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

A needs assessment undertaken for SPIDER
June - August 2016

John Owour (Dr)
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Abbreviations

DHM - Digital Holographic Microscopy
DNA – Deoxyribonucleic Acid
DSV - Department of Computer and Systems Sciences
EVA – Enhanced Visual Assessment
EVA scope - Enhanced Visual Assessment microscope
HCWs - Healthcare workers
HW – Health Worker
HIV – Human Immunodeficiency Virus
HPV – Human Papilloma Virus
IARC - International Agency for Research on Cancer
ICT – Information and Communication Technologies
Mobile ODT – Mobile Optical Detection Technologies
MoH – Ministry of Health
mPesa – Mobile Money Platform (Kenya)
NCCPSP - National Cervical Cancer Prevention Strategic Plan
NGOs – Non-Governmental Organisations
Pap smear – Papanicolaou test: a method of cervical screening used to detect potentially pre-cancerous and cancerous processes in the cervix
PM C – Policy maker County level
PM N – Policy Maker National level
SDGs – Sustainable Development Goals
SEI -Africa - Stockholm Environment Institute Africa Centre
SPIDER – Swedish Program for ICT in Developing Regions
T2D – Gynocular Triage To Diagnose
TB – Tuberculosis
UN – United Nations
UNAIDS – United Nations Joint Programme on HIV and AIDS
VIA – Visual Inspection with Acetic acid
WHO – World Health Organization
Executive summary

Conclusions

• Participants had a positive attitude towards the use of telehealth in cervical cancer screening and care in western Kenya.
• Successful use of telehealth in cervical cancer screening and care in western Kenya depends on how well the system works to overcome the underlying barriers to cervical cancer screening uptake such as lack of awareness and cultural norms.
• The use of telehealth is not new in the Kenyan context, but there is need for clearer policy guidelines to govern information sharing and storage.
• Use of telehealth in cervical cancer screening in western Kenya must involve both national and county governments because the national government runs tertiary services while the county government runs the lower level services.
• There is need for further research to evaluate cost effectiveness of telehealth in cervical screening and care.

This report outlines the key findings of a needs assessment study carried out to explore the possibility of using telehealth in cervical cancer screening and care in western Kenya. The report is informed by cross-sectional qualitative data collected through focus group discussions. The participants were different actors in the local (county) and national government health system, including representatives of women living with diagnosed cervical cancer.

Chapter 1 describes the background to the study, offers a synopsis of the structure of the public health system in Kenya and the rationale for the need for improved cervical cancer screening in the country. Kenya has a very high cervical cancer mortality and morbidity burden, a situation worsened by the high HIV prevalence which increases the risk of cervical cancer-HIV co-morbidity. It also highlights some of the barriers to cervical cancer screening and the national government’s policy on the use of ICT in healthcare. Although literature is very limited, three potential technological cervical cancer screening solutions are outlined; GynocularTM, Mobile Optical Detection Technologies (Mobile ODT) and Digital Holographic Microscopy (DHM).

The chapter also outlines the rationale for the study and the methods used for participants access and selection.

Chapter 2 outlines the key findings. The report is based on the perspectives of 17 service user representatives (women living with cervical cancer), 23 County government healthcare workers, 6 national government (referral hospital)
healthcare workers, 11 county government policy makers and 8 national level policy makers. The findings suggest an overwhelming support for the use of telehealth in cervical cancer screening and care, barriers to potential use of telehealth in cervical cancer screening. The chapter also considers both telehealth related barriers such as poor connectivity and the barriers to cervical cancer screening uptake such as stigma, cost of care, lack of equipment and cultural norms and values.

Participants also reported that telehealth was not a new concept in the country, citing various anecdotal examples of ongoing use of telehealth in healthcare provision in Kenya. Participants’ narratives implied that WhatsApp was a popular telehealth solution among some healthcare workers, to consult each other and to share clinical experiences. The participants also noted that telehealth was the next frontier in global healthcare provision hence the need to embrace it in their setting.

Chapter 3 reiterates the need for telehealth in cervical cancer screening and care. The participants said that the stakeholders in the Kenyan context are ready to embrace telehealth in cervical cancer screening and care. But there is need for more guidelines and policies to govern the practicalities of information sharing such as the type of information that can be shared, with whom and using what medium. Such policies should also specifically deal with issues of data protection and confidentiality.

Chapter 4 offers policy, practice, and research recommendations. There is need for relevant ICT and telehealth policy and guidelines at the county level to offer legal framework for potential collaboration between county and national government health care workers. All relevant stakeholders should be involved in the ongoing policy development processes at the county level.

There should be close collaboration between national and county government in the eventual implementation of telehealth in cervical cancer screening and care because patients move across the two levels of care. Lack of coordination can lead to disjointed care for the service users and wastage of resources across the two systems.

There is need for further research on cost effectiveness of telehealth in cervical cancer screening and care. This should form part of the sustainability analysis of the ultimate telehealth solution in the study setting.
1. Introduction and methods

1.1 Background
This report presents findings of a study that considered whether telehealth can link healthcare workers (HCWs) to share information with each other to improve cervical cancer screening and care in low income countries. Telehealth and eHealth are used synonymously in this report to reflect the inferred common meaning by some of the participants. The study was done in Kenya, Rwanda, and Zambia. The three countries were representative of diverse socioeconomic contexts and health systems in low resource countries. The aim of the comparative study design was to develop a telehealth implementation framework relevant to other low resource countries. This report focuses on the findings from Kenya. The findings from Rwanda and Zambia can be found at www.spidercenter.org.

The present study was phase one of a proposed five-year project. This first phase focused on needs assessment, stakeholder mapping and the development of the said telehealth implementation framework. The second phase (year two to four) will focus on the implementation of a relevant telehealth solution in at least the three study countries. There is a possibility of including more countries, funding allowing. The fifth year will involve the development and scale up of phase two and implementation of sustainability plans.

Kenya, like other countries in East Africa, has a very high prevalence of cervical cancer. The country has a population of about 13.5 million women aged 15 years or older. All these women are at risk of cervical cancer. In fact, cervical cancer is the leading cause of cancer related deaths among women in Kenya (International Agency for Research on Cancer, 2017).

The Kenyan health system suffers from acute shortage of Health Care Workers (HCWs) and inadequate cancer care services to cater for the public. According to Kenya Network of Cancer Organizations, Kenya has only 4 radiation oncologists, 6 medical oncologists, 4 paediatric oncologists, 5 radiation therapy, technologists, 3 oncology nurses and 2 medical physicists.

1.2 Kenyan health system
The Kenyan health sector consists of a public system, for profit private sector, Non-governmental organizations (NGOs) and faith based organizations. The public system consists of the Ministry of Health (MoH) and parastatal organizations. Public sector has different levels of service provision as illustrated in Figure 1.
The structure is based on health system governance that existed before 2010 when Kenya adopted a devolved system of governance. The New constitution created 47 counties out of the original eight provinces. Since then, the national and county governments have been working hard to reconfigure the new health system structure.

The national government oversees formulating national health policies and the management of national referral hospitals. County government are gradually taking over the provision of health services at county level and managing the workforce (Wakaba et al., 2014). This implies the management of provincial facilities, and lower levels, is the duty of county governments. In some cases, previous district hospitals are new county hospitals while some provincial hospitals have been upgraded to become national referrals hospitals.

Irrespective of the terminologies used to describe different facilities in the new constitutional dispensation, the service user flow is still very much in line with the illustration.

<table>
<thead>
<tr>
<th></th>
<th>Incidence</th>
<th>Mortality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Annual number of new</td>
<td>4802</td>
<td>2451</td>
</tr>
<tr>
<td>cases/deaths</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Crude rate</td>
<td>22.4</td>
<td>11.5</td>
</tr>
<tr>
<td>Age standardised rate</td>
<td>40.1</td>
<td>21.8</td>
</tr>
<tr>
<td>Cumulative risk 0-74 years (%)</td>
<td>4.4</td>
<td>2.5</td>
</tr>
<tr>
<td>Cervical cancer ranking (all ages)</td>
<td>1st</td>
<td>1st</td>
</tr>
<tr>
<td>Cervical cancer ranking (15-44 years)</td>
<td>1st</td>
<td>1st</td>
</tr>
</tbody>
</table>

*Table 1 Cervical cancer incidence in Kenya
Source: International Agency for Research on Cancer, 2017*
Kenyan health care system levels

**Level 5**
Offer highly specialised diagnostics, therapeutic and rehabilitative services.

**Level 4**
Act as intermediary between district hospitals and National referrals. Offer specialised care and oversee health policy implementation at the district level.

**Level 3**
Offer curative and preventative services at the district level. Implement National health policy agenda through the guidance of the provincial team.

**Level 2**
Curative and preventative services adapted to local population needs. Acts as first point of contact with patients in some places.

**Level 1**
Meant to be the health system’s first line of contact with service users. Offer wide range of preventative health services.

**Community Health Workers**
An army of men and women volunteers working in the villages offering an array of preventative health services. Not directly associated with the Ministry of Health structure. Increasingly becoming a vital first point of contact with healthcare.
1.3 Cervical cancer screening in Kenya
Cervical cancer is preventable through early screening and treatment (Binagwaho et al., 2013; Finocchario-Kessler et al., 2016), yet screening uptake is disappointingly low in Kenya (Rosser, Hamisi, Njoroge, & Huchko, 2015). For example, only 3.2% of all eligible women (16-68 years old) screened for cervical cancer in 2012. This is very low screening coverage for a country where cervical cancer HIV-comorbidity is also high due to high HIV prevalence, particularly in the project site in western Kenya (Nyanza) which has the highest national HIV prevalence (Camlin, Kwena, & Dworkin, 2013). About 80% of women living with HIV were unaware of their status, meaning that they were unaware of their increased vulnerability to cervical cancer.

Although the country had developed and implemented a National Cervical Cancer Prevention Strategic Plan (NCCPSP) (2002-2006), the implementation was ineffective, making cervical cancer screening accessible only in select facilities. A revised version, NCCPSP (2012-2015) aimed at ensuring that all women of reproductive age have access to cervical cancer screening and care to reduce the national cervical cancer burden. The goal of the programme is to improve the clinical infrastructure, avail trained health personnel, target most at risk groups and develop a behaviour change communication strategy. It also aims to create a conducive policy environment, develop a relevant advocacy strategy to mobilise resources and to strengthen the health system for effective monitoring and evaluation of cervical cancer services. The screening and prevention components of the strategy initially targeted at the most at risk groups. Cervical cancer screening service is integrated into the existing services such as maternal and child health and family planning services. Patients who need specialist care are referred to tertiary/teaching hospitals (Ministry of Public Health and Sanitation and Ministry of Medical Services, 2012).

A majority of the available specialist cancer screening and treatment service providers (hospitals) are in the major cities. As illustrated in table 2, seven out of eleven hospitals with specialist cancer care in Kenya are in Nairobi; one in Mombasa (the second largest city) and another one in Eldoret (the fourth largest city). Although Kenya is a major referral hub for cancer treatment and care for patients from neighbouring countries, the bulk of her own rural population have limited access to specialist services for any type of cancer, including cervical cancer.
<table>
<thead>
<tr>
<th>Facility Name</th>
<th>Location</th>
<th>Level of care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aga Khan University Hospital</td>
<td>Nairobi</td>
<td>Cancer detection and screening programmes, specialised diagnostics, chemotherapy and radiotherapy treatment, and palliative and rehabilitation care</td>
</tr>
<tr>
<td>Beacon Health Services Cancer</td>
<td>Nairobi</td>
<td>Cancer diagnosis and out-patient treatment services</td>
</tr>
<tr>
<td>Treatment Center, Coast General</td>
<td>Mombasa</td>
<td>Cancer screening, chemotherapy and surgery</td>
</tr>
<tr>
<td>Hospital</td>
<td></td>
<td>Screening, chemotherapy, and surgery treatment for several cancers – primarily breast cancer, Kaposi’s sarcoma, and surgically treatable cervical cancer. Palliative care Leukaemia, breast, cervical and prostate cancer testing services, surgery for malignant tumours, and general cancer management services</td>
</tr>
<tr>
<td>Kijabe Mission Hospital</td>
<td>Kijabe (Outskirts of Nairobi)</td>
<td>Cancer education, screening, diagnosis, treatment, and palliative care</td>
</tr>
<tr>
<td>Mater Hospital</td>
<td>Nairobi</td>
<td>Diagnosis, chemotherapy, and radiotherapy treatments</td>
</tr>
<tr>
<td>Moi Teaching and Referral Hospital</td>
<td>Eldoret with Satellite clinics in: Kitale, Webuye, Busia, Chulaimbo (Kisumu), Mosoriot, Turbo, Iten,</td>
<td>Out-patient and home-based palliative care for cancer</td>
</tr>
<tr>
<td>M. P. Shah Hospital</td>
<td>Nairobi</td>
<td>Cancer screening and treatment services (chemotherapy)</td>
</tr>
<tr>
<td>Nairobi Hospice</td>
<td>Nairobi</td>
<td>Gynaecologic oncology testing and treatment, free breast screening and fee-based cervical screenings</td>
</tr>
<tr>
<td>Nairobi Hospital</td>
<td>Nairobi</td>
<td>Limited screening, cancer treatment services (gynaecologic), stenting for oesophageal cancer patients, and palliative care services for cancer</td>
</tr>
<tr>
<td>Nairobi Women’s Hospital</td>
<td>Nairobi</td>
<td></td>
</tr>
<tr>
<td>Tenwek Mission Hospital</td>
<td>Bomet</td>
<td></td>
</tr>
</tbody>
</table>
1.4 Barriers to cervical cancer screening in Kenya
There are two key barriers to uptake of cervical cancer screening and care in Kenya; provider and user barriers. Some of the provider barriers to screening include inadequate human resources in terms of numbers and training, insufficient space in the existing facilities and supply challenges. As outlined above, Kenya has very few cancer specialists to meet the service demands for the population of more than 40 million people. On the other hand, service providers report service user barriers such as inadequate knowledge about cervical cancer, long waiting times, discomfort with male providers and fear of pain from speculum examination (Rosser et al., 2015). A review of literature on barriers to cervical cancer screening in sub-Saharan Africa found that women were concerned about the screening procedure and potential negative outcome, low level of awareness about services, embarrassment and possible violation of privacy, lack of spousal support, societal stigmatisation, cost of accessing services and health service factors like proximity to facility, facility navigation, waiting time and negative health care personnel attitude (Lim & Ojo, 2017).

In response to the need for privacy, African medical laboratory Lancet launched the COBAS 4800 HPV in August 2017. The technology detects DNA from 14 high-risk HPV types, including HPV 16 and HPV 18, which cause at least 70 per cent of cervical cancers. According to the Director of Lancet Group East Africa, COBAS 4800 technology allows women to self-collect samples for testing without the presence of a doctor or nurse. Otherwise the Kenyan cervical cancer screening is largely VIA and Pap smear based (Orang’o, Wachira, et al., 2016; Orang’o, Liu, et al., 2016).

1.5 Use of ICT in healthcare in Kenya
According to Kenya Health Sector report 2016, a study commissioned by the Dutch Embassy in Nairobi, Kenya is the only country in Eastern Africa with a comprehensive eHealth strategy and the only country in the world with a multibillion dollar turnover of mobile money platform (mPesa). The platform (mPesa) is linked to healthcare payments through schemes such as M-Tiba and CarePay. The Kenya national eHealth Policy 2016-2030 (DigiAfya) aims “to create an enabling environment for the sustainable adoption, implementation and efficient use of eHealth products at all levels of healthcare delivery in Kenya”. The policy is anchored on the guiding principles as illustrated below (extract from the policy document page 11). Health and ICT in Kenya are gradually getting interconnected and there is potential to maximise ICT solutions in healthcare provision. Various telemedicine solutions have been piloted in Kenya but so far none has had national impact. (Kenya Health Sector report 2016).
1.6 Portable ICT solutions for cervical cancer screening

A scoping review of literature found that Visual Inspection with Acetic acid (VIA) and Pap smear form the backbone of cervical cancer screening practice in Kenya (Orang’o, Wachira, et al., 2016; Orang’o, Liu, et al., 2016). This is very similar to other low income countries in the region such as Zambia and Rwanda (Sankaranarayanan, Nessa, Esmy, & Dangou, 2012), the other sites for this multi-country study. Research into modifications to VIA based screening approach involve use of digital imaging (Bateman et al., 2014) to capture pictures of the cervix as a supplement to VIA. However, evidence has shown that the use of VIA leads to significantly higher false positive diagnoses (Basu et al., 2016). This calls for more sensitive screening approaches to minimise false positives. Accurate screening can ensure efficient use of resources and prevent unwarranted stress to falsely diagnosed women, ensuring that the limited resources are spared for those in need of care. In settings such as Kenya, where services struggle to keep up with demand, making cervical cancer screening efficient could lead to reduced wastage of resources and improved public health.
1.6.1 Gynocular
A review of literature on available portable and affordable technologies that are in use or piloted for potential use in cervical cancer screening and care found limited options. One of the available solutions reported in the literature is a Swedish invention: Gynocular(TM); a portable, battery-operated magnifying device. According to its developers, Gynocular is the first truly portable colposcope in the world. It is a high resolution monocular colposcope with identical specifications to a stationary colposcope. Gynocular uses T2D (Gynocular Triage To Diagnose) cloud based software. This is a clinical record software that captures structured colposcope examination with integrated image documentation. T2D is usable on lap tops, smartphones, or desktop personal computers. Further details about T2D are accessible from http://www.gynius.se/software.

Gynocular has been piloted and confirmed effective in different socioeconomic settings. A randomised cross over trial in Sweden comparing the accuracy of Gynocular and a stationary colposcope did not find significant difference between GynocularTM and stationary colposcope in screening accuracy, specificity and sensitivity in detecting cervical cancer lesions (Kallner, Persson et al. 2015). A cross-sectional community based study in India explored its effectiveness in triaging VIA/HPV screen positive women. The study found that Gynocular can effectively be used for triaging VIA/HPV positive women with very high accuracy (Basu et al., 2016). This can minimise false positive tests of VIA acetic acid screens. Two further clinical trials in Bangladesh and Uganda (Nessa et al., 2014; Ngonzi et al., 2013), found that Gynocular was as effective as a stationery colposcope in screening cervical lesions, and can be an effective tool for triaging women for immediate care. All these studies show that Gynocular could be the portable colposcope that can overcome the high cost barrier to stationary laboratory based colposcopes. Details and specifications of Gynocular can be accessed at http://www.gynocular.se.

1.6.2 Mobile ODT (Mobile Optical Detection Technologies)
Another portable solution documented in literature is the Mobile ODT, Enhanced Visual Assessment (EVA scope). EVA scope system combines mobile phone with powerful optics. EVA scope was successfully piloted in 8 countries including Kenya (also Rwanda, Haiti, Guatemala, Botswana, Nepal, Mexico, and United States).

According to its makers website, EVA scope is a handheld mobile/portable colposcope equipped with an ultra-bright light source and powerful magnifying lens to enhance visualisation of the cervix.
Figure 3 Images of Gynocular

Figure 4 Image of Mobile ODT
It is packed in a protective hard shell and water-resistant carry case to minimise accidental damage. It is linked to the EVA mobile App which can enable secure image capture and sharing for remote consultation and patient care. The App is backed up by a secure cloud storage which enables the user to access the data anywhere in real time. This feature is particularly useful for remote consultations. More information on EVA scope are available at http://www.mobileodt.com/.

1.6.3 Digital Holographic Microscopy
Another technological solution under development is the Digital Holographic Microscopy (DHM). DHM was developed by Holocyst Intelligence System Corporation in Belgium (Benzerdjeb, Garbar, Camparo, & Sevestre, 2016). DHM has an “accompanying software that creates a rapid 3-dimensional (3D) image reconstruction of cultured uterine cervical cells directly using the container with the sample without any need for staining” (El-Schich, 2016). The aim is to cut the flaws related to VIA based systems; dependence on the observer’s eyes, observer dependent sensitivity and complex time-consuming technology.

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

The DHM system is not yet fully piloted or validated for mass usage. Both Gynocular and Mobile ODT have added functions that can be useful in work on gender based violence. They both have systems for use in clinical forensics (details can be found at http://www.gynius.se/software and http://www.mobileodt.com/sane.html).

Disclaimer:
The author of this report does not advocate for any of the solutions outlined above. The choice of a relevant telehealth solution for the second phase of the proposed project will be a local stakeholder decision. The local stakeholders will also be involved in participatory process of the development and adoption of a telehealth implementation framework.
1.7 Rationale for the project

Cervical cancer is part of routine healthcare in high income countries in western Europe or North America. Women in such settings have an opportunity to screen for cervical cancer through yearly health consultation with their physician (Weinmann et al., 2015). Women in settings such as Kenya don’t benefit from the advancements in cancer screening and care options available globally. They have very limited access to physicians or regular screening opportunities. Yet there are cervical cancer screening methods which can be successfully utilised (Binagwaho et al., 2013) in countries like Kenya. As outlined above, acute shortage of HCWs (Marful & Winter, 2015) and other barriers hinder attempts to ensure effective provision of cervical cancer care, especially in rural areas away from city based hospitals.

The current technological advancements in Information and Communication Technologies (ICT) presents an opportunity to overcome some of the above barriers to cervical cancer screening and care in resource limited settings. ICT can link HCWs with each other to share knowledge and expertise, enabling them to offer care coverage that would otherwise be impossible through the existing care pathways. ICT solutions can bridge the geographical distance between physicians and patients. They can also facilitate direct and efficient link between frontline facilities and the referral facilities, where specialist physicians tend to be based. In most cases, patients in Kenya generally have to travel long distances (Ports, Reddy, & Rameshbabu, 2015) to reach the frontline (rural) facilities.

When referred to tertiary services, the distance become even longer requiring large sums of money and many days to travel. As outlined above, most of these referral hospitals are in the major cities. Service providers also lack access to up to date information, a situation worse in rural areas without libraries or internet connectivity (Marful & Winter, 2015). ICT solutions can thus bridge the information divide among HCWs to improve cervical cancer care across the country. Mobile units are used to take services to the rural populations in many low resource settings such as Kenya. But they also pose challenges such as high resource requirements (Ganavadiya, Chandrashekar, Goel, Hongal, & Jain, 2015).

The possibilities of applying technologies in the daily aspects of life such as cervical cancer screening and care seems unlimited (2014). The potential of ICT to transform health (DeBlois & Millefoglie, 2015) has been proven but the limits are still unknown because ICT solutions are evolving very rapidly. The present study explored the applicability of telehealth to facilitate efficient and effective cervical cancer screening, prevention and control. As outlined
above, there is need for innovative approaches to tackling the cervical cancer pandemic in Kenya and in East Africa. Success in improving the uptake of cervical cancer screening and care for women will have a direct positive impact on maternal and child health improvement. Empowering women (Singh, Bloom, & Brodish, 2015) to live healthy and longer through reduced cervical cancer related morbidity and mortality will enable such women to look after their children and families, and a healthier happier society.

1.7.1 Aim and objectives
The aim of the overall project is to improve cervical cancer screening and care in low resource settings using telehealth solutions.

The specific objectives of the phase 1 study (needs assessment) reported herein were:
1. To explore the barriers and facilitators of successful implementation of telehealth solution in cervical cancer screening and care in low resource settings
2. To find out the facilitators and barriers to implementation of existing telehealth solutions in cervical cancer screening and care in different settings
3. To explore context specific health systems determinants of application of telehealth in cervical cancer screening and care in low resource settings
4. To explore the physicians’ perspectives on knowledge sharing using telehealth for cervical cancer screening and care in low resource settings
5. To develop a socio-culturally relevant telehealth implementation framework for cervical cancer screening and care in low resource settings

1.7.2 Research hypothesis
Effective application of telehealth solution to link HCWs involved in cervical screening and care can lead to better diagnosis, prevention, and prognosis for patients in resource limited settings.

1.7.3 Anticipated outcome
The primary outcome could be timely cervical cancer diagnosis and reduced morbidity and mortality among women in the project countries. Potential improvements in cervical cancer screening and care through the proposed project will therefore significantly contribute towards the achievement of SDGs (United Nations, 2015). The potential contribution towards gender equality (Singh et al., 2015) will improve maternal and child health in Kenya and the region that is still blighted by high prevalence of ill health among women and children (Alkema et al., 2015). Also, lessons learnt from the present project may be transferable to other country settings or health conditions where telehealth solutions may be relevant too.
1.7.4 Anticipated impact
The social impact of the project will be the improved public health at the national level and improved wellbeing at the individual level. There will be positive economic impact in terms of reduced cost of care for acute cases due to improved diagnosis. There is also the potential for increased national GDP due to a healthier productive workforce. The economic analyses of savings that may accrue from the use of telehealth in cervical cancer screening and care will form part of the second phase of the project.

1.8 Ethics
The study received ethical approval from Maseno University Research Ethics Committee.

1.9 Study participants
The study was informed by a mix of purposively selected participants, as illustrated in figure 7. Access and recruitment of the participants is outlined further in figure 8.
1.9.1 Recruitment
Access and recruitment of participants was carried out by the local partners (Stockholm Environmental Institute - SEI Africa Centre team). It followed the process outlined above (also used in the other two countries).

2. Findings
2.1 Study sample
A total of 65 individuals took part in the present study. The tables on the next page give a breakdown of the participants who took part in different stakeholder focus discussions.

Recruitment process

**Step 1**
Contact potential participants to inform them about the study and to request them to consider taking part in the study.

Where necessary, contact line mangers to request permission to get in touch with potential participants. Once permission is granted, contact relevant individuals to inform them about the study.

Women living with cervical recruited through cervical cancer support group.

**Step 2**
Provide potential participants with study information leaflet. Agree with potential participants on the date and venue for the focus group session.

**Step 3**
On the actual interview focus group day:
Provide an overview of the study and allow participants time to seek any clarification (information session).

Obtained consent: the participants (Participants sign consent form)

Collect data
### Table 3-6
A breakdown of the participants who took part in different stakeholder focus discussions.

<table>
<thead>
<tr>
<th>Participants</th>
<th>Group 2</th>
<th>Age</th>
<th>Year of diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>Not available</td>
<td>2015</td>
<td></td>
</tr>
<tr>
<td>P2</td>
<td>Not available</td>
<td>Not available</td>
<td></td>
</tr>
<tr>
<td>P3</td>
<td>Not available</td>
<td>2008</td>
<td></td>
</tr>
<tr>
<td>P4</td>
<td>Not available</td>
<td>Not available</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Participants</th>
<th>Group 1</th>
<th>Age</th>
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<td>2014</td>
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</tr>
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<td>P3b</td>
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</tr>
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<td>P5b</td>
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<td>P6b</td>
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</tr>
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<td>P7b</td>
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<td>P8b</td>
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<tr>
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<tbody>
<tr>
<td>T1</td>
<td>Gynaecologist consultant</td>
</tr>
<tr>
<td>T2</td>
<td>Research assistant, health information systems</td>
</tr>
<tr>
<td>T3</td>
<td>Nurse in the cervical cancer unit</td>
</tr>
<tr>
<td>T4</td>
<td>Pharmacist in the cervical cancer unit</td>
</tr>
<tr>
<td>T5</td>
<td>Clinical officer in the cervical cancer unit</td>
</tr>
<tr>
<td>T6</td>
<td>Nurse in the cervical cancer unit</td>
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<tr>
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<td>PM-C2</td>
<td>Deputy county medical lab coordinator</td>
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<tr>
<td>PM-C3</td>
<td>County HIV/AIDS officer</td>
<td></td>
</tr>
<tr>
<td>PM-C4</td>
<td>County wash hub</td>
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</tr>
<tr>
<td>PM-C5</td>
<td>County Wash Hub</td>
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<tr>
<td>PM-C6</td>
<td>County health commodity coordinator</td>
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<tr>
<td>PM-C7</td>
<td>Malaria county coordinator</td>
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<td>PM-C8</td>
<td>County health promotion officer</td>
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<tr>
<td>PM-C9</td>
<td>County vector borne and neglected tropical disease coordinator</td>
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<td>PM-C10</td>
<td>Public health officer/County WASH coordinator</td>
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<tr>
<td>PM-C11</td>
<td>County public health officer</td>
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<tr>
<td>PM N1</td>
<td>University lecturer and Tele health expert</td>
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</tr>
<tr>
<td>PM N2</td>
<td>University lecturer and head of Gynaecology department</td>
<td></td>
</tr>
<tr>
<td>PM N3</td>
<td>Program Manager, National Cancer Institute, Mhini</td>
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<tr>
<td>PM N4</td>
<td>Independent research consultant - cervical cancer</td>
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<tr>
<td>PM N5</td>
<td>Program Officer, Ministry of Health, Reproductive Services Unit</td>
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<td>PM N7</td>
<td>Head of Unit, Ministry of Health</td>
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<tr>
<td>PM N8</td>
<td>Nurse, Outreach program</td>
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**Tertiary Health care workers (Teaching and Referral Hospitals)**

<table>
<thead>
<tr>
<th>Participant ID</th>
<th>Role</th>
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<tbody>
<tr>
<td>T1</td>
<td>Gynaecologist consultant</td>
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<td>Clinical officer in the cervical cancer unit</td>
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<tr>
<td>T6</td>
<td>Nurse in the cervical cancer unit</td>
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2.2 Is there need for telehealth in cervical cancer screening?
All the participants were asked whether there was need for telehealth, if telehealth can be used to improve cervical cancer screening and care in Kenya. The following extract summarises the general response to the question.

"We have several benefits of such a system [telehealth] but I think the most obvious is that in health we have really a lot of constrained resources, so when we implement for example telemedicine or telehealth in cervical cancer management I think we will be able to make quite a lot of savings in terms of human resource whereby one specialist in one given area can be able to see several cases and give diagnosis, we are able to make savings on equipment, because we can take photographs, maybe and share them on WhatsApp or even through video conferencing, we can actually do sort of (...) as we are doing screening, for example we can use modalities which can enable us to transmit the videos from one area to the other. So, even procedures like colposcope, we can be getting instructions from a specialist elsewhere, but it’s being implemented somewhere, so it will also help us to save in terms of maybe infrastructure so that we don’t have to set up like a fully equipped unit everywhere, and then also, I would say that the current progress in terms of the medical field people are moving into use of technology, so I think going into telehealth in cervical cancer, will also be in conformity with what everybody else or where the world is moving in terms of technology. The benefits are many, those are just a few."

(PM [Policy maker] – C1, County level)

We found significant support for the potential use of telehealth in cervical cancer screening and care. The participants, though not representative of the entire Kenyan health system, offered strong arguments for telehealth in cervical cancer screening and care, and healthcare in general.

The patient representatives pointed out that anything that can lead to early diagnosis would be a great improvement on the current situation in which women are diagnosed very late with cervical cancer.

*If this [telehealth] was there then [when she was diagnosed], I would have found out sooner what I had but because it was not there, it took me a while to find out.* (P13b)

For the women, the success of any cervical cancer screening using telehealth solution depends on how well it enables women to test early and to access the care they need if they test positive.
Currently, when you even want to access the services of a doctor is going to be very difficult. At times, you will be suffering in silence. So, if there is a way that you can connect patients to the doctors … I think it would really help us [women] out in knowing their status so that they reach the doctor early enough for diagnosis. (P1b)

The above extract summarises the general view of the patient representatives who took part in the present study. All of them said they were diagnosed late. Some said they noticed signs of ill health such as excessive and abnormal bleeding early enough. But they still ended up with late diagnosis due to many barriers to screening as discussed later in this report. Thus, telehealth would make it easy for the health workers “to reach the patients before it is too late” (P7b). It can for example prevent cases of some women learning about their cervical cancer infection through severe illness, when it is too late, or through mere chance as illustrated below.

I was attending one of these teachings on cancer and then the tutor was talking about some of the signs and symptoms. I realised that some of them happened to be what I had been feeling so it encouraged me to go for this test. When I heard that there was a screening which was taking place [name of facility withheld], I went and explained to the doctor everything that I was feeling. He examined me and then referred me to [another facility]. (P12b)

The participant quoted above seemed to suggest that even though she suspected she was ill, she did not get a diagnosis until she attended a training session on cervical cancer. The patient representatives narrated similar stories about how they became aware of their infection. Just like the woman quoted above, each participant went to at least two different levels of health care facilities before they received a confirmatory test. The journeys to diagnoses thus involved significant resources for the women in terms of time, money, and anxiety while at the same time costing the health services. The women therefore felt that a well-functioning telehealth system can reduce the long process they underwent to get diagnosis. For example, the women felt that a direct link to cancer specialists for screening and after care could ensure they received support without traveling long distances. They believed a telehealth system would enable them to access the information about the relevant services and make it possible to consult relevant healthcare providers remotely. They could avoid the many trips some of them made, in some cases to the wrong experts in the first instance, before being referred to the relevant services.
I can support it [telehealth] because it can make it easy for us [women], not having to travel from one place to another [different services]. Also, the picture can be used to create awareness and let people know that such things [cervical cancer] happen. (P12b)

The above extract illustrates a conviction that telehealth can reduce the cost of care, an observation emphasised by HCWs and policy as well. Respondents said that a well-functioning telehealth system can reduce the costs in terms of time and money involved in accessing (for patients) and providing healthcare. The possibility that telehealth can lead to health system improvement was thus a welcome idea.

It is beneficial because you find that there is a lot of efficiency rather than somebody being referred to the facility and sometimes you will find that the nurse is not there and when using the mobile phone, you will talk to the nurse in charge (...) and then again, they will give you consent to let her [patient] come or bring her. I think that one will create the efficiency. (HW4b – County level)

The above extract illustrates a perception that telehealth would lead to efficiency in service delivery. It ties in with the earlier extract which illustrated that at times patients go to different facilities before reaching the relevant practitioners. The health worker quoted above noted that telehealth can facilitate prior communication to confirm referrals before sending patients. This can lead to efficient use of the existing resources (human, time, and equipment). Telehealth can enable physicians for example to consult one another and make a care decision without “making the patient to physically walk across departments or hospitals, carrying their medical files along, to get different physicians’ opinion” (T5B) before getting the right treatment.

Related to referrals, telehealth would also facilitate efficient follow up of patients. Noting that the current care pathway leads to patient loss to follow up, an effective telehealth system can ease patient follow up.

We make follow ups by tracking the patient. If the patient was supposed to come back today and she did not instead of going to see the patient you just call and remind the patient, tomorrow you’re supposed to come for screening, probably you got the patient today and the reagents are not there so you are forced to send her home, so you remind her tomorrow the reagents are there. Just make a follow up. (HW3b – county level)

The extract implies that effective telehealth system can enable healthcare providers to update the patients on the situation at the facility and keep track
of the patients so that both parties are ready for scheduled meeting. This, the healthcare workers noted, could minimise cases of patient’s showing up for care when the hospital doesn’t have a free slot due to overbooking or delays in serving patients.

Another key finding was that telehealth can contribute towards reducing the challenge of inadequate healthcare workers. This can be an important contribution given that the Kenyan health system has an acute shortage of healthcare workers, particularly in the field of oncology.

"I think it will also increase the client satisfaction ... at the moment as they come they find that we are sending them back home without services... but with a working telehealth we can improve on that"

Yeah it will help in the sense that right now (...) we have very few specialists in cancer. So, for the medical personnel who are in level one, two and three can easily be consulting the specialists through telehealth, yeah? Which will be very beneficial to the patients. So definitely it will be a big plus. Instead of referring patients for basic reasons. And even that the referring at least it will be after consultation and like the - actually will serve to be referred yeah unlike when there’s no telehealth somebody just refers the patient based on his or her own instincts. But this one will be after consultation. This will go a long way reducing the number of unnecessary visits. (T1 - referral hospital)

The above extract illustrates that telehealth can link different levels of healthcare so that expertise can be shared across the health system. As the participant quoted pointed out, the lower level health facilities have limited cancer specialists hence telehealth can enable them to access expertise from level 4 or 5 facilities where they can reach out to cancer specialists.

The benefit to patients highlighted in the above extract was an important consideration among HCWs who took part in the present study as well as further illustrated below.

"I think it will also increase the client satisfaction (...) at the moment as they come they find that we are sending them back home without services (...) but with a working telehealth we can improve on that (...) then I think we increase the uptake of cervical cancer screening (T3B – referral hospital)"
The extract suggests that patients’ satisfaction was something the HCWs wished to achieve and that telehealth can play a vital role towards achieving the goal. It can for example minimise cases of patients turning up for services that are not available. As outlined above, HCWs can confirm their availability and readiness for specific appointments, making sure that the service is available when the patient need them. The extract also implies that failure to offer the required services when needed is a barrier to service uptake. The participant thus suggests that telehealth can increase the uptake of cervical cancer screening by ensuring that patients get the service when they go to the hospitals or clinics.

The service users (patient representatives in the present study) named healthcare workers’ work load as a barrier to cervical cancer screening and care. They noted that telehealth can reduce HCWs’ work load and improve service delivery.

*On my side, I see that it [telehealth] would be good because it also reduces workload for the nurses (...) that can free time for them to see [serve] more people* (P4)

Some of the HCWs also felt that telehealth can be useful in developing self-confidence of the staff involved and to forge team spirit.

*It will increase the confidence in the service providers due to their interaction (...) the service provider in the other institution will have time to discuss their findings with a colleague who is far away, this will also bring team work between people doing the same giving the same service and the skills will improve (...) Another thing it will also make the nurse doctor relationship to be close because they will be sharing on one client.* (T10B – Tertiary level)

As a tertiary healthcare worker, the participant quoted above said that staff in lower level facilities with limited expertise in certain areas can be empowered through interacting with staff from higher level facilities. This can make such staff feel confident in what they do because they have the support from higher level experts. The interaction and knowledge sharing can also help HCWs to develop stronger team bonds across different levels of care because telehealth would require collaborative care through consultations.

Telehealth can also enable training and capacity building to improve the skills of the health care work force. Specialists from tertiary facilities can mentor staff from lower level facilities to improve their capacity to carry out better diagnoses and also to care for patients once they are diagnosed with cervical cancer.
Then we can also have a lot of mentorship programs through having daktari in UoN [Doctor at University of Nairobi], because I don’t think she can be able to move all over the country, she can be able to mentor those people who are out there, the health workers who are doing the diagnosis and treatment through still telehealth and I see this one as a way of getting a wider number of women to treat for this region and reduce the burden other than just using the telehealth to share information on how to do the diagnosis. So, a lot of mentorship, a lot of training can also go through telehealth. (PM – N6)

The above extract refers to the inability of trainers at the medical schools (for example university of Nairobi) to cover the geographical span of the country to mentor trainees. But telehealth can enable them to mentor or train HCWs remotely. This in turn would ensure that patients receive services in their locality rather than traveling to Nairobi for non-specialist care. The participant therefore believed that telehealth has a wider scope in cervical cancer screening and care, not just sharing of images for screening purposes.

The findings also show that the potential of telehealth to contribute towards increased capacity would empower staff and make them feel competent enough to provide adequate care. Through repeated sharing of images and discussing care options, HCWs can become more confident in diagnosing and treating cervical cancer through accumulated and shared experience.

Rather than using it just to send images, so that somebody else can read and treat, I see it as a way of empowering that health provider to be able to make that diagnosis and treat. So, a lot of training can go through telehealth, we can share images of the same lesion amongst ourselves and then share the way of treating that lesion. (PM-N3)

The participants also emphasised that telehealth should not just be about sharing of images. In fact, telehealth is applicable in other domains of care too as illustrated below. The participants said that telehealth can contribute significantly towards integrating care. Referring to eHealth, a terminology the participants used interchangeably with telehealth, the participant quoted below noted that the possibilities are boundless.
I mean even with insurance companies we link them between, you know nowadays the IT firms, they link with health facilities and insurance firms. So, they develop a card. The card will have all the information about the patient. When the patient goes to the hospital, the doctor just runs the card, gets all the information, previous days where the patient had been seen, maybe with the same problem or not, which drugs the patient has been on, billing is done electronically to the insurance firm. So, things have been made a lot easy that is still under eHealth. eHealth it is endless, there are so many. (PM - N1)

The participants noted that the use of telehealth was a new frontier that can change healthcare if designed to work effectively. But they noted that using telehealth to improve cervical cancer screening depended on how well it worked to tackle some of the key obstacles to screening.

"It’s quite an area of interest for us because cervical cancer is actually the leading cause of morbidity and mortality among cancer patients."

Policy Maker N5

The above extract illustrates that if the obstacles to screening such as lack of awareness and loss to follow-up can be tackled, screening can be increased significantly hence reduce mortality and morbidity.

Overall, the findings indicate boundless potential benefits of applying telehealth in cervical cancer screening and care in the study setting. The participants discussed several of such benefits as outlined above. But they also highlighted the potential barriers to effective use of telehealth in cervical cancer screening and care. The next section outlines some of the perceived barriers.
2.2.1 Information sharing

The HCWs were asked about whether they were open to information sharing between themselves and between them and the service users. The patient representatives were asked whether they would be happy for HCWs to share their health records including the possibility of sharing images taken for cervical cancer screening. In response, the patient representatives said that as long their confidentiality was guaranteed, they would not mind. Also, they reiterated the point that it could lead to early diagnosis and efficient care, they would not mind the sharing. The women noted that HCWs share their health records anyway. In some cases, the women carry their files along to different health facilities, with the risk of someone reading the content of the file at home or the file getting lost in the process.

HCWs said that information sharing was not a new concept because their practice involves information sharing, in a diverse multi-disciplinary manner (between healthcare workers, patients and even other non-clinical professionals involved in care). Some of the participants pointed out that what telehealth would add is to facilitate efficient information sharing, but not starting something new in terms of sharing patient information.

The service users’ representatives (women living with cancer) offered insights into how they moved through different levels of care to get diagnosis and then treatment. They said that telehealth can link different levels of care involved in cervical cancer screening, making relevant care more accessible for women.

*I started at Usigu [Level 1], then to Bondo [Level 2], after which I proceeded to Kisumu [Level 3/4].* (P2)

The above participant first registered her concerns at level 1 facility, she was then referred to level 2 for screening and ended up in Level 3/4 for further screening and treatment. The participant pointed out that with telehealth, Level 1 health workers can easily consult level three and make direct referral instead of going through level 2, where there may be no relevant care as in the above example. This they noted would save time and lives as discussed under the benefits of telehealth above.

Some of the participants lamented the amount of paper work in the current referral pathway, noting that such would be minimised through effective use of telehealth.
In fact, the sheet [referral form] is three copies you give her two she goes there, leaves one and she comes back with the other one so that is the proof that its all there and again apart from that we do follow ups like; I sent you to the hospital, did you go? What were you told, such things? (HW8b)

As illustrated in the above extract, patients move between facilities with forms detailing their case. This implies that if they lose the forms along the way, the process would have to start all over again, and it is difficult to follow up if they went for the referral. Although the extract shows that the health workers follow up the patients, it is challenging in practice for them to follow up each case because both sides of the system (those who referred and those who offered the service) must follow up to ensure that the patient went for the care and that they then returned the form to the service that referred her in the first instance. The participants therefore felt that a working telehealth system can reduce the burden on the patient to mediate communication between healthcare workers. It can also save the time HCWs spend following up the same patient from different levels of care.

Figure 7 sums up views on how telehealth could link, enable communication and service delivery across the entire cancer care pathway.

Participants noted that it would be important to start very small with a few pilot services to learn from ‘teething problems’ (PM – C4). The lessons learnt from the pilot phase would then inform wider implementation across more services.

I don’t know if it’s within the scope of your work, but it could really be important maybe just to use this as a pilot to have data from the different cancer sectors that we have, transferring that information to the cancer registry. (PM – N6)

But there were also concerns about piloting with government involvement. Some felt the pilot phase should not involve the government because the project would be ‘swallowed’, leaving the intended beneficiaries to continue suffering.

I know that you want to collaborate with the Ministry of Health so that the research is on the ground. If you want to do the pilot, do you have to get permission from the government? I think it should be only after doing so [pilot], and see it doing well, then you can ask for collaboration with them [government], because if you do so, at the infant stage, then it will be swallowed. We as the sufferers, we will just continue to suffer. (P1)
Figure 7 illustrating the potential cervical cancer service lineage using telehealth

Connections to other cervical cancer services (e.g. private hospitals), regional cancer services in East Africa or international linkages

Direct communication with each other and to CHWs and patients

Women
- Service users
- Potential service users

Community health workers
The above extract implies cynicism towards government run initiatives. It suggests indifference towards government led service delivery. Although the interviewer did not probe the participants further on this clear antipathy towards government, it was clear from other discussions that there was great concern that corruption was the problem as illustrated below.

*Chemotherapy took up 8000 shillings, another disease took up 9000 shillings. If you ask another person [who accessed the same service], it took 12,000 shillings [chemotherapy]. There is a lot of corruption and there is no day you will be issued a receipt [for treatment fees].

*These days we are issued receipts … but I refused getting receipts from them [government HCWs]. I wasn’t issued any receipt during chemotherapy, and they [government HCWs] don’t want patients to discuss the amount of money they paid for the treatment (…) as it is, one is asked how much they can pay, so what you say is what you pay. You realized that the next person has been billed 5,000 shillings. (concerned participant).

We have used a lot of money, then you are thinking of a partnership with the government?

2.3 Potential barriers to telehealth use in cervical cancer screening and care in Kenya

The participants were asked to outline what they thought were the barriers to potential use of telehealth in cervical cancer screening and care. The responses to the question varied but the following extract provides a synopsis of the general views expressed in the various focus group discussions.

*I think it always pains because most of these non-communicable conditions especially reproductive health we are shying off. We might have all the capacity building and all those things we are talking about [telehealth], but (…) we should find the root. The root that I see here is about our norms in Africa if actually we come in to discuss openly (…) most probably in real sense apart from being hereditary, cervical cancer has to do with sex and if we come down to the community family level, (…) change their norms to at least spread
this cervical cancer screening, because you will know you got it from where? from the man who is having the human papilloma virus. Issues about circumcision, issues about our young girls starting sexual activities at an early age. If we don’t fight that one first [the norms] we cannot fight the cervical cancer screening completely especially in Africa, in Kenya and especially in some regions like in Nyanza [present study site] (HW5)

The respondents outlined various issues that in their view can hamper or enhance the potential use of telehealth in cervical cancer screening and care in their setting. They referred to such issues as challenges or opportunities rather than barriers and enablers.

Some of the challenges that the participants anticipated included inadequate network (internet connectivity) particularly in the rural areas, the high cost of the potential system and the cultural norms around sexual health and illness. Some of the respondents were also concerned about data protection and confidentiality, lack of capacity to treat everyone who may be screened positive for cervical cancer, the health workers’ high workload and lack of expertise or knowledge on the telehealth solution that may be implemented. Apart from expertise, there was also mention of lack of interest as being a potential challenge. That some people may simply refuse to embrace change because of negative attitude towards change. Some of the participants also felt that language can be an issue when service users or HCWs have to consult with others who don’t speak their native language. Although HCWs can use Swahili or English, the issue of language can be a challenge for some service users who may not be fluent in either English or Swahili. In case the system involves community health workers, again language can be a challenge for some.

The cultural norms about sex and sexuality can also be a challenge because sexual health is culturally an inappropriate subject to discuss, yet cultural norms endorsed some sexual behaviours that predisposed women to the risk of cervical cancer.

The participants further noted that men’s attitude can inhibit or enable the successful cervical cancer screening program. The participants believed men had a great role to play in encouraging or discouraging their women to go for cervical cancer screening. Currently, men were doing little to encourage cervical cancer screening uptake. The participants added that the availability of cancer experts at the tertiary level who can be consulted using telehealth system was a key enabler, in addition to a good communication infrastructure in Kenya that can support a telehealth system.
The following subsection further outlines some of the key barriers in the gaze of the present participants.

2.3.1 Acceptability of the system

The respondents felt that some people may not welcome the use of telehealth in cervical cancer screening and care. The reasons offered include the fear of increased work load, fear of change (using a new system) and other socioeconomic factors as summarised at the beginning of this section and illustrated in the following extract.

I want to answer you. How will I allow wuon parwa insert a speculum to take a photo of me? There is a speculum that is inserted in the cervix for you to get what is there, even if they see 1,2,3. Personally, I would not agree. (P1)

“Even when you look at the nurses working here it is not 100% screening not even 50% ”

HW10b

Some of the participants noted that communal relationships and cultural norms can be huge hindrances to acceptability of telehealth. The patient representative quoted above reiterated that she would not agree to screening that involves her family member (in this case referring to father-in-law). The context of this concern is that in the villages people live among social relations and some of the relationships need social distance especially with regards to sexual health. That is why the participant wondered how her father in law (by implication) can screen her, even if it involved telehealth.

Acceptability of telehealth is directly linked to acceptability of cervical cancer screening itself. The participants noted that the uptake of cervical cancer screening is still very low because the services were not accepted for various reasons. The extract below for example highlights that even among healthcare workers, very few had screened for cervical cancer despite their knowledge about the illness. Telehealth alone may not alter the current reticence to cervical cancer screening.

Even when you look at the nurses working here it is not 100% screening not even 50% [implying less than 50% of the nurses have been screened for cervical cancer] (HW10b)

The participants also noted that for telehealth to work, people ought to be aware of what cervical cancer is, the risks involved and how to prevent or treat it. They noted that as long as the awareness stayed low, telehealth would not make a difference.
There are many sick people who are unaware, so it would be good if we got more talks on health and people who relate can seek treatment. (P8)

2.3.2 Stigma
The findings also indicate that cervical cancer is a highly stigmatised condition by even the health workers. Cervical cancer is perceived by many people as a death sentence, hence people prefer not to know they are infected even if they suspect than get tested, believing that they would soon die. Comparing cervical cancer with Tuberculosis, one participant gave an example of how it would be easier to seek a test for TB than cancer because of the stigma associated with cervical cancer. The fear of stigma was a barrier to screening, hence the potential use of telehealth in screening and care.

2.3.3 The cost of care
The participants discussed the cost of care elaborately as another challenge to cervical cancer screening, and a barrier to the use of telehealth in cervical cancer screening. The participants noted that there were direct costs involved in traveling to get treatment and paying for treatment itself for those who screened positive. Although telehealth was an intervention that can bring down travel costs, it was not clear how telehealth would affect the cost of treatment. The participants also noted that the most common screening intervention in Kenya, pap smear, is expensive for most women and the results are not instant. The results take about two to three months to come back, hence many women are lost to follow up after a pap smear sample.

I would like to add that, with cancer a lot of people are afraid to get tested because when you go and get tested, when you have no money. Example like me, in relation to the amount of money I have used so far, somebody tested now would ask himself where he can get such an amount of money. These days people are accepting to and get tested and taking their medicine but for cancer, one would go for testing be found with it and there is no money. So, I would not go testing, let it just kill me because I think that if I go and I would be found with it..., I think if there was another way, then it would really help. (P3)

2.3.4 Lack of equipment
The participants also felt that telehealth will not fully solve the problem of lack of cancer related equipment. It implies that the proposed system may not serve more people because there would be no equipment to meet the treatment demand nor the space from where to serve the patients who screen positive.
Just to contribute on what number 9 is saying, some of the reasons that probably make us not really be able to screen on a daily basis is because we are inadequately supplied with the screening requirements like if you have for instance like 10 speculums if I get an 11th client when I have used the 10 speculums, it means I won’t be able to screen until I do sterilization again. So, I will rebook and for the client when I rebook it is really demoralizing so that is the challenge we get. Not being able to screen on daily basis at any given time when the client comes in we are not well stocked. (HW3)

2.3.5 Sustainability
The participants also discussed at length the issue about sustainability of the eventual telehealth solution in cervical cancer screening and care in their setting. Noting that many projects initiated by development partners tend to collapse the day the donor walks away, they wondered how the proposed telehealth project would last beyond the initial phase.

“It would also be prudent to think of sustainability once it has started. How would it continue past even the existence of the partner?” (PM – C7)

Participants from policy makers’ group at the county level suggested that one way of making sure the project survived beyond pilot funding is to include it in the county planning (Annual Work Plans – AWP). This would ensure that the county government spares some money to carry on the project. The participants also noted that it was not just about money. Sustainability also included the human capacity needed to maintain the project as a service. Noting that there is human resource, the participants called for capacity building of the existing human resource.

“In terms of human resource, I think that we are fairly well off, but in terms of capacity building for the human resource that may have to drive the machine, that where we have a big gap.”

Policy Maker C8

Participants (HCWs and policy makers) mentioned the need to train community HCWs on the basic facts about cervical cancer, to empower them to sensitize the public within their communities to create demand for screening. The increased demand would sustain the service.
The issue of local relevance was also discussed as part of sustainability. The participants noted that the telehealth solution should be adapted to the local needs to make it relevant to the local circumstances. Furthermore, they also recommended joint working with a broad range of health system stakeholders including the central (national) government, private hospitals, NGOs, faith based healthcare organizations, telecommunication companies and regulators.

2.3.6 Overcoming the challenges
The participants further offered suggestions to increase the uptake of cervical cancer screening. By creating a demand for cervical cancer screening, they believed telehealth would find relevance in the screening process.

"From training, we remove stigma from ourselves then we talk to the community about removing stigma of cancer from themselves."

The HCWs proposed the need for training to make all HCWs sensitive to the needs of women seeking cervical cancer screening and care. The patient representatives talked of the need to sensitize the public about cervical cancer, the importance of early screening and where to get the tests. The sentiment on public awareness, or “social mobilization in the community” (HW12b), was echoed by HCWs as well. They noted that there is need to eliminate cervical cancer stigma too, to promote screening uptake.

I think we should do thorough trainings number one and from there we need to mobilize the community and create awareness of cervical cancer so that everybody is aware of what cervical cancer is we should not be ashamed of it as she said. We should remove the stigma from ourselves that is when we will remove the stigma from our clients also because when we are doing it thinking that it is a very serious thing that someone is going to die we also think nothing can be done about cervical cancer. So, after training we need to mobilize them and after training we need to remove the stigma from ourselves, before you remove stigma from yourself you cannot remove stigma from her. So that is the point we should arrive at. From training, we remove stigma from ourselves then we talk to the community about removing stigma of cancer from themselves. (HW4b)

Participants also offered suggestions that could facilitate public awareness such as the use of theatre groups. They said such performances could be based on the reality of the disease within the community hence they would create a dialogue about cervical cancer.
Maybe we can use the theatre groups so that when we have an activity we make use of them [performing art] they [community members] will talk. They will tell the community the truth of what is happening and then we will get to know what is there because they perform and they will perform with what is happening. The reality on the ground. (HW4b)

Some of the participants pointed out that there are community engagement days that can be used to sensitise people about cervical cancer.

We have the community dialogue days, action days. We can capitalise on dialogue days, (...) we can share the details, the facts about cancer screening, you can give them data, how its destroying lives of people and then they see the need of and when they come early they are diagnosed and treated. I think you will see people coming (HW7b)

The participants also suggested that village gatherings under the village chiefs and elders can be used for awareness as well. “We can use chief barazaas [village meetings]” (HW1b). Other potential fora for awareness that were suggested include churches, schools, and women groups gatherings.

Another interesting suggestion was the need to involve men in cervical cancer screening.

A little input on that I would say that for every female there is a man, so males equally need to push for their cervixes because I believe every man owns a cervix [in a relationship with a woman]. (HW9b)

My point was we need to get the men involved. We are focused so much on the woman and we are forgetting these women are not coming forward because their men are not pushing them. If the man comes into the house and says, ‘mum have you been tested?’ ‘No’ Why and you have come from the hospital do you know that this thing kills? Tomorrow you are going, she will come. Then the other thing is there is a counter [service desk at the hospital] for the men now you see the circumcision part so that they can be the same both of them and it will help it actually worked for the P&C programme involving the women mobilizing the men to come especially the young men (HW12b)

The above extract outlines the argument for involving the men in cervical cancer screening and integrating care so that services can involve both men and women. Previous research (Buchanan Lunsford, Ragan, Lee Smith, Saraiya, & Aketch, 2017; Driscoll, 2016) has shown that spousal approval is a key barrier to cervical cancer screening because some men hinder their wives
from seeking sexual health care. This thus suggest that the way to break the barrier is to involve the men as well.

2.3.7 Policy
Kenya as a country has laid great emphasis on the role of ICT in healthcare delivery and for development in her vision 2030. The eHealth policy and strategy creates space for the use of telehealth to combat the disease burden in Kenya. *I think also the training policies which the ministry is also embracing so much, the use of ICT.* (T5B P5). There was also reference to policy on cervical cancer prevention.

*The current national policy is emphasizing, in fact international policy of cancer, is emphasizing on prevention at very early level against HPV. It has been observed that HPV is a culprit in causing cancer and actually the works changing to cancer themselves. This is a sexually transmitted infection. So, immunisation is being done from as young as age nine through to fourteen because one thing once somebody has HPV, the man or the boy can transmit it to the woman without even symptoms sometimes. When it happens to grow especially in a woman, it can turn into cancer. So, you are preventing cancer right from immunisation stage and trying to give that immunisation before even they have a review in sex, that’s why they are starting even vaccinating from age nine, through to fourteen.* (PM – N1)

The participants also reported the need for other policies and guidelines to regulate practical issues that may be involved in cervical cancer screening and care using telehealth such as confidentiality and ethics of the use of telehealth in cervical cancer screening and care. There is need for communications policy at county level to guide what information can be shared through telehealth and to what extent such information can be shared, given the new federal structure. On a positive note, some of the participants from the county government reported that the government was developing policies that would guide some of the potential telehealth concerns such as confidentiality. They were therefore happy to include any relevant inputs on telehealth in the policy they were developing to make sure that telehealth is adequately covered in the county policies and guidelines.

*Maybe on policy, I think we have something that we have written on telehealth in our bill. Siaya County Health Bill, there is something that we have touched on. So maybe we can re look at it and see whether it’s advisable issues, because we’re doing the final stages, we can still ride on it to input what is missing, the gaps, so that we can use it very quickly.* (PM - C11)
Apart from guiding its use, there is also need for policy to prevent misuse of any eventual telehealth system.

*Still on the same policy, or a guideline just in place to make sure that it’s not misused* (PM – C7)

### 2.4 Telehealth is an ongoing practice

Participants further noted that some HCWs were already using telehealth in their own ‘small ways’. The relevant respondents said that potential implementation of telehealth for cervical cancer screening would build onto the experience of some HCWs in using telehealth in other aspects of care. WhatsApp groups seemed to be the most popular platform at the time of the interviews. Some of the HCWs said they were part of information sharing groups linked through WhatsApp.

*I have seen even simple things like even sharing on WhatsApp, social media, working very well. They’ll just take a photo, and send you. They are not sure what they are seeing and you somehow together work on it. On what are these results that they are experiencing.* (PM – N5)

Some of the participants said they were aware of telehealth initiatives similar to the one proposed in the present project. They recommended consultation with those involved in such related projects to learn from their experiences. The participant quoted below pointed out that learning from such ongoing projects would help in finding gaps that can be filled with telehealth solutions.

*I believe you have seen that there is also an organization dealing with something related to that [cervical cancer screening], I think in Rarieda [a region within the county], where they take a photo and that is transmitted and you can check to know which stage of cancer it is. So, I would say that you work with this team so that you can get to know what is there on the ground so that we know which area requires support that we can work on.* (PM – C8)

There was also a general sense that telehealth is the future of healthcare and that many countries around the world were already using it. Embracing telehealth in cervical cancer screening was perceived as a way of catching up with the rest of the world.

*I think going into telehealth in cervical cancer, will also be in conformity with what everybody else or where the world is moving in terms of technology.* (PM – C2)
3. Conclusion

The present study was to answer one key question: can telehealth be used to improve cervical cancer screening and care in western Kenya? The participants’ response to this question is a resounding Yes. The findings show that telehealth can be used successfully in western Kenya to improve cervical cancer screening and care, in a region that has the highest HIV prevalence hence an increased risk of cervical cancer co-morbidity for the women. Participants discussed several potential benefits of telehealth for both service users and the health system. The findings confirmed the assumption that underpinned the present study: That the use of innovative telehealth solution to link HCWs, particularly in rural remote health care facilities, to tertiary healthcare facilities can improve cervical cancer prevention, diagnosis, treatment, and care in resource limited settings. Use of telehealth can form part of the solution to some of the health system challenges such as inadequate HCWs and equipment.

Regarding the healthcare worker’s views on information sharing, the present findings illustrate that HCWs are already sharing information about their patients across different levels of care and even disciplines. HCWs are happy to embrace telehealth if it can make their work more efficient. But the present participants pointed out that there was policy/guidelines gap to moderate what kind of information may be shared, how and with whom, if telehealth were to be used. Although some HCWs were already using media such as WhatsApp to share practice related information, there were no clear policies or guidelines governing such practice. But there is an opportunity for telehealth stakeholders to work with county governments to ensure relevant policies and guidelines.

The county governments were formulating their health policies at the time of this study and welcomed input from relevant stakeholders to inform relevant policies such as County eHealth policy which would eventually govern the use of telehealth.
Overall, the present findings show that there are many benefits to be derived from using telehealth in cervical cancer screening. But any success of telehealth in improving cervical cancer screening and care depends on how the health system as a whole deals with the barriers to cervical cancer screening as outlined in the findings chapter.

This multi-country study has shown that the challenges to cervical cancer screening and care are similar across the study countries, but different in scale due to contextual differences between the the countries. Telehealth can enable sharing of good practice across the region to facilitate scaling up of existing screening programs to a robust regional cervical cancer screening program.

4. Recommendations
4.1 Policy recommendations
Kenya is one of the few countries in East Africa with a policy and a strategy on the use of ICT to improve healthcare. But the present findings show that although the national policies offer a road map on how to utilise ICT in healthcare, the county governments are still formulating their health policies following the adoption of a devolved government system. There is need to clear policy guidance on the use of telehealth in healthcare delivery so that all stakeholders can be clear about their opportunities and limitations.

There is need for all relevant telehealth stakeholders to work with county governments to inform the ongoing policy formulation processes to make sure that all issues about possible use of ICT in healthcare is clearly stipulated in line with the national eHealth policy and Kenya Vision 2030 development agenda.

4.2 Practice recommendations
There is great opportunity to improve cervical cancer screening and care through effective use of telehealth. But the process requires the involvement of all relevant stakeholders beyond the HCWs and patients.

There is need for collaboration between national government and county government for effective use of telehealth in cervical cancer screening. This is because the national government is in charge of regulatory policies and the management of the national referral hospitals that offer sophisticated cervical cancer treatment and care whereas county governments run the lower level facilities that offer screening and awareness services. Any telehealth solution in cervical cancer screening ought to involve both county and national services to cover a complete care pathway. The options opted for should be interoperable with the national eHealth infrastructure.
The present findings show that implementation of telehealth for cervical cancer screening should start with a small scale pilot phase. Also, the findings suggest that there are ongoing pilot projects in the same study setting (western Kenya) that use telehealth in cervical cancer screening. We recommend finding out the lessons learnt from such initiatives. Additionally, literature suggests that there have been many telehealth initiatives in maternal and child health and HIV prevention services. It is worthwhile gathering lessons from such initiatives to inform the proposed implementation of telehealth in cervical cancer screening and care.

The present findings also show that there is need to view eventual use of telehealth in cervical cancer screening and care as a more comprehensive service beyond mere image sharing. The system should be able to support other functions such as capacity building, continuing professional development, mentoring, managing appointments and referral services, public awareness about cervical cancer and other priority diseases and many other possibilities. The ultimate telehealth system should also be able to fit into the existing healthcare structure. Thus, it should reduce rather than increase the work load of healthcare workers.

There is need for public awareness about cervical cancer to sensitise people to take up screening. The present findings show that telehealth use will not solve the underlying barriers to screening such as cultural norms and perceptions about cervical cancer. Such awareness initiative should involve representatives of women living with diagnosed cancer to make use of ‘insider perspectives’. Telehealth could be used to form part of the awareness strategy, for dissemination of information. Other means of reaching the public with the message that were suggested include the use of theatre groups (art) and the existing village fora such as chief’s village meetings, churches, and women groups.

4.3 Research recommendations
The present study did not focus on cost effectiveness or socio-economic impact. There is need for further research on cost effectiveness of the use of telehealth in cervical cancer screening and care to make a socio-economic argument for its ultimate wider implementation. This should form part of any implementation process.
Map of Kenyan counties arrows show where data was collected. Image from Kenya Open Data Project, modified by SPIDER.
References


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

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