REPORT

Stockholms universitet

# THE USE OF TELEHEALTH IN CERVICAL CANCER SCREENING AND CARE IN RWANDA

## A needs assesment undertaken for SPIDER June - August 2016

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# Executive summary

This report presents the findings of a small-scale qualitative needs assessment study to explore the views of participants on the applicability of telehealth in cervical cancer screening and care in Rwanda. Participants were potential telehealth stakeholders from different professional and socioeconomic backgrounds. This report is the first output of a needs assessment exercise carried out to underpin the ensuing phases of the main project; proposed implementation of telehealth in cervical cancer screening and care in Rwanda. This report outlines needs specific to Rwandan context. Two related reports from similar studies conducted concurrently in Kenya and Zambia will be freely available to the reader through SPIDER's website (www.spidercenter.org). The three country reports are to feed into a unified telehealth implementation framework to be co-developed with local stakeholders out of the multi-country findings.

Focusing on the Rwandan context the aims of the study were:

- To explore the barriers and facilitators of a successful implementation of telehealth solution in cervical cancer screening and care
- To explore the healthcare workers' perspectives on knowledge sharing using telehealth
- To develop a socio-culturally relevant telehealth implementation framework for cervical cancer screening and care in Rwanda

## Methods

The project was informed by a mixed method approach for data collection and analyses. Desktop literature review and face-to-face focus group discussions with purposively selected samples from different health system actors in Rwanda were the primary sources of data. The focus group discussions were audio recorded, with consent of the participants. The resulting data were transcribed verbatim subjected to thematic analytical approach.

# Key findings

The following are headline findings from the study. Detailed analyses are provided in section 2 of this report.

## Support for telehealth

There was an overwhelming support for the potential application of telehealth in cervical cancer screening and care in Rwanda. The participants believed there was room for telehealth to:

- Enhance knowledge sharing and maximise the expertise of the locally available healthcare expertise for the benefit of many. Thus, solve the problem of shortage of expertise.
- Enable remote healthcare provision; to dwellers of rural areas as well as supporting healthcare workers based in remote areas.
- Improve health education through remote access to information.
- Improve research and evidence based practice.

*"The Rwandan health system is ready for potential use of telehealth in cervical cancer screening and care"*

## System readiness

The Rwandan health system is ready for potential use of telehealth in cervical cancer screening and care. The participants said that their health system was ready in all domain of system readiness:

- Core readiness
- Engagement readiness
- Technological readiness
- Societal readiness

## Uncertainties and concerns

There are uncertainties and concerns that may be major barriers to any potential use of telehealth in cervical cancer screening and care in Rwanda. The participants noted that the following would have to be addressed:

- There is need for further evidence on effectiveness of telehealth cervical cancer screening and care
- Acceptability of telehealth solution by the beneficiaries; healthcare workers and service users
- Data protection and confidentiality of users
- The actual cost of telehealth application in cervical cancer screening and care
- Unclear policy context

## The way forward

The participants suggested solutions to the concerns.

- Effective communication and public awareness about telehealth for cervical cancer screening and care
- Managing expectations created by telehealth enthusiasm
- Health systems strengthening
- Effective data protection
- Ensuring a user centred approach
- Training and support for the users of ICT solution(s)
- Ensuring evidence based practice

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# Glossary of abbreviations

ARV Anti Retroviral
BUP – Botswana-University of Pennsylvania Partnership
CDC – Centre for Diseases Control
DNA – Deoxyribonucleic Acid
eC3 – Electronic cervical cancer control
EMR – Electronic Medical Records
EVA – Enhanced Visual Assessment
FDA – US Food and Drugs Administration
FGDs – Focus Group Discussions
GAVI – Global Vaccines Alliance
GBV – Gender Based Violence
HCW - Healthcare workers
HIV – Human Immune Deficiency Virus
HPV – Human papilloma virus
IARC - International Agency for Research on Cancer
ICC - Invasive Cervical Cancer
ICT – Information and Communication Technologies
LMICs – Low- and Middle-Income Countries
MMS – Multimedia-Messaging Service
Mobile ODT – Mobile Optical Detection Technologies
MoH – Ministry of Health
PIA - Photographic inspection with acetic acid
SDGs – Sustainable Development Goals
SPIDER – Swedish Program for ICT in Developing Regions
T2D – GynocularTM Triage to Diagnose
TB – Tuberculosis
UB – University of Botswana
UN – United Nations
UNAIDS – United Nations Joint Programme on HIV and AIDS
USA – United States of America
VIA – Visual Inspection with Acetic acid
WHO – World Health Organisation

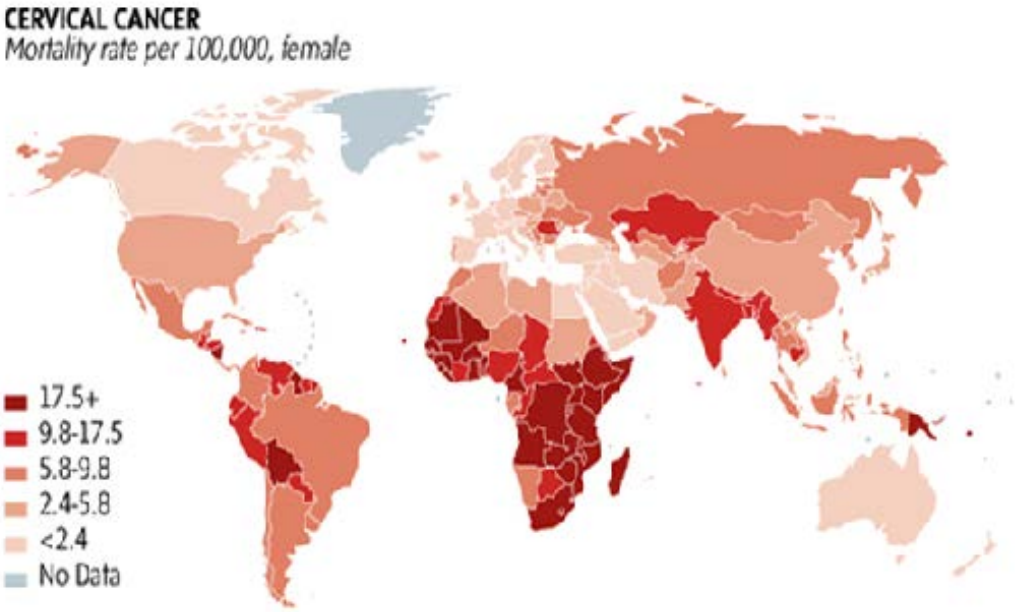


*Figure 1: Global Cervical Cancer Mortality Rates (from http://globalcancermap.com)*

# 1 Introduction and methods

This report describes the research methods and the findings of a needs assessment project that explored the applicability of telehealth in cervical cancer screening and care in Rwanda. This section of the report presents an overview of cervical cancer pandemic in Rwanda and sub-Saharan Africa as well as the aim and objectives of the study. As outlined above, this report is Rwanda specific, but the study was a tri-country project using the same methodology and carried out simultaneously in Kenya and Zambia.

## 1.1 Background

Cancer-related mortalities and morbidities in low resource settings are higher than HIV, Malaria or TB (The Economist, 2014), which are perceived as the leading killers in these settings. According to International Agency for Research on Cancer (IARC), there were about 14.1million new cases of cancer globally in 2012. About 8 million of these new diagnoses were in developing countries. Thus 70% of the global cancer burden is in Low and Middle Income Countries (LMICs) (American Cancer Society, 2015).

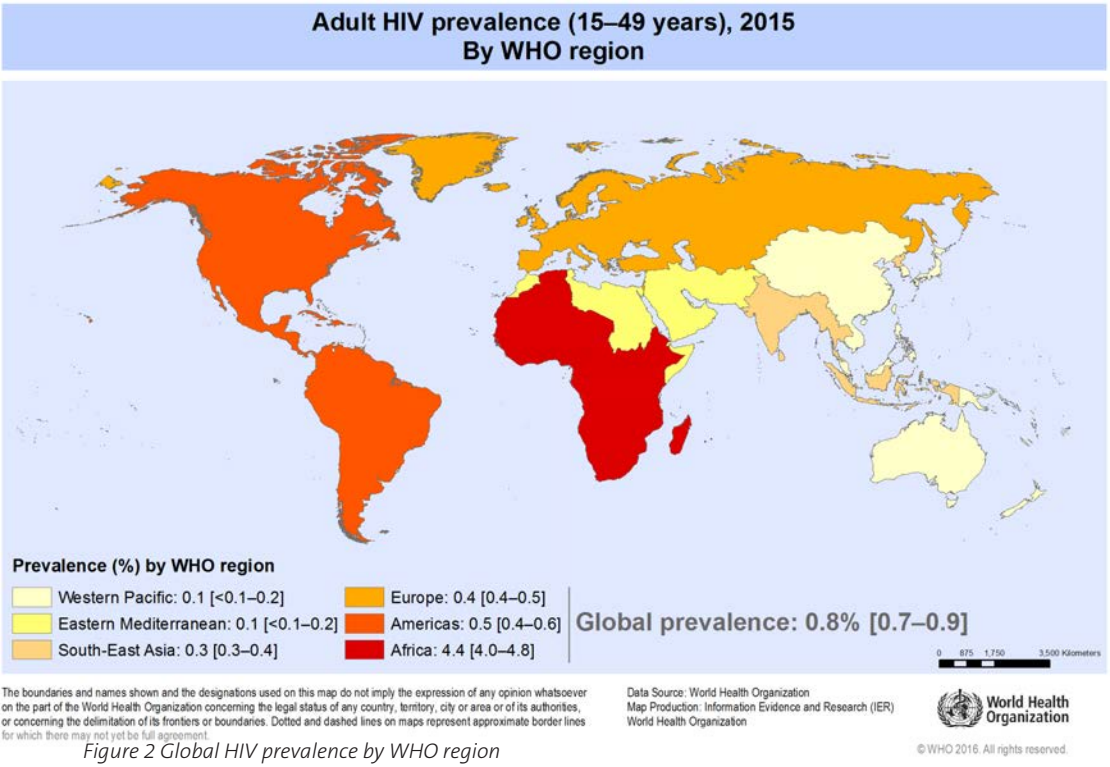


*Figure 2 Global HIV prevalence by WHO region*

In sub-Saharan Africa, cervical cancer is the most common cause of cancer-related mortalities among women as illustrated in figure 1. The region is also the worst affected by HIV (see figure 2), which exacerbates the risk of cervical cancer (Bateman et al., 2015).

### 1.1.1 Cervical cancer in Eastern and Southern Africa

Eastern Africa has the highest global incidence and mortality rates for cervical cancer (Campos et al., 2012). As outlined above, high HIV prevalence in the region, with women accounting for more than 50% of those living with HIV (UNAIDS, 2016) implies high co-morbidity with cervical cancer. There is evidence for a strong correlation between HIV infection and cervical cancer among women in sub-Saharan Africa (Bateman et al., 2015) suggesting that HIV infection increases the risk of cervical cancer, especially among younger women (Kapambwe et al., 2015).

Data from global cancer incidence, mortality and prevalence (International Agency for Research on Cancer (IARC), 2012) indicate an urgent need for effective cervical cancer prevention measures to curb the growing cervical cancer prevalence in eastern Africa. Otherwise, the high rates of

| 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. Estimated annual cervical cancer incidence and mortalities in Kenya, Rwanda and Zambia, comparing 2012 and 2020 estimates. Source: GLOBOCAN 2012. Cancer Incidence, Mortality and Prevalence Worldwide*

cervical cancer related mortalities are projected to keep rising. Table 1 illustrates the projections for increased mortality and incidence of cervical cancer in the three study countries.

Although the projections in table 1 show a gloomy reality, the good news for public health is that cervical cancer is treatable, if the right actions are taken in good time. Timely screening and treatment, if need be, (Khozaim et al., 2014) can significantly reduce mortalities from cervical cancer. However, most countries in Sub-Sahara Africa consistently suffer from failure to initiate or sustain a robust cervical cancer screening programme (Wright & Kuhn, 2012). This failure perpetuates the current trend of high mortality and morbidity of women of reproductive age, in turn causing huge socioeconomic losses (Campos et al., 2012) in the affected countries.

One of the key barriers to cervical cancer prevention in East Africa is the extremely low screening uptake (Gakidou, Nordhagen, & Obermeyer, 2008). The existence of proven simple screen and treat approaches to cervical cancer prevention (Mwanahamuntu et al., 2011) has not fully benefited women, or indeed the countries that lose thousands of women to cervical cancer annually.

In high income settings where cervical screening is part of women's routine care, early screening prevents nearly 80% of potential cervical cancer mortalities (Finocchario-Kessler et al., 2016). There is need for increased cervical cancer screening in low resource settings such as Rwanda to realise the outcomes regular screening achieves in high-income countries in terms of reduced mortalities. First, there are barriers to cervical cancer screening to overcome.

The barriers to cervical cancer screening in Eastern Africa varies between and within countries. A review of published literature on the 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 misconceptions and fear of cancer, lack of awareness about the availability of services, screening being the least of priorities unless there is a sign of ill health, and religious and cultural reasons. Service provider barriers reported from the review include failure to sensitise women about the need to screen and negative service provider attitudes towards service users. The review also found that the structural barriers revolve around accessibility. These include transportation and prohibitive high cost of screening for some women (Buchanan Lunsford, Ragan, Lee Smith, Saraiya, & Aketch, 2017), inability to access the facilities where screening is offered, long waiting times, unequal distribution of screening services across different areas, and restrictive screening policies in some contexts for example the qualifying age for screening or free screening (McFarland et al., 2016). The gender of the physician, male doctor providing screening services and the spousal approval are other reported barriers (Buchanan Lunsford et al., 2017).

*"Effective screening services therefore have to overcome the barriers preventing screening uptake in each specific context because even within each country, the local socioeconomic factors vary significantly and lead to varying impact."*

Effective screening services therefore have to overcome the barriers preventing screening uptake in each specific context because even within each country, the local socioeconomic factors vary significantly and lead to varying impact. Despite 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

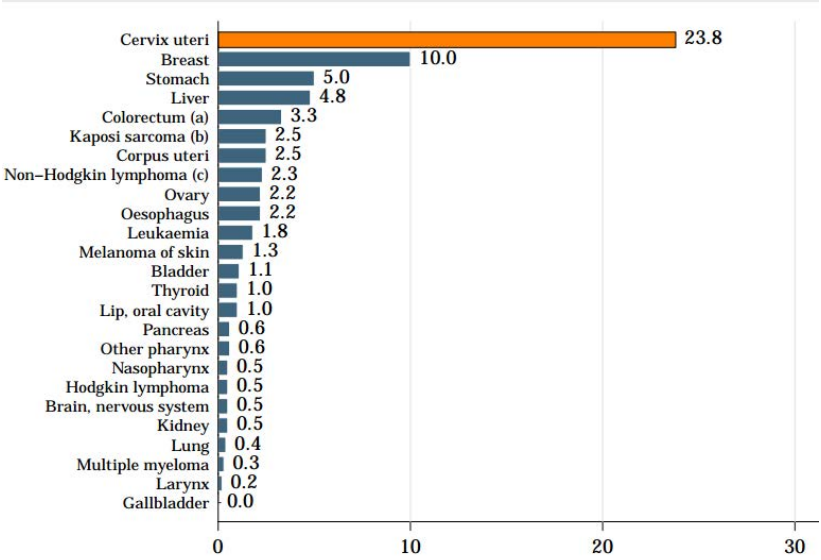


*Figure 3 Incidence of Cervical cancer compared to other cancers in women of all ages in Rwanda (estimations for 2012) Source: Rwanda Human Papillomavirus and Related Diseases Report (2016) pg.7*

established in response to the HIV pandemic in the region 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 initial financial outlays. Saved lives and less expensive treatment and care when women are screened and treated early presents economic returns on investments in screening programmes, as emergency care carries a much higher cost than early diagnosis and treatment.

### 1.1.2 Cervical cancer in Rwanda

Cervical cancer is the most common cancer among women of reproductive age (15 – 49 years old) in Rwanda (Ngabo et al., 2016). Previous studies (Mukuza et al., 2015, Ngabo et al., 2016) show that Rwanda has some of the highest cervical cancer incidence rates in East Africa. Parham et al., (2015) estimated annual invasive cervical cancer (ICC) incidence (58/100,000) and mortality (36/100,000) rates among women in Rwanda. Although some researchers may argue that the prevalence of cervical cancer in Rwanda has

not been accurately described (Makuza et al., 2015), the use of the numbers in this report is to illustrate that cervical cancer is a public health problem in Rwanda (Manirakiza, Longombe, Kyamanywa, & Rulisa, 2016) rather than claim accuracy on the prevalence or incidence statistics. The 2016 Rwanda Human Papillomavirus and Related Diseases report shows that cervical cancer is the leading female cancer (see figure 3), mostly common among women of reproductive ages (15 to 44 years). The report further indicates that about 1,366 new cervical cancer cases are diagnosed annually in Rwanda.

*"Rwanda was the first African country with a national strategic plan for cervical cancer prevention, care and control"*

Like most of the countries in the region, Rwanda has a high HIV prevalence with an estimated seroprevalence rate of 14% at the general population level (Parham et al., 2015). As outlined above, this HIV prevalence implies comorbidity with cervical cancer (Bateman et al., 2015; Kapambwe et al., 2015). Prognosis for women diagnosed with cervical cancer can often be aggravated by an HIV co-infection (Parham et al., 2015). Effective HIV treatment implies that women on successful ARV therapy now live longer, but with a risk of developing cervical cancer since HIV increases that risk (Sinayobye et al., 2014). However, the biggest challenge is not HIV co-infection but the low uptake of cervical cancer screening. Most of the women screened positive for cervical cancer are diagnosed too late (Manirakiza et al., 2016) and are unable to benefit from the available treatment and care. The need for scale up of screening and treatment interventions to cover more women (Bateman et al., 2015) in Rwanda, and indeed the rest of East African nations, is urgent and overdue.

The next subsection looks at the ongoing cervical cancer screening and prevention initiatives in Rwanda.

### 1.1.3 Cervical cancer prevention in Rwanda

Rwanda was the first country in Africa to develop and implement a national cervical cancer prevention, care and control strategic plan (Binagwaho et al., 2013). From 2011, Rwanda rolled out national HPV vaccination of all girls in grade six primary school. By 2012, the HPV vaccination program had achieved 96.6% national coverage of all eligible girls. The HPV vaccination of school girls were done on an annual basis on three designated 'health days', which have since been transformed to cover other sexual and reproductive health issues for school children beyond HPV vaccination.

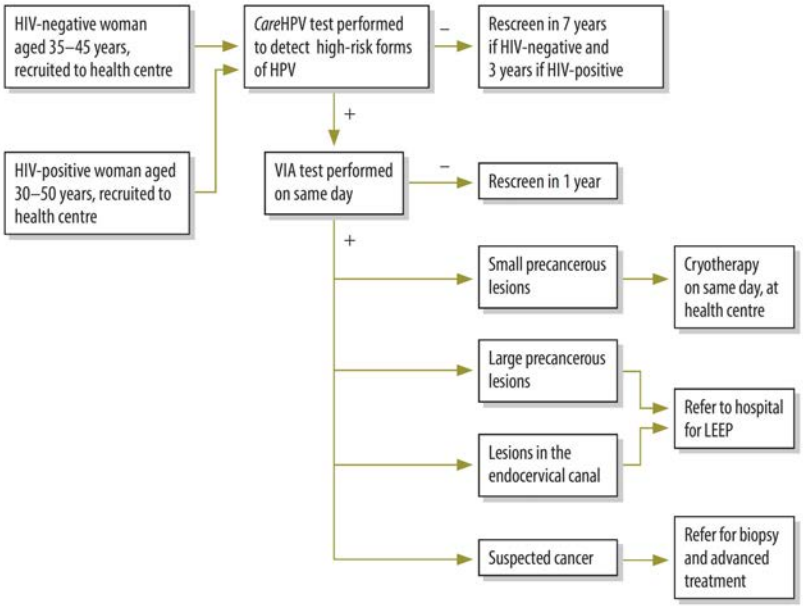


*Figure 3. Human resource training plan for Rwanda cervical cancer screeening strategy*

Furthermore, the Rwandan government also developed a care pathway (figure 3 below), to streamline cervical cancer screening, treatment and care. The cervical screening is underpinned by the use of visual inspection with acetic acid (VIA), instead of the more expensive and complex to implement 'Pap smear' which has more or less the same sensitivity and specificity as the cheaper VIA (Binagwaho et al., 2013).

To ensure adequate human resource for the successful implementation of the ambitious cervical cancer prevention programme, a training program was also rolled out from 2012. Figure four illustrates how the training programme was intended to accelerate from a few individuals who received an initial training to cover the entire country. Part of the training involved palliative care training and by 2012, about 85% of 42 district hospitals across the country had been trained on the national guidelines on palliative care.

The Rwanda cervical cancer screening and care programme was made possible by a coalition of partners, which includes the US Centres for Diseases Control (CDC). The initial vaccines and DNA testing equipment were subsidised by the manufacturers Merck and QIAGEN respectively. Global Vaccines Alliance

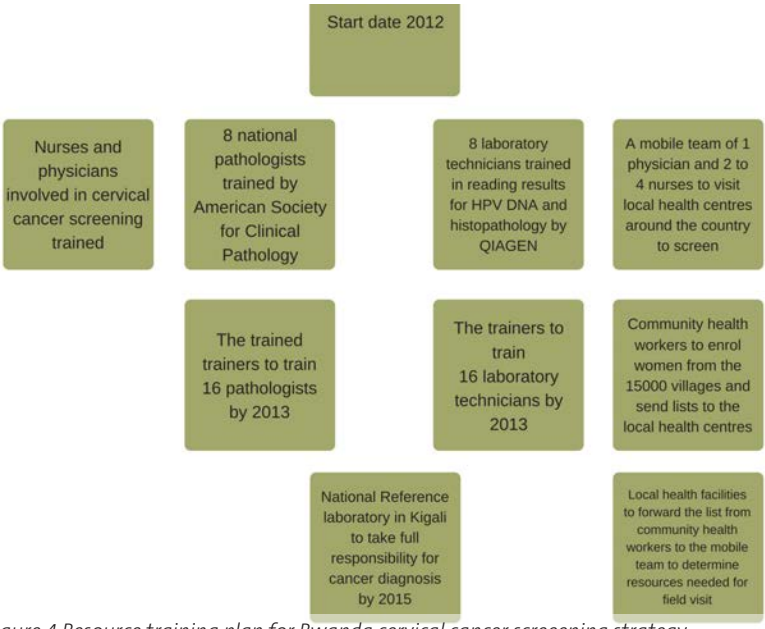


*Figure 4 Resource training plan for Rwanda cervical cancer screeening strategy*

(GAVI) took over the funding of the vaccines when Merck commitment ended in 2014. According to Binagwaho and colleagues (2013), the success of the Rwandan HPV vaccination programme shows that adequate external support, in-country political will and cross-sectoral collaboration are potent ingredients for successful nationwide cervical cancer screening and care.

Despite the successes outlined above, cervical cancer remains a public health concern in Rwanda (Makuza et al., 2015), which calls for innovative ways of improving screening uptake by women who continue to test too late (Manirakiza et al., 2016). Many women seek care when they have fully developed cervical cancer. Like other LMICs, little is known about ongoing efforts in Rwanda to explore untapped opportunities to reduce cervical cancer related morbidity and mortality using creative approaches. In many settings, the creative use of existing technologies such as telemedicine, eHealth and mHealth or the use of mobile phones and applications to facilitate cervical cancer screening and care are being explored (Hovland et al., 2010; Shalowitz, Smith, Bell, & Gibb, 2015). There is need to explore the applicability of such innovations in Rwanda to address the prevailing cervical cancer incidence.

Moreover, the Government of Rwanda under SMART Rwanda master plan emphasizes the need for the expansion of telemedicine and remote consultation systems to improve quality and access of health services. The aim is to reinforce the use of advanced medical applications like telemedicine and electronic information management and sharing across Rwanda for the benefit of the Rwandan populace (SMART Rwanda, 2015).

### 1.1.4 Telehealth

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 (WHO, 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 (WHO, 2010) to meet the healthcare requirements of patients with diverse health conditions (Totten et al., 2016). Telehealth can be summed up as a 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 for healthcare. Telehealth is not entirely a new field it 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 2017. Some form of telemedicine has existed for over 100 years (Strehle & Shabde, 2006). Telehealth in its modern form started in the 1960s (WHO, 2010).

The full potential of telehealth is yet to be realised. Telehealth changes the location where routine health care services are provided by using ICT to overcome geographical barriers thereby increasing access to healthcare services (WHO, 2010). Telehealth 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).

Despite of the lack of a universally acceptable definition, there are fundamental prerequisites that underpin 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 (WHO, 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 Organisation, 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 revolutionising 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 implies 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 (WHO, 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. However, 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.

*"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"*

### 1.1.5 Barriers to widespread application of telehealth

One of the major barriers to full utilisation 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, 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.

WHO 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 (WHO, 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 various settings. The aim is to explore what has worked in other settings that may be of relevance to low resource settings such as Rwanda. 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 utilise 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 et al., 2015). Telehealth can be used for remote coordination of radiotherapy, remote monitoring of chemotherapy, for palliative care, virtual consultation, and tele-mentoring 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, make the trip but end up not seeing a 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 ongoing. 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 seems to be VIA modifications or complementary interventions. An example from Botswana involves the use of 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% women living with HIV) (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-University of Pennsylvania partnership (BUP), the Ministry of Health Botswana, University of Botswana and mobile phone operator Orange Foundation Botswana.

The MoH 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 tele-cytology 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 Rwanda with significant successes. The Rwandan 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 as part of their screening information and outcome session. Nevertheless, the telehealth aspect involves sharing the images with remote experts who in most cases are based in tertiary hospitals in Kigali 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 Rwandan 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 Arkansas, part of rural southern USA where there are reported high mortalities related to cervical cancer due to limited access to Pap smear tests. Women with non-verifiable pap smear or VIA tests were referred to hospital facilities with telecolposcopy capabilities. There were a total of eight telecolposcopy sites across Arkansas 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 research to explore the potential use of telehealth to improve cervical cancer screening and patient outcomes. This call for further research 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.

*Figure 4 Images of the Gynocular.*
*Published with permission from Gynius*

### 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 (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 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 care while at the same time reducing the burden of treating false positives, especially in low income settings where services are not available for all in need.

#### Gynocular

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, Gynocular (TM). According to Gynius AB, the makers of Gynocular, their device is the world's first truly portable

colposcops. It is a high resolution monocular colposcope which has identical specifications to stationary colposcopes. Gynocular uses T2D (Gynocular Triage To Diagnose) cloud based software developed by Gynius AB. It is a clinical record software that enable the documentation of a structured colposcopy examination with integrated image documentation. The software can be used on lap tops, smartphones or desktop personal computers. More details about T2D can be found at http://www.gynius.se/software.

The Gynocular is interoperable and can also be used in Gender Based Violence programmes, with eTestify software (a forensic clinical record) to support health workers to accurately record signs of physical violence and sexual abuse. The system can be used as a stand-alone or integrated into EMR systems and includes consent forms. The device can therefore be an investment beyond cervical cancer screening programmes.

Gynocular has been tested in different socioeconomic settings. A cross-sectional community based study in India explored its effectiveness in triaging VIA/HPV screen positive women. The results showed that Gynocular can effectively be used for triaging VIA/HPV positive women with significant accuracy (49) thereby minimising false positive tests of VIA acetic acid screens. A randomised cross over trial comparing the accuracy of Gynocular and a stationary colposcopy in Sweden found that Gynocular was as accurate as stationery colposcopy. The study found no significant difference in screening accuracy, specificity and sensitivity in detecting cervical cancer lesions (Kallner, Persson et al. 2015). Related clinical trials in Bangladesh and Uganda (50,51) also reported that Gynocular was as effective as stationery colposcopy in screening cervical lesions and can be effective tool for triaging women for immediate care.

The results of these studies suggest that the potential of a portable colposcopy, much cheaper than the laboratory based stationery colposcopy is within reach for low income countries. However, there is need for further research on the applicability of Gynocular in low income countries, beyond the clinical trial parameters. Details and specifications of Gynocular can be obtained from http://www.gynocular.se

*Figure 5. Images of The EVA System.*
*Published with permission from Mobile ODT*

## MobileODT (Mobile Optical Detection Technologies)

The EVA (Enhanced Visual Assessment) System combines a mobile phone with powerful optics. The EVA System was approved for sales in the USA by the U.S Food and Drug Administration (FDA) in December 2016. This followed successful piloting of the technology in eight countries (Rwanda, Haiti, Guatemala, Botswana, Kenya, Nepal, Mexico, and in the United States).

The EVA System is a handheld mobile/portable colposcope equipped with an ultra-bright light source and powerful magnifying lens to enhance visualisation of the cervix. The EVA System comes in a protective hard shell and water resistant carry case. It is linked to the app, CervDx which enables secure image capture and sharing for remote consultation and patient care. The app is linked to a secure cloud storage that provides access to the data anywhere in real time, particularly useful for remote consultations. For more information, see http://www.mobileodt.com/.

## Digital Holographic Microscopy

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) (52). The instrument has an "accompanying software that creates a rapid 3-dimensional (3D) image reconstruction of cultured (53)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 soon. Unlike GynocularTM, which is portable and does not rely on computer user in real time, DHM system seems to operate directly from a computer-based software to create images. The GynocularTM can be used in the field, away from a computer and electricity supply, and the data later uploaded to the database. Both GynocularTM and Mobile ODT have developed systems for use clinical forensics (details can be found at http://www.gynius.se/software and http://www.mobileodt.com/sane.html).

## Disclaimer:

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 income countries. We anticipate to have 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 that 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 may have limited 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 of 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 as 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 current 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 the study countries (in this case Rwanda) on the applicability of 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. Thereby contributing towards the achievement of the SDGs such as goals 3 and 5 (Health, Gender equality and women's empowerment) (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 main project is to improve cervical cancer screening and care in low resource settings. The needs assessment exercise was done to provide insights into what exists and what is needed to enable the use of telehealth in cervical cancer screening, prevention and control in the selected countries (in this case Rwanda). 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. To develop a socio-culturally relevant telehealth implementation framework for cancer screening and care in low resource settings

## 1.4 Project implementation

The project was funded by SPIDER, which maintained an oversight of the implementation activities in all the three partner countries. In Rwanda, the field work activities were coordinated by Urunana DC under the guidance of Mr George Gahenda. Urunana DC worked in partnership with the University of Rwanda's College of Medicine and Health Sciences, Department of Obstetrics and Gynaecology, under the Leadership of Dr Rulisa and Mr Joseph Ngenzi Lune. Data was collected between June and August 2016.

Data collection was carried in two different phases. The first phase involved focus group discussions with purposively selected individuals involved in policy making at the national level and tertiary level health care workers drawn from referral facilities in Kigali, Rwanda. The lead researchers from Stockholm were involved in the facilitation of phase one focus group discussions in Kigali in June 2016. The second phase involved focus group discussions with purposively selected health care workers drawn from provincial to community level facilities feeding to Bushenge hospital in Western Rwanda. The second phase also involved purposively sampled women living with diagnosed cervical cancer drawn from Bushenge Hospital.

## 1.5 Methodology and recruitment

The study adhered to Rwanda National Ethics Committee requirements and received ethical approval on 20th April 2016.

Recruitment of participants was coordinated by partners from the University of Rwanda/College of Medicine and Health Sciences/ School of Medicine and Pharmacy/Department of Obstetrics and Gynaecology, Urunana DC, Bushenge provincial hospital and Mr Reuben Mugisha, who was part of the research team from Stockholm University and was key in facilitating the Stockholm-Rwanda partnership.

Data was collected using focus group discussions (FGDs). All key participants willing to take part in the study managed to take part in the FGDs. The FGD sessions were based on interview guides developed in consultation between the project team in Stockholm and local country partners in Rwanda. The FGD interview guides were designed in English and then translated to local Kinyarwanda language for use in case some participants were not comfortable using English. The FGDs for policy makers and tertiary level HCWs were conducted in English. Note that participants comfortable expressing themselves in French or other local languages were encouraged to do so through the support of Mr Joseph Ngenzi who was able to translate the discussions.

The focus group discussion in Bushenge was conducted in Kinyarwanda language and then translated and transcribed in English for data analysis.

Before conducting the FGDs, participants received an explanation on what telehealth is as a concept and a brief introduction of the organisations involved in the implementation of the study. Video-conference was used during Bushenge hospital FGD to link the project team from Stockholm University with the FGD participants at Bushenge hospital. The team from

Stockholm was able to explain to the participants the objectives of the study and what their involvement entailed through the video link.

## 1.6 The sample

This study was informed by 40 participants who took part in four different focus group discussion sessions. The groups were divided into policy makers (n=12), tertiary health care workers (n=6) from Kigali City, front line health care workers (provincial level to community level, n=15) and women living with diagnosed cervical cancer (n=9) from western Province of Rwanda.

The FGDs conducted in Kigali targeted the health system group from Rwanda Ministry of Health, Ministry of ICT and Youth, Rwanda Biomedical Center and University of Rwanda College of Medicine and Health Sciences, other tertiary health facilities from the department of gynaecology and pathology as well as NGOs working with similar questions.

The participants for the remote sites were primary health care workers as well home based healthcare givers, nurses, midwives and general practitioners and allied health personnel within the Bushenge provincial hospital catchment area. Bushenge hospital was selected because of its remote location from Kigali. This hospital is also unique in that it champions the implementation of e-health systems such electronic medical records systems as well financial management information systems and has established a videoconferencing system with the Rwanda Military Hospital.

FGD Participants in Bushenge hospital were recruited in collaboration with the hospital as well community health workers.

| Participant code | Position |
|---|---|
| A | Hospital administrator |
| B | Midwife |
| C | Head of hospital laboratory services |
| D | Lab Technician |
| E | Midwife |
| F | Gynaecologist |
| G | Midwife |
| I | Midwife |
| F | Home care health care giver |
| F | Home care health care giver |
| G | Medical Doctor in maternity ward |
| K | Radiologist |
| L | Hospital manager |
| M | Public Relations Officer |
| N | Midwife |

*Table 3 Representatives of Primary Healthcare workers (HCWs)*

| Participant Code | Age |
|---|---|
| P1 | 62 |
| P2 | 55 |
| P3 | 52 |
| P4 | 37 |
| P5 | 54 |
| P6 | 37 |
| P7 | 77 |
| P8 | 48 |
| P9 | 56 |

*Table 4 Patient representatives*

| Participant code | Gender | Employment role | Category |
|---|---|---|---|
| 1 | M | Assistant Lecturer | Education |
| 2 | M | Manager | NGO |
| 3 | F | Manager, Cervical Cancer | Health |
| 4 | M | Manager | NGO |
| 5 | M | Pathologist | Health |
| 6 | M | University lecturer | Education and Health |
| 7 | F | Public health Practitioner | NGO |
| 8 | M | ICT specialist | ICT |
| 9 | M | E-health | Health |
| 10 | M | Gynaecologist | Education and Health |
| 11 | M | Dental specialist/pathologist | Education |
| 12 | F | Lecturer | Education |
| 13 | F | Civil servant | Civil service |
| 14 | M | Gynaecologist | Health |
| 15 | M | Gynaecologist | Health |
| 16 | M | Gynaecologist | Health |

*Table 2 Representatives of policy makers and tertiary health workers*

# 2 Findings

In this section, we present the key findings from the Rwandan arm of this tri-country study. The findings presented here capture the views of all the health system members who took part in the study. They represent the views of representatives of policy makers, healthcare workers (tertiary level, provincial level, district level and community level) and women living with diagnosed cervical cancer. However, we acknowledge that these findings may not be representative of the Rwandan health system as a whole.

Telehealth being a socio-technical issue that cuts across many disciplines and affects different people, there was need to get perspectives from the different stakeholders in the potential use of telehealth for cervical cancer screening. The findings thus provide useful insights into the local key stakeholders' views on why and how telehealth can be used to improve cervical cancer screening and care in Rwanda. Being a qualitative study, many themes were bound to emerge from the diverse 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: the need for telehealth in cervical cancer screening in Rwanda, health system's readiness for telehealth, doubts and concerns about applicability of telehealth in cervical cancer screening and potential solutions to some of the identified barriers to potential use of telehealth in Rwanda. The findings reflect the interpretations we made of the participants' responses to various issues discussed. We also use extracts from some of the participants' actual responses to illustrate our interpretations. The views expressed in this report are those of authors, informed by their interpretation of the data.

## 2.1 The need for telehealth

All participants were asked if there was need for telehealth in cervical cancer screening in Rwanda. Their responses suggest a generally positive attitude towards the potential use of telehealth in cervical cancer screening. Many respondents noted that there is need for telehealth in cervical cancer screening in Rwanda because it can contribute to improving the dection and treatment of cervical cancer in the country. Some of the explanations offered relate to direct benefits and advantages of telehealth of enabling remote care and information exchange, while others relate to the potential of telehealth to contribute towards solving other challenges facing cervical cancer care and the healthcare system in general. As the following extract illustrates, there is genuine interest in using telehealth to improve health outcomes. The extract also highlights the emphasis on the need to empower women when participants noted that women should not just die because they are women.

Participants suggested that any tool that could transform the current state is welcome, hence telehealth stands a great chance if it can lead to reductions in cervical cancer mortalities and morbidities.

"*Maybe using technology will minimise the death rates. So, it can be fair for women who are just dying because they are women. So, for me, any tool which can come in to get in that would be good.*" (ICT scientist, public service)

This finding is consistent with the notion that technology is value neutral and it is all about how it is used rather than the technology itself (LeBlanc, Shulman, Yu, Hirsch, & Abernethy, 2013; Sundström, 1998).

The participants were asked to explain why they believed that telehealth was necessary in the Rwandan context. The following are some of the reasons they provided to support the need for telehealth in Rwanda.

### 2.1.1. Knowledge sharing and optimal utilisation of the few health workers

One of the major challenges facing cervical cancer management and the whole healthcare system in general is inadequate human resource for health. Many participants, themselves involved in healthcare in different ways, noted the scarcity of specialist health workers in different domains of medicine such as gynaecologists or pathologists. Thus, the capacity to screen women for cervical cancer and provide treatment and care for those who tested positive was limited. Telehealth was perceived as a potential solution to human resource shortages because it could facilitate remote care by enabling the few healthcare workers to reach out to patients in need of care in remote locations where there may be acute healthcare worker shortages. Telehealth could also enable knowledge sharing so that healthcare workers who lack certain skills can consult their more experienced or well-resourced counterparts, thereby ensuring that all patients receive adequate care wherever they are irrespective of their distance from highly specialised healthcare workers. The participants felt that knowledge sharing can be an effective way of maximising the available scarce expertise for the benefit of a wider public.

"*(…) few number of Gynaecologists. I may come for physical check-up and return home without results, just because I did not have a Gynaecologist to examine my case. Doctors are few here.*" (Patient representative)

"*one of the challenges we will have here in Rwanda is the availability of health workers (...) the cost of getting like many health workers (...) for*

*telehealth we can have like really 5 people reaching a huge amount of people who come for testing whether they have cervical cancer (...) I think, it is really practical and is not just relevant in Rwanda, but I think, in the entire Africa, it is really very important.*" (Public health practitioner, works for community development organisation)

### 2.1.2 Remote healthcare

One of the major barriers to cervical cancer screening is accessibility challenges in terms of travel distances. Some of the participants noted that the long distances that patients have to cover to find healthcare providers was a reason why telehealth was necessary in Rwanda. They observed that the scarcity of healthcare workers (outlined in 2.1.1 above) combined with distances patients travelled to get healthcare were two factors feeding off each other. Scarcity of healthcare workers meant that physicians were mainly based in urban areas hence patients had to travel from rural areas to urban areas to see a physician. Telehealth could therefore make physicians in faraway urban areas accessible to rural village women.

*"(...) you can reach as many people as possible because the need to travel from the rural area to the hospital or main centre will be shortened."*

*Pathologist*

"*(...)you can reach as many people as possible because the need to travel from the rural area to the hospital or main centre will be shortened.*" (Pathologist)

The participants also talked about the state of the infrastructure such as roads being in poor state and challenging terrains as additional factors that add to the cost of travel in terms of money and time to seek healthcare especially after a transfer has been issued. These barriers were partly to blame for late diagnosis, according to some of the participants. They believed that telehealth could cut down the time and cost of travel and enhance cervical cancer diagnosis and feedback. Patients would be able to screen closer to their villages and in a timely manner without having to wait until they have money to travel to the urban areas for cervical cancer diagnosis to be confirmed. More so, transport costs to go to urban areas for cervical cancer screening was in direct competition with the daily basic necessities such as food. Those with limited resources were likely to prioritise daily life necessities over their health.

The participants acknowledged the fact that many patients present themselves late at health facilities with advanced cancer that requires expensive treatments such as radiotherapy, which requires referral to large city hospitals and the outcome is not always good for the women. Telehealth was seen as a tool that could facilitate timely screening by eliminating the barriers outlined above leading to simpler disease management and better prognosis for women diagnosed with cervical cancer.

*"(...) early stage diseases are surgically manageable, for instance cervical cancer. Those who are picked up at an early stage are surgically managed, so radiotherapy is only for locally advanced. But the majority, if our system is working very well, we would be picking up diseases at stage 1A, 1B all those diseases are surgically manageable. And of course, initially when we start, we'll be picking up diseases that are locally advanced because the system has to start from somewhere, later on once all those diseases are picked up at the time of screening (…)"* (Pathologist, referral hospital)

*"While doing health talks we have identified that mothers have limited information on cervical cancer"*

*Public health practitioner*

### 2.1.3 Health education

Telehealth was also considered beneficial in providing health education through audio and visual media in order to solve the challenge of health illiteracy.

*"While doing health talks we have identified that mothers have limited information on cervical cancer. We need to improve the communication within sectors, cells and villages and audio and video could be used to sensitise more women on cervical cancer (...)"* (Public health practitioner, NGO)

Some of the participants pointed out that many patients do not know the symptoms of cervical cancer while others harbour various misconceptions. For example, some people seem to believe that positive cervical cancer diagnosis implies promiscuity on the part of the infected individual. Such misconceptions lead to delays in seeking screening or seeking healthcare because of fear of stigma. Not knowing where to go or avoiding seeking healthcare for fear of being judged.

*"A lot of mothers have died because of ignorance. You know, cancer of the cervix attacks mothers from secret part of the body that you cannot show everybody. Normally, when you are married to a man you can easily tell him the problem you have. But, for a widow like me, we prefer to keep silent. The widow can say:" if I tell somebody that I am suffering from the cervix, they can say I have had sexual intercourse with a man. This is why most mothers go to the doctor at the very last stage and die."* (Patient representative)

Similarly, given the fact that cervical cancer presents symptoms such as vaginal bleeding which is also a common side effect of hormonal contraceptive use, some patients confuse the two conditions and hence delay screening and treatment of cancer. Telehealth could thus be used to provide sexual and reproductive health education to many women who would then be able to identify symptoms of cervical cancer from other unrelated conditions.

*"We need to talk about this issue because, women under contraceptives usually confuse long menstruation with cervical cancer bleeding."*

*Patient Representative*

*"We need to talk about this issue because, women under contraceptives usually confuse long menstruation with cervical cancer bleeding."* (Patient representative )

### 2.1.4 Research

Another reason that some of the participants offered to justify the need for telehealth in cervical cancer screening in Rwanda is its potential to facilitate research and evidence generation. The relevant participants felt that evidence is vital for informing policy makers and justify further investments, guide advocacy for resources and their allocation, as well as application in health education.

*"The other benefit is (...) to promote research (...) In the future, it can lead to the easy way of doing research and, as well, of teaching"* (Academician, university lecturer)

Beyond cervical cancer, one participant noted that the proposed telehealth project could be a useful springboard for doing research on other types of cancer as well, hence addressing this emerging public health issue in Rwanda and other similar settings.

"*I think this research will set a precedent to do research on other types of diseases such as cancer of the breast, and cancer of the lungs so as to diagnose and treat them*" (Medical doctor, provincial hospital)

### 2.1.5 Healthcare worker - patient communication

We also found that many patients are uncertain about the healthcare they need and there was need for better communication between healthcare workers and patients. Telehealth would enable multi-directional communication using different means such as audio-visual or text based communication to enable patients to communicate with healthcare providers. The participants felt that this was important for building rapport and confidence in care.

*"Mothers are currently treated, but their confidence on treatment is still low. So, I think telehealth will enable communication between a patient and a Doctor, even at distance"*

*Patient Representative*

"*Mothers are currently treated, but their confidence on treatment is still low. So, I think telehealth will enable communication between a patient and a Doctor, even at distance.*" (Patient representative)

## 2.2 Readiness for telehealth for cervical cancer screening

Readiness for telehealth (or for any e-health solution) can be looked at from different dimensions, but all of which interact with each other to affect success because telehealth is a socio-technical issue as outlined above. Previous research (Li & Ray, 2009; Rezai-Rad, Vaezi, & Nattagh, 2012) show that the dimensions of readiness include:

**1. Core readiness**, which means the realisation of need for telehealth by stakeholders along with an expression of dissatisfaction with existing service or circumstance

**2. Engagement readiness**. A positive attitude towards, and willingness to participate in telehealth, as well as stakeholder exposure or experience with telehealth (or ICT in general). Their training, skills and recognition of potential positive and negative costs and outcomes of telehealth

**3. Technological readiness.** This refers to the availability and affordability of the required technologies for telehealth including hardware, software, network infrastructure, electricity, as well as technical support and training

**4.Societal readiness**, which are concerned with policies and protocols for communication and information sharing, consideration of socio-cultural factors and having locally relevant content for telehealth deployment.

Based on the above theoretical outlook, the present participants provided varying opinions on whether their organisations (and the Rwanda health system by implication) were ready for a successful implementation and use of telehealth solutions in cervical cancer screening. Some participants were sceptical and pessimistic about the potential use of telehealth in cervical cancer screening. Others on the other hand, were more enthusiastic about the great possibilities that telehealth could provide, while noting that some aspects of readiness might require additional input before they can facilitate successful deployment of telehealth in cervical cancer screening.

### 2.2.1 Core readiness

As evident from the previous section, the findings illustrate that there was need for telehealth as a way of solving the current challenges, along with voiced dissatisfaction with the current cervical cancer outcomes for many women who were still dying because of late diagnosis.

### 2.2.2 Engagement readiness

Many participants had a positive attitude towards possible use of telehealth in cervical cancer screening in Rwanda. Some participants explicitly said they were happy to partner with the present project in order to make tangible contributions towards the proposed implementation of telehealth in cervical cancer screening in Rwanda.

"*Telehealth is something new to me and I'm also exploring and learning about it (...) I'm interested to know what it is and also to interact with people to see how the solution is going to have impact in the community*" (Patient representative)

But participants were also aware of the potential challenges to implementation of a telehealth solution, some expressing doubts and concerns. This scepticism was a genuine concern and doubt about how receptive other relevant telehealth stakeholders would perceive the initiative, or be able to adapt to the changes that come with it. These are presented in section 2.3.

### 2.2.3 Technological readiness

Participants expressed a high sense of technological readiness for telehealth in Rwanda. They cited the infrastructure that the government of Rwanda had put in place in its efforts to promote ICT coverage and use, particularly the broadband internet infrastructure that shall facilitate telehealth. The participants noted that major hospitals and health facilities, especially in the urban areas were fully networked and many operations were already computerised. Thus, Rwanda already had telemedicine facilities.

"*The equipment available here can allow us to implement telehealth. We have a video conference, we have some cameras, and we have even organised video conferencing as you have seen today (...) we have computers and internet connection at every department.*" (Clinician, provincial hospital)

Participants also pointed out the fact that there was ongoing research and training in telehealth related programs such as health informatics at the University of Rwanda. They noted that such training was important in ensuring the supply of the necessary local skilled human recourse to run telehealth projects. Furthermore, some of the participants pointed out that the ongoing training was also vital for continuous professional development and general familiarity with ICT tools such as social media and use in other projects by some clinicians.

"*I think that we are more than ready. One of the area we have a research component at the School of Public Health, which I am interested in is evaluating health systems. Regarding capacity building, we have a department of health Informatics which is teaching tele-pathology. Regarding service delivery, although it is not our primary role, we have some service delivery. Like my colleague was saying, we have a laboratory which is using tele-pathology (...) So, it's just a matter of having some good projects. If we have some clear projects, then we can be very supportive in these issues.*" (Public health practitioner, academician at the university)

### 2.2.4 Societal readiness

Participants reported that policies needed to provide safe spaces and guidelines on the use of telehealth and other ICT tools in healthcare. However, there was an affirmative agenda by the government which was encouraging the use of ICT in all public sectors including healthcare and education. Some of the stakeholders such as the university were already teaching health information technology programs. Major hospitals were using ICT solutions such as teleconferencing and tele-pathology.

Overall, the participants said there was a general trend of adoption of mobile technologies by the general public, particularly social media. In their view, these technological adoptions imply a general societal readiness for telehealth in many life domains in Rwanda.

However, the findings also show some reservations about the socio-cultural stance particularly of the sections of the populations that were non tech-savvy such as the elderly, and the perceived general tendency for women to be shy when it comes to sexual and reproductive health problems. Some of the participants felt that such sections of the population might not be very receptive to telehealth.

## 2.3 Doubts and concerns

This subsection presents the findings on some of the reservation that the participants believed could hinder any hopes of successfully using telehealth in cervical cancer screening and care in Rwanda.

### 2.3.1 Effectiveness of telehealth

Despite the euphoria that the potential use of telehealth in cervical cancer care may come with, some of the participants expressed doubts about the effectiveness of a telehealth solution and whether the solution would have any positive impact on cervical cancer screening and care, particularly health outcomes for the affected women. Being a new tool that many participants had no prior experience with, they wondered if it really works and more importantly whether it could be cost effective compared to the current cervical cancer care in Rwanda.

"*I'm worried about the tools which have never tested and have never been used here (…) do they work? Do they give the expected outcomes, are they cost effective, compared to traditional ways of working.*" (Public health practitioner, academician at the university)

2.3.2 Acceptability of telehealth

Some of the participants expressed scepticism on the potential acceptability of the proposed telehealth solution. They wondered whether the potential beneficiaries; patients and clinicians, would embrace telehealth for cervical cancer care. Some noted that cultural constructs, norms and biases were barriers to cervical cancer screening in general but would be more prominent barriers to the potential use of telehealth. For example, there was a general reluctance to seek sexual and reproductive health care because it is 'private' and people feel shy about issues of sexual health.

Some women are put off by the gender of the healthcare worker, preferring female clinicians over male ones yet most clinicians tended to be males in Rwanda.

"*reproductive health issues that have culturally remained personal, so, when it comes to examination it goes up to a private place of someone, so it is somehow with Rwandan women exposure of nakedness.*" (Public health practitioner, NGO)

Furthermore, the fact that telehealth solutions might involve use of gadgets and taking photos of the 'private parts' and sharing them with other clinicians, was pointed out as an added factor that could affect acceptability and access of the service.

*"I want to know for a woman like my mum to accept such a device to be used"*

*Gyneacologist*

"*I want to know for a woman like my mum to accept such a device to be used (…) because, I know culturally my mum would prefer to go and see a Gynaecologist. Then adding on her head that device (…) Are the women going to accept such a device to be used for screening?*" (Gynaecologist , referral hospital)

"*Examining all the women, they just see it is a problem (...) it is a challenge (...) when you counsel her for some time (...) at the end she accepts.* **But, with taking the photo, that one I see it is a problem**" (Pathologist, referral hospital)

Another cultural construct that the participants had concerns about is the role of men in the healthcare of women. It was noted that in Rwanda, men influence the health seeking behaviour of women because women have to get consent from their husbands. The men can therefore dictate whether or not their spouses go for certain healthcare services, and possibly where, as illustrated below.

"*the husband has to consent to have his wife screened for cancer. The first thing he would say is "You are going to die with cancer, you are going to leave me with those children." And, I have met a husband who was like that, you know, he said: "Don't screen my wife." The wife comes in and says my husband has refused*" (Pathologist, academician at the university)

The above extract also shows that the men may not just be concerned about their women accessing screening services. It seems as if there is also the 'fear of

the unknown' premised on misconceptions about cervical cancer. Cancer is potentially perceived by some people as untreatable condition and positive diagnosis implies death sentence. This misconception could discourage people from going for screening, rather live longer with the disease without knowing than getting tested. The possibility that telehealth could enable such individuals know about their condition is potentially a barrier to acceptability of the telehealth solutions for cervical cancer screening.

"*You need not even mention the cervical cancer. If you tell to someone cancer (…) cancer is synonymous with a death sentence. It can't be treated, if you go for treatment, the treatment is too expensive; it's laborious to, peoples 'minds. You will have to go to India, South Africa or King Faisal (…) It is disruptive to someone's normal life and there is always the saying 'Why do you want to wake up the sleeping mind, something there;' 'So, you are diagnosing (…) so what?' (...) would rather have death as surprise rather than to see it going to happen and watch it happen when you are hopeless.*" (Pathologist, academician at the university)

The doubts expressed by the healthcare workers were whether the clinicians would embrace the change that would come with the technology. Some participants wondered if healthcare workers would for example accept and adjust to changes in the workflow and responsibilities. Another important concern raised was whether the healthcare workers had the necessary technical skills or whether they would be willing to learn new skills.

"*Who is going to be responsible for capturing the telehealth service, their qualifications and their job descriptions at all levels? (...) if we roll out the new method, is the person going to be trained, what will be their qualifications? And how are their roles going to compliment, interdisciplinary teams, nurses, laboratories and pathology. So, how are they going to work together?*" (Telemedicine specialist, academician at the university)

Some of the participants also questioned whether the clinicians or hospitals will be able to deal with the anticipated huge numbers of patients that would seek healthcare due the awareness that would be created through telehealth implementation. These participants believed that telehealth would create high demand for care that services would not cope with. The participants noted that the scarcity of health care workers was not going to be solved by the implementation of telehealth in its totality. As it stands, the scarcity of healthcare workers is part of the problem that leads to inadequate cervical cancer screening and care. The concerned participants noted that increased cervical cancer screening enhanced by telehealth could end up being useless effort and a waste of resources if patients cannot get adequate care

thereafter because of inadequate expertise in cancer care. They wondered what would be the point of screening many women if cancer treatment services such as radiotherapy were not available in the country and most patients could not afford to go to the referral hospitals. This, some participants noted, was an ethical question that telehealth implementation must consider.

*"that you screen the women but you don't offer the service. If the mother has a problem you can't attend to that problem you only screen and you leave them confused. Telehealth is going to help us do early screening of cervical cancer. Then after early screening, what? Because already they are screening but they have the problems they can't attend to. They can't provide the service; they can't give the treatment for example."* (Public health worker, NGO)

### 2.3.3 Privacy and confidentiality

Another major concern that was raised, especially when discussing acceptability of telehealth, was privacy. As alluded to in the previous sub-section regarding the fear of exposing one's 'nakedness', privacy was a major concern not just for the patients but also other stakeholders such as policy makers and clinicians. Based on their experiences from unregulated technological platforms such as WhatsApp and other social media applications, the participants wondered whether it would be possible to guarantee security, confidentiality or privacy of the telehealth information sharing. This was particularly worrisome to many participants because the proposed solution would involve storage and sharing of images of 'private' parts of the patients. There was a genuine alarm at the possibility of such images ending up in social media.

*"if we are going to use a smart phone, the population is aware of the use of social media such as WhatsApp group, these people are sharing images, how would we inform people that the images that we are going to capture will not be shared on social media such as WhatsApp group by violating patients' confidentiality? We need to assure the population that the gadget we are using is trustworthy. That the images will be secured. If these images will be used for other purposes such as education, the client must provide their consent. We need to make sure that the client trusts the system and is aware that the images will be shared with other persons or organizations they know and they trust" (Public health practitioner, NGO)*

### 2.3.4 Cost

The issue of cost came up frequently in the discussions, and it took two

dimensions: a) cost of the telehealth solution and b) cost of care for the patients screened once the telehealth solution is implemented. Participants, conscious of the limitations of the healthcare budget in Rwanda, wondered where the extra funding would come from to buy the equipment and to put in place the infrastructure needed to operationalise telehealth solution in cervical cancer screening and care. The discussion on policy in the next subsection further outlines the cost concerns including the role of health care financing (health insurance) as a source of funding/reimbursement for cervical cancer screening or the telehealth solutions.

*"the first thing to solve such a problem is money (...) This is to say that the specialist who is going to follow the patient's case must be necessarily motivated. The hospital should keep a budget for telehealth"* (Laboratory technician, at the university)

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*Laboratory technician, at the university*

The concerns over costs were also linked to questions about the sustainability of a telehealth solution that may be adopted. Some of the participants suggested adopting telehealth solution in the routine healthcare process where applications beyond the pilot projects would be funded by the government as part of the healthcare budget. The relevant participants noted that this approach would be possible if the pilot phase showed good outcomes.

*"how affordable will it be today, and how accessible is it to the most needy(...) and how sustainable?, because I was just like thinking that if they could be a fund, that would show maybe good results, maybe telehealth being a response to this problem, for certain period of time, because the political will is there, and if it could match with the results given, that would justify the need, why maybe it should be considered in the budget lines, so that the funds, the affordability, the accessibility, and the system gives certainty [sic]." (Public health practitioner, NGO)*

The above quote also highlights other concerns that ought to be addressed such as evidence based use of telehealth and demonstration of cost effectiveness and equity - having the solution accessible to all who need it rather than only those in the hospitals involved in the pilot project.

Regarding the cost of care, participants wondered how the screening service itself would be financed. Noting that insurance services did not cover cervical cancer screening at the time, participants reported the need for change in policy to address telehealth funding. More of concern, especially to the patients' representatives, was the cost of cancer treatment. This requires referral to bigger health facilities for specialised care and sometimes certain services aren't available even at the largest health facilities in Rwanda and patients have to be referred out of the country, e.g. for radiotherapy in Uganda or Kenya.

"*they do cervical cancer screening at a fee that is not covered by health insurance and after they refer a patient to somewhere else, the follow up becomes difficult, because it is not affordable; the cost of care is not affordable.*" (Public Health worker, NGO)

### 2.3.5 Policy

The gap in policy was a major concern and a key finding of this study. Despite the notable optimism about the potential use of telehealth and the system readiness outlined above, participants pointed out the prevailing policy vacuum. There were no guidelines on how the actual operationalisation of telehealth in cervical cancer screening would be governed. Although the policy on telehealth was being developed at the time, all key prerequisites of telehealth deployment such as data protection and confidentiality of patient information, consent, data sharing, liability, funding, training, implementation, and sustainability required clear policy guidelines.

"*the Ministry of Health is working on the policies, ICT policy and they are working with tele- medicine and policies right now the draft is available. So some of the concerns are to have very clear guidelines which guarantee the patient's confidentiality, the investment model for sustainability*" (Public health practitioner, civil servant)

Participants also noted the need for public awareness about telehealth to ensure that such a solution was known to the potential stakeholders to enable public 'buy in'. "Programs of awareness need to be created and advocated for." (Public health practitioner, civil servant). This would create a desire for all stakeholders to be involved and determine how their different organisations could be part of the process within their own organisational goals. Stakeholders such as insurance companies for example could create relevant packages to cover screening costs for women. But all stakeholders' engagement would depend on the policy environment created by the state.

*"elements that need to be emphasized include the aspect of preventive check-ups being supported by insurance (...) I think that, from a policy point of view, what policies can we develop to promote preventive checks so that women are encouraged to take these screenings; if the screening is done, the insurers are going to say it is too much. But, I think, this is done in the point of view of saying that this is a public service. Can at least the insurance cover the cost of materials so that these people can at least access services?"* (Pathologist, referral hospital)

Despite of the absence of clear policies and guidelines on the use of telehealth, the participants noted that telehealth was already in use in some aspects of health services delivery. As a way forward, healthcare workers should adhere to the existing practice guidelines such as medical ethics which outlines how to handle patient information with confidentiality. Since issues like confidentiality and data protection were basic medical practice requirements, the only added issue clinicians would deal with is remote information sharing, which they do anyway in their current practice.

*"some organisations are already implementing telehealth, not in the cervical cancer as such (...) they are implementing telehealth already without even having either a policy or a complete strategy"* (Public health practitioner)

*"(...) it is very clear. In our medical career, we must keep medical secret. In whatever we do, we may keep the patient's confidentiality. This means that when you are sharing a patient's information on internet, you are displaying it worldwide. So, you must know that patient's information should be kept confidential. You should share information with somebody you know very well and avoid displaying information to someone that you do not know, if you want to avoid problems. So, with telehealth, confidentiality on patient's information is something that should be respected. It should not be informal (...)"* (General practitioner, provincial hospital)

Participants noted applications such as WhatsApp are in limited use already. This raises questions about what policies should govern such usage and the ethics of the use of such social media solutions. Some of the participants said they worried about the repercussions that might come from the use of such non-regulated platform to provide healthcare and what legal frameworks were in place for protecting users against unnecessary liability or litigation. Noting that legal protection was a key factor in any potential adoption of telehealth by the healthcare workers, lack of guidelines was clearly a big barrier to any future attempts to use telehealth in cervical cancer screening in Rwanda, or any similar settings without policies in place.

*"is there some legal framework for how we protect the professionals who are using these telemedicine networks? (...) The professionals need to know they are protected. If the laws are saying this is not legal, but it is the most convenient method, where do I read it? Those are some issues that will make us say there is some device, let us use it to take the image. If I am using my mobile network, how am I sure that no one behind my career is not using the image or reading the note?"* (General practitioner, provincial hospital)

## 2.4 The way forward from the gaze of the stakeholders

All participants were asked to suggest how the concerns and worries they expressed regarding the possible use of telehealth in cervical cancer screening in Rwanda could be overcome. This subsection outlines some of the suggestions that the participants believed would ensure successful use of telehealth in cervical cancer screening.

*"So, with telehealth, confidentiality on patient's information is something that should be respected. It should not be informal..."*

*General Practitioner*

### 2.4.1 Communication and awareness creation

Oarticipants identified the need for public awareness and effective communication as a key pillar to any successful adoption of telehealth in cervical cancer screening. They pointed out that there was need for awareness on the effectiveness of telehealth, clear communication guidelines to govern privacy and confidentiality of patient information. There was need to awareness about the socio-cultural constructs which could affect acceptability, on the part of the implementers, in order to come up with mitigation strategies. There was need for effective communication about the telehealth project involving different stakeholders to ensure multiple ownership of the project.

As a new solution, some participants observed that many potential stakeholders may need to be sensitised about telehealth and its applicability. For example, the general public ought to know about the service in order to seek and utilise it. Advocates who would lobby government departments to buy-in and support the implementation and sustainability of telehealth for cervical cancer screening would also need to be sensitised so that they have accurate information to do their work.

Service users would also need to know exactly what benefits telehealth would offer them with regards to cervical cancer screening and care, how their information would be stored and any risks of harm that the use of telehealth in cervical cancer screening could expose them to. For instance, they would need assurance that any pictures of them and other personal information will not be shared with anyone not involved in their care.

Lastly, the government agencies and all other stakeholders involved in policy making will also need to be informed so that telehealth becomes part of the health system planning and government strategy. The participants noted the need to demonstrate positive outcomes from the initial pilots and cost effectiveness as a basis to lobby the government to incorporate telehealth in routine care. Some of the participants emphasized that government buy-in that will depend on demonstrated effectiveness of telehealth, will ensure funding allocation in the state budget and sustainability of the eventual telehealth solution to be adopted.

### 2.4.2 Managing expectations

Participants also emphasized the need to manage the expectations that different stakeholders may harbour for telehealth. They said that some stakeholders might expect telehealth to become a 'silver bullet' that would solve all cervical cancer screening and care issues, which will never be the case. The idea is to get a balance between the possibilities offered by telehealth and the realities of healthcare challenges such as socioeconomic barriers that would still plague the health system even with telehealth in place.

There were also concerns about the unforeseen consequences of telehealth that the participants believed should be managed well. As a new system, with limited prior experience to draw upon from other related settings, implementation of telehealth presented a leap in faith. The following extract from a clinician illustrated the need to carefully inform potential service users of the possibilities and limitations of telehealth.

"*if you are asking if these patients can be managed, I guess it would be one of the limitations of the telehealth, you can't give radiotherapy from a distance, a patient can't be in Rwanda and get radiotherapy from [another country]. I want us to take a moment to look at it, because telehealth won't create new patients or problems just exposing what's going on (...) we are not creating new diseases. We are just trying to pick up diseases at an early stage*"
(Clinician, referral hospital)

*"if you are asking if these patients can be managed, I guess it would be one of the limitations of the telehealth, you can't give radiotherapy from a distance, a patient can't be in Rwanda and get radiotherapy from [another country]. I want us to take a moment to look at it, because telehealth won't create new patients or problems just exposing what's going on (...) we are not creating new diseases. We are just trying to pick up diseases at an early stage"*
(Clinician, referral hospital)

### 2.4.3 Health system strengthening

Some of the participants acknowledged that the health system in Rwanda needed strengthening in many ways to make it effective and responsive to the needs of the populations. Some of the issues mentioned included limited funding, scarcity of specialist clinicians in cancer treatment, lack of specialized treatment facilities or options such as radiotherapy, all of which may hamper the screening program to reach the intended goal even if it is well implemented. For instance, if telehealth leads to improved screening yet services and capacity to treat those diagnosed are inadequate, then the telehealth solution will not have the full impact of having cancer cases at early stages and get them treated to have better treatment outcomes. On the other hand, the program would prevent many cancer cases through treatment of cervical pre-cancerous lesions.

Participants stressed that it was important to gear efforts towards overall health system improvement beyond just the technological solutions. That the eventual implementation of telehealth, provides an opportunity to evaluate the entire health system to see how such implementation would lead to health system strengthening rather than just a technological stand-alone solution.

### 2.4.4 Data protection

The concern about data protection was a key theme in the proceedings. The participants offered various suggestions on how to address data security. Some of the ideas put forward include having a dedicated secure system for use in telehealth and handling/exchange of clinical information. A system that is not used for other informal communication such as social media. They also proposed the use of codes instead of personally identifying information on service user records to ensure anonymity. Another suggestion was strict adherence to medical ethics which the participants felt provided an exhaustive guidance on handling confidential patient information.

*"(...) having a platform in place, that is very specific medical information from one facility to another (...) this will be safe and secure, otherwise the medical doctors and nurses are receiving information from patients and their worry is (...) [is it] going to be confidential (...) it also forms part of the ethic, so the medical doctors and the nurses, so here wouldn't have much worries, if we are going to have a specific platform that is going to be used to share patient information, between one facility to the other, between one doctor to another, and ensuring that element of confidentiality would be enough to guarantee the patient that his or her information is not going to be exposed because it is not on WhatsApp, it is not on Facebook"* (General practitioner, provincial hospital)

*"Most of us do not know other languages like English. So, for creating an adequate and effective awareness (...), you can print booklets (...) in Kinyarwanda for everybody to get the message clearly."*

*Patient Representative*

### 2.4.5 Ensuring user centredness

Even though it should be an obvious and standard aspect of system development, participants emphasized the need to ensure usability of the telehealth systems. That the system ought to be 'user friendly' and should be relevant to the Rwandan context. It should take into account factors such as the existing infrastructure and user experience and skills. The system should also have content that is relevant and acceptable by the users (healthcare workers and service users) and should be compliant with their cultural values and norms. One application of telehealth that was suggested was having audio and video media for health education and awareness creation. Nevertheless, the content of such training and awareness should meet user needs such as a language that the intended recipients can understand.

*"Most of us do not know other languages like English. So, for creating an adequate and effective awareness in villages, you can print booklets or didactic materials in Kinyarwanda for everybody to get the message clearly."* (Patient representative)

The issue of language also becomes important if there is going to be tele-consultation. Service users and healthcare workers can access experts from different locations through telehealth, including internationally. However, creation of such linkages must consider the ultimate language to be used. There is no point setting up expert consultation without a common language for running such consultation sessions.

### 2.4.6 Training and support

Participants also emphasized the need to train potential users of the eventual telehealth solution on how to use it effectively. There is need for example to train those who need computing skills to be able to use the system. Also vital is the need for skilled technical support for when the telehealth system breaks down. During the initial phases, the participants noted that there is need to have after accessible on-demand backup support from the manufacturers of the selected solution. This support should be complemented with training of local personnel to be able run and maintain the system. This is also key for sustainability of the project.

"*Technology needs to be taught still. Our country is enhancing infrastructure, but still, continuous professional training in technology is needed as well. Today, many people cannot connect themselves to the internet. So, I think, there is a need to develop ICT so that whoever is in the position to use technology might not lose the opportunity.*" (General practitioner, provincial hospital)

### 2.4.7 Evidence based practice

Participants pointed out that telehealth being a new domain in healthcare provision, there were many unanswered questions on telehealth as a new approach for addressing the cancer epidemic in Rwanda. There was lack of prior experience and scientific evidence on many issues: acceptability, effectiveness, cost and negative impact. They suggested that the project should strive to collect and synthesize evidence from different settings on different aspects of telehealth to provide evidence for scaling up, including advocacy for funding for sustainability and incorporation of telehealth into standard of care.

# 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 are 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 ongoing Rwanda 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 and roles, gender and geographical locations across Rwanda. More importantly, the study was informed by women who have been diagnosed with cervical cancer and are receiving care. They provided invaluable insights into acceptability of telehealth in cervical cancer screening in Rwanda. Reflecting on their own personal experiences, the women described how they believed telehealth would make a difference in cervical cancer care in Rwanda. For the women, hoping that telehealth would deliver the promise, any intervention that could enhance early diagnosis was highly welcome.

The study adopted a health systems approach to gather views of different stakeholders in telehealth, ranging from educators, clinicians, national policy makers, health care financing, advocates and cervical cancer patients. This triangulation of data sources ensured that the findings covered a broad range of perspectives needed to inform the implementation of telehealth in cervical cancer screening in Rwanda. It also provided an opportunity for the stakeholders to network and explore how they can work together to improve healthcare in Rwanda. 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 will be important in the proposed implementation phase to ensure that the eventual telehealth initiative is owned and led by local stakeholders.

The findings were validated by some of the participants, to make sure that the interpretations do not misrepresent the participant's view or the role of the government and the people of Rwanda.

## 3.2 Limitations

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

### 3.2.1 Method limitations

The use focus group discussions, although advantageous in encouraging dialogue by making participants feel safe in the company of others, might have led to muted responses by some participants. Participants were likely to share only what they felt comfortable sharing in a group, compared to if they were to be interviewed individually.

Although the researchers asked the participants for consent to take part in the study, the findings in this report are largely the interpretations of the researchers. The consent therefore did not cover the data interpretations. It was intended that all the participants would have an opportunity to validate the findings through a stakeholder feedback session. The researchers were to present the key findings in a simple accessible language and invite the attendees to comment on or critique the findings. However, due to resource constraints, not all participants got the chance to validate the findings.

Focus group sessions were audio recorded to ensure accuracy of data capture. However, for some of the participants, this might have limited their participation because of confidentiality concerns. Furthermore, some of the participants used vernacular or French languages to fully express their views, which might have been lost in translation during transcription to English.

### 3.2.2 Sampling limitations

The sample was not intended to be representative of all potential stakeholders in telehealth or those involved in cervical cancer screening and care in Rwanda. It is impossible to assume normal distribution of experiences and perspectives on telehealth. The aim of sampling was 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.

The sample did not include all telehealth stakeholders. Key among them were the telecom operators and regulators, who make decisions on internet connectivity across the country and will be key in any telehealth solution to be implemented in Rwanda. However, the next phase of the project will involve all in the coalition of telehealth stakeholders, as we call them in this report.

Lastly, recruitment of women living with diagnosed cervical cancer, especially from rural areas, proved a challenge due to time limitations. This will be improved upon in the next phases of the project.

# 4 Conclusions and Recommendations

Findings suggest that participants demonstrated great enthusiasm for telehealth in cervical cancer screening and care in Rwanda. They were also realistic in expressing various reservations and concerns about applicability of telehealth in cervical cancer care pathway. Of all the key concerns and barriers to potential use of telehealth, it seems like the key obstacle is the lack of clear policy to guide the use of telehealth in the proposed service area.

Although Rwanda has a great political will behind the deployment of ICT tools, and a great ICT infrastructure investment compared to other countries in the region, lack of clear policy and guidelines on the daily practicalities of using telehealth in cervical cancer screening would paralyse any system implemented without guidelines in place. However, the findings show that Rwanda was in the process of developing such policies as part of the government's efforts to actualise the SMART Rwanda strategy.

## Recommendations

We would like to endorse the recommendations (see section 2.4) as a way of giving stakeholders' voice precedence over the researchers' interpretations. The authors of this report would like to add the following to the list of recommendations drawn from this study.

- We recommend the formulation of a telehealth implementation framework underpinned by the local needs. We will be drawing a telehealth implementation framework in consultation with local stakeholders to inform the proposed second phase of the project.
- We recommend the involvement of local Rwandan researchers with a special interest in gender science or anthropological background to provide relevant context specific needs of women in Rwanda.
- Multidisciplinary team to be involved in research, monitoring and evaluation of the next phase of the project. For example, health economists to assess cost effectiveness and equity whereas clinicians can evaluate effectiveness of care.
- We also recommend the formation of and involvement of a coalition of telehealth stakeholders involving all relevant stakeholders: various government departments, civic society organizations, non-governmental organisations, private sector, academics, advocates, opinion leaders and community members. This would ensure broad ownership of the initiative and sustainability.

- We also recommend that all the relevant government bodies formulate and streamline policies and guidelines that govern telehealth ecosystem such as data protection, decision liability, information sharing and approved media for information sharing by health care workers. Potential implementers of telehealth solution for cervical cancer screening can work with relevant government departments to develop at least some practice guidelines that would make the work of healthcare workers clearer with regard to data protection and information sharing.

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

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