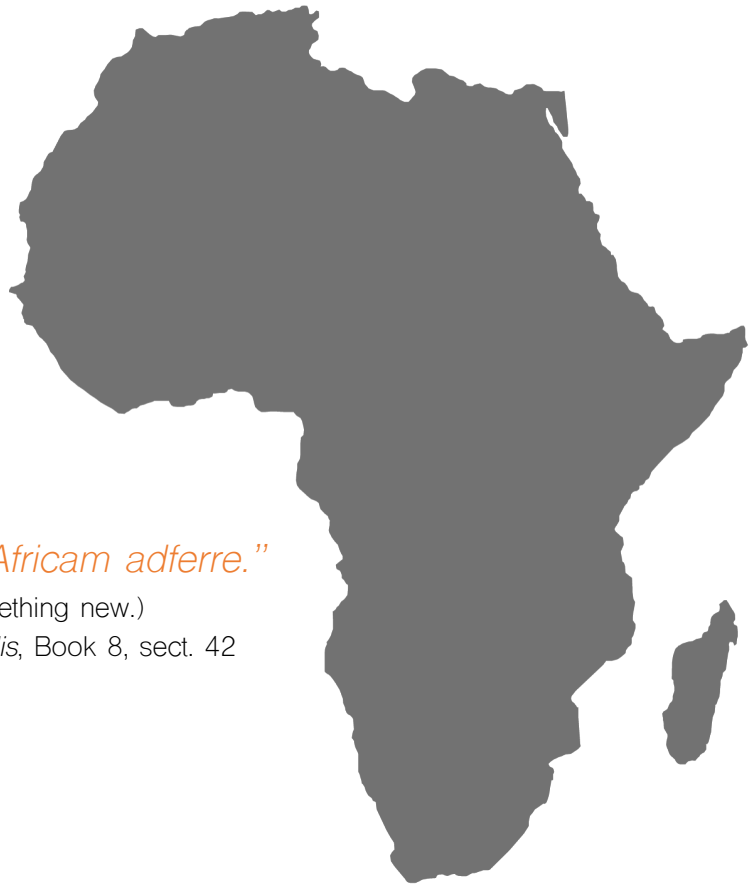


# DEVELOPING A MULTI-STAKEHOLDER, ECONOMICALLY SUSTAINABLE MODEL FOR CANCER CONTROL IN SUB-SAHARAN AFRICA

A White Paper of the Zhu Family Center for Global Cancer Prevention, Harvard TH Chan School of Public Health, The Wharton School at the University of Pennsylvania, and HEC-Paris.



*“Semper aliquid novi Africam adferre.”*

(Africa always brings [us] something new.)

Pliny the Elder, *Historia Naturalis*, Book 8, sect. 42

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## MOTIVATION FOR THIS REPORT

Over the past decade, longer life spans, an emerging middle class, and changing lifestyles in sub-Saharan Africa (SSA) have led to increased cancer rates. Cancer is predicted to increase from 12.7 million new cases diagnosed in 2008 to 21.4 million in 2030 (Ferlay, Soerjomataram et al. 2013). 78% of people in Africa diagnosed with cancer in 2008 died from the disease (American Cancer Society 2011). These statistics demand that cancer control become a priority in SSA.

Many SSA countries have experienced an unprecedented period of political stability and economic growth (The Economist) and are experiencing higher living standards, improvements in infectious disease control, and longer life spans. These countries typically have stable academic and health care systems that can provide a basis for cancer control. Investment in control will improve the health of Africans and also provide opportunities for socioeconomic development. We systematically explored opportunities to establish successful and sustainable cancer control activities in SSA, leading to improved prevention, treatment, and survivorship protocols, to ultimately improve patient outcomes.

The challenges for cancer control in SSA are substantial and require the engagement of numerous stakeholders to achieve solutions. Domains of need include advocates; policy-makers; population-based cancer registries; pathology and other diagnostic services; technology experts; funders; and clinicians and other health care professionals. SSA presents unique opportunities for research and translation of research results to improve health. Investment in research will not only improve the health of Africans, but it also provides opportunities for socioeconomic development. Many parts of SSA now have stable academic and health care systems that can provide the needed basis for developing research. Finally, knowledge of disease in SSA provides unique opportunities to improve the basic understanding of biology, epidemiology, prevention, and treatment of cancer worldwide. Therefore, it is critical to explore and identify opportunities to establish successful and sustainable cancer control activities and form relevant partnerships in Sub-Saharan Africa (SSA), leading to improved prevention, treatment, and survivorship protocols and improved patient outcomes.

Boston, Philadelphia, and Paris, 2019

## Strategies Used in this Report

We undertook a qualitative evaluation to identify opportunities for establishing successful and sustainable cancer control in SSA. Data collection was undertaken by review of the publicly available scientific literature and corporate, nonprofit, and other foundation reports. Conference attendance and site visits were conducted between November 2015 and May 2016 in the US, Europe, and Africa. Site visits to Dakar (Senegal), Accra (Ghana), Paris (France), Philadelphia (USA), Boston (USA) were conducted between November 2015 and May 2016 in the US, Europe, and Africa. Based on the data obtained, recommendations were made regarding stakeholder collaboration networks for lessons and best practices to develop linkages that can improve cancer control in the short-, medium- and long-term. Based on the data obtained, recommendations were made in three phases. In Phase 1, short- (<3 years), medium- (3-5 years), and long-term (5-10 years) actions were identified to close key resource gaps to effective cancer control. In Phase 2, best practices were revised to develop a hypothetical cancer network to improve cancer control in the long-term.

## Primary Goals and Strategies

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Analyze current and evolving cancer landscape

- Analyze state of cancer control in Sub-Saharan Africa
- Understand currently planned government improvements
- Understand disease prevalence and burden trends

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Conduct cancer control gap analysis

- Identify shortfalls to effective cancer control
- Offer short, medium, and long-term proposals to close gaps

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Identify strategic opportunities for research and collaboration

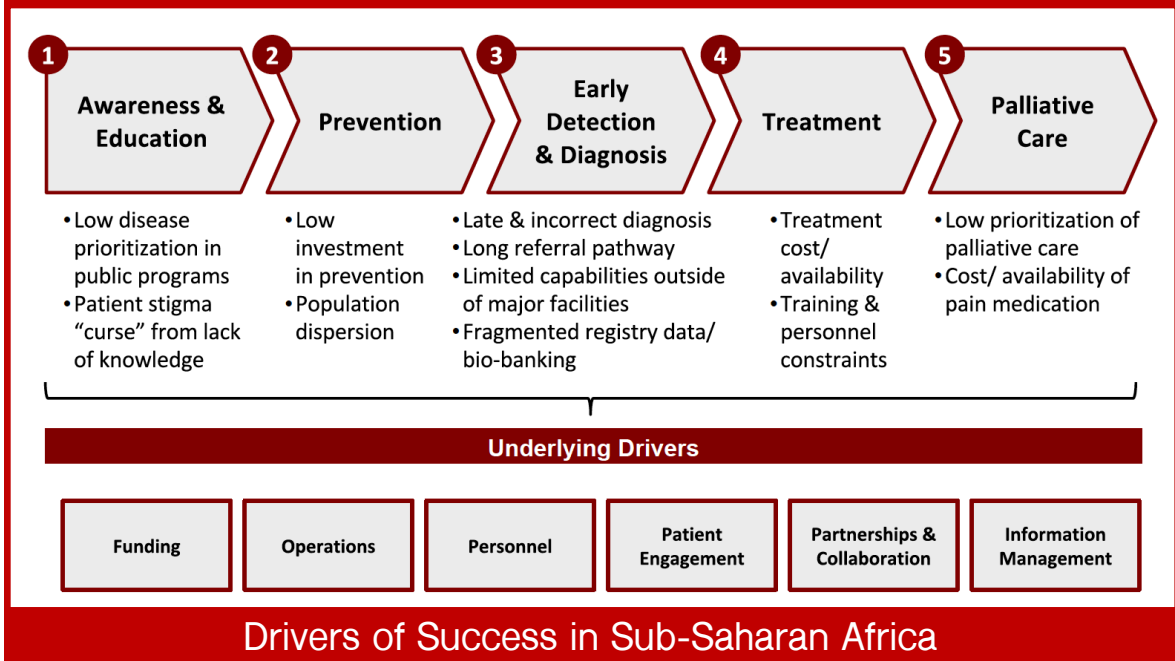
- Recommend actions for improving cancer control
  - Prioritize areas of investment for capacity building
-

# PART I. Barriers and Actions

## EXECUTIVE SUMMARY

Sociodemographic trends in sub-Saharan Africa (SSA) predict a wave of new cancer cases in the coming decades. Current SSA health systems are largely ill-equipped to manage the increasing cancer burden. Gaps exist along the spectrum of cancer awareness, prevention, early detection, treatment, and palliative care. We developed short (<3 years), medium (3-5 years), and long-term (5-10 years) proposals to close the gaps. We identified strategic opportunities for research and collaboration, including recommendation of actions for improving cancer research and treatment and prioritization of investment for capacity building. Major gaps exist in funding, operations, personnel, information management, and patient engagement. We mapped stakeholder groups consisting of implementers, funding partners, and technology companies. Long-term, we identified needs for regional public-private partnerships to develop sustainable systems for cancer control. An umbrella organizing body should be developed to promote collaboration between private, public and nonprofit stakeholders to enable better data collection, coordinated research and treatment, and help governments plan for long-term management of the cancer epidemic. Major coordination and investment are required to prepare for, and intercept, the impending cancer burden in SSA.

Figure 1: Steps in Cancer Control and Underlying



## FINDINGS AND RECOMMENDATIONS

**Figure 1** represents the major findings from this evaluation. These are summarized below. First, awareness for cancer is lower vs pandemic disease priorities: Cancer is often seen as spiritual curses (1). Given the spiritual perspective, cancer cases are often referred to healers or shamans for traditional or spiritual treatment. Health care providers in rural areas lack training on cancer, often misdiagnosing cancer as other illnesses (2). Lack of data on cancer prevalence and trends in Africa and historical focus on communicable diseases decrease government efforts on cancer research and treatment (3).

Notes:

- (1) Interview with LISCA, Senegal January 2016
- (2) BMI Research. "Industry Brief - Drop In Malaria Death Rates." 10 December 2015.
- (3) Interview with Dr Diop, Senegal, January 2016.
- (4) Interview with Dr Parkin, March 2016.

Second, prevention programs curb growth in prevalence, but are currently scarce. Economic loss by cancer is more expensive than the cost of cancer prevention, and prevention of risk factors (e.g. infections, tobacco use, and obesity) are more feasible and cost-effective than treatment. One-third of all cancer cases are preventable (1). Widespread smoking cessation programs, such as those found in western countries, are generally not found in Africa, denying the population this effective cancer prevention technique (2). Inadequate agricultural infrastructure can cause contamination, e.g. during storage, contributing to liver cancer burden in many SSA countries (3).

Notes:

- (1) World Health Organization 2016. Cancer Prevention
- (2) "Promotion of smoking cessation in developing countries: a framework for urgent public health interventions", A S M Abdullah, C G Husten, Thorax 2004;59:623–630
- (3) Fact sheet and position statement on agricultural products intended for human consumption. <http://www.cansa.org.za/files/2016/04/Fact-Sheet-Position-Statement-Aflatoxins-in-Agri-Products-Intended-for-Human-Consumption-March-2016.pdf>

Third, lack of early and accurate diagnosis is a challenge to appropriate care. Radiology facilities are too few to diagnose the population in need (1). Inadequate pathology leads to wrong diagnosis and patients either receive treatment for wrong grading, scale, or type of cancer (2). Scarcity is a problem in pathology training in care providers and researchers, and many countries have fewer than one pathologist for every million people. Lack of screening services (PAP test) and HPV vaccination lead to high prevalence of human papillomavirus (HPV) infection, causing high cervical cancer rates. Cervical cancer is the leading cause of cancer death for women in 40 of 48 countries in sub-Saharan Africa (2). 80% of patients in Africa are diagnosed at advanced stages of cancer, leading to less effective treatment protocols.

Notes:

(1) Senegal has only one Radiologist & one Gamma scan Camera for the whole country located in Le Dantec Hospital, Dakar.

(2) Visualizing cervical cancer: Leading killer of African women. <http://www.humanosphere.org/global-health/2015/07/visualizing-cervical-cancer-leading-killer-of-african-women/>

(3) Lancet Oncol 2013; 14: e152–57:Improvement of pathology in sub-Saharan Africa By Adekunle Adesina, David Chumba, Ann M Nelson, Jackson Orem, Drucilla J Roberts, Henry Wabinga, Michael Wilson, Timothy R Rebbeck.

(4) American Cancer Society 2011 Cancer in Africa report.

Fourth, high quality treatment is difficult due to limited healthcare resources and low affordability for a variety of reasons:

- Trained personnel (1): In 2015, the estimated shortage of health care professionals (792,000) will cost \$2.2+ billion annually in the 31 SSA countries. The current number of physicians practicing in SSA (145,000) represents 5% of the European total (2,877,000).
- Treatment access: ~22% of the 54 African countries have no access to anti-cancer therapies. Significant out-of-pocket expenses: Out-of-pocket health expenditure is estimated to push 100+ million people globally into dire poverty (2) (e.g., In Ghana, treatment is \$3,000+ but average monthly salary is \$300).
- 'Brain drain': African health care personnel to more attractive settings with better salaries, working conditions, career paths and support. More than half of 168 medical schools surveyed reported losing between 6 to 18% of teaching staff to emigration in the last 5 years (3).

Notes:

(1) Scheffler et al [Health Affairs 2009;28(5):849 – 862.

(2) World Health Statistics 2012, World Health Organization, Geneva.

(3) Lancet 2011;377:113- 21.

Fifth, end of life care is limited for cancer. Cancer is diagnosed at such a late stage that treatment is no longer effective, leaving palliative care as the only option for reducing suffering (1). Inaccurate forecasting for highly-controlled medications has historically lead to shortages of critical pain relief options (2). Home based care options are limited for African patients, especially outside capital cities (3). Rural families may view cancer as curse and therefore not want to treat patient. Not all rural health facilities are authorized to stock powerful pain medications necessary to properly reduce human suffering associated with late stage cancer.

Notes:

(1) American Cancer Society 2011 Cancer in Africa report

(2) Interview w/ Seneaglese National Pharmacy (PNA), 2016

(3) Interview w/ Dr Medela, Senegal 2016

# Underlying Drivers of Resource Gaps and Barriers

## *Funding*

Substantial health care financing gaps exist in SSA. SSA currently hosts 11% of the world's population and 24% of the world's disease burden, supported by only 1% of the global health expenditure (Thunell 2008). Government expenditure on healthcare is low and not expected to improve in the near future. With an average of \$14 per capita spent on healthcare and growing at 9.6% CAGR since 2006, public sector offerings are still generally of poor quality (BMI Research 2015). Both the dollar amount and the ratio of government expenditure on healthcare is lower than more developed countries (WHO 2016). For example, the Ghanaian government spent 11% of the budget on health, Côte d'Ivoire 9%, Senegal 8%, and Nigeria 6% (compared with South Africa at 14% and US at 21%).

Given competing interests for limited government funds, it is difficult to envision a budget shift that significantly expands health spending. The cost of implementation is drastically higher than realistically feasible. While private sector investment has begun, it has not reached the necessary scale to battle the increasing cancer burden. Many national cancer plans carry price tags that are unlikely to be realized. The international public sector funding is unlikely to increase to meet cancer control needs. The lack of systematic coordination between in-country public, international, and private entities increases the difficulty of finding a model for private funding of health care that is not highly subsidized by grants.

Given the limited funding and resources in the public sector, private sector funding for health care has increased and is growing. Africa's middle class is a growing consumer base that increasingly has the ability to pay into the healthcare system. The ability to offer world-class diagnosis and treatment locally has the potential to revolutionize healthcare offerings. However, there are a number of challenges to improving this system including limited human capital, talent recruitment and retention, management, and medical training (Calvert Foundation 2015). Health insurance is in its infancy in SSA and does not represent a funding solution in the short-term. Insurance schemes are normally voluntary and largely state-funded, and the vast majority of healthcare expenses are paid for out-of-pocket. Public health insurance schemes offer insufficient coverage for cancer treatment. Private health insurance companies oftentimes target wealthy individuals for their products in order to realize stock price increases rather than develop lower cost products targeting the great mass of less affluent people.

## *Operations*

While many countries have developed national cancer plans, they are generally very high-level documents with limited operationalization. Operations development is limited by lack of reliable data needed to accurately assess quality and efficiency of care, as well as the development of reliable performance metrics. Operational performance is further hindered by lack of standardized care, limited resources, and low prioritization of cancer care. Current gaps include lack of standardized referral platforms; lack of centralized purchasing and distribution system for supplies; long lead time for patient and complex patient journey; lack of capable dedicated administrative resources; limited resources in terms of infrastructure (i.e., space, beds, personnel), personnel, equipment' disconnect between



healthcare centers, physicians, pharmacies; lack of integrated health care; and lack of national and regional best practices and key performance indicators (KPI's) for audits.

Quality of cancer treatment and research operations is commonly assessed under the following KPIs: clinical efficiency, efficacy and operational efficiency, financial resource management, focus on personnel, and patient centeredness (Fountain and Gilden 2010, Ouwens, Hermens et al. 2010, Ioan, Nestian et al. 2012, Dutch Institute of Clinical Audits 2014). Examples of programmatic initiatives in SSA that have begun to address these issues include the Pharmacie Nationale d'Approvisionnement in Senegal that consolidates pharmacy orders to gain cost advantage. This initiative also attempts to maximize the use of generic medicines to reduce costs. As a result, in 2015 they achieved a 40% cost reduction in drugs purchased compared with 2014. Their experience suggests that to reduce cost of drug procurement, nationwide bulk ordering should be standardized. Morocco quantified operational targets for the number of diagnosed and cured patients (Fondation Lalla Salma and the Moroccan Ministry of Health 2010) in order to monitor the patient journey closely and set targets for steps from early diagnosis to treatment. Finally, the Dutch Institute for Clinical audits sets a nationwide best practices and KPI's to monitor cancer treatment and research (Dutch Institute of Clinical Audits 2014). Thus, it is critical to define nationwide best practices and KPI's to easily monitor the quality of cancer care.

## *Personnel*

Personnel gaps are systematic across African healthcare systems. Establishing sustainable cancer training programs is not yet a primary goal for most public authorities in SSA, through training and mentoring joint-programs in universities could be implemented to address skills gaps. Physicians currently have limited incentives to specialize in oncology, as opportunity costs can be high: Specialist training takes years to complete, during which salaries are not earned. Even after training, there may be a lack of sustained funding to guarantee long-term employment in oncology related jobs.

While increases in the number of clinical oncologists is needed, an intermediate step may be to enhance non-physician staffing, including provision of training programs that can expand the skills and practice scope of general clinicians, increase support non-physician support staff including histotechnologists, physician assistants, and oncology nurse practitioners (Adesina, Chumba et al. 2013). Development of a contextually appropriate telemedicine and e-Learning system that increases local access to accredited education and training can facilitate improvement of personnel capacity (Bediang, Perrin et al. 2014). Incentives for cancer-specific training should be increased and new incentives created.

Barriers to improved resourcing includes under-prioritization of cancer in public health policies, long training periods and high opportunity cost, inefficient information and communications technology channels for adaptable education and training, underfunding for scholarships for international study/specialized training, and lack of partnership between public and private education and training institutions(De Villiers and Moodley 2015). Despite these barriers, a number of initiatives have begun to address the limitation in personnel resources in SSA. The Human Resources for Health program in Rwanda intends to increase capacity for physicians, nurses, community health workers, pharmacists, laboratory technicians and other key personnel. Strong collaborations with international partners, and aligned principles, are critical factors for success. The IAEA-

sponsored Virtual University for Cancer Control has been launched in Ghana, Uganda, Tanzania, and Zambia. This program provides virtual training materials and a cancer training network to consolidate regional programs. Funded by the Roche African Research Foundation, the US Government, and the IAEA, centers in South Africa and Egypt operate as mentors. Finally, The AMPATH Training Institute, established in 2002 (Strother, Asirwa et al. 2013) in Kenya is led by Indiana University in collaboration with Moi University. This group has trained 2500+ Kenyans including physicians, clinical officers, nurses, nutritionists, pharmacists and technicians, psychosocial workers, and community mobilizers to address social and geographic determinants of disease broadly.

### *Patient Engagement*

Stigma and low awareness of prevention, treatment, and survivorship are major patient engagement barriers for cancer control in SSA (*Odedina, Akinremi et al. 2013*). Lack of patient engagement exacerbates gaps in cancer treatment and research. Improving patient engagement, advocacy and social mobilization is identified as a key focus area in most national cancer plans. Current patient engagement gaps include lack of awareness at all levels of treatment cycle, lack of community support, lack of awareness about preventive and treatment techniques even among health centers, and lack of effective population segmentation due to limited availability of registries. Barriers include conflicting priorities of health care administrators, insufficient stakeholder engagement, and inadequate funds.

Each country is at a different level of engagement. Communication preference and advocacy challenges can vary by region. A few countries have developed information, education and communication mechanisms and materials, including radio and television messages, posters, and information booklets for health care providers and the community. However, efforts are very segregated and face variable effectiveness. To increase overall engagement levels, lethal communicable diseases, such as Ebola, can serve as models. Success is largely attributed to support from government and NGOs. Thus, it is crucial to build partnerships with health care professionals, NGOs, and government stakeholders.

This type of cross-functional partnership can also help address stigma as a barrier for cancer control. Primary health care workers should communicate to their communities that 'cancer is survivable'. Cancer survivors can be engaged to further promote this concept. There are a number of examples of patient engagement programs that serve as models to overcome these gaps and barriers. The Life Choices Campaign (Prilutski 2010) in Ghana has been championed by the Ghanaian president to promote birth control and correct misconceptions around it. The Integrated Child Health Campaign (Prilutski 2010) in Ghana led to 96.4% of the target group having been touched as a result of exemplary collaboration between government and NGOs. These programs highlight the need for interpersonal communication, adequate resources, and stakeholder engagement.

### *Information Management*

Information gaps stymie high quality cancer care and research. High quality clinical data capture and management allows hospitals to efficiently manage their revenue; physicians to enable efficient cancer information transfer to patients, families, clinicians, MoH; population-based registries to provide cancer surveillance and research; research to quantify cancer prevalence and epidemiology; and governments and NGO's to undertake resource planning. Technological advances are needed to provide solutions for acquisition,

quality, and efficient transmission of clinical data, ensure data quality, and provide diagnosis to remote regions.

Barriers to improving information management are numerous. In many cases, patient records are inadequate or unavailable, data quality is poor, there is limited population-based data for accurate cancer registration, and IT Infrastructure is not available to support oncology practice. Incentives to maintain registry and telemedicine initiatives are limited. IT barriers include lack of funding/focus on information management, overworked clinicians, limited protocols or systems for pathology data capture, and minimal coordination between individual hospital-administered registries.

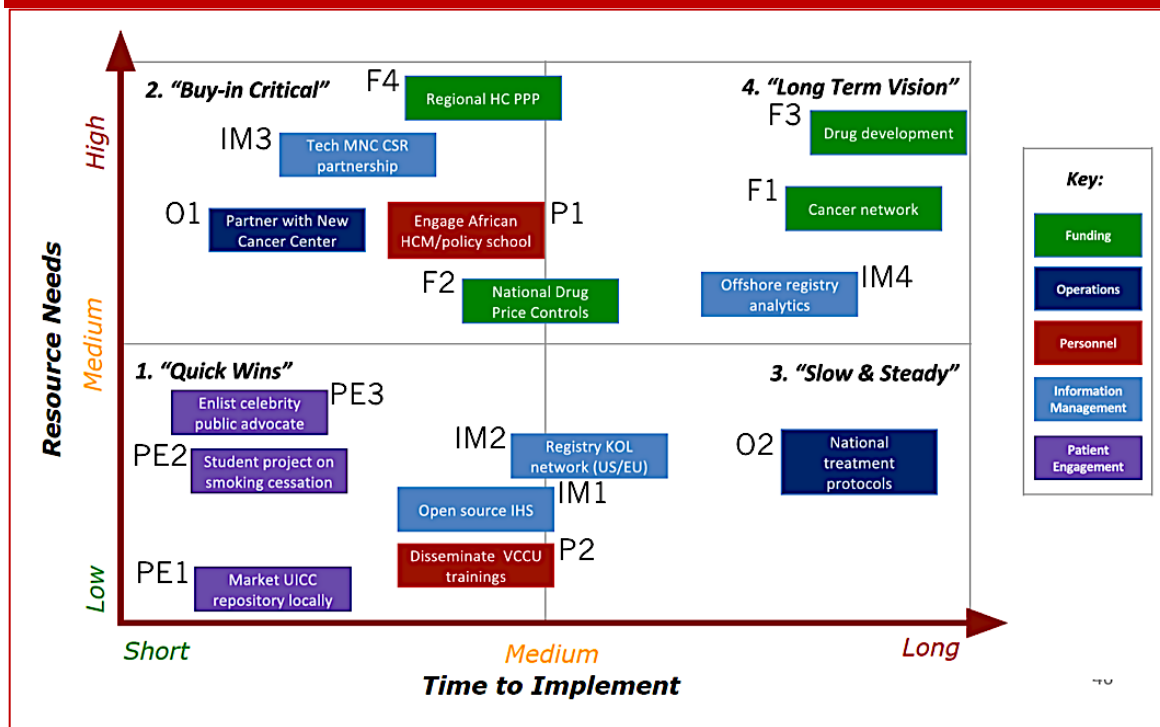
Paradigms for information management exist. “Data officers” have been used to enable data collection and input in Rwanda. These low-cost data recorders enable improved registry input, and free up physicians to handle clinical responsibilities. Madagascar offers a phone-based cervical cancer screening system in which mobile phone photos are transmitted to trained workers involved in screening (Catarino, Vassilakos et al. 2015). This approach leverages locally adopted technology and enables mass screening at low cost. A series of telemedicine (Geissbuhler, Bagayoko et al. 2007, Bediang, Perrin et al. 2014) and telepathology (Brauchli, Helfrich et al. 2002, Dalquen, Savic Prince et al. 2014) networks exist that enable clinical and research capacity. A common feature of these initiatives is that offshore expertise enables consultation, training, and mentorship of SSA clinicians to provide sustainable networks and decrease reliance of SSA centers on external expertise. Finally, artificial intelligence-enabled diagnosis is now being developed that uses supercomputer-based algorithms to identify patterns in tissue slides. These approaches, such as Dream Quark enable diagnosis that does not require human inspection of slides and can be performed remotely.

## Recommended Actions and Network Collaboration

As depicted in **Figure 2**, recommended actions were prioritized based on level of impact, and further segmented based on time to implement and relative resource needs. Two criteria were used to set these priorities: a qualitative assessment of relative resource needs (low, medium, high), and timeline (short-, medium-, and long-term). Based on these criteria, four groups of recommendations were made: 1) “Quick wins,” 2) “Buy-in critical,” 3) “Slow and steady,” and 4) “Long-term vision.” These recommendations are further categorized by the key domains of funding, operations, personnel, information management, and patient engagement described above.

With respect to funding, a network can be created to aggregate disparate financial streams in order to achieve priority goals (F1). Collaborations with MoH and NGOs can be developed to establish national level drug tenders and distribution system (F2). It will be of value to partner with private pharmaceutical and biotech companies to accelerate development of African-, country-, or region-specific cancer products (F3). Finally, using these partnerships, develop and implement regional public-private partnerships (PPPs) to increase number of high-quality care delivery sites for NCDs (F4).

Figure 2: Recommended actions prioritized based on level of impact, time to implement, and relative resource needs.



Engaging with existing or developing cancer centers in SSA presents should be prioritized (O1). These include the Uganda Cancer Institute, Cancer Diseases Hospital, Lusaka; Côte d'Ivoire National Cancer Center of Excellence; Pediatric Units of Hôtel Luxembourg, Mali; and Hôpital Mère-Enfant in Côte d'Ivoire. It will be critical to engage with MoH to offer expertise in constructing minimum protocol levels for treatment in national cancer plans (O2).

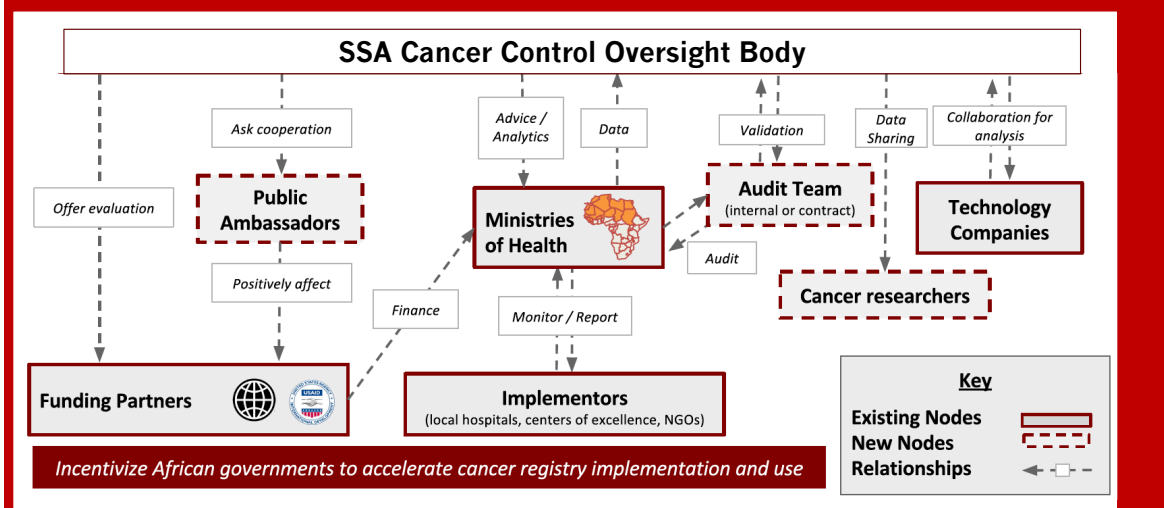
Personnel challenges are great in SSA, but they can be overcome by engaging with African universities dedicated to cancer prevention, awareness and health care management (P1). Examples of institutions include The Public Health University of Ghana and Huntsman Cancer Institute training for cancer awareness for public health officials, and Nairobi's Strathmore University Healthcare Management MBA. Given the existing infrastructure that has been created by the IAEA, a short-term impactful activity will be to disseminate and increase awareness of IAEA, and VUCC training modules to improve local awareness (P2).

Information management activities include partnering with existing providers of open source hospital IT systems to drive the digital transformation of medical records and clinical data (IM1) and collaborating to share knowledge with existing academic institutions and NGOs engaging in cancer registry development (IM2). As implied elsewhere, public-private partnerships (PPP) can be developed to partner with multinational corporations with robust corporate social responsibility and information technology systems to generate innovative approaches to registry regulation (IM3). Development of offshore analytics for cancer

registry and other data management initiatives can be fostered by the creation of a centralized data network administrator (IM4).

Finally, patient engagement is critical to the success of any cancer control activities in SSA. Patients and patient networks (PE1) can provide access and market existing cancer patient engagement products. It will also be of great value to develop exchange programs between US and SSA public health programs to share cancer related and smoking prevention marketing materials (PE2). The Scientist-Survivor program of the American Association for Cancer Research (AACR) is a venue where these exchanges could be developed. Building on successes in upper-income countries, celebrities and other "public ambassadors" should be enlisted for cancer advocacy (PE3).

Figure 3: Hypothetical structure for an oversight body for cancer control in SSA.



## Proposed Cancer Control Oversight Body

One of the biggest limitations for cancer control in SSA is the lack of a coordinating body or cancer network. Based on our evaluation, a model cancer coordinating body is presented in **Figure 3**. The proposed oversight body will operate like an international and regulatory body and coordinate long-term project implementers, technology and information management partners, funding sources, and network and advocacy roles. The collection and use of digital data, including cancer registry information, will improve treatment outcomes and serves as a KPI of network evaluation. The body would offer advisory services and coordinate funding to member countries to help them achieve information management goals. It would evaluate the member countries in terms of governance and prevalence of cancer registry. It would be empowered to disclose the analysis of cancer registry to cancer researchers, MoH, and external funding donors for their project appraisals. The Global Fund (Malaria 2015) in the context of HIV/AIDS as a potential model for a global coordinating cancer network.

Incentives exist for stakeholder collaboration through the proposed network. Funding partners would save time spent on internal appraisals and data validation. The cancer registries can enable clear and transparent measurement of funding impact, and MoH would be able to increase the number of cancer projects through increased external

funding. Data generated through the network could inform evidence-based national cancer policies. Implementers (including local hospitals and NGOs) could increase efficiency and profitability, increase transparency of cancer-related budget items, and use evidence-based advocacy for awareness. Patients could increase cooperation with the knowledge that their information leads to better in-country cancer treatment. Finally, technology companies could scale up growth of business in growth markets in SSA, quantify corporate social responsibility effects, and market a positive side effect of their business.

Creating the network requires the following action items. First, partnerships with major donors must be established and KPIs must be agreed upon. Pre-existing KPIs in prevention, treatment, and other guidelines for oncology from WHO and other international bodies must be adapted specifically to SSA. Funding request packets must be developed, and development of platforms, mentoring, open IT, and other infrastructure must begin through relationships should be built with technology partners. Finally, the oversight body itself needs to be developed to include leadership, funding mechanisms, monitoring, mentoring, audit capability, data hosting, tech partnering, and other critical functions. The coordinating body will be a long-term intervention. Public and private sectors must be able to work together for more sustainable solutions to cancer control in SSA.

## Summary Assessment and Recommendations

We have identified several critical activities for cancer control in SSA. First, outreach out to technology partners is crucial to structure demonstration projects with cancer centers and construct a “playbook” of resources to roll out best practices. Second, unified and consistent marketing to prioritize cancer control should use an integrated suite of messages consistently across stakeholder types and developing marketing materials tailored from the ground up. Key steps are to pressure test major messages, generate region-specific evidence to support messages, and disseminate localized marketing materials. Third, build deep relationships with public stakeholders. This will include building trust with MoH and relevant government bodies, highlighting the importance of research in effective public health policies, and serving as a bridge between regional governments. Finally, focus on people by increasing human resources capacity via partnership with public policy and health care management programs and engaging patients to leverage partnerships. This can include reaching out to public policy and health care management programs and integrate access to available training and patient engagement resources in stakeholder marketing materials.

We recommend the following projects to implement the activities outlined above. First, develop a personnel training model. This model will involve a detailed 3-5 year plan to improve human resources capacity for cancer control, including research. This activity will involve developing a personnel training system and model out time and resource needs to implement. For model assumptions, use existing academic figures, on-the-ground research and reach out to viable local partners. Second, develop a collaborative network oversight body for cancer control. This will involve developing and implementing an operating model, 5-year plan and performance metrics. Third, create a hospital IT demonstration project to implement a viable hospital IT system in a new cancer care and research center. This may require partnering with a private sector investor to establish a minimally viable hospital IT system. This work should be published to disseminate knowledge on financial, human capital, and infrastructure needs.

## Part II. Stakeholder Engagement

### EXECUTIVE SUMMARY

Sociodemographic trends in sub-Saharan Africa (SSA) predict a wave of new cancer cases in the coming decades. Current SSA health systems are ill-equipped to manage the increasing cancer burden, and gaps exist along the spectrum of awareness, prevention, early detection, treatment, and palliative care. Conference attendance, site visits, and literature analyses were conducted between October 2015 and May 2016 in the US, Europe, and Africa to analyze current and evolving cancer landscape in SSA and to map stakeholder groups with their roles relative to cancer control in SSA. Relevant stakeholders that need to be engaged in the development of cancer include health care implementers, funding partners, and technology companies. In the short-medium time horizon, we propose an integrated suite of messages that can be disseminated through effective informational materials across stakeholder groups. Key messages include 1) cancer burden has a broad social, economic, and political impact; 2) research is essential to effective and cost-efficient cancer control; 3) collaboration provides opportunities to gain cutting edge knowledge; and 4) cancer research investments have long-term payoffs. Effective engagement of stakeholders with clear messaging is critical for the success of cancer control initiatives in SSA.

### FINDINGS AND RECOMMENDATIONS

We identified categories of stakeholders in terms of role, influence, and focus on cancer control in SSA. The stakeholder groups identified and assessed here include patients, implementers, funding partners, technology companies, and network or advocacy bodies. A summary of the approaches to stakeholder engagement is presented in **Table 1**.

**Table 1: Stakeholder Engagement Strategies For “Quick Wins” and “Buy-In Critical” Recommendations (See Figure 2)**

Function	Area	Examples	Type	Difficulty to Engage	Engagement Strategy
Implementer	Ministries of Health	Ministries of Health	Regulatory Body	Medium to High	Engage as knowledge-sharing partner, who provides expertise to establish treatment protocols. MoH commits to collaborate and implement protocols
	Cancer Advocacy Groups and Networks	Ligue Senegalais Contre le Cancer, WHO, IAEA, AORTIC, UICC	NGO	Low	Fund and empower activities by linking it with global NGOs and funders
	Health Access NGOs	Clinton Health Access Initiative, Le Groupe Franco-Africain	NGO	Low	Engage with CHAI's new cancer initiative and connect CHAI with AORTIC to



Function	Area	Examples	Type	Difficulty to Engage	Engagement Strategy
		d'Oncologie Pédiatrique			leverage AROTIC's knowledge of SSA
	Clinicians and Academia	University Faculty, Oncologists	Clinicians and Academia	Medium	For established centers: opportunity for researchers to obtain quality data to enhance health outcomes. For new centers, provide expertise on cancer research and gains experience in SSA context.
	Public Ambassadors	Celebrities, sports figures	NGO	Low	Propose to a football player, music icon who has been impacted by cancer to be a public spokesperson/advocate
Technology Partners	Technology Platforms	IBM, Microsoft, Google; Open Source software companies and start-ups (MedX, DreamQuark)	Private	Medium	Engage with existing health care-related project (e.g., IBM Lucy, Microsoft) for analysis of big data in health care. Offer partnerships to accelerate implementation of hospital information systems in SSA.
	Telemedicine	Telemedicine networks (RAFT)	NGO	Low	Identify and collaborate teams with experience and infrastructure for SSA
Funding Partners	Private Sector	Abraaj Group, Moonshot initiative, CFAC	Private	High	Provide credible knowledge to evaluate how and where to begin investing in healthcare infrastructure in SSA
	Public Sector	National Cancer Institute, Cancer Research UK, INSERM	Public	Low	Engage with funders who are already supporting work in SSA and work together to build common strategies

## *Patients and Advocacy Bodies*

Patients are the main stakeholders at the center of cancer treatment and research and have the most to gain from activities that decrease the cancer burden. Their role crosses that of all of the other stakeholders. In general, patients lack formal organized support apart from the family and friends who support them through their journey. Due to lack of education and the stigma that may surround cancer, patients may not engage in regular treatment courses and may seek out spiritual leaders or traditional medicine. The severe side effects of some cancer treatments give the perception that alternative medicine is more effective with no side effects. In SSA, patient advocacy associations are limited. The opportunities and value drivers for the patient are to have an improved patient experience and outcomes. If this can be achieved, it may encourage patients to engage more proactively. Barriers to achieving this goal include multiple languages, as well as diverse cultural and spiritual beliefs, which make it challenging to have a unified national patient engagement plan.

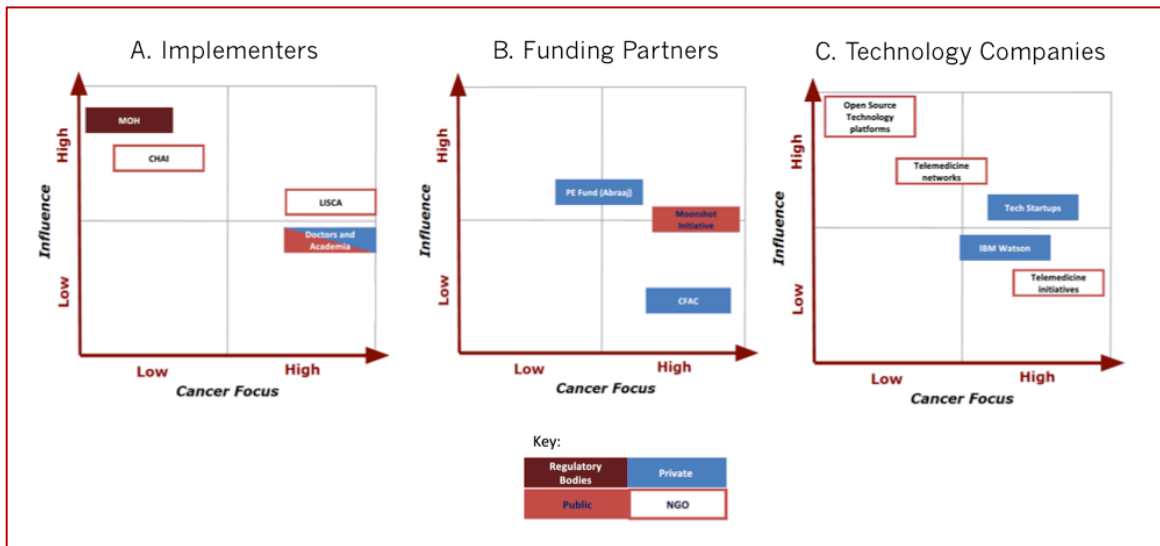
## *Implementers (Figure 4A)*

Implementers include governmental agencies such as Ministries of Health, NGOs, and the medical and academic community. Ministries of health (MoH) are highly influential stakeholders. MoH prioritize the national health initiatives and raise the awareness for cancer as a growing health problem. They create national cancer plans and strategies to combat cancer and can implement nationwide KPI's and treatment protocols for cancer care. They may also determine the government's budget allocation for health. MoH have the potential to centralize cancer treatment, lead governance and treatment/data controls, and collaborate between national and local organizations working in the cancer space. The focus on cancer differs across SSA countries. While MoH realize the growing cancer burden (and NCDs in general), they are resource-constrained and investing in cancer care requires retracting investments from communicable diseases. However, MoH have the power to raise the profile of cancer burden to channel more resources and make it a national health priority. MoH can mobilize necessary resources, create a healthy environment, a healthy investment climate for donors and investors. However, administrative capacity at MoH is stretched between diseases.

NGOs that deal directly with health, including cancer, also play an important role. Local NGOs such as the Ligue Sénégalaise Contre le Cancer, have extensive local knowledge but may lack resources or influence to implement their strategies. These groups can have influence in increasing cancer awareness and education as they are very well connected to the civil society. The organization has deep understanding about the cultural and religious aspects. This influence is hampered by the lack of resources and empowerment. They are also often poorly aligned to governments and MoH. Global NGOs such as the Clinton Health Access Initiative (CHAI) may have resources and follow effective market-based approach, yet they often lack local knowledge and are not focused exclusively on cancer. CHAI has made a major impact on people living with HIV/AIDS in the developing world by scaling up antiretroviral treatment. They have provided access and market optimization to accelerate access to effective, high-quality health products at affordable and sustainable prices by procuring bulk orders for countries. They have improved care delivery by applying an analytical approach to identify actionable solutions, and measure program performance through use of robust analytical methods to accurately inform health policy decisions. They support governments in removing financing as a barrier to health

by 1) understanding resource needs, 2) improving existing resource management, and 3) securing long-term funding. Finally, they offer human resources for health by building the health education infrastructure and health workforce necessary to produce high quality, sustainable healthcare systems. The CHAI cancer initiative is only beginning but will apply the same strategy they used in HIV. CHAI's influence is high given its resources, expertise, and global network. Their previous work in the HIV/AIDS network has allowed CHAI to accumulate significant capabilities, expertise, and meaningful local relationships.

Figure 4: Stakeholders: Relationship of Influence and Cancer Focus



Clinicians, researchers and other health professionals operate locally and know the cancer burden and the health care systems in which they work. However, they usually lack coordination due to lack of centralized governance or professional bodies dedicated to cancer. The collaboration between clinicians, researchers, hospitals and other institutions has largely been done through individual-driven initiatives. As experts, clinicians can influence the governments when they are undertaking any strategic decision; however, they have no individual power or influence to steer the strategic decisions. They often lack knowledge about market-driven approaches.

### *Funding Partners (Figure 4B)*

Most large funders have a limited cancer focus. Existing funding programs are often locally focused and highly dependent on support from development financial institutions such as development banks (e.g., World Bank), regional development banks (e.g., African Development Bank), and Bretton Woods Institutions (e.g., International Monetary Fund). Increasingly, private investors are looking for opportunities in the cancer space. For example, the Abraaj Group's Global Health Fund (The Abraaj Group 2015) is a private equity fund focused on global growth markets. Their \$1 billion Global Health Fund aims to establish sustainable, affordable, and high-quality healthcare ecosystems in Africa and South Asia. The Abraaj Group's funding goals focus on provision of services, distribution of technologies and medicines, retail pharmacies, etc. They support new, innovative healthcare businesses with the potential to scale in emerging markets by providing strategic

or operational value-addition to improve competitiveness. While they intend to achieve financial return on capital invested, the opportunity for private funding is critical, as there is a lack of capital for infrastructure and equipment in the healthcare systems in SSA. Within their focus on NCDs, cancer is of second highest importance to them (second only to cardiac diseases). The opportunities to address cancer control with private investors works well given their existing knowledge of African business climate and previous investments in other sectors. As additional private investors become interested in the healthcare sector in SSA, legal uncertainties in some SSA countries could deter potential investors.

The Cancer Financial Assistance Coalition (CFAC) is a coalition of financial assistance organizations that operates as a centralized platform of funding and donations. CFAC connects funding entities and patients to address three financial challenges: Direct medical costs, nonmedical costs, and daily living expenses. Funding is provided for individual patients seeking cancer care and treatment. Currently, CFAC is most effective in countries where personal / national insurance policies are effective.

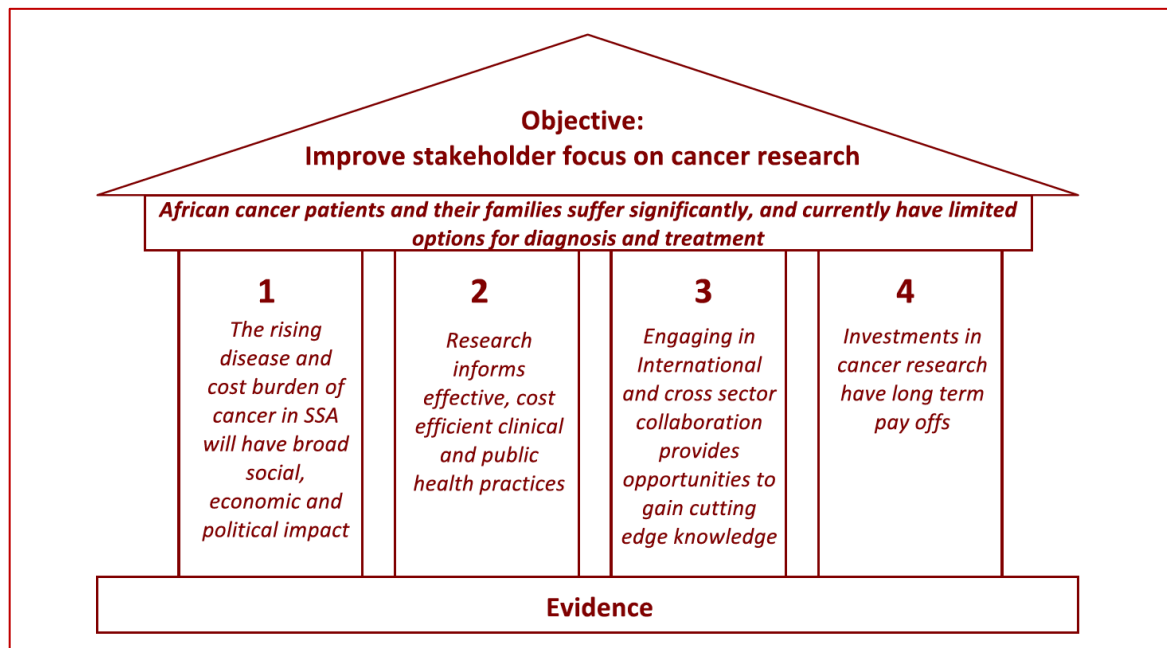
### *Technology Companies (Figure 4C)*

Technology platforms are providing solutions for healthcare data digitization that is a basis for establishing cancer infrastructure, including cancer registries. Telemedicine offers diagnostics, expertise and education (Catarino, Vassilakos et al. 2015, Ricard-Gauthier, Wisniak et al. 2015). Technology companies can bring innovative solutions for disease and data management in SSA, particularly in the context of open source systems that are accelerating healthcare digitization. Over 300 open source systems are currently available for healthcare, including the Nationwide Health Information Network, Open Clinica, and the Apple Research and Care Kits. Open source platforms, data digitalization of patient records and registries, cost efficient solutions for hospital information systems, better hospital management, and increased profitability for healthcare providers are domains in which open source software may contribute to cancer control in SSA. Most of these platforms are not focused on a specific disease type, but the potential influence on the quality of cancer treatment and research is high. Barriers to the impact of these platforms on cancer control include limited internet access, bandwidth, electricity; challenging management and implementation.

Technology startups provide innovative solutions to cancer control needs. For example, Mobile ODT provides a cheap colposcope connected with a smartphone for cervical cancer screening. Q-POC provides a miniaturized, cheap DNA sequencer for rapid cancer diagnostics, and MEDx provides a telemedicine platform and crowd-funding for patient care. Adapting innovative technologies and solutions for the low-resource setting will be critical to addressing cancer control needs. However, the influence of these activities may be moderate because of the small size of the start-ups and high risk of failure. Nonetheless, start-ups can provide solutions for a targeted problem, and are often easy to engage with.

Technology giants, like IBM Watson, are disrupting healthcare and have the potential to impact cancer control in SSA. IBM opened a research center in Nairobi in 2013, and has initiated Project Lucy, a 10-year, \$100 million initiative to address the fast-growing greatest business and societal challenges in Africa including healthcare, education, water and sanitation, human mobility and agriculture.

Figure 5: Stakeholder Marketing Strategy



## Stakeholder Marketing Strategy

Based on the information described above, we developed four key messages that can be used to improve stakeholder focus on cancer control, with the relevance of each of these messages to specific stakeholders (**Figure 5**). These messages are as follows:

### **Key Message 1: Cancer Burden Has A Broad Social, Economic, And Political Impact.**

New cancer cases and cancer deaths are anticipated to at least double in Africa by 2030, reaching 1.28 million new cancer cases and 970,000 cancer deaths[1]. Cancer takes a substantial toll on the financial security, quality of life and the future well-being of patients and their families. In African culture, burden on families is particularly great, as family members help pay illness costs. Additionally, mothers of children affected with pediatric cancers carry a disproportionate share of caretaking burden, and face challenges from missing work to transportation costs and marital instability.

### **Key Message 2: Research Is Essential To Effective And Cost-Efficient Cancer Control.**

Research forms the bedrock of health care policy in many international countries and translating research into health practice has been shown to improve patient safety and treatment outcomes[26]. In international settings, locally relevant cancer research has led to substantial cost savings in care. Allocating cancer research funding with respect to the societal burden each type of cancer imposes leads to high impact clinical and policy interventions[27].

### **Key Message 3: Collaboration Provides Opportunities to Gain Cutting Edge Knowledge.**

















Collaboration with other African governments and regional or international bodies provides opportunities for mentorship and information exchange. In 2015, 473

academic abstracts were shared among cross sector researchers during the African Organization for Research and Training in Cancer (AORTIC) Conference, enabling collaboration and consensus building ([www.aortic-africa.org](http://www.aortic-africa.org)). Partnerships involving multinational technology companies operating in African countries have promoted development of local infrastructure and human capital, while offering local market knowledge and market opportunities for companies.

**Key Message 4: Cancer Research Investments Have Long-Term Payoffs.** National-level price negotiations for critical medication in other countries have been successful in lowering cancer medicine costs; prices of medicines were between 2.7 and 6.1 times higher in Africa than the international reference prices. Buying cancer drugs privately in Africa costs an amount equivalent to between 1 and 7 months of income, leading to patients forgoing of treatment and reduced consumer purchasing power. Data generated through Africa cancer research can have substantial health impacts on African diaspora around the world.

This integrated suite of messages can be used consistently in marketing materials across stakeholders. Steps for implementing this strategy include pressure testing major messages with communications agencies, including for-profit communications and public relations firms, generate region-specific evidence to support messages, and publish and distribute marketing materials.

### Messages to Stakeholders

<b>Key Message</b>	<b>Regulatory Bodies</b>	<b>Public</b>	<b>Private</b>	<b>NGO</b>
<i>1. The rising disease and cost burden of cancer in SSA will have broad social, economic, and political impact</i>				
<i>2. Research informs effective and cost-efficient clinical and public health practices</i>				
<i>3. Engaging in international and cross sector collaboration for cancer provides opportunities to gain cutting edge knowledge</i>				
<i>4. Investments in cancer research have long term payoffs</i>				



High Relevance

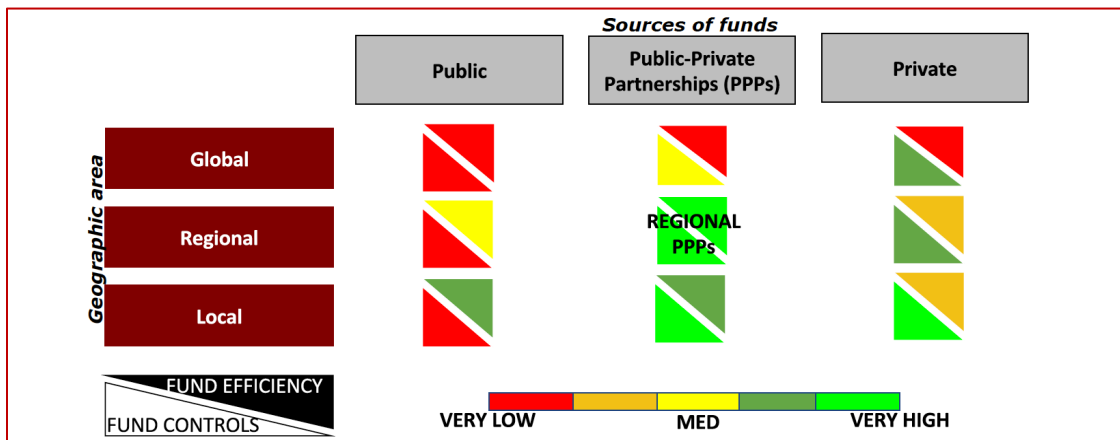


Low Relevance

Finally, our analysis suggests that regional public-private partnerships (PPP) may be optimal for the development and implementation of long-term cancer control infrastructure.

Impact on the quality of cancer research and treatment in SSA is highly correlated to sources and uses of available. Efficiency of cancer initiatives depends on geographic focus. More locally focused cancer treatment programs are generally more effective than broadly focused programs. The capacity to track funding streams highly influence the potential donations - evidence of effective fund employment leads to wider donation sources. The matrix show in **Figure 6** suggests regional PPPs initiatives can best tackle this double challenge as they have a better mix of efficiency and fund control.

**Figure 6: Regional Public-Private Partnerships Are Best Suited to Address Long-Term Investment in Cancer Infrastructure**



# SUMMARY OF KEY MESSAGES

## Engage with Private Sector for Public Health Innovation

- Improve health IT systems within hospitals and registries through immediate technology partnerships
- Work with private partners in novel cancer centers to generate viable research centers from the ground up; disseminate learnings from pilots to existing sites

## Use Unified and Consistent Marketing

Prioritize cancer research and treatment by

- Using integrated suite of messages consistently across stakeholder types
- Developing marketing materials tailored by stakeholder

## Build Deep Relationships with Public Stakeholders

- Build trust with Ministries of Health and relevant government bodies
- Highlight importance of research in effective public health policies
- Serve as a bridge between regional governments

Improved  
Cancer  
Control

## Focus on People

- Increase human resources capacity via partnership with public policy and health care management programs
- Engage patients- leverage partnerships (e. g. ACS) to pilot engagement tactics
- Disseminate and publicize available training and patient engagement resources



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