

FACILITATORS ENABLING SUSTAINABLE CERVICAL CANCER CONTROL  
PROGRAMS IN LOW- AND MIDDLE-INCOME COUNTRIES:  
STRENGTHENING HEALTH SYSTEMS IN ZAMBIA

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## **ABSTRACT**

Kalina Duncan: Facilitators Enabling Sustainable Cervical Cancer Control Programs in Low- And Middle-Income Countries: Strengthening Health Systems in Zambia.  
(Under the direction of Angela M. Stover)

By 2030, an estimated 75% of cancer deaths will occur in low- and middle-income countries (LMICs) (Bray et al., 2018). Health systems in LMICs will need sustainable strengthening to meet the growing burden. In 2020, the World Health Organization (WHO) launched the *2020-2030 Global Strategy Towards the Global Elimination of Cervical Cancer* (WHO, 2019). Screening, treatment, and early detection have proven effective in controlling cervical cancer. While sustainability of these interventions has not been extensively studied, identified barriers and facilitators to sustainability map closely to the six WHO building blocks for health systems strengthening. This linkage suggests that designing sustainable cervical cancer programs may help strengthen the broader health system.

This study strives to identify the facilitators of sustainable cervical cancer screening and treatment programs that strengthen healthcare systems in an LMIC. Using a sequential mixed methods qualitative approach, the study's aims and methods included: 1) describe the barriers and facilitators to sustaining cervical cancer programs in LMICs using a literature review and key informant interviews; 2) conduct a qualitative case study in Zambia, a country with a demonstrated sustainable cervical cancer program, using key informant interviews, document review and triangulation of data sources, to determine how the cervical cancer program strengthens the Zambian health system; and 3) develop a conceptual framework that links the

identified facilitators to sustainable cervical cancer screening programs in LMICs (results from Aims 1-3) to the WHO health systems framework using a synthesis of results from aims 1 and 2.

The results of this study provide insights into the facilitators and barriers of cervical cancer program sustainability, and ways that the cervical cancer program in Zambia strengthens the local health system. The findings build on the available evidence and inform a framework that provides guidance to countries as they are implementing cervical cancer screening and treatment programs. This research further highlights the need for future research, specifically implementation science, to inform future scale-up and sustainability of cervical cancer interventions.

*To the brave women battling cancer everywhere.*

*And to my sister, who fought—and won—her own cancer battle during this research.*

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we have to do, and inspiring to see how far we've come. Thank you for giving your brilliant minds and precious time to controlling cancer and to developing my small role in the fight.

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## **LIST OF ABBREVIATIONS**

<b>CDC</b>	Centers for Disease Control
<b>CIDRZ</b>	Centre for Infectious Disease Research in Zambia
<b>DSF</b>	Dynamic Sustainability Framework
<b>HIV</b>	Human Immunodeficiency Virus
<b>HPV</b>	Human Papilloma Virus
<b>HPV-DNA</b>	Human Papilloma Virus DNA testing (cervical cancer screening method)
<b>KII</b>	Key Informant Interview
<b>LMICs</b>	Low- and/or middle-income countries
<b>IARC</b>	International Agency for Research on Cancer
<b>MOH</b>	Ministry of Health
<b>MCH</b>	Maternal and Child Health
<b>NCI</b>	U.S. National Cancer Institute
<b>NCD</b>	Non-communicable disease
<b>NGO</b>	non-governmental organizations
<b>NHLBI</b>	National Heart Lung and Blood Institute
<b>PAHO</b>	Pan American Health Organization
<b>SDGs</b>	Sustainable Development Goals
<b>UHC</b>	Universal Health Care
<b>UICC</b>	Union for International Cancer Control
<b>UN</b>	United Nations
<b>VIA</b>	Visual Inspection with Acidic Acid
<b>WHO</b>	World Health Organization

## **CHAPTER 1: INTRODUCTION AND BACKGROUND**

### **Global Burden of Cancer**

The cancer burden will double over the next two decades in low- and middle-income countries (LMICs). If no additional action is taken, there will be 10 million additional premature deaths over the next 10 years (“World Cancer Report – IARC,” 2022). Cancer stands to impact national economies as a result of premature mortality and lost years of productivity (Shah, Kayamba, Peek, & Heimbürger, 2019). This estimated average cancer incidence rate of 159.4 per 100,000 people [world age-standardized rate for both sexes (WHO, 2018)] in LMICs may be much greater than current estimates, given poor cancer surveillance systems in these settings (Lorenzoni et al., 2018). Despite this high global cancer burden, studies estimate that only about 5% of global resources spent on cancer are spent on cancer control in LMICs (Farmer et al., 2010), and LMIC governments spend a small fraction of national health budgets addressing cancer control (Horton & Gauvreau, 2015).

A more than doubling of the cancer burden will place a significant strain on financial and human resources on LMIC health systems, which will have to more than double their healthcare provider capacity to provide services to their populations (World Health Organization, 2020). For example, cancers require specific diagnostic strategies, a skilled and specialized workforce, and interventions that are appropriately tailored to the local context (Prager et al., 2018). National health systems in LMICs will need sustainable strengthening if they are to meet this growing burden of cancer. As defined by the WHO, health system strengthening is the process of implementing changes in policy and practice in a LMIC health system, so the country can more

effectively respond to its population's health needs ("WHO | Health Systems Strengthening Glossary," 2007).

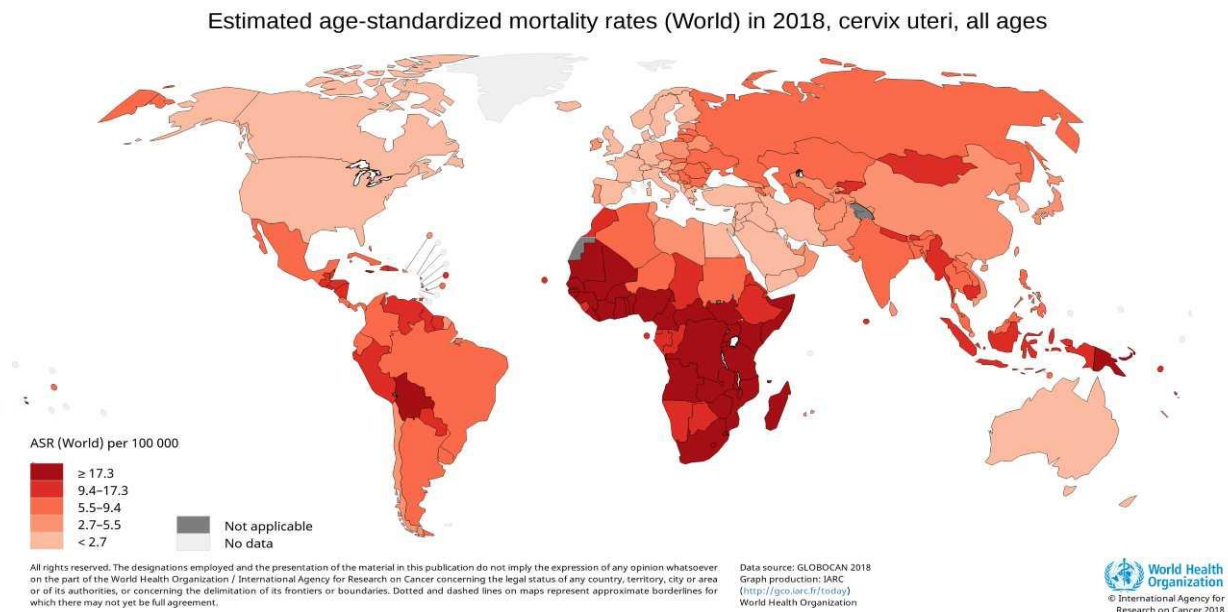
Successful disease-specific programs in LMICs, such as HIV/AIDS, tuberculosis, and malaria, can strengthen national health care systems (Desai, Rudge, Adisasmito, Mounier-Jack, & Coker, 2010; Kikuchi et al., 2018; Poore, Foster, Zondervan, & Blanchet, 2015; Rao, Ramani, Hazarika, & George, 2014; Samb et al., 2010). The case for cervical cancer programs, however, is less evident, which makes this study unique and innovative. For example, in a review of NCD programs, Samb et al. (2010) state that interventions for chronic diseases can lead to overall improvements in the health systems in LMICs, if those investments are planned from the outset of the intervention (Samb et al., 2010). As such, my research aims to explore how interventions responding to cervical cancer could lead to overall health systems improvements and sustainability in LMICs. The World Health Organization's (WHO) recent international attention on cervical cancer control may present an opportunity to leverage new cervical cancer interventions and programs in ways that can strengthen the overall health system in the countries where they are implemented.

### **WHO Cervical Cancer Elimination Call to Action**

Cervical cancer is the leading cause of cancer deaths among women in LMICs, which also have the highest mortality rates from cervical cancer worldwide (WHO, 2018) (**Figure 1**). Without an increase in available human and financial resources and services in LMICs, mortality rates due to cervical cancer will increase by an estimated 50% by 2040, with the greatest burden on the poor (Vivien D Tsu & Levin, 2008). When appropriately detected and treated, cervical cancer is highly curable. In many high-income countries (HICs) like the United States, evidence-based and cost-effective interventions have increased the 5-year relative survival rate from



cervical cancer to near 70% (CDC, 2018). By comparison, the 5-year relative survival rate for women with cervical cancer in Kampala, Uganda is 19.8% and Harare, Zimbabwe (black population) is 39.4% (“IARC Publications – PDFs online – Cancer Epidemiology – Cancer Survival in Africa, Asia, the Caribbean and Central America – SurvCan,” 2019).



**Figure 1:** GLOBOCAN 2018 Age-Standardized Mortality Rates (World): IARC/WHO

In 2019, the WHO released the *2020-2030 Global Strategy Towards the Global Elimination of Cervical Cancer as a Public Health Problem* (WHO, 2019). This global effort is a compliment to the *UN Global Joint Programme on Cervical Cancer Prevention and Control* (WHO, 2016) and is led by groups including the WHO, The World Bank, The Global Fund, GAVI The Vaccine Alliance, the Union for International Cancer Control (UICC) and Unitaid. This program represents a shift in political will and attention among international leaders and global stakeholders toward the control of cervical cancer. It potentially makes available previously inaccessible resources towards the goal of elimination of cervical cancer as a global

public health problem (Director-General, 2018; Parkhurst & Vulimiri, 2013). The WHO cervical cancer elimination targets are aggressive, aiming for 90% HPV vaccination coverage in girls by 15 years of age, 70% of eligible women screened with an HPV-DNA test at ages 35 and 45 (with appropriate follow-up), and 90% of women identified with cervical disease receiving treatment. The global strategy to accelerate cervical cancer elimination was launched virtually due to the COVID-19 pandemic on November 17, 2020 (WHO, 2019).

This global strategy to advance the control of cervical cancer in LMIC countries which have not previously planned for, resourced, nor prioritized cancer in this way, is an opportunity to identify intervention characteristics that have the potential to strengthen the health systems in which they are implemented. These facilitators and best practices may then be applied to the broader challenge of effective control of all cancers (Vivien Davis Tsu & Ginsburg, 2017). Ideally, improvements in cervical cancer should improve health systems and show return on investment in such a way that buoys political will for investments in health systems that will positively impact the implementation of national cancer control strategies for decades to come. However, an unintended consequence of prioritizing cervical cancer control could be a reduction in resources for other competing health priorities (“Screening for Cancer: Considerations for Low- and Middle-Income Countries | DCP3,” 2015).

### **Advances in Health System Readiness to Control Cervical Cancer**

There is evidence supporting the ability to integrate cervical cancer interventions into other parts of the health system effectively (Hewett et al., 2016; Sigfrid et al., 2017; White, Meglioli, Chowdhury, & Nuccio, 2017), which could contribute to sustainability of improvements in prevention and control (White et al., 2017) and may contribute to the well-being of the health system overall (“Screening for Cancer: Considerations for Low- and Middle-

Income Countries | DCP3,” 2015). For example, Sigfrid et al. (2017) found in a systematic review on integration of cervical cancer with HIV services, that integration is feasible and acceptable to patients with HIV. They cite three distinct models for integration into HIV service platforms, including integration at the same clinic with HIV services, co-location of services, and finally, coordination across the care pathway (Sigfrid et al., 2017). Another study by Hewett et al. (2016) shows how improvements in the linkages and integration of HIV and reproductive health services in Zambia increased the likelihood of clients accessing services like cervical cancer screening (Hewett et al., 2016). Given the relative large focus on tackling maternal mortality rates and expanding reproductive health interventions in LMICs, including cervical cancer services in maternal and child health (MCH) programs could lower the burden of cervical cancer and improve effectiveness of MCH programs (Singhrao, Huchko, & Yamey, 2013). Approaches that integrate cervical cancer into both maternal and child health services and HIV services will not only help address cervical cancer in high risk groups, but may strengthen systems and platforms that will address other cancers and diseases in the future (“Screening for Cancer: Considerations for Low- and Middle-Income Countries | DCP3,” 2015). There is reason to believe that investments in cancer control can be cross-cutting and improve health systems where they are implemented (Parham et al., 2015; White, Mulambia, Sinkala, Mwanahamuntu, Parham, Kapambwe, et al., 2012). This research aims to understand how these programs strengthen health systems to inform how future programming is built.

## **WHO Health Systems Building Blocks**

The *WHO Strategy for Strengthening Health Systems to Improve Health Outcomes* (“WHO | WHO health systems strategy,” 2007) presents a health systems framework (**Figure 2**) with six building blocks that are necessary for an equitable and effective health system. WHO

states that the six building blocks—service delivery, health workforce, information, medical products, vaccines, and technologies, financing, and leadership and governance—are all necessary to improve health outcomes in a country or setting. These building blocks are interconnected, and each have priority areas identified to strengthen the specific element of the system being discussed. The building blocks are integral to successful programs and interventions for cancer control; when strong, they promote health equity, access, and improved outcomes (“Reducing social inequalities in cancer: evidence and priorities for research – IARC,” 2019). Many studies document how strong health systems are critical to NCD and cancer control (“Reducing social inequalities in cancer: evidence and priorities for research – IARC,” 2019). There are also a number of interventions designed to strengthen the six building blocks of the health system. A 2012 review by Adam et al. found that most interventions studied focused on strengthening of only one of the six building blocks, with service delivery being the most targeted, followed by governance (Adam et al., 2012). There are far fewer studies, however, looking at ways that disease-specific interventions might sustainably strengthen the health system, which is what my research will aim to demonstrate.

### **Sustainability of Interventions in LMICs**

Sustainability is a multidimensional concept highly connected to the strength of a health system. Shediak-Rizkallah and Bone describe sustainability as “the extent to which an evidence-based intervention can deliver its intended benefits over an extended period of time after external support from a donor agency is terminated” (Brownson, Colditz, & Proctor, 2018). Three operational indicators of sustainability are identified as: 1) maintenance of the program’s intended or initial health benefits, 2) institutionalization of the program in its setting, and 3) capacity building in the intervention’s setting (Brownson et al., 2018; Shediak-Rizkallah &

Bone, 1998). The authors propose a conceptual framework (**Figure 3a**) and guidelines for program sustainability that includes the implementation process, organizational, and community environments.

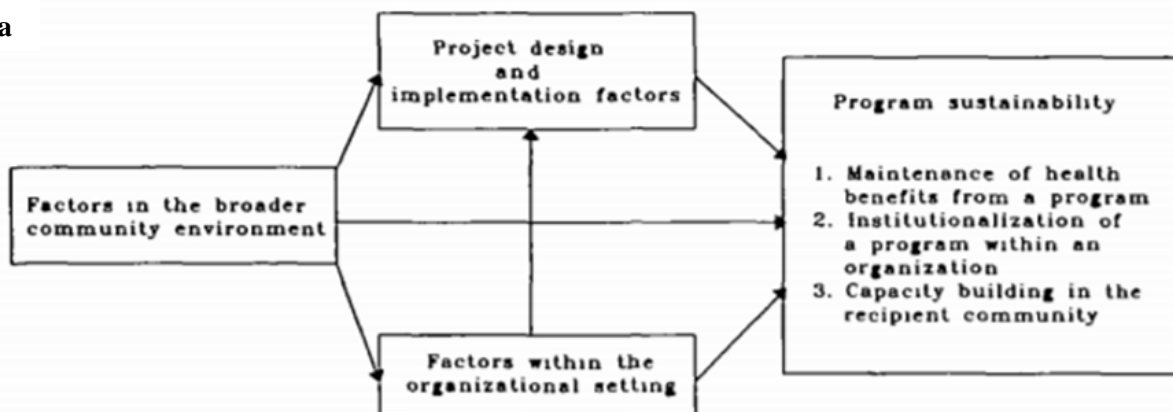
## THE WHO HEALTH SYSTEM FRAMEWORK



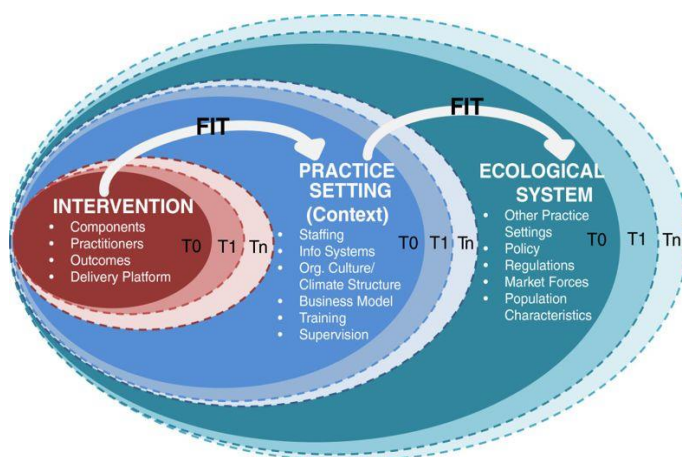
**Figure 2:** WHO Health Systems Framework

More recently, Chambers and colleagues defined sustainability based on their Dynamic Sustainability Framework (DSF) (Chambers, Glasgow, & Stange, 2013). This model looks specifically at sustainability and levels that interventions address or intersect as they attempt to achieve and measure sustainability and treats the concept as one that requires ongoing adaptation, and not as an end goal. It addresses intervention, practice, and ecological settings, indicating specific factors at play within each level and the importance of fit at each level (**Figure 3b**). Iwelunmor et al. used the DSF to further contextualize sustainability in LMIC settings. They consider interventional, organizational, socio-cultural, and community contexts to show how these factors intersect combine to create sustainability (**Figure 3c**).

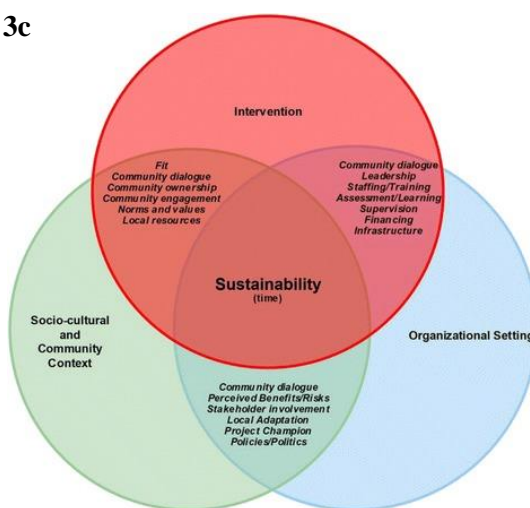
3a



3b



3c



**Figure 3a–c:** Sustainability Frameworks Proposed by Shediach-Rizkallah and Bone (3a), Chambers et al (3b) and Iwelunmor et al. (3c)

In the international development and assistance context, the U.S. Agency for International Development (USAID) defines sustainability as “the ability of a local system to produce desired outcomes over time. Discrete projects contribute to sustainability when they strengthen the system’s ability to produce valued results and its ability to be both resilient and adaptive in the face of changing circumstances. This definition integrates some aspects of the three frameworks described above and has application to programs implemented in low resource settings (“Local Systems: A Framework for Supporting Sustained Development | U.S. Agency for International Development,” 2014).

By comparing the sustainability framework components proposed by Shediak-Rizkallah and Bone, Chambers et al., Iwelunmor et al., and USAID (Chambers et al., 2013; Iwelunmor et al., 2016; “Local Systems: A Framework for Supporting Sustained Development | U.S. Agency for International Development,” 2014; Scheirer & Dearing, 2011; Shediak-Rizkallah & Bone, 1998), with the WHO Framework for Health Systems Strengthening, it is possible to begin to see how the facilitators of sustainability may be related to the intervention’s ability to strengthen the health system in an LMIC. My research uses the lens of sustainability to examine the ability of cervical cancer control programs to strengthen health systems for the broader challenge of effective cancer control in LMICs.

### **My Role in the Dissemination and Utilization of This Research**

In my current role as Director of the WHO Collaborating Center for Cancer Control, and the Branch Chief of Partnerships and Dissemination at the U.S. National Cancer Institute (NCI), , I can influence international strategies and resources related to how cancer control, including cervical cancer control. With this research, I will have an opportunity to influence and lead programs in the areas this research covers, including establishing new and productive collaborations and conducting future research on how countries can most effectively reach the cervical cancer elimination goals. The findings of this study will inform future research and programming that I direct in my role. The framework and set of recommendations will provide countries technical input and guidance to consider sustainability and systems strengthening as they are implementing cervical cancer control programs.

I will use Kotter’s Eight Step Model for Leading Change (“The 8-Step Process for Leading Change – Kotter,” 2007) to disseminate recommendations through international networks that are invested in cancer control planning, and health systems work. The Kotter

model outlines eight steps to adapting change and transforming an organization, starting from creating urgency for change, a coalition, and a vision, and leading to communicating that vision and forming a coalition and empowering people to act to create short term wins and continuous quality improvement. Kotter's model mirrors many levers of sustainability mentioned in models earlier in this proposal, making it a good fit for implementing findings in a lasting way. With this research, I am pairing my academic training in health systems, with the work I have been pursuing as part of my career at the NCI in the implementation of global cancer control initiatives to determine how facilitators of sustainability may also be leveraged to enable interventions to strengthen the health system in which they are implemented.

### **Definitions and Scope**

This study integrates the complex topics of cervical cancer control, sustainability and health system strengthening. Each have many definitions and variations in the literature. For the purposes of this dissertation, I will study secondary and tertiary prevention of cervical cancer. Secondary prevention includes Pap smear (although unlikely in most LMICs), visual inspection with acidic acid (VIA) screen and treat procedures, and/or HPV-DNA testing. Tertiary prevention, or treatment of cervical cancer, involves cryotherapy or loop excision. Primary prevention interventions for cervical cancer, referring to HPV vaccination, while a critical part of cervical cancer control, is outside the scope of this research given where vaccination programs are situated within the health system.

My research will study the concept of sustainability in cervical cancer screening and treatment programs in LMICs, starting with the definition presented in the Dynamic Sustainability Framework. This involves: “continued learning and problem solving, ongoing adaptation of interventions with a primary focus on fit between interventions and multi-level



contexts, and expectations for ongoing improvement as opposed to diminishing outcomes over time” (Chambers et al., 2013). I chose this definition for my research because sustainability in LMICs where health systems are generally weak must be much more than an intervention’s ability to outlast its funding period. Indeed, sustainability is the capacity of an intervention to continue to adapt to its context, both interventional, organizational and ecological to strengthen the system and produce desired outcomes over time (“Local Systems: A Framework for Supporting Sustained Development | U.S. Agency for International Development,” 2014). The DSF framework and definition for sustainability is the best match I have found for LMIC contexts.

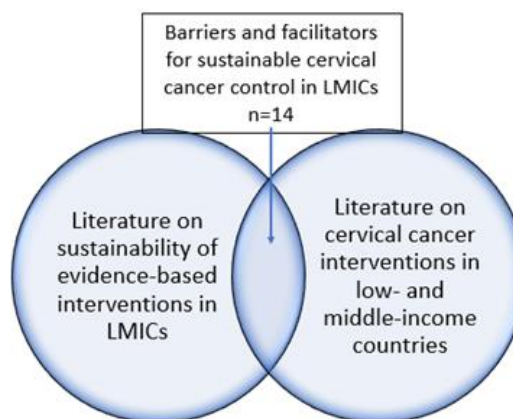
For this research , I will use the WHO definition of health systems strengthening, defined as “the process of identifying and implementing the changes in policy and practice in a country’s health system, so that the country can respond better to its health and health system challenge” (“WHO | Health Systems Strengthening Glossary,” 2007). I will also use the six WHO health system building blocks in describing the health system in detail.

## CHAPTER 2: LITERATURE REVIEW

### Rationale and Gaps in Knowledge

Prior research on sustainability of cervical cancer interventions in LMICs (Hailemariam et al., 2019; Iwelunmor et al., 2016) has typically focused on effective strategies for control of cervical cancer in LMICs, from cost effectiveness studies on primary prevention interventions (HPV vaccination), to efficacy studies on screening modalities. However, a lack of evidence about what facilitates sustainability in these contexts makes drawing operational conclusions challenging. No systematic review has focused specifically on barriers and facilitators for sustainable cervical cancer control in LMICs. As such, there was an opportunity to understand examples of effectiveness and efficiencies that can inform long-term success and sustainability, by looking at the intersection of literature related to sustainability of interventions in LMICs, and the literature related to efficacy of cervical cancer control programs (**Figure 4**). Thus, I conducted this literature review to answer the following questions:

- What are the barriers and facilitators for sustainable cervical cancer control, primarily secondary and tertiary prevention, in LMICs?
- What are the roles of government, international partners/donors, and other key players in the sustainability of these programs?



**Figure 4:** Literature Review Strategy

## Search Strategy and Eligibility Criteria

I conducted this review using the following databases: (1) MEDLINE/PubMed; (2) Scopus; and (3) Global Health. Additional studies were identified through bibliographies of existing reviews and references of articles identified with the search strategy outlined below (snowballing). The selection of databases reflects the diverse nature of research in this field, ranging from biomedical, to social-behavioral interventions, to health systems-level and policy inquiries. The search terms used in this review and described in **Table 1**, below, and the searches took place from February 1–March 1, 2019.

**Table 1: Literature Review Search Criteria**

Searches were limited to articles in English from Jan 1, 2011–March 1, 2019	
Key concepts	Key words, search terms
Cervical Cancer	Uterine cervical neoplasm [MESH] OR cervical cancer OR cervix cancer
AND	
Low- or Middle-Income Countries	Low- or middle-income countries search criteria developed by UNC’s Health Sciences Library
AND	
Sustainability	capacity building OR health systems strengthen* OR country ownership OR country owned OR scalability OR scalable OR sustainability OR “Ministry of Health” OR Government OR governance OR policy
AND	
Implementation & Integration	Program Implement* OR Implementation Strategy OR prevention OR screening OR program OR implement* OR scale-up OR Pap smear OR VIA OR VILI OR see-and-treat OR HPV DNA test OR self-sampling OR colposcopy OR cryotherapy OR LEEP OR vertical program OR horizontal program OR diagonal program OR integrated OR integrating OR leverage OR leveraging OR leveraged

The literature search was originally done for all years, but after a review of eligibility of articles from 1970–2011, I determined that articles pre-2011 had a high exclusion rate, and a high probability of being summarized in more recent literature reviews. Additionally, the 2011 UN High-level Resolution on Non-Communicable Diseases (NCDs) called for a whole-of-

government and society approach to strengthen policies and health systems for the prevention, diagnosis, and treatment of NCDs (WHO, 2011). The sustainability requirements and measures required to meet the goals outlined in this resolution have relevance to this review. This supported the decision to include literature from 2011 – March 2019. To be included in this review, articles were reviewed with the inclusion and exclusion criteria in **Tables 2** and **3**.

**Table 2: Inclusion Criteria**

Inclusion Criteria	Rationale
Presence in a peer-reviewed journal or high-quality grey literature (includes methods, etc.)	To ensure study quality is relatively high and to minimize bias.
Addressed cervical cancer control in a low- or middle-income country	To understand how interventions are being sustained in LMICs within limited health systems. High income country contexts may not be applicable to the research question.
Addressed secondary or tertiary of cervical cancer	Secondary (screening) and tertiary (treatment) prevention have strong bearing and relevance on health systems and cannot be conducted in a vertical fashion. For this reason, these types of interventions were considered.
Published in English language	To make it possible to review articles in the time allotted for this review, with no translation services available.
Studies or case studies that report/evaluate at least one implementation outcome.	Evaluation is defined as the ‘examination of the worth, merit, or significance of a program’ (Coryn, Noakes, Westine, & Schroter, 2011). This ensures the studies examine at least one implementation outcome.
Studies that address sustainability of an intervention using the key concepts described in Table 1	Sustainability refers to the ability of a local system to produce desired outcomes over time. Discrete projects contribute to sustainability when they strengthen the system’s ability to produce valued results and its ability to be both resilient and adaptive in the face of changing circumstances. Inclusion of an ex-post evaluation is one example of how an intervention would include sustainability.
Literature published after January 1, 2011 – Present	To understand what has been researched in this space following the UN high level resolution on NCDs.

## Analysis Strategy

To better understand the barriers and facilitators to sustainability, findings were coded by the prominent fields in the following areas indicated in **Table 4**. To further understand how these factors interact with health systems, articles were coded by the health systems level of the most prominent outcomes the study examined, using the following levels: intervention, practice, and ecological. These levels mirror the levels articulated in the Dynamic Sustainability Framework (intervention, practice setting, ecological system) (Chambers et al., 2013), and are emblematic of the levels articulated all three sustainability frameworks in chapter one, including those from

Shediac-Rizkallah and Bone, and Iwelunmor et al. (Iwelunmor et al., 2016; Shediac-Rizkallah & Bone, 1998).

**Table 3: Exclusion Criteria**

Exclusion Criteria	Rationale
Focus of the study population was in a high-income country	To eliminate studies not applicable to LMIC health systems/contexts.
Focus of the study was only on HPV vaccination or primary prevention	This purposefully excludes studies looking at HPV vaccination (primary prevention), as the issues involved in this are systematically different than in screening and treatment.
Descriptive epidemiological studies	These types of studies are commonplace in LMIC oncology work, but lack information or measures on sustainability or factors facilitating or preventing sustainability.
Studies that report on a pilot program or individual intervention's effectiveness in a population, with no interrogation of how that intervention may be sustained in the country	This excludes studies that report on efficacy of interventions at a certain place and time but lack long-term (or near term) sustainability measures, or even any mention of sustainability.
Commentaries unless they included very clear methods and novel research questions	This excludes commentary or case-study type articles that do not contain original research questions.
Literature reviews unless they included novel research questions	This excludes literature reviews that do not contain original research questions.
Grey literature that includes conference proceedings, new articles, books, and protocols with no original research question.	This excludes reports and bulletins type articles that do not contain original research questions.
Literature published before January 1, 2011	To understand what has been researched in this space following the UN high level resolution on NCDs.

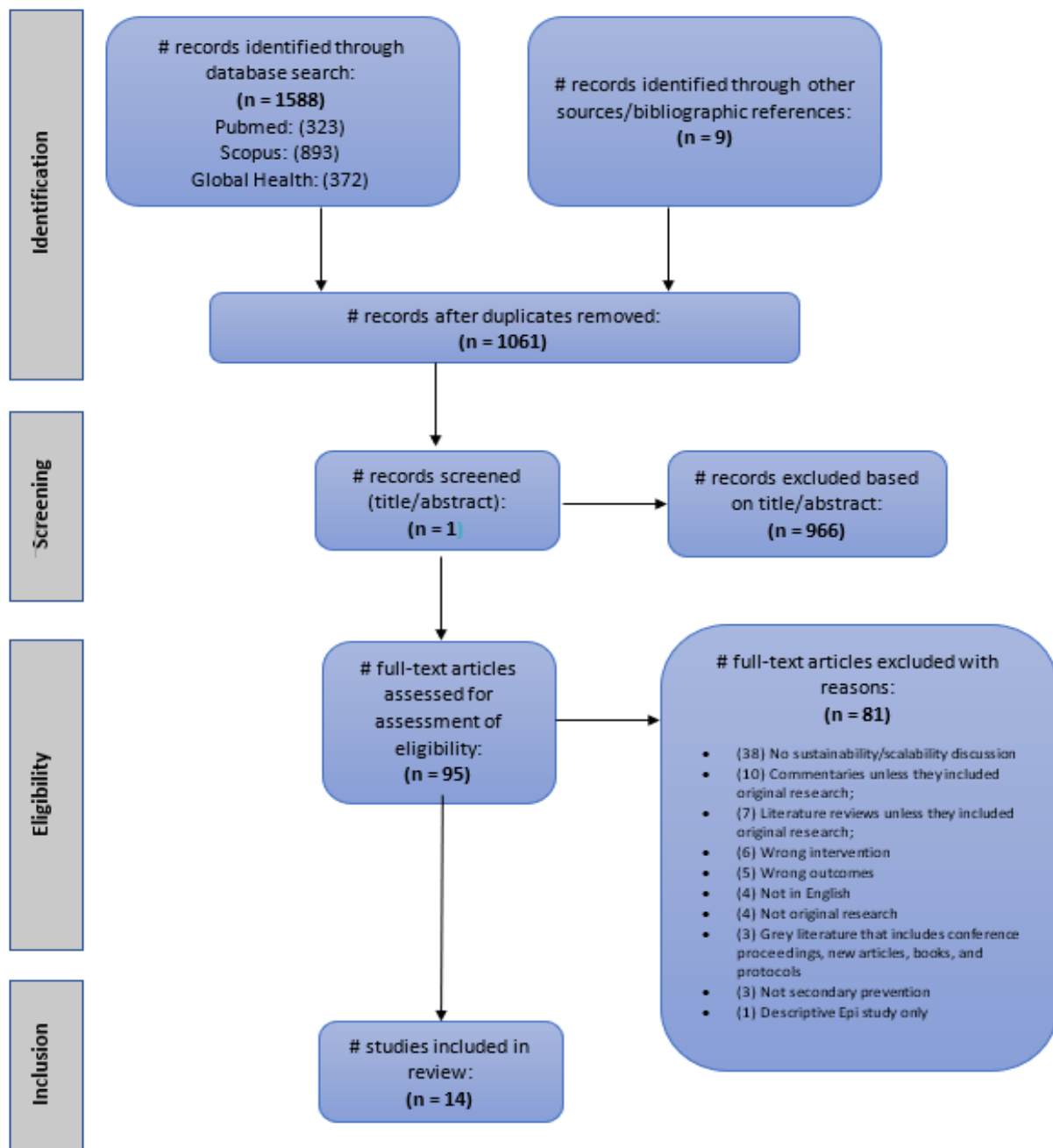
The quality of included studies was performed using the NHLBI Quality Assessment Tools for Systematic Reviews (“Study Quality Assessment Tools | National Heart, Lung, and Blood Institute (NHLBI),” 2013). These tools assess internal validity and risk of bias based on study type (observational and cross-sectional, pre-post, case-control, etc.). Each study was rated “good,” “fair,” or “poor” based on overall ranking.

**Table 4: Extraction Fields**

• Article ID (assigned by reviewer)	• Study Design	• Sample Size	• Role of LMIC Government
• Year of Publication	• Country of Focus	• Data Sources	• Role of International Partners
• Name of Journal	• Regional Focus	• Facilitators of Sustainability	• Other Key Players
• Article Title	• Variables/Factors Studied	• Barriers to Sustainability	• Limitations
• Authors	• Population	• Roles of Stakeholders	• Quality Rating/Bias

## Results

Results of the literature review are captured in **Figure 5**, which is reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Liberati et al., 2009).



**Figure 5:** Search Strategy Reported According to PRISMA Guidelines

### ***Characteristics of Included Articles***

Overall, the literature search highlighted the paucity of literature specifically measuring the sustainability of cervical cancer programs. While there are numerous cervical cancer interventions documented in LMICs since 2011, most of the excluded papers examined the feasibility or efficacy of applying cervical cancer interventions in LMICs with no discussion, measurement or examination of sustainability. Additionally, a notable body of literature discusses sustainability in cervical cancer control outside of the context of original research, and more as a commentary or narrative case study, leading to exclusion from the final set of articles. The overall quality of the included studies is considered somewhat poor an unfortunate issue not uncommon in scientific research done in LMICs (Franzen et al., 2017).

### ***Study Design of Included Papers***

Five studies (36%) were retrospective. Of these, two studies looked specifically at quality control or quality improvement measures that impacted sustainability for cervical cancer screening programs (both single visit screen-and-treat programs) (Martin et al., 2014; Ouedraogo et al., 2018). The remaining three articles examined sustainability related to a fee-for-service screening and treatment model (DeGregorio et al., 2017), the factors inhibiting and facilitating cervical cancer screening (Msyamboza, Mwagomba, Valle, Chiumia, & Phiri, 2017), and using the traditional medicine infrastructure, such as community chiefs and healers, to improve cervical cancer control (Kapambwe et al., 2019). Cross-sectional studies made up the next grouping of papers (36%). These five papers took a diverse look at sustainability by examining the perceptions of non-Government Organization (NGO) program implementers (Chary & Rohloff, 2014), stakeholder perceptions of structural influences of scale-up (McCree et al., 2015), and willingness to pay for the cervical cancer services offered in the lack of donor support (Dim, Onyedum, Dim, & Chukwuka, 2015). Two studies were cohort designs (14%), examining

the sustainability and efficacy of a training curriculum (Bernstein M., Hari A.Y., Farfel A., Patel P., & Raman K., 2018) and the adaptation of a high-income country model for cervical cancer control to a low-resource setting (Abdul Rashid, Dahlui, Mohamed, & Gertig, 2013). The remaining studies were observational (7%), and descriptive (7%), using simulation modeling to articulate advantages of coverage expansion for screening vs. an increase in frequency of screening (Campos et al., 2017). There were no studies with a randomized or controlled design.

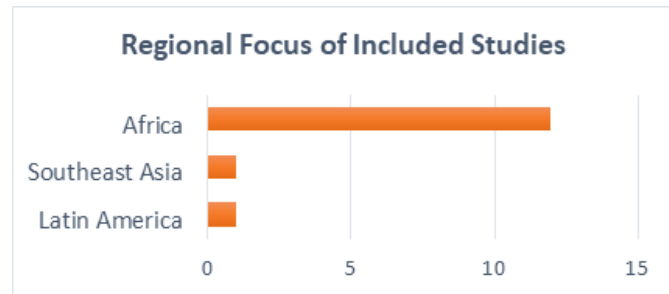
### ***Populations Studied and Data Sources***

The majority (79%) of the intervention studies included women of eligible screening age (country dependent) (Bernstein M. et al., 2018; Campos et al., 2017; DeGregorio et al., 2017; Dim et al., 2015; Kapambwe et al., 2019; Khozaim et al., 2014; Martin et al., 2014; Msyamboza, Phiri, Sichali, Kwenda, & Kachale, 2016; Ouedraogo et al., 2018; Rashid, Dahlui, Mohamed, & Gertig, 2013; Teguate et al., 2012). Sample sizes for these studies ranged from 400 women for a specific intervention, to more than 145,000 in studies examining multiple years of a national program. The remaining studies (21%) examined the characteristics and perceptions of stakeholders and implementers of cervical cancer control plans and programs. The sample sizes for these stakeholder interventions ranged from 35 individuals from a health system, to 9 provincial hospitals (Chary & Rohloff, 2014; Chibwesha et al., 2017; McCree et al., 2015). Data sources were either individuals or health facility representatives via survey, interview, or focus group (42.9%) (Bernstein et al., 2018; Chary & Rohloff, 2014; Dim et al., 2015; Khozaim et al., 2014; McCree et al., 2015; Rashid et al., 2013), or facility-or-program-based screening records from clinics, hospitals, or regional/national programs (57%) (Campos et al., 2017; Chibwesha et al., 2017; DeGregorio et al., 2017; Kapambwe et al., 2019; Martin et al., 2014; Msyamboza et al., 2016; Ouedraogo et al., 2018; Teguate et al., 2012). The heterogeneity of populations studied and data sources limits analysis and generalizability of data.



### ***Regions and Countries Studied***

Almost all included studies took place in sub-Saharan Africa (85%), including: Tanzania (n=2), Burkina Faso, Cameroon, Guyana, Kenya, Malawi, Mali, Nigeria, Uganda, and Zambia (all n=1). Other regions included Southeast Asia (7%), with a country focus on Malaysia, and Latin America (7%), with a country focus on Guatemala. Many articles



**Figure 6:** Regional Focus of Included Studies

included co-authors or main authors that are based in the U.S. or in other high-income countries.

### ***Facilitators of Sustainability of Cervical Cancer Programs***

Among the fourteen included articles, seven common facilitators of sustainability were identified (**Figure 7**): government

commitment (n=5); financing (n=4); human resources and training (n=3); involvement of research institutions or academia (n=2); adaptation to context (n=2); presence of monitoring and evaluation (n=2); and integration into other health programs (n=2). To further

Facilitators of Sustainability
1. Government commitment and/or political will
2. Financing
3. Human resources
4. Research institutions
5. Adaptation to context
6. Monitoring and evaluation
7. Integration into health programs

**Figure 7:** Identified Facilitators of Sustainability

understand how these factors interact with

health systems, articles were coded by the health system level of the intervention outcomes:

intervention, practice, and ecological (**Figure 8**) (Chambers et al., 2013; Iwelunmor et al., 2016; Shediak-Rizkallah & Bone, 1998).

	Government commitment/ Political will	Financing	Human Resources	Research Institutions	Adaptation to context	Monitoring and Eval	Integration into health programs
System Level							
Ecological	X	XXX			X		
Practice	XX	X	X			X	XX
Intervention	XX		XX	XX	X	X	

**Figure 8:** Identified Facilitators of Sustainability by Health System Level

### *Intervention Level Studies*

Six articles were coded at the intervention-level. Among these, two articles mentioned the importance of training and capacity building as a facilitator for sustainability. Bernstein et al. discussed a screen and treat program implemented in Tanzania, using visual inspection with acidic acid (VIA) and cryotherapy, which emphasized that education of healthcare workers by medical students as essential to sustainability (Bernstein et al., 2018). Chary et al., while discussing another VIA-based intervention, discussed budgeting to train replacement providers, standardizing training curricula, and offering continued supervision as key strategies to improve sustainability of VIA programs (Chary & Rohloff, 2014). Two intervention-level studies mentioned the importance of government commitment to the sustainability of interventions (Kapambwe et al., 2019; Tegete et al., 2012) and two mentioned partnerships with researchers and academic institutions that infuse resources, technical expertise, and structure that may help encourage sustainability (Khozaim et al., 2014; Tegete et al., 2012). The existence and implementation of monitoring and evaluation frameworks to measure and report on progress to secure future commitments from stakeholders (Martin et al., 2014; Ouedraogo et al., 2018), and appropriate adaptation to context were each mentioned by one study at this level (Kapambwe et al., 2019). Kapambwe et al. described an intervention to improve access to cervical cancer screening services in rural Zambia which engaged traditional chiefs as key stakeholders in the

intervention and provided increased access to cervical cancer screening, showing that adaptation to cultural context is likely a critical step to sustainability (Kapambwe et al., 2019).

### *Practice Level Studies*

Three articles examining practice-level outcomes discussed facilitators of sustainability. The integration of cervical cancer screening into existing programs was noted in two of the articles examining interventions primarily focused on practice level outcomes. DeGregorio et al. described a women's health program in Cameroon that integrates cervical cancer screening, clinical breast exam, family planning, and HIV/AIDS treatment, discussing how over years of practice, the integration model made it possible to reach more women and sustain the program because of the variety of services offered (DeGregorio et al., 2017). Martin et al. described integration of a cervical cancer screening program in Guyana, with family planning, post-partum, and HIV care as essential to sustainability (Martin et al., 2014). Two studies highlight the key role of government commitment for sustainability at the practice level, particularly regarding central coordination of programs. In Zambia, commitment, ownership, and direct involvement as implementers by the Ministry of Health resulted in continued growth of their national program since 2005. Due to government support, Chibweshwa et al. demonstrate that cervical cancer screening services achieved higher coverage than breast cancer, due in large part to the role of the Zambia government in the scale up and roll-out of cervical cancer control (Chibweshwa et al., 2017). Self-pay and willingness to pay in a fee-for service model is another facilitator mentioned by DeGregorio et al as well as Dim et al. as a key aspect of sustained, optimal health programs (DeGregorio et al., 2017; Dim et al., 2015). Additionally, task sharing as a key human resource strategy, and the importance of monitoring and evaluation are mentioned once each in studies in this level (Martin et al., 2014).

### *Ecological Level Studies*

Four articles examining ecological-level outcomes discussed facilitators of sustainability. Government commitment and financing in the form of financial commitment, support, or obligation, emerged as the most common theme and often cited as the most important factor in studies that focused on ecological-level outcomes. Campos et al. discussed the opportunity for investments in cervical cancer to improve health systems generally in the context of comparing models and tradeoffs for screening implementation (Campos et al., 2017). Adaptation to local contexts or implementation research and application within interventions was another theme among these articles. Rashid et al. describe that in a study attempting to use the Australian model for cervical cancer control in Malaysia, one must-do step in adapting the model, is to adjust it to the Malaysian context (Rashid et al., 2013).

### ***Barriers to Sustainability of Cervical Cancer Programs***

Seven barriers to sustainability were noted, including: lack of facility capacity, equipment, and supplies (n=5); insufficient human resources (n=5); lack of access, referral, and follow up systems (n=5); myths, stigma, and socio-cultural issues (n=3); poor health information systems (n=3), lack of monitoring and evaluation or quality assurance (n=2); and lack of resources (n=2) (Figure 9).

Barriers to Sustainability
1. Lack of facility capacity, equipment, medicine, and supplies
2. Insufficient human resources
3. Lack referral systems
4. Stigma, and socio-cultural issues
5. Poor health information systems
6. No monitoring and evaluation
7. Lack of financing

**Figure 9:** Identified Barriers to Sustainability

	Lack of Facility Capacity, Equipment & Supplies	Insufficient Human Resources	Lack of Referral and Follow-Up Systems	Myths, Stigma, Sociocultural Issues	Poor health information /data systems	Lack of M&E or quality assurance	Lack of Financing
Ecological	X	X	XX	XX	X	X	X
Practice	XX	XX	X		XX		X
Intervention	XX	XX	XX	X		X	

**Figure 10:** Identified Barriers to Sustainability by Health System Level

### *Intervention Level Studies*

Five intervention-level studies discussed barriers to sustainability. Noted barriers included lack of sufficient human resources and lack of access, referral, and follow up systems. Chary et al. noted that staff turnover, poor training quality, lack of continuous supervision, and a breakdown in cryotherapy referrals were the four major challenges to implementing and sustaining cervical cancer control (Chary & Rohloff, 2014). Bernstein et al. discussed barriers that included cost of equipment upkeep and transportation and supply of carbon dioxide tanks. They also discuss the challenge of follow-up and referral systems in many settings resulting in loss to follow-up and contributing to a lack of sustainable programs (Bernstein et al., 2018).

### *Practice Level Studies*

At the practice-level, four studies discuss barriers to sustainability. The most prevalent factors at this level were: poor health information systems or lack of cancer registries (n=2), cited by Chibwesa et al., and DeGregorio et al. as contributing to the inability to sustain programs by making it hard to plan for needed capacity, report on outcomes, and monitor trends (Chibwesa et al., 2017; DeGregorio et al., 2017; Rashid et al., 2013); lack of facility capacity, equipment and supplies (n=2) (DeGregorio et al., 2017; Msyamboza et al., 2016), and insufficient human resources (n=2) (Chibwesa et al., 2017; Martin et al., 2014).

### *Ecological Level Studies*

Four studies at the ecological level mention barriers to sustainability, and the barriers appear in all identified categories. The most prevalent ecological level barriers to sustainability included: myths, stigma, sociocultural issues, cited by Dim et al., and McCree et al., as a significant barrier to access and also a barrier to building a sustainable program, as these things can result in lack of government commitment, lack of community support, and lack of uptake of services (Dim et al., 2015; Kapambwe et al., 2019; McCree et al., 2015); lack of referral and follow-up systems were equally noted as barriers to sustainability at this level (Campos et al., 2017; Rashid et al., 2013).

### ***Role of Government and Other Stakeholders***

Ten studies articulated the role of national LMIC governments in sustaining cervical cancer programs and policies in their countries. Of these, seven articles identified the appropriate role of government as creating and sustaining political will, leading, and funding programs in cervical cancer control (Khozaim et al., 2014; McCree et al., 2015; Msyamboza et al., 2016; Ouedraogo et al., 2018; Rashid et al., 2013; Tegute et al., 2012). Eight articles specifically mentioned the need for government investment and the fiscal role of federal budgets and Ministries of Health in implementing programs (Chary & Rohloff, 2014; Chibweshwa et al., 2017; Kapambwe et al., 2019; Khozaim et al., 2014; Martin et al., 2014; Msyamboza et al., 2017; Rashid et al., 2013; Tegute et al., 2012). Four studies did not mention LMIC government or Ministries of Health in their research and outcomes (Bernstein et al., 2018; Campos et al., 2017; DeGregorio et al., 2017; Dim et al., 2015). This is particularly relevant for the ecological level which includes policy, market forces, regulation, and national strategy.

The role of international partners in cervical cancer control (e.g., NGOs, bilateral cooperation, multilateral organizations, etc.) was discussed in eight studies. Specifically, Dim et

al., DeGregorio et al., and Teguate et al. mention roles for international funders that revolve around providing short-term or start-up funding for research programs and interventions (DeGregorio et al., 2017; Dim et al., 2015; Teguate et al., 2012). McCree and Martin discuss the role of NGOs and public-private partnerships in working with governments to implement parts of cervical cancer plans (Martin et al., 2014; McCree et al., 2015). Khozaim et al. discuss the role of academic institutions (local to the country) as critical partners in screening programs (Khozaim et al., 2014). Ouedraogo et al. point out that non-governmental stakeholders must be coordinated under an umbrella provided by the federal government to ensure sustainable programs (Ouedraogo et al., 2018). Bilateral cooperation between countries is only mentioned in one study, that describes a pilot study in Malaysia to emulate Australia's successful health systems approach to cervical cancer control (Rashid et al., 2013).

### **Discussion, Gaps, and Implications for This Study**

This literature review sought to answer the questions: what are the barriers and facilitators for sustainable cervical cancer control (including secondary and tertiary prevention) in LMICs; and what are the roles of government, international partners/donors, and other key players in the sustainability of these programs?

Fourteen studies were identified, reporting on a range of barriers and facilitators to the sustainability of cervical cancer interventions, across three regions and twelve LMIC countries. Outcome measures were heterogeneous and so findings related to sustainability were synthesized according to barriers and facilitators, then stratified across intervention level, practice level, and ecological level outcomes. Many of the studies lacked bias safeguards; as such, findings were interpreted with limitations.

### ***Do We Understand Effective Strategies to Achieve Sustainability in Cervical Cancer Control in LMICs?***

Government commitment emerged as the most common theme among the facilitators in the articles reviewed. However, no study specifically studied government commitment and involvement long-term, to understand how, why, how much, and when, government is critical to sustaining cervical cancer programs. One reason for this could be that studies did not systematically plan for sustainability as a part of their intervention, but rather included measures of it when it did or did not occur for the reasons listed in the previous section. This finding is similar to a 2016 systematic review by Iwelunmor et al. looking at sustainability in health programs in sub-Saharan Africa broadly (Iwelunmor et al., 2016). The authors found that sustainability was often an “added-on” element after an intervention has been designed, funded, implemented [and measured] (Iwelunmor et al., 2016). Research is still needed to understand the appropriate role government plays and how their critical involvement can ensure sustainability. This type of knowledge will help researchers, program implementers, and planners ensure that the buy-in they secure up front follows patterns or recommendations that are supported by evidence.

Second and third to government commitment are funding and cost issues. In these areas the literature described these financial issues as facilitators of sustainability in the sense that “harnessing scarce resources to prioritize expansion of screening coverage may provide an opportunity to strengthen primary health care systems” (Campos et al., 2017). Studies by DeGregorio et al. and Dim et al. found that willingness to pay by women seeking cervical cancer treatment services was a factor that enabled sustainability and should be considered when structuring programs (DeGregorio et al., 2017; Dim et al., 2015). The DeGregorio and Dim studies did not examine ability to pay, which may be conflated with willingness to pay. The



integration of complex factors involved in funding of services and cost of services can both facilitate and inhibit sustainability, but the causal mechanisms are underdeveloped and in need of more study.

Factors such as the importance of adaptation to local contexts, and integration of cervical cancer screening programs into larger health systems or health interventions strike me as critically important facilitators, but have not been examined in the context of sustainable cancer control programs in LMICs (Johnson, Armstrong, Joyce, Teitelman, & Buttenheim, 2018; Kemp et al., 2018). In recent systematic reviews, Johnson et al. identified only two articles measuring sustainability as an implementation strategy to improve cervical cancer in sub-Saharan Africa (Johnson et al., 2018). One study measured the number of providers performing VIA after one year (Moon et al., 2012). The second, by Kemp et al. in their systematic review of implementation science for integration of HIV and NCD services in Africa, found zero studies looking at sustainability (Kemp et al., 2018). An additional issue noted in these reviews is that few agreed upon measures of sustainability exist. These findings corroborate the near absence, in the literature reviewed, of clear and compelling descriptions what makes cervical cancer programs sustainable.

Factors contributing to sustainability at the intervention and practice levels were recorded in more articles than ecological-level factors. These themes include human resources and training/task-sharing, monitoring and evaluation frameworks, academic or research institution involvement, and local or sub-local health systems. It is possible to conclude from the literature reviewed here that strengthening human resource capacity at all levels is likely to lead to more sustainable programs and better health systems. This is an area that deserves much more attention.

### ***Do We Understand What Impedes Sustainability?***

There is sufficient evidence found by this review and other reviews in cervical cancer control in LMICs to appropriately identify barriers to sustainability. Revisiting these barriers is important given the complex and integral relationship they have with facilitators (in some cases, they are same factor) and with health systems overall. The ecological level appears to house the most numerous barriers identified in this review, including: lack of facility capacity, including equipment and supplies, and lack of health system access, including insufficient referral and follow up systems; lack of accurate data to inform programs and policies; and to monitor and evaluate of the success of interventions in reaching their set objectives.

Lack of resources, both financial and human, spans the intervention, practice, and ecological levels as broadly and commonly identified barriers. The articles in this review highlight these as major barriers to sustainability, which is not surprising given the amount of literature dedicated to the lack of both financing for health interventions and trained human capacity in LMICs (Donkor, Luckett, Aranda, & Phillips, 2018; Romero et al., 2018). In the context of this review, these themes are important to consider because while research into what limits or challenges program sustainability is plentiful, research on appropriate ways to overcome these barriers in a way that enables sustainability within the context of an intervention or in a health system, is scant. There is an opportunity for case studies that examine how local governments or specific countries have overcome the barriers, and how their implementation strategies relate to the facilitators above.

### ***Do We Understand Ideal Roles of Actors to Promote Sustainability?***

This review presents sufficient evidence to conclude that the most important actor in promoting sustainability in LMICs is the national government, through the Ministry of Health. One study from Zambia discusses the government's willingness to engage traditional healers and

chiefs as part of cervical cancer promotion (Kapambwe et al., 2019). In Mali, authors discuss the government's role in transitioning a program from an externally-funded research program to a routine program sustained by the government (Teguete et al., 2012). More specific descriptions of roles for the federal governments and ministries are needed. Additionally, no case study examples were found that specifically describe a particular government's efforts, although several commentaries exist (Binagwaho et al., 2012; Parham et al., 2015).

Other stakeholders that emerged include community and church leaders; academic institutions (although roles of doctors, nurses, or schools of medicine are not explicitly described); research project funders; and international and local NGOs. These types of stakeholders are instrumental in some parts of sustainability, but coordination and integration within government is the one theme all have in common.

### ***Gaps in the Literature***

While there are themes that emerged as facilitators and barriers to sustainability, overall, there is insufficient evidence to conclude exactly what combination of factors lead to program sustainability and health systems strengthening. The main reason for this is the lack of homogenous outcomes and measures in the studies included. An additional contributing factor is the lack of studies that include sustainability as a primary measurable outcome.

There are high-quality grey literature (e.g., Bulletins of the World Health Organization) and evaluative articles discussing sustainability of cervical cancer programs in contexts such as Rwanda's national cervical cancer strategy (Binagwaho et al., 2013), and Zambia's population level scale-up of cervical cancer services (Parham et al., 2015), that have relevance to my research questions. I excluded grey literature and evaluative articles from this review given the lack of formal research questions and interventions, but they may document national experience of governments and other stakeholders implementing cervical cancer control. In Rwanda, as the

country launched one of the first programs for national cervical cancer prevention and control in Africa, plans for sustainability were considered early. The cost of cervical cancer prevention interventions were planned for in multi-year segments, with both private partners and the Government of Rwanda taking shares of the expense in ways that completed one another and eventually led to government ownership of programs (Binagwaho et al., 2013). This finding augments what was found in most articles on this review, documenting a role for national governments in both creating and sustaining political will and directly investing in cervical cancer programs in a sustainable way (Chary & Rohloff, 2014; Chibwasha et al., 2017; Kapambwe et al., 2019; Khozaim et al., 2014; Martin et al., 2014; McCree et al., 2015; Msyamboza et al., 2016; Ouedraogo et al., 2018; Rashid et al., 2013; Tegute et al., 2012).

In Parham et al., the authors discuss the scale-up of cervical cancer services in Zambia between 2006 and 2013, addressing issues such as integration of cervical cancer screening into existing HIV/AIDS programs, task-shifting/sharing of screening responsibilities between nurses and doctors, and the important role of government ownership and involvement in making screening programs a part of the healthcare delivery system (Parham et al., 2015). This article hits most of the systems-level barriers and facilitators elucidated in my review and provides an important case study of how a country dealt with scale-up of a cervical cancer program at a national level that can inform practice and policy elsewhere.

Another gap in the literature involves a lack of studies measuring sustainability in cervical cancer screening with HPV-DNA diagnostic technology, now the official WHO recommendation for screening (“WHO guideline for screening and treatment of cervical pre-cancer lesions for cervical cancer prevention,” 2021). All studies in this review involve only screening with Visual Inspection with Acidic Acid (VIA). Modalities for screening for cervical

cancer are evolving in LMIC contexts and while some measures of sustainability observed in these fourteen articles may apply broadly, some may need to be reconsidered as countries change their approach to screening from VIA to HPV-DNA testing. This gap in the literature is something this research study will help elaborate upon.

Generally, I found that a very limited number of original research articles address cervical cancer intervention sustainability as a primary aim or outcome. Instead, sustainability is discussed as a secondary outcome or as a portion of the discussion section. While the discipline of implementation science considers measures that directly impact sustainability, or considers sustainability as an outcome of successful programs, most intervention studies in cervical cancer have not. As such, it was impossible to compare direct measures for sustainability across studies. Rather, general themes were identified. This could complicate the reliability of the conclusions drawn from this review. Additionally, I found a lack of universal or standardized measures and frameworks for sustainability across studies. Studies measure sustainability in a variety of ways and for a variety of time periods, and without a common framework to unify results. As such, studies in this area may not be generalizable to other settings and populations.

### **Limitations of This Review**

While I made every effort to capture comprehensively the literature describing sustainability in cervical cancer prevention and control in LMICs, this review has several limitations. Firstly, few studies were determined to be of “good” quality (n=2), using the NHLBI Quality Assessment Tools for Systematic Reviews (“Study Quality Assessment Tools | National Heart, Lung, and Blood Institute (NHLBI),” 2013). The remaining studies scored as “fair” (n=5) or “poor” (n=7). A common limitation was inadequate descriptions of methodology and data sources, which lead to poorer ratings for quality.

Secondly, many studies used facility or clinic-level data for retrospective studies, which could introduce contextual bias. These data sets do not represent randomized data which does not permit a statistical analysis of cause and effect between the studied intervention and the observed outcome. The cross-sectional and observational studies were mainly descriptive, without adequate statistical analysis to determine associations between the intervention and the outcome.

Thirdly, because this review sought to assess factors impacting sustainability in LMIC settings, studies that measure this aspect in high-income settings were excluded and valuable lessons may have been lost. Similarly, this review sought to understand sustainability in cervical cancer control only, thereby excluding evidence from other infectious disease or maternal-and-child interventions that could be useful to incorporate.

Despite the limitations noted above, this is the first review to critically examine sustainability measures reported in cervical cancer interventions in LMICs. It highlights the need for more research on sustainability, undertaken with rigor, and utilizing validated frameworks and measures to report consistent, replicable, and valid conclusions, with sustainability as the main outcome considered. This research should seek examples of facilitators and combinations of facilitators that can be adopted by countries early to ensure their programs are sustained and contribute to overall better health systems. As more attention is paid to cervical cancer control in LMICs, there is an opportunity to integrate sustainability measures that can inform how interventions can improve health systems in a way that benefits not only cervical cancer patients, but all those who utilize the health system. In the next chapter, I will explain how my research aims to understand those measures and add to the evidence in this field.

Since this literature review was conducted (2011-2019), new evidence has been disseminated that contributes to the research question. The field of implementation science as it

relates to cervical cancer control is evolving rapidly and new evidence on how to best implement programs are becoming more common. A review of the literature in the past 18 months revealed one systematic review and several country-or-region-specific studies that address barriers and sustainability to cervical cancer control. A systematized review by Dykens et al (2020) reviewed sustainable approaches to implement cervical cancer screening programs in low-resource settings. This review specifically looked at program sustainment over time. The authors found similarly few papers evaluating sustainability of programs in low-resource settings (n=5), and their conclusions resembled some of the findings of this review, including facilitators of sustainability that include: 1) human resource issues including task-shifting and training; 2) a strong monitoring and evaluation system; 3) and integration of cervical cancer programs into existing health programs such as HIV care and family planning (Dykens et al., 2020).

A systematic review of Tanzania's cervical cancer program identified specific barriers and facilitators for secondary prevention. Similar themes were found for barriers to sustainability including lack of resources, human resources challenges, and stigma. Two systematic reviews looked at barriers and sustainability to cervical cancer screening in both Southeast Asia and Iran (Chua et al., 2021; Ghahramani, Kasraei, Shahabi, & Lankarani, 2020). However, neither study included an assessment or discussion of sustainability and therefore would not have been included in this literature review.

## CHAPTER 3: METHODOLOGY

### Dissertation Aims and Research Questions

The central research question of this study was as follows: What are the facilitators of sustainable secondary and tertiary cervical cancer programs that strengthen healthcare systems in an LMIC?

The aims of this study were to

- 1) Describe the barriers and facilitators to sustaining cervical cancer programs in LMICs;
  - a. Methods: literature review, key informant interviews
  - b. Rationale: As demonstrated in Chapter 2, there is a small body of existing literature that describes general barriers and facilitators to sustainability. However, critical program components that can enable sustainability have not been examined.
- 2) Determine how a demonstrated sustainable cervical cancer program strengthens the health system of a LMIC;
  - a. Methods: Qualitative case study using results of the key informant interviews in Aim 1, document review, triangulation of data sources
  - b. Rationale: Case studies are an ideal methodology to use when process-oriented questions like “why” and “how” are being posed (Creswell & Creswell, 2017). The case study approach allows me to answer my research question in a descriptive and explanatory way that relies on data collected in a natural setting. The case study approach will allow for the main method of gathering data: key



informant interviews, as well as record and document review that may add additional context that will help address the research question.

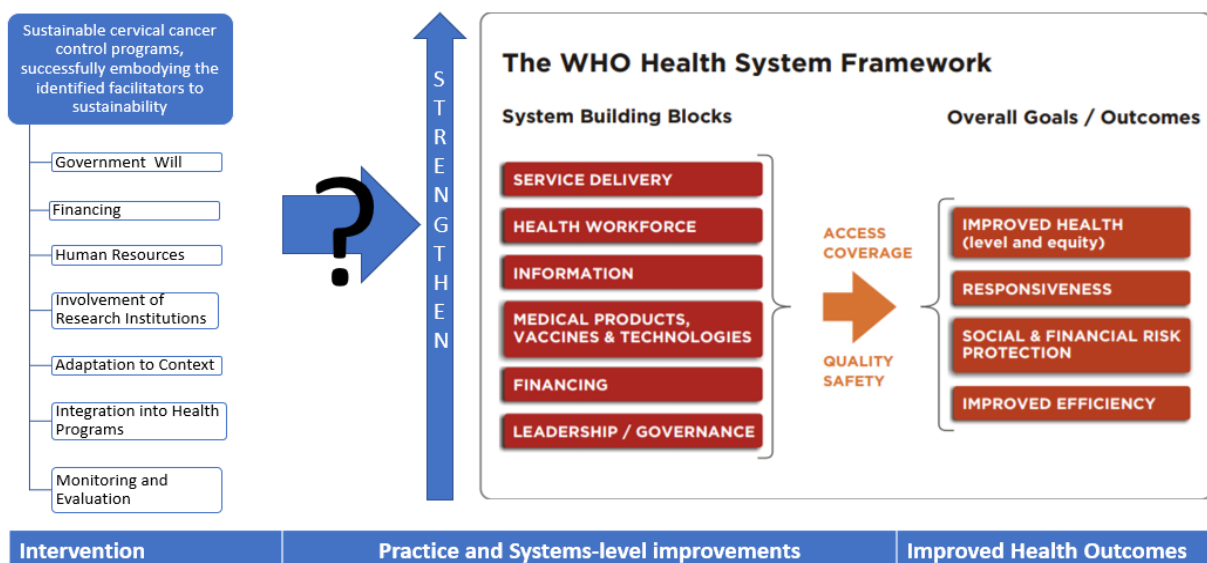
- 3) Develop a conceptual framework that links the identified barriers and facilitators to sustainable cervical cancer screening programs in LMICs (results from Aims 1 and 2) to the six building blocks of the World Health Organization (WHO) health systems framework.
  - a. Method: synthesis of results from aims 1 and 2
  - b. Rationale: One of the key benefits from this research will be creating a model that maps the identified barriers and facilitators of cervical cancer program sustainability to the WHO building blocks to draw out opportunities to create and prioritize parts of programs in the future.

## **Conceptual Model**

The third aim of my research was to develop a new conceptual framework to guide interventions and future research in this area. A new framework will guide cervical cancer interventions in achieving systems-level improvements that will result in better long-term health outcomes for women with cervical cancer in LMICs. However, in order to guide the initial literature review, I used a framework based on an integration of models proposed by Shediak-Rizkallah and Bone (Shediak-Rizkallah & Bone, 1998), Chambers et al. (Chambers et al., 2013), and Iwelunmor et al. (Iwelunmor et al., 2016) (**Figure 3a-c**) that describes sustainability in terms of system levels: implementation, organizational, and community/environment in Shediak-Rizkallah and Bone; intervention, practice, and ecological in Chambers et al.; and intervention, organizational, and socio-cultural and community in Iwelunmor et al. In chapter 2, I used these frameworks to group the prominent themes described as facilitators of sustainability: government

will; financing; human resources and training; involvement of research institutions; adaptation to context; integration into health programs and monitoring and evaluation.

The impact of these facilitators in an intervention to strengthen a health system, according to the WHO health systems framework, was assessed in my research. Ultimately, this model aims to demonstrate that if cervical cancer interventions are able to achieve sustainability and improve LMIC health systems, based on the WHO Health System's Framework (World Health Organization, 2007), they can strengthen health outcomes for other conditions. This theoretical relationship is visualized in **Figure 11**.



**Figure 11:** Initial Conceptual Model

### Country Selection for Case Study: Why Zambia?

In order to determine the country most appropriate to study, I considered the following selection criteria: regional categorization according to the World Bank, classification as a middle-income country according to the World Bank (either upper-middle or lower-middle), population size (over one million considered), a high cervical cancer burden in the country

compared to other cancers, the presence of a national strategy for cancer control, the appropriateness to conduct research in English, the presence of at least one identifiable cervical cancer intervention that has been integrated into a part of the health system, and existing relationships that I could leverage to interview key informants in the country.

### ***Regional Categorization, Income Group Classification, and Population***

I considered countries in sub-Saharan Africa (SSA) and East Asia and the Pacific (EAP) World Bank regions (“World Bank Country and Lending Groups – World Bank Data Help Desk,” 2022). I did this for three reasons: 1) the prevalence of LMICs in these regions; 2) the known high burden of cervical cancer in many countries in these regions; and 3) the representation of these two regions in my literature review. I then narrowed the list using income group classification. I specifically selected middle-income countries, either lower-middle, or upper-middle, according to the World Bank income classifications. The rationale for this is that in middle-income countries, the health system will likely have more capacity than in low-income countries, and it is more likely that an intervention could have a sustainable effect, as demonstrated by my literature review. The review found that the majority of the studies examining sustainability were middle-income countries (as compared to low). Finally, I set a population cut-off of more than one (1) million people to avoid selecting small islands that would not make good cases to compare to a larger country’s health system. These initial selection criteria left me with 17 countries in SSA and 12 in EAP.

### ***Cervical Cancer Burden and Presence of a National Cancer Control Strategy or Plan***

I then considered whether cervical cancer is one of the top five incident cancers overall in the country. In sub-Saharan Africa, this was the case in all countries (WHO, 2018). In EAP, 13 of the remaining countries met this criterion (WHO, 2018). This confirmed that the regions selected were in fact places where cervical cancer is a significant public health threat. I then

looked at whether the countries had either a National Cancer Control Strategy or a National Cervical Cancer Strategy. To determine whether or not a country had a national cancer control plan, I consulted the national plans portal on the International Cancer Control Partnership (ICCP) website (“National Plans | ICCP Portal,” 2021), a group of international organizations engaged in cancer control planning efforts. The ICCP partners are seeking to create synergies to maximize collective resources and efforts to support the development, implementation, and evaluation of national cancer control plans (“Home | ICCP Portal,” 2021). The ICCP portal houses all known national cancer control strategies from around the world (“National Plans | ICCP Portal,” 2021; Romero et al., 2018; Torode et al., 2015). These criteria narrowed the SSA list to seven candidate countries and the EAP list to four countries.

#### ***Appropriateness to Conduct Research in English and Identifiable Cervical Cancer Interventions***

I considered the appropriateness of conducting research in English in the remaining eleven countries. No countries were eliminated at this point. As a near-final step, I considered, based on my literature review and discussion with experts in the field, if countries had at least one intervention documented integrating a cervical cancer intervention into an existing health intervention. This left four countries in SSA: Ghana, Kenya, Nigeria, and Zambia, and two in EAP: Malaysia, and Thailand.

#### ***Existing Relationships With Key Informants in the Country***

Finally, to ensure cultural competency and that a partnership is possible with in-country collaborators for feasibility of recruiting and conducting key informant interviews, as well as feasibility of clearing the in-country IRB, I considered countries where I have existing relationships through my work at the National Cancer Institute. Countries where I have these relationships included Kenya and Zambia in SSA; and Malaysia and Thailand in EAP. In this last

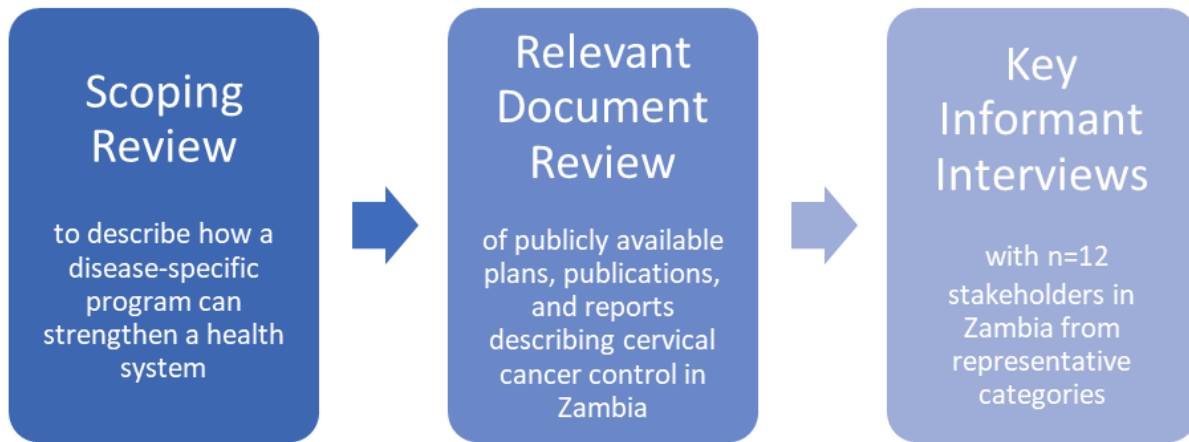
stage, Malaysia was eliminated due to IRB materials needing to be in both English and Bahasa Malay. After consultation with experts in the three remaining countries as well as in the international cervical cancer control community (including the WHO, the Union for International Cancer Control, International Cancer Control Partnership, and others), Zambia was determined to be the best candidate for my case study. In addition to meeting the preliminary criteria, conducting research in Zambia was ideal given the number and age of successful cervical cancer interventions, interest of key stakeholders and the Zambian government in conducting this research, and the ability to partner with stakeholders on the ground. Other eligible countries (Kenya, Thailand and Malaysia) could apply the tools and methods developed for this research for comparative case studies in years to come. This selection process is captured in **Figure 12**.

### **Study Design**

This study used a sequential mixed method design. In the first stage of this study, I completed a second scoping review to understand how health programs can strengthen the health system, according to existing studies. Results, interpretations, and comparisons of this review to my findings are included in Chapter 6, *Discussion*. Additionally, I conducted a document review and analysis of publicly available policies, plans, publications, and reports describing cervical cancer control in Zambia (Aim 2). I compared the information from this review with the conceptual model and additional results from the literature review to inform the refinement of key informant interview questions. In the final phase (Aims 1 and 2), I collected qualitative data through 12 key informant interviews (KIIs; see Appendix C for interview guide) with stakeholders in Zambia who are representative of the cervical cancer and health systems. The sequential process is outlined in **Figure 12**.

Region	Country	Population	Burden	NCCP	English	Intervention	Relationship
Africa (Lower-Middle)	Angola	X	X				
Africa (Lower-Middle)	Cameroon	X	X				
Africa (Lower-Middle)	Comoros						
Africa (Lower-Middle)	Congo, Rep.	X	X				
Africa (Lower-Middle)	Côte d'Ivoire	X	X				
Africa (Lower-Middle)	Ghana	X	X	X	X	X	
Africa (Lower-Middle)	Kenya	X	X	X	X	X	X
Africa (Lower-Middle)	Lesotho	X	X				
Africa (Lower-Middle)	Nigeria	X	X	X	X	X	
Africa (Lower-Middle)	São Tomé and Príncipe						
Africa (Lower-Middle)	Sudan	X	X	X	X		
Africa (Lower-Middle)	Eswatini	X	X	X	X		
Africa (Lower-Middle)	Zambia	X	X	X	X	X	X
Africa (Lower-Middle)	Zimbabwe	X	X	X	X		
Africa (Upper-Middle)	Botswana	X	X				
Africa (Upper-Middle)	Equatorial Guinea	X	X				
Africa (Upper-Middle)	Gabon	X	X				
Africa (Upper-Middle)	Mauritius	X	X				
Africa (Upper-Middle)	Namibia	X	X				
Africa (Upper-Middle)	South Africa	X	X				
East Asia and the Pacific (Lower-Middle)	Cambodia	X	X				
East Asia and the Pacific (Lower-Middle)	Indonesia	X	X				
East Asia and the Pacific (Lower-Middle)	Lao PDR	X					
East Asia and the Pacific (Lower-Middle)	Micronesia, Fed States						
East Asia and the Pacific (Lower-Middle)	Mongolia	X	X				
East Asia and the Pacific (Lower-Middle)	Myanmar	X	X	X	X		
East Asia and the Pacific (Lower-Middle)	Papua New Guinea	X	X	X	X		
East Asia and the Pacific (Lower-Middle)	Philippines	X	X				
East Asia and the Pacific (Lower-Middle)	Solomon Islands						
East Asia and the Pacific (Lower-Middle)	Timor-Leste	X	X				
East Asia and the Pacific (Lower-Middle)	Vietnam	X					
East Asia and the Pacific (Upper-Middle)	American Samoa						
East Asia and the Pacific (Upper-Middle)	China	X					
East Asia and the Pacific (Upper-Middle)	Fiji						
East Asia and the Pacific (Upper-Middle)	Malaysia	X	X	X	X	X	
East Asia and the Pacific (Upper-Middle)	Marshall Islands						
East Asia and the Pacific (Upper-Middle)	Nauru						
East Asia and the Pacific (Upper-Middle)	Samoa						
East Asia and the Pacific (Upper-Middle)	Thailand	X	X	X	X	X	X

**Figure 12:** Case Study Selection Criteria by Country



**Figure 13:** Sequential Phases of Methodology for Data Gathering for Case Study

### **Data Collection**

For Aims 1 and 3, primary data collection consisted of KIIs with twelve subject matter experts with knowledge, skills and expertise on the cervical cancer program in Zambia. Key informants included affiliated Ministry of Health staff including both managers of cervical cancer control programs (n=7), representatives from civil society involved in care delivery (n=4), representatives from technical partners involved in implementing pieces of the cervical cancer strategy (n=5), academia (n=2), and donors/funders (n=4). Participants could represent more than one category. The categories were chosen to be representative of stakeholders who can speak to the systems issues within a cervical cancer intervention, as identified by my literature review. The study participants were a diverse group of subject matter experts, all of whom worked in Zambia at the time of the interviews or had only recently relocated. They hold important technical and leadership positions. The key informants were gender diverse and represented a wide array of perspectives from public, private, partner, academic, and other perspectives.

Participants in the categories above were identified through purposive sampling (Palinkas et al., 2015). The first five interviews were selected by the researcher and knowledgeable committee members, the Zambian government, the WHO, and key stakeholder organizations in

the country. In these initial discussions, interviewees were asked to identify additional stakeholders, based on their knowledge of relevant cervical cancer programming and stakeholders in the country.

Participants were contacted through my University of North Carolina email with a standardized introduction to the purpose of the research, expectations for the interview, and strategies for ensuring confidentiality of responses. The email explained they are not obligated to participate and that declining will have no effect on professional relationships. A second email followed two weeks after the first if no response was received.

When participants agreed to be interviewed, an appointment was scheduled at a time convenient to them. Interviews were conducted over the Zoom videoconferencing network, which allows for video interaction and recording of the conversations. Interviews were recorded following participant consent, obtained verbally from the interviewee at the time of the Zoom interview. The consent form was reviewed orally, and the participants were invited to ask questions about the study. All participants were consented and interviewed in English. During this consent process, the participants were reminded they were free to choose to take part in the research study or not, and that their decision will not affect their professional relationships with organizations in Zambia, with UNC, or with the U.S. NCI.

During the consent process, all participants were informed that information they provide through interviews is confidential (i.e., not shared with anyone outside of the research team) and voluntary (i.e., they are not obligated to answer any question). Interviewees were told that they are free to take breaks, terminate the interview at any time, or decline to answer a question. Interviews lasted approximately 60–90 minutes and were comprised of a series of open-ended questions about their experience and views on cervical cancer program sustainability and how



those programs may or may not strengthen a health system. Findings from the literature review, scoping review, document review informed the development of the KII guide and allowed for refined focus on areas that emerged from the review.

### **Data Management**

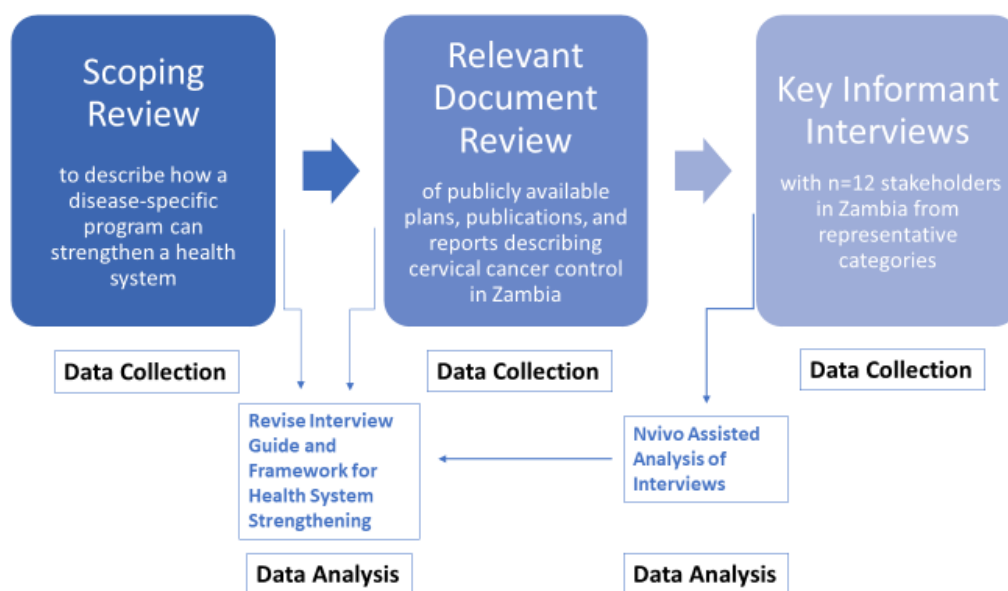
To maintain confidentiality, each participant was given a numeric identifier so their responses could not be linked to their name. Given the small sample size, in instances where the respondents' identities may be identified based on responses, examples, or perspectives, information was conveyed in a way that does not allow for direct attribution to the study participant. Digitally recorded files were stored on a password-protected laptop computer and no names were used to label the files. A file in a separate location linked the number of the interview to the participant. Interviews were transcribed using Rev.com support, and accuracy was verified with my notes and using the Zoom-generated transcript.

Once all analysis was complete and the study was concluded, recordings were destroyed so there was no opportunity to link a response to an individual. The findings and themes are presented in aggregate and no names were used in the final dissertation or in any drafts.

### **Data Analysis**

Directed qualitative content analysis (Assarroudi, Heshmati Nabavi, Armat, Ebadi, & Vaismoradi, 2018; Hsieh & Shannon, 2005) was used to elaborate on and further describe the conceptual model presented earlier in this chapter (**Figure 11**). This framework was used and refined to guide the coding and qualitative analysis of the KIIs. The initial framework includes identified facilitators of sustainability, as well as the WHO's six key building blocks of health systems (World Health Organization, 2007). The framework guided the creation of a codebook for KII analysis (Appendix E).

I used NVivo8 (QSR International, Melbourne, Australia) qualitative data software to read, manage, organize, code, and analyze thematic content of the transcripts. Each completed transcript was uploaded into NVivo. Using NVivo, “nodes,” thematic categories were created based on the results of the systematic literature review on sustainability and the broad definitions in the WHO Health Systems Framework. Within those overarching nodes, thematic sub-categories reflecting greater detail within the themes were developed, reflecting emerging themes in KIIs and informed by the literature. As new themes emerged, the coding key was revised so it was inclusive. A sample of de-identified transcripts were validated by a second, independent investigator, not affiliated with this study. This coder reviewed more than 15% of the interviews and we worked together to achieve interrater reliability. We had a resulting Kappa score of 0.91, which Landis and Koch rank as an excellent strength of agreement (Landis & Koch, 1977). More recent measurement scales also rank this score as very good agreement (Fleiss, Levin, & Paik, 2003). This process is outlined in **Figure 14**.



**Figure 14:** Conceptual Model for Data Analysis

**IRB Considerations**

I obtained IRB approval from the University of North Carolina (UNC) IRB (2020), the University of Zambia IRB (2020 and 2021 renewal), and the National Health Research Authority of Zambia (2020). Any subsequent publication of this research must be approved by the National Health Research Authority of Zambia.

## **CHAPTER 4: RESULTS**

Zambia is a landlocked, lower-middle-income African country located in the southern part of the continent with a population of about 18 million (“World Economic Outlook Databases,” 2021). Estimates for 2020 show that Zambia had at least 13,831 new cancer cases and 8,672 cancer deaths. Cervical cancer is the most common cancer in women, and the second most prevalent cancer in the country, behind prostate cancer (Ferlay J, Ervik M, Lam F, et al., 2020). The age-standardized cervical cancer incidence in 2020 was 65.5 cases per 100,000 women. There were 1800 deaths from cervical cancer in 2019 and mortality rate hovers at about 24.9% (“WHO – Cervical Cancer Profile Zambia 2021 | ICCP Portal,” 2021).

The National Cancer Control Strategic Plan (2016–2021) from the Ministry of Health in Zambia prioritizes cervical cancer, among three other cancers. The objective of the plan includes expanded access to awareness, prevention, early detection, treatment, and care in order to reduce mortality from cervical cancer by 25% by 2025. The Cervical Cancer Prevention Program in Zambia, established in 2006, is the largest public sector program in sub-Saharan Africa that trains and allows nurses to screen for cervical cancer (Pry et al., 2021). Progress on Zambia's cervical cancer prevention program has been very notable, including significantly increasing women's engagement in screening since its inception in 2006. The program has used various strategies for increasing screening coverage in the population. These strategies include educational interventions, physician reminders, or incentive programs, community-based measures, and leveraging community health workers (Pry et al., 2021). From 2015–2020, there were more than 50 publications studying cervical cancer from Zambian authors and studies

(Kayamba, Mutale, Cassell, Heimburger, & Shu, 2021), demonstrating the importance of cervical cancer control to the government, academics, and others. This research adds to the ever-growing body of evidence that can inform successful implementation of a cervical cancer program.

### **Aim 1: Describe the Barriers and Facilitators to Sustaining Cervical Cancer Programs in LMICs**

Chapter 2 outlines the findings of a systematic review that revealed the small body of literature that describes barriers and facilitators to sustainability within cervical cancer secondary prevention programs in LMICs. Findings of that review documented that barriers to sustainability include the following: lack of facility capacity (including equipment and supplies), insufficient human resources, lack of referral systems, stigma and socio-cultural issues, poor health information systems, no monitoring and evaluation, and lack of financing. Facilitators of sustainability were found to include government commitment and/or political will, financing, adequate human resources, the involvement of research institutions, adaptation to context, presence of monitoring and evaluation, and integration of programs into existing health systems. However, the literature focused on sustainability and cervical cancer interventions in LMICs is small and thus, these findings are limited.

Due to the limitations of the existing literature, key informant interviews with twelve subject matter experts with specialized knowledge in cervical cancer screening and treatment in Zambia were conducted to better understand both barriers and facilitators of the cervical cancer program in Zambia. These twelve interviews provided additional context and details to understand what qualities contribute to sustainability, and what stands in its way.

### ***KII Participants***

Participants in KIIs were a rich and diverse group of experts, with a cumulative 162 years of experience working in cervical cancer control in Zambia. The participants were gender diverse and represent perspectives from government and public sectors, private sectors, non-governmental or civil society organizations (includes cancer survivors), technical partners, academia, donor/funding groups, and clinical personnel. Participants could represent more than one category, and characteristics and time in position are outlined in **Figure 15**.

Participant Position	Cumulative Time in Role (years)
Ministry of Health, Zambia	23
Technical Partners	39
Civil Society Organizations	30
Donor/Funding Organizations	25
Clinical Staff	25
Academia	20
<b>Total Cumulative Experience</b>	<b>162 Years</b>

***Figure 15:*** Study Participants

The interviews were semi-structured, following the interview guide (Appendix C). Generally, participants expressed enthusiasm for the study and a need to better understand how to sustain and scale cervical cancer programs. Several key themes emerged from the parts of the KIIs focused on barriers and facilitators of sustainability in Zambia’s cervical cancer program.

### ***Facilitators of Sustainability***

Throughout the KIIs several discussions regarding facilitators of sustainability took place. Major themes were mentioned by the subject-matter experts who participated in the study. Key themes included the following:

- Government involvement and ownership are critical to the enabling sustainability of the cervical cancer program. Specific areas include
  - The existence of national policy documents and political will from high level leadership;
  - Implementation and coordination of the cervical cancer program through government infrastructure and systems make the program sustainable. Of note:
    - The Ministry of Health's role in coordinating the inputs and efforts of donor organizations implementing the National Cancer Control Plan and cervical cancer program;
    - The government paying healthcare workers from the national budget;
    - Decentralized clinical services with focal people in each province responsible for cervical cancer.
  - National Health Insurance expanding to cover cervical cancer screening and treatment.
- The deployment and key role of partnerships in implementing and sustaining the National Cervical Cancer Program. Of note:
  - Civil society organizations driving demand creation and creating awareness;
  - The coordination of a National Technical Working Group on the creation and implementation of strategies;
  - The long-term investment of groups like PEPFAR that continue to implement and fund programs addressing screening and treatment.

Themes that emerged less frequently but were mentioned with regularity in interviews included:

- Use of VIA as a primary screening method.

- Research and the generation of a local evidence base.

Overall, the case study reinforced some of the facilitators from the literature review, but importantly, revealed five facilitators not found in the literature. **Figure 16** below shows how the themes in the literature review and case study compare, and where they overlap.

<b><u>Facilitators</u></b>	<b><u>Lit Review</u></b>	<b><u>Case Study</u></b>
Government commitment	X	X
Financing	X	X
Human resources	X	X
Research institutions	X	X
Adaptation to context	X	
Monitoring & evaluation	X	
Integration	X	
Policy documents		X
Coordination by government		X
National health insurance		X
Civil society		X
Technical working group coordination		X
Long-term implementing partners		X
Use of visual inspection with acidic acid		X
Local research and evidence generation		X

**Figure 16:** Prominent Themes in the Literature Review and Case Study

### *Government Involvement and Ownership*

Study participants overwhelmingly highlighted multiple aspects of the Zambian government's support for the cervical cancer program as the key facilitator of sustainability. While the majority of the program is still supported by partners and donors, including PEPFAR, there are key aspects of the Zambian government support that were cited by most experts as critical aspects that enable and promote sustainability of the program. The healthcare workers—



both clinicians and nurses—who perform cervical cancer screening and treatment are employed and paid by the Zambian government. Additionally, the sites where cervical cancer screening programs are implemented are part of the government health facilities. As these sites are resourced from donor investments, it contributes to strengthening the facilities overall and enables sustainability at provincial screening sites. One participant noted,

The sustainable thing is that we are implementing in government sites. We are implementing with government health workers that are trained. The equipment stays in, in the Ministry of Health facilities.

Another aspect of government support that promotes sustainability cited by many experts was the Ministry of Health's central role in coordination and implementation of the national cervical cancer program. The presence of an appointed structure to implement the program, including a National Stakeholder Group, Technical Working Group Leads, regularly occurring meetings, and a Ministry focal person/director for the national cervical cancer program, were mentioned by many experts as key facilitators of sustainability. More than one expert noted that the salary and support for the focal person for the program was formally donor-funded, but that recently that shifted to being paid by the Ministry of Health, and that that move was critical to ensuring the sustainability of the program. Study participants lauded the work the Ministry of Health and the focal person have done to map and coordinate partners to avoid duplication and spread resources equitably. As one expert put it,

The funds that are coming into this program... the Ministry of Health is able to direct where the funds can be best applied instead of duplicating, the availability of this funding coordination really leverages the resources that are available.

The coordinated decentralization of screening services to the provincial level, and the presence of provincial focal people who are responsible for all aspects of the cervical cancer program, was another facilitator that multiple experts discussed. Cervical cancer is the only

cancer area with appointed provincial focal people, who are responsible for coordinating all aspects of the program's implementation, and report up to the National Program Coordinator/focal person. These focal people are responsible not only for the program, but for leading the process to secure provincial government support for the program, as well as buy-in among clinic staff.

National Health Insurance was not a theme found in the systematic literature review, but was mentioned by numerous experts as a critical facilitator for sustainability of the cervical cancer program. Specifically, interviewees mentioned that the relatively new NHIS (established by the National Health Insurance Act, 2018 ("The National Health Insurance Act, 2018 | National Assembly of Zambia," 2018) has increased demand for screening services, and improved access for the general population. A few participants mentioned that they believed that Zambia is one of the few sub-Saharan African countries who have cancer as a part of the NHIS package. Some screening and treatment services for cervical, breast, prostate, and colon cancer are included. This creates a financial future for the program that is outside the bounds of sole donor support from groups like PEPFAR or NGOs in the country.

Finally, almost all study participants who characterized the cervical cancer program as sustainable mentioned significant support from political and community leaders. Specifically, the former first lady of Zambia was a strong proponent of the cervical cancer program and that support from the highest office in the country played a substantial role in making the program sustainable. This was noted by numerous interviewees, and one described the power of the high-level support like this,

...we have seen that the support that is coming in country with regards to cervical cancer has been increasing, especially in the last decade because of this face that we have put in front of the program and the fact that it's coming from State House. So all policy makers

have said that they have no choice but to ensure that the [cervical cancer] program succeeds because the commands are coming right from house where the head of state sits.

The National Strategic Plan on Prevention and Control of Cervical Cancer: Zambia, 2019–2023 and the National Cancer Control Strategic Plan (2016–2021), which highlights cervical cancer control as one of four priority cancers to address, are policy documents that support prioritization and implementation of the cervical cancer program. Interviewees stated that these plans provide critical policy direction and guidance. In addition to political will and policy documents, the support from the United States PEPFAR program, including its leadership and former U.S. President George W. Bush were mentioned by some participants as helping to elevate awareness and concern for cervical cancer among high-level policy makers.

#### *Strategic Partnership*

Another main facilitator mentioned in multiple interviews can be summarized as the importance of strategic partnerships in implementing the National Cervical Cancer Program. Specifically, interviewees who represented civil society, technical partners, and donor organizations mentioned the Ministry's involvement in coordinating partners consistently as a major facilitator of the program's sustainability.

The role of civil society organizations, especially those like the Centre for Infectious Disease Research in Zambia (CIDRZ), who are implementing screening programs, was mentioned regularly throughout interviews as playing a critical role in driving awareness for cervical cancer control among the general population and healthcare providers. This was linked by two interviewees to driving demand creation, which was noted as a necessary facilitator of sustainability. One interviewee mentioned that the Ministry of Health keeps civil society organizations very close in the implementation of the cervical cancer program, due to their

ability to raise and provide funds, provide education and awareness creation, and influence patients and policy makers alike.

The final theme that emerged from mentions of partnerships was the critical role of PEPFAR and other HIV/AIDS-related organizations. The sustained partnership of groups like the U.S. Government's Centers for Disease Control and Prevention (CDC) and PEPFAR have provided opportunities to build infrastructure and systems, develop technical knowledge, and increase innovations that have all contributed to sustainability. As one interviewee explained:

But you find that most of the partners have these very strong structures. They have people from outside and technical assistance is very strong and contributes to ensuring that the standards and the outcomes on par with what is required. And yes, they do even bring in other elements, you know, innovations that might not be funded under the government.

The Centre for Infectious Disease Research in Zambia (CIDRZ) is an independent, local, non-governmental health organization that has been an active partner of the Government of the Republic of Zambia through the Ministry of Health, and other Ministries since 2001 ("About – Centre for Infectious Disease Research in Zambia," 2021). CIDRZ plays a substantial role in implementation of cervical cancer programs, including training, monitoring and evaluation, and technical assistance. Multiple interviewees mentioned the CIDRZ and the very long-standing relationship with the MoH, as well as their role in procuring consumables as both a barrier and facilitator of sustainability. The design and approach of this particular partnership was noted by multiple participants as improving sustainability prospects of the national program.

#### *Other Notable Facilitators*

Additional themes emerged less frequently, but were notable throughout the interviews. One such theme was the use of VIA as the primary screening method. One interviewee specifically mentioned the affordability of VIA vs. other screening methods like HPV-DNA screening as a facilitator of sustainability. Another mentioned the ease of implementation of VIA

compared to other, more resource-intensive screening methods for cervical cancer as key to sustainability. The materials and commodities required for VIA were noted as sustainable to procure and maintain. One interviewee touched on this issue,

We are now rolling out HPV testing for cervical cancer screening. It is still quite expensive to manage and currently its donor funded. But we are yet to look at the sustainability-related issues in the event that donor funding moved from VIA to HPV testing. Currently only VIA is sustainable.

Another notable facilitator of sustainability in the cervical cancer program was the involvement of researchers and research institutions and the availability of a locally generated evidence base. The MoH has recently prioritized research and publications and are critically examining past data to inform papers, policies, and practice. One interviewee described it well,

I think the evidence based and the strong research base that is established on local and locally-generated evidence, has helped us expand and sustain very well. It's not just something that we take and then try to implement. We actually know it works and how, using those models that work to then expand. So I think that that, that is a good aspect of our program's sustainability.

### ***Barriers to Sustainability***

Throughout the KIIs several discussions regarding barriers to sustainability took place. Overall, major themes mentioned by the subject-matter experts who participated in the study focused on health systems and financing vulnerabilities. Key themes included the following:

- Donor dependence and inconsistent or lack of government financing threatens sustainability. This included two related sub themes:
  - Procurement of essential commodities and supply chain issues;
  - Where overall ownership of the program sits and who feels responsible for its success.

- Capacity to implement the cervical cancer program as it is designed due to lack of facility infrastructure, lack of referral systems, and human resources constraints:
  - Specific concerns relate to the delivery of cervical cancer treatment and the processing of women from screening to treatment in advanced cases. Issues of ethics were also discussed;
  - Human resource capacity in certain positions was a common barrier.

Themes that emerged less frequently but were mentioned with regularity in interviews included:

- Stigma and sociocultural issues threaten the program's sustainability.
- Missed opportunities to communicate about the impact of the program and the lives saved due to its implementation.

Overall, the case study reinforced most of the barriers found in the literature review. This aligns with the initial finding from the review that barriers are better understood than facilitators.

**Figure 17** below shows how the themes in the literature review and case study compare, and where they overlap.

<b><u>Barriers</u></b>	<b><u>Lit Review</u></b>	<b><u>Case Study</u></b>
Lack of facility capacity	X	X
Human resources	X	X
Referral systems	X	X
Stigma & sociocultural issues	X	X
Health information systems	X	X
Monitoring & evaluation	X	
Financing and supply chain	X	X
Missed opportunities to show impact		X

**Figure 17:** Prominent Themes in the Literature Review and Case Study

### *Donor Dependence and Lack of Government Financing*

Most participants who categorized the program as unsustainable in some way, cited the overall dependence on donor partners and a lack of government financing in some areas as a threat to ongoing success. Overall, a lack of prioritization of non-communicable diseases, both in funding and in how the health system is designed, contribute to a lack of resources that threaten the sustainability of the program. Another participant classified government funding as 99% toward treatment of cancers, noting that almost all screening activities for cervical cancer are donor dependent. This participant also noted that government is paying staff and supporting infrastructure, but in terms of monies supporting the program, there are limitations. Within financing concerns, supply chain issues were highlighted by many interviewees, and especially notable among those from NGOs and technical implementing agencies. One participant described this issue as,

One of the reasons I say it is not sustainable is because the commodities and the equipment over 90% are procured by donors and government. The only contribution that government makes is in the infrastructure, facilities and staffing. I think without commodities, it would be very difficult to continue with the program.

One interviewee, specifically speaking about PEPFAR, mentioned that there is very little incentive for the government to fund parts of the program currently funded by PEPFAR because the program continues to fund it year after year. They noted that while the amount the Zambian government has put toward the program has increased over the years, due to the sustained (and even increasing) levels of support from PEPFAR over the years, there is no urgency to increase government support.

The concept of ownership over the cervical cancer program was also discussed by a number of interviewees when describing barriers to sustainability. Due to the role of donor organizations in supplying essential commodities, there was some sentiment that the government

is unaware of the full range of the program needs, and does not see itself as the final arbitrator of its success. Within this concern, participants expressed that this problem is pronounced in provinces where partners are fully implementing the cervical cancer program, but the MoH may not be aware of the requirements to do so.

Despite these challenges, multiple interviewees reported immediate actions that the Government is taking to address sustainability issues, including transitioning ownership of budgets to the government and setting up institutions, like a Zambian National Cancer Institute, that would hold more responsibility for the implementation of cancer control overall. One interviewee described the progress being made on this,

In its current form to the best of my knowledge, it's not sustainable because it's dependent on donor funding. So the idea is actually from the onset, this project should have a foresight of handing over back to the government. Now, whether these programs have actually been ratified into subsequent budgets and national development plans, that is something that we are actually actively working on trying to make sure it happens.

#### *Lack of Facility Capacity, Referral Systems, and Human Resources*

Experts interviewed discussed lack of referral systems, health facility, and human resource capacity as a critical barrier to sustainability, second only to financing issues, although inextricable from those issues. The largest barrier noted by experts was the lack of capacity to refer cases screened to treatment and then to treat those patients. Treatment of advanced-stage cervical cancer was the most widely cited barrier to a sustainable program noted by the experts interviewed. Many noted that treatment services are still centrally located in the capital, Lusaka, and that the turnaround time for accessing treatment, even when in Lusaka, is long. One expert shared an example of how this affects patients:

A friend of mine, her mother was diagnosed with cervical cancer in February. And she was put on the waiting list to receive therapy at the cancer hospital in August. Now my friend happens to come from a family whereby they could afford to go for cervical cancer treatment in Kenya. So that's where she's receiving her treatment. And she's just one of



the very, very few who can afford to do that. Right. So again, the sustainability of the program is being hampered by the lack of equipment and medicine at the cancer hospital.

Participants spoke about the interruptions in referral to treatment patterns, especially at health centers outside of Lusaka, as major barriers to the sustainability of the overall program. This raised questions of ethics for some, expressing concern that the program may be screening and diagnosing women who do not have options to access treatment. One interviewee spoke of the role of NGOs in filling this current gap,

There was a patient with cervical cancer is in its early stage. She could not find a treatment option near her. And then somebody reached out to me from the Ministry of Health and said, SOS. We have one patient who, if she can just get to Lusaka transport money, has a very good chance of surviving. A couple of weeks later they got back to me. And from one, I think the number grew to 12 ladies with the same story, they had no transport money. So we arranged for them to come to Lusaka. But the point is we have screened then what? The next step where I find it very sad. And that's why I say it's not sustainable. To be sustainable it should address the entire pathway—not just telling me about cancer and then leave me high and dry.

A lack of adequate providers, and in some cases, a lack of trained providers, was discussed by participants addressing key barriers to sustainability. In contrast to healthcare workers being supported and paid for by the government, other issues were raised by experts as limitations of human resource capacity that threaten the program. More than one participant mentioned a lack of human resources at the provincial and retention facility level, as the biggest area that needed to be addressed to ensure sustainability. Other specialty areas were mentioned, including surgeons (within Lusaka), and physicians (in provinces). Human resource retention in roles addressing cervical cancer was mentioned by one study participant who described the challenges of retaining health professionals,

I would say brain drain is an issue because you invest so much in people. You train them and then they just leave, and they go with a wealth of knowledge. You've got to make sure that we have succession plans for each person who's important as a control. We don't currently have that.

Another human resource issue mentioned by multiple experts is the bureaucracy that surrounds positions within the government. Specifically, one interview mentioned that when nurses and community health workers are trained via PEPFAR programs, they often are reassigned and move on from the facility or program in which they were trained. Constant training and re-training of staff due to fluidity issues was mentioned as a key barrier.

Additionally, workloads, overburden, and lack of incentives to perform cervical cancer screening in some cases were all mentioned as key barriers to adequate human resources. This is not unique to cancer services, but the general spread-thin nature of doctors, nurses, and community health workers who lead this work were identified as affecting patients, and threatening a sustainable program.

#### *Other Notable Barriers*

Throughout the interviews, other barriers to sustainability outside of the two major themes above were mentioned sparingly, but were somewhat unique from the literature review and important to note. Stigma and sociocultural issues threaten the program's sustainability by affecting ways women are accessing cervical cancer screening. The fact that the cervical cancer program in Zambia has been almost wholly targeted to HIV-positive women has had some effect on how other women access screening services. One interviewee described how, for some time, cervical cancer screening was linked to being HIV positive and it was hard for providers to communicate to women not undergoing treatment for HIV about its importance. Interviewees also mentioned that some providers were tentative to offer screening services to women not undergoing HIV treatment due to stigma associated with the service. One interviewee provided an example of a woman undergoing screening who believed the projected image of her uterus on the computer screen in her clinic room, being used to screen her for cervical cancer, was an actual removal of her womb. This message was communicated to others in her village, and

created avoidance of the clinic and a turn to traditional healers. Similarly, a story of a chief placing a clinic near his home to show support, resulted in few women accessing services due to the stigma associated with being seen at the clinic.

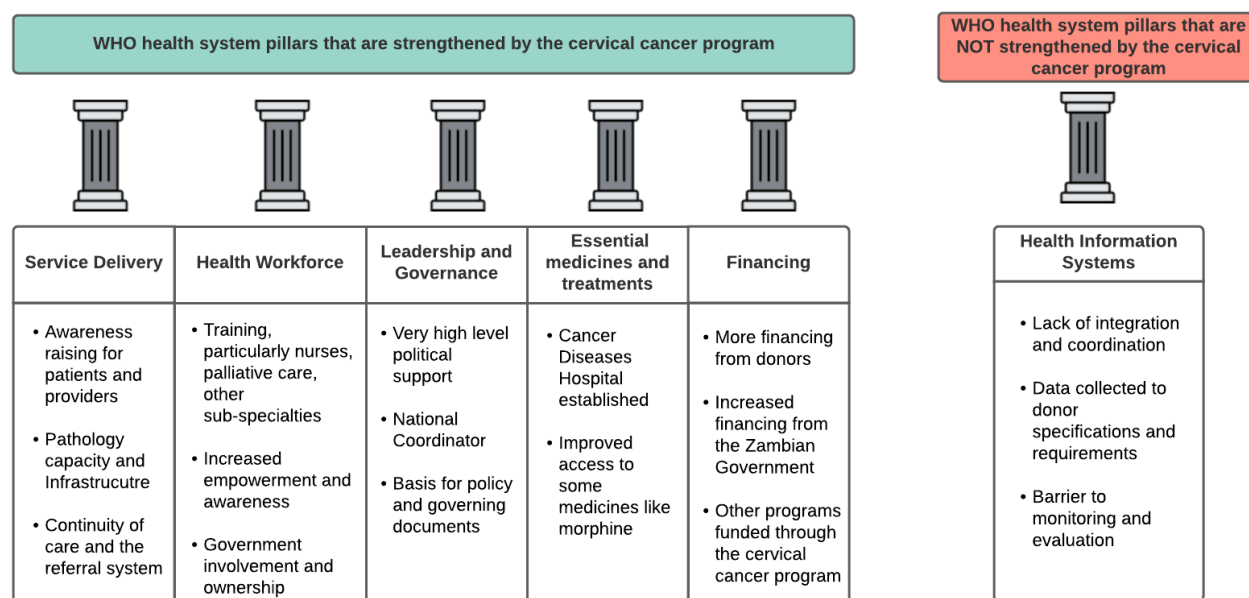
Finally, one threat to sustainability mentioned by one interviewee was the missed opportunities to communicate about the impact of the program and the lives saved due to its implementation. The need to change the narrative around all cancers, but specifically cervical cancer, as something that can be treated and cured, and to tell the story about how the national plans have saved lives, could improve the program's viability and sustainability. Because investments in cervical cancer prevention and control are not seen immediately, quantifying the lives saved, or creating the investment case, from these programs is necessary to ensure continued political will and sustainability.

## **Aim 2: Conduct a Case Study in a Country With a Demonstrated Sustainable Cervical Cancer Program, To Determine How This Program Strengthens Their Health System**

The second aim of this research involved conducting a case study of the selected country, Zambia, to understand if and how the cervical cancer program is strengthening the overall health system. Case studies are an ideal methodology to use when process-oriented questions like why and how are being posed. This approach allowed me to answer my research question in a descriptive and explanatory way that relies on data collected in a natural setting. The main method of gathering data was key informant interviews, supplemented with record and document review to provide additional context to help address the research question. Much of the policy review is summarized at the beginning of this chapter, to provide country context to the research aims. The results below are reported by the WHO Health System Building Blocks Framework, a structure that helped frame the semi-structured KIIs, and also served as an initial framework for analyzing responses. To better understand how the cervical cancer program strengthened the

health system, the results were analyzed and reflected upon using the WHO indicators and measurement strategies (WHO, 2010). Interviewees were asked if they believed the cervical cancer program had contributed to strengthening the health system in the areas below, and how. Responses were recorded as positive or negative sentiment to get a sense of how experts viewed this concept. In some cases, responses were coded as both positive and negative, as respondents shared experiences and opinions that showed both how the cervical cancer program strengthened the health system, and how it did not.

Overall, the experts who participated in this study shared views that the cervical cancer program has strengthened most (5 out of 6) pillars of the health system in Zambia and offered their input on why and how this has occurred. Some experts indicated both positive and negative sentiments, or in some cases none at all. **Figure 18** provides an overall picture of the expert opinions on how the cervical cancer program has strengthened the health system, and the following sections explore how they reported that is happening.



**Figure 18:** A Summary of KII Views on Pillars of the Health System Strengthened by the Cervical Cancer Program, and the Characteristics That Contribute to Strengthening

## *Service Delivery*

Service delivery is a vital part of any well-functioning health system. A health system should include key characteristics such as comprehensiveness, accessibility, coverage, continuity, quality, and coordination (Organization, 2010). Study participants enthusiastically commented that the cervical cancer program has strengthened the health system in many or most of these aspects. The theme of improved accessibility of the health system was common among interviewees. The cervical cancer program's influence was described as bringing care and access to the health system closer to women, with a routine point of entry at the screening centers to the service network at the primary care level. Respondents also described how the program increased awareness among providers, an element that could be attributed to improving quality and comprehensiveness of care. One expert described both of these improvements as,

I feel some women basically have found a portal in which they are able to enter the actual health system. Before the cervical cancer program, that was just like confusing. You know, they had no portal or knowledge whatsoever and neither did the healthcare workers. There was not awareness of cancer or cancer services. There's a point in my own [clinical] internship where I've looked back and said, was that breast cancer? I was all alone in a rural area. And I really didn't know... was it missed? I just, it wasn't a cancer that I was treating. So it's not just the patients who are ignorant.

Another expert described the increase in accessibility to service delivery the cervical cancer program has created:

But when we look at what has happened, we have rolled out a screening prevention program this is as close to the people as possible as a result, the service delivery has been improved, and that has been helpful overall with healthcare, because the impact for our women.

Critical awareness raising that has led to improved accessibility when it comes to language and culture was cited by some participants as an important role the program, and particularly that the Ministry of Health-led aspects of the program, has had in improving service

delivery overall. This notion was a theme in review of Zambia's recent literature and policy documents as well (Kapambwe et al., 2019; Parham et al., 2015).

Almost all experts spoke of how the cervical cancer program has strengthened histopathology capacity and infrastructure in Zambia, thereby closing a critical gap in the service delivery infrastructure. Initially, all samples were sent to Lusaka for processing and diagnosis, resulting in long turnaround times for results. In response, the cervical cancer program has funded pathology training and supported pathologists in two provinces outside Lusaka. According to one expert, the turnaround time is now less than a month for samples taken at provincial health centers. This improvement lifts pathology services for all diseases and is a very tangible way that the health system is improved by the efforts within the cervical cancer program.

Continuity of care, and the referral system, while identified as a barrier to sustainability by many participants, was also mentioned as a way the cervical cancer program has strengthened the health delivery pillar. The coordination that is afforded by having focal points for cervical cancer in the provinces, reporting to one national coordinator at the Ministry of Health, was discussed as improving referral patterns and coordination for diseases other than cervical cancer.

### ***Health Workforce***

The cervical cancer program has strengthened the training of health care workers and overall health workforce capacity, according to a majority of the experts interviewed. Overwhelmingly, participants reported ways in which the cervical cancer program has built human capacity that has benefited other parts of the health system. The cervical cancer program in Zambia is built around a government workforce infrastructure that trains nurses to deliver screening using VIA. The program has used task-sharing to move some responsibilities from doctors to nurses to improve overall capacity and number of healthcare workers who can perform

services. The sentiment of the experts interviewed was that overall, this approach and the elements described below have significantly strengthened the health system where cervical cancer programs are being implemented.

Many experts discussed the ways in which the training and education of health workers have resulted in increased empowerment and awareness among health workers. Generally, experts expressed that the training and structure offered by the cervical cancer program have increased awareness for detecting other cancers. Other experts, notably clinicians, talked about how, anecdotally, they believe early detection and diagnosis of cancers other than cervical cancer have improved. One expert believed the knowledge about how and when to refer cancer cases to the Cancer Diseases Hospital has improved due to the intense focus on cervical cancer.

Through various parts of the cervical cancer program, a number of different types of providers have been trained. More than one expert talked about training programs for surgical gynecologists, funded by outside donor groups like the Peter MacCallum Cancer Foundation and the International Gynecologic Cancer Society. Through the cervical cancer program, a training pipeline has been created for radiation oncologists. Several experts mentioned training of general gynecologists, pathologists, and cancer registrars as capacity increases that can be attributed in many parts to the cervical cancer program. Palliative care is another medical subspecialty that has been improved through the cervical cancer program. The program helped identify a gap in this area, which has created opportunities to train nurses and others to deliver palliative interventions for all cancers and diseases. Finally, one constant theme was the overall increase in the number of trained nurses who can deliver screening and facilitate appropriate referral. The structure of the nurse training program, including a strong training-of-trainers element, has

resulted in a large increase of trained professionals in the country. Referring to human resource capacity building, one expert said,

We begin to see that is cervical cancer, as well as entire program cascade has pushed the government and the Ministry of Health to strategize and see how best we can build capacity so that we treat all the cancers from the time we find them and to the final treatment aspect, in-country. We have been seeing a shift in the training of the human resources to do that.

### ***Access to Essential Medicines and Treatments***

Challenges in treatment access for women with advanced cervical cancer was an emergent theme among interviews with experts. While cervical cancer tracks ahead of other cancers in terms of referrals to treatment, there are still significant gaps in how effectively women are referred, tracked, and treated. Conversations with participants around improvements in access to essential medicines and treatments reflected these challenges but also contained beliefs that the cervical cancer program has improved access to medicines and treatment.

Among participants who believed that the cervical cancer program has improved the health system in this pillar, some advancements were noted. Perhaps most notable is that prior to July 2007, when the Cancer Diseases Hospital (CDH) opened in Zambia, cancer sufferers had only one real option for treatment: travel to Zimbabwe, India, or South Africa. Most of the patients being sent out of country for treatment were cervical cancer patients, which was costing the government a lot of money. As one interviewee described, cervical cancer was the most commonly diagnosed cancer in Zambia and the major driver of mortality, and thus, the cervical cancer prevention program was a primary lever in prompting the government to open CDH, a facility that can now treat most cancers,

I think one of the drivers to set up an oncology center that provided radiotherapy in Zambia was actually cervical cancer because the referrals out of the country for cervical cancer were much higher than any other malignancy. So I think one that's one of the



drivers to access to radiotherapy equipment... it's led to an increase the access to this service that could then be used for many other cancers as well.

The same expert mentioned the “cascade” of medicines that became more available to patients with other types of cancers due to the cervical cancer program. For example, morphine was identified as critical for late-stage cervical cancer patients, and thus procurement took place and was then expanded to all cancer patients with late-stage disease. Notably, many experts reporting that this pillar was strengthened resided within the Ministry of Health.

### ***Financing***

WHO's approach to health financing overall focuses on the core functions of revenue raising (includes government and external aid), pooling of funds (the accumulation of prepaid funds on behalf of some or all of the population), and purchasing of services (the payment or allocation of resources to health service providers) (Mukherjee, 2017). Overall, the experts who participated in this research agreed that the cervical cancer program has resulted in additional financial resources that have strengthened the health system, primarily in the category of raising funds. Generally, inputs in this pillar fell into two categories: financing from donors and funding from the Government of Zambia.

Experts expressed that the excellence of the cervical cancer program and its perception internationally as one of the best, or the best, in sub-Saharan Africa, has resulted in opportunities to bring in more money from organizations outside Zambia. Those most noted by experts were PEPFAR, the World Bank, UNITAID, and the WHO. The Bill and Melinda Gates Foundation (BMGF) and the Clinton Health Access Initiative (CHAI) are two newer donors that one participant described as being attracted to the program based on its reputation, donor trust in the program, and proven success. One expert spoke of PEPFAR's involvement,

I may not be in the position to say exactly how much, but we have seen a lot of resources that have been pumped into the health system primarily to support cervical cancer. I think PEPFAR has been quite generous to the country in the last decade or more.

The cervical cancer program has lifted to some extent, resources available for other cancers from the Government of Zambia. One expert described that while the National Cancer Control Strategy is focused more broadly than cervical cancer, that it is funded through the cervical cancer budget line. They discussed how the system strengthening that has been supported by the cervical cancer program, including referrals, access to care, pathology capacity, etc. has improved all diseases and was a direct result of the cervical cancer program. Another expert expressed how the initial push to fund cancer control overall was made possible by the cervical cancer program and the initial notoriety of the program that resulted in political will and government investment up front. It was noted that the awareness created by the cervical cancer program has prompted policy makers to include cancers more broadly in national budgets and most recently, in the services and medicines covered by the National Health Insurance Scheme.

### ***Leadership and Governance***

Overall, the sentiment of experts was that the cervical cancer program has been the primary driver in strengthening political will and support for cancer overall in Zambia. Due to the support of former first lady, Dr. Christine Kaseba-Sata, an OB/GYN who worked during her tenure to expand the availability of cervical cancer screening and treatment and enable those working in the Ministry of Health to promote and execute the program, the program grew to be a model for how the health system can prioritize and address non-communicable diseases.

A structural intervention that was instrumental in strengthening this pillar was the existence of a national coordinator position for cervical cancer. The transition from this position being funded by a cooperative agreement with the US CDC to a position funded permanently by

the Ministry of Health was cited by multiple participants as strengthening the health system and the way that cancer control governance works overall. Recently, the Ministry of Health experienced structural and personnel changes that could have threatened overall governance of cancer control, but interviewees cited that the permanency of the coordinator position ensured that the program continued with minimal interruption.

Experts shared the opinion that the cervical cancer program ultimately resulted in the creation of the National Cancer Control Plan for Zambia, an element that achieves one of the recommended WHO core indicators for health systems strengthening: *existence of key health sector documents that are disseminated regularly*. Interviewees explained that the cervical cancer program raised support for all cancers and was the impetus behind creation of the national strategy. A participant from an NGO described it as,

I think that cervical cancer raised the profile of cancers because they were able to ride on the cervical cancer platform. The cancer strategic plan focuses on four cancers—cervical cancer, breast cancer, prostate cancer, and retinoblastoma. Cervical cancer drove the development of the national strategic plan and even going forward a lot of the resources to develop and implement these plans came from the cervical cancer. So from a policy level, I think they are able to develop a number of relevant policy documents using cervical cancer momentum and resources.

### ***Health Information Systems***

The health information systems that interact with the cervical cancer program in Zambia are numerous. When discussing this topic, experts spoke of the following health information systems in Zambia:

- **Health Information System of Zambia (HMIS):** The HMIS was established in the MoH in 1996 and at the moment it covers all the health facilities in all the 72 districts of Zambia (Health, 2017).

- **SmartCerv:** A national automated cervical cancer information system which has enabled national reporting of cervical cancer control data and related HIV/AIDS data (“Fiscal Year (FY) 2020 PEPFAR Planned Allocation and Strategic Direction,” 2020).
- **National Cancer Registry:** The Cancer Registry was established in 1977 and is charged with collecting population-level cancer data from all health facilities within Lusaka (“Zambia National Cancer Registry,” 2021).

Overall, the sentiment from experts was that the cervical cancer program overall has strengthened individual data systems for cervical cancer, particularly SmartCerv, but that it has not resulted in overall improved health information systems as a health pillar. A common concern expressed by many interviewees is the lack of integration and coordination among the three main systems discussed. Many experts did express that things were “on their way” to being more integrated and more complete. However, they noted that a major barrier to strengthening, similar to what is mentioned as a sustainability barrier, is that the data that are collected are done so to donor specifications, and when funding is gone, those systems often collapse.

The main exception to the sentiments expressed above is that because cervical cancer is and has been the preeminent cancer in Zambia, the need to gather data on it has moved political will and support forward for support for the cancer registry overall. This is in line with the sentiments expressed in regard to political will and government support, discussed earlier in this chapter.

### **Notable Barriers to System Strengthening**

This study also found that there are still significant barriers in play, and several experts expressed they did not believe the cervical cancer program has strengthened certain pillars of the health system in Zambia. Health workforce over-burden was a common theme expressed among

a few interviewees. Those who reported that the cervical cancer program did not strengthen the health system cited the common problem that the healthcare providers (nurses, primarily) who are delivering the cervical cancer program, are doing so on top of an already full portfolio of duties and with very little time allotment. Experts stated the possibility of a decrease in quality of services and a threat to program implementation, as well as the morale of the health workforce.

One expert described it as,

So they have this nurse who is running HIV services, she's running the under-five clinic, and then they say, let's also train her for cervical cancer. And sometimes, you know, the training is exciting, and people get enticed by extra knowledge. Now, we're not considering that we are actually eating into whatever other services she must do. So the cervical cancer program won't be fully implemented because this person, once they really get back to the reality of what they do, won't have enough time to do that work. We're thinking about strengthening skills, but let's also think about the nurses. We are lumping a whole extra amount on an overburdened system and on them and can they really sustain this, and can they really deliver what we're asking them to do?

Referring to lack of strengthening of the financing pillar, some experts expressed that the cervical cancer program has not resulted in additional funding for the health system from the Zambian government because the interest and number of donors and donor funds has subdued the need for national funding,

I would say there's so much interest, will, and opportunity for external funding that, you know, that it has eroded the need for national funding.

## **Study Limitations**

Although I attempted to thoughtfully create criteria for country selection that yielded the most insights into how cervical cancer interventions may strengthen a health system, results may be limited to countries and health systems similar to Zambia. As the case study looks in depth at only one country, this study cannot definitively identify all the necessary ingredients for an intervention to strengthen a health system. Instead, the findings from this study build on the scant

literature regarding sustainability of secondary cervical cancer interventions in order to create a roadmap of best practices for countries to consider as they launch interventions.

A second limitation, inherent in qualitative methods such as key informant interviews, is bias, both participant selection and recall bias and researcher bias, in the development of interview guides and coding and analysis of interview data. I attempted to minimize bias by triangulating data sources, practicing reflexivity (leaving an audit trail of objective events and my perceptions of them), and frequent consultation and discussion of participants' intent. While I conducted these interviews in my role as a student of UNC's DrPH program, interviewees may be aware of my role as an employee of the U.S. National Cancer Institute, a funding institution. This could impact the responses from some key stakeholders. However, it is extremely rare for NIH to fund direct awards in LMICs; there are no awards to Zambia in the current fiscal year (2021).

A third limitation of this study is that primary data were gathered remotely due to the COVID-19 pandemic, which restricted travel. While I have visited cervical cancer screening clinics in Lusaka in the past, spending time in the intervention settings would have been beneficial during this research. I balanced this limitation somewhat by ensuring that two members of my dissertation committee live and work in Zambia. Prior to the selection of Zambia as the focus country, I ensured that there was interest in this research idea and asked if this research can be done in partnership with interested stakeholders in Zambia. This was an important criterion to ensure that the research is culturally competent and contributes to the overall health system in ways that are needed and useful.

Finally, I do not currently, and have not ever, worked and lived in Zambia and therefore my findings and their interpretation are limited by my experience as a white, U.S. citizen. I made

attempts to mitigate this bias by involving Zambian professionals in my committee and recruiting only KIIs with those currently working in Zambia. However, COVID-19 limited the collaborative actions I could take (such as conducting this research in Zambia, and including a Zambian research assistant), and this limitation must be noted.

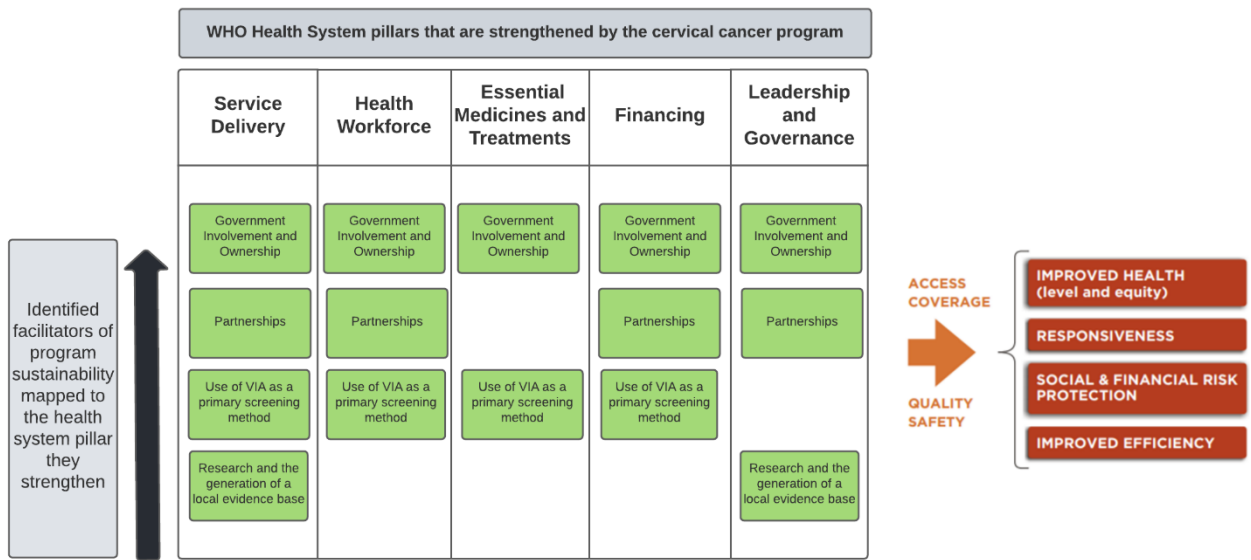
## CHAPTER 5: DISCUSSION AND RECOMMENDATIONS

Prior research on sustainability of cervical cancer programs in LMICs is limited. Research on how these programs inform the health system is even more sparse. The results of this study provide insights into the opportunities countries implementing cervical cancer programs can act upon to create sustainable programs that in turn, strengthen the health system(s) where they are implemented. The results of this study start to fill in the missing gaps in the current research. The following section describes the main outcome areas of this research, and highlights the need for future research to inform some aspects of the results. Additionally, this study revealed the key barriers to sustainability of cervical cancer programs, which provide direction in actions to mitigate these detractors.

A triangulation of the main arms of the study revealed several ways that a program like the Zambian Cervical Cancer Program can contribute to strengthening a health system. It also revealed how those aspects of the program intersect with creating a sustainable program. This overlay of data helps articulate the ways that the facilitators of sustainability within secondary and tertiary cervical cancer screening programs can strengthen the overall health system. The model outlined in **Figure 19** reveals the 5 pillars of the WHO Health System Framework that were determined strengthened by the cervical cancer program. It also lists the ways in which the pillars were strengthened. This is then tied to the identified facilitators of sustainability. This results in the revised framework that is the third aim of this research, a conceptual framework that links the identified facilitators to sustainable cervical cancer screening programs in LMICs



(results from Aims 1 and 2) to the six building blocks of the World Health Organization (WHO) health systems framework (**Figure 19**).



**Figure 19:** A Framework for How Facilitators of Sustainable Cervical Cancer Programs Can Strengthen the Health System

Importantly, while government commitment and political will as facilitators of sustainability were a finding of the literature review in Chapter 2, the information of partnerships as a facilitator was not found in the literature and is a contribution of this research. The following section highlights the five emergent recommendations (**Figure 20**), grouped by the main facilitator areas in which they fall.

Summary of Recommendations from This Research	
1	Ensure implementation, integration, and coordination through government structures
2	Make cancer screening and treatment a part of a National Health Insurance Scheme
3	Emphasize local leadership
4	Support implementation science to understand how countries can transition from VIA to HPV-DNA screening
5	Prioritize health information system strengthening

**Figure 20:** Main Actionable Recommendations from This Research

## **Facilitator of Sustainability: Government Involvement and Ownership**

The facilitators of sustainability articulated under the theme of *Government Involvement and Ownership* include political will and the creation and enactment of policy documents, implementation and coordination through government structures, and the presence of some cervical cancer screening and treatment services in the National Health Insurance Program. KIIs and document review revealed that these facilitators strengthened at least four of the WHO Health System Pillars: Service Delivery, Leadership and Governance, Access to Essential Medicines and Treatments, and Financing. There are specific models and program elements that KII's highlighted as key recommendations regarding how a program can structure itself in the future to benefit the overall health system.

### ***Recommendations Addressing Government Involvement and Ownership***

#### ***Recommendation 1: Ensure Implementation, Integration, and Coordination Through Government Structures***

Multiple experts recommended that future programs should emulate the model of implementation and coordination through government structures for other cancers such as breast cancer to ensure that programs are sustainable. In 2015, the cervical cancer program was officially integrated into the Zambia Government's public health system with an aforementioned national coordinator position, and corresponding government focal persons (Provincial Women's Cancer Control Specialists) in all provinces. All ten provinces have at least one district providing cervical cancer screening. This structure was originally designed from recommendations following a comprehensive assessment of cervical cancer control in Zambia (Chibwesha et al., 2017).

A demonstration project for breast cancer that sought to build on the framework of the Cervical Cancer Program was conducted and published in 2018. It outlined how scaling aspects

of the breast cancer program could benefit from following the cervical cancer program model (Pinder et al., 2018) and articulates much of the recommendations that flowed from this research. As countries are implementing and integrating cervical cancer programs into their existing health systems, ensuring that a well-articulated model, with state, district, or provincial focal points and a national coordinator or coordination office will ensure the program is most sustainable, but also strengthen the Service Delivery, Governance, and possibly Financing pillars of the health system.

Integration of the cervical cancer program into existing government structures was a theme common in the literature review in Chapter 2, but not something that this research revealed in the document review and KIIs. However, aspects of integration are inherent in many aspects of government coordination. The cervical cancer program is implemented through government health systems and has also been integrated into the infrastructure supported by PEPFAR.

*Recommendation 2: Make Cancer Screening and Treatment a Part of a National Health Insurance Scheme*

The National Health Insurance Scheme in Zambia was established October 1, 2019. A limited number of cancer control interventions for cervical, prostate, breast, and colorectal cancer are included in the NHIS package and covered for those who are a part of the program. The scheme includes employees from both the informal and formal sectors who contribute according to their ability to pay and private employees whose employers will partly contribute for their employee and remit contributions to the Authority. The Zambian government subsidizes for the poor and vulnerable (“NHIMA,” 2021).

The topic of National Health Insurance and Universal Health Care was not found in the literature review that informed this research, but this was a main theme that came from KIIs and

document review. Experts cited the 2019 change in health insurance policy as a main driver of what now makes the cervical cancer program sustainable. It allows people to access screening and subsequent care at a fraction of the cost that it was prior to this scheme. A 2021 study using data from the Zambia Household Health Expenditure Utilization Survey found a 6.4% overall increase in healthcare use for people with non-communicable diseases with health care, suggesting that health insurance may play an important role in improving access for people suffering from NCDs. As NCDs primarily affect households with lower socioeconomic status, health insurance may have a strong equity result in LMIC contexts (Ngwira, Bulawayo, & Hangoma, 2021).

A cornerstone of the Sustainable Development Goals (SDG) agenda is achieving universal health coverage (UHC); SDG target number 3.8 in the agenda aims to “achieve UHC, including financial risk protection, access to quality essential health care services and access to safe, effective, quality, and affordable essential medicines and vaccines for all” (Fu, Wang, Zhang, Hou, & Li, 2019). National health insurance has been shown to strengthen many aspects of the health system, and this research shows that it plays a key role in the sustainability of the cervical cancer program. As countries, especially LMICs, establish and implement cervical cancer programs to meet the WHO elimination goals and control cervical cancer, implementors and policy makers should take quick action to ensure that screening and treatment services are covered in national health insurance programs. If a National Health Insurance program does not exist, this should be considered a primary policy priority that will strengthen and sustain individual health programs and the health system overall.

## **Facilitator of Sustainability: Partnerships**

Partnerships were not a facilitator of sustainability captured in the original systematic review, but throughout the research, assumed a dominant role as a primary facilitator to sustainability and an aspect of the cervical cancer program that strengthened the health system. Specifically, the broad theme of partnerships included the input and role of civil society, the coordination of partners and partner contributions by the Ministry of Health, and the long-term investment of implementing partners, namely PEPFAR. When triangulated with data from document review, this research that the overall area of strong and coordinated partnerships within the cervical cancer program strengthened four pillars of the health system, including service delivery, health workforce, leadership and governance, and financing. There are specific program elements that KII's highlighted as key recommendations regarding how a program can structure itself in the future to benefit the overall health system.

### ***Recommendations Addressing Partnerships***

#### ***Recommendation 3: Emphasize Local Leadership***

The cervical cancer program is implemented by a number of large, international implementing partners such as PEPFAR, John Snow, USAID, CDC, Jhpiego, and others. While these long-standing partnerships were cited as an important facilitator of sustainability, the ability of these partnerships to strengthen the health system relies on coordination of their efforts from local leaders in Zambia. As additional international partners join the cervical cancer program efforts, consistent coordination through the National Coordinator ensures that their efforts are integrated into the existing program, reduces duplication, and ensures that monitoring and evaluation can happen in the national program context. An expert put this recommendation best,

Well, the, the first thing when we talk about leadership and partnership, it's about the organization of the system considering the local environment. You see, we have a lot of models for governance, and partners, but we locally really know how it works in Zambia. And with that knowledge, you know, the, the leadership knowledge and then the knowledge of the local environment and what works, I think that's the first step in sustainability and improving the health system through this program.

As countries establish programs and models to control cervical cancer, to ensure the program strengthens the health system, the partnerships made to implement the program, especially those with international organizations, should be lead and coordinated by the central governance body (usually the Ministry of Health). This is particularly essential for training programs for the health workforce, and to improve service delivery.

The role of local research institutions was a theme that emerged from the systematic review as a factor that could help sustain programs. However, one aspect, not found in the literature, that is a finding of this research, is that research to inform policy should be led by investigators in Zambia, with Zambia populations. This is another important facet of local leadership. There is a body of literature that supports this recommendation, published by investigators working in Zambia, and often part of the Ministry of Health, detailing specific interventions tailored to cultural norms and utilizing traditional infrastructures to expand access (Kapambwe et al., 2013, 2019; A. Nyambe, Kampen, Baboo, & Van Hal, 2018; N. Nyambe et al., 2018; White, Mulambia, Sinkala, Mwanahamuntu, Parham, Moneyham, et al., 2012). One expert cited that the new National Cancer Control Strategy, currently in development, aims to establish a National Cancer Institute of Zambia, which could increase research output. Another expert also mentioned a recent development of a research team at the Ministry of Health with a mandate to publish. This is evident in the many scientific papers that are coming out of institutions in Zambia in the past two-to-three years and critical for strengthening of the health system. National Cancer Control plans and cervical cancer strategies should include sections on

research priorities and plans, specifically plans to more support and generation of local evidence. Generally there is a dearth of research priorities articulated in national cancer control plans (Prabhu Das, Stevens, Muha, Sivaram, & Kosteletzky, 2019), and this should be prioritized by governments and implementing partners moving forward.

### ***Recommendations Addressing Barriers and Challenges Demanding Attention***

In addition to identifying facilitators of sustainability that strengthen the health system, this research articulated critical barriers that are having an impact on the sustainability of the cervical cancer program, and potentially threaten parts of the health system, as well. The recommendations to address these barriers follow.

#### ***Recommendation 4: Support Implementation Science to Understand How Countries Can Transition From VIA to HPV-DNA Screening***

Notably, the use of VIA screening as a primary screening method was noted by multiple experts as a primary facilitator of the cervical cancer program due to its relative low cost, and ease of training and implementation. This is a critical finding given that the WHO 2021 guidelines call for countries to pilot and scale HPV-DNA testing as a screening method, which is significantly more costly to implement on a national scale (“New recommendations for screening and treatment to prevent cervical cancer,” 2021). Thus, what was identified as a key facilitator for sustainability by many experts could transition to a barrier to sustainability that may impact more of the health system. This theme was not present in the literature review and warrants more research to understand how HPV-DNA-based screening programs can be sustainably scaled in a cost-effective manner for national governments working with implementing partners.

#### ***Recommendation 5: Prioritize Health Information System Strengthening***

Finally, Health Information Systems, as described in **Figure 18**, stood out as the only WHO Health System Pillar that was not identified as strengthened by the cervical cancer

program. This is a critical gap as health information systems are essential for monitoring and evaluation of programs, implementation planning and adjustment, and long-term costing and economic analysis. The role of international donors and splintered data collection and reporting requirements and systems to collect data are aggravators of this barrier. Priority should be given to data systems that are integrated into an overall cancer registry or HMIS, rather than standalone tracking systems. Further, international donors and implementing partners should be careful to fund data programs that achieve integration rather than opting for quick fixes to data gathering needs for monitoring and evaluation.

### **How These Recommendations Compare to Other Disease Programs**

In order to draw comparisons between these recommendations and those for other disease programs, the literature on other disease-specific programs was explored as part of the document review in this case study. Many programs have been in existence in LMICs for much longer periods of time, and some with much greater international and national support and funding. Overall, this body of literature examines how disease programs contribute to the strength of a health system, with most of the focus on HIV/AIDS programs and PEPFAR and the Global Fund, and reflects many of the recommendations of this study. Examples from most comprehensive reviews and cited studies are summarized below.

Rao et al (2013) studied the health system in India and how disease-specific programs have interacted with the pillars of the health system. They studied the National AIDS Control Program, Revised National Tuberculosis Control Program, and National Vector Borne Disease Control Program (Malaria), and examined which factors of these programs enabled strengthening. This was a large qualitative study, consisting of 103 in-depth interviews in fields that resembled those who were recruited for this study. This study had similar findings to my



research and concluded that these programs did contribute to health system strengthening in the following ways: sharing human and material resources, increasing demand for health services by improving public perceptions of service quality, encouraging civil society involvement in service delivery, and sharing disease-specific information with local health system managers.

Additionally, their recommendations were that (1) programs have explicit policies included that call out local health system strengthening and (2) the program should be embedded within the health system administration (Rao et al., 2014). These recommendations are directly in line with recommendation 1 from this study, that embedment and establishment of national policies are key parts of government leadership that can strengthen the health system.

A series of case studies examining Global Fund program's interactions with health systems, including those in Indonesia, Ghana, Papua New Guinea (PNG), Lao, and Thailand, were conducted between 2010–11. In comparing the five case studies, many of the findings mimic recommendations from this study. In Indonesia, system-wide impacts included greater awareness of governance and stewardship, and increased awareness of the need to integrate program planning (Desai et al., 2010). This reflects findings of this study that the cervical cancer program improved overall governance and national cancer control planning. In Ghana, strong government leadership facilitated health systems strengthening in the areas of financing, planning, service delivery, and demand generation (Atun, Pothapregada, Kwansah, Degbotse, & Lazarus, 2011). Government leadership and coordination was a central finding of the research I conducted. In Lao, participants regretted the lack of alignment between national priorities and the strong focus on priorities of external partners (Mounier-Jack, Rudge, Phetsouvanh, Chanthapadith, & Coker, 2010). In PNG, overall, there were concerns about sustainability given dependence on donors, a sentiment that was also found in this study. Notably, in Thailand, the

study concluded that Global Fund investments had minimal impact on health system (Hanvoravongchai, Warakamin, & Coker, 2010).

Much of the literature in this area focuses on investments of the US PEPFAR program and highlights the common critique that PEPFAR programs have not yet achieved true health system strengthening through their implementation. Systematic reviews by Biesma et al (2009) and Palen et al (2012) highlight the initial negative impact that vertical health programs, operating in parallel to the health system in many regards, can have on system health. Both call for improvements in how PEPFAR strengthens areas of service delivery, human resources, fiscal harmonization, and integration into national policy implementation (Biesma et al., 2009; Palen et al., 2012). While PEPFAR does have a stated objective for health system strengthening (Goosby, 2012), overall funding in this area since then has decreased and more recent literature calls for better coordination with domestic resources for health systems strengthening (Moucheraud et al., 2016). Two retrospective longitudinal analyses examining PEPFAR investments in Uganda and Nigeria summarized that PEPFAR did not strengthen the health system in Uganda as a result of “spill-over” benefits (Luboga et al., 2016). Whereas in Nigeria, authors document health systems’ minor improvement from PEPFAR investments, but overall cite donor dependence and misalignment with national strategy as harmful to the health system (Odekunle & Odekunle, 2016).

Overall, literature that describes how disease-specific programs may strengthen a health system support and reflect many of the recommendations of this study. Critical program elements such as strong local leadership, integration and coordination through a national system, and health system strengthening were common themes. This study reveals that inclusion of cancer into a national health insurance program, local research and evidence generation, and a

better understanding of transitions in clinical guidelines for detection may also contribute to sustainability and health system strengthening. Further research into the role of donor dependence and how negative effects can be mitigated are a theme of both this study and the disease-specific literature and should be pursued.

## **CHAPTER 6: THE PLAN FOR CHANGE**

This research has the potential to impact and inform implementation of the WHO Cervical Cancer Elimination Strategy (WHO, 2019) by disseminating a framework for health systems strengthening and action plans for cervical cancer programs in LMICs. Countries, especially LMICs, are acting now to achieve the ‘90–70–90’ triple-intervention elimination scale-up targets by 2030. Conclusions from this research will promote progress and solutions in the following two areas of the elimination strategy: 70% of women screened at least twice in their lifetime with a high-performance test such as HPV testing (at around 35–45 years of age), and 90% of women identified with cervical disease (including pre-cancerous and invasive cervical cancer) given appropriate treatment and care. The last target, 90% of girls fully vaccinated with the HPV vaccine by the age of 15, was not a focus of this research.

I have two key roles in partnerships that will benefit from this plan for change. First, as the Branch Chief for Partnerships and Dissemination at the NCI Center for Global Health, I direct our WHO Collaborating Center for Cancer Control (“Collaborating centres,” 2021). One of our four focal areas is technical contribution to the WHO Cervical Cancer Elimination Initiative. As such, I will have an opportunity to influence and lead work in this area, including establishing new and productive collaborations and conducting future research on how countries can most effectively reach the elimination goals. The findings of this study will inform future research and programming that I direct. The framework and set of recommendations will provide countries technical input and guidance to consider sustainability and systems strengthening as they are implementing cervical cancer control programs.

I also serve as the NCI Representative to the International Cancer Control Partnership (“About the Partnership | ICCP Portal,” 2021). Through this partnership, NCI regularly provides technical support to countries implementing National Cancer Control Plans. This is done through virtual tele-mentoring, national cancer control plan review, and tool creation and dissemination. Through these venues, I will have an opportunity to disseminate the findings from this research to country governments and international technical and implementing agencies who are regular partners in these efforts.

To disseminate this research, and facilitate maximum utilization of the conclusions and recommendations, I will use Kotter’s Eight Step Model for Leading Change (“The 8-Step Process for Leading Change - Kotter,” 2007) (**Figure 21**). This model, applied in both of my key roles, will help disseminate recommendations through international networks that are invested in cancer control planning, and health systems strengthening. The Kotter model outlines eight steps to adapting change and transforming an organization, starting from creating urgency for change, a coalition, and a vision, and leading to communicating that vision and forming a coalition and empowering people to act to create short term wins and continuous quality improvement. The full eight steps of the Kotter’s model were considered when designing the implementation plan for sharing results, and the conceptual model’s adoption into cervical cancer programs and interventions. Kotter’s model mirrors many levers of sustainability mentioned in models in Chapter 1, making it a good fit for implementing findings in a lasting way. More detail is provided on each step in the remainder of this chapter.

### **Step 1: Create a Sense of Urgency**

WHO’s Elimination Initiative calls for achievement of the specific targets by 2030, which is ambitious and likely impossible in some settings as countries mount efforts to control

cervical cancer more aggressively. However, scale-up to these targets is an important step to achieving the elimination goal and saving women's lives. This is an urgent need as cervical cancer is the leading cause of death in more than 42 countries (Beddoe, 2019). As LMIC governments plan and pivot to stand up and strengthen programs to meet these goals, applying the lessons learned in this research will promote sustainability and contribute to a stronger system for future initiatives.



**Figure 21:** Kotter's Eight Step Model for Leading Change

My current roles described above give me leverage to create urgency internally and externally. First steps will include preparing presentations for KIIs and Zambian leaders who were involved in this study, US NCI leadership, WHO leadership in cancer control, and holding various meetings to disseminate the findings of this research. Progressive actions in cervical cancer control have the ability to save lives and should be acted upon urgently.

A significant finding of this research that is not reflected in current literature about cervical cancer is that National Health Insurance Systems play in ensuring a program's sustainability. Given the potential newness of this information in consideration of cervical cancer programs overall, creating urgency and dialog around this focus for national governments, within the context of cancer control, is an important initial step. Given the importance of National Health Insurance to the key informants in this study, including this in the plan for change is essential.

## **Step 2: Build a Guiding Coalition**

The presentations I will conduct in Step 1 will help inform a group of technical experts who can serve as effective change leaders within the Zambian cervical cancer program, the US NCI, and within WHO as we move this work forward. At NCI I will engage scientists and program analysts working on programs related to the WHO Elimination Initiative. I will also engage the leadership of these programs, influential individuals who have a great deal of input over how NCI positions itself within this work. This guiding coalition already works together and meets regularly for a number of reasons. The goal for this particular plan for change is to integrate this work into the Center for Global Health's coordinating vision of these actors, to bring various stakeholders together regularly on this and other issues.

NCI's convening power also allows me to access a potential coalition outside of WHO and NCI, which is a key element of ensuring that evidence is applied equitably. This study was conducted on the cervical cancer program in Zambia, and many of the experts interviewed for this study have expressed interest in next steps, including publication and dissemination of results. This study also has implications for other LMICs, especially those currently looking to scale cervical cancer screening and treatment to reach the 2030 targets. NCI is convening a group

of experts to form a stakeholder input group on cervical cancer research from three regions—sub-Saharan Africa, South and Southeast Asia, and Latin America—this group will be formed of leaders and changemakers who can influence policy and programs and will be a good resource for the guiding coalition I will build. This coalition will be separate from the first initially, giving me two coalitions with which to work.

Both of these leadership coalitions should also engage around and address the issue of National Health Insurance with counterparts in Ministries of Health and in WHO. While this recommendation will engage more actors than the recommendations related to cervical cancer, using these coalitions to drive the message of the importance of NHIs for sustainability of programs like cervical cancer screening is an opportunity to influence the dialog.

### **Step 3: Form a Strategic Vision and Initiatives**

Both coalitions will utilize this research to inform the creation of a strategic vision, a timeline for action, and other shared goals. We will ensure that all change leaders within both coalitions can inform and articulate the vision clearly and concisely and in a manner that a variety of stakeholders can follow. In my position, I believe I will be able to influence to some degree, NCI leadership and WHO cancer control leadership with recommendations to address the questions and challenges laid out in this research. This will help in creating a shared vision and tools for dissemination and action that have shared messages. One important note is that the inclusion of NHIS as strategy is new and will need some workshopping with both stakeholder groups.

### **Step 4: Enlist a Volunteer Army**

The first three steps help create a climate for change within NCI, WHO, and the international stakeholder community. These next four steps engage and enable the organizations

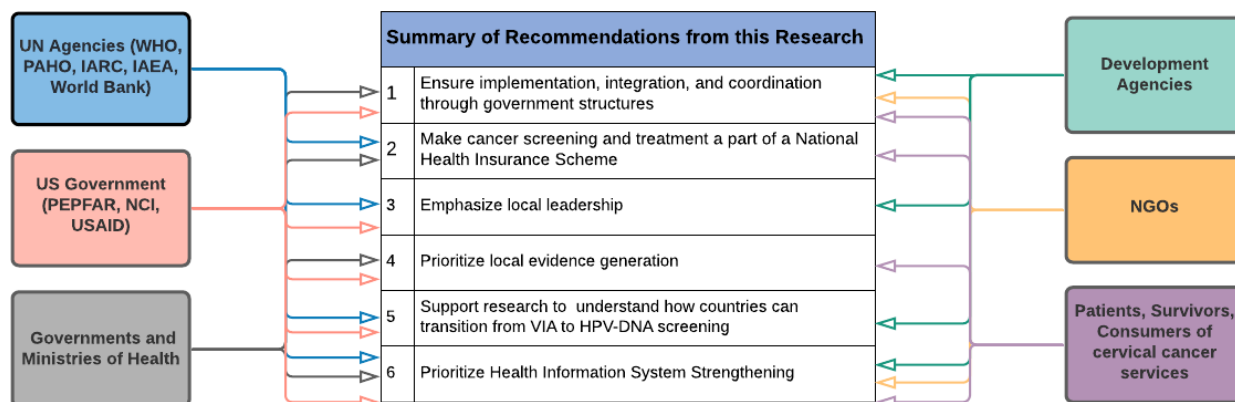


and coalitions to make the change happen. In step four, Kotter describes needing a “massive” number of people to rally around and move a common opportunity. The army must be bought-in, accomplished through steps two and three, and must drive forward with a unified vision. The “army” must communicate the change in vision powerfully and convince others to come along (Haas et al., 2019).

The “volunteer army” will include key stakeholder groups, critical to making progress in cervical cancer control and saving women’s lives on both the national and international levels. Representatives from UN Agencies (WHO, World Bank, IAEA, IARC), US government agencies (e.g. PEPFAR, USAID, NCI, etc.), governments and Ministries of Health of other nations, including Zambia, where this research took place, civil society, development agencies, NGOs, as well as patients, survivors, and other consumers of cervical cancer services will be mobilized to apply the lessons learned from this research to how cervical cancer programs are designed and implemented. To some extent, this “volunteer army” already exists through networks in place at the National Cancer Institute and through the WHO and those networks will be mobilized to act on the recommendations.

Within this army, representatives from UN Agencies will be critical advocates for recommendations 2, 3, 5, and 6. US government agencies will play a large role in recommendations 1, 3, 4, 5, and 6. National governments and Ministries of Health will be critical changemakers for recommendations 1, 2, 4, and 6. Development agencies can impact recommendations 1, 3, 5, and 6. Civil society and NGOs have big roles in recommendations 1 and 6. The patient voice, survivors, and other community consumers of cervical cancer services arguably have a role in all recommendations below, but can be advocates for recommendations 1, 2, 4, and 6. Recommendations 1 and 6 have the largest “army”, with support from

stakeholders in this army, while 2–5 are supported by three stakeholder groups each. This is shown in **Figure 22**.



**Figure 22:** “Volunteer Army” Aligned With the Recommendations Where They Will Have the Most Influence

### Step 5: Enable Action by Removing Barriers

There are many barriers to successfully implementing the recommendations of this study. These barriers occur at the international, national, local, and patient level and will require specific attention from the changemakers working toward implementation, while recognizing not all of them will be under their control. Financial resources are always going to be a challenge; donor dependence was cited by almost all interviewees and that contributes to donor-driven priorities, which may not align with the recommendations above. However, engaging development agencies to prioritize local leadership and ensure their activities are coordinated through the local context can help address.

The prioritization of support for health information systems like cancer registries may also be a unique barrier as this was a recommendation that emerged from primarily negative feedback regarding system strength. As this is a recommendation where all identified “army”

members will contribute to its enactment, it will be important to recognize the contributions of those most active and involved in making progress.

### **Step 6: Generate Short-Term Wins**

The Zambian government may be interested in the findings of this study, particularly pertaining to recommendations for program sustainability. Study findings will be shared with KIIs, many of whom serve in positions in the Ministry of Health and other implementing organizations. A summary of recommendations will be shared with these stakeholders to identify opportunities for short term wins within the cervical cancer program structure. Additional data that may inform program adjustments or enhancements can be shared, as well. Specifically, evidence on the importance of access to treatment for late stage, invasive cervical cancer cases, as a barrier of sustainability and something that is harming the overall health system, must be shared with the Ministry of Health in Zambia. Elimination goals may not be attainable if women diagnosed with cervical cancer cannot access treatment. This could lead to apathy toward screening and unethical dilemmas regarding screening without treatment capacity.

Working within groups like the International Cancer Control Partnership will allow for immediate dissemination and discussion of these recommendations to inform how best to identify short term wins. As cancer control plans and national cervical cancer strategies are created, the importance of coordination through local Ministries of Health can be emphasized. As technical review of these new plans occurs, there will be an opportunity to recommend stewardship and governance and specific models that were shown as effective in strengthening the health system by this research. The inclusion of a coordinating body in new NCCPs is a short-term win.

Additionally, I have identified bi-directional learning networks (Project ECHOs (Arora et al., 2014)) in sub-Saharan Africa, South East Asia, and Latin America, focused on global cervical cancer control that are convened by or in partnership with the NCI Center for Global Health. These networks will serve as a venue to empower individuals and countries to act on the research results from this study and share implementation data in real time. This medium allows for a bi-directional dialog on short-term wins, finding best practices and documenting actions that produce more change. The hope is that the results of this study will be used to help countries implementing cervical cancer control programs over the next 5–10 years, prioritize areas that will enable sustainability and strengthen parts of their health system through the utilization of this framework in programming design.

Finally, creating mechanisms to fund more locally relevant research, especially as it related to the scale up of HPV-DNA screening, is a short-term win that I have some influence over in my role at NCI. This can begin to chip away at the dearth in grants going to investigators in LMICs who are generating evidence that can best serve their local context.

### **Step 7: Sustain Acceleration**

The three Project ECHOs identified above will be a medium to build momentum and share progress that can help sustain acceleration. These tele-mentoring sessions allow for monthly meetings of stakeholders to keep a quick pace of exchange through the networks they create. For some of the longer-term recommendations (2, 6), sustainment of acceleration, and identification of short-term wins will be critical to make incremental gains. The volunteer army will need to monitor this progress and I will need to be consciences to continue to develop the ECHOs in ways that create opportunities for progress. The Dynamic Sustainability Framework will be very useful in this step, as it provides a foundation for research and program

implementation that facilitate ongoing learning that adapts to ongoing change and improvement (Chambers et al., 2013). As interventions are adapted for changing contexts, and institutionalized into organizational, system, and cultural contexts, the DSF will provide a framework for study and reflection for ongoing implementation improvements.

### **Step 8: Institute Change**

Institutionalizing the change needed to enact these recommendations will require years of diligent change. The coalitions within NCI and UN agencies will need to shift to better prioritizing local leadership and structures over their own organizational aims, and in many cases shift their priorities to support health systems aspects, like health information systems, that will have long-term gains, over siloed interventions. Ministries of Health will also need to begin to devote more resources—human, financial, and otherwise—to cervical cancer, if they want to see the systems benefits recognized in their countries. Implementation science will play a key role in understanding how best to scale programs for cervical cancer screening in a sustainable fashion. In cervical cancer, there is ample and growing evidence as to what screening and treatment approaches are most efficient and effective. However, implementation science studies examining how these approaches are implemented, scaled, and sustained will add needed knowledge to address implementation barriers in different settings (Broutet et al., 2021; DeBoer et al., 2020; Gopal & Sharpless, 2021; Gupta et al., 2021; Johnson et al., 2018; Moucheraud, Kawale, Kafwafwa, Bastani, & Hoffman, 2020; Rositch, 2020). Building implementation science studies into these existing integrated service delivery channels could help better explain how integration can promote sustainability and if and how integration is strengthening the health system.

## **CHAPTER 7: CONCLUSION**

The WHO cervical cancer elimination initiative is creating opportunities for research and progress unlike cancer control efforts have experienced in LMICs. There is much political attention on controlling cervical cancer globally, yet too few resources to adequately implement the programs as they are planned. There is an opportunity to use this moment to design cervical cancer control programs that have system-strengthening potential that will lift aspects of the health system overall, outside of the specific program. The results of this study begin to inform how countries, donor agencies, implementing and technical partners can shift aspects of program focus to create sustainability and strengthen the overall system where program are implemented. Samb et al (2010) state that “Many cost-effective interventions exist to address the growing burden of chronic diseases in low-income and middle-income countries; however, weak national health systems often make it impossible to deliver and sustain interventions effectively and equitably” (Samb et al., 2010). This general sentiment encompasses what will most often impede countries as they try to hit the 2030 elimination targets. And what the recommendations of this research can begin to address.

This study used systematic literature review, and a case study design including document review and key informant interviews to identify key barriers and facilitators to sustainability and then used that data to better understand how sustainable programs are strengthening the health system in Zambia, an LMIC with a heralded national cervical cancer program. This research resulted in six recommendations that can be applied to programs to create sustainability and systems strengthening that will enable better cancer control overall. Some of these

recommendations are unique to cervical cancer (understand how to transition screening methods), many are applicable to most types of cancer and even other NCDs. The recommendations are supported by research on vertical health programs' systems interactions, but also add new evidence to a relatively small and nascent field.

This research is actionable. Countries are developing strategies to hit these targets in real time and WHO recommendations and tools are evolving and ongoing. The findings from this study will be applied immediately to new studies, to communities of practice, to implementation guidelines, and technical assistance efforts. Some of the recommendations, such as including cancer screening services in the National Health Insurance Program and devoting resources to strengthening health information systems will take a great deal of momentum shift both in attention and resources. Others, like empowering local leadership, are more short-term, and can be accomplished with structural changes in how we fund programs and research, and involving community stakeholders at initial stages of all program planning.

While this research contributes to the growing literature on sustainability and health systems strengthening, it also has its limitations. The COVID-19 pandemic made initial recruitment for interviews challenging and inhibited my ability to conduct this research in Lusaka, Zambia. Clinic observation and in-person interviews would have created a different data collection experience that may have influenced recommendations. Additionally, this research speaks specifically to how the cervical cancer program in Zambia has strengthened the health system. My hope is that the results are somewhat generalizable, but similar studies in additional contexts could provide evidence to the generalizability of the results. Future research examining how these recommendations are implemented, and evaluation of their impacts can help better inform how countries should act.

Returning to Saab et al, “interventions for responding to chronic diseases can lead to overall improvements in health systems in low-income and middle-income countries, provided that such investments are planned to include these broad objectives from the outset” (Samb et al., 2010). As cervical cancer programs are prioritized and delivered in LMICs, there is an opportunity to design these programs considering the health-system improvements that are needed. This will not only strengthen the health system in which these programs are implemented, but raise the profile of NCDs in global health and national health priorities, and most importantly, save lives.



## APPENDIX A: LIST OF STUDIES INCLUDED IN LITERATURE REVIEW

<b><u>Year</u></b>	<b><u>Article Title</u></b>	<b><u>Authors</u></b>	<b><u>Main Facilitators Noted</u></b>	<b><u>Barriers Noted</u></b>	<b><u>DSF Level</u></b>
<b>2012</b>	Can visual cervical screening be sustained in routine health services? Experience from Mali, Africa.	Teguete, et al.	Government commitment; Role of academic institutions/sustain ability of research programs	None noted	Intervention
<b>2013</b>	Successes and challenges of establishing a cervical cancer screening and treatment program in western Kenya.	Khozaim, et al.	Role of academic institutions/sustain ability of research programs	Insufficient Human Resources; Lack of equipment or supplies	Intervention
<b>2013</b>	Adapting the Australian System: Is an Organised Screening Program Feasible in Malaysia? – An Overview of the Cervical Cancer Screening in Both Countries	Rashid, et al.	Adaptation to Context	Poor health information/data systems; Lack of Referral and Follow-Up System; Lack of M&E or quality assurance	Ecological
<b>2014</b>	Major challenges to scale up of visual inspection-based cervical cancer prevention programs: the experience of Guatemalan NGOs.	Chary, et al.	Humans/Training	Lack of Referral and Follow-Up System; Insufficient Human Resources	Intervention
<b>2014</b>	Evaluation of a single-visit approach to cervical cancer screening and treatment in Guyana: feasibility, effectiveness and lessons learned.	Martin, et al.	Humans/Training, Monitoring and Evaluation, Integration	Insufficient Human Resources	Practice
<b>2015</b>	Cervical Cancer Screening among HIV-Positive Women in Nigeria: An Assessment of Use and Willingness to Pay in the Absence of Donor Support.	Dim, et al.	Donor funded programs/self-pay	Myths, Stigma, Misconceptions	Ecological
<b>2015</b>	Expanding Cervical Cancer Screening and Treatment in Tanzania: Stakeholders' Perceptions of Structural Influences on Scale-Up.	McCree, et al.	Government commitment	Lack of Resources; Insufficient Human Resources; Myths, Stigma, Sociocultural Issue	Ecological
<b>2016</b>	Cervical cancer screening uptake and challenges in Malawi from 2011 to 2015: retrospective cohort study.	Msyamboza, et al.	Government Commitment	Lack of equipment or supplies	Practice
<b>2017</b>	A comprehensive assessment of breast and cervical cancer control infrastructure in Zambia	Chibweshwa, et al.	Government commitment	Poor health information/data systems; Insufficient Human Resources; Lack of facility capacity	Practice
<b>2017</b>	To expand coverage or increase frequency: Quantifying the tradeoffs between equity and efficiency facing cervical cancer screening programs in low-resource settings.	Campos, et al.	Using cervical cancer control to improve Health systems	Lack of equipment or supplies; Lack of Referral and Follow-Up System	Ecological

<b>2017</b>	Implementing a Fee-for-Service Cervical Cancer Screening and Treatment Program in Cameroon: Challenges and Opportunities.	DeGregorio, et al.	Donor funded programs/self-pay, Integration	Poor health information/data systems; Lack of Facility Capacity; Lack of M&E or quality assurance; lack of resources	Practice
<b>2018</b>	Implementation of a human papillomavirus screen-and-treat model in Mwanza, Tanzania: training local healthcare workers for sustainable impact.	Bernstein, et al.	Humans/Training	Lack of equipment or supplies; Lack of Referral and Follow-Up System	Intervention
<b>2018</b>	Expanding the Single-Visit Approach for Cervical Cancer Prevention: Successes and Lessons from Burkina Faso.	Ouedraogo, et al.	Monitoring and Evaluation	Lack of M&E or quality assurance	Intervention
<b>2019</b>	Partnering with traditional Chiefs to expand access to cervical cancer prevention services in rural Zambia.	Kapambwe, et al.	Government commitment; Adaptation to Context	Myths, Stigma, Misconceptions	Intervention

**APPENDIX B:**  
**RECRUITMENT EMAIL FOR KEY INFORMANT INTERVIEW PARTICIPANTS**

Dear [NAME],

I am writing today to invite you to participate in a research interview on sustaining cervical cancer control programs in Zambia. I am interested in learning about your role and your thoughts on how cervical cancer control programs can be sustained over time and potentially strengthen healthcare systems. This research will focus on screening and treatment programs due to their impact on the health system. HPV vaccination, while a key intervention, impacts and interacts with a different level of the health system and will not be specifically examined in this study.

Results of this study will be used to help countries like Zambia implement and sustain cervical cancer control programs. I am conducting this research to meet dissertation requirements as a doctoral candidate at the University of North Carolina at Chapel Hill, Gillings School of Global Public Health in the U.S.

Participation in this study is voluntary and confidential. Your name and institution name will not be used, and your health system will be described only in general terms.

Please let me know if you are interested in participating in an interview with me.

Best,

Kalina Duncan

## **APPENDIX C: KEY INFORMANT INTERVIEW GUIDE**

### **DRAFT INTERVIEW GUIDE FOR KEY INFORMANTS**

**Date:**

**Initials:**

**Affiliation:**

**Introduction:**

Hello, thank you for taking the time to talk with me today. My name is Kalina Duncan and I'm conducting this research as part of my doctoral degree studies at the University of North Carolina in the US. I'll start with a little background on what we'll be discussing today.

I am seeking to interview a number of highly qualified experts, such as yourself, who could comment on cervical cancer control programs. Through these interviews, I hope to 1) better understand which factors you believe facilitate the sustainability of cervical cancer control programs in Zambia, and 2) if these factors or others also facilitate to strengthen the overall health system in Zambia. This research will focus on screening and treatment programs due to their impact on the health system. HPV vaccination, while a key intervention, impacts and interacts with a different level of the health system and will not be specifically examined in this study.

This interview should take no more than 60 minutes and your participation is voluntary. You can skip any question and stop at any point during the interview. There are no right or wrong answers and I really appreciate your honest responses. Please feel free to interrupt with a question at any point and/or ask me to rephrase or clarify a question.

The information collected in this study will be kept confidential. Your specific answers will not be attributed to you or your organization. It will be used in summary form to help countries like Zambia implement and sustain cervical cancer control programs. Your participation in this study is voluntary, and there are no consequences if you decline to participate, or if you decide to discontinue the interview (which you may do at any time).

Are there any questions that you have about the research study or the interview?

Do I have your permission to conduct and record the interview? We are recording to make our report preparation easier and as a backup for our note-taking.

### **Introductory questions to better understand the participant and program:**

1. Please describe your current role.

PROBE: How is your role related to cervical cancer control?

2. How long have you had this role?

PROBE: Have you held any previous roles involving cervical cancer programs?

3. Which cervical cancer programs in Zambia would you categorize as sustainable, and why?

PROBE: Can you describe that program to me?

PROBE: Can you describe the health system setting in which it is implemented?

4. What are some of the key characteristics of that program that make it sustainable?

5. What barriers has the program experienced for sustainability? What facilitators or enablers have helped maintain sustainability?

PROBE: To what extent are partnerships between the program and its stakeholders important or not important for sustainability?

PROBE: To what extent are community organizations invested or not invested in the success of the program?

PROBE: Does the program have the capacity for program evaluation?

PROBE: To what extent is evaluation important or not important for sustainability, and why?

PROBE: Has this program adapted/evolved over time, and why?

### ***Health Service Delivery***

6. To what extent has the program improved care delivery?

PROBE: Such as: more visits (accessibility), better quality, more comprehensive, more coverage and continuity, better coordination, is the care more person centered?

PROBE: To what extent has it improved accessibility of other health services to the community?

PROBE: To what extent has it improved coordination across local area health service networks?

### ***Health Workforce***

7. To what extent has the program resulted in improved health workforce capacity?

PROBE: Has it improved training for existing health workers that improves quality of care, improves motivation, or productivity?

PROBE: Has it resulted in higher numbers of skilled health care workers for other types of medicine?

PROBE: Has it improved effective management of health workers?

***Health Information Systems***

8. How does the program interact with the cancer registry in Zambia?
9. Has the cervical cancer program resulted in improved health information systems or cancer surveillance?

PROBE: Has it improved data quality?

10. To what extent can the impact of the screening program be measured through the Zambian cancer registry?

PROBE: If not, how could impact be measured? Both impact on burden of disease and screening coverage?

***Access to Essential Medicines***

11. To what extent has the program resulted in improved access to medicines and treatments?

***Health Systems Financing***

12. Has the program resulted in additional financing that might improve the health system?

***Leadership and Governance***

13. What does leadership and governance mean to you in the work you do (on cervical cancer or other)?
14. To what extent has the cervical cancer program had support from high level policy makers ?

PROBE: If yes, can you describe those individuals, their roles, and the kind of support they have provided?

15. Has the program resulted in more support for cancer control broadly in Zambia? (e.g. has it raised the profile, resulted in more funding, other areas?).

***Closing:***

16. Do you have any additional comments that you would like to make about anything we've discussed today?
17. Is there someone else at your organization who would be a good person to talk with?

**Thank you for your time and very helpful comments.**

## **APPENDIX D: WRITTEN CONSENT FORM FOR QUALITATIVE RESEARCH (IF NEEDED)**

**University of North Carolina at Chapel Hill  
Consent to Participate in a Research Study  
Adult Participants**

**Consent Form Version Date:** \_\_\_\_\_

**IRB Study #** 19-2827

**Title of Study:** Facilitators of sustainability of cervical cancer screening and treatment programs in low- and middle-income countries: strengthening national healthcare systems in Zambia.

**Principal Investigator:** Kalina Duncan

**Principal Investigator Department:** Health Policy and Management

**Principal Investigator Phone number:** 203-803-0109

**Principal Investigator Email Address:** kalinadu@live.unc.edu

**Faculty Advisor:** Angela Stover, PhD

**Faculty Advisor Contact Information:** stoveram@email.unc.edu

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### **CONCISE SUMMARY**

The purpose of this study is to better understand the facilitators of program sustainability and how those facilitators may be related to a program's ability to contribute to overall health system strengthening. This interview should take no more than one hour and your participation is voluntary. You can skip any question and stop at any point during the interview. There are no right or wrong answers to posed questions.

The information collected in this study will be kept confidential. Your specific answers will not be attributed to you or your organization. It will be used in summary form to inform a new framework for cervical cancer control programs. Your participation in this study is purely voluntary, and there are no consequences if you refuse to participate, or if you decide to discontinue the interview (which you may do at any time).

#### **What are some general things you should know about research studies?**

You are being asked to take part in a research study. To join the study is voluntary.

You may choose not to participate, or you may withdraw your consent to be in the study, for any reason, without penalty.

Research studies are designed to obtain new knowledge. This new information may help people in the future. You may not receive any direct benefit from being in the research study. There also may be risks to being in research studies.

Details about this study are discussed below. It is important that you understand this information so that you can make an informed choice about being in this research study.

You will be given a copy of this consent form. You should ask the researchers named above, or

staff members who may assist them, any questions you have about this study at any time.

**What is the purpose of this study?**

The purpose of this study is to better understand the facilitators of program sustainability and how those facilitators may be related to a program's ability to contribute to health system strengthening in the context it's being implemented in.

You are being asked to be in the study because you are an important stakeholder in Zambia and your views on cervical cancer control programs and their ability to strengthen the health system will be very valuable to this study.

**Are there any reasons you should not be in this study?**

You should not be in this study if you do not desire to participate.

**How many people will take part in this study?**

A total of approximately 12–15 people at 8–15 institutions will take part in this study, including approximately 1–2 people from this institution.

**How long will your part in this study last?**

Your participation in this study consists of a 60 minute interview. There is no follow-up after the interview today.

**What will happen if you take part in the study?**

Your participation in this study consists of today's interview.

This interview should take no more than one hour and your participation is voluntary. You can skip any question and stop at any point during the interview. There are no right or wrong answers and I really appreciate your honest responses. Please feel free to interrupt with a question at any point and/or ask me to rephrase or clarify a question.

The information collected in this study will be kept confidential. Your specific answers will not be attributed to you or your organization. It will be used in summary form to inform a new framework for cervical cancer control programs. Your participation in this study is purely voluntary, and there are no consequences if you refuse to participate, or if you decide to discontinue the interview (which you may do at any time).

**What are the possible benefits from being in this study?**

Research is designed to benefit society by gaining new knowledge. You will not benefit personally from being in this research study.

**What are the possible risks or discomforts involved from being in this study?**

There is a risk of being identified along with your responses in this research. However, to mitigate that risk, your name will not be used and this site will be described only in general terms. Though direct quotations may be used in the final dissertation, your name and other identifying information will remain anonymous.



**What if we learn about new findings or information during the study?**

You will be given any new information gained during the course of the study that might affect your willingness to continue your participation.

**Will I receive any other clinical results?**

There are no clinical results associated with this study.

**How will information about you be protected?**

To maintain confidentiality, recorded files and associated transcriptions will be stored on a password-protected laptop computer and no names will be used to label the files. A file in a separate location will link the number of the interview to a participant. Participants will not be identified in any report or publication about this study. We may use de-identified data from this study in future research without additional consent.

All materials (recorded interviews, transcripts, etc.) will be deleted within two years of this interview.

Although every effort will be made to keep research records private, there may be times when federal or state law requires the disclosure of such records, including personal information. This is very unlikely, but if disclosure is ever required, UNC-Chapel Hill will take steps allowable by law to protect the privacy of personal information. In some cases, your information in this research study could be reviewed by representatives of the University, research sponsors, or government agencies (for example, the FDA) for purposes such as quality control or safety.

Check the line that best matches your choice:

\_\_\_\_\_ OK to record me during the study

\_\_\_\_\_ Not OK to record me during the study

**What if you want to stop before your part in the study is complete?**

You can withdraw from this study at any time, without penalty. The investigators also have the right to stop your participation at any time. This could be because you have had an unexpected reaction, or have failed to follow instructions, or because the entire study has been stopped.

**Will you receive anything for being in this study?**

You will not receive anything for taking part in this study.

**Will it cost you anything to be in this study?**

It will not cost you anything to be in this study.

**What if you have questions about this study?**

You have the right to ask, and have answered, any questions you may have about this research. If you have questions about the study (including payments), complaints, concerns, or if a research-

related injury occurs, you should contact the researchers listed on the first page of this form.

**What if you have questions about your rights as a research participant?**

All research on human volunteers is reviewed by a committee that works to protect your rights and welfare. If you have questions or concerns about your rights as a research subject, or if you would like to obtain information or offer input, you may contact the Institutional Review Board at 919-966-3113 or by email to [IRB\\_subjects@unc.edu](mailto:IRB_subjects@unc.edu).

**Participant's Agreement:**

I have read the information provided above. I have asked all the questions I have at this time. I voluntarily agree to participate in this research study.

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Signature of Research Participant

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Date

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Printed Name of Research Participant

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Signature of Research Team Member Obtaining Consent

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Date

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Printed Name of Research Team Member Obtaining Consent

## APPENDIX E: QUALITATIVE CODEBOOK FOR NVIVO

#	Primary Codes (nodes)	Emerging Themes	Files	References
	Participant Background	Ministry of Health Government	6	6
		NGO	6	6
		Technical Partner	4	4
		Academia Researcher	2	2
		Clinician	3	3
		Donor	3	3
		Context: national vs regional	2	2
		Time in Position	10	11
	Facilitators of Sustainability	Policy or Political Will	5	7
		Government funding for healthcare workers and infrastructure	2	4
		Involvement of Research Institutions	2	3
		Integration into existing programs	1	1
		Partnerships	6	11
		Implemented and coordinated through government	5	9
		Focal people for the program supported by MoH	4	4
		National Health Insurance	6	7
		Decentralization of Services	3	4
		Use of VIA	6	8
	Barriers to Sustainability	Lack of facility capacity	6	7
		Human resources	5	5
		Lack of referral systems (ethics)	6	6
		Stigma and sociocultural issues	3	3
		Supply chain	2	2
		Poor health seeking behaviors	1	1
		Lack of leadership and governance	1	1
		Financing Donor Dependent	1	2
		Ownership	1	3
		Lack of messaging about lives saved		
	Service delivery	Quality	1	1
		Referrals	4	4
		Palliative care	1	1
		Pathology/Histology	5	5
		Integration	3	4
		Awareness	4	6
		infrastructure	1	5
	Health workforce	Training	3	5
		Quality Improvement	2	3
		Awareness among staff	1	1
		Data Capture	1	1
	Information Systems	Cancer Registry	4	5
		SmartCore/SmartCerv	4	5

#	Primary Codes (nodes)	Emerging Themes	Files	References
		Funding	1	2
		Better Research and Dissemination	1	1
		Better data quality	4	4
	Essential medicines and treatments	Model	1	1
		Catalyst	1	1
	Financing	National Funding	1	1
		Donor Funding	4	6
		National health insurance	6	7
	Leadership/Governance	Policies	2	2
		Awareness	3	3
		Political Leaders	2	2
		New Partners	3	3
		Succession planning	1	1
	COVID-19 Impacts	Unintended consequences	5	8
	Recommendations	Missed opportunities	3	4
		Breast Cancer Screening integration	2	2
		Future directions	3	5

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