REPORT

Stockholms universitet

THE USE OF TELEHEALTH IN CERVICAL CANCER SCREENING AND CARE IN ZAMBIA

A needs assessment undertaken for SPIDER June-August 2016

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Executive summary

The key stakeholder focus group discussions described in this report were undertaken to form a basis for the proposed implementation of telehealth in cervical cancer screening and care in Zambia. This report focuses on the needs assessment specific to Zambian context, but similar studies were also conducted in Kenya and Rwanda concurrently. This report will feed into a unified telehealth implementation framework to be developed out of the multi-country findings.

"We found an overwhelming support for telehealth in cervical cancer screening in Zambia. "

Methods

The project involved desktop literature review and face to face focus group discussions with purposively selected representatives of different health system actors in Zambia. The focus group discussions were audio recorded and the resulting data was transcribed verbatim and analysed using thematic analysis approach.

Key findings

Below is a summary of the key issues that emerged from the thematic analyses of the data gathered from this needs assessment exercise.

A) The need for telehealth in cervical cancer screening in Zambia

We found an overwhelming support for telehealth in cervical cancer screening in Zambia. The participants offered an affirmative endorsement of the potential use of telehealth in cervical cancer screening based on numerous reasons as outlined below.

- Telehealth can bridge the gap for specialists' shortages - through knowledge sharing
- Telehealth can enable patient access to scarce healthcare workers
- Telehealth can reduce patient expenses by reducing their travel time and costs
- Telehealth can facilitate information sharing and communication between healthcare workers for the good of the patients
- Telehealth can enable economies of scale – the government can purchase less expensive equipment that serves more people across the country.

B) Uncertainties and concerns

Despite their enthusiasm regarding potential use of telehealth in cervical cancer screening, the respondents also expressed concerns about uncertainties that believed would bar any potential use of telehealth.

- There were reservations about the cost of the project and where the money would come from, who would pay for screening when the women access services and the long term sustainability of the proposed project.
- The respondents also expressed great concerns about the confidentiality of the users of the proposed system and data protection
- There was a concern that the proposed project may be a duplication of existing efforts, in which case the resources would be best used elsewhere if there was no added value to the existing programs
- The participants noted that one of the current challenges is the lack of awareness and the motivation to access services. They therefore wondered how the proposed project would create awareness among women to come forward for screening.
- The respondents also worried about how the perceived healthcare workers' apathy towards technology would be resolved.
- The respondents also had strong reservations about the equipment or system that would be ultimately selected for the proposed project. They expressed concerns about whether it will be run by local or foreign expertise, whether the developers would provide any after sales back up to ensure the project doesn't run to halt as soon as a minor problem occurs. They were also genuine concerns about data ownership and the location of the servers that will be backing up the proposed project. Ideally, they noted, data should be owned by Zambia and stored in Zambia.

C) System readiness for Telehealth

Representatives of different stakeholders or health system members expressed different perceptions about their readiness for the potential use of telehealth in cervical cancer screening and care in Zambia.

- Copperbelt region is ready in terms of ICT connectivity. The only downside is that Copperbelt is not a priority area for many potential funding partners because it's not considered dire need area.
- Universities and their affiliate training institutions are equipping students with ICT knowledge and skills to supply local ICT experts. Telehealth and health informatics should be included in the curricula of all health allied sciences training.

Zambian provinces. Map of the provinces of Zambia in English (local language). Made by User: Golbez. Wikimedia Commons

- Insurance companies are happy to engage in dialogues that would lead to the development of a plan to cover cervical cancer screening and care – just like they did with voluntary medical male circumcision (according to a representative of healthcare financing).
- NGOs may not be ready for telehealth implementation because their work relies on policy directives and services offered by government facilities. They would be ready as soon as ministerial instruments are in place.
- Mainstream health services ready and some are already using diverse forms of telehealth. But there is need for more awareness to reduce cervical cancer stigma and increase services uptake by women.

D) Policy environment

The findings suggest a lack of clear policies and guidelines that can underpin a successful implementation of telehealth in cervical cancer screening and care in Zambia.

- There is need for clarification of policy on data sharing between health care workers, what medium to use and what data to share.

- There is also vagueness in policy over who takes ultimate responsibility in telehealth decisions given that front line staff would be seeking counsel of the remote expert who on the other hand cannot see the physical state of the patient. Telehealth thus challenges the notion that a physician can only take responsibility over a physical diagnosis, since the whole idea is to enhance electronic diagnosis.
- The ultimate project will be guided by E-governance policies, approved by the Centre for ICT to ensure adherence to local policies and local ownership, under the stewardship of the Office of the President.

E) Pre-requisites for telehealth in cervical cancer screening and care in Zambia

The participants described a lot of issues that need to be considered for a successful implementation of telehealth in cervical cancer screening and care in Zambia.

- Improved network connectivity is vital
- Incorporate health informatics in health and allied workers' trainings curricula to ensure skilled personnel
- The need to build the capacity of existing healthcare workers to be able to implement the proposed telehealth system
- The need to determine who covers the cost of screening
- Involvement of all relevant ministries and government departments such as the Centre for ICT excellence and e-governance unit
- Improve health care workers' attitude towards ICT
- Telehealth should be added value not added burden to healthcare workers or existing systems
- Ensure data protection, security and integrity
- Consider scalability and sustainability of the project – not a one off project
- Develop human capacity – train technical people to manage the system and health care workers to use the system
- Culturally sensitive awareness to encourage service uptake by women

Table of contents

Table of contents

Glossary of abbreviations

CCPPZ - Cervical Cancer Screening Prevention Program in Zambia
CIDRZ - Centre for Infectious Disease Research in Zambia
eC3 - electronic cervical cancer control
HCW - Healthcare workers
IARC - International Agency for Research on Cancer
ICC - Invasive Cervical Cancer
LMICs - low and middle income countries
SPIDER – Swedish Program on ICT for Developing Regions
ZHIA – Zambia Health Informatics Association
VIA – Visual Inspection with Acetic acid
WHO – World Health Organization
UN – United Nations
UNAIDS – United Nations Joint Programme on HIV and AIDS
PIA - photographic inspection with acetic acid

1 Introduction and methods

This report describes the methods used and findings of the need assessment project that explored the applicability of telehealth to link healthcare workers in order to improve early cervical cancer screening and care in Zambia. This section of the report presents the background of cervical cancer pandemic in the study setting and the aim and objectives of the study. Although this report focuses on Zambia only, the study was a multi-site project carried out simultaneously in Kenya and Rwanda as well using the same methodology.

1.1 Background

Previous research has shown that cancer in general causes more mortalities and morbidities in low resource settings than HIV, Malaria or TB (The Economist, 2014). The International Agency for Research on Cancer (IARC) estimates suggest that there were about 14.1million new cases of cancer globally in 2012. About 8 million of these new diagnoses were in developing countries, inhabited by about 82% of global population (American Cancer Society, 2015). Thus 70% of the global cancer burden is in low and middle income countries (LMICs).

In sub-Saharan Africa, cervical cancer is the most common cause of cancer-related deaths (see figure 1 below) among women. The region is also the epicentre of heterosexually acquired HIV, which exacerbates the risk of cervical cancer (Bateman et al., 2015).

1.1.1 Cervical cancer in Eastern and Southern Africa

Eastern and Southern Africa has some of the highest cervical cancer-related mortality rates in the world (figure 1). Eastern Africa has the world's highest incidence and mortality rates for cervical cancer (Campos et al., 2012). The region is also plagued with the highest burden of HIV pandemic, with women accounting for more than 50% of those infected with HIV in the region (UNAIDS, 2016). Previous research has found a very strong link between HIV infection and cervical cancer among women in sub-Saharan Africa (Allen C Bateman et al., 2015). HIV infection seems to exacerbate the risk of cervical cancer, especially among younger women (Kapambwe et al., 2015). Given the high prevalence and incidence of HIV in the region, a high proportion of women in the region is very vulnerable to cervical cancer.

Data from global cancer incidence, mortality and prevalence (GLOBOCAN portal) suggest that unless preventive measures are taken, the burden of cervical cancer in Eastern and Southern Africa region will only get worse in the years ahead as illustrated in table 1.

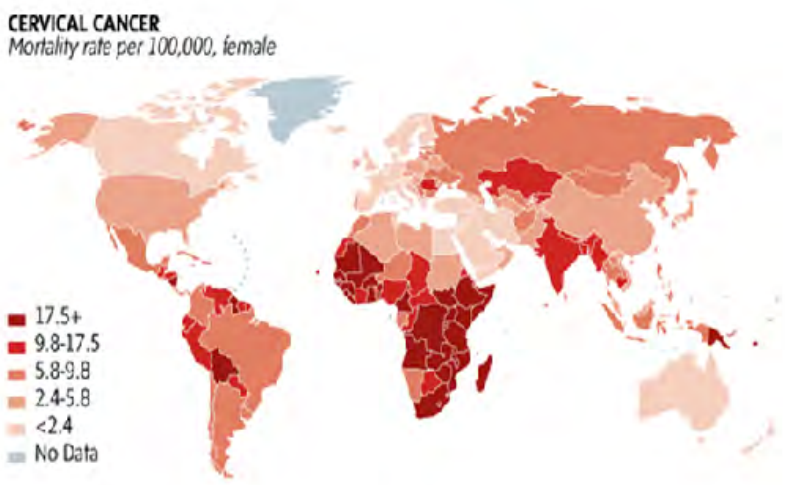

Figure 1: Illustrating cervical global cancer death rates. Source: www.globalcancermap.com

All ages estimated annual cervical cancer mortalities and incidence by country		Mortality		Incidence	
	Year	2012	2020	2012	2020
Kenya					
	Ages < 65	1758	2362	3878	5227
	Ages > 65	693	990	924	1342
	Total	**2451**	**3352**	**4802**	**6569**
Rwanda					
	Ages < 65	636	856	1177	1583
	Ages > 65	168	239	189	272
	Total	**804**	**1095**	**1366**	**1855**
Zambia					
	Ages < 65	960	1330	1875	2649
	Ages > 65	420	442	455	475
	Total	**1380**	**1772**	**2330**	**3124**

Table 1. Illustrating the estimated annual cervical cancer incidence and mortalities in Kenya, Rwanda and Zambia. Comparison between 2012 and 2020 estimates. Source: GLOBOCAN 2012. Cancer Incidence, Mortality and Prevalence Worldwide

Despite of the seemingly gloomy picture, there is a glimmer of hope. Cervical cancer is preventable, if the right actions are taken in good time. Timely screening and treatment, if need be, (Khozaim et al., 2014) can significantly reduce the current or projected mortalities from cervical cancer in eastern and southern Africa. But there is a consistent failure across most settings in sub-Saharan Africa to initiate or sustain a robust cervical cancer screening programme (Wright & Kuhn, 2012), which perpetuates the current trend of high mortality and morbidity of productive women. This in turn leads to huge socioeconomic losses to the relevant countries.

Screening rates in sub-Saharan Africa for cervical cancer remain very low despite of the existence of proven simple screen and treat approaches to cervical cancer prevention (Mwanahamuntu et al., 2011). In high resource settings where cervical screening is routine care, early screening prevents about 80% of potential cervical cancer mortalities (Finocchario-Kessler et al., 2016). This suggests that with increased screening, the huge mortalities related to cervical cancer in sub-Saharan Africa are avoidable.

A review of published research into cervical cancer screening and treatment in sub-Saharan Africa (Finocchario-Kessler et al., 2016) found that different research from different countries report different levels of efforts towards combating cervical cancer. There is evidence of primary prevention efforts mainly HPV vaccination initiatives, and secondary prevention which is underpinned by early diagnosis, commonly called screen and treat (Khozaim et al., 2014; Paul et al., 2013) . There are also tertiary prevention efforts which consists of treatment opportunities (Finocchario-Kessler et al., 2016) for those who are diagnosed with cervical cancer early enough and have access to effective treatment.

The barriers to cervical cancer screening in Eastern and Southern Africa vary between and within countries. A review of published articles on barriers to uptake of pap smear, one of the most common screening approaches in the region, found that the barriers to cervical cancer screening can be grouped into service user barriers, service provider barriers and structural barriers (McFarland, Gueldner, & Mogobe, 2016). Service user barriers include fear of cancer, lack of awareness about the availability of Pap smear, screening not a priority unless there is a sign of ill health, religious and cultural reasons. Service provider barriers reported by many of the papers reviewed include failure to sensitize women about the need to take Pap smear screen and negative service provider attitudes towards patients. The review also found that the structural barriers revolve around inaccessibility. These include the cost of screening being too prohibitive for some women, inability to access the facilities where screening is offered, long waiting times,

unavailability of the screening service in some areas and the screening policies in some contexts restricted for example the ages that qualify for screening or free screening (McFarland et al., 2016).

Despite of the existing barriers to screening as outlined above, there is evidence of increased cervical cancer screening across Eastern and Southern Africa. The existing HIV clinical screening and care structures that have been established in response to HIV pandemic in the region for example provides a framework for scaling up cervical cancer screening (Coleman et al., 2016). More so, it is cost effective for the health systems in low resource settings to screen women for cervical cancer (Nelson et al., 2016) even if the cost of setting up screening services may involve huge financial outlays. Saved life years and less expensive treatment and care when women are screened and treated early presents economic returns on investments in screening programmes.

"The high prevalence of cervical cancer in Zambia is closely associated with the significantly high prevalence of HIV in the country"

1.1.2 Cervical cancer in Zambia

Zambia has the second highest incidence of cervical cancer globally (Bateman et al., 2015). Previous studies show that Zambia has some of the highest annual invasive cervical cancer (ICC) incidence (58/100,000) and mortality (36/100,000) (Parham et al., 2015). The high prevalence of cervical cancer in Zambia is closely associated with the significantly high prevalence of HIV in the country, with estimates of HIV seroprevalence rates of 14% at the general population level (Parham et al., 2015). Some studies (Allen C Bateman et al., 2015; Kapambwe et al., 2015) have illustrated an association between HIV infections and high prevalence of cervical cancer in Zambia, and also showing that HIV worsens the prognosis for those diagnosed with cervical cancer (Parham et al., 2015). However, these high mortalities from cervical cancer are preventable with effective screening and treatment programme (Driscoll, 2016). This calls for urgent scale up of screening and treatment programme (Allen C Bateman et al., 2015) to enable more women to screen on time, to be able to benefit from the available care and to reduce the resultant socioeconomic impact of cervical cancer on the nation.

1.1.3 Current prevention initiatives

There are concerted efforts to tackle the cervical cancer pandemic in Zambia which started in 2006; Cervical Cancer Screening Prevention Program in Zambia (CCPPZ). The programme is embedded on the existing public sector platform and is integrated into the HIV/AIDS treatment care infrastructure (Bateman et al., 2015). This is the largest public sector cervical cancer prevention program in sub-Saharan Africa (Kapambwe et al., 2015). The government of Zambia, in collaboration with local and external partners manage this screening program. By the end of 2016, the government of Zambia had overall ownership of the programme.

Through CCPPZ, nurses screen women for cervical cancer using visual inspection with Acetic Acid (VIA). The VIA is supplemented by digital cervicography (digital imaging of the cervix). The images are discussed with the patient as part of their consultation with the nurses. The images can also be shared electronically using mobile phones for remote expert consultation. Depending on the VIA outcome, eligible women are then triaged for treatment. The treatment can be same day cryotherapy or thermocoagulation for observed eligible precancerous lesions, or referral for further consultation with gynaecologist or surgical procedures. This aspect of the program, called electronic cervical cancer control (ec3) is an added element that was intended to overcome perennial screening barriers such as shortage of healthcare workers and inaccessible and inadequately equipped facilities (Parham et al., 2010). Informed by the success of the pilot phase, the programme was expanded to 12 of the largest public health clinics in Lusaka, the largest province by population, and to each of the nine other provincial hospitals across the country. Within the provinces, the programme was also expanded to the large district hospitals in each province. In Lusaka, all pathological referrals are handled by the pathology department at University Teaching Hospital and the University of Zambia or private pathology service providers. Away from Lusaka, only three other provincial hospitals (Ndola, Kabwe and Kitwe) have the capacity to perform histological diagnosis. The rest of the provincial hospitals either send their samples to the University Teaching Hospital in Lusaka or private laboratories for analyses. Specimens from the hospitals and clinics are sent to the pathologist using courier services. The programme includes robust health promotion and awareness campaigns to sensitize the potential beneficiaries. To ensure standardised practice and quality assurance, a team from Lusaka does outreach sessions to other provincial facilities because the programme is well established in Lusaka (Parham et al., 2015).

So far, CCPPZ has led to the screening of many women for cervical cancer Zambia. An evaluation of the programme found that by December 2013, a total of 102,942 women had been screened for cervical cancer in Lusaka alone. This represented a 95% screening uptake by the women who were offered the chance to screen (a total of 108,330 between January 2006 and December 2013). About 20% (20,419) of all women who received confirmed test results over the period screened positive (Parham et al., 2015). This positivity rate suggests a public health concern and also provides evidence for the need for expanded screening and treatment across the country. The CCPPZ network also provides a good infrastructure on which to model the expansion of cervical cancer screening programme.

However, the success of any expansion of the cervical cancer screening programme must go hand in hand with efforts to overcome the myths and misconceptions (Chirwa et al., 2010) that hinder uptake of cervical cancer screening in Zambia. Some of these misconceptions include concerns about loss of confidentiality particularly linked to HIV stigma since screening for cervical cancer is associated with being HIV positive. The belief that a woman cannot have children after screening for cervical cancer, a fear that the womb would be removed and general mistrust of the health system. For some women, there is great stigma in being diagnosed with cervical cancer, hence reluctance to test, because it is not only linking them to socially disapproved behaviours but screening positive for cervical cancer is tantamount to a death sentence (White et al., 2012).

1.1.4 Telehealth: what is it?

There is no definitive definition of telehealth because it is a constantly evolving science, as it incorporates new technological advances and responds to and adapts to the dynamic health needs of different settings (World Health Organization, 2010). Telehealth, also known as telemedicine, can be defined as the application of information communication technologies (ICT) to provide health information and care across distances (Nickelson, 1998). Telemedicine can also be defined as ‘healing at a distance’ based on the origins of the root words from Latin “medicus” and Greek “tele" (Strehle & Shabde, 2006). Telehealth involves use of a wide range of information and communication technologies (World Health Organization, 2010) to meet the healthcare requirements of patients with diverse health conditions (Totten et al., 2016). Telehealth can be summed up as rapidly evolving merger between medical practice and technological advances.

Although telehealth has been billed as the future of medicine for decades, it still promises a unique future of healthcare. Thus, telehealth was the future of medicine in the 1970s (Strehle & Shabde, 2006), 1990s (Nickelson, 1998) and it remains the future of medicine (Rohrich & Reece, 2015) in 2016. Telehealth is not entirely a new field. Some form of telemedicine has existed for over 100 years (Strehle & Shabde, 2006). Telehealth in its modern form started in the 1960s (World Health Organization, 2010).

The full potential of telehealth is yet to be realized. Tele-health changes the location where routine health care services are provided by using ICT to overcome geographical barriers thereby increasing access to healthcare services (World Health Organization, 2010). Tele-health also helps patients save time, energy and money, and gives them more opportunities to get high quality health care services. From a healthcare provider's perspective, telehealth has the benefits of improving the continuity of care, offering an opportunity of continuing of education and increasing cooperation in diagnosis and research activities (Wooton et al, 2010).

"Although telehealth has been billed as the future of medicine for decades, it still promises a unique future of healthcare."

Despite of the lack of a universally acceptable definition, there are fundamental prerequisites that underpins telehealth: its purpose should be to provide clinical support, its intended to overcome geographical barriers by connecting users in different geographical locations, involves use of ICT, with an objective of improving health outcomes (World Health Organization, 2010).

Telehealth has been applied in numerous aspects of health care including training (Ali, Carlton, & Ali, 2015), dentistry (Torres-Pereira, Morosini, & Fonseca, 2015), counselling (Totten et al., 2016), ophthalmology (Di et al., 2015), rehabilitation (Linder et al., 2015) and in management of chronic conditions such as HIV (Saberi, Yuan, John, Sheon, & Johnson, 2013) and diabetes(Verbosky, Beckey, & Lutfi, 2016).

Telehealth has been applied across different socioeconomic settings. In high income countries such as USA and Australia, telehealth has been used to provide services to the people in remote islands or mountainous areas and to save costs of providing such healthcare (Jung, Kang, Park, & Park, 2015).

In Norway, telehealth has been used since 1995 in a TeleECG initiative which provides screening and treatment for myocardial infarction in patients away from hospitals (World Health Organization, 2010). Telehealth in different forms has become a norm in high income countries (Rechel et al., 2016) and is gradually becoming a part of standard healthcare practice in many middle and low income settings (Oldridge, Pakosh, & Thomas, 2016), where it is most likely to have the greatest impact in revolutionizing healthcare. A review of published literature indicates that the bulk of telehealth application has focused on doctor patient communication involving mainly telephone calls and text messaging (Kashgary, Alsolaimani, Mosli, & Faraj, 2016). However, advances in technological innovation imply that telehealth is increasingly becoming more than just telephone and texting services.

Telehealth can be most beneficial to rural and marginalised communities in developing countries because these populations perennially suffer from lack of access to healthcare (World Health Organization, 2010). The application of telehealth in low resource settings, often plagued by acute shortage of physicians, for example has the potential to maximise the existing low staffing levels to provide quality healthcare to the populations. A study in Bangladesh, one of the countries with acute shortage of trained health workers, found that linking village doctors (informal healthcare workers) with physicians can enhance healthcare in settings with shortage of trained health workers (Khan et al., 2015). A systematic review of published literature on the use of mobile technologies by community health workers/the frontline health care providers in low resource settings found that community health workers have used mobile technologies in advancing various global health agendas particularly in reproductive health, maternal and child health and HIV (R. Braun, Catalani, Wimbush, & Israelski, 2013). In fact, shortage of physicians is not just limited to resource limited countries. In richer nations such as the USA, telehealth is seen as a pragmatic solution to physician shortages as well (Rimsza et al., 2015).

Telehealth thus has the potential to address the challenges in providing accessible, high quality and cost effective healthcare in both high and low income countries (World Health Organization, 2010). Telehealth can address the health disparities in rural areas and ensure same quality of care (Marcin, Shaikh, & Steinhorn, 2015; Rimsza et al., 2015) through sharing the same expertise that would, under normal circumstances, be only available to city dwellers or those in proximity to specialist or referral facilities in most of the low income settings. Furthermore, telehealth can enhance collaboration in the health systems and improve coordination of care (DeBlois & Millefoglie, 2015) thereby improving health system efficiency and effectiveness of care.

But successful application of telehealth solutions requires user needs assessment and their success can only be measured by all stakeholders' satisfaction (Becevic, Boren, Mutrux, Shah, & Banerjee, 2015). One of the goals of the current project was to provide insights into the perspectives of potential beneficiaries of the proposed telehealth solution and then assess user satisfaction at a later phase of the project.

1.1.5 Barriers to widespread use of telehealth

One of the major barriers to full utilization of the potential of telehealth globally is the cost factor. Telehealth is still an evolving field and the costs associated with some of the promises it offers to healthcare provision cannot be ascertained beforehand. A 2009 survey by the World Health organization on the status of eHealth in member states found that the majority of the member states wanted more information on costs effectiveness of telehealth. Key barriers to implementation of telehealth in developing countries include high cost, inadequate infrastructure, inadequate policies and lack of technical expertise However, some of the factors that are considered more relevant to high income countries such as legal issues pertaining to patient safety and confidentiality, competing health system priorities and lack of demand for telehealth solutions (World Health Organization, 2010), ought to be considered in low income settings as well.

A systematic review of published literature on the barriers to health information exchange in low income settings (Akhlaq, McKinstry, Muhammad, & Sheikh, 2016) found that the lack of importance given to data in decision making, corruption and insecurity, lack of training and inadequate infrastructure seem to be some of the major challenges to implementing health information exchange. The review also found that a lot of previous research emphasised the importance of strong leadership and clear policy direction coupled with the financial support to acquire essential technology, improve the communication network, and provide training for staff were very vital in enhancing implementation of telehealth. Equally important is the need to involve local stakeholders to ensure that local stakeholders perceive the relevance and the merits of the telehealth solution to their immediate needs.

The World Health Organization recommends that member states should take the following initiatives to reap the potential of telehealth; create national agencies to coordinate telehealth initiatives, ensure relevance to their context, ensure cost effectiveness, consistently evaluate the system and adequately fund telehealth as part of integrated health system (World Health Organization, 2010).

1.1.6 Telehealth in cervical cancer screening and care

This sub-section focuses on literature documenting examples of telehealth solutions that have been or are currently being used in cervical cancer screening and care in different settings. The aim is to explore what has worked in other settings that may be of relevance to low resource settings such as the Zambian context. However, the paucity of literature suggests that the application of telehealth in cervical cancer screening is still in its infancy. Below is a summary of the few accessible studies that have reported attempts to utilize telehealth to enhance cervical cancer screening and care in various contexts.

A review of literature on the applicability of telehealth in remote management of gynaecologic malignancies in the USA found that telehealth can take screening to women in rural areas(Shalowitz, Smith, Bell, & Gibb, 2015). Telehealth can be used for remote coordination of radiotherapy, remote monitoring of chemotherapy, for palliative care, virtual consultation, and telementoring of local surgeons. The reviewers noted that telemedicine can be used for planning care and treatment, for surgery, adjuvant surgeries and palliative care. Telehealth, or teleoncology as they termed it, is therefore a potential solution to the geographical barriers to quality gynaecological cancer care for women in remote areas (Shalowitz et al., 2015). It is worth pointing out that in some settings in sub-Saharan Africa, 100 miles from the nearest nurse not oncologist is a norm for some women. In some cases, those who manage to travel the 100 plus miles to the nearest health service are not guaranteed of receiving the care either. Many at times, they make the trip but end up not seeing health professional due to numerous factors such as long queues and shortage of healthcare personnel or equipment.

A number of initiatives involving application of telehealth solutions in cervical cancer screening in low resource settings have been piloted or are on-going. But so far, the most cost effective screening initiative of choice in many settings is the visual inspection of the cervix enhanced by the application of acetic acid (VIA) (Whitham, 2016). VIA is cheaper than the traditional cytology based screening and very relevant to resource limited settings (Quinley et al., 2011) where cytology based screening is prohibitively expensive to rollout across the country.

Most of the attempts to enhance cervical cancer screening using telehealth solutions seem to be VIA modifications or complementary interventions. An example from Botswana involves the use cervix photographs, termed as photographic inspection with acetic acid (PIA). The Botswana model involves taking images of the cervix using mobile smartphones and transmitting the images to remote experts through multimedia messaging service (MMS).

In the pilot phase, the remote expert was able to review and recommend positive or negative diagnosis for 82% (total sample of 95 HIV positive women) (Quinley et al., 2011). Following the success of the pilot phase, the Botswana ministry of health (MOH) has since 2014 scaled up the project to cover 19 sites across the country, renaming it Kgonafalo (Mobile Telemedicine Programme). The project covers cervical cancer, oral medicine, dermatology and radiology. The project is a public-private partnership between Botswana-Upenn partnership (BUP), the MoH Botswana, University of Botswana and mobile phone operator Orange Foundation Botswana. The ministry of health provides the core funding and Orange foundation provides the mobile phones and the network on which the program is run. To ensure continued support and local ownership, the servers of the project are housed by the MoH. The key benefits of the project so far have been the reductions of unnecessary referrals and improved patient outcomes. The project also benefits from strong commitment and leadership from local stakeholders. (Ndlovu, Littman-Quinn, Park, Dikai, & Kovarik, 2015).

In a different example, Singh and Badaya (2016) recommended **telecytology** for the Indian context. Focusing on the need for real time diagnosis to minimise loss of women to follow up, they argue for the use of mobile cytology equipment carried in a van fitted with a satellite equipment and automatic imaging system. The idea is to capture the images of pap smears at the rural screening site and send them to the experts at a tertiary laboratory via the satellite equipment. The authors noted that the system however may not capture all women who are positive for cervical cancer, but would be suitable for screening programmes whose main goal is to screen as many women as possible.

Visual inspection enhanced with the application of acetic acid and complemented with digital photography has been used in Zambia with significant successes. The Zambian program, called electronic cervical cancer control (eC3), uses a digital camera to capture images of the cervix (Cervigrams). The images can be used for discussions with the patient during as part of their screening information and outcome session. But the telehealth aspect involves sharing the images with remote experts who in most cases are based in tertiary hospitals in Lusaka for consultation and further diagnosis. One of the goals of eC3 is to bridge the gap between screening and diagnosis in order to facilitate screen and treat model thereby minimising the loss of patients to follow-up (Parham et al., 2010). A similar approach to the Zambian model was also piloted in Madagascar (Catarino et al., 2015), where VIA was complemented by the use of Smartphones to take digital images of the cervix after acetic acid application.

In the USA, telecolposcopy has been used in Akansas, part of rural southern USA where there are reported high mortalities related to cervical cancer due to limited access to pap smear. Women with non-verifiable Pap smear or VIA tests were referred to hospital facilities with telecolposcopy capabilities. There were a total of 8 telecolposcopy sites across Akansas during the pilot period. The authors noted that the project reduced travel times and costs associated with face to face visits significantly. (Hitt et al., 2016)

Overall, there is limited data on the use of telehealth in cervical cancer screening. The available interventions seem to be all VIA based. While cost effective for low income settings, VIA has its own limitations in terms of accuracy and triaging patients who may require further care. But the more reliable colposcopy is not feasible in low income settings. One common conclusion drawn from all the above initiatives is that all the authors recommend further researcher to explore the potential use of telehealth to improve cervical cancer screening and patient outcomes. This call for further researcher position the present study in the path of attempting to provide further insights into the possibility of using telehealth to scale up cervical cancer screening in low resource settings and to improve care and outcomes for women diagnosed with cervical cancer.

1.1.7 Technological initiatives

The previous subsection has largely demonstrated that VIA and its derivatives form the bedrock of the current cervical cancer screening practice of choice in low resource settings (Sankaranarayanan, Nessa, Esmy, & Dangou, 2012). Most of the reported technological modifications involve supplementary use of digital imaging (A. C. Bateman et al., 2014) to capture pictures of the cervix as outlined in the previous section. However, critics of VIA argue that it leads to diagnoses of significantly high numbers of false positives (Basu et al., 2016). There is need for more sensitive screening approaches to minimise false positives to ensure that the women most in need get the care and to save on unnecessary treatment and care that results from false positives, especially in low income settings where services are not available for all in need.

One technological innovation that may fill the gap, of lack of portable and affordable cervical cancer screening tools, is the Swedish invention; portable, battery-operated, magnifying device (GynocularTM). According to Tyros Biopharma, the makers of GynocularTM, their device is the world's first truly portable colposcopy. It is a high resolution monocular colposcope which has identical specifications to stationary colposcope. The device has been tested in India for its effectiveness in triaging VIA and HPV positive women with significant accuracy (Basu et al., 2016).

Focus group discussions.

The images are blurred to ensure the anonymity of informants.

Research Assistants Lushomo Shanaube and Natasha Chung

The device was also evaluated for its accuracy in contrast to stationery colposcopy, comparing diagnoses given by nurses and doctors in a randomised controlled trial (Nessa et al., 2014; Ngonzi et al., 2013). The findings showed no accuracy difference between GynocularTM and stationery colposcope in detecting cervical lesions. More so, there was no difference between doctors and nurses either in detecting cervical lesions using either stationery colposcope or GynocularTM. However, there would be need for further research on the applicability of GynocularTM and for training of nurse colposcopists to enable effective use of the intervention to improve screening of women in rural areas (Nessa et al., 2014). Details and specifications of GynocularTM can be obtained from http://www.gynocular.ca/.

Another technological candidate that may become useful in cervical cancer screening in the near future is the Digital Holographic Microscopy (DHM) developed by Holocyst Intelligence System Corporation (Belgium) (Benzerdjeb, Garbar, Camparo, & Sevestre, 2016). The instrument has an "accompanying software that creates a rapid 3-dimensional (3D) image reconstruction of cultured (El-Schich, 2016) uterine cervical cells directly using the vial containing the sample without any need for staining" (Ibid).

The aim is to eliminate the flaws related to VIA based systems; dependence on the observer eye, sensitivity being observer dependent and complex time consuming technology.

DHM system consists of a microscope attached to a charge coupled device camera and a computer. DHM analyses data between laser light entering and the light leaving the cell, which changes when it passes through the cell and the change is recorded in DHM and ultimately used to create a cellular image.

The DHM system is still undergoing review and may not be available for mass usage at the moment. Also, unlike gynocular which is portable and does not rely on computer user in real time, DHM system seems to operate directly from computer based software to create images. The gynocular can be used in the field, away from a computer and electricity supply, and the data later uploaded to the database.

"We are not making any specific recommendation on the appropriate technology in this report. That choice will be made in consultation with all relevant stakeholders who will be involved in the second phase of the project"

There is also the EVA scope, a mobile/portable colposcope equipped with an ultra-bright light source and powerful magnifying lens to enhance visualization of the cervix. It is linked to EVA mobile App which can enable secure image capture and sharing for remote consultation and patient care.

We are not making any specific recommendation on the appropriate technology in this report. That choice will be made in consultation with all relevant stakeholders who will be involved in the second phase of the project, starting with a joint development and adoption of an implementation framework to be informed by this study. The technologies outlined above are merely examples of the current technological solutions that may be usable in a telehealth based platform to enhance cervical cancer screening and care in low resource settings. We anticipate having a broader list to choose from once the implementation phase is reached.

1.2 Rationale for the study

In high income settings such as Sweden and other OECD countries, cervical cancer screening is a routine service offered to women during yearly health consultation with the physician (Weinmann et al., 2015). But in many low resource settings such as the proposed countries of focus, most women don't have access to regular contacts with physicians or regular screening opportunities, although cervical cancer screening methods vary and can be implemented easily (Binagwaho et al., 2013) in most of these settings. These resource limited settings are also plagued by acute shortage of healthcare workers (Marful & Winter, 2015), which impedes attempts to ensure effective provision of care to the populace, especially in rural areas away from teaching hospitals.

In the current era of exceptional advancements in Information and Communication Technologies (ICT), there is an opportunity to strengthen the health systems in resource limited settings by linking healthcare workers to share knowledge and expertise and to provide national coverage that would otherwise not be efficiently achieved by simply relying on the existing clinic/facility based care pathways. Part of the challenge in providing services to the rural populations are the distances involved between frontline facilities and the referral facilities where specialist physicians tend to be based. In most cases, patients have to travel long distances (Ports, Reddy, & Rameshbabu, 2015) to the frontline facilities as well, and even longer distances to the referral hospitals which are mainly based in major cities. There is also lack of information resources such as libraries in rural areas, a problem further worsened by poor internet connectivity in some settings (Marful & Winter, 2015) even though more and more information sources are becoming electronically accessible. This implies that healthcare workers in rural areas don't have access to information they may require to enhance their practice.

One common solution to the challenge of distances in resource limited settings is the use mobile units to take services to the rural populations. Although the only viable option for reaching the underserved in rural areas, mobile units also come with challenges such high resource requirements (Ganavadiya, Chandrashekar, Goel, Hongal, & Jain, 2015). However, as Hällgren et al., (2014) observed, the possibilities of applying technologies in the daily aspects of life of the society, such as healthcare delivery, seems unlimited.

The proposed project attempts to fill the healthcare workers' gap and geographical distance patients have to cover to access cervical cancer screening services through use of available technologies to share the existing knowledge for the good of a larger population than the current system is serving.

As outlined above, there is need for innovative approaches to tackling cervical cancer pandemic in sub-Saharan Africa as a whole.

The goal of the present study was to provide contextual information about Zambia regarding the possibility of using telehealth solutions in cervical cancer screening and care. The focus on cervical cancer is an effort towards empowerment of women in a region that still lags behind in terms of maternal and child health (Alkema et al., 2015). Any improvements in screening, prevention and control of cervical cancer through the present project will contribute towards gender empowerment in the region through improved health and quality of life for women. Thus contribute towards the achievement of sustainable development goals such as goal number 3 and 5 (UN, 2015). As Sing et al., noted, gender equality is a potential strategy for improving maternal and child health in Africa (Singh, Bloom, & Brodish, 2015).

1.3 Aims and objectives of the project

The aim of the overall project was to improve cervical cancer screening and care in low resource settings. The study was to provide insights into how best to link up healthcare workers so that the can share collective knowledge and skills between them to enhance cervical cancer screening, prevention and control in the selected countries (in this case Zambia). The objectives of the study were:

1. To explore the barriers and facilitators of successful implementation of telehealth solution in low resource settings.
2. To identify the facilitators and barriers to implementation of existing telehealth solutions in different settings.
3. To explore context specific health systems determinants of telehealth implementation in low resource settings.
4. To explore the physicians' perspectives on knowledge sharing using telehealth in low resource settings.
5. v. To develop a socio-culturally relevant telehealth implementation framework for cancer screening and care in low resource settings

The project aimed at addressing barriers and facilitators of the possible use of telehealth in cervical cancer screening and care in Zambia. It also explored the contextual requirements that ought to be addressed before potential use of telehealth in cervical cancer screening in Zambia. The project involved different types of stakeholders to explore a holistic health system representation of view regarding how and what kind of telehealth solutions may be relevant to the Zambian context.

1.4 Project implementation

The project was funded by the Swedish Program for ICT in Developing Regions (Spider), which maintained an oversight of the implementation activities in all the three partner countries. In Zambia, the field work activities were coordinated by Zambia Health Informatics Association (ZHIA) under the guidance of Dr. Charles Chengo between June and August 2016. Data collection was carried in in two different phases. The first phase involved focus group discussion with a purposively selected individuals involved in policy making at the national level and tertiary level health care workers drawn from referral facilities in Lusaka and Copperbelt province in Zambia. The lead researchers from Stockholm were involved in the facilitation of phase one focus group discussions in Lusaka in June 2016. The second phase involved focus group discussions with purposively selected health care workers drawn from provincial to community level facilities. The second phase also involved purposively sampled women living with diagnosed cervical cancer. All these groups of participants were drawn from the Copperbelt province, Zambia.

1.5 Methodology and recruitment

The study adhered to Zambia National Health Research Ethics requirements and received ethical approval from ERES Converge Research Ethics Board.

Data collection involved use of focus group discussions, with a flexibility to conduct key informant face to face interviews if need be. All the key participants willing to take part in the study managed to take part in the FGDs. The FGD sessions were based on a question guide developed in consultation between the project team in Stockholm and local country partners in Zambia. One patient representative was interviewed as a key informant representing women from very rural areas.

To recruit study participants, ZHIA sent out email invitations to various representatives of the desired participants groups requesting them to consider taking part in the project. The relevant study information sheet was attached to the email invitation to provide the prospective participants with details about the study. Taking part in the study meant attending a focus group discussion on a selected date and time. The various stakeholder groups invited included policy makers from Lusaka and Copperbelt province, tertiary level health care workers from Lusaka and Copperbelt, provincial level healthcare workers (including community health care workers) and cervical cancer patient representatives, all from Copperbelt province.

The study information sheet provided the prospective participants with an overview of the project, why it was being carried out, who was carrying out the project and the potential benefit from the findings. The prospective participants were also assured of their anonymity, confidentiality and voluntary participation in the study. The email also urged those who were contacted through the list generated by ZHIA in consultation with other local stakeholders to forward the invitation to other individuals they know of whose role may be insightful to the study. A total of twenty (20) individuals were invited to consider taking part in the study as policy makers. Overall, 4 tertiary level HCWs, 4 ministry of health representatives (two of whom withdrew from the study), 3 Provincial level HCWs, 2 representatives from private medical schools, two medical insurers and a representative from Cervical Cancer Screening at CIDRZ took part in the study. Eleven (11) cervical cancer patient representatives were also recruited and interviewed.

The FGD question guides were designed in English. Those used in FGDs with provincial level HCWs and patients' representatives were translated to local language (Bemba), in case some participants were not comfortable using English. The FGDs for policy makers and tertiary level HCWs were conducted in English. All the interview guides were approved by the local ethics committee.

After the FGD with patients' representatives was done, the researchers realised that there was limited representation of rural women since the participants in the FGD were mainly semi-urban dwellers. The researchers decided to seek rural women through purposively targeted recruitment at the local cervical cancer screening services in the Copperbelt. However, these efforts resulted in the recruitment of only 1 participant who was a resident of rural village at the time of their study. It was very important to get the perspectives of women from the rural villages to provide insights on what it means to be diagnosed with cervical cancer as a rural dweller living far away from health services.

1.6 The sample

This study was informed by a total of 39 participants who took part in four different focus group discussions. Groups were divided into policy makers (n=12), tertiary health care workers (n=6), front line health care workers (provincial level to community level, n=11) and women living with diagnosed cervical cancer (n=9). The sample also included a woman living with cervical cancer who was recruited on the basis that she resided in a remote rural village setting unlike focus group participants who resided in semi urban settings.

The data were collected between June and August 2016.

Table 2 - Representatives of policy makers and tertiary health workers

Participant identity	Professional background	Gender	Work location
A	Doctor	M	Nchanga
B	RN	F	Chiwempala
C	RM	F	Chiwempala
D	RM	F	Chawama
E	RM	F	clinic 1
F	RM	F	Nchanga
G	EN	F	Nchanga
H	RM	F	Chawama
I	RM	F	Kabundi
J	RM	F	Nchanga
K	RM	F	Nchanga

RM - Registered midwife
RN - Registered nurse
EN - Enrolled nurse

Table 3: Representatives of Primary Healthcare workers (HCWs)

Pseudonym	Age	Residence	When diagnosed	Treatment	Hospital where treatment
Leyla	28	Nchanga North	2014	Hysterectomy (Uterus or part of it removed)	Ndola
Nancy	47	Chikola loop	2014	LEEP and Hysterectomy	Nchanga (LEEP), Kitwe Central
Moly	40	Nchanga North	2014	Hysterectomy	Ndola
Clara	23	Nampundu	2014	LEEP	Nchanga
Rosie	45	Lulamba	2015	N/A	Ndola general
Hope	57	Nchanga North Chilabombwe mine	2014	Radiotherapy	Cancer Disease Hospital
Harper	42	township	2014	N/A	
Joy	47	Chilabombwe	2014	Radiotherapy	Cancer Disease Hospital

Table 4: Representatives of women living with diagnosed cervical cancer

2. Findings

This section outlines the key findings arising from the thematic analysis of the data from the field work in Zambia. These findings present the collective views of the health system members who took part in the study. The findings thus represent the views of representatives of policy makers, healthcare workers (tertiary level, provincial level, district level and community level) and representatives of women living with diagnosed cervical cancer. Although not generalizable across the entire Zambian health system, these findings provide useful insights into the local stakeholders' views on whether or not, as well as how telehealth can be used to improve cervical cancer screening and care in Zambia. Being a qualitative study, many themes were bound to emerge given the personal perspectives expressed by the various participants involved in the study. This report focuses on what we considered as the key themes from the data analyses: Rationale for telehealth in cervical cancer screening in Zambia, system readiness for telehealth, policy environment and pre-requisites for the use of telehealth in cervical cancer screening and care in Zambia.

2.1 The need for telehealth in cervical cancer screening in Zambia

We wanted to hear from the participants whether or not, and how, telehealth could play a role in improving cervical cancer screening and care in Zambia. We therefore asked all the participants: *Is there need for the use of telehealth in cervical cancer screening in Zambia?*

The participants expressed an overwhelming support for telehealth in cervical cancer screening in Zambia. The responses suggest an affirmative endorsement of the potential use of telehealth in cervical cancer screening in Zambia. The participants provided different reasons why they believed telehealth could be beneficial to the health system. Some of the participants for example noted that use of telehealth would help minimise human errors by enabling timely screening and care through enhanced timely consultation between different levels of relevant healthcare personnel.

"It may reduce error percentages on what is going on" (Participant 3, Policy maker)

The participant quoted above observed that the current system was prone to errors and a suitable telehealth solution could help minimise the errors, hence make healthcare more efficient.

The participant quoted above observed that the current system was prone to errors and a suitable telehealth solution could help minimise the errors, hence make healthcare more efficient.

"I was s referred to Ndola Central Hospital where I was [...] told the cancer was stage 2B and the doctor wanted to refer me to Cancer Disease Hospital in Lusaka. But when I went back I was admitted and I was seen by another doctor who said the cancer was in the early stage and I did x rays there was no need to go to cancer disease hospital. I was seen by different health care workers so that they are sure of the diagnosis and the treatment to give me" (Leyla, patient representative).

The above extract illustrates that the use of telehealth could reduce the cost of such double consultations by enhancing information sharing and consultations to improve patient care. The patient was seen by two doctors, to make care judgement. Telehealth would minimise such costs of care and enhance consistency by enabling knowledge sharing and possibly continuing medical education to enhance efficiency of the system.

Application of telehealth in cervical cancer screening was also seen as a solution to the problem of geographical distances between patients and the healthcare specialists. This would for example reduce patients' travels times to different healthcare specialists by linking available specialists remotely.

"there is a lot of room to reduce the gaps in many services offered in the country. Looking at pathology for example as an area of acute shortage [...] tele pathology for example can fill the acute shortage of pathologists in the country [...] this can ensure that expertise reach the rural areas without specialist covering physical distances [...] where we have human resource shortages" (Participant 1, policy maker)

"the process will be faster because when you travel you are just given appointments and then again you have to travel back. So if tele-health is implemented the appointment can be made using the phone to lessen the inconvenience of travelling back and forth" (Nancy, patient representative).

The linkage of healthcare workers was seen especially vital in specialities where there are acute shortages of healthcare workers such as pathologists. As illustrated above, telehealth would enhance the sharing of the scare human resource capacity to improve diagnosis and care of cervical cancer patients across the country.

Although not directly mentioned, it was also implied that telehealth would play a role in redistribution of healthcare workers, hence ensuring equity across the country. A participant noted that currently, most consultants are based in Lusaka. There is rural urban inequality in healthcare workers' distribution which then leads to rural urban inequality in healthcare access and outcomes for the patients.

"we need telehealth for consultations [...] services are arranged such that more specialists are concentrated in Lusaka and less or none in district areas. Telehealth can make consultations easier" (Participant 8, policy maker)

"the process will be faster because when you travel you are just given appointments and then again you have to travel back. [...]"

Nancy
Patient representative

A participant noted that it may not be easy to redistribute healthcare workers across the country or train enough workforces to meet the national requirements in the near future. But telehealth could enable real time consultation and feedback remotely by sharing the available resources.

"If we have telehealth [...] we can do consultations in real time and provide feedback quickly. This may cut the costs both for government and individuals. For example, save clients time spent traveling to see specialists" (Participant 8, policy maker)

Telehealth could reduce the costs the patients incur while travelling long distances to see the doctors. It could also reduce the costs to the government by reducing the need to invest in expensive equipment across the country. Thus there would be an opportunity for the government to benefit from economies of scale. In other words, use the few expensive equipment available to serve a larger population across the country. Additionally, early diagnosis of cervical cancer would also reduce the need for intensive healthcare that is otherwise incurred by the government when women are diagnosed too late, with advanced stage cervical cancer. Lastly, women diagnosed early could benefit from available treatment and return back to their work or other economic engagements thereby benefiting the socioeconomic capital of the country.

"early diagnosis reduces costs. So if telehealth can improve early diagnosis, costs of care can be reduced hence reduced costs overall" (Participant 11, policy maker)

Participants also noted that one common problem most programmes face, including the on-going cervical cancer prevention programme, is the loss of patients to follow up. It was their hope that telehealth would strengthen the care pathway by enabling healthcare workers to follow up patients to remind them of appointments and to communicate the outcome of their diagnoses in a timely manner.

"Telehealth can improve continuity of care by strengthening care pathway" (Participant 2, policy maker)

""early diagnosis reduces costs. So if telehealth can improve early diagnosis, costs of care can be reduced hence reduced costs overall""

Participant 11
Policy maker

"I think telehealth is needed in Zambia because there are patients who are given review dates but they don't go back. So if there was telehealth, patients can be reminded a day before the review date not to miss the appointment. It can also help in making follow ups because cervical cancer is killing a lot of people nowadays" (participant C, primary healthcare worker)

From an ICT point of view, telehealth would make ICT more relevant to health care. Thus people would start seeing ICT as more than just a tool for emails but an integral part of the health system. Thus successful telehealth solution would enable all stakeholders to appreciate the role of ICT and hopefully make a case for further investment in ICT.

"It brings about issue of relevance of ICT people. People always wonder what ICT people do. So telehealth makes us relevant and illustrate what IT can contribute. We are happy when people are talking technology" (Participant 10, policy maker)

However, despite the stated need and the evident optimism to use telehealth to improve cervical cancer screening and care expressed by the participants, some of the participants sounded a word of caution. The implementation of telehealth could lead to the creation of unmet demand.

The proponents of this view noted that the Zambian health system is weak, as is evident from the literature, marred with acute shortages of healthcare workers, funding gaps and poor infrastructure. There is therefore a danger that successful screening could overburden an already weak health system. This could lead to ethical challenges since there is no point in screening someone if they can't be treated. But an equally powerful counter argument was provided by some of the participants who argued that the current problem is low diagnosis which is leading to high mortality rates. Any solution that would minimise the problem of late diagnosis was worth going for and then dealing with any subsequent demand for care.

"It is a screening tool [...] we don't want to screen women late. If telehealth can increase coverage, it is worth going for [...] regarding demand, if we can screen more people, the demand will definitely go up" (Participant 3, policy maker)

Given that people are being diagnosed late for cervical cancer and most of them end up dying soon after diagnosis, it was felt that screening needs to be intensified. That it would be ironical to maintain the status quo and shy away from the potential of increasing screening of women through telehealth, whereas in the current state the problem is low screening rates which are leading to high mortalities. The moral argument is to do screening as part of health systems strengthening rather than keep status quo for fear of causing huge demand that may not be met. It was also noted that it is worth remembering that not every woman screened will be positive for cervical cancer screening and it would help provide a true picture of the pandemic which is largely based on modelling.

Some of the women living with cervical cancer added that telehealth would not only be useful in diagnosis as outlined above, it would also be very handy in creating awareness among women. For example, awareness messages could be relayed through mobile phones to sensitize women to go for screening.

"Tele-health is important because every person now has a phone and therefore can easily receive sensitization information unlike every time walking to the hospital for such information besides a lot of people don't know that screening is free" (Rosie, patient representative)

"*Tele-health is important because most women don't know the signs symptoms of cervical cancer, so they sit back but if they see pictures or messages on the phone; they will be compelled to go to the hospital"* (Nancy, patient representative)

The above observations suggest that telehealth had a role to play in awareness creation as well as knowledge sharing between different health system members. From the narratives of the patient representatives, if there is anything they could wish to change was to get diagnosed early enough, hence a strong focus on awareness. They blamed their late diagnosis on lack of awareness more than the lack of access to screening services.

In summing up the need for telehealth in cervical cancer screening, a participant noted that the world is quickly evolving and advances in ICT are circling the globe at a very fast pace. It was therefore imperative that Zambia as a country took up the challenge of keeping up with what was going on around the world in terms of using ICT to solve some of the public challenges such as cervical cancer pandemic.

"We are advancing in terms of technology [...] we can't afford to lag behind as a country. The world is evolving very fast, and Zambia has to be part of that evolution" (Participant 2, policy maker)

In other words, if there was no any other justification for the need for telehealth in cervical cancer screening in Zambia, then it is necessary because the world is quickly adopting and using technology in various strands of the society including healthcare. Zambia ought to be part of the evolving world or risk being left in the shadows.

2.2 Doubts and fears about use of telehealth in cervical cancer screening

The participants also expressed genuine fear and concerns about the potential use of telehealth in cervical cancer screening. As much as they believed there was real chance of improving cervical screening as outlined above, they expressed uncertainties that some believed would make the use of telehealth in cervical cancer screening a challenge Zambia. The participants said that a number of factors ought to be addressed, for telehealth to be usable in cervical cancer screening or any related program in Zambia.

2.2.1 Costs

The concerns over the costs of the proposed project and the cost of screening at the individual level because insurance schemes did not cover screening costs. There were also concerns about the long term sustainability of the potential telehealth solution.

"worried about costs involved in implementing the program, its sustainability and methods that would be used to roll out this project" (Participant 18, policy maker)

" we are ready for telehealth but I am unsure of the costs involved in implementing Telehealth" (Participant F, primary healthcare worker)

Although the use of telehealth presented a cost saving opportunity for the health system, the cost of screening was not covered by any medical insurance hence it was not clear who would meet the screening costs. The participants sought to know whether the project would cover the costs for women to screen and also fund the implementation. At the time of the study, the research team was yet to identify a potential funder; hence the question on the cost of the project could not be answered. Regarding the cost of screening, participants from healthcare financing noted that insurance companies could actually cover the cost of cervical cancer screening. But there was need to have a national dialogue about that possibility and to come up with a package just the same way voluntary male circumcision was ultimately funded. To achieve such, there would be need for the government to endorse the program and also lobby insurance companies to ensure that cervical cancer screening was a national program.

"we are ready for telehealth but I am unsure of the costs involved in implementing telehealth"

Participant F
Primary health care worker

Regarding the issues of sustainability, some of the participants noted that often projects are initiated but they end up being ghost projects as soon as the piloting is completed. That they never last long enough to transform the envisaged areas of public life.

2.2.2 Confidentiality and data protection

A significant number of participants also expressed concerns about confidentiality and data protection. They questioned how the information would be stored or shared and who would have access to the information. Noting the importance of confidentiality, there was a call to ensure that images particularly don't end up in the wrong hands.

"I would be really worried about the confidentiality that would be accorded to the information collected" (Participant B, primary HCW)

"it will be bad if you attach names to the pictures otherwise if there no names I see nothing wrong" (Rosie, patient representative)

The second extract above is from woman living with diagnosed HIV. They emphasized that to ensure confidentiality and security of the women, telehealth data should be anonymised to detach any information that could identify the person screened. In other words, the program has to ensure anonymity of the users.

This section doesn't offer any solutions to the concerns about confidentiality because they are issues that any telehealth solution will have to address thoroughly. However, the readers of this report should bear in mind that the possibility of using telehealth in cervical cancer screening is venturing into a very private realm of healthcare which needs to be protected as much as practically possible. The ongoing regulations processes in Zambia will also help in addressing confidentiality of the potential service users and data handling and management.

2.2.3 Risk of duplication - is there added value to existing programs?

Some of the participants also noted that before coming up with another intervention focusing on cervical cancer screening, it was vital to take an audit of what is currently available in Zambia and to identify what would be the added benefit of a new intervention.

"my other concern would be to figure out how this project is different from other already existing cancer screening services being provided and how this project would prompt more women access the cancer screening service" (Participant H, primary HCW)

Noting that the biggest challenge is getting women to screen using the available screening services, the participant wondered how the use of telehealth would encourage more women to screen. The participants agreed that there would be need for advocacy and awareness interventions to go hand in hand with any ultimate telehealth solutions selected. This would ensure a buy-in by potential beneficiaries and the motivation to use the service.

"how information in this project would be communicated to the clients (the techniques to be used) so that they are motivated to utilize the service. How do we make women trust the information and services?" (Participant I, primary HCW)

2.2.4 Health care workers' attitudes

We also found concerns about how the use of telehealth would overcome the perceived underlying healthcare workers' apathy towards change. Some of the participants noted that healthcare workers were used to traditional (standard) medical practice hence any disruptions to their way of working would be resisted.

"how to improve the attitude and conduct of health care workers toward clients so that women feel they need the service" (Participant B, primary HCW)

There were similar concerns about how the proposed project would change the attitude of some of the healthcare workers towards patients. The existing power imbalance means that in some cases patients have no say in most of their care decisions. Some of the healthcare workers use their power of knowledge to make all decisions for their patients, sometimes almost contemptuous towards their patients. The participants concerned thus questioned how the proposed project would reform healthcare worker attitude towards service users.

2.2.5 Telehealth solution

The participants also expressed concerns regarding the actual telehealth solution that will be selected for use in their context. Apart from the concerns about the cost of the equipment, there were also concerns about the expertise that would be required to run and maintain the system that may be put in place.

"How will the system be serviced; will it work with local manufacturers to make sure local people can be used to maintain the gadgets or do we have to fly in people from Europe or India any time things go wrong. Or sit by the phone waiting to be told what to in the middle of the night because of time differences for example" (Participant 18, policy maker)

Particular concerns were raised about whether there would be capacity building of local personnel to manage the system. The participants expressed deep disapproval of any system that would solely rely on foreign expertise. A system that would involve flying in technical support from abroad to come and fix, noting that such a system was bound to fail because of the ultimate delays that would ensue in keeping it running as the users waited for the overseas experts to solve any glitches that will obviously arise.

The participants also questioned the kind of after sales services that would come with any selected equipment. Will the developers of the equipment be responsible for any repairs after the purchase or will they pack and go as soon as they deliver the system? They said that it was important to answer these questions because they have a direct impact on the cost of running the system that would otherwise look economical at the installation phase. A related concern was to do with the developer of a potential telehealth solution being able to provide back up support themselves or if they would be contracting someone else, who would then come in with their own costing, making the system potentially expensive to run in the long term.

Another key concern regarding the ultimate choice of a telehealth solution was data ownership. The participants wondered who would own the data generated by the system, where the data would be stored and managed as well as the kind of security features that would be put in place to ensure that the data is safe.

"How will the system be serviced; will it work with local manufacturers to make sure local people can be used to maintain the gadgets or do we have to fly in people from Europe or India any time things go wrong."

Participant 18
Policy maker

"Zambia has been very relaxed in the past [...] instances where people present data about Zambia at high level meetings and conferences yet nobody in Zambia knows about the work. People get ethical approval yes, but then they do their own things and take off with all the data [...] that is changing [...] Zambia is getting strict [...] all information must be governed by Zambia's e-governance policy and all data should be locally owned and managed" (Participant 1, policy maker)

Emphasizing the changes taking place in the country regarding data ownership and security, another participant also added that apart from making sure that local data remains local, there were also efforts to streamline and unify health data in the country. The participant cautioned that any system that would be put in place to support the proposed telehealth project would have to augment the existing systems rather than create another silo of information.

"we have so many silos of information. We don't want to create another silo, which only leads to for example double reporting since the data is captured twice or three times in different silos" (Participant 3, policy maker)

2.3 System readiness for telehealth

We asked all the participants whether each of their work places was ready for a potential implementation of telehealth in cervical cancer screening in Zambia. All the individuals representing different health system members expressed different views on the level of their readiness for the use of telehealth in cervical cancer screening. The views expressed here are not the views of the organizations these individuals represented, but rather the participants' personal assessment of their organizations' readiness for telehealth.

From an ICT perspective, the choice of Copperbelt province as the site for the implementation of the first phase of the project was a "smart choice because Copperbelt is ready due to the fibre connection" (Participant 3, policy maker). The participant noted that if there was a region where telehealth could be implemented immediately, it was the Copperbelt province which had been connected to the capital Lusaka through fibre optic network. However, the downside of Copperbelt's good connectivity is that the region is not the most rural part of Zambia, with poor access to services. The regions where services are needed most are areas far away from Copperbelt and Lusaka, two of the best served provinces in Zambia as a whole. This implies that although there is a network on which to run a telehealth system in Copperbelt region, it may be difficult to solicit the support of other stakeholders such as donor agencies because the project would be seen as adding more services to those already accessing services. But the participants also noted that even within Copperbelt as a province there were many areas away from the main urban areas in the region, such as Kitwe and Ndola, that don't have access to services. An eventual project in Copperbelt region could for example improve access to the rural areas within Copperbelt province.

Representatives of educational stakeholders said that students from their respective universities and medical training schools were being equipped with basic ICT knowledge and skills. The relevant participants believed their organizations were ready for telehealth solutions in Zambia because they were already training students in ICT. This would ensure that the future health care workers were ready to use ICT solutions in their work. However, the participants noted that there was a need to include telehealth or health informatics as mandatory component of the curricula of all healthcare professionals training. Apart from training in ICT, educational representatives also noted that they were equipping their students with public health promotion skills that would be useful in developing appropriate awareness messages that would be used to sensitize the public about cervical cancer, the need to screen and where to get screened.

The representatives of health care financing noted that their organizations supported the use of telehealth in cervical cancer screening and they would be ready once the discussions were finalized and the programme gets ministerial approval. Noting that they could not have policies in place for a programme that was yet to be a reality, they added that they would be happy to sit with various stakeholders to determine how best to provide a product that would cover women for cervical cancer screening.

Most of the participants came from various units of ministry of health. They said that that their organizations were ready because they were already providing services to the population, including cervical cancer screening. Telehealth would therefore improve the way they offer those services to more people using the limited resources they have. A participant noted that telehealth is actually in use at some of the services across the country; hence it is not a new thing. As noted in the literature review section, the cervical cancer screening program in Zambia has an added component of electronic cervical imaging (eC3) to enhance consultation between healthcare workers and patients and also between healthcare workers themselves.

The participants described so many other existing examples of on-going application of telehealth solutions in Zambia, noting that it would be a timely and welcome development in cervical cancer screening. Further examples of telehealth use in Zambia include a satellite link between the University Teaching Hospital in Lusaka and a hospital in India. There is a hospital in Southern Province of Zambia that is linked to a hospital in Italy. There is sharing of electronic images between facilities. For example, Ndola central neurosurgeons are linked to University Teaching Hospital in Lusaka. Furthermore, healthcare workers do consult each other, even if unofficially. But there is no guideline on how images and related information should be managed or shared. Generally, healthcare workers use telephone to refer patients and to seek support from each other. All these show that telehealth is not a new thing to the Zambian health system, it is on-going and needs to be made smart, the participants noted.

Some of the participants strongly linked eventual use of telehealth to the use of mobile phones. Most of such participants thus believed that the country was ready for the use of telehealth in cervical cancer screening due to sheer growth in mobile phone usage as noted below.

"I mean in terms of enablers, aren't we having a lot of internet providers coming on board now? A lot of people having mobile phones, are they not enablers? Actually the use of mobile phones in Africa has now gone over 80%. According to Oxfam, in 2010, Africa accounted for 20% of mobile phones in the world, but now it accounts for 80%. Are these not enablers" (Participant A, primary HCW)

The important thing about the above extract is not the figures but the view that the growth in the mobile phone and internet service provision sectors were seen as a good indicator that Zambia was ready for telehealth solutions.

"we have had an experience in that we usually call the patients when pathology results come out. As in the use of ICT, those who leave their email addresses, we send them email telling them to come and get the results" (Participant G, primary HCW)

The above extract further illustrates the Zambian health system readiness for telehealth. It suggests that healthcare workers are already using some form of telehealth which any new programme can learn from and/or build on. Some participants noted the use of media such as WhatsApp groups to share information between healthcare workers and to consult each other as further examples of the system's readiness as well as the existing use of telehealth in care delivery in Zambia.

However, the participants noted the need to increase awareness about existing services and any eventual telehealth solution, to reduce stigma associated with cervical cancer and to enable more women to access services. As some patient representative noted, part of the problem is lack of awareness about cervical cancer and that screening and treatment are available. There is need to create awareness even if it means using *"loud speakers so that you make people aware about the system"* (Participant G, regional HCW) and *"the causes, signs and symptoms so that women are aware"* (Joy, patient rep).

2.4 Policy environment

We found that the policy context is an area that would require a lot of collaborative efforts to streamline or clarify through provision of up to date guidelines in order to enhance any potential use of telehealth in a large scale cervical cancer screening in Zambia.

The use of telehealth in cervical cancer screening would involve inter and intra departmental collaborations. It would also involve sharing of information between different levels of authority within between healthcare units.

For example, the community nurses sharing information with consultants and the national referral hospitals. The participants therefore felt that there was need to come up with some clear policies for example regarding data sharing between health care workers and what media can be used to share such information. Such a policy or guideline would for example address the vagueness that would ensue if telehealth was implemented in the current policy environment where the responsibility lies with the person seeing the patient. The envisaged scenario where telehealth would enable a community health worker to seek expert input remotely may actually deter front line staff from screening the patients and making decisions to avoid liability, given their limited level of expertise in cervical cancer. But at the same time consultants would not wish to take responsibility for a patient they have not seen physically.

The good news regarding policy context in Zambia was that different government departments such as ICT and e-governance unit under the Office of the President were in the process of formulating policies and guidelines that would govern data sharing, data integrity, data protection and related concerns that currently hinder successful application of telehealth in cervical cancer screening in Zambia. One participant noted that the Centre for ICT excellence were also streamlining their guidelines which will ensure that all technological applications received standardised objective vetting to ensure that they meet safety and security requirements stipulated by the government of Zambia.

2.5 Pre requisites for successful use of telehealth in cervical cancer screening in Zambia

This section provides an overview of issues that the participants believed should be addressed to ensure a successful use of telehealth in cervical cancer screening and care in Zambia. Some of the issues outlined below are on-going, but may need to be strengthened. The points below can be treated as recommendations from the participants in our study.

- Participants emphasized the need to improve on internet connectivity across the country because connectivity is the backbone of any telehealth solution. This made the choice of Copperbelt region for the implementation of the second phase of the current project wise. But there is need to improve connectivity or come up with solutions that don't rely on internet to reach the most remote villages of Zambia.
- Participants also recommended that telehealth and health informatics should become part of the training curricula to ensure supply of skilled and competent human resource that would successfully implement and use telehealth solutions.

- There is need to build the capacity of the existing workforce to be able to make use of telehealth solutions. This should not just focus on technical ICT skills but also on the latest knowledge and skills related to the disease in question such as cervical cancer. Noting that healthcare workers are not all specialists in cancer or indeed interested in the disease, it was important to continuously provide up to date information to existing healthcare workers to ensure they are informed of the current global healthcare trends. There is need to build their capacity so that they can be more effective in their envisaged role in cervical cancer screening. The human capacity building should also include cultural sensitivity to ensure that the sensitive social issues influencing healthcare access are taken into account by healthcare workers when designing and implementing interventions such as the proposed telehealth solution. Lastly, there was need to train more healthcare personnel in specialties of dire need such as pathology, which was seen as a health system requirement rather than a telehealth program requirement.
- A successful telehealth screening program would require cost of screening and subsequent treatment covered. Otherwise many rural patients in particular cannot afford the screening fees, where the screening program does not subsidize the cost of screening.
- A successful implementation of telehealth in cervical cancer screening would also involve engaging ALL relevant ministries and government departments such as the Centre for ICT excellence, University Teaching Hospital and E-governance unit. Also to be included are private sector players such as medical insurance companies, logistics providers such as courier services which ferry samples across the country and non-governmental organizations.
- Participants also recommended concerted efforts to improve the attitudes of healthcare workers towards ICT and their patients. Some of the participants noted that although healthcare workers are generally accused of being resistant to change, the reality is that healthcare workers are under so much pressure due huge workloads. Any telehealth solution should therefore reduce their load and not increase it. Anything that is going to increase the existing burden of care would not be easily taken up by the healthcare workers. Thus that telehealth solution should be an added value not added burden to healthcare workers or the existing systems.
- As outlined above, the participants pointed out that one area that will have to be addressed before implementing telehealth solution in cervical cancer screening is data protection and integrity. Confidentiality and data security are paramount and will require thorough attention.

- Participants also noted that a successful telehealth project would not be judged only on the basis of how many women gets screened. It will be judged on its scalability and sustainability. Noting that one-off successful pilot projects never really make an impact, the participants concurred that the proposed screening program should be sustainable because cervical cancer will not be eliminated hence the need for continuous service. Also, the program should be able to over more regions in the future.

3 Study strengths and limitations

This section outlines some of the key strengths and limitations that may have influenced the findings reported herein.

3.1 Strengths

The credibility of the findings contained in this report is underpinned by a few factors. First of all, the researchers involved in this study had a strong contextual awareness of the problem explored in this study. The researchers had the cultural and political awareness of the study context and were able to ensure that the study tools and the practicalities of the field work were relevant and acceptable to the local stakeholders. The study for example benefited from technical input of individuals directly involved in the on-going Zambia national cervical cancer screening programme, an effort to ensure accuracy and relevance of the findings and the approaches used in the study.

The study is informed by individuals from different professional backgrounds, gender and geographical location across Zambia. More importantly, the study was informed by women who have been diagnosed with cervical cancer and are on treatment. The views of these women were very important in highlighting the acceptability of telehealth in cervical cancer screening in Zambia. Reflecting on their own personal screening experiences, the women described how the potential use of telehealth could make the experiences of screening and care better and timely. Interestingly, whereas the professionals were rightly concerned about confidentiality and the ethics of using telehealth in cervical cancer screening, the findings suggest that for the women living with cervical cancer, early diagnosis and an opportunity to avoid some of the adverse consequences of cervical cancer they had faced would be a priority.

The study adopted a health system approach to gather views of different stakeholders in telehealth, ranging from educators, clinicians, national policy makers, health care financing and cervical cancer patients. This triangulation of data sources ensured that the findings covered a broad range of perspectives that would be needed in the implementation of telehealth in cervical cancer screening in Zambia.

It also gave the stakeholders an opportunity to share their views and to identify how they can work together to improve healthcare in Zambia. The views expressed in this report thus reflect different segments of the health system. In the process, a coalition of telehealth stakeholders was formed. This coalition can work collaboratively to take forward the idea of using telehealth in cervical cancer screening in Zambia into a reality that is owned and led by local stakeholders.

3.2 Limitations

This sub-section outlines some of the key methods and sampling limitations.

3.2.1 Method limitations

Focus group discussions, although advantageous in encouraging dialogue by making participants feel safe in the company of others, can also lead to muted responses by some participants. Participants were likely to share only what they felt comfortable sharing in a group, compared to in an individual interview. There was a danger that some of the participants dominated the discussions and the researchers had to carefully manage discussions to ensure that all participants had a chance to be heard, while at the same time allowing those with insights enough time to share their views as much as they wished to.

Researchers asked participants for consent to take part in the study, but the findings in this report are largely the interpretations of the researchers. The consent therefore did not cover data interpretations. Also, consent is a continuous process but the researchers did not get the chance to check with the participants if their views were correctly reflected. However, the participants will have an opportunity to validate the findings through a stakeholder feedback session where the researchers will present the key findings in an accessible language and invite attendees to comment on or critique the findings.

Focus group sessions were audio recorded to ensure accuracy of data capture. Some participants, may have limited their participation because of confidentiality concerns. Two participants withdrew from the study because they felt uneasy about providing written consent and their contribution being recorded. All participants were reassured of their confidentiality and everyone was urged to only share information they were happy to share with the rest of the group. They were also assured that the final report will only have anonymised data and that no one would be able to identify those took part in the study. All names used in this report are pseudonyms to ensure anonymity.

3.2.2 Sampling limitations

The sample was not intended to be representative of all the potential stakeholders in telehealth or those involved in cervical cancer screening and care in Zambia. It is impossible to assume normal distribution of experiences and perspectives on telehealth, hence impossible to aim for a representative sample of all telehealth stakeholders. The aim of sampling was therefore to get maximum variation in the possible sources of data to provide diversified perspectives on the possibility of using telehealth in cervical cancer screening and care.

Although our sample included people from diverse professional backgrounds and roles in the potential use of telehealth, there were other key stakeholders that were not represented. Key among them were the telecom operators who are actually in charge of connectivity across the country and would be key in any telehealth solution to be implemented in Zambia. Due to shortage of time, we did not manage to talk to such key stakeholders. However, the next phase of the project will make sure such stakeholders are included in the coalition of telehealth stakeholders, as we call them in this report.

We had intended to recruit women who had been diagnosed with cervical cancer to explore their views on how telehealth could make a difference in cervical cancer screening. Part of the aim was to recruit women from very remote rural areas, because it is the remote areas where telehealth can have a huge impact in availing healthcare (Marcin, Shaikh, & Steinhorn, 2015) to women who otherwise cannot easily access healthcare services in the urban areas. However, we could not recruit from very rural areas into the study due to several limitations including time. Our recruitment was clinic based, yet the clinics are not in a position to reach most of the women from the rural villages, even to inform such women of their screening results. It would be good to include the input of women living with cervical cancer, from remote rural areas, in the next phase of this project.

4 Conclusions and recommendations

The participants in this study, who are some of the key stakeholders in any potential use of telehealth in cervical cancer screening and care in Zambia, expressed great optimism that telehealth could improve cervical cancer screening in Zambia. The participants also shared their views on some of the issues that would need to be addressed in order to effectively use telehealth in cervical cancer screening. The findings have illustrated that indeed telehealth is already in existent in the Zambian health system in different forms.

Thus Zambian healthcare workers are indeed already using some form of knowledge sharing locally through simple tools such as WhatsApp groups or internationally through satellite linkages to overseas experts to enhance their practice. A telehealth solution in cervical cancer screening and care would therefore build on such existing precursors to create a more streamlined service that also meets the local needs. Healthcare workers expressed the desire to share knowledge with each other to keep themselves informed and also to inform their judgement regarding challenging cases they may come across. Our findings suggest all the participants believed that sharing of knowledge is beneficial for the ultimate client of the health system – the patients.

The findings outlined some of the perceived barriers to and facilitators of the potential use of telehealth in cervical cancer screening and care in Zambia. One of the key facilitators that we wish to re-emphasise is the desire and support of the local stakeholders. We found a very strong desire to embrace telehealth among the participants who came from diverse professional and social backgrounds. It was encouraging to hear women who were living with diagnosed cancer share their views on how a telehealth solution could have made their diagnosis and care more efficient and effective. Apart from the uncertainty about the potential sources of funding for the proposed telehealth project, one other key barrier to be overcome is the policy context which may hinder the effective use of telehealth in cervical cancer screening. As one participant noted, policy is always playing catch with technology and there is need to speed up policy formulation to create a conducive environment for healthcare professionals to embrace relevant technology.

Recommendations

- We recommend the Involvement of all local stakeholders in all project processes including planning, designing, soliciting partners, implementation and evaluation. The local stakeholders should not be seen as just doctors and nurses, but the entire health system composition including patients with cervical cancer, whose inputs into how to reach women with awareness interventions would be invaluable.
- We also recommend that the relevant government bodies should streamline policies and guidelines that govern key components of telehealth such as data protection, information sharing and approved media of information sharing by health care workers. Potential implementers of telehealth solution for cervical cancer screening can work with relevant government departments to develop practice guidelines regarding data protection and information sharing.

- We recommend the formulation of a telehealth implementation framework that is informed by the local needs and can be used by anyone willing to implement a telehealth solution in cervical cancer screening in Zambia, or other similar settings with limited resources. We will follow this report with a telehealth implementation framework.
- We recommend the involvement of local Zambian researchers with a special focus on gender issues or anthropological background to provide relevant context specific needs of women in Zambia that will inform the methods used in the application of telehealth in cervical cancer screening in Zambia. Research, monitoring and evaluation of the next phase of the project should involve multidisciplinary teams. Health economists for example can assess cost effectiveness and equity whereas clinicians can evaluate effectiveness of care.
- We also recommend the formation of a coalition of telehealth stakeholders involving diverse government departments, civic society organizations, non-governmental organizations, private sector, academics and community members among many others. This would ensure broad ownership of the initiative and sustainability.

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This report gives you the findings of a needs assessment study made in Zambia on attitudes and system readiness for using telehealth in cervical cancer screening and care in Zambia. Similar studies have taken place in Kenya and Rwanda and the collective findings will feed into a unified telehealth implementation frame work.

If you wish to know more about the project, visit spidercenter.org

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