PILOTING DIGITAL TOOLS TO UNDERSTAND CANCER PREVENTION IN UGANDA

A CASE STUDY OF CERVICAL CANCER PREVENTION IN WESTERN UGANDA

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I take sole responsibility for any faults that might have remained in this thesis.

DEDICATION

I would like to dedicate this project to my maternal aunt Namyalo Winfred who was recently diagnosed with cervical cancer and my late father Ssuna Patrick who died of lung cancer twenty years ago, I wish he was alive to see this project that I hope would help improve the lives of people in Uganda particularly in the area of public health interventions. Continue resting in eternal peace Dad.

STATEMENT OF OWNERSHIP

I declare that no part of this thesis has been taken from any published or unpublished material without due acknowledgement, all materials used has been fully referenced.

Sign: 

Date: 26th/ July/ 2022.

Allan Ndawula

LIST OF ABBREVIATIONS

AMREF	African Medical Research Foundation
DFID	Department for International Development
BAME	Black and Minority Ethnic
DHO	District Health Office
EVA	Enhanced Visual Assessment
GIS	Geographical Information System
GPS	Global Positioning System
HC	Health Centre
HIV	Human Immunodeficiency Virus
HMIS	Health Management Information System
HPV	Human Papillomavirus
K4C	Knowledge for Change
LMICs	Low- and Middle-Income Countries
MOH	Ministry of Health
NGO	Non-Government Organisation
RRH	Regional Referral Hospitals
SSA	Sub Saharan Africa
UBOS	Uganda Bureau of Statistics
UCI	Uganda Cancer Institute
UK	United Kingdom
UN	United Nations
UNICEF	United Nations International Children's Emergency Fund
USA	United States of America

VHTs Village Health Teams

VIA Visual Inspection using Acetic

WHO World Health Organisation

Glossary of key terms

Screening: Refers to a test carried out on people to determine those who may have specific disease symptoms.

Cancer: Refers to a disease resulting from by abnormal and uncontrolled division of cells that destroy the body tissue

ABSTRACT

Background

In Uganda cancer of the cervix is still a public health problem ranked as the leading cause of female cancer related deaths. According to the World Health Organisation (2018) Uganda has one of the highest incidence rates in the world estimated at 54.8 per 100,000 women. This is due to low uptake of available cancer services, limited awareness of the disease, and uncoordinated health systems with limited trained human resource, financial constraints, and poor infrastructure. And there is no reliable data describing population characteristics to rely on for health planning and decision making.

The fight against elimination of cervical cancer among women in Uganda does not only need clinical interventions as emphasized by most influencers such as WHO, it also needs a collective engagement involving systematic approaches and initiatives to achieve targeted prevention and control objectives.

Cancer of the cervix is totally preventable through primary interventions such as creating awareness and health education programs, HPV vaccinations and cervical screening in specific (eligible) populations. Monitoring of such interventions and determining specific locations to target eligible women would potentially be beneficial.

Aims of the study

1. This study was designed primarily to map cervical cancer awareness among the population of eligible women in western Uganda. The mapping process supports a benchmarking process to guide and evaluate cervical cancer preventative programs including screening and HPV vaccination.
2. It also aimed at mapping the spatial distribution of women eligible for cervical screening and the geography of awareness-raising interventions.
3. Finally, it used a cervical screening intervention to test the role of digital tools in tackling a wider range of public health challenges in low resource settings.

Methodology

The study used a descriptive cross-sectional survey that involved door to door household visits in the west division of Fort Portal Municipality, western Uganda. The survey targeted females aged 18 years and above. A structured questionnaire was developed on a website interface and loaded

onto a mobile device application (Epicollect). Epicollect is an Open-Source Software tool with free interfaces mobile and website facilitating field data collection and data visualisation.[1]

A mobile device (Tablet) with a remote sensing feature called the 'Global Positioning System' (GPS) was used to save location coordinates for every household visited.

Data analysis was done using Microsoft excel for statistical results and ArcGIS-online to analyse spatial/geographic data for the creation of imagery maps from the data collected.

Results

Broad themes from the study included coverage of awareness programs, the spatial distribution of women eligible for screening, knowledge about cervical cancer, and trends in terms of attendance for cervical screening. The study also captured demographic characteristics of women who have and have not attended cervical screening such as age, education and occupation.

In general, there was a high population of women eligible for cervical screening distributed uniformly over the study area with a high level of basic cervical cancer awareness among them (represented as 98% in Fort Portal Municipality). However, there were low levels of cervical screening uptake with over 80% of eligible women never attended cervical screening distributed randomly all over the study area.

Conclusion

Digital tools proved to be an exciting platform to address the demand and need for public health data for health interventions and research in developing countries for example in Uganda where the prevalence of communicable and non-communicable diseases is high in addition to pandemics such as COVID-19 and Ebola.

The study has demonstrated the powerful role that digital tools can play in guiding and evaluating health awareness interventions to support cervical cancer prevention. This provides the Ministry of Health with legitimate tools to clearly improve data collection and management, planning and monitoring and evaluation of health related interventions such as screening, community awareness-raising, HPV vaccination and treatment plans.

The introduction of digital tools in cervical cancer prevention and control intervention has made it possible for health managers and policy makers to see the potential application of the approach

[1] https://five.epicollect.net/

to control the spread of other community preventable diseases such as measles, malaria, and Ebola.

CHAPTER ONE: INTRODUCTION

Preface

This chapter introduces the research and briefly outlines the key areas of the whole study including digital tools, cervical cancer prevention and control. The chapter presents data related to cervical cancer prevalence in developing countries and particularly in Uganda. It also presents details of aims and objectives as well as the structure of the whole thesis.

Background

Cervical cancer is the uncontrolled growth of cells on the cervix. It is unique because it can take 10 to 20 years for invasive cancer to develop after mild abnormal cells and tissues are identified (World Health Organization, 2014). Pre-cancerous changes are typically diagnosed in high income settings using a PAP smear test taken from a woman in a health facility and analysed using microscopy in a laboratory. Subsequent investigations may include colposcopy and biopsy (WHO, 2013).

Colposcopy is a medical diagnostic procedure examining a woman's cervix using a surgical instrument called a colposcope. Biopsy is a medical test performed by surgeons that involves the extraction of tissue or cells from a living body to determine the presence and extent of the disease.

Smear testing is a very expensive process requiring highly trained laboratory staff and complex logistics and communication systems. Many public health facilities in Low- and Middle-Income Countries (LMICs) rely instead on Visual Inspection using Acetic Acid (VIA).

This method has been shown to be highly effective (Shastri et al., 2014; Sankaranarayanan et al., 2007; World Health Organization, 2013). The above studies, recommend the use of VIA in low resource settings because it is cost effective, it does not require sophisticated training or devices and the procedure takes a very short time to be completed. This can then trigger the possibility of instant treatment of all early invasive detected cancers as recommended by WHO guidelines (2013). At its early stages the disease is symptom free underlining the importance of early screening. Symptoms of more advanced disease include abnormal vaginal bleeding, bleeding after menopause, increased vaginal discharge and pain (Shastri et al., 2011).

In 2018, the world had an estimated 570,000 new cases and 311,000 deaths due to cervical cancer and 90% of these deaths occurred in sub-Saharan Africa ranking it the leading cause of female cancer deaths in LMICs (Ferlay et al., 2019; Nakisige et al., 2017). In Uganda, it remains the leading cause among women of both age-standardized cancer-related incidence (54.8 per 100,000) and cancer-related deaths (40.5 per 100,000) (Ferlay et al., 2019). In addition, approximately 6413 Ugandan women were diagnosed with cervical cancer and 4301 (67%) died from the disease in 2018. The study also found that human papillomavirus the main cause of cervical cancer was present in 32.2% of women tested in Uganda. This is also evident in a study by Rubaihayo et al. (2010) that highlights factors associated with high prevalence of sexually transmitted diseases among women including the high incidence of early onset sexual activities, presence of sex workers and multiple partners.

High rates of cervical cancer incidence and deaths in Uganda are mostly attributed to no or limited access to screening and human papillomavirus vaccination programmes, health education and infrastructure (Nakisige et al., 2017).

Uptake of Cervical Screening Services

A study by Ndejjo et al. (2016) reported disappointing results on cervical screening uptake ranging from 4.8% to 30% among eligible women in rural areas of Eastern Uganda. It was clear that more effort was needed to raise awareness and encourage women to come forward for cervical screening. And the WHO (2012) also advocated for more investment in health promotion and education and the development of health services data collection for routine monitoring and evaluation of cervical cancer prevention and control services.

The WHO (2019) recommends a comprehensive approach to cervical cancer prevention and control worldwide with greater emphasis on primary and secondary prevention activities. It proposed set targets to be achieved by 2030 including:

- Screening 70% of eligible women.
- Vaccinating 90% of girls with HPV vaccine by 15 years of age.
- Treating 90% of women identified with diagnosed cervical cancer.

In Uganda, the Ministry of Health Strategic Plan for Cervical Cancer Prevention (2010) indicates that all lower level health facilities (Health Centre IIIs, IVs, and Hospitals) across the country

should provide routine cervical cancer screening and refer women that need treatment for precancerous lesions to Regional Referral Hospitals. However, this is not currently happening due to several challenges such as unavailable equipment, poor infrastructure, untrained health workers and long distances to regional referral and national referral hospitals (Nakisige et al., 2017). The lack of a national database linking all cervical screening centres in the country (private clinics, non-governmental organisation clinics and public facilities) providing data about uptake for cervical screening and associated barriers in different regions and countrywide are rarely linked into national data collection systems. In addition, the lack of quality and accurate data describing relevant aspects such as location of screening sites (Maina et al., 2019), spatial distribution of eligible women and demographic characteristics (Nakisige et al. 2017), makes it almost impossible to determine cervical cancer prevalence and mortality.

Reducing the incidence of cancer of the cervix among women has proven to be a challenging global public health issue and this cuts across developed and undeveloped countries. For example, LMICs face challenges of stagnant and uncoordinated health systems, financial constraints, poor infrastructure, limited human resources, and socioeconomic factors (Nakisige et al., 2020). Uganda, as developing country, has limited access to radiotherapy and poorly functioning national cervical cancer prevention and control programs. This contributes to the high mortality rate (Nakisige et al., 2017; Ndejjo et al., 2016).

In High Income Countries (HICs) such as the United Kingdom and the United States of America, despite the health system's capacity to vaccinate, test, and the provision of specialized treatment, there is still a challenge of getting eligible women into clinics for screening especially among the Black and Minority Ethnic (BAME) groups as evident in published studies by Thomas et al. (2005) and Hennessey et al. (2018). For example, in the USA cervical screening is rates reach 79.9% of eligible population (21 to 65 years). However the prevalence of cervical cancer remains high among BAME groups characterised by low screening uptake (Harcourt et al., 2014). In the United Kingdom the cervical screening rate is estimated at 72% of eligible women aged 25 to 64 years (NHS Digital, 2019- 2020). However screening uptake remains low among BAME groups (Public Health England, 2017).

Cervical Cancer Prevention

Human papillomavirus (HPV) infection is a sexually transmitted infection (STI). As such, many risk factors for cancer of the cervix are those associated with a higher risk of all STIs such as engaging in early sexual activities, many sexual partners, engaging in unprotected sex, limited awareness of the disease, and non-attendance to cervical screening (Rubaihayo et al., 2010).

The primary mechanism for prevention of cervical cancer recommended by the WHO is HPV vaccination of young girls between 9 to 12 years of age who have not engaged in sexual activities since their immune response to the HPV vaccine is better compared to those in the higher age who might be exposed to the HPV through sexual activities. The HPV vaccine is always given in two doses between 0 to 6 months. This vaccine has proved to be effective in the prevention of HPV infections in 95% cases (Arbyn et al., 2018; Dochez et al., 2014; WHO 2014).

In Uganda, HPV vaccination programs were set up by the Ministry of Health (MOH) in 2006 and rolled out countrywide in most Community health centres and hospitals with cold chain[2] capability to vaccinate all 9 to 12 years old girls to protect them from the HPV. However, these programs are not fully functional and supported by the MOH especially in rural areas. Several challenges are faced by this program such as frequent stock outs of the vaccines, ignorance about the vaccine due to religious and cultural beliefs in the rural communities, long distances to reach health facilities, uncoordinated service plans (health centres only target primary schools which makes follow up for the second doses difficult especially when schools are closed i.e., during end of term breaks and during the current COVID-19 pandemic[3]).

The secondary prevention of cervical cancer is routine screening of the cervix to identify any precancerous lesions or invasive cancer using visual inspection with acetic acid (VIA). Those diagnosed with early lesions should then be treated with cryotherapy or thermal coagulation and those with advanced stages should be referred for further cervical cancer management (WHO 2012).

[2] Cold chain is the system used for keeping and distributing vaccines in good conditions consisting of transport, storage equipment, trained personnel, and efficient management procedures.

[3] Ugandan saw the second longest school closures in the world with schools closed for over 2 years.

Women who are HIV negative are advised to attend cervical screening once in three years whereas HIV positives should screen once every year since these women are at higher risk of developing cervical cancer at all ages (Nakisige et al., 2019; Gichangi et al., 2003; WHO 2014).

According to the Ugandan Ministry of Health (2010) and Nakisige et al. (2017), cervical cancer screening guidelines in Uganda are based on a "See and Treat" algorithm with a target age group of women between 25 to 49 years old. As noted above, most women who access public health facilities are screened using Visual Inspection with Acetic Acid (VIA). In practice, most facilities offering screening services are in Non-governmental Organisations (NGOs) complemented by screening outreach[4] in communities with some screening in the public health facilities. However, many of these do not offer a free one stop option and women diagnosed with early or advanced symptoms are usually required to access another health provider for treatment or any continuity of care such as biopsy and palliative care at their own cost.

The most common treatment option for women diagnosed with precancerous lesions is cryotherapy which relies on the use of cryo-gasses such as liquid nitrogen (PATH 2010; Nakisige et al., 2017; Ndejjo et al., 2018). Unfortunately, access to cryotherapy in regional settings[5] is predominantly in the Non-governmental Organisations, Private Not for Profit (PNFP) and private for-profit sector and incurs a fee (of around 30,000 Uganda shillings/ £6 or more). In reality, this amount is very high for women reliant on public health services, considering the average daily cost of living of a Ugandan which is less than £1.50 according to the World Bank 2019 GDP estimates.

In Uganda, midwives and nurses are the primary providers of cervical screening and any preventative interventions such as HPV vaccination, cryotherapy, and health education. This model has proven to be successful especially in facilities with nurse/midwifery leadership with 24 hours and 7 days' work-shifts. As such, cervical cancer services are not reliant on doctors and specialists who are rarely present in the health facilities (Tweheyo et al., 2019; Muhindo et al., 2017).

In developing countries, such as Uganda, the prevention and control of cervical cancer among the population should not only be looked at from the clinical perspective of providing effective

[4] These are mobile clinics taken to communities providing several health services closer to the people.
[5] Services at the National Referral Hospital in Kampala are usually provided free of charge.

screening, treatment, and vaccination programs. A range of essential nonclinical interventions such as access to effective awareness and health education are essential preconditions of preventative measures (WHO, 2012). Integration of these interventions is essential to potentially empower health systems to provide health care services depending on need. Therefore, identifying locations needing urgent health care services is paramount to evenly allocate needed health services in these locations. Studies have highlighted the potential association between the location of health facilities and the population as a metric to define geographical inequalities in health care provision (Maina et al., 2019; Shaw 2012).

Digital tools for Health Interventions

An effective health care system should have the capacity to identify and allocate resources to meet universal health needs, and especially, vulnerable populations as well as continuous monitoring problems and progress of the system. As technological innovations continue to grow worldwide, the latest fast-growing technologies can be applied in health interventions to promote better health care, enhancing health planning, decision, and policy making. This applies as much in Low- and Middle-Income Countries as it does in more advanced economies. Geographical Information System (GIS) is a computerised tool with the ability to collect, store, analyse, map and track, geographic data (Shaw, 2012; McLafferty, 2003). GIS technology allows the interpretation of georeferenced data, identifying and understanding location disparities and relationships between different spatial patterns in the form of visual maps to facilitate guided decision making (Jain et al., 2017; Cuadros et al., 2017; MacQuillan et al., 2017).

Studies have highlighted GIS technology as an effective tool in collecting, storing, mapping, and analysing large volumes of data associated with location including, for example, a database of health facility locations (Maina et al., 2019), the prevalence of diseases (Sarki et al., 2015), and health care and service availability (Salehi and Ahmadian,2017). However, without reliable, relevant data, and complete geo-referenced data, GIS cannot be considered for effective and reliable planning and policy-making in health (Mukooyo et al., 2010; MacQuillan et al., 2017).

In Uganda, the Ministry of Health (MOH) and District Health Offices (DHOs) use an electronic health information management system (HMIS) known as the District Health Information System 2 (DHIS2) to track performance and activities in health facilities across the country and districts, respectively. Activities include drug usage, outpatients, admissions, and referrals.

However, this system is facing limitations such as inconsistent updating of data, technical issues, limited internet connectivity, insufficient, accurate and relevant data as highlighted in Kasambara et al. (2017) and Sharma (2016) which make processes for decision making in health challenging.

Linking GIS technology to the existing Information Systems (DHIS2) in the health sector could yield potential contributions, for example, providing reliable, relevant, and accurate data to the Ministry of Health and the District Health Office. This could a provide a platform to better understand the importance of spatial data displayed as visual maps describing several health activities associated with location and performance in relation to the population hence optimising decision-making processes (WHO, 2012; Jain et al., 2017; Shaw, 2012). Therefore, determining locations and population that need health services can help policymakers in health to provide adequate resources to improve the provision of universal health care (Fletcher – Lartey and Carprarelli 2016).

GIS technology has been used in Uganda for some public health interventions. These include the location of maternal health care services such as caesarean deliveries Atuheire et al. (2019), the spatial distribution of leprosy Aceng et al. (2019) and in HIV-TB clustering Aturinde et al. (2019). There is a lack of data on the use of digital tools such as Geographic Information System with potential of analysing location data describing regional spatial patterns combined with population demographics that might be indicators or risk factors associated with uptake for cervical screening. Therefore, in this study digital tools were applied to assess its potential contribution in identifying eligible women for cervical screening and mapping cervical cancer awareness-raising coverage in Kabarole district to evaluate and improve the utilisation of available cervical cancer services.

The Role of Technology in the Screening and Treatment of Cervical Cancer

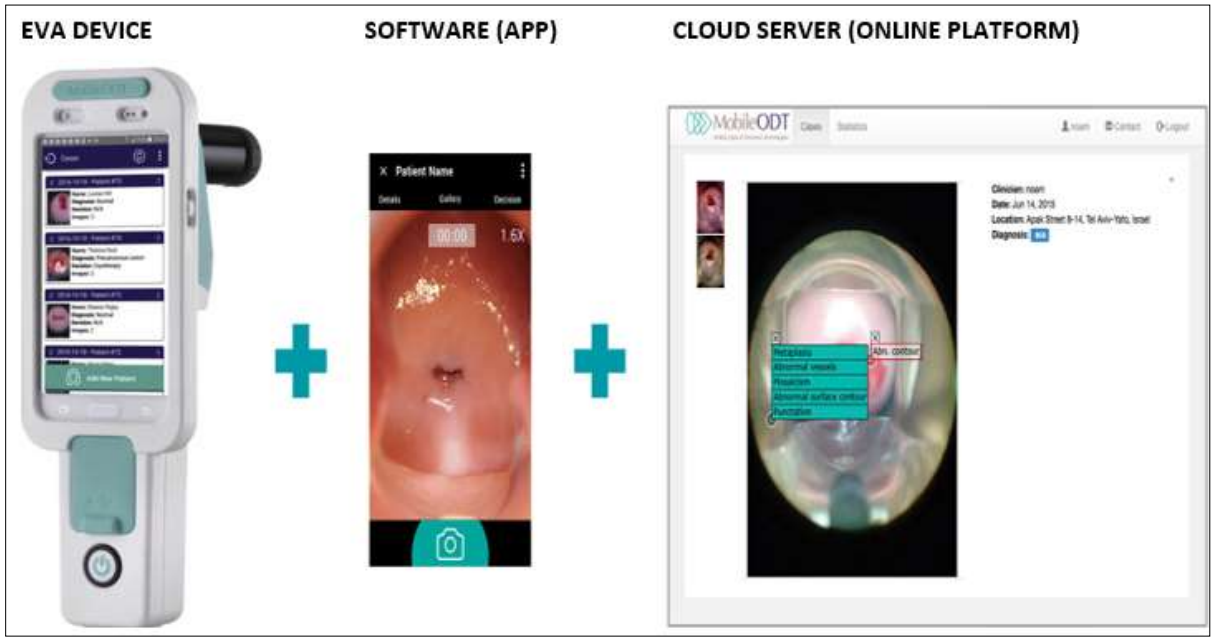
As mentioned above, the growth in technological innovations has created opportunities to build Point-of-Care devices for use in health interventions that are reliable and suitable. For use in LMICs, they must be affordable, not require expensive consumables and be easy to operate and troubleshoot (Fisher and Myers 2011).

Routine cervical screening is instrumental in the prevention and control of cervical cancer helping to identify any abnormalities of women cervix to guide health professionals to initiate

respectful treatment. On that note, a modern device (Enhanced Visual Assessment, EVA) was developed to assist health professionals during cervical screening to increase the visibility of the cervix, support telemedicine, and facilitate continuous training and mentorship, and follow-up since it stores patient information and photographs of the cervix. This supports evidence-based planning and clinical decision-making after the VIA. The EVA device is built around mobile phone technology providing user-friendly software interfaces and functions such as camera, torch and adjustable or zooming colposcopy as shown in Figure 1 below.

Figure 1 shows the outlook of the EVA device. From the left, this is the general outlook of the EVA device with a colposcope, displaying client information entered in the application on the screen. In the middle, it displays interface of the camera pointing at the cervix of the uterus showing adjustments of the lens to improve visualisation and on the extreme right it shows the image of the cervix uploaded on the website server called the Mobile ODT viewed online with internet connectivity.

Figure 1: The Enhanced Visual Assessment (EVA)



The World Health Organisation (WHO, 2013) recommends that any detection of abnormal cells arising from VIA or EVA-enhanced VIA should immediately lead to preventive treatment. This is of particular importance in LMIC settings where journeys to health facilities can be arduous

and expensive. Enabling a Point-of-Care, one stop-shop, approach limits the risk that women will simply not return for treatment.

Traditionally cryotherapy has been used in LMICs to treat abnormal cells. However, cryotherapy relies on the continuous supply of Nitrogen gases. In most public health facilities in Uganda dependency upon consumables leads to equipment underutilisation and systems failure as there is never access to petty cash to ensure continual purchase.

On that note, technology advancement introduced the Thermal coagulator device with the same feasibility to effectively treat invasive cancers as the traditional cryotherapy machine (Chigbu et al., 2020; de Fouw et al., 2019). The thermal coagulator device has proved to be more suitable for use in LMICs than the cryotherapy machine because it does not require gasses (Carbon dioxide and Nitrus oxide), it is portable, and it is electrically operated (Murokora et al., 2017; Campbell et al., 2016). The outlook of the thermo-coagulator machine is shown in Figure 2 below:

Figure 2: Thermo-coagulator Device

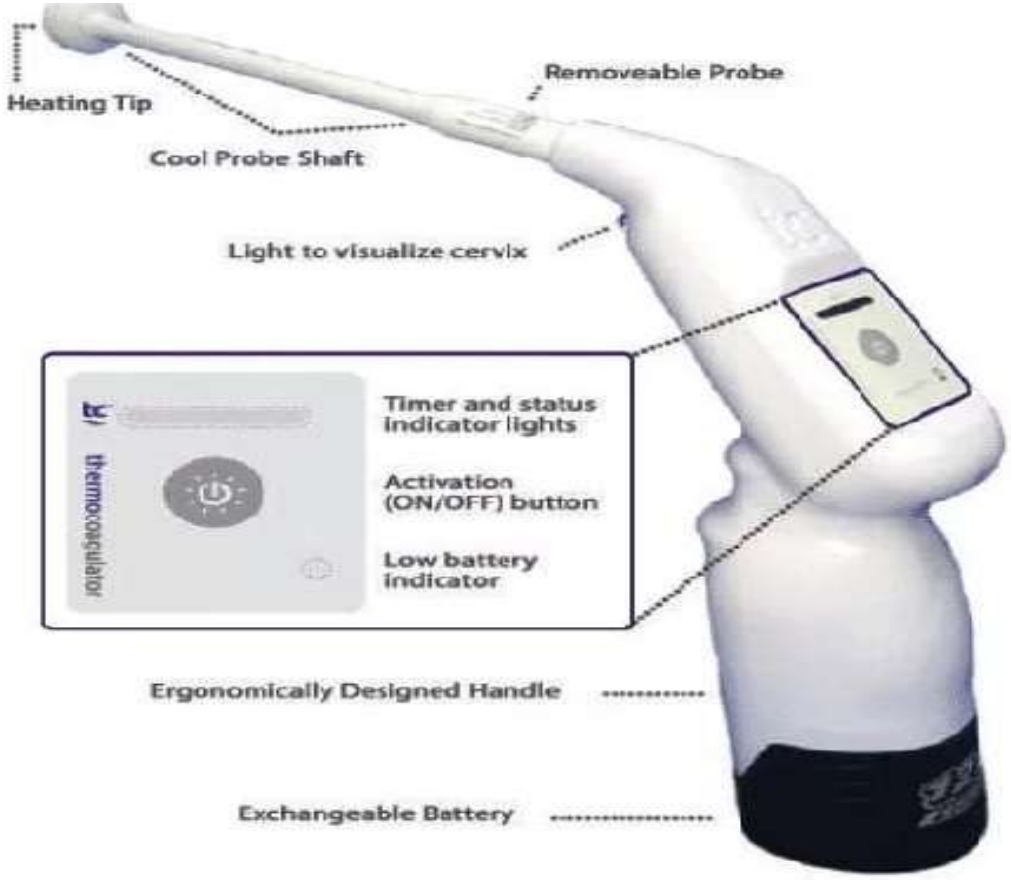
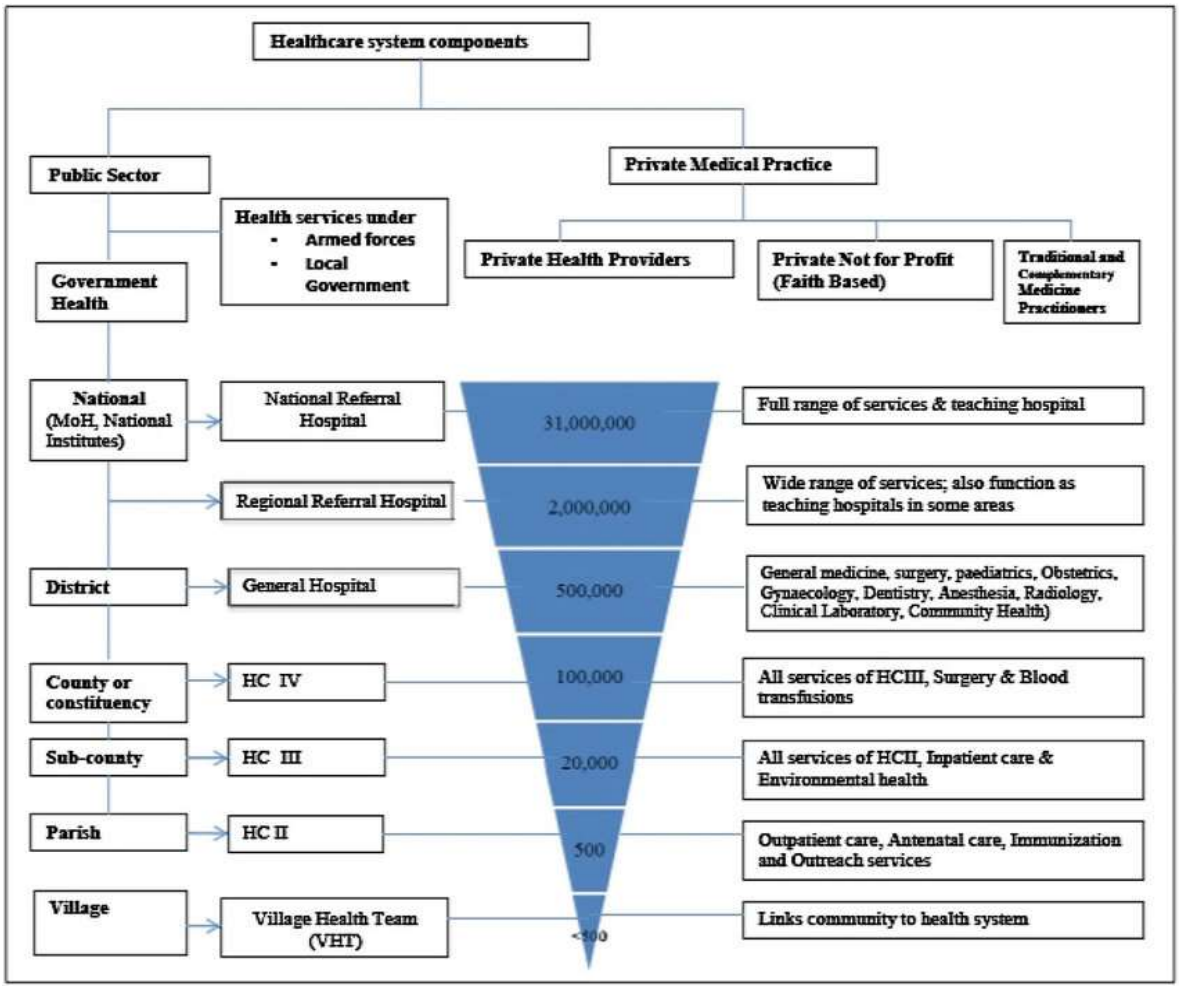


Figure 2 above shows the physical outlook of the thermal coagulator device. It is portable, can be handheld, with several removable/replaceable features such as rechargeable battery, probe (heating element) that can be autoclaved for sterilisation. This device has a simple automated procedure with indicators showing directions for usage.

The Ugandan Health System

The healthcare system in Uganda works on a referral basis; for example, lower health facilities refer patients to a higher facility when there is need for additional sophisticated health support as shown in Figure 3 below.

Figure 3: The structure of the healthcare systems in Uganda



Source: Acup et al., 2017

Uganda's health care system is divided into public sector, and private sectors. The latter comprises of private not-for-profit (largely mission hospitals / faith-based organizations), private for-profit, and traditional and complementary Medicine Practitioners (TCMPs) who are mostly informal, unlicensed providers (Kyomugisha 2008). The public sector infrastructure encourages government-led health care and consists of a hierarchically organized network of health facilities to improve access to care and promote a referral system (Kamwesiga 2011).

The hierarchy of the public health facilities consist of an ascending order, health centre (HC) I, II, III, and IV, general hospitals, regional referral hospitals (RRHs), and national referral hospitals. A HC I is the first level of the health structure who refer to a HCII. A HCI, it does not

have a physical structure (building); it comprises of the village health teams[6] (VHTs) also known as community health workers, who are trained community members that promote utilisation of health services, provide basic health education and curative services for malaria, pneumonia, and diarrhoea. VHTs are trained by the MOH through foreign NGOs and donor programs in areas such as malaria, and HIV. NGOs include AMREF, Malaria Consortium, Baylor Uganda, among others.

Health Centre 2 (HC II) facilities provide basic outpatient and community outreach services only. HCIIs comprise of nurses and nursing assistants who can treat common conditions like malaria, diarrhoea, and coughs. These refer all complicated cases they cannot treat to a HC III for further management after giving first aid.

Health Centre 3 (HC III) facilities serve every sub county level in Uganda providing general outpatient clinic, and maternity care services. HC IIIs should also have simple diagnostic testing laboratory services as per MOH health strategic plan 2015/16 - 2019/20 (PATH 2010).

HC III facilities are headed by a senior clinical officer. Clinical officers in Uganda have a different training programme to medical doctors which usually takes three years as compared to five years of medical training. The roles of Clinical Officers range from many medical and surgical tasks which are usually carried out by doctors, for example, diagnosis, prescribing drugs, treatment of various medical conditions, and anaesthesia. The biggest benefits of using clinical officers as compared to medical doctors are short training duration, the cost of employing them and high retention within health facilities (Saswata et al., 2005; Bradley et al., 2009; Hounton et al., 2009).

Health Centre 4 facilities (HC IVs) provide emergency obstetric care in addition to all the services provided at a HC III. A HC IV facility also consists of an operating theatre and inpatient departments, and as such, these facilities employ at least two medical officers (clinicians with five years of medical training) and more nurses and midwives.

Regional Referral Hospitals offer specialist medical and surgical services including mental health, ophthalmology, dentistry, and more diagnostic tests. Consultant medical staffs are available too.

[6] Village Health Teams (VHTs) were established by the Ministry of Health to empower communities to mobilize communities for health programs, distribute essential medicines and strengthen the delivery of health services at household level.

The National Referral Hospitals are set up for comprehensive specialist services although they also provide the services available in RRHs. There are only two national referral hospitals in Uganda; Mulago hospital and Butabika hospital which are both located in the capital, Kampala. Butabika is the national referral for mental health care. The Uganda Cancer Institute (UCI) in Mulago Hospital is the only centre for cancer care in the whole country with an 80-bed capacity receiving about 6,000 cases every year (Nakisige et al., 2017).

In the context of cervical cancer prevention and control in Uganda, the Ministry of Health Strategic Plan 2010, states proposed responsibilities/services for all health facility levels in the prevention and control of cervical cancer as shown in figure 4 below.

Figure 4: Proposed services for cervical cancer prevention and control in Uganda

Health facility level	Services required (standard)	Equipment required (standard)
Regional and national referral hospitals	• Health education/social mobilisation • HPV vaccination • Cervical screening using VIA or cytology • Colposcopy • Cryotherapy • LEEP • Surgery and • Radiotherapy (if available)	• Colposcopy equipment • Cryotherapy equipment • Gas tanks • Electrosurgical generator • Cervical screening equipment (speculums, consumables, and supplies) • LEEP equipment • Radiotherapy unit
District hospitals	• Health education/social mobilisation • HPV vaccination • Cervical screening using VIA • Cryotherapy • LEEP • Surgical treatment (if possible) • Referral for radiotherapy	• Colposcopy equipment • Cryotherapy equipment • Gas tanks • Cervical screening equipment (speculums, consumables, and supplies)
Health centre IV	• Health education • HPV vaccination • Screening using VIA • Cryotherapy • Referrals for LEEP, surgery, and/or radiotherapy	• Cryotherapy equipment • Gas tanks • Cervical screening equipment (speculums, consumables, and supplies)
Health centre III	• Health education • HPV vaccination • Screening using VIA • Referral for cryotherapy • Referrals for LEEP, surgery, and/or radiotherapy	• Cryotherapy equipment • Gas tanks • Cervical screening equipment (speculums, consumables, and supplies)
Health centre II	• Health education and mobilisation • HPV vaccination • Referrals for screening and treatment	• Educational materials

Source: Strategic Plan for Cervical Cancer Prevention and Control in Uganda, 2010–2014.

Patients are recommended to follow the hierarchical order while seeking health care for example from the HC II to IV, to the regional and national referrals, such that, if one level of the health centre is unable to treat and manage a patient due to lack of expertise or resources, the patient would then be referred on to the next level facility. However, this is not always the case as most patients choose and are able to directly access a higher-level healthcare facility due to convenience or the perception that only the higher-level facilities are adequately staffed and are less likely experience stock out of medicines. This lack of a clear referral health system leaves the national referral hospitals and the regional referral hospitals overcrowded leading to poor patient care, drugs and logistical stock outs hence increased mortality in the country (Ackers et al., 2016).

Despite the decentralised health system, access to health care services is still challenged by financial limitations and geographic inaccessibility to health facilities particularly in rural areas (Kyaddondo et al., 2003; Mukasa 2012).

Contextual Background

Figure 5: Map of Africa showing Uganda

Source: Google map

Non-government organizations (NGOs) involved in the study

Knowledge for Change (K4C) is a UK- and Ugandan registered Non-Governmental Organisation. It has been operating in Uganda since 2012, with the main objective of promoting and strengthening public health facilities. The core values of K4C centers on attaining sustainable, ethical, and mutually beneficial improvements in health infrastructure and the capacity of staff.

Knowledge for Change (K4C) runs an Ethical Education Placement (EEP) programme which provides sustainable undergraduate education placement opportunities aiming at improving public health services in Uganda and as well as providing reciprocal learning outcomes for the British and Ugandan undergraduates and professionals working with them (Ackers et al., 2017). As part of K4C's Ethical Education Placement programme in 2015, nursing students from Liverpool John Moores University (LMJU) undertook their nursing placements in Uganda. Their program involved medical community outreach activities with a local NGO: The Youth and Women's Empowerment[7] (YAWE).

YAWE is a small NGO operating in Kabarole district (Western Uganda) with its core activities aiming at social-economic empowerment of women and orphans and vulnerable Children (OVC) in the region especially those living with HIV/Aids. Some of the activities include HIV/Aids treatment, awareness and sensitization, psychosocial support to OVCs, vocation training, community cervical cancer screening and awareness outreaches.

YAWE is one of the partners of Knowledge for Change's Ethical Education Placement Program hosting students during their placements in Uganda and getting involved in various activities mentioned above.

During the community outreach, the students met women who raised concerns about access to cervical screening and the lack of treatment options if they are diagnosed positive. This raised several ethical issues about the advantages of cervical screening, versus the unavailability or affordability of treatment and continuous care such as cryotherapy, surgery, and palliative care by the people in the communities. Therefore, this initial consultation with the women (potential service users), initiated Liverpool students to raise funds to procure a cryotherapy machine

[7] https://www.yawefoundation.org/

(Thermal coagulator) that do not need sophisticated logistics to ensure sustainability in low resource settings shown in Figure 2 above.

Building on the use of visual inspection with acetic acid (VIA), K4C purchased a digital device called the "Enhanced Visual Assessment" (EVA) in Figure 1 above designed specifically for use in LMICs to enhance the quality of VIA. The device is built around a mobile phone with software (App), a torch and a colposcopy to enable imaging of cancerous cells. The device improves the ability to visualise the cervix when screening to empower both primary screeners and oncologists to confidently make reliable decisions. The device software provides a digital tool linked to a cloud server for easy collection and storage of patient information data easing the process of follow-up (Mink 2016; Kanyandekwe et al., 2018).

As noted above, most preventive treatment in Uganda is currently performed using cryotherapy devices. However, these face many challenges in a resource-poor setting requiring continual purchase of cryo-gasses. Funding to support this is not integrated into the current health system, with very minimal, funding for consumables at HC IIIs. This makes the purchase of such devices quite dependent upon external and continued income supply. As such, they are generally unsustainable. Fortunately, a new device (Thermal coagulator) in Figure 2 above had come on the market that has a similar effect but runs on re-chargeable batteries and is far more mobile. Cold Coagulation Therapy is a relatively new approach but has been validated in several studies (Campbell et al., 2016; Kanyandekwe et al., 2018; Maza et al., 2017). Services are delivered according to the Uganda national screening guidelines and WHO cervical screening guidelines (Nakisige et al., 2017).

In 2017, K4C set up of one of the first cervical cancer see-and-treat services in the Ugandan public sector, providing free of charge screening and on-the-spot or same day treatment for all women diagnosed with precancerous lesions at Kagote Health centre III.

However, despite several developments and initiatives such as training the service providers and equipping of the clinic with high tech devices to run the service free of charge, the turn up of women for screening remained poor, with only 148 women attending the screening service in the first 16 months of the project (between June 2017 and September 2018). As a response to the poor uptake of the screening service, there was a need to explore ways of encouraging eligible women into the clinic for screening.

Studies have highlighted limited awareness about cervical cancer as the biggest contributor to the low uptake of cervical screening among women in low resource settings (Nakisige et al., 2017; Mutyaba et al., 2007). In response to this, two community health workers also known as Village Health Teams (VHTs) were deployed to carry out a door-to-door community awareness exercise encouraging women to go forward for cancer screening, initially from households around the Kagote clinic. However, after a month's audit of the exercise by community health workers we could not determine which places (households) they had gone to for awareness raising and whether women who presented for screening were coming from the villages and households that they went to.

As a result, there was need to develop an intervention to track and map which villages community health workers went to during the door-to-door community awareness exercise in comparison to the number and location/villages of women presenting for screening at the clinic to guide subsequent mobilisations.

I received funding from the Royal Society of Tropical Medicine (RSTM) under the small grants scheme for early researchers to pilot the use of geographical information system (GIS) for health care interventions (A case study of cervical cancer). This funding was used to undertake the research described in this thesis.

The research will explore the role of digital tools in improving and optimising the planning and implementation of cervical cancer prevention and control interventions
In Fort Portal Municipality, Kabarole district, Uganda.

Objectives

- This study was designed primarily to map cervical cancer awareness among the population of eligible women in Western Uganda. The mapping process then supports a benchmarking process to guide and evaluate cervical cancer preventative programs including screening and HPV vaccination.
- It also aimed to map the spatial distribution of women eligible for cervical screening and the geography of awareness-raising interventions.
- Finally, it used a cervical screening intervention to test the role of digital tools in tackling a wider range of public health challenges in low resource settings.

Structure of the dissertation

This research is written in five (5) chapters after Introduction:

1. **Literature Review:** This chapter explores the evidence of cervical cancer prevention and control in both HICs and LMICs and application GIS for public health interventions.
2. **Methodology:** This chapter presents the methods of the whole study. It captures the overall design, materials used, sample of participants and procedure of approach and execution.
3. **Results and Analysis:** This Chapter analyses the overall data collected from the research participants. Results are also presented from the outcome of the analysed data.
4. **Discussion:** The discussion is mainly relating the findings with other previous findings from literature that includes studies and reports around the globe.
5. **Conclusion and Recommendation:** This chapter concludes and recommend the overall research findings in comparison to what the literature presents.

CHAPTER TWO: LITERATURE REVIEW

Introduction

This chapter presents literature related to cervical cancer screening with a focus on health education and awareness-raising to support the uptake of screening. After a more general review of the literature, it considers the contribution that Epicollect5 software can make to monitoring of health intervention results.

The Prevalence of Cervical Cancer Screening

Cervical cancer screening is a way of preventing cancer by identifying and treating early changes in the cervix (Bosch et al., 2013). Cervical screening is the key strategy for reducing the incidence of cervical cancer and mortalities arising from that. According to Path (2010) and WHO (2013) the recommended screening methods in High Income Countries (HICs) include Pap smear testing and HPV testing, while in Low- and Middle-Income Countries (LMICs), visual inspection with acetic acid (VIA) is recommended in addition to pap smear and HPV testing because of its affordability only found in the private sector health facilities by the minor population.

Pap smear is an examination always carried out by taking a sample (swab) from the woman's cervix and taken to the lab for microscopic examination to detect for potential precancerous or cancerous processes in the cervix. HPV testing is an examination of the cervix to detect the existence of the human papilloma virus in the cervix however it does not detect for precancerous or cancerous processes.

Visual inspection using acetic acid (VIA) involves the examination of the cervix after application of 5% acetic acid to detect any existing abnormal cells that turn white (Acetowhite) regarded as VIA positive (WHO 2013). The biggest advantage of this type gives immediate results making it potentially easier to provide treatment of the abnormal cells on the same day of the visit hence screen-and-treat model. This is the most inexpensive approach suitable in LMIC because it does not require laboratory infrastructure, it uses less logistics and equipment that are widely available, and any clinical cadre (midwives, nurses, doctors) can perform the examination after a short training. There are several studies backing up this approach worldwide such as a study done by Lee et al. (2016) and Denny et al. (2006) in South Africa which explored the effectiveness of VIA for cervical screening in developing countries These studies confirmed that

VIA method of screening as a low cost, safe, provides immediate results and can be administered to a larger proportion of women in LMICs. And in addition, a study by Nakisige et al. (2017) in Uganda that found out that VIA is the most sustainable method for cervical screening in rural areas and provides a platform for quick response since results are immediate on a single visit permitting a see-and-treat approach which is an effective approach to overcome issues such as transport costs and nonadherence to follow-up visits in case of continuous care or investigations.

The prevalence of cervical cancer screening is generally higher in high income countries than in low-income countries. The American Cancer Society (2012), for example, showed that in the United States of America (USA), the percentage of women aged 21-65 years who had a pap smear test within the past 3 years between 1987-2015 by highest level of education attained, ranged between 69.7% - 74.8%. This has been attributed to high cervical cancer awareness, availability of resources such as trained human resource and equipment. In addition, the existence of well supported and resourced national cervical cancer screening programs (WHO, 2014). However, despite the availability of resources, there are still major concerns getting women for screening especially in communities with poor socio-economic backgrounds for example the Black Asian and Minority Ethnic (BAME) and immigrants in the USA, Norway and the United Kingdom (UK) where there are low levels of education, low income and mixed cultural background (Marlow et al., 2015; Robb et al., 2010; Gele et al., 2017). In addition, low levels of education among these groups contribute to the limited awareness about health issues which can lead to high prevalence of the disease. This has also been evident in the recent COVID-19 pandemic majority of members in these communities do not come forward for screening and vaccination (Raisi-Estabragh et al., 2020; Patel et al., 2020).

On the other hand, in LMICs the prevalence of cervical screening has remained very poor, and this varies between countries impacted by various limiting factors. For example, according to World Health Survey (2002 -2004) analysis done by Akinyemiju, in 2012 the Bangladesh cervical cancer screening prevalence was rated at 1.1% compared to 57.6% for the Democratic Republic of Congo. These variations in the prevalence of cervical cancer screening were attributed to the socioeconomic and demographic characteristics of eligible women such as age, education, employment, marital status. Young, educated, married and employed women were

more likely to have attended cervical cancer screening in the past 5 years as compared to older, poorly uneducated and not employed.

According to Bradford and Goodman (2013) the low prevalence of cervical cancer screening in LMICs is due to inadequate healthcare resources and the high costs of setting up specialized clinics to provide diagnostics and treatment of cervical cancer. In countries like Uganda, the health sector either does not have sufficient funds (or fails to prioritise) to set up screen and treat clinics at different levels as stated in the MOH (2010) Strategic Plan to eliminate cervical cancer. These funds would include training of staff, buying and maintenance of equipment and sourcing logistical materials in the long run such as cryo-gases. This leaves screening mostly happening in private health facilities where they charge to access screening and any other specialized care at a cost. Although a few public facilities receive aid from foreign organizations, their functionality depends on the funds to buy basic logistical materials. This approach to screening with little if any integration and funding from the Ministry of Health is fundamentally unsustainable.

A study by Singh and Badaya (2012) in India which assessed the factors influencing the uptake of cervical cancer screening, using in-depth interviews found low levels of awareness about cervical cancer and the need for screening among Indian women. It indicated that 9% of the sampled women had never heard of cervical cancer and only 11.62 % had received at least one cervical cancer screening in their lifetime and mostly these women belonged to the higher socioeconomic class.

A similar study done on cervical cancer awareness and screening uptake at the Mater Misericordiae Hospital, Afikpo, in Nigeria revealed low cervical cancer screening uptakes of around 0.6%. This was attributed to lack of awareness, non-availability of screening centers locally, costs and time associated with screening in addition to the treatment centers for more specialized treatment and continuity of care (McFarland et al., 2016).

According to Lyimo and Beran (2012), the prevalence of cervical screening has remained low in East African Countries. In Tanzania, the uptake of cervical screening among women in rural districts found that only 22.6% of the participants had been screened for cervical cancer. The authors attribute these to the low levels of education about its prevention, socio- cultural related perceptions such as embarrassment and fear of pain during screening in addition to long distances to facilities providing screening services. A further cross-sectional study done in Kenya

looking at perceptions of risk and barriers to cervical screening at Moi Teaching and Referral Hospital showed that although most Kenyan women were willing to attend cervical screening, most women were fearful of the abnormal results after screening which might need high costs to seek specialized care for treatment (Were et al., 2011). This underlines the importance, stated above, of providing on-the-spot and free treatment services.

In Uganda, the absence of a national screening program responsible for monitoring and evaluation of available cervical cancer services countrywide is a key contributing factor to the low uptake of screening services among Ugandan women. A study by Ndejjo et al. (2016) in the Eastern rural parts of Uganda revealed that uptake of cervical cancer screening among women in some regions can be as low as 4.8% and up to 30% and this is mainly based on the negative individual perception, health facility challenges (including charging) and low levels of awareness. Negative attitudes and practices towards cervical cancer screening also extends to service providers i.e., health workers. For example, a study carried out among Mulago hospital employees found that over 80% of female employees have never attended cervical cancer screening at the Uganda Virus Institute (UCI) in Mulago, and less than 40% knew the risk factors of cervical cancer, eligibility and screening intervals. It also revealed that only 14% of medical workers in their final year of medical training were confident about using viginal speculums as a procedure for cervical screening (Mutyaba et al., 2016).

The Impact of Socioeconomic Status on Screening Uptake

The socio-economic status of eligible women can have a significant impact on the uptake of cervical screening. Several studies have cited different factors contributing to the low uptake of cervical screening such as the level of education, employment status, age, gender, marital status, location, religion and culture.

It is very well documented that in African societies men usually dominate the affairs of ‘their’ women at household level including decisions about seeking health care and financial access and covering the costs of any preventive and curative health care (Nancy, 2018). Similarly, studies by Mutyaba et al. (2007) and Kabagenyi et al. (2016) point out the role that men play in health care decision making in Uganda. They suggest that, from assistance with childcare to financial and emotional support, male partners can affect whether women access reproductive health services such as family planning clinics since they remain the sole provider of resources that can

enable women to attend reproductive health services. This is a key factor impacting cervical screening uptake.

Additionally, women's marital status also contributes to health-related decisions (Nakalevu 2009). Women who are married tend to get greater support such as financial, emotional support enabling them to have access to healthcare unlike in unmarried, divorced and single women (Kabagenyi et al., 2016). However, this does not appear to be a major determinant of intention to screen in some societies (Lee et al., 2013). For example, in rural parts of Nigeria, marital status was found not to be predictors of cervical cancer screening uptake. The key variable was the low knowledge and poor perceptions of the disease amongst women (Abiodun et al., 2014). Despite married men being supportive in helping their women to attend reproductive health services, several studies show that most men do not have knowledge of cervical cancer or the role men play in the transmission of HPV (Williams et al., 2012; Binka et al., 2019). Ignorance about cervical cancer among men indicates they are not likely to change their sexual behaviour to reduce the transmission of HPV to women such as using condoms and not having multiple sexual partners.

There are many studies that found costs associated with cervical screening in many contexts formed a critical barrier to screening especially in rural communities. For example, studies by Eze et al. (2012), Singh et al. (2012) Ndejjo et al. (2016) and Thippeveeranna (2012) show that most women from rural communities are generally poor with low or no income and most cervical screening services take place in geographically distant facilities and more so private health institutions. Therefore, access to cervical screening comes with costs of transport and service fees respectively which cannot be afforded by the majority of women in these rural communities.

In Uganda, health care is theoretically free in public health facilities inclusive of cervical screening. However, a community based-survey carried out by Twinomujuni et al. (2015) in Masaka to understand the low level of cervical screening, looking at the intention and behavioural factors, found that 4.6% women incurred costs in obtaining cervical screening services and the cost for services ranged from Uganda shillings 3000 (£0.6) to 100,000 (£20) with an average cost of Uganda shillings 43,000 (£9). These costs were reportedly prohibitive for service utilization among women from poor economic status. Many women in rural areas of

Uganda cannot afford the transport costs to facilities that offer cervical screening services which are mainly in Regional Referral hospitals located in cities or town centers (Nakisige et al., 2017; Ndejjo et al., 2017). However, some studies show that some women were willing to have cervical screening if any costs associated with the service are fully covered including transport to the health facilities and testing fees (McPherson et al., 2019).

Correspondingly, it is completely unethical to empower women to come forward for cervical screening services without a clear pathway for further investigation and treatment regardless of the socioeconomic status. This sabotages the ethical principles of medicine including beneficence where health providers should demonstrate and explain consequences and recommendations of the medical decision to the patient. And patients have a right to emergency care in case of an abnormal diagnosis regardless of their socioeconomic status (Olejarczyk et al., 2021).

The employment status of eligible women was pointed out to be another facilitator to attend screening. For example, women who are in higher level employment groups are likely to attend screening because they are more likely to be aware of the disease and the importance of screening in addition to being able to afford attend specialized or scheduled medical clinics unlike in women who are in lower employment groups or without employment. For example a study carried out by Nankya (2018) among female employees of Mulago hospital found high screening attendance among professional staff such as Nurses, Midwives and Doctors and low attendance among support and administrative staff. This is because trained staff has high level of cervical cancer awareness and the benefits of cervical screening (Ndejjo et al., 2017; Bukirwa et al., 2015).

However, other researchers assert that employment status does not contribute significantly to the prediction of intention to seek cervical screening. For example, a study by Matejic et al. (2011) in Belgrade, Serbia which was exploring the behavioral determinants in regard to seeking preventive reproductive health services did not highlight employment and occupation status of women as significant factor contributing seeking screening. The study found out that in order to empower women to come forward for screening there is need support social networks and relationships in addition to improving awareness or health literacy among women hence helping to influence health decisions.

Age was found to be a determinant of cervical cancer screening intention. Young women and older women face barriers which hinder them from utilization of available screening services including fear of abnormal results, costs for continuous health care and lack of knowledge hence low up take (Park et al., 2011 and Simou et al., 2010). In addition, individual perceptions and experiences among young and older women about cervical screening such as fear of pain using the vaginal speculums and Pap smear greatly contribute to the uptake of cervical screening (Blanc et al., 2009). Screening uptake in older women is usually low since they feel older and believe they are not at risk of having cervical cancer. This reflects the limited awareness and knowledge about the condition and eligibility criteria for cervical screening and in what intervals.

The level of education of women is also pointed out as a determining factor to screening uptake. Findings from a study by Baskaran (2013) showed that women with higher education levels are more likely to attend screening for cervical cancer than those with low levels of education. We may suggest that women who are educated have a higher understanding of health care issues and may be less likely to be influenced by popular myths than those with a lower education background (Were et al., 2011). Therefore, if women were educated and understood the importance of the screening, it would reduce the primary barriers hindering women from screening such as attitude, culture and religious barriers (Hoque et al., 2008). The level of educational attainment could also facilitate active decisions in accessing health care services including cervical screening irrespective of the marital status, employment status and age (Nankya 2018). However, studies by Ezechi et al. (2013) and Sichanh et al. (2013) did not indicate a strong correlation between education and the uptake of screening among HIV women. They mention limited awareness among women and costs associated with screening as the main determinants for screening up take among women in rural communities.

Culture and religious beliefs have also been pointed out in several studies in both LMICs and HICs as crucial determinants that affect screening up take among women (Mutyaba 2007; Cox 2010). Studies reveal that in the USA among BAME communities and in Asia, women consider cervical cancer to be caused by a girl's promiscuity (such as having many sexual partners) and this is considered as a taboo and a curse from God (Jillapalli 2020; Karbani et al., 2011). As a result of such beliefs women tend to not attend screening services as they do not want to be

associated with a disease considered to be a punishment from God. A study by Moeti (2019) in South Africa found that most families are led by males and women are expected to be submissive to their husbands and are not allowed to make health related decisions without consent from their husbands which indicates lack of spousal support when it comes to cervical screening (Nyblade et al., 2017; Atuhaire 2013). Additionally, these women may fear the implications of getting abnormal results at diagnosis because of the stress associated with these beliefs.

A study by Khan and Woolhead (2015) highlighted religion as one of the major factors associated to the low cervical screening uptake in communities with major religious groups such as United Arab Emirates where the majority are Muslims. This is largely due to religious misconceptions about cervical screening and affiliation to cervical cancer disease as a punishment from God. Similarly, religious women will always prefer being attended to by health workers from the same religion or cultural background. For example, Pakistan Muslim women may not attend screening if the medical personnel were not from her religious background because they fear embarrassment (Thomas and Saleem 2005; Vahabi et al., 2016; Padela et al., 2014; Guimond et al., 2013). Women consider abnormal results to have a severe impact on their daily operations leading to stress, decreased libido and confidence (Nakalevu et al., 2009). Cervical cancer affects the reproductive health system of women. Reproductive health matters are usually kept silent since it is socially perceived as a private matter not to be discussed. This prohibits women from accessing necessary reproductive health attention until they have advanced symptoms by which time, in LMIC contexts, it is usually too late to intervene and save a woman's uterus or indeed, her life.

In Uganda attendance at reproductive health services among women is also shaped by culture and religion. For example, Catholic and Muslim groups are not supposed to engage in any birth control activities and they believe every child is a blessing from God. And in Muslim communities male genders having several sexual partners is acceptable. Indeed many Muslim men in Uganda practice polygamy which is a facilitator to increased transmission of sexually transmitted diseases such as HPV in women (Mutyaba et al., 2007; Kabagenyi et al., 2014; Sileo et al., 2015). Individual perceptions and experiences about cervical screening procedure among women have also affected screening uptake such as the size of vaginal speculums used to visualise the cervix.

Other women believe that screening involves highly invasive procedures such as taking out the whole cervix (Atuhaire 2013; Ichaminya 2015).

In general, most communities which are socio-economically disadvantaged have not equally benefited from cervical screening programs across the world as discussed above. The delivery of Universal Health Coverage underlines the urgent need to set up cervical screening programs nearer to communities, increase awareness education about the cervical cancer and the importance of attending screening to improve women perception, ignorance and cultural taboos (Earker, 2001).

The Impact of Education and Awareness on the Uptake of Cervical Screening

Many qualitative studies have discovered that women's perceptions and limited knowledge about the importance of cervical screening influence the uptake of screening. Cervical cancer has continued to be a recognized public health problem in HICs and LMICs and this is all attributed to limited awareness among various communities in these regions which has contributed to the low uptake for available screening services hence high mortality.

Cervical cancer is largely caused by HPV which is largely transmitted through sexual intercourse. It is entirely preventable and early-stage cancers are treatable through the interventions discussed in sections above. However, there are several perceptions and lack detailed knowledge among women about the preventable and treatment interventions.

Several studies have shown poor knowledge of the disease in Africa, which even cuts across different literacy levels (Wellensiek et al., 2002). For example, a study carried out by Anorlu (2000) in rural areas of Lagos, Nigeria found that among the 500 attendees of maternal and child health clinics only 4.3% (22 women) were found to be aware of cervical cancer. This is similar in studies across Kenya Tanzania and Uganda where awareness of cervical cancer and mortality is high (Ichaminya 2015; Lyimo et al., 2012; Mutyaba et al., 2007).

In addition, poor knowledge is not only limited to local women but also trained health practitioners, who are supposed to have trained about non communicable diseases like cervical cancer and the importance of routine screening. They do not have proper knowledge about the disease either (Mutyaba et al., 2006; Anya et al., 2005).

The lack of updated national guidelines for cervical cancer prevention and control by departments of health especially in LMIC has a significant impact on the planning, monitoring and evaluation of cervical cancer services. For example, In Uganda, the MOH strategic plan for cervical cancer prevention and control was last updated ten years ago MOH (2010) with poor implementation of set recommendations.

In the UK, there is evidence that communities with high concentration of people from Black and Ethnic Minority (BAME), are associated with poor turn up for health related activities and checkups at health facilities especially for conditions without obvious symptoms such as HIV testing and cervical screening. A study by Marlow et al. (2015) in England showed that women from BAME backgrounds had poor turn up for cervical screening as compared to other British women. The author suggested that this was because women from BAME communities are more likely to be socio-economically disadvantaged with low levels of education, low perceived risk of due to inactivity in sexual activities and beliefs that cervical screening in not necessary unless a woman has symptoms. Several studies from countries associated with BAME and immigrants such as USA, Canada, and Norway found limited awareness among women from these communities and this was highlighted as the main limiting factor to attend cervical screening (Marlow et al., 2015; Lofters et al., 2017).

As mentioned in the introduction, Uganda is one of the countries with high cervical cancer incidences and mortality in Africa with over 80% of incidences present with advanced stages which are very complicated to treat (MOH 2010). This clearly explains the low level of awareness amongst Uganda women irrespective of their socioeconomic background. This is evident in a study carried in the rural areas of Uganda where screening uptake is estimated at 4.8% (Ndejjo et al., 2016).

In Uganda many women believe that abnormal screening results entirely means that a woman already has cervical cancer, and this causes anxiety and distressed at the prospect of an abnormal results (Nakalevu 2009; Lyimo et al., 2012). Women claim that abnormal results make them feel incompetent to give birth, unable to work, unclean and less attractive.

The cultural norm of secrecy that prevents women from discussing issues concerning reproductive health has also prevented women from attending cervical screening and seeking knowledge about the importance of screening (Lyimo et al., 2012). In addition to the above,

women attending maternity and reproductive health services without privacy feel embarrassed, disrespected, and loose dignity Ackers et al. (2017) which is another barrier hindering women from attending health care.

Therefore, since these are genuine concerns for women, there is a crucial need for promoting awareness interventions communicating reliable information respectfully about the need for screening among women of different age groups ignorance, individual perceptions, cultural, religious myths hence increase uptake for screening (Nakalevu 2009; Mutyaba et al., 2007; Ndejjo et al., 2016).

Cost and Screening Uptake

As noted above, the decision to have cervical cancer screening has been shown to be determined by the economic status factors impacting an individual's decision about whether to take up or not the screening. For example, several studies conducted in South Africa and Uganda found out those eligible women who were economically stable and employed, were more likely to participate in cervical cancer screening (WHO, 2010; Ndejjo et al., 2016; Nakalevu 2009; Bradley et al., 2004).

Women in minority, socio-economically disadvantaged, and rural populations have not equally benefited from Papanicolaou test (Pap smear) screening because of costs associated with the screening procedure (Garner 2003). A study conducted in the Sweden by Earker (2001) also showed that over 95% of participants had perceived seriousness associated with the outcome of the diagnosis of cervical cancer despite available free tax-funded health care system that could cover any continuity of healthcare if needed.

In addition, work by Satija, (2009) and Kaku et al. (2008) found that women with low socio-economic status are less likely to adhere to follow up of treatment leading to further morbidity and mortality from the disease unlike socioeconomically stable women.

More studies done in South Africa reported that women without partners were less likely to participate in screening Bradley et al. (2004) and this is usually in situations where women are single mothers and bread winners who do not have time to attend screening in addition to the fear of abnormal results and other associated individual perceptions related to expensive treatment.

According to Earker (2001), to improve uptake of cervical screening, it is crucial that organized screening programs take services nearer to the communities to enable screeners to access the clinics. Furthermore, this needs to be coupled with information on its importance, and increased efforts to understand (and positively change) women‘s perception of the disease (Nakalevu 2009; Maina et al., 2019). This is emphasized in the studies done in rural communities in Uganda by Mutyaba et al. (2007) and Twinomujuni et al. (2015) which found that a large proportion women in rural areas are usually too poor to afford transport costs to distant regional referrals hospitals usually providing free cervical screening hence huge hindrance to attending clinics. A study by Fort et al. (2011) in Malawi also found similar findings about the costs related to access of cervical screening services where women expressed a concern that despite healthcare being free in public facilities there is usually unexpected or hidden costs to access the health care which hinders them from coming forward for preventive reproductive health services such as cervical screening.

Therefore, as noted from above designing effective cervical cancer prevention and control approach for LMICs needs knowledge about performance characteristics of the different screening methods, and specific population characteristics. It should be a cost benefit program intended to target the needy population. The most significant part of cervical cancer prevention and control is the ability to raise awareness and screening all eligible women in the communities, coupled with surveillance (Lofters et al., 2013; Gwede et al., 2010). This can be helped using GIS technology in monitoring and planning cervical cancer services, Lofters et al. (2013) and Fletcher-Lartey and Caprarelli (2016) all suggesting being a valuable approach to determine areas with the greatest need for any interventions.

Geographic Information Systems (GIS) application for health interventions

GIS technology is increasingly becoming a vital instrument of public health in planning, monitoring and evaluation, surveillance and decision making for both communicable and non-communicable diseases (Smit et al., 2020; Pigott et al., 2015). The use of GIS technology tools in health has gone beyond mapping the distribution of prevalent infectious diseases, data collection and analysis aiding health policy makers to potentially plan, monitor and evaluate for health interventions (Palaniyandi 2015; Fletcher- Lartey and Caprarelli 2016).

GIS technology has gradually captured many fields of scientific investigations and innovations that have spatial dimensions such as spatial analysis of diseases. Spatial analysis of health services planning and interventions are some of the major public health concern of using GIS technology to potentially give visual digital maps displaying comparable layers of several variables, for example the prevalence and spread of vector borne disease (Lyseen et al., 2014; MacQuian et al., 2016).

To date, GIS technology has largely been used in HICs. For example, in 2009, the United States of America launched a multibillion program to adopt electronic health records in over 30 States with the aim of developing a comprehensive patient database to improve access to patient information facilitating decision making by family physicians hence improve health care access (Webster 2010; Xierali et al., 2013).

Data from the from the 1854 cholera outbreak in London by John Snow was digitised using the GIS technology producing visual maps showing and updating the mortality rate on more than 130 streets located in London during the Cholera outbreak that happened more than 160 years ago hence intelligence mapping can aid public health (Shiode et al., 2015). The newly generated GIS map helped to update John Snow's handwritten maps showing clear capture of streets houses and an insight of distribution of the population that is at risk and deaths from cholera. In the UK, GIS technology was used in primary health care planning to ensure equal resource allocation based on the geographical need. GIS was an essential tool in defining the profiles of service users by region supporting the planning and decision-making processes. A database of primary health care centres was set up according to the needs of the region in fields including children's medical services, drug use and mental health and to ensure that the allocation of health work force is based on the need (Ishfaq et al., 2012; Higgs and Gould 2001).

A study from Saudi Arabia found GIS technology to be essential in identifying priorities in locating places of health needs from grassroots, understand geographic gaps and ensure the provision of prompt services to those in need for example helping health planners in determining the health workers workload, monitoring of patients with their catchment areas and general assessment of health needs by region (Mahmoud et al., 2015).

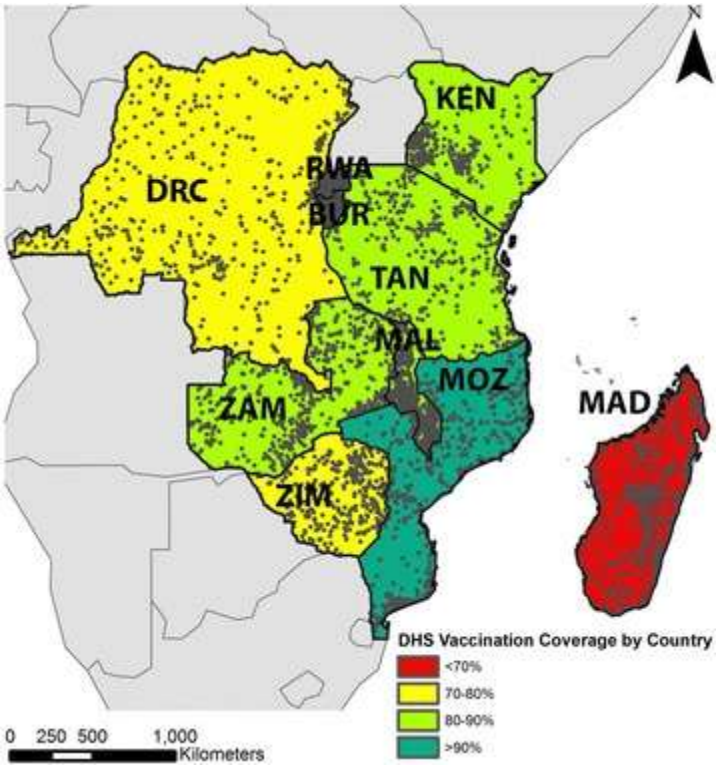
In LMICs, GIS technology has not been fully utilised on a wide scale, however many countries in these regions are beginning to be driven by the growth in the technology and adapting its use from the HICs in different sectors.

In African countries, GIS is being used in the rapid growth and transformation of health systems such as development and implementation of health information managements systems for health planning and decision making in allocation of health needs in these countries (Kriza et al., 2014; Sahu et al., 2014). Recently, GIS technology is being used as an intervention tool to track the geographical distribution of Lassa fever in some parts West Africa (Nigeria, Guinea, Cameroon, Benin, Liberia, Mali, Senegal, Burkina Faso, Sierra Leone, and Ivory Coast). The maps would act as a guide to support surveillance for timely monitoring of transmission, determining the risky population and optimal management of outbreaks (Mylne et al., 2015).

In Northern Nigeria, GIS technology was used to map the prevalence of hypertension and its comorbidities leading to mortality (Sarki et al., 2015). The study was able to determine the general geographical distribution of population which is at risk of hypertension in relation to their socioeconomic patterns, hence helping to design health interventions to tackle hypertension in low-income countries.

GIS technology was widely used to estimate clustering of measles vaccination coverage among children aged 1 and 2 years in ten African countries including Kenya, Tanzania, Rwanda, Burundi, Malawi, Mozambique, Zambia, Zimbabwe, Democratic Republic of Congo and Madagascar in comparison to the data from the Demographic and Health Survey (DHS) of 2008 and 2013 under the Measles –Rubella Initiative (Brownright et al., 2017).

Figure 6: Coverage of vaccination and DHS cluster by country



Source: Spatial clustering of measles vaccination coverage among children in sub-Saharan Africa Brownright et al., 2017.

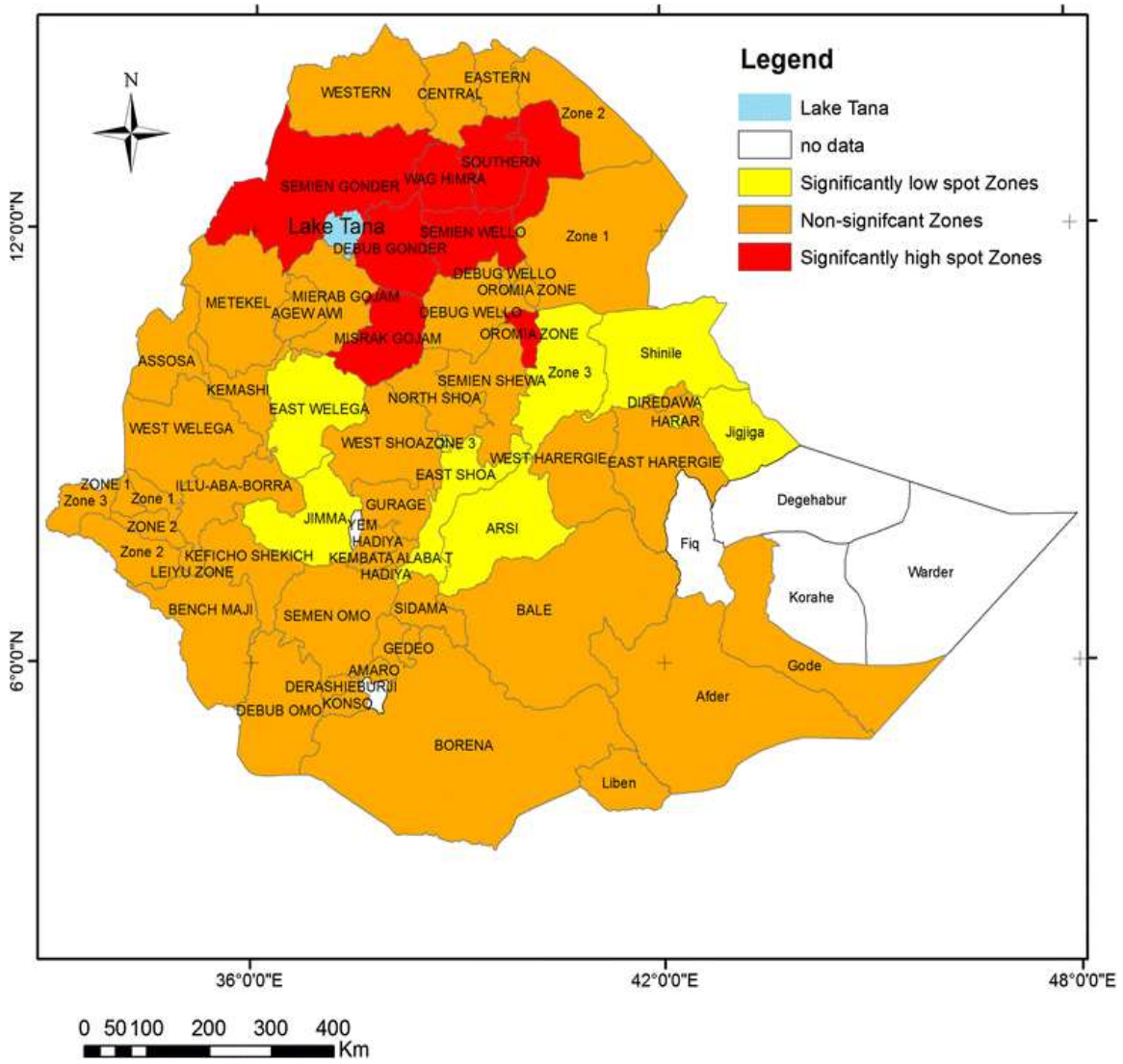
A comprehensive spatial analysis of DHS data provided a visual outlook of vaccination coverage in form of clusters each country. Most clusters that were detected with low vaccination coverage were found in countries with high vaccination rates such as Malawi and Zambia. In addition, analysis also found out that clustering of low vaccination was related to limited access to health care and low levels of health education. As such these results from this analysis provide reliable evidence to supplement immunisation activities and strengthen the interventional programs to eliminate measles in SSA based on evidence.

In addition, GIS technology was used in Ethiopia analysing the Demographic and Health Survey (DHS) 2011 data to determine the spatial distribution of childhood stunting[8] between the age of

[8] Stunting is the impaired growth and development of children due to poor nutrition

0-59 months, exploring determinant factors on individual and community level (Haile et al., 2016). Spatial analysis of DHS data produced results shown in Figure 7 below.

Figure 7: Prevalence of Childhood Stunting in Ethiopia



Source: Exploring spatial variations and factors associated with childhood stunting in Ethiopia (Haile et al., 2016).

Spatial analysis of Demographic and Health Survey data found the northern part of the country with hotspots with high levels of childhood stunting as compared to the central, eastern and western parts of the country with low levels of childhood stunting. As such, identification of areas with high level of childhood stunting provided visual evidence to support nutritional

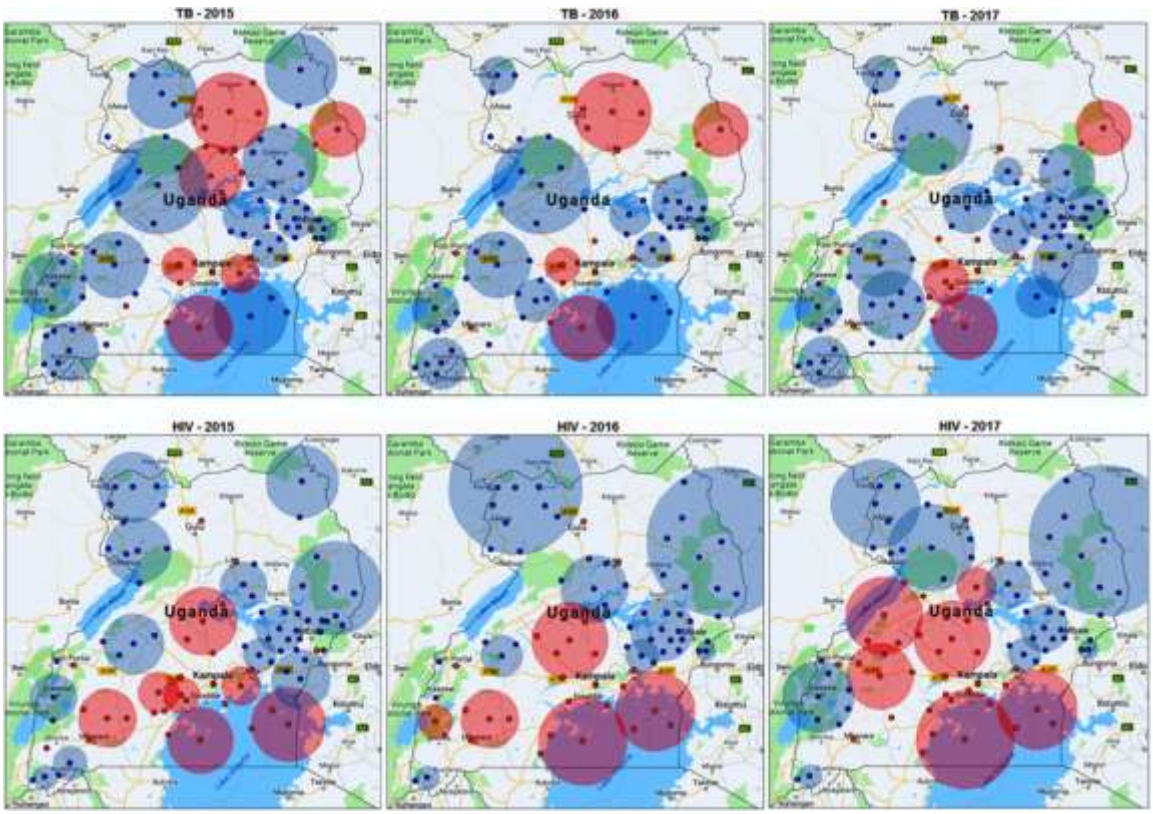
activities targeting needy areas hence strengthening interventional activities. In addition, some areas in the western parts of the country did not have sufficient data to determine childhood stunting prevalence hence making planning of interventional nutritional activities challenging due to unavailable data.

In South Africa, GIS mapping technology was used to determine the geographical distribution of HIV among persons aged 15 and 25 years based on the national HIV household survey conducted in 2003 (Kleinschmidt et al., 2007). The use of GIS effectively mapped the prevalence of HIV in South Africa identifying provinces with low levels of HIV such as rural areas of Western Cape and those with high prevalence including north-western parts of Kwazulu Natal, eastern Free State and Mpumalanga. The use of maps proved to be an effective approach that can be used in planning and guiding intervention programs targeting areas of particular need. Tanser and Sueur (2002) also discussed potential advantages of GIS application in tackling health problems in SSA for example intergration of GIS in interventional activities for pressing diseases in Africa such as malaria, tuberculosis, Ebola, cholera and HIV. The ability of GIS to produce accurtate maps locating areas with high prevalances and populations at risk provides a better knowledge to the health planners to perform accurate planning and monitoring of interventions progarms to tackle such diseases.

In Uganda GIS technology has mainly been used in malaria and HIV interventions although on a trial basis. For malaria interventions, GIS coupled with with Mobile-health was tried nationwide to track the access of of malaria diagnosis in clinical facilities and mapping potential benefit of using mobile health technologies in penetrating and tackling barries hindering preventative malaria interventions in rural areas of Uganda (Larocca et al., 2016). Therefore, the combination of GIS and M-health showed a remarkable potential to tranform the public health management system ensuring proper planning and survellinace of different challenges in communities on large scale remotely. Additionally, GIS was in used in Nothern Uganda to the map the distribution of HIV health care services and determining gaps to the access of available HIV care. This helped to show the geographical location of health facilities providing HIV care including counsellling and testing, Prevention of mother mother to child transmission (PMTCT), and Antiretroviral Therapy (ART) in addtion to tracking health service delivery gaps (Chamla et al., 2007).

A study by Aturinde et al. (2019) used spatial analysis to form an apporoach in the management of the double epidemic of Tuberclosis (TB) and HIV in Uganda as proposed by the WHO. This study used district data between 2015 and 2017 extracted from the DHIS2 managed by Ministry of Health in Kampala to investigate the geographical clustering patterns of both diseases across the country. Figure 8 below shows a map of Uganda showing geograpical clusters of TB and HIV hotspots identified after analysis of spatial data extracted from DHIS2.

Figure 8: Spatial Analysis of HIV-TB Co-clustering in Uganda



TB and HIV High (RED) and Low (BLUE) clusters across Uganda (2015–2017).

Source: Spatial analysis of HIV-TB co-clustering in Uganda by Aturinde et al., 2019.

This approach yielded meaning and visual results showing hotspot clusters with high disease prevalance rates for TB and HIV as such assisting identfying hotspot areas to be targeted for with holistic interventions aimed at tackling both diseases. Williams et al. (2011) confirms that GIS technology in health is mostly used for population health approaches to ensure health systems improvement in local communities through evidence-based practices from health determinants to

assist health planners in making decision about interventional activities targeting the most-needy or risk population. In addition, the use of GIS technology for mapping of the spatial distribution of infectious disease has potential for surveillance as shown in a study on Dengue fever control in Nicaragua (Chang et al., 2009).

And if GIS technology is combined with the provision of services for health systems strengthening, this could potentially help interventions and accurate planning to reach the needy population. This is backed by a study carried out in rural areas of Bangladesh by Robin et al. (2019) explored potential the importance of GIS in improving planning and resource allocation in rural areas. GIS maps were used to support prioritisation of underserved administrative units and clusters of disadvantaged communities to guide the district planning department to guide allocation of funds from the district budget hence improving health facility services based on the population and utilisation of services.

The use of GIS has not been fully utilized by health professionals in LMICs because there is lack of quality evidence showing how it can be used to stop the spread of diseases and technology (software, hardware, expertise) is percieved to be too costly to procure and maintain by many LMIC governments (Carlos et al., 2014). However, the increasing trend in technology and the use of mobile phones and reliable network has significantly helped LMICs because there is easy access to Open Acces softwares that do not need subscriptions and expertise supporting, storage, annalysis and surveillance for health interventions in these countires (Surka et al., 2014; Loukanova et al., 2014).

Despite the potiential benefits of GIS technology of being highly important, for accurate application and more reliable results for health interventions, interpretation mostly depends on the existing of local expertise in the health system and this has limited its deployment in LMICs which makes it difficult for people to use (Joshua et al., 2013). And in some cases, GIS technology in health interventions is misinterpreted during analysis Fisher et al (2011) and if this is due to errors then this may reflect the lack of expertise to manage for sophisticated hardware, software packages and capability for data analysis which may require specific training for reliable results.

This study will explore the potential deployment of GIS technology in the prevention and control of cervical cancer in Western Uganda.

CHAPTER THREE: METHODOLOGY

Introduction

This chapter presents the research design used in the study. It specifically discusses the target population, research instruments employed, the procedure for collecting and analysing data. It also includes a discussion of ethical considerations.

Research Design

A descriptive cross-sectional survey design was adopted to explore the role of Geographical Information Systems in guiding the administration and coverage of cervical cancer awareness-raising program and the distribution of women eligible for cervical screening in Fort Portal Municipality (West Division) Kabarole District. The survey involved door-to-door household visits by data collectors working with VHTs capturing data into a questionnaire loaded on to a mobile device with a remote sensing feature also known as GPS to record and map the location of participants surveyed.

Justification of research design

A literature search showed that cross sectional studies were the popular method used in majority of formal research projects that required collection of primary data from the study population. According to Omair and Aamir (2015), cross sectional studies can be used to determine several analytical components associated with the population. This research follows this design because it intends to collect primary data from a relatively large sample recording multiple data types from the study population (Setia et al., 2016). The design was ideal for this particular research since it involved determining the prevalence of cervical screening and other aspects related to cervical cancer awareness among participants. The same approach was used by several researchers such as Griffin et al. (2007) to find out whether personal, behaviour and psychosocial factors influenced physical activities, and results showed that psychosocial factors were less likely to change the participant's physical activity behaviour. A study by Kotwani et al. (2013) to determine the prevalence and awareness of hypertension in rural areas of western Uganda, collecting primary data through the a household-census with results showing a high prevalence of hypertension represented as (14.6%) among the 2252 participants screened and awareness of hypertension diagnosis was 38.1%.

In addition, the study design taps into potential implementation of the World Health Organisation's Strategic Plan for Cervical Cancer Prevention and Control (2019) highlighting strategies of increasing screening rates to the target specified to have 70% of eligible women screened globally by 2030.

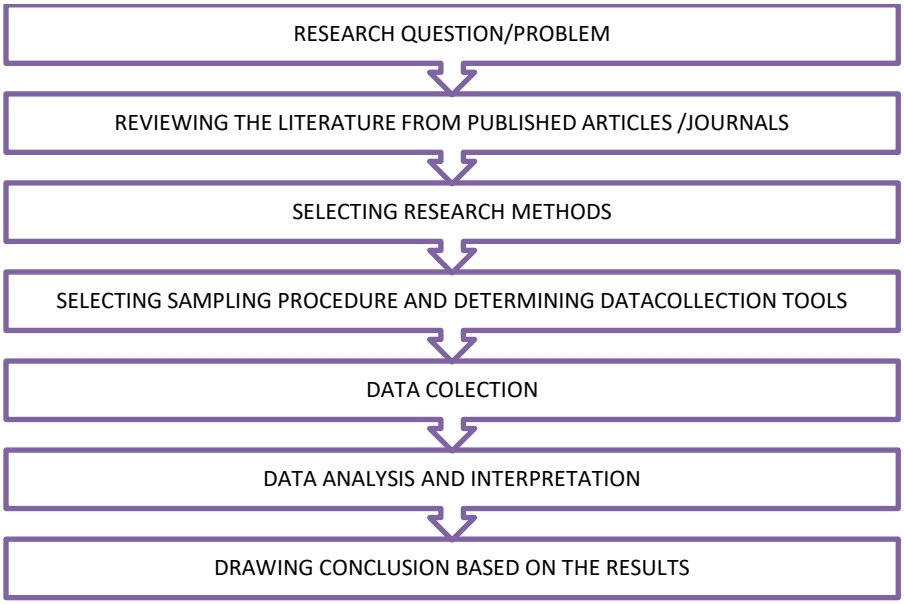
Strengths and Limitations of the Research design

The study has the advantage of allowing researchers to collect large volumes of data from a relatively wide population suitable for data analysis to present reliable results. Cross sectional surveys are usually inexpensive making it the cheapest and effective methodology to collect large datasets (Setia et al., 2016).

Omair and Aamir (2015) highlight that cross sectional surveys are the most reliable way of exploring population trends. This is because survey questions are phrased and standardised in the same way posed to participants which makes data analysis easier and enables results from the questions to be generalised to represent the broad population. This does not mean all questions are reliable because questions phrased poorly which can cause participants to respond to its meaning differently (Lee et al., 2014). This might reduce the reliability of the question.

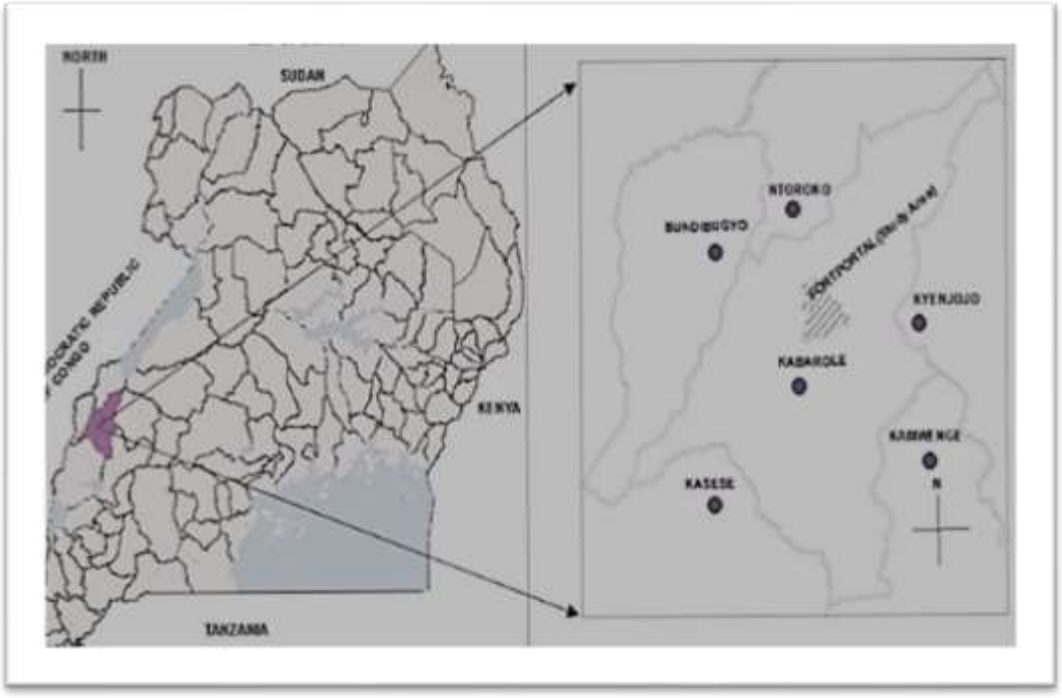
In addition, survey standardised questions do not offer flexibility and this does not give the researcher room to comprehensively examine and investigate participant responses to the questions and any slight change of the question may lead to confusion of participants' understanding of the question which may cause bias (Baird 2011). And, as cross sectional studies only provide snapshot results of a specific given time they do not consider what happens before or after data collection which makes it difficult to capture processes and changes over time.

Research process flow chart



Sample Area

Figure 9: Map of Uganda showing the location of Kabarole District and Fort Portal Municipality



Source: https://www.researchgate.net/publication/320422816_

This study took place in the West Division of Fort Portal Municipality, Kabarole District, Uganda. Fort Portal Municipality is a small town located about 300km west of Uganda's capital Kampala, geographically it lies between Latitude: 0.654444; Longitude: 30.274444 (latitude/longitude 0° 40' 28" N/30° 16' 14" E). Districts bordering Kabarole include Ntoroko, Kyenjojo, Kamwenge, Bundibugyo, and Bunyangabo as shown in Map 1 below.

Fort Portal Municipality is comprised of three political administrative divisions (Eastern, Western and Southern Division also known as Sub Counties).

In Uganda a Village is the smallest demarcated political administrative unit headed by an elected local council chairperson followed by Parish comprised of a number of villages headed by a Parish Chief. A sub county also known as a division is usually made up of more than one parish. A County also known as Municipality is made up of several sub counties or divisions represented at national level in the parliament. A district is the biggest administrative political unit made up of several counties and any municipalities in that area.

Figure 10: Villages in West Division of Fort Portal Municipality, Kabarole District

The map above shows villages found in the west division of Fort Portal Municipality where the survey took place. Most of these villages have access to the main roads including Bwamba road, Lugard road, Toro road, and Saaka road which connect Fort Portal Municipality.

Villages such as Kisenyi and Kabundaire are mainly the business hub of West Division comprising markets and shops. Rwengoma, Kahungabunyonyi, Kagote, Rukongora, Mpanga and Kyabukonkoni are mostly comprised of residential houses. Boma and parts of Njara are comprised of Fort Portal Municipality administrative offices, hotels facilities and amenities. Population distribution in these villages will be dependent on factors such as availability and proximity to services such as education, health and work.

Cervical Screening Clinic (Kagote Health Centre III)

Kagote Health Centre III (HCIII) is a government aided health facility located in Kagote village based in the West Division of Fort Portal Municipality. The facility provides a range of healthcare services including outpatient, laboratory services, antiretroviral (ART) services, maternity and cervical screening and treatment services.

Kagote HCIII provides healthcare services to the population of not only West Division but also outside the division. This is because in Uganda any patient in the country can access any health facility of their choice. According to the health facility registers patients travel over 30Km to attend Kagote HCIII. This could be due to progressive service improvements, and respectful care (Ackers et al., 2017). And to some extent the catchment area reflects the perceived quality of services and proximity of the health facility (Mutyaba et al., 2007; Zinszer et al., 2014; Ackers et al., 2017).

As such Kagote HCIII serves as the catchment area for the study area by radius and it had previously established a fully equipped cervical cancer clinic providing screening services and treatment of invasive cancer lesions for free. The clinic is supported by trained and experienced health workers with telemedicine support from oncologists based in the United Kingdom.

In addition, the provision of preventive cervical cancer services at Kagote HCIII taps into the Ministry of Health's strategic plan for the elimination of cervical cancer in Uganda (2010). The plan recommends all health centre threes across the country to be able provide cervical screening

services to all eligible women, promoting awareness-raising and provide referral pathways to women diagnosed with advanced cancers for treatment and palliative care.

Target Population

The National Housing and Population Census Report published in 2014 estimates a population of 53,786 with 27,357 females and comprising of over 14,000 households in the Fort Portal town. According to the United Nations population statistics, Uganda has a high fertility rate of about 4.7 births per woman and majority of the population between age 15 and 64 years (UN 2020). Several studies have specifically highlighted Kabarole district with a high prevalence of HIV Aids especially among women of child bearing age. This is linked to early engagement in sexual activities, multiple sexual partners, prostitution and other socioeconomic variables (Rubaihayo et al., 2010; Kipp et al., 2010; Chacko et al., 2007).

The survey aimed to enrol females aged eighteen (18) years and above residing in the west division and willing to confidently respond to the questions asked by the research assistants (midwives) at time of the visit. The questions included participants' demographic characteristics, cervical cancer knowledge, and general experiences about prior utilization of cervical screening services. Participation in this survey was strictly voluntary and all participants who agreed to take part gave verbal consent.

The World Health Organisation strategy to eliminate cervical cancer (2019) targets screening 70% of eligible women globally by 2030. The recommended or targeted age group to initiate screening is between 25 and 65 years and this should be resumed after three years among women who are HIV negative and usually once per year among HIV positive women. This is because women who are HIV positive are at higher risk of HPV infection since their immunity is suppressed making it easier to develop cervical cancer (Ghebre et al., 2017; Mwanahamuntu et al., 2009).

As mentioned above, the high prevalence of HIV in Kabarole District prompted us to include females from 18 years of age who were below the World Health Organisation recommended age (25 years) to potentially cover the population that is likely to be at risk of HPV infection.

Furthermore, achieving and demonstrating achievement of the WHO target of screening 70% of eligible women poses a challenge to many low and middle countries because there is lack of

reliable data. Data systems characterised with missing data, not updated and certainly important variables are missed out which makes data computation and analysis challenging hence biased data results such as screening uptake, incidences and prevalence. Health facilities in Uganda should be reporting progress of cervical cancer services to the MOH through HMIS monthly reporting system describing attendance, incidences, and referrals. However these are often not updated due to several challenges for example no Internet connectivity and missing data as cited by in a studies performed by Hotchkiss et al. (2010) and Muhaise & Kareeyo (2017). And the national database does not integrate all cervical screening providers linking public facilities, charities, and private clinics which make any potential benchmarking, monitoring progress, and auditing improvements of cervical screening programs challenging.

As a result there was a need to generate a secure and reliable population database with a range of appropriate information combined with GPS location to facilitate benchmarking and multivariable analysis. This could then enhance planning, monitoring and evaluation of cervical cancer preventative services including awareness-raising and screening.

Questionnaire Design

The questionnaire was developed in partnership with a Ugandan doctor Auma Judith who helped set up the service and cervical cancer project lead at Knowledge for Change (Auma 2021). After preparation of the initial draft questionnaire it was presented to midwives (research assistants) engaged in cervical screening to comment on their practical understanding of the questionnaire from a data collection point of view and identify any difficulties they had in completing the questionnaire. It was also presented to VHTs to initiate questionnaire translation to the local language.

The questionnaire included a range of questions about the demographic characteristics, location, knowledge about cervical cancer and attendance at screening services followed by information about which health facility the participant used for reproductive services and care.

Data collection on education level, employment status and age of participants was included in the questionnaire to get an understanding of the socioeconomic status of participants that took part in the study. The previous section has drawn attention to the role that age, level of education and type of employment play in determining the uptake for cervical screening. In addition, age

was also important in fulfilment of ethical boundaries and considerations to make sure minors are excluded.

The question about the number of females living in the household aged 18 years and above was included in the questionnaire so as to be able to estimate the total population of women eligible for cervical screening. Capturing the total population in the study area was ideal to determine the trend of population in different villages to potentially plan and guide awareness-raising programs.

Collection of data on cervical cancer knowledge was mainly to determine levels of awareness among the population. This is because awareness was highlighted in the previous chapter as a key determinant to health seeking behaviour. For example, a more knowledgeable population can be expected to attend cervical screening. However, according to the nature of this question (open ended) with set responses (Yes/No) there were anticipation of biasness to the results of this question and it could not bring out the factual level of knowledge (Lee et al., 2014). This is because some participants would prefer to say YES to everything because it is a powerful phenomenon for agreeing without a reflection to the questions. Therefore, results in this question should be considered carefully giving room for other factors in the context of participants' cervical screening attendance and their socioeconomic characteristics to avoid bias.

Data collection on the attendance status at cervical screening was included in the questionnaire to capture the uptake for screening services among women to create a reliable database to determine the level of screening attendance and tapping into the World Health Organisation target of screening 70% of eligible women by 2030.

The question about which health facilities participants attended for reproductive health services was included to assess whether women specifically attended government or private health facilities. This is because at that time treatment services for cervical cancer (chemotherapy) were mainly found in private facilities and Kagote HCIII is a government. And in the previous chapter researchers highlighted that people attended government facilities because services are free and those who can afford financially attended private facilities.

Participants were presented with a selection of facilities and asked to select which facilities they usually used including Kagote HCIII, Katojo HCII, Buhinga hospital, Virika hospital, Kabarole

hospital and others to include health camps, medical centres and NGOs. This question assessed whether women specifically attended Kagote HCIII because of the free available sexual and reproductive services including cervical screening. And also to provide evidence for health facility usage defining the catchment population of the health facility which could enhance planning and monitoring the progress several preventative interventions.

Collecting data on cervical screening experiences was included in the questionnaire to explore potential barriers and constraints affecting women's decision to attend cervical screening in Fort Portal. Such data would be relevant in arrangement and planning cervical cancer awareness-raising programs targeting specific barriers which are prohibiting women from attending screening.

Questionnaire Pretesting

Questionnaire pre-testing (or piloting) is used to assess the efficacy of a research instrument and whether it is delivering the kind of data required to respond to the research objectives. Pre-testing often involves a trial on a small group of people from the population under study. Teijlingen et al. (2002) and Faux (2010) suggest that questionnaire pretesting helps researchers to identify whether the instruments will provide the information expected, remove errors, and increase reliability.

The questionnaire was field tested, and all questions were in English language translated by data collectors to the respondents in the local language (Rutooro) known by most people in Fort Portal. Questionnaire pretesting was conducted on twenty participants who were asked to provide feedback on their ability to understand the questions.

All suggestions from data collectors and participants were incorporated while preparing for the final questionnaire such as not including the number of females below the age of 18 years living in the household.

Data collection and management

Data collection was conducted by two midwives and two village/community health workers (VHTs) using a mobile device with a GPS feature to capture the geographical location of participants recruited to take part in the study. The questionnaire was loaded onto a mobile device using an Open source software application known as Epicollect. This application loads

and saves the questionnaire for each entry performed by the data collector offline and later uploads on the cloud server when connected to the internet.

The use of mobile devices to collect data was adopted since it provided a quicker, cheaper, and efficient way to collect large sums of data from a wider population. This makes data management easier including accessibility, flexibility and interpretably (Freire et al, 2014; James, et al, 2013; Musa, et al, 2013). The need to capture the geographical location of women in the community made electronic data collection ideal because mobile devices have a GPS feature with the ability to accurately save the location in terms of latitude and longitude. To ensure data security, mobile devices and software have set passcodes assigned with restrictions depending on the role to limit data modification, access from unauthorised third parties and most importantly to avoid breaching of ethical diligence.

As mentioned above, the nature of Epicollect demonstrated good value because it had free access without subscription fees incurred with free web cloud server for data storage with unlimited storage. This makes transfer and conversion of data flexible into a range of formats ensuring compatibility to allow data analysis using several software such as Microsoft excel for statistical analysis.

Midwives and Village Health Teams (VHTs)

Midwives are health professionals who are trained to care for mothers and new-born babies. Most midwives in Uganda are dual trained as nurses so they will have a wide experience and knowledge base about several diseases.

In this study, two midwives were identified to be responsible for recruiting and interviewing participants gathering all required information and updating the questionnaires on mobile devices and after carrying out a short cervical cancer awareness session with the participants.

Midwives attended two training sessions on use of Epicollect software on the mobile phone. The first session involved familiarisation and introduction to the use Epicollect software demonstrating how questionnaire is downloaded, filling different data types, editing and saving on both mobile device and web server. The next session involved practicing the use of Epicollect by creating user accounts (data collector) for midwives with username and passwords, piloting data collection with tools in the community and troubleshooting any software failures.

Justification of involving midwives in the study

According to Wagner et al. (2018) household surveys conducted by trained health workers provide participants with time to discuss various health related problems in-depth to enable them to make appropriate health decisions, improve their knowledge and awareness of health problems.

And since the primary role of midwives is to ensure safe motherhood engaging with women at all levels of pregnancy and providing reproductive education to the mothers, they were suitable for promoting cervical cancer education to women during the study. For purposes of ensuring reliable data, midwives were appropriate for this role since they had prior knowledge of using mobile devices to avoid mistakes and ensuring completion of the questionnaire.

For the purposes of cervical cancer awareness, midwives had completed prior training and mentorship about cervical cancer and practical cervical screening carried out by an experienced British Oncologist and each midwife had screened at least twenty women independently.

Village Health Workers (VHTs)

Village Health workers are also commonly known as Community Health Workers (CHWs). These are community members who attained basic health care training through the ministry of health with the aim of promoting and mobilizing health developments in their localities (MOH 2016)

For the purposes of the study, two VHTs were identified to work alongside the midwives introducing them to the local communities to make sure a significant number of households is reached to recruit participants to take part in the study and also helping to give an overview of the project to the community.

The identified VHTs had an outstanding relationship with the community and were closely linked and attached to Kagote HCIII.

Justification of VHTs involvement in the study

The role for community health workers is to primarily carry out community mobilization activities to ensure the community is aware of any health related developments empowering communities to take part in decisions that affect their health. The World Health Organisation (2006) highlighted that in order to achieve universal health coverage countries should consider

integrating community health workers in to their health systems. This is to potentially increase access to quality health care in the context of primary health care services as a way of ensuring health universal coverage.

As such, the involvement of VHTs in the study was valuable since they linked data collectors to the community, identified households with eligible participants ensuring total coverage and collecting considerable amounts of data.

For the purposes of data management, as the main researcher I took full responsibility of supervising data collectors, performing routine errors checks and investigating any problems such as uncompleted forms, spelling errors or missing GPS coordinates. I joined the data collectors twice on field visits to make sure they were going to the right places and attending to any challenges they are facing with the technology.

As the principle data manager I was responsible for creating the questionnaire in the software user interface, assigning user accounts and login details for midwives, uploading all saved data from mobile devices to the cloud server, data curating and management of the database.

Geographic Information System (Mapping tool)

The mapping process used a mobile geographical information system which involved entering data using a GPS enabled mobile device. The structured questionnaire (discussed above) was uploaded onto a mobile device to record all the required information required for the study.

The mobile GIS system is a combination of different tools used to capture, store, analyse, display, manipulate and geographically reference data remotely. This system is structured around a few components including hardware, Software and users.

Hardware

Mobile devices with an enabled Global Positioning System (GPS) feature including an Apple iPad and a Samsung Galaxy Tablet. These are portable devices with large storage capacity, long lasting batteries and could easily load the software application version.

GPS is a global positioning satellite system used to determine the ground position of an object as referenced on the earth. Positions are coded as longitudes and latitudes.

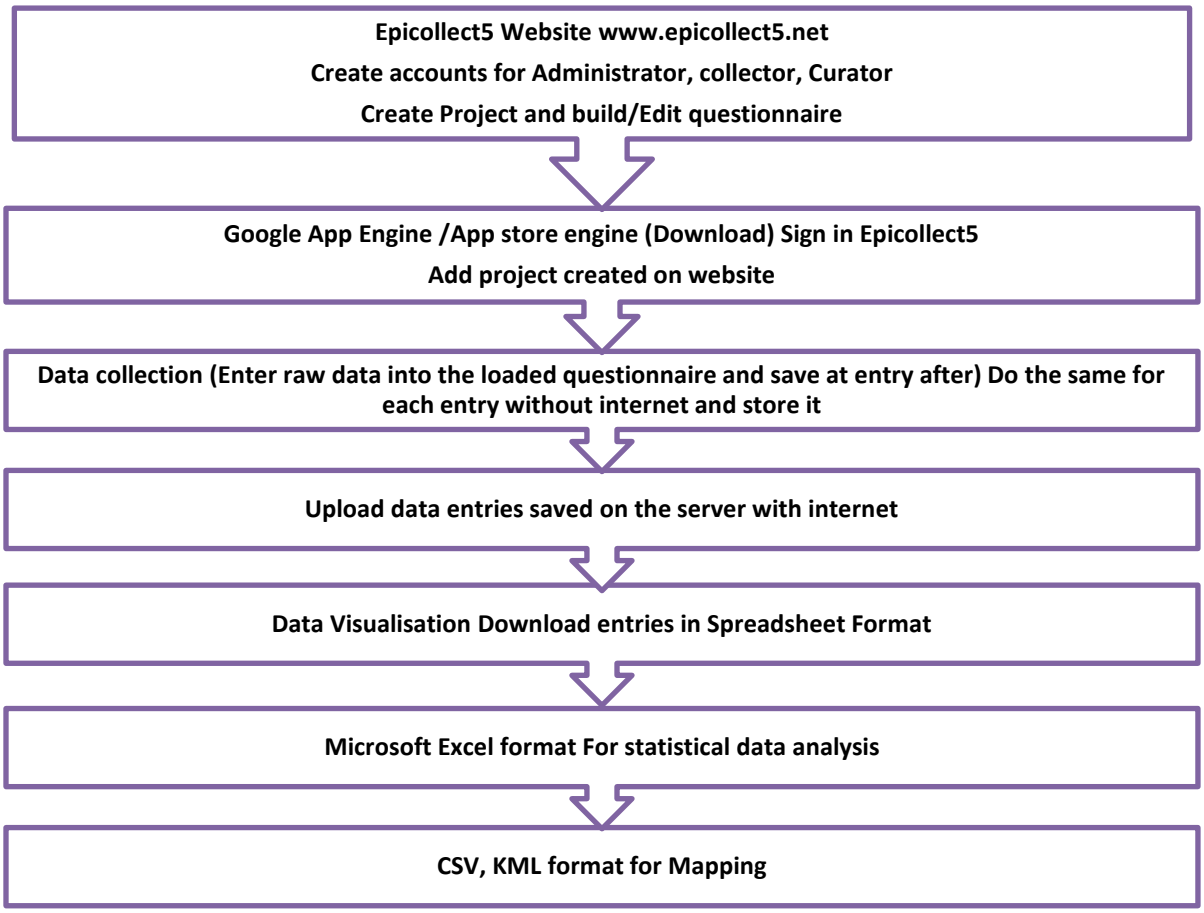
Software

An open data source software known as Epicollect (www.epicollect5.net) downloaded from the application store online on to the mobile device. This software was used in the study because of its ability to save the location coordinates of data collected using the device's GPS feature. The software had the ability to accommodate several users with different roles and restrictions such as data manager, curator, and data collectors. In addition, its ability to be accessed remotely in areas where there is no internet connectivity and reception on mobile devices used was another reason why this software was used.

Users

Users to the GIS were midwives who were data collectors in the community and the main researcher who performed data management including transfers, error checks and analysis as demonstrated in Figure 11 below.

Figure 11: Procedure of using Geographical Information System



Data Analysis

Quantitative data was cleaned and analyzed using Microsoft Excel to generate statistical results in form of tables and percentages and such as education level, employment status, age profiles, level of cervical screening attendance, and experiences of cervical cancer.

The Chi-square test was used to determine the statistical significance recorded of the percentage differences in the total responses and for all tests, alpha (α) was set at 0.05.

Spatial (location) data was analysed using the GIS software (ArcGIS) to produce results in form of visual maps including a map showing the villages where data collectors went to, the distribution pattern of participants, cervical cancer awareness and attendance of cervical screening.

Since the dataset was relatively large and comprised of multiple records and types, electronic data processing and storage were viable to incorporate spatial analysis with the available size of data. Musa et al. (2013) describes handling large data sets, GIS increases accessibility of health data by decision makers to determine resource allocation to the available population.

Ethics

Research started after getting permission to carry to out the study in the community from the Directorate of Health Services through the District Health Office (DHO) and the Town Clerk of West Division. Permission was got from the In-charge Kagote Health Centre III to release two midwives for two days a week to volunteer in data collection.

Ethical approval for the application (**HSR1819-061 – 'Community-based intervention to improve cervical screening services in Uganda; an evaluation protocol for the K4C cervical screening model)** was approved by the University of Salford Ethics Committee. Appendices 1 and 2 include the ethics approval and approval letter from Kabarole Local Government (Directorate of health services office) Appendix 2 allowing community engagement in the project.

As such, ethical approval emphasised data protection to ensure participant's privacy, confidentiality and anonimty is fullfiled by the reseacher. The password was set to limit access to the data collected on both the mobile device and web cloud to avoid access by unauthorised persons. Names of participants were not saved to ensure anonymity.

Consent from participants was obtained verbally in the local language by data collectors before the interview and upon agreeing to answer questions during the interview. This implied acceptation to take part in the study. Acceptance to take part in the study was very high since people in the study area had trust in Village Health Teams (VHTS) and health workers. Denial of participants to take part in the study was not found this could be because the VHTs had an outstanding relationship to the population.

CHAPTER FOUR: SURVEY RESULTS

This chapter presents findings from the households surveyed and the associated Geographical Information Systems (GIS) work. This chapter starts by describing the characteristics of the sample before presenting analysis of the results.

A total of 2014 participants were interviewed during the door-to-door visits.

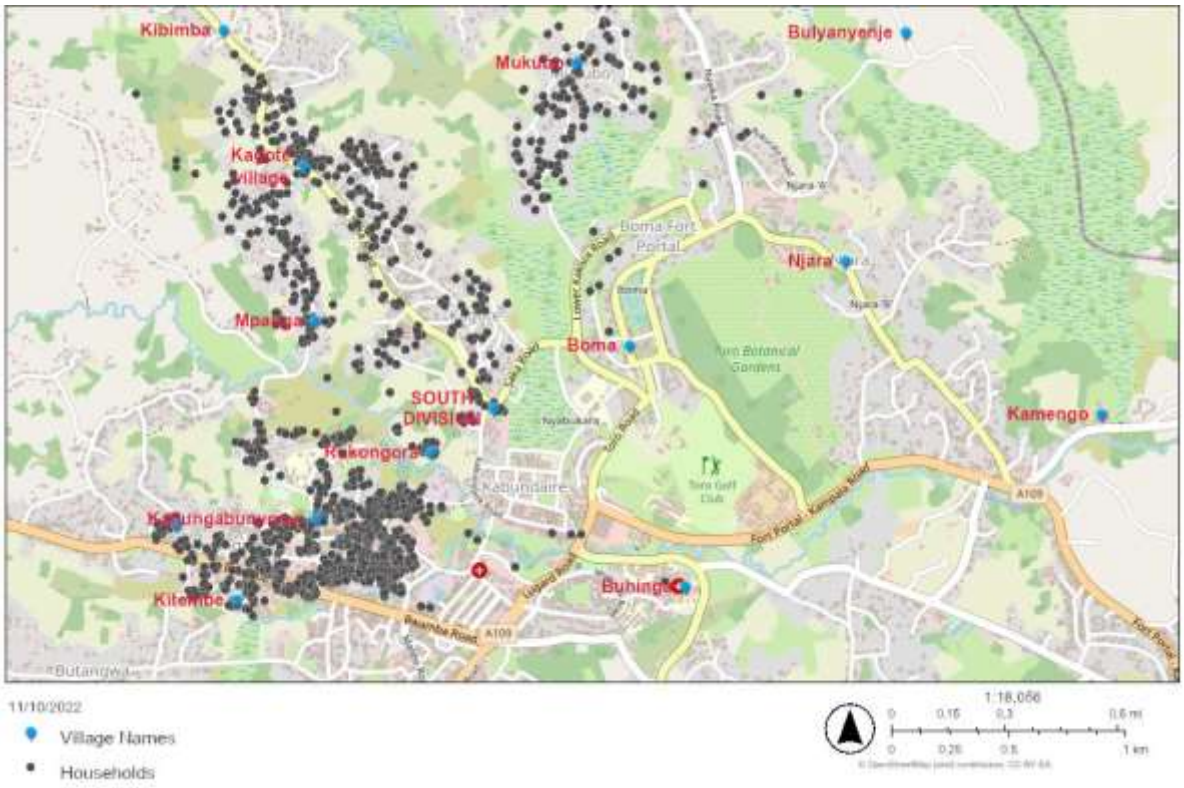
Sample Characteristics

Location: (Where did the respondents live?)

One of the benefits of combining the use of GIS with the survey tool is that we were able to map the penetration of the research assistants who worked with Village Health Workers into the Kabarole district community. During the door to door visit, research assistants used a mobile device to record participants' location data captured as Longitude and Latitude, socioeconomic characteristics, and their experiences relating to cervical cancer screening. After data collection, midwives carried out a short awareness-raising session with participants about the prevention and control of cervical cancer, mentioning facilities providing these services at no cost or free and advising them to come forward for screening.

Location data was further analyzed using ArcGIS online to present results in the form of a map as shown below. ArcGIS is an online geographical information system tool with functions of analyzing spatial or location data to produce visual maps. Access to this software was obtained from the University of Salford using the student account so no subscription was needed.

Figure 12: Map showing the Distribution of Participants



The benefits of using GIS in this way include an ability to monitor the progress of the research itself and the locations targeted. As the researchers were working in tandem with Village Health Workers responsible for awareness-raising, it also, critically, enabled us to gauge the geographical coverage of the awareness-raising process.

The map above shows the villages VHTs and Midwives reached during the door to door visits and these include Kahungabunyonyi, Kitembe, Kagote, Mukubo Kibimba Njara, Rwengoma, Kabundaire, Boma, Mpanga, and Kyabukonkoni. Of all these villages reached, most participants resided in the villages of Kahungabunyonyi, Kitembe, Kagote, mukubo and Rwengoma reflecting the concentration of residential housing facilities in proximity to the city center.

A small number of participants were reached in the villages of Njara, Boma, and Kabundaire because most of these places are concentrated with commercial housing, offices and market places. As such, Figure 12 describes the distribution pattern of women reached from different

villages to give a clear understanding of the community in terms of household set-up, road networks and the presence of health facilities.

Since the map describes the distribution pattern of participants reached during the study, this also show the coverage of cervical cancer awareness-raising programs carried out by the midwives and VHTs in the villages. This helps determine the locations to be targeted for future awareness programs to make sure information is spread evenly in the community for example in villages of Kibimba, Bulyanyenje, and Njara. In addition, these maps contributed to the planning and scheduling of awareness-raising programs in the community since it was easier to determine villages not reached and target these in the next visit hence enhancing planning.

From the above map, the distribution of women reached during awareness-raising could be used to potentially identify and locate women eligible for cervical cancer services to support the planning cervical cancer prevention and control interventions to these areas for example HPV vaccination and screening.

Who were the Participants?

As noted in the previous chapter the survey sought to target women between the ages of 18 and 65 (those eligible for cervical screening). According to the World Health Organisation (2014) the recommended age for initiating cervical cancer screening is 25. However, since strong evidence exists to indicate early commencement of sexual activity and associated HIV risk amongst younger women in sub-Saharan Africa Rubaihayo et al. (2010) and the minors not be being able to provide consent for Ethical reasons the decision was made to sample women from the age of consent (18 years old). Table 1 presents the demographic characteristics of participants, grouped into age ranges.

The age of participants that took part in the survey was grouped into a range of 6 years as shown in the Table 1 below. Over 70% (1426) of women fell within the recommended World Health Organisation target population with a further 28% (571) in the younger at-risk age group.

Table 1: Age Profile

Age group	Participants (%)	Participants (N)
18-24	28	571
25-31	38	768
32-38	18	372
39-45	8	155
46-52	4	71
53-59	2	39
60-66	1	21
>67	1	17

The survey also collected information about participants' occupations and levels of education. We might anticipate that more educated women, in higher professional groups have a higher awareness of cervical cancer, methods of prevention and, potentially be less susceptible to some of the local myths about the disease and prevention mechanisms.

Table 2: Summary of Participants' Level of Education

Education	Participants (%)	Participants (N)
Junior	0	8
Never attended school	6	115
Primary	27	534
Secondary	45	906
University	22	451

According to Table 2, over 90% of participants that took part in the survey had attended at least some years of formal education.

The current education system in Uganda consists of three levels. These include Primary, Secondary, and University (Tertiary). At the present time children are required to commence school at the age of 5 attending Primary (or elementary) schools for a period of 7 years. Children exit primary education with a Primary Leaving Examination (PLE) certificate. Students then progress into Secondary Education with some taking O levels (UCE) after 4 years and others progressing a further 2 years to A levels (UACE). Students may then continue into vocational programs or University degrees.

Given the age profile of our sample, some of the older participants would have attended school under a previous (Colonial) program in the 1930's-1960's – then known as 'Junior secondary schools' with programs combining academic and vocational study, similar to the UK further education system.

Table 2 shows that 115 (6%) women reported that they had not attended school at all. A further 534 (27%) women attended only primary school. 906 (45%) women had attended both primary and secondary education and a further 451 (22%) completed additional tertiary education.

According to UNICEF, there is low literacy rate among women in Uganda and this is attached to a lot of associated factors contributing to this such as poverty, cultural misconceptions about girl

education, school drops outs due to early pregnancies, menstruation and sexually transmitted diseases.

Agriculture being the main activity in Uganda, child labour is looked at as valuable in supporting agricultural activities for the subsistence and welfare of the family and this greatly contributes to the high fertility rate in the country of about 5 children per woman aged between 15 and 44 years (World Population Review, 2020).

Although in theory the Ugandan Ministry of Education provides free schooling, in practice some form of payment is always required and many parents who can afford choose to send children to better quality private schools. Many families will have a large number of children and have to make decisions about which of those children to invest in and mostly likely girls in rural areas are married off in exchange for monetary valuables to the family. This often results in girls not attending school at all or leaving at an early age. This situation has been exacerbated during the COVID-19 pandemic with schools closed for over 18 months and a prediction that many girls will not return to formal education (Burki et al., 2020; Mbabazi et al., 2020).

Occupation of Participants

For the purposes of this study, employment was categorised into five groups including employed, self-employed, housewife, peasant, and unemployed.

The term 'employed' means participants were earning from or working for an employer. However this category covers participants who were professionally employed and those employed to do casual jobs. The term Self-employed[9] in Uganda means participants were running their personal businesses or working on a freelance scheme. So this category involved participants who operated large, medium, and small personal businesses.

Housewives are those participants who were entirely caring for and managing their own families. Peasants were participants regarded as agricultural labourers working on a subsistence basis and Unemployed included participants who were not engaged in any paid work as highlighted in the Uganda population census report (UBOS 2016).

[9] In a Ugandan context Self- employed remuneration is only dependant on the profit got from goods or services produced https://ilostat.ilo.org/topics/employment/

Table 3: Summary of Participants occupation

Occupation	Participants (%)	Participants (N)
Employed	17	350
House wife	21	426
Peasant	9	186
Self employed	49	977
Unemployed	4	75

Table 3 shows that the majority of participants interviewed described themselves as self-employed 977 (49%) followed by housewives 426 (21%), employed 350(17%), peasants 186(9%), and those described as unemployed were 75 (4%).

Some literature has pointed that the nature of occupation or employment status of an individual significantly influences their uptake to seek health care especially in LMIC. For example individuals who were doing good paid jobs are more likely to seek and afford quality health care as compared to those who are unemployed (Park et al., 2011; Simou et al., 2010). Therefore we anticipated that women who were employed, self-employed and housewives were more likely to attend cervical screening as compared to those unemployed and peasants.

Key Findings

Sources of Information on Cervical Cancer and Screening

The survey sought to assess the sources of information women relied upon when making decisions about reproductive health and or cancer screening. Participants were presented with a range of options and invited to identify which of the following options they relied upon most heavily and these included Radio, Television, Newspapers, Village Health Workers, Word of Mouth and other sources.

Health care professionals and VHTs are responsible for providing health care services to the community to overcome any public health challenges. They also promote health education which is an important role in improving health awareness among the community members to help

reduce the likelihood of any rising health challenges in the communities. This can be addressed through using local radio stations, televisions, and newspapers. However, dissemination of health education to the community can as well be challenge due to language barriers with the existence of many languages in the country because ethnic groups and other socioeconomic factors such as myths, affordability of radios and televisions.

This can be reduced by translating health information provided by health providers into the local languages by Village Health workers and arranging radio programs targeting the different ethnic groups so as to disseminate health information in an easy and effective way to understand.

Table 4: Participants' Channel of Information

Channels of information	Participants (%)	Participants (N)
Radio	57	1148
Village Health Worker (VHT)	14	285
Television	11	221
Word of Mouth	10	192
Others	7	144
Newspapers and Magazines	1	24

According to Table 4, the majority of participants 57% (1148) relied on radio as their main source of health education. This backs the evidence from Uganda's National Media Access Statistics that highlights more people being reliant on radios as the main source of information rated at 65% (National Information Technology Authority (NITA) Survey 2017/18). The advancement in technology and communication allows a variety of platforms on which health education can be disseminated such as radio and television stations with a range of programs in different languages.

Fourteen percent of participants (285) relied on Village Health workers for health education. This explains the importance of VHTs in spreading reliable health information to the local

communities, improving health awareness, and reducing common myths and misconceptions hence increasing uptake to seek health care. As such, VHTs contribute significantly to improving the quality of primary health care through mobilising the community and implementation of health related interventions (WHO 2020).

Results identified 10% (192) participants received health information through talking to each other (Word of Mouth) this was likely because most participants were mostly from the same ethnic background speaking a similar language. As such, participants could easily discuss health issues and make decisions.

Table 5: Cross tabulation of channels of information and age profile

		Information					
Age category		**Others**	**Radio**	**Television**	**VHT**	**Word of Mouth**	**Total**
18-25	Count	51	405	84	95	63	698.00
	%	7.31 %	58.02 %	12.03 %	13.61 %	9.03 %	100.00 %
26-35	Count	62	447	89	129	93	820.00
	%	7.56 %	54.51 %	10.85 %	15.73 %	11.34 %	100.00 %
36-45	Count	29	188	34	49	30	330.00
	%	8.79 %	56.97 %	10.30 %	14.85 %	9.09 %	100.00 %
>45	Count	6	108	14	12	6	146.00
	%	4.11 %	73.97 %	9.59 %	8.22 %	4.11 %	100.00 %
Total	Count	148	1148	221	285	192	1994.00
	%	7.42 %	57.57 %	11.08 %	14.29 %	9.63 %	100.00 %

Although radio was the main source of information for all ages, the percentage table above shows 74% of older participants aged 45 years and above were likely to rely more on radios as their source of health information as compared to the younger participants of (18-25) years of age represented as 58% and 55% for those aged (26-35) years. Radio being the main source of information for all ages, this makes it the most efficient, effective, and cost-effective approach to

improving awareness coverage as a way of promoting health education in communities. This is because the radio provides real time information with potential of 24 hours broadcasting to the listeners.

A percentage of 14% (285) of participants mentioned the Village Health Teams as their main source of health education and over half of participants (147) were aged between 25 and 34 years of age and 100 out of the 192 participants in the same age group mentioned word of mouth as their source of information. These results not only demonstrate the role of VHTs in community mobilisation and promotion of health education but also the value of the door-to-door strategy in creating awareness in the community.

A total number of 144 participants relied on other sources of information. These might include the internet and social media and most of these participants are in the younger age group of 18-25 years and 26- 35 years. In the recent years, due to the increase in technology access to mobile phones, internet and social media have played a great role in the promotion of health education especially among the young population and this can greatly impact the decision to seek health care.

Cervical Screening Attendance

During the survey, participants were asked whether they had attended cervical screening before. The results to this question are summarized and cross tabulated with their socioeconomic characteristics as shown in Table 8 below.

Table 6: Summary of Cervical Screening Attendance

Participants% (N)	**Education**					
Screening attendance /Employment	**Junior**	**Never attended school**	**Primary**	**Secondary**	**University**	**Grand Total**
No	**0 (7)**	**4 (89)**	**21 (428)**	**37 (739)**	**17 (349)**	**80 (1612)**
Employed	0 (0)	0 (1)	1 (16)	3 (60)	9 (190)	13 (267)
House wife	0 (2)	2 (31)	5 (110)	9 (177)	1 (29)	17 (349)
Peasant	0 (2)	1 (18)	3 (59)	3 (69)	0 (10)	8 (158)
Self employed	0 (3)	2 (34)	11 (212)	20 (410)	5 (109)	38 (768)
Unemployed	0 (0)	0 (5)	2 (31)	1 (23)	1 (11)	3 (70)
Yes	**0 (1)**	**1 (26)**	**5 (106)**	**8 (167)**	**5 (102)**	**20 (402)**
Employed	0 (0)	0 (2)	0 (5)	1 (13)	3 (63)	4 (83)
House wife	0 (0)	0 (10)	1 (26)	1 (30)	1 (11)	4 (77)
Peasant	0 (0)	0 (2)	0 (9)	(16)	0 (1)	1 (28)
Self employed	0 (1)	0 (10)	3 (64)	1 (107)	1 (27)	10 (209)
Unemployed	0 (0)	0 (2)	0 (2)	0 (1)	0 (0)	0 (5)
Grand Total	**0 (8)**	**6 (115)**	**27 (534)**	**45 (906)**	**22 (451)**	**100 (2014)**

Table 8 shows that a percentage of 80% (1612) of participants that took part in the survey did not attend cervical screening and only 20% (402) of participants had attended cervical screening. Among participants that did not attend cervical screening, 97% (1542) of participants were

engaged in some employment and majority of these were self-employed, followed by housewives, employed, and peasants. In addition, 95% (1523) of participants had attended some level of education with a high rate among participants who attended secondary and primary education.

Among participants who attended screening (402), the results show that over 94% (376) of participants had both attended some level of education and were engaged in some employment. Attendance was higher in participants who were self-employed and attended both secondary and primary education followed by participants employed and attended university. Results from Table 8 are in line with evidence from some studies which confirm that attendance to cervical screening was highly dependent on the socioeconomic status of women for example women who were highly educated were more likely to attend screening compared to those uneducated since they are more knowledgeable about reproductive health issues, which then influence their decision to attend screening. And women who were engaged or employed in good jobs were likely to be knowledge about cervical cancer and more likely to attend screening as compared to peasants and unemployed. This is because employed women are more likely to discuss health issues among their social networks which in most case influence their decision to seek health care (Were et al., (2011); Nakalevu et al., 2009; Mutyaba et al., 2007).

Table 6: Significance of cervical screening attendance

Variable	**Received cervical screening % (n)**	**Chi Square**
Total (n=2014)	20.2 (402)	
Age		$X^2(3)=70.0$, $p<0.001$
18-25	11.2 (78)	
26-35	21.7 (178)	
36-45	29.4 (97)	
>45	33.6 (49)	
Education level		$X^2(3)=3.65$, $p=0.30$
None	22.5 (25)	
Junior/Primary	20.2 (108)	
Secondary	18.6 (167)	
University	22.7 (102)	
Information source		$X^2(4)=6.23$, $p=0.18$
Radio	20.0 (230)	
VHT	22.8 (65)	
TV	23.5 (52)	
Word of mouth	16.7 (32)	
Newspaper/Other	15.5 (23)	

The table above describes the significance of cervical screening attendance for different age groups, and education level among participants using the Chi square test. If the probability (P) value reported from the test is less than 0.05 the result is statistically significant and if the P value is greater than 0.05 the result is insignificant. The results table show that there were significant relationships in percentages screened across age groups, with those in youngest age group (18-25) least likely to have received cervical screening. The test did not show any significant differences in percentages screened across different education levels and information sources used.

GIS Analysis of Participants' Cervical Cancer Experiences

GIS allowed a dynamic analysis integrating location data with a range of other data collected from the survey to produce interactive visual maps describing participants' experiences in association with location. For example, the distribution of participants that attended cervical screening shown in Figure 13 below.

Figure 13: The distribution of cervical screening attendance among participants

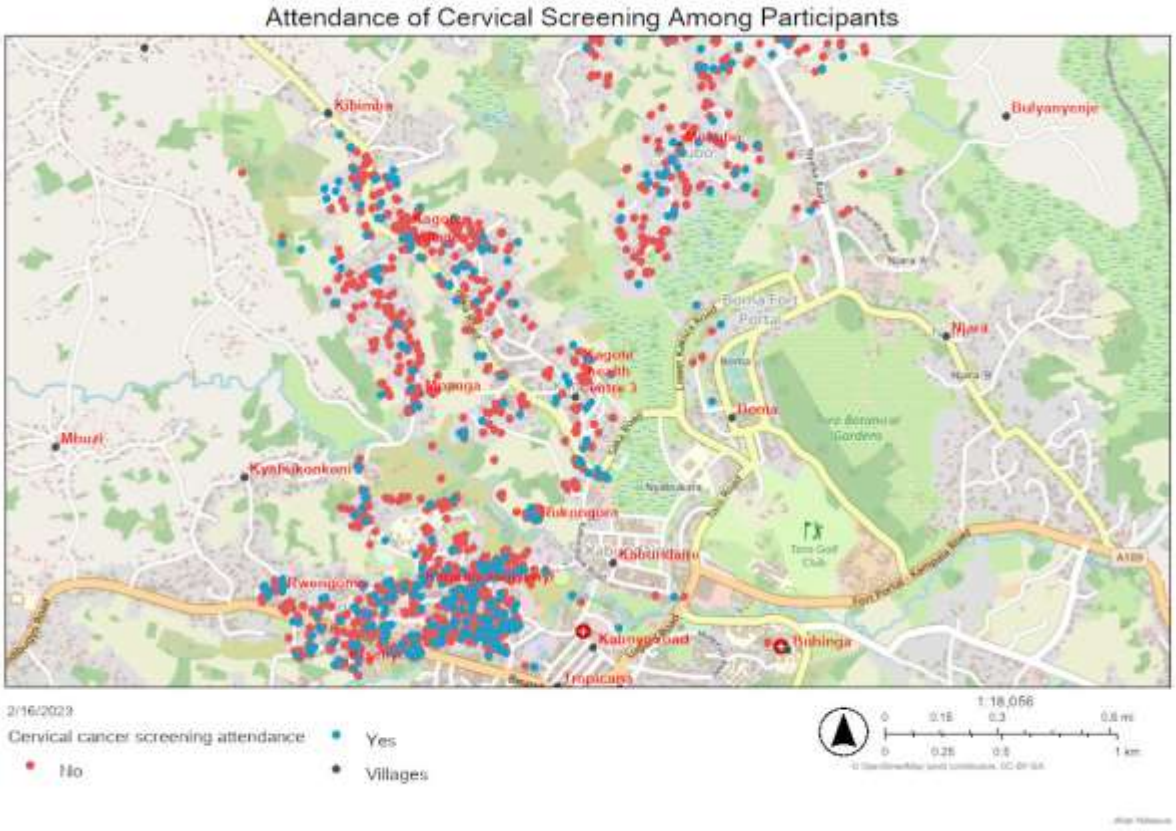


Figure 13 shows that most of the participants never attended cervical screening (Red dots) and these lived in concentrated settlements as compared to participants that attended cervical screening (blue dots) who were sparsely spread out in the study area. However, it is surprising that participants who attended screening lived in the same communities as those who never attended which showed no influence of women in encouraging other women to attend screening as highlighted in some studies that people are more likely to seek health care if they are in the same social network because they are likely to discuss health topics and make decisions. This raises the need to explore factors for the low uptake for screening among participants as asserted

by different researchers in the literature review chapter such as cultural myths and beliefs about screening, level of awareness, costs of screening, and lack of time to come forward for screening (Nakalevu et al., 2009; Ndejjo et al., 2017).

As such, this map highlighted strong evidence of the impact of GIS mapping technique in the interpretation of location data to identify possible locations of participants who had never attended cervical screening in the study area. This could potentially improve the identification of unscreened participants in the community to be included in the micro planning, subsequent monitoring and evaluation of cervical cancer awareness and screening programs to make sure all the villages are reached.

Usage of Reproductive Health Services

Table 7: Summary of facilities attended by participants

Participants %(N)	**Facility type % (N)**		
Facility Name	**Government facility**	**Private facility**	**Grand Total**
Buhinga Hospital	25 (511)	0 (7)	26 (518)
Kabarole Hospital	0 (4)	3 (64)	3 (68)
Kagote Health Centre III	56 (1137)	1 (12)	57 (1149)
Katojo Health Centre II	1 (19)	0	1 (19)
Others	1 (26	5 (103)	6 (129)
Virika Hospital	0 (7)	6 (124)	7 (131)
Grand Total	**85 (1704)**	**15 (310)**	**100 (2014)**

During the survey, participants were asked which facilities they preferred or usually went to in case they needed reproductive health services. Participants were presented with a number of health facilities grouped into government and private. As explained in chapter one, Government facilities usually provide free services to the general public however people often go to private facilities because they can afford and there a quick diagnosis and quick decision can be made unlike in government facilities.

Table 6 above shows that over 85% (1704) of participants preferred using government aided facilities when they needed reproductive health services and the majority usually attended Kagote health centre III 56% (1137) followed by Buhinga hospital 25%(511). Participants that preferred private health care 15% (310) usually went to Virika hospital 6% (124), other facilities 5% (103) which could include medical centers and small clinics, and 3% (64) preferred Kabarole hospital. This showed strong evidence that most participants were reliant on government aided facilities as compared to private health facilities, however, other participants could use both depending on their preferences since government services are not capped. In terms of diagnosis for cervical cancer, screening should be carried out in all government facilities as asserted by the MOH strategic plan (2010) at no cost. However this is not happening due to challenges highlighted by Ndejjo et al., (2016). Women who can afford tend to attend private facilities and in the case of positive diagnosis, women are likely to be referred to the National Referral Hospital (Uganda Cancer Institute) for continuity or advanced cancer treatment.

Table 8: Participants' Preference for Health Facility Usage

Participants % (N)	**Facility Type % (N)**		
Reason for using facility	**Government facility**	**Private facility**	**Grand Total**
Availability of drugs and other Materials	24 (476)	3 (67)	27 (543)
Availability of health workers	7 (150)	1 (26)	9 (176)
Not waiting for so long	4 (74)	1 (27)	5 (101)
Proximity	39 (777)	5 (91)	43 (868)
Respect to patients	8 (153)	3 (60)	11 (213)
Others	4 (74)	2 (39)	6 (113)
Grand Total	**85 (1704)**	**15 (310)**	**100 (2014)**

During the survey, participants were asked what influenced their decision to use or attend a particular health facility and they were presented with a range of anticipated options as shown in Table 7 above.

Table 7 shows that 43% (868) of participants chose to use health facilities depending on the distance or its proximity. This explains that participants were more likely to attend government health facilities closer to their households because of the better road network to access these facilities and no costs incurred in the accessing health care. In addition, 27% (543) participants attended health facilities if they had continuous drugs supply and logistical materials for needed services. However it is surprising, that a significant number of participants will attend government facilities in anticipation of having reliable and timely drug and logistical materials supply yet studies point out several challenges related to funds, procurement, supply chains, and management (Ackers et al., 2020; Godman et al., 2020).

Participants were more likely to use the facilities based on their personal experiences for example 11% (213) were concerned about the respect they receive at the facility. This highlights evidence from a number of studies carried out in LMICs and HICs that point out respectful care as a huge contributor to uptake of health care especially among women seeking reproductive health care (Ackers et al., 2017; West et al., 2017; Webber et al., 2018).

In addition, 9% (176) attended health facilities if they had available staff to attend to them and the majority chose to go to government facilities. The existence of midwives and nurses who perform 24 hour clinical shifts and providers of sexual and reproductive health services prompted women to attend government facilities which backs the evidence of some studies highlighting the high performance of midwifery or nursing led health facilities as compared to medical doctor led facilities associated with high levels of staff absenteeism in public facilities (Ackers et al., 2017; Tweheyo et al., 2017; Zhang et al., 2021).

Knowledge about Cervical Cancer

During the survey participants were asked whether they were aware of cervical cancer. This question was meant to determine whether participants were knowledgeable about the disease, its symptoms, how it is spread and prevented. However since the interview time with participants was short and the nature of the question (open-ended) participants had optional answers lined up for this question. Therefore, responses to this question might not bring out meaningful insights

from the survey because were not given time to comment or provide more information about their thoughts in regard to the question.

Despite results to this question not being meaningful as such, location data attached to these results seemed meaningful presented in a visual map using GIS mapping technique as shown in the map below. It seemed valuable to be able to determine the location of participants who were knowledgeable about the cervical cancer disease so as to find out which areas to route or target cervical cancer preventive programs depending on the need.

Figure 14: Distribution of Cervical Cancer Awareness among Participants

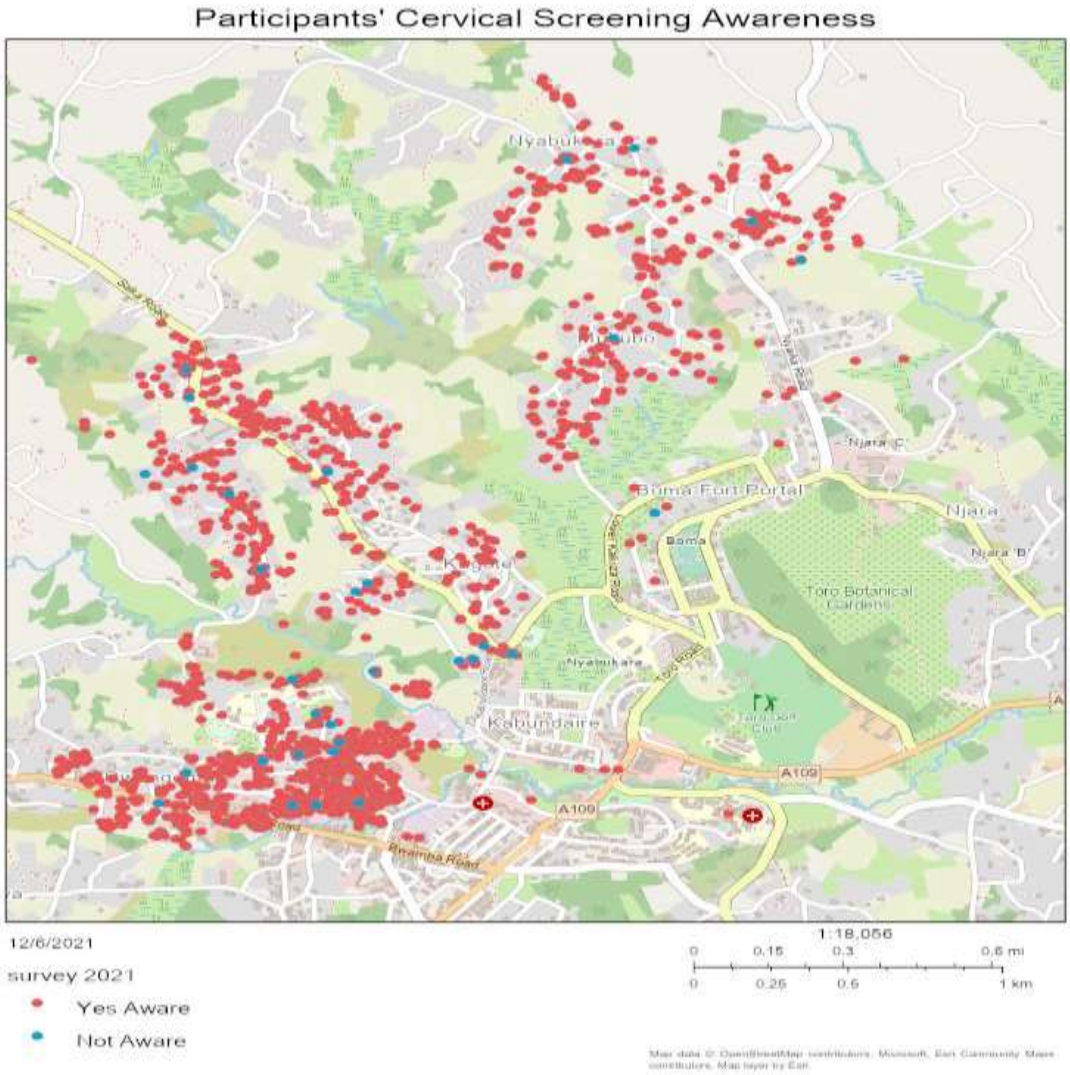


Figure 14 above shows that almost all participants that took part in the survey alleged to be knowledgeable about cervical cancer. There is anticipation that the high concentration of participants who were knowledgeable about cervical cancer was dependant on several factors such as level of education, the type of employment, and age.

The high awareness of cervical cancer among participants was partly because majority of participants had attended at some level of formal education, since reproductive health subject is usually offered from primary to secondary education. Several studies in LMICs and HIMs have highlighted the level of education as a determinant factor to behavioral change and health decision making. For example Gele et al., (2017), Were et al., (2011) showed that women who were highly educated had a better understanding of health care issues as compared to those uneducated. This also contributes to the low perceptions and myths about cervical screening among the community as mentioned in the study carried out in Eastern Uganda by Nakalevu et al., (2009).Some studies have pointed the type of occupation as determinant for taking health decisions especially among women for example women who are employed are more likely to be aware of health issues since they usually share and discuss health topics amongst them (Ampofo et al., 2020).

CHAPTER FIVE: DISCUSSION

Due to the growth of digital technology worldwide, several advanced digital tools have been manufactured including hardware and software. Such tools have largely been used to support interventions aimed at tackling a range of public health problems. The World Health Organization (2008) highlights an increase in the uptake of digital tools such as GIS in high income countries in the recent years largely due to introduction of user-friendly technologies and fall in the prices of hardware.

Geographical Information System is a digital tool which is a combination hardware and software with potential of mapping is one of the prominent rising developments in technology that is being used to structure new systems for health information and support the monitoring of public health intervention activities. Interventions including surveillance of prevalent tropical diseases such as mapping malaria transmission in Kenya Omumbo et al. (2013) and determining prevalence of Leprosy in Uganda (Aceng et al., 2019). Similarly, Sarki et al. (2015) used GIS mapping tool as an approach to determine the prevalence and spatial distribution hypertension in northern Nigeria.

This study has demonstrated the potential of digital tools to support cervical cancer awareness-raising as an intervention to promote cervical screening in western Uganda. In this study GIS has proved to be a valuable tool in the structuring and management of this health intervention in the local community. Understanding the coverage of cervical cancer awareness among the population has contributed to improvements in planning, monitoring and evaluation processes by health managers to make precise decisions of which areas needing more awareness program since results are presented through visual maps linking cervical cancer awareness and location data together. This was also similar in a study carried out by MacQuillan et al. (2017) determining the trend of birth outcomes using the mapping tool to support health programmers to target areas which are likely to be at risk of experiencing poor birth outcomes aiming at improving maternal health in Kalamazoo, United States of America.

The integration of digital technology tools in the existing cervical cancer preventions interventions such as mapping in western Uganda demonstrated the ability to display and overlay basic population characteristics concerning socioeconomic, health and awareness patterns. This digital tool provided rapid manipulation of spatial data and display of results relating to the

geography of the community showing road networks, health facilities, village boundaries and the type of settlements in different particular locations. This enables planners to identify remote and isolated locations that should be targeted for awareness activities to ensure total coverage of health information.

Since VHTs were capturing the GPS location of every household on mobile devices, analysis of location data collected using the mapping tool demonstrated the ability to track the movement of VHTs in the communities during the awareness-raising exercise showing all visited households in the community including the date and time. This hugely supported the management of VHTs' daily allocation and distribution in the communities whose primary role is health education. The tool had the potential to capture the size of the target area enabling health managers to better manage the work load in terms of the villages and households to be covered by specific VHTs. In addition, the ability to track VHTs movement and workload coverage in the community provided an assurance that VHTs actually reached the ground to create awareness and collected reliable data. As such, this strongly provides a unique approach to measuring accountability in terms of VHT performance and managing of their workload. This supports recommendations from made by Geoffrey et al. (2016) as strategy facilitate the routine monitoring of the functionality of VHTs in Uganda in order to achieve optimal health care delivery. Similarly, it also provides an important tool to respond to some of the human resource challenges facing Uganda's health system and specifically human resource management which is commonly associated with absenteeism or no show of health workers to perform their routine clinical duties at heath facilities (Tweheyo et al., 2017; Nyamweya et al., 2017).

The use of digital tools further provide an in-depth analysis of location data integrating with statistical data including population demographics, cervical cancer awareness and screening attendance producing results showing patterns in map as shown in the results chapter in Figure 13 and 14. Therefore understanding the distribution pattern of women eligible for cervical screening in the community could support the screening teams to precisely know which areas should be targeted for future screening and awareness programs. Such information has the potential to guide health managers to make reliable decisions when planning for cervical cancer preventive interventions including health education, screening and HPV vaccination in targeted areas identified on the map. At the same time, this has supported benchmarking to support the

implementation of both World Health Organisation (2017) and Ministry of Health (2010) Strategic Plans to eliminate cervical cancer. These plans both recommend greater focus and commitment to primary prevention interventions which require mapping of the distribution of available screening clinics in communities, awareness coverage and HPV vaccination coverage.

The World Health Organization (2008) recommends the integration of technology into health interventions as one of the strategies to promote universal health care especially in low resource countries. The deployment of digital technology such as GIS with potential of data collection, analysis and mapping to support cervical cancer preventative interventions such as screening and health education, which could potentially support health managers to enhance the planning processes and make evidence-based decisions during resource allocation such as human resource. In addition, assessment of needs and challenges related to low uptake for cervical screening and therefore planning for solutions including awareness-raising activities setting specific goals to ensure saturation of information in the community and helping eligible women make decisions to come forward for cervical screening. This supports the evidence from Brijnath et al. (2012) who found out that GIS technology could potentially help in enhancing the planning process to improve health service delivery providing an insight into where health services should be located and delivered. This is also acknowledged in prior studies that have shown the efficacy of GIS technology for health interventions in sub-Saharan Africa such as the mapping coverage measles vaccination in LMICs (Brownwright et al., 2017). Another recent study also established the efficacy of GIS technology in interventions to optimise the coverage of COVID 19 vaccination (Mollalo et al., 2021).

Since the technology is supported by an Open-Data-Source tool, its applicability to support cervical cancer awareness helped to develop a reliable multivariable database combining the location, demographics and socioeconomic characteristics of the population and other experiences about cervical screening to support benchmarking interventional activities. Effective benchmarking is also fundamental to robust monitoring and evaluation processes. Establishing comprehensive information system linked to a range of datasets providing a platform for potential household-level interventions with repeated monitoring and follow-ups hence improving the performance of intervention teams.

One of the challenges highlighted in studies for the low uptake for cervical screening and other health services in LMICs include limited knowledge about health services available in the community (Akinyemiju et al., 2012; Nakalevu 2009). The use of mapping technology has proved to be an effective tool to identify and locate available screening clinics closer to the community helping VHTs to encourage women to attend these clinics. And results show that in Uganda if cervical screening is aimed at including women aged from 18 years a lot of awareness has to be done to encourage the younger population to come forward for the services. As such, this also demonstrate the role of radio and VHTs in the promotion of health education among women of different socio-economic background and age groups which could potentially encourage women to come forward for cervical screening.

The applicability of technology such as mapping to support awareness-raising as a preventative intervention for cervical cancer has demonstrated the feasibility and potential for this approach to be applied in other community based health interventions. This could include activities aimed at improving the quality of health care such as monitoring and evaluation of health activities, determining the prevalence patterns of diseases, surveillance of disease outbreaks and effectively allocating of health resources to facilitated decision making by health managers to ensure a better health care.

Strength and Limitations of the study

The study was carried out using an experimental, learning-through doing approach which provided a unique experience for myself as a researcher and for my research assistants, the local health workers and VHTs. Skills were developed in the process of learning how digital tools are applied in health interventions and the technicality of producing visual results that derive meaning from the data such as maps.

The interviews were carried out in Rutooro language to allow participants to communicate and provide information in the language they understand better. Rutooro was the first language for research assistants and VHTs which made it easier for translation during community visits. As Sulaiman-Hill et al. (2014) highlights, in order to engage a positive community-based study, language is a substantial part to consider when interacting with participants. On that basis I recommend the use of local language in follow-on studies and interventions to provide an optimal medium for communication building an understanding between the researcher and

participants in order to produce accurate results. However, speaking a common language didn't not remove any risk of miscommunication between the participants and research assistants for example most participants who were aware of cervical cancer could not explain exactly what it was and this explains why they had not attended cervical screening.

Since the study was carried on learn-by-doing basis and through learning digital tools applicability was a few errors were identified with location accuracy and these were related to primary users of Geographical Information System especially during data collection. Although humans are prone to making errors, raw map data was collected by midwives in the community was supported by mobile devices or equipment with GPS enabled features with the ability to measure the location however this is always measured at certain angles and precisions and therefore no measurement is completely accurate.

In addition to the digital tools usability, although a low resolution photo of the map was adequate to show bigger features in the study areas such as roads and waters bodies, to clearly show the location of households visited and available screening points in the community a high resolution photo of the map was ideal to avoid inaccuracies. This could affect health managers when making decisions based on the low resolution maps to for interventions targeting smaller communities or population.

Although the study has demonstrated the value of digital tools in supporting awareness-raising of cervical cancer it is worth noting that mapping could not work alone in this intervention, it required a combination of other non-geographic studies or data to derive meaningful results. Despite the limitations explained above, digital tools proved to be a valuable approach that could be used to tackle public health challenges in order to improve the quality of health care.

CHAPTER SIX: CONCLUSION AND RECOMMENDATIONS

The survey was carried out in order to determine the impact of digital tools in supporting cervical cancer prevention interventions including awareness-raising and screening in Fort Portal Municipality, Kabarole District Uganda. With the aim of understanding if the approach of employing digital tools such as data collection, analysis and mapping in supporting cervical cancer prevention activities can be of use in tackling other prevalent diseases in Kabarole district.

The approach of using digital tools which involved recording the participants' location and interviews on mobile device demonstrated the positive impact technology has in the area of data collection from a large population, the ability to map, monitor, and plan particularly during cervical cancer awareness-raising campaigns in their various villages in rural western Uganda.

As the main researcher I established that digital tools can be reliable approach which can potentially be used for other health interventions locally to tackle prevalent diseases like, HIV Aids, measles, and malaria amongst others. This could be done through adopting the same method as used to support cervical cancer awareness-raising in Kabarole district, mainly using digital tools for data collection to guide planning, supervision, and monitoring processes facilitating decision and policy based on evidence. These tools give an exciting and new platform for public health interventions especially in LMICs such as Uganda to support restructuring and strengthening of the health system which is facing diverse and complex challenges with rapid population growth.

The mapping technology has been shown to have a significant impact on the management of VHT's health education activities by health managers since it allows tracking of their movements at community level displaying which households they visited and those missed on a real time basis. This improves micro-planning with the use of maps that help in presenting the location of households which is a valuable feature to determine the coverage of cervical cancer awareness coverage and surveillance to allow follow up.

Recommendations

It is recommended that from the findings of this research, the Ministry of Health in Uganda should integrate the approach of using digital tools as an approach to tackle prevalent diseases in

all communities. The findings from this study will help the general public in relation to better policy making, implementation and an opening for future research.

Recommendations for policy and practice

The findings from the study have a number of practical implications. Unless the government adopt the use of new emerging technology tools like the mapping technology to approach local interventions, many preventable diseases would thrive in many local communities. The adoptions of digital tools clearly show significance in the area of support with regards to cervical cancer prevention interventions in Kabarole district.

The findings of this study could potentially provide evidence to support other findings particularly on the positive impact it has in the area of supervision and planning.

With high prevalence of diseases like HIV Aids, malaria, measles amongst others in Kabarole district, I found digital tools to be reasonable tools in supporting interventions aimed at tackling the mentioned diseases. Therefore, if the government can employ this approach into policy and practice, it is possible to eradicate such diseases in a short period of time.

Another important practical implication is using the mapping technology as a monitoring tool for local health workers and VHT's routine health education activities providing accountability in terms of attendance and measuring performance. Monitoring of staff as a problem has long been identified and this is largely a reliable tool to monitor local public health staff especially in implementation interventions.

Recommendations for further research

Despite its limitations, this study adds more knowledge to the research world particularly with regards to applying digital tools such as mapping to tackle public health challenges. And this study equally created an opportunity for other researchers to find out if this approach could be used for other preventative and curative interventions.

APPENDIX

Appendix 1: University of Salford Ethics Approval

University of Salford MANCHESTER

Research, Enterprise and Engagement
Ethical Approval Panel

Doctoral & Research Support
Research and Knowledge Exchange,
Room 827, Maxwell Building,
University of Salford,
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T +44(0)161 295 2280

www.salford.ac.uk

5 March 2019

Dear Louise,

RE: ETHICS APPLICATION–HSR1819-061 – 'Community-based intervention to improve cervical screening services in Uganda; an evaluation protocol for the K4C cervical screening model.'

Based on the information that you have provided, I am pleased to inform you that ethics application HSR1819-061 has been approved.

If there are any changes to the project and/or its methodology, then please inform the Panel as soon as possible by contacting Health-ResearchEthics@salford.ac.uk

Yours sincerely,

Professor Sue McAndrew
Chair of the Research Ethics Panel

Appendix 2: Support Letter

KABAROLE DISTRICT LOCAL GOVERNMENT

Tel: +256 483 22575 – District Health Officer (DHO)
Tele-Fax: +256 483 23043 - Secretariat
Email: ddhskabarole@yahoo.com
ddhs.kabarole@health.go.ug

Directorate of Health Services
Kabarole District
P. O. Box 38
FORTPORTAL

Your Ref:
Our Ref: Health

Date: 25th January, 2019

To Whom It May Concern:

RE: EVALUATION PROTOCOL FOR THE K4C CERVICAL SCREENING MODEL IN KABAROLE DISTRICT, UGANDA

As the District Health Officer responsible for health services in Kabarole District, Uganda, I am delighted to support the planned research project aiming to improve cervical cancer prevention services. I understand that the K4C project, managed by Professor Louise Ackers and run in collaboration with British and Ugandan doctors and midwives, will be seeking to hear clients' and health service providers' experiences of cervical cancer prevention service integration into HIV care services, views regarding sustainability and potential scalability of the K4C cervical screening model within the local community health facilities and women's experiences with the model.

The project will involve mapping of the district and a short community awareness survey by the village health technicians (VHTs) to identify screening coverage rates and also raise awareness amongst the population. Furthermore, it will consist of health education sessions at Mountains of the Moon University, interviews of health service providers and clients (women of reproductive age), ethnographic observations and review of health facility data and reports.

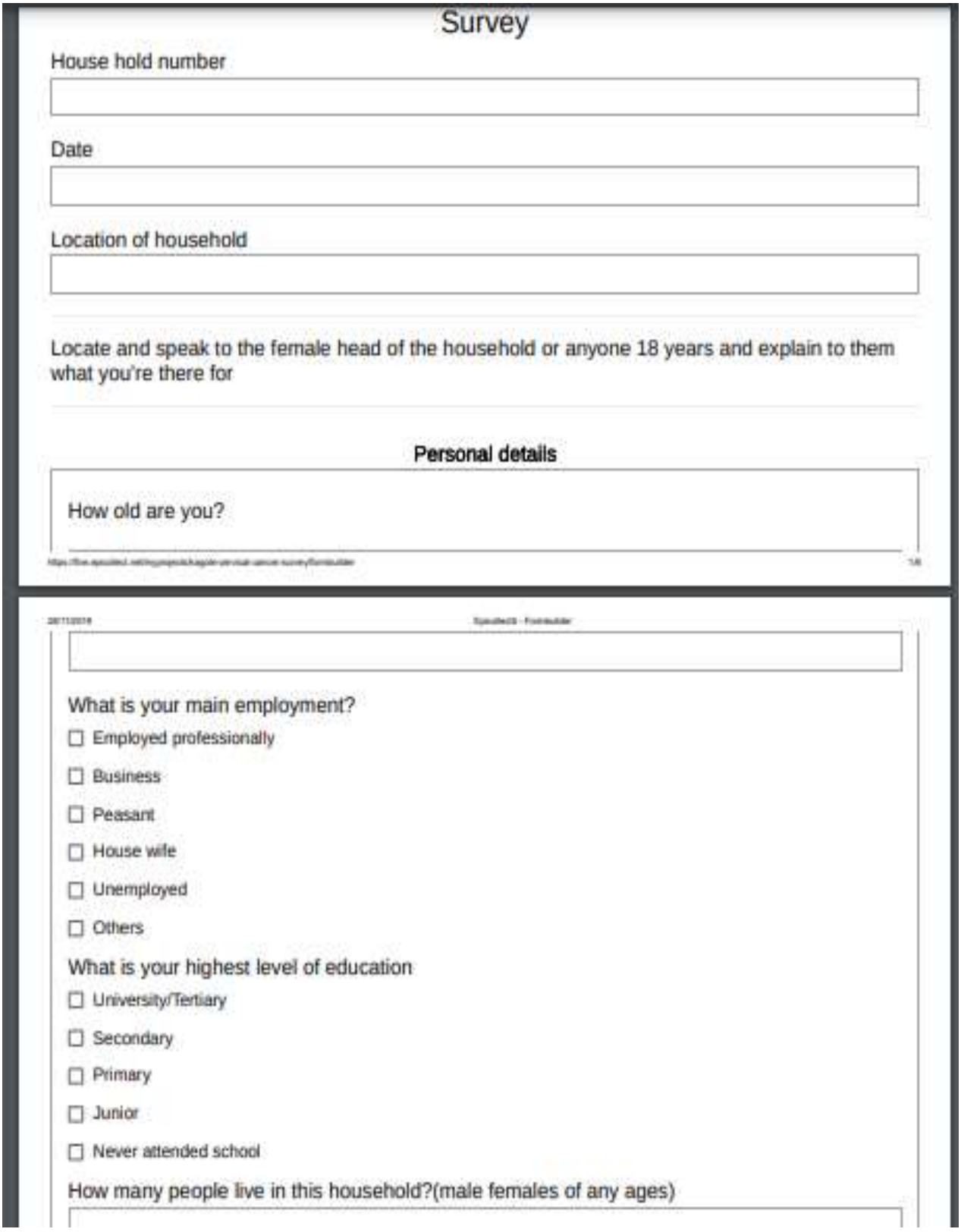
This work will be conducted with support from the Department for International Development (DfID) Small Charities Fund (SCCF). Ethical approval is being sought at both the University of Salford, UK and Mountains of the Moon University in Uganda.
We look forward to your active engagement with this project.

Yours Sincerely,

DISTRICT HEALTH OFFICER KABAROLE

Dr. Mugahi Richard
District Health Officer, Kabarole.

Appendix 3 Interview questions



Survey

House hold number

Date

Location of household

Locate and speak to the female head of the household or anyone 18 years and explain to them what you're there for

Personal details

How old are you?

What is your main employment?

- ☐ Employed professionally
- ☐ Business
- ☐ Peasant
- ☐ House wife
- ☐ Unemployed
- ☐ Others

What is your highest level of education

- ☐ University/Tertiary
- ☐ Secondary
- ☐ Primary
- ☐ Junior
- ☐ Never attended school

How many people live in this household?(male females of any ages)

How many females aged 18yrs and above live in this household

Disability

Do you have any kind of disability?

- ☐ Yes
- ☐ No

If 'Yes' what kind of disability do you have?

- ☐ No leg
- ☐ No hand
- ☐ others
- ☐ Not Applicable

Facility

What health facility do you always go to?

- ☐ Government facility
- ☐ Private facility/clinic

Names of the facility you always go to

- ☐ Kagote Health centre III
- ☐ Katojo Health centre II
- ☐ Buhinga hospital
- ☐ Virika hospital
- ☐ Kabarole hospital
- ☐ Bukuuku Health centre IV
- ☐ Others

Why do you always go to the mentioned facility

- [ ] Proximity
- [ ] Availability of drugs and other meterials
- [ ] Respect to patients
- [ ] Availability of health workers
- [ ] No waiting for so long
- [ ] Others

NB.Show respondent a leaflet on cervical cancer screening and provide brief education on cervical cancer prevention and screening

Cervical Cancer awareness

Have ever heard about cervical cancer

- [ ] Yes
- [ ] No

If Yes where have you heard about cervical cancer from?

- [ ] Radio
- [ ] Television
- [ ] News papers and Magazines
- [ ] Community health worker(VHT)
- [ ] Word of Mouth
- [ ] Others
- [ ] Not Applicable

Have ever attended cervical cancer screening?

- [ ] Yes
- [ ] No

Have ever heard about cervical cancer

- ☐ Yes
- ☐ No

If Yes where have you heard about cervical cancer from?

- ☐ Radio
- ☐ Television
- ☐ News papers and Magazines
- ☐ Community health worker(VHT)
- ☐ Word of Mouth
- ☐ Others
- ☐ Not Applicable

Have ever attended cervical cancer screening?

- ☐ Yes
- ☐ No

If yes where did you have it from (facility or place)

When /Year

If No is there any reason why you have not received cervical cancer screening?

Advise them about the voucher of 4000 how it works

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