



# **FINAL REPORT**

**EVALUATION REPORT OF BANGWE HOME-BASED CARE PROJECT**

**SEPTEMBER 2018**

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## **ACRONYMS**

AIDS	Acquired Immune Deficiency Syndrome
ART	Anti-Retroviral Therapy
CBHC	Community Based Health Care
CBO	Community Based Organisation
CoM	College of Medicine
DALY	Disability Adjusted Life Years
DHO	District Health Office
FBO	Faith Based Organization
FGD	Focus Group Discussion
HBC	Home-based Care
HIV	Human Immunodeficiency Virus
HSSP	Health Sector Strategic Plan
JCE	Junior Certificate of Education
KII	Key Informant Interview
LUANAR	Lilongwe University of Agriculture and Natural Resources
MMM	Medical Missionaries of Mary
MSCE	Malawi School Certificate of Education
NAC	National AIDS Commission
NGO	Non-Governmental Organisation
TB	Tuberculosis
PLWHA	People Living with HIV and AIDS
PHCS	Prime Health Consulting and Services
SADC	Southern African Development Community
UNAIDS	Joint United Nations Programme on HIV/AIDS
WFP	World Food Program
WHO	World Health Organisation

## **1.0 INTRODUCTION AND BACKGROUND**

### **1.1 Introduction**

An end-line evaluation of a Home-based Care project implemented for 15 years from 2003 in townships of Blantyre particularly Bangwe and Limbe was commissioned by The Malawi Home-based Care Charitable Trust. The project primarily targets AIDS patients with terminal diseases. It also reaches out to those with other chronic and terminal illnesses such as cancer, stroke and diabetes. The project interventions aim at reducing impact of poverty, poor health, stigma and limited health services. To achieve the reduced impact on these areas, the project involved trained project staff and collaborated with College of Medicine, Salvation Army, local chiefs and village health committees, local health facilities, district health office, and national health service (Ministry of Health) and National AIDS Commission.

The evaluation sought to answer three broad questions. The first is to understand what difference has the project made to the lives of people; who ended up as beneficiaries, when did they benefit within the 15-year project life span and what type of benefit did they receive. The second question to be answered is how the difference was made and whether the project approaches are aligned to Comic Relief principles in terms of grant management, use of assets and grant making policies and processes. Findings to the guiding questions have been organized according to evaluation objectives. The project is scheduled for closure in December 2018. This report contains methodology, key findings and recommendations.

### **1.2 Background**

The HIV prevalence rate in Malawi remains high and AIDS tops the burden of disease profile. Although the prevalence rate has declined over the years from 10.6% to 8.8% among the population in the reproductive age<sup>1</sup> thanks to increasing coverage of antiretroviral therapy (ART), the burden remains too much for the public health system to handle. Malawi has a high rate of poverty with 50.7% of the population living below US\$1 a day. The implication of this level of poverty is that majority of the population cannot afford privately provided health care and rely on public health care which is under staffed and under resourced. Urban poverty is high in many places and manifested in many ways including the lack of a family support system as opposed to the set up in rural areas.

In Malawi, home-based care is part of the national response to HIV and AIDS<sup>2</sup>. It is reported that approximately 75% of patients admitted at Queen Elizabeth Central Hospital are HIV and AIDS related<sup>3</sup>. The Malawi Home-based Care Charitable Trust began work in 2003 providing home-based care services to the poorest townships in Blantyre. A report for the

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<sup>1</sup> NSO and ICF Macro (2015-16 and 2010), Malawi Demographic and Health Survey

<sup>2</sup> Africa Palliative Care Association, Review of Home-based Care models and services for People Living with HIV/AIDS within and outside Africa, available at [http://www.palliativecareassociationofmalawi.org/media/data/hbc\\_review\\_report\\_2.pdf](http://www.palliativecareassociationofmalawi.org/media/data/hbc_review_report_2.pdf)

<sup>3</sup> Malawi Home-based Care Charitable Trust, available at <http://www.malawihbc.org/>

period 2006 to 2012 indicates that Limbe health centre whose catchment area the project targets had an estimated population of 210,000 people and the project reached out to 157,000 people. At that time, HIV prevalence in the area was at 27%, far higher than the national prevalence of 14%<sup>4</sup>. In 2003 The Salvation Army and the Department of Community Health at The College of Medicine started a home-based care program in Bangwe<sup>5</sup>.

From initial coverage of 65,000 the number of beneficiaries grew to 176,000. Using trained project staff and working with local chiefs, village health committees, local health services, national health services including Ministry of Health and National AIDS Commission (NAC) and College of Medicine, the project aimed at achieving two objectives namely; to reduce reluctance of patients to seek HIV testing and; to remove discrimination and stigma experienced by patients living with HIV.

The project is scheduled for closure in December 2018 and an evaluation was commissioned. Prime Health Consulting and Services (PHCS) was hired to undertake the evaluation. This report contains methodology and key findings based on objectives.

### **1.3 Project goal**

The overall goal of the project is to reduce suffering through the provision and capacity building of palliative care<sup>6</sup>. The project aimed at achieving two objectives as follows:

1.3.1 Reduce reluctance of patients to seek HIV testing

1.3.2 Remove discrimination and stigma experienced by patients living with HIV.

### **1.4 Evaluation objectives**

1.4.1 To assess the difference the project made to people's lives (what, who, where, when)

1.4.2 To assess how the project has made this difference

1.4.3 To assess approaches used by Comic Relief

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<sup>4</sup> Muula A.S, Gondwe N, (2012), Home-based Palliative Care and Support Program in Blantyre, Limbe and Bangwe

<sup>5</sup> Bangwe Home-based Care Project in Malawi, available at <https://www.ennonline.net/fex/25/bangwe>

<sup>6</sup> Muula A.S, Gondwe N, (2011), Home-based Palliative Care and Support Program in Blantyre- Limbe and Bangwe



## 2.0 LITERATURE REVIEW

HIV prevalence rate in Malawi remains high and AIDS tops the burden of disease profile. The 2011 list of leading causes of Disability Adjusted Life Years (DALY) showed that 34.9% of total DALYs are on account of HIV and AIDS<sup>7</sup>. Although the prevalence rate has declined over the years from 10.6% to 8.8% among the population in reproductive age<sup>8</sup> thanks to increasing coverage of antiretroviral therapy (ART), the burden remains too much for the public health system to handle. HIV incidence rate among men and women in reproductive age is 0.32%<sup>9</sup>. According to UNAIDS, between 2009 and 2013, Malawi reduced AIDS related deaths by 50% thanks to an increase in ante retroviral therapy (ART) coverage of 61% by 2015<sup>10</sup>. The ART coverage has increased to 69%<sup>11</sup>.

Malawi has the lowest per capita investment in health in Southern Africa with US\$39 compared to average of US\$229 for the Southern African Development Community (SADC) region<sup>12</sup>. Donors contribute a large part of healthcare financing and a disproportionately high proportion of HIV and AIDS funding. It is reported that during the period 2012-13 to 2014-15 fiscal years, donors contributed a combined 61.6%, government accounted for 25.5% and households accounted for 12.9% of total health expenditure. For HIV and AIDS, donors contributed 95% of total funding for the same period<sup>13</sup>. For a nation characterized with high poverty as has been pointed out earlier, the percentage of household expenditure on health is a manifestation of poor healthcare services in public health facilities and is contrary to the principle of universal access to healthcare which is the thrust of the national Health Sector Strategic Plan (HSSP II). The implication of this poverty statistic is that the majority of the population cannot afford privately provided health care and relies on public health care which is under staffed and under resourced. Urban poverty is high in many locations and manifested in many ways such as a lack of family support system available in rural settings.

The World Health Organisation (WHO) defines home-based care (HBC) as care given to the patient within his or her own home by either formal or informal care givers (WHO Working Group, 1999)<sup>14</sup>. The WHO (2002) defines community home-based care (CHBC) as any form of care given to sick people in their homes which includes physical, psychosocial, palliative and spiritual activities<sup>15</sup>. The goal of HBC is to provide hope through high-quality and appropriate care that helps ill people and their families to maintain their independence and

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<sup>7</sup> GoM (2017), Ministry of Health, Health Sector Strategic Plan 2017-2022

<sup>8</sup> NSO and ICF Macro (2015-16 and 2010), Malawi Demographic and Health Survey

<sup>9</sup> GoM (2017), Ministry of Health, Health Sector Strategic Plan 2017-2022

<sup>10</sup> UNAIDS (2015), HIV and AIDS in Malawi, Gap Report

<sup>11</sup> GoM (2018), Ministry of Finance, Economic Planning and Development, Program Based Budget

<sup>12</sup> GoM (2017), Malawi Growth and Development Strategy (MGDS III), 2017-2022

<sup>13</sup> GoM (2015), National Health Accounts. Also see GoM (2017), Ministry of Health, Health Sector Strategic Plan 2017-2022

<sup>14</sup> WHO Study Group on Home-based Long-Term Care (1999), Home-based Long term care: Report of a WHO Study Group. WHO Technical Report Series: 898 Geneva, Switzerland

<sup>15</sup> WHO (2002), Community Home-based Care, Action Research in Kenya, Geneva, Switzerland

achieve the best possible quality of life<sup>16</sup>. The concept of Home-Based Care has become accepted as a cost-effective way of providing care and support to HIV patients in a culturally acceptable, financially sustainable and medically relevant way. Literature shows that there are a number of models of home-based care and services, as follows: (i) Community Home-based Care; (ii) Integrated community home-based care; (iii) Government district-level home-based care services; (iv) Hospital-supported home-based care services; (v) Home visiting; and (vi) Hospice model. Of these, two models common in Malawi are CBO/NGO/FBO-hospice-supported program and hospital-supported HBC<sup>17</sup>.

In the south and north parts of Lilongwe city, Light House HBC works through existing community groups. Its approach is distinctively medical, putting nurses on full time in the community<sup>18</sup>. A home-based care program run by Medical Missionaries of Mary (MMM) in villages along the Shire river valley observed that the place to provide the best form of care for the chronically ill and the terminally ill is at home. They further noted that in a country like Malawi, where there is a serious shortage of trained doctors and nurses, this is all the truer<sup>19</sup>. A study by Esmie Mkwinda and Lekalakala Mokgele (2016) on palliative care needs in Malawi showed that PLWHAs need physical care from primary care givers due to severity of illness, integration of healthcare services, continuity of care and proper care from nurses, knowledge from nurses in several areas which affected decision making and needed financial and nutritional support<sup>20</sup>.

In the catchment area for the Bangwe Home-based Care project, a baseline report for the project period 2014-2019 showed that 90% of care in the home is linked to health services. The baseline report further showed that 90% of patients were satisfied with care on offer under the project and reported that their life had improved as a result of the home-based care. The survey also showed that 84% (n=299) of survey respondents did not know the availability of home-based care before they needed it<sup>21</sup>.

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<sup>16</sup> WHO (2002). Policy Framework for Community Home-Based Care in Resource Limited Settings: Geneva

<sup>17</sup> African Palliative Care Association, a Review of Home-based Care Models and Services for People Living with HIV/AIDS within and outside Africa, available at [http://www.palliativecareassociationofmalawi.org/media/data/hbc\\_review\\_report\\_2.pdf](http://www.palliativecareassociationofmalawi.org/media/data/hbc_review_report_2.pdf)

<sup>18</sup> Light House, Home-based Care, available at <http://www.mwighthouse.org/home-based-care>

<sup>19</sup> Medical Missionaries of Mary, Home-based Care, available at <http://mmmworldwide.org/index.php/our-work/12-countries/330-home-based-care-malawi>

<sup>20</sup> Mkwinda E, Mokgele L, (2016), Palliative Care Needs in Malawi, Care received by people living with HIV', Curationis 39(1), a1664. <http://dx.doi.org/10.4102/curationis.v39i1.1664> available at <http://www.scielo.org.za/pdf/cura/v39n1/12.pdf>

<sup>21</sup> Muula A.S, Gondwe N, Bowie C, (2017), Base line survey of Home-based Care Services in Bangwe, Limbe and in other parts of Blantyre

### 3.0 METHODOLOGY

A descriptive cross-sectional survey design employing participatory approaches was used. Most of the needed data were qualitative obtained through use of focus group discussions and key informant interviews. All interviews were transcribed verbatim and data was uploaded in the ATLAS.ti version 8.2.

Quantitative data were collected at relatively low scale from clients. Data were collected in selected villages under Bangwe and Limbe catchment areas. SPSS was used to manage and analyse data.

The research team worked with project staff to construct a sampling frame. The research team disaggregated the survey respondents and participants based on their position and roles in the project. The categories were therefore as follows:

- (i) Project direct beneficiaries: PLWHA and other beneficiaries that included those on scholarship scheme;
- (ii) Project indirect beneficiaries: Volunteers, guardians, chiefs, village health committees;
- (iii) Project management team: Project staff, project partners (College of Medicine and Blantyre DHO)

Except for village health committees which were found not to be available in all villages sampled, there was representation of all other categories of survey respondents and participants. Data were collected through structured questionnaire, key informant interviews, focus group discussions and unstructured interviews.

Data collection tools were translated into Chichewa. An informed consent was sought before starting interviews. The analysis and report writing has taken confidentiality into consideration. A pre-test was conducted as part of the training to ensure the validity of the instruments and proper translation. Recorders were used to collect data having obtained consent from interviewees. Secondary data were collected through a review of documents which included the following:-

- 1) Changing clinical needs of people living with AIDS and receiving home-based care in Malawi--the Bangwe Home-based Care Project 2003-2008
- 2) An assessment of food supplementation to chronically sick patients receiving home-based care in Bangwe, Malawi
- 3) The pattern of symptoms in patients receiving home-based care in Bangwe, Malawi
- 4) Integrated community-based care and support for orphans and vulnerable children in Bangwe,
- 5) An assessment of clinical needs of people living with AIDS and receiving home-based care in Malawi - the Bangwe Home-based Care Project 2003-2008
- 6) Evaluation of the Malawi Home-based Palliative Care Charitable Trust, Blantyre, Malawi - impact on individuals, their families and the local community

- 7) Assessing the clinical outcome of patients living with chronic illness and receiving home-based care services in Bangwe, Blantyre.
- 8) Base line survey of Home-based Care Services in Bangwe, Limbe and in other parts of Blantyre.
- 9) National Strategic Plan for HIV and AIDS
- 10) National HIV Prevention Strategy
- 11) The 2011 Stigma Index Report
- 12) Malawi Health Sector Strategic Plan.

### 3.1 Qualitative Data Management and analysis

The ATLAS.ti 8.2 software for analyzing qualitative data was used because it allowed the analysis of data, interpretation, sorting and administering textual data (Strobing, 2005).

#### Steps in Using Atlas.ti

- i. The first step was to manage the data by creating a Hermeneutic Unit (ATLAS project). This process involved importing 15 transcripts, called primary documents into the computer programme by a single researcher.  
The second step was guided by two principle modes, the *textual level* and *conceptual level*.
- ii. **The textual level:** This involved the development of codes and the testing for Reliability of the data.
  - a) Development of codes: Coding refers to naming and categorising phenomena through close examination of the data. It represents the operations by which data are broken down, conceptualised and put back together in new ways of building theories from data. Study objectives were used to develop predetermined themes that guided the process of developing a code book for the study. A code book consisting of 27 well defined codes was developed. The codes were imported in Atlas.ti ready for use. The codes will be used in identifying interesting and relevant concepts in answering the research questions.
  - b) Reliability Test: To ensure consistency of coding, since multiple coders were used, the degree of agreement between coders was calculated with a measure of Inter-Coder Agreement (ICA) which is used to infer Reliability. Three coders were identified and were given a copy of the developed Atlas project with the well-defined codes. The coders were instructed on how to quote texts and assign relevant codes by their understanding of the codes' meanings. 25% of the transcripts (4 transcripts) were randomly selected to be used for testing data reliability. The coders were instructed to identify Quotations and assign codes to the same 4 transcripts independently. Upon completion, the coders submitted their work to the researcher.  
Using Atlas.ti, the researcher went through each of the coders' work before running the ICA calculation tool. Atlas offers 4 different ICA calculations among which the Krippendorff's Coefficient was used. Specifically,

Krippendorff's c-Alpha Binary was used to measure Reliability. It was chosen because of mainly two reasons; it is applicable if coders created quotations themselves and because it accounts for chance agreement in its calculation. Its coefficient tells for each code whether the different coders have identified similar or the same areas in relation to a given meaning (code). Considering Reliability, its values range from 0 to 1, where 0 is perfect disagreement and 1 is perfect agreement (Krippendorff, 2011). Recent content analysis practice recommends Reliability coefficient of  $\geq 0.80$  to be acceptable in most situations but  $\geq 0.90$  would be acceptable to all (Arster and Poesio, 2008).

Three attempts at coding the 4 transcripts were made but the first 2 attempts generated a poor ICA (Krippendorff's c-Alpha-binary of 0.466 and 0.561 respectively). Probable challenges noted included situations where one coder did not apply a code that the other coder had used and differences in text segment size being coded. The coders were re-trained with emphasis on the identified challenges. Despite the final ICA value being on the lower end (Krippendorff's c-Alpha-binary of 0.837) of the acceptable range, we were confident to continue coding the rest of the transcripts.

- iii. ***The conceptual level:*** The process of network building was an integral part of the analysis. Using functions of the Network Manager, this level focused on framework-building, through linking codes, concepts and categories that formed theoretical networks and inductive models. This special feature of Atlas.ti, provides a comprehensive overview of the researchers' work as well as rapid search, retrieval and browsing functions. It laid the conceptual foundations upon which interpretations and explanations were based. Codes that carried the same meaning, cause and effect or other relationships were linked together to form categories. Once data were classified, regularities, variations and peculiarities were examined, and patterns were identified. Then relations between different categories were studied and a picture of the data created. This picture was complex but clearer than the initial impressions with predetermined themes.

Based on the aim of the study, we created three networks (see Appendix 6A, 6B and 6C. Also attached separately) reflecting on specific study objectives as follows:

- Project Management;
- Project Implementation; and
- Project Impact.

Following this process, the software generated output reports that enabled the building of the story presented in the report.

#### 4.0 EVALUATION FINDINGS AND DISCUSSION

The findings are informed by primary and secondary data. Primary data were collected through qualitative and quantitative approaches. In total, 133 people living with HIV responded to structured questionnaire. There were focus group discussions with PLWHA and others with chronic illnesses such as cancer and diabetes, and other focus group discussions with volunteers. Additionally, we also interviewed chiefs, 3 guardians, 2 College of Medicine staff members and a representative for Blantyre DHO who participated in the interview as key informants. Further, the Project Manager and the rest of project staff were interviewed separately.

##### 4.1 Socio demographic characteristics

Of the 133 respondents, 108 representing 81.2% were female and the rest were male. Majority (83.5%, n=133) were over 35 years old followed by those between 31 and 35 years (11.3%). Few were 30 years and below. Many respondents had primary education (56.5%, n=133) followed by those without any education (25.6%) and few had secondary education (18%). Income levels are generally low. When asked average monthly income, the range was from K1,000.00 to K400,000.00 per day. Average income was found to be K18,625.00 per month and some people reported they do not earn any income and rely on family relations and well-wishers.

**Table 1: Summary of socio-demographic characteristics**

Variable	Frequency	Percent
Sex (n=133)		
Male	25	18.8
Female	108	81.2
Education (n=133)		
None	34	25.6
Primary	75	56.4
Secondary	24	18
Main source of livelihood (n=133)		
None	13	9.8
Business	56	42.1
Salaried employment	7	5.3
Casual labour	29	21.8

*Source: Bangwe HBC Evaluation, 2018*

## 4.2 Length of period on program and relationships

Most respondents have been in the program for many years and some since it started in 2003. The period of benefitting from the program ranged from 1 to 15 years with average of 8±4 (n=127) years. PLWHAs were asked their relationship to different actors. With regard to how they relate with project staff, 65.4% (n=133) said they relate very well and 33.1% said they relate well. A typical quote representing the views of many was:

*“Our working relationship is very good. If they come here and they find that there is a patient who can't walk, we can explain to them that in this village there is a patient who is not capable of walking and won't be able to get to where they can get help. They [Project Staff] are dedicated, they walk to places that cars can't get to, ... and they examine and take care of the patient. But also when they see that the situation is too serious, they come more frequently, not just on their designated days. They do come, sometimes twice or three times depending on how ill the patient is. When it gets worse that's when they take the patient to the hospital. We should acknowledge this, we are working together very well”.* (KII, Namalo Community).

Only 1.5% said they do not relate well. Some stated that they expected food rations with drug administration and also that they expected project staff visits to be more frequent than the scheduled dates. Second to project staff are volunteers whom clients reported they work with very well or well. About half (49.6%, n=133) said they work very well with volunteers and 43.6% said they work well.

*“I would also like to add something... we are grateful ... When you are very ill and you can't come here, the volunteers tell the doctors [Project Staff] that such and such a person can't make it here, the doctors [Project Staff] make a house call and administer the medication to you. so I feel that that is very beneficial to us because of the good relationship we have with them”.* (FGD Beneficiaries, Chinupule Community).

Chiefs scored relatively low on working relationship with 22.6% (n=133) who said very well and 55.6% who reported they work well with chiefs. One participant in a focus group discussion said:

*“Our relationship with chiefs is good, but I can not say it is excellent because most of the times,... when initiatives are coming into this area we are never put at the forefront ... Sometimes there are initiatives that involve helping people in communities and even ones that involve coupons, when things like that happen here we are usually not included. So I can't say that our relationship is very good”.* (Beneficiary FGD, Namalo Community)

When asked whether project staff, volunteers and chiefs in their respective roles have been of help, 96.2% (n=133) answered in affirmative. The actors have been helpful to the beneficiaries through provision of treatment, counselling, encouragement on drug adherence, facilitating referrals to Tikondane clinic at Queen Elizabeth Central Hospital and providing transport. Other actors who were mentioned providing support to the beneficiaries included health surveillance assistants (HSAs) and churches. Village health committees are not in

place in many villages and even where respondents suspected there could be village committees, the connection to the program seemed to be non-existent.

A number of interventions have been implemented by various actors. We asked clients what interventions they received from project staff and volunteers separately. The interventions clients benefitted from project staff included treatment, counselling, physical assessment (such as taking body weight, blood pressure), environmental assessment and advice, facilitating referrals, wound dressing and TB screening. About half (56.1%, n=132) of respondents reported the interventions they receive remained the same over time while 43.2% said interventions changed over time. Clients reported they have benefitted from a wide range of interventions from volunteers and included counselling, bathing a patient who cannot take a bath themselves, monitoring drug adherence, wound dressing, remind clients of clinic days and facilitating referral. To the majority (80.9%, n=115) the interventions they benefitted from remained the same while to 19.1% interventions changed over time. When asked which interventions were most useful to meet their needs, treatment and counselling topped the list. The interventions regardless of who provided improved clients' life.

In all areas surveyed, the project was hailed to have reduced mortality from AIDS related deaths, reduced frequency of people falling sick, improved economic status of some who are working for wages or are able to do their own economic activities such as business. A resounding 94.7% (n=133) said interventions improved their life. People reported reduced frequency of falling sick, recovering from being bed ridden to start living normal life and others who were chronically ill are now able to go to work. Chiefs, volunteers and clients corroborated that before the project, mortality was very high and now mortality has declined. In Buleya village, the element of positive living could hardly be missed. Project clients in a focus group discussion stated they are healthy, they actually find someone nursing sickness as not enlightened because HIV is no longer death sentence as it was perceived before. They further said those on treatment are the ones who do not hide their status and die early. One woman testified as follows:

*"I was found HIV positive in 1995 and I have two children born while I am positive. They are both negative. I am strong and do business to take care of my family."*

Her testimony was echoed by a gentleman who said:

*"I was very sick, unable to do anything but after being encouraged to go to clinic and start treatment, here I am. I have a job as watchman and am able to earn income."*

A young man in a focus group discussion had this to say,

*"I was very sick and took leave from workplace after my mother insisted I had to go home. She later took me to clinic and I started receiving treatment. Look how I am now. I am able to walk and do things for myself. I am strong"* (Participant in a focus group discussion).

Secondary data from review of documents confirmed reduction in mortality among PLHWA. Figure below shows the mortality trend.



### **Figure 1: Mortality trend among home-based care clients**

Source: Muula A.S, Gondwe N, (2012) Home-based Palliative Care and Support Program in Blantyre, Limbe and Bangwe.

The declining trend in AIDS mortality shown in figure above was corroborated by various interviewees including chiefs. In Namalo village, a chief who is also member of volunteers and a former Traditional Birth Attendant had this to say;

*“The way things were back then, people were just dying. We did not know how these services would help us. Some people were skeptical. And a lot of people lost their lives. But the people who embraced the program and understood what they were being taught and taking their medication, those people are still around today”.*  
(Village Head woman Namalo).

### **4.3 Project methodologies and approaches**

The project staff, volunteers and the beneficiaries corroborated that the main interventions of this project involved the dispensing of medication as well as home visits or house calls wherein the patient is looked after at their home. In some communities volunteers reported visiting patients most often and as such sometimes carry out household chores for their patients.

*“When we go to the patient's house we do some chores, we sweep, we clean the house. Some patients do not have a guardian. So with some patients there is a need for us to bathe them, take care of their houses. If we have a little bit of money, we can buy the patient some food because sometimes patients do not have any food. And so we do some chores at the patient's house. If there isn't a refuse pit we dig one up so that the compound should be hygienic”* (Mwamadi and Nkhukuten Volunteers).

Project beneficiaries also concur with this sentiment. A beneficiary in a focus group discussion elaborated on the processes that volunteers follow when they are taking care of

patients, highlighting that they usually visit patients on the day before the project staff are scheduled to visit, thereby ensuring that the project staff have patient information that is up to date.

*“The good thing about these volunteers is that they visit us in our homes before the day the doctors are supposed to come. So they come and see how we are doing and we tell them...”* “I am having problems with my stomach or maybe a headache or maybe a fever.” So after visiting me they will also go see other people, so that when it gets to the Wednesday they document how many patients they have seen, maybe there will be about ten, so when the doctors come they take the files of those people and they sit on the veranda and they call us out and we go to receive our medication. That is the good thing” (Buleya Beneficiaries).

The volunteers also explained that they sometimes go round the allocated households in pairs; male and female, so as to make sure that they are no gender related hindrances when they visit patients in their homes.

*“For instance I would patrol with this lady, and she will do the work that is prudent for a female and I will do the work prudent for a man. So I think that is a benefit when we are out making house calls. So when we finish those visits we leave behind a good reputation...”* (Mwamadi and Nkhukuten Volunteers).

In some cases, volunteers even spend the night with the patient if the patient does not have a guardian and their condition is very severe. In the past, the volunteers were sometimes equipped with a care kit, which comprised of gloves, painkillers and TB testing kit.

*“...the volunteers and the village health committees, like in Chiswe village, they have a TB kit that they use on TB suspects. They are able to give the suspect a sputum pot, take the sample to the health center for analysis. When the results are out, they take them to the suspect and tell them. If they need medicine they help to get them. If the person needs to be followed up on ARV, they help as well”* (Project Staff).

In cases where the patients are critically ill the volunteers are instrumental in organizing transport to the nearest clinic or hospital. They do this by first consulting the patient’s relatives as well as the chief.

*“In cases when the patient is seriously ill, we talk to the relatives and ask for permission to take the patient to the hospital. When we are given that permission we try to organize transport, maybe there is a bicycle, and we take the patient to the clinic as quickly as we can. At the clinic when they see that the condition is serious they take the patient to Queens...and we also tell the chief if we want to take a patient to the hospital”* (Mwamadi and Nkhukuten Volunteers).

This has been corroborated by project staff who reported that they sometimes provide transport funds to volunteers to ensure that patients get to the hospital.

*“...on the interventions, sometimes we have patients that we visited in the communities, and we find that there is a need that we can’t handle, we refer them to the hospitals for further examination. If they don’t have transport and we have funds in our budget, we give them money for transport”* (Project Staff).

Sometimes volunteers are required to counsel patients and their guardians in cases where there are conflicts between the two. This generally happens when the patient is chronically ill, or in so much pain that they [patients] become hostile. In such cases the volunteers broker

peace between the two parties by teaching the guardians how to properly take care of seriously ill patients.

*“Another thing is that sometimes when we go to a patient's house we can find that there is some disharmony between the guardian and the patient. It can sometimes be that the patient is very hostile. And the guardian can sometimes abandon the patient. We are supposed to be observant of things like that when we get to a house hold. We need to assess the relationship between the guardian and the patient. How does the guardian help the patient? That is another thing that we do when we get to a household”* (Mwamadi and Nkhukuten Volunteers).

There are some instances where volunteers are able to provide some food for patients who are unable to provide for themselves. This is not part of their mandate as volunteers and it only occurs sporadically as the volunteers themselves regularly struggle to find food for their own families.

*“In terms of the patients, we regularly pay the patients a visit, some of them are not well-to-do, they do not have food sometimes. So with the volunteers we sometimes raise some money for food, whatever little we can so that we can give it to the person in need, so that they can have a little porridge* (Chief, Namalo Village).

The project staff also reported that their interventions are not just limited to medical services. They also provide funds and scholarships to orphans and vulnerable children at primary, secondary and tertiary levels of education.

*“...we provide assistance to orphans and vulnerable children. Some have even gone to university level and we're paying their school fees”*. (Project Staff).

#### **4.4 Relevance of changes to the needs of the beneficiaries**

The home-based care services in this project mainly consisted of activities such as: dispensing ARVs to HIV positive patients on specific days at centres in the village; conducting house calls where project staff and volunteers would visit patients in their homes to provide care and assist or support the guardians as well as raising awareness on HIV and ARVs.

These interventions were deemed to be relevant to the needs of the beneficiaries as documented on the needs assessment carried out by the College of Medicine. According to the project staff:

*“...at first the chiefs were told after carrying out the needs assessment with students from college of medicine. They found that 90% of the people in the areas are chronically ill and bedridden and saw the need for home-based care”*. (Project Staff).

This was corroborated by the volunteers of Mwamadi and Nkhukuten:

*“At that time...we became aware that there a lot of different illnesses plaguing us, especially diseases that have no cure like HIV, so they decided to dig around to find out exactly what was going on. When they finished investigating they decided to set up groups that would help with this epidemic”* (Mwamadi & Nkhukuten Volunteers).

The chief in Namalo elaborated on the gravity of the situation in his village before the program came, noting that there were a lot of deaths as well as scepticism about the services of the program.

*“The way things were back then, people were just dying. We did not know how these services would help us. Some people were sceptical. And a lot of people lost their lives. But the people who embraced the program and understood what they were being taught and taking their medication, those people are still around today”.* (Namalo Chief).

Whilst the project was reported highly relevant, participants expressed missed opportunity for them to input.

#### **4.5 Beneficiary and Volunteer Involvement**

The study revealed that beneficiaries and volunteers thought that there were no mechanisms made available for beneficiaries and volunteers to input into project design, implementation and monitoring. Reports from the beneficiaries and volunteers indicated that there were no consultations on how best to implement the project neither were they given an opportunity to provide feedback on how the project was being implemented.

*“We have never been given that opportunity”.* (Buleya FGD Participant).

The project officers reported to the contrary indicating opportunities were provided for the beneficiaries and volunteers to contribute to project design citing one specific example to do with provision of food to suppress drug effects. This is indicated in the statements below made by one of the Project Staff:

*“It’s possible and they are involved and give their opinions. For example, there was a time when patients would complain that some of these medications require food and we are just giving them the drugs without food. So when we conducted a survey, it was revealed that with the funds we get, there is no allocation for food. However, we tried to communicate with those in government at nutrition department to negotiate with the health centers to provide Likuni (porridge) for them. When they have enough, they call us and we take them to receive Likuni. We made it clear that our organization cannot afford to supply food but we have made negotiations with well-wishers and government and when possible you will receive. Even if it’s just a little soya. We highlight that the need they brought up is valid but this is what we can do at the moment”.* (Project Staff).

#### **4.6 Project impact on psychosocial aspects**

Besides providing medical interventions, the project intended to address psychosocial elements associated with HIV and AIDS. We asked respondents a number of questions which they had to respond as strongly agree, agree, do not agree and do not know. The table below shows frequencies and percentages of responses.

**Table 2: Beneficiary perceptions on psychosocial impact of the project**

<b>Variable</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Do not agree</b>	<b>Do not know</b>
Project reduced stigma and discrimination (n=133)	37 (27.8%)	75 (56.4%)	14 (10.5%)	7 (5.3%)
Project encouraged openness to discuss HIV/AIDS issues (n=133)	42 (31.6%)	80 (60.2%)	8 (6.0%)	3 (2.3%)
Project improved health status (n=133)	76 (57.1%)	52 (39.1%)	2 (1.5%)	3 (2.3%)
Project helped community to be accommodative to PLWHA (n=133)	39 (29.3%)	82 (61.7%)	8 (6.0%)	4 (3.0%)
Project encouraged people to go for HIV testing (n=133)	43 (32.3%)	82 (61.7%)	4 (3.0%)	4 (3.0%)
Project improved economic status	1 (0.8%)	33 (24.8%)	96 (72.2%)	3 (2.3%)

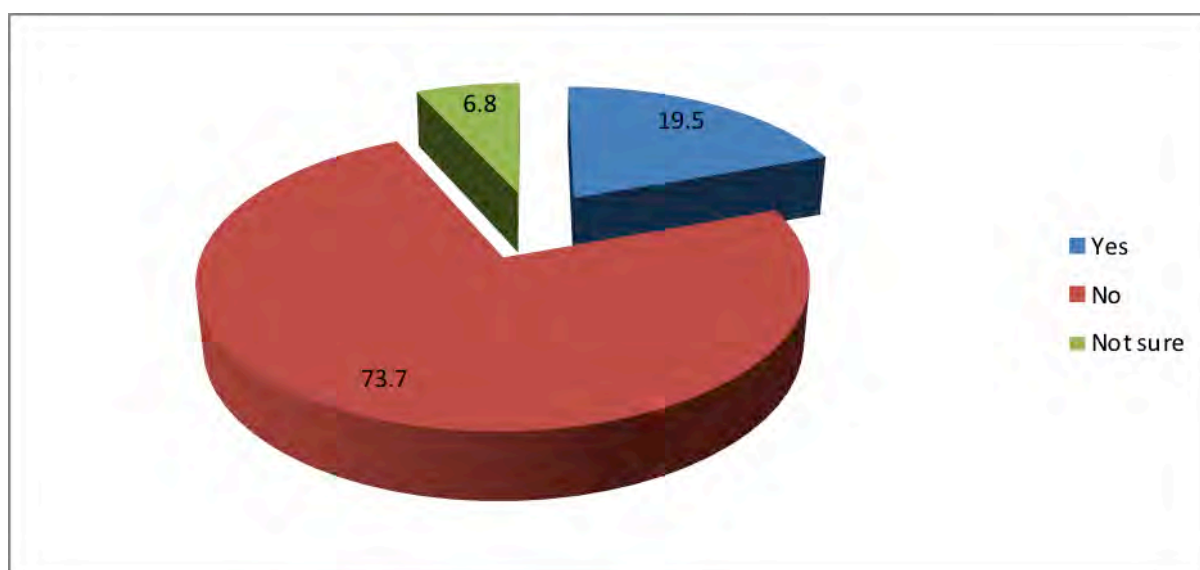
*Source: Bangwe HBC Evaluation (2018)*

The statistics in the table show that except on improving economic life, the project has performed well in improving the environment in which people living with HIV live. A combined 84.2% (n=133) strongly agreed and agreed that stigma and discrimination has reduced thanks to the project. PLWHA reported to be free in mind, open and as has been explained elsewhere in this report, there was strong aspect of positive living especially in Buleya village. In some instances, survey participants reported stigma and discrimination happen but at low scale and also that they bother less because they mind the care received. Although participants reported reduced stigma and discrimination, reading from their facial expression, they face stigma and discrimination and get bothered about it. Participants felt comfortable to mention that the home-based care project was for everyone with chronic illness such as diabetes, hypertension, cancer and management of epileptic patients. It could be the latter conditions that make them free to access the services because they feel not identified as PLWHA. It is in this regard that the project might have built confidence and self-esteem and make them more resilient to factors that would otherwise discourage them from living positively and openly access medical and psychosocial support.

Stigma and discrimination remain a challenge in Malawi (Journalist Network of People Living with HIV and AIDS (JONEHA), unpublished paper, 2017). A study on HBC in Lilongwe by Pindani, Nkondo, Maluwa, and Muheriwa (2014) reported HBC clients experiencing stigma and discrimination. Anecdotal notes from PLWHA experiences with economic development projects also confirm stigma and discrimination remain a barrier to accessing services. In a FGD, one participant shared her experience in the market where she sells vegetables, she said:

“... we just ignore them. One day someone was calling a customer to buy from him and warning the customer not to buy from people with HIV ... I decided to ignore but it pains”. (Kachere, Women FGD).

The poor scoring on economic life could be because the project beneficiaries are mostly those with weak economic base and might have had no economic activities even before they enrolled in the project. As stated elsewhere in this report however, few reported they are able to do business, have employment as security guard and other small jobs because they are in good health courtesy of the project interventions. While the project is hailed, majority are of the view that the outcomes and impact cannot be sustained if it is phased out. Figure below shows respondents' views on project propensity to be sustained.



**Figure 2: Clients' perceptions as to whether project outcomes and impact are sustainable after phase out (%)**

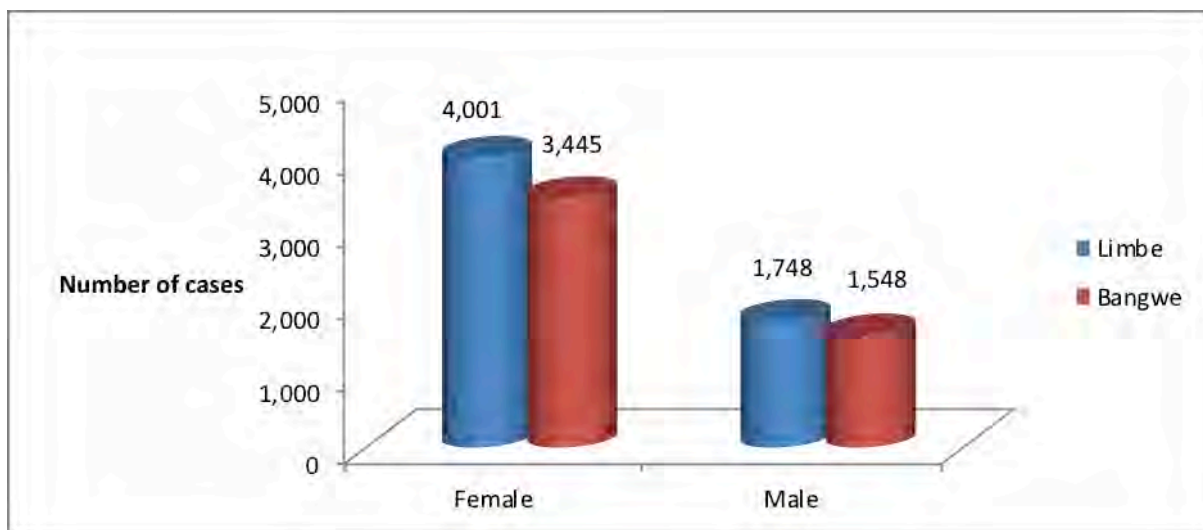
*Source: Bangwe HBC Evaluation (2018)*

It is also note worth that the project organises and facilitate identification of relative when a patient is identified and has no guardian. The project team took us to a household where a woman had terminal illness suffering from cervical cancer. We were told that the woman was alone and the project team searched for her relatives. At the time of our visit, a guardian had been identified and was attending to the patient. The project also facilitates transfer to rural home by arranging for transport of goods and the household members. We visited a case of drug resistance where a chronically sick patient is not responding to drugs and lives in very deplorable conditions. At the time she was alone, lying on the floor in her house, a house with poor ventilation and poor floor. Her young children had gone to look for casual work (ganyu). We were told by project team that an arrangement for transport to take her rural village was made but she refused stating she would find it even tougher to resettle in the village. On a positive note, we also visited a case of cure from cervical cancer. A woman had well responded to treatment and looked strong and healthy at the time of our visit. We also visited a case of household taking care of two patients, a woman and a young man both receiving treatment. The over stretching of the burden on the household could not be missed.

All in all, the project is addressing real need and by finding people in their own places, transport and many other challenges are eased.

#### 4.7 Has the project made a difference?

The project was implemented in a number of villages which are served by Bangwe and Limbe health centres. The main intervention is provision of palliative care to chronically ill patients most of them HIV positive. Over the project life, some people have benefited since 2003 while others joined on the way. In 2017, a total of 10,472 cases were attended to from January to December. Of these 5,749 were from Limbe catchment area and the rest were from Bangwe. Figure below shows disaggregated statistics of cases seen in 2017 by sex of client and catchment area.



**Figure 3: Number of cases seen in 2017**

*Source: Project reports (2017)*

The project offered scholarship to students and 31 students have benefitted from full scholarship for tertiary education i.e. tuition fees, pocket money, clothes and anything that a parent would do to a school going child. Of the 31 students enrolled in the scholarship program, 13 dropped, 3 completed diploma program at the Polytechnic, 1 completed at College of Medicine, 2 completed diploma program at Development Aid from People to People (DAPP), 3 went to Blantyre Technical College, 1 completed diploma at Malawi Institute of Tourism, 1 completed diploma program at Lilongwe University of Agriculture and Natural Resources (LUANAR), and 3 died while in school. We caught up with Mr. Harold Chinyama, a scholarship beneficiary who completed a degree program at College of Medicine and is working with Malawi-Liverpool-Wellcome Trust. Harold was identified to be beneficiary through his sister who worked as volunteer for the project. Harold is full of praise for the project which turned his socio-economic life. In an interview with him, he had this to say:

*“Between where I would be and where I am, is the scholarship program. My sister used to work as volunteer and so was earning low income. She could not manage to support me and my relatives for school. When she explained her story to the project sponsors, they enrolled us and here I am a university graduate. I am very grateful and*

*it is my wish that I also help someone or some others. In fact, I have already started reaching out to others through motivational activities which I do with friends but once I financially get settled, I want to help others.”* (Mr. Harold Chinyama, scholarship beneficiary and now working at CoM)



Mr. Harold Chinyama



Mikiyi Chinyama

Mikiyi Chinyama is another beneficiary. Mikiyi is a sister to Harold and she trained for diploma at Malawi Institute of Tourism. She worked with Sun Bird Hotels and resigned. At the time of the interview she was a housewife. She too is grateful to the program and expresses the wish to reach out to others in need when she is financially sound to help.

The one who went to Lilongwe University of Agriculture and Natural Resources is working with Karonga Agriculture Development Division and others are working in different areas. The scholarship scheme also supported 120 orphans to sit for Junior Certificate of Education (JCE) and 80 orphans to sit for Malawi School Certificate of Education (MSCE). These were provided support in form of getting a part-time teacher for them, school materials like books, and uniform. The drop-out rate for this group was reported to be very high.

#### **4.8 Sustainability of project outcomes**

Project sustainability was defined as structures that have been established to ensure that the benefits of the program were viable. At discussions with staff, volunteers and beneficiaries through KIIs and FGDs, it was reported that there were no deliberately set structures to sustain the benefits of the project. A typical example of the quote by staff was:

*“Also because we focus on treatment a lot there is nothing that we have put in place in case we stop our service”* (Project staff).

In agreement with the above sentiments, beneficiaries also stated that there were neither structures nor activities put in place to help them sustain the project benefits. However, through FGDs and KIIs, participants mentioned the following structures that may help sustain the benefits. These were: volunteers, chiefs, support groups where they exist and staff.

Participants who work as volunteers highlighted some of the factors that might motivate them to continue providing services under home-based care without pay. Some of the mentioned influencing factors included: personal willingness to be of service to fellow community



members, recognition for their generosity, satisfaction with the outcome of care, a feeling of being duty bound towards the welfare of others and their acting as role models.

A typical quote from the volunteers:

*“I believe that we can sustain the benefits of the project because people like me are willing to work without pay. Right now we are still working without pay, starting 2010 all the way until now. So in the future there would not be any problems. If we find a patient we will still be able to help them, transporting the patient to the hospital, just like we have been doing all along. If we judge that the patient needs to go to the hospital, we are able to take them to the hospital. Even in the future if it is a case that the doctors are unable to come, we will still be able to take the patients to the hospital”.* (KII HBC vice chair).

And the other one said:

*“The reason we are continuing is that we see the benefits of the project. The benefits of making house calls to patients by project staff and giving them medication, and how they are getting better. That makes us happy. We see that it is very important in our lives to help our people. It's not that we are righteous, it is only God that is righteous... And that is what gives us the strength to carry on, we will continue doing this. Up until the project leaders themselves tell us that it is over”* (FGD Volunteers, Mwamadi & Nkhukuten).

The other sustaining structure of a chief was reported to act as a bridge between the community and home-based care team as stated in this quote:

*“When we talk about this area, there are certain things that we need but do not have. So we go to the chief and we say that right now with the way things are I will not manage to make it to the hospital or manage to acquire what I lack. So if it is possible please ask the doctor [project staff] to come this week. Or maybe if not that sometimes those same people can give some money to the person so that they are able to go to the hospital without waiting for when the doctor [project staff] is supposed to come”* (FGD Buleya).

This was corroborated by project staff who stated that:

*“We can say the most important thing is the unity that the project has with the communities and the patients. Our strategy is to go through the chiefs to sensitize the communities, this is what every organization does when they have something to do in their area”* (Project Staff).

The evaluation findings showed that the project had generated high dependency of beneficiaries on medical interventions. In all areas visited, beneficiaries reported they do not imagine life without the project. They clearly said if the project would phase out, they would all die. In Chinukule village, volunteers warned they would undertake a protest march if the project stopped.

We noted that the project has not done enough to establish sustainability enhancing structures. For example, in many areas, there are no support groups. Support groups would be instrumental in mobilizing PLWHA to engage in income generating activities and other social enhancing activities beyond receiving medical treatment. Further, it was found that the project has weak linkage with Blantyre District Health Office (DHO). This we recommend

should be worked on before the project comes to an end. Ultimately efforts by non-state actors aim to complement government efforts and it is important that the DHO be involved more.

When we asked beneficiaries why they do not have support groups their response was often they have not been told on how to form support groups. Probably, lack of understanding of a support group could be thwarting impetus to establish them. Income generating activities are absent in all villages we visited yet there were commonly mentioned as some of the ways project management team should consider before phasing out.

#### **4.9 Economic Empowerment Efforts**

As one way of ensuring sustainability of project activities, the study was also interested to know if there were any project initiated economic empowerment interventions targeting the volunteers. The volunteers indicated that such efforts were not made which contradicted to what the project staff reported. The staff reported that project introduced a number of economic empowerment interventions which included Loans for volunteers, Sewing machines and briquettes for income generation. It was further indicated that the interventions were not successful attributing the failure to laziness and lack of interest by the volunteers. This corresponds to the remarks made by one of the project staff;

*“In terms of the sewing machine, others were not willing to be independent. Same for the briquettes, it all came down to laziness and the group died. At the field, we were given fertilizer money but they misused the money. They lacked ownership. The harvest was for all of us but people failed to own up”*(Project Staff).

Another one said:

*“They were given money as loans and others did not pay back. They were also given bicycles for easy movement but others claimed it as their own and not for the group. Even the chiefs would take the bicycles meant for volunteers”*. (Project Staff)

Economic efforts because of malpractices by group leaders, misunderstanding among the group members because accountability processes were not followed, and some individuals managed the initiatives as their personal properties.

When asked what they would want to see happen before phasing out the project so that the outcomes and impacts can be sustained, the following were some recommendations:

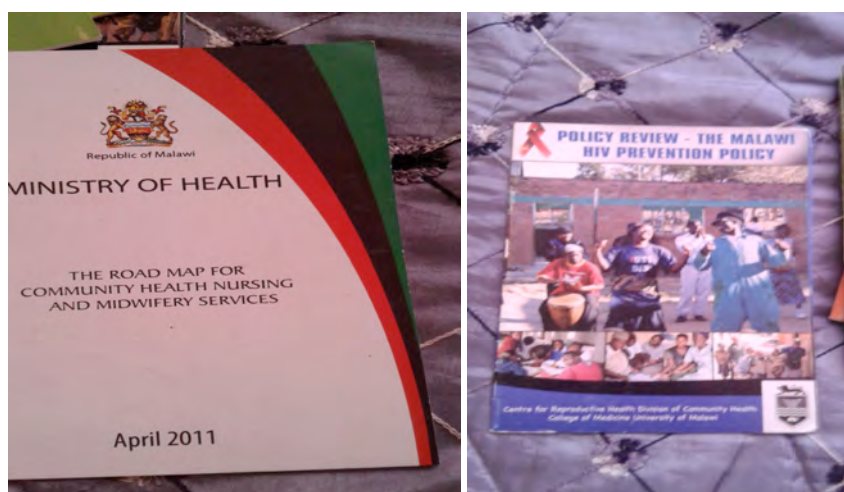
- (i) The project should link them to health facilities where they will be treated properly and without queuing for long;
- (ii) The project management team should provide start up capital for business to individuals and not as a group;
- (iii) There should be other organisation to take over;
- (iv) project should support construction of building as meeting point for beneficiaries;
- (v) Initiate village savings and loans.

They believe the recommended interventions would enable them sustain travel cost to clinic and buy food supplements. All in all, the main message was that the project should continue and that phasing out means they will all die in no time.

#### 4.10 Project contribution to policies and practices

The project has made great achievements at national, district, community and individual levels. At international level the Bangwe Home-based Care project features in publications of the Association of Palliative Care in Africa. We were shared a number of publications by College of Medicine which the project contributed. Some of the publications have informed national policies and guidelines.

At national level, the project has contributed to research outputs, academic work through students' visitations. Examples are:



**Figure 4: Some of the policy related materials the project has contributed to**

At district level, the project has enhanced various capacities of those who participate directly and indirectly. The district management team underwent a briefing and the project staff, including nurses and HSAs are kept abreast on policy matters. It was also reported that the College of Medicine conducts training sessions and refresher courses that involve community-based volunteers, to make sure that all service providers in the project are up-to-date. The DHO highlighted some of the main health care components that are included in the policy:

*“...before you’re a community based care volunteer, the policy says you have to be trained so that we know so that you know what you are supposed to do when you are in the community so that you prevent yourself from getting question or whatever and they are even told that when you’re going in the community, the policy says we should provide them with a package so that they use when they are in the community...”*  
(Blantyre DHO).

There were some specific project contributions to the documentation for scaling up efforts. For example, following the interventions of this program over the years, several best practices and procedures from the program have been adopted into national policy. The project staff reported that they have been asked to develop a manual on home-based care that can be used by volunteers.

*“...yes we were once asked to write a manual for how our volunteers work so it can be adapted elsewhere. We produced a manual for our volunteers and others. Now that manual is being used at national level for home-based care volunteers. It was designed by the project team” (Project Staff).*

In addition to this the project’s patient filing system has been adopted by the government in order to better manage patient information.

*“And to add on, one of our policies is to keep files for patients, we start with initial then the follow up. There are other organizations that keep patient names in a hardcover (book) but when they visited us and saw our system, they adopted our system of having a file for each patient. This makes us feel good that we are doing something that others can learn from and adopt” (Project Staff).*

The success of the program has led to other health care institutions forming their own home-based care initiatives that follow the Bangwe project’s blueprint. According to the project staff:

*“...and this issue of having home-based care assistants, the ministry has sort of adopted with funds restriction but they have appreciated the concept. Some organization like Tiyanjane at Queens (Queen Elizabeth central hospital) have implemented (programs) that go around the communities to visit the patients”.* (Project Staff).

#### **4.11 Achievements of the project**

From KIIs and FGDs with project staff and volunteers, the study has revealed great achievements on what the project aimed to address. The following are some of the project achievements: reduction of deaths, availability of medications for the community, reducing marginalization, caring for patients and encouraging many people to be open to receiving treatment. Example of quotes from volunteers:

*“There have been less deaths and also fewer diseases. The reason for this is, when the doctors [project staff] come like they do, if a person was suffering from a headache, they give that person some medicine, when the person takes the medicine, the medicine helps the person. It helps the person better because they don't have to go stand in line to be given two pills of Panado at the hospital. While this group can properly tell what to give a patient judging by how sick there are. The whole dose is administered whereas at other places they only give you two (pills)” (FGD Buleya).*

And another said:

*The way things were back then, people were just dying. We did not know how these services would help us. Some people were sceptical. And a lot of people lost their lives. But the people who embraced the program and understood what they were being taught and taking their medication, those people are still around today. Some of them are healthy and they are earning a living without problems. Because of the encouragement they received, taking their medication they way they are supposed to. And when they run out they should be coming back to get more. If they come here with a headache, the medication they left us here...the medication is delivered by doctors, they patients come here and get that medication. Yes”. (Namalo KII).*

This was corroborated by two project staff who stated that:

*“to the beneficiaries, there are some ... I found them bedridden, they had to be helped with everything, but after spending time with them you see them become independent, others have even gone back to work. To me, that is a great achievement that they have made such a recovery” (FGD, project staff).*

And another said:

*“I also started as a patient, I was unwell but after I meet this team I got better and started motivating and counselling others in my community. Now I am working as part of the team. I am able to dress wounds and offer ART counseling services to other patients” (FGD project staff).*

It was obvious the project and its staff are highly appreciated.

#### 4.12 How has the project made a difference?

The College of Medicine Home-based Care Project uses trained project staff and works with various actors mentioned in earlier sections. The project team consists of 3 trained nurses, 5 home-based care assistants and 150 community volunteers<sup>22</sup>. They provide basic nursing care; counselling; medical and pain relief; and support and advice for the patients’ carers. Besides these areas, the project also works on: supporting positive living support group for people living with HIV and AIDS; orphan sponsorship scheme; support to needy families for food and transport to hospital to collect ARVs; research and evaluation; and participation in national and local bodies<sup>23</sup>. In summary, the project theory of change can be explained as follows:



**Figure 5: Diagrammatic illustration of project Theory of Change**

Source: Author’s understanding based on information on the project available at <http://www.malawihbc.org/>

Interviews with various groups pointed to a common need, food supplements. Survey participants and respondents strongly recommended consideration for food supplements such as Likuni Phala and chiponde as taking ARV drugs requires that a person eats enough food.

<sup>22</sup> Comic Relief, 2016 Annual Report

<sup>23</sup> Ibid

Chiefs, guardians, PLWHA, volunteers explain the lack of food supplements as serious threat and set back. From a medical perspective, the call for consideration for food supplements is valid. From an economic perspective, the project target beneficiaries are people living in abject poverty; those who cannot afford to buy enough nutritious food indeed need the support of food supplements. When we interviewed project staff whether the need for food supplement had ever come to their attention, the response was in affirmative but said they engage government facilities and occasionally they get from government facilities and give the clients. We also learnt that World Food Program (WFP) used to support beneficiaries with food supplements but later stopped when government declared there was enough food in the country. Our recommendation is that the budget item on medical supplies should include food supplements.

**To determine the methodologies and approaches that have been most effective to bring about changes to people's lives focusing on what has worked and what has not, lessons learned and stakeholders which the implementing organisations shared lessons with.**

Recruiting volunteers and working with chiefs were found to be most impactful in harnessing ownership and commitment. Volunteers drop-out rate was found to be very high and in many cases majority or all volunteers are female. This makes it difficult when the patient is male and would need to be bathed or taken to clinic. Despite volunteers being told at the beginning that there would be no salary, we gathered that majority of people who started as volunteers and later stopped cited lack of incentives indicating they would not work for free. Those still volunteering cited the feeling to help, the understanding that the project is to their own benefit as individuals and community, the skills they have acquired in taking care of patient which could help them if they have a patient in their own household as some of the motivating factors. They however recommended more frequent refresher trainings, identification materials such as badge, coat, t-shirt or golf-shirt, medical kit and support for income generating activities to capacitate them as sometimes they buy soap and food stuff for a patient from their pocket.

#### **4.13 Project partnerships**

Project staff work with support from volunteers and chiefs to reach out to clients and their guardians. Overall our finding is that there is very good relationship between project staff and clients. Project staff are highly committed, respond to client needs, keep confidentiality and treat clients with love and care. In most villages, both clients and guardians made positive remarks about project staff. In a few villages, clients felt project interventions have changed since 'white' people left. Project staff too said they work well with chiefs and volunteers. Relationship between clients and volunteers was found to be strong and cordial in many areas except a few where clients showed some mistrust with volunteers. In one village, clients suspected food supplements meant for them are taken by volunteers and chiefs. Effective communication on food supplements is recommended. Resourcing of volunteers and guardians varied. In some villages, volunteers have gloves while in other villages they do not. Some guardians have gloves while others do not. Overall, volunteers do commendable work of identifying patients, informing project staff about the patients and encourage patients to

adhere to treatment. The quotation below emphasises some of the functions volunteers perform.

*“When the patient is seriously ill, we talk to the relatives and ask for permission to take the patient to the hospital. When we are given that permission we try to organize transport, maybe there is a bicycle, and we take the patient to the clinic as quickly as we can. At the clinic when they see that the condition is serious they take the patient to Queens...and we also tell the chief if we want to take a patient to the hospital”*  
(Mwamadi and Nkhukuten Volunteers).

We recommend that all volunteers should be provided with at least protective wear like gloves so that they are exposed to risk in the course of assisting.

There were a few partners that had an effective working relationship with the project. The main partner was the Ministry of Health through Blantyre DHO; teaching institutions such college of medicine and school of nursing whose students use the project for field training. The project staff conducted joint supervisions with the DHO not only to the project but also to other health facilities within the district as reported by the DHO. See Quote below;

*“Yaaaah we usually meet when we’re doing supervision and also the Project Officer who is Norton Gondwe is also one of the National Palliative Care and Home-based Care supervisor...they also do supervision in some of our facilities yaaaah”* (Blantyre DHO),

There is a very weak linkage with the Village Health Committee which is a very crucial structure as far as community level local government structures are concerned. This is a missed opportunity as the structure could be used as a sustainability tool. The weak relationship is expressed below by a beneficiary in Namalo;

*“There is one but they have never visited us. So there isn't any type of relationship because we have never sat down with them to discuss things”.* (Namalo Beneficiary).

#### **4.14 Effectiveness of Monitoring and Financial Management Systems**

Project management included need identification; design; implementation; monitoring, evaluation and learning as well as financial systems. We found that each component of funding source has had a baseline study implying need identification was done. Survey respondents indicated they are not involved in project design and that feedback sessions do not take place. When we asked the project team, their response on giving or getting feedback was not at variance with information provided by beneficiaries. Facilitating forum for different actors at community level to share perspectives was found lacking. This we recommend is an area for improvement.

Financial systems were found to be supportive of project delivery. There was no report that implementation of an activity ever delayed because there was no funding. In fact, project staff stated there has never been disruption in implementation for lack of funding. Similarly, the accounts and procurement offices process requisitions on time. What was reported to be an area for improvement is timely production of financial report by the accounts department in order for Project Manager to submit to donor on time.

#### 4.15 Project funding

According to the project staff, the home-based care project is currently solely funded by Comic Relief, but they have noted that the project has had several benefactors in the past 15 years. The staff note that the funding is adequate for the activities that they carry out, stating that equipment and salaries are always available.

*“Overall funding has been there and we are grateful because it is possible to have patients but without funding, they wouldn’t be assisted. So we are grateful. Even on the salaries, there is teamwork because the money is manageable”.* (Project Staff)

On the other hand, it has been noted that the funds, while readily available, are usually fixed and there are no adjustments for inflation. One member of the project staff in an FGD stated:

*“...the only problem I have heard was that the funding from Comic Relief was fixed for some years. Now the drug prices have gone up and the cost of care, salaries, fuel have all gone up and yet the prices that went to comic relief were outdated. Management had to source external funds to cater for that shortfall. Comic reliefs budget was fixed”.* (Project Staff)

Another problem that has been noted is that the funding by Comic Relief no longer supports other awareness campaigns like drama groups which were once instrumental in community mobilization.

*“...we also used to have a drama group but due to funds, it stopped. But when it was there, people would flock to see the drama group that raised awareness about this project”.* (Project Staff).

#### 4.16 Financial Management System

Overall funding has been adequate and timely despite a few challenges due to inflation. The study was also interested on how funding is being managed. As the budget holder, the Project Officer, is responsible for managing the project budget. The budget is discussed with the project staff to ensure implementation of activities is in line with its particular budget line. The Project Officer advises alternative budget lines to use upon exhaustion of a particular budget lines. This is backed up by what one of the project staff had to say;

*“But normally XXX is the one who is also responsible for the budget. Because what is supposed to happen is at the beginning of each year he is supposed to give us the budget for that particular year. So we work against that budget. Now of course there are times when um, the budget line is exhausted. When that happens it's XXX again who advises us on how we can handle that one. So he may advise, ok let's borrow from this budget line to this budget line”.* (Finance Staff).

The study has shown that there is clear segregation of duties in accounts management. This was explained as follows:

*“Of course XXX is the one who initiates every transaction. What happens is XXX issues a requisition, it's an internal requisition from the college. So when that one is issued it is submitted to our procurement department for sourcing quotations for whatever XXX needs. When they get the quotations they issue LPOs (local purchase orders) to the suppliers. Then the suppliers will supply the goods which are received here at the college. We have a stores department that side. So the goods are received that side. And then we receive an invoice from the suppliers. So the invoice, a goods received note from the stores office plus the LPO which was issued by the*



*procurement officer are the documents that we use to make a payment. Now these are reviewed by the finance officer because he is supposed to authorize the payment. Once the payment is authorized it goes to the assistant accountant who prepares the payment voucher. And then it is submitted to me. I check and i have to make sure that we have funds in the account for that particular payment. Once that is clear i also sign the payment voucher which goes to the cashier to process a cheque. When the cheque is ready, the supplier is called to come and collect". (Finance Officer).*

Among other recommended practices was the direct payment to service providers:

*"Now there is another way of making payments in which XXX for example maybe he needs fuel, it means we are not going to use an LPO. So XXX will just issue a requisition, it will come here, the finance officer will authorize and a payment voucher is processed. The cashier will issue the cheque and then XXX again will be called to come and collect the cheque. Now he is the one who handles everything in terms of making sure that cheque is delivered, he goes to the supplier and then he gets the service". (Finance Officer).*

#### **4.17 Accountability Processes**

The Accountability Processes, which formed part of the Financial Management System, was defined as ways of ensuring that financial procedures are done according to set role and regulations. Accountability processes were described as:

*"I'm the one who is very much involved in the project but apart from myself there is the finance officer who is also involved because of the review everything that we are doing on the ground. And um, we have the cashiers who also handle the other part of the project in terms of issuing cheques, releasing the cheques. And we have an assistant accountant who also handles payments for the project. So I would say they are about four of us: myself, the finance officer, the assistant accountant and the cashier. We are all involved in the project. But I am the one who is responsible for reporting now". (Finance Officer).*

The donors conducted project review missions as one way of ensuring the adherence of the project implementation to set procedures. This was also another tool to ensure accountability processes are in check.

*"Yeah. There was a time when um...the people from Comic Relief came here; a certain gentleman and a lady. I have forgotten their names because it was some time ago...i think when i just joined the project. So they came and they made a review of the project". (Finance Officer).*

The project did not commission any project audit during the 15 years of its implementation. The project was however audited through audits commissioned by the College of Medicine as an institution.

*"The Financial Records for the project were not subject to auditing. But for the college, yes. So when the college is being audited we include the project as well. So this is a - this project is also audited when the college is being audited. Because we have other projects which are audited separately from the college. And when the annual audit for the college is being conducted they are also audited again". (Finance Officer).*

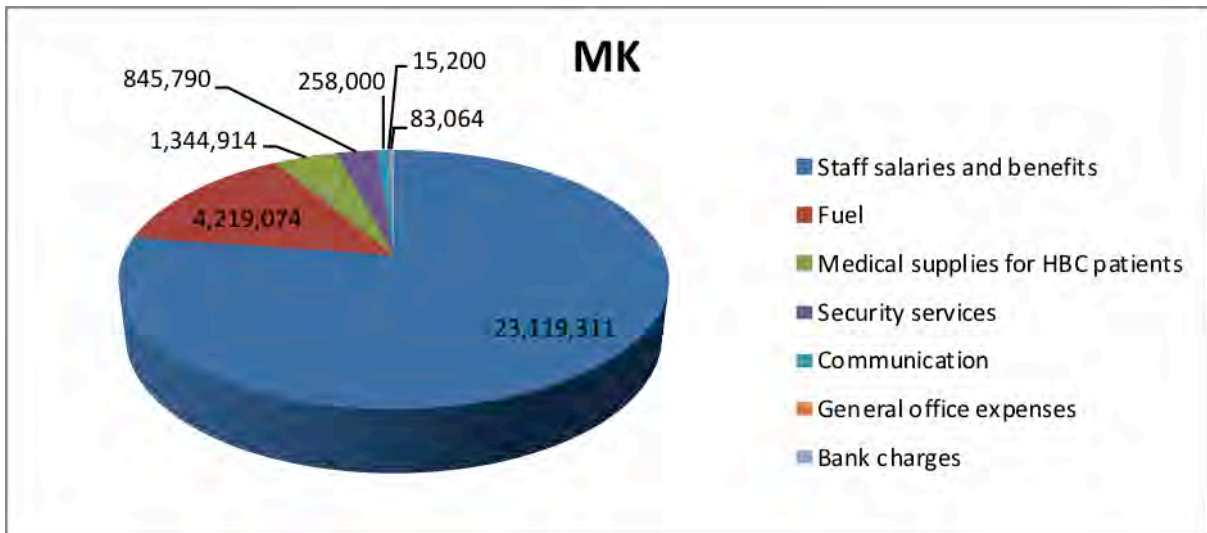
#### **4.18 Comic Relief Approaches**

In evaluating grant procedures, friendliness of reporting guidelines and frequency, flexibility in budget virement, robustness of financial controls are key aspects of examination. We interviewed finance officer who handles accounts for the project at College of Medicine. We also interviewed project staff. We found that Comic Relief grant procedures are friendly to accounts staff. The reporting period of six months was said gives accounts staff enough time to prepare and submit reports. Delays in submitting reports were reported as common though but this was attributed to large volume of work by accounts personnel as the project accounts does not have specific accounts personnel and relies on College of Medicine accounts who have other accounts to handle.

Assessment of spending procedure revealed that project staff through Project Manager issues requisition and the Procurement office at College of Medicine sources quotations upon which recommendation is made to procure goods or services. The accounts officer makes payment upon submission of invoice by supplier. There are a number of officers who approve. We got the impression that the financial controls are strong enough to detect or prevent potential fraud.

We also inquired about flexibility of the budget. The finding pointed to the fact that the current budget was approved in 2010 and has been static. This was an area of particular interest having noted that the budget items with high amounts were staff salaries and benefits followed by fuel and medical supplies in that order. The rigidity of the budget was what we found to be an area for improvement.

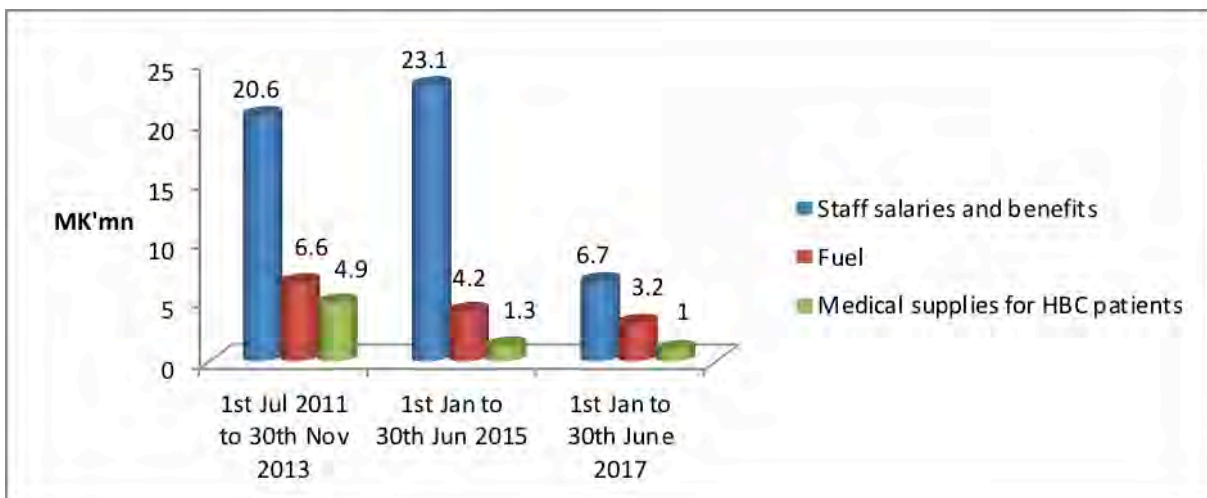
Financial information made available to the consultant suggests that the cost structure is skewed towards administration and support services. While appreciating that in delivering healthcare, salaries to healthcare workers are not supportive but actual delivery enhancing, we are of the opinion that spending on other interventions needed to show some form of balance. Fuel cost was found to be second highest. During field work, we got to appreciate the difficult terrain and wide area the project staff covers. Nonetheless, as stated already, investment in other interventions beyond medical was found to be on low scale. Examination of financial report for the project for the period 1<sup>st</sup> January and 30<sup>th</sup> June 2017 showed that out of total expenditure of K29.9 million, K23.1 million was spent on staff salaries and benefits and K1.3 million was spent on medical supplies for HBC patients. The pie chart below shows distribution of cost structure.



**Figure 6: Distribution of cost structure for 6 months period- January-June 2017**

*Source: Bangwe HBC Project*

Examination of other financial documents showed that in some periods except procurement of medical supplies for HBC patients, the rest of expenditure items were on staff costs and overhead expenses. This is the case for financial reports for the periods 1<sup>st</sup> July to 31<sup>st</sup> December 2013; and 1<sup>st</sup> January to 31<sup>st</sup> December 2012. For the period 1<sup>st</sup> July to 31<sup>st</sup> December 2015, the report shows a workshop/meeting took place at a cost of K90,000 and baseline survey was conducted at a cost of K1,971,305.49. The rest of the cost items were staff costs, medical supplies for HBC patients and overhead expenses. For the period 1<sup>st</sup> July 2011 to 30<sup>th</sup> November 2013, a workshop/meeting took place, there was training which cost K278,880, data collection cost K495,000 and external travel cost K1.7 million. The rest of cost items were medical supplies, staff costs and overhead expenses. The three major cost drivers in all financial reporting periods were staff salaries and benefits seconded by fuel and followed by medical supplies for HBC patients. We use three reporting period to show the pattern in the major cost drivers as shown in figure below.



**Figure 7: Pattern of major cost drivers**

*Source: Bangwe HBC project, various financial documents*

We are of the view that the administrative and overheads expenses do not correspond to investment that went into beneficiaries. The budget has increased nominally over the years to cover rises in wages and fuel while the relative proportions of the budget to staff, expenses and overheads have remained more or less fixed. Ultimately, the proportion of the budget invested in interventions that directly go to beneficiaries has become more and more inadequate in real terms. It was found that clients have asked for food supplements with no success, volunteers complained of less frequent refresher training and working materials such as gloves in some cases, motivation materials such as coats, identification badges, golf-shirts or t-shirts. The financial reports in the consultant's possession did not show spending on orphan sponsorship scheme. We are told by project staff that scholarship beneficiaries were linked to respective sponsors.

#### **4.19 Challenges Encountered in Bangwe Project**

Reported challenges are discussed under: management challenges and operational challenges.

##### **4.19.1 Management Challenges**

The study revealed management challenges that affect the project and these included: no feedback after monitoring visits to share solutions, volunteers are not provided with pain killers when making house calls, some health care providers at health facilities marginalize patients, lack of stretchers or wheel-chairs to transport bed ridden patients who cannot be taken on the bicycle, lack of safety materials to be used by the volunteers when doing house calls and house hold food insecurity.

The following are some of the quotes from the volunteers

*“The things that do not work for patients ... they complain to us that even though they are getting the medication, they do not have any food. In the past Clara was helping us with some food, cooking oil, beans and things like that. Even soap. But right now the patients are very concerned about taking the medication on an empty stomach. And we also see how bad their situation is when we visit them in their homes. That is something that is not right”.* (Mwamadi & Nkhukuten Volunteers).

And another said:

*“There are some patients that are used to this home-based care so for them to go back to receive treatment at the hospital, with the way things are in our hospitals, they will suffer. At the hospital, they are told there are no medicines, bandages, painkillers, these people are not working, and they have no money for transport to go to the hospital, worse to buy medications”.* (Project Staff).

And another said:

*“In terms of marginalization, a lot of projects teach us that we should not be marginalizing each other. But people are difficult. For some the marginalization stopped but for others it is still going on. The type of marginalization is that...in terms of food and the cost of living, life is very difficult. For instance, I could come to your house, let's say I have been sick on and off, and I come to live with you for a while. But it can turn out that you would be compassionate towards me while others in the house would not be happy. So these things are still happening despite the*

*lessons we are being taught. It still happens, ... is not completely over. Because some people are selfish. Some people feel superior, they think that they will never fall ill themselves. For some people ... they tell you to go and recover at your village, this is happening". (Mwamadi & Nkhukuten Volunteers).*

#### **4.19.2 Operational Challenges**

Discussion with the volunteers and project staff highlighted some challenges that affect the operations of the project such as; not enough resources for the volunteers to do house calls, lack of transport for patients to go to the hospital, and no workshops for the volunteers to improve operational skills.

#### **4.20 Project Key Lessons**

Project key lessons learnt through participating in the implementation of the project; receiving feedback from project staff, volunteers and beneficiaries. Some quotes are:

*"I have learnt that those people with chronic conditions still need support and care from us. It is our duty to cook and care for them, of course they are dying but at least they should go peacefully. We should help them whenever possible". (Project Staff).*

Discussion with volunteers highlighted some key lessons that drive their passion and commitment towards the project, these included: openness, caring for patients with love, confidentiality and identifying patients who are hiding from going to the hospital for testing and care.

A typical example of a quote by a volunteer was:

*"Since I started with this project, up to today, the lesson that I have learned is that a person needs to have compassion. Because without compassion nobody would manage to do this job. And we also need to understand what it means to be a volunteer. When we know that then we will be able to do our work without any problems. Because there is a lot that is involved with the work, for you to actually figure out what is wrong with a patient and convince them that they need help, that takes a lot of skill. On top of that, us volunteers need to be able to keep patients' information confidential. Because if we are unable to ... patients will start thinking that if they confide in us they will end up embarrassed. Those are the things I have learned" (HBC Chiswe chairman).*

And another said:

*"Some of us are comfortable but others are not comfortable. You can know that this particular person is part of our group but they are not open. They are reserved. But in terms of us here, we are comfortable. Because there are cases where we help our friends who are not aware so that they too can know. If they don't get the knowledge it will hurt them. If they do not follow our example of being open that will be their problem. We are open with each other. For example, I have explained to all my children". (FGD Buleya).*

Volunteers mentioned additional skills gained such as persuasion and counselling:

*"One of the lesson that I have seen is that we are able to know someone with a serious condition even if they try to hide it. We are able to see the signs from their illness. And so we try to convince the patient to go to the hospital to get tested and*

*when they do accept we take them to the hospital and usually they find out what is wrong with them when they get tested. Back then we did not know, we would just think that maybe it is just a headache, maybe it's this, maybe it's that. But I can say that these days I know the signs, when I see them i know how to approach the person even when they are trying to hide it. And i am usually successful. Because of this organisation I believe that this is the work that God chose for me. And i have accepted my role, i can only stop if God calls me home, but otherwise this is the work i am supposed to do” (HBC chairman).*

Feedback from the beneficiaries also indicated some factors that motivate them to take part in the project and to seek for help at the hospital whenever its necessary, these factors include; openness, living without fear and going for HTC. A typical example of a quote from a beneficiary:

*“What i have learned is that when the doctors started visiting me, they asked me if i had ever gotten tested before. And i told them that yes i had gotten tested before. And they asked me how well my immunity was. And i told them that my immunity was very low. So they asked me whether i wanted them to help me. They asked me the types of problems i was having. I told them that i was having difficulty eating and that my body was itchy. And i also told them that whenever i took medication i would end up vomiting. So they ended up giving me medication for all the ailments i have mentioned. After that they told me that they would come back the following week. When they came back they gave me more medication and they told me how long i needed to take the medication. So what i learned is that sometimes it is better to get tested early to know what your situation is, it can help you have a longer life”. (Chinupule beneficiary).*

And another said:

*“One thing I have learned is that, when this program started, it encouraged us not be afraid to live with this condition. They told us that if we feel that we are not alright we need to go and get tested so that we know what our situation is. Because of that we are very empowered. They should not stop, this program needs to continue”. (Chinupule Beneficiary).*

And another said:

*“I have also learned some things. Because when i started to fall ill, my sister did not take it lightly, she came and brought doctors here, the doctors started visiting me at home. When they started making house calls i started getting better. If someone else were to fall ill like i did, i would also not take it lightly, i would accompany that person so that they might also find peace the way i have found it. Like the way you see me now”. (Mwamadi & Nkhukuten Volunteers).*

This was corroborated by a volunteer who stated that:

*“What is keeping us going is the love/passion for the community because our patients in the community were suffering until we came in to support. Therefore, we saw that, our commitment to be a good gesture to express our love for the community in order to help the sick and poor in the community. We wanted to help to ensure that the disease do not spread because some sick people did not know what to do. So after being trained we would go around the community to help them and in some situations use our own resources”. (Mwamadi & Nkhukuten Volunteers)*

#### **4.21 Proposed Suggestions from Participants to Enhance Project Benefits**

The study was also interested in finding out proposed ideas for improvement of similar future interventions from the perspective of volunteers, beneficiaries and project staff. These are outlined as follows:

- The project should facilitate the establishment of support groups where there are none to support sustainability of some of the project interventions.
- Provision of start-up capital for businesses to reduce household food insecurity which affects medication response as well as uptake.
- Provision of food items to the beneficiaries in the form of Corn Soya Blend, maize flour, Cooking Oil to be taken by the patients so as to promote medication uptake and suppress medication side effects.
- Provision of Stretchers to ease on mobility of bed-ridden patients.
- Provision of Care Kits to volunteers which were initially being provided but was stopped.
- Convene seminars for volunteers which motivates them since they get a little allowance.

## **5.0 CONCLUSION**

The Bangwe Home-based Care project has saved lives and is hailed by beneficiaries and community members. The design of the project meets the need of PLWHA and their households and communities. The approach of working with volunteers and local structures needs strengthening by motivating volunteers and engaging actors more often to identify gaps and address them. The needs for food supplements to clients should be a matter of serious consideration.

The scholarship component needs to be continued amid addressing high drop-out rate of secondary school students. Further, the project could use those who successfully completed to motivate others still in school.

Project staff are very dedicated and serve with love and passion. However, as put under recommendations, there is need to offer staff long-term contracts to reduce staff turn-over.

Funding modalities were found to be friendly but less flexible. The project uses budget that was approved many years ago and much as some needs have emerged, the resources remain the same and virement is less possible.

We conclude that the project has achieved a lot in reducing AIDS related deaths, promoting positive living and addressing psychosocial problems like stigma and discrimination and increasing openness in discussing HIV issues. However, we emphasize that the project is not ready for phase out and a proper exit strategy needs to be development and executed.



## 6.0 RECOMMENDATIONS

On the basis of the findings, the following recommendations are made:

- i) There is need for establishing feedback mechanisms through which all actors should provide input
- ii) Taking ARVs requires that the patient accesses nutritious food. The scope of interventions should consider providing food supplements on regular basis. In the event that the resource envelop cannot be adjusted to cover food supplement expenses, the project management team should seek linkages with other partners who can provide food supplements to PLWHA.
- iii) There is high drop-out rate of volunteers. We recommend that some non-monetary incentives be considered. These include bicycles to ease their mobility, coats, gloves, badges, golf-shirts and medical kit and also more frequent refresher training sessions.
- iv) The project management team should consider offering project staff long term contracts to minimize staff turn-over.
- v) It is recommended that all volunteers be provided with protective wear like gloves at all times so that they do not get exposed to risk for doing good work
- vi) Sustainability enhancing structures are absent. We recommend revamping of Support Groups through which PLWHA should be supported with various income generating activities such as business capital, entrepreneurship skills training, machine for making briquettes; livestock production, maize mill and so on.
- vii) We strongly recommend for an exit strategy. Meanwhile the project should continue for some years while transitioning beneficiaries into phase out. Our findings show that the project is far from standing on its own and instead of establishing sustainability, it has created dependency.
- viii) Linkage with Blantyre District Hospital should be strengthened and official (s) from the district hospital should be involved in some activities including monitoring and evaluation activities.
- ix) There is need to revamp Village Health Committees and also strengthen relationship between volunteers and clients in few areas where the relationship was found not to be as strong.
- x) Although the project could be coming to an end, it is recommended that there should be an accountant or accounts assistant employed by the project and fully dedicated to the project. S/he can be based at College of Medicine and be supervised by CoM accounts staff. This we believe could speed up preparation and submission of financial reports.

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## APPENDICES

### Appendix 1: Key Informant Interview Guide

#### **Key informant interview guide- chiefs, village health committees, CoM, Blantyre DHO**

We are from Prime Health Consulting and Services (PHCS). We have been hired by the management of the Home Based Care project that has run here since 2003 to evaluate its outcomes and impact. You have been identified as one of the project beneficiaries and we would like to request you to answer some questions. The information will help project managers understand impact of the project. The information you provide will be kept confidentially and your name will not appear in the report. You are free to skip questions you feel uncomfortable to respond. Your decision not to participate will not affect your access to the services or affect your relationship with the health facility.

I proceed with the interview [ ]

I decline to take the interview [ ].

Thank the participant and end the discussion

- 
1. What can you share with me about the Home Based Care project in Bangwe?
  2. Are you involved in the project activities? If yes, how have you been involved and for how long?
  3. What roles have you played?
  4. How relevant were project interventions to your work? Target group? Policy?
  5. How have you engaged with project staff and project beneficiaries?
  6. What lessons have you learnt and how the lessons feed into your routine work?
  7. What roles if any will you continue playing after the project phases out?
  8. What government policy priorities resonated with the project?
  9. What areas do you think worked well for the project?
  10. What areas do you think did not work well for the project?
  11. What recommendations would you make for similar projects in future?

**Thank you for taking part**

## Appendix 2: Focus Group Discussion- PLHIV

### Introduction

We are from Prime Health Consulting and Services (PHCS). We have been hired by the management of the Home Based Care project that has run here since 2003 to evaluate its outcomes and impact. You have been identified as one of the project beneficiaries and we would like to request you to answer some questions. The information will help project managers understand impact of the project. The information you provide will be kept confidentially and your name will not appear in the report. You are free to skip questions you feel uncomfortable to respond. Your decision not to participate will not affect your access to the services.

Tachokera ku Prime Health Consulting and Services (PHCS). Talembedwa ndi akulu akulu aku Home Based Care project imene yakalapo kuyambira 2003 kuti tiwone zostantira ndi kusintha kumene kwachitika ndi project imenyi. Inuyo mwasankhidwa ngati modzi mwa anthu amene apundura nayo project imeneyi ndipo tikufuna tikupempheni kuti muyankhe mafenso. Zimene mutatuze zisungidwa mwa chinsinsi ndipo dzina lanu silizapezeka mu report latu. Ndinu omasuka kudumpha mafunso amene simulomasuka kuyankha. Kukana kutenga nawo mbali sikumangitsa kuti musalandirensa zithandizo ayi.

I proceed with the interview [ ]

I decline to take the interview [ ].

Thank the participant and end the discussion

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1. How did the project start?

Kodi project imeneyi inayamba bwanji?

2. If we have participants who were present when the project started, were there consultations?

Ngati pali ena amene analipo nthawi imene project imayamba, panachitikapo kafukufuku?

3. What mechanisms have been available to you to input into project design, implementation and monitoring?

Kodi pali ndondomeko zANJI zimene zilipo kuti muthe kupelekapo maganizo anu pokhazikitsa komanso poyendetsa project imeneyi?

4. How has been relationship between you and the following?

Kodi ngwirizano wanu wakhala otani pakati pa inu ndi anthu awa?

Project staff

Village health committees (Committee ya za umoyo mmudzi)

Chiefs (Mafumu)

5. What capacity development interventions have you benefitted from the project?

Kodi ndi maluso ati amene maphunzirako ndipo akupindulirani kudzera mu project imeneyi?

6. How has the project impacted on your life with regard to

Kodi project yasintha bwanji moyo wanu ku kudzana ndi

Stigma and discrimination

Openness to discuss HIV and AIDS issues

Going for HIV testing

Health status

Economic status

- a. Kusalana ndi kusankhidwa
  - i. Suzisala ndekha
  - ii. Kusolidwa chifukwa chagulu
  - iii. Kusolidwa ndialiyense
- b. Kukamba momasuka za nkhazi zokhudzani ndi HIV ndi AIDS
- c. Kukayezitsa HIV
- d. Za umoyo
- e. Za chuma

7. Which interventions have been most useful to you? Explain why

Kodi ndi zithandizo ziti zimene zakuthandizani kwambiri? Fotokozani

8. What structures if any have been established to sustain interventions beyond project phase?

Ndi chani chimene chakhazikitsidwa kuti zithandizo za project imeneyi zipitirire?

9. What other ways do you think you will sustain project gains when funding phases out?

Ndi zinthu zANJI zina zimene mungathe kupanga kuti zabwino za project imeneyi zipitirire?

10. What would you like should happen before phase out so that you can stand on your own

Kodi ndichani chimene mungafune kuchitika project imeneyi isanathe kuti muthe kuziyimira panokha.

11. What other recommendations do you have?

Kodi mungapeleke chilangizo chanji?

### Appendix 3: Interview guide of Guardians/ Volunteers

#### Introduction

We are from Prime Health Consulting and Services (PHCS). We have been hired by the management of the Home Based Care project that has run here since 2003 to evaluate its outcomes and impact. You have been identified as one of the project beneficiaries and we would like to request you to answer some questions. The information will help project managers understand impact of the project. The information you provide will be kept confidentially and your name will not appear in the report. You are free to skip questions you feel uncomfortable to respond. Your decision not to participate will not affect your access to the services or affect your relationship with the health facility.

Tachokera ku Prime Health Consulting and Services (PHCS). Talembedwa ndi akulu akulu aku Home Based Care project imene yakalapo kuyambira 2003 kuti tiwone zostantira ndi kusintha kumene kwachitika ndi project imenyi. Inuyo mwasankhidwa ngati modzi mwa anthu amene apundura nayo project imeneyi ndipo tikufuna tikupempheni kuti muyankhe mafenso. Zimene mutatuuze zisungidwa mwa chinsinsi ndipo dzina lanu silizapezeka mu report latu. Ndinu omasuka kudumphama mafunso amene simuliomasuka kuyankha. Kukana kutenga nawo mbali sikumangitsa kuti musalandirensa zithandizo ayi.

I proceed with the interview []

I decline to take the interview [].

Thank the participant and end the discussion

- 
1. What can you share with me about this Home Based Care project in Bangwe?  
Kodi munganiuze chani za project ya Home Based Care ku Bangwe?
  2. How are you involved in the project activities? If involved, for how long? What about your how you have engaged with project staff?  
Mumatenga nawo mbali yanji ndipo mwapanga kwa nthawi yayitali bwanji? Nanga anthu ogwira pa project imeyi mumagwira nawo bwanji ntchito?
  3. How many were you previously when you started as a volunteer? How many are you now?  
Munalipo angati kale mmene mumayamba ngati volunteer? Panopa mulipo angati?
  4. How relevant were project interventions to your role as a care giver?  
Zithandizo zimene zimapelekedwa ndi project imeneyi zimagwirizana bwanji ndi mbali yanu monga osamalira munthu?
  5. What lessons have you learnt and how the lessons feed into your routine work as a care giver?

Mwaphunzirapo chani ndipo mwazigwiritsira bwanji ntchito pa ntchito yanu ya tsiku ndi tsiku?

6. What roles if any will you continue playing after the project phases out?  
Mupitiriza kutenga mbal yanji project imeneyi ikatha?
7. What government policy priorities do you think resonated with the home based care activities?  
Ndi ndondomeko zANJI za boma zimene zimagwirizana ndi zokhudzana ndi chisamaliro cha kunyumba (home based care)
8. What areas do you think worked well for the project?  
Kodi ndi mbali ziti za project zimene zinayenda bwino?
9. What areas do you think did not work well for the project?  
Kodi ndi mbali ziti zimene sizinayende bwino?
10. What recommendations would you make for similar projects in future?  
Mungapeleke langizo lanji kwa pa project ena ngati awa amene angabwere mutsogolomu?

**Thank you for your time.**

**Zikomo**

#### **Appendix 4: In-depth interview guide for Project staff**

We are from Prime Health Consulting and Services (PHCS). We have been hired by the management of the Home Based Care project that has run here since 2003 to evaluate its outcomes and impact. You have been identified as one of the project beneficiaries and we would like to request you to answer some questions. The information will help project managers understand impact of the project. The information you provide will be kept confidentially and your name will not appear in the report. You are free to skip questions you feel uncomfortable to respond. Your decision not to participate will not affect your access to the services.

I proceed with the interview [ ]

I decline to take the interview [ ].

Thank the participant and end the discussion

---

1. How long have you worked under this project?
2. What experiences would you like to share with me on the perspective of:
  - a. Project management
  - b. Project interventions
  - c. Project impact on the beneficiaries, policy
3. What capacity building interventions did you receive to prepare you deliver the project?
4. In your view, did you have adequate capacity (number and skill) to deliver the project?
5. Share with us your perceived key lessons and best practices
6. What do you think were critical success factors in the project?
7. How did you engage stakeholders such as chiefs, village health committees and carers?
8. What capacity interventions did the project give them?
9. How have they shown to have been prepared to carry on with project interventions without your supervision?
10. What structures if any did the project establish to sustain project interventions?
11. How did you find funding modalities of Comic Relief in enhancing or hindering achievement of the lasting change?
12. What recommendations would you like to make?

**Thank you for your time**



## Appendix 5: Questionnaire

### Introduction

We are from Prime Health Consulting and Services (PHCS). We have been hired by the management of the Home Based Care project that has run here since 2003 to evaluate its outcomes and impact. You have been identified as one of the project beneficiaries and we would like to request you to answer some questions. The information will help project managers understand impact of the project. The information you provide will be kept confidentially and your name will not appear in the report. You are free to skip questions you feel uncomfortable to respond. Your decision not to participate will not affect your access to the services.

Tachokera ku Prime Health Consulting and Services (PHCS). Talembedwa ndi akulu akulu aku Home Based Care project imene yakalapo kuyambira 2003 kuti tiwone zozantira ndi kusintha kumene kwachitika ndi project imenyi. Inuyo mwasankhidwa ngati modzi mwa anthu amene apundura nayo project imeneyi ndipo tikufuna tikupempheni kuti muyankhe mafenso. Zimene mutatuze zisungidwa mwa chinsinsi ndipo dzina lanu silizapezeka mu report latu. Ndinu omasuka kudumpha mafunso amene simuliomasuka kuyankha. Kukana kutenga nawo mbali sikumangitsa kuti musalandirensa zithandizo ayi.

I proceed with the interview [ ]

I decline to take the interview [ ]

Thank the participant and end the discussion

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### Background characteristics

1. Sex of respondent.....*circle the appropriate*

1) Male                      2) Female

2. How long have you benefited from the program \_\_\_\_\_ years, months, weeks?

Mwapundula kwa nthawi yayitali bwanji ndi program \_\_\_\_\_ zaka?

3. What is the highest level of education you have completed?

Kodi sukulu munafika nayo pati?

1. None
2. Primary school
3. Secondary
4. College certificate
5. University degree
6. Other (specify) \_\_\_\_\_

4. What is your main source of livelihood?

**Kodi mumagwira ntchito yanji kuti mupeze zofunikira pakhomo?**

1. None
2. Business
3. Salaried employment
4. Casual labour (ganyu)
5. Other (specify) \_\_\_\_\_

5. What is your average monthly income in Malawi Kwacha \_\_\_\_\_

**Kodi pa mwezi mumapeza ndalama zingati? \_\_\_\_\_**

How old are you?

1. Below 15 years
2. Between 16 and 20 years
3. Between 21 and 25 years
4. Between 26 and 30 years
5. Between 30 and 35 years
6. Over 35 years

### **Relationships**

6. How do you work with the following? *Indicate very well, well, not very well, not sure*

**Mumagwira bwanji ndi anthu awa?..... *Lembani bwino kwambiri, bwino, osatibwino, sindikudziwa***

1. Project staff \_\_\_\_\_
2. Village health committee \_\_\_\_\_
3. Chiefs \_\_\_\_\_
4. Carers \_\_\_\_\_
5. Other (Specify) \_\_\_\_\_

7a. Have these different actors been of help to you?

**Anthu amenewa amakuthandizani?**

1. Yes                      2. No                      3. Don't know

1. Eya                      2. Ayi                      3. Sindikudziwa

7b. If yes, in what ways have they been of help?

**Ngati eya, akuthandizani munjira zANJI?**

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

### **Project outcomes and impact**

8. What interventions have you benefitted from the project staff over the years?

**Kodi ndi zithandizo ziti zimene mwapindula nazo pa zaka zapitazi?**

1. Treatment 2. Wound dressing 3. Counselling 4. Physical Assessment 5. Environmental Assessment 6. TB screening 7. Referral 8. Other. Specify \_\_\_\_\_

8b. What interventions have you benefitted from the volunteers over the years?

1. Monitor drug adherence 2. Wound dressing 3. Counselling 4. Help patient with bathing 5. Environmental Assessment 6. Take client to clinic 7. Referral 8. Other. Specify \_\_\_\_\_

9a. Did the interventions you benefitted from project staff changed over time or they remained the same?

**Kodi zithandizo zimene munapundila nazo zi zinasintha kapena zilichomwecho?**

1. Change over time
2. Remained the same
3. Can't remember properly

- a. Zinasintha
- b. Sizinasinthe
- c. Sindikukumbukira

9b. Did the interventions you benefitted from volunteers changed over time or they remained the same?

**Kodi zithandizo zimene munapundila nazo zi zinasintha kapena zilichomwecho?**

4. Change over time
5. Remained the same
6. Can't remember properly

- d. Zinasintha
- e. Sizinasinthe
- f. Sindikukumbukira

10. In your view, which interventions were most useful to meet your needs?

**Kwa inuyo, ndi zithandizo ziti zimene zinali zopindula kwambiri kukaniritsa zofuna zanu?**

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_

11a. Do you think the project interventions improved your life?.....*circle the appropriate*

**Kodi mukuwona kuti zithandizo zimenezi zasintha umoyo wanu?**

1. Yes                      2. No                      3. Partially Yes and partially No                      4. Don't know

1. Eya                      2. Ayi                      3. Osatikwenikweni                      4. Sindikudziwa

11b. If yes in question above, in what ways did the project changed your life?

Ngati eya, moyo wanu wasintha bwanji?

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12. Did the project achieve the following?.....indicate strongly agree, agree, and do not agree

1. Reduce stigma and discrimination \_\_\_\_\_
2. Encourage openness in discussion HIV and AIDS issues \_\_\_\_\_
3. Improve my health status
4. Helped my community to be accommodative to people living with HIV
5. Encouraged people to go for HIV testing
6. Improve my economic status

Kodi project imeneyi ya kwaniritsa izi? ..... *Lembani ndikugwirizana nazo kwambiri, ndikugwirizana nazo, ndi sindikugwirizana nazo*

- g. Kuchepetsa kusankhana ndi kusalana
- h. Kulimbikitsa kumasuka pokambirana nkhani zokhudzana ndi HIV ndi AIDS
- i. Kutukula umoyo wanga
- j. Anathandiza anthu amudzi kuti azivomereza anthu omwe ali ndi HIV
- k. Kulibikitsa anthu kukayezitsa HIV
- l. Kusintha kwachuma change

### Sustainability

13a. Do you think the project outcomes and impacts are sustainable when the project phases out?

Kodi mukuwona kuti zotsatira ndi zintchito za project imeneyi zitha kupitirila?

1. Yes                      2. No                      3. Not sure  
 1. Eya                      2. Ayi                      3. Sindikudziwa

13b. If yes, in what ways are the project outcomes and impacts going to be sustained?

Ngati eya, kodi ndi njira zANJI zimene zotsatira ndi zintchito zingapitire?

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

14. Which structures if any have been established to sustain project interventions beyond funding phase?

Ndi chani chimene chakhazikitsidwa kuti zithandizo za project imeneyi zipitirire?

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

15a. Are there some things you would want to happen before you are left to continue on your own?

Kodi pali zinthu zimene mungafune zitachitika musanasiyide kuti mupitirize?

- |        |        |                 |
|--------|--------|-----------------|
| 1. Yes | 2. No  | 3. Not sure     |
| 1. Eya | 2. Ayi | 3. Sindikudziwa |

15b. If yes, please mention, in order of priority, what you would want to happen before you are left to be on your own?

Ngati eya, chonde chulani kuyambira chofunikira kwambiri. Ndi chani chimene mungafune chitachitika musanasiyide kuti mupitirize?

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

16. Is there anything you would like to say that we have not covered? If so write in the space provided

Kodi pali chowongezera chilichonse imene mwina sitinafunse? Ngati chilipo lembani pamusipa

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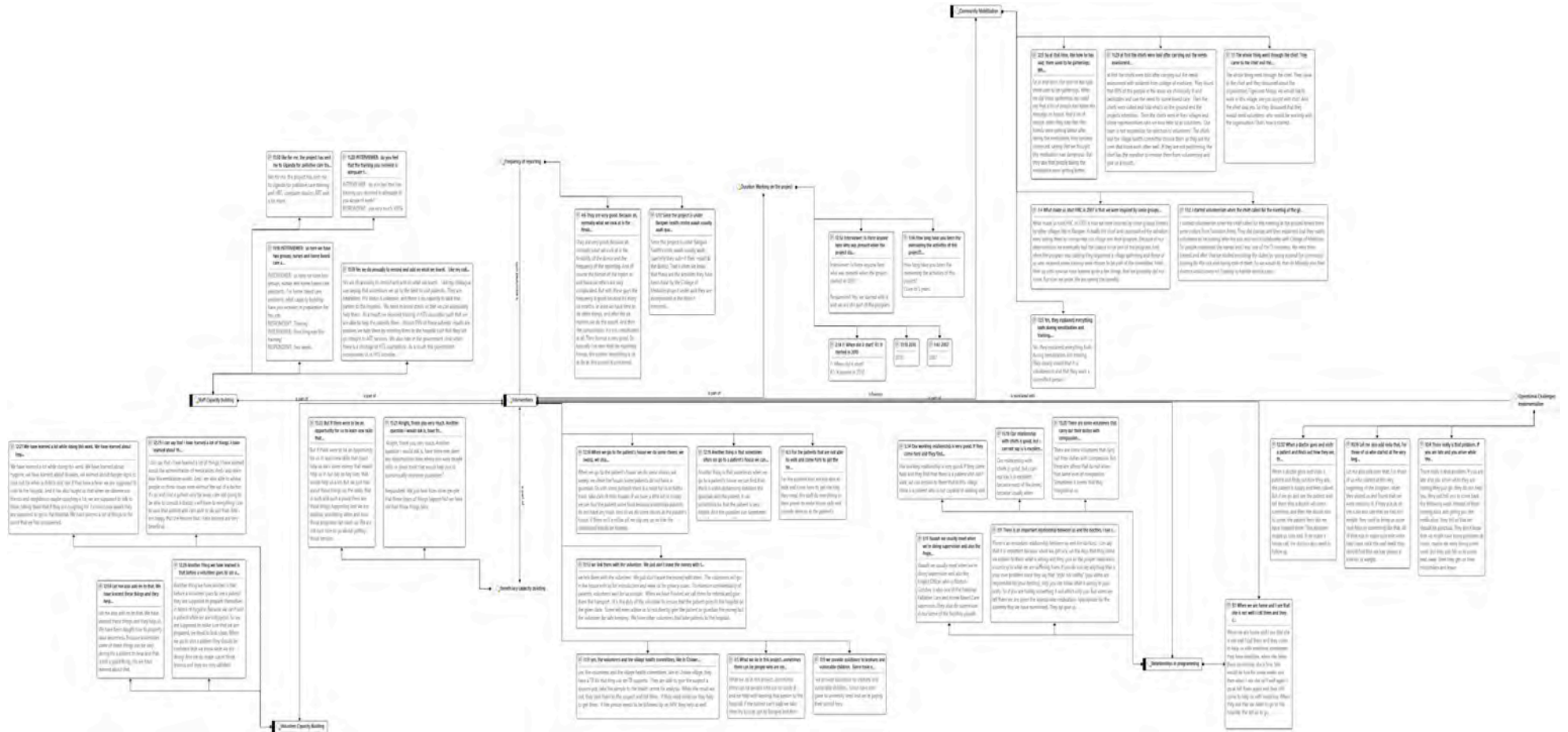
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Thank you for your time!!

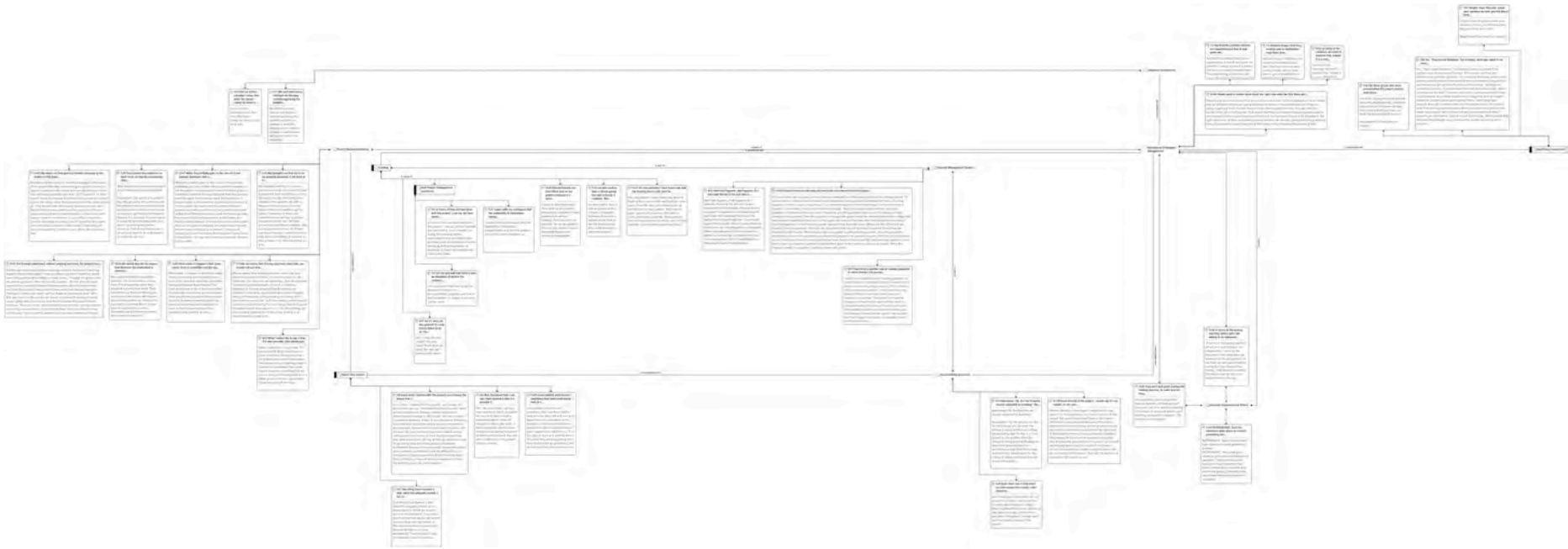
Zikomo kwambiri popeleka nthawi yanu.

# Appendix 6: Networks with codes and quotations

## 6A: Project Implementation



**6B: Project Management**



**6C: Project Impact**



