

**EVALUATION OF ANTIRETROVIRAL THERAPY INFORMATION
SYSTEM IN MBALE REGIONAL REFERRAL
HOSPITAL, UGANDA.**

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A mini-thesis submitted in partial fulfillment of the requirements for the degree of Master of Public Health in the School of Public Health, University of the Western Cape.

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KEY WORDS

Health Information Systems

HIV/AIDS

ART

Data Quality

Timeliness

Data Accuracy

Data analysis

Data use

Use of information

Availability



ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ACP	AIDS Control Program
ART	Antiretroviral Therapy
ART-IS	Antiretroviral Therapy Information System
ARV	Antiretroviral
CD4	Cluster of Differentiation 4
CDC	Centers for Disease Control and Prevention
EBR	Electronic Based Records
GFATM	Global Fund to fight AIDS, Tuberculosis & Malaria
GOU	Government of Uganda
IDC	Infectious Disease Clinic
IMR	Infant Mortality Rate
HAART	Highly Active Antiretroviral Therapy
HIS	Health Information Systems
HISP	Health Information System Project
HIT	Health Information Technology
HIV	Human Immunodeficiency Virus
HMIS	Health Management Information Systems
MAP	Multi-country AIDS Program
MMR	Maternal Mortality Rate
MOH	Ministry of Health
MPH	Master of Public Health
MRRH	Mbale Regional Referral Hospital

NGO	Non Governmental organization
OI	Opportunistic Infection
OpenMRS	Open Medical Record System
PBR	Paper Based Record
PDA	Personal Digital Assistant
PEPFAR	President's (USA) Emergency Plan for AIDS Relief
PLWA	People Living with HIV/AIDS
RHINONET	Routine Health Information Network
SOPH	School of Public Health
SSA	Sub – Saharan Africa
STI	Sexually Transmitted Infection
TASO	The AIDS Support Organization
TB	Tuberculosis
U5MR	Under Five Mortality Rate
UN	United Nations
UNAIDS	United Nations Joint Program on AIDS
UWC	University of the Western Cape
VCT	Voluntary Counseling and Testing
WHO	World Health Organization



About the Evaluation

The ART – IS at Mbale regional referral hospital is still an infant system which has been in operation for only 3 years. This is the first time this information system is evaluated for the quality of data generated from it. The evaluation revealed that the ART-IS at the hospital uses a paper based data capture system which is simple enough to allow adequate amount of data capture. It is a routine health information system that at the time of evaluation was found operational. The evaluation specifically looked at appropriateness of data collected, ease of data collection, quality of data in respect of data accuracy (completeness, correctness and consistency), timeliness, validity and availability. The analysis of data carried out by the ART-IS was assessed and so was the reporting process. Like in many evaluations, this study identified some strengths and weaknesses of the ART-IS in the above mentioned areas. The problems identified can be corrected through close monitoring of data collection process, strong leadership, and relevant training of the data collectors. Similar subsequent and even more detailed evaluations are recommended to keep the ART-IS system under check and balance.

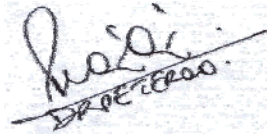
November 2008

DECLARATION

I declare that the EVALUATION OF THE ANTIRETROVIRAL THERAPY INFORMATION SYSTEM (ART-IS) IN MBALE REGIONAL REFERRAL HOSPITAL, UGANDA is my own work that has not been submitted for any degree or examination in other universities or other institutions of higher learning in Uganda or outside Uganda. Furthermore; all the sources of information herein have been indicated and given full acknowledgement in the reference list.

Peter Olupot-Olupot

Date: February 21st,2009



Signed.....



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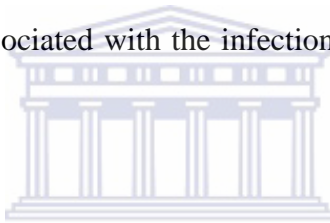
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ABSTRACT

HIV/AIDS is the largest and most serious global epidemic in the recent times. To date, the epidemic has affected approximately 40 million people (range 33 – 46 million) of whom 67%, that is, an estimated 27 million people are in the Sub Saharan Africa. The Sub Saharan Africa is also reported to have the highest regional prevalence of 7.2% compared to an average of 2% in other regions. A medical cure for HIV/AIDS remains elusive but use of antiretroviral therapy (ART) has resulted in improvement of quality and quantity of life as evidenced by the reduction of mortality and morbidity associated with the infection, hence longer and good quality life for HIV/AIDS patients on ART.



The Uganda Ministry of Health (MoH) in collaboration with the World Health Organization (WHO), the United Nations Joint Programme on AIDS (UNAIDS) and other local and international partners have established a comprehensive HIV/AIDS care programme to benefit people living with HIV/AIDS. To date the 3 year old roll-out programme in the country has covered all the eleven regional referral hospitals, one of which is the Mbale Regional Referral Hospital.

The expanding ART programmes have come with complementary information systems; the ART – information systems. This system is part of the Health Management Information System. Such a system has been in operation in Mbale Regional Referral Hospital for the last 3 years; the purpose of which is to generate information for informed decision making, planning and management. In order for the data collected to achieve this function, it is important for such data to be of good quality.

Currently the quality of data generated by the ART – IS at Mbale hospital is of doubtful quality. Furthermore, little evidence does exist on use of the data collected for effective planning and management of the Art services. Against the background, an evaluation study has been designed to assess quality of data generated by ART-IS at the hospital.

Objectives

- To assess the appropriateness of the data collected by the ART-IS,
- To assess the ease of data collection by the ART-IS,
- To determine the quality of data collected in respect of data accuracy, timeliness, completeness and validity.
- To document the data analysis used, and assess the validity of the analysis
- To assess the reporting process
- To assess the use of the reports generated.

Methodology

The study was carried out at Mbale Regional Referral Hospital (MRRH), in Mbale district. It was a quantitative, descriptive, cross sectional study designed to evaluate the ART-IS at the hospital.

The study population was comprised of the staff at the unit and a three year time delimited records particularly the weekly, monthly, quarterly and annual reports. Furthermore, bimonthly minutes of the ART programme management meetings were assessed for evidence of use of data in decision making and planning of the ART activities.

The data was collected using questionnaires and record review charts. Study data analysis was manually done. The findings were bound into a mini thesis and disseminated to all stakeholders.

Ethical clearance was obtained from the University of the Western Cape (UWC) and Mbale Hospital Research and Ethics committee before commencement of the study.

Results

The results were generated from two sources, firstly the self administered questionnaire to all the data collectors and secondly review of the ART-IS data sources.

Eleven (55%) of the data collectors responded to the questionnaire, 8/11 were clinicians. Seven of the eleven respondents said the data collected was relevant to the programme, though all the 11 noted that the data collection process was made difficult due to the lengthy and complex data collection tools, indicating a potential source of inferior data, an assertion confirmed by 9/11 respondents who reported poor quality data generated by the hospital ART-IS. Overall there is a low cost benefit ratio in the data collection process.

Only 7/11 indicators were calculated and reported by the hospital ART-IS, but none of the respondents were satisfied with the reporting of data because tables, charts and graphs were presented without accompanying notes.

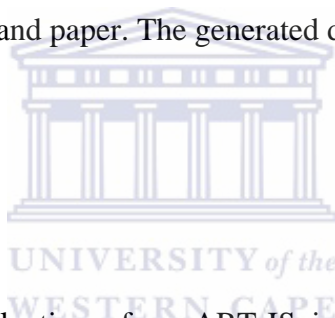
Of the weekly data, 153 (98%) of the weekly data was available in time, while only 33% of the monthly data was available in time during the 3 year study period. Two thirds of the monthly data was available in time, leaving 2/3 of the monthly reports unavailable for collation into quarterly reports and hence delayed national monitoring of targets that takes place every quarter of the year.

On completeness of the reports, an average of 85 – 100% completeness was noticed depending on the reports. The weekly reports were 85% complete while the annual reports available were

100% complete. The missing data especially in the weekly reports was due to missing or incomplete variables.

The ART programme at the hospital did not have minimum and maximum values for the data sets collected, this limited assessment of the overall time trend consistency based on the determination of abnormal values (outliers).

Perceived validity was consistent with assessed validity, while data use was limited by lack of availability of data in time. However, the available data was analyzed using basic data analysis methods using pen, calculator and paper. The generated data was reported using charts, graphs and tables.



Conclusion

This is the first time an evaluation of an ART-IS is done at the Mbale Regional Referral Hospital's ART Programme.

The simple paper based data collection system is operational. Whereas the tools where designed to generate appropriate amount of data, the lengthy data collection tools compromised the ease of their use and so this contributed to poor quality data in terms of incomplete, incorrect, untimely, invalid and inconsistent data.

Data analysis and reporting were done; however, the analysis of poor quality data in itself is counterproductive in that the output of such analysis results in misleading conclusions and when such information is used for decision making or planning the consequences are disastrous. The reporting of data using tables, graphs and charts without underlying explanations limited understanding on the progress of the ART programme at the hospital. Furthermore, the limited

use of data for an expanding ART programme at the hospital potentially causes shortages and inconsistencies in the services delivered.

It is therefore recommended that for the improvement in the ART-IS to be achieved more attention is needed in the following areas: simplification of data collection tools to capture minimum data set, collection of accurate (complete, consistent and correct), valid and timely data and ensure use of data for planning and management. Only then will the ART-IS at Mbale hospital contribute meaningfully to the effective functioning of the ART programme at the hospital.



CHAPTER 1 - INTRODUCTION

1.1. BACKGROUND

The HIV/AIDS pandemic has infected an estimated 40 million people, both children and adults globally as at the end of 2005 (Goemaere, 2006). Whereas the pandemic has been reported in all the continents, Sub-Saharan Africa (SSA) bears the greatest burden. This sub continent is home to two out of every three people infected with HIV/AIDS globally.

Uganda is an East African country in SSA with a total population of about 28 million people; composed of a predominantly young dependent population of whom 56% are children aged less than 18 years of age (Uganda Population & Housing Census, 2002). The country has experienced the HIV/AIDS pandemic for the last quarter of a century. To date there are an estimated 1.4 million people living with HIV/AIDS in this country where the national prevalence rate of HIV/AIDS is 6.4% (Wakabi, 2006). Since the epidemic started 500,000 people have died due to the disease (MOH, 2003).

The total burden of disease in the country has significantly worsened since the onset of the epidemic. Subsequently, this has reflected negatively on the health indicators. Evidently, the high Infant Mortality Rate (IMR) of 83/1000 live births, alongside the heavy under five mortality rate (U5MR) of 137/1000 live births and the unacceptably high maternal mortality rate (MMR) of 506/100,000 live births – remains amongst the worst health indicators in the region (Tawfik & Kinoti, 2003). These poor health indicator performances, especially in the last 3 decades, are attributed to the HIV/AIDS epidemic (Sewankambo, et al, 2000; MOH, 2003). Of course, other factors are contributing to the worsening health status in the country. Among them are the prolonged wars and civil strife that have predominated the last two decades. Furthermore, access

to health care as measured by the percentage of people living within a 5 km radius from a health facility is only 49% (MOH, 2003; Wakabi, 2006).

The Uganda Ministry of health (MOH) is the main provider of antiretroviral therapy (ART) for the government aided health units in the country. Through its ART roll out program which aims at reaching as many HIV infected people as possible, the MOH has instituted ART provision at all the 11 Regional Referral Hospitals in the country (MOH, 2006) including Mbale Regional Referral Hospital. These are the MOH establishments. All the MOH establishments in the country that provide ART have standardized data collection and reporting formats designed by the MOH and used by the Health Information Systems at health units countrywide. This Health Information System (HIS) is responsible for the generation of the relevant data. It was intended that the data generated would be processed into information and later used for an informed decision making process to enhance effective management of the ART services in the hospitals and at national level. This role of the HIS was conceptualized as the main driver behind continuous improvement of the management and the decision making processes in the organizations (Mathieu & Khalil, 1998).

The level of success of the HIS is likely to vary from health unit to health unit depending on the level of training of staff on the HIS, as well as the morale of staff to provide adequate, reliable, accurate and timely data. In addition the complexity of data collection tools used has a direct effect on the quality of data. Inferior data may result from any one of the following or a combination of them:

- Process problems which may cause interference of the initiation of a HIS (Williamson, Stoops & Heywood, 2001) because initiation or implementation of a HIS requires changes in an organization in terms of staffing and technical support. Prior capacity building through

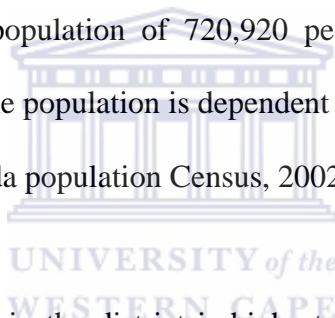
training and acceptance of new roles as well as new ideas is an important aspect. The process may also involve changing the infrastructure to accommodate and facilitate the changes brought about by the HIS. All these are not easily achieved in places where there are severe resource limitations in terms of staffing and infrastructure. Furthermore, the process should be interactive throughout data collation, compilation, quality assessment and estimation in order to maximize data accessibility, accuracy, comparability and transparency (WHO, 2007). Taking into account all of the above process issues, it is clear that alterations in the existing system or initiation of a new system altogether may and usually do, have major effects on work processes and provision of services (Hakkinen, Turunen & Spil, 2003).

- System problems involve bottlenecks in all aspects of operationalization of a HIS. These may be due to lack of a functional communication network with all the relevant departments. This is especially so when communication is not regarded as a core entity of the HIS (Giuse & Kuhn, 2003). Indeed disintegrated and diverse data is a sign of lack of a functional communication network in the HIS. Therefore integration of various data components promotes communication and work flows (Giuse & Kuhn, 2003) resulting in a communicating system that generates quality data with a good feedback process. The system may also fail to transmit the aggregated data especially when data collation tools are absent, data collectors are not committed to data collation or when the data collated is not processed, analyzed or put into use. Mathieu and Khalil (1998) state that an understanding of data quality involves understanding the process and systems that propagates, uses and stores data.
- Policy and procedural problems arise as a result of a lack of clearly spelt out policy on the HIS at either organizational, health unit or national levels. Consequently, a lot of data may be collected but little if any is utilised for operational and strategic management or for informing policy.

- Data design is a crucial component in ensuring quality data. Detailed, poorly designed and bulky data collection tools are an underlying cause for poor quality data, increased workload and discouragement of health workers in the data collection process, especially in settings with limited and ill trained health workers on HIS. (Mathieu & Khalil, 1998)

1.2. STUDY AREA

Mbale District is located in the eastern part of Uganda. It is separated from Kenya on the east by the magnificent and historical Mt. Elgon. It is 240 Km east of Kampala the capital city of Uganda. The district has a population of 720,920 people of whom 92% are a rural based population. The majority of the population is dependent on subsistence agriculture as a source of food as well as income (Uganda population Census, 2002).

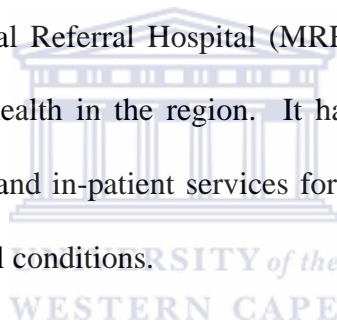


The prevalence of HIV/AIDS in the district is high at 12% (Mbale District Records, 2005) in reference to the eastern regional prevalence of 5.3% (MOH, 2006), and the national prevalence stands of 6.4% (Wakabi, 2006). The range in prevalence of 5.3 – 12% in this region is a clear indication of a great burden of the disease in the region, a reason that may explain the presence of 5 major HIV/AIDS care centres in response to the epidemic in the district. These are:

- The AIDS Support Organization (TASO), which is responsible for diagnosis, treatment, follow-up and community support of HIV/AIDS clients with a sole objective of improving quality and quantity of the life of the patients.
- The AIDS Information Centre (AIC) specializes in diagnosis and referral of newly diagnosed clients to other treatment centers. Given their role in surveillance and screening of the

population for HIV infection, AIC data therefore plays a role in estimating the prevalence of HIV infection in the general population in the region.

- The Uganda Cares mainly provides support services to the ongoing HIV/AIDS care services at Mbale Regional Referral Hospital by providing stationery, furniture and literature on the disease. Therefore, partnership and multi-institutional involvement is seen in this coalition.
- The Joint Clinical Research Centre (JCRC) is responsible for out-patient management of HIV/AIDS clients. This includes diagnosis, treatment and follow-up. It also has training programmes for health workers in the region hence building local capacity to manage the pandemic. It provides both paying and non-paying services to HIV clients in the region.
- Lastly, the Mbale Regional Referral Hospital (MRRH) is the main HIV/AIDS care health unit for the Ministry of health in the region. It has a catchment area of 11 districts and provides both out-patient and in-patient services for patients with HIV/AIDS in addition to managing all other medical conditions.



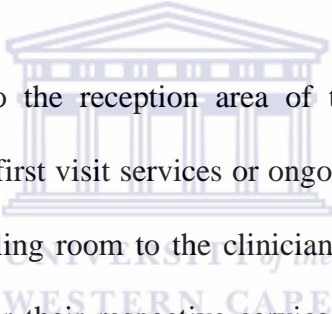
As noted above, the first 4 organizations are non-governmental organizations (NGOs) specialized in HIV/AIDS care related services. The MRRH does all medical services for both infectious/communicable and non-infectious/non-communicable health problems in the region.

1.3. THE ART AT THE MBALE REGIONAL REFERRAL HOSPITAL (MRRH)

1.3.1 THE ART PROGRAMME

The ART programme at the hospital is responsible for diagnosis, counselling, treating, follow-up, referral and logistics in HIV/AIDS care. To achieve these, the programme has departments including the clinical care department in which diagnosis, treatment, follow-up and referrals of clients with HIV/AIDS is done. There are 17 clinicians in this department, that is, 10 doctors, 2

clinical officers and 5 nurses. The counseling section is run by 2 officers both of whom have a nursing background. The programme has a health information system; the antiretroviral therapy information systems (ART-IS). It has a full time data manager and an information officer. The latter is also the nursing officer in charge of the HIV/AIDS clinic. The whole programme is headed by the coordinator, who is one of the clinicians. The HIV/AIDS services in the programme are rendered once a week on every Friday of the week. The programme targets an estimated 3,000 people eligible for antiretroviral therapy (ART) in the region, so far about 1e,070 regular clients are enrolled into the programme of which 50% are on ART (Mbale hospital records, 2008).



On a Friday, clients come to the reception area of the ART clinic; they register and are subsequently sorted for either first visit services or ongoing (follow-up) services. They are then channeled through the counseling room to the clinicians; thereafter, they may either go to the pharmacy or the laboratory for their respective services. In case of the latter, the results are taken back to the clinician who then decides on a plan of action for the patient. Often patients end the clinic day at the pharmacy for prophylactic medications with or without ARVs depending on the levels of cluster of differentiation 4 (CD4) absolute counts or their percentage (CD4%). From the pharmacy, patients go home and would return on the day of their next appointment or when their condition warrants an earlier review. The ART programme holds at least two regular meetings per month; these meetings are held on the first and the third Friday of the month. During these meetings it is hoped that matters pertaining to the running of the ART programme are discussed. Furthermore it is assumed that plans on the future of the ART services are made and documented during the meetings.

1.3.2 THE STRUCTURE OF THE ANTIRETROVIRAL THERAPY INFORMATION SYSTEM

The role of the HIS in the day-to-day running of the health services is of utmost importance in that it provides an avenue for informed decision choices at management level. The implementation of the huge HIV/AIDS therapeutic programmes has come with a complementary health information system (HIS). This HIS is now widely known as the antiretroviral therapy information system (ART-IS).

The antiretroviral therapy information system (ART – IS) has been operational at the Mbale regional referral hospital since the inception of the ART programme in July 2004. All the records for the ART-IS are kept in one place for easy accessibility and secured in a lockable cabinet for safety. Each of the drawers in the cabinet are neatly labeled with a number label e.g. IDC 2001 – 2100. This indicates that there are a hundred records in this particular drawer of the cabinet with the respective identification numbers arranged in the order shown on the label. This is intended for quick access to patient records while ensuring safety of the records.

Data collection is done on registers, laboratory forms and pre-coded structured record cards. The latter are called the ART-cards. These cards are filled in by the various cadres of staff at the clinic on the clinic days. In addition further data collection is done on the ART book.

The Data collection process starts at the registration desk in the reception area where basic demographic data such as the name, sex, age, address, occupation, next of kin and the nearest health centre are entered into the register and the ART-card.

The ART card is then passed on with the patient to the counselors, who fill in their part of the card during the session with the client. The counselors complete data on social demographics

including identification data, residential address, next of kin, disclosure status, the social factors that enhance or inhibit maximum adherence; The counselors in turn pass on the ART card to the clinicians (doctors, clinical officers and nurses) who complete the data on clinical status of the patient, presence of opportunistic infections, adherence data, treatment prescribed and the next date of appointment. These data is filled in the relevant fields on the card. From here the ART card is then passed on to the pharmacist who correspondingly fills in the required data on drug adherence, drugs and supplies.

Finally, the ART card is delivered to the nursing officer in-charge, who is also the information officer for the programme with the assistance of another nursing officer. The two then check on data completeness, accuracy and consistency before passing on the data captured to the data manager for entry and analysis. Data analysis is done manually at the unit with the aid of calculators. Thereafter, weekly, monthly, quarterly, half yearly and annual reports are then produced and made available to the staff in the unit, the hospital administration, the district health office and the ministry of health headquarters.

1.3.3 THE USE AND EVALUATION OF THE ART-IS

The ART-IS is broadly viewed as a useful tool in the improvement of the process of informed decision making in the day to day running of the ART programme because it provides useful information. It substantially improves health care quality, identifies and promotes best practices, it promotes sensitive implementation of clinical decisions and based on informed position on decisions; it establishes public policies. The quality of data generated from the ART-IS is very important in influencing the decision making process. Informed decision making solves management problems and ensures reliability of the system. The quality of data potentially

affects programme management by affecting the informed decision making process. To date, little evidence if any exists on the contribution of the ART-IS to the management and the planning of the ART programme services in Mbale regional referral hospital. This is because little use of the available data is made during the meetings, procurement process and administration of the programme. The agenda of the meetings held by the ART team in the last 3 years have no specific mention of evidence of usefulness of data in the day to day running of the programme. This may explain the reasons why antiretroviral drugs and other medical supplies are procured by the ministry of health headquarters in Kampala without considering the needs as indicated by the Mbale hospital ART programme; evidently some ARVs, especially paediatric syrup preparations have expired on a number of occasions, again raising suspicion that the demand and supply at the hospital was not taken into account hence over supply. Lastly, no local recruitment of staff has been done to specifically fill in the positions locally identified and required to run the programme. This is possibly due to poor quality and untimely data that results in information having little or no value for decision making at the time of the planning cycles. Indeed it has been widely illustrated that inferior quality data negatively impacts on the functioning of the management of an organization (Mathieu & Khalil, 1998).

The 3 year old ART – IS at Mbale regional referral hospital has never been evaluated before, consequently, little information exists on how the system performs. Against this background, it was important to evaluate how much and in which areas the ART-IS in the hospital contributes to the planning, management and decision making process of the programme. In addition, only a few staff members in the ART programme trained in data management. This again raises the possibility of inferior data being generated.

Besides the aforementioned factors, poor morale of health workers arising from poor pay, lack of compliments and untimely or total lack of feedback have been known to promote inferior data even when the staff has access to good data collection tools (Posner & Fields, 2003).

A personal communication with the ART programme information officer at the hospital (26/5/2006) confirmed the lack of feedback to the people collecting and analyzing the data arising from the ART-IS. Lack of feedback in a HIS has a negative effect on the quality of data because the data collectors become demoralized, the quality of data itself deteriorates because of accumulated lack of feedback on errors. This was earlier observed by the Health Information System Project (HISP) which noted that data quality is improved by feedback on errors and incorrect definitions of data (HISP activities, 2003). As cited above, problems arise from the process; human resources, analysis and use of information. It was therefore reasonably suspected that there was poor quality of information being generated probably arising from inferior data collected via the Mbale regional hospital ART programme.

1.4 THE PROBLEM

The objective of the ART-IS is to generate data for informed decision making in the management cycles of the ART programme. Many processes contribute to the achievement of this objective such as the generation, propagation and use of data. Once any of these is affected, the resultant data may be of inferior quality and unsuitable for informing the decision making process and planning cycles. The Mbale hospital ART-IS may potentially have poor levels of staffing, possible inappropriate data collection tools, may not use of data in for planning and management and has no evidence of having been evaluated before, all these put together and if proved right suggest inferior quality data being generated. The extent to which this has affected the performance of the ART programme is not documented, but the beginning of such

assessment is from identifying how the quality of data is being affected by the process and system of data collection, data analysis and information use. This study is set out to do this assessment.

1.5 THE PURPOSE OF THE STUDY

The purpose of this study was to assess, and if required, to improve on the quality of data and to contribute to improving the ART-IS to increase the likelihood of it being used to facilitate effective management of the ART services at Mbale regional referral Hospital, and possibly in similar settings.

1.6 AIM

To evaluate the current ART-IS in Mbale Regional Referral hospital in terms of appropriateness and ease of data collection, as well as quality and use of the information generated.



1.7 OBJECTIVES

- To assess the appropriateness of the data collected by the ART-IS,
- To assess the ease of data collection by the ART-IS,
- To determine the quality of data collected in respect of data accuracy, timeliness, completeness and validity.
- To document the data analysis used, and assess the validity of the analysis
- To assess the reporting process
- To assess the use of the reports generated.

1.8 THE SCOPE OF THE STUDY

The total evaluation of the information system would have involved the evaluation of the diverse processes involved in the entire generation, compilation, synthesis and use of the information.

The resource requirements of such an elaborate and comprehensive study were prohibitive and therefore this study was limited to assessing specific elements of quality of data.

This study therefore focused on evaluation of quality of data based on the essential elements on data quality based on two models, namely;

- ISO/IEC 9126 quality model that looks at the six characteristics of the HIS (Azuma, 2004), and
- Information System Success Model (DeLone and McLean, 2004)

Using a combination of these two models a modified version of the six characteristics of the ISO/IEC 9126 model with the elements mentioned below was assessed as being a viable and practical means of evaluating the key components of the ART-IS. The six modified characteristics assessed were:

- The ART-IS functionality in which the study assessed the ease of use of data collection tools, the usefulness of data, the completeness of data collected and the ease of access to data collected,
- The ART-IS efficiency where the following quality aspects were studied: timeliness of the reports and the use of the reports for decision making processes,
- The ART-IS support system in particular availability of the data collection tools and support supervision of the ART-IS,
- The ART-IS use in particular frequency of use of the system,
- The ART-IS user satisfaction, in this case we evaluated the data collectors' satisfaction,

- Lastly, the ART-IS benefits to the system in which case we evaluated the extent to which the system contributed to the improvement of clinical care and planning for services.



CHAPTER 2 - LITERATURE REVIEW

2.1 INTRODUCTION TO THE CHAPTER

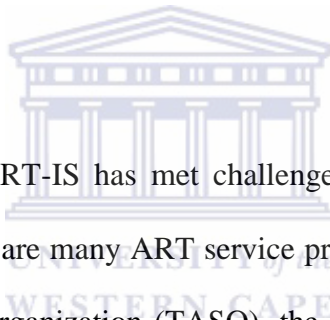
This is an evaluation study of the Health Information System (HIS) in respect to Antiretroviral Therapy (ART). The literature will first provide a brief overview of ART, thereafter the focus will be on the quality of the data collected and use of the information generated in a HIS for a health programme generally as well as for ART services in particular. In addition the literature review covers types of information systems but with a focus on routine health information systems. The aspects of interest include quality of data, quality of information, timeliness of information, use of information and a brief review of various types of evaluations of health information systems.

2.2 OVERVIEW OF ART

ART has evolved over the years from less effective, highly toxic and resistance prone monotherapy in the late 1980s to the more effective triple and salvage therapies in the 1990s (Gulick, 1997). Therefore, use of these more effective ARVs [Also called highly active antiretroviral therapy (HAART)] in conjunction with the prevention of specific HIV related opportunistic infections, has greatly improved the quality and quantity of life of people living with HIV/AIDS (HIV/AIDS program, 1998).

To achieve the desired health outcomes, ART should be adhered to according to the correct prescriptions in order to achieve undetectable HIV viral loads with subsequent recovery of the immune system, otherwise failure to use it correctly and consistently may lead to viral drug resistance and treatment failure (HIV/AIDS program, 1998).

The ART programmes the world over are relatively new, most of them are less than a decade old. This is so especially in the developing countries (MOH, 2006). However, a HIS is of particular importance to initiation, implementation and monitoring of an ART programme, because it shapes healthcare through provision of informed decisions thereby ensuring effective implementation of the ART programme (Mohd, Paul & Stergionh, 2006). In achieving its functions, the ART-IS should identify and validly collect the data that is required to effectively implement the management of the ART programme. Therefore, the high quality of data from an ART-IS is of critical importance. Consequently, when high quality data and effective use of information is achieved, clinical performance and patient outcomes are ensured (Mohd, Paul & Stergionh, 2006).



The implementation of the ART-IS has met challenges: firstly, there is no written policy at national level; secondly, there are many ART service providers in the country besides the MOH such as The AIDS Support Organization (TASO), the Joint Clinical Research Centre (JCRC), Uganda Cares to name but a few. There is no standardized ART data collection formats used for the various ART service providers, but each service provider has adopted their own format; thirdly, the capacity to implement the HIS is still limited; and lastly, the infrastructural adjustment remains a main hindrance to the initiation and implementation of a successful HIS both at the national and facility levels (World Bank, 2006; Williamson et al, 2003). This is echoed by Abouzahr and Boerma among other authors on the HIS who have noted that the challenge comes at such a time when public health policy and informed decision making processes rely heavily on prompt, good quality and reliable information whose generation is the sole role of the HIS (Abouzahr & Boerma, 2005). This process of formulation of public policy based on informed decisions requires an efficient HIS purposively set up to generate the relevant

information (McGrail & Black, 2005). This being a continuous process requires the HIS to be focused on generating appropriate and timely data. The only way to keep the HIS in line with its set purpose of generating quality data is to have regular checks through evaluations. This is of paramount importance in effecting the necessary actions and improving outcomes of the HIS in a health care delivery system.

2.2.1 DEVELOPMENT OF ART INFORMATION SYSTEMS

The complex issues relating to the health system management and patient care in the era of the HIV/AIDS pandemic has called for a specific HIS. In this vein, various international organizations including the World Health Organization (WHO) (WHO, 2006) the United Nations (UN) (UNAIDS, 2005) and the Centers for Disease Control and Prevention (CDC) (CDC, 2008), among others, have been involved in the development of ART information systems at international level. This has been possible because the guidelines provided by these international organizations have been adopted and customized by individual countries (Health Systems Trust, 2004).

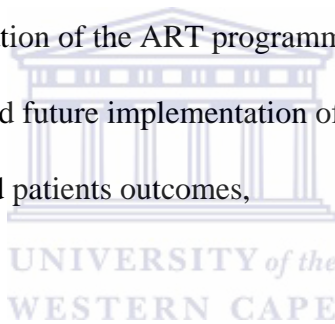
It is now common practice for international donors to insist on a health information system for any HIV/AIDS health intervention programmes they support because of its proven and sustainable benefits. This is backed up by the evidence that proper information collection, analysis and utilization have created financial savings, increased quality of health care and to enhanced health outcomes (Standfield, 2005).

In Uganda, the presidential emergency plan for AIDS relief (PEPFAR) Health Management Information System (HMIS) sub-committee provides guidance on the goals of the ART information systems. Among others Santas (2006) describes two key outputs of the ART-IS as follows:

- To enhance the potential to gather patient level and service delivery information to enhance routine patient care by collecting timely, data on relevant indicators.
- To expand dimensions in the collection of local, district and national level information to help in clinical and program dispensation (Santas, 2006).

In addition, the ART programme directly benefits from a sound information system in the following ways:

- It provides the much needed data for informed decision making,
- It identifies data underlying the conclusions arrived at by the programme management at local and national levels,
- It ensures implementation of the ART programme,
- It shapes the current and future implementation of the ART healthcare programmes,
- It improves clinical and patients outcomes,



Based on the above observations, the need for an optimally functional HIS cannot be overemphasized. It also conversely notes that almost all health programmes would have difficulty functioning effectively without the contribution of a properly functioning and effective health information system.

On the type of HIS, two authors (Santas, 2006 & RHINONET, 2006) both agree that at the facility level Electronic Based Records (EBR) play a vital role. Indeed, a cross-sectional study conducted to assess the value of the electronic medical record system in Vietnam (Tran, et al, 2004) concluded that there is a need for computerization of health information at all levels of health service delivery.

However, computerization of the HIS without achieving expanded data collection, validity and reliability would not be of much help: In a survey done in Brazil to assess the Hospital Information System and its application in epidemiology, Bittencourt, Camado & Leal, (2006) demonstrated that hospital information systems had inadequate coverage and so affected reliability. No matter which record system is operated, a HIS should have the basic components. DeLone and McLean (2004) discussed the information system model and analyzed the following aspects that need to be monitored from time to time. No doubt the ART programme would benefit from monitoring of:

- The system quality,
- Information quality,
- Service quality,
- System use,
- User satisfaction,
- Net benefits,



2.2.2 HEALTH MANAGEMENT INFORMATION SYSTEMS (HMIS)

The term Health Management Information System (HMIS) is a broad term which encompasses sub-systems of the Health Information System (HIS). These components include epidemiological surveillance, routine service reporting, specific programme reporting, administrative systems and vital registration (Rangayanakulu, 2006).

Therefore by definition HMIS is targeted monitoring, evaluation, and surveillance data used to answer key questions about:

- extent of ill-health conditions,
- disease outbreak,
- the delivery and process of promotion, prevention, treatment and rehabilitation services,

- the effectiveness of these services,
- capacity needed to improve programs, meet planning and reporting requirements, and reach goals for impacting on health status (Santas, 2006).

2.2.3 COMPONENTS OF THE HIS

The HIS has many functions arising from its components. Several interlinked components of the HIS work together to perform these functions. The input of each component is to contribute towards information for effective management of a health system. Several authors (Santas, 2006; RHINONET, 2006; & World Bank, 2006) note that the components of the HIS include:

- Human resources,
- Information collection and dissemination,
- Standards and practice,
- Regulation,
- Quality Control,
- Data analysis and feedback,
- Systems based on paper or Computer databases,
- Hard and Software.



These categorically divide the HMIS into; the resources component to run the information system and the information component.

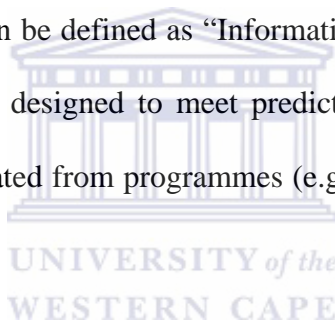
2.3 HIS FOR HEALTH PROGRAMS

Data collection is the initial stage of the information process within a health information system (HIS). Data collection may be simple or complex. The former may require only a pen and paper

and a few data collectors, while complex data collection may involve various combinations of the following: many data collectors, many different data collection forms, calculators, personal digital assistants (PDA), geographical position systems (GPS) and computers (Ties, 1991).

The classification of the HIS is derived from the methods employed to collect data. This results into two broad types of HIS. First is the routine data collection and the second one is the periodic (also called non-routine) data collection. Periodic data collection may be in the form of surveys. Initially they appear costly, but in the long run they are cheaper than routine data collection processes (Ties, 1991).

Routine health Information can be defined as “Information that is derived at regular intervals of the year through mechanisms designed to meet predictable information needs” (RHINONET, 2001, p.11). Most data generated from programmes (e.g. HIV/AIDS, TB, Malaria, STI, etc) are routine data.



A majority of developing countries employ routine data collection and they are able to sustain it (Lippeveld, 2001). It is important to note that no one method of data collection is sufficient to meet all stakeholders' demands for data. Therefore complete information for effective planning requires complementary data from both routine and non-routine sources of data, wherever this is possible (Lippeveld, 2001).

Often data collected routinely in health units requires health workers to collect it while doing their health care activities. Such data is usually primarily used for patient and health facility management.

At health facility level, routine data collection may be done using one or a combination of the following tools: forms, registers, and tally sheets. The information collected is valuable if the cost of data collected is proportional to its use benefit. This is not usually the case at health units where the cost often greatly exceeds benefit (Braa, et al, 1997). Also inaccurately collected data results in low value or useless data as it cannot be used to inform decision making processes, planning and management.

Several studies and reviews (Braa, et al, 1997; Ties, 1991; RHINONET, 2001; Mathieu & Khalil, 1998) among others have reported the following reasons for lack of information support for decision making:

- poor quality of data such as incomplete, inaccurate, inconsistent and untimely data,
- Weak analysis of data where the reports are made without in-depth interpretation of the significance of each variable or data element, making the contribution of the data to the monitoring of indicators of zero or minimal effect.
- Lack of an information culture, which typically does not value the collection, analysis, interpretation and use of data.
- Lack of health personnel trained on HIS especially those involved in data collection, entry, analysis and reporting.
- Heavy volumes of inappropriate data elements in the tools, causing overload and thereby causing lack of priority in data collection by overworked data collectors.

When data is collected using well designed tools for a HIS, improved monitoring of the programmes using appropriate variables for essential calculation of indicators and targets is achieved. There is great potential for routine health facility data to meaningfully contribute to the decision making during planning and general management, at both patient and facility level.

2.3.1 SYSTEM DESIGN AND ITS EVALUATION

The design of the health information systems are usually based on models that have been demonstrated to work. Indeed, a “successful system design should start from modeling of work process, data and information flows, and definition of concepts and their relationships” (Nyakanene & Karima, 2006 p.85). Some of the designs may involve adoption of Health Information Technologies (HIT) but these may be limited and their implementation may remain slow due to significant financial demands beyond what a developing country can affordably allocate (Poon, et al, 2006). For developing countries, simple paper based systems are the ideal, especially in resource limited settings where the performance of an electronic based system may be limited by unreliable electricity supply, lack of qualified information technology personnel, lack of support systems and safety issues. Paper based databases remain cumbersome, bulky and difficult to store, but they have been used for the present HIS with relative success. The paper based data collection tools however, need to be designed in such a way that they capture the very relevant data at the same time remaining simple and user friendly.

DeLone and McLean (2004) information systems success model highlights the various components of an information system in which quality of data can be evaluated notably: system, information, service, system use, user satisfaction and benefits.

System quality considers system performance in respect of the following – ease of use, ease of learning to use the system, response time, usefulness, availability, reliability, completeness, system flexibility and easy access. On the other hand, information quality is focused on the information produced by the system such as reports. Here the reports are evaluated for accuracy, output timeliness, reliability, completeness, relevance, availability and consistency, while service quality is focused on the overall support delivered by the service provider.

Yet use of the system looks at the extent to which the system is used, and who uses the system. Last but not least; user satisfaction is based on to what extent the system is perceived to be useful and the user's attitudes towards it. At this point it is imperative that the net benefits include benefits to an individual, a group of users, organizations and others, depending on the intentions of the programme.

2.3.2 HEALTH INFORMATION SYSTEMS (HIS) AND THE ART PROGRAMME

A HIS is a functional entity within the framework of a comprehensive health system which attempts to improve the health of individuals and populations through informing the decision making processes as well as the planning cycles. This is a very important role of the HIS. The ART programme depends largely on the information generated from the ART-IS to have informed decisions taken on plans and management issues. As mentioned above, the HIS is a management information system in which the ART-IS is part of the entire HIS at the hospital. The ART programme has two complementary systems, the ART-IS which is the information process and the management component which uses information from the ART-IS to inform decisions, planning and management processes. Therefore, the ART-IS is not run as a parallel system but an integral part of the ART programme. It is not enough to have the integral structure of the information and management processes, this is only the roadmap. These activities as noted by Lippeveld, Sauerborn and Bordard (2000 p.17) have to be integrated into a well functioning, complementary and timely flowing system if it has to be helpful, so that "in order to make the information process efficient, a HIS management structure is required to ensure that resources are used in such a way that the required information is provided in a timely fashion" . Specifically, the ART information system (ART – IS) serves to reinforce formation, support and assessment of the health services for HIV/AIDS (World Bank, 2006).

The ART-IS in the ART programme, just like the main HIS is broadly based on two recognized systems, notably; the paper based record (PBR) and the electronic based record (EBR) systems. These two systems serve the same purpose but the PBR is predominant in the developing world. From this background, it is apparent that the choice of any one system is dependent upon the country's level of economy, availability of the appropriate human resources, and reliability of the system. Such a HIS should be able to assess and augment the competence and productivity of the health programme (World Bank, 2006).

2.4 PROBLEMS RELATED TO HIS FOR ART

HIV/AIDS medical treatment programmes (ART programmes) are rapidly expanding in all countries including those on the African continent. This expanding scope of HIV/AIDS therapeutic programmes (ART programmes) poses a challenge to the implementation of an appropriate HIS (ART-IS) at country level (World Bank, 2006).

Among others, the ART programmes face the challenge of creation, initiation and use of unique patient identifiers to be used at national level and this is so, especially the convention linking the identifiers to the client (RHINONET, 2006). Furthermore, within each component of the ART-IS, that is; generation, analysis and dissemination of data; problems such as inaccurate data, incomplete data, untimely data, and invalid data may arise, and they may adversely affect the ART programme decision making (Abouzahr & Boerma, 2005). These same authors noted that the extent of the data required in terms of details and elements, is by and large greater at lower levels of the system because of its greater relevance to functions (of programmes such as the ART programme) at those levels, compared to the national level (Abouzahr & Boerma, 2005).

Ironically, even when a lot of data and information is expected and often collected at lower health level ART programmes, it has frequently been cited that there is a lack of data. In reality, this is a consequence of the inability of the ART-IS to produce consistent measures of defined indicators (Romelmann, et al, 2005). This is a situation where data is captured by the ART-IS without taking into consideration the ART programme targets and indicators. The resultant data is good to know data but no indicator can easily be calculated from such broad, non specific data. Such data is correctly labeled as being of low or no value.

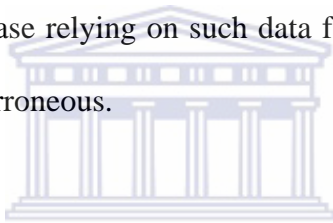
In addition, inadequate networking of the components of an information system such as the ART-IS within an ART programme results in distorted, defective and inconsistent information (Thieren, 2006). A multi centre observational and cross-sectional study in Spain (Pedrera-Carbonelle, et al, 2005) demonstrated that under-recording, bias and validity problems restricted the current data from being a source of information for health care planning and management. Similarly, analysis of the 1996 annual report from “Health for All Project” in Kinshasha (Mapatano & Piripiri, 2005) revealed that the indicators used resulted in ambiguous indicators for coverage and incidence which were reflected as above 100% and below 0% respectively.

One way to surmount this Abouzahr and Boerma (2005) suggest is to match an indicator with an essential tool for its generation. For example clinical outcome related indicators for the ART programme are best captured by an appropriately designed ART card.

Matching a tool to capture data on a specific indicator is often difficult, but an essential element required to make the HIS perform its functions appropriately and adequately. Where this is lacking indicators are calculated from a number of data collection tools resulting in work overloads and delays in information.

2.4.1 INFORMATION FLOW AND QUALITY OF DATA

When it comes to information flow between and within health units in resource poor settings, the main information exchanged is information related to management issues and patient referrals. Often such communications are hand written (Tran, 2006). Because of the loose networks between and within facilities, the information flow is frequently slow, sometimes non-existent, resulting in incomplete information in existing databases. Such incomplete information arising from poor information flow affects proper indicator calculation by distorting the numerator and/or denominator. In this case relying on such data for informed decision making processes, planning and management is erroneous.



For a long time, many health units have existed without proper health information systems. Conversely, any new information workload is usually heaped on the same scanty health information staff. In this vein, a study done to evaluate the established theories on introduction of information systems components in Germany (Garde, et al, 2006) revealed that introduction of new systems components resulted in additional workloads. In Uganda and in Africa at large, any additional work without additional pay discourages workers and this in turn yields poor output which negatively affects the quality of the data (Burkle, Ammenwert, Prokosch, et al, 2001).

2.4.2 THE EFFECT OF QUALITY OF DATA ON THE USE OF INFORMATION GENERATED FROM IT

To have ART information available for decision making requires timely production of high quality data and valid analysis of the data.

In most cases this is difficult to achieve as demonstrated by Tran and his colleagues. In their study in Vietnam they found that often a HIS existed in hospitals, but the quality of data and its subsequent usage differed (Tran, et al, 2006). Additionally, patient care processes change with the introduction of information system components. (Garde, et al, 2006). If these components yield relevant, reliable, accurate, and timely information that is subsequently put into proper use, then the patient care process as well as the performance of the organization changes for the better. The reverse is, unfortunately also true.

2.5 TYPES OF EVALUATION OF ART-IS

It has been well documented that most HIS are performing poorly because far less valid information is available than needed for effective decision making (Abouzahr & Boerma, 2005).

To achieve a proper assessment of a health care information system, an elaborate audit needs to be undertaken to include: education and training, unifying standards, and use of approved relevant tools for assessment of effectiveness of a HIS (Mihalas, Bazaran & Forcas, 2006).

In doing the assessment it has been found that use of cheap, cost effective and easy to use tools that compare practice with evidence based recommendation is appropriate (Dubey & Glazier, 2006)

The following criteria may be used to evaluate an information system:

- Verification of the quality of data (RAE2008, 2007 ; Statistics Canada, 2007) both spell out that this evaluation involves informing users of the validity of data, identification of faults that would be improved in the next data collection phase, adjustment of the current data as

appropriately as possible and in-built accuracy checks in database especially in electronic based systems.

- Description of the attributes of data quality (CIESIN, 1998) involves re-visiting definitions of attributes of quality of data, formation of a hypothesis, designing a methodology and assessing whether the current attributes match the definitions, and are in line with the hypothesis.
- Comparative evaluation; where the set standard is measured against the findings during the study. Usually a set criterion is used as a standard against which the findings are measured and evaluated for the extent to which the HIS conforms to the set standards.
- Record reviews, where the source of data is available in record form, can be used to evaluate the quality of the data.
- Data validation through cross-checking the reported data with the original source of the data, For example, clinical notes may be cross-checked by interviewing the patient, or a report may be cross-checked by checking the records from which the data was collected from, such as registers, check lists, data collection forms and the like.
- Cost evaluation of systems is when an evaluation is done using a cost analysis for each component in the system.
- Task driven evaluation is where an evaluation is done on the tasks of a health information system. Usually this is to assess the efficiency of the system.

3.0 METHODOLOGY

3.1 OVERVIEW

Chapter 3 presents a description of the methods and techniques used to collect data in terms of:-

- Study design,
- Definition of terms,
- Study population and source of data,
- Sample size and sampling procedures,
- Data collection,
- Validity,
- Reliability,
- Generalizability,
- Data analysis.



3.2 RESEARCH DESIGN:

This study was a quantitative, descriptive cross sectional study. This design was deemed appropriate for this study because there was little known about the quality and use of data generated by the ART-IS at Mbale Regional Referral Hospital.

3.3 DEFINITIONS

3.3.1 TERMS

- **Timeliness:** The extent to which data is sufficiently up to date for the task at hand,
- **Completeness:** The extent to which data is not missing,
- **Validity:** the extent to which the data collected is of value for calculation of indicators,
- **Data accuracy:** is the extent to which the data is complete, correct and consistent,
- **Relevance:** The extent to which data is applicable and appropriate for the task at hand,
- **Accessibility:** The extent to which data is available, or easily and quickly retrievable,

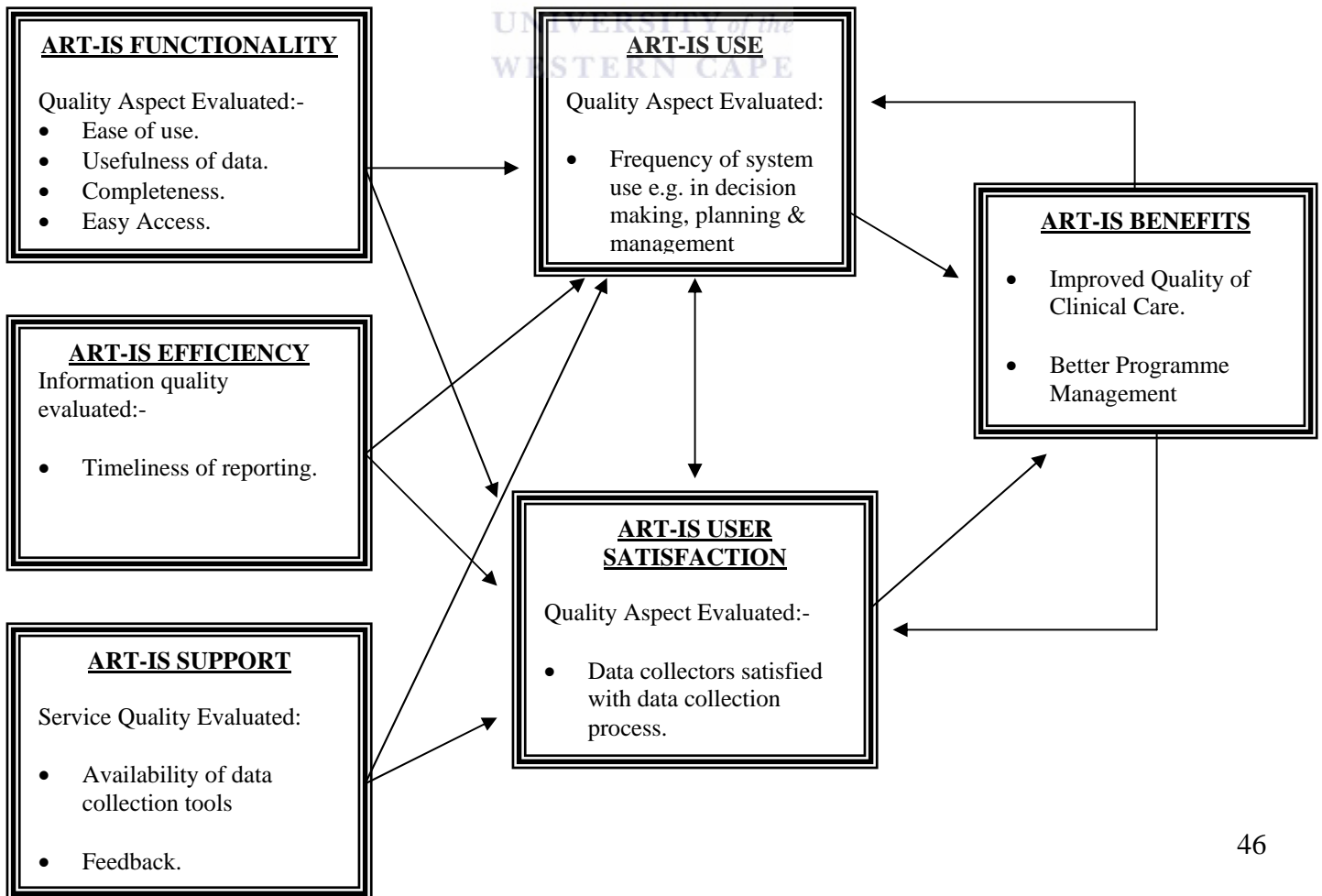
- **Appropriate amount of data:** The extent to which the volume of data is appropriate for the indicators for program monitoring.
- **Drug pick:** this is a documented event that a patient picked the prescribed drug dose.

3.3.2 QUALITY MODEL

The quality model for the evaluation was adopted from two models namely:

- The ISO/IEC 9126 quality model (Azuma 2004)
- The Information System Success Model (Delone & McLean, 2004).

Specific data quality characteristics were identified from the two models, adopted and customized as an evaluation model for this study. The figure below shows the evaluation used in the study.



3.4 STUDY POPULATION AND SAMPLE SIZE

The study population and sample size for this study were the same because the study sample was small and so all the data collectors and all the medical records during the 3 year study period of July 2004 – June 2007 were studied for purposes of details, the two are described separately below:

3.4.1 THE STUDY POPULATION

The study population was comprised of:

- All the staff at the ART clinic who are involved in data collection, processing and use were eligible. The total number of the staff involved in this process at the ART clinic was 20. Of these 17 are clinicians, 2 are counselors and one data manager. These 20 were the target respondents.

The researcher interviewed the respondents in order to describe and assess the usability of the tools for data collection and the components of the ART-IS as well as the appropriateness of data collected.

- Records: All the ART reports since the inception of the programme were analyzed for accuracy (correctness, completeness and time trend consistency where applicable), validity, timeliness and data use. They were also analysed for time trend consistency.

The following records were evaluated:

- i) Weekly aggregated data as the primary source of data,
- ii) Monthly, quarterly and annual reports collated from weekly data,
- iii) ART cards,
- iv) Minutes of the bimonthly meetings were assessed for evidence of use of information for decision making and planning for the ART services at the hospital.

- v) Laboratory forms.

3.4.2. SAMPLE SIZE AND SAMPLING PROCEDURES

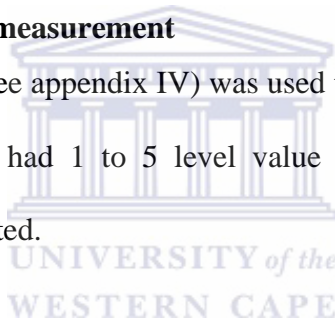
There were two samples taken in this study. The records formed the first sample. All the records for the period July 2004 – June 2007 were taken. The entire records were considered because they were few. The second sample was the data collectors. Again the entire data collectors were sampled because there were few data collectors.

3.5 DATA COLLECTION

During this study, quantitative data collection methods were applied using a pre-coded chart for records (record reviews charts) and structured questionnaires for the ART programme staff.

a) Quantitative scale of measurement

A scale of measurement (see appendix IV) was used to assess each of the data quality aspects in (a) above. The scale had 1 to 5 level value with the relative importance of a sub characteristic being evaluated.



b) Methods of evaluation

Manual assessment of the weekly, monthly quarterly, half yearly and annual reports of the ART-IS in Mbale Hospital for the three year period July 2004 – June 2008 was done. The assessment involved documenting completeness (if all columns are filled in), accuracy (if proportions sum up, completeness, correctness and time trend consistency of data), timeliness (if report date matches the dates it was supposed to be available), and the relevance of data (to assess how applicable the data is for calculation of indicators set, and how helpful the data is for decision making). Accuracy checks were done in two ways:

- General accuracy checks – where spelling errors were looked for, completeness of data was checked and correctness in which the data elements such as date, age, sex, address and other relevant data elements in a tool were entered in the right fields.

- Specific accuracy checks where the following variables were checked:
 - Proper dates and proper completion of data tools,
 - Determine minimum and maximum limits for the variables, especially for the drug picks
 - Time trend consistency to determine how the data varied over a period of time and comparing between months of the same year and similar months for the different years,
 - Number of cases per location such as district and county, where applicable.

c) The process of evaluation

(i) Data collection

- Here only routinely collected data by the Mbale hospital ART-IS was considered.
- All the weekly, monthly, quarterly and annual records were identified, assessed and graded for accuracy (completeness and correctness) and availability of data in time.
- Validity assessment was done in two ways first the validation of the correctness of the source of data collated and validation of the indicators calculated.

Each report was tallied according to the category it fell under in the evaluation scale. Time trend consistency and proportions of the records that met the evaluation criteria for accuracy (completeness and correctness), validity, consistency and availability of data in time were computed and reported.

Only standardized definitions of both individual data elements and indicators were used to assess if the indicators were useful in terms of reliability, appropriateness, validity, ease of collection and specificity of the indicator, respectively.

- The Mbale hospital ART-IS data collection tools were assessed for usability. A questionnaire designed for this assessment (see appendix II and III) was administered to the staff involved in data collection at the unit. Of particular importance, assessment of how user friendly the data collection tools were; was done. The data collection tools that were assessed included patient records, ART-card, register, the ART book, and laboratory forms.

(ii) Processing data:

An evaluation on how data was processed was done.

Here a scale (see appendix) was used to measure the degree to which the data was;

- Available on time within one week of the deadline,
- Correctly filled in 90% of the fields entered,
- Complete in 90% of the fields required,
- Consistency over the time period ,

(iii) Presenting data:

An assessment of how appropriately the data were presented was done through interviewing the data collectors and data users. For example were the tables, graphs, maps, if any available, presented appropriately?

(iv) Using information

An assessment of whether the data was referred to in arriving at decisions taken recently was done. This was through a review of all the minutes of the meetings held during the study period.

(viii) Timeliness and reporting of data

Here we evaluated whether the data is available in time was done. The baseline for timeliness was considered to be the time when the report was scheduled due and when needed by the staff responsible for managing the ART programme. In addition, reporting of data was assessed, first to find out whether it is ever done, and if so was the data reporting appropriate.

(vix) Reliability

Here an assessment on reliability of indicators calculated was done.

(X) Validity

- **Perceived validity**

Here an assessment was done on the extent to which the data collectors considered the data to be true and correct.

- **Assessed validity**

Here validity of the indicators calculated was done.

3.6 GENERALIZABILITY

The results and recommendations from this study can probably be generalized to the hospital ART-IS in the region and the country at large as long as those ART-IS were set up at the same

time and have the same data collection and analysis methods as well as the same level of staffing levels and training as the Mbale regional hospital ART-IS.

3.7 STUDY DATA ANALYSIS

The data collected from the study was sorted according to content, coded and analyzed manually in the following ways:

- Simple counts of proportions of reports available were done on the overall records of interest. For example in the 3 year period we were interested in, we expect 156 weekly reports, 36 monthly reports, 12 quarterly reports and 3 annual reports.
- Proportions of each of the following aspects were reported: accuracy (completeness and correctness), validity, and timeliness.
- The proportion of potential indicators reported was assessed.
- The proportion of indicators correctly generated was calculated.

- Use of information was assessed from the proportion of minutes of meetings that have documented actual use of data.

- Proportion of ART staff trained on data collection, data accuracy checks, data analysis and use of information for management was ascertained.

3.8 ETHICS

Ethical clearance to conduct this study was obtained from the research committee of the University of the Western Cape, and that of the Mbale Regional Referral Hospitals.

Confidentiality was observed at all times during the study. In particular, patient information was treated with utmost care and safety to ensure confidentiality. Information obtained from health care staff at the ART-programme was treated confidentially. In the data collection tools, patient identifiers and participants' names were not used.

In addition to informed consent, participant autonomy and rights to withdrawal and non-participation in the study was observed. In case of withdrawal or non-participation, the respondent's wish was respected without requesting for any further explanations for their actions (see appendix I)



CHAPTER 4 – RESULTS

4.1 CHAPTER OVERVIEW

In this chapter results are presented under three main areas: firstly a brief description of the respondents is provided, secondly the analysed questionnaire responses from the study populations and thirdly the results of the quantitative assessment of the quality aspects of data collected by the ART-IS are summarised.

4.1 THE DESCRIPTION OF THE RESPONDEDNTS

The table 1 below summarises the cadres, numbers, levels of education and responsibility of the respondents

Table 1 Description of the data collectors

Respondents	Number	Level of education	Responsibility
Clinicians	8	Ranged from certificate in nursing to graduates in medicine	Data collectors for the various relevant fields in the data tools related to clinical work
Counselors	1	Certificate in counseling.	Data capture in relevant fields related to counseling of clients
Data manager	1	Graduate in statistics and software sciences	Data entry and data analysis
Information officer	1	Certificate in nursing	Data collation and reporting weekly and monthly.

Eleven (55%) out of the 20 data collectors responded to the questionnaire. These respondents included 8 clinicians, one counselor, one data manager, and one information officer.

Only 2 (the data manager and information officer) were trained on data collection and analysis.

Overall the clinicians (8/11) were the majority and their involvement in data collection makes them key players in the quality of data collected.

The information officer and the data manager were directly responsible for the data accuracy checks, data entry and data analysis.

4.2 RESPONSES TO THE QUESTIONNAIRE

4.2.1 APPROPRIATENESS OF THE DATA COLLECTED BY THE ART-IS

The views of the data collectors on the information collected were varied. Less than a half (4/11) of the respondents said the data collected was inappropriate for the programme. They scored the data collection tools as being too detailed and collected more data than needed. For this same reason they added that the tools were not easy to complete and hence not friendly tools. All those who cited these reasons, were clinicians. Conversely the other 7 / 11 respondents who included the data manager, the information officer, the counselor and 4 clinicians reported that the data collected was relevant for the program. It was interesting to note that of the 8 clinicians who responded to the questionnaire, 4 (50%) of them supported either view. However, it is noteworthy that the 4 clinicians who cited unfriendly data collection tools and inappropriate data were involved in clinical care only, while those who reported in favour of the data collection tools and the appropriateness of the breadth and depth of data collected were involved in both the clinical care of patients as well as the core management issues of the ART programme.

The information officer and the data manager both confirmed that the data collected was adequate for the calculation of the indicators and put their estimates of adequacy at 100%, though both scored the level of completeness of the entire data at 50-75%.

4.2.2 EASE OF DATA COLLECTION BY THE ART-IS

All the eleven respondents did not think that the data collected had a positive cost benefit ratio. Data collection was thought to be enormous given the high number of data collection tools that were too detailed as well and benefits derived from the information generated was thought to be minimal. Overall, ease of data collection was hindered by the heavy workload arising from too

many data collection tools and very detailed tools used by same scanty staff doing clinical and other services.

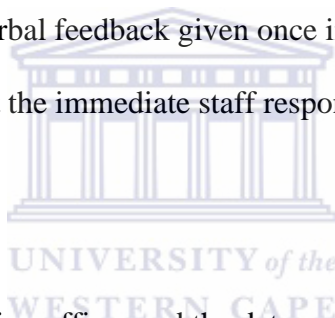
4.2.3 QUALITY OF DATA COLLECTED BY THE ART-IS

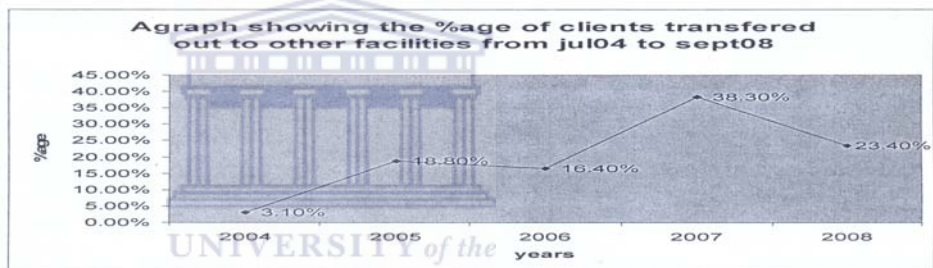
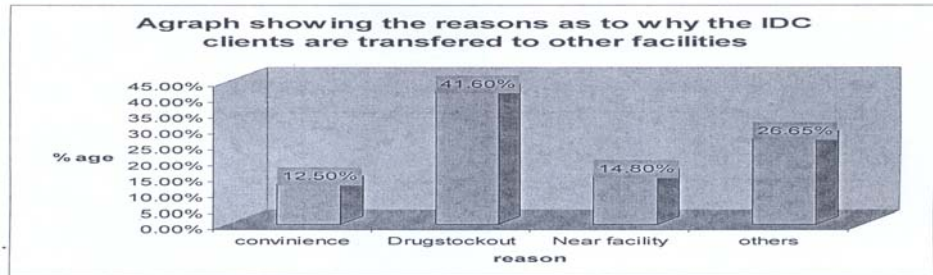
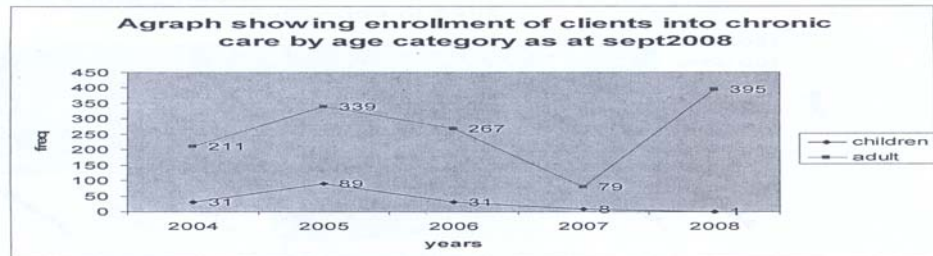
Only two respondents reported that the information collected was of high quality. These were a counselor and one clinician. The rest reported poor quality data citing incomplete data (5/11), inaccurate data (4/11), untimely data (5/11), and very few (1/11) thought the data was invalid. This suggests that the data collectors themselves are uncertain of the quality of data generated and therefore are unlikely to use it for decision making.

It was noted by all the respondents that the feedback on error checks, quality of data and use of data was not prompt; it was verbal feedback given once in a while by the ministry of health quality assurance team and not the immediate staff responsible namely the information officer and the data manager.

4.2.4 DATA ANALYSIS

This was done by the information officer and the data manager. Manual data analysis using calculators was being done. From a total of 29 indicators spelt out by the national ART-IS, only 11 were designated to be collected by the Mbale hospital ART-IS, of which 7/11 (64%) were being calculated and reported by the hospital ART-IS. The analysed information was presented in form of tables, graphs and pie charts as shown in the illustration below.





4.2.5 REPORTING PROCESS

On the reporting process, all the respondents (11/11) were not satisfied with the reporting of data. They cited use of graphs, tables and charts without any accompanying notes explaining what had happened or why the data reported was of that nature. They also cited that little if any information was deduced from the reports on the progress or performance of the ART programme.

4.2.6 USE OF REPORTS GENERATED

A majority of the respondents (9/11) stated that the ART programme did not base decisions on the programme on the data generated locally. A complement to this assertion was based on the information available at the clinic where procurement of supplies and drugs was directed from the ministry of health headquarters who determined the quantities of supplies and drugs rather than basing them on the demand and supply at the hospital ART programme. In addition, recruitment and posting of staff was unfortunately not influenced by the workloads at of the ART programme in the hospital. Furthermore, mechanisms to cope with the expanding ART programme services were not based on the existing evidence of available information.

4.3 THE RECORDS

The records were the second study population. All the data collection tools used by the ART - IS are accessible because they are kept in the clinic, readily available because they are in the office of the data manager who readily avails them to the data collectors and are secured in a lockable cabinet. The records were evaluated with the aid of structured record review charts specifically designed for this purpose. All records of the ART-IS in the 36 month (i.e. 3 years) from July 2004 (time of inception of the ART program) to June 2007 were evaluated. The following records were specifically assessed: the list of indicators produced, the weekly collated data, the monthly reports, the monthly meeting minutes, the quarterly and annual reports available at the ART clinic.

Table 2 description of the records evaluated

RECORD TYPE	Number	What was evaluated	Value of record
ART CARD	1	Data elements	<ul style="list-style-type: none">• Determine if data definitions are valid and standardized• Determine which indicators can be calculated from the data collected via the ART-card.

REGISTER		1	The data fields captured, correctness of data entered and number registered per clinic day	<ul style="list-style-type: none"> Determine accuracy and completeness of data entry
REPORTS	Weekly	156	Timeliness, validity, accuracy and Completeness	Immediate data for use and indicators produced.
	Monthly	36	Accuracy, validity Completeness, timeliness	Monthly reports and quality assurance and support supervision
	Quarterly	12	Accuracy, completeness, validity and timeliness	Time trend consistency
	Annual	2	Timeliness, validity and accuracy	Consistency
MEETING MINUTES		13	Use of data	Documentation of use of information

4.4 THE ART-IS

4.4.1 GUIDELINES AND / OR MANUALS

The ART programme had no manual at the clinic for the operationalization of the ART-IS. Most of the guidelines for operationalization were obtained as notes from training workshops, introductory notes in the data collection tools and feedback from support supervision from the quality assurance team that regularly visits once every 3 month from the ministry of health headquarters.

4.4.2 DATA COLLECTION AND COLLATION TOOLS

Paper based tools were used for data collection by the ART-IS. The tools used for data collection included the register book, the ART-card, the ART book, the laboratory forms, weekly, monthly, quarterly and annual reports.

The data collection is done by various cadres in the ART team as shown below. All the data collection tools were supplied from the ministry of health. The information which accrues from this process is then collated by the information officer ready for entry, followed by analysis, reporting and later availed for use.

Table 3 data collection and collation tools at the Mbale Hospital ART-IS

Name of tool	Number of fields	Used by	Purpose
Register	7	Counselors, Information officer and data manager	Capture general information such as date, names, age, sex, contact details
ART-card	16	Counselors, clinicians, information officer and data manager	Data for calculation of indicators
ART book	22	Nurses and data manager	Capture details of clients started on ART, adherence of clients to ART,
Weekly report	9	Information officer and data manager	Data for calculation of indicators
Monthly reports	11	Information officer and data manager	Data for calculation of indicators
Quarterly reports	8	Information officer and data manager	Progress reporting on ART programme activities and monitoring of targets
Annual reports	8	Information officer and data manager	Progress reporting and monitoring of targets
Laboratory forms	5	Clinicians & laboratory personnel	Laboratory data



4.5 APPROPRIATENESS OF DATA COLLECTED BY THE ART-IS

The appropriateness of data collected was assessed based on the extent to which the data collected was of sufficient breadth and depth to calculate the required indicators. The data generated by the ART-IS was appropriate to calculate 11 indicators, though at the time of the hospital ART-IS assessment only 7 indicators were being calculated.

4.6 ART-IS DATA QUALITY

Here the results are presented under each of the elements of data quality evaluated. This includes sections on: availability of data on time, accuracy of data, completeness of data, time trend consistency and validity of data.

4.6.1 AVAILABILITY OF DATA ON TIME

An evaluation of availability of data on time was done on all the following: weekly, monthly, quarterly and annual reports. The evaluation was done using appropriate data abstraction tool (see appendix). Table 4 summarizes the findings on availability of weekly reports on time, while table 5 does for monthly, quarterly and annual reports. The ART-IS had weekly data/reports completed on the same clinic day which falls on every Friday and so corresponding to end of the week.

Table 4 Availability of weekly data on time within 24 hours of data collection

Characteristic	Number	Outcome
Available on day of the clinic	153	In time
Available 2 days after the clinic day	00	Nil
Available 3 days after the clinic day	3	Delayed report
Available 4 days after the clinic day	00	Nil
Available 5 days after the clinic day	00	Nil
Available 6 days after the clinic day	00	Nil

The results in this table indicates that almost all (98%) of the weekly reports were available in time, so making them timely for use for collation into monthly reports.

Table 5 Availability of monthly, quarterly and annual data on time

Report type	Characteristic	Number	Outcome
Monthly	Available within 1 week of the date report was due	12/36 (33%)	Available in time
	Available after 2 weeks of the date report was due	00	Nil
	Available after 3 weeks of the date report was due	00	Nil
	Available after 4 weeks of the date report was due	00	Nil
	Available beyond 4 weeks of the date report was due	24/36 (67%)	Unavailable in time
Quarterly	Availability within first month of the last weekly report date for the previous month	12/12 (100%)	Unavailable in time
Annual report	Availability within first month after the last day of the programme year	02/03 (67%)	Unavailable in time

The monthly reports, however, were not as timely as the weekly reports despite being the collation of weekly data and so were the quarterly and annual reports. Only 33% of the monthly reports were available in time. This means that most data 67% was not available for potentially useful decision making and planning cycles that occurred during this period when they were not available, this is especially so for decisions that could possibly not wait for availability of such

delayed information, for example data on procurement of medications, mechanism to cope with heavy workloads and the like.

4.6.2 ACCURACY OF DATA COLLECTED

The assessment was done on:

- Extent to which data was filled in the correct fields,
- Extent to which the data was complete in the reports,
- Time trend consistency,

A margin of within 10% limit was allowed, that is, any record that was filled to 90 – 100% with the correct data in the expected fields was considered accurate.

Table 6 shows the correctness of the weekly, monthly, quarterly, and annual data.

Table 6 Correctness of the weekly, monthly, quarterly and annual collated data for the period July 2004 – June 2007

Report type	Characteristic	Number of reports available and assessed	Outcome
Weekly	Data correctness at 90% and above	98 (63%)	Above 50% of the records are correctly filled
	Data correctness at 89% and below	58 (37%)	Incorrect data in over a quarter of the records.
Monthly	Data correctness at 90% and above	34 (94.4%)	Almost all the fields were correctly filled with data abstracted from correct data elements in the weekly reports
	Data correctness at 89% and below	2(5.6%)	Small level of incorrect monthly data compared to that in the weekly reports
Quarterly	Data correctness at 90% and above	11 (94%)	Correctly collated from the relevant data elements from monthly reports
	Data correctness at 89% and below	01 (08%)	An incorrect filled report when compared to data source in the monthly reports.
Annual	Data correctness at 90% and above	2/2 (100%)	Correctly filled out from correct data elements from monthly data reports
	Data correctness at 89% and below	00	Nil

4.6.2.1 COMPLETENESS OF DATA

The weekly, monthly, quarterly, and annual data collated was assessed for completeness. Here fields in the columns and rows were checked. An allowance of 10% was made. Table 7 summarizes the findings of this assessment.

Table 7 Completeness of data

Report type	Characteristics	Number of reports available and assessed	Outcome
Weekly	Above 90% complete	133 (85%)	Complete data
	Below 89% complete	23 (15%)	Incomplete data
Monthly	Above 90% complete	34 (94.4%)	Complete data
	Below 89% complete	02 (5.6%)	Incomplete data
Quarterly	Above 90% complete	11 (92%)	Complete data
	Below 89% complete	01 (08%)	Incomplete data
Annual	Above 90% complete	02 (100%)	Complete data
	Below 89% complete	00 (00%)	NIL

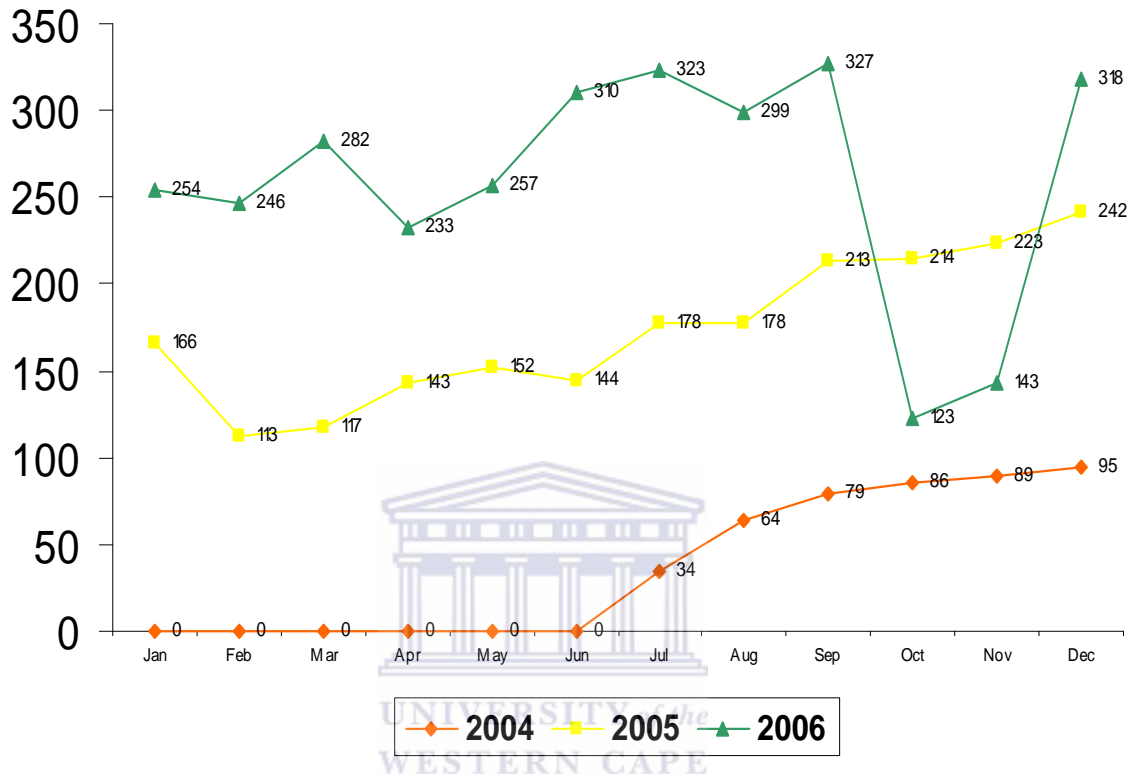
Of the weekly records that were incomplete, 8/23 (35%) were also incorrectly filled in.

4.6.2.2 TIME TREND CONSISTENCY

The histogram below demonstrates time trend consistency on drug picks for the 3 years period between July 2004 and December 2006. There was a dramatic fall in the patient drug picks between September – December 2006. This was because most of the ARV drugs were out of stock at the clinic and patients missed to pick their medications from this clinic. This reflects the reality and hence the data available on time trend consistency based on drug picks was correct.

Figure 2 Time trend consistency of drug picks at the ART clinic

GENERAL TREND OF MONTHLY DRUG PICKS BY YEAR (2004, 2005, 2006)



These results shows the ART programme expanded and could not cope with the large number of patients so there were the shortages of the drugs especially October – November 2006. These two months were also inconsistent with the rest of the months in 2006 and similarly with the the same period in 2004 and 2005.

4.7 VALIDITY OF DATA

4.7.1 Validation of sources of data

Validity of data was assessed using monthly and weekly reports. Table 8 shows the proportion of data that was of value for calculation of indicators .

Table 8 the extent to which data collected was of value for calculation of indicators

Characteristics	Number valid	Number invalid
Weekly Data: the extent to which the weekly data reported was a true value of what was collected	133 (85%)	23 (15%)
Monthly Data: the extent to which the monthly data reported was a true value of what was collected	02 (11%)	34 (89%)
Quarterly Data: the extent to which the quarterly data reported was a true value of what was collected	00 (00%)	12 (100%)
Annual data: the extent to which the quarterly data reported was a true value of what was collected	00 (00%)	02 (100)

Validity of the weekly data as a reflection of the value that the data generated was for calculation of indicators. The invalid sources of the weekly reports were randomly spread throughout the study period. As a result, they affected almost all (90%) of the monthly reports studied and these in turn affected the quarterly data and subsequently the annual reports. This was because all the invalid sources of the weekly data were also used to complete the monthly reports making the monthly, quarterly and annual data inaccurate and hence of inferior quality.

4.7.2 Validation of indicators

Table 9 summarizes the indicators and their characteristics. All the indicators are monitored nationally.

A detailed evaluation of indicators calculated and reported by the Mbale hospital ART-IS to demonstrate their usefulness in monitoring the ART programme in terms of their reliability, appropriateness, validity, ease of collection, and specificity (RAVES) was done.

Table 9 Indicators calculated and reported by the Mbale Hospital ART-IS

Indicators	Indicator description	Type of indicator	Characteristics				
			R	A	V	E	S
1	Percentage of HIV+ patients in general care who have been assessed for ART eligibility at every visit	Output	Y	N	Y	Y	Y
4	Percentage of HIV+ patients who are in general care or receiving ART assessed for active TB at every visit	Process	Y	N	Y	Y	Y
7A	Percentage of new patients receiving ART who have met eligibility criteria	Output	Y	N	Y	Y	Y
11	Percentage of HIV+ patients identified with active TB who are referred for TB treatment	Process	Y	N	Y	Y	Y
13A	Percentage of patients on ART who are adherent to ARV medicines	Output	N	Y	N	N	Y
16	Percentage of patients who started ART within the past 6 month that have shown clinical improvement	Output	N	Y	N	Y	Y
28	Percentage of HIV+ children and infants in general care who are assessed for ART	Output	Y	N	Y	Y	Y

RAVES is an acronym for: reliable, appropriate, valid, easy to collect and specific respectively. Y = Yes, N = No

Overall none of the indicators calculated and reported, had all the attributes of being ‘RAVES’ however, 5/7 were valid, all of the indicators (7/7) were specific, only 2/7, that is indicator 13A and 16 above were appropriate while 1/7, that is indicator 13A was not easy to collect data on and calculate it. Given these nature of the attributes of these indicators, their usefulness in monitoring targets was varied and all indicators needed to have all the attributes of being ‘RAVES’, a difficult status to achieve for each and every indicator in a set of indicators, but useful attributes in order for the set indicators to monitor targets set. .

The data collected was also adequate for calculation of 4 more indicators. This data was available but none of these 4 additional indicators were being calculated. This was because the quality assurance monitoring team from the ministry of health had restricted initial indicator calculation and reporting to 7 indicators above as a phase one strategy then move on to the next set of four indicators in phase 2.

4.8 Data use

Information use was determined by assessment of the minutes of meetings held and assessing the actual documentation of actions and plans made by the ART programme based on the available information from the ART-IS and any missed opportunities of actions that would have been taken in this study period. In all the 13 sets of meeting minutes, at no time had the ART team taken a decision or made plans based on available data. On the other hand some of the missed opportunities included: use of the available data to procure ARVs, use of workloads to determine the staffing levels among others.

4.9 Data analysis done

The analysis that was done by the information officer and data manager was manual analysis and basically was to calculate indicators. The example below shows how the indicators were being calculated:

Indicator (7A): Percentage of new patients receiving ART who have met the ART eligibility criteria

Numerator: Number of new patients who were started on ART and met the ART eligibility criteria in specified period of time (for this case the researcher used per month)

Denominator: total number of new patients started on started on ART in a specified period of time (for this evaluation the researcher used per month)

Target: 100% of patients receiving ART have met eligibility criteria

Table 10 monitoring of the target of the indicator 7A for period June – September 2005

Month	Numerator (N)	Denominator (D)	N/D X 100	%
June	10	12	10/12 X 100	92 (-8)
July	27	41	27/41 X 100	62 (-38)
August	23	32	23/32 X 100	72 (-28)
September	24	46	24/46 X 100	75 (-25)

Table 11 monitoring of targets of indicator 7A for period June – September 2006

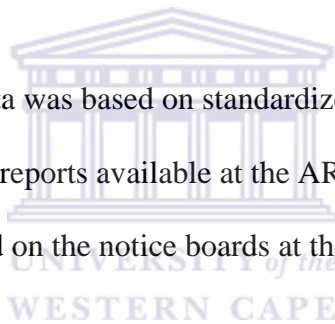
Month	Numerator (N)	Denominator (D)	N/D X 100	%
June	12	12	12/12 X 100	100
July	25	25	25/25 X 100	100
August	13	13	13/13 X 100	100
September	19	19	19/19 X 100	100

In the analysis, it was evident that the definition of the indicator was taken into account in identification of the numerator and denominator. Then calculation was done with conversion of the product to percentage to allow for comparison.

Based on the above the right principles of the basic analyses were correct and adhered to.

4.10 Reporting process

The process of reporting of data was based on standardized report formats of the weekly, monthly, quarterly and annual reports available at the ART clinic. These were made into graphs, tables and charts and displayed on the notice boards at the clinic premises.



CHAPTER 5 – DISCUSSION

5.1 CHAPTER OVERVIEW

Chapter 5 discusses the functioning of the ART-IS in relation to the objectives of the study. It specifically deals with all the objectives in the study covering the aspects of data collection, the ease of data collection, appropriateness of data collected, data quality aspects, data analysis and reporting process by the Mbale hospital ART-IS.

5.2: APPROPRIATENESS OF THE DATA COLLECTED

Although entire assessment of appropriateness of the data was difficult to achieve in totality in this study, this assessment was based on the determination of the extent to which the volume of the data generated was appropriate for the required indicators. The results obtained indicated the views of the respondents and the characteristics of the indicators calculated respectively.

Four out of eleven respondents reported inappropriate data generated citing too many tools used for data collection, work overload due to too few data collectors and that the tools were too detailed and hence unfriendly. The nature of the data collection tool determines the depth and breadth of the data collected. A very brief data tool may not collect adequate data while a very detailed tool may collect more data than required. To achieve the balance an appropriate tool should be designed to match the indicators of interest to be calculated. A data tool that collects relevant data for calculation of indicators of interest has good quality that any data collection tool should have in order to collect a minimum data set.

Too many and very detailed tools as reported in this study only work against achievement of quality data by being unfriendly, of low cost benefit ratio and causing work overloads. It is therefore only just to say that the ART-IS at Mbale hospital collects inferior data, a situation which is fueled by the fact that there were few data collectors. Subsequently

the data generated by the hospital ART-IS was inappropriate in terms of content. Evidently, the ART-IS was designed at national level to report on 29 indicators, however, the ART-IS at the hospital collects data on 11 but reports only 7 indicators at present. This indicates that the hospital ART-IS had partial contribution to the national monitoring of targets as it calculates only 7/29 indicators.

For any indicator to qualify as useful indicator, it should be reliable, appropriate, valid, easy to collect and specific respectively. The available data at ART – IS at the hospital could generate 11 indicators. Only 7(64%) were being generated. This means the tools used for generating the data were appropriate, but this does not necessarily mean the data was appropriate owing to the fact that other factors such as data collection tool design, number of data collection tools, the level of details in the data tool and training of data collectors on HIS play a big role in its determining how appropriate the data collected is.

Based on the indicator characteristics, our findings indicate that all the 7 indicators were specific, while only 2(28.5%) of them were appropriate. Overall, the usefulness of each of these indicators was only limited because none of the indicators had all the desired indicator quality characteristics.

While the indicators were designed by the National ART Programme, the data available at the Mbale Hospital ART – IS was appropriate for all the indicators the programme was charged to calculate. This reflects under use of data for indicator calculation and so limitations in ART programme monitoring at hospital level as well as the monitoring of targets at national level.

Involvement of clinicians in the management of planning issues of the ART programmes makes them appreciate the appropriateness of the data generated. Of the 7(64%) who reported appropriate data generated, 4(57%) of them were clinicians. These 4 differed from the same number of clinicians who noted that the data generated was not appropriate. The difference between the two groups was that the latter were clinicians involved in the data collection but not in management or planning issues of the ART programme. Therefore, involving clinicians in data collection in the ART-IS as well as

management issues of the ART programme was of beneficial effect as it creates appreciation of appropriateness of data collected. It would also improve the overall quality of data because when health staff who appreciate data are involved in generation of data, there is a high likelihood of then generating correct, accurate, timely and consistent data.

Adequacy of data for the task is only reflected on the extent to which it contributes to the calculation of the indicators for programme monitoring. Therefore, because the data collected was of sufficient amount to calculate the indicators required of the hospital ART-IS, it is only just to conclude that the data was adequate but only that its quality was in question.

5.3 EASE OF THE DATA COLLECTION BY THE ART – IS

Ease of the data collection is reflected in the ease of use, ease of access and ready availability of the data collection tools.

In terms of ease of use of the data collection tools, aspects of accessibility, comprehensibility, attractiveness, number and length of the data collection tools were assessed.

All the eleven data collectors reported that data collection using the current tools was not easy, stating that the tools were too many (8 tools), too detailed; for example, the ART Card had 16 fields, while the ART book had 22 fields. The more detailed the tool as reflected by the number of fields, the more cumbersome to fill it and the unfriendly the tool is. This discourages the data collectors who often will leave data out in the fields of the tool and so creating inferior and untimely data.

The same data collectors were also occupied in either clinical work or counseling. And because of too much detail in the tools they were not easily comprehended. All these findings are supported by earlier work by Mathieu & Khalil (1998) who reported that the simpler the data collection tool the easier it is to use it and this results in complete,

correct and accurate data hence good quality data. Lengthy tools consume a lot of time to fill them. In a busy clinic, where clinicians are also involved in data collection, the tendency to attend to patients outweighs the need to have a lengthy time consuming data tool filled. (RHINONET, 2006).

Almost all (9/11) of the data collectors noted that the ART Card used for collection of the data for calculation of the patient clinical outcome indicators by the ART – IS at the ART programme is lengthy with 16 fields to fill, crowded and unattractive and difficult to comprehend easily (see appendix IX). Because of this, a lot of fields were left unattended to or missing data at the end of the data collection day, especially in the follow up section of the card and therefore loss of continuity of data.

On average there are 1,070 regular patients reviewed per months. If they are evenly distributed over 4 weeks in a month. It means about 265, patients are seen every Friday of the week since the clinic is run once a week on Fridays only. This reflects heavy workloads for the scanty health workers at the clinic resulting in limited time for data collection. Heavy workload alone is known to discourage data collectors. This accompanied by low morale compounds the situation even if the data collection tools are the best available (Garde, et al. 2006), this results in poor data quality resulting from complex data collection tools.

In addition, complicated and detailed tools affect the efficiency of the data capture, entry, analysis and interpretation. Reports especially the weekly, monthly quarterly and annual were easily filled in by the information officer because they had fewer data fields notably, 9, 11, 8 and 8 respectively which allow relevant data capture for the calculation of indicators of national interest for the monitoring and evaluation of the ART programme targets.

The characteristic design of the weekly reports allows for easy completion and hence availability of those reports in time.

The hospital ART-IS provides safe, easy access and ready availability of data collection tools. This is commendable as it provides safety as well as saving time required to pick and fill out the tools. Inaccessible and unavailable tools are a primary cause of lack of data.

Training of data collectors on the HIS is relevant in enabling them to appreciate the importance of quality data for decision making and planning (Mihalas, Bazoran & Forcas, 2006). Only 2 (20%) of the data collectors have had formal training at an orientation workshop related to ART-IS. Both of them have appreciated the depth and extent of the data collected and therefore training remains pivotal for creating understanding of data collection tools for data collectors. Furthermore, training of data collectors on HIS enables them to assess tools for effectiveness and use data (Mihalas, Bazoran & Forcas, 2006). In addition, training makes it easier for the data collectors to interpret data variables easily and so making data variables easy to collect data on.

In addition to training, involvement of the data collectors in the core management issues makes clinicians involved in the data collection appreciate the need for data. On job training especially in the role-play may achieve a lot for settings where training may be an expensive venture.

5.4 AVAILABILITY OF DATA IN TIME

Availability of data in time is an essential aspect of data quality. Once data is available in time, it will be available for planning and management needs (Mathiew & Khalil, 1998). This is one of the objects of the ART-IS, but the extent to which timeliness of data was achieved by the hospital ART-IS was varied. This study found that 153(98%) of the weekly data in the study period was available in time, while only 33% of the monthly data was available in time and disappointingly none of the quarterly or annual reports were available in time at Mbale Hospital ART-IS.

Given the fact that most ART programme returns, procurement and supplies are done on quarterly basis, the non – availability of the quarterly reports in time rendered these reports’ contribution to the procurement and supply process insignificant.

The monthly data is also used for monitoring targets and comparing performance of the different ART – programmes nationwide. Monitoring is done quarterly, yet 2/3 of the monthly reports were late by at least 4 weeks from the report date. On the other hand, the quarterly reports were late by at least one month from the date of the report. The Mbale Hospital ART programme may not have benefited from ongoing monitoring and performance evaluation which is scheduled 4 weeks from the date of the monthly report.

The availability of all (98%) weekly reports in time was a good start, however, their use was limited by delayed collation into monthly reports.

Only 12 (33%) of the monthly reports were available within 4 weeks from the date when the report was due, meaning 24 (67%) were not available even by the end of the next quarter. For this reason, monitoring of targets by the calculated indicators in the previous quarter was not possible. For this same reason, comparing the performance of the Mbale Hospital ART programme with the 12 other similar programmes nationwide was not possible.

5.5 DATA ACCURACY

Three aspects of data accuracy were considered in the assessment of the Mbale Hospital ART- IS quality of data. These were data completeness, data correctness and time trend consistency.

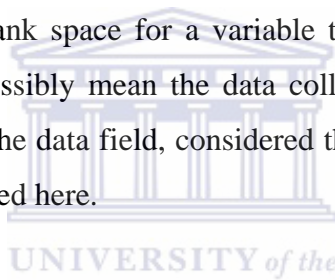
5.5.1 DATA COMPLETENESS AND CORRECTNESS

This study found that the level of completeness of the weekly, monthly, quarterly and annual reports were in the range of 85% - 100%, with the weekly reports being at 85% and the annual reports at 100%.

It is noteworthy though that these were not absolute levels of completeness as the study allowed for 10% margin, that is, any record which had 90 – 100% of the data fields completed was considered complete. The more the data fields in a tool, the more likely the level of completeness of data was low. This was the case with the weekly reports which had more than the quarterly of annual reports. The 15% of the weekly reports had grossly missing data of more than 10%.

The sources of the missing data were sought and found to be either missing or incomplete variables. The causes of missing primary data or misleading data were not immediately established owing to the need for an in-depth and prolonged investigation. Some blank spaces in the primary data were noted.

The meanings of a blank space for a variable that should have been filled-in was not apparent and could possibly mean the data collector forgot to fill in the data, did not know the response to the data field, considered the data field not applicable or any other possibility not mentioned here.



Just having all fields in the rows and columns in the data tool filled-in does not necessarily mean the data is accurate. For example, 100% of the data fields in the two annual reports were filled in but the study pointed out that errors in the weekly reports were collated into monthly reports and subsequently to quarterly and annual reports.

However, correct, complete, consistent and therefore accurate data can be achieved through various ways including appropriate design of the data tools to take care of clarity of the tool, short relevant tools, training of data collectors and ensuring adequate committed staff on data collection, (Bakker & Bekke, 2006).

Such level of accuracy may be enhanced by use of software programmed to have relevant mandatory fields entered, rejection of a blank entry, spell checks and date codes.

Ninety eight (65%) of the columns in the weekly records were significantly (more than 10%) incomplete, making the value of these data low. Such incomplete data is not useful

for collation of monthly records, if it is used, then the systematic error will be passed on to the monthly, quarterly and annual records and the trend continues. This was the case with the findings of data generated by the Mbale hospital ART-IS. The implications of these include wrong decisions, wrong actions and in – appropriate plans. The best way to circumvent this is to prevent such errors from occurring. These may be through checking of errors, cleaning the data before collation and data entry.

5.5.2 TIME TREND CONSISTENCY.

The other way to assess data accuracy is to map out time trend consistency. One of the ways to assess time trend consistency is to have minimum and maximum values and determine the outliers and reasons for the outliers. The value for this approach is that it helps in determining the trends in terms of expansion of services and therefore helps in planning.

This study found that the ART programme at the hospital did not have minimum and maximum values determined at the beginning of the programme and so a limitation in terms of what could be assessed in this regard. However, the monthly number of the drug picks was considered appropriate to give a picture of time trend consistency.

The finding of the general rising trend on monthly basis throughout the study period was indicative of expanding services in terms of patient initiating on ART and coming for drug refills. This trend continued till October-November 2006 when there was dramatic fall in the drug stocks. This means the service expanded while the stock levels remained the same or the drug stock increase was not commensurate to the expansion so causing a deficit in the ART services.

5.6. VALIDITY

Perceived validity was consistent with the assessed validity in this study. Therefore this undermined the ability of the dataset to correctly enable correct calculation of each of the seven indicators.

5.7. DATA USE

The ART-IS at Mbale Hospital is simple, and potentially generates useful data. The lack of availability of certain data on time has limited the use of data.

Only 33% of the monthly data was available in time yet monthly data was useful in collation of quarterly and annual reports. Evidently, none of the 13 reports of the meeting minutes had any evidence of use of data for planning or management issues. On the other hand, procurement of drugs and supplies would have been influenced by data available and so would staff recruitment.

This strongly suggests that the data generated was of inferior quality in terms of timeliness and quality of information available.

5.8 DATA ANALYSIS

There was evident basic but appropriate data analysis using pen, calculator and paper. The indicators were appropriately being calculated, however the level of accuracy of the raw data used potentially affected the outcomes of the data analysis.

5.9 REPORTING

Data was appropriately reported using conventional methods of charts, graphs and tables and pasted on the walls and notice boards.

5.10 RELIABILITY

The ART-IS data from Mbale Hospital is reliable to a certain extent. When looked as a whole one may say the data is unreliable. However, looking at it critically, some parts of the data collected are indeed reliable.

CONCLUSIONS

This is the first time an evaluation of an ART-IS is done at the Mbale Regional Referral Hospital's ART Programme.

The simple paper based data collection system is operational. Whereas the tools were designed to generate appropriate amount of data, the lengthy data tools compromised the ease of their use and so this contributed to poor quality data in terms of incomplete, incorrect, untimely, invalid and inconsistent data.

Data analysis and reporting were done; however, the analysis of poor quality data in itself is counterproductive in that the output of such analysis results into misleading conclusions and when such information is used for decision making or planning the consequences are disastrous. The reporting of data using tables, graphs and charts without underlying explanations limited understanding on the progress of the ART programme at the hospital.

The limited use of data for an expanding ART programme at the hospital potentially causes shortages and inconsistencies in the services delivered.

Improvement in the ART-IS is needed in the following areas: simplification of data collection tools to capture minimum data set, collection of accurate (complete, consistent and correct), valid and timely data and ensure use of data for planning and management. Only then will the ART-IS at Mbale hospital contribute meaningfully to the effective functioning of the ART programme at the hospital.

RECOMMENDATIONS

1. The detailed and complex data collection tools should be simplified to allow for relevant Simple data collection. This will also improve on the cost : benefit ratio of data collection
2. Train all data collectors including clinicians in data collection and importance of collecting complete, correct and consistent data.
3. Improve the quality of data by ensuring regular pre-collation data accuracy checks, especially the aspects of accuracy (Completeness, correctness and consistency), timeliness, and validity.
4. Increase the number of data collectors so that the workload does not overwhelm the existing data collectors at the expense of quality of data generated. This may be done by reallocating staff from other units in the hospital to the ART programme and to cater for staffing needs in the ART program through submission of restructuring reports to the ministry of health.
5. Improve on reporting by including explanations on the trends on the tables, charts, graphs with accompanying explanations.
6. There is need to start using data for planning and management issues of the ART programme especially in areas such as staffing to solve the problem of workloads, procurement of supplies and drugs to solve the problem of drug stock outs and training needs of the staff on HIS among others. To achieve this, data need to be timely to enable availability of data for planning and management purposes.
7. Feedback be regularly given preferably in written form from the data manager and information officer on data accuracy checks.
8. Guidelines and manuals on operationalisation of the ART-IS be availed to the staff involved in data collection.
9. The study found that the ART-IS was not evaluated before. It is therefore recommended that timed periodical evaluations be done on appropriateness of data, data quality, data validity

and use of data for decision making and planning of the day to day running of the ART-IS at the hospital.

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APPENDIX (I)

INFORMED CONSENT FORM

I am a post graduate student at the University of the Western Cape (UWC) in South Africa, undertaking a Masters in Public Health (MPH). I am doing a research project at the Mbale Regional Referral Hospital ART – program to evaluate the ART – information system at the hospital. This research project is in partial fulfillment of my MPH degree and will be bound into a mini-thesis.

During the study, you will be required to fill in a questionnaire which will serve as the data capturing tool for the study project.

You are not required to write your name in the Questionnaire for confidentiality reasons.

The study will be published in the university's library and in a scientific journal. A copy of the study will also be provided to Mbale Regional Referral Hospital.

I appreciate you giving your time to this study which will help in the understanding of the level of operation and usefulness of the ART-IS in the hospital.

No direct benefits will accrue to the participants during the study. All your rights to participate in the study will be observed.

If you have any questions, please feel free to contact me at e-mail: polupotolupot@yahoo.com or call me on +256 772 457217.

Thank you.

DR. PETER OLUPOT-OLUPOT

Please Sign below if you have understood and are willing to participate in the research project as outlined above.

Signature : _____
Print Name : _____
Date : _____



Appendix (II)

QUESTIONNAIRE FOR DATA COLLECTORS

A study on ART-IS in Mbale regional referral hospital in Eastern Uganda

	IN CLEAR	ID. NUMBER
DEPARTMENT		
ENUMERATOR		

SECTION A: SOCIAL DEMOGRAPHIC DATA OF RESPONDENT

1. Date of birth.

DD	MM	YYYY

2. Date of interview.

DD	MM	YYYY

3. Date when you started working in the unit.

DD	MM	YYYY

4. Your gender.



Code	Sex	Check
1	Male	
2	Female	

5. Profession.

CODE	TRAINING	CHECK
1	NURSE	
2	DOCTOR	
3	C/OFFICER	

SECTION B: DATA COLLECTION

6. Do you collect data?

CODE	RESPONSE	CHECK
1	YES	
2	NO	

7. Have you been trained on data collection?

CODE	RESPONSE	CHECK
1	YES	
2	NO	

If yes, what training did you receive?

.....

8. What data collection tools do you use? (Tick all that apply)

CODE	TOOL	CHECK
1	Tally sheet	
2	Register	
3	ART Card	
4	Forms	

9. Is the data you collect sufficiently accurate for your purposes?

CODE	RESPONSE	CHECK
1	YES	
2	NO	
3	Unsure	

10. If yes to 9 above, what level of accuracy do you gauge the data collected to be?

CODE	% LEVEL OF ACCURACY	CHECK
1	0 – 25	
2	26 – 50	
3	51 – 75	
4	76 - 100	



11. Where do you get the data collection tools you checked in 7 above from?

CODE	ORIGIN	CHECK
1	LOCALLY	
2	MOH	

12. Do you have regular shortages of data collection tools?

CODE	RESPONSE	CHECK
1	YES	
2	NO	

13. Are the formats of data collection tools friendly (Friendly tool is easy to use, does not take long time to fill, is not very lengthy).

CODE	RESPONSE	CHECK
1	YES	
2	NO	

14. Do you have any guideline on data collection?

CODE	RESPONSE	CHECK
1	YES	
2	NO	

15. What method do you use to compile data?

CODE	METHOD	CHECK
1	Calculator	
2	By hand	

16. Do you gauge the data you collect to be adequate for planning purposes?

CODE	RESPONSE	CHECK
1	YES	
2	NO	

Thank you for your time. We hope you enjoyed our study.

END



APPENDIX (III)

QUESTIONNAIRE FOR INFORMATION OFFICER / MANAGER OF ART PROGRAM

A study on ART-IS in Mbale regional referral hospital in Eastern Uganda

	IN CLEAR	ID. NUMBER
DEPARTMENT		
ENUMARATOR		

SECTION A: SOCIAL DEMOGRAPHIC DATA OF RESPONDENT

1. Date of birth.

DD	MM	YYYY

2. Date of interview.

DD	MM	YYYY

3. Date when you started working in the unit.

DD	MM	YYYY

4. Your gender.

Code	Sex	Check
1	Male	
2	Female	

5. Profession.

CODE	TRAINING	CHECK
1	NURSE	
2	DOCTOR	
3	C/OFFICER	

SECTION B: DATA COLLECTION COMPLETENESS AND ACCURACY

6. Do you collect data?

CODE	RESPONSE	CHECK
1	YES	
2	NO	

7. Are you trained in data collection?

CODE	RESPONSE	CHECK
1	YES	
2	NO	



8. What data collection tools do you use? (Tick one you use in your department)

CODE	TOOL	CHECK
1	Tally sheet	
2	Register	
3	ART Card	
4	Forms	

9. Is the data you collect accurate?

CODE	RESPONSE	CHECK
1	YES	
2	NO	

10. If yes to 9 above, what level of accuracy do you gauge the data collected to be?

CODE	% LEVEL OF ACCURACY	CHECK
1	0 – 25	
2	26 – 50	
3	51 – 75	
4	76 - 100	

11. Where do you get the data collection tool you checked in 7 above from?



CODE	ORIGIN	CHECK
1	LOCALLY	
2	MOH	

12. Do you get shortages of data collection tools?

CODE	RESPONSE	CHECK
1	YES	
2	NO	

13. Are the formats of data collection tools friendly (Friendly tool is easy to use, does not take long time to fill, is not very lengthy).

CODE	RESPONSE	CHECK
1	YES	
2	NO	

14. Do you have any guide line on data collection?

CODE	RESPONSE	CHECK
1	YES	
2	NO	

15. What method do you use to compile data?

CODE	METHOD	CHECK
1	Calculator	
2	By hand	

16. What score of completeness in percentage do you give to the data collected?

CODE	% LEVEL	CHECK
1	50 – 75	
2	76 – 100	

17. Is the data collected adequate for calculation of all the indicators you are supposed to calculate at this health facility?

CODE	RESPONSE	CHECK
1	YES	
2	NO	
3	DON'T KNOW	

18. If the answer to 17 above is NO, what percentage of indicators are you able to calculate with available data? (Give actual estimates)

CODE	% LEVEL	CHECK
1	0 – 25	
2	26 – 50	
3	51 – 75	
4	76 - 100	

SECTION C: TARGET POPULATION



19. Do you know the catchment population of this health facility?

CODE	RESPONSE	CHECK
1	YES	
2	NO	

20. If answer to 19 above is yes, what population do you serve?

21. Where did you get this figure from?

CODE	OPTION	CHECK
1	Population Census	
2	District records	
3	Your records	
4	Other	

SECTION D: TIME SPENT ON REPORTING

22. How much time do you spend completing the following?

(i) Register books per day?

CODE	TIME	CHECK
1	0 – 1 Hour	
2	2 -3 Hours	
3	4 – 5 Hours	
4	Over 6 Hours	

(ii) Weekly Reports?

CODE	TIME	CHECK
1	0 – 2 Hours	

2	3 - 5 Hours	
3	6 - 8 Hours	
4	Over 8 Hours	

(iii) Monthly Reports?

CODE	TIME	CHECK
1	0 - 2 Hours	
2	3 - 5 Hours	
3	6 - 8 Hours	
4	Over 8 Hours	

23. When do you aggregate data?

CODE	TIME	CHECK
1	Daily	
2	Weekly	
3	Monthly	
4	Other	

24. When do you send reports to MOH head quarters?

CODE	TIME	CHECK
1	Monthly	
2	Quarterly	
3	Half Yearly	
4	Annually	

SECTION E:

DATA ANALYSIS & INTERPRETATION *the*
WESTERN CAPE

25. Do you analyse data?

CODE	RESPONSE	CHECK
1	Yes	
2	No	

26. Do you present data?

CODE	RESPONSE	CHECK
1	Yes	
2	No	

27. If yes to 19 above, how do you present data?

CODE	RESPONSE	CHECK
1	Graphs	
2	Tables	

How often?

CODE	RESPONSE	CHECK
1	Always	
2	Sometimes	

28. If NO to 25 above, why not?

CODE	TIME	CHECK
1	No time to do it	
2	Don't know to do it	

3	Not my work	
4	Other: State	

29. Do you calculate indicators specific for ART?

CODE	RESPONSE	CHECK
1	Yes	
2	No	

If yes, which indicators?

.....

.....

.....

.....

SECTION F: FEED BACK & SUPERVISION

30. Do you get feed back from offices you send your reports to?

CODE	RESPONSE	CHECK
1	Yes	
2	No	

31. If yes, what sort of feed back

CODE	RESPONSE	CHECK
1	Written	
2	Verbal	

SECTION G: TRAINING

32. Do you have training on the data management?

CODE	RESPONSE	CHECK
1	Yes	
2	No	

33. If yes, what training?

TRAINING	CODE	
	1	2
	Yes	No
Data Collection		
Data analysis		
Use of information		
Computer training		

SECTION H: PLANNING & USE OF INFORMATION

34. Do you have an action plan for data collection and reporting in your health facility?

CODE	RESPONSE	CHECK
1	Yes	
2	No	

35. Have you been participating in planning sessions for this health unit?

CODE	RESPONSE	CHECK
1	Yes	

2	No	
---	----	--

36. Do you use the local data in drawing up action plans for ART programs?

CODE	RESPONSE	CHECK
1	Yes	
2	No	

If yes, give an example where you used the data for planning

.....

.....

.....

37. In what form is the data used?

CODE	FORM OF DATA	CHECK
1	RAW DATA	
2	ANALYSED DATA	
3	REPORTS	
4	NONE	

38. Do you gauge the data you collect to be adequate for planning purposes?

CODE	RESPONSE	CHECK
1	YES	
2	NO	

39. If yes to 38 above, which planning is it most adequately more useful?

.....

.....

40. If NO to 38 above, then which other information do you require for adequate planning purposes?

.....

.....

.....

Appendix (IV): RECORD ASSESSMENT TOOL

(I) Availability of data on time (Monthly reports)

- a) **Record:** Monthly report
- b) **Variable:** Availability of data on time.

Assessment

1. Date when report is due

DD	MM	YYYY

2. Date when report was made

DD	MM	YYYY

3. Score scale

CODE	TIME WHEN REPORT WAS MADE	SCALE	CHECK
1	WITHIN ONE WEEK	1	
2	1-2 WEEKS FROM DEADLINE	2	
3	2 -3 WEEKS FROM DEADLINE	3	
4	BEYOND 4 WEEKS FROM DEADLINE	4	

(II) Availability of data on time (weekly reports)

- a) **Record:** Weekly collated data sheets for weekly ART clinics
- b) **Variable:** Availability of data on time.

Assessment

1. Date when report is due

DD	MM	YYYY

2. Date when report was made

DD	MM	YYYY

3. Score scale

CODE	DAY WHEN COLLATION DONE	SCALE	CHECK
1	ON DAY OF CLINIC	1	
2	2 ND DAY OF THE CLINIC	2	
3	3 RD DAY OF THE CLINIC	3	
4	4 TH DAY OF THE CLINIC	4	

5	5 TH DAY OF THE CLINIC	5	
---	-----------------------------------	---	--

(III) Correctness of Data

- a) **Record:** Weekly collated data sheets for weekly ART clinics
- b) **Variable:** Correctness of data.

Assessment

- 1. Level of correctness required: 100%
- 2. Allowance of error: up to 10%

Score scale:

CODE	CORRECTNESS	SCALE	CHECK
1	90% OR ABOVE	1	
2	89% OR BELOW	2	

(IV) Completeness of Data

- a) **Record:** Weekly collated data sheets for weekly ART clinics
- b) **Variable:** Completeness of data.

Assessment

- 1. Desired level of completeness 90% or above,
- 2. Any weekly record which is 89% complete or below is not adequate for report making process,
- 3. The percentage is calculated from the data elements reported as a proportion of the whole data elements to be reported.
- 4. Score scale:

CODE	COMPLETENESS	SCALE	CHECK
1	90% OR ABOVE	1	
2	89% OR BELOW	2	

(V) Time trend consistency

- a) **Record:** Monthly report.
- b) **Variable:** Consistency.

Assessment

- 1. To compare trends between months,
- 2. To detect any unexplained changes in trends of the number of HIV/AIDS clients attending ART clinics on monthly basis,
- 3. Score scale:

CODE	VARIABLE	SCALE	CHECK

1	MINIMUM – MAXIMUM VALUES	1. NORMAL	
		2. ABNORMAL MAX	
		3. ABNORMAL MIN	
2	PARTS VS WHOLE	1. ADD UP	
		2. DON'T ADD UP	
		3. NOT CALCULATED	
3	PREFERENTIAL END DIGIT	1. PRESENT	
		2. ABSENT	

(VI) Indicator assessment

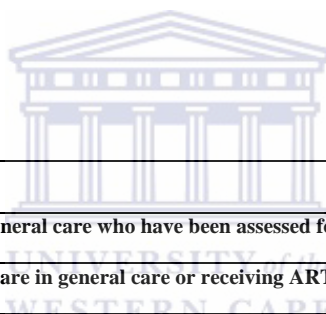
a) **Record:**

- ART Cards,
- Copy of outline of indicators at ART clinic,
- Reported indicators (reports)

b) **Variables:** Indicator characteristics.

Assessment

1. Reliability (R).
2. Appropriateness (A).
3. Validity (V).
4. Ease of collection (E).
5. Specificity (S).



Indicators	Indicator description	Type of indicator	Characteristics				
			R	A	V	E	S
1	Percentage of HIV+ patients in general care who have been assessed for ART eligibility at every visit						
4	Percentage of HIV+ patients who are in general care or receiving ART assessed for active TB at every visit						
7A	Percentage of new patients receiving ART who have met eligibility criteria						
11	Percentage of HIV+ patients identified with active TB who are referred for TB treatment						
13A	Percentage of patients on ART who are adherent to ARV medicines						
16	Percentage of patients who started ART within the past 6 month that have shown clinical improvement						
28	Percentage of children and infants in general care who are assessed for ART						

(VII) Validity of data

a) **Record**

- Weekly reports,
- Monthly report,

b) **Variable:** validity of data

Assessment

1. What proportion of report data were drawn from correct data sources,
2. Desired 100% reports made from correct data sources.
3. Score scale

CODE	% of reports drawn from correct data sources	SCALE	CHECK
------	--	-------	-------

1	100	1	
2	99% OR BELOW	2	

Appendix (VIII): CHECK LIST

<u>ITEM</u>	<u>FOUND</u>	<u>YES</u>	<u>NO</u>
1.	Filled in registers	<input type="checkbox"/>	<input type="checkbox"/>
2.	Filled in report forms	<input type="checkbox"/>	<input type="checkbox"/>
3.	Filled in ART cards	<input type="checkbox"/>	<input type="checkbox"/>
4.	List of indicators	<input type="checkbox"/>	<input type="checkbox"/>
5.	Seen how data is analyzed	<input type="checkbox"/>	<input type="checkbox"/>
6.	Reports for 12 months	<input type="checkbox"/>	<input type="checkbox"/>
7.	Seen work plan	<input type="checkbox"/>	<input type="checkbox"/>
8.	Minutes of meetings	<input type="checkbox"/>	<input type="checkbox"/>
9.	Written feed back	<input type="checkbox"/>	<input type="checkbox"/>
10.	Data presented	<input type="checkbox"/>	<input type="checkbox"/>
11.	Records kept in safe place	<input type="checkbox"/>	<input type="checkbox"/>



Appendix (IX) ART CARD

ART Program: _____

Unique # HIV CARE/ART CONTINUATION CARD # _____ Name _____

Date Check box if scheduled. Write in alternative pick-up if #	Follow-up date	Duration in months since first starting ART/ current regimen	Wt.	If Pregnant EDO/PMTCT? FP/no FP If FP write method(s) if child write height	Function Work/Playing Amb Bed	WHO clinical stage	TB status (see codes)	Potential SIDE EFFECTS	New OI, Other problems	Cotrimoxazole	Other meds dispensed	ARV drugs		CD4	Hgb, RPR, TLC, other lab	Refer or consult or link/ provide if hospitalized, # of days
												Adhere/ Why	Regimen/ Dose dispensed			
<input type="checkbox"/>																
<input type="checkbox"/>																
<input type="checkbox"/>																
<input type="checkbox"/>																
<input type="checkbox"/>																
<input type="checkbox"/>																
<input type="checkbox"/>																
<input type="checkbox"/>																
<input type="checkbox"/>																

Pregnancy/family planning status if woman is of childbearing age:
P = Pregnant
 If pregnant, give estimated due date (EDD) and write PMTCT if referred to PMTCT.
 If not pregnant and on family planning
 If using FP, note methods (note: more than 1 method may be recorded)-use codes for FP methods.
 No FP = Not pregnant and not using FP
Codes for TB status (check on each visit):
 1. No signs or symptoms of TB
 2. TB suspected and referred for evaluation
 3. Currently on TB treatment. Record TB card #
 4. Sputum = TB suspected and sputum sample sent or record results

Codes for potential side effects or other problems:
 Zoster
 Pneumonia
 Diarrhea
 Fatigue
 Headache
 Rash
 Anemia
 Abdominal pain
 Jaundice
 FATT changes
 CNS: dizziness, anxiety, nightmares, depression

Codes for new OI or other problems:
 Zoster
 Pneumonia
 Diarrhea
 Thrush-oral/vaginal
 FEVER
 COUGH
 Difficult breathing
 Immune reconstitution inflammatory syndrome
 Weight loss
 Unlabeled discharge
 PID pelvic inflammatory disease
 GIUD genital ulcer disease
 Ulcers-mouth or other

Codes for why poor adherence:
 1. Toxicity/side effects
 2. Shared with others
 3. Forgetful
 4. Not better
 5. Too ill
 6. Stigma/discrimination/privacy issues
 7. Drug stock out-dispensary
 8. Patient lost/misplaced out of pills
 9. Delivery/travel problems
 10. Inability to pay
 11. Alcohol
 12. Depression
 13. Other

Codes for ART adherence. Estimate adherence for twice daily ART using the table below:

% Adhere = no. pills taken: x 100	
Total no. of pills dispensed	
Adherence	%
G(good)	> 95%
F(fair)	85-94%
P(poor)	< 85%

COMPREHENSIVE HIV CARE Patient Card

<p>Unique # </p> <p>District.....Health Unit.....District Clinician/team..... Name.....Pt Clinic No..... Sex: M <input type="checkbox"/> F <input type="checkbox"/> Age.....DOB.....Marital status..... Address: Subcounty.....Parish..... LC..... Phone (whose): Care entry point: <input type="checkbox"/> MTCT <input type="checkbox"/> Private/O Inpatient IDU <input type="checkbox"/> <input type="checkbox"/> Medical Outpatient <input type="checkbox"/> Under 5 <input type="checkbox"/> Ado/Sex Self-refer CBO <input type="checkbox"/> <input type="checkbox"/> TB <input type="checkbox"/> Outreach <input type="checkbox"/> <input type="checkbox"/> STI <input type="checkbox"/> Others <input type="checkbox"/></p> <p>Treatment supporter/med pick-up if ill: _____ Address: _____ Phone: _____ Home-based care provided by: _____ -Pregnancy status _____</p>	<p>Date _____ Enrolled in HIV care _____ ART Therapy _____ Medically eligible Clinical stage _____ Why eligible <input type="checkbox"/> Clinical only <input type="checkbox"/> CD4#% _____ TLC _____ Medically eligible and ready for ART _____ Transferred in from _____ ART started _____ Start ART first-line-original regimen: _____ At start ART: Weight <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Function <input type="checkbox"/> Clinical stage <input type="checkbox"/> Substitute within first-line: New regimen _____ Why _____ New _____ Why _____ Switch to 2nd line (or Substitute within 2nd line): New regimen _____ Why _____ New _____ Why _____ New _____ Why _____ Transferred out _____ To where: _____</p>
1st-line	2nd-line

Appendix (XI) REPORTING OF DATA

