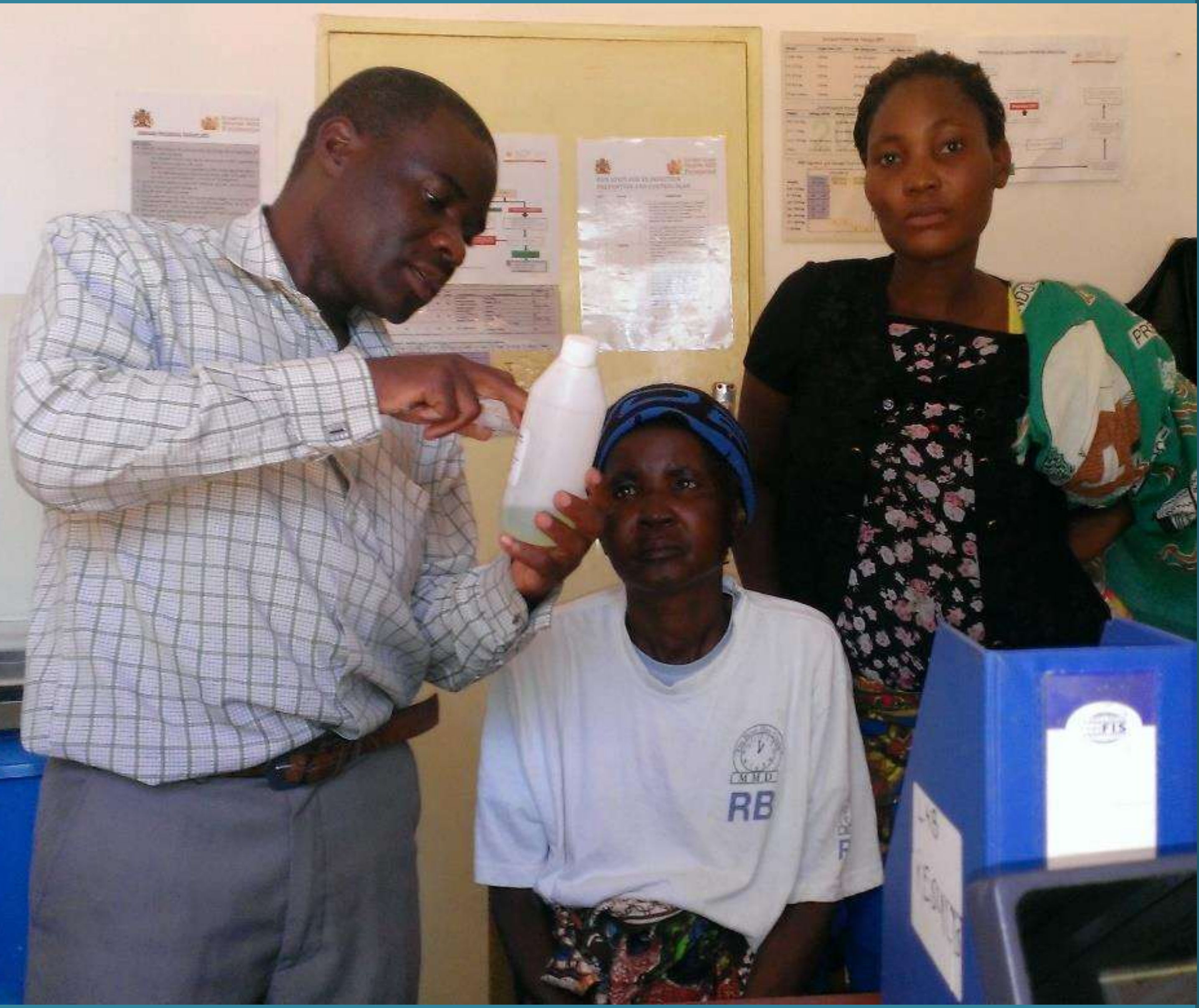
Palliative Care
ASSOCIATION OF MALAWI

# Integrating palliative care in Central and Northern Malawi



August 2015 – June 2017

# Executive Summary

## Palliative care in Malawi

Between August 2015 and June 2017, the Palliative Care Association of Malawi (PACAM) implemented the STEP-UP programme in the Central and Northern regions of Malawi. This followed successful implementation of the programme in the Southern region over the previous four years.

**The STEP-UP programme aims to integrate palliative care into publicly funded health services in Malawi** by raising awareness about, confidence in and access to palliative care services at district level. It involves providing resources to help district hospitals set aside a dedicated room for palliative care clinics; running awareness raising and training sessions for doctors, nurses, clinical officers, pharmacists, social workers, volunteers, religious leaders and others; facilitating clinical placements to help health workers see good palliative care in action; mentoring district hospitals to ensure their palliative care services are of good quality, and supporting districts and the Ministry of Health to collect information about the impacts of palliative care. The programme is funded by the True Colours Trust.

From August 2015, STEP-UP worked in the Central and Northern regions to:

- increase support for palliative care at district **management** level
- increase **knowledge** about palliative care amongst health workers
- improve the quality of palliative care available in **hospitals**
- improve the quality of palliative care available in **communities**

There are nine districts in the Central region and six districts in the Northern region. PACAM worked with 14 out of 15 of these districts over a two year period. The fifteenth district was not included as it is an island in Lake Malawi and logistical reasons prohibit regular visits.

The STEP-UP team comprised a programme manager (clinical officer), nurse and project manager, with other members of the PACAM team contributing to specific activities such mentoring and data collection. Each of the 14 districts allocated a palliative care coordinator to work with the programme.

To examine the impacts of the programme, the team:

- conducted a baseline assessment of all 14 districts
- collected follow-up data from districts during 56 supervision visits
- collected records of service use, medication use and other indicators
- surveyed people during training and mentorship (730 surveys)
- did 131 follow-up interviews with management and frontline teams
- collected case studies and photos

## Increasing management support

To increase support for palliative care at district management level, the PACAM team:

- **visited every district** four times over a two year period, visiting members of the management team on each occasion (one district was visited twice due to management instability)
- provided awareness raising **orientation sessions** for the district management teams in 14 districts (1 informal and 13 formal sessions)

As a result of these activities:

- 100% of management team members interviewed from each district said they were **more aware** of what palliative care is, why it is important and how district services can help
- every district included palliative care in their **District Implementation Plans** (the annual strategy that sets out resource allocation and priorities for the district)
- all districts that had not allocated a **dedicated room** for a palliative care clinic previously did so
- management **allocated staff** for palliative care where this had not already been done. In some cases more senior or experienced staff replaced others as palliative care coordinators because management understood more about the skills and resources needed
- in 2017, 87% of palliative care coordinators said that their **district management teams were more supportive of palliative care** and were allocating more resources (such as staff time and rooms) compared to two years ago

Staff turnover in District Health Management Teams can be high, so awareness raising and advocacy about the importance of appropriately resourcing palliative care is an ongoing activity.

*Photo: District Health Management Team, PACAM and donors in Ntcheu*

## Increasing knowledge amongst hospital workers

To increase knowledge about palliative care for hospital workers, PACAM:

- ran five-day introduction to palliative care **training sessions**, with 40 participants. The training targeted the districts that baseline assessment found to be most lacking in trained providers
- facilitated **26 clinical placements** so people who had attended training could experience palliative care first-hand in a centre of excellence. All clinical placements were held in centres of excellence in the Southern region of Malawi which were set up as part of an earlier phase of the STEP-UP programme
- worked with two sites in the Central and Northern regions regarding becoming clinical placement sites in due course (this work continues)
- ran a **refresher course** in palliative care for those who had undertaken five-day training in previous years. 28 people took part
- ran a course about **palliative care for children** with 28 participants (two from each district)
- ran four palliative care **coordinator meetings**. One of these meetings was focused solely on the Central and Northern region and the rest were open to coordinators from the Southern region as well to help form a national community of practice
- trained 14 palliative care coordinators in the Central and Northern regions in **leadership skills**
- supported five people to undertake a distance learning international **Diploma** in Palliative Care, including one member of the PACAM team
- ran an orientation workshop for 14 **health promotion officers**

As a result of these activities,

- 100% of people attending training said they had **improved knowledge and confidence** about palliative care compared to before training. Average confidence in providing palliative care rose from 2.8 out of 5 before training to 4.8 out of 5 after training
- follow-up interviews found that health workers **put things into practice** after the training, including improving pain relief
- districts reported an increased number of workers now **actively providing** palliative care. Refresher sessions were found to help motivate workers, resulting in some becoming focal people or champions in their districts
- the **number of people accessing palliative care** increased, particularly children which increased from 1,129 in 2014 to 2,828 in 2016. This 150% increase is likely due to raised awareness about palliative care and increased confidence amongst providers to make referrals and to support children with palliative care needs
- there was **improved networking** between sites including sharing during national meetings and posts on PACAM’s social media
- a **strategy for promoting palliative care** in districts was developed

## Improving palliative care in hospitals

To improve access to and the quality of palliative care available in district hospitals, the STEP-UP programme:

- provided **funding** to help buy equipment or furnish rooms to be used as palliative care clinics. Ten out of 14 districts offered funding in the Central and Northern regions have used the funds as of June 2017 and the other four districts are being helped to submit proposals or gain quotes for using the funding
- agreed messages for **posters and promotional materials** to be distributed to districts. An agreement has been reached with the Ministry of Health about the materials to be produced and messages have been developed ready for printing as posters and leaflets
- undertook **mentoring and supervision visits** to each of the 14 districts (twice yearly visits) to monitor the quality of services and provide support where needed. In total there were 56 visits
- worked with the Ministry of Health to improve the quality of record keeping about palliative care, including an agreed set of indicators to be embedded in the **national data reporting system**
- promoted learning from the STEP-UP programme **internationally**, including via presentations and posters at the African Palliative Care Association (APCA) conference

As a result of these activities, the following benefits were gained:

- staff reported that **palliative care was more organised and private** after rooms were allocated and refurbished as dedicated palliative care clinics. All 14 districts have allocated a room to use as a palliative care clinic
- in interviews, patients and families said they were grateful for the care they were receiving and felt like they were being cared for as 'whole people', who had valuable contributions to make
- the number of adults and children receiving palliative care in the Central and Northern regions rose from **3,660 in 2014 to 9,082 in 2016**. This is a <u>148% increase</u>. 2017 figures are expected to be even higher
- across the Central and Northern regions use of **liquid morphine** increased from 203,350ml in 2014 to 1,139,726ml in 2016. This is a <u>460% increase</u>
- 1,777 adults and children received morphine in 2016 compared to 1,141 in 2014, a 56% increase.
- the documentation and approach used for supervision visits and monitoring impacts was **strengthened and streamlined**, with unnecessary information removed and more user-friendly forms available to support better quality data collection and reporting. It is expected that this will promote better use of information to keep improving services in future

## Improving palliative care in communities

To improve the quality of palliative care available outside district hospitals, the STEP-UP programme:

- ran **awareness raising sensitisation sessions** for religious leaders, traditional healers, social workers, health surveillance workers and other community stakeholders. An event was run in eight regions, with a total of about 163 participants. Half of the 14 districts were targeted for this activity in 2015-17, with the expectation that the other districts would receive an orientation workshop in 2017-19 if further funding is granted
- ran **training for home-based care volunteers**. A total of 138 volunteers were trained in seven planned districts. Seven out of 14 districts were targeted for this activity in 2015-17, with the expectation that the other seven districts would receive support to train home-based volunteers in 2017-2019 if further funding is granted. The seven regions selected were different from those that received the orientation session, so that each of the 14 regions received either an orientation session or home-based care volunteer training

As a result of these activities,

- 100% of the home-based care volunteers trained said they knew more about palliative care as a result of the training and **felt more confident in providing palliative care in people's homes**
- follow-up interviews with patients and family members found that **families were more likely to be supported by volunteers at home** in areas that had received training. Touching stories were provided about how patients were grateful that a volunteer visited to attend to their needs and families said they benefitted from emotional support as well as a few minutes away from the patient to do other chores whilst a volunteer sat with the patient. This short respite helped families do chores such as washing and cooking or to go out to do shopping which they might otherwise have found difficult to manage whilst sitting with patients
- at 100% of the orientation sessions, stakeholders said that they learnt something new about palliative care or **their role in supporting palliative care** in their community. Traditional healers and religious leaders began to refer people to palliative care clinics
- the self-reported confidence of community stakeholders and volunteers increased after sessions and districts reported more referrals from the community for palliative care services

## Key learning

The value of the **STEP-UP model** for integrating palliative care has been reinforced. The STEP-UP model involves targeting hearts and minds at the most senior levels (Ministry of Health and district management teams) as well as providing knowledge, resources and support to frontline staff and the grassroots community level. This model acknowledges that knowledge alone is not enough to integrate palliative care into publicly funded health systems and that both tangible resources (funding for rooms, printed resources) and ongoing support (mentoring) are essential ingredients.

Factors that were found to be particularly helpful for integrating palliative care into publicly funded health services included:

- targeting **senior officials and frontline teams** simultaneously for awareness raising
- advocating for senior officials to include palliative care in annual **budgets** and undertaking sensitisation regularly because people have many competing priorities to allocate funds to and staff turnover can be high
- providing both information and **financial resources** to pump prime change. Districts are more likely to contribute their own funds and staff if they are also getting funding from elsewhere
- working with both hospitals and **community teams** to ensure palliative care is embedded at different levels of the health service
- seeing a **wide range of people** as members of the palliative care team, including traditional healers, religious leaders, management teams, doctors, nurses, clinical officers, social workers, health promotion and education officers, data officers and others
- **using data** to help show where improvement was needed, by making good use of baseline assessments and tracking changes over time
- allocating team members within STEP-UP to have **responsibility for collecting data** to show progress and keep everyone motivated
- working closely with the **Ministry of Health** to ensure project objectives are linked to national priorities and to support change on a national level

A key learning point from this phase is the importance of developing good **data collection mechanisms** at both national and district level. PACAM is particularly proud of the work done to agree indicators with the Ministry of Health which will be embedded into the national data reporting system. This means, for the first time ever in Malawi, districts will be required to report on progress in palliative care as part of national health system performance management. Progress will be assessed against pre-set targets. The Ministry of Health plans to implement the indicators from 2018. This is a major achievement and means that palliative care is being viewed as important for national monitoring alongside other key health and wellbeing indicators.

## Next steps

The True Colours Trust indicated that four years of funding may be granted for STEP-UP in the Central and Northern regions, dependant on progress in the first two years. The STEP-UP programme achieved all of its objectives for August 2015 to June 2017, with almost all planned activities completed or underway.

In the two year period from August 2017 onwards, if funding permits, priorities for STEP-UP will include:

- **strengthening national coordination of palliative care** in Malawi, including redeveloping the PACAM website and providing an online palliative care directory and membership database, developing a communications plan and resource mobilisation strategy, setting up PACAM regional offices and providing a PACAM newsletter. It is important to strengthen PACAM as an organisation to continue all the other training and development work for services and workers

- **supporting the national quality assurance process**, including embedding national quality indicators by training coordinators and data officers, working with the Ministry of Health to train supervisors annually, supporting the Ministry to analyse and feed back annual monitoring indicators to every district with tips for improvement, running drugs taskforce meetings and preparing a briefing about increasing dedicated staff for palliative care. PACAM needs to work at a strategic level in order to make lasting change in Malawi

- **extending palliative care into communities** including training champions in every district (volunteers, traditional leaders), linking champions to PACAM members and developing simple posters for local communities. STEP-UP has done a lot of work with district hospitals and it is now time to concentrate more on joining this up with the community – not just through sensitisation, but by having ‘champions’ on the ground to promote and support palliative care. Training these people and keeping them motivated will bring a new unpaid workforce of people to spread the palliative care message

- **strengthening palliative care infrastructure**, including building up clinical placement sites, supporting districts to provide training rather than always being reliant on the STEP-UP team and improving the prescribing and use of morphine in sufficient doses. This will build sustainability so the gains made will continue after STEP-UP ends

Malawi has made huge strides over the past decade to integrate palliative care into publicly funded health services. Much of this progress has been supported by grants from True Colours Trust. In the final phase of STEP-UP, from August 2017 onwards, putting in place activities to sustain these gains and reduce reliance on external funding will be of central importance.

# Contents

*Photo: STEP-UP team with True Colours Trust representatives*

This report was written by the PACAM STEP-UP team. PACAM would like to thank True Colours Trust for funding STEP-UP, the Ministry of Health for working alongside PACAM to improve the quality of palliative care, The Evidence Centre for technical support and the District Health Management Teams and frontline staff and volunteers who are making sure people with palliative care needs and their families get the physical, emotional and spiritual support they need.

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# 1. Overview

## Background

Malawi in Southern Africa has a population of more than 17 million people. The population is growing rapidly, up from about ten million people just 20 years ago. The population is almost doubling every 25 years. Malawi has a progressive national health service, with publicly funded health centres and hospitals offering free care at the point of access. Most other countries in Central and Southern Africa require people to pay fees to see doctors or nurses or receive hospital care. However, there is great demand for these free services in Malawi and the population remains relatively rural and poor, with limited knowledge about health and limited access to services. This means many people are living with medical conditions that are life-limiting or life-threatening, and such conditions are often diagnosed in the later stages, meaning people may not survive long after their diagnosis.

It is estimated that at least 200,000 people may be affected by life-limiting conditions in Malawi, including cancer and HIV/AIDs.[1] Research has found that about half of people with some forms of cancer die within one to two years of diagnosis in Malawi.[2] Therefore publicly funded health services must have the skills and capacity to support people with such illnesses.

Palliative care involves providing relief from the symptoms and stress of an illness that cannot be cured. The goal is to improve quality of life for both the patient and their family. In 2002 Malawi officially introduced the concept of palliative care, as recommended by the World Health Organisation. Home-based care was set up, particularly to support people with HIV/AIDs. However in 2006, research estimated that just five organisations in Malawi provided palliative care services, that there was no national coordination of palliative care and that most people in need of such care did not receive it.[3]

Just a decade later a great deal has changed. In 2017 all central and district hospitals provide palliative care, a national organisation oversees coordination alongside the Ministry of Health and the number of people receiving palliative care continues to grow. Many of these changes are at least partly attributable to the work of PACAM, supported by the True Colours Trust. In just ten years palliative care has been integrated into publicly funded health services. This report describes progress in the Central and Northern regions between August 2015 and June 2017.

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[1] Kendig CE, Samuel JC, Tyson AF, Khoury AL, Boschini LP, Mabedi C, Cairns BA, Varela C, Shores CG, Charles AG. Cancer treatment in Malawi: A disease of palliation. *World J Oncol* 2013; 4(3): 142–146.

[2] Msyamboza KP, Manda G, Tembo B, Thambo C, Chitete L, Mindiera C, Kishindo Finch L, Hamling K. Cancer survival in Malawi: a retrospective cohort study. Pan Afr Med J 2014; 19: 234.

[3] http://oxfordindex.oup.com/view/10.1093/acprof:oso/9780199206803.003.0013

## Report structure

The True Colours Trust recognised that as a small country with limited centralised resources, Malawi was finding it difficult to upskill health providers and embed palliative care into publicly funded services. From 2011, True Colours Trust has been supporting the STEP-UP programme to address this issue.

Between 2011 and 2015, True Colours Trust worked with partners to fund the STEP-UP programme to help build up palliative care in the Southern region of Malawi. Evaluations conducted by the African Palliative Care Association (APCA) and The Evidence Centre found that the STEP-UP approach helped to increase the number of children and adults receiving palliative care, increase the availability of essential medication such as morphine, and improve knowledge and skills amongst leaders, healthcare providers and other stakeholders.

From August 2015 onwards, True Colours Trust funded the Palliative Care Association of Malawi (PACAM) to expand the STEP-UP programme into the Central and Northern regions of Malawi. This report outlines the aims of the STEP-UP programme for this ‘third phase’, the extent to which each of the objectives have been met and some of the key learning points.

This section overviews the STEP-UP programme objectives between August 2015 and July 2016. (This report is submitted earlier than the planned August 2017 deadline at the request of the donors to support earlier decision-making about next steps).

The following sections describe the activities used to achieve each objective in turn and the impacts from those activities.

The final sections explore lessons that STEP-UP has learned from work in the Central and Northern regions and planned next steps.

The intended readers of this report are True Colours Trust team members and board members.

PACAM plans to continue disseminating the impacts and lessons learnt through conference posters, presentations and journal articles and through our website.

## STEP-UP aims

The overall goal of the STEP-UP programme is to support the provision of sustainable, accessible palliative care services for adults, children and their families through district health services. From August 2015, STEP-UP began work in the Central and Northern regions of Malawi.

Over a two year period, the overarching aims of the STEP-UP programme were to:

1. increase knowledge and awareness of palliative care among members of **District Health Management Teams** so that they support the development of palliative care in their districts, including incorporating palliative care into District Implementation Plans

2. increase **knowledge and awareness** about palliative care among staff in 14 district hospitals in the Central and Northern regions of Malawi

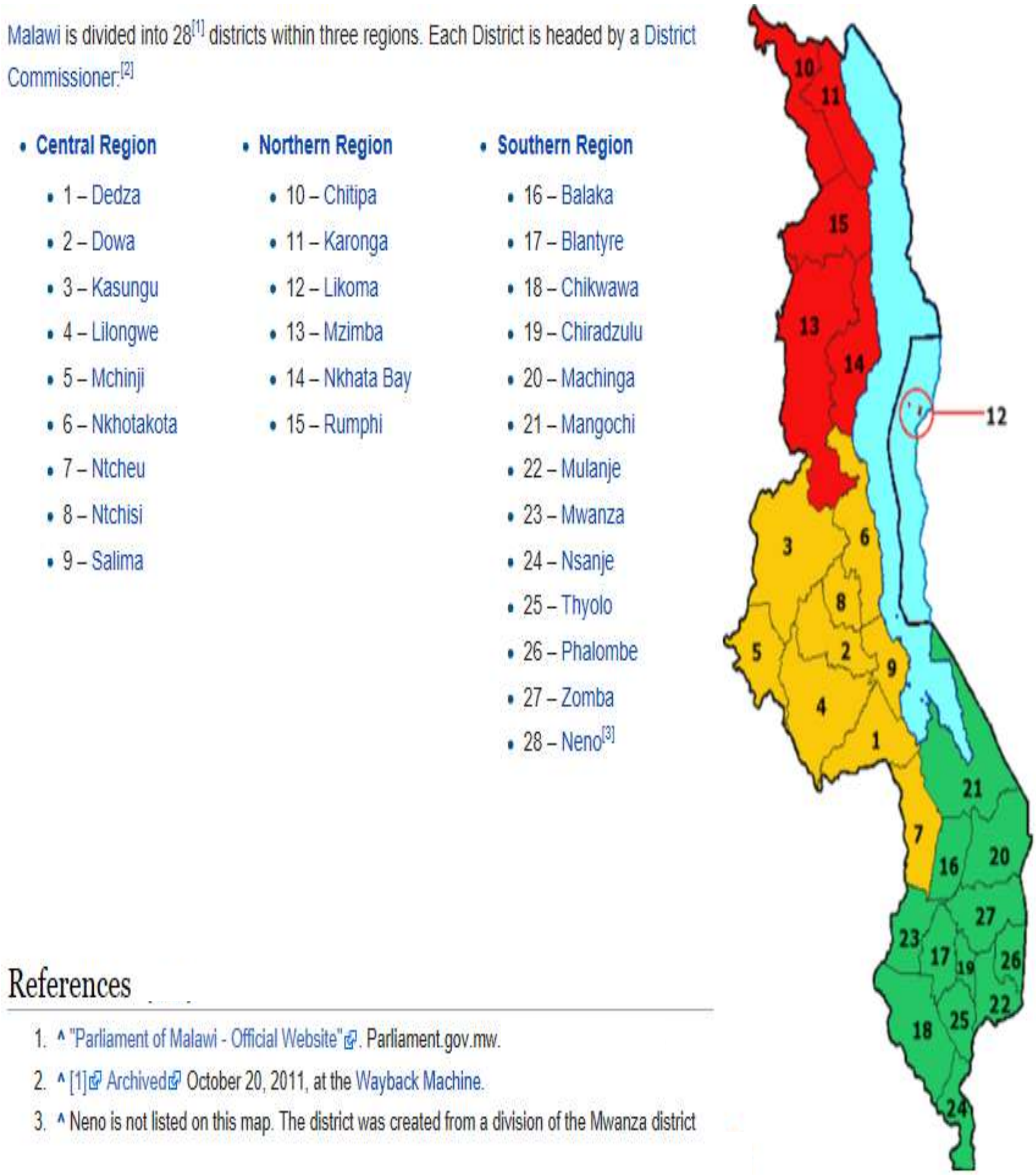
3. improve the **quality of palliative care** provided in district hospitals by increasing the number of adults and children who receive palliative care and the number of people who have access to pain relief

4. improve the **palliative care provided outside hospitals** by increasing knowledge and awareness amongst home-based care providers and other community stakeholders

As shown in Figure 1, there are nine districts in the Central region and six districts in the Northern Region (one of which has two district hospitals). One district is on an island in Lake Malawi so it was decided that this district would not be a focus for the programme in this phase, due to logistical issues accessing the district. It was also decided that due to funding and capacity issues not all 14 districts in the Central and Northern Regions would gain the same level of support in the first two years. The True Colours Trust advised PACAM to develop a four year programme, with years three and four dependent on good progress being made in years one and two. Therefore PACAM developed a programme of activities whereby all 14 districts gained some support in the first two years, and seven districts received additional support in some areas (with the expectation that the remaining seven areas would receive this additional support in years three and four).

The activities undertaken to achieve each of the programme aims are outlined overleaf. Each section begins with an overview of the activities undertaken, followed by an outline of the impact and extent to which the objective was achieved.

*Figure 1: Districts in Malawi*



Malawi is divided into 28[1] districts within three regions. Each District is headed by a District Commissioner:[2]

- **Central Region**
  - 1 – Dedza
  - 2 – Dowa
  - 3 – Kasungu
  - 4 – Lilongwe
  - 5 – Mchinji
  - 6 – Nkhotakota
  - 7 – Ntcheu
  - 8 – Ntchisi
  - 9 – Salima
- **Northern Region**
  - 10 – Chitipa
  - 11 – Karonga
  - 12 – Likoma
  - 13 – Mzimba
  - 14 – Nkhata Bay
  - 15 – Rumphi
- **Southern Region**
  - 16 – Balaka
  - 17 – Blantyre
  - 18 – Chikwawa
  - 19 – Chiradzulu
  - 20 – Machinga
  - 21 – Mangochi
  - 22 – Mulanje
  - 23 – Mwanza
  - 24 – Nsanje
  - 25 – Thyolo
  - 26 – Phalombe
  - 27 – Zomba
  - 28 – Neno[3]

## References

1. ^ "Parliament of Malawi - Official Website". Parliament.gov.mw.
2. ^ [1] Archived October 20, 2011, at the Wayback Machine.
3. ^ Neno is not listed on this map. The district was created from a division of the Mwanza district

Note: the map shows that the Central and Northern regions are significantly larger than the Southern region and there is a much greater distance being travelled to each individual region by the STEP-UP team. 'Region 12' on the map above is an island in Lake Malawi and is not part of the STEP-UP programme.

## STEP-UP programme team

The True Colours Trust funded three full time roles for the STEP-UP programme, but this funding was used flexibly as all members of the PACAM team contributed to the programme. The programme was overseen by a programme director (clinical officer), with support from a project manager and a full-time programme nurse. Other members of PACAM contributed to administration, mentoring and supervision visits, strategic work with the Ministry of Health and data collection.

## Collecting feedback about impacts

PACAM used the following methods to collect information about STEP-UP impacts for this report:

- a **baseline visit** and survey was undertaken to assess the capability and current service provision of 14 districts
- follow-up data were collected about progress during four **supervision** visits with each district (56 visits in total)
- **records** about service use, medication use and other indicators were collected using standardised templates developed in conjunction with the Ministry of Health. Data were stored on Excel spreadsheets
- people who took part in training sessions were surveyed before and after the sessions to see whether their levels of knowledge and confidence had changed. We also surveyed people during mentorship visits to track changes over time. **730 surveys** were collected
- people taking part in short awareness raising or orientation sessions were asked to give verbal **feedback** about what they had learnt at the end of sessions
- **131 follow-up interviews** were conducted with management teams, frontline workers and volunteers to gain quotes and feedback about any changes people had made in practice after training, clinical placements or other support
- those taking part in higher education courses were asked to write **summaries** of how these opportunities had impacted on the care they provide and their careers
- **case study** stories and photos were collected during site visits
- the PACAM team held **meetings** to reflect about lessons learnt and next steps

Technical support was provided by an independent organisation to assist with data collection templates, interview questions and data analysis but all data were collected by the PACAM team. PACAM assigned a staff member to lead monitoring and evaluation of the programme.

# 2. Management support

## Aim

STEP-UP aimed to increase knowledge and awareness of palliative care among members of the District Health Management Teams (the leadership team that oversees publicly funded health services in each district) so they support the development of palliative care and include palliative care in District Implementation Plans (the annual strategy that sets out healthcare resource allocation for the district).

## Activities

The activities undertaken to achieve this aim included:

- **visiting** District Health Management Teams during regular supervision visits (14 districts each received supervision visits over a two year period)
- running an **orientation session** for all members of the District Health Management Team in each district to make them aware of palliative care (13 orientation sessions were completed and the 14th district received informal ongoing orientation as they were not stable at the beginning of the programme)

In addition to these activities, it was planned to organise an educational visit for representatives of the District Health Management Teams from two sites that performed well during 2015/16 as part of a strategy to upgrade their district hospitals to become additional clinical placement centres. The educational visits have not been completed as the two sites to become clinical placement centres have just been confirmed, in partnership with the Ministry of Health and the district teams. The two sites are Ntcheu and Rumphi. The educational visits to other clinical placement centres will take place later in 2017. Management and staff sensitisation about becoming clinical placement centres has taken place.

## Impacts

Overall, this STEP-UP objective has been achieved.

Although introduced by the Ministry of Health about 15 years ago, in practice the concept of palliative care remains unclear and unknown to many people within and outside of health services in Malawi. District Management Health Teams decide how staff and finances will be allocated in each district so raising awareness about palliative care amongst these teams was essential for ensuring that palliative care was offered in district hospitals and appropriately resourced. The District Health Management Teams have a mandate over all the health services at district level regardless of whether they are publicly funded, private or faith based.

When visiting District Health Management Teams, STEP-UP found that most team members did not know what palliative care was or why it was important. After visits from STEP-UP:

- 100% of districts said they wanted to be part of the programme
- 100% of management team members interviewed during follow-up visits said they **knew more about palliative care** as a result of STEP-UP
- 100% of districts **allocated a room** to be used as a palliative care clinic at least once per week
- one district topped up funds provided by STEP-UP for room refurbishment to purchase a shipping container to be converted into a palliative care clinic
- 100% of districts included palliative care in their **District Implementation Plan** which means that this service was seen as a priority to gain funding (compared to 64% before STEP-UP)
- 100% of districts allocated **at least one staff member** to work at least some of the time on palliative care services
- some districts assigned full-time staff to deliver palliative care
- some districts assigned more senior workers to act as palliative care coordinators when they understood how important this service is
- in some districts members of management teams **attended training** for community stakeholders such as religious leaders or community volunteers. Their visible presence at events showed that senior officials were committed to embedded palliative care at all levels
- in most districts, management teams now **receive reports** from palliative care team members regularly describing how many patients have been seen and the availability of essential medications. This helps the management teams take an active role in overseeing the quality of the service and in addressing any challenges or barriers the delivery teams may be facing
- in an anonymous survey conducted in June 2017, 87% of district coordinators said management teams were more supportive of palliative care than one year ago

*Photo: Member of Nkhotakota District Health Management Team speaking during home-based care volunteers training*

District Health Management Teams have been positive about the ongoing support provided by STEP-UP (see Box 1). Ensuring that visits were not just one-off was important. Management teams may have high rates of staff turnover so it is important to keep raising awareness. The number of services competing for funds is high, so strong national advocacy from STEP-UP about the ongoing importance of palliative care has helped to keep this on the agenda.

> *"Palliative care in our districts has become one of the programmes that are easy to follow because [our palliative care providers] are able to come up with a work plan and regular reports. We believe mentorship and clinical placement has increased staff confidence. This must continue. The approach is good because now everyone is aware of what is happening, unlike in the past when activities were not properly coordinated."* (District nursing officers for Ntchisi and Mchinji)
>
> *"STEP-UP has helped us improve palliative care. There are more providers trained. We have procured furniture and equipment for the palliative care room which is now well equipped. Mentorship visits help us identify gaps and improve on them. We would like mentorship more often. We still have challenges in having enough staffing for the palliative care clinic. We should train more nurses as they are more easily available than clinicians. So much has changed in a short time."* (Management team representation from Rumphi)
>
> *"The knowledge transfer has been excellent during mentorship and training. There is improved service delivery at our district. Patient care has improved. We see this is important now."* (Management team representation from Chitipa)

*Box 1: Example of management support*

STEP-UP has focused on building management support. At the beginning of the project, all districts were visited to sensitise the District Health Management Teams about project aims, coverage and activities. Then every time the STEP-UP team visited for supervision (twice yearly), on arrival in the district, the mentorship team would give a courtesy call at the District Health Management Team briefing them on the activities they would do in the two days. This included mentorship in the clinic, home visits, and meetings with coordinators, conducting palliative care survey and collecting data on the impacts of the project. At the end of each visit the STEP-UP team returned to the management team to brief them on the findings and agree a way forward. The management teams were always engaged and eager to think about how to improve. There was much positive feedback about this engagement.

> *"Visits help to identify our challenges and weaknesses and allows us to grow and improve. We also learn new things from those who mentor us."* (Member of a District Health Management Team)

All districts have reported improvements in management support. Examples of successes include:

- dedicated providers running palliative care clinics, for example in Chitipa and Ntcheu
- identification of deputy palliative care coordinators at facility level, for example in Kasungu
- Chitipa runs palliative care clinics every day
- management supported the purchase of a shipping container for use as a palliative care clinic in Ntcheu. They put in more funds than the STEP-UP small grant. The composition of the DHMT has changed during the cycle of the STEP UP project. The Team present now is very different from the team present at the project inception. However the support is still the same. The new management has released two full time providers to run the palliative care clinic
- 100% of the districts reported that palliative care is now in the District Implementation Plan
- in Mzimba, home visits have been funded

# 3. Increasing knowledge

## Aim

STEP-UP aimed to increase knowledge and awareness about palliative care amongst health workers in district hospitals.

## Activities

The activities undertaken to achieve this aim included:

- **training** 40 health workers about in palliative care, targeting districts that have fewer trained palliative care providers based on baseline data collection. These 40 workers took part in a five-day Introduction to Palliative Care course
- supporting two workers per district to undergo **clinical placements** to see palliative care first-hand in centres of excellence. In total 26 people have completed clinical placements, with two more booked
- conducting a **refresher course** for nurses and clinical officers who were trained in palliative care but were struggling to provide palliative care services. A total of 28 people took part
- providing training about palliative care for **children** for 28 workers (two from each district)
- identifying **focal people** to champion children's palliative care in the districts
- conducting **leadership training** for 14 palliative care coordinators
- facilitating four **coordinators meetings** to share experience and progress. Coordinators from all regions in Malawi take part in these events, which are held approximately every six months
- conducting an orientation workshop about palliative care promotion for 14 **Health Education Officers**, one from each district
- supporting five people to undertake distance learning for an international **Diploma** in Palliative Care, including one PACAM team member (STEP-UP nurse)

## Training

The capacity of staff to provide palliative care has been enhanced through training an additional 40 palliative care providers spread across the Central and Northern regions, refresher training for 28 palliative care providers and training 28 providers in children's palliative care. Furthermore, in order to increase the capacity to manage palliative care services, local coordinators were oriented on leadership skills. All training sessions were positively evaluated and follow-up interviews recorded that participants are now able to apply knowledge and skills obtained during the training in their daily activities.

The approach taken to training focused on helping people embed their skills in practice. PACAM and the Ministry of Health agreed that there is a need to reduce largescale rollout of introductory five-day training courses because this is now reaching saturation point. At this stage, it is more important to ensure that people who have been trained are supported to use what they learnt rather than continuing to train new people who are then unable to use that knowledge in practice.

*Photo: Participants receive certificates at the end of a training session*

### Community of practice

As part of upskilling providers, STEP-UP has established a national community of practice for those working in palliative care. Palliative care coordinators and other stakeholders meet every six months or so to share good practice and learn from each other. The palliative care coordinators are key people in the district implementation of palliative care so giving them an opportunity to learn from each other is important to build good practice and support sustainability. STEP-UP is targeting work in the Central and Northern regions, but coordinators from the Southern region, where STEP-UP was previously implemented, all attend the national coordinators meeting too. At the meetings, each coordinator shares progress from their districts and case studies describing best practices, development initiatives and challenges.

### Clinical placements

Clinical placements involve attaching trained providers to a well-established palliative care site for a minimum period of two weeks. This gives them exposure to different conditions that require palliative care. They work under the supervision of experienced palliative care providers who are committed to transferring their skills to these upcoming palliative care providers. In total, 26 people have undertaken clinical placements during this phase of STEP-UP, with two more scheduled. All of the providers completed their placements through the two sites that STEP-UP helped to develop as clinical placement sites in the Southern region during an earlier phase: Mulanje and Mangochi District Hospitals.

It was expected that this phase of STEP-UP would include development of two further clinical placement sites, one in the Central and one in Northern region. There was a delay in agreeing the sites that were performing most effectively with the Ministry of Health, but two sites have now been selected for further development in the second half of 2017. It is planned that by 2018 these sites will both be operating as clinical placement centres.

### Promotional resources

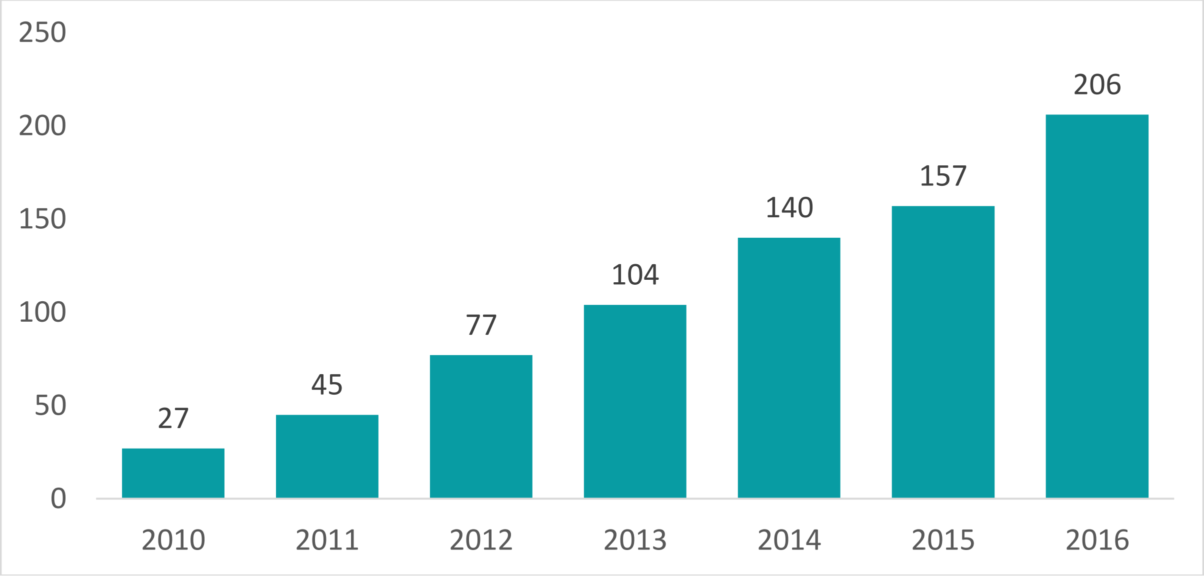
STEP-UP engaged health promotion and education officers through a workshop to orientate them about the concept of palliative care so that palliative care could be prioritised in the educational messages provided locally. The programme wanted to empower these officers to take the lead in developing health information and education materials to promote visibility of palliative care services, raise awareness to improve access. This is work in progress. Messages have been developed and are ready for printing (there was a delay due to a change in personnel at the national Health Education Unit. This approach helps to build sustainability because it is not about STEP-UP doing everything, but rather encouraging teams to come together to do things themselves that will be acceptable and appropriate locally.

## Impacts

This STEP-UP aim has been achieved, though some activities are being completed in the final half of 2017.

As a result of the training and clinical placements, there are now a **greater number of health workers aware of palliative care and trained to provide palliative care** or make referrals to the service. In 2014 the number of providers trained in palliative care was 140. In 2016 this had risen to 206, a 47% increase.

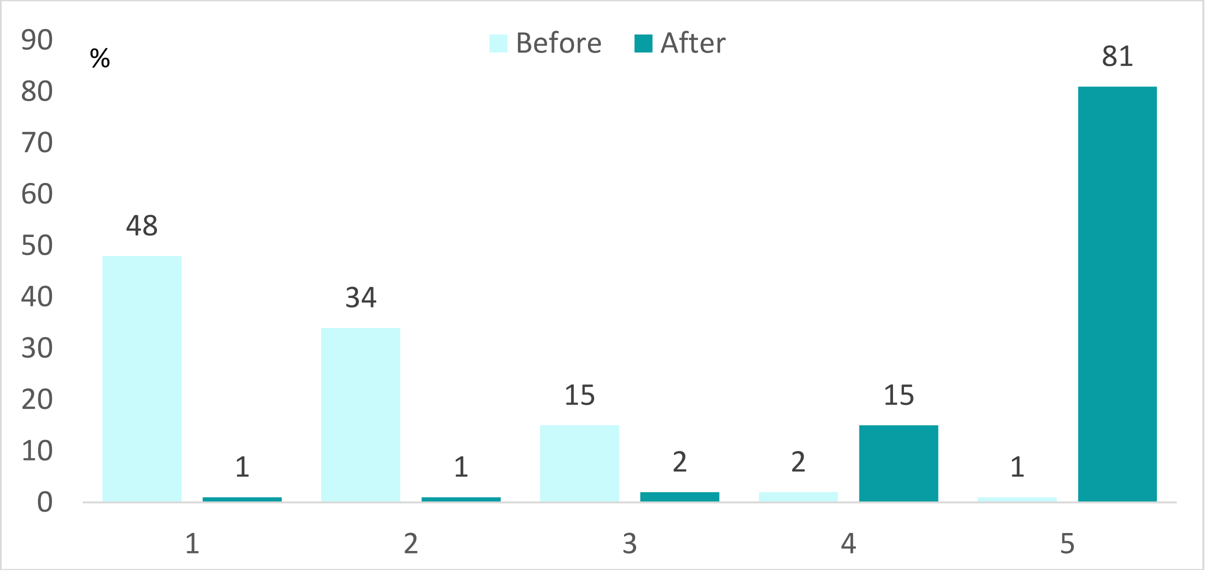
*Figure 2: Providers trained in palliative care in Central and Northern regions*



Note: This data has been provided by districts. STEP-UP began in the Central and Northern regions in mid-2015. Prior to that, providers were trained by the Ministry of Health.

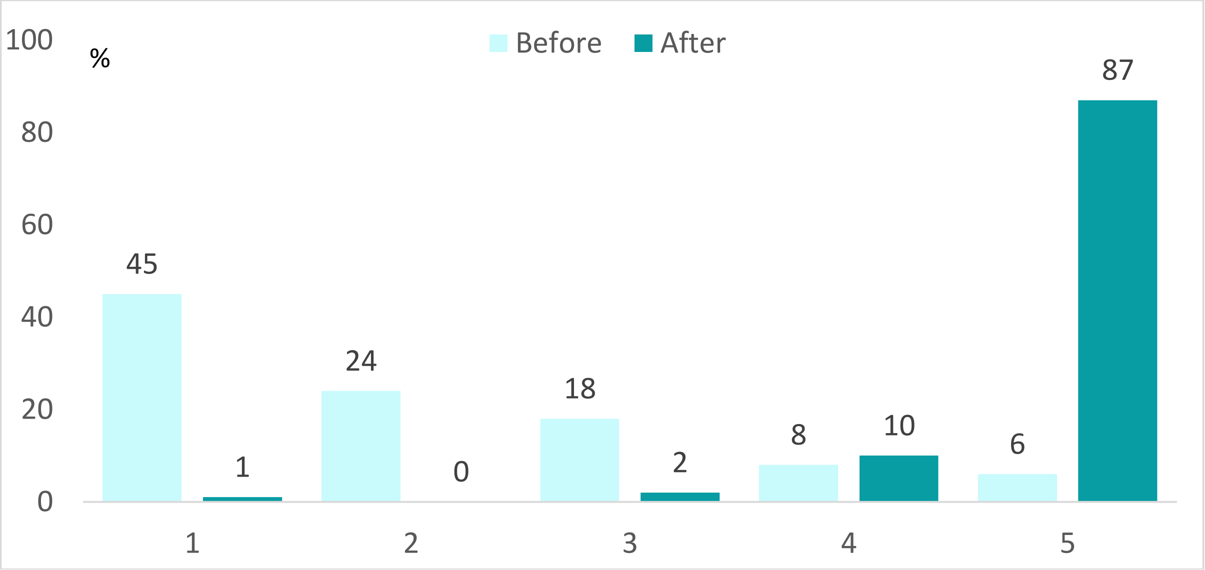
It is not so much the number of people trained that is important but the extent to which they learnt things and were able to put them into practice. Prior to STEP-UP, our baseline data suggested that training was not associated with improved knowledge or practice. Figures 3, 4 and 5 show how knowledge and confidence improved before and after taking part in the STEP-UP training. This is based on short surveys undertaken with participants before and after the training sessions. The five day palliative care training, refresher course and training in children’s palliative care all had similar impacts on knowledge and confidence so the results have been combined. Before the training, most people scored themselves as a 1 or 2 out of 5 in terms of knowledge and confidence in palliative care. After the training, most people scored themselves as 5 out of 5. **The average confidence score increased from 2 to 4.8 out of 5**. This is a statistically significance difference, which means it is unlikely to have happened by chance ($p<0.05$).

*Figure 3: Change in knowledge about palliative care before and after training*



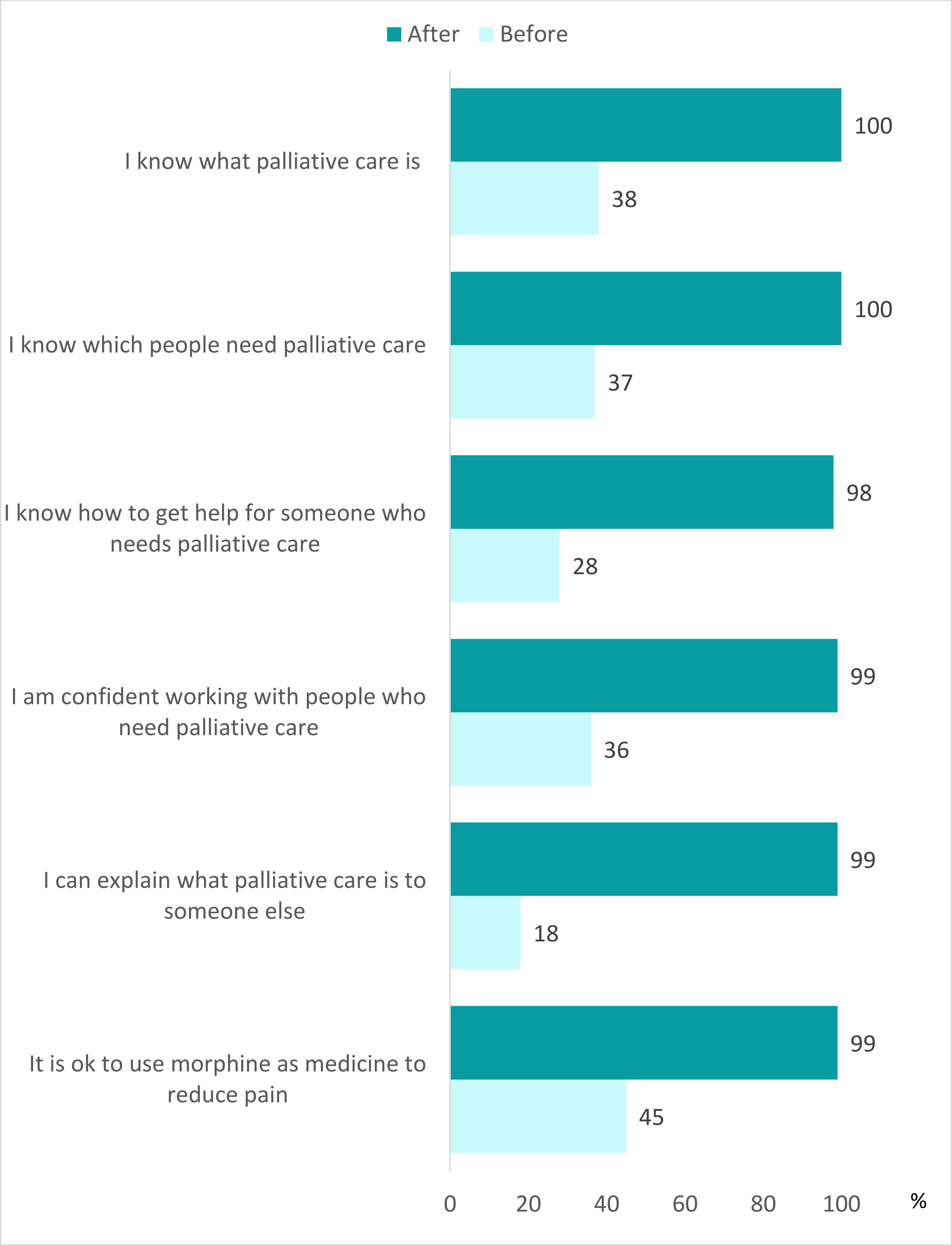
Note: The question asked 'on a scale of 1 to 5, where 5 is the highest, how much do you know about palliative care?' The results are based on feedback forms completed by 96 people before and after introductory and refresher training and training in children's palliative care (100% response rate). All types of training were equally well evaluated.

*Figure 4: Change in confidence to provide palliative care*



Note: The question asked 'on a scale of 1 to 5, where 5 is the highest, how confident are you about palliative care?' The results are based on feedback forms completed by 96 people before and after introductory and refresher training and training in children's palliative care (100% response rate). All types of training were equally well evaluated.

*Figure 5: % of providers agreeing before and after training*



Note: The results are based on feedback forms completed by 96 people before and after introductory and refresher training and training in children's palliative care (100% response rate). All types of training were equally well evaluated.

In follow-up interviews conducted several months after training, providers and management teams said that the training had been put into practice. They said that training, coupled with ongoing mentoring to check on implementation, had significantly improved knowledge and confidence and had a direct impact on the quality and quantity of palliative care available.

> *"It was an eye opener on palliative care. It increased my interest and willingness to provide palliative services. As well as gaining knowledge about palliative care I also learnt about keeping good records and monitoring and reporting regularly using the forms. Now patients are well registered and provided with good services."* (Clinical officer from Karonga)
>
> *"Now I am able to confidentially take the patient history and assess patients holistically. I can educate patients on the side effects of drugs and progress of the disease. We can safely store our drugs and keep good records. I am able to score pain. I have better skills and can help patients more."* (Medical assistant from Kasungu)
>
> *"Palliative care trainings have improved palliative care services especially in child care since children who need palliative care services are now seen by providers and are assisted accordingly. Wednesday clinics have been set up for the children for palliative care and are working well."* (Nurse from Mchinji)

In our baseline assessments and follow-up interviews we found that providers who were trained before STEP-UP lacked confidence to provide palliative care. Providing a refresher course proved useful. Districts reported that as a result of this refresher training **staff were more motivated** to work in palliative care services and referrals to palliative care increased. Some people who attended refresher sessions became local champions or focal people in their areas.

> *"A lot of palliative care patients are accessing services now and a high standard of care is given to these patients. The palliative care clinic is now running every day. This is because providers are now able to remember some of the necessary skills for the palliative care clinic that we may have forgotten. It also encourages us to fulfil our duties. It gives us a refresher or wake up call."* (Clinical officer from Kasungu)
>
> *"The training imparted knowledge and skills to the providers. Afterwards coordination among the providers was strengthened. This leads to more clients being seen. We identify gaps and come up with solutions together which strengthens the team work."* (Nurse from Mzimba South)

This was similar to the children's palliative care training, where every district identified a champion for children's palliative care after the training.

Clinical placements added extra value (see Boxes 2, 3 and 4).

> *"The clinical placement has helped me a lot because I learnt so many things from our friends. For example, administration of bleomycin. At first we were just giving it through intravenous but when we visited our friends we saw that they also give it even intramuscular. After the placement identification of patients who need palliative care and the number helped has increased."* (Nurse from Kasungu)
>
> *"Soon after the patient has been identified, we register the patient in the palliative care register then drugs are dispensed. The patient is given an appointment date for follow up. If she/he has failed to report we make proper follow ups either through the trained Health Surveillance Assistants or guardians. We learnt all this during clinical placement and have adapted it for our district."* (Provider from Dowa)

People who attended clinical placements said they made practical changes to the services in their districts when they returned. Common improvements were related to record keeping and drug storage.

> *"When I went to Mulanje for palliative care clinical placement, I learnt how our colleagues are filing patient records. They arrange them in such a way that makes record retrieval very easy. We have since implemented the same. The files are arranged alphabetically and separated."* (Clinical officer from Ntcheu)
>
> *"We saw the importance of proper filling during clinical placement and we also learnt how to do proper filing of records. Now when patients come, we easily pull out their case files."* (Nurse from Mzimba)
>
> *"'We noticed that our colleagues keep palliative care drugs in the clinic so that patients do not have to go and queue for these essential drugs. We have implemented the same in our clinic since the palliative care clinical placement.'* (Nurse from Kasungu)

Reports from all of the districts indicated that **all providers who went on a clinical placement are now actively involved** in delivering palliative care services. This is an improvement from our baseline data which found that although a good number of health professionals were trained in palliative care, they were not actively involved in delivery of palliative care. STEP-UP's clinical placement activities has increased access to palliative care services by ensuring there are more people providing these services.

*Box 2: Example of the impacts of clinical placements*

An example of the impacts of clinical placements comes from Chitipa where one nurse and one clinician were sent for clinical placement to Mangochi. These providers completed five-day introduction to palliative care training in 2013 using a small grant from True Colours Trust to Chitipa. However there was no funding to provide clinical placements to embed what they learnt.

In 2016, the palliative care coordinator for Chitipa passed away suddenly. This was a big blow for the district. However the team identified committed providers to help the district move forward. One of these, a nurse, was earmarked for the position of district palliative care coordinator and was sent for clinical placement in Mangochi to train for this role.

The nurse said he learnt many things in Mangochi. Some things Chitipa has been able to immediately apply to practice, including running palliative care clinics for children.

> *"One we learnt is to run separate clinics for adults and children. When we presented our desire to the District Health Management Team to run clinics on separate days, they agreed. Now Chitipa runs children's palliative care clinic on Mondays."* (Nurse)

During a mentorship visit, the STEP-UP team was taken to visit a child under five years of age with sickle cell. The child and her family knew they were booked in to the palliative care clinic on Mondays.

> *"We are booked on Mondays. It is good that the clinic for babies is on Mondays because then we do not have to wait for hours as in the past when both adults and children were seen on the same day. It's faster now. However, when there are emergencies, we are allowed to visit the clinic any day."* (Mother)

In Chitipa the palliative care clinic for adults runs on Wednesdays and Fridays. The providers on duty on these days also conduct ward rounds to identify palliative care clients.

Another thing applied from the clinical placement was having more than one staff member facilitating palliative care. Chitipa now has a palliative care nurse who coordinates palliative care activities at the facility, in addition to the palliative care coordinator for the district. This nurse also runs the antiretroviral clinic for people with HIV/AIDs and the non-communicable diseases clinic. Since many palliative care clients are also on antiretroviral therapy and others have non-communicable diseases, this means they are all attended to by the same nurse and this makes record keeping and coordination of services very easy.

This is an example of how going on a clinical placement not only helped individual providers learn more, it also had impacts for how services are run.

*Box 3: Personal account of a clinical placement*

*"I am Chifundo Msokwa working in Nkhata Bay. After the five days training in palliative care, I was implementing what I learnt but with challenges. I was also privileged to go for clinical placement where I gained practical experience of the holistic care approach and management of palliative care patients. Previously I had no much knowledge on management of these patients holistically, that is physical, spiritual and psychological. I learn that hospitalised patients with palliative care needs must to be reviewed for them to be managed holistically. The holistic assessment form is now being filled in without skipping a part, knowing that each and every part is important and helps in managing the patients holistically.*

*Now I have knowledge that palliative care patients are not managed at clinic only but also at home (home based care) through outreach clinics. I also have knowledge on the importance of family and community involvement in palliative care service provision.*

*I am now equipped with knowledge that the bereavement support helps, especially to the relatives of the deceased and shows that the provider really cared for the patients by relieving the psychological problems.*

*Identifying people who need palliative care is easier than before clinical placement. Before patients with severe burns or with chronic wound infections were not being taken as palliative care patients. We now offer palliative care to more people. We also know how we should keep our patient records and is easier to trace them.*

### *Box 4: Another personal account of a clinical placement*

*"I am Justina Chikhasu working in Dowa district. During clinical placement I learnt a lot from the providers who were there especially areas like:*

- *having a small room where all palliative care services are done, for example health talks, provision of cancer drugs like vincristine, titration of morphine to patients who are having persistent pain*
- *doing ward rounds*
- *conducting home visits and seeing how patients welcomed us after visiting them and how their happiness increases after our visits*
- *I also acquired much knowledge and skills on holistic assessment*

*After the clinical placement we continued pushing for a palliative care room and now we have one, buts small.*

*I am able to implement what I learned with all confidence like participating in ward rounds, administering cancer drugs and all necessary drugs, home visits as well as routine visits*

*The photo shows me at a home visit, which I learnt about during clinical placement."*

The five people completing international diplomas are being supported to become the next generation of leaders in palliative care in Malawi, which once again has implications for sustainability.

The training and placements likely **increased the number of people receiving palliative care**. These changes are described in the next section, focused on palliative care services in district hospitals.

# 4. Palliative care in hospital

## Aim

STEP-UP aimed to improve the quality of palliative care available in district hospitals, including increasing the number of people receiving palliative care and the number receiving pain relief.

## Activities

To achieve this aim, STEP-UP:

- provided **financial resources** to help refurbish clinic rooms. All 14 districts have allocated a room or space to act as a palliative care clinic. Ten out of the 14 districts have received and used funds to buy equipment or refurbish rooms. The other four districts are being supported to submit good quality proposals to help them access the funds
- provided **mentorship and supervision visits** twice yearly to 13 districts (four visits over a two year period)
- developed and implemented a **monitoring and evaluation** system to evaluate the programme
- supported better data collection by districts and the Ministry of Health, including streamlining data collection forms and developing a set of **indicators** that will become part of the national data reporting system for all districts

One activity that was planned but is not yet complete is supporting districts to promote the visibility of palliative care services by providing posters to display palliative care messages in hospitals, health centres and community venues. As outlined in the previous section, PACAM has worked with the Ministry of Health and Health Education Officers from each district to agree messages and branding. Posters are ready to be printed and these will be disseminated to all districts in the final half of 2017.

Additional activities undertaken to disseminate good practice included providing presentations and posters for the African Palliative Care Association conference in Uganda and organising the national commemoration of the World Hospice and Palliative Care Day.

### Palliative care clinic rooms

All 14 districts have set aside a designated room for palliative care services. STEP-UP supported improved access and quality of the service by offering funding for room refurbishment and procurement of equipment such as drug cupboards and chairs. Room refurbishment funding has been disbursed to ten districts: Chitipa, Karonga, Rumphi, Ntcheu, Dedza, Ntchisi, Kasungu, Mchinji, Nkhotakota and Salima, with the other four districts currently submitting proposals or finalising quotes.

Box 5 describes how providing funds motivated one district to add extra resources from their own budgets to create a standalone palliative care clinic.

*Photo: Palliative care clinic equipment purchased as part of STEP-UP*

### *Box 5: Creative use of room funding for palliative care in Ntcheu*

All 14 districts were offered a one-off grant for palliative care room refurbishment. Common items procured were shelves, lockable cupboards, chairs, examination couch, files and painting the rooms. However in Ntcheu the case was different.

Ntcheu started providing palliative care in 2010. Services were provided in a shared room in the physiotherapy department. The clinic was done once a week on Fridays while the physiotherapy clinic was done daily including on Fridays. This posed a challenge. The place was very congested and many other clinics were running along the same corridor so there were long queues.

Ntcheu used the funds from STEP-UP towards buying a shipping container to turn into a palliative care room. The management team added funds to the STEP-UP grant to cover the cost of the container. The clinic is now able to run every day. Patients immediately noticed a difference.

> *"I like this new site better. In the previous place we would line up for hours only to be told by the clinicians that we were on the wrong line and so had to start all over. But in this new place, we can never go wrong. While on this queue, we are sure that we will be assisted every day because there are providers on duty every day, a nurse and a clinician."* (Patient)

The photos show the container arriving, how it has been furnished and patients waiting outside.

## Mentorship visits

The aim of mentorship visits is to improve the quality of palliative care service delivery in district hospitals and to continue to raise the knowledge and skills of staff. This includes lobbying for management support, following up to ensure implementation of action points from previous visits, transferring skills about patient identification and holistic management through role modelling by STEP-UP team members and discussion of difficult cases, and auditing patient records for monitoring.

Mentorship visits last two days. At the start of the visit, STEP-UP usually joins the hospital's morning meetings and briefs staff about the objectives of the visit. STEP-UP then observes and participate in a palliative care clinic. After the clinic there is usually a team meeting with all the providers where the STEP-UP team give observations about how the district is running the palliative care clinic. Education sessions are held where providers are given a chance to ask questions and get a presentation on a palliative care topic of their choice. Records are checked to ensure that the district is correctly collecting and using data and indicators. On the second day, STEP-UP members accompany the hospital team to undertake a home visit, often with a home-based care volunteer.

> *"Mentorship helps us keep motivated and encourages us to do a better job. They see how things are working on the ground and make recommendations. An example is that our morphine doses were too low so they gave us confidence in that."* (Nurse from Mchinji)

*Photo: Mentorship in Ntchisi with STEP-UP nurse and Ministry of Health*

## Strengthening the use of data

STEP-UP recognised that an important part of integrating palliative care into publicly funded health services was ensuring that good records were kept about what was happening to support improvement and help track change over time. In addition to developing a robust monitoring strategy for assessing the impacts of STEP-UP, over the past year STEP-UP has worked with the Ministry of Health to agree a set of national indicators against which all districts will report. This will be part of the national quality assurance monitoring system. In line with this, supervision and monitoring record forms for districts have been revised.

In the course of implementing STEP-UP activities, the team realised that it was a challenge to monitor the impacts of the work. Districts were not collecting data regularly or accurately and there was no consistent method or tools in place. STEP-UP introduced palliative care registers to help districts keep clear records of the number of patients seen. However there was a need to tackle the issue at national level, both to ensure consistency but also so that palliative care was visible in the national markers of service delivery and quality reviewed by government.

Malawi has never had a national monitoring system to track changes in palliative care. All other major programmes by the Ministry of Health have indicators integrated into the national Health Information Management System. Up until now, palliative care has not. The Ministry of Health compiled an annual report based on figures collected during supervision visits (by STEP-UP) but details were not available by region or district.

A major achievement of the STEP-UP programme is to facilitate development of core indicators that will be monitored every year at national level. The process involved drafting indicators, with external technical support; holding two stakeholder meetings with the Ministry of Health and others to refine and agree indicators; and finalising definitions and calculations.

The indictors include a mix of tracking service use over time (number of adults and children receiving palliative care; proportion of deaths receiving bereavement visits, dispensing of morphine and so on), staffing (proportion of providers trained who are actively providing palliative care) and infrastructure issues (availability of different levels of pain management drugs). Box 6 lists the indicators (in development).

In the next phase of STEP-UP, palliative care coordinators and data officers will be trained to collect and use the indicators and the Ministry of Health will be supported to analyse and provide annual feedback to each district. Each district has a dedicated Health Information Officer who coordinates data collection from all health programmes. The Ministry of Health's Health Information Management Unit is now inserting palliative care indicators into the Health Information Management System. STEP-UP overviewed the indicators at the national palliative care coordinators meeting in June 2017.

*Box 6: Draft national palliative care indicators*

**SERVICE USE INDICATORS**

- Total all people who received palliative care in the year
- Total NEW people registered for palliative care in the year
- Proportion of new patients who had cancer or HIV/AIDs
- Total number of contacts / visits for palliative care in the year
- Proportion of contacts that took place outside hospital
- Proportion of palliative care patients who received morphine
- Proportion of patients with severe pain who received morphine
- Proportion of deaths where families received a bereavement visit

**RESOURCE INDICATORS**

- Proportion of days per year that level 1 pain drugs were available
- Proportion of days per year that level 2 pain drugs were available
- Proportion of days per year that level 3 pain drugs were available
- Quantity of liquid morphine dispensed in mls
- Proportion of palliative care activities in the District Implementation Plan that were implemented during the year
- Proportion of palliative care sites that received supervision at least twice per year

**STAFF INDICATORS**

- Proportion of providers ever trained in palliative care who are currently providing palliative care
- Proportion of volunteers ever trained in palliative care who are currently providing palliative care
- Proportion of facilities with at least one full time palliative care provider
- Proportion of sites meeting minimum requirements for staffing palliative care services

Note: As well as collecting total figures, all indicators are divided by adults versus children (<12 years) and females versus males. Definitions and calculation guides have been prepared for indicators. The indicators are undergoing review and finalisation by the Ministry of Health.

*Photo: One to one mentorship to support capturing palliative care data*

*Photo: Collecting feedback from patients about palliative care services*

## Impacts

This STEP-UP aim has been achieved, though there continues to be work to do to strengthen the quality of palliative care in hospitals.

Observation during mentoring visits and follow-up interviews suggest that palliative care is **becoming more visible** in most districts. There is improved management understanding and support for palliative care and this is evidenced through statements from the management team, allocation of resources and the placement of posters and signs around hospitals.

Every district has a **room for palliative care** service delivery.

> *"Getting funds helped us have a separate room for palliative care. That helped us a lot for privacy. We have a spacious room for service delivery, there is privacy and we are now having enough time and space for thorough assessment of our clients The safety of the drugs is much better in our room than before when we had no palliative care room."* (Nurse from Ntchisi)
>
> *"Having a room for palliative care makes the service better and more visible. Patients are free and able to explain the problems and what is worrying them in privacy."* (Health assistant from Rumphi)
>
> *"It is very helpful to have better facilities. We can store our records and medicines. We can see patients. We can feel the service is valuable and valued."* (Nurse from Nkhata Bay)

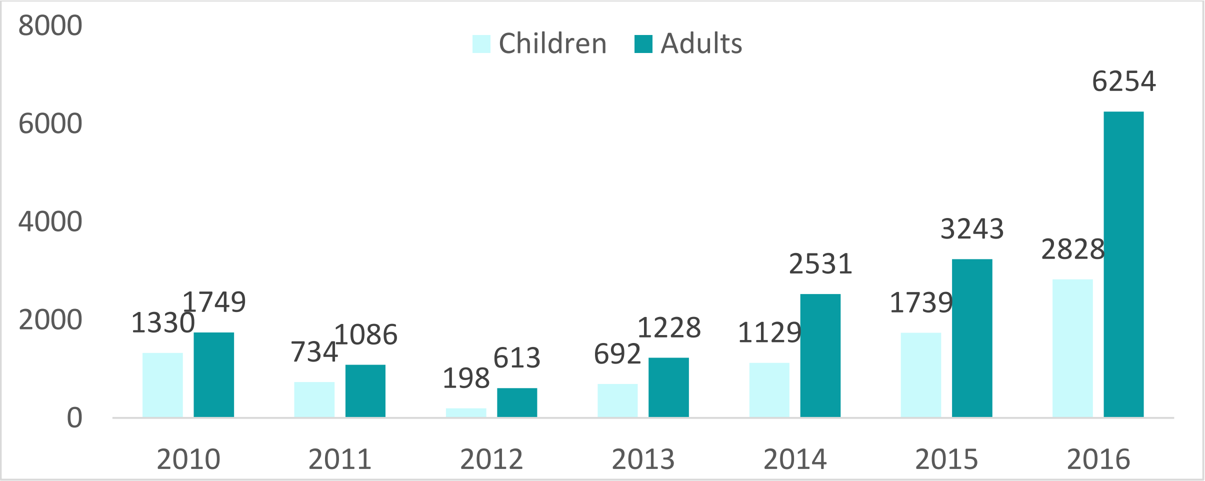
In one district the clinic is integrated into the HIV clinic. Palliative care coordinators have now all developed a monthly roster to cover clinics and these rosters are circulated to all the sections of the hospital. Districts have set up internal **referral systems** to improve the identification of patients who may benefit from palliative care. Clinicians on wards are able to identify patients and refer them for palliative care services which means the service is recognised at the facilities.

All districts are now using **palliative care registers** to keep records of the people supported. Drugs for pain relief and symptom control were available at most clinics, including morphine.

There are an **increased number of people accessing the service**, particularly in districts such as Kasungu and Mchinji. Figure 6 shows the increases in people receiving palliative care over time. For comparative purposes, Table 1 provides a breakdown of the Central and Northern regions compared to the Southern region, where STEP-UP was implemented earlier.

Prior to STEP-UP, in 2014 a total of 3,660 adults and children received palliative care. **In 2016, after STEP-UP was introduced, a total of 9,082 adults and children received palliative care. This is a 148% increase**. We expect 2017 figures to be even higher.

*Figure 6: People receiving palliative care in Central and Northern regions*



Note: Data were provided by districts. Not all districts kept complete records. STEP-UP began in the Central and Northern regions in mid-2015. There have been rapid gains in access to palliative care since then.

**There have been improvements on all key indicators for access to services and essential medicines** (see Table 1). Dispensing of liquid morphine increased from 20,3350ml in 2014 to 1,139,726ml in 2016, a 450% increase. The raw number of people receiving morphine increased but not the portion of all palliative patients receiving morphine (see Figure 7).

*Figure 7: Proportion of child and adult palliative patients receiving morphine*

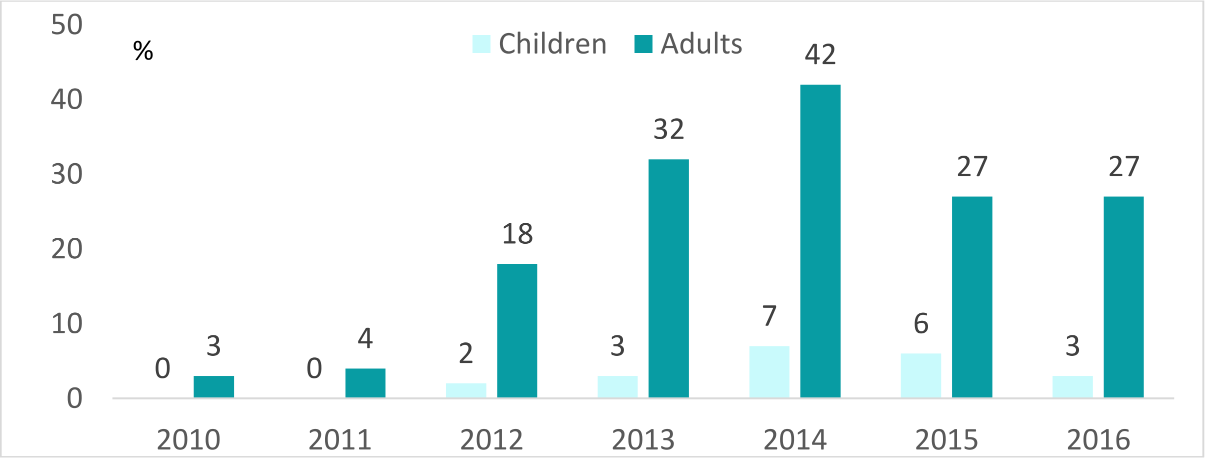


*Table 1: Changes in key indicators over time*

| | 2010 | 2011 | 2012 | 2013 | 2014 | 2015 | 2016 |
|---|---|---|---|---|---|---|---|
| **ALL REGIONS** | | | | | | | |
| District hospitals with palliative care (/28) | 22 | 25 | 25 | 25 | 26 | 27 | 27 |
| Palliative care in District Implementation Plan | 10 | 14 | 17 | 20 | 21 | 22 | 23 |
| New adult patients | 2647 | 3310 | 2984 | 2753 | 3821 | 4413 | 6597 |
| Total adult patients | 5192 | 6884 | 7776 | 9275 | 14010 | 17139 | 23344 |
| New child patients | 1475 | 917 | 452 | 1067 | 1512 | 2323 | 3594 |
| Total child patients | 1495 | 943 | 1143 | 4031 | 5408 | 7801 | 10584 |
| Adults on morphine | 949 | 1743 | 1487 | 2316 | 4147 | 4205 | 5944 |
| Children on morphine | 2 | 6 | 82 | 127 | 243 | 454 | 1023 |
| Liquid morphine (mls) | 35000 | 52857 | 150447 | 271677 | 628261 | 1287852 | 1846327 |
| Providers trained | 114 | 144 | 219 | 282 | 354 | 443 | 526 |
| Volunteers trained | 118 | 100 | 283 | 339 | 451 | 528 | 429 |
| **CENTRAL AND NORTHERN REGIONS** | | | | | | | |
| District hospitals with palliative care (/15) | 11 | 11 | 11 | 11 | 12 | 13 | 14 |
| Palliative care in District Implementation Plan | 6 | 6 | 6 | 9 | 9 | 10 | 14 |
| New adult patients | 1418 | 770 | 273 | 813 | 1410 | 2113 | 3808 |
| Total adult patients | 1749 | 1086 | 613 | 1228 | 2531 | 3243 | 6254 |
| New child patients | 1330 | 734 | 195 | 675 | 1047 | 1616 | 2658 |
| Total child patients | 1330 | 734 | 198 | 692 | 1129 | 1739 | 2828 |
| Adults on morphine | 59 | 47 | 108 | 394 | 1065 | 879 | 1679 |
| Children on morphine | 0 | 4 | 4 | 22 | 76 | 98 | 98 |
| Liquid morphine (mls) | 0 | 0 | 5800 | 82995 | 203350 | 634454 | 1139726 |
| Providers trained | 27 | 45 | 77 | 104 | 140 | 157 | 206 |
| Volunteers trained | 48 | 0 | 95 | 201 | 347 | 431 | 312 |
| **SOUTHERN REGION** | | | | | | | |
| District hospitals with palliative care (/13) | 11 | 13 | 13 | 13 | 13 | 13 | 13 |
| Palliative care in District Implementation Plan | 4 | 8 | 11 | 11 | 12 | 13 | 13 |
| New adult patients | 1229 | 2540 | 2711 | 1940 | 2411 | 2300 | 2789 |
| Total adult patients | 3443 | 5798 | 7163 | 8047 | 11479 | 13896 | 17090 |
| New child patients | 145 | 183 | 257 | 392 | 465 | 707 | 936 |
| Total child patients | 165 | 209 | 945 | 3339 | 4279 | 6062 | 7756 |
| Adults on morphine | 890 | 1696 | 1379 | 1922 | 3082 | 3326 | 4265 |
| Children on morphine | 2 | 2 | 78 | 105 | 167 | 356 | 925 |
| Liquid morphine (mls) | 35000 | 52857 | 144647 | 188682 | 424911 | 653398 | 706601 |
| Providers trained | 87 | 99 | 142 | 178 | 214 | 286 | 320 |
| Volunteers trained | 70 | 100 | 188 | 138 | 104 | 97 | 117 |

Note: STEP-UP was implemented in the Southern region from 2011 and the Central and Northern regions from mid-2015. Indicators are based on data provided by districts. All districts provided data but districts may not have kept complete records of all patients.

### *Box 7: Mentorship and supervision*

The photo shows palliative care providers and interns listening carefully during mentorship in Mzimba.

Two patients were reviewed in the clinic. One had severe burns on his body including head, chest, back and arm due to epilepsy. He had been in the hospital for ten weeks when the PACAM mentorship team visited him. Healing was in progress but the wounds on the face and head had a lot of pus and dead tissues due to hair blockages. PACAM enquired why the palliative care providers had not organised a clean shave for the man but they said he was hostile. PACAM asked the man if he wanted a shave and he agreed but said he did not have money to go to the barber shop. This showed the man was not hostile, he just could not afford a shave.

The shaving and cleaning was done. It took three hours to clean the man fully and involved two palliative care providers, PACAM and some student nurses. After the shave, the man looked clean and was very happy. He took a mirror from his pocket and looked at his face and smiled. It boosted his self-esteem. The guardians were also happy and said *“our patient now looks smart and attractive.”* The guardian said *“I’ve seen the benefits of coming to the palliative care clinic. If we had not come to the hospital my relation would have died sometime back.”*

The providers were also impressed because while as they thought the man was hostile, they were surprised that he was calm all through and never complained. One provider said *“Now I know how good it is to insist on good practices for our patients. Without the shave, the man was going to stay many more weeks because the wounds had developed puss. However after the shave, all the puss was gone and the wounds started drying.”*

**The impacts are not just about numbers and statistics. They reflect a real change in the quality of palliative care being provided**. An quote from Nkhata Bay shows the impact that STEP-UP support, mentorship and advocacy of palliative care services can have for people with palliative care needs and their families.

> *"[After a mentoring home visit] the mother said 'before the intervention no-one would enter this room because of the bad smell. Now we can sit close to [the patient] without noticing anything. Thanks to the palliative care programme, now the patient can smile. She is no longer in shame and her face is bright.' [The patient] says she can now clean dishes and do some household chores. It has made a big difference to the patient and family after the home visit"* (Reported by provider from Nkhata Bay)

*Photo: Happy patient and mother after a home visit*

Whilst this is all good progress, there remain areas for improvement in embedding palliative care. A lot of work is taking place in most of the districts but there is poor documentation and data management. This is improving but there is more work to do to train people how to keep records appropriately and use information to keep improving their services.

Staff shortages in the district hospitals are impacting on access to palliative care. There are multiple tasks assigned to each provider in most districts which makes it difficult for health workers to prioritise palliative care. One of the initiatives that PACAM wants to lead in 2017-19 is advocating for full-time palliative care providers nationally. Our mentorship visits have shown increased capacity of providers to manage palliative care cases, but in clinics that do not have designated staff it is difficult to retain the knowledge and skills gained through mentorship.

More could be done to identify people with palliative care needs. Districts are not identifying everyone on wards who would benefit. In part this is due to lack of capacity in the palliative care service to cope with everyone, but ward staff could also have more knowledge and confidence about referring people for palliative care.

Morphine has been readily available and is being prescribed in all districts. Now an ongoing activity is to monitor prescribing practices and ensure that all patients identified with severe pain are offered this medication in appropriate doses. We believe dosages are generally too low.

Some providers continue to lack confidence when managing palliative care patients owing to the fact that they were trained a long time ago and have not been exposed to complicated cases through clinical placement. This reinforces the commitment of PACAM to offer refresher training and to facilitate as many staff as possible to go on clinical placements.

More could also be done to improve the organisation and integration of palliative care services. For instance, some patients are given multiple appointments to attend the palliative care clinic for cancer on one day and the HIV clinic on another day, for instance. This is costly for the patient in terms of time and resources.

In most districts staff do home visit for patients who live nearby that they can walk to. They are unable to visit people who live further away due to a lack of transport to take them to these places.

These issues are raised solely to note that there remains work to be done to strengthen the quality of palliative care in district hospitals. A significant amount has been achieved in the first two years of work in the Central and Northern regions, but ongoing supervision and support will be crucial for sustaining and further heightening the gains made.

# 5. Care in the community

## Aim

STEP-UP aimed to improve access to palliative care outside district hospitals by increasing knowledge and awareness amongst home-based care providers and other community stakeholders.

## Activities

The activities that STEP-UP undertook to achieve this aim included:

- training 118 **community home-based care volunteers** in six out of the seven target districts. Due to capacity and funding constraints, seven districts were targeted for support in 2015-17, with the other seven districts scheduled to receive support from August 2017 onwards, further funding permitting
- conducting an **orientation workshop** for community stakeholders such as health surveillance assistants, social workers, religious leaders and traditional healers in eight districts. Due to capacity and funding constraints, seven districts were targeted for this type of support in 2015-17, with the other seven districts scheduled to receive support from August 2017 onwards, further funding permitting. Districts received either home-based care volunteer training or orientation sessions in 2015-17, not both. In subsequent years, districts will be offered the other activity, funding permitting

*Photo: Community members dancing in welcome and happiness*

### Community awareness raising sessions

STEP-UP conducted awareness raising sessions involving multidisciplinary teams at community level including social workers, traditional leaders, traditional healers and health surveillance assistants. The workshops are each one day long. They were conducted in Ntchisi, Ntcheu, Dowa, Kasungu, Ntchinji, Mzimba south, Rumphi and Dedza. A total of about 163 community members attended these workshops. The aim was to ensure that the wider community understood the concept of palliative care, knew about the services in their district and felt able to help identify patients and refer people to facilities.

*Photo: Awareness raising session for community stakeholders in Mzimba*

*Photo: Supporting people in local communities*

### Home-based care volunteer training

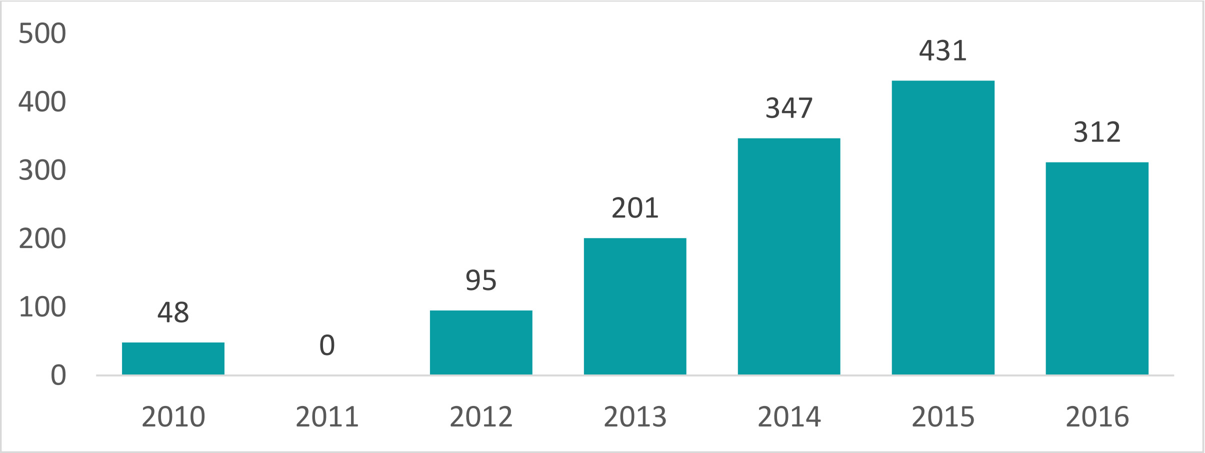
Most people in Malawi die at home without seeing a health worker. Many of these patients have palliative care needs and often they die in pain with most of their symptoms unattended to. In Malawi over 80% of the population live in rural areas which are usually some distance from health facilities. Following World Health Organization recommendations, Malawi set up home-based care volunteering as a sustainable model for reaching people in local villages and communities.

STEP-UP provided one day training for home-based care volunteers in seven districts. This reached 138 people. It was planned to reach 140 volunteers but two people did not attend.

Each participating district was asked to identify two community-based organisations or support groups from which 10 volunteers could be trained in palliative care. This would mean there would be about 20 new trained volunteers per district. The training involved facilitators from the same district for easy follow up. This is again part of the sustainability plan of STEP-UP. Instead of creating reliance on a central team, support is provided to local people who can continue the work after STEP-UP leaves. In each district three facilitators were identified, including the district palliative care coordinator.

The sessions were run with support from the District Health Management Teams. This was another way of strengthening the relationship. All trained home based care volunteers were directly linked to the hospital to strengthen patient referral systems and follow up.

*Figure 8: Volunteers trained in palliative care in Central and Northern regions*



Note: STEP-UP began in the Central and Northern regions in mid-2015. Prior to that, volunteers were trained by the Ministry of Health or other organisations ad hoc. 2017 figures will be higher as STEP-UP undertook a number of volunteer training sessions in 2017.

*Photo: Home-based care volunteers in Lilongwe with their certificates*

*Photo: Volunteers from Karonga with their local training facilitators*

## Impacts

This STEP-UP aim has been achieved, though there remains much work to do to rollout palliative care awareness and support into wider communities.

As a result of the community awareness raising sessions, all districts involved have reported **increased referrals to palliative care services** from community stakeholders.

Follow-up interviews showed that people who attended the awareness raising sessions learnt about palliative care and thought they could take a **more active role in identifying patients** who could be helped.

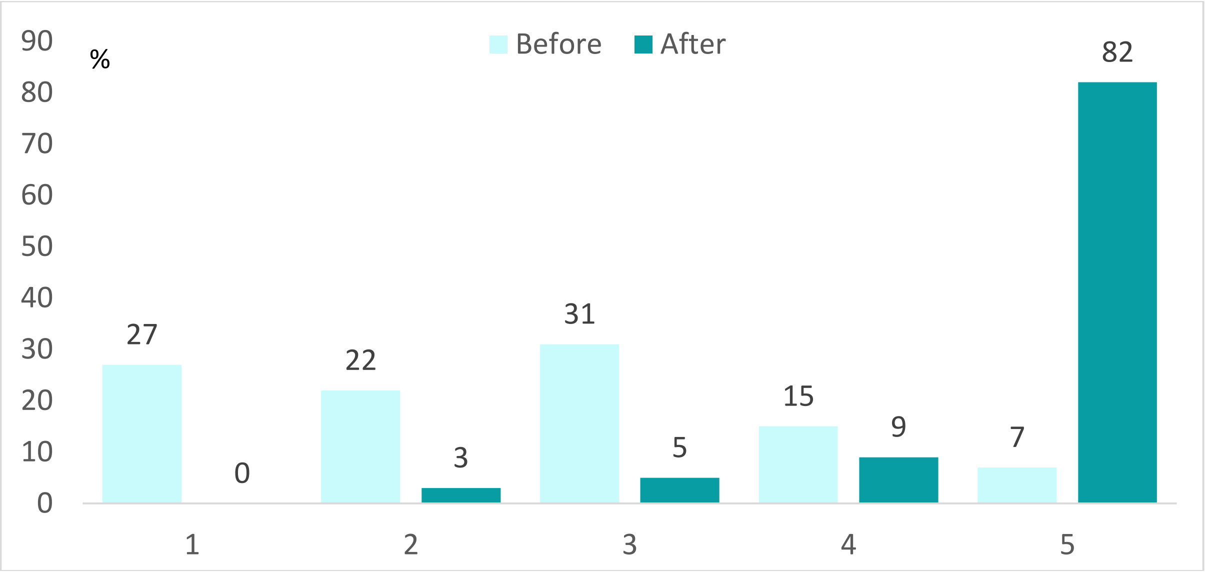
> *"Some patients come to us but we don't have much to offer in terms of pain management. Now our eyes are open we will be working with the hospital."* (Traditional healer from Ntchisi)
>
> *"As Health Surveillance Assistants, we are based in the community but we didn't know that when a patient is discharged for home-based care he or she can be referred back to the hospital when the condition worsen. This knowledge will help us help more families."* (Health Surveillance Assistants from Mzimba South)

Figures 9, 10 and 11 show how knowledge and confidence improved after the orientation sessions. People may not want to admit that they have limited knowledge at the outset or they may not be aware of how much they do not know. Even so, on all indicators there was an improvement in self-reported knowledge after the sessions.

The average self-reported score related to confidence about palliative care increased from 2.6 out of 5 before the orientation sessions to 4.6 out of 5 afterwards. This is a statistically significance difference, which means it is unlikely to have happened by chance ($p<0.05$).

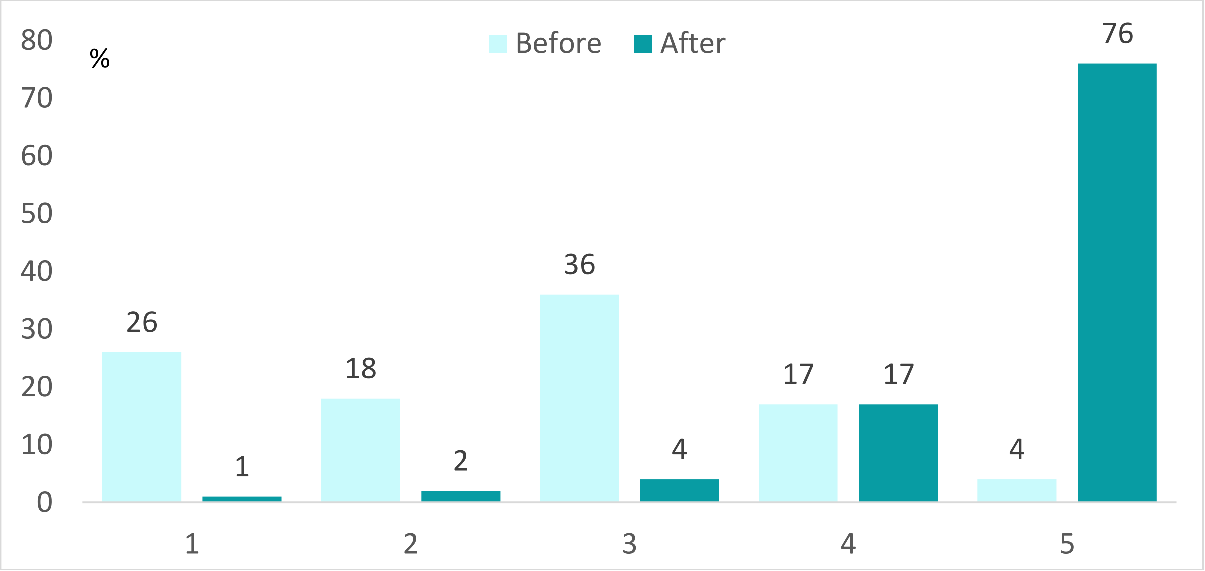
Box 8 shows how increased awareness and confidence in palliative care amongst community stakeholders had direct impacts for patients in the community.

*Figure 9: Change in knowledge amongst community stakeholders*



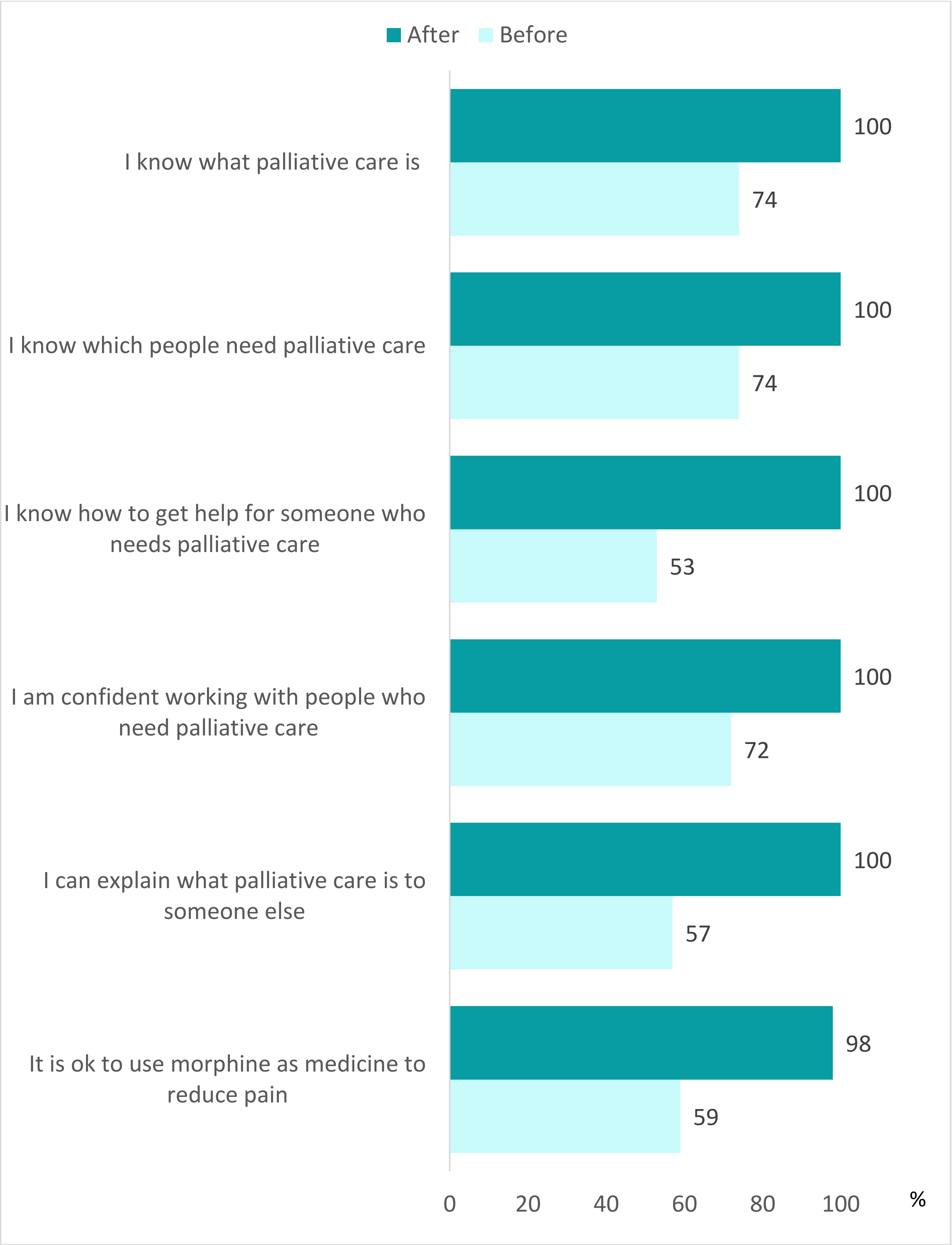
Note: The question asked ‘on a scale of 1 to 5, where 5 is the highest, how much do you know about palliative care?’ The results are based on feedback forms completed by 163 people before and after orientation sessions (100% response rate).

*Figure 10: Confidence about palliative care amongst community stakeholders*



Note: The question asked ‘on a scale of 1 to 5, where 5 is the highest, how confident are you about palliative care?’ The results are based on feedback forms completed by 163 people before and after orientation sessions (100% response rate).

*Figure 11: % of community stakeholders agreeing before and after training*



Note: The results are based on feedback forms completed by 163 people before and after orientation sessions (100% response rate).

*Box 8: Example of results from orientation of Health Surveillance assistants*

A new activity for STEP-UP in 2015-17 involved orientation of a wider range of community stakeholders. An example is an orientation session for Health Surveillance Assistants and other cadres in Rumphi (one of the seven districts to receive this support in this phase). The purpose was to raise awareness of palliative care services in the community, to increase patient identification and improve referrals. Health Surveillance Assistants work in the community and do not have advanced clinical training, but are there to provide patient education, advocacy and referrals.

In Rumphi after the orientation session, the Health Surveillance Assistants immediately started putting what they learnt into practice. For instance one Health Surveillance Assistant identified a patient who had had an ulcer for many years and was in severe pain. After hearing about palliative care services, the Health Surveillance Assistant referred the patient to palliative care where he was further referred to Mzuzu Central Hospital. At the central hospital his leg was amputated.

> *"I was in severe pain for many years. The wound was very pain full as if someone was putting fire on it. I was crying day in day out. My wife was also crying by my side. The pain was piercing my heart. If these people had not come I would be dead by now. I was beating my leg all through and even my back started aching. I was even crying while I slept. But now I am well. I have no pain. My wife has gone to fetch for firewood which she sells to make some money. Before I got sick, I was making bricks and selling but I can't do that now so I want to open a shop so I can be sitting in the shop."*

There were similarly important benefits from the volunteer training. As a result of training home-based care volunteers, districts said that care is more **integrated** between hospital and the community. Hospitals have received referrals from home-based care volunteers and hospitals have let community organisations know when patients return home so they can be followed up by volunteers.

Volunteers said they felt **more knowledgeable and confident** as a result of the training.

> *"I learnt new skills like how to approach the patient. Now we know how to interact with the patients and build a relationship and show love. Patients have appreciated that we are visiting them more than we used to do before the training due to more knowledge. More members are now volunteering in the community. We are better at record keeping using registers. We can counsel patients better."* (Volunteer from Ntcheu)
>
> *"We see a lot of people. Now we know more about how to help. Since the training I have been telling families that they can take people to the clinic rather than keeping them at home."* (Volunteer from Chitipa)

Figures 12, 13 and 14 show self-reported changes in knowledge and confidence amongst the volunteers. Average confidence to provide palliative care increased from 2.4 out of 5 before training to 4.4 out of 5 after training. This is a statistically significance difference, which means it is unlikely to have happened by chance ($p<0.05$).

Importantly, there have been **direct impacts on care for patients**.

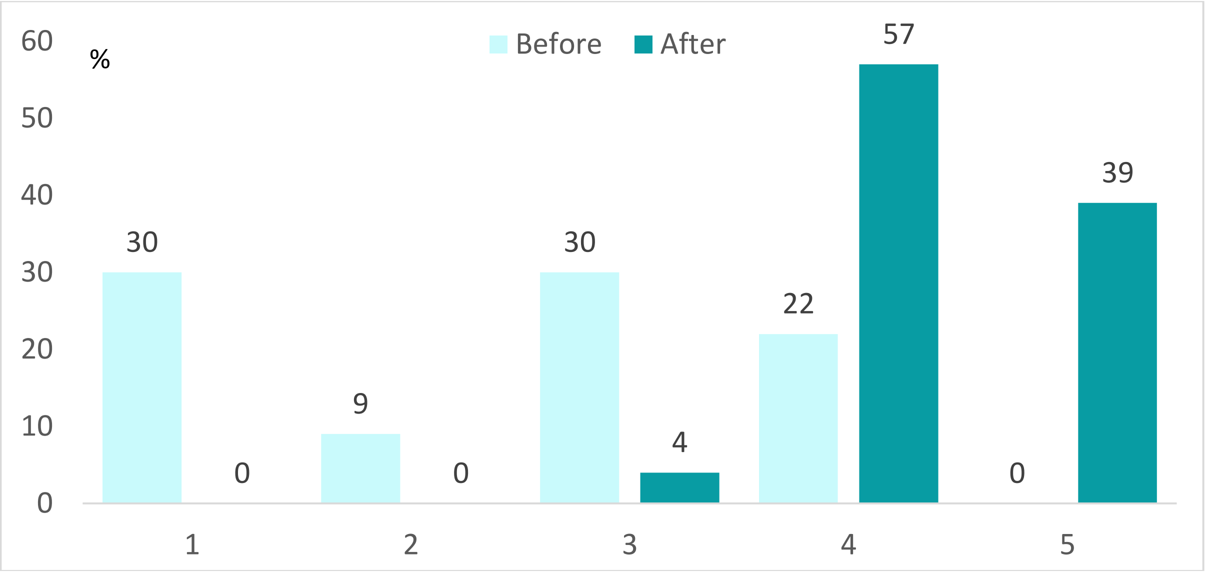
> *"Since the training, the people in the community have more confidence in us that we are doing the right things. After seeing our activities, some families are able to call us when they have patients. Our group now have 56 patients."* (Volunteer from Karonga)
>
> *"Since we started submitting our monthly reports to the palliative care coordinator, we do not have challenges to supply us drugs for the home-based care kits. The palliative care coordinator uses the report as evidence of the work we do. Before that, it was difficult to get these drugs."* (Volunteer organisation from Ntcheu)
>
> *"I'm now able to identify more clients in the community and refer them to the facility. Since the palliative care orientation, I've managed to counsel more patients than before because I now have more confidence. Since palliative care is holistic, the spiritual component encourages patients and families very much."* (Volunteer)

In interviews patients and families reported that they received more visits from volunteers. Some patients said they felt grateful that volunteers were there to support them and so their families had someone to talk to. Some family members said that having a visit from a volunteer gave them a short amount of respite from their caring responsibilities so they could do other chores whilst the volunteer sat with their family member (see Box 9).

*Photo: Patient can't hide his smile as a volunteer visits*

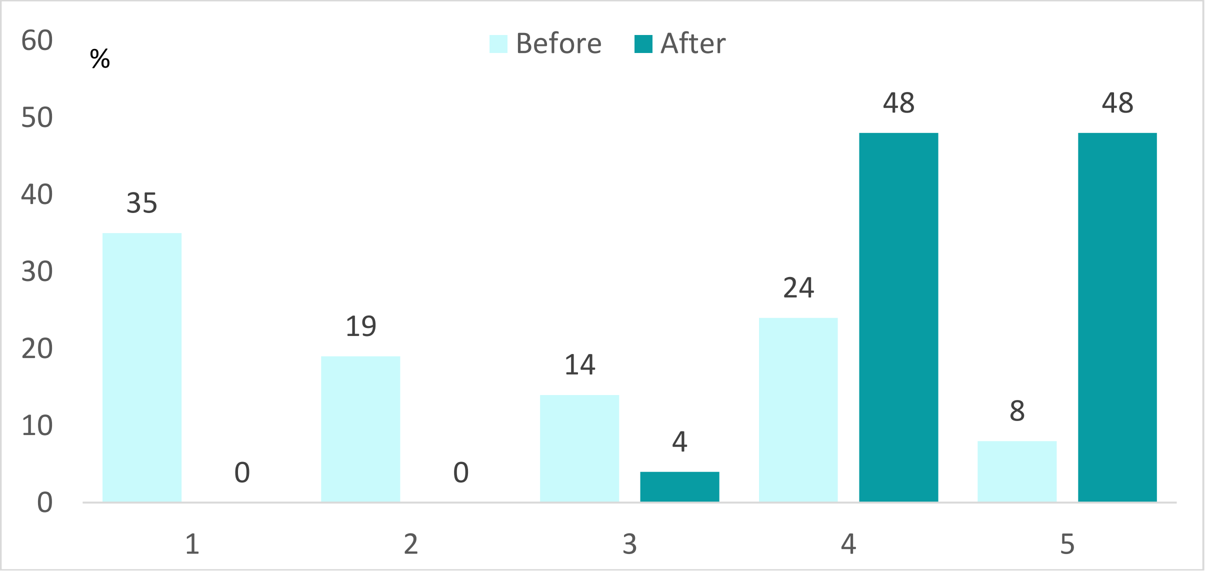
Whilst these are all positive impacts, much remains to be done to improve access to palliative care outside district hospitals. Training 20 volunteers per district is a small step forward but the districts cover a massive area. In future years STEP-UP would want to continue rolling out training to volunteers as well as exploring how health centres could be involved.

*Figure 12: Change in volunteer knowledge before and after training*



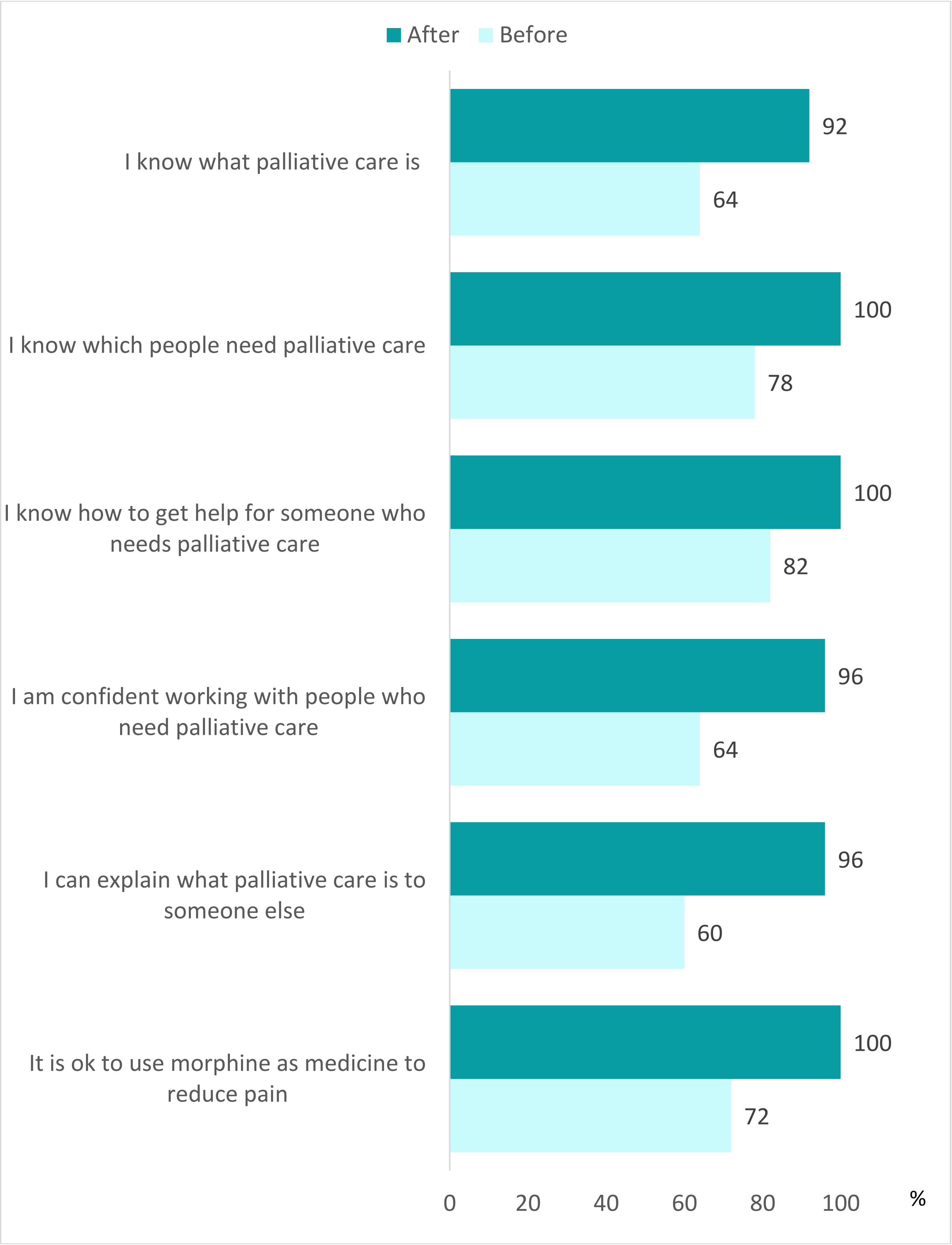
Note: The question asked 'on a scale of 1 to 5, where 5 is the highest, how much do you know about palliative care?' The results are based on feedback forms completed by 37 people before and training (31% response rate). Not all volunteers were invited to provide feedback.

*Figure 13: Change in volunteer confidence to provide palliative care*



Note: The question asked 'on a scale of 1 to 5, where 5 is the highest, how confident are you about palliative care?' The results are based on feedback forms completed by 37 volunteers before and after training (31% response rate).

*Figure 14: % of volunteers agreeing before and after training*



Note: The results are based on feedback forms completed by 37 volunteers before and after training (31% response rate). Feedback forms were not given to all volunteers as facilitators were from local areas and not all followed procedures.

*Box 9: Example of the impacts of palliative care training for volunteers*

Training community home-based care volunteers in palliative care helps these volunteers to identify patients in local communities and refer them for further management. When the patients return to the community, the volunteers can continue to support them. An example is in Karonga, where two community organisations providing volunteers were identified and 10 volunteers were trained from each of the two organisations. The volunteers then began to visit people in the community regularly.

The photo below shows a patient who had a stroke (in blue) during a home visit. There is one male volunteer and three female volunteers, plus the patient's wife. The wife said the volunteers really help them.

> *"These volunteers visit us quite often as they are able to encourage me as well as my husband. When they come, at times I ask them to wait as I quickly rush to do one or two things outside the home which I cannot do when there is no one to stay with my husband. The visitors also help me to fetch water. While visiting us, they help talk to my husband to keep him alert so he can heal quickly as he is struggling to talk. They engage him in conversations as part of therapy for him to regain his speech."* (Patient's wife)

During mentorship and supervision in May 2017, the STEP-UP team visited one group of volunteers at Mpata. The group reported that they had managed to identify 56 patients since the training in February 2016. They indicated that since the training the community has more confidence in them to deliver care. They also said that they are also more confident in their service provision due to the skills they learnt during the training. However they indicated they have challenges with drugs for the home based care kits and that they walk long distances to visit the clients. They also indicated they needed bicycle ambulances to be able to carry some patients to the hospital as the need arises.

# 6. Lessons learnt

## STEP-UP model

This phase of the STEP-UP programme has been very successful. In just two years, PACAM has helped to integrate palliative care into 14 districts in the Central and Northern regions. These regions are widely geographically dispersed and each covers a broad area, so the achievements are no mean feat when considering the logistics of travel and organisation.

A large number of activities have been completed including:

- 14 orientation sessions for management teams
- a total of 56 mentoring visits to districts
- four national palliative care coordinators meetings
- one five-day introduction to palliative care course for 40 people
- one three-day refresher training session for 28 people
- one training course in children’s palliative care for 28 people
- two workshops for palliative care indicators
- one workshop for 14 health promotion officers
- supporting 26 clinical placements
- supporting five diploma students
- eight community orientation sessions with 163 people
- seven training programmes for 138 home-based care volunteers
- four conference presentations and posters

However, STEP-UP is not about ticking off a list of activities, but rather about implementing a well thought out model to embed palliative care.

**Strategic audience**
The STEP-UP model involves appealing to people’s hearts and minds. The target audience is the most senior levels of management (Ministry of Health and District Health Management Teams) as well as frontline staff and the grassroots community level. Combining a bottom-up (staff-focused) and top-down (management-focused) approach has the greatest impact.

There is improved visibility of palliative care at both national and district level. The government has praised PACAM for its work. An example is that PACAM was invited to review progress on national non-communicable diseases activities and to help plan priorities for 2017-2023. It was observed that palliative care was the only area of the non-communicable diseases workplan where all activities and priorities had been achieved and PACAM was commended for supporting this. Working at the highest strategic levels as well as at the frontline is part of the STEP-UP model. Policy makers say they are now aware of palliative care and see it as a priority, whereas this may not have been as explicit previously.

### Using information for improvement

PACAM believes that STEP-UP has been successful because there have been significant improvements since the baseline data collected before work started in the Central and Northern regions. Before STEP-UP most districts had no dedicated operating space for palliative care clinics, but the project has completely changed this. Using data to continually guide our planning and monitoring our effectiveness robustly are both components of the STEP-UP model. The activities we prioritise are based on identifying the needs of districts from their feedback and our observations and we follow up every six months to track progress.

We have influenced the Ministry of Health to integrate palliative care indicators into the national Health Management Information System. This combines our strategic focus and our use of data to guide improvement. Never before have districts been asked to officially report on palliative care so we hope that integrating indicators into the national reporting system will strengthen the status of palliative care further.

### Targeting publicly funded services

In the past, organisations sometimes thought it was difficult to work with the public health delivery system to promote palliative care so palliative care services were mainly visible in faith-based facilities and non-governmental facilities. STEP-UP has made a breakthrough and now even the other facilities are looking up to the developed public health facilities for support in palliative care development. Targeting the publicly funded health system in order to make palliative care sustainable is part of the STEP-UP model.

### Experiential learning

Two clinical placement centres developed by STEP-UP in the Southern region have been used to support districts in the Central and Northern region. They have even taken placements from existing centres of excellence such as the Palliative Care Support Trust and Queen Elizabeth Central Hospital who could not cope with capacity demands. This is another component of the STEP-UP model: recognising that in order to build capacity at the frontline, experiential learning is important. Placements show providers good palliative care in practice, allowing them to see role models and to adapt processes to their own contexts.

### Pain relief priorities

Another component of the STEP-UP model involves making sure that pain relief medications are accessible and appropriately used. Originally morphine was erratic in its supply in Malawi but due to continuous sensitisation and capacity building all districts are now able to stock morphine most days of the year. This is the first step and now we are looking forward to building capacity on good prescribing practices. In a way the exact priorities of STEP-UP are developing. As we achieve one of our goals, for example increasing access to morphine, then we identify new gaps such as nurses not being able to prescribe, prescribing in insufficient doses and lack of follow-up and titration after the original prescription.

### Additional resources

The STEP-UP model acknowledges that knowledge alone is not enough to integrate palliative care into publicly funded health systems and that both tangible resources (funding for rooms, printed resources) and ongoing support (mentoring) are essential ingredients in addition to knowledge and training.

### Regularity of contact

Using existing structures is an important ingredient of STEP-UP. We targeted district teams, and in particular District Health Management Teams, as a way in to services. Rather than setting up new project teams or hierarchies, we worked with the existing structures and aimed to embed services into the established systems.

Maintaining regular contact with the districts was important. Each district was visited every six months. In addition, districts were invited to attend group activities in between visits including national coordinator meetings twice per year. A specific activity such as an orientation session or volunteer training was also held in each district.

### Local ownership

We used a participatory approach to design and implement STEP-UP activities. As well as helping to design priorities, members of District Health Management Teams and palliative care coordinators actively participated in delivering events. For instance management team members and coordinators co-facilitated training for local volunteers. Having local facilitators co-lead events supported sustainability by building up links between the volunteers and the hospital teams and by ensuring district teams took ownership for ongoing support.

*Photo: Trained community volunteers*

## Helpful and hindering factors

A success factor for STEP-UP is having a **strong and cohesive team**. PACAM has restructured itself as an organisation to fully integrate the STEP-UP team. This means that STEP-UP team members not only have a role in the programme, but also wider strategic issues and advocacy at PACAM. As in most teams, there remain differences in working styles and personalities, but PACAM has been proactive in fully integrating STEP-UP into the organisation rather than seeing it only as a 'project'.

With the permission of the donors, True Colours Trust, funding from STEP-UP was used flexibly to help recruit a Finance and Administration Manager for PACAM who contributes not only to STEP-UP but other PACAM programmes. Having an **understanding donor partner** who is committed to ongoing funding means that PACAM is beginning to flourish as an organisation, which in turn strengthens our delivery of activities to embed palliative care.

Additional staff members from PACAM have become part of the STEP-UP team, taking part in training and in mentorship visits and playing a key role in collecting information. The evaluation lead at PACAM has undertaken significant work to collect quotes, input survey forms and compile statistics to showcase the impacts achieved.

The **monitoring and evaluation system** used for this programme has been applied to PACAM as an organisation (with a monitoring framework developed to measure progress towards meeting the organisation's strategic objectives) and to all other PACAM projects. In fact, the evaluation approach and tools developed by STEP-UP is now being rolled out to other organisations. For example, PACAM is running one of several projects funded by USAID. USAID liked PACAM's tools and approach so much, it asked that PACAM be used as a role model to implement the same indicators and tools across all 16 organisations taking part in that programme (in different countries).

In terms of programme delivery, **getting senior management involved** early in the districts has been crucial for the success of STEP-UP as these people control budgets, room allocations and staff time. Small incentives, such as funds towards room refurbishment can encourage District Health Management Teams to set aside a room for palliative care and to allocate staff.

As well as helping districts, providers and patients, STEP-UP has had benefits for PACAM as an organisation. The top five benefits have been:

1. contribution of STEP-UP staff to undertake other roles within the PACAM team, including management and support activities
2. contributing to funding of key staff within PACAM such as a Finance and Administration Manager that work on other PACAM programmes, not solely STEP-UP
3. building skills and capacity which could be applied to other projects, including skills in project management, human resources, data collection and analysis
4. support and funding for PACAM organisational review and technical support which helped with our strategic plan and other activities in addition to STEP-UP
5. helping PACAM achieve its objectives as outlined in the strategic plan, including much greater visibility of PACAM as an organisation. Thanks to the work of STEP-UP, all districts and many senior policy makers are now aware of PACAM whereas previously the activities of PACAM were known amongst a narrower group

There are however some challenges. Whilst good progress has been made to strengthen PACAM as an organisation, the organisation remains reliant on a small number of donors and is finding it difficult to cover core staff and premises costs in the longer term. In order for the gains of STEP-UP to be sustained, **ongoing national coordination** is probably required in the immediate future. However PACAM does not yet have a robust resource mobilisation strategy. The funding of PACAM staff on a project by project basis means it can be difficult to find time to undertake broader strategic coordination activities for palliative care.

Gains have been made in each district but districts are often slow to provide information or organise activities. This is hindering advocacy efforts to promote visibility of palliative care for better access. Not all people trained in palliative care are actively providing the service, as districts do not allow the staff to prioritise this service due to many competing demands.

On an exchange visit to Kenya, the STEP-UP team learnt the value of having proactive palliative care coordinators actively involved in management teams. Coordinators who were able to operate at this senior level were more likely to have resources allocated to palliative care and to be providing high quality services at district and community level. In Malawi, palliative care coordinators are committed but may lack skills, confidence or training in **programme management and senior engagement**. STEP-UP did run an introduction to leadership skills to attempt to address this, but more work could be done to ensure that coordinators are proactively campaigning and advocating for resources in their districts rather than relying on STEP-UP.

**Regular contact** with the district through coordinators meetings and mentorship visits is key to sustaining gains. Palliative care coordinators and providers receive regular support, but engagement with District Health Management Teams revolves around brief engagement during mentorship. More regular activities targeted at management level would help keep the profile high. Whilst costs may prohibit managers travelling for centralised events and it would not be cost-effective to run management events in every district regularly, activities could be run at zonal level whereby management team representatives from three or four districts take part.

**Prescribing practices** for pain relief in districts remain a concern. The number of patients on morphine is almost equal to the number of people experiencing severe pain which is a positive sign however most of these patients are being under dosed or their doses are not reviewed despite the progression of the disease. This reinforces the need for ongoing mentorship and clinical placements. A more detailed focus on appropriate prescribing may be something to consider for the next phase of the programme.

## Insights for other areas

Other countries considering strengthening palliative care services, may consider the following suggestions based on learning from STEP-UP:

- In decentralised management structures, the equivalent of District Health **Management Teams** are a key entry point into the district and should be encouraged to participate in the planning and implementation of any intervention related to palliative care. This is because they are critical in resource mobilisation and allocation.

- **Combining** a bottom up (staff-focused) and top down (management-focused) approach may have the greatest impact.

- Setting up a network of local coordinators within existing services is sustainable and creates buy-in. Palliative care coordinators should be well chosen as they need to be **proactive** locally. They need to ensure regular team meetings and develop monthly rosters of providers to staff palliative care services.

- Small **pump priming** for purchasing equipment or refurbishing rooms can make a big difference in whether or not a room is allocated for palliative care.

- It is not good enough solely to set up good palliative care services. Effort also needs to go into strengthening strategies to ensure patients are **identified** on wards and in outpatient clinics. Many patients miss out on having their palliative care needs met.

- It is important to think about the whole person when providing palliative care. People may have more than one condition. Integrating palliative care clinics with the clinics for other non-communicable diseases can be useful rather than solely focusing on HIV and cancer alone. **Coordinating appointments** will reduce time, travel and costs for patients and their families rather than attending multiple appointments.

- Palliative care service delivery remains a team effort and requires **ongoing support**. One-off interventions will not work to sustain the service on the ground, so ongoing follow-up is needed. Training alone is not enough. Prior to STEP-UP, some providers in the districts had been trained by the Ministry of Health but there was no follow-up support and management often did not know they had trained providers in their district so were not making use of them. Having a co-ordinated approach that informs management and fuels a constant supply of trained providers is necessary for sustainability. For example, clinical placements after training can help to embed skills and make changes to service delivery. They are not only useful for individual providers, but also for facilities because providers bring back new ideas about how systems and services should run. Regular contact with the district through forums such as coordinators meetings and mentorship visits is also key to sustaining gains.

- **Training community workers** may improve the referral system and improve the quality of palliative care provided at home and can be a vital way to get knowledge about palliative care out into communities and rural areas, where people have little access to health services.

- It is important to **monitor implementation** of the palliative care roster and documentation of patients in palliative registers. Keeping good records is essential for monitoring change and planning improvements. Reviewing the quality of data collection regularly through supervision visits is important and collating information nationally can help to show which districts and topic areas may need extra focus.

- Pharmacy technicians and District Medical Officers can take the lead in conducting ongoing **Continuing Professional Development** (CPD) sessions about morphine use. Prescriptions are often too low a dose so increasing the availability of morphine is a good first step, but only one stage of the journey.

- District Health Management Teams or similar need to supervise and follow up on the activities of the providers, so that there is **accountability** for achieving the goals set and so more people benefit from palliative care.

# 7. Next steps

In 2015, the True Colours Trust gave a broad commitment in principle to provide four years of funding for STEP-UP in the Central and Northern regions, dependant on progress in the first two years.

PACAM is pleased to report that the STEP-UP programme achieved all of its objectives for August 2015 to June 2017, with almost all planned activities completed or underway. The impacts assessment shows that there was increased knowledge and confidence about palliative care amongst management teams, frontline staff and community stakeholders and volunteers; that palliative care became embedded in District Implementation Plans; that processes for palliative care were strengthened in district hospitals, and that good progress was made in the number of people receiving palliative care and pain relief medication. This is particularly encouraging given the large geographic area of the Central and Northern regions (much larger than the Southern region).

However, this report has highlighted that much work remains to further strengthen palliative care in Malawi. We have achieved a good basis, but now need to turn our efforts to more strategic-level initiatives and building in sustainability so palliative care continues to flourish after STEP-UP ends.

In the two year period from August 2017 onwards, if funding is granted, priorities for STEP-UP may include:

1. **Strengthening palliative care infrastructure**. This may include continuing to build up clinical placement sites and supporting districts to provide training and awareness raising rather than always being reliant on the STEP-UP team. Importantly, we would like to focus on improving morphine prescription and use. We have found that whilst morphine is being prescribed routinely for palliative care patients, the doses are often not sufficient to provide appropriate pain relief. Making inroads into nurse prescribing may be a priority here.

2. **Extending palliative care into communities**. This may include training champions in every district (volunteers, traditional leaders) to promote palliative care locally and linking these champions to PACAM members for ongoing support. It may also involve developing simple posters for local communities to raise visibility. STEP-UP has done a lot of work with district hospitals and it is now time to concentrate more on joining this up with the community – not solely through sensitisation, but by training active 'champions' on the ground to promote and support palliative care. Training and keeping these people motivated will bring a new unpaid workforce of people to spread the palliative care message. This is a potentially sustainable model of palliative support for those living in rural and remote regions where health professionals seldom venture.

3. **Supporting the national quality assurance process.** This may include embedding national quality indicators by training palliative care coordinators and data officers about how to use new monitoring tools and supporting the Ministry of Health to analyse and feed back annual monitoring indicators to every district with tips for improvement. This is crucial so the information collected is used to guide practice. This priority may also include working with the Ministry of Health to train supervisors every year so consistent mentoring visits are undertaken to build good practice. Other activities could include running drugs task force meetings and other strategic national activities and preparing a briefing about increasing dedicated staff for palliative care. PACAM needs to work at a strategic level in order to make lasting change in Malawi. Over the past two years we have focused on delivering specific project activities for STEP-UP but it is now time to take this to a more strategic level where we can have lasting impact.

4. **Strengthening national coordination of palliative care** throughout Malawi, with a focus on ensuring that PACAM is well placed to provide information, resources and support to teams on an ongoing basis. This may include upgrading the PACAM website and providing an online palliative care directory and membership database; implementing a communications plan and resource mobilisation strategy to ensure that organisation is more sustainable; and developing a PACAM newsletter to share good practice. It is important to strengthen PACAM as an organisation in order to continue all the other training and development work for services and workers.

Box 10 provides examples of possible activities, to be discussed further with the donor. The theme running through all of these plans is to build in sustainability. PACAM is proud of the achievements of STEP-UP in 2015-17. We know there is much more to be accomplished, but the number of people accessing palliative care and the quality of care has improved. For the first time ever, palliative care is integrated into all district health services – the key goal of STEP-UP.

*Box 10: Examples of potential future activities for STEP-UP*

**Strengthening national coordination**

- facilitating national coordinators meetings twice per year
- commemorate World Hospice and Palliative Care Day as a way of raising awareness of palliative care issues
- conduct palliative care members update meetings in five zones twice per year
- contribute towards the salaries of PACAM personnel who take part in the programme such as the Executive Director, Programme Director, Finance Manager, Finance Officer, Administration Assistant, Project Officer, technical support officer admin and one support staff
- contribute towards office running costs on a cost sharing basis with other projects

**Supporting national quality assurance**

- support the Ministry of Health to roll out APCA Palliative Care standards to measure the level of palliative care being provided in various sites
- embedding national monitoring framework by training coordinators and data officers in use of new national indicators
- support Ministry of Health to report back trends in data to individual districts
- coordinate national supervision and mentorship at least twice per year, including training supervisors
- conduct national drug taskforce meetings to monitor the supply chain for palliative care drugs

**Extending palliative care further into communities**

- support districts to train more community home based care volunteers

**Strengthening palliative care infrastructure**

- develop and implement an exit strategy to include forming a national palliative care supervisory team to be coordinated by the Ministry of Health
- continue improving capacity to manage patients through refresher courses, mentorship visits and clinical placements
- support districts to conduct sensitisation meetings to increase awareness about the palliative care services available
- provide clinical support to the two new clinical placement sites in order to maintain standards
- conduct refresher courses for prescribers and pharmacy staff on management of palliative care drugs including morphine

Note: the above list contains <u>examples</u> of potential activities to be refined further in discussion with True Colours Trust.