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Applying the Collaborative Approach to Requirements Gathering in the Development of a Buruli Ulcer Database in Ghana

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A Special Studies Project report submitted to the

Public Health Informatics Program

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Abstract

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One of the conclusions made at the 2011 WHO Annual Buruli Ulcer Meeting, Geneva Switzerland was the requirement to strengthen surveillance. The call was made for the development of an accurate and robust database which would serve as a repository for Buruli Ulcer (BU) surveillance data. This would provide a reliable and accurate source of information for various stakeholders and also foster more collaborative work between countries which are endemic with BU by facilitating easier transfer of information and sharing of ideas.

Stakeholders of BU have varied goals and objectives and perform different tasks within countries and across the globe. However, they are united by a collective vision of controlling the disease. By applying the concept of Collaborative Requirements Development to the design of a BU database, it ensures the database developed does not become a silo. With emphasis on interoperability and collaboration, this concept highlights the involvement of all stakeholders in the development of a database by incorporating their goals, objectives and needs in the design of the database. Involvement of stakeholders at the onset and throughout development leads to a stronger willingness by stakeholders to support and contribute to it.

An electronic BU database is envisioned that meets the standards of the World Health Organization (WHO). This database would be scalable to other countries reporting Buruli Ulcer cases. It would ultimately serve as a repository for data collection on various activities related to the disease across the globe.

Various stakeholders identified in Ghana included WHO, local and international researchers, non-governmental organizations, Ministry of Health, Ghana Health Service, various health facilities and Community Based Surveillance Volunteers (CBSV's). Key personnel from the various organizations were identified and invited to join focus group discussions or individual interviews. Study staff also observed collection of surveillance data from points of origin in the Ashanti and Greater Accra Regions of Ghana through each level of care as well as transmission of data from the local, regional, and national levels. This provided insights into how data on cases are managed and processed. Information obtained was summarized and recommendations made based on the summary of findings.

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<u>Dedications</u>

I am grateful to God Almighty for how far He has brought me. This work is dedicated to my husband, Mawuli Honu whose support and encouragement provided the strength to complete this project. And also to my son Sedinam Honu whose interesting toddler conversations helped ease my stress.

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Chapter 1: Introduction

Background

Buruli ulcer is a debilitating skin disease which mainly affects the limbs and the trunk. The disease is listed among WHO's list of neglected tropical diseases. Though some aspects of the disease are known, much is still yet to be discovered. This includes the mode of transmission. In order to be able to aid researchers as well as other stakeholders in learning more about the disease, surveillance has to be strengthened. Currently, surveillance has been established at sentinel sites across the globe to capture information on the disease. Data obtained from these sites are a combination of paper and electronic format.

One of the conclusions made at the 2011 WHO Annual Buruli Ulcer Meeting, Geneva Switzerland was the requirement to strengthen surveillance. The call was made for the development of an accurate and robust database which would serve as a repository for BU surveillance data.

Stakeholders of BU have varied goals and objectives and perform different tasks within countries and across the globe. However, they are united by a collective vision of controlling the disease. By applying the concept of Collaborative Requirements Development to the design of a BU database, it ensures the database developed does not become a silo. With emphasis on interoperability and collaboration, this concept highlights the involvement of all stakeholders in the development of a database by incorporating their goals, objectives and needs in the design

of the database. Involvement of stakeholders at the onset and throughout development leads to a stronger willingness by stakeholders to support and contribute to it.

An electronic Buruli Ulcer (BU) database is envisioned that meets the standards of the World Health Organization (WHO). This database would be scalable to other countries reporting Buruli Ulcer cases. It would ultimately serve as a repository for data collection on various activities related to the disease across the globe.

Problem Statement

The Global Buruli Ulcer Initiative (GBUI) of the World Health Organization in outlining its goals states the improvement of surveillance in countries that are endemic with Buruli Ulcer (BU) as a key approach to better understanding and controlling the disease [1]. At the 2011 WHO Annual Buruli Ulcer Meeting it was concluded that strengthening surveillance would require among other things, an accurate and robust database which would serve as a repository for BU surveillance data. To be able to understand the mode of transmission of the disease as well as accurately ascertain the disease burden, useful information has to first be gathered and then meaningful information gleaned out of the data.

Purpose Statement

The ultimate vision for this research is to be able to design and deploy an electronic BU database which is fully functional and scalable to all countries that report BU activity. This

database would as much as applicable, incorporate the needs and requirements of stakeholders of BU and would serve as a repository for the different kinds of data capture from BU surveillance and other BU activities. Industry standards prescribe various steps to the design and development of a database. Incorporating these with lessons learned from other organizations within the context of BU, presents a roadmap for the achievement of this vision. The objectives of this project are to:

- Gather information as to how BU data are collected, transmitted, analyzed and disseminated.

- Evaluate the current system of database management in place in Ghana.

- Gain insight into strengths, weaknesses and challenges of the current system of data management.

- Understand the needs and expectations of stakeholders for a database for BU.

- Propose recommendations for the improvement of the current system.

Achieving these objectives would ensure a database modeled on the collaborative approach to database designs and provide a strong foundation to address the problem outlined.

Significance Statement

An accurate and functional database can be used to generate meaningful hypotheses. It can also be used to provide information to answer pertinent research questions. An electronic BU database would provide a reliable and accurate source of information for various stakeholders including clinicians, epidemiologists, program officers, local and international researchers and

non-governmental organizations (NGO's). This would also foster more collaborative work between countries which are endemic with BU by virtue of the fact that having a common platform for surveillance data across countries would facilitate easier transfer of information and sharing of ideas. As more systems migrate to electronic platforms, there is an apparent need to provide a fast, efficient and accurate electronic database to support BU surveillance across countries.

<u>Glossary</u>

BU – Buruli Ulcer

CBSV – Community Based Surveillance Volunteer

CDC – Centers for Disease Control and Prevention

CHIM – Center for Health Information Management

CSI – Collaborative Software Initiative

DCD – Disease Control and Prevention Department

DHIMS – District Health Information Management Systems

DHIS – District Health Information System

GBUI – Global Buruli Ulcer Initiative

GHS – Ghana Health Service

ICT – Information and Communication Technology

IEEE – Institute of Electrical and Electronic Engineers

KCCR – Kumasi Center for Collaborative Research

LHD – Local Health Department

MOH – Ministry of Health

NACCHO – National Association of County and City Health Officials

NBUCP – National Buruli Ulcer Program

NGO – Non Governmental Organization

OPD – Out Patients Department

PCR – Polymerase Chain Reaction

PHII – Public Health Informatics Institute

WHO – World Health Organization

Chapter 2: Review of the Literature

Disease Background

Buruli Ulcer is a disease which affects the skin and subcutaneous tissues [2]. It is caused by the bacteria Mycobacterium ulcerans [2]. The disease develops in various stages starting with a small painless nodule which later progresses to an edema. The ulcerative stage occurs when the edema ruptures to produce huge ulcerations. Ulcers are normally found on the limbs and trunk [2]. The disease is found in several sub-Saharan African countries as well as in Australia [2]. Currently, the mode of transmission of the disease remains unknown though it has been associated with wetlands and marshy areas [2]. The mode of treatment has changed recently from surgery to treatment with antibiotics [3]. A combination of oral rifampin at 10mg/kg of body weight and intra-muscular streptomycin at 15mg/kg body weight has proven effective in resolving the disease in humans [3].

The first reported case of BU in Ghana was in 1971 at the Korle-Bu Teaching Hospital in the capital Accra [3]. Currently, BU is endemic in six out of the ten regions of Ghana [4]. Due to the extensive scarring resulting from the disease and its dominant occurrence on the limbs, joint immobility becomes a major complication after treatment. This results in loss of livelihood and stigmatization.

Collaborative Approach

The Standish Group's 2009 CHAOS Summary Report identified that only 32% of Information Technology projects developed were delivered on time, within budget and had the required features and functions [5]. 24% of projects failed either due to cancellation prior to completion or were delivered but never used. 44% of projects were challenged by either being late, over budget and/or with less than the required features and functions [5]. Some health information systems designed in the past to enhance efficiency, accuracy and reliability within health systems stand alone and are unable to communicate with other information systems thereby defeating the very purpose for which they were built. These systems have become present day obstacles to effective communication. In spite of The Institute of Electrical and Electronics Engineers (IEEE) efforts in providing guidelines which have shaped industry standards, database and software designs continue to suffer failure in meeting expectations [6].

Proponents of a new paradigm, contend that a collaborative approach to requirements gathering is essential in achieving quality and efficient database designs. It has become increasingly clear that the era of designing information systems based solely on one agency or stakeholder requirements should be phased out to give way to a collaborative approach to database designs. The Public Health Informatics Institute (PHII) of the Global Health Taskforce in collaboration with the National Association of County and City Health Officials (NACCHO) propose collaborative requirements development as the new way of conceiving public health information systems [7]. In assisting Local Health Departments (LHD's) in the United States to achieve interoperability, PHII designed a methodology to integrate the information systems of

all LHD's. The Requirements Development Methodology proposed hinges on collaboration, a key component which is missing from standard industry procedures. The 3 step method involves a Business Process Analysis, Business Process Redesign and Requirements Definition. The Business Process Analysis involves bringing together all stakeholders to identify goals and objectives, model context of work, identify business rules, describe tasks and workflow and finally identify common task sets. This analysis essentially answers the question "How do we do our work now?" The Business Process Redesign phase requires a rethinking of how work should be done. This involves examining the business process to identify inefficiencies and repeatable processes. It also involves refining the business processes and rules, remodeling the context of work and eventually restructuring tasks and workflow. Based on the optimized, redesigned process, Requirement Definitions can then be enumerated and used to build a database which incorporates the goals, objectives and needs of the various stakeholders thereby ensuring a health information system is functional to all at various levels and sectors [7].

A functional example of this approach is a product by the Collaborative Software Initiative named CSI Trisano [8]. This is a surveillance system which can be easily modified by any type of public health official in the United States to facilitate mandated disease reporting, case management, outbreak tracking, electronic laboratory reporting, health alert communication as well as Centers for Disease Control and Prevention (CDC) reporting [8]. The system was designed using a collaborative approach in which thought leaders from like-minded entities brainstormed to emerge with a collective vision. Based on the vision, a team was set up to

define the features required for the fulfillment of the vision. This ultimately led to the design of the system [8].

Key lessons learned from the PHII exercise and the development of CSI Trisano can be applied to the development of a database for BU. Like LHD's, stakeholders of BU have varied goals and objectives and perform different tasks within country and across the globe. However, they are united by a collective vision of controlling the disease. By applying the concept of Collaborative Requirements Development to the design of a BU database, it ensures the database developed does not become a silo.   This approach emphasizes interoperability and collaboration between systems with a goal of facilitating utilization by multiple stakeholders. It also ensures that it falls within the framework of electronic health information systems envisioned or put in place within the countries in which it will operate.   Finally, this concept also emphasizes the involvement of all stakeholders in the development of a database by incorporating their goals, objectives and needs in the design of the database. Involvement of stakeholders at the onset and throughout development leads to a stronger willingness by stakeholders to support and contribute to it.

Country Background

A 2008 report of the evaluation of the surveillance system in Ghana provided some insight to the current structure of the system in place. This report was prepared by Emory University in collaboration with WHO. BU is endemic in six out of the ten regions in Ghana [4]. The regions are divided into districts and in some cases further sub- divided into sub-districts. There were 170 districts in the country as of 2006 [9]. Some districts report BU whiles others in the same

region do not. Surveillance has been established at sentinel sites to capture information on the disease and data obtained from these sites are currently a combination of paper and electronic format. Additionally, some NGO's provide auxiliary services to support early detection, treatment and rehabilitation of BU patients. Research groups also contribute to surveillance by providing laboratory diagnosis of the disease.

2009_Ghana_BU_ Cases_By_Districts
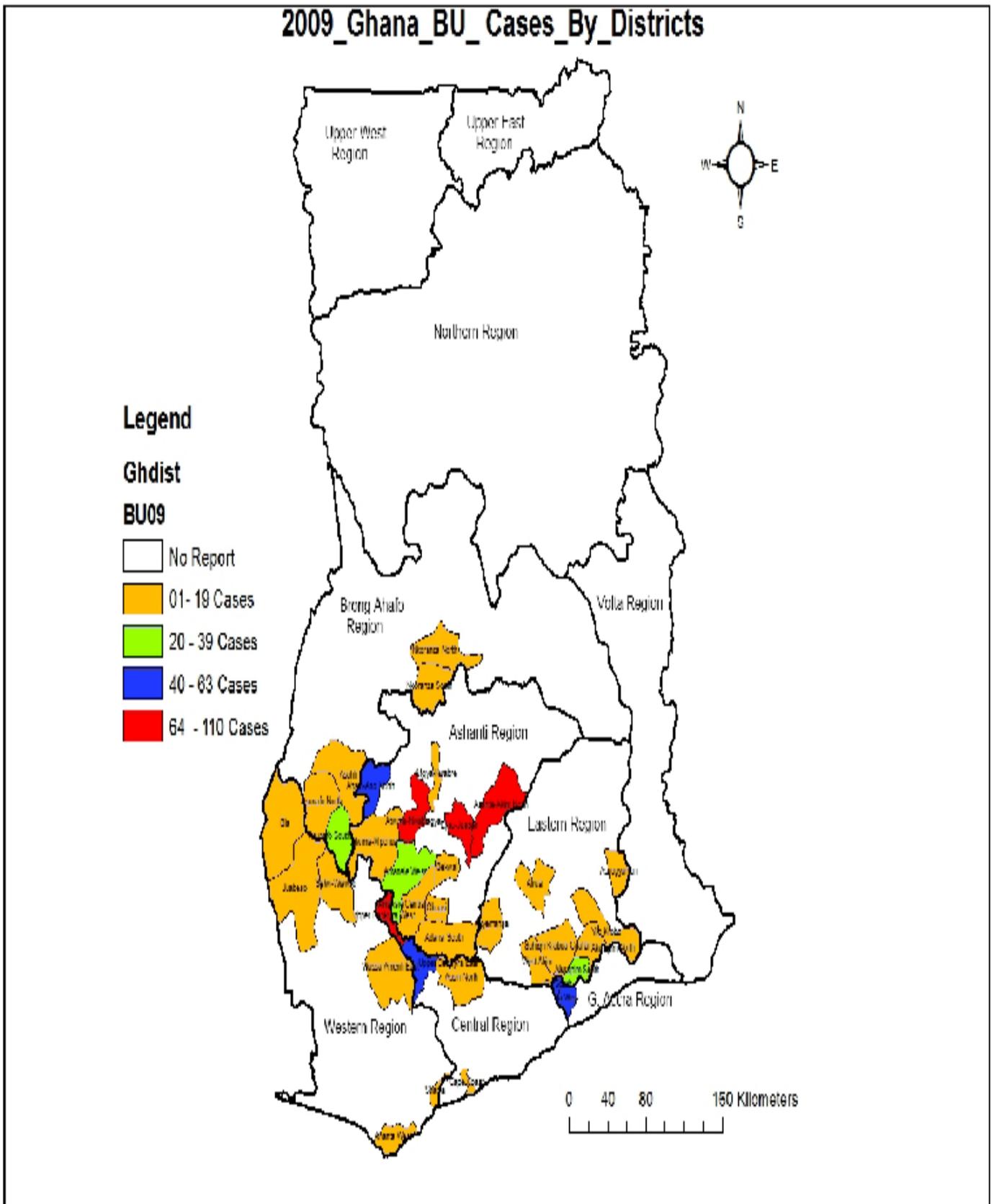
Chapter 3: Methodology

Geographic scope

In 2011, the Ashanti and Greater Accra Regions in Ghana reported the highest number of BU cases [4]. Two areas from these regions were chosen for study. The Agogo sub-district which falls within the Asante-Akyem District in the Ashanti Region was selected. Agogo Presbyterian Hospital and Ananekrom Health Post were the two facilities chosen for study due to the high number of cases reported from Ananekrom and being referred to Agogo Presbyterian Hospital. Agogo Presbyterian Hospital has also been touted by many as the most structured in terms of BU surveillance.

In the Greater Accra Region, Ga West district was chosen and Amasaman Hospital elected as the facility for study. Amasaman Hospital is situated in the district capital Amasaman and therefore records BU cases from a wide catchment area.

Stakeholder Selection

Both local and international organizations with vested interest in BU were identified. These include WHO, local and international researchers, non-governmental organizations, Ministry of Health, Ghana Health Service, various health facilities and Community Based Surveillance Volunteers (CBSV's). Key personnel from the various establishments were identified and invited to join focus group discussions or individual interviews.

Information Gathering

The health facilities selected for study hold BU clinic days on Wednesdays; individuals with suspected BU present on this day. After obtaining oral informed consent, the patient was observed as he/she navigated the healthcare system. The processes of antibiotic dispensing, wound dressing and monitoring of treatment outcomes were also observed. The data collected from these activities were followed through the transmission chain within the facility and then at the district, regional, national and research levels to determine how data are collected, stored, processed, utilized and transmitted from one stage to the other.

Focus group discussions were conducted with CBSV's which centered on the tools and methods used to collect data from suspected cases identified in the community. Focus group discussions were also conducted with health workers associated with the BU wards. This discussion focused on how data from BU patients on admission varied from data collected during clinic days. Focus group discussions conducted with hospital administrators centered on the use of surveillance data gathered from BU to enhance decision-making and planning. All focus group discussions were conducted in a private environment. Supervisors and officials in authority were excluded from discussions to foster participation and honest discussions within the focus groups. Focus groups were limited to a maximum of six participants to enhance easy facilitation. Face to face as well as telephone and Skype interviews were conducted with various stakeholders within and outside Ghana to better understand how BU data is utilized by their various organizations and how utilization can be improved. One underlying focus which ran through all the focus group discussions and interviews centered on various stakeholders'

recommendations for BU database development as well as perceived benefit from a BU database. Interview and focus group guide questions can be found in Appendices A to C. Business processes and recommendations collated were emailed to the respective contributors for verification and clarification purposes before inclusion in the report.

Inclusion and Exclusion Criteria

Health workers associated with the BU wards but who have not been working regularly with BU patients for more than six months were not eligible for the focus group discussion or interviews. Personnel from the Ministry of Health and Ghana Health Service who do not directly utilize BU data in their area of work were not considered for interviews. CBSV's recruited for focus group discussions were those who were active in the area of study.

Limitations and Assumptions

BU surveillance is not standardized across Ghana. Time and monetary constraints did not allow for study of each sentinel site. Findings from this study may not reflect the processes or recommendations from other sites where BU surveillance is performed.

Chapter 4: Results

General Overview

BU01, BU02 and BU04 forms are widely used for data collection in health facilities that report BU cases (See appendices D, E, F). The BU01 form is used for capturing clinical data at the health facilities whiles the BU04 is used to capture specimen collection data for laboratory diagnosis. The BU02 form summarizes data from the BU01 for upward transmission to the district and regional disease control officers as well as the NBUCP office. An electronic format exists for the BU02 form to facilitate faster transmission via email attachment.

CBSV's actively seek cases in their communities and refer them to health facilities which are known BU treatment sites. These are usually district hospitals or community clinics. Self, family and community referrals have also been observed. At the facility level, a day in the week is designated a BU clinic day and a BU focal person for the district facilitates activities during the weekly clinic days. Each district that reports BU has been assigned a BU focal person. This focal person facilitates all activities related to BU in the various health facilities within their jurisdiction. The BU01 form is used to capture information on new cases that present on that day. Laboratory specimen is then taken from the patient in the form of a swab or fine needle aspirate. Clinical diagnosed patients are then supplied with medication. The full dosage regimen of treatment medication is given to patients who opt to continue with treatment at facilities which are closer to their homes. They are allowed to take the medication as well as

the BU01 form to their preferred treatment facility but are required to report back after a specified period for treatment progress to be monitored. The BU01 form is also used for patients that require hospital admission. Laboratory diagnosis for BU is generally carried out at facilities that are associated with on-going BU research. Some facilities through a Ghana Health Service (GHS) directive to send specimen for diagnosis to the Noguchi Memorial research laboratory do so on a regular basis. Other facilities do not comply with this directive hence do not receive laboratory diagnosis. Health facilities bear the transportation costs and Noguchi Memorial research laboratory bears all other costs. The BU04 form is used to capture data on specimens collected for laboratory diagnoses. Some facilities also have laboratory request forms which they use to capture specimen data.

Generally, the structure and scope of data collection and transmission at the facility level for out-patients is largely dependent on the specifications of the research team operating from that facility as well as the data collection and processing systems established by the facility. In addition to the BU01 forms, patients admitted to the BU ward have a hospital medical record folder which is processed according to the hospitals rules for data collection and transmission.

The BU focal person summarizes information from the BU01 to the BU02 form on a monthly basis. The BU02 which is in quadruplicates is forwarded to the district disease control officer. At the district level, all facilities that report BU cases in the district are required to submit their BU02 forms on a monthly basis. Transmission from the district level to the regional and national level varies. Some district disease control officers transfer the data to electronic

format whiles others maintain the paper format. Additionally, some disease control officers forward data directly to the NBUCP as well as their respective regional disease control officer whiles others only forward it to their regional disease control officer. At the regional level, regional disease control officers collate information from all districts that report BU cases and forward it to the NBUCP office and other designated offices.

The NBUCP office receives BU data from different levels of the hierarchy. Some regions experience delays in sending data to the national level. This has resulted in some instances, data being received directly from some health facilities on a monthly basis. In other instances, data are received directly from the district disease control officer. Information analyzed at the NBUCP office is disseminated twice a year to the Disease Control and Prevention Department, the Regional Health Directorate, Regional Directors of Health Services as well as the WHO country office. This occurs in the middle and at end of the year. In addition, informal feedback is sent to all personnel who send BU data directly to the NBUCP office as well as persons who have expressed interest in the data across the globe. This is done via a mailing list on a quarterly basis.

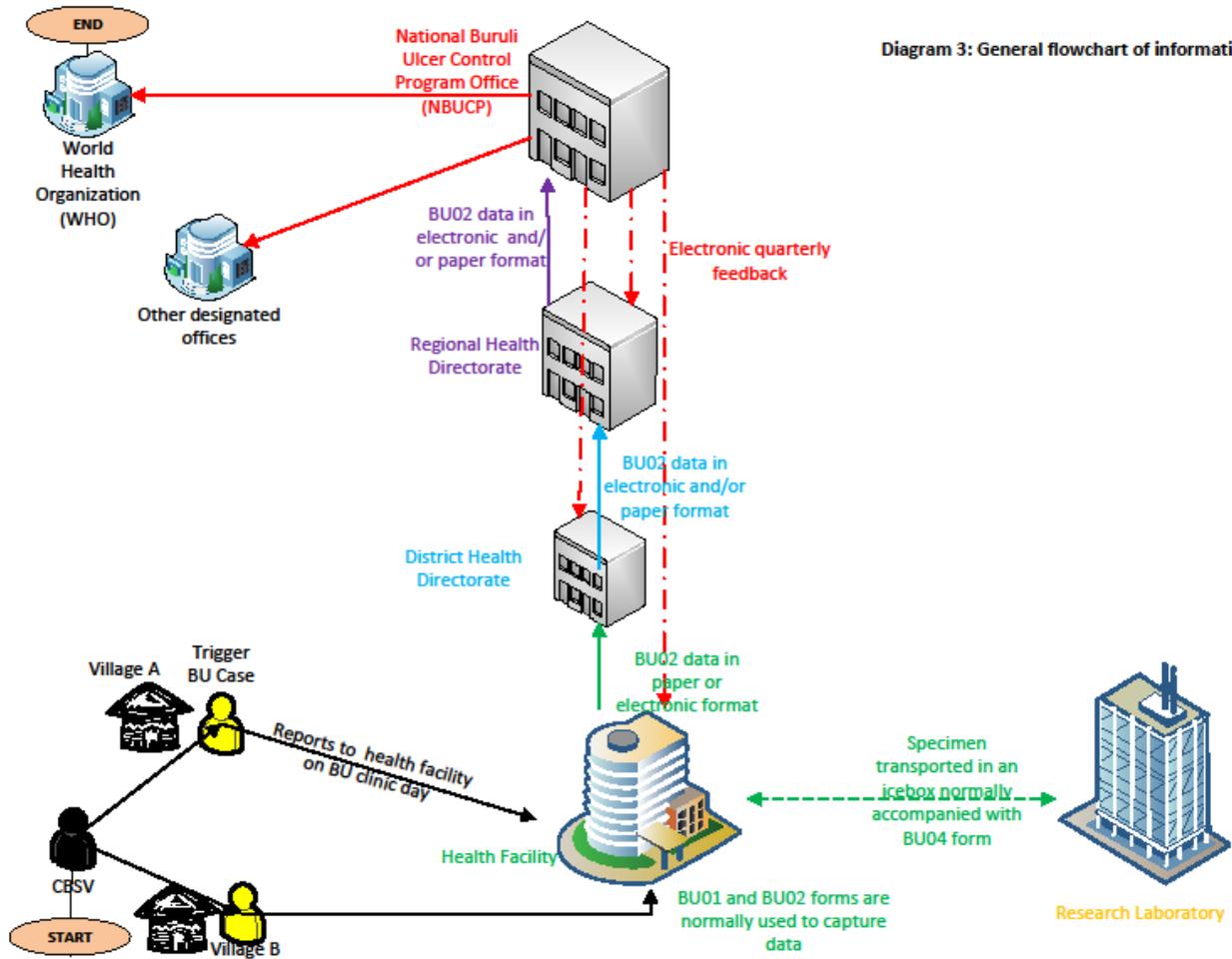Diagram 3: General flowchart of information

END

World Health Organization (WHO)

Other designated offices

National Buruli Ulcer Control Program Office (NBUCP)

Diagram 3: General flowchart of information

BU02 data in electronic and/or paper format

Electronic quarterly feedback

Regional Health Directorate

BU02 data in electronic and/or paper format

District Health Directorate

BU02 data in paper or electronic format

Village A

Trigger BU Case

Reports to health facility on BU clinic day

CBSV

START

Village B

Health Facility

BU01 and BU02 forms are normally used to capture data

Specimen transported in an icebox normally accompanied with BU04 form

Research Laboratory

Comparison with Some Emory University Buruli Ulcer Reports

Comparison between current state analysis and 2008 BU surveillance evaluation report

A comparison between this current state analysis and the BU surveillance evaluation carried out in 2008 as a joint effort between Emory University and WHO shows some improvements in certain aspects of the surveillance system whiles other issues persist.

CBSV's are still actively involved in case searches within their communities but issues and challenges raised in 2008 remain largely unresolved. The surveillance system still lacks standardization as slightly different approaches to information flow are used at different locations. Improvements demonstrated include the fact that reference laboratories currently use Polymerase Chain Reaction (PCR) test for diagnosis and a pilot project has been initiated to test the feasibility of PCR testing in low resource laboratories through simplification of methods. Also, early detection programs at certain locations have improved BU outcomes and reduced the cost of treatment.

In-depth analysis of buruli ulcer surveillance data conducted by Jason Baumgardner, Emory University

An in-depth analysis of Buruli ulcer surveillance data was conducted by Jason Baumgardner in 2011 to produce useful information from BU surveillance data in Ghana. This analysis provided some insight into how data can be structured to best provide meaningful information. Surveillance data between 2007 and 2010 were analyzed.

Some of the major challenges faced during analysis of the data were those associated with data cleaning. Some discrepancies were observed between the total number of cases recorded from the individual case listings and those recorded from the summary sheets. Ambiguities were also observed in some treatment center names, village names and district names. A number of records showed names with different spellings for the same items. Additionally, some treatment centers and villages were recorded to be located within different districts creating ambiguity as to where they actually belonged. It was recommended that data capturing be standardized to minimize these discrepancies and ambiguities.

Buruli Ulcer Surveillance in Agogo Sub-District

Community Based Surveillance Volunteer (CBSV) Processes

The data collection and transmission process is triggered by identification of a suspected BU case in the community. A CBSV has jurisdiction over a number of hamlets and villages and actively seeks out cases in his/her area. A CBSV is usually an individual who resides in one of the communities and is well known in his/her area of jurisdiction. Once a suspected case is identified, the CBSV refers the person to Agogo Presbyterian Hospital and is rewarded with monetary incentives courtesy Noguchi Memorial Research Institute and Kumasi Center for Collaborative Research (KCCR). Additionally, KCCR reimburses patients for transportation costs for each visit to the hospital. These incentives are made possible through grant money provided by these researchers. Tools used to record data at this point include personal notebooks and a Patient ID card supplied by Kumasi Center for Collaborative Research (KCCR).

The Patient ID cards capture data such as the person's name, village, contact person, doctor's name and date to report at Agogo Presbyterian Hospital. This card is given to the patient to be taken to the hospital. The notebooks are used to record the date, name, age and sex of suspected cases for their personal records. Small flipcharts are also used to educate the communities about early detection of BU however no information is recorded from this exercise. Some CBSV's have mobile phones and occasionally call the BU focal person to provide information about a suspected case. Though all the CBSV participants in the focus group had no idea how the information they capture on the ID cards is used, they stated that the periodic meetings organized by the BU focal person was very helpful in providing useful feedback on the state of BU detection in their respective communities. They also reported the use of a community register named CBSV tally sheets used to record other diseases of public health concern once a month. Supervisors were said to visit on a quarterly basis to monitor data recorded on the register. This has however not been consistent.

Agogo Presbyterian Hospital Processes

Outpatient Care

Suspected cases report to the health facility on Wednesdays which is the BU clinic day. A BU focal person is present at the hospital and coordinates all activities of the clinic day. The BU focal person fills out the BU01 form in duplicates, keeps a copy and gives the duplicate to the patient. The patient is asked to provide the copy to any other treatment facility where care is sought. Patients may choose to seek care at health facilities located closer to their communities due to travel expenses and difficulty traveling. Agogo town does not report any BU cases

currently; all cases are from surrounding towns and villages. Patients are required to return to Agogo Presbyterian Hospital every two weeks in order for the duplicate forms to be reconciled and also for progress of treatment to be monitored.

Two specimens are collected from BU lesions of suspected cases. The information is recorded on two different forms: a research team designed form and the BU04 form. This is due to the fact that two different research groups operate at the facility. KCCR has a research team which travels to the hospital on clinic days and collect specimen and information on new and existing patients. The research team collects specimen and record data on their own laboratory request forms. The specimens are analyzed for their research purposes. Other activities carried out by the research team which were observed include tracing lesions to record lesion size and monitor increase/decrease in size, taking photographs of lesions and recording drug compliance, drug toxicity and side effects on designed follow-up forms.   All data except photographs are paper-based and transferred to an electronic database located at their office in the Ashanti Regional capital of Kumasi. The German-funded research being carried out by KCCR boasts an extensive web-based database for all their BU activities in multiple countries. Unfortunately this database was not accessible for observation.

The Noguchi research team on the other hand, has set up a laboratory at Agogo Presbyterian Hospital on a pilot basis to perform PCR tests. Information on the second specimen collected is recorded on the BU04 form and sent to the laboratory together with the specimen for analysis.

Agogo Presbyterian Hospital also has a facility designed laboratory request form which is used interchangeably with the BU04 form.

Recurrent cases are issued BU01 forms which are stapled to their old BU01 forms. Laboratory confirmations serve to support clinical diagnosis. Clinically diagnosed cases have the choice of receiving treatment from health facilities close to their villages and are issued with their antibiotics.

<u>Admitted Patients</u>

Once clinicians have determined that a BU case requires hospitalization, patient data is shifted to the hospital's records system. This comprises a patient medical records folder which contains the BU01 form as well as patient clinical chart sheets. An Admissions/Discharge book is used to record information such as name, date of admission, town and date on which patient was discharged. The folder is kept at the ward until the patient is discharged at which the folder is sent to the Records department for filing on the day of discharge. A Returns book is used to record the date on which the folder was sent for filing and the records official who received the folder. The folders are then filed according to Year and Patient Number. Discharged BU patients who return to the hospital for review are required to go through the normal slow process of folder retrieval from the Out Patient Department (OPD). This is due to their being shunted unto the hospital records system upon admission. Since BU folders are no longer kept at the BU ward upon discharge, BU patients are affected as are other patients by challenges

faced by the Records Department regarding folder retrieval. This results in long waits of several hours to gain access to folders.

A BU09 form (Appendix G) is available for use in the event that a patient on admission has to be referred to another hospital. This is however, rarely used.

Collation, Transmission and Feedback at Facility Level

The BU focal person collates data on the BU01 form on to the BU02 form. This form exists in colored quadruplicates. Agogo Presbyterian Hospital retains the green copy whiles the other copies are forwarded to the district office. The district office retains the pink form and forwards the remaining copies to the regional office. The blue form is kept at the regional office and the white form sent to the NBUCP office. Electronic copies of the BU02 designed on an MS Excel spreadsheet is emailed to the NBCUP before the end of every subsequent month. The paper formats are however not as timely.

Quarterly review meetings are held by the BU focal person to provide feedback to CBSV's and health workers involved in BU work at Agogo Presbyterian Hospital and other community health posts in the surrounding villages. This is based on quarterly feedback reports sent by the NBUCP. Occasionally, national annual reports are provided by the NBUCP to the facility.

Laboratory Processes

The Noguchi Memorial Research Institute of the University of Ghana has established a laboratory at Agogo Presbyterian Hospital to conduct diagnosis of BU. This is a pilot project to determine the feasibility of conducting a simplified version of the PCR test by trained personnel. Researchers from the institute conduct parallel diagnosis, monitor and enforce quality control measures at the Agogo Presbyterian Hospital BU laboratory. This research is funded with grant money solicited by the institute.

Specimen collected on BU clinic days (Wednesdays) are analyzed at the Agogo Presbyterian Hospital BU Laboratory. A patient's specimen is divided into two aliquots; one remaining at the hospital laboratory for analysis and the other sent to the research institute for analysis. The BU04 form or the facility designed laboratory request form accompanies each aliquot sent to the institute. A photocopy of the form is sent together with the institutes' aliquot in an icebox to the capital, Accra via public transport. This usually arrives by midday on Thursdays. The icebox is fetched from the transport station and transported to the University. A minimum of 3 and a maximum of 7 samples are received on a weekly basis. Once samples are received, data on the laboratory request or BU04 forms are transferred into a notebook and the requisite diagnostic test conducted. Results from the Agogo Presbyterian Hospital BU laboratory are made available the following day (Thursdays) and emailed in an excel format to the officer in-charge at the institute. Results from the institute are usually made available on Fridays and emailed in a separate but identical excel format to the laboratory personnel at the Agogo Presbyterian Hospital BU laboratory and copied to the BU focal person. Results have been

continually added to the excel table since the inception of the project and backups are made periodically to prevent data loss.

Occasionally, discrepancies are observed between the results produced by the Agogo laboratory and the institute. These discrepancies are always of the same nature, in that, the Agogo Presbyterian Hospital BU laboratory would record a negative result indicating absence of BU whiles the institute would record a positive result. On such occasions, a phone call is made to the BU focal person and names of patients affected by the discrepancies emailed as well. The Agogo laboratory personnel are instructed to re-do the test and if results remain the same, the institute repeats the test. Results of this test are entered in the Institute's excel spreadsheet and emailed on Saturday to the BU focal person and copied to the Agogo Presbyterian Hospital BU laboratory personnel. A follow-up phone call is made to the BU focal person for clarification purposes. In the event that the frequency of discrepancies escalates over a period, the Agogo laboratory is instructed to suspend diagnosis until adjustments and re-training have been conducted. During this time, the institute continues to provide diagnostic services to the facility.

Challenges faced by this current system set up between the hospital and the research institute is the frequent blank fields left unfilled when the laboratory request forms are sent with the specimen. The most frequent fields left blank include place name (community where case resides), classification (whether a new or recurrent case), category of lesion and the date the samples were sent to the institute. The facility designed laboratory request form by its generic design does not provide for the capturing of information such as the classification. Its use in BU

data capturing therefore results in the loss of valuable data. This and the BU04 form however are still being used interchangeably.

TIMELINE

WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
• BU Clinic day. • Specimen sent to Agogo Presbyterian Hospital BU laboratory.	• Agogo Presbyterian Hospital BU laboratory results are ready and emailed to Noguchi. • Noguchi receives specimen samples by midday.	• Noguchi results are ready and emailed to BU focal person and also copied to Agogo Presbyterian Hospital BU laboratory personnel. • Detected discrepancies are emailed.	• Discrepancies resolved.

KCCR also provides laboratory confirmation for patients enrolled in their research study. Results are recorded on BU04 forms and returned to Agogo Presbyterian Hospital on their following visit. Results from KCCR are therefore provided one week after specimens are collected. Discrepancies in results occasionally arise between the two research teams. This is often resolved by re-testing.

Ananekrom Health Post Processes

Patients who opt to receive treatment at Ananekrom present at the Health Post with their copy of the BU01 form and the medication issued from Agogo Presbyterian Hospital. The dosage section of the BU01 form is ticked appropriately after each dose has been administered by the health worker. No other records are kept of BU activity at the Health Post. The health officer in charge therefore is unable to provide basic information such as the number of BU cases treated over a period of time. Suspected cases who present at the Health Post are promptly referred to Agogo Presbyterian Hospital for clinical diagnosis. Where suspected cases have lesions, wound dressing is provided before referral. Lack of electricity, infrastructure, personnel and other logistics pose huge challenges to the health post in providing quality healthcare.

District Level Processes

A copy of the BU02 form is forwarded to the district office by the BU focal person. The other copies are forwarded to the regional office. A BU06A form (Appendix H) is available for recording BU treatment outcomes by district supervisors on visits to the facilities. This is however not done.

Regional Level Processes

The regional office is required to collate and summarize BU data from the districts and forward it to NBUCP. Information provided from the region to the NBUCP is usually duplicates of data forwarded by the health facilities or district office. The lack of processed information from the regions coupled with reporting delays causes the NBUCP to solicit data directly from health facilities or district office.

National Level Processes

The electronic data received from Agogo Presbyterian Hospital via email is stored on a laptop and backed up on an external drive by the NBUCP program officer. Data is aggregated into quarterly period intervals. Although data from facilities and districts are required to be reported quarterly, it has been stepped up to monthly reporting in a bid to improve compliance with data reporting. This strategy largely appears to be working as Agogo Presbyterian Hospital as well as many other facilities and district disease control officers report on a monthly basis. Timely reporting is defined by NBUCP as the receiving of data for the previous month by the middle of the subsequent month.

Analysis is performed based on person (what age groups are affected the most), place (communities with highest frequency of cases) and lesion category. Standard guidelines for data analysis are currently not available. Analysis is performed with a variety of software including Epi Info, MS Excel and Quantum GIS. The use of pivot tables as a major tool for data collation was identified. This has made data manipulation easier and faster. A feedback

template is used to report current trends as compared to the previous quarter. This is emailed to the BU focal person on a quarterly basis.

Data cleaning was noted as one of the big challenges associated with processing data received from the various health facilities, districts, and regional disease control officers. Different spellings given to the same community requires time and effort to reconcile before data aggregation can be carried out. In some instances, health workers in health facilities, districts, or the region alter the template provided for the electronic format of the data. This results in data that varies or additional column headings thus making analysis cumbersome. Additionally, compliance to timely reporting has largely affected data collection at the national level. Although a timely reporting comparison table is disseminated frequently to name and shame late reporters, it still remains a big challenge. Personnel at all levels would benefit from formal training in data management as current skills are based on self knowledge and trial-and-error.

Diagram 4: Flowchart of information system at Agogo Prsbyterian Hospital
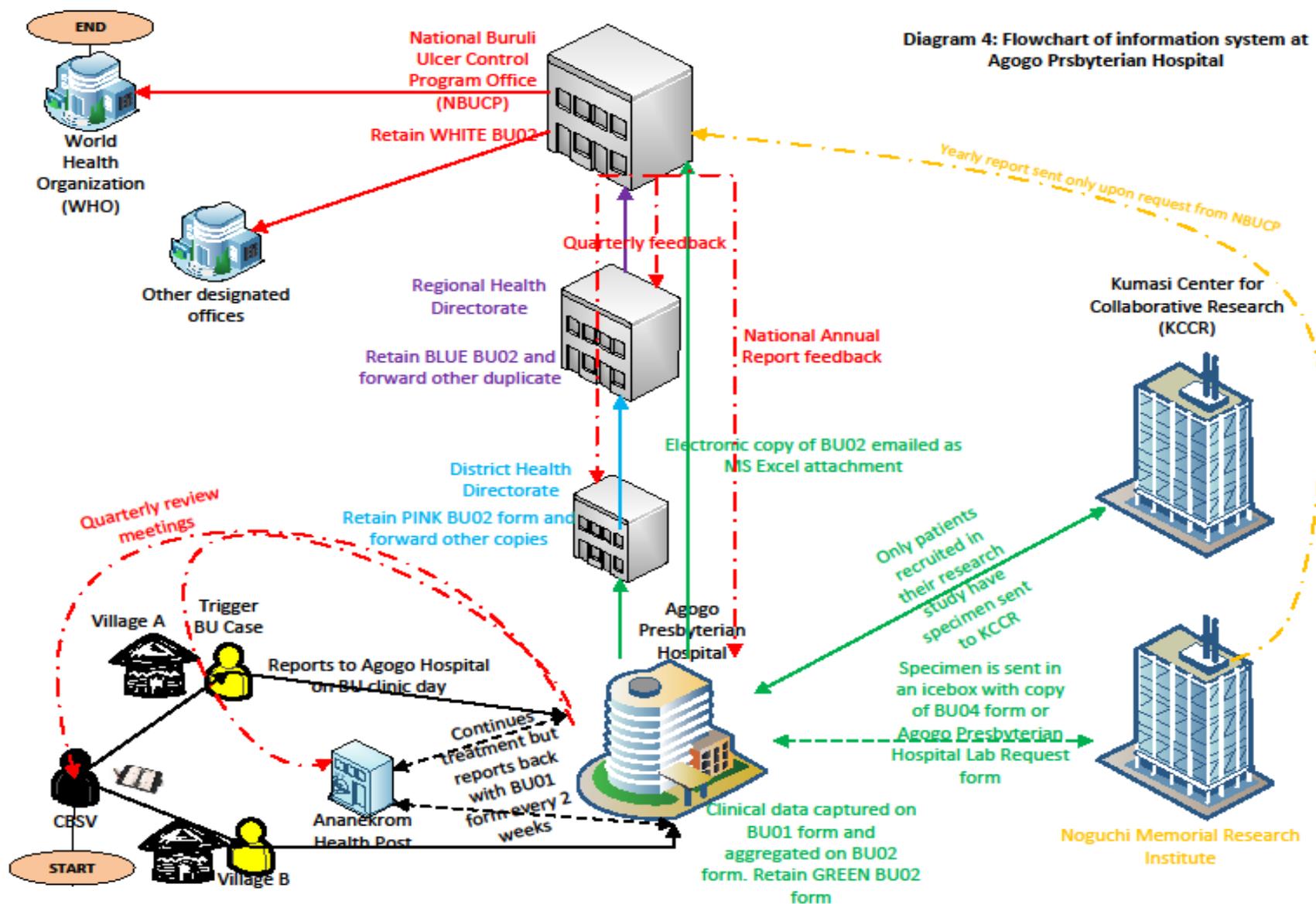
Buruli Ulcer Surveillance in Ga West District

CBSV Processes

CBSV's actively seek out cases in their various communities and refer cases to the Amasaman Hospital. Unlike in Agogo, they do not issue suspected cases with Patient ID cards and are not given any monetary incentives for cases referred. Patients are not given any reimbursement for transportation costs. They have flipcharts used to educate communities on early detection of BU. The CBSV's also routinely report other diseases on a CBSV tally sheet.

Amasaman Hospital Processes

Outpatient Care

Once a patient reports to the hospital on a BU clinic day (Wednesdays), they are asked to go for a medical records folder from the Out-Patient Department (OPD). This process unlike what pertains at Agogo, requires patients to go through the normal hospital system of accessing folders which makes it time consuming. Upon retrieval of the folder, a patient then reports to the BU ward. Here a BU01 form is used to record clinical data. This is however not in duplicate like what pertains in Agogo. However, a Facility BU Registry issued by the NBUCP is used to record information on all patients that come to the facility with suspected BU at the BU ward. This registry is in the form of a hardcover book. Positive laboratory confirmations for BU are indicated in the registry. The information recorded in the registry is essentially information captured on the BU01 form. A research team from the Noguchi Memorial Research Institute provides diagnostic services to the BU clinic and is present every BU clinic day to take

specimens. The BU04 form is used to record laboratory data. Unlike what pertains at Agogo, they do not use Amasaman Hospital laboratory request forms interchangeably but only use the BU04 forms. When a patient opts to receive treatment at another health facility, the BU01 form is given to them to take along together with their medications. They are required to report to the hospital after four weeks and again after eight weeks for progress of treatment to be monitored. The BU01 forms are returned by the patient and kept in the patient's folder only after treatment is complete. The folders are stored at the BU ward instead of the Records Department, a practice which is different from what pertains in Agogo.

Admitted Patients

The BU01 form is also used for admitted patients. These are kept in their medical records folder together with other medical records. Unlike Agogo Presbyterian Hospital, once a patient is discharged, their folders are kept at the BU ward and not sent to the Records Department. They are filed by Year and Patient Number which is similar to Agogo Presbyterian Hospital's filing system. This way, patients that report for reviews and follow-ups shortly after being discharged have faster access to their folders. Conversely, if they report to the hospital for other conditions other than BU, they have to report to the BU ward before their folders can be retrieved.

Folder retrieval after a number of years have elapsed since a patient was discharged however is a time-consuming process. This is most likely because proper filing procedures are not adhered to causing folders to be misplaced.

Collation, Transmission and Feedback at Facility Level

The district disease control officer doubles as the BU focal person at Amasaman. Positively confirmed cases from the BU registry are captured on the BU02 form. This is later entered by the BU focal person in an MS Excel template provided by the NBUCP.   This electronic format is emailed to the NBUCP on a monthly basis.

Personnel from the Records Department also periodically record information from the BU registry. The total number of BU cases that presented at the hospital is manually counted from the registry and incorporated into annual reports prepared for the hospital's administrators.

The BU surveillance system suffers many challenges at Amasaman Hospital. Currently because the district disease control officer also serves as the BU focal person, increased workload and time constraints makes full dedication difficult. Also, due to renovation works carried out at the hospital in 2010, the facility's copy of the BU02 has gone missing for that year. Additionally, nurses at the BU ward do not update the BU01 forms when patients undergo surgery, leaving blank information on the BU01 form. Vital information such as date discharged is also frequently missing preventing duration of hospitalization from being easily calculated.

Laboratory Processes

A second research team from the Noguchi Memorial Research Institute different from the team at Agogo Presbyterian Hospital provides diagnostic services to the Amasaman Hospital. BU04 forms are used to collect data on specimens taken. Additional research data is captured using

Noguchi designed forms. Due to proximity to the Amasaman hospital, research team members collect specimens on BU clinic days and personally transport them in an icebox to their laboratory. Confirmation results are recorded on the BU04 form and returned to the facility on the next visit. Thus feedback for diagnosis is received a week after specimens are taken, a period slightly longer than that for Agogo Presbyterian Hospital. This process though not electronic eliminates the problems associated with the photocopied forms used for Agogo Presbyterian Hospital diagnosis. Other reporting sites around the country that send specimen to the Noguchi Memorial Institute for diagnosis however receive feedback via email or phone call.

District Level Processes

The district sends electronic copies of the BU02 data are sent to the regional office upon request. Hard copies are forwarded to the regional office at the end of the year. Data received from other reporting facilities are collated and analyzed by age distribution, sex, classification and category. This information is used to make decisions pertaining to community education.

Feedback is received from the NBUCP in the middle and at the end of the year. Also, due to proximity, regular stakeholder meetings are held between the NBUCP and the district office to discuss BU activities and provide feedback.

A challenge faced at this level is the lack of geographic information. Some cases do not originate from the district thus finding the location of these cases becomes difficult. Also,

because the BU01 forms are not updated correctly at the facility level, filling out the date of discharge column on the BU02 forms are impossible.

Regional Level Processes

The region is required to collate and summarize BU data from the districts and forward it to NBUCP and other designated offices. Challenges faced by the Ashanti Region pertain in the Greater Accra Region. As stated earlier, information provided from the region to the NBUCP is usually duplicates of data forwarded by the health facilities or district office. The lack of processed information from the regions coupled with reporting delays causes the NBUCP to solicit data directly from health facilities or district office.

Diagram 5: Flow chart of information transmission at Amasaman Hospital

Diagram 5: Flowchart of information transmission at Amasaman Hospital
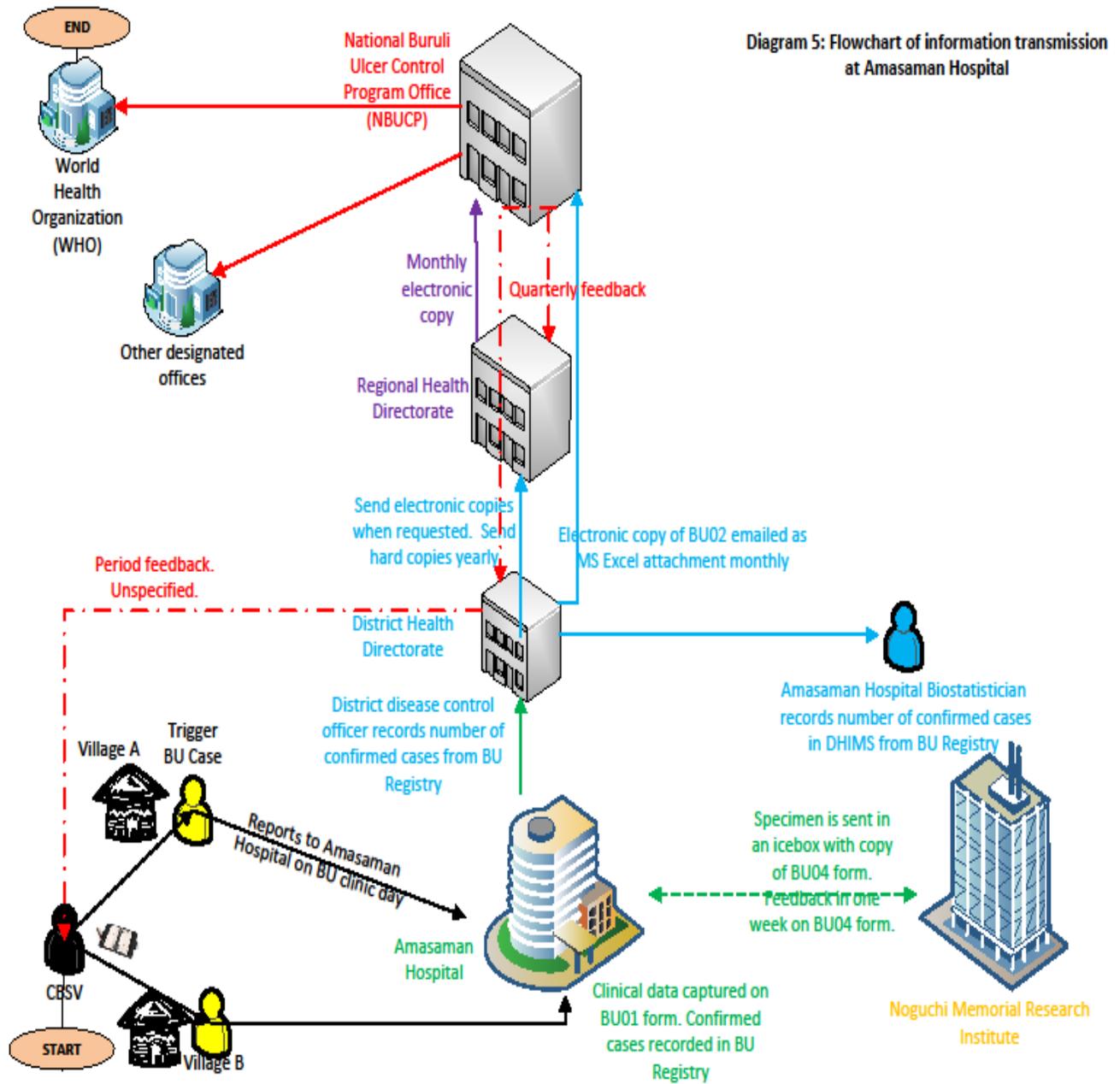
Results for Stakeholder Interactions Using the Collaborative Approach

Hospital Administrators

Members of this focus group considered BU as a public health interest and stated that BU activities were incorporated in the routine activities of the Public Health Unit of the hospital. Challenges observed with BU data management as stated included lack of structured reports providing critical comments on current situations across country from the NBUCP. This lack of feedback prevented them from knowing how well their health facility was doing compared to other facilities across the country. Information regarding whether targets set for BU had been met or not were also not forthcoming from the NBUCP. Targets met or exceeded they claimed, would serve as motivation to hospital staff and CBSV's from those communities. It would also present a clearer picture as to where more effort needs to be applied.

Hospital Administrators in the focus group stated their desire to understand through statistical analysis why a particular community would report extremely high number of cases compared to adjacent communities. They also stated as a matter of observation that most cases that presented at the facility resulted from some kind of trauma hence more information was needed to test this hypothesis. Hospital Administrators also stated their desire to investigate the relationship between diet of a BU patient and time taken for healing to occur.

Members of the group lamented the amount of outstanding debts accrued as a result of BU treatment. After providing treatment for BU patients for free, re-imbursement of funds was mentioned as a big challenge.

All were of the view that with advancements made in Information Technology and its wide availability, an electronic database for BU was required. Though lack of funds to support the purchase of hardware, infrastructure and human resource training was cited as a major drawback, all were quite enthusiastic about embracing the implementation of new electronic systems in the hospital to support BU surveillance if it were made available.

Recommendations

It was recommended that comparative performance feedback be provided to facilities so as to be used in managing hospital systems, allocating funds and learning positive strategies from other facilities involved in BU surveillance. Also, feedback on early detection targets as met, exceeded or not met should be made available to facilities. It was also suggest that since most BU cases that presented to the facilities were as a result of some kind of trauma, capturing this information on the BU01 form was very essential. They further recommended that the cost of treatment of each BU patient be captured as part of the surveillance data.

Local and International Researchers

Researchers interviewed were interested in the prospect of having a database which would serve as a repository for data gathered on various aspects of BU. Most commented that having

access to other researchers' data as well as sharing their own would foster communication and the sharing of ideas for the common good.

Recommendations

It was recommended that the ZN and PCR columns of the results section of the BU04 form be re-designed to capture separate results for a Swab (S) or a Fine Needle Aspirate (FNA) under those columns. This would ensure that information was not lost when these fields were left blank at the time specimen was being taken.

Some researchers suggested that the development of a database should include the prospects of integrating mobile phone and SMS technology as a means of data capturing. Additionally, possible parameters suggested for capture in the database included those for stigmatization, cross-cultural aspects, quality of healthcare, treatment outcomes, barriers and solutions for early detection as well as logistics.

Most researchers stated the inclusion of spatial data as very pertinent to the database. With regards to temporal information, it was suggested that unambiguous and specific format for date fields should be assigned in the database. This would eliminate the confusion associated with date entries. It was also suggested that 3 letter district codes be assigned to districts to provide standardization. Standardization of place names was also recommended for the database. Information on whether a patient has opted for treatment at another health facility was also recommended for capture in the database.

Issues of ownership and intellectual property rights were raised concerning the database. It was advised that these issues be thoroughly addressed and user agreements well defined to promote trust and contribution to the database.

It was also requested that an inventory of genotypes currently isolated be compiled and integrated into the database. This would create a genotype bank to serve as a resource for molecular epidemiologic work.

Hospital Health Workers

The hospital workers cited some challenges with the BU01 form during the focus group discussion. They stated that the current practice was to base antibiotic dosage on a patient's initial weight recorded at time of first visit. The BU01 form did not provide a means of capturing changes in weight of a patient during the duration of treatment in order for the dosage to be adjusted accordingly. They acknowledged observing some patients on admission gaining or losing significant weight enough to warrant a change in dosage regimen.

They also stated that the column on the BU01 form used for monitoring antibiotic treatment was inadequate in capturing accurate information on antibiotics dispensed. They explained that rifampin was usually administered at dawn whereas streptomycin was administered in the morning. Thus if for any reason one or the other could not be administered, ticking (or not ticking) the column did not provide accurate information as to which drug was dispensed.

Another challenge cited with the BU01 form was the fact that information which was vital to assessing a patient and ensuring continuity of quality healthcare through different nurse shifts was not available. Examples mentioned were progress of wound healing, type of dressing used and swabs taken. Additionally, it was mentioned that a patient's medical history could not be determined from the information captured by the BU01 form.

Members of the focus group noted that when some patients present initially to the facility, they do not divulge truths about the onset and other circumstances relating to the disease. They claim that whiles on admission however, patients tend to develop some rapport with hospital staff and are more open to discussing such issues and other issues relating to their health.

BU patient medical records folder storage and retrieval was highlighted as a big challenge in handling patients who have to return to the facilities for review or because of disease recurrence. Some issues mentioned included the fact that sheets from folders sometimes get detached during the process of folder retrieval. Others also stated that folders get missing or misplaced often, especially for patients who return to the facility after a long period of time.

Recommendations

They recommended that the BU01 form be converted into a booklet to be able to accommodate the capturing of information such as patient weight charts, medical history and treatment progress. They also recommended that electronic copies of this information be made available in a database at the BU ward or consulting room to facilitate faster access to

patient information when they report to the hospital. They stressed the fact that the front end of the database should be familiar, meaning it should be similar to the paper format already in use. Closed ended questions should be used to capture information in the database to reduce the time used to enter data. It currently takes about five minutes to fill out information in an admitted patient's folder.   It was also requested that trial versions of any BU software be provided to them for pre-testing so they could provide input and propose modifications to make it useful.

It was suggested that questionnaires designed to advance research into how BU is transmitted be circulated in BU wards and nurses be incentivized to fill these out at some point during a patients stay at the ward.

National Buruli Ulcer Control Program (NBUCP)

It was stated that currently, templates used for data capturing allow for additions but not for the removal or modification of fields that are no longer essential. An example proffered was the broad age distribution intervals currently being used by WHO. These intervals were said to hinder a sharper focus on age distribution of the disease this analysis did not offer adequate information for decision making.

It was also pointed out that BU reporting focused on the number of cases that reported to health facilities and the treatment given. No information was currently captured on patients after they had left these health facilities or after treatment was complete. This echoes the

sentiments highlighted by other stakeholders about the need to capture comprehensive data on treatment outcomes.

Recommendations

It was recommended that the database be designed such that the age distribution is modified to capture information on children under the age of 5 years. It was also suggested that the database capture information to enable treatment outcome analysis as well as have geographic mapping capabilities.

A 3 tiered electronic database system is envisioned whereby health facilities report electronically to the districts in a timely fashion. Laboratories involved with diagnosis would also be able to report electronically to the health facilities as well as the NBUCP. The second tier of the system would involve districts being able to analyze and summarize the data to some degree and have the capacity to forward this information to the regional disease control officers electronically. The third tier would involve transfer of information between the regions and the NBUCP. The NBUCP in managing this system would have access to information from all levels of the system across country.

Disease Control and Prevention Department (DCD)

The DCD strives to attain a data management system which is functional and accurate and able to provide information to support decision making at all levels within Ghana's health system. It is envisaged that this data management system would provide the means to be able to view

historic trends in disease as well as issues of public health interest and the ability to make comparisons with current trends in order to make predictions for the future. The system would have the capacity to track health parameters over time and the resultant information gathered, processed for decision making.   This system would also have the versatility to support referencing of new research findings especially those concluded for Ghana and sub-Saharan Africa as well as global trends. This would afford stakeholders the opportunity to benchmark findings in their locality with published references.

The purpose would be the utilization of such information to shape academic education with the aim of building capacity based on current trends as well as modify health practices to improve healthcare. The objective therefore is to have a repository of data where information from all branches of the Ministry of Health would reside. From this repository different programs and offices could then query for information thereby steering away from the obstructive trend of different programs having databases which are not interoperable. The department understands the need for collaborative efforts from all stakeholders and highlights the need to strengthen communication efforts between the various branches of the Ministry of Health.

Recommendations

It was stated that some data requirements from a BU database would stem out of the current objective of the NBUCP which is to step up early detection of the disease to prevent disability and reduce cost of treatment. It was therefore recommended that a BU database should not merely capture indicators being previously collected but also parameters that could be used in

measuring disease outcomes. It was further explained that indicators which describe person, place and time were parameters that were essential in determining incidence. Also, logistics information and inventories of development partners were necessary in distributing logistics for treatment and education. However, parameters required to answer pertinent questions in order to predict treatment outcomes were also required. This would provide solutions to issues such as definitions for treatment success or failure. It was stated that case definitions could materialize from proper data design, collection and processing.

It was suggested that the BU database should represent a realistic approach to data collection. In that, routine data should be trimmed down such that data requiring weekly, monthly, quarterly or yearly submissions should be clearly defined and systematically structured at the data collection points. This would prevent the often experienced situation of programs being overwhelmed with data collection in a bid to meet the demands of external development partners to the detriment of patients.

In order to maximize the use of limited resources it was advised that integration of similar processes should be considered. In this regard, it was recommended that in designing a BU database, avenues to integrate other Neglected Tropical Diseases and skin conditions similar to BU should be exploited.

It was suggested that GPS coordinates be incorporated in the design of the database to be able to identify clustering. Also, the design of the database should be such as to eliminate or reduce the challenge of data incompleteness currently experienced with BU data.

It was finally recommended that in developing a database for BU, an underlying requirement should be the ability for interoperability with the Center for Health Information Managements database.

Center for Health Information Management

The Center for Health Information Management (CHIM) was founded in 1961 and charged with the duty of overseeing Health Information Management Systems throughout the Ministry of Health. The center is the home of the District Health Information Management System (DHIMS).

DHIMS-1

DHIMS is a data aggregation tool currently used nationwide to gather and transmit some surveillance data from facilities up the hierarchy of the Ghana Health Service. It operates on an MS Access platform and displays data entry screens identical to the paper formats originally used for data collection. It can also perform basic analysis of data. For example a list of defaulting facilities who have not submitted data returns for the month can be queried and printed out. Some basic reports, frequencies and graphs can also be created with the software.

DHIMS started as a pilot project in 2004 as proof of concept. The primary aim of rolling out the system was to determine whether a system of this nature could be implemented and sustained in the Ghana Health Service environment. This proof of concept was in response to the call to change the manner in which information was transmitted and utilized throughout the health system. Previously, all facilities reported in paper format and these forms were required to be forwarded to the respective regional offices by the districts. It was at this level that data were converted to electronic format. The regional offices had Excel templates in which this information was entered after which it was forwarded to the Regional Director of Health and copied to the District Director of Health. This arrangement meant that districts did not have access to their own data in a timely fashion for use in planning or management. The regional directors therefore made decisions on behalf of the districts. The districts on the other hand, not being required to process the data, were merely acting as forwarding agents. Districts that ventured to extract or process some data in the past were faced with the task of using calculators to aggregate data from the various facilities. Stakeholders therefore agreed that the districts needed to have ownership and more control over their own data and be able to manipulate them to support decision making and planning at the district level. In order to achieve this, a tool which was uniform and structured across country was needed to assist the districts to process the data before forwarding to the regions. The DHIMS-1 was therefore implemented to test the feasibility of this venture. 20 districts were initially selected for the pilot project but by 2008 all districts in the country were trained in the use of DHIMS.

Currently, health facilities that have DHIMS-1 but no internet service, after data entry, copy the data unto a pen drive and send to the districts. Those that do not have the software continue to submit paper forms. At the district level, most facility data is collated and converted to electronic format (DHIMS and Excel). A copy of this is forwarded to the regions but the primary data remains at the districts. The regions merge the data and forward it to CHIM and other designated departments.

The challenges of DHIMS-1 are typical of software being used as proof of concept. The primary concern of CHIM in this case was to tackle logistics and human resource issues and not issues of software functionality. Not all the data capturing instruments used in the health system is incorporated into DHIMS-1. Of the 71 forms currently being used, only 17 major ones are present on the software. The software is also not flexible and suffers from lack of interoperability. DHIMS-1 clearly has no place in the vision of the Ministry of Health and its partners to achieve an integrated health data management system.

DHIMS-2

The platform for the old DHIMS has been changed and the number of data capturing instruments expanded to ultimately include all 71 forms. DHIMS-2 is a web-based system operating on a District Health Information System (DHIS 2) platform. The DHIS 2 platform is an open source system which runs on Java and was created as a joint effort between the University of Oslo and South Africa Department of Health. The platform has interoperability

capacities and can support other systems such as SMS reporting via mobile phones. It can also be expanded to accommodate changes and additions to systems.

DHIMS-2 is currently being prepared for pre-testing and is expected to be rolled out in January 2012. It still maintains the data aggregation structure of its predecessor but lends itself to easy modification to suit a particular health program's data capturing needs at any level. It also boasts a GIS component which can produce dot representations and an i-report component used to produce customized reports. A picture capturing component is not included for DHIMS-2 but it was stated that the platform it operates from (DHIS 2) can be re-programmed to accommodate it if any of the program directors requested it for their data capturing needs. An offline version of DHIMS-2 would be available for data entry in districts that do not have broadband internet access and rely on cell phone modems. Querying the system would however require internet access. It is expected that after data entry is completed with the offline version, district officers can then plug in their modems and upload the information to save cost. Discussions are also ongoing with the University of Oslo and its Indian partners to use DHIS 2 to develop a Medical Records System for the Ghana Health Service. So far, a prototype has been developed.

CHIM has been instrumental in successfully placing a Health Information Officer in every district office and some regional offices and has also expanded its technical support team at the national level. Mobile phone network services are also currently available in every district capital where the district offices are situated hence internet service in some form is

guaranteed. It is also anticipated that the initial reservations expressed by health workers during the implementation of DHIMS-1 would be absent for DHIMS-2 since the concept has now been widely accepted. Implementation of DHIMS-1 was initially met with resistance because of unfamiliarity with the new reporting protocols. Finally, it is anticipated that because DHIMS-2 is web-based, easy access to data would foster easy sharing of data.

The major challenge of DHIMS-2 is largely expected to be organizational in nature; the same challenge which plagued DHIMS-1. The limiting factor to the success of DHIMS was identified as data entry at the district level. It was explained that parallel systems which exist within the health system makes it difficult for information to be merged and transmitted. Different program officers at the districts enter their program-specific data into DHIMS or their own program-designed templates. This information ideally, should be shared between program officers and Health Information Officers who are tasked with the duty of merging all the information and forwarding it to the appropriate recipients. The lack of information sharing at the district level creates a parallel system in which different programs forward their data up their respective chain of command to their national offices. The information therefore is not easily accessible by CHIM. Sensitization and training programs have been outlined to address this issue with the rolling out of DHIMS-2.

Recommendations

With the backdrop of the Ministry's new direction of trying to achieve integrated systems, it was suggested that a BU database could be designed and integrated into DHIMS-2 if the

program director articulated input and output requirements to CHIM. By so doing, the database could benefit from training and sensitization programs as well as technical support offered to data entry personnel at all levels. An alternative recommendation was that a BU database could be developed on the DHIS 2 platform by external developers thus ensuring interoperability with DHIMS-2.

World Health Organization

The Global Buruli Ulcer Initiative has taken initial steps towards the development of a BU database. Currently, a MS Access based software called the Buruli Ulcer Information Management System (BIMS) has been designed and is in the pre-testing stage. The data entry screens of BIMS are similar to the BU paper format being currently used in the country and would be useful for capturing clinical data at the facilities level.

Recommendations

It was recommended that the design of a BU database should provide a basic framework that BU surveillance in other countries could modify for utilization but which would also support interoperability between these surveillance systems. It was also advised that the database be made simple so that data entry at data-collection points do not become cumbersome thereby leading to inaccuracies.

Non Governmental Organizations

Officials of NGO's interviewed work alongside researchers as well as the NBUCP to provide education at the community level and training for health workers and CBSV's. They also provide specimen collection services to augment the work of researchers in the communities in which they operate. Data collected from these activities are analyzed and reports sent to their sponsors.

Recommendations

It was recommended that detailed disability information be captured in the database. Also suggested for capture was information regarding position of disability on the body as well as movement limitations and wound care. Healthcare practices such as the use of gloves, hand washing, proper bandaging techniques to minimize disability as well as proper disposal of dressing material were also suggested as useful data required to improve treatment outcomes.

Community Based Surveillance Volunteers

When asked what motivates them to do their work, all CBSV's in the focus group stated concern for the future of the children in their respective communities as the strongest motivation factor. Some stated the debilitating effects of the disease on a sibling while growing up as the factor that drew them to volunteer. On the issue of whether prestige was a factor of motivation, all stated that their community perceived them as rich by virtue of the fact that their work was associated with the health system and also foreign researchers. This wrong perception, they stated, was an issue they have had to grapple with when for example they

have to borrow someone's mobile phone to place a call to their BU focal person about a case. Prestige therefore was a hindrance rather than a motivation for them.

Recommendations

Though no specific recommendations were made regarding a BU database, they recommended the provision of mobile phones, better means of transporting cases they identify as well as the provision of outer wear such as raincoats and wellington boots as a good means of enhancing their work thereby strengthening the BU surveillance system.   They also recommended awarding certificates of commendation or prizes to CBSV's of long standing in recognition of their contributions. They stated that this would serve as a form of motivation for other CBSV's.

Ghana Health Service, ICT Department

This department is relatively new and was created out of the Finance Department. It is currently working on software standards for the Ghana Health Service. Although fixed guidelines, policies and standards have not emerged so far an enterprise architecture has been designed and officials working to outline laws similar to HIPAA to protect patient health information.

Chapter 5: Conclusion and Recommendations

General Summary

The aim of this project was to use the Collaborative Approach to requirements gathering to evaluate the current system of BU data collection and management in Ghana and also understand the needs and requirements of various stakeholders. This would be useful in the development of a BU database that would serve the needs of different stakeholders. Through direct observation, interviews and focus group discussions insight was gained into how the current system runs and also the expectations of various stakeholders.

Recommendations

It is quite clear that CBSV's are the bedrock of BU activities in Ghana. Special attention should be paid to this group and time and effort invested in their training. Incentives should be provided to further motivate them in their activities. Recommendations targeted at CBSV's which would be beneficial for effective utilization of an electronic database include:

- Training to highlight the importance of data collection and data management in BU.
- Sensitization to the development of newer technology for data capture, for example SMS Technology through regular workshops.
- Provide logistics and incentives to enhance CBSV work.
- Improve communication and rapport between CBSV's and other levels of the hierarchy.

Advanced data capturing processes begin at the facility level hence strengthening processes at this level is important in preserving data integrity. Recommendations include:

- Re-designing data capturing instruments to capture data which is relevant to current BU surveillance and research.

- Standardizing these data capturing instruments across all health facilities that report BU.

- Standardizing information system processes across all health facilities within the limits of hospital systems.

- Providing data management training to hospital personnel who handle BU data.

- Provide technological infrastructure to support electronic collection and transmission of data.

- Liaising with other programs as much as possible to maximize utilization of resources.

District health offices are the first point in data collation processes within the system. These offices should be equipped with resources to perform this task effectively and efficiently. Recommendations include:

- Utilizing existing human resource like the Health Information Officers in each district to process data received from health facilities.

- Developing standards for BU data management and analysis within the framework of the Ministry of Health.

- Training personnel in advanced data analysis and management processes.

- Sensitization to the development of newer technology for data capture, for example SMS Technology through regular workshops.

Regional health offices are required to collate all BU information from reporting districts and disseminate to the appropriate offices. The lack of timely reporting and data processing has contributed significantly to the decline in proper reporting protocols within the BU reporting system. Recommendations at this level include:

- Providing regular training and sensitization through workshops to personnel at the regional offices who handle BU data to "market" the disease and bring it to the forefront.

- Training personnel in advanced data analysis and management processes.

- Where applicable Regional Health Information Officers could be utilized to process BU data.

The NBUCP currently conducts the most in-depth analysis of BU data. To support their efforts and the sustenance of an electronic database the following are recommended:

- Improve communication between NBUCP and CHIM in order to utilize existing electronic systems for BU reporting where available.

- Provide advanced training in data management to personnel at the NBUCP office.

- Standardize information capturing instruments and processes at this level.

- Provide technological infrastructure to support processing and dissemination of information.

- Liaising with other programs as much as possible to maximize utilization of resources.

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APPENDICES

Appendix A

Interview Guide for Hospital Administrators Focus Group

1. In your strategic goals for the hospital where does BU stand in the grand scheme of the hospital compared to other programs?

2. What kind of data/feedback from the district/regional/national level will help in achieving these goals or make the work better?

3. What kind of data/information do you want to be able to give to the district/regional/NBUCP that they haven't requested for?

4. What kind of analysis do you want to be able to do on your own with the data that you have?

5. How do you feel data collection can be improved in the hospital with regards to BU?

   - How do you feel data analysis can be improved?
   - How do you feel data transmission can be improved?

6. What challenges/barriers might you face in implementing new databases at the hospital?

   - What about in modifying existing databases?

7. Is there anything we haven't talked about that you may want to share?

Appendix B

General Interview Guide

How do you do your work now? *(Focus group exercises)*	How should the work be done? *(Optimizing the processes outlined in column 1)*	How can a database support your work? *(Recommendations from focus groups and individual interviews)*
Do you use BU01/ 02/03 forms?		What kind of information do you want to get out of the data to help you do your work better?
How is the data stored presently?		What kind of analysis do you want to do with the data?
How is the data transmitted up the chain?		How do you feel data collection, analysis or transmission can be improved?
How is data transmitted from the facility to the district offices/ regional offices?		
What step in the data collection process is the slowest and how do you propose it can be made faster but easier and more efficient?		
What steps in the process are repetitive?		

Appendix C

Interview guide for policy makers

- What database does the Disease Control Department operate? What is DIHMS and what is its scope?

- How is DIHMS integrated with other systems in operation like the HIV and Malaria systems?

- What policies have been set up to regulate databases and software's developed for use within MOH?

- How is DIHMS linked with other sources of data? If it is not, how can this be achieved? For example linking DIHMS with NHIS.

- Are there plans of using cell phone/ SMS technology for surveillance?

- How should a BU database be designed to be most useful to Disease Control in terms of content, functionality, integrability, etc?

- What are the immediate and long term goals for health databases in Ghana?

- Is there any issue that has not been raised in this discussion that should be mentioned?

Appendix D

Buruli Ulcer Treatment Card – New   BU 01.N

Health facility:_____	Date of clinical diagnosis /admission (dd/mm/yy) ___/___/___
Name of health worker:_____	Date of healing (dd/mm/yy) ___/___/___

Name of patient _____ ID#:_____

Address (village or town) _____

District _____ Region:_____ Country _____

Age (yrs) _____ Sex ☐ Male ☐ Female

Weight (Kg) _____ Profession_____

CLINICAL HISTORY AT DIAGNOSIS

Duration of illness before seeking care (weeks)_____

Use of traditional treatment?   ☐ Yes   ☐ No

Limitation of movement at any joint   ☐ Yes   ☐ No

Previous treatment with streptomycin ☐ Yes (Duration in days:_____) ☐ No

REFERRED BY:
☐ Self   ☐ Former patient
☐ Health worker   ☐ School teacher
☐ Community Volunteer
☐ Other, specify_____

CLINICAL FORMS
☐ Nodule (N)   ☐ Plaque (Q)
☐ Oedema (E)   ☐ Ulcer (U)
☐ Osteomyelitis (O) ☐ Papule

CATEGORIES	☐ Category I: A single lesion ≤ 5 cm in diameter	☐ Category II: A single lesion 5 – 15 cm in diameter	☐ Category III: A single lesion >15 cm in diameter , multiple lesions, critical sites, osteomyelitis
LOCATION OF LESION(S)	☐ Upper Limb (UL) ☐ Lower limb (LL)	☐ Abdomen (AB) ☐ Back (BK)	☐ Buttocks and Perineum (BP) ☐ Thorax (TH) ☐ Head and Neck	**CRITICAL SITES** ☐ Eye ☐ Breast ☐ Genitalia

LABORATORY CONFIRMATION

Specimen taken: ☐ Yes   ☐ No   Date specimen taken: ___/___/___

Specimen type: ☐ Swab   ☐ Fine Needle Aspiration   ☐ Biospy

Results	ZN	☐ Positive	☐ Negative	Date / /
	PCR	☐ Positive	☐ Negative	Date ___/___/___
	Histo	☐ Positive	☐ Negative	Date ___/___/___

TREATMENT TYPE (Tick all applicable)   ☐ Dressings   ☐ Antibiotics   ☐ Surgery (Date:___/___/___)   ☐ Prevention Of Disability

DOSAGES	Rifampicin: _____(mg)	Streptomycin: _____(mg)	Other (name):_____:_____(mg)

Cross out (X) each day after administering both antibiotics;   If antibiotics not taken, indicate with a symbol (Ø)

Day/Month	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	Total Doses

TREATMENT OUTCOME
☐ 1a: Antibiotic treatment completed   ☐ 2a: Healed without surgery   ☐ 3a: Healed without limitation of movement at any joint   ☐ 4: Referred for further treatment
☐ 1b: Antibiotic treatment not completed   ☐ 2b: Healed with surgery   ☐ 3b: Healed with limitation of movement at any joint   ☐ 5: Lost to follow up   ☐ Died

Appendix E

LABORATORY EXAMINATION REQUEST FORM - BURULI ULCER — BU04

Health Facility_____

Name of patient_____ Age (yrs)_____ Sex: ☐M ☐F

Address_____ District_____ Patient ID No_____

Classification: ☐ New   Category of lesions: ☐ I (Single lesion <5cm diameter) ☐ II (Single lesion 5-15cm diameter)
☐ Recurrent   ☐ III (Single lesion >15cm diameter, multiple lesions, critical sites)

Clinical forms: ☐Nodule (N) ☐Plaque (Q) ☐Oedema (E) ☐Ulcer (U) ☐Osteomyelitis (O)

Specimen type: ☐Swab ☐Fine Needle Aspiration (FNA) ☐Biopsy   Date of specimen collection ___/___/___

Type of lab examination(s): ☐Ziehl-Neelsen (ZN) stain ☐Polymerase Chain Reaction (PCR) ☐Culture ☐Histopathology

Reason for requesting lab confirmation

☐ Diagnosis of a new case ☐ Follow-up of a patient during antibiotic treatment (week of antibiotic treatment):_____

☐ Diagnosis of a recurrent case (end of last antibiotic treatment (date/month:_____ ☐ Follow-up of a patient after antibiotic treatment

Name of person requesting examination:_____   Signature_____

RESULTS (To be filled by laboratory)   Lab Specimen No_____

	ZN	PCR	Culture	Histopathology
Date: / /				
Date: / /				

Comments:_____

Name of scientist providing results   Name of laboratory   Date ___/___/___

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Appendix F

Register of Buruli Ulcer Cases

BU02

Treatment centre_____ District_____ Region_____

Month_____ Year_____

No	Date of clinical diagnosis (dd/mm/yy)	Name	Age (yrs)	Sex M/F	Village/Town	District of residence	Patient classification New/ Rec	Limitation of movement at any joint (Yes/No)	Referred By	Clinical form(s)	Category of lesion	Location of lesion(s)	Specimen collected (Yes/No)	Treatment Type (Tick All Applicable)			
														Drainage	Antibiotics	Surgery	POB

^a Patient classification:

New :A person presenting with an active BU lesion who has not been treated in the past with S&R.   OR
A person treated previously by surgery alone or by traditional treatment presenting now with an active lesion

Recurrent: A patient who has completed S&R and lesion healed with or without surgery reporting with another lesion or reactivation of same lesion

^b Referred By :
Self (S)   Healthworker (HW)   Community Volunteer (CV)
Former Patient (FP)   School Teacher (ST)   Other(OT)

^c Clinical form(s)
Nodule (N)
Plaque (Q)
Oedematous (E)
Ulcer (U)
Osteomyelitis (O)
Papule (P)

^d Category of lesion
CAT I : Single lesion < 5cm in diameter
CAT II: Single lesion 5–15cm in diameter
CAT III: Single lesion >15cm, multiple lesions, critical sites, osteomyelitis

Location of lesion(s)
Upper Limb(UL)   Lower Limb (LL)   Abdomen (AB)
Back(BK)   Buttocks & Perineum(BP)
Thorax (TH)   Head & Neck (HN)

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Appendix G

National Buruli Ulcer Control Programme-Ghana

Buruli Ulcer Referral and Transfer Form BU09

PART A: PATIENT'S DETAILS

From: (health facility) _____ Town/Region _____

To: (health facility) _____

Name of patient: _____ Age: _____ Sex: _____

Patient's address _____

Patient'sPhone contact _____

Clinical Form(s)

Nodule (N) ☐ Plaque ☐ Oedema ☐ Ulcer ☐ Osteomyelitis ☐

Location of Lesion(s)

Upper limb(UL) ☐ Abdomen(AB) ☐ Bottocks/Perineum(BP) ☐ Head/Neck ☐ Genitalia ☐

Lower Limb(LL) ☐ Back(BK) ☐ Thorax (TH) ☐ Eye ☐ Breast ☐

Laboratory Results

PCR +Ve ☐ Histo +Ve ☐ ZN +Ve ☐
     -ve   -ve   -ve

Drug Treatment:

Patient on BU drugs Y/N _____ If Yes , type of drugs _____ Start date: ___/___/20___

If patient registered Unit BU No. _____ District BU number: _____

Other treatment, speficy: _____

Reason for Transferral/Referral - Tick in the appropriate box below (either A or B or C):

A- This patient is referred to your health facility for registration and starting BU treatment ☐
B- This patient is transferred out to your health facility to continue and complete BU treatment ☐
C- This patient is referred to your health facility for your consultation and special care ☐

* In cases of transfer out (patient already registered at the referring facility) this form should be accompanied by a copy of the BU01 Form; the referring facility should keep the orignal copy. Patient's original District BU no. should be maintained at the time of making a treatment outcome

Date: ___/___/20___ Name of officer: _____ Signature: _____

-- ✂ ----------

PART B: TREATMENT OUTCOME REPORT

N.B: For all transferred-in patients, the receiving health facility should cut and send this portion back to the original health facility (where the patient came from), as soon as the result of treatment is known

From: (health facility) _____

To: (health facility) _____

Name of patient: _____ Age: _____ Sex: _____

Patient's address _____

This patient has attended for further treatment:

Result of treatment:

antibiotics treatment completed ☐ antibiotics not treatment completed ☐ Healed without surgery ☐

Healed with surgery ☐ healed without limitation of movement at any joint ☐ Died ☐

Refered for further treatment ☐ healed with limitation of movement at any joint ☐ Lost to follow up ☐

This Facility BU No _____ District BU number: _____

Date: ___/___/20___ Name of officer: _____ Signature: _____

-- ✂ ----------

PART C: REPORT OF ATTENDANCE

Return this part to the transferring facility as soon as patient has reported.

From: (health facility) _____

To: (health facility) _____

Name of patient: _____ Age: _____ Sex: _____

Patient's address _____

The above patient reported at this unit on (date) ___/___/20___

Date: ___/___/20___ Name of officer: _____ Signature: _____

Appendix H

National Buruli Ulcer Control Programme-Ghana
Quarterly Treatment Outcomes Report Form BU06a

Name of facility_____ District_____ Region_____

Report for the period: [ ] Jan-Mar   [ ] Apr-Jun   [ ]Jul-Sep   [ ] Oct-Dec   Date of report (dd/mm/yyyy)_____

Patient ID/No. on BU02	Date of clinical diagnosis	Patient Classification (New/Rec)	Clinical Form(s) N, Q, E, U, O,P	Category of lesion I, II, III	Laboratory Results					Treatment Outcome										Remarks
					Type of Specimen: (FNA Swab Tissue)	ZN (+ve, -ve)	PCR (+ve, -ve)	Histo	Culture	Antibiotics Completed	Antibiotics Not Completed	Date Antibiotics started dd/mm/yyyy	Date Antibiotics completed dd/mm/yyyy	Healed Without surgery (Enter Yes/No)	Healed without limitation of joint movement (Enter Yes/No)	Defaulted (Yes/No)	Lost to Followup (Yes/No)	Transferred Out (Yes/No)	Date Wound completely Healed dd/mm/yyyy	

Appendix I

National Buruli Ulcer Control Programme -Ghana
Logistics Order Form BUO6b

Name of facility_____ District_____ Region_____

Request for the period: [ ] Jan-Mar   [ ] Apr-Jun   [ ]Jul-Sep   [ ] Oct-Dec   Date of request (dd/mm/yyyy)_____

Total No. of cases reported in the quarter			Total No. of patients still on admission	
Total No. of patients discharged in the qtr			Total Amount Spent on Patients In the Qtr	

Medicines	Used during quarter	Previous stock	Present stock	Needed	Comments
Streptomycin Injection (1g)					
Rifampicin (caps 300mg)					
Rifampicin (caps 150mg)					
Clarithromycin					
Dressing Materials	**Used during quarter**	**Previous stock**	**Present stock**	**Needed**	**Comments**
Cotton wool (250g)					
Cotton wool (500g)					
Gauze (sterile , 240 per box					
Crepe bandages					
POP (15cm per roll)					
Plaster tapes (15cm per roll)					
Syringe 5ml					
Syringe 2ml					
Water for injection 2ml					
Normal saline					
Sample containers					
Swab sticks					

Stationery/Forms	Used during quarter	Previous stock	Present stock	Needed	Comments
BU01 (Patients card)					
BU02 (Facility register)					
BUO4 (Lab. Request form)					
BU06a (Cohort Analysis form)					
BU06b (Logistics Request)					
BU09 (Referral/Transfer Form)					
Wound Dressing chart					