strengthen government health systems to deliver sustainable palliative care.

In Kenya, the government has directed that palliative care is integrated into the 11 large provincial hospitals in the public health system. The Kenya Hospice and Palliative Care Association received a grant of £129,232 to support this objective over a one-year period. Activities include training health workers, mentoring of hospitals and developing national guidelines.

In Malawi, the Palliative Care Support Trust is working to integrate palliative care into district health services in the southern region and to ensure palliative care is included in the budgets of these districts. A grant of £206,360 was made available over an 18 month period. The programmes are both due to complete this phase of their work in December 2012.

In both Kenya and Malawi there have been important changes in how people think about and provide palliative care. This document summarises the lessons learned about what works best based on feedback from more than 60 people in Kenya and more than 100 people in Malawi. Health professionals, managers, patients and members of the programme team in Kenya and Malawi provided feedback during site visits, interviews and group discussions.



# Programme in Kenya

Kenya has a population of about 40 million people. The average life expectancy is about 54 years and there is a high rate of HIV and cancer. Health services are offered through government funded hospitals and health centres, as well as through private hospitals. The government has identified palliative care as a priority and set a national policy requiring provincial hospitals to provide palliative care services.

In a one-year programme, the Kenya Hospice and Palliative Care Association is helping to develop palliative care units at 11 large provincial hospitals. To achieve this goal, KEHPCA:

- ran **five-day training sessions** for about 20 health professionals from each hospital followed by a three-day clinical placement at a local hospice. The aim was for 220 healthcare professionals to be trained across the 11 hospitals;
- provided a **two-hour continuing medical education session** at each of the 11 hospitals to raise awareness about palliative care among about 50 additional staff from each hospital. The aim was to raise awareness amongst 550 staff across the 11 hospitals. Evening sessions were also run with doctors in the regions;
- helped eight independent hospices to offer **mentorship** to the hospitals. Each hospital was partnered with a local hospice. A two day training session was run bringing together staff from hospices and hospitals and hospices were given capacity building grants and travel costs. It was hoped that hospices would conduct at least two mentorship visits to their twinned hospital per year;
- helped hospitals develop their palliative care units by giving **funding to refurbish rooms** and buy computers, providing posters and books and setting up an online forum where professionals could share information;
- helped develop **palliative care guidelines** for hospitals including assessment forms, referral guidelines, morphine reconstitution guidelines, morphine prescription guidelines and data collection forms. These guidelines will be released nationally by government in the second half of 2012.

Box 1 provides an example of how these activities had an impact at one hospital.

### *Box 1: Developing palliative care in Machackos, Kenya*

Machackos is a large hospital in a big town. It serves three large geographical areas with a combined population of more than three million people. The area is relatively barren and dry and there is a great deal of poverty.

#### *Outcomes*

The hospital allocated a building for a palliative care unit with four good sized rooms: a waiting area, a consultation room, an office and a bathroom. In addition to a palliative care co-ordinator, the unit is staffed by a nurse and administrative support. The unit runs an outpatient clinic once weekly and sees adults and children on wards each day, as needed.



*Refurbished building*

The unit is raising awareness about palliative care within the hospital, at other hospitals and at health centres in the region. The palliative care co-ordinator runs lectures at other organisations to encourage them to make referrals. Trainee nurses also visit the unit to ask what the palliative care team does.

KEHPCA has trained 22 doctors, nurses and other professionals about palliative care at this hospital and these professionals are now referring people to the palliative care unit. Those who attended the training say that they have changed the way they support patients.

*"The five-day training was helpful. It changed the way that patients are managed... I feel more confident in my skills and I can be left in charge with patients now."* (health professional)

Pharmacy staff suggest that the training has helped **raise awareness** among clinicians about the value of morphine and that morphine use has increased on wards.

*"Before people were scared to prescribe morphine because of addiction. There is still more work to do but attitudes are changing. Before morphine was just prescribed for cancer but now this has been expanded to support other pain relief."* (pharmacist)

Professionals working on wards say that **patients are suffering less** and dying more peacefully.

*"Things are better now that the palliative care unit has been set up. Patients are suffering less now psychologically."* (health professional)

### *Success factors*

Having a strong champion who put time into developing the service helped this hospital move forward quickly. There was also a focus on **engaging senior management** and getting a wide range of staff involved.

*“There are many different priorities for us and not many resources. Being shown what palliative care is and why this will help make services better is good. We need to know how palliative care can be offered without using a lot more resources and how doing this will help the local people.”* (senior manager)

Having **patients involved in advocating** for the service can be a powerful way of showing managers and health professionals what a difference palliative care and appropriate pain relief can make. Patients spoke at the launch event for the unit.

Another key success factor was **setting up palliative care as a distinct department** in the hospital rather than a small unit within another department. Having the status of a department means that palliative care is represented at management meetings and is also involved in other subcommittees where decisions are made about resources.

*“Being there at management meetings means you are recognised. That means if there is a cake being divided you can fight to have your share.”* (member of the palliative care team)

Acknowledging that there is already a system in place and thinking about how to use it to best advantage is important when integrating palliative care. The focus should be on building on existing structures, rather than inventing something new.

The local team believes that the KEHPCA programme is particularly useful because it does not merely focus on raising awareness using classroom training, but also includes a clinical placement and ongoing mentoring.



*Palliative care team and pharmacist*

*“If other people want to set up palliative care at their hospital, then it is like climbing a staircase. You are going uphill sometimes and there are lots of different steps or things to do. Getting people trained up and having passion is one step. Having practical teaching at a placement is an important step. Having hospital administrators with you is another step. And keep following up to show health professionals on the wards, patients and managers what you are doing and how it is working well.”* (member of the palliative care team)

# Programme in Malawi

Malawi is among the world's least developed countries and has one of the lowest incomes per capita. The health service is free but is particularly overstretched. The number of people requiring palliative care is increasing due to the burden of HIV and cancer.

The largest government referral hospital in Malawi, Queen Elizabeth Central Hospital, began offering palliative care about a decade ago. A team specifically for children has been set up as well as a team for adults. The teams provide palliative care in hospital and, where possible, follow up after people are discharged. But it is difficult to provide good follow up care because people often live far away. Extending palliative care into district hospitals would ensure that people can get the care they need closer to home. Therefore the Palliative Care Support Trust developed the STEP UP programme, led by the children's palliative care service (Umodzi), as a way of expanding palliative care into the districts in the southern region of Malawi. Six districts received the most targeted training and support, and the other seven districts received general advocacy. The six districts most eager and ready to integrate palliative care were selected as a starting point. Thus, over an 18 month period, the programme is:

- visiting the most **senior management** in all 13 districts in the southern region to inform leaders about palliative care and get funding allocated to palliative care;
- providing funds to run **advocacy and other events** in all 13 districts to raise awareness among community leaders, managers, professionals, volunteers and the public;
- providing **five days of training** to 120 professionals. 15 staff were invited from each of six districts and five professionals from each of the other districts were invited;
- offering the opportunity for 48 staff to attend a two week **clinical placement** at the main regional hospital to put their theoretical learning into practice. Six staff from each of the six hospitals and two staff from each of the other hospitals were invited;
- **training 120 volunteers** who provide home-based care spread across the six districts;
- providing funds for six district hospitals to **refurbish rooms** set aside for palliative care;
- offering ongoing **mentoring** and support across six districts.

Box 2 provides an example of how these activities had an impact at one hospital.

## Box 2: Setting up palliative care in Mwanza, Malawi

### Outcomes

Mwanza has a motivated palliative care team led by a hospital dental therapist who can prescribe medication. A small room has been allocated as a palliative care clinic and posters are being put up around the hospital reminding patients and professionals about pain relief. Palliative care protocols have been developed and a referral system has been set up with a form that hospital departments use to make the palliative care team aware of patients who may need help.

*“STEP UP is helping us do things more quickly by joining up and sharing ideas. We have moved from being about 20% along the journey to about 60%, which is a big change in less than a year. There is more to do, but without STEP UP we would still be in the initial stages.”*  
(senior manager)

There is reportedly more **joint working** and sharing of information between teams in the hospital and between the hospital and other services. This has resulted in changing attitudes and knowledge among some members of staff.

*“Now professionals and leaders understand why patients come to hospital for palliative care. Before they thought that people should stay home and just suffer or die. But now we know that something can be done. So there is a gradual change in knowledge that drugs are available and there is help from the hospital – a change in both professionals and patients.”*  
(health professional)

A community advocacy event has been run to **raise public awareness** and community workers’ understanding of what palliative care is and what pain relief is available. This included music and drama, followed by informal talks. Engaging with traditional leaders was essential because these leaders are very influential amongst local communities. If traditional leaders (chiefs) are positive about the concept of palliative care, then they are likely to promote this to community members and help refer people on for care.

The work undertaken by the palliative care team in Mwanza has reportedly resulted in **changed attitudes** among some patients.

*“Through palliative care, people and their families know how to look after themselves better even if they have an incurable condition. They can still live and have less pain and take joy from everyday things.”* (member of the palliative care team)

Palliative care has been inserted into the district’s **local strategic plan** and budget and there is better access to pain relief drugs. The programme has taken steps to ensure greater communication between Central Medical Stores and the district hospital pharmacy. There is reportedly more awareness among doctors and pharmacy staff about what palliative care is, why the drugs are needed and how much is needed.

## Success factors

The way in which the STEP UP programme worked with the district is important. The programme did not seek to mandate changes that should be made, but rather to **work in partnership** and suggest potential ways forward. Ownership and control was placed with the district themselves, rather than being imposed by an external body.

*“The STEP UP programme does not dictate what we should do. They make suggestions.”*  
(senior manager)

Time was spent **engaging with senior leadership**. Having support from senior leaders is seen by the Mwanza team and by the STEP UP team as a key success factor in why this district has progressed so rapidly.

*“For this programme to work the DHO [District Health Officer] needs to be very supportive. It also helps if the DHO and the hospital become members of the Palliative Care Association so they are part of that wider network, always prioritising palliative care.”* (senior manager)

**Clinical placements** at the regional hospital were valued. Key champions from the district have had an opportunity to work in the regional hospital for a two week period and mentoring has been provided. Mentoring is thought to be useful because the regional team visit and observe how things are working ‘on the ground’ and can provide suggestions for ongoing improvement.

This model is now being rolled out to remote health clinics in the district: once each month, someone from the district palliative care team is visiting remote clinics to provide supervision and feedback. An action plan is written up following each visit. This is an example of how the STEP UP model is being transferred and embedded at local level. It is also part of the broader sustainability plan in that the aim is for the district to ultimately extend training in palliative care to as many workers and volunteers as possible, leaving the STEP UP team to focus on providing clinical placements and mentoring.

Having an opportunity to share ideas and improvements with other districts is valued.



# Successes

The programmes in Kenya and Malawi are due to complete their work in December 2012 and an evaluation is underway to show the number of palliative care units set up, the number of people helped, the number of professionals trained and changes in professionals' attitudes and behaviours. Speaking to those running the programmes and leaders, health professionals and patients at local hospitals, it is clear that there have been some major changes already.

**Health professionals say they have learnt a great deal** about supporting people with life limiting and/or life threatening conditions. Before, it was thought that little could be done to help people diagnosed with cancer, HIV or other diseases.

*“Before patients were discharged without being told what was wrong with them. They would come back the same day and wouldn't know what to do with the drugs they were given. Now this has changed. Providing training for palliative care has helped because people can be seen by professionals who know they will not die straight away and they can get ongoing care.”*  
(health professional working in a hospital in Malawi)

Professionals who have been trained know that there is a lot they can do to support people psychologically, socially, spiritually, practically and in terms of pain relief.

*“I have learnt that with symptom management, pharmacological and non pharmacological methods should be tried together. The message is to treat symptoms very aggressively.”* (health professional at a training session in Kenya)

*“Because of the training I recognise that palliative care patients have social and psychological and spiritual and finance needs, not just physical needs. You won't have the capacity to address all these needs so use other services that already exist.”* (health professional working in a district hospital in Malawi)

**The attitudes of senior healthcare managers are also changing.** Palliative care is more of a priority. Rooms are being allocated for palliative care clinics and in some cases funding is being set aside for ongoing training and development.

*“Before I did not know what palliative care was. Now this is one of our successful services. It makes a difference to people’s lives, so they are not in pain.”*

(senior manager from a provincial hospital in Kenya)

**Behaviour has changed.** Previously pain relief such as morphine was used infrequently because professionals may not have known how to prescribe it or may have feared the consequences of addiction or side effects. It was also difficult to get supplies. Now, health professionals and pharmacists are using morphine regularly and better links have been set up to access the drugs.

*“Before there was a fear of prescribing morphine among clinicians. Now this is changing. We have morphine on hand and we know how to use it.”*

(health professional working in a provincial hospital in Kenya)

**Families** are also attending hospitals because they know that help is available. Most importantly, there are changes where it matters most: for people who are unwell and in pain.

*Mrs A lived in a rural area of Kenya. She felt very unwell so her mother took her to the local hospital where Mrs A was diagnosed with advanced cervical cancer and HIV. She had spine metastases and was in great pain. Her family had brought her to hospital to die. Before the palliative care service was running, health professionals said they might have thought there was nothing they could do for Mrs A. But a palliative care unit had recently been set up, and this made all the difference. The palliative care team worked with Mrs A and her family. They gave her morphine for pain relief and taught her mother how to feed and bath her. They put Mrs A in contact with people living close by who could help with practical things. Mrs A was able to be discharged home and spent time with her family. She died shortly after discharge, but Mrs A and her family were happy. She died at home, without pain, in good spirits, surrounded by people who cared for her.*

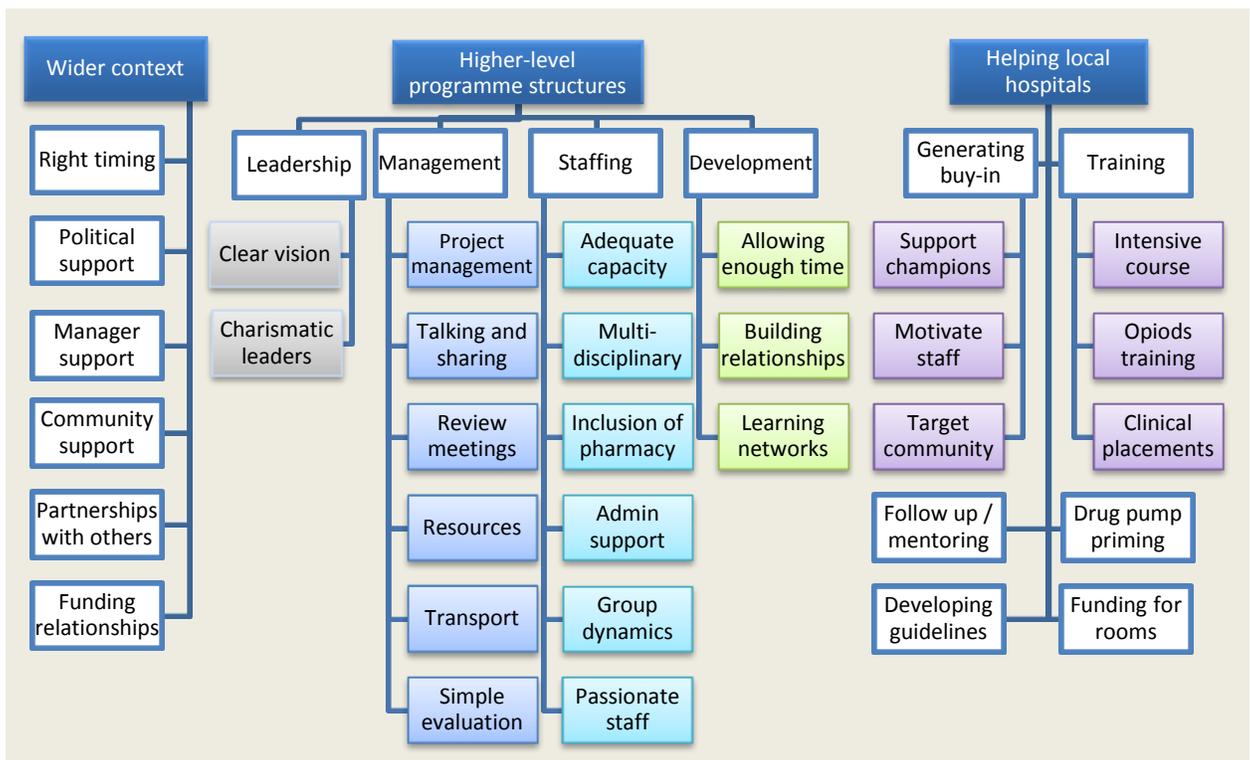
# Essential features

We can learn a lot by looking at what has worked well in Kenya and Malawi. There is no simple recipe that will guarantee success, and every area must adapt things to local needs. But there seem to be several key components to consider when setting up palliative care services:

- the **wider context** that can help or hinder services
- **structural features** of national or regional programmes set up to help develop services
- the type of **activities** used by regional programmes or in individual hospitals

This framework provides a model for integrating palliative care into health systems. The 'programme structures' component is relevant for national or regional programmes set up to help develop palliative care across multiple hospitals. The 'local hospitals' component is relevant to individual hospitals as well as those running regional or national programmes. The 'wider context' component is relevant to both individual hospitals and larger regional programmes.

## *Three essential pillars for palliative care services: context structure and activities*



## The wider context

### *Timing*

The programmes in Kenya and Malawi have achieved a great deal in a short space of time. There are many factors that have helped with this success. However it is also important to note that **the programmes came at an appropriate time**. There was an appetite for building palliative care into public health systems. In both countries the government had recognised this as a priority and had already begun some work in this area. In terms of the ‘innovation curve’, the foundation work had already been done and the programmes were able to move forward quickly. Other areas wishing to follow in the footsteps of Kenya and Malawi would do well to consider the wider social and political context and whether the ‘time is ripe’ for an initiative of this nature. In unsettled times, where there is negative political change or where there is no will to support improved human rights, there may be other priorities than integrating palliative care.

### *Political support*

In Kenya and Malawi there was political support to develop palliative care in public health services. This was not something that was being imposed externally, but something that government leaders themselves were keen to develop further. For instance, in Kenya, a lot of work had already been done with government to create a national policy supporting palliative care. This was helpful in that it meant that all of the provincial hospitals were required to offer palliative care services.

In Malawi, the Ministry of Health included palliative care in policies and instructed district hospitals to implement palliative care as part of home based care and to set up palliative care teams. However, implementation of that directive was different from one hospital to another. The government acknowledge the impact of the STEP UP programme in moving things forward.

*“STEP UP is helping us get things done faster. They are our friend. Instead of doing things slowly ourselves, STEP UP is helping us go quickly... We work together.”* (government official from Malawi)

In short, some level of local, regional or national government support appears useful when developing palliative care in publicly funded health systems. This need not be ‘direct orders’ from government to set up palliative care, but knowing that **government see this as a priority** can motivate hospitals to allocate resources to palliative care and release staff for training.

## *Building partnerships*

Another thing that the programmes in Kenya and Malawi had in common was making good use of partnerships with other organisations.

*“The main advice I would give others wanting to roll out palliative care is to reach out to other organisations. Don’t try to do everything yourself. Do things in partnership with others. Meet with other organisations and work together to make changes.”* (member of the programme team from Malawi)

In Kenya, privately funded hospices were drawn on to work in close partnership with publicly funded hospitals. This had many benefits, including strengthening referral procedures, giving teams a better understanding of what other partners do and tying the new services closely to established organisations, which had often been set up by local communities. This also has benefits for sustainability, with ongoing relationships built between hospices and hospitals.

In Malawi, there were close links with the national Palliative Care Association. Managers and health professionals were encouraged to become members so they could benefit from regular newsletters and networking opportunities. Another example is in the use of community volunteers from non-governmental organisations. Rather than identifying and training a new pool of volunteers, STEP UP worked in partnership to train volunteers from other organisations.

The lesson learned is that **programmes need not try to make changes alone**. There are many resources and potential partners in the broader community, and it is worthwhile making use of these when integrating palliative care.

## *Community support*

In both Kenya and Malawi, effort was made to **engage with community and traditional leaders**. In Malawi this was a formal part of the programme, through community advocacy events. In Kenya this was done on a more ad hoc basis, with individual hospitals and health centres organising their own meetings with community leaders as appropriate. Although the methods used differed, the underpinning concept was the same: it is important to generate as much interest and support from the wider community of leaders and members of the public as possible so a ‘bottom up’ groundswell of demand is created alongside a ‘top down’ mandate from government and managers. These leaders can place pressure on health services to offer good quality palliative care and can raise awareness and make referrals themselves. This helps to solidify the referral pathway between the community and hospital services.

### *Targeting local leaders*

Letting leaders know that there is something that can be done to help even the most unwell people is important, because this is about changing deeply held attitudes and misperceptions.

*“Administrators are normal people, but with many competing priorities. We have to decide what to spend money on and there is not much money to go around. If we are informed about what palliative care is and why it is important, then we are more likely to do something about it.”* (manager at a hospital in Kenya)

Both programmes recognised the **importance of local leadership**, but the way leaders were engaged differed. In Malawi, a systematic process was used to meet with and gain support from health service leaders and other community leaders. The team attended meetings, gave presentations and followed up with personal visits from a local clinical champion. Meeting with groups of leaders face to face worked better than letters, telephone calls or other indirect means of communication. Sharing personal stories or showing how palliative care services may be able to help the brother, mother or son of a leader also helped to gain buy-in.

In Kenya, hospital managers were approached on visits to each hospital and managers were invited to attend awareness-raising sessions alongside other staff if they wished, but overall the approach was more ad hoc.

The more structured approach taken in Malawi may or may not be appropriate for use in other contexts, but it has worked well locally to engage senior managers. Senior leaders in districts have heard about the concept of palliative care and have pledged support. Leaders have bought into the concept and taken ownership of palliative care services. Rooms have been set aside, budgets have been allocated in strategic plans, managers have become members of the national Palliative Care Association and there is a desire to roll out palliative care into community venues.

In contrast, in Kenya although some individual leaders are supportive, palliative care remains just one priority among many for hospital leaders. There seems to be less overt support and ownership from leaders. There are very passionate clinicians and positive changes are being made, but not engaging as explicitly and in as much detail with hospital leaders from the outset may have had an impact. In Kenya the focus was more on engaging with government leaders than hospital leaders.

### *Funding support*

Building **relationships with donor organisations** is important. There was a will in Kenya and Malawi to develop palliative care and this may have moved forward without external funding support, albeit more slowly. However pump priming funding from external agencies has meant that work has progressed at a much faster pace. Without external funding, it is unlikely that there would have been a central team co-ordinating activities and so hospitals would have progressed at their own slower pace, and perhaps using less consistent approaches.

In this case, the Waterloo Coalition has been flexible with the partners, providing additional funding to support transport costs, being understanding when timelines need to be extended and taking a supportive role. Having such a professional and sympathetic donor and taking steps to build strong relationships with funding agencies is important for sustainability. Whilst both the programmes in Kenya and Malawi would ultimately like to see palliative care as self sustaining, in these initial development stages it is likely that continued external funding will be sought to maintain momentum. For this reason, the programme teams say it is important to build trust with funders and to demonstrate at every opportunity that funds are being well spent.

*“There are many competing priorities for funding. When you have a good funder you have to go the extra mile to show them that you are worth their support. You have to show them they can trust you and that you are doing good things – that they are making a difference by giving you money. Having a good relationship like that can be the difference between moving ahead or standing still.”* (member of the programme team from Kenya)

In Malawi there was always an eye on the sustainability of the work, so STEP UP petitioned for districts to include funding for palliative care in their strategic plans. This ensures that districts are not solely dependent upon external donors and helps to demonstrate that a budgetary commitment is being made to palliative care services.

## Managing national or regional programmes

The wider context is an important pillar when setting up palliative care services, but so too is the way in which the implementation process is managed. This section focuses on the characteristics of a national or regional programme being set up to support the development of palliative care. Whilst some of the lessons may be useful to an individual hospital, the main focus is on wider regional programmes aiming to help develop palliative care across a larger number of hospitals.

### *Programme leadership*

It is important to have strong and charismatic leaders running any regional or national programme set up to help develop palliative care. However, in terms of sustainability, it is not useful to rest the success of programmes on individual team members. So whilst individual people were important in Kenya and Malawi, it is perhaps more important to consider the style of leadership used which may be replicated in other areas.

A key part of the programme leadership in Kenya and Malawi involved having a **clear vision** from the outset about what will be achieved and how this will occur – and being able to articulate this simply and forcefully. Programme leaders that have this broader vision and can motivate wider teams to share the vision and move it forward are essential.

Although the programmes targeted stakeholders at many different levels, including government and senior health managers, it was not a ‘top down’ approach in the sense that nothing was imposed by programme leaders. The programmes saw themselves as **partnering with the local areas to create change**. Both programmes drew on a range of partners and worked as a team. Having a positive attitude when barriers emerged was also part of the inclusive leadership approach.

*“It is important to work as a team. You can’t achieve anything in isolation. You have to look at things as a challenge rather than a problem. It will be a long process but we can make real changes.”*

(member of the programme team from Malawi)

### *Good management of national or regional programmes*

A key success factor in Kenya and Malawi was solid project management. In both cases there was a **dedicated project management role** in the team to organise activities, with administrative support. It takes time to organise training sessions for each hospital, clinical placements, training for volunteers and mentoring visits. Having a role dedicated to facilitating these management tasks ensured that the programme activities remained a priority and that hospitals were followed up regularly to ensure progress.

**Good communication** was essential. Regular communication was needed amongst three main groupings:

- within the programme teams and their partners (such as hospices running training in Kenya, or between children's and adults palliative care services in Malawi)
- between the team and hospitals
- between the team and wider stakeholders (such as reporting back to government or funders)

In some cases communication was not as regular as it could have been and this created challenges. But when communication was regular, all partners were happier. Using multiple communication channels to get the message across worked well, such as combining in-person meetings with follow up telephone calls or emails. All of the hospitals have email access, but some staff within hospitals did not have their own email addresses, including some palliative care co-ordinators. A learning point may be to encourage individual staff to set up email addresses and to use this facility more regularly to share information. A short monthly email newsletter outlining programme activities and learning points from other areas could be useful for keeping progress at the forefront of people's minds.

Having **review meetings internally** worked well for some members of the programme team. The key point is to have these regularly enough for all members to feel their views are being heard and so everyone has as much involvement as they wish in the planning process. With larger teams, such as in Malawi where both children's and adult palliative care services are involved, there is a danger that decisions may be made without involving all team members. Having regular internal meetings is a way to alleviate this and avoid any perception of a top down management style.

Having access to **good infrastructural resources** has been important for these programmes. Computers, photocopiers, internet access and office space may all sound like basic requirements, but recognising these resource needs from the outset and allocating a budget, time and space for them was useful. When teams have a good space to work from, then they may feel more motivated and more able to proceed professionally. This was true of the programme teams in Kenya and Malawi, as well as the hospital teams they worked with – where having a room and office furniture allocated for palliative care made a big difference.

Another important factor is the **availability of transport**. Allocating funds for a vehicle and fuel is important in programmes seeking to influence change across a wide geographical area. In Kenya and Malawi multiple visits have been made to locations some distance away from the central team and having ready access to a dedicated vehicle has been useful. Having external support for a vehicle was especially important in Malawi where access to vehicles was very tight and where fuel shortages and price rises had a major impact. This may also be useful for individual hospitals wanting to roll out training to health centres or to do outreach visits for patients.

A final aspect of the management process that has made a difference is evaluation. The Waterloo Coalition worked with an external partner to set up a quantitative evaluation to support the programmes and document successes. The evaluation team did many positive things, such as visiting the programme teams and partner hospitals early on and running workshops to inform people about the evaluation process and what was required. However, there are also some learning points. Rather than concentrating on the most simple way to measure whether the programmes had achieved their objectives, the evaluation required hospitals to complete long questionnaires – and to do so every quarter. These included questions that the hospitals found confusing and as a result people interpreted things differently and provided data of varying quality and quantity. The evaluation process became a burden. This has three negative consequences: it distracts clinicians from offering palliative care because they are spending time collating long records instead; it gives people a negative impression of evaluation so they may feel less inclined to participate fully; and it provides inaccurate data upon which to base decisions about programme success and continuation.

**Good evaluation is essential** because it can help people share the things they have learned, feel proud of their work and support ongoing development in other areas. It can show what works well and what works less well to facilitate real change. A lesson learned is that in future, programmes in resource poor settings should use an evaluation design that does not have a large burden for participants. Short and simple surveys, supplemented by visits to collect qualitative data can work well. Evaluation should be about ‘telling the story’ of programmes rather than merely collecting numbers so a simple evaluation strategy that mixes qualitative and quantitative methods and is very focused would work well.

### *Staffing of national or regional programmes*

Supporting a change in attitudes and behaviours is a major task, especially over a short period of time. This is not something that can be done by just one or two people, and the programme teams were **staffed with a realistic number of professionals** - about three or four people, plus a much wider support network. Having an adequate number of team members and capacity to draw on staff from outside the core team worked well in both countries. The core team was kept relatively small, but staff from hospices in Kenya or from the regional hospital in Malawi were drawn on as needed to help facilitate training or undertake mentoring visits.

Having staff who were passionate about making a difference was useful, including administrative support and drivers. This helped to create a team atmosphere where everyone was focused on the same goals.

In Kenya and Malawi, the programme team was **multi-disciplinary**. There was a mix of doctors and nurses and support staff. In Malawi, it worked particularly well to have a **pharmacist** as part of the core team. As pain relief is such a central issue in palliative care, steps need to be taken to address this thoroughly when integrating palliative care into public health systems. A lesson from these programmes is that merely making morphine or other medications available is not enough. Instead, it is important to train both pharmacy staff and clinicians about ordering and using it. There are real fears about side effects which need to be addressed so that people can weigh up the pros and cons given the potential shortness of time that people have left. In Malawi, this information was imparted by a pharmacist because it was felt that pharmacy technicians and doctors may be more willing to listen to someone who specialised in medicines management. Professionals like to work with and take advice from people from their own profession. The pharmacist could also follow up medication orders made by hospitals to ensure they were actioned promptly at the Central Medical Store and could advocate at a national level for increased access to medications. This role was seen to be central to the rapid uptake of liquid morphine in Malawi.

*“The best part was the drug advocacy officer [pharmacist] because I really get now why ordering those drugs is important and I keep everything well stocked. I can also help the doctors choose what to prescribe and get the right dose. If you only focused on doctors and nurses then maybe the drugs wouldn’t be there when they need them and patients would suffer.”*

(pharmacy technician working in district hospital in Malawi)

### *Development resources*

Allocating resources and time for development is another component of larger regional or national programmes. In both Kenya and Malawi, the task was ambitious – the programmes aimed to support the development of palliative care in just 12 to 18 months. In some areas palliative care services were already operating or the concept was known, but in other areas the programme was beginning from scratch.

Having a short timeframe can be useful because it pushes people to move forward promptly and achieve as much as they can within a limited period. However, really embedding change is not about running as many training events or setting up as many units as possible within the shortest amount of time. Sustainability requires a change in attitudes and behaviours and this can take time.

In Kenya, the government policy meant that hospitals were primed to want to move quickly to set up palliative care units but in Malawi there was no such mandate so a practical approach was taken: the six districts most eager and with most capacity to offer palliative care were selected as the main focus. In other words, those with a real interest were targeted first, with a plan to support those who were less interested or less able as part of a wider roll out. By **working with the most interested people first**, it may be possible to get ‘quick wins’ and to get other hospitals and funders interested in taking part.

Both programmes had an eye on **sustainability from the beginning**. The programmes are of a limited duration, but the teams aimed to build strong partnerships with other organisations that may eventually be able to carry the work forward.

Setting up **learning networks** was also tested. In Kenya, KEHPCA used its conference as a way of sharing learning – with one day before the conference allocated to sessions from this programme. An online forum was also set up for hospitals but this has worked less well than hoped. Although people were enthusiastic about using the internet to share ideas, the forum has not been well used – perhaps due to a lack of time, or lack of structure or familiarity with the use of forums. To facilitate better use of such resources it may help to set aside an hour each month where everyone is invited to log on and share ideas about a particular issue set by the programme team. This would help to get people into the habit of using the forum and would show that people can get useful ideas from others.

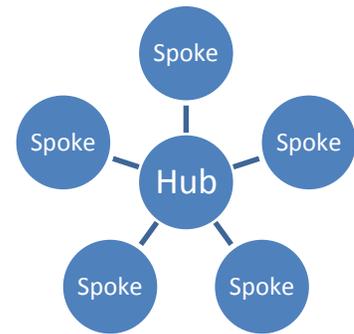
In Malawi, participants were linked with a national organisation that offers conferences and newsletters as a way of sharing learning. Meetings were also set up to bring together all of the palliative care co-ordinators in the region and these were well received. Hospitals liked meeting and learning from others and this appears to have had a useful function in both programmes.

## Supportive activities

The third pillar of developing palliative care in publicly funded health systems involves the specific activities that are used to facilitate change. This is relevant to what an individual hospital may do. It is also relevant to a national or regional programme set up to support change.

### *Multifaceted model*

Hub and spoke models have one team or unit at the centre, with other teams or individuals feeding into or gaining support from the central team. The overall model used in both Kenya and Malawi was a variation of a 'hub and spoke' approach whereby the programme acts as a centralised resource, with local hospitals being developed as satellite centres.



The hub and spoke approach also applied to **how teams were set up within hospitals** – with a palliative care unit (perhaps comprising just one or two people) forming the core and professionals within various hospital departments trained to provide referrals and support. In Malawi the STEP UP team used their work at the main regional hospital as a model to illustrate this approach to the district teams. At the regional hospital, staff from wards were informed about palliative care so they could identify relevant people and refer them to the specialised palliative care team. Referral forms were placed on wards which staff could complete and drop in to the palliative care team. The palliative care team also invited staff members from wards to attend orientation sessions to learn about palliative care and hear success stories. This drove up referrals and meant that professionals felt more comfortable with the concept of palliative care.

This 'hub and spoke' type model was replicated at district level in terms of who was trained and was reinforced when professionals attended clinical placements at the regional hospital.

*“We have trained many members of hospital departments so they can recognise who needs palliative care. The palliative care team itself is small so we can't do everything. We need others to be able to identify people who need palliative care. We tried this approach at our hospital and then showed the districts how to use it at their hospitals too.”* (member of the programme team in Malawi)

The analogy of a hub with many spokes can also be applied to the many methods of training, awareness-raising and gaining buy-in used by the teams in both Kenya and Malawi. Learning from these programmes suggests that **effective activities may include:**

- ensuring that managers and **decision makers** see palliative care as a priority and one that they can do something about (through advocacy)
- **training professionals** to identify people needing palliative care (through awareness-raising sessions)
- training a palliative care team in provinces or districts to undertake a **holistic assessment of the patient's needs**
- being able to **prescribe** appropriate medications (through training for professionals and pharmacy staff)
- ensuring that patients are able to **access** appropriate medications (through providing morphine and training pharmacists how to order it and through national advocacy)
- ensuring that **follow up care is available for patients** (through training home base care volunteers or working with hospice staff)
- ensuring that there is some **follow up to support professionals** providing palliative care (through mentoring and creating networks)

In other words, Kenya and Malawi have taught us that it is not enough to merely train health professionals, it is also important to provide follow up support to those trained and to ensure that the structures and environment are in place to allow palliative care services to develop fully.

*“We cannot just focus on helping people do clinical work in palliative care. You cannot do good clinical work if the structures are not in place. We have to create an environment in which clinical work can flourish.”*

(member of the programme team in Malawi)

## Getting buy-in

Gaining buy-in is about getting a range of partners and professionals to understand and support the concept of palliative care and also to take ownership of the idea themselves.

*“You need to target people’s hearts and minds, not just give facts and figures. You need to make it their own idea, rather than something that comes from outside. You need to show what’s in it for me and my people.”*  
(health professional working in a provincial hospital in Kenya)

The programmes in Kenya and Malawi aimed to build up acceptability towards palliative care by:

- working with **national partners** so the programmes were seen as being ‘part of the solution.’ This in turn had favourable effects for how the programmes were viewed locally;
- **targeting senior level managers.** This worked particularly well in Malawi where the programme team gave presentations to leaders at district and hospital level. Local areas identified those who would be influential and stakeholder meetings were used to good effect;
- **triangulating awareness-raising** amongst managers, health professionals and members of the community;
- using a **mix of activities** to raise awareness such as training, advocacy and increasing visibility through setting up rooms and providing resources;
- thinking about **sustainability** from the beginning. In Malawi this was done through building funding into the strategic plans of districts. In Kenya it was done by getting hospices and hospitals to work together and through developing national guidelines in partnership with government.

The key people who need to be involved to ensure success include government partners, senior managers from hospitals, senior managers from other services at regional or district level, traditional leaders and other community leaders, health professionals to act as clinical champions, a wider group of health professionals to act as a support network and make referrals, community volunteers, patients and their families and funding organisations.

Having **managers and clinicians side by side** at awareness-raising events can be helpful for making sure everyone is getting the same message – and so participants see that managers are giving the topic of palliative care priority.

*“Getting all types of professionals together with administrators to hear about palliative care is good. You all hear the same message and you can see that this is something that is important.”* (health professional from a hospital in Kenya)

Using existing meetings to target managers and professionals can be useful. Rather than setting up a special gathering, in Malawi the STEP UP team attended pre-planned meetings of all the senior leaders in a district. This had the advantage of targeting as many relevant people as possible, but also doing it in a cost effective manner and at a time when the leaders had already planned to meet to discuss other things.

Getting **buy-in from the wider community** is also important. Advocacy events have been run which draw together community leaders and members of the public, but the benefits of these are less certain. This is not to say that they are not beneficial, but they were just beginning at the time of writing so the impacts were not clear.

A learning point is that having a mix of internal and external people involved in engaging with leaders and the wider community is useful. External people such as a central programme team bring a sense of status and kudos which can spark leaders’ interest in the topic. But having internal people then lead the charge helps to cement palliative care as a locally owned idea.

### *Supporting local champions*

Developing champions in local hospitals is important. In Kenya and Malawi, in most cases the local champion was a health professional working as a palliative care co-ordinator, but in some parts of Malawi the most senior leadership were also champions and were heavily involved in planning local activities. Having a mix of clinical and managerial leaders from local areas and a central leadership team worked well to approach integration from many angles. The programme team could bring external expertise and resources and the local clinical and managerial team could focus on how these resources might best be integrated into their services.

Having a doctor, dentist or other professional that can prescribe drugs leading the palliative care team may be useful, as may having professionals who carry **senior status** and are able to interact with managers and decision making committees to ensure that palliative care remains highly visible and is allocated funding.

### *Classroom training*

The programmes in Kenya and Malawi have helped changed attitudes and behaviours amongst the managers and professionals that they have worked with most closely. The components of the programmes that seem to have been most successful include providing an intensive level of training (five-days rather than a short course), including training about prescribing and ordering opioids, offering clinical placements so professionals can apply their learning in practice, offering follow up mentoring support and combining these activities with awareness-raising education among the wider hospital team and the wider community.

A key success factor is **not concentrating on just one type of training or support**, but rather taking a broader approach: some professionals are trained in depth to gain an understanding of palliative care and in tandem work is done to create a supportive team environment and physical environment in which they can work.

*“It is good to take part in the course, but you also need other things to help you. The course gives you more knowledge about how to help people with an incurable illness physically and psychologically and spiritually, but you need other things too like a good room to work in and professionals on the wards to make referrals and enough morphine and other drugs so when you prescribe it people can get it easily.”* (health professional from a district hospital in Malawi)

In Kenya, **training about medications** is included in the standard five-day programme. In Malawi, information about opioids is offered in a separate course. On one hand it is useful to have opioids covered in the main training because this means that everyone is more aware of pain relief strategies. On the other hand, having a specific course about opioids means that pharmacy technicians and the clinicians most likely to prescribe can be targeted with this information. This is not an either/or decision and both models have advantages.

Having **clear criteria** regarding who should take part in training is important, especially where attending training may be seen as a perk or have some financial rewards. This is something that could be developed further, with the programmes having more standardised written criteria for the types of people who should attend training. Suggesting that at least one senior manager takes part alongside clinicians would also be beneficial, so that managers have a clearer idea of what the training involves and the implications for providing services and allocating resources.

### *Clinical placements*

Seeing how to offer palliative care in practice is very powerful – perhaps moreso than merely learning the theory and facts about palliative care in classroom training. In Kenya and Malawi, clinical placements were used to help professionals see good quality palliative care offered in day to day routine practice.

Clinical placements were used differently in each country. In Kenya, everyone who takes part in five-day training is expected to undertake a three-day clinical placement at a hospice, however participants decide when this will happen. In Malawi, about one third of people who take part in five-day training are able to undertake a two-week placement at the regional hospital. People who apply are allocated set dates. In Malawi, people are eager to take part in the placements and have found them extremely valuable. The demand outstrips availability.

*“When I attended the clinical placement I was impressed with the way the nurses acted and how they run things there. I got a lot of ideas to bring home and I also thought about how I could improve my skills ... It was inspiring.”*  
(health professional from a district hospital in Malawi)

In contrast, in Kenya people are less keen to complete a clinical placement. They may be concerned about taking an extra three days away from work and some may not see the value of a placement in a hospice rather than a hospital. In Malawi, clinical placements are promoted as an integral part of the support available whereas in Kenya this is seen more as an ‘add on’, with some training participants not aware that this will be a requirement. One model is not necessarily any better than another, and until the evaluation of impacts is available it is difficult to comment about relative benefits. A lesson learned though is that clinical placements may work well when integrated into the training programme from the start and seen as ‘compulsory’ rather than an optional add on.

To have most benefit, **clinical placements need to be well structured and have clear learning outcomes**. It may be useful to have a list of objectives or expectations so that each placement site is offering placements in a similar and structured manner. People from hospitals may want to spend time in a larger hospital for their clinical placements to support their learning and career progression. It may help to get professionals more interested in clinical placements if the benefits for career progression are highlighted and if continuing professional development (CPD) points are tied to their completion, rather than given after attending a classroom course.

### *Ongoing support*

Having follow up contact from trainers and ongoing mentoring may be essential for embedding the material learnt in practice and for keeping morale and motivation high. Health professionals and managers from both Kenya and Malawi said that when external people visit it helps to demonstrate that this is a serious issue and that palliative care is a priority.

**Mentoring** took a while to establish in both countries and different definitions of mentoring were used. In Kenya, the visits tend to be about clinical supervision (observing and pointing out areas for improvement) and in Malawi there is an additional focus on helping to build the structures and environment needed to maintain palliative care in district hospitals.

In Kenya, mentoring is undertaken by hospices which were given short training and some written guidelines prepared by an external agency. In Malawi, mentoring is undertaken by members of the core programme team. Neither programme appears to have focused on the resources or support that mentors themselves might need. Travel costs and basic expenses are provided, but there is perhaps scope for development in the extent to which standardised topics and objectives are covered. It may be worthwhile to think about what mentors need to support their work, such as a written checklist to guide visits.

### *Providing resources*

Having **funds to help refurbish rooms** or provide a computer or desk for local hospitals has been useful in Kenya and Malawi for three reasons. Firstly, it gives the palliative care co-ordinator somewhere to work and see patients – so it has a very practical function. Secondly, it makes palliative care visible within the hospital because specific resources and space has been allocated. Finally, and this cannot be underestimated, it boosts the morale of palliative care teams because they feel that their work is seen as important and is being invested in.

In both countries, some hospitals said that they would have been unlikely to have been allocated a room by senior management if the offer of external funding for refurbishment was not available. Thus, it may be important to think about what small incentives will support managers to move forward with palliative care.

In Kenya, another facet of providing resources has been the development of **national palliative care guidelines**. This was done in partnership with government and other organisations. The guidelines include assessment forms, referral guidelines, morphine constitution guidelines, morphine prescription guidelines and data collection forms. These will be released in the second half of 2012.

# Development checklist

The learning from Malawi and Kenya can be summarised as simple checklists. List 1 contains top tips for individual hospitals and List 2 contains tips for those wanting to set up palliative care on a wider scale, co-ordinated by a regional or national programme.

## *Top tips for individual hospitals*

- Talk to managers** as often as possible so they know why palliative care is important and how it could help improve services, increase staff morale, increase efficiency and reduce suffering among patients and family members.
- Ask managers to **set aside resources** for palliative care, including enough money to purchase pain relief medications regularly and maybe a motorbike for outreach.
- Allocate a **hospital room** that is large enough to be used as a palliative care clinic so palliative care is visible and so a specific palliative care team can be formed.
- Make sure that at least one or two people have palliative care as their **whole job** role, so they don't have to juggle doing other things.
- Set up a **rota of doctors and nurses** to run a drop-in palliative care clinic at least once per week and have staff available to visit wards when a referral comes in.
- Train as many people as possible**, from all cadres of health professionals. Training could be run once each year to provide a refresher and to account for staff turnover. Select people carefully to take part in training. These people need empathy and compassion and have to be able to use what they learn in practice.
- Run short awareness-raising **orientation sessions** so staff on hospital wards learn about the palliative care clinic and know how to make referrals.
- Use a **referral form** so that departments can easily inform the palliative care team when someone needs help and have the team visit wards regularly to check in.
- Reach out to **community organisations** to help with follow up at home. Volunteers from community organisations may be eager to help and get more training.
- Keep in touch with other areas and organisations to **share learning** and get new ideas.

### *Top tips for wider development programmes*

- ☑ Identify a **partner at government level** and contact government leaders regularly to let them know what is happening.
- ☑ Approach the **senior decision makers** in local areas to help them understand what palliative care is and that patients can be helped. Using personal stories can help. Ask senior managers to make a commitment to providing resources and following progress – a signed memorandum of understanding can work well to gain buy-in.
- ☑ Approach traditional leaders and other **community stakeholders** so they are aware of the programme and can pledge support publicly – local leaders can refer others.
- ☑ Petition senior managers to **allocate resources** towards palliative care, such as an appropriate drug budget and space for a palliative care clinic. This will make the changes sustainable for a longer time. Build in a budget for transport because the distances travelled are large.
- ☑ Run **short awareness-raising events** so that a large number of professionals have heard of the concept of palliative care and will be encouraged to make referrals. Train as many professionals as possible about palliative care to account for staff moving on.
- ☑ Run **longer training sessions** for a smaller number of professionals, including training about prescribing opioids. Use selection criteria to help choose which professionals would benefit most from training, including a mix of professions and those with real empathy for palliative care. Include clinical placements as an integral and required part of training.
- ☑ Include a **pharmacist** on the team helping to set up palliative care and work with central medicines supply organisations to improve access to pain relief medications because professionals may become disillusioned if drugs are not available.
- ☑ Include **follow up support** to keep professionals and managers motivated, such as regular telephone calls or mentoring visits.
- ☑ **Monitor progress** to share success stories but keep evaluation quick and simple.