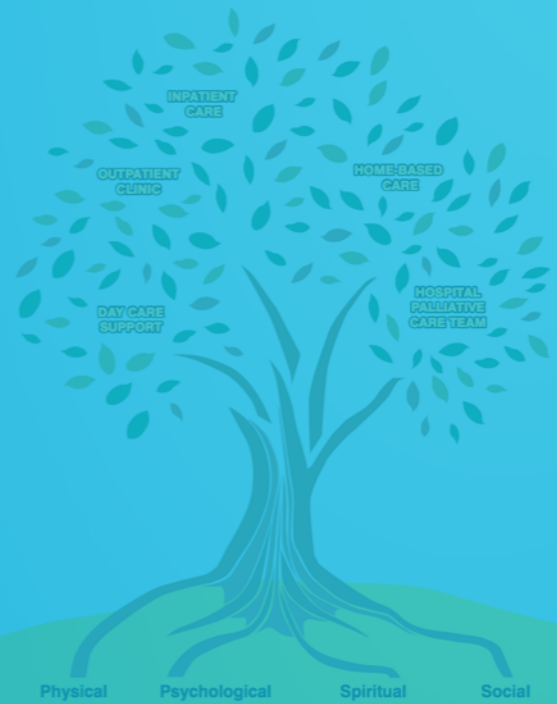


Report

Evaluation of the Palliative Care Toolkit



Palliative Care Toolkit
Improving care from the roots up
in resource-limited settings

THE WORLDWIDE PALLIATIVE CARE ALLIANCE
Advancing hospice and palliative care



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September 2015

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Abbreviations

APCA	African Palliative Care Association
HBC	Home Based Care
HtH	Help the Hospices
IAHPC	International Association of Hospice and Palliative Care Associations
PC	Palliative Care
WHO	World Health Organisation
WHPCA	Worldwide Hospice Palliative Care Alliance

Introduction

The Palliative Care Toolkit: *Improving care from the roots up in resource-limited settings*, was developed in 2008 with support from the Worldwide Hospice Palliative Care Alliance (WHPCA) in partnership with Help the Hospices (HtH), now operating as Hospice UK.

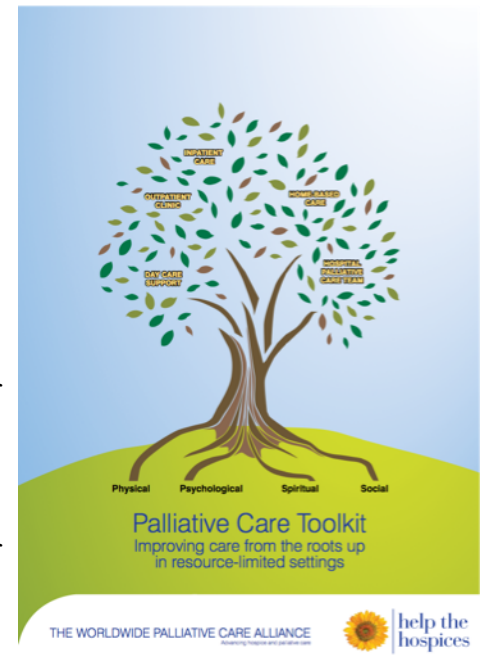
The aim of toolkit was to strengthen the capacity of health care workers to deliver quality holistic care to individuals with life threatening illnesses and their families. The rollout of the toolkit sought to expose and introduce health care workers, particularly those in resource poor settings, to the concept and principles of palliative care as well as provide strategies to apply the approach in local settings for enhanced coverage of quality care.

The Toolkit has been in use in various parts of the world since it was first published. It is against this background that WHPCA commissioned an independent evaluation of the Toolkit to better understands the scope of its use worldwide, and the impact it has had on community and grassroots palliative care. The evaluation is expected to inform the revision of the Toolkit and the appraising of options for scale-up of community driven palliative care around the world.

The evaluation sought to answer the following questions:

- ① *Where in the world has the toolkit been used? Has it been used more in certain countries/ regions/ settings?*
- ① *What is the profile of people who have used /do use the toolkit?*
- ① *How is it used?*
- ① *What impact has the toolkit had on:*
 - *Knowledge, confidence and practice among individual healthcare workers at different levels?*
 - *Palliative care services (organizational level impact)? and*
 - *Palliative care in different settings (hospice service / community based / hospitals)*
 - *Beneficiaries of palliative care: by age - children, adults and older people (over 50), by illness type?*
- ① *What are the factors that have encouraged or hindered success of the toolkit?*
- ① *What other impact has the toolkit made?*

This report provides the findings of this review and proffers recommendations for the refinement of the toolkit and strategy for its access. The report has four sections; Chapter 1 provides the summary background and Chapter 2 details the methods used in the review. This is followed by a descriptive and analytic outline of the findings in Chapter 3. Conclusions and recommendations drawn from the findings are summarized in Chapter 4.



Methods

2.1 Evaluation Framework

Using the traditional results chain framework {which recognises results at four different levels: after *Inputs and Processes*, leading to *Outputs* in the immediate/short term that contribute to medium term results commonly referred to as *Outcomes* and ultimately long lasting changes in the form of *Impact*}, the development and rollout of the Toolkit can be viewed to have comprised a set of inputs that include human resources, finances and material resources which enabled certain processes/activities such as the dissemination and marketing to be undertaken. In the short term, the availability and enhanced access to the toolkit globally is anticipated to have paved way for the its utilization in the medium term resulting in improvements in systems for palliative care provision and good coverage of quality palliative care in the long term.

This summary theory of change provided a logical starting point for assessing the intervention i.e. developing and disseminating the toolkit. At the micro-level, the assessment of the effectiveness and impact of the toolkit was however guided by the use of the Kirkpatrick's Model. Although, the model is primarily used for assessing training effectiveness, its approach remains relevant due to the common focus on capacity building. Kirkpatrick's Model recognizes four levels of assessing effectiveness:

- i. Reactions* - assess the user's perception of the relevance, appropriateness and user - friendliness of the content, structure and delivery of the toolkit
- ii. Improvement in Knowledge* - did users acquire knowledge? What knowledge was gained and by who?
- iii. Practice/Application* - what have been the changes in practices? (National, Institutional) e.g were new structures or institutional arrangements set-up to better respond to the need?
- iv. Results* - What are the levels of PC development - What is the coverage and quality of PC services?

2.2 Details of Study Design Elements and Approach

Study Design: - The study made use of a Cross-Sectional Study Design, which applied both quantitative and qualitative techniques (Mixed Methods).

Study and Reference Population - Institutions (Private, Government, Community) offering palliative care services were considered to be the primary unit of measurement in the study and were drawn globally though with a focus on developing regions. The findings are therefore inferable to developing regions global setting.

Sampling Strategy and Sample Size - All institutions offering palliative care services in the developing regions (excluded USA and Europe) were eligible for inclusion in the study. The list of institutions registered under the International Association of Hospice Palliative Care (IAHPC) and national and regional palliative care bodies constituted the sampling frame from which organisations were targeted for a request for participation. Key informants were purposively sampled for interviews to provide more in-depth reflections on the study matter. Of interest were key PC strategic persons or advisors, policy makers, and representatives from implementers. A total of 10 Key Informants were purposively selected with guidance from the WHPCA team.

Outcome and Study Factors - The outcomes of interest included access to the Toolkit, utilisation of the toolkit, Practice levels, beneficiaries and levels of PC development (for country). Study factors included Geo-Location (country and region), types of institution and type of health worker.

Data Collection Methods and Tools - Data collection was undertaken through an Online Survey Methodology and telephone

based in-depth interviews of key persons. A structured questionnaire that covered both Outcome and Study factors was developed and used to craft a corresponding electronic online template using Survey Monkey. This approach allowed for easy access to the data collection tool by target groups globally, easy entry by participants and a quick turnaround in both responses and collating of data. A semi-structured interview guide was also developed to aide the in-depth interviews with key informants. The review of literature was also essential and was guided by a framework and key questions. Some of the main documents reviewed include: The Palliative Approach Toolkit (Universty of Quensland 2012), A Handbook of Literature in Africa (APCA), APCA Standards for Providing Quality Palliative Care Across Africa (APCA 2011), Palliative Care - Cancer Control Knowledge into Action (WHO) and Integrating PC into HIV Services: A Practical Toolkit for Practitioners (FHI360). The framework of the literature review sought to facilitate a general assessment of the PC Toolkit in two core domains of i) Additionality and Complementarity i.e *inform the review in terms to relevance*; ii) Conformity to Standards and Best Practices i.e *relate to accuracy and adequacy*.

Data Analysis - The following analysis techniques were applied:

Descriptive Statistics were used to provide a descriptive overview of the outcomes of interest.

- *On limited occasions, multivariate analysis was used to assess associations between outcomes and some study factors.*
- *Geo-Information System (GIS) mapping was used to provide a visual description of where the Toolkit has been used. As part of the data collection tool, data on Geo-Location such as Country and Region was collected and used for mapping.*
- *Qualitative data analysis techniques, primarily content analysis across thematic areas, were applied to the qualitative data obtained through the in-depth interviews.*

The above analysis is presented in the form of Standard Output Tables, Graphs/Charts, GIS Maps and Quotes in the Findings section of this report.

2.3 Implementation Strategy

The following steps were undertaken in the execution of the study:

1. Listing of Organisations - using the IAHPD Database and some regional and national umbrella organisation registries,
2. Development of Tools,
3. Distribution - this involved a combination of direct email distribution using contacts from Master Register (from Step 1) and the different options for Survey Collector in Survey Monkey (Email Link, Email Invite, Website Embedding). The survey was also marketed through online platforms such as eHospice.
4. Data Collating and Analysis and
5. Report Writing

2.4 Limitations

The following limitations of the study are acknowledged:

- The toolkit was never monitored or regulated in its distribution
- The evaluation relied entirely on e-mail and telephone access and no on the ground assessment to confirm findings hence there was no way to ensure adequate coverage of services



Findings

3.1 General Profile of Respondents

A total of 104 individuals responded to an Online Survey, of which 99 completed the questionnaire. This represents a 73% response rate relative to the total listed organisations that were deemed eligible to participate. The majority (46%) of respondents were stationed in Africa whilst slightly over a quarter (28%) were from South Asia. South America also contributed a significant share (15%) of participants.

Figure 1: Regional Location of Participants (n=104)

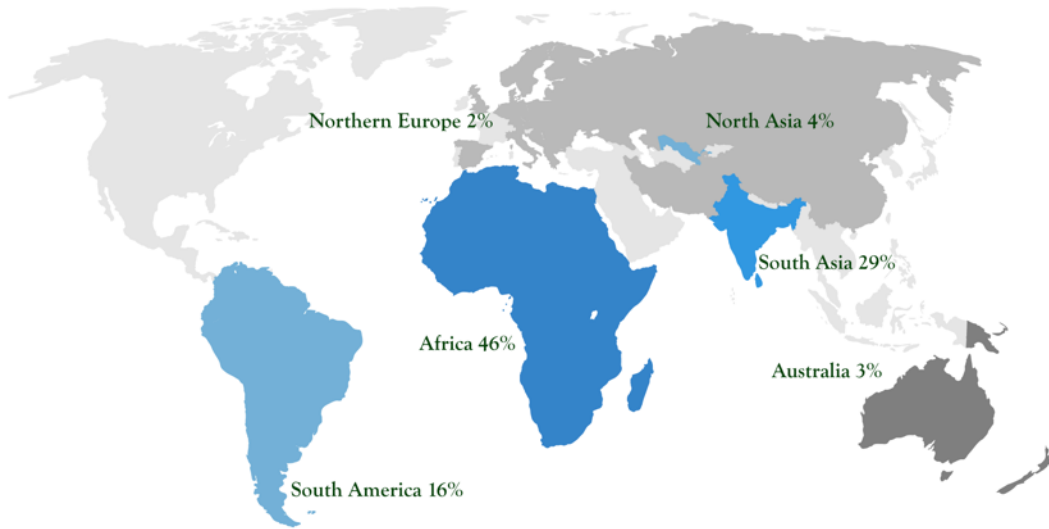


Fig 2 shows that participants were drawn from a wide cross-section of service delivery settings including Private PC Organisations or Hospices, which contributed over a fifth of participants; and Public and Private Health Facilities as well as Academic Institutions although no Development Partner or Donor participated.

Only a fifth of respondents were stationed in a rural setting whilst more than half of the individuals were either from an In-Patient Unit (34%) or Home Based Care Unit (30%) - Figure 4. The group of 'Other' participants comprised of individuals with various professions that included palliative care practitioners (nurses and doctors), coordinators of PC programs, lecturers at tertiary institutions and general medical practitioners. Although there is a likely overlap between reported Job Titles and professions, e.g Social Workers who are Project Coordinators, the categories deduced from the job titles show that the majority 52% of respondents reported their title as a Medical Doctor (includes Physicians)-Figure 3.

Figure 2: Type of Organisation

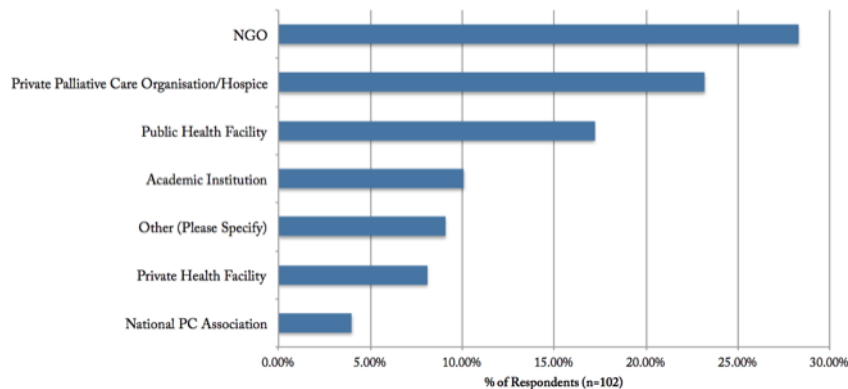


Figure 3: Deduced Categories for Job Titles

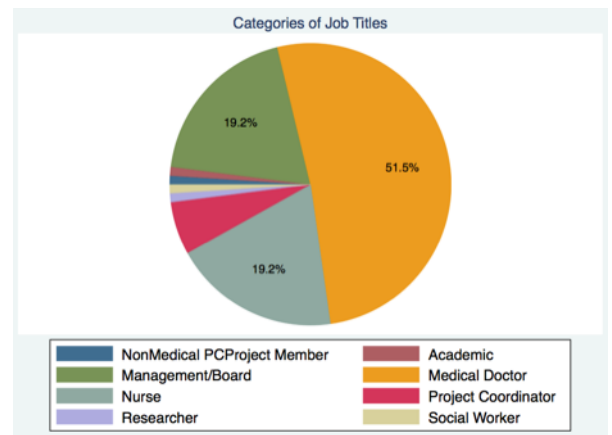
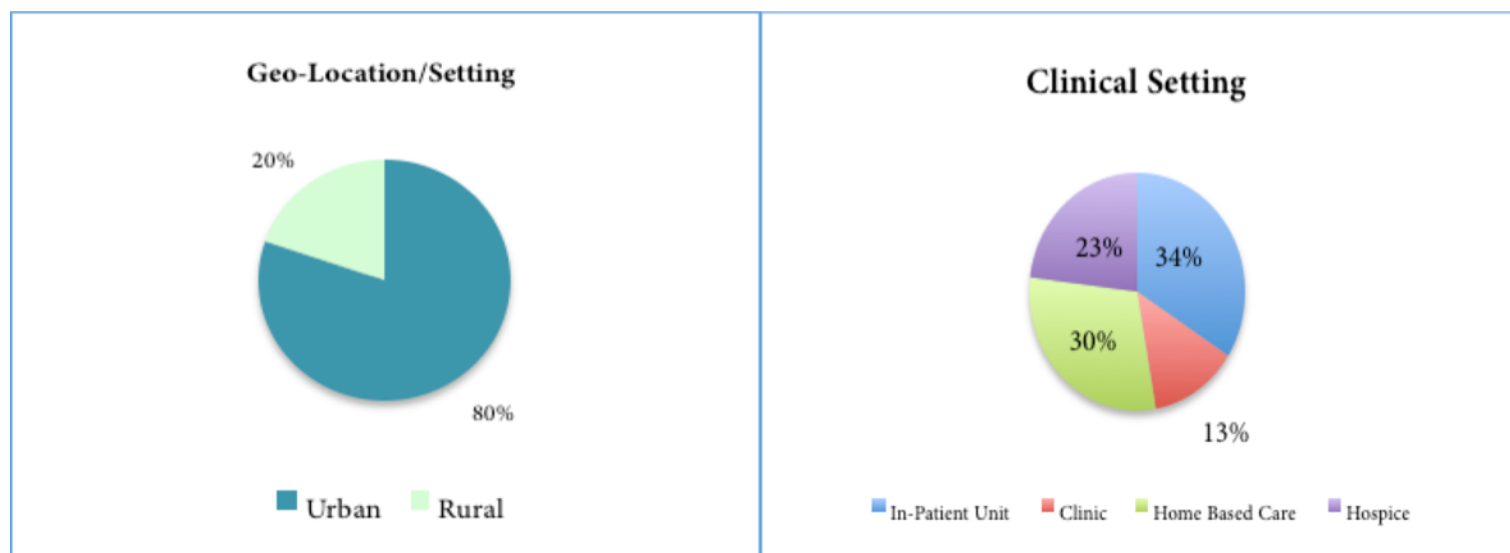


Figure 4: Geo-Location and Clinical Setting



A total of 10 key informants participated in telephone/Skype based in-depth interviews. The respondents comprised of senior palliative care practitioners with several years of palliative care practice and teaching as well as leadership in various capacities in the field of PC. Eight of the 10 respondents are involved in palliative care teaching. Three also participated in reviewing and contributing to the toolkit during its development.

3.2 Purpose and Relevance of The Toolkit

The background information relating to the Palliative Care Toolkit reflects a focus by the developers to craft a practical tool that may be used to develop capacity of individuals and organisations to provide palliative care in resource limited settings. The development of a Training Manual that is aligned to the Toolkit also indicates the intention for the dual use of capacity strengthening through training and use of a guide in service provision.

The key persons interviewed in this review share a similar understanding of the intention of this resource, particularly with regards to the intended use and target settings.

Extract from PC Toolkit Introduction

...written to empower health workers in resource-poor settings to integrate palliative care into the work they are doing by grafting the missing elements of care onto what is already in place. It takes a 'can-do' approach, showing that good basic palliative care can be delivered within existing community and health structures by people without specialist training,

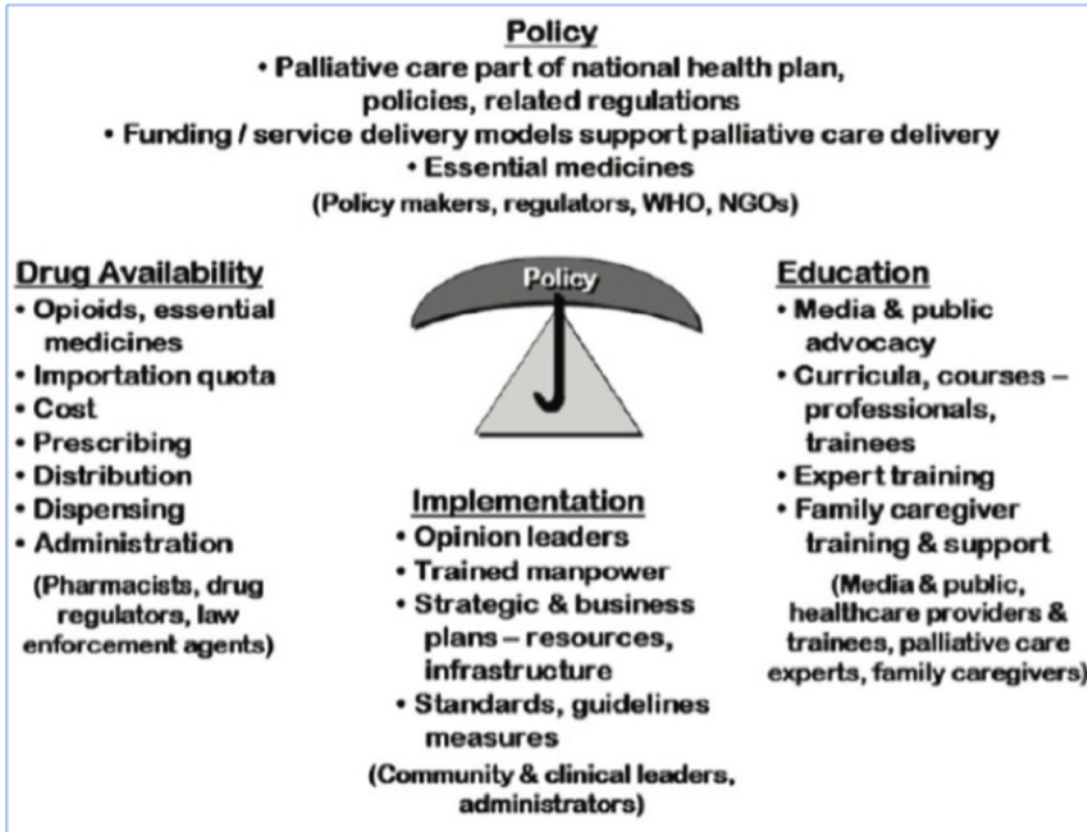
"I understand it was a tool for anybody involved in palliative care from doctor right down to village health worker and volunteer level so that anybody could feel enabled and felt that they were able to do something to help people with life limiting conditions", PC Practitioner and Trainer

Several reviews of the need for palliative care in the past decade have shown significant deficiencies in PC service provision largely owing to the lack of PC knowledge amongst health workers and communities amongst other systemic factors such as the absence of PC Policy Frameworks and unavailability of essential PC medicines. PC Education remains one of the four pillars of the recommended strategic framework for population based PC programmes - Figure 3 .

The majority of developing countries have only started in recent years to introduce palliative care in the pre-service medical and nursing curricula. The consequence of the existing gap in pre-service PC teaching has been the glaring paucity of PC knowledge amongst practicing service providers and negative attitudes towards PC.

"this toolkit really came at a right time because the reality is the majority of us out there have not been knowledgeable of PC. In my country, it was only introduced in medical and nursing school two years ago and we only expect those graduates to be practicing in five or more years to come", PC Practitioner (MD) and Coordinator

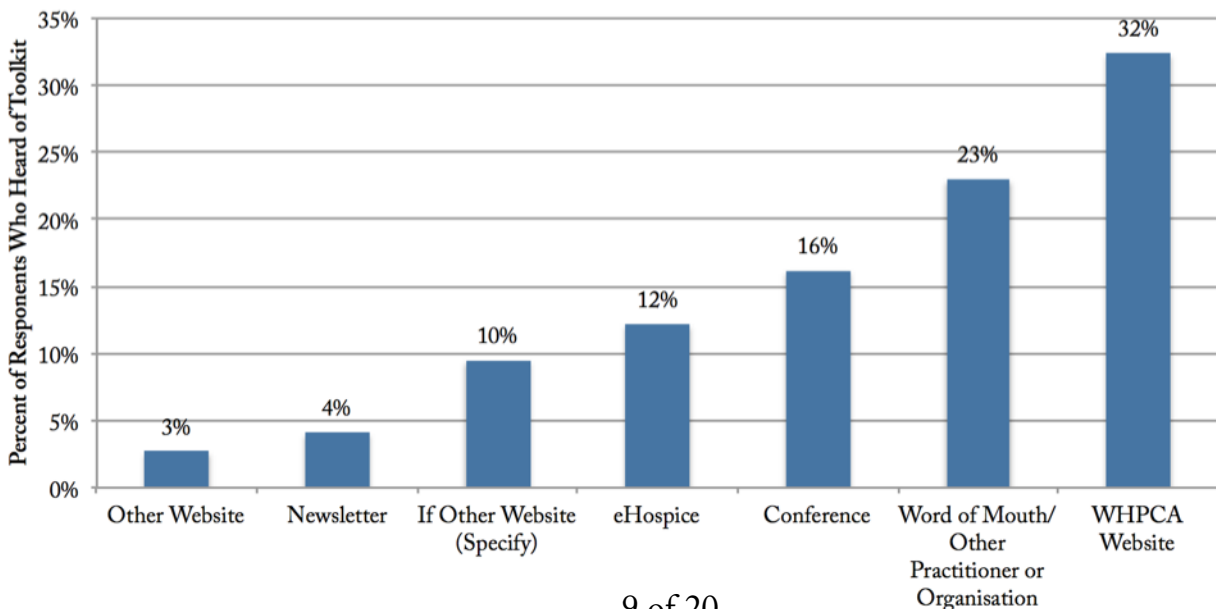
Figure 3: Enhanced WHO Public Health Model



Despite the efforts to also provide palliative care teaching to practicing practitioners in the past years, the teaching has largely been through a series of presentations and talks without pre-defined curricula. Service provision was also not guided by guidelines or standards and only in recent years have there been noteworthy investments in Guidelines, Standards and Toolkits. The Palliative Care Toolkit was commended for being complementary to other resource materials in terms of content and structure. Other resources that have been mentioned include the APCA Standards and another toolkit: Integrating Palliative Care into HIV Services (FHI 360). The literature review did corroborate these perceptions as there was a notable consistency in the accuracy of palliative care messages shared, conformity to general guidelines of palliative care provision as expounded in resources such as the APCA Standards and complementarity particularly in delivery approaches and tools.

The PC Toolkit has been accessible to the target groups. Three quarters (75%) of the respondents reported having heard of the toolkit. Nearly a third (32.4%) of the 74 respondents who heard about the toolkit got to know of the toolkit through the WHPCA Website. Some individuals accessed information about the toolkit from conferences (23%) and word of mouth/ other professions (16%). The eHospice platform was also a notable source of information relating to the toolkit constituting 12% of the sources of information.

Figure 4: Source of Information on Toolkit (If Yes, How Did You Know of The Palliative Care Toolkit?, n=74



The spatial distribution of respondents to this survey as well as that for individuals who reported having heard and having seen the toolkit (in whatever form electronic or hard copy) does show that the resource was widely accessed and particularly in the developing countries where most of the survey data was obtained.

Figure 5a: Distribution of Survey Respondents (Dot Size =1 and Randomly Distributed in Country)

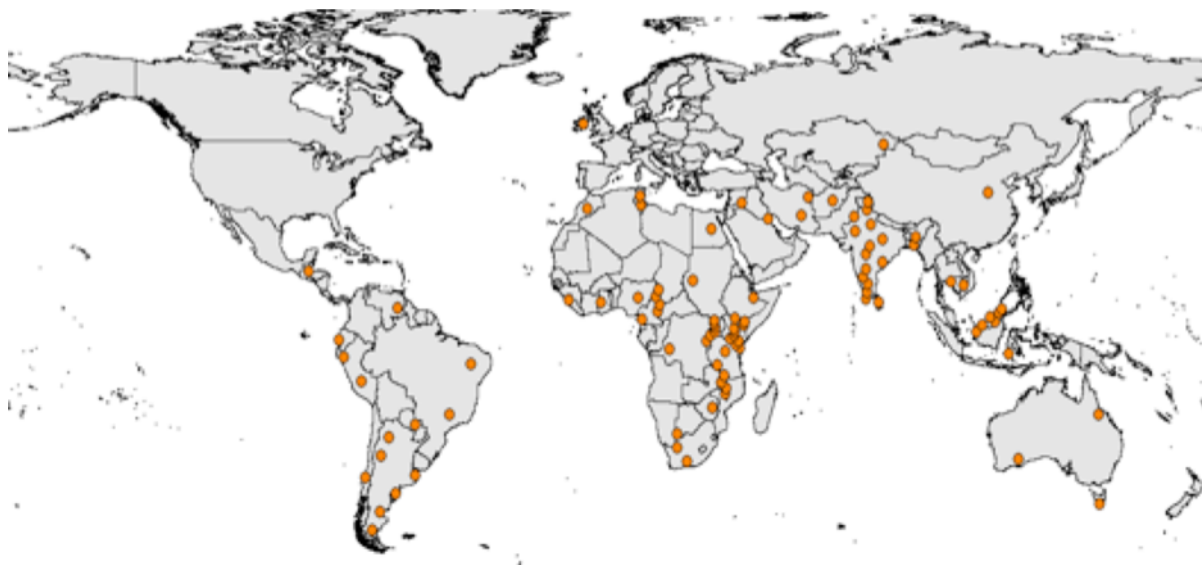
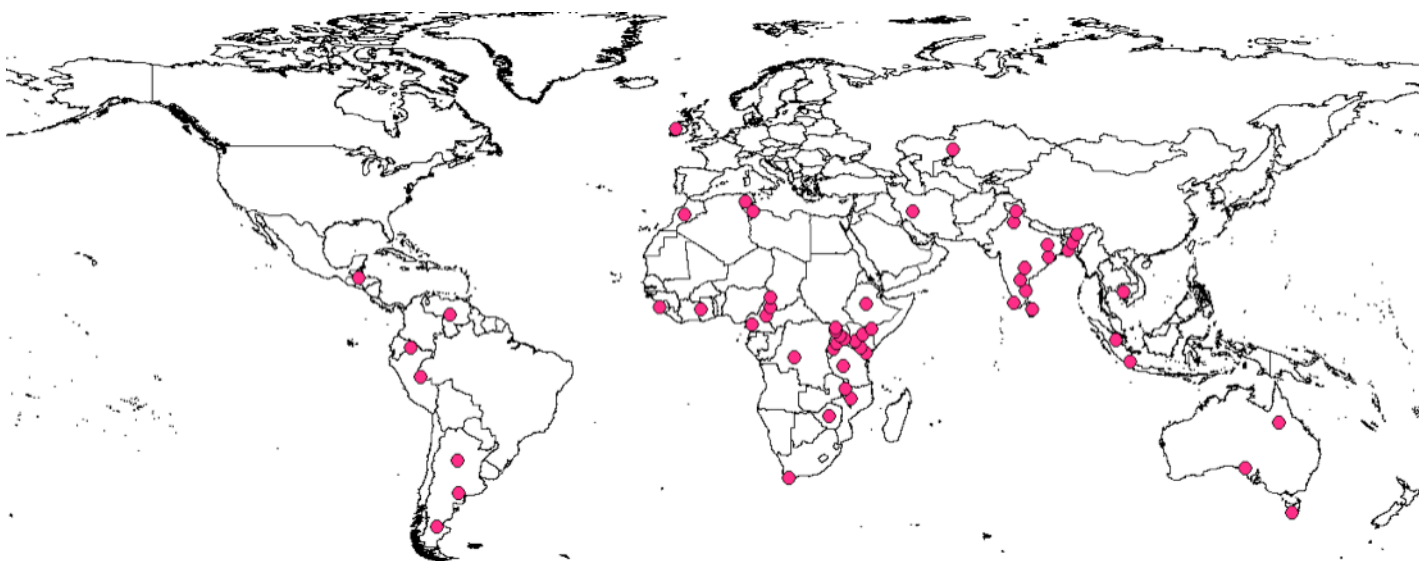
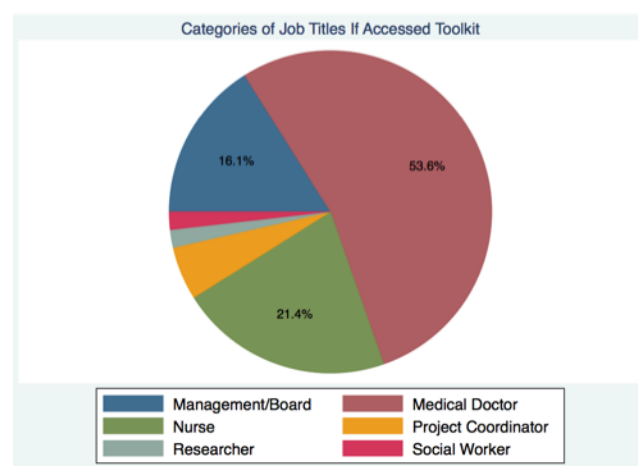


Figure 5b: Distribution of Survey Respondents Who Heard and Seen the Toolkit (Dot Size =1 and Randomly Distributed in Country)



Only 56 (57%) of the 99 survey respondents had access (sight) of the toolkit either in electronic or hard copy? Only these respondents continued to respond to detailed questions relating to the toolkit. Similar to the overall distribution, the majority of those who reported having had access to the toolkit were in fact medical doctors (53%) and nurses (21%). This therefore provides a useful context for the interpretation of findings on the perception of the toolkit.

Figure 6: Categories of Job Titles For Those Who Accessed Toolkit



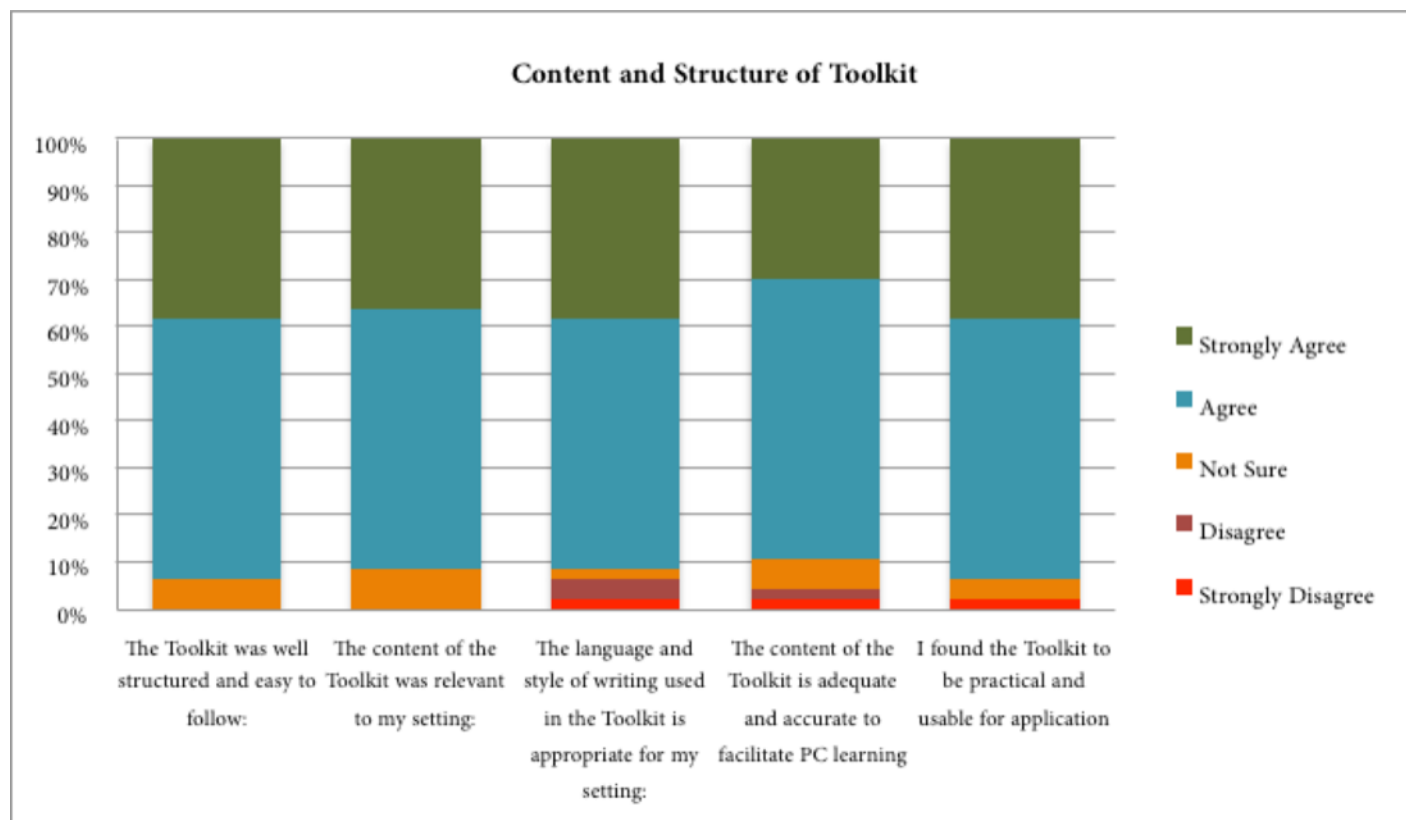
The toolkit is largely being accessed through the websites as an electronic copy but the discussions with key persons show that there is downstream access, particularly at the community level, through the trainings. It is standard practice that those who are providing the training and using the toolkit as a guide print copies for participants who typically include doctors, nurses and village health workers. Internet access is still minimal in most communities and the printed copies present the best option for cascading the resource. A fifth (20%) of survey respondents indicated accessing the toolkit through “Other”, which predominantly is constituted by print copies from various sources. Nearly all people interviewed and those who have been involved in using the resource in training indicated the need for funds to support the printing as this may hamper access. Generally, the distribution plan for this resource was cited as an area that may require further reflection.

3.3 Content and Structure of the Toolkit

Survey respondents and key persons feel the toolkit has appropriate content for introducing palliative care and is well structured to facilitate easy comprehension of essential PC aspects that would ordinarily be presented in a complex manner when using the traditional didactic approaches.

Fig 7 shows that at least 90% of the 56 respondents either *agreed* or *strongly agreed* to positive statements representing five tracer indicators for quality of content and structure of the toolkit. These findings were supported by the in-depth interviews, which indicated that users of the toolkit generally feel the content is well structured, facilitates learning and that it is practical and easily applicable.

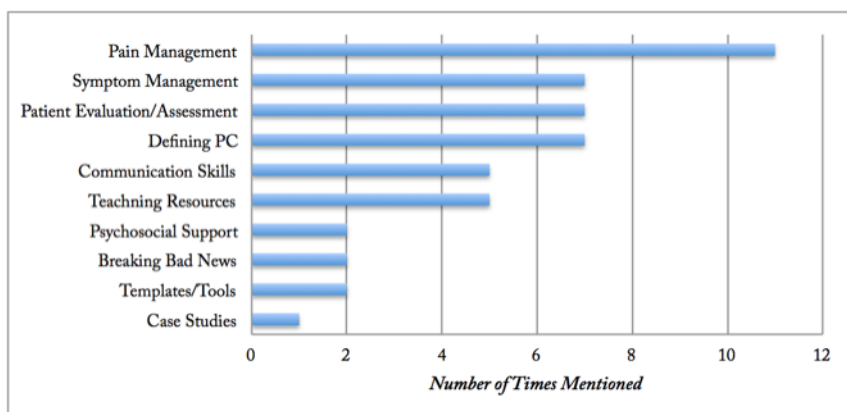
Figure 7: Perceptions on Content and Structure of Toolkit (Select Statement That Best Describes Your Level of Agreement), n=56



Respondents felt the format of the toolkit was easy to read and use and allowed for selective printing of sections for reference. Users have found the content to be very appropriate and accurate to facilitate learning. The sections that were specifically mentioned to be very helpful appear to cut across the content of the resources as some cited communication skills, pain assessment, symptom management, breaking bad news and general description of what palliative care is as shown in Figure 8.

The analysis of the various responses and insights from the in-depth interviews suggest the strength of the content lies in its simplification of the concept of palliative care for easy comprehension as well as facilitating learning or introduction of PC to non-medical practitioners. Although, nearly all informants felt the simplification allowed for better understanding even amongst health professionals, some felt there would be need to include additional materials if the toolkit is to be relevant for medical personnel. The reasons for this were that medical personnel may need more detail in certain aspects, for example in Symptom Control and Pharmacology.

Figure 8: Content Found Helpful (What content did you find most helpful?)



“I have personally found it to be extremely useful, it is very helpful, but I do feel it may require some additional content to suit the medical practitioners. Some detail in the scientific aspects would certainly add value”, PC Practitioner (MD)

It was further opined that some health professionals developed a negative attitude towards the simplified nature of the resource and would prefer a more detailed writing. The general feeling provided is that the toolkit is a very useful and appropriate resource for introducing palliative care particularly to the non-medical personnel. One survey respondent indicated:

“More detail - it was very basic - OK for community workers and low level nurses but that is all”, Survey Respondent

Although nearly all respondents felt there was little that could be taken away from the toolkit, several suggestions were proffered on how to strengthen the content. Whilst some respondents suggested improving the depth in general, some were specific and suggested the following topics for either addition or further elaborating.

- *Ethics and Legal Issues in Palliative Care*
- *Psychosocial Care (Detail)*
- *Children's Palliative Care - Working with Teenagers*
- *Spirituality in the African Context*
- *Pharmacology*
- *Disease Burden*
- *Symptoms and symptom management*
- *Natural History of Disease*
- *Holistic Approach (not described in-depth...)*
- *Counseling*
- *Breaking Bad News*
- *End of Life Care*
- *More on wound assessment and management*
- *Rating scales for ADL's and cognitive impairment*
- *Clarifying terms - palliative care, end of life care, (community) home based care*
- *Morphine compatibility with other drugs (ie syringe drivers)*

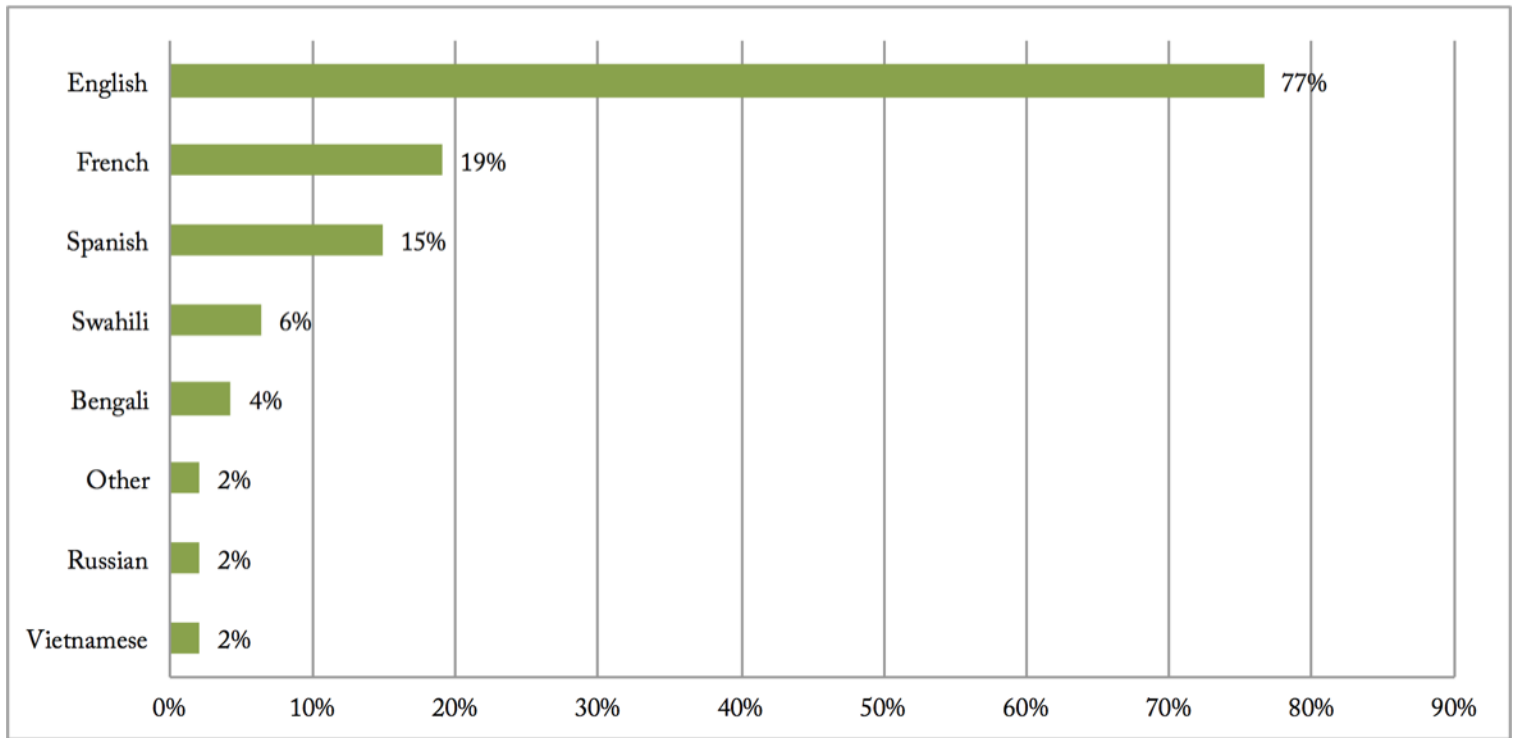
Although informants suggested one or more topics that could be included or further detailed, nearly half further suggested the need for caution in further unpacking some the sections citing the risk of diluting its major strength of being applicable to a wide cross-section of individuals including non-health personnel.

“In reality you can expand every section of the modules but the truth is that has never been the purpose of the toolkit, it would lose its purpose and virtue of ease of understanding amongst different individuals of different backgrounds”, PC Practitioner (SW)

Another experienced educator in palliative care also noted:

“It should be understood that this is an excellent first level resource for introducing palliative care, which is even applicable to physicians but should you want to go in-depth on any of the components then you may complement with other second level resource materials. For instance, I use this alongside the training manual for guiding the teaching but complement it with the APCA Handbook on Palliative Care”, PC Practitioner and Educator (MD).

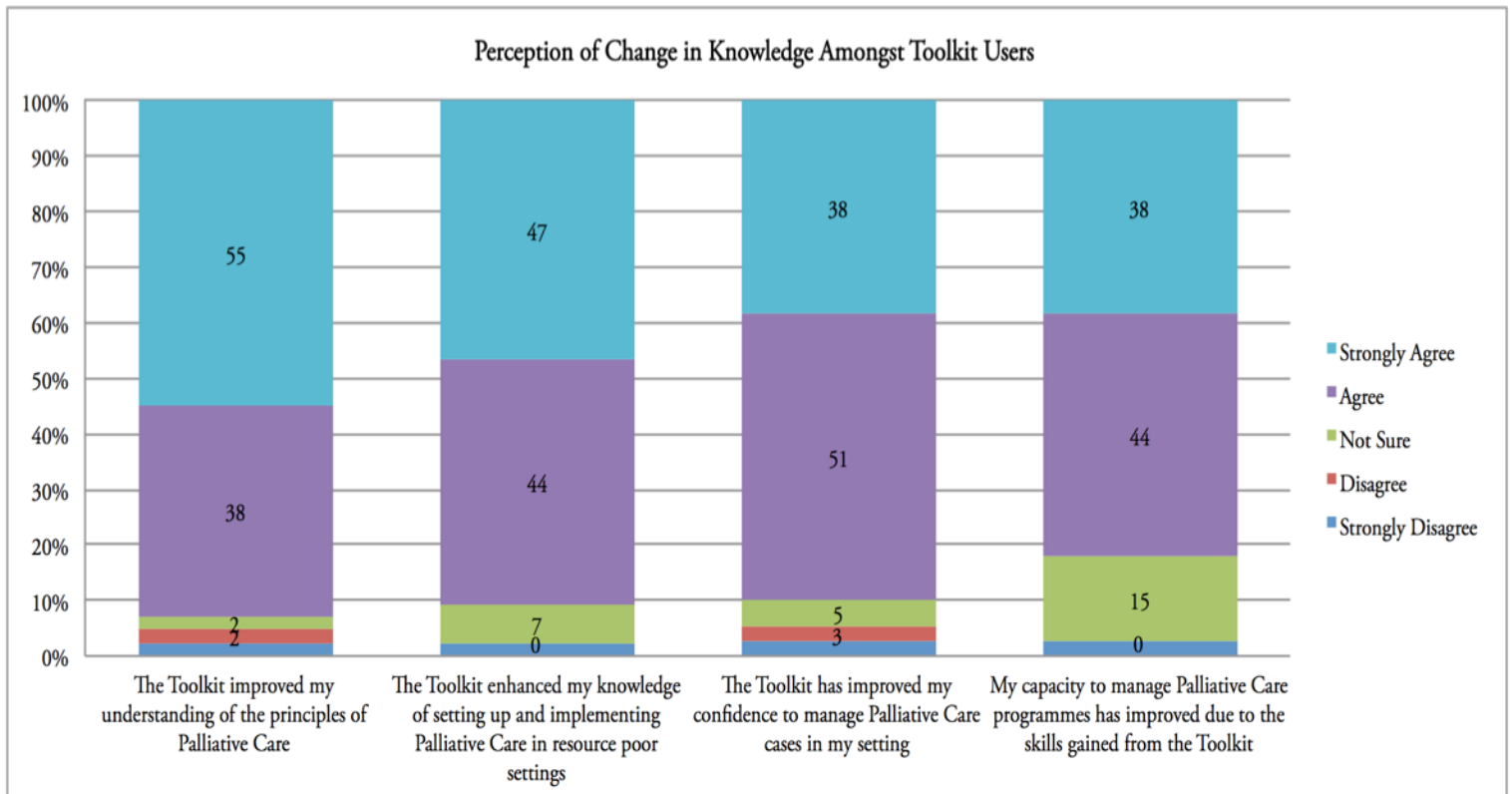
Figure 9: Languages Used in Toolkit Use (In what language have you used the PC Toolkit?)



3.4 Contribution to Palliative Care Knowledge

The toolkit has contributed to improving the PC knowledge of users and amongst those who have received training. Fig 10 shows that at least 90% of respondents who have used the toolkit felt it had improved their understanding of PC, enhanced knowledge on establishing and implementing PC in resource poor settings as well as improved confidence for case management. A slightly lower percentage (82%) felt it had improved capacity to manage PC programmes.

Figure 10: Perception of Change in Knowledge (Select Statement That Best Describes Your Level of Agreement), n=56

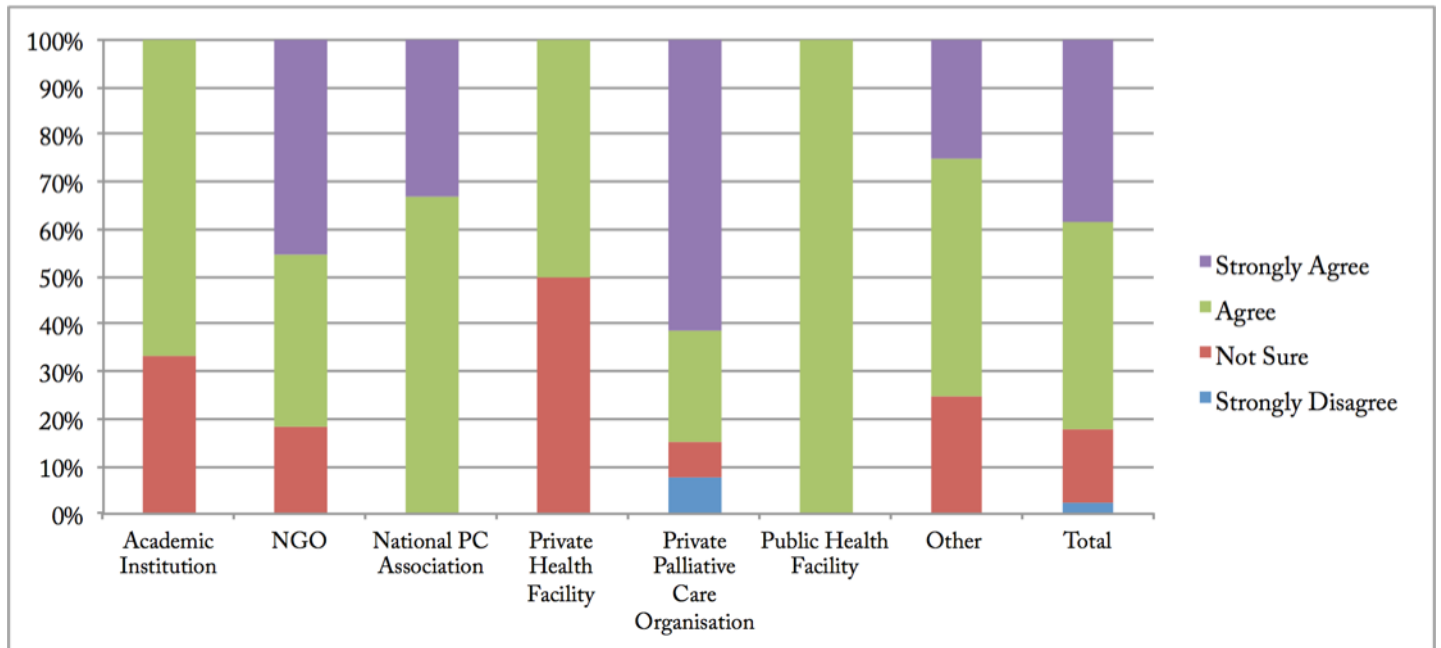


These views were further corroborated by the informants who shared some specific examples of learning areas that have improved and these included knowledge on communication, breaking bad news, pain assessment and generally the use of the various tools (contained in the toolkit) during service provision. It was however noted that although the effect on knowledge gain may be minimal for some medical practitioners in settings where PC teaching had advanced, the toolkit acted as a refresher and guide and which also influenced the attitude of the health worker to embrace it as an integral part of the care

process and not only for the dying and that it is not restricted to a specialist setting but can be undertaken with available resources.

Respondents from palliative care institutions showed a greater proportion (62%) of individuals that strongly agreed with the assertion that the toolkit enhanced their capacity to manage palliative care programmes.

Table 2: Perception of Change in Capacity to Manage PC Programmes (Select Statement That Best Describes Your Level of Agreement), n=56



Generally, the informants felt most practicing professionals who have been trained using the toolkit have gained knowledge as they had minimal previous palliative care teaching during pre-service education.

“personally, I was surprised. It was like discovering a new field of medicine because we never had heard of this during our training,” PC Practitioner (MD)

A recent report on Cairdeas Sahara, a new palliative care project in Mauritania in West Africa which recently completed the country’s first ever training of health care workers in palliative care also provides evidence of the tool’s effect on building PC knowledge. A total of 16 nurses and four (4) health related workers were trained using the toolkit in February 2015. The training was conducted in French over five-day period. The training review described the training as **“Novel, excellent training”** and states:

“Most of the participants had never heard of palliative care during their professional training or careers and everyone rated the week as being either ‘excellent’ or ‘very good’”, Training Review

Despite the overall knowledge gains associated with the toolkit, it was observed that there is potential for additional benefits associated with the content areas suggested for inclusion or further elaboration. Some informants felt that should more detail be provided in the areas such as spirituality, end of life care as well as relating palliative care to the disease burden (including epidemics such as Ebola), this may help to improve knowledge on how to apply PC in different settings and going beyond just the understanding of the principles.

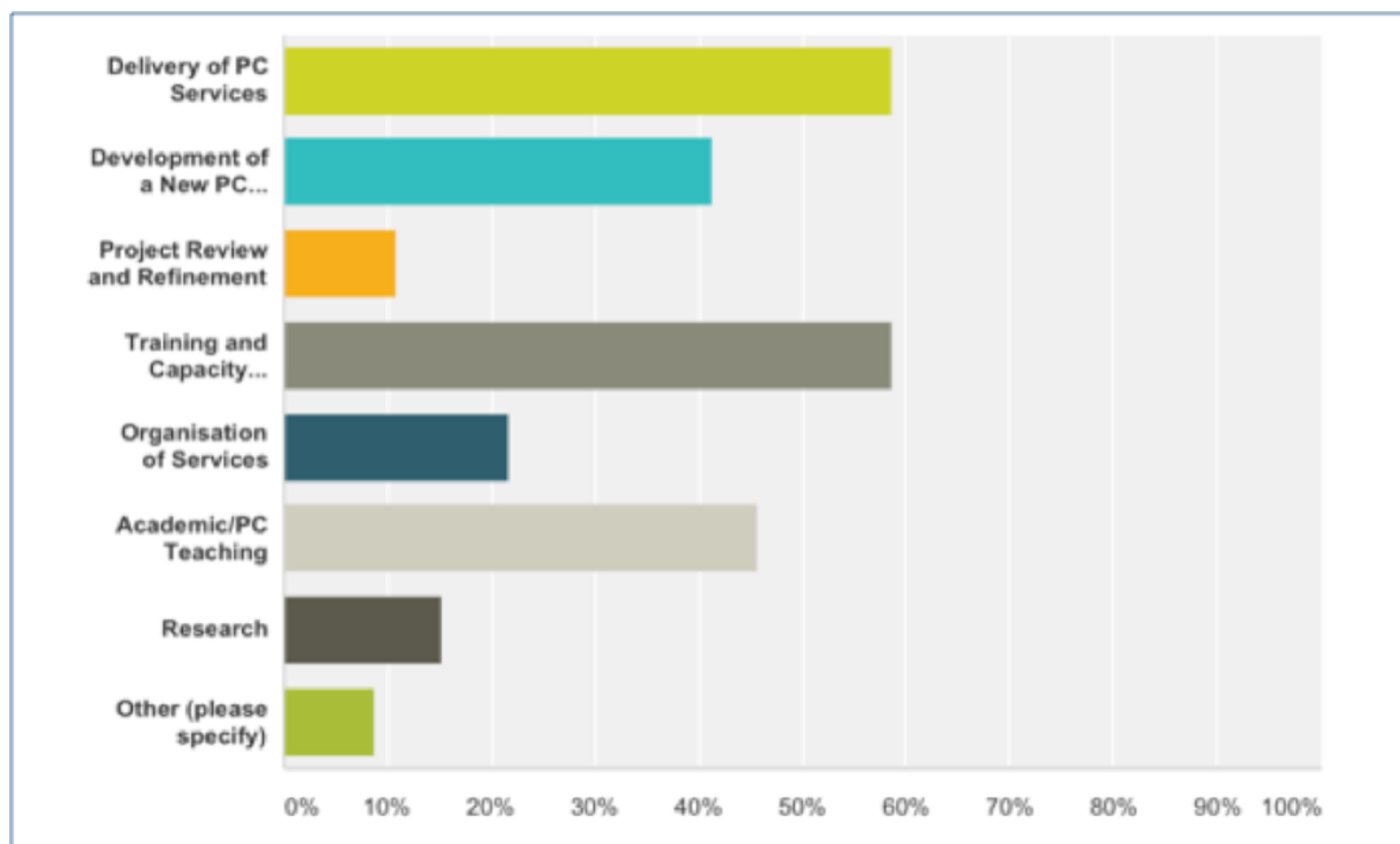


It is against this background that one key informant suggested viewing the knowledge gains as arising from exposure to palliative care teaching to which the toolkit would have contributed to but complemented by other resources and approaches such as clinical modeling.

3.5 Application of Toolkit

There is strong evidence of the use of the toolkit and of the application of recommended practices contained in the toolkit. Slightly over 85% of respondents confirmed using the toolkit as part of their work. The most frequently mentioned domains of use of the toolkit included Training and Capacity Building (59%), Delivery of PC Services (58%), Academic Teaching (45%) and Development of a New PC Curriculum (41%).

Figure 11: Use of PC Toolkit (Please specify any actions you have undertaken that have been facilitated by the Toolkit), n=56



A review of the specific services shows that more than half of those who used the toolkit applied it in reviewing and updating training curricula. This is a significant finding given the anticipated downstream effect of training.

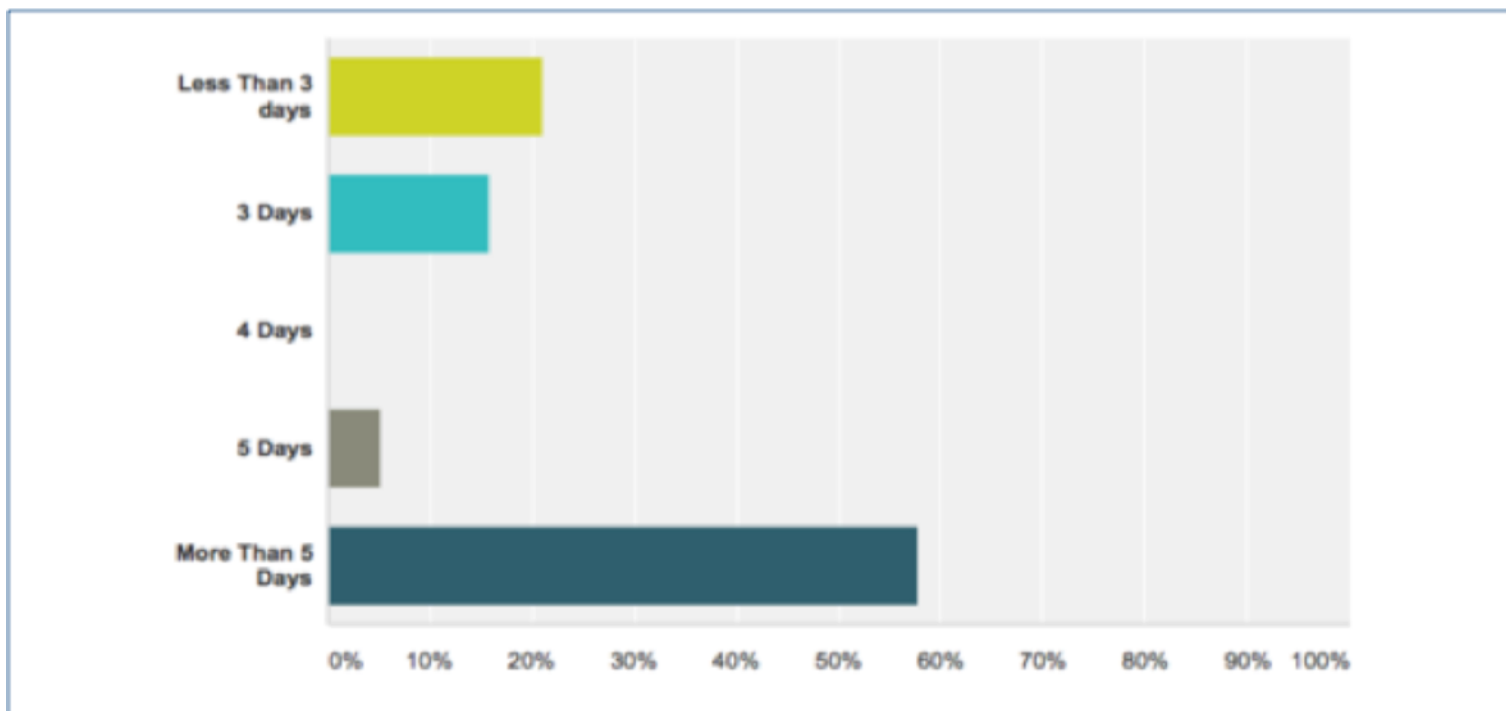
Table 3: Use of the Toolkit

Answer Options	Response
Conducted operational and/or academic research based on the framework of the Toolkit	13.6%
Other	15.9%
Conducted a review of existing programmes and identified areas for strengthening	29.5%
Reorganised the delivery of palliative care services	38.6%
Developed new palliative care services or programmes	43.2%
Developed or reviewed training curricula	54.5%
Transferred PC knowledge to others through teaching/training based on the Toolkit	75.0%

It is worth noting that a quarter of the survey responses learnt of the toolkit through training provided by either individual PC Practitioners/Trainers or by PC/Hospice Institutions. At the same time, some respondents also provided training to other groups.

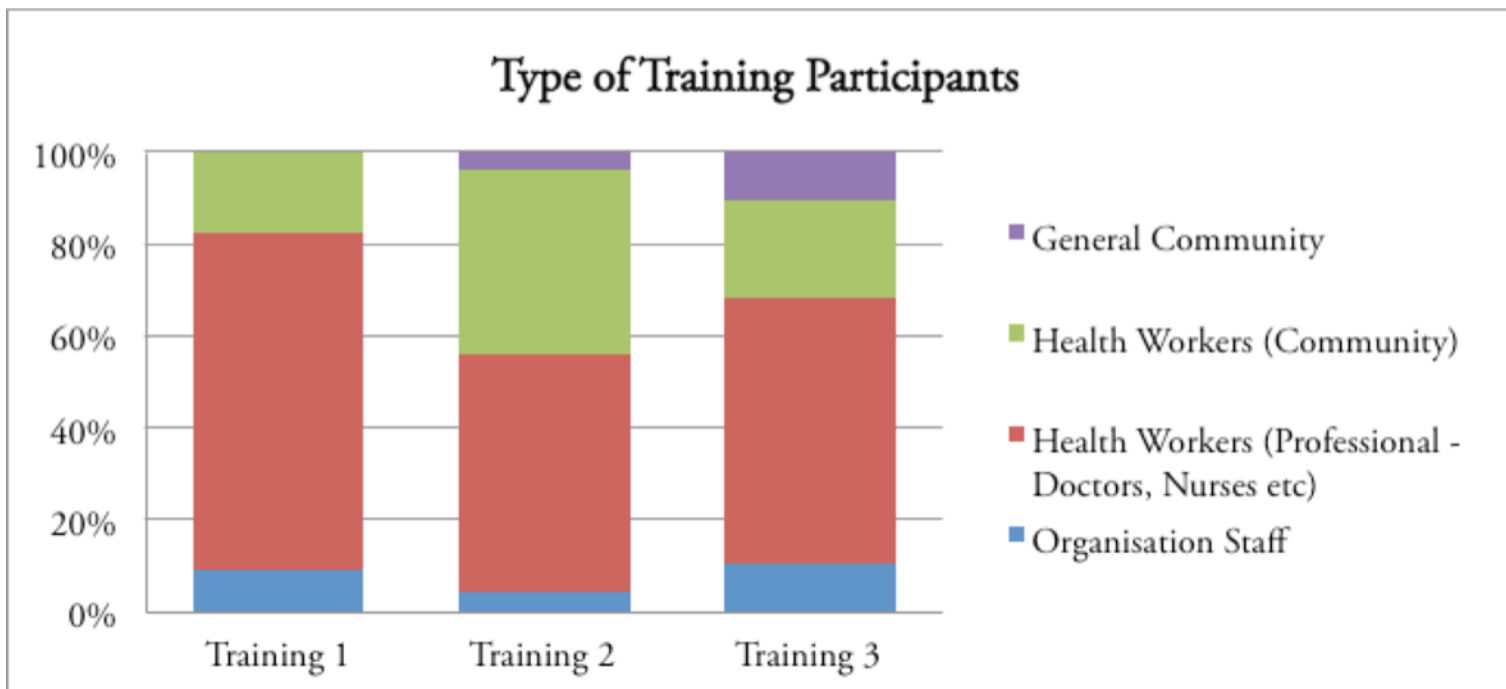
The duration of the trainings provided by the respondents and that made use of the toolkit ranged for one day to 14 days whilst the number of participants for workshops would start from as low as two to a maximum of nine. This is consistent with the duration of the trainings received by those who reported having to know of the toolkit through training. Fig 12 shows that the majority (58%) of those who access the toolkit through training had done so through a training that lasted for more than 5 days.

Figure 12: Duration of Training Received (If Trained, Specify the Duration of the Training Received)



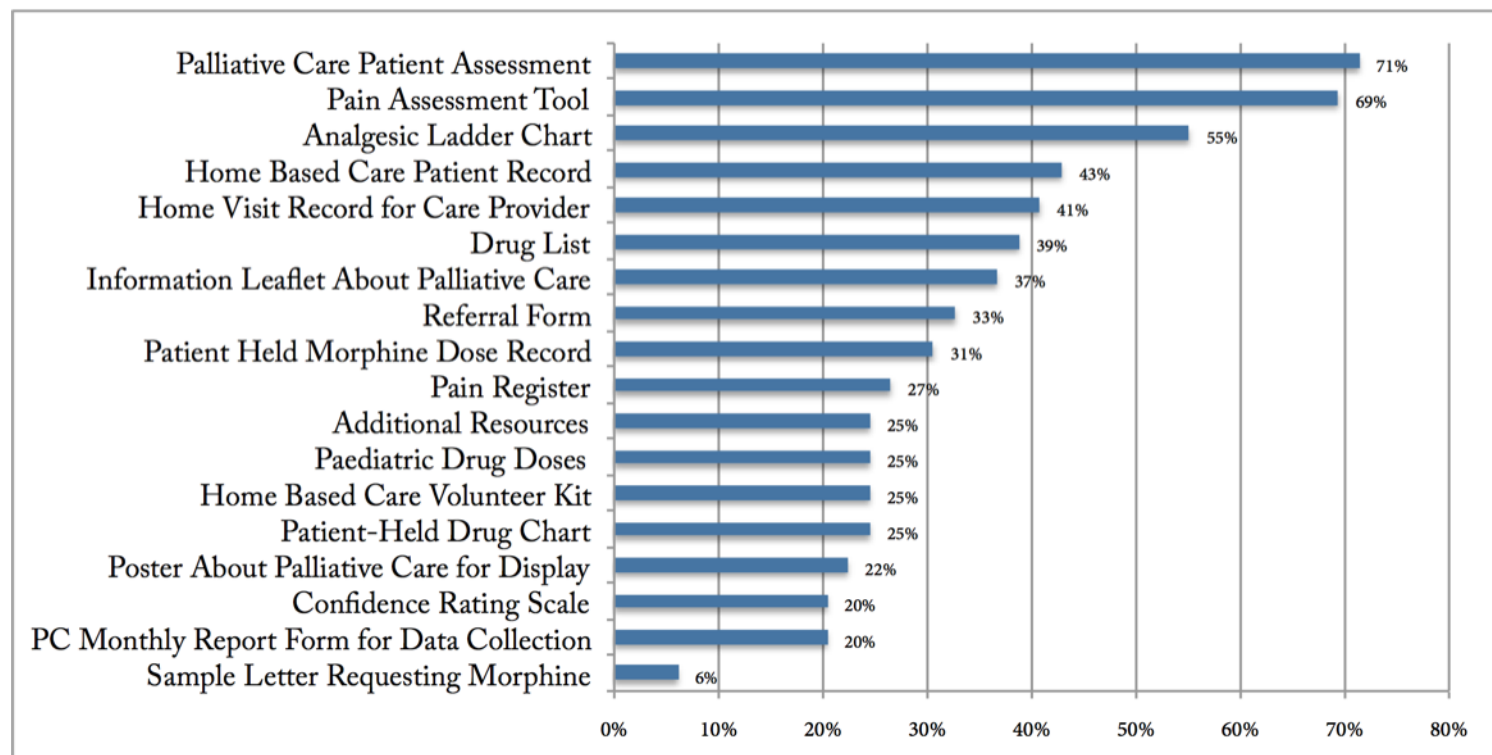
The main recipients of the trainings were Professional Health Workers and Community Workers.

Figure 13: Training Participants



Respondents also indicated using the toolkit in the delivery of services, primarily as a guide and in the application of the tools for care processes and documentation. Commonly used have been the PC Patient Care Assessment, Pain Assessment Tool, the Analgesic Ladder Chart and HBC Patient Record as indicated in Fig 14.

Figure 14: Tools Used (Which of the following tools were used?)



Some respondents also indicated using the toolkit for PC programme/project development, particularly in shaping the design. Similarly, programme reviews have made use of the toolkit to benchmark performance. Some respondents also cited use of the toolkit in Academic PC Teaching and Research. Though not listed amongst the response options, the toolkit has also been applied in advocacy for the introduction or scale-up of palliative care services. The latter has also been fostered by the toolkit's "Can Do" approach, which facilitates the enabling of service provision in different settings.

3.6 Results of Applying the Toolkit

The toolkit has contributed to the dissemination of palliative care knowledge across different settings and individuals including medical and non-medical personnel. As earlier indicated, the resource has been used as a primary tool to train doctors, nurses and community health workers. Considering the widely documented gaps in palliative care knowledge, the toolkit can be argued to have increased access to palliative care knowledge and ultimately the per capita coverage of service providers with palliative care knowledge. Slightly over three quarters (77%) of respondents who reported having used the toolkit were part of care teams that provided care to 7,181 children and 34,575 adults. Although this study cannot be definitive with regards to the contribution to patient outcomes, it does find merit with the suggestion that the toolkit contributes to access to palliative care for patients in different settings. This is primarily facilitated by the training and use by individuals or institutions.

The toolkit may have also facilitated broader level changes although examples are generally reflective of unique or isolated incidences. The following provides a narrative of how this tool helped shape the development of palliative care in one of Africa's countries.

"My country is one of the first that accelerated the development of a national palliative care programme. A national Palliative Care Policy was established in 2008 and I was involved in the process of development after having been invited and received some initial 10-day training from an NGO [name specified] operating in the country. We tried implementing palliative care at the district hospital but it was difficult due to competing priorities and focus on other disease burden. Around that time, we had some visitors from Europe and one of them gave me a copy of the toolkit. I was surprised, if not shocked, because it was like discovering a new field of medicine. I had not been exposed to other palliative care resources other than the slides from the initial training I received and would occasionally reference. The toolkit was marvelous as it put all the components in one, in a very clear, easy to follow and practical way. We pioneered the dissemination of palliative care thereafter and facilitated the development of a national curricula based on the toolkit. Palliative care has been integrated in our public health sector and since 2012 all districts have been trained using the national curricula"

It is apparent from the views of respondents that the toolkit has played a crucial role in the dissemination of palliative care but that its benefits could be optimized if used in a complementary way with manual (for education) and other resources at different levels; and making consideration of the context when applying it.



Conclusions and Recommendations

The palliative care toolkit has been used widely across most countries and utilized in service delivery, training and capacity building and academia. The design, content and format of the toolkit has been highly accepted and is regarded as very relevant to the target groups and settings given the capacity gaps in palliative care knowledge and service delivery. The content, in particular and the way it has been written, stands out as a key strength as it is largely seen as a tool that has put together essential aspects of palliative care and delivered it in a way that is easily comprehended by medical and non-medical personnel. It is acknowledged to be an excellent tool for introducing palliative care and one, which may be used as an entry level and complemented by other resource materials. A number of topics or areas were suggested for additional refinement but respondents generally provided the communal perception of adequacy in content for first level palliative care information dissemination. There is strong evidence of the application of theoretical aspects of palliative care as well as the tools in practice. Although not explicitly or directly effecting change in practice as an individual tool, the findings of this review show that it is a significant contributor to the efforts enhancing knowledge and practice in palliative care as well as the overall access to quality palliative by patients with life threatening illnesses.

Based on the gaps and opportunities discussed alongside the findings, the following recommendations are proffered to the developers of the toolkit as well as the users.

1. Content Review

- a. Consider reviewing the listed topics suggested for inclusion in Section 3.3 and craft the content that may be desirable to add bearing in mind the need to maintain the comparative advantage presented by the non-bulky, easy to read nature of the current version. Emphasis was however placed on placing additional content on Symptom Control and ensuring Ethics in Palliative Care stands out.
- b. Some reference resource materials require updating - there is need to ensure all reference materials included in the toolkit have been updated and reflect additional resources that have been introduced
- c. There is need to reflect different contexts and settings on the examples and illustrations.

2. Quality Assurance in Translations

- a. Review and refine accuracy and context appropriate meanings for all the translations

3. Formatting: - Consider an eLearning Platform with interactive resources that may be used in self and/or facilitator guided sessions

4. Distribution Plan

- a. A Distribution Plan for the resource should be developed and should consider options for in-country distribution networks that leverage on existing structures such as the national palliative care organisations. Training budgets should factor the costs of printing the resource material for sharing with participants. Other digital options that are less dependent on continuous Internet access should also be considered. For instance, mobile versions that are WhatsApp compatible may be an innovative distribution route, which may reach out to a far greater audience. Although, likely to reach the urban population with good Internet access, adverts with links to the resource may also be sent through the mobile versions. There may be several options and what is critical to have a documented strategy for distribution, which is effected. Link the distribution with marketing efforts.

5. Guide on How To Use:

- a. For training and education purposes; it is important that the toolkit be considered as part of package of other resources such as the Training Manual and other second level resource materials.
- b. Develop a one-pager guide on "*How To Use The Toolkit*", which would assist users to customize the toolkit to their own setting and also make use of complementary resources. For instance the guide may provide steps on how to model for introduction level training alongside the training manual.

