

# **Developing a Buruli Ulcer community of practice in Bankim Cameroon: a model for Buruli Ulcer outreach in Africa**

## **Authors:**

## **Abstract**

Buruli Ulcer (BU) is a neglected tropical disease primarily found in West Africa and largely effecting the rural poor. It has a known cause and cure, but an unknown route of transmission and a poorly understood incubation period. If not treated early and in a timely manner by a 56-day course of antibiotics, BU often progresses to an advanced state requiring prolonged wound care and skin grafting. If left untreated or treated late, BU does not kill, but may render the afflicted permanently disabled.

In the Cameroon, previous efforts to identify BU early through the mobilization of community health workers (CHWs) yielded poor results. In this paper, we describe the successful creation of a BU community of practice (BUCOP) involving multiple stakeholders from clinic staff and former patients to CHWs and traditional healers. A community of practice is based on all stakeholders sharing a common objective, a common basic understanding of a focal problem, and mutual respect for what each stakeholder contributes to a process of problem solving. In the pilot project described, the creation of a BUCOP resulted in active and sustained community involvement in BU case identification, reduction in health care seeking delay, and a decline in treatment drop- out leading to better treatment outcomes. It also led to sustained partnerships between health staff, CHW, and traditional healers. CHW came to play a more active role in organizing BU outreach activities, and case follow -up resulting in a marked increase in their status within their community. Healers valued the partnerships established with health staff and

found they gained more from collaboration than they lost from referral. An innovative outreach education also netted impressive results. Over the course of the project there was a shift from CHW and healers referring suspected cases of BU to clinics to self- referral. In addition to a significant rise in the number of cases of BU identified, treatment adherence rates rose and treatment dropout rates declined. The process of creating a BUCOP in a remote part of the Cameroon is described and lessons learned are highlighted.

Keywords: Buruli ulcer, community of practice, community outreach, culturally sensitive health education, health system strengthening

## **Introduction**

Buruli ulcer (BU) is one of several neglected tropical diseases that afflict the rural population of sub-Saharan Africa, especially the poor living in areas with poor access to health infrastructure (WHO 2006). The term neglected disease refers to infectious diseases that have not enjoyed the level of attention (and funding) paid to HIV/AIDS, malaria, and tuberculosis (TB), the focus of the United Nations Millennium Development Goals (Manderson et al., 2009). BU stands out as one of the most disabling of all neglected tropical diseases. The large majority of cases of BU have been identified in West Africa particularly the countries of Benin, Cameroon, The Congo, Cote D'Ivoire, Ghana, and Nigeria.

Buruli Ulcer (BU) is caused by *Mycobacterium ulcerans* (MU) a microorganism belonging to the same genus of bacteria as tuberculosis and leprosy. Primarily found in West Africa, BU has a known cause and cure, but an unknown route(s) of transmission and poorly understood incubation period (Bratschi 2013, Trubiano et al 2013; Yotsu et al 2015). BU manifests as necrotizing cutaneous lesions. Thirty-five percent of lesions are located on the upper limbs, 55% on the lower limbs, and 10% on other body parts (Trubiano et. al 2013). In Africa, about 48% of those affected with BU are children under 15 years of age (Bratschi et al 2013), and males and females are affected equally.

If not treated early and in a timely manner, BU often, but not always, progresses to an advanced state requiring prolonged wound care and skin grafting. If left untreated or treated late, BU does not kill, but may render the afflicted permanently disabled. Early diagnosis and treatment are the only ways to minimize morbidity and prevent disability. Notably, at present most cases (68%) of BU are diagnosed at a late stage—categories II and III of the disease (WHO 2013). Beyond non-

identification in its early stages, and delay in seeking care, there is some evidence suggesting that distinct phenotypes of BU may be more likely to progress to severe forms of BU (Capela et. al 2015).

Prior to 2005, when effective antibiotic treatment was discovered for treating early stages of BU , treatment for all cases of BU required surgery. Antibiotic treatment with streptomycin injections and oral rifampicin for 56 days proved to be highly successful in early (category one) BU cases. Once treated with appropriate antibiotics, there is a very low rate of BU relapse (ref). When BU cases are not caught early, however, those with more advanced category two and three BU often require surgery and skin grafting followed by months of supervised wound care. The key to community management of BU is identifying cases in the early stages of the disease, and enrolling the afflicted in treatment programs with minimal delay and sustained adherence to treatment.

In this paper, we describe a pilot project conducted in Bankim District Cameroon that proved to be highly successful in establishing a BU community of practice (Figure one). A community of practice is an assemblage of stakeholders committed to a common objective, a common basic understanding of a focal problem, and mutual respect for what each stakeholder contributes to a process of problem solving (Lave and Wenger 1991, Wenger et al 2011). In the case of BU, this entails health staff, community health workers (CHW), and traditional healers sharing a common understanding of the signs of BU, collaboration in encouraging the afflicted to seek and continue BU treatment, open lines of communication between stakeholders, and mutual respect for what each contributes to the process of healing which includes, but extends beyond the management of BU as a disease

## Figure One: BU Community of Practice

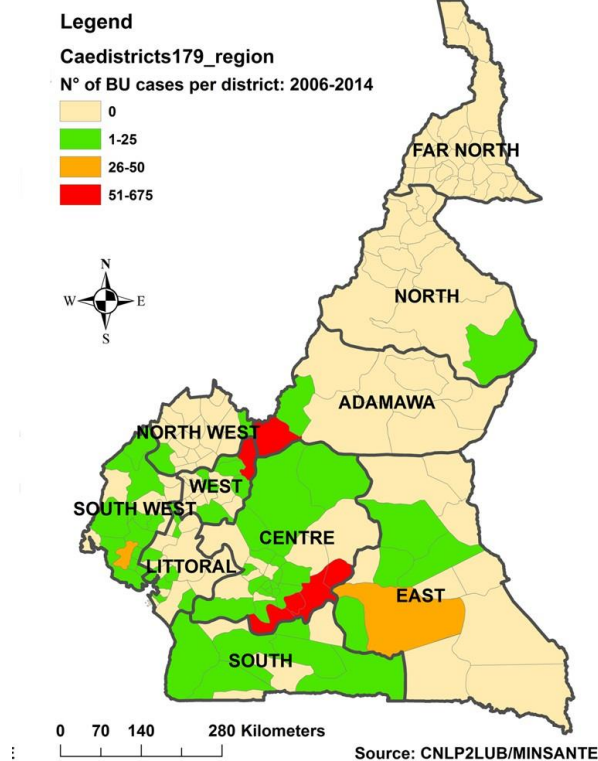
### Four essential characteristics: Domain, Community, Practice, Mutual Respect

- **Domain**: the shared area of interest that defines an identity for the CoP:  
Identification and treatment of Buruli Ulcer
- **Community**: formed through members engaging in joint activities, information sharing and mutual assistance, the community is mobilized
- **Practice**: Members adopt common frames of reference and an appreciation for core practices that facilitate problem solving and enable interaction. It is through dialogue, participatory learning, the sharing of experience, and feedback that a common sense of identity is gained thru participation in a BU COP.
- **Mutual respect**: Established when each member comes to appreciate what other kinds of members contribute to problem solving such as illness identification, patient support, care management, etc.

### Setting

BU has been identified in 64 of Cameroon's **XX** districts. Bankim district, the focus of this paper, is located northwest of the Adamawa region of Cameroon bordering Nigeria. It has one of the three highest prevalence rates for BU in the country (Tabah et al 2016).

### 2006 - 2014 BU by district map of Cameroon



The central treatment and referral hospital for BU in the Cameroon is the Ayos District Hospital located in the southern part of the country. Until recently, BU patients from all over Cameroon had to travel considerable distance to be treated at Ayos, a journey many were reluctant to make. Over the last decade, Cameroon's National BU control program has trained clinic staff to provide BU treatment in its early stages in many regions of the country and has established five diagnostic and advanced treatment centers. Another two BU treatment centers are soon to be functional (Tabah et al 2016 ).

Bankim is located in a remote region of Cameroon having environmental factors favoring the presence of the MU microorganism responsible for BU. The district is situated in the Mape River Valley, where a dam was built to generate hydro-electric power more than twenty-five years ago.

The Mape Dam splits the area into isolated islands and scattered villages. In the last two decades, increased irrigation has enabled rice cultivation. Rice farming has been identified as a possible risk factor for BU transmission (ref ). Inhabitants of the region also engage in the growing of maize, cassava and peanuts as well as various forms of hunting and fishing. Much agriculture is done on plots of land some distance from villages during the months of January to May, and many inhabitants also seek employment in Nigeria from November to April. Population movement is both fluid and seasonal.

Bankim Health District is a challenging place to initiate a community outreach program for BU due to both its rugged terrain and the wide variety of ethnic groups inhabiting and moving in and out of the region. These groups speak a variety of languages and dialects in addition to French and Pidgin English. The region is inhabited by Tikars, Yambas, Mambilas, Kwanjas, Fulanis as well as ethnic groups hailing from the neighboring Western, North West, Centre and Adamawa regions of Cameroon, and Nigeria. This required BU outreach activities to be carried out in multiple languages and for the research team to seek the approval and support of Christian and Muslim clerics, influential traditional healers, and local chiefs. There are seven paramount chiefs responsible for the welfare of Bankim district. The project staff had to gain the permission of each paramount chief before they could initiate outreach activities in their domain. The feasibility study took place in the jurisdiction of the paramount chief of Bankim town, a forward thinking, but cautious leader. Once on board with the project during other chiefs agreed to participate during the pilot phase of the project.

## Formative research design and methods

This community- based intervention employed a three phase, seven stage formative research process summarized in (Table One).

Table one: Seven stages of formative research adapted for Buruli ulcer

<b>Stages of Formative Research 1-7</b>			
<p><b>Stage One and Two</b></p> <p><b>Research “Why” and “What” Questions</b></p>	<p><b>‘Why’ questions</b></p> <ul style="list-style-type: none"> <li>• Why don’t villagers come for free Bu treatment</li> <li>• Why do they come late?</li> <li>• Why don’t they complete therapy or drop out</li> <li>• Why do they consult traditional healers for chronic wounds?</li> </ul>	<p><b>“What” questions</b></p> <ul style="list-style-type: none"> <li>• What predisposing factors influence health care seeking practices (HCSP) for BU</li> <li>• What local illness perceptions and practices influence HCSP BU</li> <li>• What are enabling factors influencing HCSP</li> </ul>	<p><b>“What” questions about health services</b></p> <p>What are local concerns related to health service utilization for BU</p> <p>What are local perceptions, rumors, concerns about BU treatment</p> <p>What are local perceptions of government health services: trust, fears,</p> <p>What is staff and health volunteer motivation for engaging in BU outreach</p>
<p><b>Stage three</b></p> <p><b>Research “How to” Questions beginning with</b></p> <p><b>Identifying health service research problems</b></p>	<p>How can we identify BU in early stages when easiest to treat?</p> <p>How can we make BU programs more accessible and acceptable?</p>	<p>How can we enable patients to follow the course of BU therapy recommended?</p> <p>How can we be more innovative and effective in delivering BU services?</p> <p style="text-align: center;">–</p>	<p>How can we motivate community health workers to be more proactive in BU outreach?</p> <p>How can we involve traditional Healers in BU programs as partners and not see them as obstacles</p>



<p><b>Stage four</b></p> <p><b>Research “How to” identify and asses BU intervention options</b></p>	<p>Generate intervention options with key informants</p>	<p>Assess the strengths and weaknesses of intervention options, Swat analysis</p>	<p>Response by different stakeholders with different needs and vested interests</p>
<p><b>Stage five</b></p> <p><b>Research “How to” best implement most promising interventions</b></p>	<p>Feasibility and pragmatics of implementation</p>	<p>Details matter</p> <ul style="list-style-type: none"> <li>• Who, when, where, how much</li> <li>• How best to introduce and organize?</li> </ul>	<p>Exploration of supportive collaborations</p> <p>Identify likely challenges and bottlenecks</p>
<p><b>Stage six</b></p> <p><b>Monitor interventions</b></p>	<p><b>Monitor in in real time</b></p> <ul style="list-style-type: none"> <li>• To facilitate mid-course correction</li> <li>• Reflection, refinement</li> </ul>	<p>Maximize and create opportunities for presenting feedback to stakeholders and engaging in dialogue</p>	<p>Facilitate Problem solving process</p> <p>Provide positive as well as identify problems</p>
<p><b>Stage 7</b></p> <p><b>Evaluate short term effectiveness and long term impact of interventions</b></p>	<p><b>Outcome evaluation</b></p> <ul style="list-style-type: none"> <li>• Evaluate Intended outcomes over time</li> <li>• Community awareness of BU</li> <li>• Data on suspected and confirmed cases of BU identified by community stakeholders – by category of disease</li> </ul>	<p><b>Process Evaluation</b></p> <ul style="list-style-type: none"> <li>• <b>Establishing new lines of communication and social relations that enable outreach and patient support</b></li> <li>•</li> </ul>	<p><b>Impact Evaluation</b></p> <ul style="list-style-type: none"> <li>• <b>Sustained community stakeholder involvement in community of BU practice</b></li> <li>• <b>Collaboration that extends beyond BU</b></li> <li>• <b>Improved status of CHW, and reputation of hospital</b></li> <li>• <b>Healers seen as partners in health programs and as having a role in emergency response and preparedness</b></li> </ul>

Table 2 depicts what was entailed in each of the three phases of the BU project.

**Table two: Three phases of COP research following seven stage model of formative research model**

Research phase	Formative research stage	Year	Core Activities	Role of social scientist
<b>Phase one</b> <ul style="list-style-type: none"> <li>• Baseline data collected prior to intervention</li> <li>• Identify problems</li> <li>• Generate, and weigh intervention options,</li> <li>• Work out details of intervention strategies</li> </ul>	Formative research stages 1-4	<b>2010</b>	Three researchers conduct focused ethnographies *Former BU patients and community members  *Health system and staff *Community health workers *Traditional Healers	Ethnography  Health service Research  Action research to identify potential intervention strategies
<b>Phase two (two parts)</b> <ul style="list-style-type: none"> <li>• <b>Proof of concept (POC) study</b></li> <li>✓ Monitoring</li> <li>✓ Refinement</li>   <li>• <b>Pilot study (PS)</b></li> <li>✓ Monitoring</li> </ul>	Formative research Stage 5-6  -	<b>* POC 2011-2012</b> Social scientists facilitate <b>* Pilot 2013-2014:</b> Year one social scientists facilitate *Year two <b>Staff take over implementation</b>	*Facilitate Implementation of intervention in early stages *Monitor and make suggestions for mid-course correction	Implementation Research  Ethnography: Participant -observation
<b>Phase three Evaluation</b>	Formative research stage 7	2016	*Outcome evaluation *Process evaluation: shifts in social relations, partnerships, task shifting & task sharing, role identity, new norms and practices *Impact evaluation -- sustainability and larger effects beyond BU	Ethnography: Data triangulation from mixed methods: Interviews, case studies, meeting observations, focus groups  Evaluation (Qualitative and quantitative data)  Follow up ethnography

In the first phase of the project, a team of anthropologists conducted interviews with **current (N=)** **and former** BU patients **(N=)** as well as health staff **(N= )** to identify predisposing, enabling and health service related factors influencing health care seeking for chronic ulcers as well as

reasons for treatment delay, and treatment drop out for BU patients offered free treatment. They identified barriers to treatment related to perceptions of why wounds that did not heal, fear of and trust in the hospital, and pragmatic issues related to transportation, housing, and the availability of food for patients and caretakers when treatment required hospitalization. The three anthropologists were then embedded in separate communities to investigate the current role of community health workers and healers in chronic ulcer management, existing BU detection activities, patterns of treatment referral, and household wound care decision making in different seasons. Health staff interaction with BU patients, CHW and healers were also observed in the community, at the district hospital, and in local clinics. Research methods employed included participant observation, key informant interviews, prospective and retrospective case studies of BU patients, semi-structured interviews incorporating “what if” scenario, and observations of social interactions between health staff and community members.

At the end of 4 months of intensive ethnographic research, the anthropological team presented their findings at a workshop attended by the head of the Cameroon national BU program, Fairmed an NGO providing support for neglected tropical disease (NTD) surveillance and treatment activities in the region, and the doctor in charge of Bankim district hospital. In keeping with stage 2-4 of formative research, they also presented data on what different stakeholders saw as possible means of more proactively involving community members in BU detection and the kinds of support that might reduce treatment delay and drop out.

Two sets of concerns were raised at the workshop. The first concern entailed the need to at once respect local culture while at the same time address cultural beliefs and practices that posed

barriers to BU management. This required gaining the trust of local leaders and healers , and enlisting their support if not active collaboration in a new BU outreach initiative. The key question raised was : is it possible to involve healers in community- based BU outreach such that they could be part of the solution to late BU identification and treatment, instead of being a big contributor to the problems of treatment refusal, delay, and drop out? The second concern was how to address logistical issues related to transporting impoverished patients to clinics for treatment, and supporting them if they needed to remain at hospital for some time.

The second phase of research entailed a small scale proof of concept (POC) study of a package of proposed interventions to enhance BU outreach in 2011-2012. The social science team actively participated in the development and testing of a culturally sensitive BU outreach program seen as a means to establish a BU community of practice. The twin objectives of the intervention were to raise consciousness about BU using mass outreach events, and to use these events as a staging area for establishing collaborative relationships between clinic staff, chiefs, CHW, traditional practitioners, and recent BU patients who had a positive treatment experience. A second part of the POC was a testing of patient support interventions involving transportation, and when necessary housing and food provision for patients while receiving treatment.

The POC was carried out in three health areas. It produced positive outcomes warranting a larger scale pilot study in Bankim district. In the second part of phase two, a larger pilot study was launched after upgrades to the hospital and rural clinics were made to better handle what was anticipated to be a larger number of patients based on the success of the POC. As noted in Table two the role of the anthropological team shifted over the course of the pilot project. During the

POC and the first year of the pilot study, the anthropology team played an active role assisting in the implementation of the intervention package and monitoring interventions enabling mid-course correction. Anthropologists acted as change agents and were consulted by clinic staff when problems arose requiring problem solving. Gradually, implementation of all intervention activities was turned over to health staff, CHW and leaders of healer groups. By the second year of the pilot study, anthropologists assumed the role of participant observers monitoring outreach and referral activities, and documenting cases of successful partnerships as well as the ways in which problems were solved by members of BUCOP.

Phase three of the project took place 12 months after the social science team removed themselves from Bankim. The researchers returned to the Bankim and conducted an outcome, process and impact evaluation to assess the effectiveness of the intervention in terms of BU identification, health care seeking, and adherence to treatment as well as BUCOP stakeholder collaboration in the absence of social scientists as change agents. Attention was focused on whether COP member partnerships and lines of communication were sustained.

During this evaluation phase of the project hospital records were reviewed and **XXX** Interviews and **XXXX** focus groups were carried out **with XXX** CHW, **XXX** healers, **xxx** health staff, **XXX** local and government administrators responsible for health activities in the district ( ) and **XXX** BU patients recently treated at health care facilities in Bankim. The three anthropologists who had carried out baseline data on health staff, CHW and healers were responsible for investigating shifts that had occurred in their working relationships with other BUCOP members as well as changes in their social status in the community and health system. Broader impacts of the project were assessed as well. Chief among these was whether collaborative relations established for community-based BU management could serve as a

foundation for other health initiatives i.e if the COP model was a viable means of health service strengthening creating a true partnership between and community and hospital staff. .

### **Ethical considerations**

Ethical clearance and research authorization for the project was secured from the National Ethics Committee of the Cameroon Ministry of Health.. The District Medical and Sub-Divisional Officers granted authorization for local entrance into the region and community leaders beginning with the Paramount Chief of the Tikars. Informed consent was obtained orally after all informants were assured that their participation was voluntary, that the information they shared was confidential, and that they had the right to decline to be interviewed at any point during the project.

### **Results:**

The following research results are presented by phase of research to create a meaningful narrative.

#### **Phase one**

Four sets of observations made during phase one formative research may be briefly highlighted:

1) local perceptions of chronic ulcers encompassing BU, 2) health care seeking patterns for chronic ulcers, 3) health staff , CHW and healer interactions; and 4) problems in BU identification and treatment warranting intervention

##### **1. Local perceptions of chronic ulcers**

Chronic ulcers that do not heal, a hallmark of BU, are often but not always, attributed to the local disease category Mbouati (Atom in other parts of Cameroon- Pouillot et. al 2007;

Giles-Vernick et. al 2015), a spirit affliction that is also the sign of special power accorded to the afflicted. Informants across all ethnic groups voiced the opinion that both Mbouati and BU co-existed in the region, some believing that only healers could determine the difference between the two and transform Mbouti into a chronic physical ulcer (nbong: a widely used Tika term) amenable to successful treatment. There was widespread speculation that in recent years BU the type of nbong health staff call BU had increased in the region following the dam project and the introduction of rice farming.

## 2. Health care seeking for chronic ulcers

Local healers are very popular in the region and often turned to as a first source of treatment for skin disease, lesions and ulcers, especially if they do not heal and are linked to witchcraft or Mbouati. Healers in the region commonly use herbs, incantations, talismans, and “vaccination” (cutting, burning wounds, etc.) to treat chronic ulcers. While healers work independently, many are members of healer groups which answer to the paramount chief of Bankim recognized to be the chief of healers in the district. Healers have close ties to village chiefs and are called upon to offer blessings and protection to the community.

The hospital was not a place villagers commonly readily turned to for treatment of BU for three reasons. Community members were afraid of hospital based BU treatment as it was associated with operations and amputation. Second, they had little interest in being referred to Ayos hospital as it was far off and in a place foreign to them. Third, despite BU treatment being free, people feared the indirect costs of treatment and hospitalization. There was also some confusion about what if any treatment was offered free. While medicines for BU supplied free of cost by the government NTD program, treatment for other chronic ulcers was not free. Some community

members perceived free treatment for some, but not all, patients having skin lesions as acts of favoritism. Others felt that if one did not have a social connection with someone at the hospital the quality of care they would receive would be poor.

### 3. Health staff: healer and CHW relations

Healers did not have close working relations with clinic staff and did not refer cases health staff. In the five years prior to the research project no recorded case of BU had been referred by a healer to Bankim Hospital or any satellite clinic. When healers visited Bankim hospital at the request of patients, they did so secretly. Healers also had little contact with CHWs.

Community health volunteers attended meetings at the district hospital when called to do so by, but played a very minimal role in outreach. They were given standard WHO educational materials focused on the signs of BU, but were not involved in actively educating the community about BU. By in large, they only identified possible BU cases when the disease control officer (DCO) from Bankim hospital personally visited their village by motor bike and directly asked CHW to be shown villagers having chronic wounds. In the five years prior to the research project, CHWs identified only 48 possible BU cases, and when visited by the DCO. More BU cases were identified by the DCO when he was motivated to search for cases the year before the intervention as the result of a foreign research project. The project required cases and offered incentives for their detection. CHWs did not see themselves as having a clear role in organizing BU outreach activities and they were not in close communication with clinic staff.

### **Interventions identified from formative research**

Four types of interventions were suggested by phase one research and supported by health officials as a means of promoting a BUCOP. First a new outreach education program (described



below) was needed to raise community awareness about BU and its treatment, address obstructive rumors, win the confidence of the community in the quality of new ways of treating BU, and fostering hope as a way of diffusing fear. Second, CHW and healers needed to be mobilized, more actively involved and given a proactive role in both case identification and referral and patient follow up and psychosocial support. Third, given that visiting the hospital for 56 days of treatment was outside the reach of many households due to cost and travel difficulties it was clear that education alone was not going to solve the problem of treatment delay. Transport, and when necessary lodging and feeding patients and those who care for them were necessary. Fourth, more serious patients unwilling to travel to a referral hospital like Ayoos needed to be treated in Bankim. As such, upgrades in BU care needed to be made at the hospital and outreach programs needed to inform the local population that high quality treatment was now available at the district hospital.

**Stage two: Proof of concept study (need exact dates 2011-2012/ 2013—better to have some mos in 2013 if activities were going on once PP introduced to match yaws table)**

An intervention package addressing these four areas of change was developed after options were weighed in keeping with stage four formative research. The first component, seen as a cornerstone for building a COP, was the introduction of a culturally sensitive community-based BU outreach program bringing clinic staff and community stakeholders together. An education program was already being developed by West African social scientists participating in the Stop Buruli Consortium including the team from Cameroon after each had conducted stage one formative research in their country and reviewed previous studies of BU. As would be expected, differences within and between the three countries participating in Stop Buruli (Benin,

Cameroon, Ghana) existed, but a majority of the BU perceptions and concerns identified were found to be variations of common themes.

The education program developed and tailored for each Consortium country is the subject of a forthcoming publication. In brief, it took the form of an image-rich PowerPoint presentation on BU delivered by local teams equipped with generators, computers, LCD projectors and sound systems. A question–answer format was adopted with new questions added as they arose during community meetings. Outreach meetings were designed to be interactive, not passive, and questions were invited from the community. As such, the educational presentation was designed to change and be the product of an iterative process. Ongoing social science research investigated how best to respond to questions in a way that was at once scientific and understandable to local audiences. Messages and visuals were tested and changed as needed. **Table three** presents a brief description of the major sections of the PowerPoint presentation (available on XXXX website), each designed to deliver a different type of message designed to either educate, inform, display collaboration or offer hope in the form of a cure .

**Table three Format of Stop Buruli Outreach education**

<b>Nine sections of outreach education program</b>	<b>Key messages conveyed</b>	<b>Issues downplayed or emphasized</b>
Signs and symptoms of BU, how to recognize the disease and need to treat early	Visuals of physical signs of BU in different stages.  Visual and tactile cues suggesting that a lesion, abscess ulcer or edema may be BU.  Progression of disease if not treated	Category one and two BU depicted, but not category three as this evoked great fear

<p>High risk environments and modes of transmission</p>	<p>High risk environments where one is more likely to be exposed to MU</p> <p>Focus was on addressing incorrect ideas about BU transmission and contagion</p>	<p>Less time and attention was allotted to risk environments and possible modes of transmission as the science is inconclusive and behavior change related to exposure to water sources difficult given the local reality</p>
<p>What clinic staff do to determine if the affliction is BU or some other disease</p>	<p>Why health staff take swabs, what they look for under the microscope, why medicine for BU is specific and not the same as medications used for other ulcers.</p>	<p>Step-by-step explanation of what staff do along with pictures- to offset fears and rumors about what health staff is doing , and to increase trust</p>
<p>Effective and ineffective treatments for BU</p>	<p>Why 56 days of pills and injections are needed</p> <p>Why herbal medicine for this disease does not lead to a cure even if a wound is dried</p>	<p>Agricultural analogies used to convey the idea that medication is taken beyond cure of wound to get at the roots and seeds of BU as a systemic infection in the body</p> <p>Pictures used to show inappropriate treatment, how drying wound is not curing, and effectiveness of medication after herbal medicine has failed to treat the wound</p>
<p>Traditional healers and rapid referral to clinics</p> <p>Emphasis on rapid referral</p>	<p>Positive messages about exemplar healers who recognize signs of BU and rapidly refer patients to clinic after spiritual protection is offered.</p>	<p>No message disrespecting local practices as superstitious (as found in WHO promotional materials).</p> <p>Respect for traditional healers' role in offering spiritual protection for those for whom this is a concern</p>

Quality of care at the clinic	Quality of care offered by staff: pictures of what care in the clinic looks like, approachable staff, hygienic conditions, empathetic caretakers, etc.	To offset fear and evoke confidence
Before and after pictures of BU related wounds successfully treated	Pictures of BU treatment, and the healing process at different stages  Depict the healing of ulcers on different parts of the body	Pictures depict patients of different ages and gender
The presentation ends on a note of hope.	Testimonials of patients who have been cured speak of their experience and to the quality of care they have received at the clinic.	Open microphone –some testimonials are planned and others are spontaneous
Questions from the audience	On any topic related to information presented or any other issue related to BU	Open microphone

Over the course of the POC the education program was developed, and pretested. Community outreach education meetings were held in the evenings in # ( only note # where PP was conducted during POC (limited number) —not full 36 ) village locations. CHW were responsible for organizing meetings and inviting chiefs, local healers, and former patients to attend. Programs were treated as social performances where roles in the BUCOP were enacted. Chiefs and healers were seated in places conveying respect and were invited to voice their support for the program using a microphone, itself a symbol of power. Research revealed that

CHWs' role in organizing meetings boosted their status in the community and this motivated them to become more actively involved in BU outreach activities.

Social scientists trained the DCO to deliver the PowerPoint education program and were on hand to assist in responding to questions from the community. After the program was complete, hospital staff were then on hand to screen community members for wounds they suspected might be BU. During the POC study, 21 suspected cases of BU were identified at XXX outreach meetings, (see table four below). Of these 19 (90.5%) were confirmed (or treated for BU ???) as BU of which 10 were category one or early category two cases. In villages too remote to reach with audio and visual equipment, CHW delivered key messages from the PowerPoint presentation orally, used posters depicting the signs of BU supplied by the WHO, and held interactive question and answer sessions. Sixty suspect cases of BU were identified by CHW during these activities of which 37(62%) were confirmed (or treated for BU??). Nineteen cases were category one or two BU. Notably, as a result of POC educational activities, ninety-eight suspected cases of BU were self-identified by household members of which 45.9% were treated (or confirmed) for BU. Of these cases 25 were category one or two. By comparison, XXX cases were self-referred in 2009-2010. Another 17 cases were referred by former patients of which 11 (64.7%) were treated for BU (or confirmed).

To gain a sense of just how effective the POC was in detecting cases of BU consider that in 2010 the year before the feasibility study, an intensive house to house NTD survey was conducted in Bankim in late March to mid-April (not the most opportune time for a survey). Health staff and researchers visited 9,344 households (48,962 people). The survey yielded 25 suspected cases of BU, of which six were confirmed by polymerase chain reaction tests PCR (Bratschi et al. 2013).

The second component of the POC study was provision of free transport to clinics for category one and early category two BU patients not requiring hospitalization and living 3–7 KM from clinics. Motorcycle taxis were hired to deliver BU patients to the hospital for the duration of treatment. For those who lived too far to render this feasible, housing was secured for them near clinics in facilities termed halfway houses. Halfway houses were tested in both the town and more rural areas. In Bankim town, patients received treatment and their wounds were monitored by hospital staff. In the rural areas, staff traveled 8–10 km daily from clinics to administer treatment to patients. Patients and caretakers remaining at halfway houses were supplied a food ration. XXX patients took up residence in half way houses during the course of their treatment. Anthropologists monitored social interaction between patients of different ethnic groups and found that they bonded around a common disease identity and supported one another during the treatment process. Notably, the treatment adherence rate during the POC for all patients was 94 % compared to \_\_\_\_\_% in 2009-2010. This was in part due to the support of health staff and CHW, in part due to providing resources, and in part because of the support of traditional healers.

The third objective of the POC study was to see if traditional healers would participate in BU outreach and be proactive partners in a BUCOP. In brief, after obtaining support from the paramount chief of Bankim town, a meeting was held with a core group of 10 popular traditional healers who were members of a healer association. These healers were interviewed and chosen as exemplars. In the first meeting, the healers were asked if they had the power to treat ulcers and wounds caused by spirits and witchcraft without directly touching the wound, and to transform them into ulcers curable by medication (nbong) . Healers responded in the affirmative. A

working collaboration was formalized that addressed both biomedical and ethnomedical treatment concerns.

Clinic staff explained to healers that in order for their BU treatment to be most effective, patients needed to be referred quickly and wounds needed to be left undisturbed and not treated with traditional medicines. Clinic staff acknowledged that they had no expertise in the mystical aspects of treatment such as removing spiritual affliction, protecting the patient when vulnerable to forces of malevolence, nullifying obstructions to the healing process, or dealing with patient fears of malevolent spirits during treatment. Healers were asked to attend to these spiritual and psychosocial aspects of treatment, while clinic staff used medications and bandaging to take care of the physical aspects of the disease.

A contract, suggested by the healers, was signed. Two key components of the contract were that members of the group promised to refer all new patients having possible signs of BU to the hospital within 10 days of seeing them and that healers would not treat the skin of patients. Healers were allowed free access to the hospital and half way houses to offer psychosocial support and spiritual protection. They were also offered a small amount of money to pay for accompanying patients to the clinic for screening. The social science team monitored their adherence to the contract. All of the participating traditional healers adhered to the contract and XX (#) referred patients promptly to the hospital without treating the skin. Forty-nine suspected cases were referred by traditional healers during the POC, of which thirteen were treated (confirmed?) to be BU. All these patients were visited by healers in the hospital and completed treatment.

### **Stage three: Pilot project (March 2013 –March 2016)**

Five modifications in the intervention were made based on lessons learned during the POC study. The first entailed the use of a new WHO promotional video for BU in the outreach programs prior to presentation of the PowerPoint. Videos are popular in rural Cameroon. Although, the new video was not designed for educational purposes, it appreciated for getting across the theme of hope. Research revealed that community members did not comprehend much of the language used in the video, but were happy to see images of patients who were cured. The messages in the video did not duplicate or clash with the messages presented in the power point presentation and the two were found to work together well.

A second modification was using CHWs to engage in simultaneous translation into local languages. Health staff would present PowerPoint slides in French while a community health worker would translate the messages into local languages (Fulani, Pidgin English, Kwanja, Mambila, Yamba and Tikar). A familiar style of presentation often seen in Pentecostal churches was adopted by teams of presenters with messages passed back and forth in a free and easy style. Research revealed that although, repetitive for those who understood multiple languages, translation and the style of communication was responded to positively, even though it increased the duration of activities.

A third modification involved expansion of the number of traditional healers involved in the BUCOP. The first group of healers were carefully screened exemplars chosen to model best practices. In the pilot study, all healers in three health areas were invited to participate in the BUCOP. These healer groups were given training using the PowerPoint presentation as a common reference point for instruction and visited by health staff periodically. Healer groups



met every XXX months to discuss cases and were invited to participate in community outreach activities in their locales, often working along with CHWs. As in the feasibility study, they were paid a small honorarium for their efforts.

A fourth modification entailed an upgrade to the half way houses and hospital wards. During the POC concern about the hygiene of halfway houses related wound care. Two halfway houses with bore wells were constructed in rural areas to be visited by mobile health staff. At Bankim hospital, both a BU ward and a well laid out and hygienic dressing room were constructed. A second surgeon was also stationed at the hospital such that most skin grafts could be carried out in Bankim rather than being referred.

The fifth shift involved the role of the social scientists. In the POC, social scientists played an active role as facilitators of all intervention related activities being tested. In the pilot project, clinic staff implemented all intervention activities. For the first XXX months of the pilot project social scientists monitored community response to interventions, identified problems and assisted clinic staff engage in mid-course correction. They then left Bankim for XX months to ascertain whether interventions were sustainable without their presence as change agents.

### **Outcome evaluation**

During the pilot project ##### large scale community outreach education programs were conducted reaching XXXXX people (estimate how many people attended), and XXX school based programs were conducted (match with yaws table). ### CHWs and 65 healers were trained in BU detection. Table four presents case referral and treatment completion data from both the POC and pilot intervention years.

Revise this table –there are calculations wrong and missing –make this perfect

Community of Practice Stakeholder	Category of BU	2011-2012 (2013 early??)			2013-2015 or march 2016 If so check #s			Total		
		Susp	Conf	Treat Adhere	Susp	Conf		Susp	Conf	Treat Adhere
Community Health worker	Category 1	60	7		78	6		138	13	35 ()
	Category 2		12			9			21	
	Category 3		18			8			26	
	<b>Total confirmed</b>		<b>37</b> 30.0			<b>23</b> 29.5			<b>21 (91.3)</b>	
Traditional healers	Category 1	49	3		59	7		108	10	30 ()
	Category 2		7			7			14	
	Category 3		3			8			11	
	<b>Total confirmed</b>		<b>13</b> 26.5			<b>22</b> 37.3			<b>17 (95.2)</b>	
Former patient	Category 1	17	1		16	1		33	2	9 ()
	Category 2		3			2			5	
	Category 3		7			3			10	
	<b>Total confirmed</b>		<b>11</b> 64.7			<b>6</b> 37.5			<b>6 (100)</b>	
Self/family initiated*	Category 1	98	10		145	16		243	26	
	Category 2		15			35			50	
	Category 3		20			30			50	
	<b>Total confirmed</b>		<b>45</b> 45.9			<b>81</b> 55.9			<b>79 (97.5)</b>	
Health staff and screening	Category 1	21	4		18	1		39	5	
	Category 2		6			2			8	
	Category 3		9			3			12	
	<b>Total confirmed</b>		<b>19</b> 90.5			<b>6</b> 33.3			<b>6 (100)</b>	

Total	Category 1		21			10			30	
	Category 2		30			26			56	
	Category 3		47			49			88	
	<b>Total confirmed</b>		XXXX		118 (94.4)	XXX X			XXX	

\*Its family initiated but they will consult a Community Health Workers, former patients and Healers.

**I can only finish the analysis when I am sure the table is correct**

### Referrals

- Emphasize shifts

### Adherence with BU treatment

### Knowledge of BU (THINK BEST DISCUSSED IN SEPARATE EDUCATION PAPER)

### Traditional healers

Sixty five (??) healers agreed to participate in the pilot, and 55 remained in the BUCOP and adhered to the healer: health staff contract. Of these fifty five, 38 were active participants defined by either referring suspected cases, providing support to patients in hospitals/clinics, or participating in outreach education programs. The contribution of healers to the success of the pilot study was not limited to numbers of patients referred. Their support of all BUCOP activities gave the activities increased legitimacy and respectability, and many self-referred patients who were hospitalized requested healers to visit them and offer protection and support.

## **Process and Impact evaluation**

The goal of the pilot project was not just to mobilize individual stakeholders to become more actively involved in BU identification and referral, but to create an interactive and supportive BU Community of Practice (BU COP) and to forge working relationships between all stake holders. This entails all stakeholders sharing a common BU identification and prompt treatment goal, mutual respect and support, ongoing communication, and opportunities to share information about each other's BU related activities. Research revealed that a BUCOP has indeed emerged in Bankim. The status of CHWs has risen markedly since they have become actively involved in arranging outreach education and screening programs for their communities. They are now working closely with clinic staff and serving as translators during educational meetings. A closer working relationships with clinic staff has empowered them to play a more proactive role in both referring and following up suspected BU cases.

Former patients in the community have been recognized as having first hand BU expertise during outreach meetings and offer testimonials that are appreciated by the community. BU is both less feared and less stigmatized as a result. Clinic staff feel positive about the formation of a BUCOP because they now have a much closer working relationship with local communities and CHWs as well as local healers. The presence of local healers at hospital meetings dealing with community outreach has been well received, by both staff and healers alike.

Healers have continued to participate in the BUCOP even after funds were no longer available to support meetings and pay transportation cost for accompanying patients to hospital. The social capital and status healers have gained outweighs any financial loss they have incurred for referring patients. They take pride, in offering protection to patients so that medications can act

effectively, and supporting them during the duration of their treatment. Healers in the hospital have been warmly received by both BU and other patients residing in the wards, and while they receive no payment for their BU related activities they often receive gifts when patients are cured. Health staff have been pleasantly surprised by a rise in the number of BU cases being referred and recognize this as a sign of the hospitals increasing the reputation. One testament to growing trust in the hospital is consultation by members of the Fulani ethnic group, who had previously been reluctant to seek treatment for BU. Outreach education delivered in pidgin by a trained Fulani community health worker and a few success stories have paved the way for greater contact with this community.

## **Conclusion**

A recent review of the impact of two decades of social science research on neglected tropical diseases (Bardosh 2014) came to the conclusion that while this research has generated important insights into health care seeking and community response to programs, the research has not been used effectively in program development and implementation. This study provides a case study of a program that benefited from multistage formative research contributing to program development, implementation, monitoring, mid-course correction, and evaluation. We have presented a pioneering attempt to establish a BUCOP that we feel has great potential for other community based disease surveillance and management programs. As a final note, we would argue that the collaborative relationships established between stakeholders in the community are having a positive impact beyond BU. The collaborative relations established by the BU COP have increased the credibility of other public health efforts in the area such as vaccination programs. Establishing a COP such as this has great potential in the area of emerging disease preparedness. Should a disease like Ebola strike Bankim, collaborative relationships between

clinic staff and CHWs, chiefs and healers would enable a rapid response. If the 2015 Ebola outbreak in West Africa taught us anything, it that an important part of health system strengthening is establishing strong relationships with the community. Trust and lines of communication enable swift action and means of local problem solving.